LIVING IN THE SHADOW OF FEAR

An Interactionist Examination of Agoraphobia

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Abstract

This thesis investigates the experience of agoraphobia among one hundred research participants by focusing on how social interactions contribute to the onset, the unmanaged symptoms stage, and the managed symptoms stage of this anxiety disorder. The study investigates how social interactions such as family upbringings, familial stressful events, one-off and clusters of traumatic events and accumulated stressful events can contribute to the onset of agoraphobia. It examines how research participants’ social interactions during their primary and secondary school years, youth, everyday life, travel, marriage/intimate relationships, parenting, post secondary education and employment were affected during the unmanaged symptom stage of agoraphobia. Participants’ experiences of the public perception of agoraphobia, stigma and discrimination, coming out experiences and family and friends’ reaction to agoraphobia are also explored. The third stage of the study examines social interactions that hinder or promote the management of agoraphobia. The former are found to include hiding panic attacks, making excuses, using flawed personal coping mechanisms and alcohol. Social interactions that were found to assist in the management of agoraphobia include labelling and learning about the mental illness from others, using companions in public places and situations, and seeking help from knowledgeable health professionals. Other forms of interaction that helped with management included participants’ usage of Internet chat-rooms and websites as well as the discovery of faith and spiritual experience. Finally the study investigates research participants’ changed social interactions following their emergence from the shadow of agoraphobia.
Introduction

Traditionally, psychological studies on panic attacks and agoraphobia have studied the physiological, cognitive and behavioural aspects of this anxiety disorder. These studies have shown that people with agoraphobia usually have the physiological symptoms of an initial panic attack in a public place and situation, which are accompanied by cognitive processes that interpret the physical symptoms as causing loss of control or even death. While some people flee the public place or situation to escape the panic attack, other people simply endure the panic attack, as escape is difficult or is socially embarrassing to do. Generally, people with agoraphobia develop a fear of recurring panic attacks and develop avoidance behaviour in the same or similar places and situations.

This Ph.D. thesis intends to make an original contribution to social knowledge by showing how social interactions shape, and are shaped by, agoraphobia. The study argues that social interactions happening around the person can contribute to the onset and development of agoraphobia. Also, the study argues that people with agoraphobia suffer a serious socially disabling anxiety disorder that adversely affects their everyday social interactions during the unmanaged symptoms stage of agoraphobia. In addition, the study argues that people with agoraphobia can engage in social interactions that contribute to their long-term management of agoraphobia.

The Ph.D. thesis commences with a literature review that will include studies on the social interactions that happen around the onset of, the unmanaged symptoms stage of, and the managed symptoms stage of agoraphobia. The literature review will identify where there is a consensus of knowledge, contested knowledge and absence of knowledge on social interactions. In addition, the literature review will create a framework of social interactions to be studied in order to reveal how these social interactions individually and collectively influence, and are influenced by, the experience of agoraphobia.

The theory chapter will present three symbolic interactionist theoretical frameworks to be used in the analysis of the findings data. The three symbolic interactionist perspectives are Blumer “Symbolic Interactionism Perspective and Method”, Goffman “Stigma Notes on the Management
The methodology chapter will use the literature review’s framework of social interactions to construct surveys and interview schedules that will gather data on those social interactions from a sample population of people with agoraphobia. The theory chapter will present Interactionism as the theoretical framework to analyse how research participants’ social interactions affected, and were affected by, their agoraphobia.

The finding’s chapter (1) will present research participants’ data on the social interactions occurring around the onset of agoraphobia, such as family upbringing, familial stressful events, one-off and clusters of traumatic events and accumulated stressful events. Then, finding’s chapter (2) will present research participants’ data on the social interactions occurring during the unmanaged symptoms stage of agoraphobia, including primary and secondary school years, youth, everyday life, travel, marriage/intimate relationships, parenting, post-secondary education and employment. In addition, finding’s chapter (2) will present research participants’ data on the role of public perception, stigma and discrimination on social interactions with family, friends and significant others. In finding’s chapter (3) research data will be presented on the social interactions that hinder or help research participants’ management of agoraphobia, such as hiding their panic attacks, making excuses, personal coping mechanisms, alcohol, labelling and learning about agoraphobia, companions, health professionals, Internet, support groups, faith and spiritual experiences. Also, finding’s chapter (3) presents research participants’ data on changes to their social interactions following their emergence from the shadow of agoraphobia. The finding’s chapter (4) will summarise the data from the previous three chapters.

The discussion chapter will use the three Interactionist perspectives to frame discussion on major themes identified in the finding’s chapters. The conclusion will then summarise the major thesis’ findings and make recommendations for further research on the role of social interactions happening around agoraphobia.
Chapter 1  Literature Review

The majority of studies reviewed on panic attacks and agoraphobia were clinically based and excluded data on social interactions. This literature review has sought to use studies that included data on social interactions happening to people with agoraphobia. Therefore, the literature review includes both historical and more recent studies as sources of data on social interactions for this thesis.

Historical Perspective of Agoraphobia

The historical origins of the term agoraphobia are embedded in the mythology and everyday language of Ancient Greece. In Greek mythology the God ‘Phobos’ was alleged to be able to inspire fear into his enemies which caused them to flee (Thorpe & Burns, 1983). Greek warriors would commonly paint the face of Phobos on their masks, shields and/or protective armour to create fear and cause flight in their enemies. Therefore, Phobos (or phobia) became associated with the onset of ‘fear’, ‘terror’, or ‘panic’, which induces flight or avoidance. In the Greek language the term ‘agora’ referred to a market place or a place of assembly, though alternatively some modern authors translate ‘agora’ as meaning open space or a public place. Hippocrates, the forefather of modern medicine, (Greece 4th to 5th century BC) reported on the actions of a person with agoraphobia by describing an individual who “through bashfulness, suspicion and timorousness will not be seen abroad, loves darkness as life…he dare not come in company for fear…” (Thorpe & Burns, 1983 p.2). Hippocrates discourse shows that people with agoraphobia have been present in the populace at least since the beginning of medical science.

Since Ancient Greece, a number of modern writers have reported agoraphobic symptoms occurring among the populace. In 1621, Burton, the author of ‘Anatomy of Melancholy’ wrote: “Montanus speaks of one that durst not walk alone from home for fear he would swoon or die…or, if he be in a throng, middle of a church, multitude, where he may not well get, though he sit at ease, he is so misaffected” (Thorpe & Burns, 1983 p.2). In 1770, Sauvages describes a
woman who suffered dizziness when entering a public building, and in 1870, Benedikt used the term *Platzschwindel* which translates into “dizziness in public places” (Thorpe & Burns, 1983).

The modern term of ‘agoraphobia’ is normally credited to the German psychiatrist, Westphal, who published in 1871 (or 1869 according to one source), a monograph entitled ‘*Die Agoraphobie*’, which described agoraphobia as a fear of open spaces (Thorpe & Burns, 1983, Clarke & Wardman, 1985). Westphal’s monograph described three male agoraphobic sufferers who experienced intense anxiety (including panic attacks) while walking in specific outdoor locations such as empty streets or across public squares (Mathews, *et al*. 1981, Clarke & Wardman, 1985, Greist, *et al*. 1986). Westphal observed that the agoraphobic sufferers’ fears worsened when the individual attempted to cross an open space which had no visual boundary (Mathews, *et al*. 1981, Clarke & Wardman, 1985, Greist, *et al*. 1986). For example, a clergyman reported feeling dizzy when he attempted to travel through an open space, which lacked a boundary fence (Mathews, *et al*. 1981, Clarke & Wardman, 1985, Greist, *et al*. 1986). However, the same clergyman was able to travel around the open space comfortably using the boundary hedges and trees or alternatively using his umbrella to restrict his field of vision (Thorpe & Burns, 1983). Also, Westphal observed that these agoraphobic men often sought the companionship of a trusted person when venturing out into public places (Thorpe & Burns, 1983). Westphal made the observation of a particular gentleman who regularly sought the companionship of a prostitute, without immoral motives, to accompany him to the safety of his front door (Thorpe & Burns, 1983). Westphal also noted that these agoraphobic men tended to use alcohol to suppress their symptoms, which enabled them to travel through a public place with comparative ease (Thorpe & Burns, 1983). Unfortunately, Westphal’s usage of the term agoraphobia led to the incorrect impression of agoraphobia, as involving a specific fear of public places or open spaces, instead of agoraphobia simply occurring in public places (Thorpe & Burns, 1983). While people with agoraphobia often avoid public places where previous panic attacks have occurred, it is not the fear of the public place that causes avoidance, instead it is the fear of having subsequent panic attacks in that place, beyond the apparent safety of their home (Clarke & Wardman, 1985). Also, Westphal’s studies of agoraphobia tended to attribute agoraphobic symptoms as a mental health problem primarily afflicting males, as the studies concentrated on male agoraphobia occurring in public places (Gournay, 1989). However, the
lack of studies on female agoraphobia in public places may have been due to the higher social acceptance and ability of women with agoraphobia to withdraw from public places into a domestic role within the family home.

Modern Perspective on Agoraphobia
In the 20th century, psychological research has shown that agoraphobia is a complex anxiety disorder. Clinical case studies have shown that people with agoraphobia often experience an initial panic attack in a public place (Craske & Barlow, 1993). The traumatic nature of this panic attack often causes the individual to avoid, or endure with marked distress, being in those public places (Craske & Barlow, 1993, Read, 1996). People with agoraphobia, during a panic attack, often feel trapped and unable to escape from the public place (Kleinknecht, 1986). Also, the person will often feel increasingly anxious about showing any outward appearance of the anxiety/panic symptoms to others in the public place, which would cause social embarrassment and/or negative value judgements (Kleinknecht, 1986). Thereupon, people with agoraphobia often excessively monitor their bodily sensations or responses for any anticipatory warning of an emerging panic attack, as well as attempting to inhibit any socially embarrassing appearance of anxiety symptoms to other people (Kleinknecht, 1986). Therefore, people often develop anticipatory anxiety towards the onset and/or manifestation of any psychological and physiological symptoms which are associated with an imminent full-blown panic attack occurring in these public places or situations (Kleinknecht, 1986). People with agoraphobia normally develop a fear of future panic attacks recurring in the same or similar places and situations which leads to avoidance and the development of a personal and social disability (Kleinknecht, 1986). This could result in people with agoraphobia often feeling socially inferior, vulnerable, isolated and alienated from others, due to their psychological and socially disabling condition.

Panic Attack Symptoms
People with agoraphobia endure both psychological and physiological distress during a panic attack. The panic attack’s psychological symptoms include: an overwhelming fear of being unable to escape, de-realisation (feelings of unreality), depersonalisation (being detached from oneself), fear of fainting/collapsing, fear of losing control, fear of sanity or going crazy, fear of
physical illness, endurance or dread of situations, fear of social embarrassment, feared loss of consciousness and incapacitation and the fear of imminent death (Weekes, 1977, Craske & Barlow, 1993, Lazarus & Colman, 1995). The physiological symptoms most commonly endured during a panic attack include: palpitations, paraesthesia (tingling sensations and numbness), sweating, chills or hot flushes, trembling or shaking, shortness of breath and feelings of being unable to breathe, difficulty in swallowing food and feelings of choking, chest pain or discomfort, bladder or bowel incontinence, nausea, feelings of unsteadiness, blurred vision, faintness, and hyperventilation (Chambless & Goldstein, 1982, Read, 1996). A person will often experience a combination of these psychological and physiological symptoms, to different degrees of intensity during, a panic attack (Kleinknecht, 1986). Also, people can experience these panic attack symptoms for several minutes to several hours (Kleinknecht, 1986).

Medical science has shown that the combination of the person’s physiological and cognitive processes are central to triggering a panic attack (Andrews, 1999). In a panic attack, the person begins to hyperventilate which creates a carbon dioxide and oxygen imbalance, as well as experiencing muscle tension which causes secondary physical symptoms (e.g. dizziness, rapid heartbeat, etc) leading to mental and emotional distress. The person’s cognitive process reacts to the physical distress by creating a internal dialogue that is fearful of the panic attack symptoms and feels fearful of being able to escape the place and/or situation. The person’s fearful thoughts and feelings then trigger the flight response from the feared panic attack occurring in that place or situation (Andrews, 1999).

People with agoraphobia constantly monitor their bodies for the warning signs of an imminent panic attack (Saul, 2001). People will often start to avoid places and situations which cause panic-like bodily sensations, such as simply walking up a flight of stairs which would change their breathing patterns and heart rate (this simple physical exertion could be interpreted as a possible sign of an imminent heart attack). When people begin to avoid places and situations to evade the psychological processes and physiological sensations of a panic attack, then the agoraphobic avoidance response becomes established (Saul, 2001).
Finally, agoraphobia has been commonly referred to as the ‘fear of fear’, as the individual develops a fear of experiencing the feared psychological and physiological symptoms associated with a panic attack (Greist, et al. 1986, Emmelkamp, et al. 1992).

Phobic Symptoms

A full understanding of agoraphobia requires that the nature and role of phobia is fully understood. Phobia is a fearful response attached to objects or situations which objectively are not a real source of danger (Friedman, 1950). The fear is often disproportional to the actual demands or dangers inherent in the situation (Marks, 1969). For example, a person with agoraphobia who experiences a panic attack in a shopping mall will attach the fear experience to the place, instead of the underlying psychological and physiological dysfunction. While the person experiencing the panic attack is often aware that the fear is irrational and unreasonable in the circumstances, they are unable to understand the real source of the fear and feel helpless to manage or overcome the fear (Berkowitz & Rothman, 1960, Clarke & Jackson, 1983). The spread of agoraphobia often lies in the similarity between places and situations (Salzman, 1983). For example, a person who is fearful in a large public place such as a shopping mall is often fearful in a movie theatre, or at a church service. While phobia implies a fear of an object or situation that causes flight to safety, agoraphobia involves both the fear of being fearful as well as the fear of being separated from a safe place or situation (such as home) which would markedly reduce the original fear. Therefore, agoraphobia is a flight from fearful sensations and from the feeling of separation from safety, as well as a flight to a place of safety where the fear is absent.

Public Places and Situations

Clinical case studies of people with agoraphobia have shown that the most common public places and social situations avoided include: leaving their home unaccompanied, being alone in a public place, travelling through a public place, crossing bridges or streets and arriving in new and different places (Vittone & Uhde, 1985, Hallam & Hafner, 1978). Also, people with agoraphobia avoid large public places, especially with large numbers of people, as well as travelling in elevators and consuming food or drink in public places (Hallam & Hafner, 1978, Arrindell, 1980). However, people with agoraphobia do not simply have a large set of specific
phobias in public places (Kleinknecht, 1986). Instead, people with agoraphobia fear having an unexpected or situational predisposed panic attack, in a wide range of places or situations from which escape may be difficult (or embarrassing), and in which help may not be available in the event of the panic attack (Salkovskis & Hackmann, 1997). Therefore, researchers argue that it is not the place or situation that triggers the anxiety, instead it is the person’s concern about their distance from, and inability to reach, the safety of their home, (Clarke & Wardman). When the person with agoraphobia reaches the safety of their home, fear (psychological and physiological symptoms) rapidly decreases (Clarke & Wardman).

A common assumption is that a person with agoraphobia can escape the fear of fear by retreating into their home. Tragically, a significant number of people with homebound agoraphobia often fear the onset of panic attacks occurring in anxiety inducing situations within the home environment (Greist, et al. 1986). It seems that the common elements of agoraphobic avoidance in public places are readily transferable to the family home, in that the fear of being trapped in an anxiety-inducing situation can occur in any environment (Greist, et al. 1986).

Degrees of Agoraphobia
According to the Diagnostic and Statistical Manual of Mental Disorders, 4th edition (American Psychiatric Association, 1994), there are three degrees of agoraphobia; this includes mild, moderate and severe agoraphobia (Norton, et al. 1991, Antony & Swinson, 2000). People with mild agoraphobia engage in some avoidance of or endure under distress public places and social situations (Jacob & Lilienfeld, 1991). For example, the person outwardly appears to live a relatively normal lifestyle such as travelling alone, when required, to public places (work), while at other times hesitating to travel long distances unaccompanied (Jacob & Lilienfeld, 1991). People with moderate agoraphobia develop a more restrictive lifestyle (Jacob & Lilienfeld, 1991). For example, while the person is able to leave their home alone, they are often unable to travel beyond a short radius from the safety of their home, unless accompanied by a trusted companion (Jacob & Lilienfeld, 1991). The person may begin to avoid large public places, such as shopping in a large supermarket at peak trading times (Craske & Barlow, 1993). People with severe agoraphobia have the most restricted lifestyle of all sufferers (Jacob & Lilienfeld, 1991). These individuals are often housebound, and are often unable to leave their
home, even with a trusted companion (Jacob & Lilienfeld, 1991). Generally, people with agoraphobia develop a degree of agoraphobia that remains relatively consistent over time (Craske & Barlow, 1993). However, research has shown that a significant number of people with agoraphobia experience a waxing and waning of their degree of agoraphobia on a daily basis, as well as over their respective lifetimes (Craske & Barlow, 1993).

An alternative to the American Diagnostic and Statistical Manual of Mental Disorder’s degrees of agoraphobia has been promoted by Goldstein and Chambless’ research on simple and complex agoraphobia (Davey, 1997). In Goldstein and Chambless’ research they suggest that physical illness, drugs or past trauma causes simple agoraphobia. However, complex agoraphobia that affects the majority of patients emerges from their childhood, due to the lack of a secure base that would normally create independence. The children’s lack of a secure base of independence arises from over-protective parents, overcritical or unpredictable parents, too much responsibility in the family home, the threat of parental separation, or sexual abuse were seen as contributory factors in undermining the children’s secure base of independence. In most cases, these children suffered from several of these contributory factors. The lack of a secure base was seen to lead to the children’s tendency to suppress, deny or avoid painful feelings and problems that appeared insoluble. This social conditioning led to the children developing chronic anxiety, lack of self-sufficiency, non-assertiveness, inability to function independently, fear of being alone and an exaggerated sense of their own destructive power should feelings of anger be expressed. These personality characteristics were seen to undermine their ability to cope constructively with conflict and stress in everyday life. These pre-agoraphobic children tended to suppress painful emotions and avoid conflict leading to the development of anxiety and depression, which in later life culminated into the physical and psychological symptoms of panic attacks and avoidance during periods of stress in their lives (Davey, 1997).

In later life, the pre-agoraphobic person usually develops an abnormal dependency on relationship partners, who are assertive in anxiety inducing situations (Hafner, 1977, Hafner, 1982). The pre-agoraphobic person then suffers an unexpected panic attack, following a stressful life event (Thorpe & Hecker, 1991). The stressful life event is often embedded within the context of interpersonal conflict in the marriage/relationship (Thorpe & Hecker, 1991). The
person’s pre-existing lack of assertiveness, self-sufficiency and independence means that the individual is unable to cope with the panic attack (Thorpe & Hecker, 1991). Also, the person struggles to accurately attribute the source of the panic attack (Thorpe & Hecker, 1991). Therefore, the traumatic nature of the initial panic and their inability to manage the situation creates anticipatory fear of future panic attacks occurring in the same situation (Thorpe & Hecker, 1991). Finally, the complex agoraphobic develops panic symptoms in a range of anxiety inducing situations and then develops a dependency on safe places, people and situations (Thorpe & Burns, 1983).

People with simple agoraphobia do not show the same personality characteristics, or familial experiences of complex agoraphobia (Thorpe & Burns, 1983). Instead, people with simple agoraphobia experience an initial panic attack caused by a specific one-off traumatic life event (Thorpe & Hecker, 1991). These specific one-off traumatic life events include drug experiences, physical problems such as hypoglycemia or traumatic events such as a street mugging, rape, earthquake, etc (Goldstein & Chambless, 1978, Thorpe & Hecker, 1991).

Another alternative explanation of the differing degrees and progression of agoraphobia was written in ‘Living Fear Free: Overcoming Agoraphobia’, where the author divides the different degrees and progression of agoraphobia into five stages: the latent, active, functional, recovering and recovered agoraphobic (Green, 1985). A person with latent agoraphobia lives a limited lifestyle where the individual is not living to their full potential. It could be that a large number of people who live a limited lifestyle for no apparent reason might have an undiagnosed latent form of agoraphobia. A person with active agoraphobic develops a more limited lifestyle following an initial panic attack that occurs for no apparent reason in a public place. The person with active agoraphobia begins to fear entering public places and situations due to the fear of a recurring panic attack. A person with functional agoraphobia has had the initial panic attack and will attempt to continue to live a normal lifestyle, though admittedly an increasingly limited lifestyle, while battling to suppress their anxiety/panic symptoms. Ultimately, a significant number of people with functional agoraphobia become homebound, as the individual is no longer willing or able to fight the overwhelming fears occurring in public places. Finally people who are recovering from agoraphobia develop the new attitudes and
management strategies (self-taught or health professional assisted), which enable them to begin to reclaim a life beyond the control of the fear of fear. Finally the recovered agoraphobic has developed positive attitudes and is able to cope in any previously anxiety-inducing place and/or situation (Green, 1985).

Functional & Homebound Agoraphobia

In ‘Living Fear Free: Overcoming Agoraphobia’ the author described in detail the two major manifestations of agoraphobia - functional and homebound agoraphobia. The most common manifestation is functional agoraphobia, while the most severe is homebound agoraphobia (Green, 1985). A person with functional agoraphobia is less limited in their degree of daily functioning and is able to leave their home environment. However, depending on the degree of dysfunction, the individual will be able to do some activities and unable to do other activities, depending on the waxing and waning of their levels of anxiety associated with the situation. For example, the person may be able to do supermarket shopping on a quiet afternoon, but be unable to enter the same supermarket during a hectic lunch time period. Generally, a functional agoraphobic will venture into public places with a support person who offers a ready source of assistance should a panic attack occur at any unexpected time. Some people engage in an agoraphobic lifestyle of enduring moderate anxiety in public places and avoiding unnecessary exposure to these situations, without being aware that they have a mild form of functional agoraphobia. These people often see themselves as safety conscious, especially in anxiety inducing situations and may also state a preference for a home orientated lifestyle, thereby avoiding the hectic pace of modern life. Generally, these people do not seek medical intervention as the self-imposed limits of their lifestyle are acceptable to themselves and significant others such as partners, friends and families. However, when the person begins to adopt an increasingly limited lifestyle, the individual enters a downward cycle of avoiding situations without understanding their reason for adopting an increasingly restrictive lifestyle. Thereupon, the person develops a sense of confusion as their ability to function fluctuates on a daily basis for no apparent reason. Generally, this daily ebb and flow of agoraphobic symptoms reflects the changing levels of anxiety in their daily life (Green, 1985).
While homebound agoraphobia is less common than functional agoraphobia, it is more severe in limiting the daily lives of sufferers (Green, 1985). A person with homebound agoraphobia withdraws into a reclusive lifestyle, which often causes the termination of social relationships and the disruption of education and employment. The homebound agoraphobic often suffers social isolation and alienation, which severely undermines the personal and social wellbeing of the sufferer. A significant number of people report feeling better as the daily public confrontation with fear is avoided, and most of these individuals simply force themselves to adjust to their reclusive lifestyle. However, agoraphobic symptoms can also invade the home environment and the sufferer is often forced to retreat into specific parts of the home environment. While people with homebound agoraphobia may appear to be acting abnormally, in reality, the flight from public places is a normal response to the threatening reoccurrence of overwhelming fear. For example, imagine a person who leaves their home to walk to the park, whereupon they are attacked by a stranger and severely traumatised. Generally, the person’s decision to avoid the place where the physical attack occurred would be seen as a normal response. Therefore, the person with homebound agoraphobia’s avoidance of public places where traumatic and overwhelming panic attacks are constantly reoccurring should be seen as a rational and normal response (Green, 1985).

There are a number of clinical case studies, and autobiographical accounts written by people with homebound agoraphobia which describe the disabling severity of this degree of agoraphobia. In one clinical case study a 70 year old woman reported spending 14 years trapped in her family home (Green, 1985). However, one account succinctly illustrates the powerful role of fear in homebound agoraphobia. This involves a woman who risked smoke inhalation or burning to death, by her refusal to leave her home during a fire, due to the fear of confronting a panic attack lying in wait beyond the front doorstep. However, for a significant number of people with homebound agoraphobia, their daily struggle with anticipatory anxiety and panic attacks within the home, without any escape to a safe place, creates a living hell. In one account a woman spent eight years in a large walk in closet (wardrobe), unable to venture into other parts of her home due to the fear of a panic attack. Tragically, people with homebound agoraphobia suffer a further restriction, in that their inability to travel beyond the family home often denies them access to GPs or Clinics for initial assessment and medical
treatment. However, mental health professionals who are contacted by family or friends can often visit the family home and assist the person to successfully manage their anxiety, enabling them to venture out into public places (Green, 1985).

While people with homebound agoraphobia will avoid leaving the safety of their home, most will arrange for a partner or family member to complete publicly orientated tasks (e.g. supermarket shopping) (Kleinknecht, 1986). However, some people with homebound agoraphobia can leave their homes with a trusted companion during a waning in the anxiety disorder. However, the person may be unable to enter any and all public places with this trusted companion (Kleinknecht, 1986).

Prevalence of Agoraphobia
According to clinical studies about 3.5% of all New Zealanders are affected by agoraphobia, which is similar to other Western countries (Agoraphobic Support Group Canterbury, 2001). In the United States of America, national surveys have shown that the percentage of people with agoraphobia ranges from 1.2 to 5 percent (Uhlenhuth, et al. 1983, Robins, et al. 1984, Norton, et al. 1991). However, in Western countries the actual rate of agoraphobia may be higher, as until recently, a larger number of patients have been misdiagnosed and treated for other psychological disabilities (Clarke & Wardman, 1985). In Western countries, agoraphobia is the most reported of all anxiety disorders (Clarke & Wardman, 1985). Western studies have shown that the prevalence of agoraphobia occurs across the social strata of gender, class, ethnicity and nationality (Greist, et al. 1986).

Age of Onset
There have been several studies on the age of onset of agoraphobia. In the 1977 United Kingdom’s ‘National Survey of Agoraphobia’ the mean age for the onset of agoraphobia was 28.0 years (Burns & Thorpe, 1977). The mean age of onset for females was higher at 28.5 years, compared to 24.3 years for males. In addition, 9% of the respondents reported their age of onset of agoraphobia at 16 years and under, and 13% reported the age of onset occurring at 40 years and over (Burns & Thorpe, 1977a). However, the research showed that a higher number of people with agoraphobia tend to report the onset of agoraphobia in the 20 to 30 age
group. Unfortunately, the survey did not reveal the reason for the sex differences or the reason for the differing ages of onset of agoraphobia.

The National Survey of Agoraphobia’s findings that 9% of respondents reported the age of onset of agoraphobic symptoms at 16 years has been investigated further in another research study (Berg, et al. 1974). This research revealed that people experiencing the onset of agoraphobia prior to 15 years of age often suffered from school phobia and were more prone to develop severe agoraphobia during later adult life (Berg, et al. 1974).

Since the National Survey of Agoraphobia, additional studies have investigated the age of onset of agoraphobia. In the 1977 clinical study of 30 married women with agoraphobia (hospital outpatients) the mean age of onset of agoraphobic symptoms was reported as 31 years (Buglass, et al. 1977).

In a 1985 study of 423 psychiatric outpatients (sample population included different anxiety disorders) the research showed a mean age of 26.3 years for the onset of agoraphobia with panic attacks (Thyer, et al. 1985). Further analysis of the research data showed that 51% of people with panic disorder reported onset at 25 years, within a range of 3 to 51 years (Thyer, et al. 1985).

In a 1986 study of 75 patients with panic disorder and/ or phobic disorders, the researchers determined that the average mean age of onset for panic disorders was 29.6 years, compared to panic disorder with agoraphobia at 33.6 years (Wittchen, 1986). The research revealed that 21% of research participants had an age of onset of panic disorder with agoraphobia between 11 to 20 years and 22% between the 41 to 50 years (Wittchen, 1988).

In a 1988 study of 125 patients (behavioural therapy patients) the average age of onset was 27 years for agoraphobia with panic attacks (Cottraux, et al. 1988).
In several North American studies the prevalence of agoraphobia is consistently between 18 and 45 years, with a significant decrease in the 50 and over age group (Wittchen & Essau, 1991).

The literature review of these research studies has revealed that the onset of agoraphobia occurs between the mid-teens to the late middle age group. Generally, the age of onset of agoraphobia occurs in peaks between the ages of 15 to 20, 18 to 35, and 30 to 40 years (Marks & Gelder, 1966, Mendel & Klein, 1969, Thorpe & Burns, 1983, Wittchen & Essau, 1991). Some clinicians have argued that the reason for the onset of agoraphobia in these different age groups is that stressful life events can occur during peak times in our lives including; teenage conflicts, marriage, childbirth, divorce, redundancy, mid-life crisis, death of a long term partner, etc (Wittchen & Essau, 1991). Some studies have shown that women have a higher risk of developing agoraphobia at a younger age while men have a higher risk of developing agoraphobia in the older age group (Wittchen & Essau, 1991). A possible explanation is that traumatic or stress life events are occurring among women in their youth or middle age (pregnancy, childbirth, sole parenting, parenting the teenage years, etc). The higher risk of developing agoraphobia in the older male age group may be due to mid-life stress including divorce, redundancy, or the death of their partner who is usually their unofficial support person/trusted companion in life.

The literature review of studies has shown that the onset of agoraphobia can occur at different ages with some sex differences affecting the age of onset (Wittchen & Essau, 1991). The studies either measured the onset of agoraphobia by requiring the patient to state when the initial panic attack occurred or when full agoraphobic symptoms developed. Therefore, the research methodology in these studies affected the determination of the mean ages, as the initial panic attack may precede the development of full agoraphobic symptoms by weeks, months or several years. For example, a United Kingdom survey on the onset of agoraphobia has shown that the initial panic attack is usually followed on average 15 months later by the full onset of agoraphobic symptoms. Another determining factor in establishing the age of onset is that the research participants’ data is usually gathered retrospectively, which means that the accurate
recounting of the age of onset is relying on the reconstruction of their memories (Wittchen & Essau, 1991).

Social Factors in Agoraphobia

Generally, psychological studies have studied the age of onset, symptoms, and/or successful management of agoraphobia (Hudson, 1989). Some psychologists argue that social causes and consequences can be detected in some people with agoraphobia and not in other cases. Several psychologists argue that while social factors play an indirect and contributory role in the onset and prognosis of agoraphobia, their importance varies among case studies. Finally, one psychologist argued that knowledge on the social cause and effect of agoraphobia was irrelevant to the successful treatment of people with agoraphobia. Therefore, research has been primarily psychological in orientation and social causes and consequences have often been undetected, ignored or discounted by the medical researchers. However, several social scientists argue that agoraphobia is caused by social problems inherent in family upbringing, stressful life events, etc. Also, social scientists argue that agoraphobia has social consequences in the form of disrupted relationships, alcoholism, educational failure and unemployment. A large number of clinicians concede that stressful and/or emotionally exhausting social factors will significantly hinder treatment programmes for people with agoraphobia. Generally, patients with agoraphobia who are recovering in a positive social environment will have a more successful outcome in their treatment programme. Several social scientists argue that a vicious cycle exists between social cause and effect (stressful life event causes – agoraphobia – which causes stressful life event). However, most psychologists and sociologists agree that the unravelling of social cause and effect embedded within personal psychological dysfunction is extremely difficult (Hudson, 1989).

Family Upbringing

Several research studies have argued that people with agoraphobia come from over-protective, restricting, controlling, critical, frightening and rejecting family backgrounds, which undermine independence in the pre-agoraphobic child (Terhune, 1949, Roth, 1959, Marks & Gelder, 1965). Thorpe & Burns, 1983, Klerman, et al. 1993). The pre-agoraphobic child in adult life develops an over-dependency on their marriage partner and constantly struggles to preserve the
stability of the marriage and family life (Thorpe & Burns, 1983). However, when a stressful event threatens, such as a separation or divorce, the person lacks the coping skills to manage the increasing level of stress and anxiety, which results in the initial panic attack that leads to agoraphobia (Goldstein & Swift, 1977).

However, several recent research studies have challenged the claim that people with agoraphobia are raised in stable families (Snaith, 1968). According to Dr. Alan Goldstein, Director of the Temple University Agoraphobia and Anxiety Program, people with agoraphobia are raised in six categories of unstable and/or dysfunctional families (Parker, 1982, Goldstein & Stainback, 1987). These six types of families include: parent(s) who are overly-critical of their children, parent(s) who are overly-protective of their child, parent(s) who place an unreasonable amount of responsibility on the child, including care responsibility for a parent who is chronically ill, has depression, alcoholism or agoraphobia, parent(s) who have unpredictable behavioural patterns due to their alcoholism, agoraphobia or other psychotic occurrences, the parent(s) premature death or abandonment causes separation from the child, and families where sexual abuse is occurring to the child, usually by a male relative who was intoxicated at the time.

Dr. Goldstein’s research of predominantly female clients (85% females and 15% males), shows a number of gender orientated social factors occurring prior to the onset of agoraphobia. (Goldstein & Stainback, 1987). Parents who are over-critical and/or overprotective are often more strict on a female child (e.g. eating habits, clothing, dating) than a male child. Also, parental overburdening of care responsibilities on children would affect the female child more than the male child (e.g. responsibilities for caring other siblings, sick and aged relatives, etc…). Finally, the female child often suffers an increased risk of abuse from a male relative’s alcoholism or sexual abuse (Goldstein & Stainback, 1987).

Several research studies have supported Dr Goldstein’s arguments, in the 1976 Maternal Overprotection Questionnaire, the mothers of 21 patients with agoraphobia scored significantly higher than other mothers of non-agoraphobic children in the over-protectiveness scale (Solyom, et al. 1976). In a 1976 study, 33% of agoraphobic patients reported an extremely
unhappy or disrupted childhood, of these 12% reported this an important factor in the onset of their agoraphobia (Shafar, 1976).

In the 1977 United Kingdom National Survey of Agoraphobia indicated that 37% of agoraphobic respondents reported that their mothers were overprotective, with a significantly higher incidence among female respondents (Burns & Thorpe, 1977). In addition the survey showed that 43% of respondents reported that their fathers were strict and unaffectionate. In a 1977 study of agoraphobic patients 13.1% reported that their fathers and 28.1% of their mothers as well as 34.9% of their siblings had nervous disorders requiring medical treatment. Several studies have lent support to Dr Goldstein’s research on the role of abuse or neglect in pre-agoraphobia children (Burns & Thorpe, 1977).

Studies have shown that the abuse and neglect of a pre-agoraphobic child by the father often causes the mother to become over-protective of the child (Chambless, 1982). Therefore, the role of the over-protective parent is seen as an over-reaction to the negative role of their partner in their parenting role (Chambless, 1982).

Dr. Goldstein’s research on the six categories of families argues that dysfunctional family upbringing causes people to develop personality characteristics which are central to the onset of agoraphobia (Goldstein & Stainback, 1987). These six categories include: lack of self-sufficiency, non-assertiveness, inability to cope with conflict, avoidance of stressful situations, inability to function independently and an exaggerated sense of their own destructive powers. While Dr. Goldstein’s research tends towards psychology, it raises an awareness of the relationship between preceding social factors and the development of personality trait presence at the onset and occurring during agoraphobia (Goldstein & Stainback, 1987).

Studies have shown that step-families or blended families have a higher prevalence of members with agoraphobia than other family groups (Buglass, et al. 1977). The reason for the higher incidence may be due to the occurrence of trauma on children following a marriage failure and the stress of relationship adjustment to a stepparent and stepsiblings in a developing blended family group. The loss of contact with a biological parent did not appear to be a factor in the
higher incidence of agoraphobia in blended families (Chambless, 1982). Some studies have argued that separation from a parent (divorce, absence or death) does not appear to be the cause of agoraphobic symptoms (Webster, 1953). Instead, social scientists have argued that the uncertainty of parental relationships in family groups creates “anxious attachment” in the developing agoraphobic child (Bowly, 1973). Therefore, the presence of an unstable parent (alcoholic) or an unstable relationship (conflict-orientated biological families or blended families) would have a greater role in the onset of agoraphobic symptoms in the child, than the death of a parent (assuming the family group regained stability following the parental death).

In a British survey of 963 people with agoraphobia, it was revealed that a high percentage (37.6%) were separated from their parents due to a variety of reasons including divorce, illness and military service for 3 months or longer (Thorpe & Burns, 1983). Also, 42.1 percent of respondents stated that their fathers were strict and 43 percent stated that their mothers were over-anxious. Significantly, a higher number of women stated that their fathers were unaffectionate and that their mothers were overprotective, compared to the male respondents. Also, the research showed that respondents had a high incidence of behavioural problems as children (Thorpe & Burns, 1983).

In the survey the following behavioural problems were recorded.

<table>
<thead>
<tr>
<th>Behavioural Problem</th>
<th>Percentage</th>
<th>Behavioural Problem</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nightmares</td>
<td>30.7%</td>
<td>Bedwetting</td>
<td>13.7%</td>
</tr>
<tr>
<td>Sleep Walking</td>
<td>11.6%</td>
<td>Stammering</td>
<td>3.6%</td>
</tr>
<tr>
<td>Nail Biting</td>
<td>29.5%</td>
<td>Thumb Sucking</td>
<td>6.7%</td>
</tr>
<tr>
<td>Trouble with Police</td>
<td>2.1%</td>
<td>Difficulty in Forming Friendships</td>
<td>28.6%</td>
</tr>
<tr>
<td>School Phobia</td>
<td>32.4%</td>
<td>Feeling to Easily Hurt</td>
<td>69.7%</td>
</tr>
<tr>
<td>Fear of the Dark</td>
<td>45.8%</td>
<td>Fear of Animals</td>
<td>13.1%</td>
</tr>
<tr>
<td>Other Fears</td>
<td>46%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Source: Thorpe & Burns, 1983)
The research shows a high incidence of the fear of being hurt (risk taking activities), school phobia and difficulty in forming friendships (social situations) and the fear of the dark (anxiety inducing place) (Thorpe & Burns, 1983). However, the percentage of respondents reporting nightmares, bedwetting, nail biting, thumb sucking and stammering as children is similar to the general population (Thorpe & Burns, 1983).

In summary, the research on the effect of family upbringing on the onset and development of agoraphobia is a contested site of knowledge. Some research studies indicate that family dysfunction, especially overprotective mothers, occur more often in the lives of people with agoraphobia. However, some studies argue that an insignificant correlation exists between family dysfunction and agoraphobia and such gathered data has failed to show a conclusive causational linkage between family dysfunction and the development of agoraphobia.

Pre-agoraphobic Children

In a 1974 literature review of child developmental material, there appeared to be no significant difference in the incidence of fear occurring among young female and male children (Maccoby & Jacklin, 1974). A summary of research studies show male and female children are equally vulnerable to developing fear at a young age. However, studies have shown that children who are exposed to “frightening experiences”, often develop phobia and anxiety disorders more than other children (Bowlby, 1975). A 1981 research report on Japanese 11 to 23 year old school students, showed a higher incidence of fear among older female students compared to their male peer group (Abe & Masui, 1981). It could be that the Japanese female students are more vulnerable to “frightening experiences”, than males due to differing cultural and experiential factors in their lives (Gournay, 1989a). However, research studies have been unable explain the reason for some children who are exposed to traumatic events not developing agoraphobia while developing other mental health problems (Clarke & Wardman, 1985). Some research studies argue that school age children may develop agoraphobic symptoms immediately following exposure to traumatic events (Clarke & Wardman, 1985). However, the school child may manifest other mental health problems, which hide the agoraphobic symptoms, or are misdiagnosed with a different type of anxiety disorder (school phobia or social phobia), or fail to be assessed for any mental health problem at all (Clarke & Wardman, 1985). Some studies
have argued that people with agoraphobia suppress traumatic events as children, and it is in later life that similar traumatic personal or social events trigger the initial panic attack (Clarke & Wardman, 1985). For example, a parental divorce may cause separation anxiety symptoms in a child, which are suppressed. However, in later life a marriage separation may re-awaken these separation anxieties and result in an initial panic attack which is seemingly unexplainable, causing the person to flee the place in which it occurred. Also, the reason some people experience the re-awakening of childhood trauma and others do not, may be that some children receive assistance to resolve the anxiety immediately following the traumatic event while the agoraphobic child may receive no assistance at all. For example, parents who reassure and support the child during a divorce may lessen the likelihood of the development of anxiety disorders in later life. Also, role models such as family members, teachers and peer group may allow a person with childhood trauma to develop life skills that prevent panic attacks during later life crisis (Clarke & Wardman, 1985).

Finally, some research studies argue that a specific traumatic one-off event is not particularly important in the onset of agoraphobia (Saul, 2001). These studies argue that school aged children who are overly protected from risk taking activities develop a lack of confidence and assertiveness to cope in anxiety causing situations. This is particularly relevant when parents with agoraphobia role model anxiety symptoms and avoidance behavioural patterns in anxiety inducing situations to a developing child (Saul, 2001).

School Years

While social scientists may argue about the rate of agoraphobia among school aged children, one study has explored the effect of agoraphobia on afflicted school children (Chandler, 2002). In clinical studies of school age children with agoraphobia a common number of physical symptoms are reported prior to their arrival at the school including; abdominal pain, diarrhoea, bladder complaints, nausea, headaches and other signs of illness. The physical symptoms rapidly disappear as soon as the child avoids school attendance. A parent and child conflict ensues over the apparent manifestation of a physical illness prior to their departure to school and its sudden disappearance when the child is allowed to stay at home. Studies have shown that some school age children with agoraphobia are frightened during bus rides that a horrible
or embarrassing event will happen while travelling on the school bus, which often leads to their refusal and/or avoidance of travelling on the bus to school. Generally, school children that are frightened of travelling on school buses experience the symptoms of diarrhoea, bladder weakness, vomiting, feelings of going crazy, or being sick without ready accessibility to help or assistance. However, some children with agoraphobia are able to travel to school, without undue concern, during the bus ride until their actual arrival at the school, whereupon the child develops the same dread of physical symptoms occurring in the school classroom. These school children often attempt to avoid classroom attendance, leave the school classroom during the day, refuse to attend school, or drop-out of school to escape these unpleasant experiences. In addition, some children with agoraphobia will avoid field trips, school performances and even changes in teachers (the existing teacher may possibly act as a trusted companion for the student, which enables them to endure the classroom environment) (Chandler, 2002).

School children with agoraphobia are at a major disadvantage in comparison to other school children and suffer significant disruption in their academic and social development (Agras, 1985). Agoraphobic school children lose the companionship of their peer group and are unable to engage in normal children’s playground games and activities. This undoubtedly affects the learning and social experiences of the school child (Agras, 1985).

School Phobia

In Guidano & Liotti (1983) account many agoraphobic adults reported school phobia during their childhood (Zarb, 1992). In the account, the person suffering school phobia as a child was seen to have similar cognitive dysfunctional properties as an adult with agoraphobia, such as the fear of serious physical and/or psychological harm (e.g. vomiting or fainting), the inability to deal with perceived external dangers, the fear of losing control (e.g. crying, shouting, or going crazy in front of others), and the fear of social disapproval and condemnation from others (e.g. teachers and students). In addition, the school phobic sufferer often avoided the school environment and required the company of a trusted family member or friend to the school gate. A debate rages on whether or not school phobia is a specific type of phobia in school children or a embryonic form of agoraphobia (Agras, 1985). Some clinicians view school phobia as an
apparently specific fear and/or avoidance of school, while other clinicians argue that school phobia is an emerging form of agoraphobia (Agras, 1985).

Social research on whether school phobia is an embryonic form of agoraphobia has centred on whether people (as adults) with agoraphobia have reported a higher incidence of school phobia than other populations. A major project studying the linkage of school phobia and agoraphobia, involving the case histories of 66 people with agoraphobia and simple phobia, revealed that 44 percent of people with agoraphobia reported school phobia, while only 24 percent of people with simple phobia reported having school phobia (Agras, 1985). Research studies have also sought to establish a link between parents with agoraphobia, and school phobia in their children. In a 1974 survey questionnaire of 786 women with agoraphobia, 14 percent reported having children (11-15 year olds) with school phobia (Berg, et al. 1974). In addition, another research study has shown that a high number of agoraphobic mothers have children with school phobia (Chambless, 1982). Generally, school-aged children develop school phobia at secondary schools with 9 percent of female students and 5 percent of male students affected (Berg, et al. 1974). The higher incidence of school phobia among school-aged girls is mirrored with the incidence of agoraphobia among women (Chambless, 1982). School phobia occurs most often in the 7-15 year old age range, while agoraphobia tends to develop in the mid to late teenage years (Berg, et al. 1974). While these research studies have argued that school phobia may be an embryonic stage of agoraphobia among school aged children, researchers have argued that the low percentage of people with agoraphobia reporting school phobia means that insufficient data exists to show that school phobia is a precursor to agoraphobia (Berg, et al. 1974). Unfortunately, research into the linkage between school phobia and agoraphobia is retrospective, which tends to reduce the reliability of the data (Thorpe & Burns, 1983).

**Traumatic Events**

In the United Kingdom’s national survey of 963 people with agoraphobia, 70.3% of respondents stated that a single traumatic event immediately preceded the initial panic attack, prior to the onset of agoraphobia (Thorpe & Burns, 1983). There are a number of studies that argue that a single traumatic event occurs immediately prior to the initial panic attack without any apparent warning signs (Ost & Hugdahl, 1981). In a 1959 study, 83% of the research
participants reported a single precipitating traumatic event (Roth, 1959). In a 1984 study, 38% of patients with a panic disorder stated that their separation from their partner occurred in the year prior to the onset of their anxiety disorder (Katon, 1984). Also, 16% of the patients reported a near-death experience and 9% of the patients reported the death of a close family member or friend occurred prior to the onset of their initial panic attack (Katon, 1984). In another 1984 study involving 58 patients with agoraphobia, 81% reported that at least one significant life event occurred immediately prior to the onset of their panic attack (Last, et al 1984). The significant life events included; conflict within marital and familial relationships, child-birth/marriage/hysterectomy, death or illness of significant others and drug reactions (Last, et al. 1984). In a 1986 study of 60 patients with panic disorder and agoraphobia, 63% reported a one-off traumatic event occurring six months prior to the initial panic attack (Breier, et al. 1986). In the study, the most common stressful event was the threatened or actual separation from a significant person in their life (Wittchen & Essau, 1991). Finally, a 1989 study of 56 patients with panic disorder and agoraphobia revealed that 42% had suffered a major life event in the month prior to the initial panic attack (Lelliott, et al. 1989). The research participants reported the familiar incidences of childbirth, marital/familial conflict, threatened or actual separation from a significant other, illness or death in a partner, and financial problems (Lelliott, et al. 1989). In summary, a significant number of studies support the argument that traumatic life events occur at or near the time of the initial panic attack.

The accompanying graph lists the major traumatic events reported in the 1977 United Kingdom Survey of People with Agoraphobia:

Table:

<table>
<thead>
<tr>
<th>Traumatic Event</th>
<th>%</th>
<th>Traumatic Event</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Person directly exposed to a traumatic event out of home</td>
<td>32.23</td>
<td>Death of a family, friend or close relative</td>
<td>23.04</td>
</tr>
<tr>
<td>Major Illness</td>
<td>13.10</td>
<td>Child-birth</td>
<td>7.83</td>
</tr>
<tr>
<td>Person witnesses traumatic event happening to others</td>
<td>5.87</td>
<td>Major Illness affecting family, friend or close relative</td>
<td>4.37</td>
</tr>
<tr>
<td>Strained marital relationship</td>
<td>3.77</td>
<td>Strained family relationship</td>
<td>2.71</td>
</tr>
<tr>
<td>Miscarriage</td>
<td>1.81</td>
<td>Other</td>
<td>5.27</td>
</tr>
</tbody>
</table>
While studies have revealed the role of traumatic social events, an American Sociological Association paper reports that traumatic life events can divide into natural and social phenomena (Magee, 1996). The social phenomena includes the social events recorded by previous researchers and extends the list to include sexual abuse, victim of crime, work stress, redundancy and significant health problems (Marks, 1969). The natural phenomena included fires, floods, tidal waves and earthquakes (Magee, 1996).

However, some studies have challenged that claim that a single specific traumatic event causes the initial panic attack that precedes the onset of panic attacks (Buglass, *et al*. 1977, Greist, *et al*. 1986). In a 1966 study, only 10% of research participants cited a single preceding traumatic event occurring prior to the initial panic attack (Friedman, 1966). One clinician argues that people must have a high level of pre-existing stress caused by smaller successive stressful events that weakens the individual emotionally prior to the single traumatic event that triggers the panic attacks (Asso & Beech). Several studies suggest that a succession of stressful life events create the personal, emotional and social instability that precedes the initial panic attack associated with the onset of agoraphobia (Dohrenwend & Dohrenwend, 1974, Hudson, 1989). In one study, 83% of people with agoraphobia reported the presence of smaller successive stressful stress factors occurring when around the time of the single traumatic event, which then seemingly triggered the initial panic attack (Shafar, 1976). In a 1985 study of patients with panic disorder, 80% of patients indicated that several major stressful life events had occurred within six months of the initial panic attack which preceded the onset of agoraphobia (Uhde, *et al*. 1985, Gold, 1989). In a 1987 study, 75% of patients with agoraphobia identified ongoing stressful life events happening at the time of the initial panic attack (Aronson & Logue, 1987). In another study, 91% of people reported that ongoing stressful events preceded their initial panic attack prior to the onset of agoraphobia (Gold, 1989). In another clinical study, 96% of the patients reported ongoing stressful events played a significant role in the development of their agoraphobia (Gold, 1989). Finally, further research studies have shown that an average of 85% to 95% of people with agoraphobia, report ongoing stressful events happening around the time of the single traumatic event that happens prior to the initial panic (Roth, 1959). While studies show that a succession of stressful events are occurring prior to the initial panic attack, the one-off traumatic event appears to be the actual catalyst for the initial panic attack. This
research suggests that people who have pre-existing high levels of stress are particularly vulnerable to suffering a panic attack when a traumatic event occurs.

The Female Experience of Agoraphobia

A significant amount of research has shown that women report a higher incidence of agoraphobia than men, leading some clinicians to describe agoraphobia as a ‘woman’s syndrome’ (Fodor, 1974, Clarke & Wardman, 1985). In one major clinical study of 1,200 people with agoraphobia, a staggering 95 percent of patients were women (Marks & Herst, 1970). However, the majority of clinical studies on agoraphobia and sex difference have shown that on average 75 percent of agoraphobic patients are women (Marks, 1969, Uhlenhuth, et al. 1983, Robins, et al. 1984).

The accompanying table shows a range of studies over a 30-year span, which supports the view that women report a higher incidence of agoraphobia compared to men (Thorpe & Burns, 1983). While the percentage ranged from 63 percent to 89 percent, all of the studies reviewed have shown that the majority of people reporting agoraphobic symptoms were women.

Table:

<table>
<thead>
<tr>
<th>Researcher(s)</th>
<th>Year</th>
<th>Number of Subjects</th>
<th>Percentage of Women</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tucker</td>
<td>1956</td>
<td>100</td>
<td>89%</td>
</tr>
<tr>
<td>Roth</td>
<td>1959</td>
<td>135</td>
<td>70%</td>
</tr>
<tr>
<td>Warburton</td>
<td>1963</td>
<td>53</td>
<td>89%</td>
</tr>
<tr>
<td>Klein</td>
<td>1964</td>
<td>32</td>
<td>81%</td>
</tr>
<tr>
<td>Marks &amp; Gelder</td>
<td>1965/6</td>
<td>84</td>
<td>89%</td>
</tr>
<tr>
<td>Snaith</td>
<td>1968</td>
<td>27</td>
<td>63%</td>
</tr>
<tr>
<td>Solyom, et al.</td>
<td>1974</td>
<td>43</td>
<td>90%</td>
</tr>
<tr>
<td>Shafar</td>
<td>1976</td>
<td>68</td>
<td>87%</td>
</tr>
<tr>
<td>Chambless</td>
<td>1978</td>
<td>27</td>
<td>78%</td>
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<tr>
<td>McPherson, et al.</td>
<td>1980</td>
<td>56</td>
<td>66%</td>
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(Source: Thorpe & Burns, 1983)
Studies on the higher reported incidence of agoraphobia among women have argued that child development and sex role stereotyping have had a major effect in shaping pre-agoraphobic women. In studies on child development, the female child is seen to be more vulnerable to parental over-protectiveness within the mother-child relationship, than male children (Chambless, 1983). At the same time, the father- (female) child relationship often involves parental disinterest, remoteness, instability and (occasionally) complete rejection (Chambless, 1983). Therefore, the child is raised to be fearful in anxiety-inducing situations (over-protective mother) and lacks exposure to risk taking activities (neglect by father) (Chambless, 1983). Thereupon, the female child becomes overly concerned for her personal safety in fearful situations and develops the self-perception of a victim, which is reinforced by actual and media presentations of women as victims (Kagen & Moss, 1962, Chambless, 1983). Together, the family and gender role upbringing tends to create a dependent personality which causes the young women to enter into dependent-orientated relationships with men (Chambless, 1983). Also, the female tendency to focus on relationships, encourages a family nest mentality which promotes the safety of the family home (Saul, 2001). However, marital relationships can often suffer as both parties feel resentment towards the other person due to the dependency nature of the relationship (Chambless, 1983). As a housewife, she becomes socially isolated and is overly fearful of social contact and overly concerned about criticism from others in social situations (Chambless, 1983). While the homebound agoraphobic housewife wants to be socially active and employed, she is usually too unassertive, low in self-esteem, anxious and depressed to challenge her situation (Chambless, 1983). These women are often excessively worried about their physical health, often reporting profuse specific and vague somatic symptoms to doctors (Chambless, 1983). As a parent, her daughters have a greater chance of developing school phobias, which some argue is an emerging form of agoraphobia (Chambless, 1983). Thereupon, the inter-generational cycle of maternal concern and anxiety resulting in the child’s fearfulness begins anew (Chambless, 1983).

In five major population studies in the USA, UK and Sweden the average age of onset of agoraphobia among women was between 16 and 40 years of age (Marks & Lader, 1973). Research studies have argued that the higher rate of agoraphobia among women includes an interweaving of child development and long-term sex-role stereotyping, which pressures
women to adopt passive social postures in response to fearful situations (Fodor, 1978). For example, in children’s stories, classroom readings and television programmes, the female character is often portrayed as a helpless victim requiring the rescue of a dominant male (Fodor, 1978). These characterisations of women create a stereotyping of women as unassertive, weak, helpless, dependent-orientated victims in anxiety-inducing situations (Chambless & Goldstein, 1982). Also, the higher incidence of physical and sexual abuse of women and media reportage of crimes committed against women (domestic violence, sexual offences and murder), undoubtedly reinforces this sex-role stereotype of women as helpless victims in society (Saul, 2001). Due to gender stereotyping, one researcher has argued that young women are overly protected in anxiety inducing situations and have less exposure to being alone in public places due to parental “chaperoning” or the tendency for young women to travel in groups for safety and social companionship (Maccoby & Javcklin, 1974). Some researchers argue that the social construction of gender roles both encourages the development of agoraphobia, as well as preventing women from developing anti-phobic character traits (Wolfe, 1984). In contrast, male sex-role stereotyping encourages men to actively confront fearful situations alone, which fosters assertiveness and confidence (e.g. the male peer group use of risk-taking dares, to test the courage of other members) (Speltz & Bernstein, 1976). Since the rise of feminism and the social change in gender roles, young women are increasingly engaging in traditional male-orientated risk taking activities which is seen as the reason that the higher reportage of agoraphobia among women is on the decrease (Thorpe & Burns, 1983). However, some feminists argue that middle aged and older women raised in traditional families are feeling increasingly pressured to succeed occupationally while simultaneously lacking the self-assurance to succeed, which is increasing anxiety disorders in this age group (Fishman, 1980).

In the majority of psychological studies, a larger number of women have reported a higher incidence of homebound agoraphobia compared to men. These studies have argued that women suffer the more severe form of homebound agoraphobia due to gender-orientated social factors (Clarke & Wardman, 1985). Traditionally, the patriarchal society expected men to work in public places, while women have been socially pressured into working in the private space of the family home. It seems that at the onset of agoraphobia both men and women want to retreat to the perceived safety of the family home. However, the social expectation and pressure on
men to continue working in public places, provided a form of unplanned behavioural therapy (exposure), which prevents the development of homebound agoraphobia. Also, the social acceptance towards men drinking alcohol during lunch-time meals, means that men could suppress anxiety symptoms and continue functioning at their work in public places, admittedly often in detriment to their long-term well being (e.g. alcoholism). In contrast, the social expectation of women to work exclusively in family home, especially following child-birth, meant that women could more readily withdraw into the home which assisted the development of the more severe form of homebound agoraphobia (Clarke & Wardman, 1985).

In the 1970s, the ‘United Kingdom National Survey of Agoraphobics’ gathered data from 963 survey responses from people with diagnosed agoraphobia (Thorpe & Burns, 1983). The survey’s investigation included the reported concern of men and women to different social situations affected by their agoraphobia (Thorpe & Burns, 1983). The research showed that 41.96% of men expressed their concern about an inability to work compared to 14.18% of women (Thorpe & Burns, 1983, Greist, et al. 1986). The possible reason that women reported less concern about paid employment reflects the social acceptance towards their withdrawal into the traditional role of unpaid housework and childcare in the home, while the higher rate of men concerned with unemployment may reflect that male self-esteem is linked to paid employment in public places (breadwinner role). Both women (28.85%) and men (28.57%) cited the lack of social contact or social restrictions as a social factor adversely affected by agoraphobia (Thorpe & Burns, 1983, Greist, et al. 1986). A larger percentage of women (14.18%), compared to men (8.93%) reported marital disharmony (Thorpe & Burns, 1983, Greist, et al. 1986). It could be that women partners, as the ‘emotional caretakers’ of the relationship may tend to be more concerned about the maintenance of the marriage or relationship than their male partners. The research revealed that 11% of women, compared to 4.46% of men reported travel restrictions as a major social factor affected (Thorpe & Burns, 1983, Greist, et al. 1986). However, the higher incidence of homebound agoraphobia among women would seem to explain this gender difference.

Studies have shown that agoraphobic women with children often have a lower frequency of panic attacks, as well as lower chronic anxiety and depression than other women (without
children) with agoraphobia (Chambless, 1983). Also, women with a larger of number of children have less frequent experiences of panic attacks, chronic anxiety and depression. A possible explanation is that agoraphobic women with children (living in the family home), resign themselves and mentally adjust to the restricted lifestyle of the housewife/mother role. Some clinicians have argued that the agoraphobic mother unintentionally uses the child in a protective role (trusted companion), which reduces the frequencies of panic attacks and agoraphobic symptoms. In several studies women reported that their children were more useful in the role of a trusted companion (support person) than their male partner. Unfortunately, studies have shown that when the child leaves the family nest, the mother often experiences an increase in their agoraphobia symptoms. Alternatively, the homebound agoraphobic woman’s ability to have a more positive and meaningful relationship with her children raises her morale and avoids the downward spiral of agoraphobia symptoms (Chambless, 1983). Also, the agoraphobic mother may be forced to engage in gradual exposure in social situations and public places, due to the needs of the child. For example, the mother may feel obligated to attend a local play-centre to encourage the child’s social development.

Medical research on the sex-differences between men and women in their reportage of agoraphobia has included biological differences (Gournay, 1989). According to medical research, the possible reason for the higher incidence of agoraphobia among women is the hormonal differences between men and women (Gournay, 1989). While the majority of medical research on menstrual and hormonal fluctuations in agoraphobic women ignores the social context, some social research argues that male testosterone encourages risk taking behaviour, while female oestrogen fluctuations inhibit risk taking behaviour (Marks, 1970). Traditionally, females were discouraged from engaging in masculine risk-taking behaviour prior to and during their menstrual cycle (Marks, 1970). Therefore, women had less exposure to anxiety-causing stimuli, which reduced their development of confidence in anxiety-inducing situations (Marks, 1970). However, a research study of 18 pre-menstrual agoraphobic women has shown that only 6 reported that hormonal fluctuations increased the severity of their agoraphobia symptoms, including avoidance of anxiety-inducing situations (Buglass, et al. 1977). In a major review of community studies in the United States of America, United Kingdom and Europe, women were shown to have a 200 percent higher likelihood of developing anxiety and panic disorders.
compared to men (Marks, 1987). Further research has indicated that the same high prevalence of a female predisposition to anxiety disorders occurs in Asia, Africa and South America (Rachman, 1978, Gournay, 1989).

The Male Experience of Agoraphobia

Several clinical studies argue that men actually have the same or a similar rate of agoraphobia as women (Voss, 1980). These clinicians argue that the reason men appear to have a lower incidence of agoraphobia, is due to the unwillingness of a large number of men to report anxiety symptoms to their GP or community mental health agency (Voss, 1980). Clinicians speculate that men avoid reporting their anxiety symptoms due to their gender-orientated socialisation, which teaches males that it is not “masculine” to show or admit to fear in anxiety-inducing situations and to avoid showing weakness, especially mental or emotional weakness, to others including health professionals (Goldstein & Stainback, 1987).

A secondary reason is that men with agoraphobia often use alcohol to suppress their anxiety and/or panic symptoms in public places and situations, which would then reduce the number of men seeking orthodox medical treatment (Goldstein & Stainback, 1987). For example, a study of alcoholic rehabilitation centres revealed that 45% of male patients had agoraphobia. Some clinicians argue that studies, which use psychiatric clinics or support groups, would attract a higher number of women, while studies using Alcoholics Anonymous (AA) or drug and alcohol centres would show a higher incidence of agoraphobia among men. Therefore, the alleged higher incidence of agoraphobia among women may simply be a data bias caused by the usage of groups that naturally attract higher numbers of women. The research has shown that the number of men with homebound agoraphobia is significantly lower than the number of women. Social research argues that it is less socially acceptable for men to leave paid employment and withdraw into the home as compared to women. Some clinicians have argued that the social pressure on men to maintain paid employment unintentionally encourages these men to develop coping strategies for anxiety in public situations (Goldstein & Stainback, 1987).
Marriage and Agoraphobia

In social work studies on the effect of agoraphobia on marriages/intimate relationships, social theorists have used the ‘family systems theory’ to provide the theoretical framework to interpret their case studies. The family systems theoretical discourse argues that families are a complex system of relationships, where each family member struggles with other members to meet their needs (Hudson, 1989). In family systems theory, the ideal ‘family group’ consists of family members who have achieved a balance between achieving their rights and accepting their responsibilities within the family group. However, when a family member has a psychological disability such as agoraphobia, family systems theorists argue that the marriages/intimate relationships and/or families have unintentionally been operating in a subtle and complicated way to create and maintain the agoraphobic symptoms in the family member. Generally, family systems theorists argue that agoraphobia is caused by inter-personal conflict within the marriage/intimate relationship and/or family group. Therefore, clinicians using the family systems model argue that the whole family group must adjust its system of functioning to cause a significant change in the agoraphobic family member (Hudson, 1989).

The family system theories have gained support from studies on the effects of parental upbringing and marriage, on women with agoraphobia. Studies have shown that pre-agoraphobic women are raised in families where the father is emotionally remote and physically withdrawn from close involvement with the family group (Webster, 1953). In addition, the mother is usually maternally dominating and overprotective, which causes pre-agoraphobic women to lack personal confidence and coping mechanisms in anxiety inducing situations. These pre-agoraphobic women were often attracted to partners who appeared confident and assertive in anxiety-inducing situations. The pre-agoraphobic woman’s development of panic attacks is seen to occur when her partner fails to provide confidence and assertiveness in anxiety-inducing situations or leaves her alone in anxiety inducing situations. The husbands/male partner’s actions can often contribute to the maintenance of the agoraphobic symptoms. For example, a husband/male partner may threaten to leave the relationship due to resentment towards the panic symptoms, which could raise the women’s level of stress and increase the likelihood of further panic attacks. Alternatively, a male partner may take charge of public roles and responsibilities, which undermines his partner’s confidence in anxiety inducing
A research project exploring the relationship between parental upbringing and marriage on women with agoraphobia studied the development of dependency in three married women with agoraphobia (Goodstein & Swift, 1977). The research showed that a dominant mother and a lack of parental nurturing inhibited the development of confidence and self-esteem in these three women. The three pre-agoraphobic women then sought spouses who reportedly showed strength and stability, which seemingly compensated for the weakness in the women. Researchers showed that the spouse’s masculine self-image was enhanced by the chance to exert power and control over their apparently weak and dependent wives (Goodstein & Swift, 1977).

However, several studies have argued that male partner’s masculine self-image often unintentionally reinforces their partner’s self-perception of lacking the ability to cope in anxiety inducing situations (Hafner, 1982). For example, spouses/partners of women with agoraphobia, are often overly protective of their partner who is suffering a panic attack, without realising that this masculine overprotection is actually reinforcing the avoidance of confronting fearful situations as well as deepening the dependency-orientated nature of their relationship (Hafner, 1982).

While family systems theory attributes responsibility to the whole family for causing and maintaining the agoraphobic dysfunction of one family member, other studies argue that the family member with agoraphobia is the source of family dysfunction (Dumont, 1997). These clinicians argue that the family member with agoraphobia places strain on the marriage/intimate relationship as well as family life. Also, the person with agoraphobia’s apparent helplessness and dependency on their partner and/or other family members generates resentment in both parties. While the person with agoraphobia resents feeling helpless and dependent on other family members, their partner (or other family members) may feel manipulated into undertaking a greater share of the social and emotional roles in the relationship, due to their agoraphobic partner’s alleged ‘problem’ (Dumont, 1997).
In some studies on marriages and families the parents, partners and children of people with agoraphobia are usually forced to accommodate the reclusive lifestyle of the sufferer (Kleinknecht, 1986). This often includes limitations on the social and recreational activities of all family members beyond the family home. For example, a partner who undertakes all public place orientated tasks (e.g. shopping, children’s outings, parent-teacher meetings, etc) will often have to reduce their own social and recreational activities to create time to meet these social obligations. Unfortunately, these families often struggle to gain informal (friends) or formal (social agencies) support, as the family member with agoraphobia appears perfectly normal, especially in the family home (Kleinknecht, 1986).

When conflict occurs in a marriage/intimate relationship, the partner with the agoraphobia usually suffers a significant deterioration in their agoraphobic symptoms (Mathews, et al. 1981). For example, in one study of marital stress and agoraphobia, 87 percent of people with agoraphobia stated that domestic arguments aggravated their anxiety problems (Mathews, et al. 1981). Also, inter-personal conflicts are cited as a major contributing factor in relapses among people with agoraphobia (Jansson, et al. 1984). Therefore, some clinicians argue that family conflict is a major contributing factor in the onset, maintenance and relapse of agoraphobia (Hudson, 1989).

While some clinicians view agoraphobia as having a detrimental effect on relationships, several clinicians have speculated that agoraphobia can often prevent marriage failure (Greist, et al. 1986). These clinicians argue that a partner of a person with agoraphobia may undertake more relationship building (nurturing) roles compared to the average person. For example, partners of people with physical (e.g. cancer) or psychological illness (agoraphobia) may become more supportive of a suffering partner. Also, clinicians argue that when a person with agoraphobia is unable to perform a family role in a public situation, their partner or other family members may assume this role with unintended positive consequences. For example, a father who may begin attending kindergarten or play centre sessions with their child, due to the mother’s inability to leave the home, would undoubtedly develop a closer relationship with the child. However, clinicians concede that regardless of the unintended positive consequences, the large majority of partners and family members are pleased when the person with agoraphobia regains their
independence, allowing family members to return to preferred pre-agoraphobic patterns of family life (Greist, et al. 1986).

Studies have shown that a significant number of people with agoraphobia are in marriages/intimate relationships with a partner who has an anxiety disorder (Saul, 2001). Several clinicians have argued that people with anxiety disorders seek a similarly affected partner who will readily identify with their condition and will be non-judgmental. However, one clinician has argued that when both partners have an anxiety disorder (or different mental health conditions), then a successful treatment programme for one partner could weaken the marriage/intimate relationship. The clinician argues that the successful treatment of one partner may cause resentment in their partner, causing conflict. Also, when the partner successfully managing their agoraphobia begins to change their lifestyle, it will often require changes in their partner who is still struggling with a psychological disability. For example, a partner successfully managing their agoraphobia may want to resume social engagements in public places, while their partner with social phobia would resist any attempt to engage in those social activities. However, some clinicians have argued that the successful recovery of one partner often assists the other partner in recovering from their psychological disability, which then improves the marriage/intimate relationship. Finally, one study makes the excellent observation that the success or failure of the marriage following a successful treatment programme, has less to do with the actual anxiety disorder, and more with the partners’ ability to change and adjust to new roles within the relationship (Saul, 2001).

Feminist studies of married agoraphobic women argue that these women exhibit an extreme stereotype of conditioned female behaviour (Fodor, 1974). The study argues that women are conditioned as children to exhibit the extremes of helplessness, dependency and lack of assertiveness, which causes women to choose a partner who complements these self-perceptions and attitudes (Fodor, 1974). Therefore, the male masculine sex-role (dominant and overprotective) reinforces the female sex-role stereotype (weak and dependent), which causes the emergence of agoraphobic symptoms in women (Fodor, 1974). However, another researcher has argued that male partners of agoraphobic women often have similar anxiety problems (Fry, 1974). It could be that the male partner’s anxiety disorder causes him to exhibit
extreme feminine sex-role stereotypes (lack of assertiveness and dependency) rather than overly masculine sex-role stereotypical (confidence and strength) behavioral patterns.

Social research into sexual relationships and agoraphobia has shown that loss of sexual arousal is a common occurrence, often when the partner with agoraphobia has developed depression, which can create stress in the marriage/intimate relationship (Gournay, 1989). However, the successful management of the agoraphobic and/or depressive symptoms normally improves sexual interest, which can lessen stress in the relationship (Buglass, et al. 1977, Gournay, 1989). In conclusion, the positive or negative impact of agoraphobia on marriages and relationships is often dependent upon the willingness and ability of people to respond constructively to changes occurring within the relationship.

Companions

Several research studies have investigated the role of the companion in the ability of a person with agoraphobia to cope with anxiety/panic in anxiety-inducing situations. One study has stated that people with agoraphobia often develop a personal attachment to a trusted companion whose presence reduces their anxiety symptoms in public places (Clarke & Wardman, 1985). This study argued that people with agoraphobia develop separation anxiety when the trusted companion is absent, this is especially common among people with homebound agoraphobia (Clarke & Wardman, 1985). For example, a housewife with agoraphobia will often make constant attempts to maintain telephone contact with a partner who is at their place of employment, as a means of reassuring themselves of their partner’s availability in the case of a panic attack (Clarke & Wardman, 1985). However, studies have shown that some people with agoraphobia will prefer to be alone in an anxiety-inducing situation, due to their unwillingness to disclose their anxiety to another person (Greist, et al. 1986). Also, studies have revealed that some people with agoraphobia are concerned that a support person or companion may attempt to hinder their flight from the anxiety-inducing situation (Greist, et al. 1986).

One study has shown that 95% of people with agoraphobia are more fearful in an anxiety-inducing situation when unaccompanied by a trusted companion (Marks, 1970). The trusted companion can be a parent, spouse or partner, or children who provide them with a feeling that
they are not alone should a panic attack strike in a public place or situation (Daley & Salloum, 2001). The person does not necessarily require a human companion, as a pet can often provide a feeling of security in anxiety-inducing situations (Chambless & Goldstein, 1982). It seems that the human or non-human companion is not the source for the increased sense of security to the person with agoraphobia (assuming a fox terrier wouldn’t be overly useful during a panic attack). However, the person may attach some form of fear reducing quality to the companion, which reduces their anxiety. For example, a person who is patting and stroking their fox terrier may feel a calming physical sensation, as well as shifting their focus from their anxiety symptoms to focusing their attention on their dog. Therefore, a person with agoraphobia, accompanied by a human or non-human companion can expand their safety zone to an admittedly limited degree (Chambless & Goldstein, 1982).

Alcoholism

In a study on people with agoraphobia and the incidence of alcoholism the research showed that 10% to 20% of patients had an alcohol abuse problem (Bibb & Chambless, 1986, Saul, 2001, Barlow, 2002). In another small study 40% of people with agoraphobia and/or panic disorder reported alcohol or substance abuse (Wittchen & Essau, 1991). Several studies have attempted to determine whether or not alcohol abuse precedes or follows the onset of agoraphobia (Wittchen & Essau, 1991). One study has shown that some people with agoraphobia use alcohol to suppress the panic symptoms following the onset of agoraphobia (Wittchen & Essau, 1991). Also, studies have shown that people with anxiety disorders develop alcohol dependency problems more rapidly than the general population (Mullaney & Trippett, 1979, Gold, 1989). However, the usage of alcohol often prolongs and deepens the panic symptoms, as well as adversely affecting any prescription medication the patient is using for the anxiety disorder (Gold, 1989).

Studies have shown that while the majority of people with agoraphobia are women, the majority of people with agoraphobia who suffer alcoholism are men (Saul, 2001). In Canadian research on the gender difference in alcohol usage it was argued that it is more socially acceptable for men to drink excessively to suppress anxiety symptoms, when compared to women. In addition, males with anxiety disorders are more willing to use alcohol to suppress
their symptoms. The Canadian research claimed that men are more inclined to believe that alcohol is an acceptable and practical means to cope with anxiety symptoms, compared to women. However, the Canadian research revealed that almost 1 in 3 women who were alcoholic had either a panic disorder and/or agoraphobia. While males with agoraphobia have a higher incidence of alcohol abuse compared to women, these same agoraphobic women have a significantly higher rate of alcoholism than women did in the general population (Saul, 2001). While studies have shown that there is a higher incidence of alcoholism among men, the increasing usage and misuse of alcohol by younger women may increase the incidence of alcoholism among women with agoraphobia (Gournay, 1989). Also, social scientists argue that the higher incidence of prescription medication abuse among women, may inadvertently be the reason for the lower number of women abusing alcohol to suppress their anxiety symptoms. (Gournay, 1989).

**Depression**

Psychological research has shown that people with agoraphobia report a higher incidence of depression (Thorpe & Burns, 1983). People with agoraphobia who are homebound suffer higher levels of depression, than other people who are able to function in public places and situations which is no doubt due to the higher rate of social isolation suffered by people who are homebound (Emmelkamp & Cohen-Kettenis, 1975). Psychologists argue that the social isolation of agoraphobia lowers confidence and self-esteem and causes the onset of depression (Greist, *et al.* 1986). Also, psychologists argue that the later the onset of agoraphobia the higher the occurrence of depression (Greist, *et al.* 1986).

One American research study has suggested that 20% of people with panic disorders (commonly associated with agoraphobia) attempt suicide (Saul, 2001). This percentage is higher than people with major depression and twenty times the rate among the general population. Should additional studies support this high percentage then a possible explanation for the higher rate of suicide attempts could be the personal and socially disabling effect of agoraphobia. Also, the agoraphobic person’s avoidance of public places, contact and situations means that peer support is inaccessible for the sufferer. Several studies have shown that peer support is a major factor in suicide prevention (Saul, 2001).
Several studies have shown that people with agoraphobia are often chronically anxious and are usually worried about some upcoming or recurring life event (Marks, 1967, Snaith, 1968). Also, people with agoraphobia who are chronically anxious or worried often suffer worse agoraphobic symptoms and will often have a tendency towards hypochondriac symptoms (Buglass, et al. 1977). For example, a person with agoraphobia experiencing the bodily sensation of indigestion will often believe that a heart attack is imminent or alternatively that a headache is actually an undiagnosed brain tumour (Clambless & Goldstein, 1982). Consequently, a large number of people with agoraphobia make unnecessary visits to general practitioners and hospital accident and emergency departments (Clambless & Goldstein, 1982).

An Australian study has shown that people develop agoraphobia more often in summer than winter months (Greist, et al. 1986). The reason people seemingly develop agoraphobic symptoms in summer months is that physiological changes, such as increased heart beat and breathing rates, sweating and dizziness during physical activity is more noticeable in the warmer climate (Greist, et al. 1986).

Some research studies have shown that people with agoraphobia have a higher than normal incidence of social phobia (Goldstein & Chambless, 1978). However, the combination of a disabling psychiatric disorder, loss of confidence and self-esteem, feelings of inferiority, lack of social contact, as well as the fear of others’ negative value judgements, no doubt contribute significantly to the higher incidence of social phobia (Burns & Thorpe, 1977, Arrindell, 1980).

Anxiety Management
There is a major debate among clinicians on whether or not agoraphobia can be completely cured or requires ongoing management over a lifetime. Some clinicians argue that a person with agoraphobia will continue to experience some waxing and waning in their anxiety disorder symptoms over their lifetime following medical intervention (Clarke & Wardman, 1985). However, clinicians argue that the reason for relapses is due to interpersonal conflicts, physical ill health, mental fatigue and other high stress situations (Clarke & Wardman, 1985). For example, in a 1979 study, a clear relationship was shown to exist between the relapse of agoraphobia and marital dissatisfaction (Milton & Hafner, 1979). This occurs in ‘compulsory
marriages’ where the spouse feels obligated to stay in a difficult marriage due to the continuing dependency of the agoraphobic partner, while the agoraphobic partner feels obliged to remain phobic and dependent on the marriage partner, as the removal of the phobia would increase the desire to leave the marriage, which would engender concern in causing a re-emergence of panic attacks (Fry, 1962). However, this does not mean that people with agoraphobia can never resume a normal life, as the usage of cognitive/behavioural management techniques and/or medication can reduce the reoccurrence and intensity of future panic attack symptoms (Clarke & Wardman, 1985). Also, partner support (relationship re-adjustment) and active involvement in support or self-help groups markedly reduces the recurring incidence of agoraphobia (Hand, et al. 1974, Sinnott, et al. 1981, Mathews, et al. 1977).

In the United Kingdom’s National Survey of Agoraphobics, 66.1% of respondents expressed concern about their ability to fully recover from agoraphobia (Thorpe & Burns, 1983). Ironically, the research revealed that 45% of agoraphobic sufferers experienced panic attacks when thinking about their inability to fully recover from agoraphobia. Therefore, the researchers argued that an agoraphobic sufferer’s relapse of panic attack symptoms could be caused by self-defeating thoughts, which induce anxiety symptoms (Thorpe & Burns, 1983).

The successful management of agoraphobic symptoms can cause the reawakening of other suppressed psychological problems in the individual. In one study, a patient reported an increase in depression; agitation and paranoia as the agoraphobic symptoms decreased (Thorpe & Burns, 1983). In another study, a person, upon completion of their treatment programme, developed alcoholism, aggression and violent jealousy in their marriage. Undoubtedly, the agoraphobic person’s preoccupation with the symptoms of their anxiety disorder often means that other psychological problems are suppressed, ignored or superseded by the agoraphobia. Several research studies have shown that a relapse of agoraphobic symptoms can occur several years later, after the completion of a successful treatment programme (Thorpe & Burns, 1983).

However, recent research studies have shown that when people with agoraphobia successfully complete a treatment programme, their personal wellbeing, communication, social skills, sexual
interest, employment prospects and life chances improve, which reduces their stress levels and anxiety symptoms (Saul, 2001).

**Social Implications of Treatment**

According to most research studies, people with agoraphobia seek medical treatment in their thirties (Marks, 1969, Marks, 1987). In one study, people with agoraphobia sought medical intervention between the ages of 23 to 29 years (Craske, *et al.* 1990). In another study, the average age of people in treatment programmes was 34 years (Breier, *et al.* 1986,). In yet another study of 68 patients the average age of treatment was 39 years old (Shafar, 1976). Therefore, people with agoraphobia usually seek medical treatment in the 20 to 40 year age groups. Studies have shown that people sought medical treatment from GPs about three years after the onset of panic attack symptoms and waited five years until seeking healing from a spiritual or religious healer (Thorpe & Burns, 1983). One study has argued that people with agoraphobia are able to avoid approaching GPs and/or mental health agencies by using a partner who enables them to successfully avoid confronting their symptoms of agoraphobia in public places (Goldstein & Stainback, 1987). For example, a housewife/mother with agoraphobia who is unable to enter public places will often be able to use a partner to do the supermarket shopping, attend play-centre or attend PTA meetings (Goldstein & Stainback, 1987). Some social research has been conducted on the social implications confronting people who are successfully managing their agoraphobic symptoms and are attempting to return to a ‘normal’ life. These studies tend to explore readjustment issues within marriages/relationships and families.

In the family systems theory, the family group is seen to operate as a self balancing system of relationships, where changes in one family member which threaten to disturb the family balance, cause other family members to take measures to re-establish the balance within the family group (Agras, 1985). Family systems theorists argue that when a family member begins to successfully manage their agoraphobia, then several changes can happen in the family group. Firstly, the family group could successfully adapt to changing roles in the family group. For example, a housewife/mother who is successfully managing her agoraphobia may resume the family supermarket shopping or attend kindergarten with her child alone, which will require her
partner to readjust by no longer exclusively performing those roles. Secondly, as a family member begins to successfully manage their agoraphobia, another family member may develop problems. For example, a husband/partner may develop jealousy towards a formerly homebound partner who begins to assert her independence by reclaiming a social life beyond the family home. In a study of husbands/partners of women successfully managing their agoraphobia, one partner attempted suicide, two developed depression and several others became jealous of their spouse’s reclaimed freedom. Finally, the family group may become dysfunctional and self-destruct, as family members make changes following the family member’s successful management of their agoraphobia. For example, a partner successfully managing their agoraphobia, who was previously unwilling to divorce an unfaithful or abusive partner due to their dependency on that person may pursue a separation/divorce once the dependency on their partner no longer exists (Agras, 1985).

Several clinical studies have argued that rapid intensive treatment programmes, which excluded the partner’s involvement, created relationship problems (Barlow, et al. 1983). These clinicians argue that intensive treatment programmes can cause rapid changes in one partner, without preparing their partner for dramatic changes in the relationship (Barlow, et al. 1983). The lack of knowledge and preparation for rapid and dramatic changes in the roles and responsibilities within the relationship are often cited as the commonest cause of marital problems (Barlow, et al. 1983). Therefore, the successful treatment of agoraphobic symptoms can lead to spousal resistance or the development of dissatisfaction within the marriage and family group (Liotti & Guidano, 1976). Finally, a significant number of studies argue that the successful treatment of a person with agoraphobia, involving relationship counselling with the spouse/partner, enables a successful readjustment in the relationship during and following the treatment programme (Webster, 1953, Lazarus, 1966, Milton & Hafner, 1979).

Clinical studies have shown that problematic marriages tended to adversely affect the treatment of the agoraphobic person (Agras, 1985). Generally, the more unsatisfactory the marriage/relationship the higher the incidence of the relapse of agoraphobic symptoms. According to clinical case studies a person will cling to their agoraphobic symptoms to
maintain the stability of a marriage when the other partner is resistant to any changes in their spouse and relationship (Agras, 1985).

While research studies debate whether or not the successful management of agoraphobia affects marriages/relationships and families, some researchers argue that people with agoraphobia have the same rate of relationship happiness or failure as the non-agoraphobic population (Gournay, 1989). A significant number of non-agoraphobic couples decide to separate or divorce following a partner’s successful involvement in other ‘treatment’ programmes (e.g. relationship counselling, anger management, drug and alcohol). Therefore, people with agoraphobia should not feel that their marriages are more problematic compared to other marriages. Instead, marriages and relationships, irrespective of the presence of agoraphobia, require partnership management skills when any changes occur in the relationship context.

Studies on the social implications of a successful management/treatment programme of long-term and/or severe agoraphobia include their ability to return to education and/or employment. Those studies that argue that school phobia is an embryonic form of agoraphobia, express the concern that agoraphobia causes educational under-achievement in secondary school-aged children (Chambless, 1983, Wittchen & Essau, 1991). Also, studies suggest that people who develop agoraphobia during tertiary studies attain a lower level of educational achievement, compared to the general population (Canino, et al. 1987). In the United Kingdom’s National Survey of Agoraphobics, involving 963 people with agoraphobia, their educational attainment was shown to be extremely low, with merely 11.9 pursuing educational opportunities upon leaving secondary school and merely 0.7 percent attending a University for tertiary studies (Thorpe & Burns, 1983). Therefore, people developing school phobia or agoraphobia during secondary and tertiary education could possibly have lower educational achievement and life chances.

There have been several studies on the social implications of unemployment among people with agoraphobia and the attempted return to employment of people successfully managing their anxiety disorder. In the United Kingdom’s National Survey of Agoraphobics survey of 963 people with agoraphobia, 60% of respondents were registered as unemployed (Thorpe &
Burns, 1983). In the survey, 83% of the people who were unemployed stated that their anxiety disorder prevented them from attaining employment (Burns & Thorpe, 1977). In addition, of the 40% of people who were employed, 48% stated that their agoraphobia prevented them from changing their current employment (Burns & Thorpe, 1977). These people stated that their reluctance to search for better employment included the increased travelling distance from their home which affected their ability to manage their anxiety disorder (Burns & Thorpe, 1977). Also, people stated an unwillingness to accept promotions that increased their public speaking roles and required the acceptance of more responsibilities (Marks & Hearst, 1970, Burns & Thorpe, 1977). These people expressed concerns that any absence from work due to panic attacks resulting from increasing stress associated with these roles and responsibilities, would endanger their new present employment position (Marks & Hearst, 1970, Burns & Thorpe, 1977). While people with agoraphobia struggle with an anxiety disorder, often the job seeking role causes secondary mental health problems such as depression, which hinders both their successful management of agoraphobia and their employment seeking activities (Thorpe & Burns, 1983). The long-term consequences for people with agoraphobia regarding unemployment, is the development of welfare dependency, financial stress, declining socioeconomic status and life chances (Torgersen, 1979). In contrast to the plight of people with agoraphobia who are unemployed, the United Kingdom’s National Survey of Agoraphobics, has shown that people who acquire employment report a significant improvement in both their anxiety disorder and life chances (Thorpe & Burns, 1983). Also, agoraphobic men have a significantly higher employment rate than women with agoraphobia (Thorpe & Burns, 1983). This gender difference could be explained by the higher incidence of severe agoraphobia (homebound) among women.

Technology and Agoraphobia

In western societies the expansion of communication technology networks has impacted dramatically on the lives of the average citizen (Agras, 1985). Increasingly, people are communicating with other people in the public domain (i.e. Internet) from the comfort of their homes. The increasing usage of the Internet may assist people with agoraphobia to gather information on their mental illness and treatments, as well as enable social contact with others similarly affected (e.g. chat-rooms and online support groups). However, the Internet may

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enable some people with agoraphobia to avoid panic attacks in public places by socially withdrawing to the safety of the chat-room in their home (Agras, 1985).

**Social Class and Environment**

Social research has shown that people with agoraphobia are represented in all socio-economic groups (Hudson, 1989). Anecdotal social work evidence shows that people with agoraphobia who shift from low socio-economic areas (sub-standard housing & high crime rates - real or imagined) often show significant improvements in the management of agoraphobic symptoms. Also, social work case studies have shown that people with agoraphobia who shift from in-patient care to low socio-economic inner-city areas often suffer a relapse in agoraphobic symptoms. There are several theories to explain why that social class and social environment affect agoraphobic symptoms. One social theorist has argued that people with agoraphobia who live in high crime areas are more likely to feel fearful in seemingly crime-ridden public places. Therefore, the person’s concern about safety in public places is reinforced with the knowledge of actual crime (endangering personal safety) in the community environment. For example, elderly people are constantly receiving the message from media reports and their peer group of the danger of venturing alone into public places due to street crimes. Another social theorist has argued that the absence of social integration (the presence of multiple and caring relationships) in a neighbourhood may contribute to the development of agoraphobia. People are often more socially isolated when they live in un-integrated neighbourhoods consisting of people who are often experiencing dysfunctional relationships caused by adverse social factors (e.g. crime, unemployment, welfare dependency, etc). A clinician commented on the common occurrence of young working class housewives coming from close-knit communities who developed agoraphobia following a shift into large housing estates. Another clinician described how a patient’s agoraphobic symptoms declined when she began to become involved in community groups within the inner-city environment. Generally, social theorists agree that lower socio-economic environments do not cause the onset or maintenance of agoraphobia, instead the stress of coping alone in a hostile environment seems to have a contributing role in the onset and maintenance of agoraphobic symptoms (Hudson, 1989).
Urbanisation
Several studies have shown a correlation between increasing urbanisation and people reporting agoraphobic symptoms (Wittchen & Essau, 1991). In one study, the rate of reported agoraphobia tended to be higher in the more urbanised areas: 4.6% in the central city area, 4.3% in the suburban areas, and 3.7% in small towns in rural areas (Robins, et al. 1984). In another study the rate of agoraphobia was 8.2% in the urban area and 4.6% in rural areas (Canino, et al. 1987). These studies tend to indicate that the higher the population concentration in a geographical area, the higher the incidence of agoraphobia. However, one study on the rate of agoraphobia in western cultures, which estimated a 1.2 to 3.8 per cent occurrence, argued that a similar prevalence occurred in African and Asian countries (Gournay, 1989). This study concluded that western urbanisation was not a significant factor in the rate of agoraphobia. However, the study failed to stated whether or not the African or Asian percentage were drawn from high population density areas or sparse rural areas (Gournay, 1989).

Religion
All research studies reviewed have shown that religion does not seem to have a role in the onset or development of agoraphobia. However, a number of people with psychological disabilities use traditional spiritual support and/or faith healing to alleviate personal symptoms and to reduce social isolation.

Conclusion
The literature review has shown the current body of knowledge on social interactions that are present in agoraphobia. This study will make an original contribution to social knowledge by gathering and analysing research participants material on these social interactions to determine how the various social interactions shape, and are shaped by, agoraphobia.
Chapter 2  Theoretical Perspective

Thesis Rationale for using the Interactionist Approach

Sociological theories tend to focus on the role of macro-level structural forces (conflict and functionalist discourses) on groups of individuals. However, the symbolic interactionist theoretical framework focuses on micro-level social process occurring within individually encountered social interactions. The Interactionist approach will enable the deconstruction of the social processes occurring at the onset, unmanaged, and managed symptoms stages of agoraphobia, which affect the lived experiences of research participants with agoraphobia. The Interactionist theoretical perspective on micro-level social processes makes it the ideal theoretical framework for analysing micro-level social processes and social interactions in the lived experiences of research participants. The thesis will use Blumer’s and Goffman’s theoretical frameworks from their publications; *Symbolic Interactionism - Perspective and Method* (Blumer 1969), and *Stigma - Notes on the Management of Spoiled Identity* (Goffman, 1973). These Interactionist theorists and their theoretical frameworks are ideally suited to analysing meanings, social process in this thesis. Schur’s book entitled *Labeling Deviant Behavior* (Schur, 1971), has been included as its Interactionist oriented labelling approach will be useful in exploring one of the key themes in this thesis.

These Interactionist perspectives will be applied to the analysis of four key themes in this thesis. Blumer’s theoretical framework will enable the exploration of agoraphobia as self-interaction influenced by social processes occurring within social interactions and situations. Goffman’s theoretical discourse on stigma and its management will allow an investigation of the relationship between the stigmatised (people with agoraphobia) and others (partners, companions, etc). Also, Goffman’s theorising will enable an inquiry into people with agoraphobia’s perception of the boundaries of normalness, and how they perceive their relationship with ‘normals’ in the social world. Finally, Schur’s revision of the labelling approach will allow the deconstruction of research participants’ interactions with health professionals, including the role of the therapist in the defining and treating of agoraphobia.
Historical Origins of Interactionism

The historical roots of Symbolic Interactionism, or Interactionism began with the American pragmatist philosophers, Peirce, Dewey, Cooley, and Mead who theorised on the subjective meaning of human behaviour, social process, and pragmatism (Coser, 1971, Lindesmith, et al. 1999). The pragmatist philosophers, Peirce, Dewey and Cooley emphasised the role of social interaction in achieving orderly daily life, rather than large scale social structures, social forces and laws. This philosophical perspective placed the emphasis on social interactions that involved the usage of symbols in communication and social interaction where others construct Self through communication and interaction (Coser, 1971, Lindesmith, et al. 1999).

John Dewey’s (1859-1952) theoretical contribution to the philosophy development of Interactionism was his view that an interaction existed between humans (as biological organisms) and the natural world and that as humans we could only be understood in relation to our environment. According to Dewey, the role of thought was to allow humans to adjust to their environment (Coser, 1971, Gingrich, 2000).

In 1892, Charles Horton Cooley (1864-1929) began teaching at the University of Michigan, where he theorised on the subject of the Self. Cooley emphasised the interconnectedness of the dualism of society and the individual and believed that the two could only be understood in relationship to each other. Cooley’s concept of the looking-glass was heavily influential on Mead’s theorising on Self, which influenced the paradigm of symbolic interactionism (Coser, 1971, Gingrich, 2000).

Both Dewey’s and Cooley’s theories were influential on George Herbert Mead (1863-1931). Mead as a Professor of Philosophy at the University of Chicago from 1894 to 1931 taught a course entitled “Social Psychology”, which was regularly attended by graduate students from the Sociology Department. Mead called his theoretical approach “social behaviourism”, which focused on the role of the conscious mind, self-awareness and self-regulation of social actors. According to Mead, the individual’s concept of Self emerged from the social interaction where the individual takes on the role of the “other” and internalises the attitudes that he/she perceives in the real or imagined other. Mead’s view that the interaction of the individual’s self-conception (“I”) with the perceived generalised view that others have of the individual
(“me”) was central to his theorising on Interactionism. In Mead’s philosophical framework he focused on the subjective meaning and experience of human behaviour within social processes. In Mead’s theorising, the human group was essential for the emergence of consciousness, the mind, a world of objects, the possession of self, and human behaviour as a form of constructed acts. While Mead did not write a book; he followed the “oral tradition” of instruction and published numerous articles and book reviews in his lifetime. Mead’s lecture notes were published in several books following his death by his former students. These books included *Movements of Thought in the Nineteenth Century*, (1936); *The Philosophy of the Present*, (1932); *Mind, Self and Society*, (1934); *The Philosophy of the Act*, (1938), which formed the theoretical foundations of symbolic interactionism. In the *Mind, Self and Society*, (1934) the key aspect to his theorising on symbolic interactionism was understanding how the individual mind and self arose out of social process (Coser, 1971, Gingrich, 2000).

While Mead is recognised as the founder of symbolic interactionism, it was Herbert Blumer (1900-1987), who in 1937 coined the term, “symbolic interactionism”. Blumer, one of Mead’s graduate students at the University of Chicago, took Mead’s ideas and developed them into a sociological theoretical framework, and formulated the most prominent version of this theory. Blumer promoted the interactionist perspective throughout the early 1950s at Chicago, and then in California where he was a professor at the University of California in Berkeley. Among Blumer’s graduate students at the University of Chicago, were Erving Goffman (1922-1982) and Howard S. Becker (1928). Goffman became a professor at Berkeley and later at the University of Pennsylvania. Goffman used the symbolic interaction approach to examine human interaction in different social settings. His major contribution was his analysis of the interaction order - social situations where two or more individuals are in one another’s physical presence. In addition, to studying the interaction order in ordinary social situations he examined interaction in prisons and asylums (i.e. total institutions), to show how individuals used various means to maintain their sense of selfhood. In the 1960’s Becker devised and presented the labelling approach in his book *Outsiders: Studies in the sociology of deviance*, (1963). Becker conceptualised deviance in terms of societal reactions to rule-breaking and applied it to the analysis of criminal offending. In the 1970s, Edwin Shur expanded the labelling approach to include concepts such as negotiation and bargaining, which he applied to the psychiatric diagnosis of patients (Coser, 1971, Gingrich, 2000).
Blumer - Introduction to Symbolic Interactionism

In Symbolic Interactionism - Perspective and Method’ Blumer presents three premises about human interaction, which forms the basis of symbolic interactionism. The first premise is that people act towards things on the basis of the meanings that the things have for them. These ‘things’ include physical objects (e.g. drugs), other individuals (e.g. a research participant), categories of people (e.g. people with mental illness), institutions (e.g. mental hospitals), guiding ideals (e.g. patient rights), activities of others (e.g. medical supervision) and any other situations that a person may encounter in their everyday life. The second premise is that the meaning of these things is derived from, or arises out of social interaction with other people in daily life. For example, a doctor’s peer group discussion about a patient’s symptoms would most likely lead to the attachment of medical meanings to the patients condition. The third premise is that these meanings are handled, and modified, through an interpretative process that the person uses in dealing with the things they encounter in their daily life. For example, the doctor would interpret the self-report of their patient from concepts developed from their medical training background (Blumer 1969).

The Symbolic interactionist perspective challenges the traditional approach of the social and psychological sciences to meaning. The social and psychological sciences were seen to take meaning as given and viewed it as unimportant, or regarded it as merely a neutral link between the social and psychological factors responsible for producing human behaviour. In addition, the meaning of things that affect human behaviour seemed to be overshadowed by psychological factors of stimuli, attitudes, conscious or unconscious motives, perception and cognition which were seen to produce human behaviour, and sociological structural and functionalist discourses on social structures, social positions, status, social pressure, group affiliations, roles, culture, norms and values which were seen to be central in explaining human behaviour (Blumer 1969).

The social and psychological theoretical framework meant that studies on human behaviour simply searched for initiating factors and the resulting behaviour, which eliminated the need to explore and understand the role of the meaning of things in human actions. Some social and psychological theoretical frameworks simply merged meaning into the initiating factors, or reduced the role of meaning into a neutral transmission link between the initiating factors and
the resulting behaviour. In comparison, the symbolic interactionist theoretical perspective locates the meanings that things have for humans as central in formation of human behaviour (Blumer 1969).

The traditional social and psychological sciences’ approaches toward meaning are further challenged by symbolic interactionism. The traditional approach to science was “realism” where the observer would simply observe the object to recognise its meaning, as the meaning of the object was seen to emanate from the intrinsic properties of the object. The alternative traditional approach towards meaning was that it arose through a coalescence of psychological elements operating in the individual, such as attitudes, feelings, ideas, memories, motives and physical sensations. In contrast, symbolic interactionism rejects the traditional approaches that locate the source of meaning in the object or the mind of the observer. Instead the formation of meaning comes out of interaction between humans. To the symbolic interactionist, the person’s development of meaning towards a thing arises out other people’s acts towards them in relation to that thing, which defines the thing for the person. Therefore, meanings are socially produced through the defining activities occurring in interaction with other people (Blumer 1969).

While the meaning of things arises out of interaction with others, and is derived by the person from that interaction, the development of meaning involves an interpretative process. The process of interpretation initially involves the person indicating to themselves the thing towards which they are acting, and then identifying to themselves the things that have meaning. This internalised social process involves the person’s engagement in self-interaction in the form of internal dialogue. Secondly, the process of internal dialogue and interpretation enables the person to handle the meanings attached to the thing. The process of interpretation is a process where meanings are formed, used and revised as frames for the guidance and formation of action. Therefore, the role of meaning is embedded in the process of self-interaction (Blumer 1969).

The symbolic interactionist theoretical framework for analysis on society and its members is based on a number of basic ideas referred to as “root images”. These root images address the following matters of human societies, social interaction, objects, actors and actions and the
interconnection of actions. The theoretical framework starts with the basic idea that human societies consist of individuals engaging in action. An individual performs a multitude of activities as they encounter others in order to deal with situations. The individual may at times act singly, collectively, on behalf of, as representative of, or as part of a group. These activities belong to the acting individual and are carried out by them in relation to the situation, in which they have to act. Therefore, the first and foremost basic root image is that human society consists of humans engaging in action (Blumer 1969).

The second root image is that a society consists of individuals interacting with others and that activities between individuals arises predominantly out of interaction between one another. An individual interacting with others must take into account the actions (or intended actions) of others and direct (or redirect) their own conduct in those activities according to the actions (or intended actions) of others. Therefore, social interaction is seen as a process that forms human activities. Blumer divides these social interactions into non-symbolic interaction, where an individual responds to the actions of others without interpreting the action, and symbolic interaction is where the individual interprets the action of others (Blumer 1969).

The third root image is that human “worlds” consists of objects and that these objects are the product of the process of social interaction. An object is anything that can be indicated or referred to and are usually classified into three categories (1) physical objects, (2) social objects and (3) abstract objects. The nature of an object consists of the meaning that it has for the individual for whom it is an object. The meaning attached to the object shapes how the object is seen, is acted towards, and is spoken about by the individual. An object may have different meanings to individuals, due to individuals attaching different meanings to the object through their interaction with others towards that object. However, individuals often develop similar meanings towards an object through interacting with others that share a common meaning towards the object. Finally, the social process of interacting between individuals means that objects are created, affirmed, transformed and dismissed (Blumer, 1969).

The fourth root image is that humans are acting organisms that make indications to others and interpret the indications of others. According to Mead, the ability of humans to be acting organisms requires them to possess a concept of “self”. This simply means that a human can
see themselves as an object in their own actions and act towards themselves and are guided by their action towards others on the basis of being that object. For example, a person who is a doctor will act towards himself/herself and be guided in interactions with others (e.g. doctors and patients) on the basis of being a doctor. The person’s ability to become a self-object emerges out of the process of social interaction with others that defined the individual as that object (e.g. a person becomes a doctor through interactions occurring at medical school). Meads argues that a person’s ability to become an object requires them to engage in role-playing where they placed themselves in the position of others and viewed or acted towards themselves from the others perspective. For example, a therapy student learning counselling skills could role-play a therapist and talk to herself as she believed a therapist would talk to him/her as a patient. This role-playing allows us to define ourselves as objects through others. The theoretical acknowledgement of the concept of self recognises self-interaction (internal dialogue) as a social interaction in that people addresses themselves as people who are responding thereto. This self-interaction enables the individual to make indications to themselves of the meaning of objects and their relevance or importance to actions. The social process of making indications to ourselves and responding to those indications thereto enables the making of what is the object, gives it a meaning and allows for that meaning to form the basis for directing its actions. Therefore, humans who are engaging in self-interaction are not merely a responding organism, but an acting organism that acts on the basis of what it takes into account (Blumer, 1969).

The fifth root image is that humans’ ability to make indications to themselves means that they must interpret in order to act in their environment. The individual must construct and guide their actions to handle situations where action is required by ascertaining the meaning of the actions of others and undertake actions based on those interpretations. Therefore, human interaction involves individuals engaging in activities occurring in a flow of situations in which the individual has to act, and that the action is based on what the individual notes, how they assess and interpret what they note and the lines of actions that are mapped out from those notes (Blumer, 1969).

The final root image is that group life consists of, and exists in, the fitting of individual lines of action to the group. When these lines of action come together they create and constitute “joint
action” - a societal organisation. The joint action is different from any one act as well as from their aggregation. The joint action is distinctive in its own right, as its character lies in its articulation, as set apart from what is articulated in the individual lines of actions. Therefore, the joint act can be identified and handled without having to separate and engage the individual lines of actions. In Blumer’s essay he makes three observations on the joint actions. The first observation was that in human societies the majority of joint actions are stable and repetitive, where people act towards each other on a shared understanding of how to act and how the other will act. In these join actions pre-established and common meanings exist that enable individuals to know what actions are expected from participants, which enables each individual to guide their behaviour according to those meanings. A society’s ability to maintain pre-established and repetitive joint actions requires the same meanings and individual lines of action fitting together to renew the joint action. However, pre-established and common meanings are constantly threatened by new and emerging problematic situations that give rise to new meanings and lines of actions, leading to the formation of new joint actions. Therefore, stable and repetitive joint action is continuously vulnerable to the pressures placed on meanings from new social processes. The second observation was that traditional sociologists saw human societies as extended connections of actions that constituted group life. To these sociologists, the large complex networks of interlinkages and interdependent relationships created a system that regularised patterns of participation for a diverse range of people undertaking a diverse range of actions. This sociological perspective placed importance on the study of “systems” rather than the importance of meaning in explaining human behaviour. In Blumer’s essay he argues that people participating in systems occupy different points in the system and engage in actions at those points on the basis of the meanings they have developed through interaction with others at that point in the system. The human system should not be seen to function automatically due to some inner dynamics or the requirement of the system; instead its function is dependent on individuals at different points doing something that is the result of their definition (sets of meanings) of the situation where they are required to act. In addition, the individual’s sets of meanings that lead to actions are produced through a process of social interaction localised at that point in the system. Therefore, the system’s ability to function is dependent on the processes of interpretation that occurs among the different participants positioned at different points in the system. The third observation is that any new joint action emerges from and is connected to previous joint actions and that joint actions by
necessity have arisen out of a background of previous actions of individuals. Those individuals engaged in the formation of a new joint action bring with them objects, sets of meanings, and pre-existing interpretations into the new joint action. Therefore, joint action represents both a linkage of activities of individuals and a linkage in previous joint actions (Blumer 1969).

In summary, the symbolic interactionist’s theoretical approach views society as comprising of individuals engaged in living their lives through the process of social interaction and self-interaction. The thesis’ usage of the symbolic interactionist theoretical framework will enable the researcher to analyse the research findings to show the role of social interaction and self-interaction in the development of meanings, objects and lines of action, etc associated with agoraphobia.

Goffman - Stigma

The 1973 reprint of Goffman’s book ‘Stigma - Notes on the Management of Spoiled Identity’ has been selected for this thesis to provide the theoretical framework to explore the themes of stigma and normalness. The thesis’ theoretical exploration of stigma and normalness will include the discredited and discreditable, social information, visibility, personal identity, biography, biographical others, passing, techniques of information control and covering. In addition, the theoretical exploration will investigate the relationship between the stigmatised and others, social and personal identity, ambivalence, professional presentations, in-group alignments, out-group alignments, politics of identity, deviations and norms, the normal deviant and stigma and reality. The major advantage of this Interactionist theoretical framework is its proven relevance and usability in studying people with mental illness shown by the regular citing of material in the book from this stigmatised category. Therefore, this theoretical framework promises to provide an excellent tool to analyse the research participants’ lived experiences on the two themes of stigma and normalness.

In ‘Stigma - Notes on the Management of Spoiled Identity’, Goffman begins with the premise that society establishes a means to place people into categories, where their attributes are seen as natural and ordinary in those categories. In everyday social interaction a person’s ascribed membership to a category of attributes establishes their ‘social identity’ in the setting. In this social interaction the actor is expected to conform to the attributes of their category in the
established setting. When people ascribe a person as belonging to a specific category this characterisation creates a ‘virtual social identity’, while the person’s actual category and attributes are their ‘actual social identity’. When a person is seen to possess an attribute that makes them different to others in their category, and when this attribute is less desirable, the person’s status is reduced among others. When this less desirable attribute has a significant discrediting effect it is referred to as stigma. This stigmatised identity is a special discrepancy that exists between virtual and actual social identity. However, stigma is more than an attribute, it is the relationship between the attribute and its stereotype (Goffman, 1973).

In Goffman’s discourse, stigma is applied to two groups, the discreditable and the discredited. The discreditable person assumes that their attribute is unknown or is not perceivable to others (e.g. people with non-visible disabilities such as mental illness), while the discredited person assumes that their difference is known about, or is immediately evident to others (e.g. people with visible disabilities such as the physically disabled). A person can be both discreditable and discredited to others at the same time (i.e. a person with non-visible and visible disabilities (Goffman, 1973).

Goffman argues that normal’s attitudes and actions towards the stigmatised who are seen as not quite human, lead to various acts of discrimination, which effectively reduce the life chances of the stigmatised individual. The normals’ construction of a stigma involves theorising and adopting an ideology to explain the inferiority of the stigmatised individual, as well as using specific terms in their daily discourses to impute undesirable attributes to the individual, such as ‘madman’, ‘crazy’, ‘possessed’. Should the stigmatised person express defensiveness to the usage of these terms, their response is seen to be a part of the category of undesirable attributes. The stigmatised person’s regular contact with normals creates and maintains an awareness of others’ perspectives and discourses on the stigmatised person’s failings. The stigmatised person’s awareness of these perceived failings often induces feelings of shame, self-hate and self-derogation. The stigmatised person often has to accept the loss of respect from others that would have been extended to the unstigmatised attributes of his/her social identity (Goffman, 1973).
According to Goffman, the stigmatised person can attempt to respond to their situation by taking direct action to correct the objective basis of the undesired attribute. For example, a person with mental ill health disabilities may seek psychotherapy to correct their condition. However, the stigmatised person’s attempt to return to a normal status or to acquire the status of a person who is seen to have corrected their undesirable attribute can lead to victimisation through exposure to fraudulent practises (e.g. scientifically untested therapy). The stigmatised person can respond to their situation indirectly through mastering activities that are seen to be beyond the reach of the person with the undesired attribute, such as a person with a mental ill health disability undertaking study that requires a high level of rational thought. In addition, the stigmatised person can attempt to present an unconventional interpretation to the character of their social identity, such as a person with a mental ill health disability who is seen as “eccentric”, wearing clothing worn by alternative lifestyle groups. The stigmatised person may attempt to use their stigma as an excuse for failure, or see the undesirable attribute as a blessing if it is felt that a lesson has been learnt. Alternatively, the stigmatised person may develop an awareness of the undesirable attributes of normals, such as their ignorance and intolerance towards stigmatised peoples (Goffman, 1973).

While Goffman’s theorising acknowledges that the stigmatised and normal would often avoid each other in daily life and that the stigmatised person would often suffer hostility, suspicion, self-isolation, anxiety and depression due to this avoidance, he focused on the relationship between the stigmatised and normal in ‘mixed contacts’ where they were in the same ‘social situation’. The stigmatised person in the mixed contact situation may feel unsure about how they are thought of, identified, categorised and received by the normals. The stigmatised person may also feel self-conscious about the impression that they are making about themselves to normals. In addition, the stigmatised person may feel that normals’ praise of their completion of everyday activities reinforces the impression that their ability to complete ordinary tasks is the exception to the rule. The stigmatised person may feel that the sighting of any of their failings by normals will be interpreted as an attribute of their stigmatised difference. For example, a person with depression showing grief following a tragic event may have their grieving interpreted by normals as evidence of their depression. In this scenario the stigmatised person is likely to feel an invasion of privacy by their failing being perceived in the presence of normals. The stigmatised person’s response to these encounters may be
defensive and cowering or undertaken with hostile bravado, both of which can lead to negative repercussions. The stigmatised person may appear too aggressive or too ashamed and in both scenarios and be seen as too willing to read unintended meanings into normals’ actions. Due to the problems in the mixed contact situation, the stigmatised person and normals may feel anxiety, self-consciousness and experience interaction-uneasiness. Ultimately, the problems in mixed contact situations leads to normals acting towards the stigmatised person as a non-person (Goffman 1973).

Goffman argues that the stigmatised person’s over-exposure to problems in mixed contact situations means that they’re likely to develop strategies to manage their spoiled identity. The stigmatised person’s management of their spoiled identity is often undertaken with the aid of a sympathetic other. The sympathetic other may be a person who shares the same stigma as the stigmatised person who can instruct them how to manage their stigma and provide acceptance and moral support as required. Sometimes the stigmatised person enters a stigma category with sympathetic others. The stigma category will often be formed into a small social group that provides organised support for its members (i.e. support groups). These small groups enable members to share their stories and form friendships. These small-organised groups can often act on behalf of their members through advocating for the rights of the stigmatised person to various audiences of normals and the stigmatised. The speakers of these groups present the case of the stigmatised in their public discourses and many stigmatised speakers are role models of successful adjustment and normalisation. These speakers and groups often publish material to give voice to their members, to disseminate success and atrocity stories, create a sense of belonging among members and identity enemies of their group. These publications may include the advertisement of resources required by the stigmatised person to successfully cope in their daily life (Goffman 1973).

The leaders (i.e. speakers) of these groups often develop a career through their attainment of political, financial or occupational position in the group. These leaders in making a profession of their stigma are obliged to deal with representatives of other categories, which means that they socialised beyond their stigma category. The leaders’ interaction with representatives of other categories may undermine their social interaction and their representation of members. Also, the leaders’ representation of the stigma to others may simply reflect their personal
experience of the stigma, which may be unrepresentative of members’ experiences (Goffman 1973).

Goffman believed that the stigmatised person could acquire support from a ‘wise’ person as well as a sympathetic other. The wise person is a normal who is sympathetic to, and has an intimate knowledge of the life of the stigmatised person and is accepted by the stigmatised person as an ordinary other. The normals change into a wise person often involves a heart-changing personal experience towards the stigmatised and requires validation and acceptance by the stigmatised persons. Therefore, the stigmatised person’s acceptance of the wise person bestows a courtesy stigma upon them. However, the wise person’s appearance of carrying the burden of a stigma that is not actually theirs can annoy the stigmatised and normals and their continuing acceptance by the stigmatised is often in doubt. In addition to the sympathetic wise person, the relative of the stigmatised person can fulfil the role of a wise person. In this case, the stigmatised person and the wise person are sometimes seen as the same by normals. This sharing of stigma to the relative can cause strain or termination their relationship with the stigmatised person. However, some relatives’ respond to their de-facto stigmatisation by embracing and living alongside those in the stigmatised category. Whether the wise person is a sympathetic normal or socially related, a significant number will often work in organisations that cater for the needs of the stigmatised person/group (Goffman, 1973).

Goffman states that people who share a similar stigma have a similar ‘moral career’ that causes and affects their commitment to the same sequence of personal adjustments. These stigmatised individuals have a similar conception of self and have a similar socialisation experience (learning experience) around their condition. The stigmatised person’s socialisation process involves them learning and adopting the normals’ point of view towards the stigmatised category. The stigmatised person learns the normals’ beliefs about the identity of the stigmatised category and allows the stigmatised person to know what it would be like to possess that stigma in society. In addition, the socialisation process involves the stigmatised person learning that they have the stigma and the consequences of possessing that stigma. The interplay and timing of these two parts of the socialisation process (moral career) is important in forming patterns and establishing the foundations for the future moral careers of the stigmatised in normal society Goffman, 1973).
In Goffman’s discourse he mentions four patterns in the moral careers of the stigmatised. The first pattern involves people with inborn stigma who are socialised into a disadvantageous situation while learning and adopting normals’ standards which are beyond their reach to achieve due to their stigma. In the second pattern, family members and others form a protective capsule around the young stigmatised person who is sustained through information control. These family members prevent devaluing definitions from reaching the child while allowing other conceptions to penetrate the protective capsule to reach the child, especially if these assist the child to develop a normalised identity. The third pattern relates to people who become stigmatised in later life, or learn in later life that they have always been discreditable. While people who become stigmatised in later life do not require to radically review and reorganise their past experiences, those people who learn in later life that they have always been discreditable will struggle to re-identify themselves since they have been socialised into thinking that they are normal and that the stigmatised are deviant. The fourth pattern includes people who are initially socialised into an alien community, who must then learn the values and norms of the valid community (Goffman, 1973).

Goffman argues that people can feel ambivalence towards their stigmatised category due to their socialisation towards normals and the stigmatised. The stigmatised person may oscillate between identifying, participating and supporting the stigmatised and normals. The person will go through ‘affiliation cycles’ where the special opportunities for in-group participation are accepted or rejected. The stigmatised person’s relationship with their own informal community and formal organisations is important in enabling them to review their moral career. In these own informal community and formal organisations the stigmatised person can single out or elaborate on past experiences, which shaped their beliefs and practices towards people who share their stigma and normals. The stigmatised person’s recall of past experiences, enables them to identify life events that were turning points in their moral career, as well as using these life events to account for their current position. The stigmatised person’s interaction with group members which involves sharing stories enables them to learn that group members (and themselves) are simply ordinary human beings (Goffman, 1973).

Goffman’s theorising continues with an exploration of the stigmatised persons’ management of information to protect their personal identity in mixed contact situations. While the
discredited person has little control over information related to their stigma and will attempt to manage tension during social interaction, the discreditable person can attempt to control information about their stigma in mixed contact situations. Those discreditable persons who conceal information about their stigma (e.g. mental illness) during mixed contact will be accepted by others who are prejudiced against persons with that stigma. Should the discreditable person decide to reveal their actual social identity they must decide whom, how, when and where to tell or not to tell; to let on or not to let on; to lie or not to lie; to display or not to display; and so on (Goffman, 1973).

The most relevant information about the stigmatised person is their social information. The term ‘social’ information refers to the stigmatised person, through bodily expression in the presence of others, conveying their characteristics. When these signs steadily and routinely convey social information they are referred to as ‘symbols’. Should a sign convey a desirable characteristic it is called a ‘status symbol’ or ‘prestige symbol’. However, should the sign convey a undesirable characteristic then it is referred to as a ‘stigma symbol’. These stigma symbols include signs that convey an informational function (e.g. a person who has scars on their wrists showing a attempted suicide), and signs which convey social information Signs that convey social information can be congenital, or a permanent part of the person, or impermanent signs. Those signs employed to convey social information are usually stigma symbols. These signs can have different meanings to different groups, as the same category is designated but differently characterised. The challenge for the stigmatised person is the management of social information when dealing with being seen ‘with’ others. (Goffman, 1973).

Goffman states that the stigmatised person’s ability to manage social information is heavily influenced by the visibility (or perceptibility) of their stigma and the presentation of these signs in social interaction informs others of their social identity. The stigmatised person’s regular and routine presentation of these signs means that they must develop strategies to counter its effect in interactions with others. While the stigmatised attempt to manage information to reduce the visibility of their stigma, the success of these strategies is dependent on the decoding abilities of the normals in the mixed contact situation.
Traditionally, the stigmatised person’s management of social information was seen to occur mainly in public places between strangers. In these mixed contacts, the stereotyping of people in the stigma category influences the normals’ responses to the stigmatised person. In contrast, the social interaction occurring in private places where a close relationship exists between the stigmatised and normal, is seen induce responses of sympathy, understanding and a realistic evaluation of personal qualities of the stigmatised person. However, Goffman argues that normal’s familiarity may not reduce their contempt for the stigmatised person. While the normal may live, work, and play alongside the stigmatised, they may continue to retain their societal formed perceptions of persons in that stigma category (Goffman, 1973). For example, a person who ‘comes out’ as gay may acquire positive support from family members due to their familiarity with them, while other family members react negatively due to societal stigma towards gay persons. Therefore, the stigmatised person may be required to manage social information in private and public places (Goffman, 1973).

Goffman states that the stigmatised person’s management of stigma is dependent on whether or not they are personally known to others. In small-established social groups, other members will personally know a member as a ‘unique’ person. The term unique refers to people who have an ‘identity peg’ (e.g. a particular article of clothing) and people with a set of facts (e.g. life history) particular to themselves which distinguished them from others. The combination of identity pegs and a life history, which are attached to an individual, establish their personal identity. Therefore, personal identity requires differentiation between the person and all others and around this is built a single continuous record of social facts to which other biographical facts can be attached (Goffman, 1973).

Goffman states that the stigmatised person’s biographical facts are maintained in the minds of intimates and/or the personnel files of an organisation. This means that the person becomes an object for biographical recording. The stigmatised person can attempt to present in these biographies a social role, which is different from their role in the stigmatised category. The stigmatised person’s ability to manage social facts about themselves is dependent on the segregated audience’s knowledge about the ‘informational connectedness’ of facts within the biography. The stigmatised person’s management of their biography can enable them to socially misrepresent themselves and mask their personal identity. The person’s stigma and
their concealment of this stigma often become a ‘fixed part of their personal identity. When the discreditable stigma and the social misrepresentation are discovered the stigmatised person is discredited and their reputation is damaged (Goffman, 1973).

The stigmatised person’s management of their personal identity creates a division among others, into the knowing and the unknowing. The knowing have a personal identification of the individual, while the unknowing do not have a personal biography of the individual. The key difference is ‘how much’ is or is not known about the stigmatised person by others. The stigmatised person’s problem in managing their social and personal identity is whether others know about them, and whether the stigmatised person knows that they know about them. The key point is that different people have different amounts of information about the stigmatised person, which affects their perception of their personal and social identity (Goffman, 1973).

When the stigmatised person’s stigma is invisible (e.g. agoraphobia) and is known only to the person possessing it, the role of ‘passing’ arises. The person with an invisible stigma may attempt to pass as normal to others to receive the benefits of being seen as normal. However, the person’s attempt to pass as normal can be undone by those who have personal identification of them and have biographical details that are incompatible with their passing as normal. The stigmatised person can sometimes be forced to live a double-life of attempting to pass as normal, while attempting to conceal information about their stigma. The stigmatised person’s attempt to pass as normal creates the danger of being blackmailed by those who know their real personal and social identity. Also, the stigmatised person risks inadvertent disclosure when those who know the biography of their real stigmatised identity come into contact with those who know the socially constructed biography of the normalised identity. The stigmatised person must attempt to pass as normal in different spatial worlds, which includes forbidden places, civil places and back places (Goffman, 1973).

Goffman states that the problems and consequences of passing include the unanticipated need to disclose discrediting information to others, such as the disclosure of discrediting information to receive some form of benefit. The stigmatised individual often feels under pressure to elaborate a lie further to prevent disclosure to others of the actual truth, The stigmatised person’s use of adaptive techniques could hurt the feelings of others or create
misunderstandings with others. Also, the individual’s concealment of their stigma may cause them to display another stigmatising behaviour to others. In addition the individual’s successful passing as a normal may leave them open to learning what normals ‘really’ think of those individuals’ in that stigmatised category. The individual normally does not know how much information is known about them by others, and risks exposure through failing to effectively hide their stigma, by their stigma being revealed by others who know, or accidentally revealing the stigma during social interactions. Also, the individual’s attempt to pass may be complicated by the presence of people who share the stigma, who are aware of the techniques being used to conceal that stigma, and who tell others of the persons stigma and their tricks to hide it. Finally, the individual may be confronted by others who have learnt about the secret and the attempted deception (Goffman, 1973).

The stigmatised person’s control of identity information has a special bearing on close relationships. The stigmatised person’s forming of a close relationship often involves spending long periods of time together, which increases the chance of discrediting information being revealed. In addition, the parties will feel obliged to share an appropriate amount of intimate facts about themselves as part of the trust and mutual commitment required in building a close relationship. Therefore, the stigmatised person begins the relationship concealing information, which is then compromised and becomes deficient when the parties exchange personal information. These ‘post-stigma’ relationships are likely to make the discreditable person feel honour-bound to release further facts about themselves (Goffman, 1973).

Traditionally, the passer (i.e. discreditable person) is seen to pay a psychological price in attempting to pass as normal when this deception could collapse at any given moment. However, Goffman argues that this psychological price is not universally experienced by the stigmatised. The passer may feel torn between the normal group and the stigmatised group, in that the passer will not fully identify with the normal group and will feel feelings of disloyalty and self-contempt when unable to take action against ‘offensive’ remarks made against the category they are passing out of, by the members of the new group. The passer will need to develop contingencies to manage problems that are unthinking routines for normals. In all of these situations the passer will need to have place and time where they can refurbish their
disguise, and rest from the passing without losing control over their personal information (Goffman, 1973).

While the stigmatised person’s personal identity and social identity divide the world of people and places differently for them, these two frames can be applied to studying the everyday life of the stigmatised person. The key concept is the day-to-day activities that link the person to their social situations. The stigmatised that are discredited endure a routine of restrictions regarding their social acceptance. These discredited individuals often use the strategy of concealing or obliterating the signs that are seen as stigma symbols. Alternatively, the discredited person will present the signs of their stigma as the sign of some other attribute, which has less stigma attached. A strategy of the discreditable individual is to divide the world of people into a large group who are told nothing of the stigma and a small group who are told everything about the stigma. This small group then provides help and support to the stigmatised individual (Goffman, 1973).

A major source of help and support for the discreditable person is their intimates who can help them mask their stigma from others. The intimate can help and support the discreditable person to function without the person or others necessarily knowing. A group of intimates may form a protective circle around the discreditable individual, allowing them to think they have been fully accepted as normal, which may be untrue. These intimates will be more aware of the discreditable person’s difference and the attached problems than the actual individual. This means that the management of stigma involves others as much as the stigmatised individual. The stigmatised person can often rely more on an intimate who shares their actual stigma to help them in passing as normal than other intimates who have knowledge of the stigma who not in the stigma category. This type of cooperativeness often happens among circles of stigmatised individuals who are personally to each other in the circle. In mixed contact situations the stigmatised person may continue their strategy of passing as normal by deliberately failing to acknowledge an intimate or handling any greeting or interaction with the intimate discreetly in the presence of the normal. (Goffman, 1973).

Both the discreditable and discredited will voluntarily maintain distance to avoid intimacy with others which requires the divulging of information. The physical distancing ensures that
the discreditable or discredited person will not spend time with the other, this reduces the chance of unanticipated events that force the disclose information. In addition, the physical distancing restricts the ability of the other constructing a personal identification of them. The stigmatised person’s avoiding of contact with others reduces the chance that their stigma will be established as part of the biography that others have towards them (Goffman, 1973).

According to Goffman, an option for the discreditable person is to voluntarily disclose their information, which ends the need to manage this information, leaving them to simply manage the resulting uncomfortable social situations as a discredited person. The discreditable person on becoming a discredited person will then use the adaptive actions of the discredited. One method of disclosure for the discreditable person is to wear a highly visible sign that shows their difference to normals and their belonging to a particular stigma category. The discreditable person’s wearing of these stigma symbols allows others to continuously perceive their difference, while other some stigma symbols only provide fleeting evidence of difference. Goffman states that a ‘disclosure etiquette’ exists where the person admits their failing as a matter of fact, with the supporting assumption that others will not be concerned by this disclosure, an assumption that prevents these others from saying they are concerned. A stigmatised person may reach the stage where they feel that they should accept and respect themselves and should no longer conceal their failing to others. Thereupon, the person has to unlearn their concealment techniques as well as voluntarily disclose themselves to others. When the stigmatised person enters this phase of their moral career they are typical seen as mature and as well-adjusted individuals (Goffman, 1973).

While the discredited must manage the tensions in mixed contact situations and the discreditable must manage information in mixed contact situations, both of these techniques come together in managing the visibility and obtrusiveness of the stigma. The stigmatised person’s objective is to reduce the tension by managing information, which reduces the size of the stigma in mixed contact situations. This process is referred to as covering, which includes the person showing concern for a thing incidentally associated with their stigma, an individual restricting the display of failing centrally identified with that stigma, and anything associated with the organisation of social situations (Goffman, 1973).
Goffman surmises that the concept of social identity is that it allows the consideration of stigmatisation, while concept of personal identity enables the consideration of the role of information in the management of stigma. Goffman introduces the concept of the ego identity that allows an exploration of what the individual feels about their stigma and its management and the advice received in these matters from others. The stigmatised person will often feel some ambivalence towards himself/herself and will tend to stratify his/her ‘own’ according to the degree that their stigma is apparent and obtrusive to them. The stigmatised person will then adopt the attitudes of normals towards the more evidently stigmatised individual. The stigmatised person’s separation from the more evidently stigmatised individual shows a sharply marked oscillation in their identification. Also, to the stigmatised person, self-betrayal and betrayal of the more evidently stigmatised person is the development of social alliances with normals. As the stigmatised person increases their social alliances with normals, the possibility exists that they will see themselves as no longer having a stigma. In addition, the stigmatised person may exhibit identity ambivalence when seeing a person sharing the stigma acting in a stereotypical matter in mixed contact situations. The stigmatised person may feel repelled and then shamed having seen these stereotypical behaviours. In addition, the stigmatised person may feel acute ambivalence when caught in the process of ‘nearing’, that is, when the person comes into close contact with an undesirable instance of their stigma category while in the company of a normal (Goffman, 1973).

Goffman states that professionals help the stigmatised individual to cover certain standard matters. The professional will suggest a desirable pattern to cover these standard matters, which include how to reveal or conceal their stigma; how to deal with tricky situations; the support that should be given to their own stigma category; the type of social contact with normals that ought to maintained; the types of prejudice against his/her own stigma category that ought to be ignored and the types of prejudice that should be challenged; the extent he/she should present as normal to others; the extent he/she should receive different treatment; the facts about his/her stigma category that they should be proud of; and the ‘facing up to’ his/her differences (Goffman, 1973).

The professional will warn the stigmatised person against attempting to pass completely as normal, or fully accepting as their own the negative attitudes of others towards them. The
stigmatised individual will be warned against ‘minstrelization’ where the person ingratiatingly acts out to normals all the undesirable qualities associated with their stigma category, which leads to the life situation of a clown or fool. In addition, the professional will warn the stigmatised person against ‘normification or deminstrelization’. The stigmatised person is encouraged to have distaste for individuals who engage in covering without making a secret of their stigma. These codes of conduct provide the stigmatised person with a list of appropriate attitudes regarding the self. The stigmatised individual’s success in the usage of these codes of conduct is seen as real and worthy, which combined produce ‘authenticity’. The professional who advocates these codes of personal conduct can make the stigmatised person become a critic of their social situation, which creates a social consciousness absent in normals in the same social situation. In addition, the professional’s advice to the stigmatised individual often deals with a private and shameful part of their life. These professionals are normally present in the following two groups - in-group and out-group (Goffman, 1973).

Goffman states that the stigmatised individual’s real group is the aggregate of people who share the same deprivations due to having the same stigma. The spokesperson for this group will claim that the stigmatised person naturally belongs to the group. The stigmatised person who accepts the group membership is seen as loyal and authentic, while the person who rejects the group is seen as craven and a fool. Therefore, the nature of the stigmatised person is generated by the nature of their group affiliations. This in-group alignment may lead to secessionist ideology, which leads the stigmatised person to praise the special values and contributions of group members to normals in mixed contact situations. The stigmatised person who previously passed or covered their stigma may flaunt the stereotypical attributes of their group. In addition, the stigmatised individual may openly challenge the disapproval of normals in mixed contact situations and fault the utterances of the wise person in their group (Goffman, 1973).

The stigmatised person’s politicising of their life experience can make their life even more different from normals, and drawing attention to the group’s situation consolidates the public image of their difference as real and their fellow-stigmatised as constituting a real group. However, the stigmatised person who advocates will often use the language and style of normals and the pleas presented, the plight reviewed, the strategies advocated, are part of the
expression and feeling that belongs to the whole society. Therefore, the stigmatised individuals
disdain for a society of normals that reject his/her group can only be understood in that
society’s conception of pride, dignity and independence (Goffman, 1973).

The stigmatised are normally required to see themselves from the perspective of a second
grouping, which comprises normals from the wider society. This group uses psychiatric
discourse inspired by normals, which advocates that people who adhere to their discourse are
mature and adjusted, while people who don’t are impaired, rigid, defensive and lacking in
inner resources. The group advises the stigmatised to see themselves as fully human like
normals. The group argues that the stigma is nothing in itself, that the stigma should not cause
shame, and the person should not try to conceal the stigma. In addition, the group argues that
hard work and persistence will enable the person to achieve ordinary standards. The group
proposes a strategy for dealing with normals on the assumption that it is not the normals’
inherent nature to discriminate against the stigmatised, instead the problem lies in normals’
ignorance towards the stigmatised (Goffman, 1973).

The group will advocate a strategy for the stigmatised person to tactfully handle normals in
mixed contact situations. This strategy involves the education of the normal to make them
accept that the stigmatised person is fully human. In this case, the more the stigmatised person
deviates from the norm, the more he/she can claim possession of a subjective standard that
enables them to model what normals ought to feel towards the stigmatised. Should the
stigmatised person encounter normals who struggle to ignore his/her failing, then the person
will try to help the normal and the social situation through making a conscious effort using
matter-of-factness, detachment, and levity to ease the tension. In mixed contact situations the
stigmatised may refer to their stigma in the language used among their own, and the language
employed about them when normals are among their own, this provides normals with the
temporary status of wise persons. Alternatively, the stigmatised individual may introduce their
stigma as topic for serious discussion in an attempt to reduce its significance as a topic of
suppressed concern. The stigmatised individual may inform normals that their efforts to reduce
concern were effective and appreciated. In addition, the stigmatised person is to tactfully
accept unsolicited offers of interest, sympathy and help from normals. In summary, the group
of normals advocates that the stigmatised accept themselves as normal to ease the tension for normals in mixed contact situations (Goffman, 1973).

Goffman argues that professionals require the stigmatised to make a ‘good adjustment’ by cheerfully accepting themselves as essentially the same as normals, while at the same time withholding themselves from situations in which normals would struggle to accept them. The advantage to normals in encouraging the good-adjustment is that the unfairness of the person carrying a stigma is never presented to the normal audience; it means that normals will never have to admit to their lack of tactfulness and tolerance; and normals can remain relatively uncontaminated by intimate contact with the stigmatised and unthreatened by the identity beliefs of the stigmatised category (Goffman, 1973).

Goffman states that the in-group and out-group both present an ego identity for the stigmatised person, the in-group through political phrasings and the out-group through psychiatric phrases. The stigmatised person is promised that both of these lines will lead to an acceptance of self, dignity and self-respect. In reality, the stigmatised person’s politically or psychiatry framed self is simply a voice for the respective group that talks for them and through them. In the political and psychiatric discourses the stigmatised person is told that they are normal human beings who belong in the wider group. However, the stigmatised person is then told that they are ‘different’ and it would be foolish to deny their difference. This defining of difference, of course, derives from the viewpoint of normals in society. Therefore, the stigmatised individual is told that they are normal and that they are not normal. The stigmatised are then trapped in an argument concerning how he/she ought to think about themselves, that is, their ego identity. At the same time the professionals in these two groups will simultaneously push the stigmatised person in different directions by telling them what they should do and feel about what they are and are not, and all of this is advocated as being in their best interests (Goffman, 1973).

Goffman’s essay on stigma suggests that others can subject any individual to stigmatisation at any place or time in their life. That stigma management is a normal part of everyday life, a process that happens when a group asserts identity norms which individuals fail to acquire or achieve in their life. This suggests that all humans can play the role of normal and the stigmatised depending on the identity norm. In society, all human beings share the same
psychology framework and are mentally equipped to play either of these roles. A person with a stigmatised status may acquire a normal status and vice versa. These transformations appear to be sustainable as the individual adopts a new alignment within a frame of reference that he/she had known about before residing in the other. Therefore, the roles of stigmatised and normal exhibit parallels and similarities, such as the stigmatised and normal both withdrawing from contact with each other as a means of adjustment; both feeling that they are not fully accepted by the other; both feeling that their conduct is being watched too closely, and both staying among their ‘own’ to avoid problems with the other (Goffman, 1973).

Goffman concludes his essay by stating that stigma and normalness is not a concrete part of the person, instead it is a social process that constructs a perspective about an individual. These perspectives arise in social situations through the norms that play upon the encounter. In a situation one set of norms will dominate while other norms will be cast into the role of deviant. The normals and stigmatised will interact with each other in complementing dual roles. Since stigma and normalness are the products of social processes, a person can be placed and participate in either the normal category or the stigmatised category. However, the person in the stigmatised category will have to manage tension (as the discredited) and control information about their personal and social identity (as the discreditable) to effectively manage their spoiled identity.

The advantage of using Goffman’s theoretical framework in this thesis is that it enables the social processes that affect the discreditable identity of people with agoraphobia to be explored. Also, the theoretical framework will enable the relationship between people with agoraphobia (discreditable) and their partners, companions, etc (normals) to be examined. The theoretical framing enables concepts such as visibility, personal and social identity, and biography, etc to be applied to people’s experience of agoraphobia. In addition, the theoretical discourses on passing, covering, and the management of tension and information will be useful in exploring research participants’ experience of social interactions with normals. Finally, the Interactionist theories around ambivalence, in-group alignments, out-group alignments, and the politic of identity allow the concept of normalness to be explored among research participants with agoraphobia.
Schur – Labelling Approach

In 1971, the American sociologist Schur wrote ‘Labeling Deviant Behavior” which explores the usage of the labelling approach in the study of deviance and social control. This thesis will use this Interactionist perspective to explore the role of health professionals (e.g. doctors and therapists) in labelling and treating people with agoraphobia. In Schur’s book he uses this theoretical framework to identify the labelling and control processes involved in the psychiatric diagnosis of people with mental illness. Therefore, the labelling approach, as a theoretical framework, promises to provide an excellent tool to analyse the research participants’ experience of therapists’ diagnoses and treatment.

Schur states that the central doctrine of the labelling approach is that deviance and social control involve processes of social definition. The societal definition of “normal” and “abnormal” are socially defined within the context of specific periods of time, cultures and subcultures. Those thoughts, feelings and behaviours, which are defined to be normal in one social setting may be defined as abnormal in a different setting. It is the social processes that shape social definitions of thoughts, feelings and behaviours as normal or abnormal, not the individual who actually commits these actions. In addition, the individual’s defining of their actions as being normal or abnormal is the product of these social processes (Schur, 1971).

The social definitions of behaviour are continually shaped and reshaped by social processes occurring within social interactions. The social processes involve formal and/or informal responses and counter-responses which enables social definitions of deviance to be attached to individual’s thoughts, feelings and behaviours, as well as shaping the individuals self-conception, role and actions as being that of the deviant. The individual’s development of a self-conception, role and actions of deviance leads to their “commitment” and “career” as a deviant. Schur acknowledges George H. Mead and Herbert Blumer theorising that the development of “self” (self-conception) is a process, not a structure and also that the individual’s concept of self is the product of a reflective process that occurs within social interactions, instead of a structure of determining factors operating upon the individual. Therefore, the individuals development of “self” as a deviant arises from their reflection on, and acceptance of social definitions produced from social processes involving formal and informal responses and counter-responses occurring within social interactions (Schur, 1971).
The social definition of behaviours as deviant then leads to the creation of rules to control those individuals who commit those behaviours. The breach of these rules leads to the creation of social problems, which then requires agencies and agents of social control to attempt to regulate, control, or terminate (Schur, 1971).

The labelling approach focuses on both the social-psychological aspects of identity formation in social interactions, as well as the rule making and social control processes occurring at the organisational and societal levels. Schur states that “human behaviour is deviant to the extent that it comes to be viewed as involving a personally discreditable departure from a group’s normative expectations, and it elicits interpersonal or collective reactions that serve to “isolate”, “treat”, “correct”, or “punish” individuals engaged in such behavior (Schur, 1971, p. 24). This definition implies that deviance is an act that is relative, changeable, a matter of degree and that the degree is dependent upon the extent the behaviour is seen and responded too. In addition, the definition implies that deviance and control are interrelated, and the understanding of one requires an understanding of the other (Schur, 1971).

Schur’s discourse continues with an exploration of the specific processes involved in the labelling of deviance. The processes of labelling that contributes to deviance outcomes for the individual, involves the three levels of collective rule-making, interpersonal reactions, and organisational processing, which are undertaken by several “audiences”. The first “audience” is society as a large and complex network of groups and interests from which general reactions and labelling (i.e. collective rule-making) occur towards various forms of behaviour. The second “audience” comprises those people with whom a person has regular interaction (i.e. interpersonal reactions), and by whom he/she is positively or negatively “labelled”. The third “audience” includes the agents of social control for official organisations (i.e. organisational processing) (Schur, 1971).

The labelling approach could be seen to place too much emphasis on the audiences’ labelling of deviance and insufficient emphasis on the reality of the deviance. For example, the labelling theorist would analyse the social processes involved in the labelling of mental illness as deviance, rather than any actual behaviour deriving from the mental illness, such as hearing
voices. The labelling theorist would not attempt to argue that the actual behaviour of mental illness would not occur unless it was defined as “deviant”. Instead, the labelling theorist would state that mental illness must be understood and explained in its social context, as different social settings lead to different definitions and reactions to mental illness. For example, in early Christian society mental illness was defined as a form of demonic possession, requiring spiritual intervention, while post-Christian society defines mental illness as a medical problem requiring therapy and/or drug intervention. These differing societal reaction processes affect the nature, distribution, meaning, and consequences of the behaviour, whatever the involvement of other contributory factors in the deviant behaviour. Therefore, the labelling theorist’s interest is in the social context of the behaviour and its subjective meaning for individuals in social interactions (Schur, 1971).

The level of collective rule-making “audiences” in defining and controlling deviance can be broadened to include a conflict perspective by recognising that the most powerful audience that responds to rule breaking by individuals and small groups is the well-organised, sizeable minorities or majorities who have considerable power in social situations (Lofland, 1969, Schur, 1971). For example, the well-organised and sizeable minorities of mental health professionals would be seen to be a powerful “audience” in the labelling and treatment of people with mental illness.

The level of interpersonal reactions involves stereotyping, retrospective interpretation and negotiation. The concept of stereotyping reflects social actor’s need, in complex social interactions, to order their expectations to enable them to predict the actions of others to the extent that is sufficient for them to coherently organise their own behaviour. However, the social actor’s selective perception, which often occurs in this process, creates the potential for the reactions to be based on inaccurate assessments. Schur presents Thomas Scheff’s labelling-oriented analysis of the mass media’s representation of mental illness, where he suggests that the public (social actors) order their expectations of, and predict the behaviour of people with mental illness in social interactions, from the selective and stereotypical images of the mentally ill in the mass media (Scheff, 1966). Therefore, in interpersonal reactions stereotyping significantly influences the expectations of others, and creates serious response problems for the person defined as deviant (Schur, 1971).
The concept of retrospective interpretation involves the mechanisms where others come to view the deviant in a “new light”. Schur provides Erving Goffman’s analysis on mental patients case records, which he argues act as a mechanism that creates “a new view of the patients ‘essential’ character” (Goffman, 1961). The psychologists and psychiatrists’ usage of these case records, formed from biographical reconstructions, influences their expectations and response to the behaviour of the patient (Schur, 1971).

The concept of negotiation involves an agent of control’s usage of their discretionary power to negotiate with those labelled as deviant. The commonest form of negotiation in these relationships is bargaining, which involves direct bargaining between the parties. Typically, the agent of control’s discretion is influenced by the stereotyping and retrospective interpretations of the deviant, as well as organisational imperatives to produce an outcome to manage the deviant. Schur’s discourse on the bargaining between agents of control and deviants includes psychoanalyst, Michael Balint’s, description of the bargaining which occurs in psychiatric diagnosis (Schur, 1971). Balint’s description of this negotiation involves the doctor and patient engaging in a process of “offers and responses” where a mutually accepted diagnosis is reached (Balint, 1957). This suggests that the agent of control and the deviant have complementary roles in the bargaining process and that both mutually benefit from its outcome. However, Balint states that the doctor performs an “apostolic” function in the bargaining process by defining ideas on how the patient ought to behave when unwell and then induces (converts) the patient to have the illness that the doctor thinks is appropriate to the situation (Balint, 1957). The doctor and patient are seen to actually have unequal power in defining the situation, with the doctor’s definition having considerable influence in determining the outcome (Scheff, 1968).

At the level of organisational processing, agencies and agents of control follow policies, procedures and practices regularly that enable them to define and control individuals labelled as deviant. The stereotyping (e.g. classifications), retrospective interpretations (e.g. client records) and bargaining (assessment and service delivery) organisational processes influence the policies, procedures and practices directed towards the individual. An important theme in organisational processing is recognising the political power and economic resources of
agencies and agents of control to define and control the individual who is officially labelled as deviant. A theme in the organisational processing of deviants is the status degradation ceremony where the deviant is stripped of their status, such as the medical procedures involved in processing a person entering a mental hospital. Another theme involves retrospective rationalisation where the individual, through retrospective interpretations does not have their prior identity (non-deviant) validated (Schur, 1971).

While Schur’s theorising has explored the social processes that define and attempt to control deviance, he identifies one of the major consequences of these processes – “role engulfment”. In his discourse, the label of deviant engulfs the individual’s other roles. The social processes (i.e. social definition and social control of deviance) occurring in interactions cause the individual to become “caught up in” the role of deviant and the individual’s role of deviant begins to dominate their personal identity (or concept of self). Also, the individual’s behaviour is increasingly organised around the role of deviant and any cultural expectations linked to the deviant role, gain precedence over any other role expectations of the individual. In addition, the deviant role becomes increasingly present in his/her everyday activities and lifestyle. Therefore, “role engulfment” is the social-psychological impact of the deviant role on the individual (Schur, 1971).

The key theme in role engulfment is that as an individual assumes more of the roles of the deviant, the more likely they will develop a conception of self as others have defined them. For example, newly diagnosed patients who readily conform to the role and routines of the mental patient in a psychiatric ward, are more likely to define themselves as mental patients, as originally diagnosed by the hospital doctors. While some individuals will initially resist the definition of deviance for their behaviour, the more others define and treat them as deviant, the more likely they will start to conform to the role in those social interactions. At the heart of role engulfment lies “master status”, where the increased salience of the deviant role dominates all other roles belonging to the individual. (Schur, 1971).

The individual’s response to the acquisition of a deviant “master status” can include an attempt at deviance disavowal, which involves “de-labelling” and “re-labelling” processes. Generally, these processes are difficult and uncertain, where the individual has to separate themselves
from the processes that label their behaviour deviant and participate in processes that re-label their behaviour as normal. For example, a person would have to leave the psychiatric ward and return the community to successfully rid themselves of the label of a mental patient. In addition, the person would have to participate in normalised behaviours with others in the community to attempt to have themselves re-labelled as normal by others. Therefore, an individual’s attempt to de-label and re-label often includes the management of information around their spoiled identity (Schur, 1971).

The advantage of Schur’s theorising on the labelling approach is that it provides a useful theoretical framework to explore the role of therapists and therapy in agoraphobia. The labelling approach allows the social processes involved in defining agoraphobia to be fully explored. Also, the role of mental health service providers and therapists as “audiences” can be examined including their collective rule making, interpersonal reactions and organisational processing of people with agoraphobia. This will include therapist’s stereotyping, retrospective interpretations and negotiations towards patients with agoraphobia. In addition, the labelling approach enables an investigation of the tendency towards therapists contributing to role engulfment among patients with agoraphobia. This includes patient’s attempts to de-label and re-label themselves as normal.

In conclusion, the thesis theoretical frameworks are ideally suited to exploring the findings data to reveal and explain how micro-level social processes shaped the lived experiences of research participants with agoraphobia. Blumer’s Interactionist theoretical approach has shown the importance of micro-level social interactions in shaping meanings, interpretations, and lines of actions in everyday life. This theoretical approach will be valuable in deconstructing agoraphobia as self-interaction in the discussion of the findings. Goffman’s Interactionist theoretical framework has shown the nature of the relationship between the stigmatised and normals, which includes the discreditable managing information and the discredited managing tension in mixed contact situations. This theoretical framework will be useful in exploring the nature of the relationship between people with agoraphobia and normals in everyday life. Also, Goffman’s theoretical framework has shown that the stigmatised and normals play interchangeable roles that blur the boundaries between these two groups. This theoretical framework will allow an investigation into the concept of normalness among people with
agoraphobia. Schur’s labelling approach has shown that normals as ‘experts’ formally and informally process the stigmatised through negotiation and bargaining micro-processing in close contact situations. The labelling approach will enable the writer to examine his personal experience of being processed through diagnostic assessment and cognitive behavioural therapy small group treatment programmes, which involved negotiation and bargaining micro-processing. The theory chapter concludes that the Interactionist theoretical frameworks are the most ideally suited tools for the task of deconstructing the lived experience of agoraphobia.
Chapter 3  Methodology

This research project uses a triangulation of research methodologies to gather data, including a literature review of studies, survey questionnaires and interviews. The literature review has had a major role in identifying where there is a consensus of knowledge, contested knowledge and absence of knowledge on the social interactions that shape, and are shaped by agoraphobia. The literature review’s identification of contested knowledge and absence of knowledge has been instrumental in the construction of the survey questionnaires and the selection of topics for the interviews. The survey questionnaires and the interviews provide the new data that will make an original contribution to knowledge on the role of social interactions that shape, and are shaped by agoraphobia.

The Agoraphobia Support Group (Canterbury) was selected for this research project as it offered several advantages:

- The ASG ensured access to a sample population of people who had experienced the onset, unmanaged and managed symptoms stages of agoraphobia.
- The ASG provided research participants with an established psychological and emotional support network.
- The ASG provided sufficient volunteers for the project.

In March 2002 the Ph.D. student made a verbal and written presentation (research topic statement) of the proposed research to the Agoraphobia Support Group Committee (ASG). The Ph.D. student explained the research objectives, methods, and ethical guidelines to ASG Committee members. The ASG committee fully supported the proposed project, with an accompanying offer to facilitate ASG members’ involvement by allowing the researcher access to the membership mailing list (following signing of a confidentiality form). The Ph.D. student then prepared a research proposal and made a Human Ethics Committee application for the project. When the University of Canterbury approved the research, the Ph.D. student submitted pilot survey questionnaires to ASG committee members who gave feedback, which allowed the Ph.D. student to make changes prior to the dissemination of the survey questionnaire to ASG
members. The Ph.D. student then wrote a newsletter article for the ASG monthly newsletter that informed members of the research project and the intention to solicit members as voluntary research participants. The Ph.D. student then sent ASG members an envelope (marked confidential) that included; a letter of introduction (e.g. research objectives and possible outcomes), an information sheet (e.g. research methods, volunteer rights and ethical guidelines) a consent form, and a copy of a survey questionnaire with a stamped reply envelope. Those ASG members who completed and returned a survey questionnaire were sent a second letter that included a thank you for completing the questionnaire, an invitation to be interviewed, with an accompanying information sheet and consent form.

The PhD research was conducted using ethical guidelines to protect the research participants in the project.

- The researcher had fully explained in terms meaningful to the research participants, the purpose of the research, the research methods and any implication of the research for people with agoraphobia.
- Research participants were provided with all the relevant information that was required by them to enable them to give informed consent before completing a survey questionnaire and/or interview.
- The research was conducted on the principle that the research participants should not be harmed. Therefore, a research participant who felt any physiological, psychological and/or emotional distress could terminate their involvement in the research project.
- The research participants completed the survey questionnaires and interviews in their home environment, which allowed them to feel safe, comfortable and relaxed during the research process.
- All research participants who volunteered for interviews were informed of their right to any support persons during the interview. Also, research participants were informed of their right to have breaks during the interview and/or terminate the interview at any given time.
- All interviews were taped and typed up as verbatim transcriptions.
- All survey questionnaires and interview transcriptions were given a code number to ensure that personal details were kept confidential.
• The researcher informed research participants of the usage of, secure storage of, and publication of their data.
• The research participants were given an assurance of the maintenance of confidentiality and anonymity throughout the research project. Therefore, in the publication of the research report, all research participants were given a code number and all identifying material was removed or changed.
• The completed survey questionnaires data (hard copy) and audio taped interviews data (transcribed into floppy disk files) were kept in a locked filing cabinet in the researcher’s home office. When the research project is completed the data will be placed into secure storage so it remains accessible to only the researcher for usage in further agoraphobia studies. Should the data files no longer be required for further analysis after a period of five years they will be destroyed.

Sample Population
In the Ph.D. study a total of 107 ASG members completed and returned survey questionnaires. The ASG members included people medically diagnosed with agoraphobia, people medically diagnosed with agoraphobia and other anxiety disorders, and people who had not been medically diagnosed with agoraphobia, but met the medical diagnostic criteria (DSMIV) for agoraphobia. The people who were medically diagnosed with agoraphobia included a large number of individuals who were medically diagnosed with other anxiety disorders. This raises the concern that people medically diagnosed with agoraphobia and other anxiety problems may provide research data that is significantly different from people who simply have agoraphobia. For example, a person with agoraphobia and social phobia may report in the survey questionnaire their avoidance of school social situations, due to their social phobia, instead of their agoraphobia. Therefore, the Ph.D. student sought to address this concern by making sure that all survey questions (and interview questions) asked research participants for the specific effect that their agoraphobic symptoms had on their lives.

The Ph.D. student decided to merge the research data of people with medically diagnosed agoraphobia with those people medically diagnosed with agoraphobia and other anxiety disorders, as the research targeted the agoraphobic experience of both groups of research
participants. Also, the Ph.D. student believes that any division between the two groups would be artificial as the different medical diagnosis often relies exclusively on the accuracy of the self-report of patients, as well as the clinical evaluation of the mental health professional. For example, some people who were only medically diagnosed with agoraphobia may have actually had other secondary anxiety disorders that were not diagnosed. The person may have reported their primary symptoms (i.e. agoraphobia), and neglected their lesser secondary symptoms (i.e. social phobia), in their self-report to their health professional, which would then have limited the medical diagnosis to that of simply agoraphobia. Alternatively, the health professional could have limited their medical diagnosis to agoraphobia by focusing on the primary symptoms and setting aside any other secondary symptoms (i.e. other anxiety disorders).

The sample population also includes people who have not been medically diagnosed with agoraphobia. For these people to be included in the sample population, the individual had to meet DSMIV diagnostic guidelines of having at least 4 out of the 10 panic symptoms during their panic attacks and having at least 3 out of the 5 avoidance behaviours which include (a) anxiety about being trapped in places or situations from which escape might be difficult (or embarrassing), (b) avoidance or endurance with marked distress places and situations, where they feared having panic attacks, and (c) avoidance of a cluster of places or situations (i.e. leaving their home, travelling on a bus, being in a supermarket, etc). However, people were not required to have had anxiety about being beyond the help of others or requiring a companion when entering situations where they feared a panic attack, as these were seen as secondary factors in agoraphobia

Seven survey questionnaires that were completed and returned by ASG members failed to meet the DSMIV diagnostic criteria and were discarded. This meant that the sample population was reduced to 100 research participants. Therefore, in this study 100 research participants completed and returned survey questionnaires. Of the 100 research respondents, who were asked to be interviewed by the researcher, 25 research participants agreed to being interviewed. The list shows the distribution of people medically diagnosed with agoraphobia (with or without other anxiety disorders) and people who had not been medically diagnosed with agoraphobia, but met DSMIV diagnostic criteria.
People Medically Diagnosed with Agoraphobia

- Agoraphobia (27)
- Agoraphobia & Generalised Anxiety Disorder (22)
- Agoraphobia, Generalised Anxiety Disorder & Social Phobia (2)
- Agoraphobia, Generalised Anxiety Disorder, OCD & Post-traumatic Disorder (2)
- Agoraphobia, Generalised Anxiety Disorder, Social Phobia & Specific Phobia (1)
- Agoraphobia, Generalised Anxiety Disorder, Social Phobia & Separation Anxiety Disorder (1)
- Agoraphobia, Generalised Anxiety Disorder, Separation Anxiety Disorder, Social Phobia, OCD & Post-traumatic Stress Disorder (1)
- Agoraphobia, Generalised Anxiety Disorder, Social Phobia & Post-traumatic Stress Disorder (1)
- Agoraphobia, Generalised Anxiety Disorder, Specific Phobia & Post-traumatic Stress Disorder (1)
- Agoraphobia & Social Phobia (6)
- Agoraphobia, Social Phobia, OCD & Specific phobia (1)
- Agoraphobia & Post-traumatic Stress Disorder (2)
- Agoraphobia, Separation Anxiety Disorder & Specific Phobia (1)
- Agoraphobia & Separation Anxiety Disorder (1)
- Agoraphobia, Specific Phobia & Post-traumatic Stress Disorder (1)
- Agoraphobia, Social Phobia & Post-traumatic Stress Disorder (1)
- Agoraphobia & OCD (1)

People Not Medically Diagnosed with Agoraphobia

- People with at least 4/10 Panic symptoms and 5/5 Avoidance behaviours (8)
- People with at least 4/10 Panic symptoms and 4/5 Avoidance behaviours (8)
- People with at least 4/10 Panic symptoms and 3/5 Avoidance behaviours (12)
Age Range

The list of research participants shows that research participants often had other anxiety disorders. Therefore, the researcher was careful that all survey and interview questions focused on the research participant’s experience of agoraphobia and not their other anxiety disorders. The graph shows that research participants ranged in age from 21 to 70+ years old.

The chart shows that the research project age range covered young adult (20+) to late middle age (70).

Gender

The pie chart shows the gender ratio of the sample population.

The chart shows that the sample population was heavily biased towards women, which reflects the seemingly high incidence of agoraphobia among women.
Ethnicity
The majority of research participants were Pakeha (European) due to the high percentage of Pakeha (European) in the Canterbury region. A small number of Maori and Pacific Island people participated in the research project. However, the low number of Maori and Pacific Island people meant that a cultural analysis of data would have been meaningless.

Geography
The majority of research participants live in the city of Christchurch with a small number living in the outlying rural areas.
The social interactions that contribute to the onset of agoraphobia

The Findings chapter begins with research participants identifying the social interactions that they believed contributed to the onset of their agoraphobia. In the family structure and upbringing section, some research participants are shown to believe that primary socialisation contributed to their pre-disposition to panic attacks and avoidance behaviours. In the family stressful events section, some of these research participants indicated that familial stress then triggered their panic attacks with the accompanying avoidance behaviours. In the traumatic events and accumulated stress section other research participants claim that they developed agoraphobia following one-off or clusters of traumatic events and/or accumulated stressful events. The chapter concludes by identifying the age that research participants experienced their initial panic attack that preceded the development of their agoraphobia.
Family Structure and Upbringing

In the study, the majority of research participants were raised in nuclear families as children (0 to 12 years) and as youths (13 to 18 years).

Table:

<table>
<thead>
<tr>
<th>Parent(s)/Caregivers of Research Participants</th>
<th>0 to 12 years</th>
<th>13 to 18 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Both biological parents</td>
<td>91</td>
<td>79</td>
</tr>
<tr>
<td>Single parents</td>
<td>6</td>
<td>13</td>
</tr>
<tr>
<td>Step parent</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Foster parents</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other types of family groups</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

In the research project, some research participants believed that their family upbringing (primary socialisation) was a major contributing factor in their development of agoraphobia in childhood. In the survey questionnaire, 54 out of the 100 research participants reported that their parent(s) regularly modelled anxiety during their family upbringing. Of the 54 research participants, 70% stated that their mothers, 19% that their fathers and 11% that both their parents regularly modelled anxious behaviour. In addition, 65% of the 54 research participants reported that they developed panic attacks and avoidance behaviour as children. Therefore, the survey data shows that research participants believed that parents who regularly modelled anxious behaviour contributed to their development of agoraphobic behaviour.

A significant number of the research participants who reported that a parent modelled anxiety during their family upbringing, identified their mothers/female caregivers as the role model.

I suspect that my mother might have had it… There were some things she wasn’t happy doing and she always avoided…She would always avoid going out to the letterbox for instance (Code 156).

My mum didn’t go to places and we went on these convoluted journeys to avoid those things she didn’t like – like tunnels (Code 45).

I didn’t do much risk-taking as a child as my mother was an anxious type of person and my father was never around to do those things (Code 31).
I was very wary of taking risks as a child, my mother always panicked and my father never did anything that encouraged my building of confidence (Code 27).

My mum told me that she had panic attacks in the church. She told me one day about having these feelings that I now know are panic attacks (Code 33).

I think there are a lot of things I have learnt from her, including panic and avoidance. One comes to mind is lifts, now I’ve always been scared of being in a lift on my own and I think I learnt that from my mother because she was scared of lifts also, because I can remember we once went into a lift and I really picked it up off her that she was so scared by the way she acted and I think I probably picked that up off her (Code 63).

She is a really nervous person herself and I think that is probably where it all stems from - her nervousness with me as a child. I think she is agoraphobic, I think it is a learned behaviour, she is cautious, I think that she would actually just worry and worry about me to the point that it would be hard to do anything without her reading something into it, you know, she is almost over-compassionate, she is practical, it sounds kind of hard, but I imagine that if I said I had a headache or I hadn’t feel really well, I would have to go outside or it is too hot in here, I feel a bit sick, that she would be thinking, oh my God, are you alright? What can I do? Breathe, just breathe or whatever, you know, like she would kind of be over nervous for me...(Code 269).

My mum use to dread going away in the car – every Christmas we used to go to Hawea, and mum would hide because she couldn’t stand hills and she lost it. She couldn’t fly and lots of things, and the two of us worked out that agoraphobia was exactly what she had. And she still has panic attacks, she doesn’t realise she’s having them because she’s always worrying. She’s got a big family – 12 kids and she’s always worrying about one of them and she gets herself uptight, and I say, “Mum, calm down”. And this is what she’s like. But mum’s mum and she’ll never change. She’s always there for her kids, and it is deeply ingrained. One of my brothers was having panic attacks – he ended up in the hospital twice because they thought he was having a heart attack, but I think he is alright now – I haven’t seen him for a while. So it just goes to show, that it is out there and a lot of people have got it (Code 41).

The home environment was so screwy, there was a high degree of paranoia because my mother experienced the power of the sixth sense, and she was so paranoid about everything that I grew up with fear, so that fear became enormous and there were a whole lot of other sort of clusters of things that went with that. I think the world is a very scary place that we couldn’t trust, you know, that was the message we got from our mother, you couldn’t trust anyone, people were after me, they were after me, this was what she would project on us. Everybody was dangerous, life was pretty scary out there, and at the time I thought you know, as I got older and hit the teenage years, I obviously challenged that, I wanted to break out and have that
freedom, but then as I got older it started to take control again. I became responsible, it started and I began to feel much more fearful I would think of not having the ability and not valuing anything about myself, or not being able to do things (Code 281).

In addition, some research participants reported that their fathers/male caregivers modelled agoraphobia.

Well, it is in the family, it is something that my father suffers from, and my sister suffers from too. My father would panic all the time about little things and he didn’t like being alone in public places (Code 67).

Some research participants stated that they learnt in later adult life that their parent(s) had agoraphobia. This disclosure often happened when the research participant confided to their parent about their own agoraphobia.

I told my mother that I had agoraphobia when I found out, and it turns out that so did she years ago, she was exactly the same (Code 41).

While some research participants were fully aware of their parent/caregiver’s anxiety symptoms, a number of research participants were unsure as to their parents/caregiver’s mental health due to their age as a child and/or their parent/caregiver’s lack of disclosure of their condition to them as a child.

I suspected that my mother might have had it, I can’t be absolutely sure of course, but I do feel that she might have had a touch of agoraphobia too, it is just little things that you notice when you are in a family and when I look back now I think she did have it actually (Code 156).

I think my mum was affected…I think she went through anxiety a little bit, but I didn’t know this at the time, it was only years later when I started thinking back and thinking that mum might have had problems too, like I can remember her going through different things and she’s not a very confident person and in the last few years I’ve noticed she doesn’t like going up in a lift or she won’t catch the bus into town, and she wouldn’t go out because the town has changed such a lot and I thought, mum you’re using excuses (Code 105).

While a significant number of research participants reported that their mother/female caregivers modelled agoraphobia, a larger number of research participants stated that they believed their development of agoraphobia was due to their mother/female caregiver’s failure to instil
confidence or assertiveness in them as children. This lack of parentally instilled confidence and assertiveness often meant that the child was passive, anxious and struggled to cope in anxiety inducing situations.

Girls were raised to be very passive, don’t take risks, avoid conflict...so I think women often developed much less personal confidence and had lower self esteem, and were more likely to develop feelings of anxiousness. While boys were more encouraged to climb the tree and fall out of it, and take more risks and of course their confidence was a lot higher. I’ve noticed with people I’ve talked to in the support group, one of the things that seems to come over is the lack of confidence in the family upbringing and of course when they go into these different situations and they are having this anxiousness it just takes over because they haven’t learnt how to manage it (Code 67).

However, one male research participant indicated that his father failed to provide a masculine role model, which undermined his confidence or assertiveness in risk-taking situations.

I never did that much with my father, like camping or other outdoor things, I didn’t really have a ‘masculine’ role model, and I didn’t do the things that are meant to make you a man – the macho type of man, which meant that I never developed the confidence to take risks (Code 303).

Another male research participant believed that New Zealand culture taught him to suppress his feelings, especially those feelings associated with a perceived weakness such as anxiety in risk-taking situations.

I grew up with male role models like the All Blacks who were very seen as being the type of man we should aspire to be, quiet, strong, who could take a injury in his stride, which is a load of bullshit (Code 56).

In a large number of cases, research participants reported that their parents/caregivers struggled with depression and/or alcoholism, which suggests that the parents/caregivers lacked confidence and assertiveness in their own lives, which undermined their ability to instil these character traits in their children.

My childhood was very chaotic where my mum was very depressed and often not there and my father was an alcoholic and you never knew how he was going to be, so you never had the chance to learn how to manage your own problems as a child (Code 45).
I had a very hard childhood in the sense that I had an alcoholic father who was violent to my mother a lot and occasionally to me, and I used to always be in fear of him coming home drunk. He was mostly violent after drinking, and that went on all through my life, and that is why I don’t like going anywhere where people are drinking. I don’t like people near me. I have lived with anxiety right through my life like that, that kind of anxiety (Code 37).

Well, I’ve grown up with all sorts of problems in the home, and I ended up with three alcoholics in the home in the end, first it started with my father, and then later in life my two brothers, and then me being the only girl having to look after my mother. I was only 11 when I first started having to look after my mother and that, so I virtually had my young life ruined basically. I was under a lot of stress, and it is only since I’ve been on my own that it has all sort of subsided and I’m managing to keep my own health right, slowly but surely. (Code 156).

The research participants believed that their parents/caregivers were unaware of their struggle with anxiety as children. The parents’ apparent lack of awareness of their child’s anxiety suggests that they may have been unaware of the need to instil confidence in their child and the need to teach them coping mechanisms to manage anxiety.

I can remember being very young and having anxiety when I was trying to go to sleep, and having to meet just what I’d call natural anxiety due to not really getting on with one parent for a while, just from me rebelling…I didn’t tell my parent about the anxiety I was feeling because I was rebelling, which I realise now robbed me of the chance of learning how to manage my natural anxiety as well as the other anxiety (Code 93).

Some research participants reported that their parents/caregivers’ actions contributed to their loss of confidence in specific situations. According to one research participant, her parents appeared to be ignorant of the effect of their actions on the confidence of their children.

My father’s driving was terrible, he was apt to drink far too much, it was very erratic driving, all over the road sort of thing. I can still remember this road we used to come home at night after visiting friends and I would be in the back seat and I remember my parents having really great arguments about not letting him drive, and he was going to drive come hell or high water sort of thing, and we would be swerving all round this very little windy narrow road that had a stream running down below it …and my mother would be yelling at him, saying we would go over the edge and crash and die and he would be telling her to get lost, and I remember hiding down in the back seat sort of trying to get away from it, but I couldn’t… When I began driving I had a fairly old car and I know I was anxious about driving on that road…everything was still very vivid in my mind (Code 89).
Some research participants believed that their own actions as children contributed to their development of anxiety in later adult life.

When I was about 3 or 4 years old, I turned the key and locked my mother in the outside washhouse. Then I couldn’t unlock it. I panicked and ran into the kitchen (very high door handles) and shut both doors. I could hear Mum calling out, but she was pregnant and trapped. I had a real tantrum on the floor, but I was terrified. After a while Mum attracted the attention of a woman passing by and they came into the kitchen and Mum soothed me. But all my life I have felt panicky whenever I can’t get away (Code 31).

I think I had the first episode when I was about four, and I didn’t really want to go – it was actually a race meeting that my parents were going to, and I can remember being sick at the races in public, and virtually at that moment I wasn’t with my parents, and from then on for the rest of my life I have virtually had this fear that I might be sick when I’m out. So from that particular time, I thought that anyone might be sick or I might be sick. Sometimes I think it is happening to me again and I start feeling sick. And then I start getting panicky – I’m not sure which way that goes. I don’t necessarily feel sick before I go out. Sometimes I get a bit churned up, but it doesn’t always stop there. And I’ve had a couple of times when I was sick when I was out, and I got panicky and the more panicky I got, the sicker I got (Code 37).

One 62-year old research participant believed that her parents’ suppression of her confidence, assertiveness, individuality and independence was a reflection of the 1940’s approach to the upbringing of children.

I was conditioned into agoraphobia when I was a child. It was very much that children were to be seen and not heard, and you didn’t answer back and you didn’t have opinions, and you weren’t allowed to argue back. You were pushed down all the time, it is sort of like you were being indoctrinated to be passive and compliant, and you weren’t allowed to develop self-confidence, and trying to break out of that mould to try to be you, was very difficult (Code 89).

Research participants who were raised as single children believed that they had failed to develop confidence and assertiveness due to the lack of sibling rivalry and conflict. One person saw the combative nature of sibling rivalry as providing the ideal training to learn assertiveness skills for later adult life.

I was an only child so I feel that I never had the chance to learn a lot of skills that you need on a day-to-day basis to handle conflict…When you are raised with brothers and sisters you learn to argue, “I’m going to have that apple”, you know,
“I’ll tell mum”, ‘I don’t care”, at least that child is learning to make a stand and they might know that mum or dad is going to go crook, but when you are the only one you don’t have any of that, you can feel very isolated and insular sort of thing. (Code 89).

However, the presence of a sibling did not guarantee rivalry or combative encounters in all families. Also, one research participant reported that their sibling shared anxiety symptoms similar to themselves. This meant that neither child could assist the other in developing confidence and assertiveness in combative situations. In addition, the absence of a risk-taking sibling robbed the other child of a confidence-inspiring role model.

I had panic attacks at primary school, probably when I was ten years old. My younger sister had it earlier, she started having attacks when she was four years old (Code 67).

In some cases the social isolation of being an only child was compounded by the absence of a peer group that would have allowed the only child to engage in risk-taking play to develop confidence and assertiveness.

My father worked all the hours God sent, so there was only my mother and myself, I am an only child and I do prefer my own company; I am quite happy with my own company. My mother didn’t take me out, and there wasn’t much to go to, if I did go I went on my own. Being an only child meant that I didn’t have siblings to do things with, which would have built my confidence in dealing with different things and situations, perhaps that’s the reason I didn’t have the chance to develop the confidence as a child. I didn’t have a lot of social skills. There weren’t many children at our school that lived in the township where I did, they all lived out on farms, so there were only about half a dozen children that you could actually socialise with, and we really didn’t socialise. In the country you just made your own fun (Code 22).

One person believed that her over-protective parent sheltered her from anxiety inducing situations, which contributed to a lack of confidence and assertiveness. In addition, the child developed a dependency on the presence of others in anxiety-inducing situations in later life.

My parents were very protective, my father was very, very protective of me…I would never go into town alone – like dad would take me if I wanted to go…I would never go on a bus at night-time and go up to the square, I was very, very immature. So I never built up my confidence to do things alone (Code 289).
While some parents unconsciously failed to instil confidence and assertiveness in their child, parental abuse, consciously undertaken, undermined the development of these character traits in other children. Some research participants stated that the abuse was often severe and an ongoing feature of their family life.

My parents did something to me and I went through a terrible trauma, and that must have set it off, but they still don’t recognise it (Code 79).

I’ve grown up in a very abusive and dysfunctional family, you know, and of course all sorts of things at home and that I feel have led to this agoraphobia (Code 156).

When I was a teenager my own mother tried to kill me… My dad snatched the knife out of her hand…I’ve never forgotten it. I think that is the reason I developed my fear (Code 201).

Child abuse really affects ones confidence and self-worth (Code 76).

In addition to parental mental and emotional abuse during family upbringing, some research participants reported that a traumatic experience, such as sexual abuse in their childhood led to the development of agoraphobia. The research participants often linked the effect of the traumatic event to their development of agoraphobia when they sought the reason for the start of their agoraphobia in later life.

I think it first began when I was raped as a young girl down at the park…I was about 15 or 16 and my mother didn’t believe me at the time and my father was the only one who could help, the panic attacks started happening at that time (Code 201).

It probably started when I was quite young, I was about five or six or something, and if I went to pictures or anything like that I always sat on the aisle and always looked for the exit, I never liked sitting and eating with other people. Like when you’re travelling you go to someone else’s place for a meal, I would sit there and I couldn’t eat anything. So that was right back when I was quite young. The eating part didn’t stop until I was about 13, and going to other people’s places. I wasn’t very struck on that until I was about 13…I went to a counsellor she said it was because I was sexually abused as a child, when I was about five or six, and she thought that that might have been what caused it in the first place (Code 22).

While some research participants stated that sexual abuse contributed to their onset of agoraphobia, other research participants believed that a feeling of being unsafe in a place or
situation following a traumatic event caused them to develop anxiety and avoidance behaviours.

One of my earliest memories is of going to school in the infant stage...there was an old man and we were not allowed near his house because he had been interviewed by the Police for indecency with boys. I was in the corner shop one day and he dropped a key down my back and tried to put his hand down my back to get it out, and then just after that I got really scared because I had to go past his house on the way to school, and it kind of escalated from there really. So I tried to work out different ways so I wouldn’t have to walk to school basically, and then it got to the whole area and it became a fear of even going to school that I might see him around or something like that (Code 45).

I have had a kind of fear of being harmed by people, so being outside then obviously the fear increased. Some people I’d be absolutely fine with and then there were other people I could sense very quickly if someone wasn’t quite right, or I felt like I might be in danger from them (Code 45).

One person reported that anxiety-inducing thoughts and feelings associated with a childhood trauma were triggered by a similar event in later life.

I actually pinpoint it to years ago when I was about 7 or 8 – my father shot my dog and it didn’t die, so he bludgeoned it with an axe, and I heard the screaming of the dog and it didn’t bother me for years and years, and then when I was 22 there was a dog next door that started and it was the same noise and everything just came back, and since then – 10/11 years later and I still just freeze inside when I hear that noise, even if I don’t hear it I am anticipating it. If I hear a dog or knew of a dog that was close, I would freeze, especially around my home, because I have no control, but if I am at someone else’s house, I don’t care because it is not my problem. But because I am here and this is my home and everything I care about, I can’t do anything about it, so that is what frightens me – I have no control, so I strategise what I can do, like I come in and just get on with something and dodge it. I spent three years inside a bottle on alcohol to get rid of it, which didn’t work. I ballooned up to 100 kg which, was not a good move, but it is what you do because you are desperate. I began experiencing trouble going to supermarkets, going outside, and it was really ‘out of the blue’. It was a bizarre thing – life was pretty good. And then it was just sort of bang, and on it came and then like anxiety, depression kicked in with it all, so that is how it started (Code 56).

Some research participants reported that a combination of their parents/caregivers’ role-modelling of anxiety, over-protectiveness, failure to instil confidence and assertiveness, and/or abuse failed to equip them with coping mechanisms in perceived anxiety inducing situations in later life.
When I was about four years old I couldn’t go out. I was always panicky about going out (Code 37).

I don’t believe my parents helped me to develop the confidence I always felt uncomfortable in anxious situations (Code).

I think I had panic attacks all through my childhood on and off when I was struggling to cope with something happening around me (Code 92).

I had a real lack of confidence as a child and I didn’t seem to have much ambition in adult life (Code 256).

I was agoraphobic as a child…I can remember the situations where I felt anxious…like every week I would come home from school with a tummy ache, you know, like I would have to go to the sick bay and my mum would have to come and get me, and my mother would talk to the woman who used to work in the sick bay, the office lady and she always still thinks of me as the girl she had to attend to at school (Code 269).

At school I felt panicky there were situations that I had to get out of, or wanted to get out of, I just wanted to go home, I just wanted my mum, I just wanted to be gone…I remember my mother was home every day after school, and I can remember calling out and thinking where is she and I’d be shouting mum, mum, mum and she’d come and say what is it, and then although I was only little, but I knew at the time it was a bit strange to be shouting and I’d have to think of something like you’ll never believe what happened today, and to think of something to have warranted the urgency in my calling for her, and I knew I was making things up, because I knew I was making reasons to call her up because I just desperately needed to see her because I felt so anxious (Code 269).

One person stated that their inability to cope with anxiety often led them to hide their agoraphobia out of a sense of shame. The person’s sense of shame persisted until maturity in adult life enabled them to make their disclosure to loved ones.

I always felt ashamed of how I felt (panic attacks) and I certainly would have never have told them. I did tell my mother, but it wasn’t until I was about eighteen or nineteen (Code 45).

One person who developed agoraphobia as a child’ viewed it as a socially constructed illness with psychological and physical symptoms.

I personally feel that agoraphobia is a learned behaviour, learned during your childhood. It becomes a way of thinking and feeling as much as it is physical symptoms (Code 76).
A number of research participants stated that their grandparents, uncles and aunts, parents and siblings had likewise developed agoraphobia, thereby creating agoraphobic families. However, a significant number of research participants did not know whether or not extended family members had agoraphobia due to the lack of openness about mental illness in those families.

My grandfather had anxiety and depression and my sister and I have agoraphobia (Code 67).

My whole family suffers from what we called ‘nerves’ - anxiety and tears. I never cruise along on a level plane. I am either up or down (Code 227).

I feel most of my problems are hereditary as my mother has suffered with depression all her life. My grandmother had a nervous breakdown at 16 my mother has had several breakdowns in her 20’s and I had one at 11. My mother, sister and myself are on anti-depressants (Code 202).

I had an aunt who was really fearful and she just didn’t leave home and I didn’t know at the time, but it was later on that I found out that she had it (Code 256).

I had two aunties and a cousin who got agoraphobia, we hadn’t been close - my auntie was in Timaru. The other one was in Dunedin at the time, and my cousin’s in Timaru, so it is not as if I was living with them or having a lot to do with them or anything. I know that other members of my family have got it, so maybe it is genetic – I don’t know (Code 22).

I think other family members have got agoraphobic stuff too - three of them do - the same agoraphobic stuff (Code 281).

In search for the answer to “Why did this happen to me”, I suspect that there may be a hereditary aspect to the illness. I have been told about behaviour in past generations that sound like anxiety attacks, but were never labelled as such. After all these years, I have become philosophical about the panic. I am determined not to be a victim, and try and get on and enjoy life (Code 97).

The research participants’ reports of the presence of agoraphobia among their close and extended family members may indicate a genetic pre-disposition to this anxiety disorder. However, the presence of agoraphobia among family members may simply mean that these individuals were exposed to a family upbringing similar to those of the research participants. A significant number of research participants who had agoraphobia during their parenting years reported that their children developed agoraphobia, while research participants who developed agoraphobia after their parenting years did not report the presence of agoraphobia in their
children. This suggests that research participants’ family upbringing may have been the major contributory factor to their children developing agoraphobia, more than a genetic transference.

My younger daughter says that she doesn’t like going in crowds now, though she used to, but doesn’t now, and my youngest son he used to go to the shop with me, but he says “I can’t go any further Mum”. I thought then that he had symptoms of it too (Code 22).

I’ve got two sons the same way, probably much like me, in that they suffer from some anxiety, but maybe not quite as bad as what I have, but they both are a little bit like that (Code 37).
Family Stressful Events

In the study, 89% of research participants reported that major stressful events occurred to one or more family members during their family upbringing.

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<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Number</th>
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<tbody>
<tr>
<td>A</td>
<td>One or more family members had died by accident or illness</td>
<td>43</td>
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<tr>
<td>B</td>
<td>One or more family members suffered from depression</td>
<td>42</td>
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<tr>
<td>C</td>
<td>One or more family members suffered alcoholism and/or a drug addiction</td>
<td>40</td>
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<tr>
<td>D</td>
<td>The family regularly struggled with financial problems</td>
<td>35</td>
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<tr>
<td>E</td>
<td>One or more family members were emotionally abusive</td>
<td>34</td>
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<tr>
<td>F</td>
<td>One or more family members had a anxiety disorder</td>
<td>32</td>
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<tr>
<td>G</td>
<td>One or more family members suffered from a medically diagnosed mental illness</td>
<td>26</td>
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<tr>
<td>H</td>
<td>One or more family members were mentally abusive</td>
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<tr>
<td>I</td>
<td>One or more family members had a chronic physical illness</td>
<td>25</td>
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<tr>
<td>J</td>
<td>One or more family members were physically abusive</td>
<td>23</td>
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<tr>
<td>K</td>
<td>One or more family members separated from the family due to abandonment or divorce</td>
<td>21</td>
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<tr>
<td>L</td>
<td>One or more family members showed symptoms of a non-medically diagnosed mental illness</td>
<td>20</td>
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<td>M</td>
<td>One or more family members committed suicide</td>
<td>13</td>
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<tr>
<td>N</td>
<td>One or more family members were sexually abusive</td>
<td>13</td>
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<td>O</td>
<td>The family regularly moved from town to town</td>
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<td>P</td>
<td>One or more family members had a significant disability</td>
<td>8</td>
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<tr>
<td>Q</td>
<td>One or more family members declared bankruptcy</td>
<td>4</td>
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The possible effect of these major stressful events occurring to family members could have been a significant increase in anxiety occurring within these families. Also, the presence of a parent(s) regularly modelling anxiety, as well as the anxiety inducing effect of a major ongoing stressful event within the family, may have conditioned the child to develop anxious behaviour in perceived anxiety inducing situations.

In the study, the most stressful event for research participants was the death of a family member whether through suicide, illness, accident, old age, or any other cause. In the survey questionnaire, 43% of research participants reported the death of a close family member (i.e. parents, siblings, grandparents, etc…).

My mother suffered and died from leukaemia (Code 67).

My mum passed away when I was young, she had a heart problem (Code 3).

(1) Grandmother died when I was 15 – she lived with us and (2) Mother died when I was 16 – cancer (Code 203).

Father died at age fourteen years old…My sister died when I was thirteen (Code 304).

Fathers illness (long-term) and eventual death, mothers long-term schizophrenia, leading to chronic familial stress (Code 281).

I was aged 19 years when my father was tragically killed. The impact of my father’s death caused major upheaval and sadness in the family as he was greatly loved (Code 169).

My father died when I was 9 years old – accidental overdose of anaesthetic during minor surgery (Code 190).

My father died when I was aged 12. My Aunt was killed, so my cousin who was like a sister was taken away. My Nana died; all three people went from my life in about 12 months (Code 266).

In 1997 (Dad was 40 years old – I was 17) we were told he had 6 years to live. He lived six months. Aged 18, my 75 year old Grandmother died. (Code 104).

My sister drowned at age 2 (I was 6 years old). Parents started drinking after this event. I saw a cousin killed under a pole at 4 years of age. She was 5 years of age.
Panic attacks caused by this most of my life, it was a very graphic and traumatic experience. (Code 13).

My brother’s death (Code 287).

Losing both sets of grandparents very young due to illness was a very hard blow. I was particularly close to my maternal grandparents who died in their sixties from heart disorders. Their deaths took a while to get over. A very close family friend committed suicide, which has also had quite an emotional impact on the family and myself (Code 59).

My Grandparents were tragically killed in a traffic accident (Code 256).

My Nana on my mother’s side died when I was 12 years old. Also, my little cousin died (aged 9 years) from cancer when I was 12 years old, our families were very close (Code 297).

Another common stressful and ongoing event was the presence of mental illness in families. In the survey data, 42% of research participants stated that a family member suffered from depression, 32% that a family member suffered from an anxiety disorder, 26% that a family member suffered from some other medically diagnosed mental illness, 20% that a family member regularly showed symptoms of a non-medically diagnosed mental illness, and 13% had family members who committed suicide. This data shows that a significant number of research participants were raised in families where mental illness was an ongoing and contributing factor to significant anxiety in the daily life of the family group.

I think that approximately seven family members suffered from anxiety – but it was not diagnosed, nor even acknowledged (i.e. chronic anxiety). I was mentally abused in the family by the lack of emotional support, expression of and acknowledgement of emotions and feelings (i.e. anger, sadness, grief, guilt, shame, fear, joy, love, affection, etc) exhibited by everyone in our family and relatives. Also, the lack of and acknowledgement of respect for each person as a unique separate individual, their strengths, talents and vulnerabilities; exhibited by criticism, put-downs, gossip, superficial communication, aggressiveness (verbal), passivity, exclusion, distancing, clichés like so and so is weak; “Don’t panic” (everybody was panicking and anxious!)… (Code 2).

In some cases the family member with a mental illness had been institutionalised in a psychiatric hospital, which increased the level of anxiety within the family. In addition, the families that ‘sent away’ an anxious family member instilled in their child a fear of institutionalisation if they disclosed their anxiety symptoms in later adult life.
Mother had severe post-natal depression, was committed frequently to Porirua and Lake Alice institutions through siblings’ early childhood and into adolescence (Code 98).

My mother was admitted to a mental hospital for a 2-year period due to a nervous/mental breakdown (Code 210).

While on holiday in Timaru one Xmas holidays, my father collapsed at the Timaru carnival and was put in Timaru hospital. We were told he’d had a ‘nervous breakdown (Code 213).

My mother had a nervous breakdown when I was a teenager she went away for a couple of weeks (Code 148).

The institutionalisation of a family member could lead to a prolonged separation that no doubt increased anxiety in the family group. In one instance, the family hid the shame of the institutionalisation of the mother by telling her children she was dead.

Mother went into a mental hospital when I was a child due to a “Breakdown”. We were told she was dead, found out she was alive accidentally (Code 302).

In addition, the hospitalisation of a parent could increase the stress placed on a child who was required to take on greater responsibilities within the family. This responsibility tended to fall upon the eldest child in the family.

Mother in hospital a lot – I had responsibility (being the eldest) for the rest of the family during those times (Code 193).

Also, the attempted or completed suicide of a family member compounded an already stressful family life. The repeated suicide attempts of family member created an extremely high level of uncertainty and anxiety about the future actions of the affected family member.

My mother-suffered bouts of depression with many attempted suicides, which it appears, were not intended to kill but just to draw attention (Code 210).

My mother was diagnosed with mental illness, and my brother was also diagnosed with mental illness and hung himself (Code 303).
In some families, the presence of mental illness was compounded with the presence of alcoholism. In the survey questionnaire, 40% of research participants stated that a family member was alcoholic.

My mother was an alcoholic, and my paternal aunt and maternal grandmother suffered anxiety problems (Code 108).

I think my mother was touched with agoraphobia. My eldest sister became an agoraphobic in later life. One sister was an alcoholic…(Code 1).

Father alcoholic (non-abusive) my age 1 to 10 years (Code 44).

(1) My mother and father breaking up, (2) Not being able to see my father and (3) Living with an alcoholic (Code 207).

Some research participants believed that the family member’s dependency on alcohol was to manage and hide their struggle with anxiety and depression. A large number of the research participants who disclosed that their family member was an alcoholic stated that it was their the father who was the affected family member.

I am sure my father drank heavily at pubs (not at home) to retreat from my mother. I now speculate that alcohol also gave him false courage to cope with and hide his anxiety disorder (Code 97).

The presence of a family member who was an alcoholic often led to the abuse of other family members. The combination of alcoholism and abuse no doubt would have increased the level of anxiety among family members.

I came from a very dysfunctional family that was very abusive because of alcohol (Code 156).

My step-dad hit my mother twice – once was my fault. My step-dad was an alcoholic (Code 92).

In some families the emotional, mental, physical and/or sexual abuse was a common occurrence, which no doubt placed the family in a high state of anxiety. In the survey questionnaire, 34% of research participants stated that their family member was emotionally abusive.
My mother had an argument with my sisters and kicked them out. I saw my sister’s boyfriend arguing with her and I cried (Code 32).

In the survey questionnaire, 25% of research participants stated that their family member was mentally abusive. In some instances the mental abuse was directed at a specific family member. However, the mental abuse of one family member in the presence of other family members could have increased the anxiety among all the family members.

On many occasions my drunken father, when he was driving, would start violent arguments with my mother (I was on the back seat at these times). I can still remember vividly the arguments and the specific streets (very steep, windy and narrow) (Code 89).

In the survey questionnaire, 23% of research participants stated that their family member was physically abusive. Whether the family member physically abused one specific family member or all of the family members, would have made little difference to the fact that the level of anxiety would have increased in the whole family.

Watched my father crack my mother’s head open with a vase from the table, while under the influence of alcohol. When 16 years old, father had beaten me on my bare buttocks with a twig (branch) from a tree. Possibly from checking him from hitting my mother (Code 37).

Mother strict Christian (including hitting children) after half-hour silent bible reading! Sort of stuff still justified by ‘spare the rod and spoil the child’ ideology (ritual spanking with tools, straps, hairbrushes, etc). Believe me it doesn’t work and is very damaging. (Code 44).

My father’s temper was bad and he would hit us, sometimes with a broom and a leather belt or anything he could get hold of and my mother would have a lot of breakdowns (Code 41).

In the survey questionnaire, 13% of research participants stated that their family member was sexually abusive. In some families there were multiple stories of abuse that further compounded anxiety in the family home.

A family member sexually abused me from 5 years old to 7 years old (Code 22).

My grandfather emotionally, mentally and sexually abused me as a child (Code 175).
I was aged approximately 18 years. I was sexually and physically abused (Code 302).

Sexually abused and physically abused. I can’t talk about it in detail, but generally men tended to abuse girls physically and sexually as they thought it was their right. This was a church elder and a church Sunday school teacher. Also, a neighbour (man) was sexually abusive. I told no one. Later in my forties, I discussed it with sisters some had the same treatment but in a different way, by the same man. Physical abuse was normal in those days. Everyone seemed to be battered to make them be good, obedient children. Church teaching was a big influence in that (Code 227).

While abuse was a major contributing factor to creating a climate of anxiety in families, the presence of other stressful factors was sufficient to cause anxiety in families. In the survey questionnaire 35% of research participants stated that their families regularly struggled with financial problems. This included 4% of research participants whose families went bankrupt.

I think my family did regularly struggle with financial problems (Code 297).

Our family suffered poverty. Sometimes we had food, most of the time not. We are an extended family and relatives came and went as I was growing up. When the relatives came, then the food was plentiful. My grandparents came over from the Islands a few times and my mother would prepare the best foods for them, while we either went without or ate scraps (leftovers). My mother would be given Christmas gifts for us (i.e. boxes of biscuits, chocolates, etc) and we never got to eat them because she gave them away to other relatives. Other stressful matters were when our parents would buy things for themselves (i.e. chocolates) and hide them in their room and eat it for themselves. This would hurt us that they would do such a thing. My dad would say there was too many of us to go around and there would not be enough. That was his logic (Code 274).

Father went bankrupt – had to shift houses, money was tight (Code 88).

Another stressful factor for children was events leading up to and following the separation and divorce of their parents, which contributed to the uncertainty, and anxiety in the life of the child.

When I was about six my parents separated for about six weeks and the three of us were sent to an aunt’s to live. Then they got back together, but my father had affairs and so did my mother. There were so many rows over this and money that they divorced (Code 148).
Parents separated for 2 years when I was 16-18 years old (Code 193).

Some stressful events that occurred in families were beyond the control of the family member, but no doubt contributed to the anxiety within the family group. In the survey questionnaire 25% of research participants reported that a family member suffered from a long-term illness or disabling accident.

My mother and sister had a very bad car accident (Code 32).

Mother and several sisters suffer problems with weight, being very obese (Code 310).

In some families, an overly strict upbringing caused anxiety in the child. Some research participants attributed the strictness to the domineering personality of their parent/caregiver and their strict adherence to a belief and its values.

Too much dominance and “perfectionist” values by mother made it impossible to live with her at times (Code 201).

Strict church beliefs, all family members part of same church, all gathered 3 times a week, 10 to 20 people. Larger group on Sundays 50 to 120 (not just family) (Code 114).

In some families, immigration was a source of anxiety as it disrupted and/or destroyed family and friendship networks. In the survey questionnaire 10% of research participants reported that national or local migration contributed to anxiety in the family.

We lived through a long period of tension in our lives when the family were posted overseas to Cyprus for 3 years. Terrorist activities meant my father carried a gun at all times and I do remember worrying about this, and we were very protected – we weren’t allowed to travel anywhere on our own – we had a very restricted social life with friends (aged 11 to 13 years old). I did worry constantly that one of our family members would be killed. I didn’t discuss this with my parents as I though they would think I was silly (Code 116).

We moved from all our family, friends and our home in the North Island, to a totally new environment, home and high school to a new job for Dad in the South Island (Code 289).
Traumatic & Accumulated Stressful Events

In the study, 75% of research participants reported that a one-off or cluster of traumatic events and/or an accumulation of stressful events occurred prior to their first major panic attack. The chart and table shows the traumatic/stressful events that preceded the first major panic attack of the research participants.
<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>A close family member or friend had died.</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>I had been under major work-related stress.</td>
<td>18</td>
</tr>
<tr>
<td>C</td>
<td>I had experienced a traumatic event out of my home.</td>
<td>15</td>
</tr>
<tr>
<td>D</td>
<td>I had recently had a very bad social experience (party, family gathering, etc).</td>
<td>12</td>
</tr>
<tr>
<td>E</td>
<td>I had suffered a long-term illness.</td>
<td>12</td>
</tr>
<tr>
<td>F</td>
<td>I had a major conflict with my parent(s).</td>
<td>11</td>
</tr>
<tr>
<td>G</td>
<td>I had witnessed a traumatic event occurring to another person.</td>
<td>11</td>
</tr>
<tr>
<td>H</td>
<td>I had recently had a very bad travel experience (aircraft, train, ship, etc).</td>
<td>10</td>
</tr>
<tr>
<td>I</td>
<td>I had been the victim of school bullying.</td>
<td>9</td>
</tr>
<tr>
<td>J</td>
<td>I had separated from or divorced my partner.</td>
<td>9</td>
</tr>
<tr>
<td>K</td>
<td>I had recently had a major conflict (fight) with my partner.</td>
<td>8</td>
</tr>
<tr>
<td>L</td>
<td>I had ended a relationship with a girlfriend or boyfriend.</td>
<td>8</td>
</tr>
<tr>
<td>M</td>
<td>I had become engaged or married.</td>
<td>7</td>
</tr>
<tr>
<td>N</td>
<td>My partner or I had a child.</td>
<td>7</td>
</tr>
<tr>
<td>O</td>
<td>I had a bad drug experience.</td>
<td>7</td>
</tr>
<tr>
<td>P</td>
<td>I had been separated from one or both parents.</td>
<td>5</td>
</tr>
<tr>
<td>Q</td>
<td>I had suffered a major illness.</td>
<td>5</td>
</tr>
<tr>
<td>R</td>
<td>I had suffered a major accident.</td>
<td>5</td>
</tr>
<tr>
<td>S</td>
<td>I had a major financial crisis.</td>
<td>5</td>
</tr>
<tr>
<td>T</td>
<td>My partner or I had a miscarriage.</td>
<td>4</td>
</tr>
<tr>
<td>U</td>
<td>My partner or I had become pregnant.</td>
<td>3</td>
</tr>
<tr>
<td>V</td>
<td>I had a near-death experience.</td>
<td>3</td>
</tr>
<tr>
<td>W</td>
<td>I had been a victim of crime</td>
<td>3</td>
</tr>
<tr>
<td>X</td>
<td>I had been involved in a fire.</td>
<td>3</td>
</tr>
<tr>
<td>Y</td>
<td>I had been made redundant.</td>
<td>2</td>
</tr>
<tr>
<td>Z</td>
<td>I had suffered a large number of job applications (interview) rejections.</td>
<td>1</td>
</tr>
<tr>
<td>Z1</td>
<td>My partner had suffered a long-term illness.</td>
<td>1</td>
</tr>
<tr>
<td>Z2</td>
<td>My partner had suffered a major accident.</td>
<td>1</td>
</tr>
</tbody>
</table>

(Note: A stressful factor can be present in more than one group).

In the Relationship group of factors the death of a family member was the most common and stressful event that preceded the first major panic attack. The family deaths primarily included close family members such as grandparents, parents and children.

My father received a phone call on a Sunday night telling us my Grandparents had been involved in an accident in their car. My Grandfather died instantly and my Grandmother was in a coma for 6 weeks before she died too. It was the following week I had my first attack though it wasn’t till years later that I realised what had happened (Code 256).

My father died in March 1991 and I began having panic attacks and anxiety attacks during the day and sometimes I do, but not very often, and I mostly have them at night (Code 79).

My only child was killed in an avalanche…I think the fact they didn’t find my son’s body has affected my recovery from anxiety (Code 227).

In addition to the actual death of a family member, the impending death of a close family member was often the stressful factor that triggered the first major panic attack. One research participant stated that she had only suffered minor panic attacks until the stress of her father dying triggered the ‘Big Panic Attack’.

I was in a pretty bad relationship at the time and he just used to put me down and would think there was nothing wrong with me…I had little panic attacks when I use to think there was something wrong with me. I was afraid of stuff and I didn’t know why. And then I was ending that relationship and at that time my father was dying, and I had a really big one, what I call “The Big Panic Attack”. I used to flat on my own, but this particular night I stayed at my mum’s place, I got there and there was quite a few of the family around because my dad wasn’t expected to last, and I went to bed and then I – something happened – my heart wouldn’t stop racing, I was sweating, I wanted to run away, I didn’t know what I wanted to do, and it was the most dreadful thing. Luckily my doctor who I had at that stage, he didn’t live too
far away and he was quite a good doctor and he actually came out to my mother’s place and slowly put an injection into my arm so I could sleep (Code 41).

One research participant spoke of the onset of her panic attacks following the death of her mother. In this case the person’s panic attack happened in circumstances similar to that of her mother’s death. The mother’s death occurred while she was waiting for a bus and her daughter’s panic attack happened while travelling on a bus. The research participant’s attempted bus journeys and the accompanying memory of her mother’s death involving a bus journey triggered her anxiety and resulting panic attacks.

My mother was waiting in the square (Christchurch) to catch the bus home and she collapsed and died of a heart attack…I had my first major panic attack on a bus following that event (Code 1).

While the majority of research participants stated that the traumatic event happened immediately prior to the initial panic attack, in some instances the traumatic event happened up to two years prior to the onset of agoraphobia. In the following case the research participant initially coped with the trauma of their family member’s death, but the delayed shock of the death eventually overwhelmed the individual and the panic attacks then started.

I’d had a son killed in Oamaru, which was a pretty big blow, and I’d nursed my mother who died of cancer…My husband had lived the last 18 months of his life of that two years with a heart condition of which he died. These deaths happened within two years, so I had a fairly hard couple of years…I had to take charge of the rest of the family and I think that gave me strength. I didn’t have time to think about myself. But all of a sudden it caught up with me and then I got panicky really bad, I didn’t go out or do anything (Code 37).

While the death of a family member was the most stressful event that happened in research participants’ lives, there were other stressful factors that caused a high level of anxiety. This stress involved the forming of intimate relationships, the day-to-day functioning of relationships, abusive relationships, and the ending of relationships. To begin with, the forming of intimate relationships at school (i.e. secondary, university, etc) was often a stressful event in research participants’ lives.

I was waiting for a phone call from a girl I liked…I wound myself up about it all day as I was very nervous about it. The next day I was emailing at university and I had a panic attack (Code 88).
When de-facto relationships emerged out of these intimate relationships’ the day-to-day stress that often occurs in relationships led to high levels of anxiety.

I had a bad relationship with a man I was living with that made me stressed and anxiety-ridden (Code 181).

In one instance, an extremely abusive marriage where the partner was controlling and manipulative led to panic attacks. In this case, a downward spiral into depression accompanied the panic attacks.

My husband was very controlling and manipulative, he was into pornography and wife swapping… My husband told me that I wasn’t any good at sex and the only way he could get turned on was to read pornography first…He wife-swapped with his mates, anyone who wanted me could have me…I was a creature of no worth and if I wanted to get his approval he’d get me to perform oral sex on his mates…My husband’s insistence with the wife-swapping drove me spiralling downward into depression and panic attacks (Code 289).

When an abusive partner left the relationship, the threat of self-harm from the former partner caused more anxiety to the individual. Also, the uncertainty and the ongoing anxiety of the threats of self-harm contributed to the onset of panic attacks.

My partner left me and then told me he was going to commit suicide – I started having panic attacks after that (Code 41).

In addition to abusive intimate relationships, the other major form of abuse was child abuse within families. Several research participants reported various forms of abuse including sexual, physical, mental and emotional abuse.

When I was nine I was molested by my uncle, while my aunt and parents were drinking in the next room. I was upset and thinking about it afterwards when I had my first panic attack (Code 304).

Raped aged seven (Code 24).

My own parents sexually abused me when I was a child; I was forced to have sex with my mother when I was 16, which was unreal (Code 8).

I tried to think what could have caused it, and I actually pinpointed it to years ago when I was about 7 or 8 – my father shot my dog and it didn’t die, so he bludgeoned it with an axe, and I heard the screaming of the dog and it didn’t bother

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me for years and years, and then when I was 22 there was a dog next door that
started the same noise and everything just came back, and since then – 10/11 years
later and I still just freeze inside when I hear that noise, even if I don’t hear it I am
anticipating it (Code 35).

In some cases the research participants reported that their anxiety was made worse by
separation and divorce.

I separated from my partner…the stress of the relationship breakdown led to very
high levels of anxiety (Code 89).

In one case, the person reported that their anxiety increased during custody battles following
the relationship breakdown. However, the individual fought back against both her ex-partner
and the panic attacks for the welfare of her child.

My ex-partner threaten to take my (our) child from me (one previous kidnap
attempt) this time helped by his lawyer, through a litany of lies. He’s powerful,
vicious and has money to get whatever he wants. He is a man desperate for control.
I am pleased to say that despite the panic attacks, I fought back and he only got
limited access (Code 44).

In the Illness/Accident group of factors, the stress of a personal illness often led to the first
major panic attack. The types of illness were varied including dental surgery, miscarriage,
cancer, heart disease, food poisoning and depression.

When I was 32 years old the agoraphobia fully developed at that time I had my
tooth out and I’d had a haemorrhage after it, and I went to get on the bus and I
couldn’t get out of there quick enough, but I had to sit there because I had an
appointment. That was the start of, you know, a proper agoraphobia. Also, I had a
miscarriage as well. So, all those sort of things built up (Code 22).

I had lots of chest infections and was told I had an old TB scar (Code 33).

I was being treated for infertility when I had an ectopic pregnancy. During the
operation I came round – couldn’t breathe. I had my first panic symptoms two
weeks later. I had four-wisdom teeth out and four weeks later – I had my first major
panic attack. Then my Grandmother died, two brothers and sister in-law were
injured in a car accident in front of us…Doctor rang and told me I had cancer, but I
could be cured of it…I then got depressed and started having panic attacks (Code
81).

Heart disease (Code 303).
After an operation in September 1994, I kept feeling unwell, so I was afraid to go out, in case I felt unwell, that’s when it all started (Code 3).

At the age of nine I was suddenly separated from family and taken to the hospital (food poisoning) (Code 188).

I was diagnosed with depression, probably in 1998…I’d been really, really sick…I just battled through and then my two grandparents died within three months of each other and after that I went really down and was really sick. I hid in my bedroom, I didn’t want to come out, didn’t want to see anybody, and they tested me for everything under the sun until they finally decided that it was panic disorder and agoraphobia (Code 67).

In addition to the stress of a physical and/or mental illness, the anxiety of an impending natural health-related experience could prompt a panic attack in some individuals. In one instance, the natural stress accompanying a pregnancy increased the individual’s anxiety to an unnatural level. In another instance, the birth of a new baby preceded the mother’s panic attacks.

I had had minor panic attacks in earlier years (during my teens) but considered I had just got dizzy in crowded places, etc. My first major attack was 3 weeks into my third pregnancy. I was completely incapacitated by anxiety attacks, until 2 years therapy at Princess Margaret Psych Unit gave me back some control (Code 97).

It actually started when I had my first baby, when he was three weeks old I got this peculiar feeling right through me - I panicked, and it kind of started from then on (Code 33).

Alternatively, a personal accident could precede the first major panic attack. The research participants often had the panic attack immediately following the accident. However, some people had the panic attack months after the accident when they were in a similar situation to the original accident.

My panic attack followed a bad fall (Code 238).

At age 7 I was knocked over by a truck while crossing the road. I broke both my legs. I remember trying to stand up and in a state of hysteria screaming “I’m going to die, I’m going to die” – I’ve had panic attacks ever since (Code 203).

I was taking our children to QE11 swimming and we got hit from behind by a car. I had whiplash quite bad and the children were very shaken up and the car was out of action for about six weeks. Then 3 or 4 months after I’d had the car accident I was driving home from my sister in-law’s and had my first panic attack. The panic attacks were mild and then my mother-in-law got killed in a car accident and she
had lived in a cottage on the farm with us, and virtually the day after that happen I began to have major panic attacks (Code 148).

While research participants spoke of the onset of panic attacks following their illness or accident, several individuals spoke about their increase in anxiety when a family member had a major illness or accident. The research participant’s high level of anxiety for the welfare of their family member then preceded their first major panic attack.

Traumatic events seem to put me in a state of major panic. When I was 28 years old, I was told that my mother had 6/9 months to live (cancer), being the eldest and her next of kin I had to carry the burden. Two years later my 10-year old son was killed on his bicycle. Five years ago was told as next of kin for my no.3 son that he had about 3-weeks to live (cancer) if his chemotherapy didn’t check the cancer (major panic). He is still in remission and back at work after 18 months of operations and treatment. Three years ago my husband of 25 years died of a heart attack – another panic (Code 37).

My mother was sick with leukaemia (Code 67).

A close family member suffered a serious illness (Code 269).

In the Travel group of factors, the stress of travel preceded the first major panic attack. Research participants stated that the most common mode of travel that caused anxiety was flying which is a common phobia in the general population. The other form of travelling that caused anxiety leading to panic attacks was the car trip, where the trauma of travelling as a child (car-sickness) was linked to the onset of panic attacks in adult life.

My first panic attack occurred on an aircraft ½ way between Australia and New Zealand. On returning to New Zealand after a 2-week holiday on the Gold Coast in Australia. I did not let on to anyone I had a panic attack and just got on with life (Code 21).

I had a horrifying plane trip in Africa on the same type of plane as had exploded in mid-air the previous year. After that terrifying trip I had to fly six more times, which gave me a lot of anxiety (Code 102).

I was unwell and on a long plane journey and became so worn out I thought I could not stand (take) any more, that I could not escape, I started to have panic attacks (Code 211).

On holidays, blamed travelling (car-sickness), but the real reason was panic, about being sick in public and not reaching toilets (Code 114).
In the Environmental group of factors, the stress of changing and adapting to a new and different environment often triggered the onset of panic attacks. A number of research participants stated that the shift from a safe, secure and comfortable environment into a place that felt unsafe made them feel anxious and trapped. These feelings of anxiety and entrapment preceded the onset of panic attacks. Then the individual began to withdraw from the public place into the safety of their home.

We shifted from a extremely safe, secure, happy environment on an RAF base in Singapore to a noisy, over-crowded, insecure, open drains with rats in the middle of the township of Singapore. This was the first panic attack – I felt I couldn’t cope with the feeling of being hemmed in on all sides – no garden, etc (Code 116).

I moved from a small country town to a large city – which is when the panic attacks started (Code 170). My panic attacks started sometime after I left Wales, and all of the family came to New Zealand to live (Code 243).

I was approximately 12 or 13 years old when I walked into the post office, which was absolutely crowded and I took fright by sweating, heart racing, started to cry, and I ran out and went back home. Only to be abused by my mother for not doing the business I was supposed to do (Code 156).

I think that just going to different places and I started getting these panic attacks…There were different situations that I couldn’t go into, and I thought why am I feeling, you know, funny (Code 35).

I only feel safe inside my bedroom. If I want to go for a walk I don’t feel safe, and I panic in the car and at the supermarket. I can’t go out with a friend for lunch, as I want to come home to my bedroom. I feel I can’t go anywhere by myself (Code 279).

In the Drug Experience group of factors, a bad drug experience sometimes preceded the first major panic attack. The research participants reported a wide range of drugs that they believed contributed to their onset of panic attacks. These drugs included illegal drugs, prescription medication, coffee, alcohol, and de-sensitising injections.

I got them (panic attacks) occasionally (1 every 3yrs) and then they became a regular event. I was experimenting with drugs at the time and my psychologist believes this could have contributed to the panic attacks...(Code 92).

I started having panic attacks when I withdrew from sedatives (Code 17).
The panic attacks were probably aided by the use of stimulants such as coffee and alcohol. Prior to the attacks, binge drinking the night before would have primed the body for this response (Code 98).

I had a bad drug reaction to a prescription medicine when I was 25 years old. I required hospitalisation – it was a hideous experience (Code 190).

I was having a series of de-sensitising injections for hay-fever and had a reaction to the fifth injection – caused a vicious circle of worry, it would continue happening again and again leading to panic attacks and agoraphobia at different times in my life (i.e. post-natal depression and menopause) (Code 193).

In the **Work-related** group of factors, a stressful workplace experience sometimes preceded the first major panic attack. The stressful workplace situations included starting work at a new workplace, the demands of workplace performance and workplace harassment.

- I had just started working at a new job (Code 16).
- I was working in a very busy environment managing a hair salon – exceptionally busy (Code 175).
- I hated my job and was harassed by my work mates (Code 86).

In addition to workplace related stress, research participants cited their school life as the stressful factor. This stress appeared to be linked to over-studying and the stress of external exams and internal assessments.

- As I didn’t perform well with 5th Form exams I worked extremely hard in 6th Form and with the internal assessment, managed to pass all subjects (Code 169).
- Overly studious – academic (Code 27).

In the **Victimisation** group of factors, a personal experience that victimised the person preceded the first major panic attack. These personal experiences included being a victim of a house burglary, a stalker and a practical joke. In these three cases, the individuals lost their confidence, and suffered increased levels of anxiety prior to the onset of panic attacks.

- It started really when we got burgled, and I probably spent two days lying on the couch crying, thinking I was going mental and that was when I called a psychologist, and I started seeing her, that was really good (Code 92).
The main thing that provoked me into panic attacks is that an elderly guy about three years ago was hanging around town and he’s well known for abusing women and getting hold of them sexually no matter what age group, and he was beginning to approach me too much even when I was with a partner. He asked me to go around to cook and clean for him, and then he began following me around town for a number of weeks. I found he was hanging around near Burger King behind one of the big stone pillars there, and it was really frightening me, and I began noticing bad tremors going through my body, and I was really freaking out all over the place and I didn’t know what was happening to me at the time, and when he approached me near a shopping spot and asked me if I would go away with him for a dirty weekend, that gave me – just like it is now - the cold shivers, and I didn’t know what the heck was happening to my body, and I just had a feeling of fear (Code 88).

The night before my panic attack the couple we went camping with, the man threw a crayfish at me. I woke in the dark later with fear, which led to a panic attack, but didn’t know what it was then – that was about 26 years ago. I’ve continued to suffer from anxiety ever since even after dealing with things with prayer and counselling; didn’t find medication successful (Code 218).

While the research participants’ data has been presented in categories of single stress factors, in a large number of cases the research participants reported that a multiple of stressful factors had happened prior to their first major panic attack. However, these multiples of stress factors were often a combination of the single stress factors, such as a death, relationships, accidents/illness, travel, environment, travel, drug experience, workplace, and victimisation.

I can remember it was a result of a very stressful year, almost 30 years ago. Car accident quite serious, no one was badly injured. Grandmother died. Husband was away for 10 weeks working aboard. Baby quite sick while husband was away. Moved house and mother came from Scotland supposedly for 6 months, stayed with us for 8 years (Code 11).

I think I was pretty stressed, I was busy being the perfect wife. I had the house clean all the time, and one night a week I did baking and sewed dresses, knitted, etc. The house was built, but not really finished, no fences, I could never ever relax. On Sundays when I wanted to read outside, there were always cars driving along the street looking at all the new houses. And my husband wanted me to work all the time. I never had a rest (Code 31).

(1) My nephew was terminally ill with a genetic disorder and was very ill and died in 1998, (2) I had a horrible new boss at work, (3) my husband had an operation on his wrist and was off work for a month and I had to drive him everywhere (Code 94).
I had an illness (but not major). Began holidays after first year of study in a new course (Code 101).

Illness of father, death of father, death of grandmother, in conjunction with school exams (Bursary) the same week (Code 104).

(1) I was living alone (single) in the UK – my parents came to UK on holiday – I criticised my mother in an outburst, accusing her of never doing anything, but sitting there and criticising. On and after that trip I became acutely aware of how my parents (and 2 older siblings) expected me to fit in with them, their plans, their wants and noticed this as a chronic pattern of behaviour towards me (i.e. controlling me), in my family. Also, I fitted in with other people’s wants - friends; colleagues; employers; flatmates; boyfriends, etc. (2) I was looking for work for the 90th plus time and a new home with negligible money to my name (i.e. less than 100 pounds at the time). Not knowing what to do, what I wanted to do; and based in the greater London area and not wanting to go back to live and work in Central London again. I didn’t want to do temporary work, but feeling that was my only choice or low-paid live in work, nannying or housekeeping. (3) Work-related stress - I was driving in central London, which I’d done before, happily for work, for Dial-a –Ride (a door-to-door service for physically disabled people). I began to feel “trapped” in major traffic jams, while trying to get disabled passengers, who I felt responsible for, to their destination by a specific time; trying to negotiate major traffic congestion, navigate and keep the disabled person satisfied by getting there safely and on time. I began to feel like I was in a vice, which was closing in on me! (4) Living in London on 4 pounds nett an hour, doing as many hours as possible to increase my take-home pay, having very little life, relaxation, enjoyment outside of work, which was indicative of most of my employment. (5) Redundancy: although all my work has been of a temporary, short-term nature, usually I’ve decided, or at least known, the end date from the start; 2 months before my panic attacks, a temporary job unexpectedly ended, at the time my parents were due to visit the UK. (Code 2).

In December 1994, my daughter had a serious car accident (head injuries). My elder son left home the same time to work in Wellington. In May 1995, my mother passed away. I had a minor operation that same year. Also, that year my younger son was suicidal at the age of 15 years. He was diagnosed as having Aspergers Syndrome (Autistic Spectrum Disorder). He has needed unceasing care and direction all his life. My elder two children were chronic asthmatics since babyhood. Unfortunately, my husband doesn’t feel able to deal with health issues, so it was left to me. In 1998, my son was referred through his school to Youth Speciality Services, without going into detail - that final experience I believe was the catalyst for my first panic attack, which happened while asleep at 1 am 6th September 1999 (Code 108).

I can’t remember exactly when my panic attacks started, but it was as a result (I believe now) of having been in a stressful relationship and not having faced or grieved over the loss of my parents. It was probably about 10 years after my father
dying at age 54 of a heart attack, followed by the suicide of my mother 2 years later, that panic attacks started. Until then, I hid behind my 3 children but as they became more independent I began to face reality (Code 209).

Stress in general caused by social isolation and an unfulfilling job (Code 235).

A number of smaller events occurred over the years leading up to my first panic attack when I was 45 years old. Abnormal smear, work stress, daughter unwell, shifting house, son, hospital visit, etc (Code 265).

About 11 years ago I got thyroid cancer, and I didn’t know what was wrong with me at the time, because my life was just one big panic attack basically. Until I realised what was wrong with me and they had to whip it out and the next few years after that until I could get the medication right I was always horrible. But then it came right. But the other stresses like giving birth – that was bad – I think coming home with my first one – he’ll be 16 next month – coming home with him was, you know, you’re home now what do you do, but I suppose most women go through that. Any time that there has been stress in my life, there have been the panic attacks – you know, the hyperventilating and stuff like that. I feel like that at the moment, although my stress levels are fairly well controlled – they are not high like they used to be, but my older son has ADHD and he is such a handful – he really is, and he is very stressful to live with, but I am dealing with that. We’ve made new rules and that for this year and we are just trying not to get ourselves stressed. When I do get stressed I will sort of get myself down by doing my breathing. You’ve got to be conscious of it when you’re like that, because you know that you’re not breathing properly until you relax and get the old breathing going properly again (Code 41).

When I was eighteen I was driving in a car up to Nelson with my partner and bang – I didn’t know what was happening. I was hyperventilating, and we stopped at a dairy and got a brown paper bag because I thought it was asthma and just kind of went to bed and hoped that it would be a physiological thing and that it would go away in the morning, but it didn’t. When I look back I was under a lot of stress at the time. I had left my job, was in a new relationship, and in a new flatting environment, things like that which at the time I didn’t think were stressful just mounted up and triggered the panic attacks (Code 93).
First Panic Attack
In the survey questionnaire, 85% of research participants recorded their exact age when they had their first major panic attack. The graph and table show the age of the research participants when they had their first panic attack.

Table:

<table>
<thead>
<tr>
<th>Age</th>
<th>Research Participants</th>
<th>Age</th>
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</tr>
</thead>
<tbody>
<tr>
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<td>6 to 10 years old</td>
<td>8</td>
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<td>16 to 20 years old</td>
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<td>21 to 25 years old</td>
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</tr>
<tr>
<td>26 to 30 years old</td>
<td>10</td>
<td></td>
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</tbody>
</table>

The research shows that the peak period for the first panic attack was the 11 to 15 age range, which remained reasonably steady through the early and mid 20’s, then began to decrease in the late 20’s through to the 31 to 35 age range and then markedly declined in later adult life.
Conclusion

In conclusion, the research has shown that some research participants believed that their family upbringing was a major contributory factor in their onset and development of agoraphobia as children. Several of these research participants believed that their parents/caregivers’ regular role-modelling of anxiety, over-protectiveness, discouragement of risk taking, inability to instil confidence and assertiveness, and disempowerment through neglect and/or abuse undermined their development of confidence and assertiveness and ability to learn and use coping strategies in anxiety inducing situations as children. The research has also shown that a significant number of research participants believed that one-off or clusters of traumatic events and/or ongoing stressful situations contributed to the onset and development of agoraphobia in adult life. The study concludes that a significant number of research participants had their initial panic attack in their childhood and youth with a greater number having their initial panic attack in adult life.
Chapter 5    Findings Chapter (Part 2)

The Social Interactions affected during the Unmanaged Symptoms Stage of Agoraphobia

In Findings chapter (part 2) the study presents research participants’ personal accounts of the social interactions that were affected during the unmanaged symptoms stage of their agoraphobia. The chapter begins with research participants’ personal accounts of having a panic attack and its effect on their social interactions. The chapter continues with research participants’ personal accounts of the impact of panic attacks and avoidance behaviours on their primary and secondary school years as well as their youth. The chapter presents research participants’ experience of struggling with agoraphobia in daily life, which includes travelling and social interaction in public places and situations. The chapter then explores research participants’ encounters with public perceptions towards agoraphobia and mental illness, which leads to the making of excuses to hide their agoraphobia. The chapter shows research participants’ experience of ‘coming out’ about their agoraphobia and the reaction of family members, friends and others. Also, the chapter describes research participants’ experience of the effect of agoraphobia on their marriages/intimate relationships, parenting, post-secondary education, and employment. The chapter concludes with research participants’ accounts of the most severe form of agoraphobia – homebound agoraphobia – which led to social isolation and alienation.
Life Story of a Panic Attack

One research participant graphically described her first major panic attack. This account includes her mistaken comprehension of what was happening to her, the call to the emergency services, the spread of panic attacks into other places and situations, the avoidance of those places and situations where she feared a panic attack and the withdrawal into the safety of her family home.

I felt that I couldn’t breathe, and then I felt like my heart was pounding. I made it worse by reacting the way I did instead of dealing with it. I thought I was having a heart attack, and that I was going to die in seconds. I just thought I was going to pass out just like that. I had no idea it was a panic attack at all. My husband rang an ambulance…when they arrived they knew straight away it was a panic attack and they asked me if there was anything that had upset me…They gave me a brown paper bag to breathe into, so after that I carried a brown paper bag with me all the time, so that I wouldn’t need to call the ambulance again…. I continued to have panic attacks, It wasn’t always full panic attacks all the time...I remember I was pegging out the washing and I felt like I was floating, sort of light-headed. Then I started having a problem when I was standing in a queue in the bank, I’d come over real hot and sweaty, and I’ve got to get out. In the car sitting at the traffic lights waiting until they turned green again so I could escape the feeling of impending doom. I would go miles out of my way to get where I wanted to go without having to go through traffic lights. I started avoiding, definitely avoiding. Then I began planning my daily life to avoid more and more because it seemed to be happening everywhere. I tried to not go anywhere because I couldn’t go to that shopping centre, and I couldn’t go to that bank, and then I couldn’t drive down that street, and it just got worse, it ruined my life in the end, and then it was like I could only do things say in the morning because if I got up and did them first thing in the morning, I could get things done and get back home and I’d think, I’ve done it. But then it got to the stage I was starting to worry at night about where I had to go in the morning, and it just got worse… It could just come out of the blue. I would wake up in the morning and open my eyes and think, I’m feeling quite good, so I’d hop in my car and drive to the shop and go to the bank or whatever quickly, and it was like if I can get home before lunch time, then I felt safe sometimes at home, safer anyway, because if I had anxiety at home it wasn’t as bad as happening out there...because you just didn’t know when it was going to strike. It ruined my life (Code 105).

In research participants’ interviews the initial panic attack was normally described as an overwhelming and terrifying experience and the subsequent panic attacks continued to frighten and traumatising the individual.
I remember the day when I first had a panic attack, but I didn’t know what it was, and I had been to my sister-in-laws up at Sheffield and called into the shop to get milk and that, I got into the shop and then all of a sudden had this terrible feeling of something terrible was going to happen to me, my heart started beating fast, and I felt sick, tight in the chest, and felt like I was going to pass out, and it really frightened me (Code 148).

I thought I was going mad. I didn’t know what was wrong with me. I just felt very overwhelmed by it (Code 45).

All research participants spoke about the struggle of making sense of what was happening to them. To research participants the overwhelming and terrifying thoughts and feelings that swept through their minds and bodies were unlike any other experience that the individual had ever had in their life. The overwhelming majority of research participants could not relate a life experience as fear-inducing as their experience of a panic attack.

I didn’t know. I was scared out of my mind because I didn’t know what was happening to me and I’d never experienced anything like this before. I really thought there was something really wrong with me… (Code 156).

I didn’t know what was happening to me, to be honest I had no idea. (Code 33).

My first panic attack - I didn’t realise it was a panic attack, I didn’t know what it was, I felt totally out of control, and really scared. I couldn’t breathe, I thought that I was going to die. I believed I was on the verge of a breakdown, I didn’t know what was going on really… (Code 93).

My worst fear is that something is going to happen to me. (Code 37).

I thought I’m mentally unstable, but I didn’t know what was wrong with me. There was something not quite right. I was having these funny thoughts and I didn’t know why I had these funny thoughts. I was scared of everyday things that I shouldn’t be worried about. I was afraid of things and I didn’t know why. I didn’t know what was happening to me (Code 41).

In addition to the overwhelming and terrifying thoughts and feelings, some individuals reported a sense of not being fully grounded in reality during and following a panic attack.

What I found absolutely intolerable was the physical symptoms, and feeling like I was unreal that sort of feeling, feeling ungrounded (Code 281).

A significant number of research participants spoke of the compulsive cognitive processes involved in a panic attack. One research participant described the role of their internal dialogue
in constructing a worse case scenario, that they believed would result from their panic attack symptoms (i.e. a rapid heartbeat signalling an impending heart attack and their death).

When I have a panic attack one thought will come into my brain and it just keeps clicking over and over, its very compulsive. This compulsion of thinking a certain thought all the time just kind of gets a hold and takes over my thinking and I start to feel panicky about what I think is about to happen to me. I lose control of my thinking and all the physical symptoms tell me that the thinking is right – I’m going to go crazy or die…then I have a full panic attack (Code 274).

One research participant spoke of the compulsive cognitive construction of a worst case scenario (e.g. individual stops breathing and crashes the car) and the equally compulsive monitoring of their body for signs of the impending worse case scenario. This combination of compulsive thinking and self monitoring led the individual to flee the situation to escape their overwhelming and out of control state of mind and body.

When I drive my car I start to feel the tightness in my neck, and my whole body starts to tighten and I feel like I can’t breath, and I have to force myself to breath and keep driving because if I don’t then I’d crash and die. I can’t control the thoughts that I can’t breathe and I’m always monitoring how my throat feels. I struggle to control what I’m thinking over and over and I try not to focus on my throat. But I can’t and I panic and stop the car and get out. I have to escape the thinking and the feelings that are happening in the car that I can’t stop (Code 31).

Another research participant stated that their over-analytical mind fuelled their compulsive internal dialogue. In addition, the person struggled to distract their thinking sufficiently to disrupt the compulsive thoughts and feelings.

You get fixated on one thing, like you’re having trouble breathing and you start to think you’re going to die, and that’s it once something is locked in it goes around and around at a 100 miles an hour and you can’t stop it and that thinking feeds the panic and you don’t seem to have the ability to switch it off at all (Code 56).

A number of research participants spoke of the struggle happening within their internal dialogue, between the powerful, repetitive, and compulsive panic-inducing thinking and their rational self, battling for presence and control over their anxious mind and body.

I definitely have the need to control what’s happening to me when I start to have panic symptoms. But I panic that I’m losing control of trying to control the panic-
like symptoms. It's like a vicious circle of battling for control and fearing what will happen if you lose control of what is happening to you (Code 92).

To me panic attacks are about really believing that you’re losing control of your mind and body, and then knowing that you have to fight to control those thoughts and sensations from getting out of control, which makes the panic attacks even worse (Code 93).

One research participant commented that their need to control their panic-inducing thinking contributed to the actual onset of a full panic attack.

I think the reason I had panic attacks was a lack of trust in myself, which undermined my feeling of being in control of the situation… I let go and just allow the process to happen instead of trying to control it just in case it goes wrong. That is probably the key for me – just through letting go really. It is really hard, one of life’s challenges. That is where the meditation has been so amazing because you are actually just letting everything go when it is stressful and it is OK. I can immediately get to that peaceful place and just let it all go. I don’t have to control it, and it’s just great. I wish everybody could trust and simply let go (Code 93).

Often individuals battled their compulsive self-defeating internal dialogue in an attempt to rationalise what was actually happening to them.

I just felt weird and my heart was just palpitating, really fast. I thought it’s not a heart attack because there’s no pain, but I started thinking about my mother who had died and I never came to terms with it, and it was her heart and she’d never had a heart problem, but my goodness – it was all the thoughts that I was creating trying to explain my problem (Code 108).

A number of research participants commented that their compulsive internal dialogue and over-analytical minds turned them into chronic ‘worriers’. The person’s constant worrying often led to a reoccurrence of panic attacks.

I worry a lot, I find it hard to control it. It gets out of control like I can get anxious but they might not be things that I need to actually lose sleep over. But I wake up in the night thinking about them again. I worry over everything – it sounds ridiculous, but I usually find something to worry about (Code 37).

I don’t get colds or ‘flu, I keep very healthy...The annoying thing is that I can’t take advantage of it my doing the things that I should be able to do because of the worry about having panic attacks (Code 37).
In one case the research participant worried about the possible social embarrassment caused by a panic attack. In another instance the person felt drained as well as embarrassed.

My fear is that I am going to make a fool of myself, embarrassing myself (Code 37).

Panic attacks are very mentally, physically and emotionally draining as well as embarrassing (Code 86).

A large number of research participants were so frightened of the panic attack and social embarrassment that they fled the public places to the safety of their homes to avoid both panic-like symptoms and the possible embarrassment. However, the individual’s wish to escape the panic attack by fleeing home was often stopped by the social situation and/or feared social embarrassment.

I was standing in the post office in a queue and then all of a sudden I got a bad attack of nerves… I didn’t want to make a scene…but I ended up in tears and everything…I just had to go home (Code 156).

My first panic attack – I was on a jury in the court - and I felt, oh my God, I want to get out of here, I can’t cope with this, I thought why do I not want to go back in, and why am I feeling all closed in. We were the centre of attention really – in those days, everybody read to the jury and everyone could look at you, and you couldn’t move and get out of it, I mean you couldn’t just get up and walk out, because everybody would be looking at you again. I wasn’t in control of that situation, but I went back and spent the whole week out with the jury. That was the first time I ever felt panicky and realise that things were not right (Code 35).

In the Lyttelton road tunnel, you can’t do a U-turn and simply drive back out. (Code 35)

Having had the panic-like symptoms, research participants often struggled to understand what was happening to them. In most instances the person saw the panic-like symptoms as a personal weakness that was unique to them, rather than a mental illness that affected others.

I thought it was just me, I just thought I was weird. (Code 92).

I thought I was just a weak person (Code 156).

I thought it was a personal problem, that it was my fault (Code 274).
I saw it as a personal weakness, until I read about it and found that it is a medical problem and it was quite helpful knowing that others had it as well (Code 22).

In many instances the individual felt that the panic-like symptoms were a sign of physical ill health.

I didn’t know they were panic attacks then, I actually started thinking that there must be quite a lot of things wrong with my physical health (Code 281).

I believed that the problem was my physical health, because there were certain circumstances where I was becoming breathless and nervous and having to wring my hands and just generally getting quite nervous and I thought that I’d had some sort of stroke or heart condition. I went to the doctor countless times just to be told that it was stress and that I needed to chill out. But it didn’t abate and I noticed that as soon as I became stressful, the symptoms became worse, I was sure I was having a heart attack or a stroke or something like that and I would go into an emergency doctor just to make myself feel better (Code 281).

I really thought there was physically something wrong with me. I started having blurred vision and things just didn’t seem real, and I had palpitations and I thought, “Oh my God, I’m going to die (Code 56).

I didn’t really know what was wrong with me, I was just so scared, I kept thinking something was physically wrong and they weren’t picking it up. I thought there was something wrong with my heart because I felt the heart palpitations and I would skip heartbeats, and the tightness in the chest. I felt that it was a heart thing and they hadn’t picked it up. I thought it was a medical reason, not a mental health problem… I still have that nagging doubt that there is still something physically and well as mentally wrong. It has taken me a long time, I still have that battle a bit even now if anything happens, I think is that an anxiety attack or is it something else, there is always that doubt still (Code 148).

For some research participants, the symptoms of a physical illness were confused with a panic attack. This was due to the similarity between panic attacks (i.e. hot and cold flushes, sweaty hands, light-headedness and difficulty in breathing) and common illness like the flu virus.

I couldn’t tell the difference between flu and panic attacks symptoms. I was so used to having panic attacks, that the whole time that I had the flu I was stressing that I was actually having a panic attack or I was going to have one. I try to breathe, to take a deep relaxing breath, but I can’t due to the flu and then I panic that I can’t breath and so it goes on (Code 92).
In a number of cases the research participant, believing that the panic symptoms were a sign of an imminent medical crisis, contacted emergency services. It seems that the emergency service call-out and hospitalisation provided some comfort to the individual in that the medical service personnel were able to assure them that the panic symptoms were not a sign of a impending medical crisis.

I had this weird feeling and my heart was going flat out and I thought I’m having a heart attack. I dialled 111 for an ambulance...when they arrived they put the monitor on my heart. They said that my heart was racing at about 120 beats, but they couldn’t see anything else wrong because the graph was looking OK...anyway they whipped me off to hospital, so that was my first visit to the hospital (Code 108).

In some instances, the research participant’s frequent usage of emergency services for no apparent medical reason meant that the individual had to create a ‘story’ to justify their call for help. However, the person’s usage of stories to justify the calling of emergency services undermined their credibility as individual with a real health problem – agoraphobia.

I thought how am I going to justify this visit, so I said to the operator that I think I’m having an asthma attack. When the ambulance arrived they said we saw you last time, what’s the problem? I didn’t ring the ambulance after that, I didn’t think they’ll believe me again (Code 108).

All research participants reported that their panic attacks increased in frequency and spread into different situations.

I had panic attacks for about a year, I thought I would come right...then they started getting more frequent – different ones for different situations (Code 35).

Research participants reported that escaping the situations/circumstances where the panic attack was happening, or it could happen, became of paramount importance. However, some research participants believed there were no escape from the panic attacks.

At the start I always left, or went to the toilet and chilled out, or sort of took time out...I always managed to leave. But there are some situations where I get trapped - the hairdressers is still a big issue, when I got my hair coloured it was like it was going to take forever, and as soon as she got three quarters done, I thought Oh my God, I can’t leave. I thought I’d have to leave with half my hair done...I don’t think there are many occasions where I couldn’t get out of the situation. I always
managed to go out of the room when things got that bad, I would go to the toilet or leave the room for some reason (Code 92).

The panic never goes away no matter how much I do to get rid of it, the panic never goes away (Code 37).

The struggle with panic attacks often led to a significant loss of confidence in the individual. The loss of confidence would often last a long time. In addition, the lack of confidence brought about by the first major panic attack often robbed the individual of the feeling that they could cope with future panic attacks.

In the earlier days it took a lot of confidence away from me (Code 37).

I’ve had a real lack of confidence before, during and after the panic attacks (Code 274).

I had always been such a confident person, and I guess that was one of the things that family noticed in me, that I got quieter and I just wasn’t confident (Code 148).

I really lost confidence… I’m a very cautious person now (Code 79).

I had no confidence and low self esteem for ages (Code 92).

I’ve got no confidence at all and I only wish I could get it back. I’m terrible, I am not very confident at all, I’m afraid. I feel that I’ve got a long way to go yet to try and build myself up again (Code 156).

I had no confidence, no confidence at all (Code 105).

I loss a lot of confidence following the first panic attack. I definitely think that my lack of confidence was the biggest factor in my not being able to deal with subsequent panic attacks (Code 67).

The decrease in personal confidence often led to a loss of confidence in being able to do normal everyday things.

I always felt that everybody was better than me, that everybody was busy doing all these things which I would have loved to have done, but I didn’t feel capable of doing at that stage (Code 33).

I definitely have a lack of confidence. I am scared to be out there because of a panic attack (Code 67).
Some days I feel really good about myself, and some days I hate myself. There is nothing anybody can say or do that makes it better. I really hate myself when I feel like that. When I’m like that I get really down about myself, I hate myself, nothing is right, nothing I can do, put on, or wear is right (Code 67).
Primary School

In the survey questionnaire, 40% of research participants reported panic attacks (or panic-like symptoms) and avoidance of places or situations at primary school. In addition, 4% of the research participants stated that they had had panic attacks, but were either unable to avoid the situation or simply endured the panic attack in the situation.

The chart and table show the primary school situations where research participants, reported panic attacks (or panic like symptoms) and avoidance behaviour.

Table:

<table>
<thead>
<tr>
<th>Code</th>
<th>School Situation</th>
<th>Number of Research Participants</th>
<th>Code</th>
<th>School Situation</th>
<th>Number of Research Participants</th>
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<tbody>
<tr>
<td>A</td>
<td>Social events</td>
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<td>H</td>
<td>Responsibility</td>
<td>13</td>
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<td>I</td>
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<td>12</td>
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<td>17</td>
<td>J</td>
<td>Classroom.</td>
<td>10</td>
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<tr>
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<td>Sports events</td>
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<td>Bus</td>
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<td>Library</td>
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<tr>
<td>F</td>
<td>Choir</td>
<td>13</td>
<td>M</td>
<td>Sick room.</td>
<td>3</td>
</tr>
<tr>
<td>G</td>
<td>Sports teams</td>
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138
The table shows whether the 40 research participants had panic attacks and avoidance behaviour in school situations that were frequently encountered, infrequently encountered or both frequently and infrequently encountered.

Table:

<table>
<thead>
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<th>Description</th>
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<tr>
<td>Research participant had panic attacks and avoided infrequently encountered school situations.</td>
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</tr>
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<td>Mixed.</td>
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</tbody>
</table>

- Frequently encountered school situations include: travelling to school, school classroom, school playground, school assemblies, school choir (regular member), school sports teams (regular participant), school library, school responsibilities such as librarian, council, etc…
- Infrequently encountered school situations includes: school field trips, school social events, school sick room, school performances, school sports events.
- Mixed includes both frequently and infrequently encountered school situations
Secondary School

In the survey questionnaire 43% research participants reported panic attacks (or panic-like symptoms) and avoidance of places or situations at secondary school. In addition, 8% of the research participants stated that they had had panic attacks, but were either unable to avoid the situation or simply endured the panic attack in the situation. The chart and table show the secondary school situations where the research participants, reported having panic attacks (or panic like symptoms) and avoidance behaviour.

Table:

<table>
<thead>
<tr>
<th>Code</th>
<th>School Situation</th>
<th>Number of Research Participants</th>
<th>Code</th>
<th>School Situation</th>
<th>Number of Research Participants</th>
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<td>Responsibility</td>
<td>18</td>
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<tr>
<td>G</td>
<td>Field trips</td>
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The table shows whether the 43-research participant had panic attacks and avoidance behaviour in school situations that were frequently encountered, infrequently encountered, or both frequently and infrequently encountered.

Table:

<table>
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<td>Research participant had panic attacks and avoided infrequently encountered school situations.</td>
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</table>

- Frequently encountered school situations includes: travelling to school, school classroom, school playground, school assemblies, school choir (regular member), school sports teams (regular participant), school library, school responsibilities such as librarian, council, etc…
- Infrequently encountered school situations includes; school field trips, school social events, school sick room, school performances, and school sports events.
- Mixed includes both frequently and infrequently encountered school situations.
Primary & Secondary School

This chart shows that the 40% of research participants (primary school) and 43% of research participants (secondary school) had panic attacks and avoidance behaviour in similar school situations.

Table:

<table>
<thead>
<tr>
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</tr>
<tr>
<td>C</td>
<td>School assemblies.</td>
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<td>17</td>
</tr>
<tr>
<td>D</td>
<td>School field trips.</td>
<td>32</td>
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<td>E</td>
<td>School sports teams</td>
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<td>F</td>
<td>School responsibilities such as librarian, council</td>
<td>31</td>
<td>15.5</td>
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<tr>
<td>G</td>
<td>School sports events.</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td>H</td>
<td>School classroom.</td>
<td>25</td>
<td>12.5</td>
</tr>
<tr>
<td>I</td>
<td>School choir</td>
<td>24</td>
<td>12</td>
</tr>
<tr>
<td>J</td>
<td>School playground.</td>
<td>24</td>
<td>12</td>
</tr>
<tr>
<td>K</td>
<td>Travelling on the school bus.</td>
<td>15</td>
<td>7.5</td>
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<tr>
<td>L</td>
<td>School library.</td>
<td>12</td>
<td>6</td>
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<tr>
<td>M</td>
<td>School sick room.</td>
<td>8</td>
<td>4</td>
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</tbody>
</table>

In the study the research participants spoke about the anxiety they experienced in the daily ritual of walking, cycling or travelling on the school bus to and from school.

Walking to school made me feel very anxious (Code 45).

I sometimes had panic attacks on the way to school and went back home (Code 164).

I had to bike down a major road to school, which had a large park alongside, which made it very open… I couldn’t avoid this, and it affected me deeply (Code 203).

I had a bad panic attack and blacked out before I went in the school gate (Code 238).
I always wanted my mum to walk me to school, but my mum actually left when I was about six weeks old and she was very intermittent with her parenting, and she suffered quite severely with depression, and I always wanted her to be with me. Then sometimes she would be supposed to pick me up from school, and I remember this from being quite young and she wouldn’t be there, and I would be just panicking having to walk home by myself (Code 45).

I used a lot of energy wondering and worrying about how I was going to get to school and get home. I lived in a street with twin Italian boys and a couple of girls the same age as me, and I felt safe in that group, if we walked to school in that group I felt fine, but I used to always have these anxieties that they wouldn’t turn up or they’d be playing sport and I’d have to walk home by myself. As long as I knew they were going to be there I would be fine, I felt safe, but if they weren’t I wouldn’t take any notice in class for a whole afternoon if I knew I had to get home by myself. I think it was just to do with the fact that I would have worried so much about it I had someone to walk home with. And then I think you go into that whole cycle of losing confidence and things like that (Code 46).

I was panicky walking home from school (Code 41).

While these research participants had panic symptoms which encouraged avoidance, the state and parental requirement of school age children to attend school meant that they were forced to simply endure these panic attacks and attend school.

I was late to school one day and I felt to panicky to go into the classroom, so I went home and made out I was sick and my mother sent me back to school! (Code 213).

I think my mum kind of enforced exposure work really, because mum would say well, you’re going to school today and I had to go. I must have been very receptive to exposure because I sort of got over the panic and went on to intermediate and high school and did all that sort of stuff and it didn’t kind of happen again until I was about 20 something (Code 269).

Some children tried to avoid the anxiety that was happening at school by manipulating their parents into helping them to avoid school attendance. Alternatively, the child having failed to avoid school, continued to attend school and avoided those activities they were able to.

I tried to avoid going to school and I tried to get my parents to take me out of school productions and things like that (Code 37).

I remember being in school assemblies and sitting there, especially during the Summer time when it was hot, and thinking I have to get out of here because I feel
panicky and then standing up in front of everyone, going outside and getting outside and thinking, Oh, I don’t feel so bad, I feel OK now (Code 92).

I didn’t get involved in school performances, choirs or any other social events. I just avoided (Code 45).

I would avoid all school situations if I had the choice. I hated school and panic attacks were regular occurrences (Code 289).

Public speaking would have been a problem, but I always managed to avoid that position (Code 108).

School assemblies – could not avoid them, but recall on a number of occasions having to leave a school assembly, due to what I now realise were panic attacks (Code 92).

Only avoided school camps (Code 94).

I made out that I had a sore throat and couldn’t perform in a small girl’s choir in 4th Form at school concert. I was too timid and anxious to do so (Code 213).

For the majority of research participants the enforced exposure work meant that they were able to sufficiently endure their anxiety to function at school and avoid the slide into homebound agoraphobia. However, the school children’s enforced exposure work without the appropriate anxiety management strategies (Cognitive Behavioural Therapy) meant that they continued to struggle with low levels of anxiety, often throughout their school life.

In my early primary school years (approximately the primers) I sometimes wet my pants because I was so frightened…I had “Butterflies” in my stomach sometimes; the term we used as children, before a school concert and singing solo in the concert (Code 2).

To some research participants, the combination of anxiety and enforced attendance at school often made them feel trapped in the school situation. No doubt this feeling of entrapment in the school situation added to the anxiety of the individual

I didn’t really like school very much, I had to sit there and I couldn’t get out. I felt trapped in the classroom (Code 22).

I was agoraphobic as a child, I was about five or something…I had some situations that I had to get out of, or wanted to get out of, I just wanted to go home and just wanted my mum. This happen every week I would have to go to the sick bay and my mum would have to come and get me, and my mother would talk to the woman
who used to work in the sick bay, the office lady and she always still thinks of me as the girl she had to attend to at school (Code 269).

To these school children the daily stress and anxiety became a normalised part of their school life. One research participant spoke of the normalisation of panic attacks and accompanying depression in their day-to-day school life.

I always felt like I didn’t fit in… it took me a long time to settle in there… if anything that was new, anything that caused a change in life I couldn’t handle it. That is when the panic attacks and the depression pretty well lived together - side by side at school (Code 289).

Unfortunately, the majority of research participants did not inform their parents or teachers about their daily struggle with anxiety, as they believed it was a normal part of them themselves and their life.

I had a lot of problems in the schoolroom… but I tried my best. I didn’t tell my parents or teachers or any friends how I was feeling and about the anxiety, I just kept it to myself, I thought it was just normal for me to feel stressed (Code 79).

Some children were unable to express themselves to their parents, teachers or fellow students about their feelings of anxiety. One research participant stated that their inability to talk to others about their anxiety was their fear of social embarrassment and the possible negative value judgement of others. In some cases the child felt that their anxious feelings were a sign they were going crazy, which they then kept hidden from others.

The other students began to make very negative judgements about me. It was very sad, I felt very sad, I wanted to cry but I didn’t … there was really no one to talk to. I had friends, but I didn’t speak about it because I thought it was quite embarrassing, and we never spoke about it (Code 274).

At secondary school I would have panic attacks before PE (Physical Education), it was awful, I can still remember feeling the terror… of course I didn’t know what they were. I thought I was going crazy. I didn’t talk to anyone about it I just kept it inside me (Code 289).

A large number of the research participants commented in the interviews that they did not know that their anxiety ‘feelings’ were panic attacks. It was often later in adult life that the individual learnt that these ‘feelings’ were actually the symptoms of a panic attack.
During Standard 1 to 4, I often stayed home from school. I wasn’t fully aware that the symptoms I had were called panic attacks (Code 75).

The first panic attack I can remember was at a school trip to the movie – Watership Down – but I did not know at that time that this was a panic attack (Code 202).

The first panic attack I had I didn’t realise what it was happening. It wasn’t until I was an adult that I sort of looked back and knew what had happened to me. I was fifteen and my grandparents had been in an accident, my grandfather was killed and my grandmother lived another six weeks…It was the school sports day and started having these panic symptoms like my eyes just started going funny - blurred vision…I asked someone to get me to water…I had a drink of water it just cleared it up like that. And that is what I have done ever since. I have a drink of water, which takes the anxiety away and clears it up (Code 256).

My panic attacks were not diagnosed until later in life (Code 156).

Those research participants, who did inform their parent(s), felt that their anxiety was simply viewed as a normal part of their character, which meant that their families did not act upon the disclosure of their problem.

I always panicked at school, I’ve always really, really panicked about anything and I just thought that was common. I think my parents thought it was common too, just normal for me because that is what I have done, always panicked about something minute, ever since I can remember I’ve always panicked (Code 67).

One research participant stated that her anxiety made her manipulate her teacher, so she could escape the school environment.

My teacher knew that I was always feeling anxious and I would work around her to go home (Code 297).

Another research participant, who did inform others, received support to help her with the panic attacks. However, the individual was careful to limit her self-disclosure to those friends whom she could rely on to act in a calming and supportive role.

As I got older, into high school, I let my friends be aware of what I was going through, and what was actually wrong with me. They were able to pick it up before I actually picked it up myself, they could see me getting a bit jittery and they would try and calm me down before anything major happened (Code 67).
Whether the research participants received support or not, the daily struggle with anxiety led to a loss of their self-confidence. In addition to their loss of confidence, there was also the loss of enjoyment in their school life.

I had no confidence in myself (Code 37).

I did well at school and had a great group of friends, but I was plagued by panic attacks since I was fourteen and so I did not really enjoy high school (Code 52).

The research participants’ decreasing confidence and continuing struggle with anxiety often caused social isolation and alienation. This included a feeling of uneasiness and discomfort around other students, a feeling of being different from others, a wish to be alone, as well as an inability to form supportive friendships.

I felt uneasy (anxious) all time, I couldn’t relax, I felt too uncomfortable to be around schoolmates (Code 79).

I avoided other students, especially in corridors, as much as possible (Code 86).

I felt uncomfortable with people around (Code 79).

I did not like to be different than any one else (Code 67).

A lot of the time I wanted to be (used to being) on my own (Code 279).

I never made friends that easily at school. I had a few friends, and I still don’t make friends that well even now because I’m not a very good conversationalist, and sometimes I wonder if I would make friends easier if I was more confident (Code 156).

In addition, the lack of confidence and anxiety negatively impacted on their academic studies. This included class participation, academic performance and ability to complete school examinations.

I was so nervous at times, that I didn’t comprehend all lessons…(Code 22).

I couldn’t read in front of the class (Code 32).

I felt sick in exams – particularly the first hour and I felt continually stressed as I couldn’t avoid the situation – often my mind would become blank. I failed exams owing to this abnormal level of anxiety (Code 169).
At secondary school I was having a lot of panic attacks, that made me dead quiet in class (Code 274).

I didn’t like going to school; I kept in the background. I was always a bit anxious. I couldn’t cope with stress… I feel that I missed out on a lot of my education due to anxiety (Code 22).

The research participants’ downward spiral of decreasing confidence and anxiety often led to the fear and avoidance of a wide range of school situations.

I didn’t feel confident at school…I was always late for school because I would avoid going to the last minute…I would be terrified of arriving late for class without a note to explain my absence…the Sister would strap late-comers (Code 274).

I had very high anxiety and fear of certain school situations (Code 170).

I hated going to Mass (I’m Catholic) at the Basillica - it was so large to me at the time and I felt so small (Code 203).

I didn’t like going on school camps and to swimming sports (Code 202).

I hated field trips, exams and assemblies (Code 207).

Group social situations (Code 175).

I didn’t want to go on school camp. I was so anxious that I had to be taken home again (Code 227).

Prize giving was hell (Code 7).

Having to take notices to other classes (Code 24).

Swimming and tests (Code 63).

At primary school I avoided school camps (Code 94).

School camps and field trips (Code 207).

Talking in front of the class (Code 238).

Unfortunately, the research participants’ lack of confidence, daily struggle with anxiety and social isolation made them vulnerable to school bullies who preyed on passive and socially isolated victims.
I was bullied at school a lot, some of the guys picked on me because I was one of the passive kids, and they used to pick on me a bit. They would sometimes punch me in the stomach and knock the wind out of me (Code 79).

I remember feeling sick a lot of the time, I always felt intimidated – I was small, very small – I was always being picked on and being put down, and that sort of thing at school (Code 37).

I lacked self-esteem and was a timid child… I avoided the playground too because of the bullying (Code 297).

I was always struggling with anxiety and after the bullying began I started having major panic attacks on the bus and outside the classroom in the corridor, wherever the bullies were I had major panic attacks (Code 31).

I was bashed up a lot at school, I was not strong enough to fight back (Code 223).

One research participant spoke of his fear that his ‘weakness’ would leave him vulnerable to bullying. Therefore, he hid his anxiety from other students who were seen as potential bullies.

I didn’t tell anyone that I was having problems with anxiety, I didn’t want others to know I was weak and ripe for bullying (Code 79).

In some cases, it was the teacher who bullied the child into participating in school activities that induced anxiety. The teacher’s bullying methods undermined the child’s developing confidence, and significantly increased their anxiety in that school situation. In addition, the child would have developed higher levels of anxiety with these authority figures, which further undermined their development of confidence.

When I was at primary school, my primary school teacher… told me to get in the swimming pool and at that time I couldn’t swim and I had a fear of water and it was deep water. He said if you don’t get in now I’ll chuck you in and that’s what he did. I was starting to drown, and was taking in water, and two boys I knew pulled me out. After the event, I began having panic attacks, but I didn’t know what was happening to me. The teacher got a rap over the knuckles for that, and I think one of the boys who pulled me out I think he told one of the other teachers about it, and the headmaster then told the teacher off (Code 79).

The fear of my male teacher was so intense that I would have panic attacks. I told no one as I thought no one would believe me (Code 289).
I was afraid of the sports lady teacher who made us have showers with all the cubicles open while she watched. I was very shy and it was a horrid time. I used to try to be off school that day (Code 227).

I was at St James Catholic School, and if I was late I would sit in the corridor and be absolutely terrified of the Sister because I knew I would get the strap or be humiliated in front of the class. That was the first time I experienced fear, great fear of the nuns (Code 274).

One research participant spoke of her school life when the lack of confidence, the struggle with anxiety and the bullying from others drove her deeper into panic and avoidance behaviour in adult life.

When I was in the 1st and 2nd form I went to a country school, I was incredibly shy, I had really bad self-esteem, and the boys used to tease me because I was shy and for some reason the headmaster who was a teacher singled me out. If I didn’t finish my maths or couldn’t do something, he hauled me out in front of the class and put me down saying how stupid I was, and he used to ring my parents and say how spoilt I was and I was a horrible little girl...The teacher was wanting to set up a school choir...I couldn’t sing, but that was another excuse to get me out in front of the class and say how useless I was that I couldn’t even sing properly, and that went on every day for two years...I can always remember it, he had a daughter in the same class, and she had done something, and he said, “Right, over to the office” and he got the strap out and went over and administered his punishment and came back and was whacking the strap on his hand and I was absolutely totally terrified of him and I felt all this fear....On the weekends I would come right because he wasn’t around, but when it was time for school, then the fear and terror of going to school and being constantly mentally abused by this man would come back...Then I left school and for years and years later the panic attacks still kept coming whenever I got stressed or depressed, and I was a constant worrier (Code 289).

Other research participants recalled their humiliation at school, which caused them to develop panic attacks.

I was involved in a play and it was going to be in front of the whole school, and I made up the play, I wrote the play and I chose the people who were going to act in this play and it was a big story, and when I finally went out to do my part, I froze, I had stage fright and I was humiliated. I was very embarrassed and every time I saw a student they would either turn away from me or look at me like, that’s that girl who made a fool of herself on the stage. I couldn’t understand why I was like that, I was so confident at writing the play and directing the play and acting the character, because I was very good at mimicking people, and when it came to the crunch I just froze, I couldn’t do it. I lose my confidence in myself I’ve panicked ever since (Code 274).
I was very gifted at sports at primary school; I played netball, softball, and basketball. Then I got into the 3rd Form, I think I was misunderstood by my PE teacher and I was sent into the middle of the court and was told to stand there for the whole period of the class, and then my PE teacher came up to me at the end and said, “You have the ability to do anything in sports and you choose to talk and to be a nuisance in my class and for that I have no time for you, you are absolutely nothing to me. If you want to waste your time, fine, you just do that”. She blew my confidence, and from that time on I lost my confidence and courage and I lost my talents and ability to play sport. Then I began to have panic attacks during PE and sport (Code 274).

In some instances the research participants’ decreasing confidence and self-esteem, ongoing panic attacks, school bullying, social isolation and deteriorating academic abilities led to individuals dropping out of school. This inevitably affected their future education, employment and life chances.

I was in the 6th form and I started having panic attacks, it tipped me over the edge, so I finished college (Code 45).

I stuck it out until I was sixteen, but because of the persistent panic attacks I dropped out (Code 52).

I found that a Catholic education was for those that excelled in their academic studies as well as those who were talented in sports.... those who were quiet and passive children like me they didn’t pay any attention to, we were simply allowed to slip through the system and eventually drop out (Code 274).

One research participant in the survey questionnaire wrote of her school experience that captures the experience of a child struggling with anxiety at school.

I was nervous and anxious at primary school, in some classes and with some teachers, if I had to read aloud; or wanted to ask a question – I didn’t; or if for some reason the teacher/class’s attention was focused on me. At secondary school I avoided – I did not put myself forward. I was rarely in a sport team even though I was athletic and talented or participated at a lower level that I was potentially capable. I never took part in drama or similar performances; although I was in the school choir – but never as a solo – even though the music teacher and other people indicated I had a “voice”. I held back, from fully participating in any group or classroom event – reluctant to voice my opinions, ideas, to be active, to draw attention to myself in some way, even though I was intelligent, energetic, etc. I never achieved close friendships with males/females at and outside of primary or secondary school – like a best friend or “clique” of friends. I always hovered on the outside of groups of friends, doing enough to be acceptable, but never “in” the group; was occasionally “teased” (mild bullying) at school, like others, which
always made me anxious! It would have been very difficult for me to “avoid” formal activities without drawing attention to myself or playing truant both at primary school (a small country school – no more than 20 pupils throughout my primary school years); and at a private boarding school for girls during my secondary school years. I never went to the school ball at the end of sixth form; nor did I mix with other pupils after school in my primary school years; nor during holiday times in both primary and secondary school years. I felt that secondary school, especially was something I had to endure, there was nowhere else to go (Code 2).
Young Adult

In the study, several 21-year olds reflected on the effect that panic attacks and avoidance behaviour had on their teenage years. All research participants spoke about missing out on their youth, this included opportunities to do things, growing up like other teenagers, socialising and forming relationships, social drinking, socialising in public places, and simply having fun like other young adults.

When you’re 18 to 22, its like the social years when you go out when you’re a teenager and a young adult and you drink lots of alcohol and you get sick and you party all night, and I did none of it. It was hard because I was in my peak years of socialising, I should have been hanging around with friends and drinking and socialising and having fun. I should have been in a group of 18 year-olds and going out and smoking dope, but I missed out on my youth because I was having panic attacks and that’s what pisses me off because I feel that I missed out. I missed doing what every 18/19/20 year old is doing, and now I am grown up (Code 92).

When I look back and I think, shit I did nothing that other people did, especially when you hear stories like we went on this big booze trip and we just stopped off wherever we wanted to, and I can’t tell those stories (Code 77).

It has probably restricted me actually. I have probably given away lots of opportunities to do things, like I’ve probably missed a lot of growing up, missed the big parties, missed going through – as some girls do - lots of boyfriends. I just missed growing up like a normal teenager, being out there doing funny things and missed opportunities with friends, and things like that (Code 67).

In addition to the inhibited social life, the missing out included avoidance of ‘normal’ youthful pursuits. These youthful pursuits included travelling overseas (OE) and participating with friends in public entertainment.

I missed out on going to Australia, I should have gone and done the fun rides and stuff…I know I should have gone on the rollercoaster, but if I had a panic attack and we were being dragged up this big long frame or going through a dark, scary tunnel, and would have thought shit I’m trapped on a scary ride with things leaping out at me…I really should go and do it, because you only live once and I’m probably only being held back because I’m a scaredy cat, and because I might have a panic attack (Code 12)”.

One research participant who was able to socialise spoke about the need for a ‘safe’ person to accompany them during their socialising to provide support in case of a panic attack. The
person’s dependency of the accompaniment of a safe person often inhibited the spontaneity the youthful actions.

I couldn’t go out on an impulse… I had to have my partner with me… I couldn’t go anywhere without him, like if the girls were just going to the pub, I had to wait for my partner to come because I couldn’t just go off without him… as he made me feel safe (Code 299).

However, one research participant stated that she simply endured the panic attacks and didn’t allow it to affect her social life. However, the person commented that her forced endurance of the panic attacks often reduced her pleasure of social outings.

As a teenager and going to things… I’d always feel sick before going, and I would think I wouldn’t go, but I always managed to get there. I wouldn’t go along feeling good about it, but I wanted to do it and I didn’t want to miss out. I was always glad when it was all over and the next day when I felt alright again (Code 37).
Struggling with Everyday Life

Several research participants spoke of the advanced planning required to undertake normal everyday activities. The primary reason for the plan was to make the person feel safe when venturing into places and situations where they feared a recurring panic attack. However, the individual’s need to plan in advance often prevented spontaneity in their daily life. In addition, the planning required to prevent their exposure to panic attacks reinforced their belief that it was normal for panic attacks to happen in those ordinary situations. Therefore, the planning allowed the individual to function through advanced avoidance of the panic attacks that were out there waiting to happen when they ventured out.

If we go to a show at the Town Hall, I have to ring up beforehand – in fact, I went to a show at the Theatre Royal a couple of years ago, and the lady gave me a plan of the theatre so that I could ring up and book my tickets, I could say exactly where I could sit, because there are only certain places I can sit, and it would have to be by the door. So, things like that I can’t just say to someone, we’ll go to the pictures, you go and grab the tickets, here’s the money – I’ve got to go and ask if there are any seats at the back on the edge (Code 35).

I worked it out that if I wanted the post office, I’d go in when it wasn’t crowded, I’d try and work it out so that I could go when perhaps only half a dozen people were in there, that I could cope with, but if there were any more well I just couldn’t cope so I’d leave it and just went back when it was less busy, and I did that for years, I had to plan everything to work around my agoraphobia (Code 156).

I couldn’t be spontaneous and do something like go to the movies during the holidays, like I couldn’t just say let’s go and do something (Code 148).

One research participant reported that a single panic attack in a specific place or situation would often disrupt the planned activities of a day. The seemingly simple task of travelling on a bus to a dental appointment could be easily disrupted by a single panic attack during the journey.

One day I needed to go to the dentist, I had to get a bus into town… I started having a panic attack on the bus, so I got off and walked home. (Code 256).

Another, research participant spoke of the anxiety that arose from thinking about what could go wrong during a everyday activity. The person’s catastrophe thinking increased their anxiety, which raised their likelihood of having a panic attack during the activity.
My mother is in hospital at the moment and I thought, oh my God, I’ve got to catch two buses to get to PMH. And I was thinking, I don’t know if I can do this, but I’ve been very lucky in that I’ve been able to get rides, so I haven’t really had to put myself to the test. I think I could do it. I could go to town, but I would be pretty stressed out to start with. Once I got on the bus I would probably be alright. I would be a bit stressed out thinking that I had to do it (Code 22).

A number of research participants heavily relied on medication to enable them to function and complete everyday activities.

I couldn’t go out to the letterbox without being absolutely terrified. I went to a doctor and got put on Valium, and that made me feel really good. I would have a Valium before I went out the door before I did anything like going out and catching a bus and going into town. I was having counselling in town too – that would put me into a terrible state just the thought of going on the bus, so I’d have a Valium for that as well (Code 289).

When the research participant was able to complete their journey to the destination their ability to function was impaired by their panicking over the decisions they had to make in that situation.

I always find it hard to make decisions when I come in to do shopping, I panic about whether I should buy this item now, when its full price, but I know I can take it home on the bus, or should I wait until its on sale, knowing that I may not be able to come in on the bus next week because of the attacks. (Code 37).

One research participant spoke of her failure to complete an everyday task, such as grocery shopping which undermined her willingness to risk trying to do the activity again.

When I go grocery shopping…I come up to the counter, I’ll stand there sweating and the sweat will be pouring off me. I used to get the shakes, and they would say, “Are you alright, are you cold?” and I’d just say, “No, it’s just a panic attack”. And not very long ago I had such bad attacks that dad had to wheel me out in a wheelchair. I refuse to allow myself to be affected in such a way again so I won’t go shopping…(Code 289).

Generally, the research participants simply endured the panic attacks and continued to function in their daily lives. Often the people were the primary provider or caregiver, and had to force themselves to endure the panic attacks in different places and situations for the benefit of their dependants.
I wasn’t at the point where I couldn’t leave the house, I was still managing to go to work, and do that…I was still managing to function daily, but just not in all situations (Code 92).

I didn’t want to go to the shops, but I had to because I was on my own with two daughters, so I had to go to the shops and things, so I just did it. So I just had to force myself to go (Code 256).

Sometimes I have bad days. Sometimes when I go out I don’t feel entirely uncomfortable, but what I don’t do now is avoid them – I try and expose myself to them. Depending on what is happening I my life at this moment in time, sometimes I feel absolutely fine and sometimes I don’t feel so good, and some days I have real acute anxieties about going out, but I am 100 times better than I used to be (Code 45).

I think that with my husband working away it has probably been good for me, because although I know I was stressed, I’ve had to do things. I’ve not said I’m not doing that or not picking the children up from school, I had to do it because there was nobody else. So I think I have done a lot of things that I had to do (Code 33).

My partner bullied me into going to work when I was sick with anxiety, so I would end up going to work and putting up with this illness, but it just made my anxiety worse (Code 274).

Research participants often believed that their panic attacks would fade as they persevered with everyday activities, such as driving to work. However, the individual’s endurance of panic attacks, without an accompanying strategy to reduce their presence and effect, meant that the panic attacks did not decrease. Thereupon the individual became trapped in a cycle of recurring panic attacks and endurance tests, which steadily reduced their resolve and energy to continue functioning in these everyday activities.

I can remember driving to work and thinking I had to drive on my own…when I’m alone, that is when it gets worse. I don’t want to be far away from home, but being away from home on my own is the pits…On the first day when I had to drive into town I thought this is going to get easier and then after nine months, it’s exactly like what it was on that first day…I thought that’s it, I am not driving into town because it isn’t getting any better. I was thinking that the first day at a new job you are going to be nervous, but I had first day nerves every day for nine months, so then I thought I am not driving into town again, I am not doing it any more and then things kind of went downhill from there, things just got more and more difficult for me (Code 269).
Several research participants stated that the fear of having a recurring panic attack caused them to avoid a large number of everyday places and situations. These places and situations included going to the movies, shopping malls, using a lift, travelling on a bus, attending church, sitting in a hairdressers chair and sleeping at night.

I wouldn’t go to the movies, I wouldn’t go in a lift, I wouldn’t travel in a bus… I would think Oh, oh, I don’t know if you should go in there, I used to say to myself – your mind might have another panic attack (Code 35).

One Christmas I went shopping with my mother, my brother and sister in law and their children – we went to Riccarton Mall. The place was really crowded…and I was sitting there with my brother, the others were shopping, and I said excuse me, but I have to get away from here. And he just said it will be alright, they’ll be back soon. He just didn’t understand (Code 79).

What used to put me into big panic attacks was having to go down and get on the bus with people, too many people, I’m alright one-on-one, but get me in a crowded bus and the panic attack would come and I’d see the walls coming in on me, and I’d have to get out (Code 289).

I struggled to attend mass at the Cathedral…I think its because I had my first panic attack there (Code 33).

I was avoiding a lot of places where I was scared I’d have a panic attack (Code 156).

I don’t think I will ever lose the scariness of it…I am still terrified of going to the hairdressers because I know what will happen…I feel that I’m about to have a panic attack, and I’ll be trapped in the chair…I would much rather cancel the appointment (Code 92).

I didn’t like to hop on a bus, that would be a panic I didn’t like going in shopping centres, banks, even travelling into the country – I don’t know why that happened, but sometimes being out in the open or being too far from home or something made me panic…When I stepped out of the house it felt like it was to far to get back to if you needed to in a hurry (Code 105).

I had a panic attack in the middle of the night; I woke up with a rapid heartbeat that I though was a heart attack…after that I was too scared to go to sleep. I can remember sometimes lying in bed and feeling my neck and shoulders tightening up and then my whole body start to feel real tense. (Code 31).
As research participants began to have panic attacks and avoided more places and situations the more their lifestyle became restricted. Several research participants spoke about setting time limits when travelling to and from home (i.e. safety).

I manage my lifestyle with agoraphobia by setting limits. I would go to school sports when I felt comfortable. It has been like a little box with boundaries about what I feel comfortable with. I am comfortable being out about two hours including travelling there and back. My life is built around life two-hour travel limits (Code 22).

I telephone the takeaway place with my order, so I don’t have to stand in a queue and endure feeling intense anxiety while I’m waiting to escape (Code 92).

While research participants’ avoidance of day-to-day activities reduced their independence, the avoidance of social contact led to increasing social isolation.

I would ring up on a good day and make a plan with a friend, and then when the day came I’d have that much anxiety I’d feel sick, I’d phone and say “I can’t come over, I’m sorry” (Code 92).

Agoraphobia is a very crippling and restricting thing to have. It stops you doing many things you would otherwise quite like to do. It prevents your meeting people and basically “having a life”. When you think you’ve got it beat it rears its ugly head again (Code 59).

One research participant commented that he was unable to plan ahead due to the concern that the panic attacks would disrupt the planned social event. The inability to plan social activities severely restricted the socialising of the person with agoraphobia and their partners, families, etc.

I can’t plan anything. My partner said we’ll have blah and blah over on Saturday night and I said don’t do it, just don’t do it at the moment until I feel OK. I would do it tonight, it wouldn’t bother me, but tomorrow it might be different. It is that feeling of being trapped again by getting people over and the thought that they are going to be here for the next four hours and I can’t escape (Code 56).

However, the research participant’s avoidance of public places and social situations did not necessarily reduce the occurrence of panic attacks. In one case, the person’s retreat into the family home did not stop the panic attacks. Instead their home became divided into safe and unsafe places – wherever the panic attacks happened or did not happen.
I didn’t cope very well out in public…I just kept on having these panic attacks, they didn’t stop even when I stayed at home. They happened in the morning so I stayed up late at night so I could sleep through the morning, they happened in the bath so I only had showers, they happened in the lounge so I stayed in my bedroom, they just keep coming (Code 156).

In most cases the longer the period of time that had lapsed since the individual had done the activity, the harder it was to venture back into the same place or situation. In most cases research participants had avoided for years, a place or situation where they feared having a panic attack.

I hadn’t been into town for about eight years; I hadn’t been to the pictures for about 30 years until I went on the Anxiety Disorders course. I nearly flipped at the noise, especially since there was a crowd and we were sitting really close and the screen was huge. I would sit there and sit it out (Code 22).

As research participants began to avoid their daily activities, they began to develop strategies to ensure that others took over their responsibilities. Thereupon, parents, partners, family members, friends, neighbours and others often became unwittingly drawn into the individual’s strategy of avoidance of their fear. Some research participants developed excellent skills in manipulating others to help them avoid various activities without disclosing the real reason - agoraphobia.

I took the kids halfway to kindergarten one day and I just lost it, so I came home, and I think it was then that I started getting the lady up the road to take them. You become a bit tricky in how you do things – you think, I can’t do that, what am I going to do and so you work it out (Code 41).

I would arrange things, or arrange for other people to help me or do something for me, so I wouldn’t have to go out and do it. I could stay here and be happy. I developed little strategies to save me from exposing myself to uncomfortable situations. I suppose it is quite clever when you stop and think about it (Code 41).

I did get other people to pay bills at times, but they didn’t know they were helping my agoraphobia. I got very good at avoiding things that I didn’t want to do, passing it to somebody else without them realising it, I told them I couldn’t do it, I didn’t have the time or they were going that way and all those sort of things. I got real good and people wouldn’t realise – well, I don’t think people knew that I was making excuses. I got really good at excuses (Code 105).
Alternatively, those individuals who could not manipulate others to undertake everyday tasks, ventured out during quiet times of the day to do everyday activities.

It all depends on the time of day – for instance I went mid-morning to the South City Mall and there is a really nice place down there and I felt really relaxed (Code 79).

A large number of research participants required a family member or friend to accompany them into various public situations. The presence of a support person tended to calm the person having the panic attacks. In contrast, those research participants that went into public places and situations unaccompanied often struggled with their anxiety.

My partner used to take me to the mall while we were together then we separated, so I began walking down to the mall by myself…I would have panic attacks and begin to shake and I would feel that my body was going to get out of control, so I would go and sit down. I would quickly have something to drink and try to occupy my mind with other things. The thing overtook me again, but the thing was I was in there and I was alone, that made it much harder (Code 201).

I describe that fear like a pack of dogs barking at you, so I wouldn’t go out the gate, I wouldn’t go for a walk, even now, I won’t go for a walk on my own (Code 289).

One research participant often left an event prior to its finish to escape the feeling of being trapped in a perceived anxiety-inducing situation. While other research participants would often think of the ‘how to’ required to escape the situation.

We always miss the end of the rugby, we would leave like 10 minutes before the end so that I wouldn’t feel trapped in the jam of people trying to leave at the same time… we would rush to the car and put the radio on to hear the final score, because we never got to see the end (Code 269).

I use to think how long will I be there for, what excuse can I come up with if I want to leave early, things like that (Code 281).

I had situations all the time which caused anxiety…I would start thinking of how I could get out if I needed to (Code 281).
Travel Restrictions

A large number of research participants reported suffering panic attacks when travelling in cars. These panic attacks often led to the avoidance of short everyday trips, such as travelling to work. Some people reported that their panic-like symptoms increased at traffic lights, in middle lanes of traffic and at road works. The reason for the increase in panic-like symptoms is the feeling of being trapped in a place/situation that is beyond their control to readily escape. Therefore, the fear of not being in control in a place/situation is a major component in the onset of panic attacks.

I had to stop work because I couldn’t drive to work any more. I just hate driving, because of the panic attacks (Code 269).

I panic at the traffic lights and in the middle lanes of traffic – if I am in the middle lane, I feel that I can’t get out, it’s a feeling of being trapped. Some times I think Oh my God, and I grab hold of the wheel, because I just want to get out and leave the kids and the car, it is just too much… I got caught in road works one day and I got all panicky, but I managed to settle myself down with deep breathing… (Code 35).

In addition to research participants having panic attacks in cities and towns, a number of people struggled to drive in the countryside. The most common place/situation where people had panic attacks was driving on motorways. The possible explanation is that motorways are more likely to heighten anxiety than normal roads, (i.e. the number and speed of cars, etc). The motorway is bordered by large open spaces, which create a perception of being a long distance from home (i.e. safety zone) and the long stretches of non-stopping areas that would create a feeling of being entrapment.

I couldn’t get on the open road, like I would start going out to Halswell and then I would start feeling very nervous, and that is when I used to find I would have to try and get out…I wouldn’t go on the motorway if I was driving…I still get really nervous, and I don’t like driving on my own, I just won’t go out (Code 281).

I have a lot of problems with panic attacks in the country. The wide-open spaces cause me a lot of anxiety. I don’t know whether I am ever going to get home or whether something might happen to me, but it is just those thoughts running around inside my head, am I ever going to get home (Code 79).
While some research participants struggled to drive on motorways, others reported difficulty in travelling over bridges. A possible explanation is that the person felt anxious approaching and driving onto the bridge and then felt trapped and unable to immediately escape, especially on long spanned bridges.

I had to go out to Kaiapoi to see another friend who is agoraphobic, and she couldn’t get over the Waimak bridge. But I went, I got over there. But there is one bridge, the Raiakia bridge, the long bridge – I went to Timaru one year with a friend and the kids and I said to her that I would have to take a pill to get over that bridge. I was on Atrovine in those days. I took a pill to settle me to get over the bridge (Code 35).

Similarly, a research participant reported feeling trapped mid-way across Cooks Strait on the ferry.

I did get terribly, terribly panicky about going on the ferry. I don’t like the ferry. It was a beautiful calm day, but I still felt sick. You can’t get off it halfway – you just have to stay there. When we came back, I wouldn’t go on the ferry again (Code 37).

One research participant reported that flying was equally difficult due to the feeling of being trapped without an escape route.

I get a bit anxious about flying, I know it is only about an hour up there, but you can’t get off – that’s a problem (Code 37).

In one instance, the research participant was so overwhelmed by a panic attacks while driving, that she almost loss control of the car and hit a telephone pole.

I was coming home from a friend’s place one late afternoon and it was nearly half-dark, and I had a panic attack inside my car, when I was actually driving the car. I swerved over and parked my car on the side of the road. I missed a pole by inches, a great big telegraph pole and I just missed it by inches. I just sat there until I was right again. And then I just drove home quietly (Code 79).

In a large number of cases, the research participant developed personal coping strategies to enable them to continue to travel without endangering their lives or those of their passengers. One research participant’s strategy was to reduce the perception of a long trip by dividing the trip into a journey of landmarks. As a landmark was achieved she felt more reassured of her
ability to complete the trip. In addition, the physical stress of a long trip was reduced by regular breaks.

I don’t want to travel too far away from home. I feel safe and comfortable and I don’t want to go beyond my safety limit. When we travel by car we usually have to have lots of stops, if it is a route we have been on quite a few times I have landmarks, I think right we’ve got to this landmark, now we’ve got to get to the next one…When I achieve a landmark it is like a kind of reassurance. It means it’s not that much further to go. Instead of one seemingly long open-ended journey it seems to break it up into bits. This is a kind of coping strategy for travelling far from home (Code 22).

One research participant’s strategy to travel long distances was to extended her comfort zone by travelling around the country in a camper-van – her home away from home.

We plan to travel around New Zealand by camper-van…That would be my base, an extension of my comfort zone beyond my home…it would be safe (Code 37).

In one case, the presence of a partner helped to calm the individual sufficient to allow her to drive. At other times her partner drove, which enabled her to continue to have a relatively normal life (e.g. shopping).

It did affect my driving; I just didn’t go and do things that I used to do. I tried to do it on my own, but there was still that anxiety and of course it was there wherever we went, if we went out or got invited to things, and as it got nearer the time I would get very anxious, sometimes to the stage where I just would say that I wouldn’t go. I tried not to do it, but there were times when I did. It just depended on how anxious I was and whether I knew the people and the situation… I was lucky that my husband was in business and he could take time off to drive me places. I couldn’t drive into town, and I couldn’t drive too far, and I felt better if the children were in the car with me, I felt better if someone was with me. I just didn’t like being on my own. (Code 148).

A number of research participants commented that travel was seen as a major event in their day-to-day life. To a person with agoraphobia a short day trip on the weekend would take on epic proportions – similar to climbing Mount Everest.

People at work would ask what you did in the weekend. They would say we went to Akaroa for the weekend, and in my mind I would think, gee they’re brave, how did they do that, just went to Akaroa for the weekend. I thought for me that would be such a big undertaking. I turned down offers of different trips at times with people
because I thought I just can’t cope with going – I would rather just stay at home (Code 89).

One research participant became resentful about the time it would take to prepare for a major trip. She challenged the sense of spending months of time and effort preparing for a trip that would last one week. People with agoraphobia often use the ‘excuse’ of the time and effort required to learn cognitive/behavioural to avoid undertaking tasks that would take them out of their comfort zone.

We have a family wedding to go to in Australia in six months…my husband says to me – just go and get some counselling so we can get on the plane. I don’t want to do that, if you’ve got to put six month’s work into it, for something that only lasts a week, it doesn’t really seem to make much sense to do it. I don’t need to go to Australia for this wedding – like its no big deal, is it (Code 105).

While day-to-day travel and weekend excursions were problematic for individuals, the most traumatic event was overseas travel. The further the distance from the safety of their home the more intense the anxiety and likelihood of panic attacks.

That is a big bugbear right at this moment – travel. I’ve been to Hawaii and I did enjoy it, but I still had this awful feeling all the time – one half of me was trying to enjoy it and the other half was feeling anxious all the time and just wanted to get back home. I did go there and I’ve been to Australia. I was not quite so bad in Australia as I was in Hawaii, but Australia felt a lot closer to home than Hawaii, so perhaps that feeling a bit closer to home, like about three hours, I could be home again (Code 37).
Social Restrictions of Agoraphobia

A large number of research participants stated that panic attacks often disrupted or prevented their engaging in social activities. One research participant spoke of her unwillingness and inability to leave the safety of her family home to visit family and friends. To prevent social isolation she encouraged and manipulated family members and friends to visit her within the safety of her home.

The panic attacks meant that we didn’t do much visiting at all...family just came to visit us or it was just too bad. We missed out on the socialising aspect and the relationship aspect and I didn’t have a 21st, my parents simply came to my home (Code 92).

While research participants reported being able to manipulate family involvement in everyday activities (e.g. visiting), they were often unable to manipulate major family events to suit themselves. Often at family functions (e.g. weddings, funerals, etc) the individual simply had to endure the panic attacks. It could be that the fear of a negative family reaction to non-attendance at an event out-weighed the fear of panic attacks.

I felt uncomfortable, but I just had to go and I couldn’t get out of going to those major occasions like Christmas or weddings or funerals (Code 105).

However, some research participants admitted that the fear of panic attacks was a greater concern than the fear of negative family reactions. These individuals simply avoided all family gatherings. This led to significant social isolation and estrangement from the family group.

It’s very isolating, I am alone which I don’t mind, I like being alone, and sometimes the family get together and do things without me, which is fine, I don’t care. I would just freak anyway (Code 274).

Several research participants stated that they participated in social activities out of a sense of social obligation to other family members. One research participant stated that she went to the ballet to please her daughters, but that her enjoyment was ruined by her feelings of being trapped in a ‘dreadful’ place without an escape route. Another, person regularly attended her daughter’s musical performances, out of a sense of social obligation, though her enjoyment of the social experience was minimal.
I went to the Bolshoi Ballet many years ago for my birthday, I was shouted by my daughters. The ballet was beautiful, but it was the most dreadful place, we had to sit up ‘in the Gods’ and we were in the middle of the second row and I couldn’t see the exits. That wasn’t a very comfortable evening. I really didn’t like that at all. (Code 22).

I don’t like going out, I feel like I am going to faint and as soon as I start thinking that, I feel a hundred times worse. As soon the music starts, the feelings magnify on me and I have to get out quicker. Otherwise it gets worse every minute, the air around me and the bodies around me – it all makes it worse. There are a lot of places I won’t go because of this feeling…I force myself to go if my daughter is performing. She sings classical music, and if she is performing I will go. That is the only reason I will go…I try and watch what is going on around me, but I am so pleased to get back to the car and go home. I don’t even like walking out while there are people around me pushing and shoving, so the quicker I get out the better (Code 37).

Often the social event’s environment (e.g. noise, crowds) contributed to the unpleasantness of the social experience as much as the panic attacks.

Sometimes in the past if I walked into a pub and the music was blaring and the people are talking and there is lots of movement then sometimes it was just too much, and it automatically puts you into a sense of unreality because you walk in there and it is hard to hear anyone talking, and the only things you can hear real clearly are what is in your head. I’ve never got really panicky, but it is not a comfortable feeling being in there (Code 92).

While research participants did attend various family and social events, the individual was often focused on safety strategies during their attendance. The most common safety strategy was formulating an escape route from the family/social event. In one case, the person restricted her social commitments to within walking distance of her home. This allowed her to ‘escape’ to the safety of her home as and when required, with the ability to return to the events later. A number of research participants appeared to use the formulation of an escape route to offset their anxiety. It seems that the formulation of an escape plan reinforced the belief that panic attacks would happen, which created a self-fulfilling prophecy.

I think I’ve only been out to the Strip - the main place for teenagers – twice, I’m not really interested, I would rather be at home snuggled up on the couch with my man. I’ve never been a big party person, in-a-big-group person. I just don’t like being in a crowd – I hate it. I absolutely hate it. I think the biggest crowd I have been in was two months ago when I went to the Red Hot Chilly Peppers concert, and I did
really well. It was probably the biggest crowd I have ever been in and I coped really well. It was just over there and I knew I could come home and have a wee breather and go back and I didn’t need to, but I knew I could just walk across the road and come home to the dog and cat. I knew that I could come home (Code 67).

In one case, the person’s panic attacks and avoidance had led them to become completely estranged from their close and extended family members. In the interview, the person spoke of forcing herself to go into public places, often enduring high levels of anxiety, to meet anyone who could help her overcome her feelings of loneliness.

I spend most of my time over at the Mall because I am so lonely; I couldn’t possibly sit here all day and not see anybody. The Mall is just next door, it is huge in there and I go in there and sit and I have a cup of coffee now and again. I spend my time reading, I like to read, I spend my time in there amongst people because I need those people around me and I quite often get a lot of people who talk to me as well, so that is my reason for going over there, because I am so lonely here and I couldn’t possibly stay in this little flat all the time. I mean you can see for yourself the size of it and there is never much on telly either. If I see my neighbours I talk to them, but I keep pretty much to myself, because we’ve got a young fellow that lives over there in No 20, he’s a bit of a troublemaker, so I tend to keep in a bit because I can’t deal with the trouble and that you know. That’s another thing with my agoraphobia, I can’t deal with problems the same because I’m likely to go into a panic attack and I don’t want to do that, so I try to avoid problems and trouble. I start to shake and perspire and get upset, and I know it is to do with my panic attacks and that, so I try to live a quiet life if I can to avoid it. I’m not too bad on the whole, and I’m certainly a lot better to what I was, but I still tend to avoid problems and I think it is a lot better since I’ve been on my own. I’ve been on my own about 18 or 19 years now, so I’ve been working through a lot of my problems in that time with the help of my doctor, so I am gradually coming right (Code 156).

In another case, the research participant stated that she had forced herself to go into public places with friends to maintain friendships and thereby reduce the chance of social isolation.

I went out, but I always had that scared feeling…I didn’t enjoy going out…but I did make myself get through them because I didn’t want people to know. I was frightened that if they knew there was something wrong with me that I would lose them as friends (Code 105).

In most cases research participants forced themselves to participate in the social activities, which were essential for the social life of the family (e.g. school), while withdrawing from social activities they simply could not force themselves to do.
I used to be involved in the Playcentre, and the Red Cross…I pulled back from them and I found that really hard because it isolated me from the community. I did feel kind of isolated a bit, but I really had to push myself to do things with the kids. I still tried to be mother-help at school, which was one of the things I managed to cope with, I pushed myself to do that (Code 148).

However, as the research participants became more socially isolated, their confidence to function in social activities decreased. This meant that individuals struggled to retain and use the basic skills, such as making conversation, that are required to function during social activities. In some instances, the individual saw their panic attacks as a sign of a socially dysfunctional personality.

I push myself to go to some social gatherings. I sometimes know people there and after you’ve got over it being a nice day or how are such and such, you’re searching your mind for conversation. I don’t have the confidence for conversation, and I’m often feeling anxious at the time…I will try and push myself, but I feel like a lost soul, so I’ll just go home. (Code 89).

I felt like I was the only person having these experiences. I actually thought there was something drastically wrong with me, that I was socially dysfunctional (Code 31).

Some research participants stated that the panic attacks and avoidance led to social isolation that ruined their lives. All research participants reported that the most common result of social isolation was overwhelming feelings of loneliness. In addition, the panic attacks, avoidance, social isolation and loss of confidence often blended together to force the individual into a downward spiral of mental ill health.

It is hell! Because of this menace disease I am a lonely person. I do not go out to regular social events because of it. You lose friends, respect from work colleagues, you become your own best friend (Code 274).

I couldn’t socialise, so it ruined my whole life, it has been a hard time for me. I still don’t make friends that well even now (Code 156).

Being alone is overwhelming, I seem better when someone I like and feel easy with is in the home. Angry men make me run! I get so afraid of people I cannot say no so I withdraw. I detest criticism, I come from a highly critical and gossipy family. I lead a very restricted lifestyle. I no longer drive or enter shops. I buy clothes from catalogues. I carry a phone with me at all times to ‘call for help’. Until recently I blamed the person, situation, etc when I panicked not the disorder (Code 190).
A number of research participants began their downward spiral with the onset of panic attacks and avoidance, which resulted in a loss of confidence and motivation that was followed by social isolation and depression. The blend of anxiety, loss of confidence, social isolation and depression led to greater mental ill health and in some cases attempted suicide. The research cannot state the specific number of people who completed suicide at the end of this downward spiral, due to the absence of these individuals in this research project.

I have had regular periods of anxiety and depression where the panic attacks cause me to become isolated and unable to do shopping, family parties, go to church or even go for a walk (Code 289)

Agoraphobia is always present, and I struggle with the depression and the loneliness too. I’ve got no motivation or anything like that now, so one thing has lead to another sort of thing, you know (Code 156)

I though about ending it… I didn’t want to live a life that was like that. I felt there was nothing to live for and I had no-one to talk to regarding this problem (Code 93).

The panic attacks and the fear will just come over me…Since last year I have had a really bad dose of depression. I often feel suicidal, it’s like a fog coming in and the blackness would come over me and my heart would start going, and I would feel absolutely terrified, but there was nothing that was making me scared. The fear would come and it would be really nasty and what I’d do, I would think of suicide. I had it all worked out what I was going to do, and then I would phone emergency and they would get someone to visit me. My mum came and lived here and every time I had a panic attack she would come and hold me and pray for me. I’d do the deep breathing and that used to help (Code 31).

I would rather have a broken leg – at least I can say I’ve got a broken leg and I’ve got this cast on for six weeks, but at the end of that I’m going to be normal again. But these overwhelming thoughts and you think the only way – for me – in the way I was brought up; my father was quite a pessimistic type of person and I am that way too – I can be that way and my thoughts go on and on and finally I think of suicide. It is always there and always will be and it is who I am, and I tried once. The overwhelming thoughts make you think this is the right way to go and I’ll just go with these thoughts and I think of all the bad things that have happened in my life and you can’t see anything good, and nothing seems real and I’m not coping with outside, and things are never going to be normal again – those thoughts, and I just think I can’t go on like this every day, so you do think of escape routes and that’s the final one. And that is definitely there and I fight that every day (Code 56).
Agoraphobia brought me to my knees– I just took one sleeping tablet after the other, slowly slit my wrists and waited, and luckily at the time my ex-wife came home and found me, otherwise I wouldn’t be here now. It was down to that, just at an absolute end of my tether (Code 56).
Missing Out on Life Experiences

A large number of research participants reported that they missed out on life experiences due to the disruption to their day-to-day life, inability to travel, and reduced socialisation due to agoraphobia. One research participant commented on the daily struggle to achieve goals in life.

I was just functioning day-to-day, one panic attack to the next. I was probably only functioning on ten per-cent of my real potential (Code 93).

Another person stated that her panic attacks repeated in cycles, which meant that some weeks she was able function and other weeks she was unable to function. This meant that her ability to have life experiences was dependent on what stage she was in the cycle of panic attacks.

I have missed out on a lot of life experiences. It seems to come in cycles, for weeks. I can be really good and go out, then it comes back with a vengeance. But I don’t think I will go back to the bottom again (Code 22).

One research participant stated that the day-to-day struggle with agoraphobia had led her to missing out on a social life, especially the forming of relationships, which had led to social isolation in her youth. However, the person was able to gather the strength to function in her workplace, behind a facade of wellness that enabled her to protect her income and material lifestyle.

I couldn’t look at what it was doing to my life, it was just about living each day and hoping that – half the time hoping that I would die, so in that way looking back it affected me – I didn’t let it affect my work – it is amazing how strong you can be and how strong your facade can be. It affected my social life hugely, which involved relationships. It affected natural growth because I was stuck, so I missed out on eight years between 18 and 26 (Code 93).

A research participant viewed her struggle with agoraphobia as a waste of her life in that it had caused a loss of confidence, brought shame into her life and created dependency upon medication.

I have wasted all these years thinking there was something wrong with me, losing confidence, and being ashamed of my self because I couldn’t cope without a tranquiliser (Code 302).
Another research participant commented on the fact that agoraphobia and the missing out on life experience had robbed her of developing the confidence and self-esteem to set goals for the future.

I think that having gone through all this, it leaves you with a lack of confidence and low self-esteem. I feel like I won’t be able to do anything that I try to do now (Code 45).

One research participant spoke about the goals that they would have liked to have had achieved in life. The person spoke about how their lack of confidence and ability to socialise in public places (due to panic attacks) had prevented marriage. In addition, the lack of confidence had prevented the seeking of better employment and travel.

The panic attacks stopped me from going out and meeting people and going to parties, it forced me to spend more time alone, instead of going out and socialising and meeting potential partners…I would have liked to have just got things done and move on in life. I would have got a better job, I could probably have got married and maybe travelled (Code 79).

Another research participant commented that agoraphobia prevented her from doing the things she would have loved to do. These dreams included ballroom dancing and travel overseas. However, the struggle with panic attacks had prevented her from pursing her dreams and she had admitted that she had become trapped in an unwanted lifestyle for many years.

I would have loved to have had done modelling, and dancing - ballroom dancing. I always watched it if it was on telly and I think you tend to dream away a bit and imagine yourself doing it or something. I would have loved to travel as well, that is something else I would have loved to done. I would have loved to have had travelled overseas. I have never been out of Christchurch, I’ve been stuck here…There are other things that come into it as well, but the agoraphobia is the biggest reason that I haven’t done these things (Code 156).

While research participants commented on missing out on life experiences, some individuals added that they had led an unfulfilled life. The combination of a lack of confidence and agoraphobia had made a number of individuals feel a large part of their life had been taken from them. In several cases, the research participants hoped to become the person they had once been, prior to the onset of their agoraphobia.
I was not able to live a full life, as I would have liked, both socially and in general (Code 303).
Having agoraphobia has made me feel I have not done enough with my life. There are lots of things I would like to do with my partner, like going on holiday, or away for the weekend, or just going for a drive or to a party together. I would like to go home to Wales at some time to see my family, but am unable to at this time. You lose confidence in yourself, I am hoping to get my life back and be the person I had once been (Code 243).

Agoraphobia is part of my history, and I’m sure that this isn’t how I wanted my life to turn out, and I’m sure a lot of people feel like that with their lives. There are a lot of things I would have liked to have done, but I never did because I couldn’t go, I would have liked to have been a lot more involved in sports and drama and all sorts of things (Code 45).

One research participant stated that they had tried to acquire qualifications to improve their life chances. However, the lack of confidence and the occurrence of panic attacks had hindered their ability to complete the course.

I had always intended – what I had always hoped was that I could do some qualifications and get a better job and income. I knew of course that I would be unable to do any these things, so I just keep putting it on the back burner. I often think, especially the last couple of years since the kids left home, should go back and get an education…I can remember going on a course, I couldn’t even tell you about it, because a lot of the time I had anxiety, I just couldn’t think clearly and I couldn’t stop feeling like a failure, but it was just too scary (Code 105).

One person spoke of their missing out on having a more adventurous lifestyle due to agoraphobia.

It has affected the quality of my life. I don’t know what I would have done with my life if I hadn’t had agoraphobia – I think I would have been more adventurous in my life (Code 37).

Older research participants believed that they had missed out on doing things, due to the lack of knowledge and support for people with agoraphobia in earlier years. Also, the social stigma of mental illness and institutionalisation had made it difficult for them to seek help from professionals. These missing years were due to agoraphobia, lack of knowledge, services and supports and stigma towards mental illness that deterred the seeking of assistance.
It annoyed me a bit at the time that I missed out on doing things, but I haven’t dwelt on it at all, I can’t change it now because it is in the past. I remember seeing some young girls at the support group and thought that they are fortunate in being able to or know about how to get help, because any of those sort of problems you didn’t mention because you thought you would be put out at Cherry Farm – you were either normal or you were not (Code 89).

Agoraphobia has ruined so much of my life I feel I have missed out on so much, such as a social life. A big part of the trouble being that doctors didn’t understand and know what it was years ago so I had to put up with it for 31 years which is a big chunk out of my life. When I first explained it to my doctor at the time he more or less said it was just nerves and kept giving me valium that did no good whatsoever and doctors that I saw later more or less said the same thing (Code 102).

Some research participants who felt that they were missing out on life experiences became envious of others who were unaffected by agoraphobia and were able to undertake these life experiences. In one case, the person became annoyed that they had the means to enjoy life overseas travel, like tens of thousands of other New Zealanders, but was unable to due to their mental illness.

It annoys me when people say they want to go to Australia, but can’t because of the cost and I think, here I am, financially I can go, but I can’t - it just seems ridiculous (Code 35).
Public Perception of Agoraphobia

A number of research participants stated that they believed that the public was misinformed and therefore ignorant about the true nature of agoraphobia. One person stated that the public often confused specific phobias with agoraphobia. The public perception of specific phobias is that these fears have a minimal effect on people’s lives (e.g. a person with a fear of heights can simply avoid height-related situations), while agoraphobia is much more disabling, as it usually affects a large number of everyday activities. In addition, the person believed that the public tended to minimise the disabling effect that panic attacks had on individuals. It seems that a large number of the public have had one or two panic attacks in their lives, which shaped their perception that panic attacks are simply an unpleasant experience. However, people with agoraphobia often report having frequent overwhelming and terrifying panic attacks, which are very distressing and disabling experiences.

I found that in telling people that many of them didn’t have a clue what it was, they didn’t know what is agoraphobia. How do you put into words so that they can understand what it is, then you get some twit who has got a specific phobia, so they think you’re scared of flying, spiders or whatever and you are not at all. This is a fear that I live with every day, and it covers so many areas of my life. Someone said to me, “Oh, you can’t get on a plane”. I can’t walk out the front door, I can’t get to the garden, I can’t have people over, shall I just carry on the list? I get that all day. I also find – another pet hate of mine is someone who says, “I am so anxious and depressed today”. God, I hate that! I think, Jesus, one day and you’re anxious – you’re not anxious, you want to try it for six weeks and you’re thinking I can’t make the toast this morning, I want to go back to bed, pull the pillow over my head and just die. That’s when you are anxious and depressed, when you are grabbing at straws to get a tablet from the doctor that is going to make you feel better – that’s depressing (Code 56).

Another research participant believed that the public perception of agoraphobia was based on publicised misinformation. A large number of reputable dictionaries define agoraphobia as a fear of open spaces (i.e. agora [open spaces] and phobia [fear of]). The presence of reputable publicised misinformation impairs public understanding and forces the person with agoraphobia to educate ‘others’ about their illness.

A lot of people look at what it says in the dictionary and it says a fear of open spaces, so sometimes when you talk to someone who doesn’t understand, you’ve actually got to address the misinformation first, before you can have a more accurate understanding (Code 148).
What I have struck is that either people don’t understand or they have misinformation, so you have got to actually explain what it is not sometimes. If you look in the dictionary with agoraphobia it is a fear of open spaces and people think that is not going to have much of an effect on your life is it? And then you really have to educate them that it is not that, it is actually a fear of fear (Code 93).

One research participant stated that people were often ignorant about agoraphobia, until they themselves or a family member developed the mental illness. Also, the person with agoraphobia was often ignorant about the illness until coming into contact with others afflicted with agoraphobia. In addition, the public and the person with agoraphobia were often ignorant about the treatment options for agoraphobia.

You only know about the people out there because you yourself have it and you’ve met them through groups or something like that. But for the general public who hasn’t met anybody with agoraphobia they wouldn’t know anything about it. They wouldn’t know about the treatments either (Code 41).

Another research participant reported that health professionals were often misinformed about agoraphobia (This theme is explored in the - Health Professional - section).

I put my back out a while ago and went to a Chiropractor. He must have looked through my notes before I went in. He said “I see you have agoraphobia that is why I put that skylight up there”. I’m thinking right, what has the skylight got to do with agoraphobia, and I said, I haven’t got claustrophobia, I’ve got agoraphobia. He said “Oh, are they different?” He thought because there were no windows in his room, he’d better put a skylight in for those people with agoraphobia, because he though that we simply feel claustrophobic in enclosed places, he just didn’t understand agoraphobia (Code 148).

One research participant was able to use the public misperception that agoraphobia was a form of claustrophobia to enable her to escape the feeling of entrapment in places, where she felt panic attack symptoms.

People don’t understand about agoraphobia, so I tell them I have claustrophobia as people know straight away that claustrophobia is being a fear of being closed in, so it allows me to get out of places without having to explain about agoraphobia (Code 35).

While research participants reported that the public appeared to be misinformed and/or ignorant of agoraphobia, due to publicised information (e.g. printed material) some research participants
believed that the electronic mass media played a role in shaping public perception towards mental illness and agoraphobia. One research participant believed that television programmes tended to portray people with mental illness as helpless and pathetic human beings that required improved institutionalised care. Also, these mass-media images contribute to the public perception that people with mental illness (i.e. people with agoraphobia) are abnormal and require separation from ‘normal’ society for treatment in improved institutions.

I watched a television documentary the other day and this guy was mumbling incoherently, and was chained to the wall. The interviewer asked what was wrong with this person, and someone said he’s mental, he’s sick, he’s got a mental illness. The interviewer said why don’t you have him in a proper place, and they said we don’t have the facilities for that, so they had him chained up and he’d been there for about 10 years and was sitting in his own faeces and urine, and was just babbling away. I think this is what people are going to think of me when I mention mental illness. This is the picture they are going to have, of people babbling away, living in filth in mental institutions. (Code 274).

(Note: This documentary may have been about mental institutions in a developing nation)

Another research participant commented on the lack of men seen having panic attacks in films and television programmes. A large number of films and television programmes present men as heroic characters (i.e. Arnold Schwarzenegger in the Terminator), to promote the sale of millions of male action-orientated videos, DVD’s, PC and console games to young adult males. Unfortunately, the media’s presentation of real men with real issues would not be as commercialised as these cartoon macho images of men.

Oh that would be the day if they had a man having a panic attack on the TV, wouldn’t it? I don’t think so – it is only just becoming normal to talk about women having panic attacks. I think it will be another couple of years before men are allowed that privilege (Code 92).

While research participants had argued that film and television programmes presented negative images of people with mental illness, one person believed that the mass media was able at times to promote positive images of people with mental illness. When a Hollywood celebrity makes a public disclosure about having a mental illness, their higher socially valued status helps to promote a positive image of sufferers of the illness, as well as promoting public/media discussion about the nature and effects of the illness.
It seems to be in the movies now… Jody Foster has it, or is it Kim Bassinger, she came out that she’d had it, I think it was Kim Bassinger, she was stuck in her house for six months and couldn’t leave it… It kind of helps that famous people can also suffer from it too. It seems like it’s is getting more talked about. (Code 92).

There was a Oprah programme a year or so ago that was about agoraphobia. It had a special guest who had been a singer in a very successful boy band; it may have been Westlife, who had developed agoraphobia. I think the fact that people had seem him as a ‘normal’, ‘successful’ and ‘well adjusted’ guy before the panic attacks made them more sympathetic towards people with agoraphobia. He wasn’t seen as a some loser or weirdo, and it helps to have someone like Oprah on your side promoting a really positive image of people suffering with this illness (Code 31).

Several research participants commented on the - Like Minds Like Mine – mental health awareness advertising campaign. One research participant stated that the campaign improved public awareness of panic attacks and agoraphobia. Another person believed that the television advertisements showed people with mental illness to be talented and another person argued that the campaign promoted people with mental illness as valued persons, in that the person was valued, prior to and following their development of mental illness.

I think a lot of people took notice of those Like Minds Like Mine ads on TV, the ones about panic attacks and agoraphobia. I think they are brilliant and they have opened people’s eyes (Code 201).

It’s like the thing they are promoting on telly at the moment. There are very talented people out there but there are still a lot of people prejudiced because they think they are mental (Code 56).

What got me about the ads was that people were valued because of their achievements, but they also had mental health problems and were still valued as people (Code 92).

Another research participant saw the television advertisements as re-educating, de-stigmatising, and normalising people with mental illness. The Like Minds Like Mine campaign’s usage of local celebrities challenged the public’s negative perception of people with mental illness as individuals with little or no social value.

I just think that the commercials are really neat and show that things have come a long way. I think it is really good that we are becoming more informed, and it’s making it OK for people to be more open about their mental illness. It reduces the stigma because everybody knows they are OK. They are normal people (Code 105).
One person reported that the Like Minds Like Mine campaign inspired her to manage her agoraphobia. The Like Minds Like Mine campaign provides positive role models for people struggling with mental illness who lacked hope for a better future.

When I saw the Like Minds Like Mine ads, I though gosh those people are so brave… and if they can cope with their experience, then I can too (Code 269).

Two research participants commented on the Like Minds Like Mine campaign’s usage of John Kirwin, which showed that even a national hero and sporting icon could have a panic attack. The John Kirwin segment promoted a powerful image into the Kiwi male psyche that real men can and do have anxiety at times.

You see John Kirwin, an All Black icon, and all the macho bullshit that goes along with it, and here he is actually having a panic attack in a rugby test (Code 269)

When the first ad came out with John Kirwin I wanted to go on the ad and say yeah, me too (Code 92).
Stigma and Discrimination

One research participant was concerned that family and friends would view his panic attacks as a sign that he was ‘nuts’. The person was fearful that the negative label and its associated stereotypes would damage his reputation (i.e. hard worker, homeowner, etc).

I don’t tell everybody about this, because people think, oh God, he’s nuts. I mean, this year Christmas day came and we were going to someone’s house who I’ve known for years and years – they’ve seen me through marriage, divorce, coming out of the closet, and I walked in on Christmas day and had a major panic attack. I don’t know why, and I had to come running home to get something to calm me down which was tablets… They actually saw me have a panic attack and I know they can’t see anything physically, they just think what the hell’s wrong with him, he’s a nut, because that is what people assume, they think you’re nuts. I am quite intelligent I think, I’ve got a nice home, I’ve worked hard for it, but if people see that side of you, they think what a nut (Code 56).

Other research participants reported that their families and friends were supportive of them as a person with a mental illness. However, the stigma of being seen as a ‘crazy’ person by others made them feel uncomfortable around these people.

I didn’t want to be seen as being mentally unstable, because there is still stigma attached to mental illness (Code 41).

I knew my friends and family, and I knew that they knew me, and that wasn’t really a problem, it was other people. Some people would thought that I’d just gone crazy, so when it came to strangers I wasn’t very comfortable, I just wanted to avoid them too so that they couldn’t see (Code 41).

One research participant stated that he felt that he did not belong to society due to feelings associated with his mental illness. It could be that the knowledge that his everyday life experience was different from those of ‘normals’ contributed to his feeling of not belonging in society.

I can go to the supermarket one day and get around, get everything, get up to the checkout and out and the next day because I am feeling a little bit crazy, so-called crazy, going to the supermarket is just a daunting task. I don’t feel like I fit in and I feel everyone is looking at me, and I do feel different. I don’t feel like I belong. I feel different from others who I think are normal You do feel different, you don’t feel part of everything (Code 56).
Two research participants believed that others saw their panic attacks as a ‘joke’. It could be that the public lack of knowledge, and the invisibility of panic attacks meant that others could not fully understand the seriousness of the illness and its effect on people’s lives.

There were people who sort of joked about it, especially, people who I had to get to do things for me because I couldn’t do things for myself. (Code 79)

I don’t think people out there really understand people with mental illnesses at all. It has been all my life since I was 16 and I’m 42 now. I think it is a joke to some people out there, because they just don’t understand. There is a lot of ignorance around and about… if they had to go through it themselves, they would see it is not something to be laughed at (Code 201).

One person was fearful that the public disclosure of their having panic attacks would lead to them being negatively labelled (e.g. psycho) and institutionalised.

I didn’t tell people I was having panic attacks, because I didn’t want to be judged as a psycho or something. I had a fear of having to go into Sunnyside, and I didn’t want to be put in there and I didn’t want all my friends and family to know that I had to go there. I used to worry about that, I used to say to my partner, don’t put me in Sunnyside (Code 92).

While a large number of research participants describe themselves as having a mental illness (i.e. psychiatric illness), others preferred to label agoraphobia as a anxiety disorder (i.e. psychological problem). One person believed that labelling agoraphobia as a mental illness brought unnecessary stigma and discrimination upon the individual. It seems that the usage of the term anxiety disorder would enable the person to escape a lot of the stigma and discrimination associated with a psychiatric illness, such as schizophrenia. However, the labelling of agoraphobia as a secondary psychological problem could undermine consumers struggle to have it seen as a serious illness.

(Code 105) The label mental illness didn’t affect me – I don’t use those words to describe it. I just say that I suffer from anxiety or panic attacks. I never say I’ve got a mental illness. I don’t use those words, so perhaps that is why I don’t have any problems.

I believe that agoraphobia is a psychological problem more that a psychiatric illness. But a lot of people out there wouldn’t know the difference between those two words, and because of that they don’t fully understand and they are placing it in the wrong context (Code 201).
Hidden Agoraphobia

There were various reasons that research participants hid their agoraphobia from family, friends and others. Two research participants reported that the reason they did not tell their families was to prevent them from worrying about their mental health problems.

I didn’t want to worry my family I suppose more than anything. I was just thinking, come on, pull yourself out of it, get on with it, snap out of it - like you just could. However, that is easier said than done (Code 148).

I haven’t told my mum because of a negative reaction, it would be overwhelming, she would just worry about it (Code 269).

Another research participant was fearful that public disclosure would lead to negative value judgements. In addition, the person was struggling to fully understand what was happening to them (i.e. whether the illness was a sign of madness) without trying to explain to others and suffer stigma and discrimination.

I was too scared to tell anybody in case they thought I was mad or something, and that is why I didn’t talk to anybody. I didn’t even know what it was myself, what was wrong with me, and of course as I said, I just thought people would think I was just mad (Code 156).

One research participant stated that she was able to avoid stigma and discrimination by being selective about whom she told about her panic attacks. The person was careful to inform those she could trust, and avoided informing those whom she believed would treat her differently after the disclosure.

I haven’t suffered any stigma because I haven’t told many people about the panic attacks, because of the fear of discrimination. I’ve really got to know them very well before I say anything, so that they won’t treat me differently afterwards. I have to know that person and know whether it is safe to tell them. I am very selective about who I tell, otherwise I hide it (Code 22).
Another research participant hid her agoraphobia from family and friends, believing that she did not need to inform them of her problem, as she believed that her panic symptoms would simply fade away in time. A large number of people with agoraphobia, who lack knowledge about the illness expect that it will simply fade from their lives, thereby reducing the need to tell others, such as family and health professionals.

I was in denial, I wouldn’t tell anyone because I hoped that by December I’ll be over it, and then nobody would have need to have known anyway (Code 269).

While research participants had different reasons for hiding their agoraphobia from others, all of them had to develop strategies to keep their secret. One person reported that she kept the panic attacks a secret from other family members by shifting the focus of attention from her on to other family members’ problems.

I went to great lengths to keep the secret from everyone. I went to great lengths to keep whatever was going on in our family secret. You learn not to share your feelings with anyone, but you also get very good at talking to people and being there for other people, so that you don’t have to talk about yourself (Code 45).

Another research participant reported that she put on an ‘act’ to hide her agoraphobia from other family members. In this case, the person’s ability to appear capable of performing everyday tasks allowed her to hide her anxiety from other family members

I came from a big family and I was the oldest, and I could cook and garden and do all the other things that needed to be done on a farm. I appeared capable of doing everything, but I hid the fear I felt. I never let on to others, I put on a bit of an act (Code 148).

One research participant reported that she had to make ‘excuses’ to hide her agoraphobia from the family. In this instance the person reported that she became skilled at making excuses to avoid doing things that made her feel anxious, with the resulting risk of having a panic attack.

I hid my agoraphobia by not telling family, I had to make excuses for not doing things, and I got really good at it. I didn’t tell my husband until about three or four years ago. He didn’t have any idea (Code 22).

Another person was able to hide her agoraphobia from family members by selecting places where she knew she would avoid panic attacks. This meant that the person was able to achieve
her need to avoid panic attacks and kept her panic attacks in other places/situations secret from other family members.

I used to choose all the places we would or would not go to, to avoid having a panic attack in front of the family (Code 124).

While research participants tried different strategies to hide their agoraphobia from family, friends and others, their ability to hide their problem sometimes failed. In one case, the person’s loss of confidence was noticeable to other family members.

I’d always been such a confident person, and I guess that was one of the things that family noticed in me, was that I got quieter and I wasn’t confident, even having them out for a meal was like a big deal (Code 148).

Sometimes when the research participant successfully hid the truth of their agoraphobia from family, the family members began to suspect other reasons for the individual’s avoidance of family gathering. In this case, the family believed that their family member avoided family gathering because they were a ‘snob’, which would have led to increased social isolation for the individual.

My husband’s family, I don’t think they feel especially fine about me – I think they thought I was a bit of a snob because I didn’t want to be there when they went on picnics and things like that and I didn’t go (Code 41).
Making Excuses to Hide Agoraphobia

Several research participants reported making excuses to family, friends and others to avoid entering places and/or situations where they feared having panic attacks. These research participants would use lies and deception to protect their privacy, and to avoid social embarrassment.

If anybody said to me, “What’s wrong, why aren’t you going out?” I’d say mum is not very well and I’ve got to stay at home, or I’ve got to do this or I’ve got to do that. I didn’t go out a lot because I didn’t want to go out with friends in case I had an attack (Code 67).

I told a lot of lies to get out of going to family occasions. I use to tell family that I had the flu to avoid having to go to family wedding and funerals. It was easier to lie and possibly hurt people’s feelings than face the danger of having a panic attack in a place where I couldn’t escape without making a scene – like a church wedding (Code 31).

I often had to say I don’t feel well and I can’t go out, or make all sorts of excuses (Code 45).

I’d lie to people… my neighbour would ring up and ask me over for a cup of coffee, but I couldn’t go across the road because of the panic attacks, so I’d say you come over here. Putting on that smile all the time and pretending (Code 105).

I’d make some excuse not to go. I had trouble riding in cars, and I’d make some excuse as to why I couldn’t go, and I wouldn’t go… I never told anybody the true reason, but I think I tend to be more open now about it (Code 156).

Some research participants argued that making excuses was a form of social survival. The fear of negative value judgements, social embarrassment and the resulting social alienation forced these individuals to develop the skills of lying and deception, which they may not have otherwise developed during their life.

I made excuses because I felt ashamed of having a mental illness (Code 281).

I was very cunning in getting out of going to places where I feared having a panic attack, you’d do anything to avoid it. You can become very creative in getting out of that situation and appear quite normal. It is not a selfish act, like I’m going to piss you off by not being at your wedding; it is a total survival thing. You will survive no matter what it takes. I lie for survival, not to get an advantage, but to survive… I am not going to tell you because you will think that I am a nut, so I am going to tell you what will get me from out of going. And it becomes very natural,
you can just lie through your teeth very well. I do the same at work – it just got to the point where my excuses ran out. But you do become very creative…I had a religious upbringing too and you are meant to be a good person, but with the agoraphobia I developed such good skills at lying, deceiving, and misleading. I could feel my feet burning…I think you develop other skills, which you wouldn’t have done if you hadn’t had agoraphobia. Things that wouldn’t have developed so well if it hadn’t been for agoraphobia – like lying and deceiving to socially survive (Code 56).

While some research participants admitted using excuses for social survival, some individuals reported using excuses to manipulate people into doing things that they could not do themselves, due to their panic attacks, this enabled them to survive everyday life (i.e. purchasing food and paying bills).

I did get other people to pay bills at times, but they didn’t know they were doing that. I got very good at avoiding things that I didn’t want to do, passing it to somebody else without them realising it wasn’t because I couldn’t do them, or I didn’t have time or they were going that way and all those sort of things. I got real good and people wouldn’t realise – well, I don’t think people knew that I was making excuses. I got really good at excuses (Code 105).

I couldn’t go into a supermarket or a dairy because of the fear, so I had to pretend that I was physically unwell so that family and friends would do the shopping Had I not done that then I wouldn’t have eaten (Code 31).

In addition to research participants’ making excuses (i.e. lying) to family and friends; some individuals lied to their own children. Two parents admitted to lying to their children, so that their children would not be upset or harmed by the knowledge that their parent had a mental illness. Unfortunately, the parents’ lack of honesty to their children about their mental illness damaged their relationships with the children.

I use to lie to my children; to get out of going anywhere or taking them anywhere I feared going to. It did all sorts of damage in the long run (Code 105).

As a parent I didn’t want to put the knowledge of my mental illness on my children, It made for a very dishonest parent/child relationship (Code 35).

Two research participants reported telling thousands of ‘little white lies’ and making so many excuses to family and friends that lies and deception became a part of their everyday lives
I was telling thousands of little white lies to avoid going out. I use to get people calling up for lots of different things, do you want to go to the tennis, we’re going to this movie, I’m moving house, can you help me shift the fridge, can you come and pick me up, my car has broken down. All that sort of stuff…there were thousand of things I had to lie to avoid (Code 269).

I make excuses. I am tired, I’ve got work the next day, or something like that – I’ve got plenty of good excuses (Code 67).

In one case, the research participant was able to use a truthful reason to avoid a situation, while hiding the other reason, that they had agoraphobia.

I had an invite to go over to the coast at the end of the month just for a day, and I thought, hell, it is a long way to go for a day… I was able to say no I’ll have to go to work which was perfectly true, but at the same time in my mind I thought I’ve got an authentic reason because I wouldn’t really fancy driving over to the coast with her and back due to the anxiety (Code 89).

In addition to research participants using lies, some reported telling half-truths to avoid places and situations. In this case, the research participants regularly used the label claustrophobia, to hide their agoraphobia. It seems that people with claustrophobia are less socially stigmatised, and are more readily accepted and understood, compared to people with agoraphobia. Therefore, the research participants were able to escape their panic attacks (i.e. the person was able to shift to the seat closes to the exit) and avoid stigma and misunderstandings.

I went to a funeral about three weeks ago and the undertakers went to close the doors and I said to the undertaker that I suffer from claustrophobia and when the doors are shut I get a funny feeling, and he said, “Look, there’s a seat right by the door”. So I don’t care, I just tell them straight out, but I say claustrophobia, because they understand that (Code 35).

I make excuses to hide my agoraphobia, like when my girls went on a school trip to the North Island before Christmas – I couldn’t go, but I told the teacher that I have claustrophobia, I tell people that, because they don’t know about agoraphobia (Code 35).

One research participant stated that her deceiving of others to hide her agoraphobia had become a normalised part of her life.

I didn’t have any trouble making excuses. I don’t lie; I simply omit to tell the whole truth. I’ve done that my whole life – it is something that I am so used to doing that it is kind of normal for me to do it. (Code 45).
Another research participant identified herself as a ‘Master of Disguise’ due to her ability to hide her agoraphobia from others and avoid places and situations where her panic/avoidance symptoms could be noticeable to others.

I remember reading in a book where the author said that people with agoraphobia are masters of disguise, because they hide it from their family, from work colleagues and are very good at making excuses to get out of situations without coming across as being abnormal (Code 45).

While one research participants identified herself as a Master of Disguise, other people stated that their lying and deception was harmful to their self-image. In one case, the person became a worrier and felt depressed about becoming a liar. Another person faced an internal conflict about hiding their agoraphobia or being honest with their family and friends. It seems that people with agoraphobia who use lies and deception to avoid places and situations where they fear having a panic attack, develop a crisis of identity between being a truthful individual and a dishonest individual who regularly lies and deceives family members, friends and others.

The phone would ring and I would think who is that and what are they going to ask me. I would think that every phone call was somebody wanting me to do something outside of my comfort zone. Then I’d have to tell a lie or engineer my way get out. I became anxious when the phone rang and I worried about the harm the lies were doing to me – I felt really depressed that I was becoming somebody I didn’t want to be – a liar (Code 269).

I had a major internal conflict between the fact that I wanted to be an honest person and honest with people that I care about, but at the same time I do have to make these excuses to manage my problem I mean, particularly with family, you know, because you know that they will actually support you, but even in knowing that it is sometimes not enough to want to tell them (Code 269).

While some research participants were able to make excuses to successfully hide their agoraphobia, other problems emerged from regularly making excuses. In one case, the research participant suffered marital problems due to her partner alleging that she was being an anti-social person.

I would make excuses to avoid going out with my partner. I would say that I couldn’t find childcare, I would say that I wasn’t feeling well. It has been problematic in our relationship because he would say that he didn’t think I was being very sociable (Code 281).
Also, one research participant reported that making excuses and manipulating people led to social isolation. In one case, the person reported that people lost interest in her due to her regularly making excuses. In another case, the person believed that people suspected the reason she was making excuses was that she did not like them. It appears that the persons’ making of excuses (or lying) would raise suspicion among those being regularly misled and lied to, which would led to a negative reaction such as abandoning of friendships.

My social network tended to shrink after I started making excuses. I would make excuses about where I could meet people, or I arranged to see them at specific places where I felt safe. You avoid places and situations that are uncomfortable such as going out in a crowd or whatever. But some people start to lose interest in you if you won’t go to the places they like as well (Code 281).

I felt uneasy about telling some of my boyfriend’s friends because they have been his friends since he was a teenager. I didn’t want to come along and be seen to be different. I told him I didn’t want him to tell them… they started thinking something was really wrong, that I didn’t like them because I used to make a lot of excuses (Code 67).

While a number of research participants regularly made excuses, most individuals developed the confidence to tell the truth to family friends and others.

I’ve gone to these different confidence and self-esteem classes, and I’ve learnt that you can tell the truth and it doesn’t really matter what other people think anyway (Code 89).
Coming Out

One research participant summarised the ‘need’ for people to come out about their agoraphobia. This person argued that her coming out was a need to tell others about her true self. It seems that people with agoraphobia that have suffered panic attacks and avoidance for many years feel that the thoughts and feelings are a part of their identity. In addition, the person wished for family and friends to understand and accept them as a person with a mental illness.

When I decided to tell my mother, I got mum to come around here and I just told her my life story. I had to do it, it was like I didn’t want my mother to die and not know who I really was. It was just something I needed – as her daughter – to do. It was really hard because I felt in a vulnerable state as well, and I kept saying to her I’m not blaming anyone I need you to know this is for me. I don’t know if she got that bit. (Code 93).

Several research participants reported that they were very selective about whom they told about their agoraphobia. One person commented that she made disclosures to those she trusted and continued to hide the truth from strangers, while another informed people on a strict need to know basis. One student stated that she kept the information within her group of school friends, whom she could trust not to tell others. Another person reported that people didn’t believe that she had panic attacks, due to the lack of visible symptoms and two other people commented that there seemed to be a lack of awareness, among those they had told, about agoraphobia

Whether I told or not depended on who it was, or if I felt I had to tell. But I wouldn’t tell strangers. I would try to hide it from them (Code 41).

I tell the people that matter, like most people know, but I don’t really need to tell the people that don’t know. It is not affecting them or my relationship with them (Code 269).

I have been very selective with the people I tell, especially at my school, I stuck with the small group of friends that knew, and I knew that they wouldn’t say anything (Code 67).

I am very selective in who I tell and who I don’t tell... as time has gone on I’ve been much more open with people – but people don’t believe me. They say, “No, no, you haven’t got that because you’re fine – we know you and you’re fine”, because I’ve managed to hide it so well. We were talking about panic attacks at work the other day and I was talking about it, and one of them said, “God, you
don’t know what you’re talking about. What would you know about that?” and I said, “Well you know, you’d be surprised (Code 45).

I only told a select few that I had agoraphobia. They had never heard of it (Code 124).

A lot of people cannot understand agoraphobia or any mental illness (Code 21).

One person stated that she told others that she had panic attacks when the subject came up in conversations. It seems that the more that mental illness becomes normalised through ordinary conversations, the more chances that people with agoraphobia will be able to feel comfortable to talk about their mental illness.

If someone I’d just met opened up to me about their problems, or were talking about – there are so many disorders these days – I would not have a problem saying that I have an anxiety disorder. If I don’t know them very well and they open up to me, it is like OK (Code 93).

One research participant compared the ‘coming out’ experience of agoraphobia to that of his coming out as a gay person. In this case, the person argued that his sexual orientation was seen simply as a part of his identity, while the social stigma and discrimination towards mental illness forced him to stay in the closet about his identity as an agoraphobic. It appears that the research participant had a similar choice to people who are gay or lesbian, to hide their identity and avoid discrimination, or tell the truth and be themselves.

Coming out as having agoraphobia was bigger than anything, bigger than gay, gay is nothing, it’s just life, being gay is just what I am and who I enjoy. But being agoraphobic is definitely a bigger hurdle, to come out and say to everybody I’m agoraphobic, I feel like they think I’m nuts. So I wouldn’t tell them and I would become creative and wouldn’t tell them, I would do anything but tell them. Coming out as agoraphobic is definitely a bigger thing (Code 56).

One person reported that telling family members about her agoraphobia was a challenge in that she did not want to ‘freak’ them out or make a fool of herself. People with agoraphobia may face an emotional challenge when informing family, friends and others of their hidden identity.

I think just saying it sometimes is the hardest thing, because there is so much emotion involved. I did tell my sister-in-law and my brother, I wrote them a letter, because I knew that I couldn’t just say all the things I wanted to say in a sentence that would be coherent. So I wrote them a letter and outlined it – I probably did 50
drafts of it. I didn’t want to freak them out, and I didn’t want to paint myself as a ridiculous fool. They came around and said thanks for the letter, it was really good, anything we can do kind of thing, and it was so low key that I knew that they understood and there was no big drama, which was really good. I definitely had a big sense of relief, like when the phone rang I could say to my brother, “No, that is just not going to happen” and I didn’t need to lie any more about it (Code 31).

One research participant worried about family and friends’ reaction to her disclosure of having agoraphobia. In this instance, the person feared social isolation and alienation from their family group.

It is just a worry about how other people are going to react and whether they’ve shut you out (Code 56).

Several people struggled to inform others of their mental health problem. One individual was struggling herself to understand the illness and therefore felt unable to explain to others. In addition, she feared that telling others would lead them to think that she was a mentally unstable person. Another individual stated that she felt a bit stupid in telling others about her agoraphobia, as well as suspecting that they would think she was mentally unstable too.

I was too scared to talk to anybody in case they thought I was mad or something, and that is why I didn’t talk to anybody. I didn’t even know what it was myself, what was wrong with me, and of course as I said, I just thought people would think I was just mad or something (Code 156).

I felt a bit stupid telling people I had agoraphobia. I didn’t know whether they’re think I was a bit odd. I didn’t know (Code 22).

One research participant called upon other people with agoraphobia to speak out about their mental illness, hoping that the more public discourse about mental illness, the more chance it will become normalised like other health-related problems such as gallstones.

I’ve learnt to speak out. What is there to be ashamed about in having a panic attack? You know, I’ve got a gallstone, well I’ve got a gallstone, so what? People have mental problems, well let’s try and help them. Why cover it up, you know, that is why I like the world now, in a way it is opening up. No, speak out, definitely speak out (Code 108).
Family, Friends & Co-workers Reaction

One research participant reported having a panic attack after she had told a friend about her agoraphobia. In this case, the description of, and discussion about, panic attack symptoms triggered the person’s panic attack. It appears that people with agoraphobia who tell their family and friends about their panic attacks can be affected by others’ tendency to over-discuss and analyse the panic attack symptoms, which triggers their cognitive processes into a downwards spiral towards a full blown panic attack.

I told a friend that I was having a lot of panic attacks, and it turned out that she had them as well. Then she told me about her panic attacks and that triggered a panic attack for me because she was going on and on about the symptoms and that made me very self-conscious about my anxious thoughts and feelings (Code 92).

Two research participants reported that telling their family member or friend led to the discovery that the family member and friend had had panic attacks too.

I didn’t know that other people had panic attacks too. It wasn’t until I told a friend that I learnt that she was like me, she stayed at home and brought up a family because of the fear of going out into public (Code 108).

I did tell my mother I had agoraphobia when I found out, and it turns out that so had she had it, years ago (Code 41).

When research participants told family, friends and others about their agoraphobia, some experienced negative reactions. One research participant reported that she was unable to make her partner understand the terrifying nature of daily panic attacks.

I’m sure my husband thinks I’m an idiot and a nut sometimes, but he has been very supportive I suppose. He has a very limited understanding of panic attacks. I often say to him, “I’ll like to give you an hour inside my mind when I’m having a panic attack – just one hour and then try that for day after day after day for seven days in a row, then you would understand how I feel”. But it’s like a man trying to understand a woman having a period, he won’t understand it because it is something he is never going to have. He is never going to understand even if I want him to, that’s just life (Code 15).

Another, research participant stated that her family and friends did not believe that she had panic attacks.
My family and friends didn’t believe me, they’d say, “Oh come on, you can’t be like that. You’re an outgoing sort of person” (Code 41).

One person stated that she was made to feel that she was abnormal (e.g. mentally ill). In addition people joked about her mental illness and treated her as a devalued cognitively impaired person.

When I say to people that I have a mental illness, but I am not mental, I just have panic attacks, they think you are not normal and people sort of joke about it, thinking it is not normal. People think that there is something wrong with me and they have to do things for me and that I can’t think straight and that I am mental (Code 79).

Another individual reported that her work colleague treated her like a social outcast (e.g. leper) and another person commented that she was treated differently than she had been previously treated. In both cases, the public disclosure of having a mental illness changed people’s perception of the person with agoraphobia.

When I explained to a working colleague that I had had a breakdown she didn’t understand it. She took it like I was a leper and she stood right back and gave me an eyes wide open, and oh my God, keep away from you look, and I thought I’m not a leper, I just wanted someone to understand (Code 274).

I have had people who I’ve told, who have treated me differently the next time we have met. You can tell by their facial expressions that they are looking at you like you’re different, and if you are walking up the corridor they will turn around and go the other way (Code 274).

I confided in my husband’s older son’s wife that I suffer a mental illness and panic attacks and that went right around the family, they treated me differently after that. I could tell that, when I was around his daughter she would give me a really scowled look which said, “You’re sick!” and I felt really bad about it, but I thought she doesn’t understand, just try and be patient and she is a lot younger than me and maybe one day she will grow up and find that I’m not a threat (Code 274).

One person commented that friends gave unhelpful advice that trivialised her mental health problem. Another person stated that her family were intolerant, lacked understanding and made her feel stupid.

I would have a lot of panic attacks when I was riding in a car… I had a friend who said just sit back and shut your eyes and I’ll put on some nice music. I said that is
not the point, I’m not getting over it, and this isn’t going to help my situation (Code 89).

My family aren’t very tolerant or understanding, they just think I’m being stupid - having anxiety symptoms (Code 86).

One research participant reported that her mother reacted negatively to the news that she had a mental illness because she did not want to be blamed for causing her daughter’s mental health problem.

I rang my mum, and told her that I had been having panic attacks and that I had been to a therapist because I felt that I was going crazy, and she said, “Oh, did they blame it on the parents? They always do” and that was all that she said, so I was like OK, I am definitely alone. It was like trying to reach out, but no that was it, I am not going to talk to anyone about this. Because that is what people say, you’ve just got to deal with it yourself (Code 93).

Another person stated she lost a large number of friends due to their lack of willingness to understand her mental illness. In this instance, people’s lack of understanding about panic attacks and avoidance led to their avoidance of the research participant.

I lost a lot of friends through them deciding to stay away, because they could not understand and their not wanting to understand. It really did upset me, I thought I can’t be bothered with them if they are not going to try to understand (Code 67).

Several research participants reported that a common reaction to their public disclosure about panic attacks was that people told them to simply ‘snap out’ of the panic attacks or alternatively, that the person with agoraphobia should simply assert control over their thoughts and feelings. If people with agoraphobia could ‘snap out of it’ or instantly assert control over their mind and body then they would not have agoraphobia.

I remember telling two or three people and they didn’t understand and it was like they said snap out of it, get on with it, well, we all get stressed, but I didn’t even try to say that I couldn’t snap out of it, I knew I couldn’t snap out of it, but I didn’t talk to those people again. I don’t mean I didn’t talk to them, but I didn’t speak to them about my problems again. I soon found out who supported me and who didn’t understand (Code 105).

It would be nice to meet someone who doesn’t say - Just snap out of it (Code 59).
I took a while to tell my friends – and even now some don’t know. The worst thing I ever had said to me was “It’s in your mind – why don’t you just control it – it’s your mind”. Which was hard because I already felt crazy and out of control (Code 92).

While some research participants had negative experiences, some people stated that telling family, friends and others had been a positive experience. One research participant reported that the public disclosure of her agoraphobia acted as the catalyst for forming true friendships. In addition, the person was able to identify her true friends from shallow friendships during her time of crisis. One person reported that the public disclosure enabled her friends to be more understanding of her behaviour in public places and situations. Another person stated that telling friends the truth enabled them to become understanding and supportive in places and situations where she was having panic attacks. In addition, one person stated that talking to friends helped her when she was feeling down and gave her hope to overcome her panic attacks.

I’ve been very lucky with my friends and family. They have been very supportive (Code 41).

I have told some people about the panic attacks and they have become really true friends. Telling people the truth about who you really are does help to sort out true friends from people who don’t really care about you (Code 31).

I told one of my best friends and she said to me, “God that makes sense because sometimes I just couldn’t understand why you behaved in the way you did” (Code 45).

I feel safer with people that know the truth. When I am at the movies with them, and I suddenly say I have to go outside for 10 minutes, I know that they will not be distressed. They will say we’ll come out and get an ice cream or something with you… I know that some of my friends if I said to them, “Would you take me home”, they would not say, “I just want to do two more things, I’ve just got to go to the bank or whatever”, they would just take me home. I totally trust them with that, because I believe that they would do that (Code 269).

My friends are very supportive, that is what I love about friends. True friends will be there through thick and thin, and we support one another. When I’m down the best thing really is to talk about it and they will listen and then tell me about somebody else who has gone through the same thing that reassures me that there is a way out (Code 108).
In addition to research participants reporting positive reactions and practical support from telling family, friends and others, one person stated that family support was important in enabling them to recover from the downward spiral of mental illness.

If I didn’t have my family support, I don’t think I would have been able to pick myself, having support is really important (Code 67).

One research participant argued that it was easier to tell family, friends and others, following the successful management of their panic attacks. It seems that the person had a better knowledge of their agoraphobia following a treatment programme and was more confident and assertive to deal with any problems that arose from telling people about their mental illness.

I’ve told family and friends, not so much when I was suffering from it, but now that I am, like you know, probably recovered or just sort of having one or two attacks…I don’t think I wanted them to know. Like I think it is easier to talk about things after it has happened (Code 92).

One person reported that it was easier to talk about mental illness to another person who had a mental illness, due to shared life experiences. Another person commented that a nurse, who was knowledgeable about panic attacks, was very understanding and supportive. It appears that the research participants who made a public disclosure to people knowledgeable and/or experienced about panic attacks had more positive reactions than those research participants who told family, friends and others who were ignorant and/or misinformed about agoraphobia.

I’ve told one person apart from my partner, a woman I’ve worked with for 12-13 years who suffers from depression. She is the only person I’ve been honest with, she understands having been through depression. There have been times I’ve looked at her and thought I’m not as bad as you, and then she turns around and looks at me and obviously thinks she’s not as bad as me, so we compare one another, but we can laugh about it which is good (Code 56).

A friend who is a nurse asked if I had had palpitations, and did I have dizziness…she was very understanding and very open and caring about it. She could understand what was happening to me (Code 79).
Marriage/Intimate Relationships

In the study, 82% of research participants reported that they were married or in an intimate relationship during their agoraphobia, while 15% of research participants were not married or in an intimate relationship during their agoraphobia and 3% of the research participants did not complete this section (Missing Data)

Of the 82 research participants, 78 people stated that their marriage/intimate relationship was affected by their agoraphobia while 4 people stated that their marriage/intimate relationship had not been affected by their agoraphobia.

The graph and table shows the reports of those research participants who stated that their partners reacted positively to their development of agoraphobia.

![Partners Positive Reactions](image)

Table: Partners Positive Reactions:

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>My partner encouraged and supported me to seek medical treatment.</td>
<td>48</td>
</tr>
<tr>
<td>B</td>
<td>My partner acted as my support person during my agoraphobia.</td>
<td>35</td>
</tr>
<tr>
<td>C</td>
<td>My partner was more dependable and supportive during our relationship</td>
<td>28</td>
</tr>
<tr>
<td>D</td>
<td>My partner was more protective and comforting of me.</td>
<td>23</td>
</tr>
<tr>
<td>E</td>
<td>My partner was more willing to do out-of-home activities for me.</td>
<td>14</td>
</tr>
</tbody>
</table>
The survey data shows that 48 out of the 78 (62%) research participants reported that their partner encouraged and supported them to seek medical treatment. This data shows that the majority of the research participants had a partner who appreciated the seriousness of their panic attacks and/or avoidance symptoms. In addition, 35 out of the 78 (45%) research participants stated that their partner acted as their support person. This data shows that a large number of research participants relied on their partner to be their support person. However, the data shows that 43 out of the 78 (55%) research participants did not rely on their partner as a support person (Note: In the Support Person section the research participants identify their other support persons). Also, the survey data showed that 28 out of the 78 (36%) research participants reported that their partner became more dependable and supportive in the relationship and 23 out of the 78 (29.5%) research participants stated that their partner became more protective and comforting of them. This survey data has shown that most research participants did not report an increase in the dependability, supportiveness, protectiveness or the comfort offered by partners. Also, 14 out of the 78 (18%) research participants reported that their partner was more willing to do out-of-home activities for them. Though the partner’s willingness to do out-of-home activities had a positive effect of building a closer relationship, it would have reinforced the agoraphobic symptoms of the person with agoraphobia (i.e. person avoiding out-of-home activities). In summary, a significant number of research participants did report that their partner had reacted positively to their development of agoraphobia. However, a larger number of research participants reported a negative effect on their marriages/intimate relationships.

![Agoraphobia's Negative Affect on Marriages/Intimate Relationships](chart.png)
<table>
<thead>
<tr>
<th></th>
<th>Table – Partners Negative Reactions</th>
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</thead>
<tbody>
<tr>
<td>A</td>
<td>My agoraphobic symptoms have undermined my confidence and feelings of worth to be in a relationship</td>
</tr>
<tr>
<td>B</td>
<td>My partner was indifferent towards my agoraphobic symptoms.</td>
</tr>
<tr>
<td>C</td>
<td>My agoraphobic symptoms have adversely affected my ability to go out on dates.</td>
</tr>
<tr>
<td>D</td>
<td>My partner was unwilling to acknowledge that I had a mental health problem.</td>
</tr>
<tr>
<td>E</td>
<td>My partner was unwilling to talk to me about my problem.</td>
</tr>
<tr>
<td>F</td>
<td>My partner was resentful about assuming the extra out-of-home responsibilities that I was unable to do.</td>
</tr>
<tr>
<td>G</td>
<td>My partner became abusive following the onset of agoraphobia.</td>
</tr>
<tr>
<td>H</td>
<td>My agoraphobic symptoms have adversely affected my ability to have long-term relationships.</td>
</tr>
<tr>
<td>I</td>
<td>My partner was unwilling to commit to the relationship due to my agoraphobia.</td>
</tr>
<tr>
<td>J</td>
<td>My partner was less willing to attend social events with me.</td>
</tr>
<tr>
<td>K</td>
<td>My partner left the relationship.</td>
</tr>
</tbody>
</table>

The survey data shows that 16 out of the 78 (20%) research participants were no longer able to date due to their agoraphobia. No doubt the occurrence of panic attacks in public places and social situations would have made dating more of an ordeal than a pleasure. In addition the survey shows that 27 out of the 78 (35%) research participants reported that agoraphobia undermined their confidence and feelings of worth in their marriage/intimate relationship. The survey has shown that agoraphobia causes a significant loss of confidence and feelings of self-worth in the individual to form and be part of a relationship. The survey shows that 20 out of the 78 (26%) research participants reported that their partner was indifferent towards their agoraphobia. In addition to the partners indifference, 13 out of the 78 (17%) research participants reported that their partner was unwilling to acknowledge that they actually had a mental health problem and 11 out of the 78 (14%) research participants stated that their partner was unwilling to talk about their mental health issues. Also, 9 out of the 78 (11%) research participants had partners who were resentful of having to do extra out-of-home activities. It could be that the partners reported indifference and unwillingness to acknowledge or talk to
their partner about their agoraphobia, was due to the invisibility of panic attacks, which means that the partners could not ‘see’ a problem to react to. Also, the partners’ unwillingness to do extra out-of-home activities for a ‘ill’ partner would have been due to the lack of physical evidence of an actual illness. The survey shows that 9 out of the 78 (11%) research participants suffered abuse following the development of agoraphobia. A possible explanation for the abuse of these research participants (i.e. women) was that their agoraphobia disabled them from performing the domestic duties expected from their abuse-prone husbands/partners. In addition, 8 out of the 78 (10%) research participants reported that their agoraphobia prevented them from maintaining long-term relationships, 4 out of the 78 (5%) research participants that they had partners who were unwilling to commit to a relationship and 3 out of the 78 (4%) research participants had a partner who was unwilling to attend social activities with an agoraphobic person. The partners’ unwillingness to form and commit to long-term relationships, as well as attend social activities with an agoraphobic person shows that agoraphobia can be very disruptive to relationships. Tragically, 2 out of the 78 research participants reported that their relationships ended due to agoraphobia.

In the study, single research participants spoke about the adverse effect that agoraphobia had on their ability to form intimate relationships. Research participants stated that agoraphobia had hindered their forming of intimate relationships, due to their loss of confidence, shyness, anxiety and forced social withdrawal, which had led to their social isolation and loneliness.

I became quite shy and lacked confidence, I would probably say that I have avoided relationships (Code 98).

There have been times over the years when I have lost my confidence. I would withdraw into myself and become quiet, which was hard for family relationships (Code 148).

Don’t trust myself to enter new relationships (Code 181).

I had feelings of no confidence, not helpful with relationships – leads to communication problems (Code 193).

Spent long periods of time alone and had to learn to deal with it (Code 81).

It is very hard to meet new friends. Sometimes I don’t feel strong enough to make new friends; other times I just want to be left alone (Code 114).
I have never been able to establish a long-term relationship, sexual or platonic; because I feel insecure and anxious around men…there was never a deep enough level of communication to form the relationship (Code 103).

I withdrew from social contact. I wasn’t close or involved with people in general. I live alone (Code 303).

In one instance, the research participant complained that his agoraphobia prevented him from trying out other people while he was in an intimate relationship.

Although I have been with my current partner for 3-4 years. It (agoraphobia) has hindered me from seeing who else is out there. Try new people etc (Code 293).

While some research participants struggled to form intimate relationships, other research participants were able to form intimate relationships. However, these people reported that their relationships were often adversely affected by agoraphobia. One person reported that she hid her true self (i.e. the person hid her agoraphobia) from partners, due to a fear that they wouldn’t understand and/or would make a negative judgement, which made her relationships shallow, deceptive and valueless. Another research participant feared that if she informed her partners of her panic attacks then she would be ridiculed.

I didn’t reveal my true self to any partner in case they judged me or didn’t understand me. My relationships were pretty much a lie, pretty worthless (Code 93).

I didn’t want to tell my partner as I thought he would probably ridicule me. But I had to tell my partner because I was going to the group therapy things, so I had to tell him then. He didn’t say anything, he didn’t really understand. I brought a video-tape home and he watched that or some of it, and then I’ve seen bits in magazines and things like that and I’ve said to him, this is how I feel and he has read that and I think he probably has a better understanding of it, but it is never mentioned (Code 22).

Several research participants reported that their partners didn’t understand their panic attacks and avoidance behaviours at the onset of their agoraphobia. Admittedly, the research participants would have struggled to make their partners understand the nature of panic attacks, since there was a lack of physical cues and verbal descriptions would not be sufficient to convey the overwhelming, terrifying and disabling experience of a panic attack.
My partner found it very hard to understand at first but he learnt along the way… it wasn’t until I was getting better that he kind of figured it (Code 94).

He said he understood, he really didn’t until maybe about a year ago when he said I think I kind of understand now. But he didn’t understand for ages (Code 92).

My partner is a wee bit understanding but has a long way to go. He still is ignorant of my illness (Code 274).

Although my husband has become more understanding of my problem, in the earlier years because he didn’t really understand it, he couldn’t accept that I wouldn’t go to crowded picture theatres or crowded buses (Code 59).

My previous partners have not been understanding of my anxiety (Code 98).

My husband was supportive, but in his words he really didn’t understand it (Code 75).

In one case, the research participant’s own lack of understanding about her panic attacks meant that she was unable to help her partner, friends or family members understand her mental illness.

My relationships with my partner, friends and family have at times been terribly strained due to the impact of agoraphobia. I feel now that it was due to a total lack of understanding of the condition. I didn’t know for years what was wrong with me and neither did anyone else (Code 169).

In another instance, the research participants reported that her partner’s lack of understanding led to his expectation that she should simply ‘snap out’ of the panic attacks. It seems that, the ‘snap out of it’ attitude towards people with anxiety disorders and depression is a common occurrence.

My husband found coming to terms with my problems difficult at first. He was originally one of the ‘snap out of it’ type persons (Code 265).

One research participant commented that her partner’s lack of understanding led to frustration due to her cancellation of social activities. However, the person reported that her partner became more supportive as his knowledge about agoraphobia and supportive techniques increased.
My partner did not really understand what I was going through and could not understand why I didn’t want to go to parties and socialise. My partner got frustrated when I constantly cancelled plans that I had made when feeling more stable. My partner tried to support me through this though and once he began to understand the seriousness of the illness he became more of a support/companion and I was able to teach him techniques that he could use to help me (Code 92).

One research participant stated that as well as a lack of understanding her partner failed to provide emotional support during her struggle with agoraphobia.

My partner wasn’t emotionally there for me, really let me down. I think women are better at handling emotional problems, because we have a wider view of the world, whereas a lot of men are very narrowly focussed, but I guess their brains are just wired up that way (Code 108).

In addition, several research participants stated that their partners lacked practical skills to provide appropriate support during their panic attacks. It appears that these partners wished to encourage and support their partner to overcome these panic attacks, but the lack of understanding about panic attacks and breathing and relaxation techniques would have severely undermined their value as support persons.

I think my husband is a very quiet person and he was supportive, but not in the communicating way. He would listen to me, but if I was really anxious he could never say, “Do your breathing, come on breath in, and blah, blah, blah”. He is a very loving; affectionate person and he would give me a hug and say you’d be alright… When I was really anxious he’d never say anything, he’d put his hand across and hold my hand, but he wouldn’t say, “Well come on, do your breathing”, it was like I’m here for you but you’ve got to do it. (Code 148).

I’m sure it made it very difficult for my partner. He was always caring and loving but didn’t know how to help (Code 266).

I have been divorced twice and while married had very little practical support from either partner (Code 289).

As a couple I talk about ‘problems’ while my partner prefers to not discuss issues. Therefore, my partner was unhelpful in one sense, but did not add to the problem. I believe that my partner didn’t really understand what was happening to me, and didn’t know how to help either (Code 320).
My husband couldn’t handle my panic attacks. Whenever there is sickness or the kids, he just sorts of backs off because he really doesn’t know how to handle it, and I’ve noticed that all his life (Code 108).

One research participant stated that in addition to her partner’s lack of understanding and practical support he appeared to be ignorant of her having panic attacks in different places and situations. This research participant stated that she had to continually make known to her partner her discomfort and anxiety in different places and situations. Since the research participant’s panic attacks were invisible to her partner, he had no physical cues that she was having anxious thoughts and feelings in that place or situation.

I talk about how uncomfortable I feel and that I find it difficult, but I am not really that clear with him I guess, and I think sometimes he might forget, because on so many other levels I seem to do OK, I think he forgets that I actually do get really uncomfortable and quite nervous (Code 281).

Another research participant reported that her partner was practical and supportive during her panic attacks. However, she argued that a partner had to have had a panic attack themselves to fully appreciate its overwhelming and terrifying effect upon an individual.

Most of my partners are supportive, but I believe only someone who has had a real panic attack can truly understand (Code 44).

While some research participants stated that their partners’ lack of understanding and support during a panic attack was a problem, some research participants reported that their anxiety led to stress and conflict within their marriage/intimate relationship. One research participant reported that her partner adversely reacted to her anxiety and that the relationship did not return to ‘normal’ until she had gained control over her panic attacks.

At one stage, I thought things weren’t working out with my husband, we went through a bad patch for about a year and it was me, it wasn’t him. He was reacting to me. We got through it, and once I became confident and the more I listened to my relaxation tapes and I would be really normal, things got better (Code 41).

One male research participant believed that his sharing of his burden (i.e. anxiety) with his partner placed a large amount of stress on their marriage.
The agoraphobia had a bad effect on my relationship with my wife. She is the only person I would ever discuss issues with and I think I became very dependent on her because of that. I didn’t have other people that I could have shared the burden with, so she had to take all of it, which wasn’t fair and placed a lot of stress on the marriage (Code 31).

Several research participants commented that their unwillingness and inability to go out with their partner on social outings caused stress in the relationship. Also, the partners expression of impatience, resentfulness and anger towards the person, due to their avoidance of social outings and their inability to ‘get over’ their anxiety, often escalated the stress within the marriage/intimate relationship.

Going through the agoraphobia just wrecks so much, because you don’t want to do anything with your partner or go anywhere. I wouldn’t go to the pictures; there was no way in hell that I would go to the pictures. And it is just little things, like why don’t we go to the pub. Well, I’m not going there. Well, if that’s the way you feel, and it was hard (Code 41).

It put a lot of stress on it. He could be very helpful and supportive at times and at other angry, resentful, impatient (Code 81).

My partner felt resentful towards me because I was not able to attend some social functions (Code 150).

Over fifteen years of panic attacks, my husband and I have been through cycles of his tolerance and frustration with my illness. At times, he has had to step away and get on with his own life, i.e. he has travelled frequently on his own, because I am such a difficult travelling companion (Code 97).

My husband has always been there for me but I have felt resentment at times, which he has acknowledged when I talked to him about it. He is aware of my anxieties but does not and cannot fully understand the feelings of panic, as he has never been in the same situation. I do feel that I am a nuisance to him, as I always have to have an aisle seat whereas he would rather be in the middle of the middle row of a theatre. I still think my husband feels that I should be able to get over it (Code135).

A large number of research participants stated that a major stressful factor in their marriage/intimate relationship was their struggle to socialise with their partner in public places and situations. These research participants were often forced to become socially reclusive due to their panic attacks, and often forced themselves to attend social activities to appease their partner who was a more out-going person.
In our first married years we rarely went out or away together (Code 252).

I was reluctant to go out socially. It had a huge impact on our relationship (Code 81).

It affected our group socialising, his work parties (Code 175).

The panic attacks prevent social outings with my partner (Code 84).

My husband is a very outgoing person, whereas I am a fairly quiet person. We would go out and he wouldn’t come home when I felt I needed to come home, and we would be the last ones there and that would really bug me and I would start getting panic symptoms (Code 22).

I change my mind suddenly not wanting to do something we’d spent time planning to do. It happens all the time. I have to try and fight it and make myself go so he won’t be disappointed (Code 227).

I am not as sociable as I would like to be. There are times I think that he would like to go out more than we do (Code 281).

I think it did put more of a strain on our relationship, because he wanted to go out and I couldn’t. So that was the main impact that it had (Code 92).

I forced myself to go to functions I would have preferred not to attend, for the sake of my husband. Maybe at the peak of my illness, he did forgo some outings, as they would have been too traumatic for me. He understands, as he has had an anxiety problem himself from time to time (Code 209).

At one point my agoraphobia was so bad I did not go out anywhere except to work and back, therefore our social life was severely affected. This made life very difficult for my husband who has been great at not giving me to much grief over my problems (Code 202).

He plays rugby so I’m expected to go to prize-giving and try a sit through long speeches in a crowded hot room, which I hate. There are places I won’t go, but do make myself go to lots of social events with him so he’s not too hard on me (Code 59).

In addition to the research participants forcing themselves to attend, or avoiding, social activities, many people had to force themselves to attend or avoid important family-related events since the avoidance of these family-related events (e.g. family weddings, funerals, etc) would have damaged their relationships with family members.
We didn’t go to family weddings and gatherings... I can’t say I’m a real fan for going to those. I went to one a few years ago and it was on the Black Cat that goes around the Akaroa Harbour. They thought that would be nice. I didn’t go on the boat. The others all went, I just went to the reception (Code 22).

This is the first Christmas I’ve had without having dinner at my father’s side. My father’s side is the one that we lost the two grandparents; we’ve had three Christmas’ since then – the two Christmas’ that we’ve had, I absolutely dreaded. I hated it – I had to keep locking myself away in rooms and having attacks, and just really panicking, really panicking, and this year I had lunch with my partner’s parents and we went to dad’s parents for just ten minutes and that was all I could cope with, and then we went and had tea with my mum’s side. It sounds awful, but that is just the way it is. When that family get together I have real bad attacks, really bad attacks, I just hate it and just want to get out (Code 67).

I could only go to funerals if I sit at the back (Code 35).

My husband is going to Australia in August for a wedding, our nephew’s wedding – my girls are going and they expected me to go, and I said no way I can do it. I haven’t got the time to do the counselling and don’t know if I could do the breathing and relaxation on the flight (Code 35).

While most research participants were able to force themselves to attend family-related events and everyday social activities, most chose to hide their agoraphobia from others. The research participants appeared to hide their panic attacks from family and friends during the family-related event and/or everyday social situation to avoid drawing unwanted attention to themselves. In some cases, the person avoided the family-related event and/or everyday social situations to enable them to hide their panic attacks from others and avoid the occurrence of the actual panic attacks.

I was unwilling to meet his family and friends...I would have panic attack symptoms... I felt like the attention was on me. I would avoid meeting them. (Code 32).

I have avoided situations (e.g. skiing as a family outing) I am very good at masking my avoidance of situations from others (Code 203).

I have seen agoraphobia as a weakness and have gone to great lengths to hide symptoms and use avoidance techniques. This has resulted in me displaying same bizarre/unusual behaviour when required to attend social functions or visit certain places/areas. Which my family and friends have not understood – thus putting great strain on relationships (Code 45).
I was unwilling to disclose to my others that I was having panic attacks. It is hard to relax sufficiently to put other people at their ease (Code 211).

In some instances, the research participants hid their panic attacks from their partner at family-related events and in social situations. In one instance, the person simply made excuses to her partner to avoid attending those situations.

I covered up my agoraphobia in social situations, I didn’t tell my husband I just made lots of excuses for not going out (Code 22).

One research participant reported that her partner expected her to perform her social duties irrespective of her anxiety.

I never admitted/discussed. I was just expected to do my duty (Code 7).

While research participants struggled to perform social duties with their partner, which often led to a strained relationship, some research participants reported that panic attack symptoms often impaired their sexual performance, also contributing to stress in the marriage/intimate relationship. The research participants stated that their impaired sexual performance was due to lack of self-confidence, a feeling of unhappiness, depression and the side effects of anti-depressants, anxiety, tiredness, and the perception that sensations associated with sexual arousal were signs of panic attack symptoms.

It affects your sexual life, you’ve got no confidence, you are unhappy and depressed (Code 41).

I think it did affect the sexual side (Code 148).

Due to having to taking anti-depressants it has badly affected our sex life (Code 299).

The agoraphobia made me feel anxious and tired, and that sort of affected the relationship, because physically and mentally I was worn out. I felt that I couldn’t give any more of myself. During intimacy I felt deep down that I was going to have a heart attack. I would feel my heart beat increasing and that sort of thing, and it was like oh my God if I have sex then something really bad is going to happen. I though if my heart starts racing because of the intimacy, then I’m going to have a heart attack. So I withdrew from my husband at times sexually, always fearing that I was really having a heart attack and would die (Code148).
One person stated that the forced unequal division of labour contributed to stress in the marriage. In this case, the housewife/mother was unable to do various everyday tasks due to the mental and physical exhaustion brought on by her panic attacks, which meant that her husband was required to do a greater share of the domestic labour.

In a husband and wife relationship it can take its toll, we’ve never separated we’ve never even been close to it, but we really had to work on it, because there were times when it was really hard and it must have been really hard for him in trying to run the farm and looking after me and there were times I would be so exhausted that I could hardly do anything and he had to do more, at home (Code 148).

Two research participants stated that the source of the stress within their relationships was their partner’s stress-related problems, rather than their own struggle with agoraphobia. While people have commented on the stress that their anxiety disorder caused in their marriages/intimate relationships, there would have been a large number of other causes of stress in these relationships too.

In the early days I found it very hard coping with myself and my husband, who was a very stressed man and had a lot of problems of his own from his childhood. I am pleased to say we have got through it and will have been married 30 years next year (Code 33).

I felt that I wanted that sort of support, but he had a lot of stress himself... I felt that I was the one who had to keep the family going which I had to do because he was away a lot (Code 33).

In one case, the research participant’s demand for immediate support from her partner during a panic attack led to a high level of stress in the relationship. The research participant’s sense of helplessness and desperation caused her to become verbally abusive towards her partner when he failed to instantly meet her support needs.

When I felt a panic attack coming on I would want him to do things right then and there. I would say to him you need to do this for me and I would say you can’t go out because I can’t go out, and if I want to go out you have to come. I knew he though I was being a bitch. I would say I’m sorry, but I needed you to do it because I was having a panic attack. I couldn’t get up and move and I needed something done now, and if I do say something like that, can you just be aware that I might be having a panic attack and I might need it done now, rather than later. I know for the
last year that I must have been a real annoying bitch, but I needed his attention. (Code 92).

The research participant believed that her partner became frustrated with her ongoing panic attacks, their inability to socialise, and her lack of progress in addressing the panic attacks.

We had lots of talks, I was sitting there saying I need you all the time and you can’t go out and we can’t go out and do stuff together because of the panic attacks... It was probably very frustrating for him because I wasn’t getting better immediately either (Code 92).

Several research participants reported that they felt guilty due to having to burden their partner with their panic attacks, avoiding social outings and making regular demands for support.

I do not like talking to my husband about my phobias. I feel guilty that he has so many extra things to do for me (Code 243).

At times I felt guilty, as I would not go out on family outing with him and our boys (Code 41).

I feel so dependent unable to hold down a job and I have to live in a guilt situation of dependence with him (Code 24).

The research has shown that a significant number of research participants were in stressful relationships due to problems associated with their anxiety disorder. In some cases, the stressful nature of the marriage/intimate relationship spiralled downwards into abuse.

My first husband was very controlling and demanded more from me than I was capable of, and got very impatient with my inability to cope. The relationship deteriorated until he hit me, and I walked out (Code 86).

My first partner was unwilling to acknowledge my problem, he was abusive; physical, mentally and emotionally (Code 287).

I started getting terrible panic attacks once a day, sometimes twice a day, and I wasn’t coping very well with the kids, and every time there was a bit of stress, I’d get sick, and it was awful. I couldn’t handle the constant episodes with my husband, he used to say things like, “Look at you, you’re fat, you’re fatter than my mother, who’d want you?” and “I wouldn’t sleep with my mother, so I’m not sleeping with you” and things like that. Then he would always talk about me being a bad mother, and he wouldn’t help, he’d go off fishing or do something he liked. I didn’t have the self confidence or self worth to be able to cope, I just used to take in
really the sickest things of what he said, and he used threats of physical violence, and I was scared of him, and he’d say, “If you don’t do this, I’m going to do this” and he’ll bash his fist through the wall – it was awful and so in the end I left him. The marriage was to be my dream, I loved him, but I left (Code 289).

One person stated that her partner made her feel stupid (i.e. mental and emotional abuse) due to her causing him embarrassment in public places. Another person reported that her lack of confidence and self-esteem meant that she let men treat her badly in relationships.

He doesn’t really want to know, he thinks I’m stupid, he wants me to shut up about it and get on with it and never cause him embarrassment (e.g. running out of somewhere in public (Code 31).

All my relationships have been abusive – mentally and physically – I have no self-confidence or self-worth and let men treat me badly (Code 278).

Another research participant stated that being in an abusive relationship caused her anxiety and resulted in agoraphobia. It appears that the person’s loss of confidence in an anxiety-inducing relationship and the fight/flight nature of an abusive relationship were a contributing factor towards her development of the panic/avoidance symptoms of agoraphobia.

I had major anxiety and agoraphobic symptoms due to living in a very abusive marriage some years ago (Code 218).

Several people reported that their agoraphobia had made them weak individuals, lacking in confidence and self-esteem, which meant that they tolerated abusive behaviour from their partner, which was unacceptable. It seems that people with agoraphobia can become trapped in unsatisfactory and/or abusive relationships, due to their mental illness undermining their confidence to assert themselves in the relationship. Also, some people with agoraphobia would be unable to cope with the daily strength-sapping nature of their illness and the resulting relationship problems at the same time.

I saw agoraphobia as a weakness and found that my self-esteem and self-confidence were very low. I also tolerated unacceptable behaviours in my partner as I felt I deserved no better (Code 45).

My agoraphobia has trapped me in a relationship where I feel used and abused but I am too afraid to leave (Code 210).
The mental illness affected my ability to cope in the mentally abusive relationships (Code 289).

Another reason that research participants were entrapped in unsatisfactory and/or abusive marriages/intimate relationships was their dependency on their partner as a support person. The partner would often do out-of-home activities that the person feared to do due to panic attacks.

I started relying on him to do more stuff for me, whereas when I was on my own I had to force myself to do things (Code 41).

I had a boyfriend, he wasn’t a real boyfriend, I’m sure he really liked me – he was my security, because he had a car that I felt safe in, and because he really liked me he was there and he looked after me a little bit (Code 45).

While some research participants stated that they struggled to leave unsatisfactory and/or abusive relationships, one person reported that she had been able to leave her relationship by forming a new relationship that enabled her move on with her life.

I wasn’t getting any support from my partner, and I was scared to leave him because it was would mean more change for me. I guess I sought friendship elsewhere… I used to work at a Karaoke Bar and ended up having a few drinks at night with one of the barmen and just spending a lot of time with him. I split up with my partner very soon after that (Code 93).

However, one person reported that after leaving her marriage, her problems with anxiety increased. While the partner had been in the family home he had taken the children to public events, which the mother was unable to do due to her panic attacks in those public places and situations.

I was quite happy – I’m not saying I was fully happy, but it was a shame for the kids because with them being with me being on my own and still having anxiety and things, it was hard on them at times. I did would avoid going to the school for things, and there was only me they had to take them. I didn’t take them to things, so they missed out on a lot of things like that. It was frustrating for them. I can remember crying at times because I was just sick of it. Just sick of the feelings of anxiety, and not being able to do things with them… they’d ask me to do something and I can remember just crying, because I knew I couldn’t but I wanted to. If I’d had a partner, they he would have been able to take them (Code 105).

While the research shows that a significant number of research participants had problems in their marriage/intimate relationships associated with their agoraphobia, a substantial number of
research participants stated that they had partners who were positive and supportive during the unmanaged symptoms stage of their agoraphobia.

I gave my partner approximately 8 years ago the option to find some one else without agoraphobia. She was happy with everything; we married 2 years later…(Code 21).

He has been absolutely awesome. I think after two weeks when I started going out with him I told him, because I thought I might as well tell him now and he can just think ‘No I don’t want to be involved” and bugger off. I didn’t want to go through a few months of us getting to know each other and then finding he can’t cope with it… After two months of being together I had a really bad day and I was just an absolute mess, and it was really hard for him, but since then everything has been fine. It took him a while, but he understands (Code 67).

I have been very fortunate that I have a wonderful partner who has supported me (Code 98).

My husband is really good – he understands. He knows what I’m like and knows what I can do and can’t do, so he is very helpful in that way. He will say to me, “Are you alright?” or “Are you feeling a bit funny?” and I’ll say I’m alright. Or he’ll say we’ll go outside and get some fresh air, or whatever. Or I’ll just say to him I can’t do that, you’ll have to do that on your own. It is helpful to have him with me, especially at the hospital, things like that. I can go and see somebody at the hospital - I know this sounds ridiculous - and I walk in, if I get in that far, and walk straight out again and get fresh air and go back in again in my own time. When he is with me, he just stays at my side – even the girls know now that if mum goes in and goes straight out again that they just explain that she is feeling a bit stressed (Code 35).

Well, my husband has never made a fuss of it, he has been understanding and very supportive. He tries to give me confidence, saying he will look after me and I will be alright. Just try and relax and get on with it, and I will look after you (Code 37).

Hasn’t really been a problem for us as husband is kind, loving, considerate and understanding (Code 124).

My husband and children were very supportive which helped enormously…We are a close family – they were tolerant, concerned and encouraging – positive outcome for me. Relationships were never in jeopardy even though they didn’t really understand why certain situations made me very uncomfortable (Code 116).

He’s willing to find out more information to understand them properly (i.e. panic attacks) (Code 287).

My husband was wonderful (Code 94).
In some cases, the research participants who had reported negative experiences in their first marriage/intimate relationship stated that their new partner was more supportive of them.

My new partner is very supportive, loving, comforting of my problem (Code 67).

My new partner has been more protective, more helpful, and more considerate. He has helped me to be more confident by being amazed that I can cope at all during a bad attack and he gets very concerned during times when the panic attacks are more frequent or intense (Code 86).

The research participants stated that the advantage of a positive and supportive partner was their ability to act as a support person during a panic attack in a public place or situation.

I felt that if I fainted or anything like that, that he could pick me up and take me home, I used to take him to supermarkets at… It was huge and I went in there and I went through the door and looked down and I thought there is no way I am going in there at all. (Code 41).

I relied on him immensely (e.g. shopping, doctors visits)… (Code 81)

He (husband) went everywhere with me. If he couldn’t come, I would stay home (Code 124).

My husband used to have to come to the supermarket with me. When there was a place we had to go to, I used to stick to him like glue because he was there as support for me (Code 41).
Parenting

In the survey, 39% of research participants reported that agoraphobia affected their parenting/childcare abilities, while the other 61% of research participants stated that agoraphobia had no effect on their parenting/childcare abilities for the following reasons:

- The research participant’s agoraphobia had no effect on their parenting abilities.
- The research participant did not have children.
- The parent had older children (adult) during their agoraphobia.
- Due to agoraphobia they were unable to form a relationship, to have children.
- The person did not live with their children.
- The person decided not to have children due to the fear of the child inheriting agoraphobia.
- Missing Data.

The table shows the effect of agoraphobia on the parenting of the 39 research participants.

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Parenting
The major findings of the survey data are that 18 out of the 39 (46%) research participants were unable to accompany their child or children on school trips, or long distances trips due to agoraphobia. In addition, 16 out of the 39 (41%) research participants were unable take their child or children to out-door recreational activities, due to their agoraphobia. This data shows that any parenting-related activity that involves travel is problematic for parents with agoraphobia. The survey data shows that 10 out of the 39 (26%) research participants were unable to take their child or children to after school sport events, or school performances due to agoraphobia. This data shows that parents with agoraphobia often struggled to support their children’s involvement in after-school activities. The survey data shows that 8 out of the 39 (20%) research participants could not take their child or children to visit his/her friends, 5 out of the 39 (13%) research participants were unable to take their child or children to visit extended family. This data shows that parents with agoraphobia often struggle with supporting their child or children in developing valuable social networks among friends and extended family members. The survey data also showed that 5 out of 39 the (13%) research participants
struggled to take their child or children to the doctor and/or dentist due to agoraphobia. This research data raises the concern that some parents with agoraphobia are unable to access primary health care for their children, which could endanger the wellbeing of the child. The survey shows that 4 out of the 39 (10%) research participants were unable to take their child or children to church, due to agoraphobia. These parents may believe that faith and religious rituals were important in their children’s spiritual development, and their inability to take their children to church would have undermined their feeling of being a good parent. Finally, the survey data shows that 3 out of the 39 (8%) research participants were unable to attend their child or children’s pre-school or kindergarten sessions due to agoraphobia. These parents may have willingly participated in the formal early educational development of their children had it not been for their agoraphobia.

In the study, research participants spoke about the struggle of parenting and coping with agoraphobia. Several female research participants believed that mothers who are often the primary caregiver were more likely to have their parenting adversely affected by agoraphobia, than the father who played a supporting role as parent/caregiver.

I think a mother with agoraphobia is more affected because she is the one that spends the most time with the children. It’s the old story the mother holds the family together (Code 99).

The only effect it had on my parenting was that I wasn’t able to do the outdoor activities like fathers. Fortunately, my kids are all into play-station and computers so they didn’t want to go camping anyway (Code 35).

Two research participants spoke about their fear that their children would develop agoraphobia due to their modelling of anxiety and avoidance of places and situations.

I tried not to put my fears onto the children, as they grew up, I had a problem with lifts so we have always taken the stairs (Code 35).

I was worried that this is something that I could pass on to my children by modelling it to them (Code 22).

One parent worried that she would pass her lack of confidence and insecurities on to her children.
I have always been a shy person with not much confidence. I don’t know if this is because I suffered from agoraphobia or not but I was aware of trying not to pass on my insecurities to my children, though probably not very successfully (Code 256).

Several research participants stated that they had decided not to have children due to the possible risk that their child or children would develop agoraphobia. In one case, the research participant’s partner did not want to have children with her due to her agoraphobia. It seems that the research participant’s decision to not have children was based on the belief that genetic factors and/or learnt behaviour caused mental illness.

I developed agoraphobia after my first child... I decided that agoraphobia was too dreadful a thing, to have any more children. I wished I myself had never been born (Code 44).

I have decided not to have children, partly due to my panic disorder (Code 59).

I was afraid to have a second child, I felt I couldn’t look after two with my anxiety problems (Code 190).

My partner was unwilling to start a family because of my illness (Code 170).

Of those research participants who decided to have children, several stated that they felt guilty about their parenting decisions and abilities. The parents’ feelings of guilt included; their decision to have children, modelling of anxiety, failure as a positive role model, inability to do things with their child, letting their child down, burdening their child with adult responsibilities, the ongoing effect of anxiety on their developing child, and the adult development of agoraphobia in their children.

I felt guilty about putting my own need to have children above the risk that they would suffer from agoraphobia in their lives (Code 31).

I kind of blamed myself thinking that perhaps I projected more of how I felt on to him. Like I would say oh no, I can’t do this, I’m too panicky (Code 148).

I went to Farmers with my son, I wouldn’t go upstairs in the lift and I didn’t want to go up the escalator either. I felt like I was letting my son down –not a strong role model (Code 213).

I feel as if I have let my children down really badly (Code 22).
I feel bad as I have never really done a lot of out-door family type activities with my children, as have always been too nervous or anxious to do it (Code 278).

I feel cheated out of supporting my daughter in her schooling for 2 years. Also, the pressure it put on her, due to the fact that I couldn’t leave the house, so she had to do all the shopping for 2 years, she was 9 to 11 (Code 218).

I feel guilt. It has affected my relationship with the children, especially when they were younger when I was probably a bitch. I was always uptight and of course having my oldest one with ADHD, I used to be really stressed (Code 41).

When she was an adult had a stillborn baby and then developed agoraphobia, it affected her life with continued anxiety and she is now 31, so it’s affected both our lives, which is so frustrating and annoying (Code 218).

Several of the research participants stated that they lacked confidence in their parenting abilities due to agoraphobia. In addition, one research participant felt weakness and incompleteness as a parent.

The major effect on my parenting has been my lack of confidence. I think that has come through with the kids. I occasionally see a lack of confidence with my oldest daughter. I can’t put my finger on anything, but she is pretty outgoing. What I’ve found with my daughters, is that they are encouraged at school to have more confidence in themselves and to try things. I did try to encourage them, but I suppose they could see me not having confidence in myself and although I would take them places, I wasn’t confident (Code 256).

Some activities are off limits, the most notable being skiing and walking in exposed areas such as the Port Hills, also walking in the open around large cities such as Sydney. It’s unlikely my family would recognise this but it does affect me/my feelings of weakness/incompleteness as a parent who enjoys participating in activities with his family (Code 203).

A number of research participants reported that their lack of confidence in themselves and their panic attacks caused a major disruption to their attendance at family events. These family events included; family visits, family travel, family holidays and formal family functions.

I was unable to handle the stress of looking after the kids by myself, if I had to take them somewhere, I would get the anxiety and trapped feelings (Code 21).

There have been occasions when I was unable to visit my mother-in-law with my young children. My husband had to take the children alone (Code 108).

I missed out on early baby days of walks and holidays (Code 252).
I have not accompanied my children on trips that have involved aircraft or ferry travel. This has included holidays, funerals, and weddings (Code 98).

One research participant stated that when she was unable to take her children to family-related activities her partner took them alone. While the parents ensured that their children attended family-related activities it was often as an incomplete family unit.

I have been unable to do a lot of things with my children. We have not been able to do things as a family, my husband takes them everywhere and I am unable to go with them (Code 243).

While research participants reported that they didn’t take their families to places where they felt feelings of anxiety and/or feared the occurrence of panic attacks, the research participants would take their families to places where they felt safe and comfortable and/or were accompanied by a ‘safe’ person.

I used to take the children to the Museum and the Art Gallery, because I felt comfortable there. I couldn’t drive anyway, so it was quite difficult for them to go to anything and because I didn’t really mix with many people, people didn’t say, “I’ll give them a ride” or something like that (Code 22).

My husband always came with us. I was lucky that we are farming so he could take the time to help do these things… I never really ran around much outside playing any sort of sport with our children. I was always scared and only did this when my agoraphobia was under more control (Code 148).

It was difficult for me to take them out at night, or pick them up in town, even with my own car, but usually my husband was able to do that, and I often went with him. There was one class the children went to, about two miles from home, towards the airport, not many houses around, at night, and I hated that (Code 31).

Some research participants used their children as a ‘safe’ persons when they when into public places and situations.

When I became housebound, I would have to send my son out to get the shopping (Code 169).

I could would push myself to go out and my son was my ‘companion’ (Code 190).
One parent would use her children as a distraction from her anxiety in public places. It appears that the parent was able to use the caregiver role (i.e. concern about others needs) as a distraction from focusing on her needs in public places and situations.

When the children were in school in Wellington I had to go down and pick them up, and sometimes when I would be waiting outside school and I would feel uncomfortable, but I did it. At times I felt really uncomfortable and I did have to talk to myself when these funny feelings were coming on. I would actually talk to the children or I would do something and then my mind would go off it. I used to distract myself with the children and I found that helped me a lot (Code 33).

In some instances the research participants’ requirement for a safe person to accompany the family into public places and situations created dependency in the relationship. Also, the research participants’ usage of their partner and/or children to do out-of-home activities reinforced their avoidance behaviours.

There was always someone who could take them to things if I couldn’t (Code 33).

I relied on people to do a lot of the running around for me so that my children could attend outside activities (Code 162).

I don’t take or pick her up from her friend’s house, if the parents can’t take her then she doesn’t get to go (Code 304).

When one of the children went on a picnic out to one of the teacher’s houses or out of town or whatever, I would get someone to collect my kids for me because I couldn’t do it (Code 41).

To avoid walking to kindergarten, I would get the girl down the road to take the kids. She didn’t know and it wasn’t until a couple of years ago I actually told her that I had agoraphobia and I had needed to use her to take the kids (Code 41).

While some research participants reported disruption to family-related events, others stated that their attendance at school-related events was equally disrupted by their agoraphobia. Some research participants reported making excuses, avoiding or forcing themselves to attend the school events. The school-related activities that were disrupted included; pre-school activities, swimming sessions, music and dance classes, young mother’s groups, school sports, mother-help, school concerts and school camps.
I was unable to take my child to a pre-school organised activity e.g. swimming sessions, music and movement group or new mum coffee group (Code 150).

When it was school sports day I used to figure out when my children would be running and I wouldn’t go there until they were just about to run. At school concerts, I wouldn’t hang around and if I could get out of it I would. I never went to any of their concerts… I felt that I really let the children down (Code 22).

I was reluctant to be mother help at school. I have never attended the night performance of school concert. (Code 81).

I forced myself to attend school performances, but always I sat on the aisle, near the exist (Code 210).

My parenting years were difficult, as I had to attend many school activities, that nearly always brought on panic attacks. I always had excuses to leave early (Code 209).

I have tried to be a ‘normal’ mum throughout the years. This has been my highest priority in life. My husband would say that our 3 children have been affected to some extent by my illness, e.g. never going on school camps with them etc. There have been a few times I have not attended functions at school, but I have always done voluntary work at school, and taken them to all out of school activities (Code 97).

One mother believed that the disruption to family-related activities and school activities, caused by her panic attacks, hindered her daughter’s social integration into the wider community. In addition, some parents stated that they became overly protective of their children in anxiety-inducing situations.

I have ideals about what it is to be a good parent, you have to be socially connected and involved in the community… I wonder sometimes if we are sufficiently socially connected to the community. I’m not involved with the church, I’m not involved with other groups. I avoid going to see things in the community because of panic attacks. I worry that our daughter is missing out on being part of a wider social network. I think that if we are not socialising, what is she learning from us about connecting with other people (Code 281).

I feel perhaps that I was overprotective of my children at times (Code 75).

I try not to put too much pressure on them and I protected them from any fraught situations at home i.e. during husband’s unemployment (Code 193).
While parents struggled to do out-of-home activities (i.e. family-related and school-related), some parents simply withdrew into the family home. Some women were able to use their caregivers and homemakers’ roles as a means to withdraw into the family home to avoid public places and situations (e.g. paid employment).

When we would go to a party and I would get very uptight and would want to go home. Then I had my first baby and I felt safe and secure in my own home. I was so wrapped up in my children. I stayed at home a lot (Code 37).

I am happy to be at home with children – no drive to be at work causing undue stress…(Code193).

However, several research participants reported that their daily struggle with panic attacks was worsened by having to fulfil different roles and responsibilities in their families. The research participants had to force themselves to perform these duties and endure the panic attacks, as no other individual could or would take on these roles and responsibilities.

You try to be everyone to everybody and you try to do everything, and you really can’t do it. You definitely try to do these different roles and meet your different responsibilities – but you can’t do it (Code 41).

It was hard work coping with the anxiety everyday as well as performing my role as wife and mother. I was never one to raise my voice or yell or scream I just kept it in, the panic attacks. I think I had anxiety where someone else might have had a mental breakdown or something else (Code 105).

I had to force myself to go on, before I knew I could actually do it, and I would just keep going out, I had to do it to be a better parent because I’ve got a financial responsibility to do so (Code 281).

Being a mother was a battle – I carried on and tried to do as much as I could and would take my son out for walks, but I didn’t feel comfortable, but I still made myself do it. I didn’t keep myself locked inside, or anything like that, I tried to do what I could. I got my son in at a kindergarten, which was a private one because he couldn’t get in the other, and someone used to take him in the morning, but then I had to go and pick him up. I had to do all these things, even though sometimes I wasn’t feeling kind of comfortable, but I just did it because I had no option… My husband worked away a lot so I had no choice but to do things for my children, pick them up from school, take them to activities after school. We had immigrated to New Zealand in 1979, so I had no support systems and just had to get on with life (Code 33).
Sometimes the research participants were unable to perform the roles and responsibilities required in the family group. One research participant was unable to attend the birth of his child and another person was unable to do out-of-home activities with their children

I was unable to attend the birth of my first child due to the fear of having a panic attack at the hospital (i.e. trapped in the delivery room) (Code 320).

As a family unit we quietly go about what we have to do. Just means I can’t do some things on my own, so we do it as a family (Code 21).

One research participant was able to transfer her role and responsibilities on to others. In this case, the parent arranged so that other parents would transport her child, allowing the child to visit her friends, while the parent maintained her avoidance of public places and situations.

Prior to agoraphobia we would just get up and go anywhere on a whim, we were always visiting etc. But now my daughter’s friends have to come to our house to play and their parents take them home not me (Code 304).

While research participants struggled with their panic attacks, attending out-of-home activities and performing role and responsibilities in their families; a large number hid their illness from their family members and others. Parents tried to hide the truth from their children by putting on a brave face, to protect them from fearing that they would develop agoraphobia.

I have always tried to be positive and for years hid the condition from my son (Code 169).

My daughter is unaware of my problem, she is eight, it is very hard to put on a brave face, but I manage it (Code 310).

I tried to hide it from them, I don’t think that I communicated it, I didn’t want them saddled with the ideal that they would be crippled by it too (Code 22).

Another parent felt she was unable to explain her fear to her children. She reported that her children unfortunately interpreted her avoidance of school-related activities as a lack of interest in them.

The child thought that I didn’t care about what they did at school because I didn’t go to activities at school. But how do you tell a child that you have this fear (Code 238).
One parent didn’t tell her children that she felt anxiety in public places, because she didn’t want their knowledge of her anxiety to make her feel more self-conscious and anxious in that public place.

I don’t say much about it really to the kids. They don’t ask me much about it – I don’t like to tell them because I don’t want them to think that mum gets funny in different place that would make me more anxious in those places (Code 33).

While parents with agoraphobia tried to hide their struggle with anxiety, some children were able to tell that their parent was unwell.

I tried to hide my anxiety from my children. But my middle daughter would stare at me and say, “Are you not feeling well mum?” and I’d go, “No, I’m fine”. But she always sensed that something was wrong. She was the only one who used to able to pick it. I still don’t know to this day how she knew how I was feeling. (Code 105).

In some cases, the parent delayed telling their children until they were older, so that they had the mature to be more understanding of their parent’s illness.

Now they are older, they understand the truth but when they were young they were ignorant (Code 35).

My children…were unaware of what was happening ‘In my head’, as they were too young to pick up on what was going on at first. Their realisation came in their teens and they would basically ‘Laugh me through’ things (Code 116).

While a significant number of research participants reported negative effects, other people stated that they had a positive parenting experience during their agoraphobia. One parent believed that her parenting skills in helping her children manage anxiety had been improved by her own agoraphobic experience. One parent felt that the struggle with agoraphobia had made her a stronger mother. Also, a parent stated that her children provided a distraction from her agoraphobia, and another parent reported that her teenager children were very supportive during her agoraphobia.

I think if the children were going to have anything, I would rather they had agoraphobia, because I know about it and I know what to do about it, than something I don’t know about and have to learn about (Code 67).
It hasn’t affected my parenting, as my kids were teenagers when I had this and they actually helped me a lot (Code 3).

While I was parenting I did not have as many problems with my agoraphobia due to my mind being focused on the children (Code 135).

I am pleased I have had agoraphobia as it made me a stronger person and mother (Code 94).
Post-Secondary School Education

In the survey questionnaire 55% of research participants reported that agoraphobia affected their post-secondary school education. Of the 45% of research participants who reported that agoraphobia did not play a role in their post-secondary school education, some stated that agoraphobia had had no effect on their educational performance since their agoraphobia either occurred prior to, or after their post-secondary school education. Several research participants stated that they had not undertaken post-secondary school education.

The chart and table shows the effect of agoraphobia on the post-secondary school education of the 55 research participants.

<table>
<thead>
<tr>
<th>Code</th>
<th>Number of Research Participants</th>
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<tr>
<td>A</td>
<td>25</td>
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<td>B</td>
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<td>C</td>
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The chart illustrates the distribution of research participants across different codes.
The major findings of the survey data have shown that 26 out of the 55 (47%) research participants reported a loss of confidence in their ability to undertake post-secondary education and training. In addition, 25 out of 55 (45%) research participants were unable to undertake education and/or training that required public speaking. The survey data showed that 21 out of 55 (38%) research participants could not undertake education or training to up-skill to improve their employment chances, and 16 out of 55 (29%) research participants could not engage in workplace-related training. Also, 8 out of 55 (15%) research participants dropped out of work-related training programmes. The data showed that 20 out of 55 (36%) research participants were unable to travel long distance to attend education or training courses. Finally, 13 out of 55 (24%) research participants were unable to attend lectures, tutorials, and classes; 14 out of 55 (25%) research participants dropped out of courses and 9 out of 55 (16%) completely dropped out of the school, college or university.
The survey data has shown that a significant number of research participants had their post-secondary school education disrupted by agoraphobia. In the interview data, research participants spoke about the daily effect of panic attacks on their educational performance. Two research participants spoke of the fear induced by merely thinking of attending a tertiary institution. One person spoke of the fear of having panic attacks while trapped in a lecture among other students.

I still feel panic symptoms at the thought of attending a tertiary institution (Code 150).

I often feel that I’d like to go back to University and do a Masters or something, and the thought of that fills me with terror. I’m terrified of the lecture, trapped in with all those other students (Code 281).

A large number of research participants spoke about their lack of confidence in their ability to study and their ability to cope with panic attacks in tertiary environments.

I could never have attended tertiary education, I had no confidence and no self-esteem, and I would be too anxious to take in the lectures (Code 22).

I have done volunteer remedial reading at the local high school and they have from time to time asked if I would train to become a teachers-aide but I lost confidence, due to the anxiety, to engage in education (Code 148).

At the moment my confidence is still too low to resume education (Code 59).

I probably would have gone onto university, as I was a top stream student at high school. But the daily struggle with a nervous condition prevented this from happening (Code 59).

I haven’t had the confidence to sit in a classroom. My stress levels skyrocket and I can’t learn. Agoraphobia has left me a quivering wreck in these situations. I really want to succeed (Code 293).

When research participants were willing and able to attend tertiary institutions, the anxiety that they felt towards travelling to the education/training provider was a barrier to their educational pursuits. In the research, one person spoke about being unable to travel by bus to their local university. Another individual feared having panic attacks in a car while travelling long distances on field trips, and one person feared flying to conferences.
I can’t travel long distances on buses by myself, and the bus takes about an hour to get into the city to the nearest University (Code 3).

I think twice about courses that include field trips. I haven’t been able to go on ‘art holidays’ with my class, because I would have to travel 200 miles by car to get to the place (Code 31).

As a school principal I limit my professional development to courses to places that I am familiar with. I avoid large conferences or training that involves flying or staying in large hotels (Code 98).

When research participants were able to travel to the polytechnic or university, the next hurdle was confronting the physical environment of the tertiary provider. Several people spoke of their feelings of anxiety and doubts about being in lecture auditoriums, classrooms and examination rooms.

I did a tertiary qualification in 1999, and while my agoraphobia wasn’t a huge issue at that time, I remember feeling very anxious and doubting my abilities to stay in the lecture room (Code 104).

I have attended many night classes but was never totally comfortable at being trapped in a classroom. Gave up a photography course when claustrophobia prevented me from staying in the dark room. Although only slightly agoraphobic now, I’m reluctant to attend any classes at the moment since my last experience (Code 209).

I hated the large classrooms (Code 210)

The three-hour exam period was a threat in the large auditoriums (i.e. nervous symptoms making me want to go to the loo) (Code 27).

While some research participants struggled with the physical environment, other people with agoraphobia struggled with the fear of being public embarrassed in a public place. One person spoke of their fear of suffering the social embarrassment of having a panic attack in front of other students, while another person feared being trapped in the social environment of a classroom when the panic attack actually happened. One individual feared that her panic attacks would be more visible in a small group environment. Finally, the fear of panic attacks and resulting social embarrassment led one individual to develop strategies to minimise their class contact.
I wanted to go to Polytech, but I found the thought of having a panic attack in front of all those people to overwhelming (Code 32).

I often felt anxious about having a panic attack in class among other people (Code 31).

I don’t like small group work, I fear that I am more likely to be visible if I have a panic attack… I hold back and won’t express my views and avoid tutorials… I have not gone on to do post-graduate university because of the ‘intensity’ of the small group work (Code 281).

I would think of how I could get in and out of classes, like turning up just before they started and just leaving straight away so that I didn’t feel there was a possibility of getting trapped among other students (Code 31).

In addition to research participants struggling with the social environment, one person commented that the style of teaching created problems for their anxiety. While the teacher spoke for long periods of time the students were forced to remain passive, which allowed the anxious student to focus on their anxious thoughts and feelings, leading to the increased likelihood of panic attacks.

In the classroom situation we have to listen to the person speaking, while we sit there being quiet. I often start to think about my anxiety levels and feeling trapped that can often lead to a panic attack. (Code 135).

The research participants’ struggle with the physical, social and teaching environment of the tertiary institution often adversely affected their educational performance. Several people spoke of their inability to concentrate, follow instructions and retain and recall information due to anxiety and panic attacks.

Self-consciousness overwhelms me. I have difficulty concentrating and following instructions because I feel so anxious (Code 24).

I started a computer degree at University but could not concentrate well enough due to the anxiety to get the grade (Code 21).

I probably would have liked to have studied, but the anxiety meant that I couldn’t retain a lot of things (Code 22).

When I attempt to study even very basic things my mind goes tense and I feel very anxious and I’m unable to relax and concentrate (Code 218).
Exams scare me to a point where my mind blanks out and I sweat, heart beats fast and I am a nervous wreck. When doing exams I fail because of high anxiety (Code 274).

One research participant stated that his educational performance was impaired due to having to take time off from his studies because of anxiety. In another case, the person’s educational performance suffered due to the avoidance of field trips, using the excuse of sickness.

I had to take time off at one stage because of my illness (Code 31).

I have avoided some activities related to study – citing sickness to miss a field trip while at university (Code 203).

While research participants often struggled with the educational environment and their educational performance one person was able to use her partner as a support person, which enable her to manage her anxiety sufficiently to attend courses. However, the requirement to have her partner as a support person often restricted her choice of courses to those shared by her partner.

I have only been able to attend courses that my partner (companion) had an interest in and also attended (Code 269).

In addition to research participants’ educational under-performance, the presence of high levels of anxiety reduced the enjoyment of post-secondary education.

Agoraphobia had a major effect on my education, especially my enjoyment of education. For example, I struggled with panic attack symptoms in lectures, tutorials and avoided field trips (Code 320).

The major consequence of research participants’ impaired educational performance has been a restriction of their life chances. One person stated that their panic attacks and resulting impaired educational performance had reduced her confidence, career chances, income-earning potential and future retirement plans. Another individual felt that their impaired educational performance had ruined their ability to study full-time, to self-study and their life in general.

I still have panic like symptoms and avoid some educational and work training situations. This undermines my personal confidence and I believe is harmful to my long-term career development, future income earning and retirement (Code 320).
Agoraphobia has destroyed my life. I can only cope with minimal stress. I can’t study full-time! As for self-study outside lectures and labs, I find this difficult because of anxiety levels. The fear of panic attacks beats the fear of failure (Code 235).

In the case of a teacher, the struggle with anxiety in the classroom led to a change in lifestyle, including her employment in the teaching profession.

I have changed my lifestyle. I am no longer able teach full-time due to anxiety. I’m unsure whether or not I’ll ever return to full-time teaching. I am looking at jobs outside teaching (Code 169).

While a number of research participants felt that their education had been ruined, some people had developed strategies to overcome their anxiety in tertiary institutions. One person gathered information and visited the tertiary institution before the commencement of her studies, which enabled her to lessen her anxiety through gradual exposure to the environment.

I have to get information and visit new places before going to them (Code 101).

One research participant learnt to manage her anxiety disorder by reducing her naturally occurring anxiety caused by full-time employment, performance anxiety and tiredness.

I felt myself getting close to ‘burn out’ during the year I undertook university studies. This was probably due to working full-time over the same period and a degree of performance anxiety and tiredness. I decided for my own sake, that if I was to undertake further tertiary studies in the future, I would do it alongside part-time work, rather than full-time (Code 104).

Some research participants simply endured the uncomfortable level of anxiety and completed their courses.

I enrolled in a night-time course at Hagley, and then last year I did an adult education writing course. When I first did these, I was anxious and felt uncomfortable at times, but I did it (Code 33).

Have just completed a polytechnic course – involving one day a week, found first 1½ hours is the worst – most days – feel very proud of myself (Code 81).
I went to University and hated everyday day of it, the panic attacks in the lectures and tutorials. I made myself finish my degree because I knew I would get a better job than the local freezing works (Code 98).

One research participant manage to arrange sitting examinations alone and undertaking less stressful work placements as a means to reduce her anxiety levels. Another person selected courses that she felt minimised her risk of anxiety.

I sat tests/exams on my own…less stressful clinical placements as suggested by tutors (Code 101).

I select courses that I believe will minimise my exposure to anxiety (Code 281).

Several research participants chose to do correspondence courses to complete their post-secondary education. While the correspondence courses enabled the person to study without the anxiety associated with attending a tertiary institution, the usage of home-based study reinforced avoidance behaviours and social isolation.

I prefer to do correspondence courses (Code 210).

I just do correspondence courses at home where I feel comfortable (Code 238).

The thought of going to school really scares me, I would have to study at home through correspondence if I wanted to go back to my studies (Code 281).

I chose correspondence school to avoid panic attacks at university (Code 31)

I was able to do correspondence courses in book keeping…(Code 37).

I do correspondence to improve my chances in the employment area, I don’t want to go back to school, I get panic attacks in places and around people, which undermines my abilities to prove myself (Code 201).
Employment

In the survey questionnaire 88% of research participants reported that they sought employment and/or were employed during their agoraphobia. Of the other research participants, 3% were not seeking employment or employed during their agoraphobia and 9% of research participants did not complete this section (Missing data).

In the survey data, of the 88 research participants who reported that they sought employment and/or were employed during their agoraphobia, 60 research participants stated that their job seeking or employment was affected by their agoraphobia, while the other 28 research participants stated that their job seeking or employment was not affected by their agoraphobia. The 28 research participants included those who stated that they simply endured panic attack symptoms and would not allow it to affect their job seeking or employment.

The table shows the effect of agoraphobia on the job seeking or employment of the 60 research participants.
Table:

<table>
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<tr>
<th>Code</th>
<th>Description</th>
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<tbody>
<tr>
<td>A</td>
<td>Agoraphobia caused me to lose confidence in my ability to gain employment.</td>
</tr>
<tr>
<td>B</td>
<td>I have been forced to go onto a welfare benefit.</td>
</tr>
<tr>
<td>C</td>
<td>I have avoided job interviews.</td>
</tr>
<tr>
<td>D</td>
<td>I have been forced to leave employment.</td>
</tr>
<tr>
<td>E</td>
<td>I have been prevented from changing my employment out of fear of leaving the safety of my current workplace.</td>
</tr>
<tr>
<td>F</td>
<td>I have been unable to seek employment (or promotion) that would have required public speaking.</td>
</tr>
<tr>
<td>G</td>
<td>I have been unable to accept employment (or promotion) that would have required travelling a long distance from home.</td>
</tr>
<tr>
<td>H</td>
<td>I have been unable to accept employment (promotions) that would have increased my responsibilities</td>
</tr>
<tr>
<td>I</td>
<td>Agoraphobia has caused me to develop a poor work history.</td>
</tr>
<tr>
<td>J</td>
<td>I have had a high turnover of jobs due to agoraphobic symptoms occurring in the workplace.</td>
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</table>

The major findings of the survey data are that 31 out of the 60 (52%) research participants lost confidence in their ability to gain employment and 16 out of the 60 (29%) research participants actively avoided job interviews due to their agoraphobia. The survey data has shown that 12 out of the 60 (20%) research participants were unable to accept employment (or promotion) that required travelling a long distance from home, and 10 out of the 60 (17%) research participants could not accept employment (or promotion) that would have increased their workplace responsibilities. Also, the survey data has shown that 14 out of 60 (23%) research participants were prevented from seeking better employment due to the fear of leaving the safety of their current workplace. The survey data has shown that 16 out of 60 (27%) research participants were forced to leave their employment, and that 6 out of the 60 (10%) research participants had a high turnover of jobs due to panic attacks occurring at their workplace. In addition, 22 out of 60 (37%) research participants were forced onto a welfare benefit due to agoraphobia and 9 out of 60 (15%) research participants stated that they had developed poor work histories due to their illness.
The study has shown that a significant number of research participants had their employment disrupted by agoraphobia. In the survey comments and interview data, the research participants spoke about the effect of panic attacks and avoidance on their employment. A large number of research participants reported a significant loss of confidence in themselves, in seeking employment, and of having value to a prospective employer. This lack of confidence and the accompanying anxiety disorder led to the avoidance of employment.

I probably could have done more for myself if had more confidence (Code 81).

My confidence is not the greatest for seeking employment due to ongoing panic attacks (Code 59).

Since the agoraphobia began I have lost a lot of confidence for applying for new jobs (Code 218).

I have avoided applying for jobs (Lack of confidence to apply for jobs) (Code 256).

I have not applied for positions that I am very well qualified for that require me to move out of my comfort zone (Code 98).

I feel that with my anxiety problems I’m no use to an employer, and my husband provides anyway (Code 297).

I felt that I couldn’t go into a job, due to my fear of having panic attacks, but I thought no, that is just giving in to a fear. That is why I tried to ignore the feelings, but it wasn’t that easy to do (Code 201).

In several cases, the research participants had poor work histories that made it difficult to construct curriculum vitae (C.V.) that would impress a potential employer. Also, research participants often felt unable to explain that an anxiety disorder was the reason for the gaps in their employment histories due to the stigma around mental illness. In addition, research participants often lacked referees for their C.V. due to their poor work histories. Therefore, the research participants’ combination of a lack of confidence in themselves, their devalued C.V., poor work histories and lack of referees undermined both their willingness and ability to seek employment.

My work history is scattered, I began as a nurse but always feared the responsibilities associated with nursing, so I’ve had varied jobs all my life mostly short term (Code 44).
Due to my disrupted work history, caused by agoraphobia, I have trouble in putting together a good C.V., also I lack confidence to look for employment (i.e. a combination of feared panic attacks, a poor work history and a real lack of confidence) (Code 320).

I lack confidence in seeking employment, especially as my C.V. has a large gap in the employment section, and informing an employer that the gap is caused by mental illness doesn’t enhance one’s job prospects (Code 320).

When I went for the interview, the lady rang up one of my references, she asked if there was anything that would be detrimental to my employability and the referee said that I get panic attacks, and I thought, that’s pretty rough, I haven’t had them regularly for quite a long time, and I don’t think they are detrimental to my employment, I can deal with them… (Code 92).

One research participant was so fearful of having panic attacks at work that she became ill. In addition, she was forced to make plausible excuses to avoid going out to workplaces where she would be forced to endure panic attacks.

The thought of going to work and having panic attacks made me ill. I would find different excuses not to go out to look for work (Code 299).

While research participants struggled to seek employment, a significant number of people were able to force themselves to seek employment that was manageable with their agoraphobia. The primary reason that people forced themselves into the workforce was economic survival. Those research participants without a partner in employment were under more pressure to return to the workforce than people who could depend economically on their partner who was in paid employment.

I had to push myself to do something, I had to support myself and I didn’t want to never be able to go out the front door again (Code 45).

I used to think, I’m never ever going to get out and now I’m not going to be able to go to work… I can’t go to work I can’t go outside, oh no, how are we going to eat (Code 92).

One female research participant found it more socially acceptable for women to avoid the paid workforce and become financially dependent on a partner, while a male research participant was unwilling not to seek paid employment and didn’t want to become financially dependent on his partner.
I didn’t have a problem leaving work, I simply got pregnant (unplanned) and that solved the problem of how to avoid panic attacks at my work (Code 144).

I would have felt very uncomfortable not working and becoming dependent on my wife (Code 203).

In some cases, the first hurdle to seeking and gaining employment was the actual interview. One research participant described how she required medication to suppress her anxiety to enable her to participate in job interviews.

I found it really hard going applying for jobs and the time I did get one it was actually my next door neighbour and I think I took a couple of tranquilliser pills for the initial interview (Code 256).

A large number of research participants stated that their selection of workplace was dictated by their need to avoid perceived panic-inducing situations. Though the research participants’ selection of safe workplaces may have reduced the occurrence of panic attacks, their career and workplace choices became severely restricted, so they often became trapped in unsatisfying workplaces and their income earning potential and employment status declined.

I consciously avoid workplaces where I know I might panic (Code 227).

When I look for a new job, I think about what I don’t want to do, not want I want to do. I don’t want a job where I will have to endure panic attacks I don’t want a job that involves too much talking and dealing with too many people, or too many meetings, too many intense situations and I couldn’t do that day in and day out – it would be too much anxiety to deal with all the time (Code 281).

My employment and career goals have been set by my agoraphobia and by what I was comfortable doing (Code 22).

I find myself only looking for part-time positions in small companies where there are few staff members (Code 210).

The agoraphobia has been at its worst these past 10-12 years. I hoped to be teaching but couldn’t (Code 190).

I found it hard to find a job that I like and is compatible with my agoraphobia (Code 114).
I had a lack of confidence and low self-esteem, so I mainly did jobs like cleaning, cooking or gardening, so I could remain in the background and avoid taking any responsibilities (Code 24).

I am currently on Cipramel tablets and attempting a return to nursing as Cipramel has increased my confidence and I’d love a ½ decent wage plus societal status (Code 44).

When research participants had successfully acquired employment in a ‘safe’ workplace the next hurdle for some individuals was actually travelling to the workplace. The three major hurdles were panic attacks occurring when people were travelling to and from work, the person’s increased feeling of anxiety the greater the distance between home and their workplace, and the lack of a supportive travelling companion.

I don’t drive anywhere due to panic attacks, so it’s hard to get to places (Code 3).

My problem wasn’t work, as it doesn’t stress me at all, but it was getting from the car park to work…(Code 35).

I had to walk to and from the bus-stop each day, which was a nightmare trying to get to work and home again. (Code 102).

The difficulty wasn’t being at work it was waiting in the Square for the bus to go home, that’s when I felt panicky (Code 31).

If a position comes up which is too far away, I feel unable to travel that far on my own (Code 162).

While research participants reported struggling with travelling to the workplace, other people reported that the real struggle for them was trying to manage their anxiety in the workplace environment. The anxiety often arose from dealing with the daily stresses of the workplace that included: the initial settling into a new workplace, the workplace environment, learning work skills, the fear of having panic attack and resulting public embarrassment, the struggle with suppressing panic attacks, an inability to relax, impaired work performance due to worrying about anxiety, handling customer relations and conflict situations, the avoidance of perceived anxiety-inducing situations and the unwillingness and inability to take on responsibilities in the workplace.

I struggled the first three days at work with anxiety. The first day I spent whole time just freaking out, not able to work, close to tears, and ended up just saying I
feel sick, I’ve got to go. The second day I did it again and ended up leaving work, calling my partner and going to a doctor, and just bawling my eyes out at the doctors, and saying, “I don’t know what’s wrong with me”, but by the third day I had sort of chilled out…(Code 92).

I find that the building, ventilation, people, stress levels, and hours all have to suit me. Therefore, it is hard to find suitable employment (Code 97).

When I was in the workforce I would be panicky because I wouldn’t know what I was doing, even though I had the ability to type, I didn’t understand other things and I would get really upset. My first job was working for Statistics and I had to put information into the computer, but also I had to use my own intelligence or common sense to figure out what I was supposed to put into the computer and I couldn’t do it, so I did one paper for a whole 8 hours trying to figure it out and I felt a failure, but I persevered and that is when I started getting really bad panic attacks (Code 274).

I was always fearful of having a panic attack at the work place (Code 31).

When I became anxious my hand shakes and people would say to me, “Why is your hand shaking?” And I would feel to embarrassed to explain it (Code 45).

I worked in a Kentucky Fried place for quite a few years where I simply endured the panic attacks (Code 105).

I was always struggling to suppress the anxiety so it wouldn’t escalate into full panic attacks (Code 31).
It’s hard to relax at work (Code 211).

I wasn’t able to do the work that well because of worrying about my anxiety (Code 207).
I am disappointed in myself that I’m not working to my best ability (Code 209).
I have discovered that I have ambition but the anxiety about performing adequately has been limiting. I know I can do well yet I hold back (Code 281).

It was stressful working with different clients – I limited the number I worked with and avoided new clients (Code 101).

It was difficult for me to cope in teaching…I would love to seek a job situation without continual conflict, which is part of teaching (Code 169).

I avoided certain situations (Code 203).

I hated attending meetings (Code 195).

I hated taking patients up and down the lift at the hospital (Code 213).
I had a lack of confidence in my abilities at the time, and a reluctance to take on increased responsibilities. Also, a reluctance to change employment, as I feel relatively ‘safe’ in my current work environments. It helps that in both my current employment, I can move around the workspace, and am not stuck in one spot all day, which was the case when working in the bank (Code 104).

One research participant described the multiple anxiety-inducing factors that affected her experience of working in a fast food outlet. The large workplace environment with the high volume of customers contributed to her fear of having a panic attack in a large public place with the resulting public embarrassment and ridicule in front of a large number of customers. In addition, she was fearful that she would be beyond the help of family and friends.

When I left school I got a job at Burger King – I was there for two weeks and I had to leave – I just didn’t like the environment, because it was so big and there were so many people coming in and out all the time that I was scared that I was going to have an attack and there was going to be all these people looking at me who didn’t know me and there was nobody there to help me through it, and I didn’t feel there was anyone I could trust to tell them what I was going through, and then I had two months off and my father actually got me a job with one of his best friends and it was good. I felt good because I knew he was there all the time, and if anything happened I knew I could go to him and say look, I’m having an attack – I just want to sit out here for a while. I always feel that everybody is going to look and laugh which is what some people do. They think you are absolutely insane (Code 67).

While research participants struggled with perceived anxiety-inducing situations in their workplace, some research participants reported formulating strategies to avoid those situations. The strategies included: the courier who uses the stairs to avoid using the lift to deliver her packages, the Nurse Maude employee whose home visits enable her to reduce her exposure to the working environments, the house cleaner who cleaned empty house to avoid others, a self-employed woman whose partner acted as a support person in the workplace, a school leaver who worked for a family member with whom they felt safe, a home-based self-employed woman who was able to stay in the safety of the family home, a woman who regularly used medication to enable her to work and one woman who simply accepted staying in her safety zone.

As a courier I would rather run up four flights of stairs to deliver a package, than try to go up in a lift, I can I do it – but it is easier to run up the flights of stairs (Code 35).
My part time Nurse Maude job enables me to stay a short time at each house (great for a agoraphobic!) (Code 209).

I did housework for people because I had the house to myself (Code 22).

I worked for my husband, I felt safer at work (Code 31)

When I left school I went to work for family member. I couldn’t cope with going to work anywhere else (Code 94).

Self-employed husband and wife home-based business, allowed me to be home (safety) (Code 252).

I find that I have to be on drug therapy to maintain employment (Code 97).

I guess I’m happy at doing volunteer work… I guess I’m happy in my comfort zone (Code 148).

While research participants struggled with pani c attacks in their workplace, some research participants reported the added struggle of deciding whether or not to inform their managers, and/or supervisors and/or co-workers of their condition in an attempt to solicit support in their workplace. Those research participants who decided to make a public disclosure often reported a negative reaction. These reactions included: stigma towards people with mental illness, lack of acceptance, lack of understanding, confrontations, and accusations of work avoidance.

I struggled with people’s negative attitudes towards mental illness (Code 201).

I find it very hard for people to accept us – as soon as you mention the words - mental illness - or they see it on a job application form, they are not so keen on you (Code 201).

I find the workforce very hard and not being able to be accepted with my illness (Code 274).

I told my employer that I was having trouble with panic attacks – but he didn’t understand (Code 92).

Confrontations with junior staff members (Code 7).

I told my bosses after three months of being at work, and they are really good with it because I’ve started going down and have had days off and they thought that I was being a bit lazy, and then I think some of my colleagues found it hard because I would take a couple of hours off in the morning just to have a wee sleep, and I would come to work and I would look fine. I didn’t look sick, and yet I’d had some time off sick and they were having a hard time coping with it. One of them really
can’t understand, because you can’t physically see something and he is very wary about what he says to me, but the others are fine, they are really good. But that is just his way of coping, he just doesn’t understand (Code 67).

One research participant reported that she couldn’t inform her employer, due to her own lack of understanding about what was happening to her in the workplace. It seems that a significant number of people in the undiagnosed stage of agoraphobia are unable to inform others of the reason for their irrational thoughts and distressing feelings.

I was a clothing machinist by trade and that was very stressful for me and quite often I had a panic attack at the job and I’d burst out into tears and all sorts of things and start shaking and goodness knows what, and I’d just get up and walk out. I couldn’t tell my employer that I had a problem, because I didn’t know myself what the problem was, so I couldn’t explain it to him at the time either, and he didn’t keep me on anyway because I used to just walk out (Code 105).

In one case, the research participant faced a severe reaction from managers and co-workers, which included a manager’s betrayal of confidential information and gossip among co-workers leading to ostracism, harassment and victimisation.

I talked to my manager about the panic attacks and she seemed to be trying to be an understanding employer. I said to her please don’t tell anyone about this illness. But she told the staff… the gossip it went right around, it was a vicious cycle, and of course it just made my anxiety worse. I went to the senior manager and said that there is one person in particular who is making my life really hard – she spreads vicious rumours about me, and everybody ostracises me and if this continues I will go further… I’ve tried to speak to the people, who were making my life hell, and they denied the whole thing and they kept denying it, even my manager denied the whole thing. But in the end I was forced to change managers, and I don’t trust anyone now, I don’t say much to anybody. I just needed help, why didn’t someone try to understand and just be kind and just let me be… (Code 274).

I have suffered ostracism by my fellow colleagues. I put on a brave face every time I go to work and do my best to ignore any harassment. I do sometimes stick up for myself which gets me further in depth of my problem as this fuels others to judge and be more nasty towards me (Code 274).

While the research participant struggled with panic attacks and the associated problems in the workplace, she was pressured to continue work by her partner.

I would have liked to have left my work, but my partner isn’t supportive of that. I get hell from him when I stay home (Code 274).
My partner didn’t understand my panic attacks, and whenever I got sick he bullied me into going to work, so I would end up going to work and putting up with this illness (Code 274).

While some research participants reported that their manager and co-workers reacted negatively, others stated that they had a positive and supportive experience from informing others. In this case, the research participant had to encourage and support others’ understanding of her to gain their acceptance.

I think why I’ve got so much support is because I’ve decided to be open about it. I’ve decided to let them see what is happening to me and that is the only way they can really understand about it. Some people don’t like it and shy way from it, but some people do try and understand. That is what I’ve learnt through all of this. I have definitely found that it is best to be open. Yes, coming out in the open is the best way I can manage it (Code 67).

Several research participants reported that they had become trapped in their workplaces due to panic attacks and associated problems. The reasons that led to their entrapment included: the unwillingness to leave their comfort zone, a feeling of being unable to do anything else, and an unwillingness to move from a workplace where their agoraphobia was known and accepted.

I have stayed in the same job, because I am in my comfort zone and tell myself that I am suited to it (Code 135).

I have been in the same job for 13 years due to a feeling that my anxiety would not let me do anything else (Code 56).

I have worked for the same company for 13 years and just moved into new positions as they came up. I have felt unable to work in a different organisation where my history of this illness was not known (Code 150).

While some research participants were able to continue to work, others were forced into unemployment. The reasons that research participants were forced to leave their employment included: the need to seek less stressful employment, the over-usage of sick leave, the need to have a break from struggling with agoraphobia, and decline in work attendance and performance.

I quit my computer job due to agoraphobia, to do a low stress electrical job…(Code 21).
I had to resign from a senior bank officer position because of my panic attacks and agoraphobia, as they couldn’t hold my position for me while I took increased bouts of sick leave. After 4 years on a sickness benefit (undertaking voluntary work during some of this period), my confidence and self esteem was left very low, with me doubting my abilities and worrying about a relapse of my agoraphobia (Code 104).

I have left both my jobs after finding I needed a break from the anxiety (Code 97).

I handed my notice in last week at work after 13 years in the same job because my work performance – and I wrote a letter to my employers – and my attendance was so badly affected by the way I was feeling over the last month, that I couldn’t justify being there. My performance wasn’t good because I was thinking, God, I’m going to have a panic attack – it is not good because I’ve got 22 people relying on me in this rest home, what if I go mad and there’s a fire and I can’t handle it, and I don’t think that is right (Code 56).

While the research data has shown the negative impact of agoraphobia on employment, some research participants reported that employment had a positive effect on their agoraphobia. One research participant stated that by forcing herself to go to work she had prevented herself from withdrawing into her home and possibly developing homebound agoraphobia. Another person reported that she was able to use part-time employment as a stepping stone to full-time employment and a better life, while another person saw her period of agoraphobia as a time out to think about what type of work she wished to do.

I have managed to hold down my job the whole time I have suffered from agoraphobia, in a way it helped me deal with it and get past most of the issues that the agoraphobia had caused me. Basically, I had to work, so this made me get up and going when I really wanted to hide away forever (Code 202).

I would choose part-time jobs that I would think that I was able to do… I gradually built myself up to be able to work in an office environment… I knew after doing that first job that I was capable of doing other things, so I kind of built myself up step by step and now I feel quite proud of myself… I couldn’t have done it in one big leap. I couldn’t have even contemplated doing the job I’m doing now (Code 281).

It has been during this period of agoraphobia that I have finally realised what work I want to do with my life and I am looking forward to looking for work, but I still have a way to go yet with dealing with the agoraphobia/panic attacks (Code 304).
Welfare Beneficiaries

In the study, 22% of research participants reported that their employment was adversely affected by agoraphobia to the degree that they were forced to register onto a state welfare benefit. The table shows the types of welfare benefits.

Table:

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<td>Community Wage (Unemployment)</td>
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<td>Sickness benefit.</td>
<td>6</td>
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<td>Invalids.</td>
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<td>DPB.</td>
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In the survey questionnaire, 22 research participants reported that agoraphobia had either prevented them seeking employment or had forced them to become unemployed. In the interviews, one person stated that the 2½ years of job hunting, failed interviews, ongoing unemployment, and her ongoing anxiety had led to a worsening of her panic attacks.

The panic attacks got worse and worse, when I was unemployed for 2½ years. My panic attacks increased due to the stress and anxiety, I tried and tried to get jobs, and went to a job clinic and looked around and I went for job interviews. I nearly got a job once, but then I missed out (Code 79).

Those research participants who were unable to acquire, or to retain employment reported that they had been forced onto a state welfare benefit.

I suffer with agoraphobia and depression and that’s got me on the Invalid benefit I’m not sure that I will ever go out to work because of these two things (Code 156).

I spent a long time on a benefit – I think it was about 28 years. I know that’s terrible. I am not sure my being on a benefit for 28 years was the agoraphobia or just a lack of confidence or whether they are linked together or not (Code 256).

The Social Welfare department put down on the computer that was I was mentally incompetent, I was incapable of doing a job (Code 201).
Due to the anxiety I do not have the confidence to apply for jobs, so I went on the
dole (Code 256).

I am still struggling with my agoraphobia – I probably won’t get employment – I’d
stay on the benefit (Code 297).

One research participant who was forced onto a welfare benefit felt categorised and devalued as
a welfare beneficiary, especially being labelled as having a psychotic illness. It appears that
people with agoraphobia on sickness/invalid benefits suffer the double social stigma of being
mentally ill and being welfare beneficiaries.

I went on the sickness benefit out of desperation, absolute desperation. There is a
lot of stigma when you go on a benefit, they put you in a category – they put me in
psychotic illness or something like that, but that’s fine. If I need something, I’ll just
do it (Code 56).

While the research participant felt the social stigma of being on a welfare benefit, he argued
that as a waged worker (and taxpayer) for 20 years, he felt entitled to state support until he had
recovered sufficiently from his agoraphobia to be able to return to work.

I think there is a lot of stigma about being on a welfare benefit, but then I think I’ve
paid into the Tax Department the last 20 years and never been on the dole, so I
don’t really care. I know there are people who are ripping it off and have been on it
for years and years. But if I use it for six weeks or two months, I am not going to
feel any stigma about it. I can hold my head up – I’ve worked really hard, I own my
own home, my own car, I hardly owe any money, I’ve worked long and hard, so I
deserve a little bit to give me a breather (Code 56).

While some research participants registered as welfare beneficiaries to receive financial
assistance, one individual who didn’t want the social stigma of a welfare benefit relied on her
parents for financial support.

I don’t like the idea of going on a benefit. When I was really, really sick mum and
dad supported me and I was at home (Code 67).

In the interviews, the research participants who were forced onto welfare benefits commented
on the daily life of being stigmatised individuals. These research participants stated that the
1991 National Government welfare benefit cuts had caused financial struggle, that welfare
benefits had made them feel like devalued persons (i.e. nobodies), and that welfare agencies
were controlling through the beneficiaries indebtedness.
The fact that the National Party cut the benefits back in 1991 did not help, and they haven’t gone back. They’ve never gone back to what they were, never, and that has hurt everyone. I seem to think that they treat us as nobodies because we’re on an Invalid’s Benefit (Code 201).

It’s a financial struggle to be on welfare, I find it a bit of a nuisance. I only wish that I could go out to work (Code 156).

They think because they are paying us, we have to do as they tell us because if we don’t, then they threaten to take our benefit off us, so that is what I hate. We have had to borrow money off them to get a fridge and a washing machine and have to pay them back, and while we were paying them back we are in debt to them, so we are therefore under their thumb, if you like, while we are paying them back. And I don’t like it (Code 201).

A number of research participants commented on the performance of WINZ as the state provider of welfare benefits. These research participants commented that WINZ was overly bureaucratic, and treated people as numbers (i.e. client numbers).

I started on the Unemployed Benefit, and then I ended up on the Sickness Benefit and now I am on the Invalids Benefit. You have to fill out papers all the time (Code 156).

WINZ are pretty pestery like when you get the mail and you think, not another WINZ letter, there is always something from them, but that’s life. It is just their bureaucratic ways of doing things, you are just a number, and all I hope is that one day when I have to fill out a form I am having a good day because if I’m not I won’t be able to fill it out (Code 56).

One research participant believed that a WINZ case manager had contributed to a worsening of her panic attacks, due to a negative attitude towards people with mental illness.

My WINZ case manager said she didn’t think that anybody with a mental illness could do a course and pass, and when I said I did it, she said you must have cheated, and I don’t believe in cheating I’m afraid, I use my own head. You get nothing from cheating and you’re not learning. She said to me that people with mental health problems have brains like chickpeas, and I thought, crumbs, how can people say that, I told her, if she is in welfare, she shouldn’t be in the Sickness and Disability Section if she doesn’t understand things like that (Code 201).

I have had panic attacks at WINZ due to the stress, so I have begun to avoid going to the WINZ department… At WINZ, they kept jabbing me about mental health issues, my body is tightening and I just try and relax, but the case manager begins to taunt me and taunt me with no, we’re not doing this, no, we’re not doing this,
you’re good for nothing. It makes me really anxious and I can’t breathe. I said you are making me angry, in other words I was the victim again, I said you are making me feel that way with your attitude… Due to the problems with WINZ, my stress has been piling on and piling on and that is when I become angry and finally break down (Code 201).

I believe that unless you understand what a person is going through, you shouldn’t be there. The case managers should be trained. There should be ongoing training programme for people who work in WINZ (Code 201).

(Author’s Note: The research participant later transferred to another branch and case manager and both her case management and panic attacks markedly improved).

Some research participants felt that people with agoraphobia were seen as too challenging for WINZ to place into suitable employment. One research participant believed that people placed on the Invalids benefit were seen as less employable than other types of beneficiaries. Another person interviewed believed that she had been allowed to fall through the cracks as an unemployable person.

I would like to give up the Invalid’s Benefit. I don’t believe I need to be on it. I was on Sickness Benefit and I did OK on that and I at least had a chance to work. While you are on the Invalid’s Benefit they just write you off as a lost cause. WINZ treat invalids as though we are basically nobodies, but unemployed people and sickness benefit people seem to have the opportunity of working. It makes me wonder if they have their targets, of so many people a month, that they target the people who they think will be easy to get employed (Code 201).

At WINZ they sort you into those who are the easiest to place in real jobs and those in the too hard basket. Then they send you to the jobs that are the easiest to fill with hard basket cases and this makes it easy for them to meet their quota. In other words, crap jobs! If you’ve been placed in the too hard basket they basically don’t spend much time on you. I wouldn’t risk taking any job from them, no way (Code 201).

I was on Welfare and I was put into the too hard basket – too hard for them to find a job for me, and I seemed to sit there for quite a long time. I was let slip through the cracks Code (256).

While some research participants believed that WINZ was not enabling them to acquire employment, other research participants were frightened that WINZ would arrange employment that would place them into situations where they feared the occurrence of panic
attacks. It seems that research participants who were forced to leave their original employment due to agoraphobia are often concerned that a return to the workplace will lead to their entrapment in a situation where they will experience recurring panic attacks.

I am sick of WINZ, I am expected to take any jobs that they think are suitable, but I don’t know whether they are suitable or not, I don’t know if my anxiety will allow me to do the work, but if you don’t take the job, they cut your benefit. What right have they got to decide what job is suitable and what job is not? (Code 201).

While some research participants were fearful of a return to the workforce, most wished to get off the welfare benefit.

I hate being on a benefit myself – I’d rather work full time (Code 201).

I want to get off the benefit. I don’t want to be on it all my life. We’re on such a low income and it limits our options, our housing, and what we want to do. (Code 201).

I’ve gone on the Sickness Benefit which is totally against me because I’m not a lazy person, I’m a get up and go and do things person, but the panic attacks have got the best of me and I can’t perform my best for someone else. I need to get myself right, so I’ve allowed myself six weeks on Sickness Benefit to try and get myself right and then approach everything new again (Code 56).

I want to get off the dole and get a job I can do, so I can feel better about myself - I don’t want to spend my life labelled as a dole bludger (Code 31).
Homebound Agoraphobia

In the study, 53% of research participants reported that they were homebound for various lengths of time due to agoraphobia, while 44% of research participants reported that they did not become homebound and 3% of research participants did not complete this section (Missing Data).

The chart and table shows the length of time that the 53 people reported being homebound with agoraphobia.

**Homebound**

![Graph showing homebound time]

**Table:**

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The survey data shows that 53% of research participants were forced to become homebound by their agoraphobia. Of the research participants who became homebound, 70% were homebound for less than a year, while the other 30% were homebound for over year. This research data shows that the individual’s length of time spent homebound tended to be of a short duration within the lifecycle of agoraphobia. While the length of time spend homebound was short, the interview data will show that it often had a major effect on the individual.

In the interviews, research participants stated that their withdrawal into the family home was an escape from the panic attacks happening in public places. One person spoke of withdrawing into the family home to escape the panic attacks that were happening at the hairdressers and doctors.

I didn’t want to go out the front door. I couldn’t even go and have my hair cut because to have to sit in a hairdressers and not being able to get out because I felt scared, and I couldn’t go and sit in the doctor’s surgery for the same reason (Code 45).

The withdrawal into the family home enabled the individual to feel safe and secure from the threat of recurring panic attacks.

It is safe and secure, when I’m at home. There is no longer the threat of panic attacks (Code 37).

One research participant described the family home as a haven of safety and security where she could relax from her forays into public places. This research participant who was struggling with anxiety in public places, was often ‘hanging out’ to escape the panic attacks and acquired relief from that anxiety upon returning to the home. This sense of relief no doubt reinforced the internal dialogue that their home was a safe place.

I had to force myself to go out, even though I felt uncomfortable because this is what I had to do to be a parent. I found it very stressful, I was hanging out to get home and just relax, home is like a haven. It still is, it is the place where I feel safe (Code 281).

One female research participant believed that it was easier for women to leave the workforce and withdraw into the family home for longer periods of time, compared to men who she believed were expected remain in workforce.
When I began to have panic attacks at work, I talked to my husband about leaving work. We worked out a budget so that we could live on his wage while I looked after the house and garden and children (Code 12).

One male research participant felt that he had to continue in the workforce, to avoid negative social judgements for being dependent on a female partner, if he became homebound.

I couldn’t leave work, my wife works… I didn’t want people to think that I had simply thrown in my job to live off her (Code 203).

A common theme among research participants was the constant fear of leaving the family home and confronting panic attacks in public places where previous panic attacks had happened. The person’s withdrawal into the family home became the ultimate form of avoidance behaviour towards the threat of panic attacks.

I think it affects everything in your life because the whole time…there were lots of times I wouldn’t go out because I was scared – I wouldn’t tell anyone the reason. I’d just say I don’t want to go, and so it becomes quite easy to avoid (Code 45).

I didn’t want to go anywhere with anyone I just wanted to stay at home all the time… (Code 269).

While some research participants were completely housebound, other individuals reported being were able to venture out and around their sections for short periods of time. In one case the individual was able to extend their safety zone by using distraction techniques.

I woke up and I thought I’ve got to ring up Buy and Sell and advertise my car, and I’ve got to clean the car, and I’ve got something else to clean up and something else to do, and it all felt like a mountain. An absolute mountain because I knew I would have to go outside for at least an hour…I put my headphones on to provide a distraction, and then went outside and did what I had to do (Code 56).

In one case, the research participant tried to draw others (e.g. hairdresser) into the safety of her home to avoid venturing out into a public place (e.g. hair salon) where she feared having a panic attack.
I would rather pay someone to come and do my hair in my house than go to a salon…I tell people that they have to come to my house, into my comfort zone, to do my hair (Code 92).

In addition, research participants often had to hide their homebound agoraphobia from family and friends. In one case, the person was able to maintain social contact with family and friends, while keeping his agoraphobic behaviour unexplained from onlookers. A persons unexplained agoraphobic behaviour may cause some social awkwardness to all parties.

Friends came over last night and later that night I had to go out and see them off… I couldn’t go past the front door, and they sort of knew, they knew and could tell there was something funny going on like why didn’t _____ come out the front door and say hooray. But I just couldn’t do it…I know that things will come up and it will always been an ongoing battle (Code 56).

One research participant who completely withdrew into the family home described herself as becoming like a hermit. The life of a hermit implied a complete withdrawal from normal social life with the resulting social isolation.

I tended to stay in and that and I felt a bit like a hermit, you know. I often think that the major thing for me was not being able to make myself go out in case I had a panic attack (Code 156).
Conclusion

In conclusion, the study has shown that research participants’ lives were affected by their agoraphobia. The research shows that 40% of research participants had their primary school education, and 43% of research participants had their secondary school education affected by panic attacks and avoidance behaviour during their school life. The study reveals that a large number of research participants struggled to perform a wide range of everyday activities due to their fear of recurring panic attacks and that the occurrence of panic attacks in specific everyday activities often disrupted their ability to do other tasks dependent on that specific everyday activity. In addition, research participants had to plan everyday activities to reduce the risk of panic attacks. The research shows that agoraphobia had a major effect on research participants’ ability to travel, whether to work, visiting family and friends or travelling overseas. The study reveals that research participants’ struggle with agoraphobia negatively impacted on their social lives and led to social isolation and alienation. The research shows that some research participants believed that the mass media’s portrayal of people with mental illness had created a negative public perception towards them, and some research participants reported suffering stigma and discrimination due to their public disclosure of having a mental illness. The study has shown that research participants often hid their panic attacks and avoidance behaviour, from family, friends and others, by regularly making excuses (i.e. lying) to avoid places and situations where they feared having a panic attack. Also, some research participants lied to protect their privacy and to avoid the social stigma and discrimination associated with mental illness. However, the research reveals that a large number of research participants did decide to disclose their mental illness, which resulted in both positive and negative reactions from family, friends and others. In some cases, the positive reaction led to close and supportive relationships, while a negative reaction led to social rejection and social isolation. Undoubtedly, the research participants’ public disclosure of agoraphobia shaped their future relationship with family, friends and others. The study has shown that research participants’ marriages and intimate relationships were affected by agoraphobia. In some cases the presence of panic attacks and avoidance behaviour could cause stress and abuse in relationships, and at other times led to a close and supportive relationship to develop between the couple. In addition, the research revealed that research participants’ parenting experience was often adversely affected by agoraphobia, especially by restricting social interaction.
between the parent and their children. The study has shown that research participants’ high levels of anxiety and panic attacks adversely affected their post-secondary education, which caused a significant number of research participants to fail to enrol, participate and/or complete post-secondary education, which affected their employment, income earning potential, and life chances. The research reveals that a significant number of research participants had their employment adversely affected by agoraphobia. In some cases, the research participants were forced out of employment onto a welfare benefit. These research participants suffered the double social stigma of having a mental illness and being welfare beneficiaries. Finally, the study, showed that a large number of research participants suffered the most socially disabling experience of all - homebound agoraphobia. The research participants’ experience of being homebound was often the most distressing and disabling form of agoraphobia and led to social isolation, a downward spiral into depression and robbed them of valuable social support that existed beyond the safety of their home.
Chapter 6  

Findings Chapter (Part 3)

The Social Interactions that Contributed to the Management of the Symptoms of Agoraphobia

In Findings chapter (part 3) the study presents research participants’ personal coping mechanisms that contributed to the management of the symptoms of their agoraphobia. The chapter begins with research participants using personal coping mechanisms (e.g. flight) that reinforced their avoidance of panic attacks. In addition, some research participants are shown to use alcohol to suppress their panic attacks in public places and situations, which can lead to other health problems. The chapter presents research participants experience’ of labelling and learning about their panic attacks and avoidance behaviours, which leads to their awareness of having a mental illness. The chapter then explores research participants’ usage of the Internet to acquire further information about this mental illness. The chapter shows research participants’ encounters with health professionals and explores the role of treatment programmes and medication. Also, the chapter presents research participants’ accounts of the importance of social interactions (e.g. companions and support groups) in managing their agoraphobia. The chapter then presents research participants’ personal experience of the role of faith and spiritual experience in successfully managing their panic attacks. The chapter concludes with research participants’ descriptions of the emergence of a post-agoraphobic identity following the successful management of this mental illness.
Personal Coping Mechanisms

While the research has shown that the research participants struggled with both their agoraphobia and its effect on the various aspects of their social life, most also struggled to develop a coping strategy for their ongoing panic attacks. All research participants reported that their initial coping strategy for panic attacks was the avoidance of the place or situation where the panic attacks occurred. Unfortunately, the persons’ strategy of avoidance of where they feared having panic attacks led to social withdrawal from these places and situations.

I just avoid, avoid, and avoid. I can manage the panic attacks when I avoid situations, through not going, avoiding the situation, that’s how I can control it. I just completely avoid it. I haven’t been in a lift for 20 odd years (Code 35).

I used to try and work things out so that I didn’t have to go anywhere. I just didn’t do anything I just avoided. That was fine for me up until a point (Code 41).

I think family got a bit annoyed about it, especially not going places and I even stopped visiting my mother. I would ring her instead. I used to have people here, like family and that, and that was fine, but I never went to their place or anything (Code 41).

I was watching Fear & Loathing in Las Vegas – I can’t watch really mind-tripping movies – I was watching that one and I’d already seen it, but for some reason it was just really intense, and I thought oh my God, I’m having a panic attack, so I got up and went running out (Code 92).

I would leave early, or I would wait till the last minute before things started so that there weren’t too many opportunities for lingering and I still avoided some social situations. When I go to parties, I get edgy, so I don’t go to them very often, so if there are about 100 people standing around talking, I just panic and then I’ll drop the food and I’ll just go (Code 281).

Several research participants reported using distraction techniques as a coping strategy. In this strategy the individual tries to disrupt and suppress their anxiety-inducing thoughts with other thoughts. People would often use a distraction technique that had worked during a preceding panic attack. The person would then become reliant on the distraction technique to manage their panic attack. Some of the distraction techniques included: counting, drinking water, writing and reciting affirmations.
It is helpful to be doing something where your mind is distracted, rather than just sitting there and thinking I wish this would finish so I can get out of here. (Code 22).

I’ve done counting to take my mind off it. I have found that the more you think about it, and try to get out of it, the worse it gets (Code 256).

Counting works for me, I’ll just go how many books are on that bookshelf? And I’d count them (Code 92).

I was waiting on my friends and began to feel panicky, so I had to go to a cafe and have a little drink of water. Having a drink of water acts as a distraction. It stops me thinking about how bad I’m feeling (Code 256).

When I was on the bus and I began to feel panic symptoms I would take out the piece of paper and pen that I carried all the time and would write about anything to take my mind off the impending panic attack (Code 31).

I quite often do talk to myself mentally, and I find that is one way of controlling my anxiety. I give myself affirmations, I keep on saying them to myself, and I do find that helps me. You can say it as many times as you like throughout the day, you’ve got to get your subconscious mind believing, you are programming your subconscious mind and believing, so once you programme your subconscious mind it will get easier. I’ve still have a lot of negative thoughts that I’ve got to try and get rid of, so I am working on the affirmations… Agoraphobia still sort of runs my life a little bit even now, even though I know as much as I do now, it still tends to run my life a little bit. There are still things I won’t do, I still have trouble riding on buses and I still have trouble riding in cars, I mean I will ride in them as long as people don’t go too fast for my liking, funnily enough they might only be doing 50 kilometres/hour and I start to panic at anything over that, and if they whiz around corners and things like that, I tend to get a bit upset…It still tends to rule my life, so that is when the affirmations come into play, I pick out 1 or 2 sayings written in the book that I like. I suppose that I am a bit of a spiritual person really at heart, but it was just that these were in the book and I just copied them out… I sit in the chair and try and relax a little bit and start saying them. It does pay to relax a little bit. I get terribly distracted, and if I start to feel anxious I start to say my affirmations and I find them quite effective for me. I think we all have our own way of dealing with things and that is one way that I find helps me and gives me comfort and that is the reason I do my affirmations (Code 156).

One person stated that her coping strategy was to take ‘time out’ from her hectic lifestyle. Also, the person read to increase her knowledge about agoraphobia and its effective management. It seems that the modern (super) women’s increasingly hectic lifestyle increases her daily anxiety as she attempts to complete a multitude of tasks in a limited time frame.
When I have one or two bad days of feeling just a bit anxious, I need to back off a bit and take it easy and pamper myself a bit, and it comes right. I try to get more sleep and stop pushing myself too much at those times when I am feeling anxious. I have to stop thinking that I’m superwoman, and accept that everybody gets tired and anxious, and everybody can let it get bad. I guess you learn that as time goes on as you read more and increase your knowledge (Code 148).

Another person reported that her coping strategy involved planning a travel route where she could stop at ‘safe’ places for timeout from the panic attacks.

I do have other coping strategies, I remember when I was driving I was thinking, I know a woman who runs that garage or I know a man in that shop, I could stop at any of those places if I needed to…You actually plan your route according to safe places you can stop (Code 269).

One person reported that having a travelling companion with them during a panic attack was helpful in their management of the panic attacks, in the sense that the companion could provide comfort, reassurances and support.

I think something that helps me when I’m having an attack is someone always being there – I hate being alone, I absolutely hate being alone when I’m having an attack, whether it is a friend or my partner or anybody, I like them to be there. It’s a comfort to know that I am going to be alright and they are there to talk you through it (Code 67).

Several research participants reported using legal and illegal drugs, such as cigarettes, cannabis, and alcohol to suppress their anxiety and panic attacks. One person argued that the panic attacks drove her to search for a coping strategy that would enable her to survive the attack. The research participants’ search for, and development of coping strategies seems to arise out of the desperation and need to survive, which is triggered by the fight/flight response inherent in panic attacks.

I use cigarettes to help with panic attacks, but am at present trying to give up smoking (Code 201).

With anxiety, you know, you will either use drugs, you’ll smoke cigarettes, you’ll take cannabis, you’ll do anything to try and relieve the symptoms. That is what I thought to myself, I wonder if a little wine at night would help me. And then I thought, hang on a minute, there is alcoholism in our family, so I thought, no, then I thought smoking, but I hate the sight of cigarettes, so I still had to keep looking. You will find something to help your anxiety, it is an in-built thing in us, if are
frighten, it is self-survival. That is the mechanism, but unfortunately it is out of control when it gets to how we’ve experienced it, because there is too much happening (Code 108).

While some research participants developed strategies to cope with panic attacks, some people simply endured the panic attacks in the public places or situation, due to the lack of having an effective management strategy. In some cases, the endurance of anxiety and panic attacks acted as a form of forced exposure without the accompanying anxiety management strategies. Therefore, the person’s forced exposure to, and endurance of panic attacks in public places and situations did not lessen the frequency or intensity of the panic attacks because the person lacked a strategy to deal specifically with the thoughts and feelings causing the panic attacks.

I think I only gave in once to the panic attacks… I felt really terrible enduring the panic attacks but I didn’t give in to them again (Code 22).

If you had to be there and you can’t get out of it, you know you are going to be really, really anxious, but you control it. I had to go to my uncle’s funeral about 8 years ago and it was right over the other side of town and I said to _____, “Oh God, I don’t know about this”, and he said, “You’ll be fine, all your family is going to be there, you’ll be fine”. I couldn’t go into the chapel, I stood at the back with an aunt, and I knew I was shaking and anxious and stuff like that, but I got through it and once I got through it we went and had a cup of tea, I was fine (Code 41).

I sort of just have to push myself, it is only me because I am the only one who can do it, so I did do that and I did get highs on it, sort of my little achievements (Code 89).

Several research participants stated that having a personalised coping strategy often hindered the usage of medically approved techniques (i.e. cognitive behavioural techniques). The person developed a reliance on the personalised coping strategy in a crisis situation (i.e. having a terrifying panic attack), that discouraged them from using a new and untried coping strategy. In most cases, the research participants preferred to use a partially effective personalised coping strategy that was known to have some effect on suppressing the panic attack, than use a medically approved technique, that simply promised better management results.

I had developed my own personal coping strategies, which sometimes work for me, but now I’ve been trained to approach it differently through one of these (Anxiety Disorders) courses, but when you are actually in the situation you are so tempted to use the old and trusted method than the new breathing method, so the breathing goes out the window, until I sort of settle down and then I can start to do my
breathing again. I think we tend to get into some bad habits don’t we, and if it works once in that situation and gets you settled down, it is very hard to let go of it. Even if it is detrimental, as long as it works there and then. This makes learning and training a little more difficult, as well as trying to put it into practice because of that, especially on a bad day, and then sometimes on other days I am quite all right (Code 22).

One person read various articles on agoraphobia to acquire ‘tips’ to manage her panic attacks. The more public information about panic attacks and their management in the mass-media the greater the chance that people will learn medically approved management strategies than developing flawed personal coping strategies.

I read articles and things about agoraphobia, it helped to learn all the little hints and tips and all those little things (Code 89).
Alcohol Usage

In the study, 36% of research participants stated that they used alcohol to suppress their agoraphobia. The table shows the frequency of alcohol usage by the 36 research participants who used alcohol to suppress their agoraphobic symptoms.

Table:

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<tr>
<td>The person regularly used alcohol to suppress their agoraphobia</td>
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</tr>
<tr>
<td>The person excessive usage of alcohol to suppress their agoraphobia led to dependency problems</td>
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In the study, 9 out of the 15 (60%) men stated that they used alcohol to suppress their anxiety, compared to 27 out of the 85 (32%) women who admitted using alcohol to control their anxiety. One male research participant argued that it was more socially acceptable for men to drink than women in public places and situations. Another person believed that men would prefer to use alcohol than to admit to having an anxiety disorder. Finally, one male research participant stated that he believed that men use alcohol to hide their emotions (i.e. anxiety) from others.

I use to go to parties and drink my self under the table, especially with ‘boys’ drinking games at parties (Code 31).

I think men are too scared to admit to their fear, so they drink until they don’t feel the fear anymore (Code 185).

It’s that stereotype of real men don’t show their emotions that keeps a lot of men from sorting out their anxiety problems. They would rather get pissed than admit they have an anxiety problem (Code 150).

Several research participants stated that their usage of alcohol was as a form of self-medication. One person reported that she would use alcohol prior to entering places and situations where she feared having a panic attack, while other people stated that they would use alcohol to settle their nerves in social situations (i.e. parties).
If I have to go somewhere, I would have a glass of wine or something before I went. It was like a self-medication. I wasn’t taking drugs or anything (Code 41).

I use to drink and smoke to settle my nerves, when I was panicky it was relaxing, but it became a crutch, but I found giving up not that hard – I used the patches… (Code 256).

I was a regular drinker, I drank about once or twice a week and in the weekends, just when I was going to parties and stuff like that. I would drink to stop feelings of being panicky (Code 274).

One person argued that alcohol enabled her to have the confidence to deal with her panic attacks, while another person saw alcohol as an escape from her panic attacks. Another person stated that alcohol enabled both an escape from the panic attacks and allowed them to enjoy places and situations (i.e. the garden), where they had previously felt anxiety and had panic attacks. It seems that, the usage of alcohol enabled people to have the confidence to function in places and situations where they feared having a panic attack, as well as making them feel better about themselves at the same time.

I turned to alcohol to give me confidence to deal with the panic attacks (Code 274).

I use alcohol as a escape from the panic attacks I didn’t speak to anyone about the panic attacks, it was just something I was hoping would go away and alcohol was the only way that I knew to make myself feel better (Code 92).

On Sunday night I sat down and actually had a whole bottle of wine, which is unusual for me and it was great, it was wonderful, it was utopia. It was just great – I could go outside, stand on the front lawn for an hour, and it wouldn’t bother me… Alcohol is just a way out, otherwise you think you’re go mad (Code 56).

One person reported that he had to keep both his agoraphobia, and his excessive drinking to suppress the panic attacks, hidden from his employer. Another person stated that she would use alcohol to get through work-related meetings.

I had to keep my panic attacks and using alcohol a lot, hidden, so I wouldn’t lose my job. It became evident once or twice, but generally I kept it pretty hidden. Alcohol is very good at hiding things (Code 56).

If I had to go out to a meeting or something I often used alcohol, so I didn’t feel so anxious, and that was often enough to get me through (Code 45).
Another person stated that the usage of alcohol was only partially effective in suppressing the anxiety, and when the effects of the alcohol wore off the anxiety returned. However, the person argued that the alcohol allowed time-out from anxiety and that the side-effects (i.e. hangovers) of alcohol were less distressing than the panic attacks.

The alcohol was partly effective, it took 90% of my anxiety away, I looked at it at that stage as my only coping mechanism and it was a break from feeling the anxiety all the time, from feeling that my mind was spinning. The alcohol gave me time-out from anxiety, but it had its own side effects. The hangovers and waking up the next morning and the anxiety was still there, but the hangover was just so minute compared to my anxiety (Code 93).

Several research participants became worried that their usage of alcohol to suppress their anxiety would lead to alcoholism. In one case, the person had a family history of alcoholism, which increased their fear of developing a dependency on alcohol. Another person deliberately restricted his access to alcohol to avoid the downward spiral back into alcoholism.

I was worried that I might become too dependent on alcohol, because my father was an alcoholic, and my brothers and sister had drug and alcohol issues, so I felt that I had a really strong family history of alcohol abuse (Code 45).

I won’t have any more than one bottle of wine in the house because I would just be back into it again (Code 56).

In some cases, research participants developed a dependency on alcohol to suppress their anxiety symptoms. It appears that these research participants would have struggled to function due to their panic attacks, while using alcohol as a form of self-medication enabled them to function. However, the regular usage of alcohol to enable the individual to function meant that alcohol became a crutch for the individual.

I used alcohol to suppress my anxiety, but I became an alcoholic, now recovered for 11 years (Code 133).

I use drinking as a crutch (Code 41).

I use to used alcohol a lot to suppress my anxiety symptoms I was what I call a functioning alcoholic. I worked full-time. I worked 7.00 am to 3.00 pm each day six days a week, I’d get home around 3.20 pm and by 3.25 pm I’d have had a tumbler of wine and I’d drink a cask a night – three litres of wine a night just to drown it out. The next morning I’d wake up and feel like a run-over jam tin – you’d
just feel awful and you would go to work and you’d keep going and you just functioned – you just do what you have to, but as soon as I got home and I started to get those feelings again, I think, right it’s time for another wine. And I just sank into the bottle again. At the same time the body was breaking down, the liver was had it. I bloated out – I was so big and really fat, which is not my build at all. (Code 56).

One person reported that alcohol effectively suppressed his panic attacks. However, the usage of alcohol led to alcoholism, which merely replaced anxiety as the disabling factor in his life. In addition, his attempts to stop drinking meant that he had to abandon the only effective coping strategy he had for suppressing panic attacks. The individual became trapped into a cycle of alcohol dependency, the feared return of agoraphobia, the lack of a coping strategy and a return to using alcohol to suppress his anxiety.

While the alcohol helped me to function at a basic level, it limited what I could do - I’m a nurse aide, and I’d have to give out insulin and when you’re sitting and shaking, you’re not relaxed and the patient isn’t relaxed. It definitely affects your work, and writing progress notes was pathetic. The alcohol fixed the anxiety problem, but then the alcohol became the problem (Code 56).

I was dependent on alcohol to take my anxiety away, and I knew it was something I couldn’t do all the time, I knew that something had to stop, but for the meantime it was the only way I could cope (Code 93).

It’s been hard to stop drinking when it helps to suppress the anxiety symptoms. I mean, it is hard not to turn back to the booze (Code 56).

While some research participants chose to use alcohol to suppress their anxiety, some people used marijuana instead. One person reported that marijuana triggered her panic attacks, which were more intense and harder to control than other panic attacks.

I had to stop to smoking dope because every time I had some, I had very intense panic attacks, and the panic attacks would go on for ages. One time I had something to smoke and I just couldn’t stop the panic attacks, I found that I couldn’t relax and chill out. (Code 92).
Labelling and Learning about Agoraphobia

A large number of research participants reported that they did not know the name of their mental illness for many months or years. In addition, people often struggled to understand whether their unlabelled panic symptoms were a sign of a unique personal weakness, physiological problem, mental illness, social inadequacy or some other illness/disorder.

For many years I didn’t realise what I was suffering from (Code 27).

Sometimes I wonder if it is a mental illness or is it a genetic thing or is it a social thing. I don’t know (Code 45).

While a large number of people struggled to identify and understand their problem, most learnt that their problem had a label - panic attack - by chance. One person learnt that she was not alone or unique in having strange thoughts and feelings when she spoke to a stranger in a public bar who had the same panic-like symptoms. Another, person learnt that her feelings had a label – panic attacks – from a co-worker during a workplace conversation, while another person learnt that others have panic attacks at a art group.

I was at a bar one night and I met a guy who started talking to me. He spoke about having these ‘symptoms’ and I was like wow! - he sounds exactly like me, yeah! (Code 93).

A lady gave me a book about people who have panic attacks. I read it and thought this sounds like me, you know I’ve had that happen to me. I think that is the scary part, thinking that you are the only one like it (Code 105).

I was just talking at work one day and saying how when I went somewhere, I felt all fluttery and she (co-worker) said you were having a panic attack, and hyperventilating. I said, God what’s that, and she said to me that I should go to my doctor and you can be referred to a psychologist, which I did (Code 35).

I met a lady at art class and she had the same sort of things (Code 22).

While some research participants learnt to label their strange thoughts and feelings as panic attacks through conversations with other people, some research participants learnt about panic attacks and agoraphobia through newspapers, leaflets, magazines, books, libraries, radio talk-back, Citizens Advice Bureau and the Internet.
I didn’t know what agoraphobia was until one day we got the Wellington paper and there was a write-up by this lady and she was at Massey University doing some course, and it said how she panicked going shopping and different places. She said that every so often when she was like this she had to take antidepressants to allow her to lead a full life and when I read it then, that is when I first heard about agoraphobia. I’d never heard about it before then, and that was the first time – I’ve still got the cutting – I read it and said to my husband this is what I’ve got (Code 33).

I think I read something that sounded like what I had. It might have been a magazine or something. That is how I learnt that it actually had a name (Code 256).

I was in the library one day and there was a leaflet on the counter and I picked it up and there was a write-up about agoraphobia. It had some phone numbers at the bottom… I then got books about it, I got quite a bit of information about it from reading books about it. I think it does help a lot, because I was quite bad at that stage and felt at that stage it was very helpful (Code 33).

I bought a book called Panic Attacks. I remember buying it at a London bookshop, and I read that when I was in London, so that really gave me in insight into what I was actually going through. I started to kind of understand it. I’ve got one up there called Panic Attacks and then I’ve got one up there called The Power of Now – the books have just been one of the things that have helped me (Code 93).

I’ve done lots of reading. I’m not a big reader unless it is something really interesting, but of course when it is your daily life and you’re trying to function, yes of course you’re interested. I’ve just read all over the show. I’ll pop into the library to look at something and I’ll quickly pop over and have a look at something or other, but I don’t sit there reading for ever – I just pick out the bits I want. I have done a lot of reading (Code 56).

I was listening to the Alan Dick Show (Radio Pacific) one Sunday night on the radio when somebody began talking about all these symptoms and I thought that sounds like me (Code 41).

I thought this is getting ridiculous – other people are able to go away and do things, and I’ve got to try and do something about it, so I rang up Citizens Advice and asked for places where I could get some sort of counselling. They gave me a few different names. (Code 89).

I rang the Citizens Advice Bureau and I asked them where I could go for help and they told me to ring Princess Margaret Hospital (Code 41).

I went on the Internet and typed in panic attack, and came upon all this information. I thought, oh my God, what is this and I thought that is what I get (Code 92).
Research participants reported that the Mental Health Resource Centre and The Agoraphobic Support Group (Canterbury) were a valuable source of information on panic attacks and agoraphobia. In addition to research participants labelling and learning about their panic attacks and agoraphobia, they were able to talk to others similarly affected.

I was initially scared to go into the Mental Health Resource Centre. I was scared stiff because family and friends called me mental, and I didn’t want that label, I have psychological problems, not a mental illness. Anyway, I went into the place and I really enjoyed it. The Agoraphobic Committee and their library, the information and the tapes, and the other resources are excellent. I found the tapes pretty relaxing and not only that, the chat-sessions there are very good, they are very pleasant and it is nice for the people to meet together. I went to my first meeting at Knox Church, I was amazed at the number of people there, and it turned out that I knew one or two of them. They said I was the last person they though would have this illness and I thought the same about them (Code 201).

One person stated that the reason she sought information about panic attacks was to identify their cause and to learn how to prevent them from happening again. Another person stated that it helped to clarify their understanding of agoraphobia. However, sometimes the misunderstanding and confusion about agoraphobia continued.

Panic attacks are a darn terrifying experience, every one of them were, and you want to know what is causing it. I thought it was a physical thing, because I’d had all these physical problems. But once I knew, after I’d done a lot of reading, that it was the thoughts that were creating it, the next phase was how to turn it around (Code 108).

I actually thought that agoraphobia meant that people couldn’t go into small rooms or in a lift and things like that. I thought that was what agoraphobia meant. That was my version of what the word meant before I read about it (Code 37).

I still had that nagging doubt that there was still something physically wrong as well as mentally wrong. It has taken me a long time, I still have that battle a bit even now. I’ve been really good for quite a long time now, but there’s still that feeling if anything happens, I think is that just an anxiety attack or is it something else, there is always that doubt still (Code 148).

Several research participants reported that there were benefits from learning the name of, and information about, panic attacks and agoraphobia. These benefits included the knowledge that there were treatment programmes and support from other people with agoraphobia which reassured them that they weren’t alone or going crazy or mad.
I went and bought books, I borrowed them, I got them out of the library, all about panic, anxiety, stress, the whole lot, and I had to fill my mind up to reassure myself that was what I had (Code 108).

It was quite comforting to know that other people are suffering the same sort of thing (Code 274).

It was helpful to know that there were other people also had panic attacks. I had thought that I was the only one that had it. I went to Anxiety Disorders course and I met other people – there was a lady there who came from Austria and there was an Australian girl who was gay, and there was bloke there who was Dutch and he had plenty of attacks (Code 79).

An important piece of the learning was that I wasn’t mad I get a bit fearful of a label… I try to push the label stuff away. I guess it sort of makes me feel that it might be about madness, and I don’t think I am I know I’m not. (Code 281).

I use to think I was crazy, before I learnt that others had the same thoughts as me – I’m not alone (Code 31).

I think I felt better and I picked up quicker when I learnt that what I had had a name - agoraphobia - because I thought yes, there is something wrong, but at least I know now what it is and I can start to look for a treatment. (Code 148).

One person stated that their panic attacks could have been ‘nipped in the bud’ if they had had information much earlier in their life, also other problems associated with the panic attacks (i.e. avoidance behaviours) could have been prevented from developing as well. Another, person agreed that learning about panic attacks earlier would have made a difference, but added that agoraphobia was not spoken about in her youth.

I probably could have ‘nipped it in the bud’ the first panic attack, if I had known what was happening to me…if I had got more help then it most probably wouldn’t have continue on – I felt that the longer I went, I ended up with more problems. Following the original panic attack I ended up avoiding, you know, it just kept getting bigger and bigger (Code 105).

Had the agoraphobia been acknowledged earlier it would have made a difference - because you never heard about it, when I was a lot younger you never heard of things like that (Code 22).

One person stated that the information enabled her to feel that she had more control over the panic attacks. Another individual stated that she was able to use the information to reduce her anxiety and prevent an impending panic attack.
I think the more information you know, the better. It is like anything, the more you learn the better informed you are. I’ve learnt to relax more, and I’m able to do something about it now (Code 148).

I would use the information to help me self-talk myself out of feeling the anxiety. I would say to myself, “Now come on don’t be so silly, buck your ideas up, you know, you are going to be alright, just relax your shoulders and take a few deep breaths… I could often avoid an attack by doing this, only because of the fact that I’d learnt so much about it (Code 156).

Most research participants reported that publications on panic attacks and agoraphobia were helpful by providing diagnostic names and descriptions, as well as practical advice and recommended treatment programmes, though a number of research participants reported that they either didn’t want the label of mental illness, they mis-diagnosed themselves using the material, or they struggled to match their thoughts and feelings with the descriptions of panic attacks and agoraphobia in the literature.

I didn’t ever want that label of having a mental illness. I think it was because I didn’t think I had a mental illness. I kind of thought I can analyse and I can be rational, so I can’t have a mental illness. I still think it is OK for other people to have the label, it’s that whole thing about mental illness – you say it is OK for everyone else to have a mental illness, but I don’t want that label. So even though you can rationalise and say it is absolutely fine for everyone to have it, you judge yourself for it (Code 45).

I actually self-diagnosed myself because I did a lot of reading and looking at those symptoms that I had in specific situations (Code 281).

I read a lot of leaflets and magazines and books about anxiety disorders. But I wasn’t sure about whether my symptoms completely matched agoraphobia or social phobia. I sometimes think that the labels make these anxiety disorders look like the symptoms are fixed and can be put into boxes, when my symptoms tend to float around, from one box to the next (Code 31).

I had some sort of agoraphobia, but I often felt that the books didn’t quite describe me. I’ve got a fear of being harmed which is slightly different, and that fear is when I’m out – I’m still trying to figure it out (Code 45).

One person reported that she actually increased her ‘list’ of mental health problems by reading mental health related publications and another person stated that testimonials increased her anxiety about her ability to overcome her panic attacks.
I would read books that I would read stuff into it, I guess I internalised it quite a bit, like thinking I had attachment disorder and all those sorts of things, which wasn’t helpful (Code 281).

All these testimonials about you’ve lived with it for ten years and all this, and I thought, oh my God, I’m never going to get over it (Code 92).

One youth argued that there wasn’t a lot of literature on panic attacks and agoraphobia for the younger person. The youth commented that the published material was dominated by scientific jargon and overly intellectualised words. It seems that, there are a number of publications with stories of adult experiences of agoraphobia, however, there is a lack of children’s or young person’s books that talk about panic attacks and agoraphobia.

I’ve been to the library lots trying to get different books. The books that I find have big words, massive words that don’t make any sense, a lot of scientific jargon that doesn’t help. There are no books from personal experience, I thought I could find something to give me confidence. There are no books at all that someone younger than me could read and say, Hey, I can relate to this. There’s nothing out there for anybody my age or younger. I wanted to feel like I wasn’t the only one and I think my sister felt the same and my mother, she wanted to let us know that we weren’t outcasts. But we felt there was nothing out there to help us (Code 67).
Internet

In the study, 55% of research participants reported that they used the Internet, while 37% of research participants stated that they did not use the Internet (i.e. lack of access) and 9% of research participants did not complete this section (Missing data).

Of the 55 research participants, 25 research participants stated that they used the Internet to assist in the management of their agoraphobia, while 30 research participants stated that they did not use the Internet to assist in the management of their agoraphobia.

The table shows the usage of the Internet by the 25 research participants.

Table:

<table>
<thead>
<tr>
<th>Code</th>
<th>Internet Usage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>Searching for information on agoraphobia.</td>
<td>18</td>
</tr>
<tr>
<td>B</td>
<td>Locating information on medications.</td>
<td>12</td>
</tr>
<tr>
<td>C</td>
<td>Accessing on-line support groups for people with agoraphobia.</td>
<td>7</td>
</tr>
<tr>
<td>D</td>
<td>Reducing social isolation.</td>
<td>6</td>
</tr>
<tr>
<td>E</td>
<td>Using chat-rooms to talk to other people with agoraphobia.</td>
<td>3</td>
</tr>
</tbody>
</table>

The survey data shows that a number of research participants use the Internet to search for information on agoraphobia, medications and to gain social support (e.g., the majority of Internet users were in the 20 to 30 age groups). The increase in the presence of personal computers in the family home and the readily accessibility of the Internet in family homes may contribute to an increase in the number of people with agoraphobia using it as a source of information and support.

In the survey comments section and interviews, several research participants commented on the multitude of uses that the Internet played in helping to manage their agoraphobia. Several people stated the Internet enabled them to increase their knowledge about agoraphobia and recommended treatment programmes.
I had just been diagnosed with agoraphobia and told that cognitive behavioural therapy could be helpful... so I looked up cognitive behavioural therapy on the Internet to learn more about it and to see whether it was worth following up on (Code 92).

I think the Internet site did have a major role in building my knowledge about agoraphobia (Code 92).

I tried to educate myself a bit using the Net (Code 91).

In addition to research participants searching for information on agoraphobia, some people used the Internet to check out medications, their possible side effects and alternative treatments. The Internet seems to provide a larger volume of information in less time, compared to other public information providers (i.e. libraries).

The doctor prescribed me anti-depressants, so I went on-line to check them out and find out about any dangerous side effects (Code 31).

I searched the Internet for information on treatments for agoraphobia, because there wasn’t much in the public library (Code 9).

In addition to people searching for formalised information on the Internet (i.e. medical definitions of agoraphobia and information about different medications and treatments), some individuals explored various websites searching for personal stories on these subjects. The Internet enables a large number of people with agoraphobia to ‘publicise’ their personal stories, who would normally be unable to use other traditional forms of publishing, such as books and journals.

I thought I would like to learn about other people’s experiences by reading their stories (Code 92).

In addition to research participants searching for personal stories about agoraphobia, the Internet enabled one person to locate age-appropriate material.

I went on a web-site that had a lot of personal stories from people of my own age, young people (Code 9).

While one research participant looked for personal stories, another person searched for people to chat to about their experience of agoraphobia. One person reported that the Internet chat-rooms allowed her to retain social contact, while she was homebound. It appears that research
participants who were homebound were able to reduce their feelings of social isolation through using the Internet.

   It was sort of comforting being able to talk to people – I like to talk to people– you can go in there (i.e. chat room) and say you are having a bad day and that you’re not able to leave the house – I think it did play a major role because I had nothing else (Code 92).

In addition, the Internet websites enabled research participants to chat to people who were of a similar age, the same gender and shared common interests.

   I went on a web-site – Panic/Anxiety Disorders – that had a list of people according to age and gender, who had written a little bit about themselves and their interests. Also, some people stated whom they wanted to talk to, a boy or girl of similar age and interests. It was wonderful for a person trapped at home, as long as you didn’t get too involved, which wasn’t hard since most seemed to live in the United States (Code 9).

While, some people reported that the Internet reduced their social isolation, one person argued that the long-term usage of the Internet chat-rooms undermined their willingness and ability to challenge their fear of panic attacks in public places.

   The chat-rooms were fine at the start – I wasn’t so lonely. But as time went on, it reinforced my avoidance of going out into the public to meet (Code 199).

However, one person argued that Internet chat-room conversation caused him to go out and meet people in public places.

   I began talking to a girl on the Net and she encouraged me to meet her at a coffee shop for a date, so I had to go out (Code 222).
Medical Intervention

In the study, 91% of research participants reported when they had their first major panic attack and when they sought medical intervention for their agoraphobia. The graph and table show the length of time that elapsed between each research participant’s initial panic attack and when they sought medical intervention.

Table:

<table>
<thead>
<tr>
<th>Description</th>
<th>Number</th>
</tr>
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<tbody>
<tr>
<td>Less than 1 year elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>31</td>
</tr>
<tr>
<td>1 to 5 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>15</td>
</tr>
<tr>
<td>6 to 10 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>18</td>
</tr>
<tr>
<td>11 to 15 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>6</td>
</tr>
<tr>
<td>16 to 20 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>5</td>
</tr>
<tr>
<td>21 to 25 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>6</td>
</tr>
<tr>
<td>26 to 30 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>3</td>
</tr>
<tr>
<td>31 to 35 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>4</td>
</tr>
<tr>
<td>36 to 40 years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>2</td>
</tr>
<tr>
<td>40+ years elapsed between the initial panic attack and the seeking of medical intervention.</td>
<td>1</td>
</tr>
</tbody>
</table>
The study shows that 31 out of the 91 (34%) research participants sought medical intervention within one year of their first major panic attack, while 15 out of the 91 (16%) research participants sought medical intervention 1 to 5 years after their first major panic attack. In addition, 18 out of the 91 (20%) research participants sought medical intervention 6 to 10 years after their first major panic attack, while the other 27 research participants reported seeking medical intervention ranging 10 to 40+ years after their first major panic attack. These findings show that about 1/3 of research participants seek immediate medical treatment, about 1/3 access medical treatment in the medium term and, about 1/3 acquire medical treatment in the long term.

In the survey questionnaire, 7 out of the 15 (47%) men and 15 out the 85 (20%) women stated that they did not seek medical intervention from a health professional, because they did not want to show emotional weakness. In one interview, a research participant suggested that the reason studies show that men are less affected than women by agoraphobia was that males tend to avoid health professional because it threatens their macho self image.

If you are a Kiwi male you know that if you’re having problems with anxiety, and you tell others, then you’d be seen as a wimp and that includes a male doctor (Code 56).
Health Professionals

In the study, 76% of research participants reported having problems informing at least one of their health professionals, while 19% of research participants reported that they had no problems informing their health professional of their agoraphobia, 5% of research participants did not complete this section.

In the study, 15 out of the 76 (20%) research participants stated that their agoraphobia prevented them from visiting a health professional (i.e. fear of leaving home, using public transport, being in public places, etc).

While some research participants were prevented from seeking medical attention due to their agoraphobia, other people reported that their lack of knowledge hindered their seeking of medical intervention. In the survey, 33 out of the 76 (43%) research participants believed that their thoughts and feelings (i.e. panic attack symptoms) were a personal weakness instead of a mental illness, which meant that they saw no reason to visit a health professional. Also, 26 out of the 76 (34%) research participants did not realise that their panic attacks were symptoms of a known mental illness that affected others. In addition, 24 out of the 76 (32%) research participants were unaware that a health professional could be helpful and 41 out of the 76 (54%) did not know that treatments (i.e. cognitive behavioural techniques & medications) were available to help in the management of their illness.

While some research participants reported that their lack of knowledge hindered their seeking of medical intervention, other people reported that they wished to hide the knowledge of their mental illness from health professionals and family members. In the survey, 43 out of the 76 (57%) research participants did not want to appear to be a mentally unstable person to their health professional, while 22 out of the 76 (29%) research participants did not want to show emotional weakness to their health professional. In addition to the research participants who wished to hide their agoraphobia from their health professional, some people did not want family members to learn about their agoraphobia, by their visits to a health professional. In the survey, 15 out of the 76 (20%) research participants did not want their family (i.e. parents,
partner and/or children) to become aware of anxiety problems by arranging a visit to their family health professional.

When research participants did decide to seek medical intervention, some struggled to inform their health professional of their problem. In the survey, 12 out of the 76 (16%) research participants felt unable to describe their symptoms (i.e. thoughts and feelings) to their health professional, and 14 out of the 76 (18%) research participants were worried their health professional would not believe them. In addition to people being worried about their health professional’s ability to diagnose their ‘problem’, other people worried about what the health professionals would recommend as a suitable treatment for their ill health. In the survey, 23 out of the 76 (30%) research participants were worried that their health professional would pressure them into using medication and 27 out of the 76 (36%) were concerned about the possible side effects of the medication.

In the study, research participants commented on their initial contact with health professionals. In several cases, the person believed that their panic attack symptoms were a sign of a physical health problem.

I didn’t realise for a long time, that my panic attacks/agoraphobic symptoms were a mental health issue, thought that it was a physical problem (Code 27).

I wasn’t aware my symptoms were a result of anxiety. Initially my first symptoms resulted in GP testing for heart problem (Code 104).

I thought I had a heart problem (I had thought that since the first panic attack because of the racing heart). When the panic attacks became frequent I consulted a GP (At that time I lived in a small town) who said I was suffering from stress and to go home and rest. I did but the attacks continued (Code 169).

In most cases, the GP began their investigation by eliminating a physical cause for the panic attacks. However, some patients struggled to accept that their physical symptoms, such as heart palpitations were not a sign of an underlying physical health problem.

I went to see my doctor I had at that stage, and he checked me all out and said there’s nothing really wrong with you. There was nothing physically wrong with me; I was fit and fine (Code 16).
I when to see my GP and he checked on my heart, he obviously knew what it was, but he seemed to think it would be a good idea to check on it anyway to see that everything was fine. He then said, “You’ve had a panic attack (Code 41).

I was just so scared, I kept thinking something was wrong and they weren’t picking it up, physically, I still thought there was something wrong with my heart because I felt the heart palpitations and would skip heart beats, and the tightness in the chest, I still felt that it was a heart thing and they hadn’t picked it up. I thought it was a medical reason, not a mental health problem (Code 148).

I went to the doctor and he said straight away that it was anxiety and that I wasn’t having a heart attack, but he wrote on a wee piece of paper which I put on my fridge it was past drama and I didn’t believe it because I thought, no he’s got it wrong (Code 105).

Several people reported that their first contact with health professionals was the emergency services. It seems that a number of people with agoraphobia contact the emergency services believing that their panic attacks symptoms are a sign of a physical condition that requires emergency medical attention (e.g. heart attack).

I was admitted twice to hospital by ambulance because of my panic attacks. The St John ambulance staff was very reassuring on their call-outs to me (Code 108).

I woke one night unable to breath and with my heart racing. I thought I was having a heart attack, so I made my partner phone for an ambulance. I was told that my heart was fine and that I had had a panic attack… Several days later I had the same breathlessness and rapid heart beat – I panicked on top of my panic attack – what if they had been wrong and I did have a heart problem. A part of me tried to say to myself that this is a panic attack, but the other part of me said what if I’m wrong and I die, so I called the ambulance (Code 31).

One person reported that the emergency service personnel were usually comforting and reassuring of them. However, the health professionals’ reassurances were interpreted as being dismissive of the seriousness of the symptoms.

I have told a Psychiatrist and nurse at Psychiatric Emergency Service. They said very little. I’m always being told “How good I am”, “I’m a lot stronger than I think”, and “Patients in hospital would be on 6 times your medication”. Those sort of comments. Funnily, enough I feel rotten at times especially when I’m worrying about the future… many a time I don’t feel strong and am suicidal (Code 213).
While some research participants reported that their first contact with health professionals was through the emergency services, most sought medical attention from their general practitioner, (GP) however, some people reported that their panic attacks often disrupted their visit to the GP. The panic attacks often affected the individual’s ability to travel to the doctor, wait in the waiting room or meet the doctor.

I struggled to walk down the road because of panic attacks, so I couldn’t go to the doctors, and a lot of doctors don’t seem to want to do home visits unless you’re old, infirm and dying (Code 31).

When I go and wait at the doctors waiting room I want too hurry up and get it over with. I feel really anxious and if more than 5-10 minutes pass, I feel like just walking out. (Code 279).

I feel like running away in the middle of an appointment (Code 190).

When research participants did visit their GP they often struggled to inform them of their illness. One person reported that her shyness inhibited her discussing her thoughts and feelings with the family doctor. Another person was frightened that a disclosure of her symptoms would lead to her being labelled as mentally ill and institutionalised, also one individual feared that she would be seen as a unfit caregiver for her children.

I had always been very shy and this stopped me form talking to my doctor about what was happening to me (Code 156).

I thought I’d be labelled as crazy and tossed in a loony bin and the key thrown away (Code 32).

I was afraid that my doctor would think I was unable to properly look after them (Code 266).

One person reported that she had difficulty in describing her symptoms to her doctor, due to the generalised nature of her symptoms, also the person struggled to accurately report her thoughts and feelings to her doctor. Another person reported that her first doctor had been unable to properly diagnose her panic attacks, which delayed her receiving appropriate treatment. Since health professionals are heavily reliant on their patients’ self-report of symptoms to make a diagnosis about a mental illness, an incomplete or inaccurate self-report can lead to an inaccurate diagnosis and an inappropriate course of treatment.
I found it difficult to describe my symptoms – there were many. It was difficult to explain how and what I was feeling (Code 101).

My new GP told me that I should have got treatment when I first started having the panic attacks. I tried to explain to my first doctor, but I couldn’t explain my symptoms to him and he didn’t understand what was wrong with me. I think that 4 years elapsed before I receive the right treatment for it. My doctor reckons that it is much harder to get over it, when you’ve not had treatment for that length of time (Code 244).

Several research participants reported that their health professional did not believe that they had a real illness. One person believed that health professional did not believe she was ill, because she looked too healthy.

The health professional said it was all in my head (Code 41).

The health professional had no understanding of my problem (Code 56).

I wasn’t believed (Code 190).

I always looked bright and in good health. I felt that there never looked to be anything wrong with me (Code 37).

Another, person reported that her doctor appeared puzzled by her symptoms, which made the person feel that she was stupid for reporting such symptoms.

I tried to explain my panic symptoms to my doctor… She is a lot younger and she has never been subjected to someone like me. She was totally naïve to it and she didn’t give me much sympathy, she was more puzzled by it and sort of like gave me the impression that I was very stupid (Code 274).

A significant number of research participants stated that their health professional appeared to be ignorant about agoraphobia. In some cases, the health professional misdiagnosed the agoraphobia as depression and prescribed Valium and/or anti-depressants. In addition, some health professionals were ignorant of treatment programmes for people with agoraphobia.

I felt that in the early days a lot of the doctors didn’t understand it (Code 33).

My previous GP couldn’t comprehend my feelings or let me talk about the symptoms (Code 201).
If there was a problem when I first went to the doctor, it was getting across to him (a locum) just how I felt. He suggested that I go for “long walks”. I didn’t find this at all helpful. It wasn’t until my GP returned that I felt I was being heard, and I asked to see a counsellor as I needed to talk to someone, and I was sent to see a psychiatrist who diagnosed agoraphobia (Code 75).

I attempted, on one occasion, to seek help from a GP. My usual GP was on leave and a locum stood in. I explained my problems to this person and he practically laughed at me and said it was all in my head. This GP was around his mid fifties to late sixties. This is going back 10 years ago… (Code 274).

I stopped trying to get help after my first year of agoraphobia as no doctor or counsellors had anything more to say to me except I should just relax and stop working so hard (Code 21).

Well, they just think you’re a wee bit depressed at the moment. And that you will get over it (Code 35).

When I first had panic attacks and agoraphobia my GP didn’t seem to know what I was talking about. It was all put down to nerves and I was given Valium (Code 218).

GP did not really help. GP kept treating me for Depression – Not Panic Attacks (Code 310).

I was prescribed anti-depressants and told I would have to put up with the feelings (Code 164).

Some of the GPs I found are hopeless they have a lack of knowledge, lack of willingness, it seems, to address or even go near the possibility that there might be something here that is treatable through some programme or that there might need to be a referral, they never seemed to be interested in that (Code 281).

It was their lack of knowledge that there was such a thing as a ‘Anxiety Disorders Unit’, as well as not knowing where to go for specific or specialised treatment (Code 77).

At first I sought help from GP and was put on anti-depressants, things improved but when it flared up again at different stages in my life. I often didn’t go to the doctor. It took quite a long time before any mention of the Anxiety Unit at Princess Margaret Hospital was offered to help me (Code 148).

In addition to health professionals’ lack of knowledge about agoraphobia, some doctors showed an unprofessional attitude towards patients. One male patient argued that a male doctor had shown a lack of empathy for a person suffering from anxiety disorder. Another male patient
stated that it was harder to inform a male doctor than a female doctor, as he felt uncomfortable
informing the male doctor that he suffered anxiety symptoms, in case it showed that he had a
weak male character.

I prefer a woman doctor. Oh, I don’t mean I want a namby pamby type of person. I
just want someone who has a slight understanding, mentally and emotionally and I
didn’t find that with men doctors at all, and quite frankly the experiences I’ve had
with male doctors has been awful, absolutely awful. Two weeks ago when I went
to get my Arapax I knew exactly what I wanted, and I had to go to a local doctor
who was a man, and he was just absolutely awful, absolutely atrocious in the way
he dealt with me. I really wished I had someone there because it just wasn’t
professional at all, and I suppose it is that stereotype ‘don’t show your feelings’. He
was very judgmental. I said to him – I’d had years of experience in this – and I’m
in the medical profession and I know how people should act, and I said I want to go
on Arapax which I had already discussed with my doctor, it was already on the
computer and he already knew what I was thinking of doing, and I said I would like
to start them now. “Oh well. I see you’ve had a problem with alcohol” and I said
“Yes, years ago”. “Well, you’re what I call a dry drunk then” and I said “I beg your
pardon?” This was just completely unprofessional, I know about this man. It
really put me off, but I got what I wanted anyway. So I got my prescription and
moved on and I go and see my GP tomorrow. He was very unprofessional and once
again it put me off that man stereotype thing. I mean, it was like talking to a brick,
there was no give or take, it was just like talking to a brick (Code 56).

I was born and bred in the country, where boys did outdoor stuff, like trail-biking,
shooting and camping. Our role models were the ANZAC soldiers and the All
Blacks. So I didn’t like telling my male doctor that I was having panic attacks, I felt
like I was presenting myself as a poof, a weakling, a woman (Code 31).

While a large number of research participants believed that their health professional was
ignorant about their panic attacks, one person claimed that her health professional’s ignorance
and failure to inform her that she had panic attacks meant that she suffered with the problem for
longer than she should have done. Another person concurred earlier treatment would have been
better for her management of the panic attacks.

Well for quite a while nobody actually ever said you are having panic attacks, you
have agoraphobia. I wish that our doctor had said this is what you are having, this
happens sometimes, you won’t die from it, but she didn’t. It was all very well for
her to say we’ve checked you over and everything is fine, but to me that meant
nothing because people can do that and die the next day and that is truly how I felt.
I got sent to a heart specialist and put on the machines and everything it made no
difference. It didn’t make me feel any more secure, I still think if they’d just said
that is what is wrong with you and explained it I don’t think it would have gone on like it has. That is the way I feel anyway (Code 148).

I feel that if I had got treatment earlier I would have been a lot better. I got medical treatment 13 years later after the first panic attack (Code 33).

One research participant reported that she went to her doctor for medical advice about another mental illness, which then led to her being sent to Princess Margaret Hospital and diagnosed with agoraphobia. Some research participants have other mental illness (e.g. depression) that mask the presence of agoraphobia and delay its diagnosis.

I though I was going out of my mind, because of these strange thoughts and feelings I was having, as well as the feeling of depression… I actually went to my doctor and begged him to do something about my depression, and he sent me up to PMH and it was them who diagnosed me with having the agoraphobia as well, so that answered a lot of questions for me. It proved that I wasn’t going out of my mind or anything (Code 156).

Some research participants stated that their health professional took longer than necessary to diagnose their agoraphobia. The research participants believed that the reason for the delay was that they were misdiagnosed (e.g. depression) or dismissed as simply having ‘nerves’.

I didn’t get any treatment from my doctor for many years, other than tranquillisers. I wasn’t told I had agoraphobia. I actually figured it out after reading a ‘self-help’ book (Code 31).

It took 2 years to diagnose – they said I was depressed - I wasn’t depressed, I was just frustrated not knowing what was wrong with me (Code 252).

Although, I have had panic attacks since the age 20, I was not diagnosed till my mid-40s with agoraphobia. In the past the GPs would just prescribe medication for my nerves, which I didn’t take, as I did not like feeling like a zombie. I was lucky to have a GP when I was in my 40’s who was studying to become a psychiatrist that my disorder was picked up and he sent me to PMH for an assessment (Code 135).

While a large number of research participants had negative experiences with health professionals, most persevered with their search for a health professional that was knowledge about agoraphobia and was able to provide appropriate treatment.

The first GP just kept telling me that I was stressed and to chill out. I went to a few other doctors with no luck. One GP tried to prescribe me Prozac, but I didn’t want it, because I knew what it had done to others. Then a friend recommended a GP
who she said was very good. She asked me about all of the symptoms which I’d had over the years, and she explored, she asked me more about when did it happen, what fears do you have, she really took the time to do that, which was fantastic. I went there once a week for ages… She did that Cognitive Behavioural Therapy for the first half an hour, and then I had homework to do and we talked about it, and it was brilliant…I think the CBT stuff is really useful, it was so practical. It was fantastic. It was really good because it was something really tangible that I could actually do, therefore it was appropriate for getting better, but that was the turning point, especially about getting the car and driving out of town… Had it not been for her I would still be looking for a doctor until I found one who could help me (Code 281).

I have found a doctor now who is very good. He has been to lectures and things like that, and he is right up with the field… He is quite knowledgeable and up to date on various treatments (Code 22).

In some cases, the research participant did not have to search around for a health professional, as their family doctor was sufficiently knowledgeable about agoraphobia and treatment programmes.

Our GP was just magnificent. He found out what I was going through, what my father was going through too, he actually went to some course to learn more about it because we were the first family he’d had with it, and he read a lot of books to help us with it. He was just wonderful, he was just absolutely wonderful (Code 67).

My family doctor was quite sympathetic towards me. He took a long time to tell me about agoraphobia and the treatment courses (Code 88).

Several research participants reported that a knowledgeable health professional often made them feel that they were normal and gave them hope that they would be able to overcome their mental illness.

He told me that my thoughts and feelings (panic symptoms) were normal, and that I wasn’t going crazy which was the best thing that a professional could have told me (Code 93).

When I went to the new doctor she told me what panic attacks were and how they could be treated. When I left the doctor’s surgery I felt that I she had given me the hope I needed to get back in control of my life (Code 31).

In addition to the knowledgeable health professional’s ability to provide information and basic treatment for people with agoraphobia, they acted as gatekeepers to community mental health
services. A large number of research participants reported that the health professional often referred them to the Anxiety Disorders Unit

The doctor said, “I think you’re got a panic disorder” and wrote me out a reference to the Anxiety Disorders Unit (Code 35).

However, a number of research participants reported that the Anxiety Disorders Unit had a long waiting list for assessments and treatment programmes. In most cases, the health professional was able provide the patient with some coping strategies (i.e. breathing techniques) and/or medication (i.e. anti-depressants) while they waited for their appointments. Unfortunately, people with agoraphobia who are made to wait a long period of time for full treatment, risk a deterioration in their mental health (i.e. more panic attacks and avoidance) and become more reliant on flawed personal coping strategies such as alcohol. In addition, the long wait for assessment and treatment meant that person’s life was more likely to be adversely affected (e.g. damaged marriages/relationships, disrupted education and employment, etc).

My partner phoned the Anxiety Disorders Unit when they were in Princess Margaret and they said you need a referral from your GP, and so we went to a GP and said I needed a referral… but then it took months from sending the referral to the actual assessment (Code 269).

The waiting for the assessment is an awfully long time, and it is just a pity sometimes that – I mean it is fabulous that they’ve got this, because I know other places haven’t – but it is that waiting to get in which is hard (Code 148).

I had to wait five months for the assessment and then another four months for the treatment course, and in that time I developed all these bad coping strategies, which I had to unlearn to enable me to learn to use the proper techniques (Code 31).

I waited months and months – I had to wait like six months or something, but I kept thinking, next week, next week, not realising it was so far off, because it was so hard to live through that time (Code 105).

I had to wait for ages to get on the course, When I first went in I think they said that it would be 9 months wait, but those 9 months came and went and they didn’t get in touch with me and time went on and on, My name must have fallen under the couch or something, so I’ve forgotten how much longer I waited. I do remember that they were apologetic about the delay because I got lost in the system (Code 89).

The funding for mental health is just shocking – that is what I feel, I mean, I always used to say and I knew that I didn’t have enough guts to commit suicide, but
obviously a lot of people have. I haven’t, but I used to think that if I knew I had to wait that long for help, when I was thinking tomorrow they will ring me or next week they will ring me, not knowing it was six months before they were going to ring me. If I’d been a different type of person, I may have taken my life because it so ruins your life, it ruins your life, you know, but I often used to say that, I used to think that if I’d known it was going to be six months before I got any signs of help and had to live that every day, 24 hours a day, would I have made it. And in that time from when I first had the problem to when I got here, I had huge other problems in my life and it had got bigger than what it was at the beginning. Also the longer the wait for treatment, the worse it is and the more parts of your life are affected, there is more to actually try and rebuild (Code 105).

One person believed that the long waiting lists for assessments and treatment courses were due to a shortage of clinicians, which were not employed due to a lack of funds. In addition, the person stated that his panic attacks had worsened while he was waiting for the treatment programmes to commence. The person’s deterioration in mental health, while he was on the waiting list, meant that he had more difficulty learning to manage his increased anxiety on the treatment programme. The person concludes that more clinicians and treatment programmes would enable people with agoraphobia to have their anxiety treated earlier (i.e. nipped in the bud), which would reduce the likelihood of adverse effects on marriages/relationships, education, employment, etc.

What struck me with waiting lists was when I went on it there was a waiting list to get the assessment, and then there was a waiting list to get on the course. By then I was so bad that I actually dropped out of the course, I dropped out after day one, so I was one of those people. Then I had to wait for a clinician to become free for one-to-one sessions, and she got me through the treatment. It is just shocking. It is just life today I suppose in health, but if they had more funding and had more help for people a lot sooner, surely they must save money in the long run. It can strike in any walk of life and not just people who can’t go to work… I have the suspicion that the ordinary person has figured it out that if you get the treatment early, you are going to have less problems, but somehow it doesn’t seem to happen at the top and it is not just with this, a lot of mental illness really… its unfair when you have a treatment that can nip it in the bud. It just seems so needless. I suppose it comes down to having the money to employ more clinicians. It is always comes down to money, money money (Code 105).

One research participant reported that attending her assessment at the Anxiety Disorders Unit was a traumatic event, due to her increased feelings of anxiety. It seems that people with agoraphobia who normally struggle to be in public places and situations can struggle to attend treatment programmes situated in public buildings.
I went to the Anxiety Disorder Unit. At my first interview, I sat there and I thought to myself, I really shouldn’t be here, there are other people who really need to be here more than me, and I just refused to talk about it. She could not have got an accurate assessment of me at all because I thought I shouldn’t be here really, she should be spending time with someone else… I didn’t know if I’d ever go back because I found it really traumatic up there. I can remember getting out of the office and thinking I can’t manage, I can’t walk down the stairs in this place to my car – I mean I vomited I was so anxious – and I just felt I am not in control. I can remember thinking to myself do you want to live like this for the rest of your life, then you have to go back. So I had to go back, so I told one of my best friends and she came with me a week later, and that really helped just having her there. I then went on the course… (Code 45).

I have found the Anxiety Disorders Unit “group therapy” sessions a huge help – but it was a hurdle to get there in the first place. It is very frustrating that the courses that you need to attend to help yourself, are the situations you fear the most (Code 150).

One person reported that the Anxiety Disorders Unit clinician struggled to decide on the right diagnostic label for their condition. In some cases, a patient can report clusters of symptoms belonging to more than one anxiety disorder, making it difficult for the clinician who must rely on the patient’s list of symptoms to make a diagnosis that will then enabled the person to be placed on the appropriate treatment programme.

They couldn’t decide if it was social phobia or agoraphobia, but then after a while they seemed to decide it was swung more to agoraphobia because of me not driving and finding it hard to go places (Code 148).

In most cases, the clinician placed the research participants into treatment programmes that comprised a small group of similarly affected individuals. The one clinician to a small group of patients is a more cost-effective form of treatment than one-to-one sessions. However, some research participants reported that they struggled to manage their anxiety disorder to participate in the small group environment. In these cases, the person did one-to-one sessions, which were more successful for them.

I couldn’t go on an Anxiety Disorders Unit programme with others, my preference is one-to-one counselling (Code 31).

I wouldn’t do an Anxiety Course. I would pay to go privately one-to-one - not in a group, definitely not (Code 35).

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I feel better in the one-to-one counselling than in group therapy. In the three weeks course, we didn’t know each other fully enough after the three weeks, and there was a lot of smiles, body language-wise, and even just politeness and talking seems to have gone down the drain (Code 201).

I had been for an assessment and was diagnosed with agoraphobia and social phobia. The clinician put my name down to go on a three-week course. The first day was a real challenge – just getting there I mean. I was able to travel on the bus to the course – a real achievement. Then I had to sit for a good part of a day with the clinician and six strangers. I felt really anxiousness and uncomfortable in that group - I didn’t do at all well. As a person diagnosed with social phobia I don’t think that a small group was the best situation for me to in. The following day I began to go but I couldn’t do it so I dropped out of the course – that was really embarrassing for me – I thought the clinician would be really upset with me and think that I was a bad person. However, the clinician was quite nice about it, and arranged for me to do one-to-one sessions that were excellent (Code 31).

While one person reported struggling with the small group environment, other people stated that they enjoyed the social environment as well as benefiting from the treatment programme.

It was a three-week course and I found that it was wonderful. I still do quite a lot of the things I learnt there… When I’m uptight I use the breathing and relaxation I’ve learned. I always remember to just relax the body and it just seems to work. I did find that I got a lot from that course (Code 37).

Another person commented that she struggled to understand the relevance of cognitive behavioural therapy to treat her panic attacks. Since the idea that simply changing her thoughts, breathing pattern and reducing her muscle tension would reduce the frequency and intensity of their panic attacks was difficult to accept.

I couldn’t identify with it at the time. It just wasn’t of interest to me. I couldn’t understand how that could help me. I didn’t see what it was going to do for me (Code 93).

I was referred to the Anxiety Disorders Clinic, but once again it was the same old treatment, breath in, breath out, hold your breathe, and it just wasn’t working. It just didn’t work – I tried, I really tried and I am not the sort to sit down and listen to a tape of someone I don’t know and sit there clenching my buttocks and imagining a brook – it just doesn’t work (Code 56).

I couldn’t accept that all I had to do was breathe differently and relax and that would stop this overwhelming fear that I would die – It seemed too easy to be true (Code 44).
One person reported that she was unsuccessful in attempting to use the cognitive behavioural techniques once she finished the course, and she resumed her avoidance of places and situations where she feared having a panic attack.

At Princess Margaret Hospital we were taught to visualise a situation, I would visualised just going up to the entrance of Lyttelton tunnel, then I went with my husband to have a go. The first time we went, the girls started arguing in the back, so I said no I can’t do it, the second time we got there and I said stop the car and he said I can’t stop the car here, but I made him stop and I got out. Then the third time, I went into the tunnel; I was in there about five seconds when I said I don’t know what I was worried about. We went through the other side and the next day we went down there with my sister-in-law to go through it again and I couldn’t do it – I couldn’t come back through, so that was it and I’ve never done it again (Code 22).

Another research participant stated that she tried to use the breathing and relaxation techniques to control her panic attacks, but the breathing and relaxation techniques merely kept her mind on the panic attack, which increased her anxiety and the intensity of the panic attack. Another person stated that the breathing and relaxation tapes worked for some individuals and not for others such as himself. In addition, one person believed that applying the breathing and relaxation theories during a real panic attack was extremely difficult to do. While some research participants struggled to use the breathing and relaxation techniques, other people praised their effectiveness in reducing their anxiety. It appears that the research participant’s successful usage of breathing and relaxation to reduce their anxiety was largely dependent on their willingness and ability to use the skills and their trust that the techniques would actually work.

The trouble with the breathing and relaxation was that it kept my mind on the fact that I was having a panic attack. The only way I could stop thinking about the panic attack was to stop using the breathing and relaxation techniques and simply leave and avoid the situation (Code 92).

I found the relaxation tapes didn’t work. I am not the sort of person to sit there imagining some lovely stream with a mountain behind me and sitting in a caravan in peace and quiet. It doesn’t work like that for me, some people have that ability, good on them. I am a realist, I believe in what I see, and it just wasn’t working for me at the time – when I am having a major panic attack, it’s not working and it still doesn’t work. I found it kind of very wishy-washy…The breathing, the relaxation, the muscles, the tension, the whole lot, and squeezing my buttocks just didn’t work.
It just didn’t work. I just found it a waste of time, so I suppose after a year of that, I just got sick of it and turned to the bottle (Code 56).

I don’t think that current treatment programs are necessarily effective. I’m not a fan of behaviour therapy as it was of little use to me (Code 235).

It is good in theory, it is good practising it, but when it actually comes to the time to start breathing, you are thinking about why am I shaking, what is my heart doing, you are not thinking about I need to breathe now. I have tried it, like as I’ve got older I’ve managed to apply it more and calm myself down more, and actually do it before I get too bad, but sometimes it works and sometimes it doesn’t (Code 67).

I loved the relaxation and breathing workshop. I highly recommend that. It was quite positive, I can’t remember the exact number, but it had a good turnout and the lady who took it she was a very good tutor (Code 201).

In addition to research participants struggling with using the breathing and relaxation techniques, others struggled to do the exposure tasks. In one case, the person cheated by avoiding the exposure work component of the Anxiety Disorders Unit treatment programmes. Those people who do attempt to use cognitive behavioural treatment to manage their agoraphobia, require a much higher level of commitment, perseverance and work ethic, than people who simply use anti-depressants to control their anxiety. The possible reason that New Zealanders are using more anti-depressants to control anxiety is that is simple to use and requires very little effort on the part of the individual.

The clinician would give me a task to do and tell me to go away and do it. Well, I wasn’t going to go away and do it. There was no way I was going to do it (Code 41).

We had to go and get on the bus that goes up and down the city and I couldn’t get on the bus, so that was something we had to do as a group. I was just beside myself inside the bus, but everyone was really supportive in the group (Code 45).

I went on the Anxiety Disorders course and cheated my way completely through it, which wasn’t difficult. We had to go out in the afternoon to do our exposure work, like going on buses or into lifts, but I just walked around the shops for the whole afternoon… I found the course unbearable and not even vaguely helpful (Code 269).

It’s hard to use the CBT stuff during exposure work – it’s a lot easier to go to the doctor and get a prescription for a bottle of pills – I call anti-depressants the lazy person’s medicine (Code 31).
Some research participants completed the Anxiety Disorders Unit treatment programme without achieving effective management of their panic attacks/agoraphobia. One person reported a feeling of hopelessness as no alternative medically approved treatment programme seemingly existed.

I did the Anxiety Disorders course, the group sessions and the one-to-one counselling and I had hoped that there would to be an end point to my panic attacks, but in fact there isn’t one. I felt hopeless at one point because I thought these are the experts, I’ve done the bloody course and I’m still not fixed, and this is the only course in the South Island. There is obviously nothing else I can do, so for a while I felt quite helpless. I know that going through the system I looked like I was improving myself, but I didn’t feel like I was and I couldn’t see any way of that changing, like I said I’d done the course and what else do you do after that, what is the next step (Code 269).

A number of research participants reported that having completed the Anxiety Disorders Unit’s treatment programme, it was common to have a relapse due to their poor anxiety management practices. Therefore, it was important that the Anxiety Disorder Unit ran relapse prevention programmes, for past patients. For some people to successfully maintain their mental health, they require ongoing relapse prevention programmes. However, the clinician’s input into relapse prevention reduces clinician’s availability for new clients on the waiting list for assessments and treatment programmes.

When I left the course I was ok for a month or so and then the panic attacks started coming back again (Code 22).

When I started going to the course I felt really good. I was going along really well and then all of a sudden, I crashed. I just went straight down, like in tears and I couldn’t go to work and all that sort of thing. The clinician taught me that this is perfectly normal, you had a relapse, and you are on the way up now (Code 35).

The Anxiety Disorders course taught me a lot of skills and was very useful in managing my anxiety. But I began to stop doing the breathing and relaxation, I never seemed to have the time and then stressful things would happen and I would be back to square one - panic attacks. I think it would really valuable if people could redo the course, and have a second chance of getting all the information deeply ingrained in their minds. I feel that just doing the course once teaches you skills and gives you the information, but it does really get programmed deep inside of you and that’s where it has to be because that’s where the panic thoughts live (Code 31).
I often felt that it was just a pity that there wasn’t the support afterwards for a while from the Anxiety Disorders Unit itself, and I know it must be very difficult because I know how busy they are, but I thought it would be good if every month or twice a year if they could contact people and ask how you are going, and I guess that might have helped (Code 47).

While some research participants reported struggling to complete the Anxiety Disorder Unit’s, treatment programmes due to waiting lists, lack of clinicians, small group therapy and the cognitive behavioural techniques, other people stated that they had a very positive experience in using the service. However, most people stated that the course required personal commitment and hard work to be successful.

When the Anxiety Disorders course finished my horizons kind of broadened then, because I started going further afield and staying away from home for longer amounts of time. I got back that feeling that I could do anything and go anywhere, and I that I was making progress and I was doing OK. You just have to keep plugging away at it, it is hard, to get my breathing under control and to relax my body. I have to get my mind under control to calm things down, which is sometimes hard to do (Code 269).

I have had panic attacks since age three. At 16 years old they became bad and then at 20 years I could not leave home. With the help of Anxiety Disorders Unit I can now leave home again, go to public places, drive and walk down the street. I still find public transport and going long distances from home hard. But have been taking small steps to work on them (Code 207).

I had been to the Anxiety Disorder Unit for a week and I came home and did all the bits and pieces like listening to the breathing and relaxation tapes, I felt a lot better (Code 22).

The course changed my life. It just changed my life around because I believed them. They spent so much time on teaching me, learning about my symptoms, my first signs, and I learnt so much it was like wow! I just wish that someone had let me know beforehand, because I had all that time when it did affect my life… (Code 105).

I must admit that it did help and I did feel better than I had when I actually started the course… I felt I could do something about it. Sometimes it was really hard, I’ll think that its not working, its not working, why isn’t this working, and you keep on trying, but it certainly did help (Code 148).

I went to the Anxiety Clinic when it was at Princess Margaret Hospital. It was the best thing that ever happened to me. I went in and I had the interview, there were heaps and heaps of paper tests to fill out. I saw a counsellor who put my name down
for a course, which I did. That was a three week course – it was very intense, it was extremely intense, and I was quite hard because a lot of the other people were really, really bad, but some of them weren’t too bad… I think it was the second day we went into this department store and got into the lift. I thought I’m not getting in that, but everyone had got in the lift and I thought I’ve got to do it, everyone else is doing it, so we got in and went up to the next floor and got out and we’d all survived. We had to go back down, and that was the first thing that I’d ever done and I felt really relieved afterwards, but as we went through the course we were taught how to cope with our fears and stuff… It takes a long, long time, it really does, but I did everything I had to do and I even drove out to Birdlings Flat on my own and stayed there for while and then came back – that was one of my tasks I had to do – that was in the last week, and by the time I finished the course I felt really good (Code 41).

You can feel worse before you feel better, and some of the side effects I had from it was that I had more heartbeats and that sort of thing and the tiredness and I kind of felt more down really, and after the three weeks I started to pick up a bit and started to feel better and a lot of those symptoms disappeared, and I started to feel, like I was more controlled, and I could do more (Code 148).

One person commented on the importance of the relationship between the clinician and the patient, for their progress in the treatment programme. Some community mental health programmes, as human services are dependent on the ‘human factor’ in service delivery. The human factor is the friendliness, approachability, empathy and communication abilities of the clinicians

I did the course and I met _____ (name of clinician) and she was like my absolute godsend because we just clicked - and I saw her on a one-to-one basis for one or two times a week (Code 77).

A number of research participants commented that the Anxiety Disorders Unit group treatment programmes were beneficial because they brought together similarly affected individuals. The small groups helped people to feel normal (i.e. the presence of other people who appeared normal who also had agoraphobia), and enabled them to feel that their thoughts and feelings were understood by other, which reduced their feeling of social isolation.

I hadn’t met anybody else with agoraphobia until I joined the course… everyone there was exactly the same, and they weren’t mental and they didn’t look crazy. They just looked like ordinary people (Code 41).
There were quite a wide variety of people, which was quite an eye-opener to me (Code 89).

What I liked about the course was hearing others talk and saying I know exactly how you feel, and for somebody to know how you feel is so important. Family and friends don’t really know what it is like, if you haven’t been through it, it is very hard to understand how it affects you (Code 148).

I knew that other people were suffering from it, so I didn’t feel isolated (Code 35).

One person stated that knowing that the Anxiety Disorder Unit existed gave her a feeling of reassurance that she would be able to manage her agoraphobia.

It is important to know that the Anxiety Disorder Unit is there for me. I’m sure that _____ (name of clinician) won’t be there forever, but just knowing that she is only a phone call away has she helped me so much – it is kind of comforting (Code 45).

The successful completion of the Anxiety Disorders Unit treatment programme often meant that the person reduced their dependency on anti-depressants to suppress their anxiety disorder.

My GP sent me to the Anxiety Disorders Unit, and I did the anxiety course, which really helped me come off the antidepressants (Code 148).

One research participant commented on the fact that New Zealand has a lack of treatment programmes for people with agoraphobia. Unfortunately, people who are homebound or severely restricted in their travel can not simply move to a place that has a treatment programme.

When I was in New Plymouth the other week, my sister’s daughter-in-law is agoraphobic, but there’s no treatment up there for her, there’s nothing…so I’m going to send her my manual from the course, because there is nothing there at all for people like her up there. It is really sad because we have it all down here, so I said to her to come and live in Christchurch (Code 41).

While most research participants had been to their GP and the Anxiety Disorders Unit, others preferred to use a private psychologist or a counselling service. In one case, the person stated that it was very beneficial to her treatment to have a counsellor who had had panic attacks, as it enabled a shared understanding and empathy between the two individuals. Another person stated that her psychologist was pro-active and accompanied her on exposure work.
I first went to the Cashmere Counselling Centre about my anxiety disorder, the counsellor said that she had had panic attacks before and that was great. I thought that was awesome because you can’t understand them unless you’ve had them, you can’t understand the enormous effect it has on everything, it is not just a panic attack, it affects everything, so having that knowing between her and I was great (Code 93).

The psychologist I went to was proactive – she was like we are going out to the mall today and you are doing nothing else today. She was proactive and I think that is what people need, is someone to say right, we are going out because you don’t know your fear until you face it (Code 92).

However, some people report bad experiences with counsellors, due to an apparent lack of knowledge and understanding about panic attacks and agoraphobia. In addition, one research participant believed that there were ‘charlatans’ who offered treatment programmes, who had little or no understanding of agoraphobia.

I did go to a few counsellors, I had a very bad experience with a counsellor, but looking back on it now my parents regret not taking it further. We had a really bad experience that made me go down again, just stupid things that she did when it wasn’t the right thing to do. I think it was her not being able to understand it either, because there hadn’t been a lot out about how to cope with it, and looking back on it now it wasn’t the way she should have handled it. Yes definitely, my first counsellor was hopeless and didn’t help us as a family (Code 67).

The counselling doesn’t do anything for me – I talk about life and things, and then it gets me uptight and I take it out on someone, and it doesn’t stop the attacks at all (Code 79).

In my experience there are many ‘Charlatans’ claiming to have expertise or have achieved good results of recovery from agoraphobia, and are very willing to take your money, but in hindsight they have little knowledge of agoraphobia and its symptoms (Code 269).

While some research participants preferred using the services of private psychologists to avoid the Anxiety Disorders Unit waiting list, the professional fees were prohibitive for some people. People with agoraphobia on high incomes are able to access treatment sooner than other people, and are more likely to avoid a significant deterioration in their mental health from being on waiting lists for publicly funded treatment programmes.
I went to a private psychologist to avoid the ADU long waiting list, but you have to have the money to afford them, it’s very expensive, it’s the old public system – free and wait, verse the private system – pay and get it now (Code 31).

This psychologist was $120 an hour, and I went for about four sessions and I couldn’t afford it, I couldn’t and I found it was just a little bit too clinical for me, but what I got out of it was really good (Code 93).

In some cases, the research participants decided that healing themselves was preferable to private or public treatment programmes.

Through those visits to the psychologist I realised that I have to fix myself, it is actually up to me, and that was really scary and I found that was a really huge thing to come to a realisation of, but now it is the best thing that I have been taught the truth (Code 93).

A case of ‘physician heal thyself’ (Code 7).
Medications

Several research participants reported that prescription medication had enabled them to return to a normal life. Several people had been on medication for many years and wondered whether they could live without them, and two individuals stated that they did not want to be reliant on the medication for the rest of their lives. Another person took prescription medication when she had to attend a major event, and one individual reported that the medication made her feel better, as well as suppressing her panic attacks.

I’ve just gone on to an antidepressant called Arapax, in the last six weeks which has helped knock off the edge of the anxiety, and the last few days I’ve started to get a bit of relief which is good (Code 56).

I told my doctor about the panic attacks and he prescribed Valium. I had been on Valium off and on for quite a few years, I don’t know if I could manage without them (Code 22).

I have been on Arapax for a long time now, I often wonder how I’d feel without the medication, but I’ve never tried (Code 124).

I didn’t want to be on tranquillisers just to get me through the day. I needed to do it myself. I didn’t want to be like that. It was just needed them to do major things (Code 35).

I could do anything with Atrovine. I could go to church and sit in the middle row; I could go to a funeral and things like that without any problem… I didn’t want to be on them forever (Code 35).

I said to my doctor that I only wanted to use pills if I had something really big on. I didn’t want to take them every day. Only if I was going somewhere and I thought I would need a pill (Code 35).

I was put on Valium and pumped up with those, and they were good, they made me feel quite good and there were no panic attacks (Code 289).

One research participant stated that Hormone Replacement Therapy was helpful in suppressing her anxiety and panic attacks. It may be that a woman going through menopause with the hormone imbalances may be susceptible to higher than normal levels of anxiety, which would increase the likelihood of panic attacks.
I went on H.R.T. and I felt a lot better and seemed to be able to cope with situations better. When my body is run down or I am very tired then I feel vulnerable. I used to have a lot of anticipatory anxiety, as well as panic attacks (Code 33).

While some research participants reported that the positive effects of prescription medication on their anxiety, other people stated that the medication caused unpleasant side effects such as generalised feeling of illness, stomach upset and feelings of queasiness, intoxication, heart palpitations, loss of concentration and impaired functioning.

The GP picked up what was wrong with me and threw me on all sorts of pills absolutely threw me around, all sorts of antidepressants and stuff. That’s why it has taken me years to go back and try something else, because they actually threw me around too, the tablets, which really put me off with the side effects. It was something wicked…there was a lot of turmoil at the time and I just found tablets were no use (Code 56).

My doctor wanted me to try Prozac and I sort of hummed and haaed and I wasn’t that keen, but I thought I’d try it, because if it doesn’t work I can always go on Doxican again, and I was just terrible, I just curled up in a ball, like in a foetal position and I couldn’t get out of bed. I was like that for 2 or 3 days and in the end my husband got me out of bed and said right, back to the doctor. I had had a bad reaction to it. That put me off even more, thinking Oh my God, if this is the new one out, well you can forget it, and I wouldn’t go back on the Doxican (Code 148).

I got quite bad again then and I decided I really didn’t want to go on the antidepressants again because I just hated that six weeks of feeling worse and terrible (Code 148).

The doctor put me on Valium. That was how they treated it, but putting me on Valium made me feel sick. I got a real queasy feeling in my tummy when I went out or anything, and so I decided that I should go off it (Code 37).

I am on Arapax, and she did give me some other pills and they were a bit strong and made me feel a bit wobbly and a bit sort of a feeling of being drunk sort of thing. They were a bit strong, so she gave me something else (Code 79).

The drugs made me feel sleepy, I felt like I was turning into a robot… I was zombie-like, (Code 274).

I was on the antidepressants for about 6 months to a year. I think it was Doxican, which made me feel worse and I began having lots of heart palpitations and that sort of thing (Code 148).
The antidepressants kept me too drugged up during the day, not being able to think and I had concentration loss, and plus the heat from the sun like we were having at the same time, and I found I was more able to think better at night-time (Code 201).

Drugs were just shutting off my mind, just keeping me calm, but I wasn’t functioning and that is what I hated about it because I thought when I come off them, I’m going to be exactly where I was, and I had to find a new way and this was the only way that I could function (Code 108).

In some cases, the person had been prescribed medication that was later shown to be inappropriate for that individual. In one case, the person stopped taking their medication to prevent further harm to themselves. Some people stop taking their medication due to its failure to suppress their panic attacks and/or its side effects.

I told the new doctor what I’d been taking and about the really bad side effects, he said you shouldn’t have been on them. And I thought thank you. I did the right thing taking myself off them (Code 201).

In another case, the person had a phobia of medication that prevented them from taking drugs to suppress their anxiety and prevent panic attacks.

I have a phobia of chemicals/drugs, so I couldn’t take medication for the panic attacks (Code 86).

In addition to the prescription medication side effects, some people believed that long-term use of the drugs would create dependency problems. A number of the research participants stated that having ready access to medication was often sufficient to reduce their anxiety and the incidence of panic attacks. It seems that the psychological effect of the medication (i.e. person has a reassurance that in an emergency that a tablet will alleviate the panic attack) is as important, if not more important, than the actual physiological properties of the medication.

If I knew I was going out somewhere I would take a Valium before I went. It wasn’t an addiction – it was a crutch. The Valium made the symptoms sort of die down a bit (Code 22).

The doctor gave me some tablets years ago – I think it was Valium – and I went through a stage when I took them out with me. I never used them, but I always had them there just in case, as a safety thing, so that if I needed them, I had them there. I am on medication, but if I can try and keep off it, so I am not one to just take them unless I feel that I need them. There were times when I was stressed out when I felt
I needed them and went to the doctors and she would give me enough for four weeks or such until I came right again, and then I was OK (Code 33).

I learnt that medication would control these panic attacks that I was having, medication made me feel good, medication blanked everything out and made me feel like I couldn’t get hurt any more… I started taking quite a lot of prescription-based medicine, I was on antidepressants, I was on painkillers, and I was on anti-inflammatories and muscle-relaxants because I used to get strange pains. Also, in those days you could buy Codral forte which had a high dose of Codeine in it, and pain killers over the counters and all that sort of stuff, and then I’d double and triple-dose some of the things. I spent about 15 years or maybe more on pills, because it wasn’t until 1985 that I came off them… I was having counselling out at Hillmorton they call it now, and the very first thing they attacked was my medicine, she said, “You shouldn’t be on Antophan, it is highly addictive, so they took about half of my medicines off me, but at home I had them behind bookcases, a bit like an old alcoholic, I had medicine everywhere, in coat pockets, in bags so that I wouldn’t be without anything, anywhere at anytime (Code 289).

In some cases, the general practitioner’s over-prescription of medication enabled the person to develop a dependency problem. In one case, the person had spent thirty years on medication for panic attacks. It seems that some general practitioners fail to adequately monitor their patient’s usage of medication. Unfortunately, the patient’s dependency and desperation for a medicated escape from their anxiety made them incapable of monitoring their own drug usage.

I have been on tranquillisers for panic attacks since I lost a child to ‘cot death’ I was aged thirty. I had no help from any doctor until I turned 60. I weaned myself off the drugs and was only taking them when I knew I would have a panic attack, when going to places I’d had a panic attack before (Code 302).

When my husband was due to come home, I would go and get into a right old state because the kids had made a mess or I hadn’t done something and the medication was really good for stopping me from feeling panicky and the feeling that I was going to die. One day I had a panic attack because I had to go down to the school, and I felt like I was dying and I couldn’t cope with it, so I took some more pills, usually Valium, Valium was pretty good and I had a doctor I could go to, and whatever I wanted he would give me, no problem (Code 289).

In one case, the person’s dependency on prescription medication to suppress her anxiety led to an accidental drug overdose.
One night I had been up all night and was really tired, so I went out to the kitchen, made myself a cup of coffee, downed some more tablets and a couple of sleeping pills on top to make me sleep, and the next minute I woke up and I was in bed and I’d lost 24 hours (Code 289).

One research participant argued that the taking of prescription medication reinforced her self-image that she was not normal, since a normal person doesn’t need to take medication to do everyday activities.

I feel that using medication to make a person feel normal can make them feel less normal than other people because they have to take medications. I think that people should be able to do normal things and a normal thing would be able to go to the supermarket and be OK about it and not have to get a bottle of anti-depressants to do it (Code 31).

Finally, one person made the logical observation that prescription medication does suppress anxiety, but fails to change the cognitive and behavioural patterns that cause the panic attacks to happen.

The anti-depressants do suppress the panic attacks, but they don’t solve the underlying cause of panic attacks – the thoughts and behaviours that led to panic attacks (Code 31).

While the research has shown that people with agoraphobia have both positive and negative experiences of orthodox medications, some of the research participants who reported that they had had negative experiences of orthodox medications preferred to use homeopathic remedies for their anxiety. One research participant reported that she learnt about homeopathic remedies from family and friends. In the interviews the most common homeopathic remedy cited was rescue remedy and also women’s multivitamins. One person stated that the natural remedies were slower to work, but had less harsh side effects than orthodox medications. However, another person warned that people could become dependent on homeopathic remedies the same as orthodox medications.

My doctor put me on Prozac. It was terrible, I curled up in a foetal position and couldn’t get out of bed and I was like that for 2 or 3 days… I had had a bad reaction to it. That put me off so I tried homeopathic remedies instead (Code 148).

I found out about homeopathic remedies from family and friends. (Code 148).
I use Rescue Remedy (Code 148).

To help myself with the agoraphobia I am taking women’s multivitamins at the moment. I went to a chemist and he said that vitamins help you when you are under a lot of stress. I thought that it might help with my anxiety (Code 201).

The nature remedy is probably much slower to act, but then I’m not having the side effects either, it’s weighing up its effectiveness and the absent of side effects (Code 148).

I reached the stage where I couldn’t go anywhere without having my rescue remedy in my bag. It wasn’t that I used it, I had it to feel safe that I had something that could prevent the panic attacks (Code 92).

I think that people should be able to do normal things and a normal thing would be able to get on a plane and be OK about it and not be dependant on having a bottle of rescue remedy in your bag (Code 93).
Companions

In the study, 78% of research participants reported that they had required a companion to accompany them into a public place and/or situation where they feared having a panic attack. While 17% of research participants stated that they had not required a companion and 5% of research participants did not complete this section (Missing Data).

The chart and table shows the type of companion that the 78 research participants required to accompany them into places and situations where they feared having a panic attack.

Table:

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I have required my partner to accompany me into situations.</td>
<td>55</td>
</tr>
<tr>
<td>B</td>
<td>I have required friends and/or neighbours to accompany me into situations.</td>
<td>37</td>
</tr>
<tr>
<td>C</td>
<td>I have required other family members to accompany me into situations.</td>
<td>35</td>
</tr>
<tr>
<td>D</td>
<td>I have required my children to accompany me into situations.</td>
<td>22</td>
</tr>
<tr>
<td>E</td>
<td>I have required my pet to accompany me into situations.</td>
<td>13</td>
</tr>
<tr>
<td>F</td>
<td>I have required a volunteer to accompany me into situations.</td>
<td>7</td>
</tr>
<tr>
<td>G</td>
<td>I have required a health professional to accompany me into situations.</td>
<td>6</td>
</tr>
<tr>
<td>H</td>
<td>I have required a social worker to accompany me into situations.</td>
<td>5</td>
</tr>
</tbody>
</table>
Note: In the survey questionnaire one person stated that a psychology text-book was her ‘companion’ in these situations as she could read the section on techniques that reduced her anxiety, also one person stated that her employer accompanied her into situations.

The study shows that research participants tended to rely for support on those whom they were emotionally close to; this includes partners, family members, friends and pets, and to a much lesser extent on professional support from health professionals, social workers and volunteers. It seems that research participants preferred to use support persons who were familiar and trusted by them. The second graph and table shows the different types of support that research participant reported that they required from their companion.

![Type of Support](image)

Table:

<table>
<thead>
<tr>
<th>Code</th>
<th>Description</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>I depended on my companion to be dependable and supportive.</td>
<td>48</td>
</tr>
<tr>
<td>B</td>
<td>I depended on my companion to be protective and comforting.</td>
<td>40</td>
</tr>
<tr>
<td>C</td>
<td>I depended on my companion to be assertive and confident.</td>
<td>33</td>
</tr>
<tr>
<td>D</td>
<td>I depended on my companion to show strength and stability.</td>
<td>32</td>
</tr>
<tr>
<td>E</td>
<td>I depended on companion to do out-of-home activities (i.e. shopping, doctor visits).</td>
<td>29</td>
</tr>
</tbody>
</table>
This survey data shows that research participants required companions to provide mental, emotional and practical support. The survey comments and interviews explored the research participants’ expectations of the role that a companion would play in managing their agoraphobia.

The study shows that women are more likely to use a companion to accompany them into places and situations where they fear having a panic attack. In the survey questionnaires, 69 out of the 85 (81%) women stated that they used a companion, while 9 out of the 15 (60%) men indicated that a companion accompanied them into situations. The possible reason that women used a companion more than men is that they were more willing and able to ask family members and friends to accompany them into situations where they feel uncomfortable due to anxiety. In addition, a female research participant could invite other women to accompany them shopping without having to inform them about their agoraphobia, while a male research participant would have to rely on their partner, as asking other people (men or women) to accompany them in public places would appear unnatural.

When I wanted to go shopping I would telephone my sister or one of my girlfriends to go on an outing. I didn’t have to tell them about the panic attacks, because going shopping with friends is no big deal (Code 11).

When I was with my wife she would go everywhere with me, but after we separated I didn’t have a companion. I wasn’t about to ask my mother or sister to go to the supermarket with me to hold my hand and I wasn’t about to phone a mate to ask the same thing either (Code 31).

A large number of research participants reported using a trusted companion as a ‘safe person’ when they were in a place and/or situation where they feared having a panic attack. Most of these research participants stated that they did not want to be in a public place or situation alone.

You have to choose a person you can trust (Code 193).

I felt safer with a companion (Code 81).

I would feel uncomfortable going into situations where I would be on your own. I can’t go to a market by myself (Code 67)
When I have gone through bad panic attacks, I have felt faint and feel better with someone in a public place (Code 207).

I felt more comfortable having somebody with me (Code 265).

Just having someone with me helps. I can’t be alone in situations (Code 304).

Several people reported that they required a companion who provided mental and emotional support. These people stated that a companion had to be understanding of the seriousness of their panic attack, inspire confidence in their ability to cope, offer reassurances, be a calming influence, reduce pressure, and support them.

They know and understand when I am having a panic attack (Code 67).

My husband was my rock and he is so patient and understanding (Code 1).

They understand what the problem is (Code 27).

I always felt more confident with someone else to talk to and encourage me to stay, remind me of correct breathing, etc (Code 209).

Confidence, understanding, strength and support (Code 84).

He made me feel more confident that I could cope (Code 41).

He made me more confident and lessened my awareness of what was happening to me (Code 293).

That I would be reassured that I was alright (Code 116).

My partner provided a small measure of reassurance (Code 210).

The only companion is my wife who calms me by her presence (Code 203).

You feel better when someone is there to calm you (Code 223).

It gave me a sense of security and protection to have a friend to go places with me that I trusted, helped relieve the pressure (Code 218).

I want a companion who offers support (Code 75).

My partner is very supportive when we are in these situations (Code 287).

I need someone to support me should I become anxious (Code 269).
In addition to mental and emotional support, some research participants stated that a companion needed to offer social support. In this case, the companion would be willing and able to help them to escape the social embarrassment of a panic attack in a public place/situation. In some cases, the companion would make excuses on behalf of the person with agoraphobia to help them avoid social embarrassment.

Sometimes just having someone there for support feels like it takes some of the spotlight off me (Code 59).

Someone else is able to explain my quick exits (Code 150).

Several people reported that they felt safer knowing that a companion would be able to provide practical support when they were having a panic attack in a public place and/or situation.

When I feel anxious, especially on the bus, having a companion with me makes me feel safe (Code 3).

I know that if anything happens to me I have help close at hand (Code 16).

Some research participants reported that they worried that their panic attack would cause them physical harm, and/or the panic attack would make them vulnerable in a public place. These people stated that they felt safer and more secure with a companion in a potentially unsafe situation.

I need someone to take over where my anxiety became overwhelming. One of my beliefs was that I would die, I rationalised that my partner would be there should I have a life threatening heart attack or accident (Code 281).

I feel more comfortable around people, I think because I can always ask for help, I can always – well say I was going to flop down with a panic attack, somebody would be there to pick me up (Code 108).

I felt safe and I knew that when I woke up from passing out, I wouldn’t have a huge crowd around me (Code 32).

I always felt that if I were sick or fainted somebody would know who I was - I am prone to fainting in these situations (Code 37).

Someone to trust and ensure safety (Code 77).
They will help when I become panicky, faint, collapse, etc (Code 190).

I like to have someone, a companion to be there with me. If there is not someone there, I get to the point where I just can’t cope. I can’t stop crying, I get to the point where I find it hard to breathe, that is probably one of the major things when I find it hard to breathe and think I am going to die”. If there’s someone there if I stop breathing, even though I know I am not going to, knowing there is somebody there helps in that if the worst did happen, there is someone there to help (Code 67).

One person stated that she took a mobile phone with her at all times, so that she could contact a family member or friends in the case of an emergency. Some people with agoraphobia carry mobile phones in public places and situations to make themselves feel safer by having a life-line with them at all times.

I bought a cell-phone to take everywhere with me. I always have my cell-phone and then I know that I can always get in touch with somebody. I always travel with a little personal phonebook with numbers and everything. I also tell someone where I’m going in case my cell-phone doesn’t work. Just little things like that so I can get in contact with someone (Code 67).

Several research participants required a companion for practical support to allow them to function in their daily life. In some cases, the companion was able to transport the person when and where they required. This included helping research participants to escape a public place when they had a panic attack.

I need to be driven to where I’m going to (Code 11).

The benefits were in travelling. My partner would drive in situations where I feared having an anxiety attack. I also needed her to be proximate so she could help if things became uncomfortable (Code 98).

I know that if I do have an attack that my companion will take over and remove me from the place that is causing the problem (Code 289).

At the time I felt they would be able to remove me from the situation (Code 162).

My husband is very understanding and he knows that if I leave the situation, I’m having a panic attack (Code 35).

Helping me find an escape route in a hurry (Code 135).

The companion is someone who knows you well and will make sure you get safely home (Code 164).
It gives me a sense of security that I will be able to get back home (Code 169).

A primary benefit was knowing they could drive me home during periods when I felt my concentration levels, during the panic attacks, would have made it unsafe for me to drive (Code 104).

They could take me home, if I panicked (Code 124).

Someone to drive me home (Code 94).

A companion makes it easier to get away (if in a shop) (Code 252).

Somebody who knows me and will drive me home… My husband is a volunteer ambulance driver, felt safe most of time (Code 148).

Several people reported that taking a companion with them when they did daily tasks was helpful, as talking to a companion helped them to distract themselves from thinking about an impending panic attack. The research participants attempted to use conversations with companions to disrupt their panic-inducing thoughts, in the same way that some people used counting or affirmations as distraction techniques.

It was comforting to have someone to talk to, even if they weren’t aware of it, to stop dwelling on the situation and cause a panic attack (Code 22).

My companion helps keep me from panicking. He talks to me confidently, especially where I feel that I might get trapped if I have a panic attack (e.g. elevators, gondolas) (Code 31).

I know there’s help available, and having a companion also distracts me from entertaining panic thoughts and feelings (Code 76).

It gives me someone to distract me, when I feel panicky (Code 278).

The person talks to you (i.e. reassurance), which may take your mind off yourself and be enough of a distraction for you to realise that yes, you are ok (Code 202).

Being able to talk to my partner and having him near me helps (Code 243).

A companion is a distraction from my own self-consciousness (Code 175).

It takes the mind away from dwelling on the having an attack (Code 256).

A companion helps by being sociable and taking my mind off things (Code 79).
They knew what I was going through and could assist with distraction techniques (Code 92).

I found being with a family member kept my mind off thinking about my fears and I felt safe and normal (Code 102).

They could talk to me so I tried not to think about my situation (Code 124).

A companion must have the ability to comfort and to help me talk through the anxiety (Code 77).

Distraction from own thoughts, and encouragement to do things (Code 101).

One person reported that she was able to use thinking about family members (i.e. children) as a distraction technique.

When my children were young, if I felt anxious I would put my mind on them (Code 33).

One individual reported that a companion enabled her to become grounded in the place and/or situation, which enabled her to regain control of her anxiety-inducing thoughts and feelings.

Having someone to talk to somehow ‘grounds’ me. I talk to express myself and make sense of my world. It helps me enormously (Code 44).

While most research participants relied on human companions, some people would use animals to accompany them into public places. The person had an emotional attachment to the pet, which lent reassurance to the individual that they were not alone. Also, the pet owner would be able to distract themselves from their anxiety by attending to the animal, through talking to, patting and stroking the pet.

When I began to feel anxiousness, I would sit at bench and pat my dog. It took my mind off myself and I felt more relaxed (Code 31).

I felt safe when having my dog with me (Code 45).

I take the dog with me and the dog sits in the car, so he goes everywhere with me, and I know that he is in the car if I am not feeling well, or I feel that I’m going to have an attack, I go and sit in the car and I feel heaps better when he is there. I’ve known other people have dogs and it calms them down (Code 67).
As research participants struggled to control their panic attack they often relied on the companion (human) to take-over the decision-making role, and/or do the task they were no longer able to do due to the panic attack.

As my thinking can become quite irrational when under stress, my family all know to give me clear, positive feedback. They also take over decision making, while I concentrate on relaxation and breathing exercises (Code 97).

When I’m in a high state of anxiety, I found it difficult in remembering what health professionals, were saying to me, so I relied on my partner to remember information for me (Code 170).

I need a companion, who is able to have a clear head to help me, as mine is dizzy after a panic attack (Code 310).

My companion provides backup if I’m not able to complete the task (Code 56).

My companion helps to do the supermarket shopping. I could not do it myself, due to my feeling of being trapped while I am standing in the queue at the checkout counter to scan items from the trolley. A companion can help by standing in the cue. Therefore, a companion takes the stress out of the situation (Code 21).

Finally, several people stated that a companion helped them to escape a panic attack by enabling them to completely avoid places and situations, by either allowing them to escape to the safety of the companion’s car or transporting them back to their home.

He was and is very supportive and would always hold my arm or hand – saying ‘you’ll be fine’, would I like to go back to his car and leave (Code 299).

If I panic out in public there has been a car to go to and hide (Code 24).

If I feel uncomfortable in the mall I’ll go and sit in the car and calm myself down and then come home (Code 67).

While a large number of research participants stated that their companions were helpful in the management and avoidance of their panic attacks, other people reported that they had had negative experiences with companions. Some people stated that companions often failed to be supportive due to their lack of knowledge and understanding of agoraphobia.

Sometimes that person has not understood why I am panicking and therefore is not supportive following the panic attack (Code 150).
Companions often have a lack of understanding of the seriousness of panic attacks and my need to leave the situation where I was having the panic attack immediately (Code 81).

People can’t be bothered with you, because they don’t understand why you panic (Code 124).

They can become impatient because they don’t understand and are not very supportive, which increases my anxiety (Code 162).

Other people have difficulty understanding why you can’t go to places by yourself (Code 164).

If the person doesn’t understand panic attacks, it can make you feel worse (Code 207).

Several people stated that the reliance on a companion meant that they had to plan daily excursions into public places around the availability of a companion. The dependency on the accompaniment of a support person restricted the person’s ability to act spontaneously in their daily life, due to the advanced planning required to ‘fit’ excursions around their companion’s timetable.

My day-to-day planning involves managing my partner’s time schedule so he can be with me in situations (Code 92).

I had to organise timetables to accommodate companion (Code 269).

I had to wait until my partner was available to accompany me into public places, which meant that I was never free to come and go like other people (Code 31).

While some research participants reported that they had to plan their daily life around their companion, some people stated that their companion often had to restrict their activities to accommodate the person with agoraphobia.

It has also limited my partner’s wish to travel extensively (Code 98).

I felt that I was holding my friend from doing what she wanted to do (Code 63).

My partner would love us to travel together, but I can’t handle travelling a long way from home, so we don’t go (Code 31).
Some research participants reported having a negative experience when they became separated from their supportive companion in a public place and situation.

If my husband was with me I felt less anxious, but if he walked away and I couldn’t see him I would panic (Code 33).

I panic if I lose sight of them (Code 190).

A number of people stated that their companion would attempt to talk to them during their panic attacks, which was unhelpful in alleviating their anxiety. In some cases, the companion’s comments increased the anxiety felt by the person with agoraphobia. Often the companion’s attempt to help through communicate was undermined by their inappropriate attitude and ignorance of agoraphobia, which upset the person with agoraphobia.

In one situation (a gondola) the talk was all wrong (“the doors are shutting, its too late to get out now”) and I had to tell him to shut-up (Code 31).

Most companions were fine – I did however have one friend who had a “snap out of it” attitude and this made her more of a hindrance, than help, as a companion. She wasn’t very reassuring and having her with me tended to increase my anxiety, because of her attitude and lack of understanding (Code 104).

When my husband picks up that I am in a panic situation he will start talking to me, trying to take my mind off it, but it actually makes me feel worse. I ask him to please shut-up, which occasionally makes him angry with me, which in turn makes me feel guilty (Code 135).

A large number of people reported that a major problem with having a companion was that they often felt embarrassed when they had a panic attack that was noticeable to the companion. In some cases, the research participants felt their anxiety increase as they struggled to suppress a potentially embarrassing panic attack.

It’s embarrassing to have a panic attack (Code 16).

The embarrassment of having a panic attack, when the companion is not aware of my panic attack tendencies (Code 21).

Some situations it’s better not to have a companion in case I embarrass them (Code 22).
My companion won’t come with me, and I have to run and get away from the embarrassment, because I get angry and then I can’t stop crying (Code 24).

It can be embarrassing as other people guess you are mentally unstable or incapable of getting on with it yourself (Code 59).

Embarrassment – it takes more mental energy to be aware of where they are and can mean that I sometimes feel very bad for interfering in their enjoyment of an event or party, etc (Code 86).

If my companion is not equipped to understand my irrational panic behaviour, it can be very embarrassing for the both of us, so I try and avoid such situations (Code 97).

Embarrassing him (husband) or her (daughter) and myself, often coming home earlier because I couldn’t cope when they wanted to stay (Code 148).

Embarrassment, fear of not-understanding my fear, or what is causing me to react the way I do (Code 201).

Even though my partner is supportive I still feel embarrassed and ashamed (Code 287).

If you are with someone that does not know about your problems it can be embarrassing to leave what should be a ‘normal’ everyday situation (Code 202).

In addition to people reporting social embarrassment, some individuals expressed the concern that their panic attack would upset their companion, cause them embarrassment, and/or frighten them.

They would know something was wrong (Code 101).

Fear of having a panic attack in front of them – feeling like a failure (Code 181).

I fear that they will panic and think I’m dead (I pass out) (Code 32).

Sensing their fear and/or doubt made things worse (Code 170).

Sometime when my companion is my 10-year old daughter I get worried that I will panic and upset her, which adds to my anxiety (Code 304).

Some research participants were fearful that their companion would think that they were irrational. In one case, the research participant believed that her partner would no longer love
her if she appeared mentally unstable. Another individual commented that appearing irrational undermined their sense of pride in themselves.

Sometimes people who are close to you think your fear is irrational and find it very difficult to understand (Code 169).

He might not love me anymore and thought I was strange (Code 41).

I lost my sense of pride (Code 128).

One person who hid her agoraphobia from her companion commented that she struggled to act ‘normal’ when accompanied by her companion into places and situations where she felt anxious.

I hated having to act so called ‘normal’ in front of them when I felt anxious out in public (Code 56).

Another major problem reported by research participants was that their companion would sometimes force them to stay in a place and situation where they felt anxious and feared an impending panic attack. The people then felt trapped in the place/situation, which heightened their anxiety and increased the likelihood of them having panic attacks.

When they didn’t understand that I didn’t want to be in some situations, and kept me there (Code 293).

He sometimes pushed me stay, which made my anxiety worse (Code 252).

Sometimes the person hasn’t understood and made me feel worse by forcing me into situations that I was not comfortable in (Code 278).

One research participant stated that she felt pressured by her companion to do tasks, which she took longer to do due to her anxiety.

Sometimes I feel pressured for time and have been unable to do the activity in my own time (Code 289).

Several research participants argued that when a companion helped them to avoid their panic attacks by taking them out of the place or situation, it undermined their willingness and ability to use cognitive behavioural techniques to manage their agoraphobia.

He would always turn around and take me home if needed (Code 1).
I had one friend who I found to be good, if I needed her, because she sort of understood as much as she could understand, but then in other ways she didn’t help me at all because she helped me avoid some things. However that was nice because that was what I wanted at the time, but at other times I could go knowing that if I wanted to do a U-turn and wanted to go back, she’d do it, which I liked (Code 105).

The problem with a companion is that they often think they’re helping by getting you out of the situation, which is what you want them to do. When it would have been better if they had encouraged me to use the breathing and relaxation techniques, which I had been taught to do in those situations.

Several people stated that they didn’t like to have a companion as it undermined their confidence to manage their anxiety and their feeling of independence. In addition, the person’s dependence on their partner as a support person placed strain on the relationship.

I become too reliant on him to take the lead, reinforcing my lack of confidence (Code 281).

I don’t like asking for help and being ‘needy’ (Code 44).

I’m a very independent person – goes against the grain to require someone to help me (Code 213).

The relationship at times became intolerant because of my dependency on her to do everyday things (Code 98).

While the research participants have spoken about the negative experience of human companions, one individual stated that her inability to take her dog (i.e. animal companion) into different public places and situations undermined her ability to manage her anxiety.

I struggle sometimes because I can’t take my dog (companion) everywhere (Code 45).
Support Group

A large number of research participants who had been through the Anxiety Disorders Unit treatment programme became involved in the Agoraphobic Support Group (ASG), through attending open meetings, chat groups, social events, receiving newsletters, etc. However, the Anxiety Disorders Unit had not treated a small number of research participants involved in the ASG.

In the interviews, one research participant reported that her attendance at a ASG monthly open meeting required a full day of advanced planning for a meeting that usually last about 2 ¼ hours (i.e. 6.15pm to 7pm the chat group, 7pm to 8pm guest speaker, and 8pm to 8.30pm supper). In this case, the person left the open meeting earlier due to their anxiety. A major problem for people seeking group support is their ability to travel to, and participate in a group environment, especially for people with social phobia and agoraphobia.

I found out about the Agoraphobic Support Group open meetings and I spent the whole day planning about how to get there and where I was going to park, and all of that...I went to one of the meetings and sat there and thought I can’t stand it and I went out. They were lovely people, it was just me (Code 45).

One person confirmed this view by stating that she had to learn to control her anxiety sufficiently to be able to attend a group that was established to support people in developing the ability to manage their agoraphobia. The research participants who were able to attend the group meetings were more able to manage their panic symptoms than others, such as people who were homebound.

I would have to force myself to go, but I would have to be able to control my panic (Code 79).

*Note: The ASG committee arranges for a committee member or volunteer field worker to make home-visits for those people with agoraphobia who are unable to attend group meetings in a public place.*

Those research participants who were able to attend the ASG monthly open meeting reported that it was a positive experience. These positive experiences included the feeling of belonging among other people similarly affected with agoraphobia, enjoying the company of others and
being informed by guest speakers on subjects relevant to the effective management of agoraphobia.

I found the group really well worthwhile and wished someone had given me this help years ago (Code 302).

I just felt like I was really welcome, the very welcoming attitudes, and the fact that I was sitting in a room with a heck of a lot of people that have what I had. And we laughed. I found the talks really interesting. (Code 93).

In addition, several research participants stated that the ASG enabled them to meet, talk to, share and learn from other people with agoraphobia. In most cases, the ASG contact meant that people could see that they were not alone in suffering from panic attacks.

It was helpful just talking about it and sharing with people who had the same sort of problems (Code 256).

The reason I joined the Agoraphobic Support Group, was so I could have the support of the other people and we talk about how we felt, what we were going through, and it was a tremendous help to me and I thought it was marvellous having other people to talk to (Code 156).

At the open meetings it was good to able to meet twenty other people that had some understanding of how I felt at times. I know everybody is different, but that was good to see that there were other people out there – its like a AA meeting where there are other people with similar stories. Yes, that side of it was good, knowing that there were other people the same (Code 56).

I listened to one person who said that they couldn’t go through a tunnel because they had this great fear and I thought that’s me (Code 274).

One research participant reported that belonging to the support group with other similarly affected people made them feel more ‘normal’, as well as not being alone.

I felt like I was sitting in a room where for once I wasn’t a freak (Code 93).

In several cases, research participants reported that they felt less distressed about their problems with panic attacks after they had met people more adversely affected by panic attacks at the ASG meetings. In one case, a person stated that she felt more confidence about her management of panic attacks after meeting people who were less able to control their panic attacks and avoidance behaviours.
I know this will sound bad, but it’s good to meet people worse off than yourself – you don’t feel that life has been to hard on you after all (Code 94).

It was great to know that I wasn’t the only one affected by this problem, it was just like – oh my God, there are other people like this, and it is not just me. There were a few select friends that I told, but I didn’t really talk about it because I didn’t want people to think I’m a nutter or something, and that is a typical attitude that people used to have, and it was a wonderful feeling really, I was on a real high, I just felt – my confidence came back so quickly on different things, and it was just neat talking to other people and realising well, I don’t feel so bad after all because there were people there who were a lot worse than I was. It made me think how lucky I was because I can do some of the things that some of these people can’t do (Code 148).

One person stated that while the support group brought together people who shared the same label – Agoraphobia – there were many noticeable differences between people in their intensity of panic attack symptoms and avoidance behaviours. In addition, one person felt that the difference between peoples’ experience of agoraphobia meant that it was difficult for her to relate to other people in the support group.

I’ve got this label that I’m agoraphobic, but I haven’t got all these symptoms, that it is all a little bit different. I mean I might share some of the symptoms, but there are also differences. Like there might be one person who is homebound and can’t cope with any situation, while there will be another person who can actually go to those situations and simply endures those symptoms, so people are a little bit different here and there (Code 274).

I went to the support group for a wee while, but I didn’t find that terribly helpful because people there seemed to be such a lot worse than me…They didn’t seem to have the same sort of things that I kind of thought I had. They seemed to have different sort of anxieties to me…There were people who couldn’t even go out to the letterbox and they’d talk about things that were really bad. I thought that I’d never been that bad and that I couldn’t mix with these people…(Code 37).

One research participant commented that at an ASG open meeting, she had met friends, whom she had not known had agoraphobia. Some people who hide their agoraphobia are often unaware that other family and friends have the mental illness until a chance encounter causes a disclosure.

What I didn’t expect when I went to my first meeting at Knox Church, was the number of people there, it turned out that I knew one or two of them. They had been too nervous to say anything, they said well we were the last ones to think that you
would have it and I thought well, I felt the same about them. I just felt that you’ve got to face the problem and deal with it (Code 201).

In addition to ASG members receiving psychological and emotional support from other members, some people provided or received practical support to do gradual exposure work.

I was in the Agoraphobic Support Group – we were one of the first ones to get it going in those days, and I would take people out who couldn’t go on the bus. I would go with them for a couple of stops on the bus…(Code 35).

Finally, a large number of ASG members who had spoken positively about their experience in the support group commented on the importance of the friendships that they had formed, and had sustained them, through their recovery from the unmanaged symptoms stage of agoraphobia. In some cases, the ASG facilitated the forming of these friendships through a buddy system, where similar people were paired together for mutual encourage, support and friendship.

In the ASG newsletters they send out and I still get them, they set up a Buddy Support System and it said there are people in these areas if you want to contact them, contact us, and they put me on to this lady. She lived just around the corner, so I used to go and visit her once a fortnight. I would have been about 26 and she was probably in her early 40s, but that didn’t matter. We got on really well. She is a very open person, which allowed me to be open. I kind of just talked a lot about what I had suppressed all those years and it was quite exciting. It was like finding a best friend (Code 93).

I went to the Agoraphobic Support Group, which I found immensely awesome – they had a Buddy system, and I buddied up with this lady from my neighbourhood and I would go and visit her once a fortnight (Code 93).

I meet a person through the support group, we lived near to each other, she used to come around here a lot and I used to go to her place, so we saw a lot of each other and I think having that support, that you can talk to each other about it, as well as knowing that there are other’s with it - I felt that was a great help at that time (Code 33).

It makes quite a difference being in a group of strangers and having one person that you know. It’s like a Buddy system. I have never told the person that their my ‘safe person’, but sometimes someone will say, “Are you going into town?” and I’ll say “Yes” and they’ll say. “Can I come with you?” and I’ll say, “Yes, that’s fine”, but I don’t tell them that I’m anxious or anything like that. It is like the Buddy system without the person knowing that they’re part of my Buddy system (Code 22).
While research participants stated that belonging and participating in the ASG had been a positive experience, some people reported that there were negative aspects to belonging to the support group. Several people felt that they had to leave the support group after a period of time to enable them to move on with their lives. In these cases, people felt that their continued presence in the support group, with people who were still struggling to manage their agoraphobia would re-awaken past negative experiences and undermine their recovery from the unmanaged symptoms stage of agoraphobia.

I got to the stage where I didn’t want to go to the meetings any more because you are hearing everybody else’s problems and what they are feeling. I was like that when I started and that is when I needed the support from them, but I got to a stage where I wanted to go on and get away from that, and that is when we all did our own kind of thing. I still see them, but that is why I kind of never carried on with the group and even with the group now (Code 33).

I found the support group good for a time, but when you are getting better, and living your life, listening to people going through what you went through in the early days brings it all back (Code 33).

I remember there was a young lady called ______ and I used to go and pick her up because she was almost practically housebound because she couldn’t go to the shops or anything, and I think sometimes it drags you down. You think, when they can’t do things or you are talking about your own fears or what you had, that it can actually take you backwards (Code 35).

I have been going to go to the Agoraphobia Support Group here, but I feel like I’ve been there and done that. You couldn’t afford to stay there for years and years. It would just keep pulling you back (Code 34).

In some cases, the research participant left the ASG and stopped attending meetings due to a change in their circumstances.

I loved talking to other people… I thought I was lucky really, and then I got a job and I stopped going (Code 256).
Faith and Spiritual Experience

In the study, a research participant spoke about the onset of her panic attacks caused by the stress of a volatile and violent marriage. The person sought help from a disbelieving doctor (i.e. medical intervention) and an unhelpful priest (i.e. religious intervention), which she believed contributed to the deterioration of her mental health. The person then sought spiritual intervention for her deteriorating mental condition, which led to a personal experience and relationship with Christ. The person believed that her personal relationship with Christ was a turning point in her management of agoraphobia. The person’s self report of the overwhelming nature of the spiritual experience and unconditional love shows that the presence of powerful thoughts and emotional feelings can suppress the thoughts and feeling that trigger panic attack symptoms and avoidance behaviour of agoraphobia.

My husband was a volatile man and it was a violent relationship and he is a druggie too, so it wasn’t a good mixture. I think the stress in that relationship started the panic attacks… I went to a doctor and explained to him about my strange thoughts and that I just couldn’t have any peace, and he just laughed at me and said, “There’s nothing wrong with you”, and I said, “There is!” and he said, “No there isn’t, you’re just imagining it”. I went away absolutely distraught and disappointed and desperate because I needed help, so where do I go for help, so I went to a priest. I rang a priest and he came and started talking about God will help you if you pray, that was fine, but I wanted help this instant. I wanted some sort of help from him; he gave me no help at all. Then I started to get suicidal, that was the lowest point in my life. I can look back and see a vision of myself in a dark black place and I was on my own and I was in a foetal position and my spirit was dying. I asked God, to help me leave this body and in that moment something unusual happened. There was a light and then there was God’s voice and I just felt calm, I felt unconditional love coming from him, and how do I know it is God, because I could feel his spirit and knowing this, that someone great was with me, and I thought wow! You know. I thought to myself I don’t need a priest, I don’t need a doctor, I don’t need anybody, I have found God, and I found him here in my house, and I was really happy… I know for certain that God will take this away, he is the only one who will, no scientist, no doctors, they treat your symptoms, but it is like a band-aid you know, but I feel that mental illness is a spiritual matter, I believe it is between yourself and God. This was a real turning point, I really believe in God without all the religious antics. I had no more panic attacks, absolutely none. I was normal and back to my old self. There was a new love of human kind, more love, more understanding, more patience; I was more loving towards my children, a real personality change. It was all positive. (Code 274).
In another interview a research participant stated that she believed that her agoraphobia had been a part of God’s plan to bring her to salvation. She believed that the trials and tribulations of her panic attacks and deteriorating mental health had been essential in making her search for God’s intervention and salvation. The research participant could have felt more confidence about her ability to control her panic attacks, due to believing that the panic attacks could be stopped through her becoming a devout believer. Therefore, the person developed a powerful spiritual internal dialogue that suppressed the thoughts and feelings that would have continued triggered panic attacks.

“I’m beginning to think that’s God had me have these panic attacks as part of his plan to make me seek his help. I do believe that, I really do. That to me is a reassurance, it is a comforting thought really to think that God cared that much to bring it, to make me seek him out and to be saved. I knew there was a God, but he wanted a personal relationship with me. That is the most empowering thing when I think wow, he loves me and we have to come to know him and open up the door as he says, and he’ll come in (Code 108).

I do think that we have to go through the experience to come to the final answer. It was like St Paul, look what his life was like, and so to me we all have to go through those trials and tribulations, and to seek him, because God says to seek him, and once you find him, well your life can then be a lot of satisfaction and joy (Code 108).

The research participants reported that following their spiritual encounter and the development of a personal relationship with Jesus Christ, the next step in embedding their faith and preventing the return of panic attacks was reading inspirational scripture – the bible. Undoubtedly, the reading and embedding of scripture in the conscious mind assisted in suppressing anxious thoughts and feelings that could lead to a panic attack.

“I had to go to God for help, and that is where I went. I thought now I will search the scripture, and my son gave me a lovely bible and he said to me, “Mum, Christians should not have anxiety, it is opposed to God’s word”, so I read the bible from Genesis to Revelation, I read the whole bible, and it took me a year (Code 108).

Several people reported that prayer helped them when they felt panic symptoms. It seems that the person’s concentration on the prayer would have distracted them from the thoughts that were triggering their anxiety.
I feel my faith has got me through it, if I am out and if I feel uncomfortable I say a little prayer and I get through it (Code 33).

I do pray a lot as well, because I feel that helps me (Code 32).

I can be out in the car sometimes and I can be waiting at the traffic lights in a long queue, I can sometimes feel a bit anxious, and I sometimes say a prayer, it makes it go away, you know what I mean (Code 33).

While some research participants believed that God, faith and prayer would help them overcome their fear more that medical intervention, other people believed that God had used doctors and medication to help them manage their agoraphobia.

I believe that faith in God and prayer can overcome fear, where doctors and medication often fail. I had been to a doctor and the moment I walked into his surgery, he said you have anxiety and depression and he wrote out a prescription for anti-depressants… I told him there is a better way, I’ve got my scriptures to read, so the pills are still sitting up in the cupboard (Code 108).

As a Christian, it’s the faith that he will be able to help me if not in a miraculous way, then through doctors and even medication (Code 76).

One person reported that in addition to the spiritual experience changing her thoughts and feelings, her faith led her become more outgoing as she became less self-focused and began to help others, as she believed her faith required her to do.

I feel I have to get to know Jesus Christ himself and become like him. That is what he wants us to be… I feel he wants me to be able to be caring, kind, courteous, and helpful to others. He doesn’t want me to be locked up in myself, but to get out and help others (Code 108).

Some research participants then decided to regularly attend church to share fellowship with other like-minded believers. It seems that church attendance enabled them to develop spiritual and human support to manage their new life free from panic attacks. In this sense the church fellowship would have provided similar support to secular bodies such as the Agoraphobic Support Group.

I went shopping for a church… I wished to find one that suited me, I finally found a church that I was happy in, and then I got baptised… I enjoy the service every Sunday with my church family (Code 108).
While some research participants have reported that their faith, religious practices and church attendance had had a positive effect on their agoraphobia, several people stated that their Christian belief and practices had had no effect on their management of their mental illness. In one case, the person had had a panic attack during a church service, which meant that they were fearful of returning to church. This could have happened because the church environment is similar to other public places (e.g. supermarket, shopping mall, etc), where people often have their initial panic attack and then develop avoidance behaviours.

My faith hasn’t played any part in helping with my agoraphobia, and I don’t go to church (Code 22).

The church seems to bring on my panic attacks for some reason – I don’t know why – I think maybe it’s because, it was the first place where I had a panic attack (Code 31).

While some research participants had a Christian spiritual experience some people had a non-Christian spiritual experience that was helpful in the management of their agoraphobia. In one case, the person sought a spiritual counsellor who helped in the healing of past childhood experiences, which were seen as contributing to her anxiety. Some people with agoraphobia that have had a traumatic experience require a closure that allows them to reduce the anxiety they feel towards the experience.

I’ve been on a huge spiritual journey. I was in a Health Food Shop one day and picked up a free magazine called Input, and it had this advertisement for a spiritual counsellor and I went along and I still see her now after 2½ years. I think its great, like she’s given me tools to cope with myself. I did a lot of inner child healing, I went back to my childhood and talked a lot about things that happened in my family upbringing, it cleared a lot of emotional stuff and really nurtured my spiritual side (Code 93).

In this case, the person stated that the spiritual experience and emotional healing was accompanied by personal growth that helped to reduce her anxiety. Similar to the Christian spiritual experience the non-Christian spiritual experience would have created an internal dialogue (i.e. self-talk of healing) that was more powerful than the thoughts that triggered panic attacks.

I am on a lifetime journey of personal growth and healing emotional issues and anxiety as I go along. Sometimes it still can be painful, but now it is like, OK lets
just play this out, what am I going to learn from this panic, and I’ll just clear some other belief that was in my conditioned mind (Code 93).

In addition, the person believed that the effective management of agoraphobia required a holistic approach that included the mind (i.e. mental health), body (physical health), social wellbeing (i.e. social relationships) and the spirit (i.e. faith) of the individual.

To undo my agoraphobia I have had to learn that it is in my body, my mind and my spirit. In my body I do that yoga and walking and that gives you a sense of well-being, in my mind I’m always watching what I’m saying and making sure it is loving for me, and that I’m not giving my negative thoughts any power. And my spirit I do my meditation and through improving relationships with people (Code 93).
Successfully Managing Agoraphobia

In the study, several research participants stated that the first step in successfully managing their anxiety disorder was learning about agoraphobia. One person believed it was empowering to learn and understand what had been happening to her (i.e. labelling and learning about panic attacks). Another, person felt empowered learning that she was not alone in suffering from this mental illness and one mother felt that she had the information that would enable her to help her son who had developed agoraphobia. Therefore, a prompt health professional’s diagnosis and the acquiring of accurate information on agoraphobia is an essential component of successfully managing this mental illness.

It was unbelievably horrible but I feel that it is all behind me now because now I have a much better idea of what is happening to me (Code 44).

I find that researching it (agoraphobia) helps me a lot to understand (Code 201).

It’s important to realise that you’re not alone in suffering from this crippling condition (Code 293).

I’m grateful for all the information available these days and am trying to use my knowledge now to help my son who is a similar makeup to me (Code 209).

While some people reported that they wished to know the ‘cause’ of their agoraphobia, one person believed that knowing the reason for the onset of their agoraphobia made no difference to their management of the illness.

I like to put the puzzles of my life together, so I was a person who wanted to know the reason ‘why’ I developed agoraphobia. However, I found that knowing ‘why’ wasn’t that important, as it wasn’t going to actually make a difference (Code 87).

One research participant argued that it was important to continually gather information on techniques for the effective management of panic attacks. This information can be gathered through health professionals, support groups, libraries, Internet web-sites, etc.

I think information that teaches people how to control the panic attacks is important. The more information the better. It is like anything, the more you learn the better prepared you are to deal with the problem if it happens again (Code 148).
Another person stated that it was important to tell others about the panic attacks and to ask for help. The person argued that by talking about panic attacks and avoidance behaviours, people would learn that they were not alone and that support groups existed to help people with agoraphobia. The same person stated that it was important to immediately seek medical treatment for panic attacks to prevent the condition becoming worse.

I think you’ve got to talk about it. I think that it plays a important role in your recovery when you talk about it, especially at the beginning because a lot of people have the same feelings that you’ve got, and you are learn that you’re not on your own, and there are other people with it I think it is important to go to support groups and talk to others to gain encouragement and support (Code 33).

I think if I had got treatment a lot earlier, maybe I might not have got as bad as I did (Code 33).

One research participant argued that people with agoraphobia had to make a serious commitment to a treatment programme to ensure a successful outcome. In this case, the person stated that the ongoing usage of cognitive behavioural techniques were essential to effectively control agoraphobia. Another person stated that perseverance with treatment was important to the long-term successfully management of agoraphobia.

You can manage your agoraphobia. You have to learn the techniques and keep them up such as combating “Negative Self Talk”... The breathing and relaxation techniques also help a lot, but the key is to continue to use these techniques and not to stop when you start feeling better (Code 170).

There is only thing that I would like to say to everybody that does have agoraphobia and that is just to hang in there and that is what I am trying to do, I am just trying to hang in there and ride it out sort of thing, and hopefully one day it will get to the point where I can just not worry about it anymore (Code 156).

A large number of research participants stated that developing their confidence was a major factor in successfully managing their agoraphobia. Some people stated that their increase in confidence was accompanied by a reduction in their anxiety. A confident and assertive person will have more control over their cognitive behaviour, and be more able to manage their anxiety than a person who lacks confidence about their ability to control their anxious thoughts and bodily feelings, who then becomes a victim to their fear-inducing mental and physical state.
I notice a real difference in my confidence following the treatment. It’s amazing how more confident I feel to go out and do the things I want too (Code 33).

I definitely see the need for increased confidence to reduce anxiety – the two things go hand in hand. I am very confident about a lot of things, and I have got more confident in the last ten years. I’ve become more confident in myself, and probably more assertive like in making decisions and that goes hand-in-hand with the lessening of my anxiety symptoms (Code 37).

My confidence goes up and down, like my anxiety, but knowing that my family is always there to boost me back up, that is definitely where I get my confidence to carry on (Code 67).

I have heaps more confidence. I don’t know where it came from, but it came from somewhere. I think I always had it, but the anxiety kept hidden. Now that my confidence is back up my anxiety is back down where it belongs (Code 92).

You have the ability to pick up your confidence and boost your self esteem and you can get stronger and stronger and the anxiety will become weaker and weaker (Code 92).

The more you overcome your anxiety, the more confident you become, and then it just snowballs. It like when you’re struggling with anxiety it snowballs downhill, and then it snowballs the other way when things are going good. At this particular point in time I am a very happy, confident person. It is an amazing thing getting over agoraphobia (Code 41).

One research participant stated that people with agoraphobia should steadily increase their confidence by completing graduated exposure tasks in small steps, as recommended in cognitive behavioural therapy treatment programmes. Therefore, an increase in personal confidence was seen as a key component of successfully managing agoraphobia.

I believe that you have to take little steps to build your confidence when you do exposure work. If you can do it in small steps you can do anything, absolutely anything. I never ever thought that there was a cure, but now I know. You can control it, you definitely can. It is a miracle really – I look upon it like that because I’ve come such a long way (Code 41).

Several research participants stated that they had forced themselves to do graduated exposure tasks to manage their agoraphobia. While people struggled to complete exposure tasks, most individuals stated that the tasks became easier to do.

There have been times when I’ve forced myself to go out (Code 256).
When I had one or two panic attacks...I tended not to want to go to certain places but I tried to make myself to go if at all possible (Code 265).

I am now learning to cope and deal with things better. I force myself to go out more and into social situations and am slowly finding it easier (Code 278).

It was hard going, but it does get easier. When you learn to manage it, it does get easier...I did make myself do things (Code 33).

I feel I have beaten this condition by forcing myself to do everything and not give up and let the agoraphobia beat me and control my life! (Code 202).

I force myself into situations that I don’t normally do. I usually stand back and not say anything. A week ago I typed something out for my mother, and the family were meeting at a graveside because it was the anniversary of her death, and I typed out this beautiful thing about what I wanted to say about my family members and letting my mother know what was happening in the family, and people were greatly impressed. I stood out there and I spoke in a very loud clear voice, and I thought I could never do this, I would stand back, but I made myself do it, I think I can do it, why not, go for it, otherwise you’re going to miss out (Code 274).

Another person believed it was important for people with agoraphobia to feel proud when they began to successfully manage their panic attacks especially since people with agoraphobia often have to struggle to assert positive self-talk (i.e. internal dialogue) to suppress the negative thoughts that trigger panic attacks.

I look at what I’ve accomplished and I feel quite proud of myself, and I will not go back to being like I was again (Code 41).

One research participant stated that it was essential to differentiate between rational thoughts and those irrational thoughts that would trigger a panic attack. This suggests that the successful management of agoraphobia required the development of critical self-awareness and rationalism to maintain a healthy functioning mind.

Sometimes a stray thought, like I can’t breath properly, will sneak into my mind and I’ll think, what is happening to me. I tell myself its actually nothing, it’s just an irrational fear...its important to know the difference between a real fear and a irrational fear. I don’t want that downward spiral way of thinking that leads to a panic attack (Code 93).

Another person stated that people with agoraphobia need to take ‘time out’ to relax, as well as monitor their bodies for signs of stress and tiredness, which makes them more susceptible to
panic attacks. Therefore, stress management is an important part of successfully managing agoraphobia.

I think relaxation is a big thing and I think that taking time out for myself, and listening to my body telling me something is wrong is important. I used to burn myself out actually, and I wasn’t looking after myself. It’s important to listen to yourself and if you do feel that you are getting panicky, you’ve got to sit down and look at what is happening. Sometimes you’re over tired – sometimes when I’ve been really tired, I can find that it affects me more. When I am feeling good I can do anything, but I think you do have to listen to yourself, I really do (Code 33).

Several research participants believed that other issues in their life had to be resolved, to enable them to reduce the anxiety that was contributing to their agoraphobia. It could be that the stressful issues that needed to be resolved to reduce anxiety, are the same issues that contributed to the onset of the panic attacks and the development of their agoraphobia.

When I went to relationship counselling and began to resolve my martial problems, my anxiety lessened, as well as my panic attacks (Code 31).

I went to counselling and we talked a lot about fears, there were a lot of fears. I saw the agoraphobia as symptomatic of something else going on, something that was a bit deeper, and that the fear was really a symptom of a lack of confidence, the lack of something that needed to be resolved (Code 281).

To get control of my agoraphobia, I had to also address these other parts of my life. I’ve met some people who take the approach that they’ll single out the agoraphobia and try to address that, but other people will say I am having relationship problems, I’ve got to sort that out at the same time (Code 93).

I was having a lot of stress at work which I believed caused my panic attacks, so it made sense that I had to learn stress management to handle the situation at work, as well as learn CBT to manage the panic attacks (Code 77).

A number of research participants who were successfully managing their agoraphobia, stated that they monitored themselves for increasing stress which was a ‘early warning system’ of impending panic attacks. These research participants believed that stress was a major contributing factor to their relapse into panic attacks and agoraphobia.

When I feel a bit stressful it is like an early warning system saying that I’ve got to take time-out. I’ve got to do the various things that are going to lower my stress or just kind of change my perspective about what is happening, and just say, OK just go with the flow (Code 93).
I am constantly monitoring my body and watching my stress levels, for early warning signs of a return of agoraphobia (Code 281).

When I am feeling a bit stressed that is usually the first sign that the anxiety is about to set in... I think you can read yourself better than any doctor and you become aware of your symptoms, and you know what to do about it, when it starts to happen (Code 148).

I have learned to use stress as an ‘early warning’ system, as issues in my life can be dealt with whilst still minor and the danger of panic attacks are reduced (Code 7).

In the interviews, some research participants stated that they believed that they had ‘fully recovered’ from agoraphobia. These people argued that since they had not had panic attacks for a very long period of time, this proved that they had fully recovered from agoraphobia. In comparison, other research participants stated that they believed that they would have to manage their agoraphobia for the rest of their lives. These people stated that they had had periodic relapses, which proved that they still had agoraphobia. These people reported that the later panic attacks (i.e. during a relapse) were less frequent and severe as those that had occurred during the unmanaged symptoms stage of their agoraphobia. However, one person stated that the relapse took them back to square one.

My agoraphobia is no longer a problem (Code 94).

I feel free now (Code 274).

I have fully recovered from agoraphobia. I have been panic free for 5 years now (Code 304).

I guess that agoraphobia will always be a part of my life. It’s like an acceptance that I will always be an agoraphobic. I found it quite hard when I thought I had sort of come right, and then it would all of a sudden just flare up again. I tried fighting it all the time, and it really took me a long time to accept this is my life. I accept that there could be times in my life when it does flare up but I have the knowledge and skills now to deal with it (Code 148).

I always knew that I was going to have a setback one-day, but when I had it I got really annoyed with myself because it was like – I shouldn’t have allowed that to happen, you know, I couldn’t even figure out what was bothering me or I used to get really angry with myself because I used to think that I shouldn’t have, even though they told me that I would have setbacks. But I used to get really angry because at the beginning I thought I was past that point of being able to control things before they got too far, and that used to annoy me (Code 105).
I’ve had relapses, it usually when I’m extra tired, or a bit stressed out or I don’t get enough sleep then I can feel anxious and I start having panic attacks... I watch myself more now and I look after myself more. I have learnt to know when I’m under too much stress (Code 148).

The treatment programme through the Anxiety Disorders Unit has given me my life back. I suspect agoraphobia will always be part of my life but I’m in charge of it now. I know what to do if I feel an attack coming on. I have the skills to cope and that is the most important thing. I live life and enjoy it. Eating well, regular exercise and being healthy and assertive with people around me add to my positive environment, which I try to nurture. Life is good! (Code 169).

Sometimes I think I have recovered, because I haven’t had a panic attack for 6 or 7 months and life is going along real easy and then boom I have one. I felt like I have had taken probably about 1,000 steps backwards, back to square one. (Code 92).

One person compared the management of agoraphobia to managing alcoholism, in that people had to be careful not to return to the patterns of thinking and behaving that they had done during the unmanaged symptoms stage of their illness/addiction.

I don’t think that you ever get over agoraphobia – it is not something that you can have complete recovery from – I don’t think. I admit that things are a hundred times better than they were, but there are still bad days and there are still the scars from it, and you have to be really careful that you don’t slip into old patterns, because it is really easy to slip back into. I think it is something that will always be with me, but I kind of feel it is a bit like being an alcoholic, you may not be drinking but you are still an alcoholic. I may not have symptoms, or I may have them under control, but I know that it wouldn’t take much to – you know, if I wasn’t vigilant – that I could slip back into those old ways and habits (Code 45).

While some research participants reported that they had recovered, or were managing their agoraphobia, other people who had completed cognitive behavioural therapy were still continuing to struggle with their agoraphobia. Some people stated that had resigned themselves to enduring panic attacks for the rest of their lives.

I do not have a single memory of not waking up and feeling fearful of what I have to do that day, as a child it was going to school, college, university and as an adult, social functions and work. Having received treatment for my agoraphobia I still have fears but realise that by continued exposure therapy, life can get easier. The day I walked to my letterbox without feeling fear, in fact not even thinking about the event, was to me a miracle (Code 45).
Since having treatment my symptoms have reduced significantly – but I do have some symptoms still (Code 281).

I haven’t recovered from agoraphobia after completing the treatment. I guess the most difficult thing for me is knowing that I will never be completely free of this curse and I wonder what I will be like in my senior years – reclusive? (Code 203)

I know I will always suffer agoraphobia, I think I am dealing with it, the best way I know how, however it never goes away and the illness can cause one a lot of heartache (Code 16).

I have learnt to live around agoraphobia, and just continue with life (Code 35).

When I first got this horrible thing it crippled my life in nearly every aspect. Now after having had help to deal and cope with it, I am a different person. But it never really goes away completely (Code 41).

It took me a long time to accept that I have a life-long condition and that only with medication and regular support, will I stay on top of this. I feel that I am intelligent, strong-willed and independent and I don’t like that this condition as it undermines my confidence and makes me feel different from “normal” people (Code 150).
Post-Agoraphobic Identity

In the study, a large number of research participants reflected on how their experience of agoraphobia had shaped their sense of identity. All of the research participants who spoke about their sense of identity stated that agoraphobia had had a major effect on shaping them as a person.

It has definitely shaped who I am. I would be a lot of different things if I wasn’t agoraphobic (Code 56).

A large number of research participants reported that agoraphobia had adversely shaped their sense of identity. One research participant stated that she had been forced to develop an identity that she did not want. Another person believed that agoraphobia had forced upon her an unwanted identity and that she had been prevented from having life experiences that would have shaped a different identity. Also, one person stated that agoraphobia had prevented their development of a social identity in the world, due to the expression of their true self being restricted to the safety of their family home, and one individual no longer felt that she belonged in ‘normal’ society.

It is a part of my identity, but not the identity that I ever wanted (Code 45).

It definitely has shaped who I have become, and who I haven’t become; it really pisses me off. I would have liked have done a lot of things, that would have shaped me as an individual, during my life (Code 56).

Agoraphobia has definitely shaped me as a person…I’d be more out there doing things and being what I want and the social side of being out in the so-called world and seeing other people and what they do, and lifestyles and that sort of thing. But when agoraphobia kicked in it was “Oh no, you mustn’t go there” – it has shaped me that way, this is pushing back against what I want to be. When I am at home, I do say what I want, and act how I want because it is the only place where I feel comfortable being myself, but not outside of my comfort zone (Code 56).

I don’t feel like I belonged to normal society (Code 93).

In addition, several research participants stated that agoraphobia prevented personal growth by forcing them to live a very restricted life. People who are surviving day-to-day have less chance of developing to their full potential than others who are not similarly affected.

I have learnt to live with limits (Code 89).
You can’t grow when you are just surviving (Code 45).

Another person believed that agoraphobia suppressed parts of people’s identities. In this case, the person argued that people with agoraphobia were creative and talented, but that agoraphobia often suppressed that part of their identity.

I think a lot of people who suffer from agoraphobia are very talented people, I am quite arty farty – I can sit down and I can create this or paint that, but if I’m feeling a little bit irrational on the other side, no way in hell! I did some painting in the winter and all of a sudden, slam –the irrational fears came in and I just couldn’t cope with doing the painting, so I thought I’ll put that away and come back to it some other time when I’m feeling better, and I haven’t been back to it since six months later because of that irrational fear (Code 56).

A large number of research participants reported that a significant lack of confidence was an inherent part of the agoraphobic identity. Some people reported having a major lack of confidence prior to the initial panic attack, which plummeted further following the development of their agoraphobia while other people stated that they had been confident prior to the initial panic attack, but had then lost their confidence as they developed the restricted lifestyle of agoraphobia. In addition to a lack of confidence, research participants reported that agoraphobia undermined their self-esteem, assertiveness and that some had become introverted due to the lack of confidence and the restricted lifestyle.

I had little confidence during my childhood and when I had my first major panic attack as a young adult, my confidence plummeted (Code 31).

I use to be a very confident person… I had a lot of work-related stress and I had a major panic attack… I lost my confidence in doing everyday things (Code 256).

Well, I think in the earlier days it took a lot of confidence away from me, or I didn’t have the confidence – I don’t know which came first with me – whether the anxiety came first or whether I didn’t have confidence first. I’m not sure which one it was because it started too young, but if I’d been more confident as a child, I would have done a lot better than what I have done (Code 37).

It’s given me a lower self-esteem, and affects my assertiveness in my behaviour, (Code 201).

I won’t say or do what I need to do or think (Code 67).
It has made me a kind of weak person. I truly feel that it has made me a weak person because at the time I didn’t know what it was, let alone know how to control it or anything like that (Code 156).

I don’t have a lot of confidence, and lack of self-esteem. I have become a fairly introverted person because of my lack of confidence and that I am not a very outgoing person (Code 22).

Several people reported that they had lost their sense of independence due to their forced dependency on others to do everyday activities.

I was a very independent person, never relying on anyone, but now I always have to ask for rides. It’s really annoying not being able to go on buses by myself, to do what I need to do, always having to worry if I have an appointment, how am I going to get there causes a lot of anxiety (Code 3).

While a large number of research participants had reported that agoraphobia affected their sense of identity, one person stated that negative reactions of others to mental illness had shaped their identity. In addition, some research participants commented that they had hidden their ‘agoraphobic’ part of their identity to avoid stigma and discriminations from others. One person stated that her deceiving of others to hide her agoraphobia adversely affected her sense of identity. Another person reported that by playing the role of a person without agoraphobia, to hide her agoraphobia from others, she had lost her sense of identity.

I know I am a normal person, but some people don’t see me as a normal person. Sometimes I do think of myself as different – I think I am different because people have made it that way. People have made me feel like I am different because of their reactions, the understanding that they don’t have, the knowledge that they don’t have made me feel different (Code 67).

I learnt to hide my panic attacks, so that people wouldn’t think I was a nutter and treat me differently (Code 308).

I am worried about what people are going to say about to me (Code 67).

If I am having a real down day and I’m with someone I don’t know, I’ll act and I’ll pretend that I’ve had a really stressful day at work. I hide the real reason that I have panic attacks (Code 67).

I think it has been negative in that I’ve become very good at hiding my panic attacks and deceiving people, which I don’t think is good (Code 45).
I remember when I was going to counselling I remember saying that I felt like I was being so many things to so many people, I had hidden so much from so many people being what so many people want me to be, that actually at the end of the day I didn’t really have a clue who I was, and that is the one thing that I came out with, thinking who the hell am I now. I’ve realised I’ve done this whole thing of hiding things and kind of misleading for my own protection, and misleading what people will think of me that nobody knew who I was (Code 45).

While a large number of people reported that they struggled with their sense of identity due to agoraphobia, some people reported that their true identity had begun to emerge as they gained confidence and control over their fear.

I am so much more confident now. I just feel like I’ve survived, and I feel like I’ve got through that (Code 92).

It was a living hell, but know I feel like I’m becoming a real person, this is me. I am not consumed by fear like I used to be. I’m breaking out. I feel like I’m walking towards the end of the tunnel and the light is starting to come in, and as you start doing things, you walk out into the light (Code 41).

I feel that I now have my true identity back after many years of my true identity being kind of suppressed and never allowed to flourish (Code 111).

There were the hard times and that, but now I look back on what I went through and how I am now. I know I’ve had to grow a lot and find my strength as a person to overcome agoraphobia. I wonder what would I have been like if I hadn’t had the agoraphobia. I may have been still lacking in confidence and not accepting challenges in life (Code 33).

A number of research participants believed that their post-agoraphobic identity had been positively shaped by the agoraphobic experience. These people stated that they had become more self-aware, compassionate, caring, giving, attentive, empathic, understanding and tolerant towards others.

It made me go inside because the pain was so bad, it made me go inside, and a lot of people don’t do that at the age I did it at, and I think that now I’m 31 and I really have delved inside and I’ve still got lots of my life left, so I think that’s really cool. I was a Lifeline counsellor last year for the year, and it gave me all the qualities to get through that to have the compassion and understanding for people who were calling and having panic attacks (Code 93).

I think it has probably made me a bit more compassionate towards people (Code 45).
It has shaped me to be a nicer person, because I’ve gone through so much with the agoraphobia I am probably more giving and caring than I may have been beforehand but when you come through something like this you feel like you can help other people (Code 41).

I have more knowledge about that and like to help people like me (Code 92).

I think as a person I have become more open and definitely open to other people’s feelings and needs, more caring I think (Code 67).

I think it has made me a very good listener (Code 45).

It has probably made me more aware of how other people feel and being more – like if family of friends phone with a problem. I think you have more understanding and listen better. I think it just makes you more aware of things I think and not take them for granted so much (Code 148).

I probably have a lot more empathy for other people (Code 281).

I think it has made me more tolerant of other people’s feelings because I’ve been through it all myself (Code 22).

While I don’t have fond memories of my worse days with agoraphobia (it was a very low, demoralising and uncomfortable phase of my life), I do however believe it has made me a stronger person. I now have had opportunities to do things I wouldn’t have had otherwise (e.g. attend overseas conferences as a “consumer”). I also have faced my fears in other aspects of my life, which I wouldn’t have done prior to my agoraphobia. I also think it has helped me to be a more tolerant, patient and understanding person around other people with disabilities. I’m always aware that I need to look after myself and know my limits with what I undertake, and not feel guilty for saying ‘No’ when I need to. Getting plenty of sleep and exercise has been beneficial for me. Agoraphobia will be with me for life, as I can’t be ‘cured’ however my response to how I react to the symptoms (anxiety) and triggers will make the difference in the future as to whether I allow it to take over my life again, I believe (Code 104).

In addition, a large number of research participants stated that the agoraphobic experience had made them stronger people. The person’s emerging sense of strength enabled them to successfully manage their agoraphobia and to develop (or rediscover) their sense of identity.

It’s been a rough road but has made me emotionally and mentally stronger (Code 211).

I think it has made me stronger, and more understanding (Code 92).
I’m a much stronger person now, it has made me realise how strong I am, and it has taught me qualities of compassion, unconditional love, and non-judgemental understanding, and I just feel blessed, I really do. I feel blessed that I have got the strength to heal myself, because there are a lot of people out there who haven’t, so I’m pretty lucky. I wouldn’t change it – I wouldn’t wish it upon my worst enemy but I would never change it (Code 93).

One person speculated that the onset of agoraphobia had been positive in that it had forced her to change from a lifestyle that lacked direction.

I was working in a factory and things were just going along and they could have just gone along for ages, so in a way I guess the panic attacks sort of kick started me to get into another career and do other stuff (Code 92).

Another person reported that her agoraphobic experience had led to the forming of close supportive relationships and had enabled her to confront other issues in her life.

I think in a way it is the best thing to have happened to me, even though my life changed overnight and in a bad way. I have learnt so much, how to relax, what is really important in life, meet the most wonderful people and found out how many wonderful friends I already had. I had to seek counselling and deal with events of the past, which I probably would never have done if I wasn’t forced to (Code 304).

Finally, one person stated that more public awareness of agoraphobia would enable that people with agoraphobia be their true selves.

I think that as the public becomes more aware of agoraphobia, it will become easier to talk to people, and then it will be easier to be my true self (Code 148).
Conclusion
In conclusion, the research has shown that research participants often developed personal coping mechanisms to help them manage their panic attacks. However, the coping mechanisms sometimes reinforced avoidance of panic attacks or failed to properly manage the panic attack symptoms. In addition, some personal coping mechanisms hindered individuals’ learning of medically approved cognitive and behavioural techniques. The research has shown that a significant number of research participants used alcohol to suppress their anxiety. Some research participants stated that they used alcohol as self-medication prior to entering a place or situation where they feared the onset of a panic attack. Alternatively, some research participants stated that they used alcohol at the place, or in the situation, to reduce their awareness of anxiety symptoms that preceded a panic attack. Also, a few research participants stated that they used cannabis to suppress anxiety symptoms. The study shows that research participants often struggled to label and learn about their agoraphobia and usually learnt about their agoraphobia through chance encounters from various sources. The research participants labelling and learning about their agoraphobia was often the first step towards the management of their mental illness. The research on Internet usage showed that research participants acquired information and social support that may have been difficult to access from public places, especially for those people who were homebound. However, the research shows that the usage of the Internet could reinforce avoidance behaviours. In the study, medical intervention was shown to yield mixed results with a number of research participants having stated that ‘chance’ was a major factor in locating a health professional with an understanding of agoraphobia and knowledge about appropriate treatment programmes. Several research participants stated that they struggled to describe their panic symptoms and that general practitioners often struggled to make accurate diagnoses using patients self-reports. The research has shown that research participants were often forced to wait long periods of time for assessment and treatment, and this contributed to a worsening of their mental health and led to an deterioration in their daily functioning, relationships, education and employment. Also, research participants stated that their inability to pay for private health professionals (i.e. psychologists, therapists, counsellors, etc…) affected their access to timely medical treatment. The group and individual treatment programmes were shown to yield mixed results, dependent on the personal commitment and perseverance of the person with agoraphobia. Also, a number
of research participants reported an improvement in their management of their panic attacks following treatment, while others continued to search for a solution. In the study, research participants were seen to often use orthodox medications and homeopathic remedies to suppress their anxiety and in some cases, people developed a dependency on drugs to function in their daily life. The research has shown that research participants tended to use companions as both a support person and a ‘safe’ person. A support person provided encouragement and practical support for the research participant to live their day-today life. However, some companions unconsciously reinforced safety and avoidance behaviours by assisting the person to escape places and situations where they feared having a panic attack. The study has shown that the Agoraphobic Support Group (Canterbury) has played a major role in helping research participants construct supportive social networks that encourage and support their management of agoraphobia. However, the research has also shown that once people have begun to successfully manage their agoraphobia it may be appropriate for them to leave and move on with their life. The research has shown that faith and spiritual experience had a positive effect on some research participants’ management of their anxiety. While the research participants stated that supernatural powers were responsible for the improvement in their mental health, the argument can be made that the success of spiritual intervention is located in the role that powerful self-affirming internal dialogue has in reducing stress and displacing anxiety-inducing thoughts and feelings that lead to panic attacks. The study has shown that some research participants believed that they had fully recovered from agoraphobia, while other people believed that they would have to manage it for the rest of their lives. Finally, the research has shown that some research participants report a new (or suppressed) identity emerges following the management of their agoraphobia, which leads to an improved quality of life. This concludes the research findings; the following discussion will use the literature review and the findings to discuss how social interactions shape, and are shaped by agoraphobia.
Chapter 7  Findings (4) Chapter - Summary

This chapter will present a summary of the research data from the three findings chapters’. This research data will then be analysed in the Discussion (themes) chapter. This chapter begins by summarising the family upbringing, familial stressful events, and traumatic and accumulated stressful events that contributed to research participants’ onset and of agoraphobia. The chapter proceeds with a review of the research participants’ self-interactions and social interactions that occurred during their panic attacks and avoidance behaviours. The chapter continues with a summary of research participants’ primary and secondary school experiences, which were affected by agoraphobia. The chapter then summarises the effect of agoraphobia on the everyday life, travel and social interactions of research participants in public places and situations. The chapter proceeds to review research participants’ usage of personal coping mechanisms and alcohol, to enable them to continue functioning in social interactions and settings. The chapter progresses by summarising research participants’ labelling and learning about panic attack symptoms. The chapter then moves on to summarise health professionals’ role in shaping research participants’ perception of their mental illness. In addition, the chapter reviews the role public discourse on mental illness had in the stigmatisation of research participants, affecting their social interactions with family, friends, and others. The chapter then presents a summary of research participants’ attempts to protect their social status by hiding their agoraphobia from others and making excuses to avoid social interactions with other people in public places and situations. The chapter continues by summarising research participants’ reports on the affect of agoraphobia on their marriages/intimate relationships, parenting, post-secondary education and employment. The chapter then reviews research participants’ usage of companions, support groups, faith and spiritual experiences to help them to start to manage their agoraphobia. The chapter concludes with a summary on research participants’ experiences in successfully managing their agoraphobia and the emergence of a post-agoraphobic identity, which positively shaped their concept of self and their social interactions.
Family Structure and Upbringing

The literature review’s studies on the family structure and upbringing of people with agoraphobia, has shown that they usually came from stable and close knit families (Terhune, 1949, Roth, 1959, Marks & Gelder, 1965). This study supports those studies by showing that 91% of research participants, from birth to 12 years old, were raised in nuclear families (i.e. both biological parents) and 78% of the research participants, aged 13 to 18 years old, were raised in the same nuclear families. Therefore, people with agoraphobia in the literature review and research participants in this study appeared to be raised in stable family structures.

In the literature review, studies suggest that family upbringing, where mothers and daughters’ social interaction was limited to low risk-taking activities (i.e. home-based), undermined the daughters’ development of confidence and personal coping mechanisms required to manage stress in anxiety-inducing situations. This study suggests that male research participants also failed to develop confidence and personal coping mechanisms to manage stress in anxiety-inducing situations due to their fathers/male caregivers not engaging with them in risk taking activities. In addition, in the study, a significant number of male research participants reported that their parent/caregiver regularly suffered from and modelled anxiety in various public places /situations. It seems that female and male research participants who did not develop confidence and personal coping mechanisms for usage in perceived anxiety-inducing situations were more susceptible to the flight response following the onset of panic attack symptoms.

In the study, both male and female research participants reported that their mother was the parent/caregiver who regularly modelled anxiety, which suggests that the mother as the primary caregiver had more influence in shaping the child’s development than the father, especially in families where the father was the out-of-the-home provider, and the mother was the stay-at-home caregiver.

In the literature review, the ‘family system model’ showed that family members’ interaction can often contribute to the development and maintenance of psychological disabilities in a family member (Hudson, 1989). Dr. Alan Goldstein, Director of the Temple University’s Agoraphobia and Anxiety programme, argued that people with agoraphobia are often raised in
families where a family member suffers alcoholism, anxiety, depression or chronic ill health (Goldstein & Stainback, 1987). Also, these families often suffer abuse, premature death of a family member or abandonment by a family member (Goldstein & Stainback, 1987). These stressful interactions between family members create the high levels of stress that contribute to panic attacks. In this study, the overwhelming majority of male and female research participants came from stable nuclear families (i.e. parents and biological children). However, 91% of the female research participants and 80% of the male research participants reported that severe familial stressful events occurred during their family upbringing. The familial stressful factors include the loss of a family member due to accident or illness (42%) divorce or abandonment (21%) and suicide (13%). Other stressful factors involved various forms of abuse by a family member including emotional abuse (34%) mental abuse (25%) physical abuse (23%) and sexual abuse (13%). Also research participants reported family members who suffered various health problems such as depression (43%) alcoholism (40%) an anxiety disorder (32%) and an undiagnosed mental illness (26%). Lastly, research participants reported financial problems as a familial stress factor (35%). In the study, of the 54 research participants who reported that their parent(s) regularly modelled anxiety, 70% stated that the role model was their mother, 18.51% that the role model was their father and 11% that both of their parents regularly modelled anxious behaviour. Of the 54 research participants, 65% stated that they developed anxious behaviour as children. In summary, the study suggests that parent(s) who regularly model anxiety and do not role model anxiety-coping mechanisms during familial stressful events may contribute to their children’s development of agoraphobia.

**Traumatic and Stressful Events**

In the study, people’s internalisation of trauma (self-interaction) due to a one-off traumatic event or cluster of traumatic events, or accumulated stressful events occurring within a social context, is seen to influence the internal and external interaction of the individual. For example, a person mourning the death of a close family member with other family members (a self-interaction interwoven with social interaction) may become anxious and/or depressed which influences their self-interaction and social interaction with others (personal withdrawal and social isolation).
In the literature review, studies showed that one-off traumatic events, clusters of traumatic events and accumulative stressful events included; a difficult childbirth, marital/familial conflict, the threatened or actual separation from a significant other (e.g. partner), the sudden collapse of a significant relationship, an illness/accident, the death in a partner, family member or close friend, financial problems, a near-death experience, bad drug reaction, sexual abuse, victim of crime, work-related stress, redundancy, exposure to a traumatic event out of home, or the witnessing of a traumatic event happening to others (Marks & Hearst, 1970, Shafar, 1976, Clarke & Wardman, 1985, Katon, 1984, Last, et al. 1984, Lelliott, et al. 1989, Wittchen & Essau, 1991).

This study supports those studies by showing that one-off or cluster of traumatic event(s) and/or accumulated stressful social interactions influenced the onset of agoraphobia. In the study, people indicated that social interactions within marriages, families and other relationships were a major source of traumatic event(s) or accumulated stressful events. This includes forming relationships, engagement/marriage, marital/familial/friendship stress, relationship conflict, family abuse (sexual, physical, mental and/or emotional), termination of relationships, bad social experiences, financial crisis, and the death of a friend or family member, etc. In the study, people indicated that social interaction around health-related issues affecting themselves and family members were a major source of traumatic event(s) or accumulated stressful events. This includes the abrupt onset of a major mental and/or physical illness, a major accident causing a significant injury and/or long-term disabilities, hospitalisation, and caring for a partner who had suffered a major accident or developed a long-term illness. Also, in the study, people indicated that social interaction around travel and environmental issues were a major source of traumatic event(s) or accumulated stressful events. This includes a bad travel experience, moving to a new living environment, adapting to a new social environment, conflict with social environment (e.g. neighbours), a traumatic event occurring in a public environment and experiencing environmental stress (e.g. excessive noise). In addition, in the study people indicated that social interaction in the workplace contributed to traumatic event(s) or accumulated stressful events. This includes school life, over-studying, exams and assessments, starting work, work performance, workplace harassment and redundancy. Finally, people indicated that social victimisation also contributed to traumatic event(s) or accumulated
stressful events. This includes being a victim of school bullying, crime, publicly humiliating jokes and social embarrassment.

The study shows that little gender difference occurred in the incidence of trauma as 73% of men and 75% of women reported that a one-off or cluster of traumatic events and/or accumulated stressful events preceded their initial panic attack. In addition, both male and female research participants reported a similar range of one-off or cluster of traumatic events and/or accumulated stressful events. Therefore, the study shows that male and female research participants are similarly affected by traumatic events and/or accumulated stressful events prior to the initial panic attack that triggers the onset of agoraphobia.

In summary, the study has shown that one-off traumatic events, cluster of traumatic events or a series of accumulative stressful events that precede the initial panic attack occur within social interaction, and that panic attacks and avoidance behaviours then influenced social interaction (e.g. social withdrawal).

The Initial Panic Attack

In the study, panic attacks were shown to be an overwhelming and terrifying experience for individuals. The research participants believed that they would lose control of their body and/or lose control of their mind during a panic attack. The research participants then attached fear-related meanings to their panic attack symptoms and reacted to both the panic attack symptoms and the attached fear-related meanings. In addition, people constructed an internal dialogue on the basis of these fear-related meanings during a panic attack. For example, a research participant experiencing heart palpitations would attach the fear of dying (i.e. from a heart attack) onto the panic attack symptoms and then construct an anxiety-inducing internal dialogue around the fear of their impending death. That person who is then fearful of their impending death starts to compulsively monitor their body for escalating panic symptoms, which reinforces their anxiety-inducing internal dialogue of the impending worse case scenario.

In the study, people spoke of the struggle between the powerful, compulsive, repetitive, over-analytical (i.e. self-monitoring) anxiety-inducing internal dialogue and the ability to assert their
rational self which could properly interpret and attach rational meanings to panic attack symptoms.

The study shows that research participants often confused the symptoms of a physical illness with that of a panic attack, due to the similarity between panic attacks (i.e. rapid heart beat, light-headedness and difficulty in breathing) and medical conditions such as heart attacks. Therefore, research participants can be seen to attach a meaning (e.g. physical illness) to their panic attack symptoms, which then influences their actions (e.g. seeking medical treatment).

The study has shown that research participants initial overwhelming and terrifying panic attack led to their avoidance of places and situations where the panic attack had happened. Also, these people reported that their panic attacks increased in frequency and transferred to similar places and situations where the initial panic attack had occurred. Research participants were shown to struggle to comprehend as to what was happening to them during a panic attack, and many believed that the place and situation was the actual trigger for the panic attack. These people attached a fear-related meaning to those places and situations and reacted to that fear-related meaning when entering those places and situations.

In the study, research participants stated that the fear of panic attacks was interwoven with their fear of social embarrassment in public places and situations. While research participants’ fear of panic attacks often inhibited their re-entering of public places and situations, the fear of social embarrassment often inhibited their escaping the panic attacks by fleeing the public place/situation.

The study suggests that research participants with agoraphobia act towards their panic attacks on the basis of the meaning that they have attached to the panic attack symptoms. For example, a person with agoraphobia who has a panic attack often attaches the fear of an impending life threatening crisis (e.g. heart attack). While the literature review has shown that psychological studies present a panic attack as a collection of psychological and physical symptoms, this study findings show that a sequence of social factors occur at the onset, during, and following the panic attacks. In addition, the study’s findings show that research participants’ attachment
of meanings to panic attack symptoms is central to the cognitive, behavioural and physiological sequence.

The cognitive, behavioural and physiological sequence includes:

- Research participants had a low level of confidence (or suffered a significant loss of confidence), prior to the initial panic attack.

- The lack of confidence (or significant loss of confidence) was due to high levels of stress.

- Research participants who had a lack of confidence (or loss of confidence) and high levels of stress were more prone to experience panic attack symptoms.

- The panic attacks’ occurrence in various places/situations (e.g. supermarket shopping, hanging out the washing, bank queue, or seemingly ‘out of the blue’) appears to be a random chance factor.

- The research participants experiencing the panic attack symptoms are normally unable to identify an external source for their panic attack, in contrast to people with specific phobia who are able to identify an external source for their panic attack symptoms (e.g. spiders, snakes, etc…).

- The research participants’ lack of an external focus for their panic attack meant that they tended to focus internally on their panic attack symptoms which led them to them identifying (attach meaning to) the panic attack symptoms as the actual feared object (e.g. panic attack symptoms as life threatening).

- The research participants’ focus on their panic attack symptoms, with the attached meaning of fear to those symptoms triggered the flight response. In addition, these individuals attached the fear of losing control of their mind or body to the panic attack symptoms.
• Therefore, fight/flight action is a response to the fearful meanings attached to the panic attack symptoms that originally triggered the fight/flight response.

• The research participants’ lack of confidence then caused them to flee (i.e. flight response) from the panic attack symptoms occurring in that public place/situation.

• As the research participants’ fled the panic attack, their panic attack symptoms subsided as the bodily movement used the surplus chemicals (oxygen and adrenaline) fuelling the panic attack symptoms. Panic attacks cannot be maintained indefinitely as the chemical imbalances caused by the panic attack symptoms return to normal levels during the flight response.

• The research participants’ flight from the panic attack, with the resulting reduction in the intensity of the panic attack symptoms, caused them to attach to the ‘flight’ action the meaning that it is a effective coping mechanism for panic attacks.

• Research participants who had an overwhelming and terrifying panic attack often attached to the place/situation a fear of a recurring panic attack upon re-entering that place/situation. Also, research participants who attached fear onto their panic attack symptom’s experience often monitored themselves for signs of panic attack symptoms when re-entering those places/situations, which increased their stress and triggered the panic attacks symptoms that then lead to another flight response.

• Research participants who had panic attacks in public places/situations usually flee towards their home, due to their pre-existing attachment of the meaning of safety to their home. In addition, some of these people attached the fear of social embarrassment to their panic attacks, which led to their avoidance of public places and situations where others could see their undignified flight from their panic attacks’ symptoms.
Research participants who were struggling with panic attacks and continually fleeing, often suffered a significant loss of confidence, which robbed them of the confidence to use coping mechanisms in the future to manage their panic attacks.

Primary & Secondary School Years

In the literature review, studies argued that there was a low incidence of agoraphobia among school children, and that school children who suffered anxiety had school phobia instead of agoraphobia (Chambless, 1982, Agras 1985, Chandler, 2002). The study’s findings challenge these studies, as research participants reported a high incidence of panic attacks and avoidance during their primary and secondary school years. The findings show that 40% of research participants had panic attacks/avoidance at primary school, and 43% of research respondents had panic attacks/avoidance at secondary school. In addition, 45% of the research participants who reported panic attacks/avoidance behaviours at primary school, and 37% of research participants who had similar experiences at secondary school stated that their panic attacks and avoidance behaviours continued into their adult life after leaving the school environment. The study’s findings show that a high percentage of research participants were experiencing agoraphobia (not school phobia) in a public place/situation (e.g. school environment), which transferred to other public places (e.g. supermarkets) in later adult life.

The study’s findings show that panic attacks and avoidance at primary school and secondary school occurred equally between male and female research participants. In the findings, 40% of men and 41.11% of women had panic attacks and avoidance behaviour during their primary school years. In addition, 46.66% of men and 42.35% of women had agoraphobia during their secondary school years.

In the study’s findings, several research participants reported that they had panic attacks without actually developing avoidance behaviours during their school years. This study argues that school children with agoraphobia who are forced by parental expectations and state regulations to regularly attend school, simply endure the panic attacks in the school situations where escape is difficult (e.g. school bus, classroom, assembly). This finding suggests that a significant number of school children have functional agoraphobia, which goes unrecognised
by parents and/or school authorities due to the lack of the outward appearance of physical symptoms and/or absentee behaviour. School children often do not disclose their panic attacks to parents, teachers, counsellors or health professionals, as they interpret their panic attack symptoms as a personal weakness, and are fearful of the negative judgements from interacting with others (e.g. informing others). The study’s findings show that a higher number of research participants had unreported and undiagnosed agoraphobia, as school children, than would have been expected from the low numbers indicated in the literature review.

In the study, research participants reported that panic attacks at school were less intense, less frequent and not as disruptive to their life as later adult panic attacks. A possible explanation is that the parental and state requirement of children to regularly attend school created a ‘forced exposure’ situation where the child learned to suppress their anxiety, which arrested its development. In later adult life the lack of parental and state enforced exposure in public places and situations meant that the panic attacks could become more intense, frequent and disruptive in their lives (e.g. person becomes homebound).

In the literature review, some studies state that school children develop agoraphobic symptoms immediately following an exposure to a traumatic event, while other studies argue that a traumatic event is not sufficient to cause agoraphobia among children (Clarke & Wardman, 1985, Saul, 2001). The study’s findings show that while some research participants developed agoraphobia following a traumatic school-related event (e.g. school bullying), other factors including family upbringing and familial stressful events were major contributory factors in the development of agoraphobia among these research participants as school children.

In the literature review an author speculated that school children with agoraphobia would suffer a significant disruption in their academic and social development (Agras, 1985). In addition, a study showed that school children with agoraphobia often had panic attacks while travelling to school, in the school classroom, on field trips and during school performances, which would disrupt academic and social activities (Chandler, 2002). The study’s findings confirm this speculation by showing that research participants who had agoraphobia at school, reported that panic attacks and avoidance behaviours affected their travelling to school, participation in the
classroom, playground, assemblies, choir, performances, sports teams, field trips, social events, and school responsibilities such as librarian, council, etc.

The findings have shown that female and male school children are equally affected during their primary and secondary school years by agoraphobia. In the study 40% of male research participants and 41% of female research participants reported having had panic attacks and avoidance behaviours at primary school. At secondary school, 46% of men and 42% of women indicated that they had panic attacks and avoided places/situations. In summary, this research shows that both male and female research participants were affected by panic attacks and avoidance behaviours during their school years. While a similar number of male and female research participants had panic attacks and avoidance during their school years, female research participants were more likely to report their panic attacks and avoidance to health professionals in later adult life. It could be that the male research participants had infrequent contact and were less socialised into informing health professionals than female research participants who were more socialised by contacting health professionals for contraception, antenatal/post-natal care, children’s vaccinations, as well as reading health related articles in women’s magazines.

Youth
This study supports other studies in that it shows that agoraphobia had a major impact on the lives of young adults. This study shows that the major effect of agoraphobia in this age group is that youth miss out on youth orientated experiences including; youthful spontaneity, forming casual intimate relationships, social drinking, socialising in public places, participating with friends in public entertainment (e.g. rock concerts) and travelling overseas.

Struggling with Everyday Life
In the study, research participants were shown to fear having panic attacks, and avoided a large number of public places and situations where they feared having a reoccurring panic attack. These places and situations include: the movies, shopping malls, lifts, travelling on a bus, churches, sitting in a hairdressers chair, etc. Therefore, the research participants restricted their everyday experiences due to the fear that they attached to public places and situations of triggering their panic attacks and causing loss of control or social embarrassment. These
research participants restricted their everyday experience of public places and situations by limiting their time spent in public places and situations, as well as limiting the distance they were willing to travel from the safety of their home. In addition, research participants planned their everyday activities in advance (e.g. routes, companions), to make themselves feel safe when venturing into public places and situations. This planning robbed the individuals of a feeling of freedom and spontaneity in their daily life and normalised the expectation of panic attacks in public places and situations. The research participants’ combination of advanced planning, time and travel restrictions led to an increasingly restricted life-world of everyday experiences.

The study has shown that research participants often had a whole day of activities disrupted by a single panic attack (e.g. a panic attack travelling on the bus disrupts a trip to the supermarket, which reduced their participation in community activities). Therefore, the study shows that research participants self-interaction (i.e. panic attack) is interwoven with their social interaction (e.g. travelling on the bus), which influences that specific social interaction (e.g. unable to complete bus ride to supermarket). In addition, research participants would often worry excessively about having a panic attack in a social situation, to the extent that they talked themselves out of engaging in those activities. Therefore, the person’s self-interaction often involved an internal dialogue of anxiety-inducing thoughts about having a panic attack that then inhibited their undertaking of social interaction in community activities. The research participants’ excessive anxiety-inducing thoughts and worrying often affected their cognitive functioning (i.e. decision making) in the public place/situation situation. Therefore, the study shows that research participants’ self-interaction (e.g. anxiety-inducing thinking) and social interaction (e.g. public participation) were often happening at the same time.

In the study, most research participants simply endured their panic attacks while continuing to struggle to complete everyday tasks in public places/situations. In these cases, people often became reliant on coping mechanisms such as distraction techniques to enable them to function normally in their self-interaction (e.g. control their anxiety inducing thoughts) and their social interaction (e.g. public participation). The study shows that research participants often developed personal coping mechanisms to avoid panic attacks in public places and situations.
These strategies included venturing out during quiet times of the day to do everyday activities, or asking/manipulating parents, partners, family members, friends, neighbours and others to undertake tasks for them. In addition, research participants often used a companion to accompany them into various public places and situations. However, when the research participants were the primary provider or caregiver, they had to often force themselves to endure their panic attacks during these everyday activities (e.g. paid employment, family shopping, etc) for the benefit of their dependants. In the study these people often believed that their panic attacks would simply fade if they persevered with their everyday activities. However, the lack of effective coping mechanisms to reduce anxiety meant that the panic attacks did not decrease, which led to individuals being trapped in a cycle of recurring panic attacks, steadily reducing their resolve and energy to continue these everyday activities.

**Travel Restrictions**

In the study, research participants regularly attached the fear of having a recurring panic attack to public places and situations, which then shaped their experiences in those places and situations. In the study, people would attach the fear of having a recurring panic attack during the use of different modes of transportation, including: walking, cycling, cars, buses, trains, ships and aircraft. In addition, people regularly attached fear to a wide range of travelling environments including: overseas, cities, towns, and countryside and often felt fearful and trapped in traffic conditions such as traffic lights, in middle lane of traffic, travelling over long-spanned bridges, on the motorway or stopped at road works. It seems that the person’s attachment of fear to having a panic attack and being in a place/situation where they could not readily escape, increased their likelihood of panic attacks.

The study shows that research participants’ fear to travel situations often affected their everyday life experience including: travelling on everyday trips (e.g. school and employment), weekly trips (e.g. grocery shopping, paying bills and doctor appointments), and periodically, long distances (e.g. visiting extended family and friends). In addition, travelling, whether everyday, weekly or periodically required major preparations (e.g. mental preparation, designing safe routes, and arranging companions, which were excessive for the task. People’s
fear of travelling created a life-world of experience that was socially and economically restrictive and disconnected them from social interaction in the community.

In the study, research participants’ were shown to develop personal coping mechanisms to deal with the fear of having panic attacks during travel including: the usage of excuses to avoid travelling, the avoidance of travelling at busy times, the avoidance of feared traffic structures (e.g. bridges, motorways, etc), accompaniment of a companion as a ‘calming’ influence, distraction techniques and regular breaks.

In summary, the study has shown that agoraphobia has a major effect on research participants’ ability to maintain their social interaction with the community due to the major disruption to their ability to travel.

Social Restrictions of Agoraphobia

The study shows that research participants often forced themselves to endure panic attacks in public places and situations to maintain the social life of their families (e.g. parents with agoraphobia attending school performances), while withdrawing from social activities that were seen as less important to the social life of the family. Also, people regularly struggled to attend major social events (e.g. family weddings and funerals, etc) which sometimes led to family estrangement and social isolation from offended family members. Alternatively, research participants often manipulated family members and friends into visiting them in their home, to avoid travelling away from the safety of their own homes.

In the study, people who did regularly attend family events out of a sense of social obligation to other family members often felt anxious and trapped in the place/situation, which ruined their enjoyment of the family event. In addition, people often struggled to retain confidence and use social skills, which are essential to interaction during social activities and therefore became more socially isolated. The social consequence is that individuals become trapped in the daily cycle of panic attacks and avoidance, as well as missing out on a social life. These people are often prevented from doing the things that they love to do. In these instances individuals miss out on pursuing their dreams, while becoming trapped in an unwanted lifestyle for many years
which leads to an unfulfilled life. In the study, many research participants believed that the reason they had missed out on doing things in life was due to their panic attacks, their lack of knowledge of agoraphobia, lack of services and supports and the stigma towards mental illness.

Public Perception of Agoraphobia
The study shows that research participants often struggled to understand their agoraphobia and were often unable to properly explain their mental illness to others. These research participants believed that the public was often ignorant and misinformed about agoraphobia and its effect on sufferers’ lives. People argued that the public perception of agoraphobia was constructed by the mass media (e.g. television programmes) and publicised misinformation (e.g. dictionaries that incorrectly defined agoraphobia). Some people reported that family, friends and others either dismissed or minimised panic attacks as an unpleasant experience and ridiculed the individual’s claims that it was a very distressing and disabling experience. Therefore, the public reaction to people with agoraphobia was directly influenced by the meanings attached to the mental illness by mis-information in the public domain.

In the study, research participants stated that they either feared, or had experienced, negative value judgements from family, friends, colleagues and others, due to negative attitudes towards mental illness. People reported being labelled as ‘nuts’ or ‘crazy’ and in some instances were ‘joked about’ by family, friends, colleagues and others. In some cases, the stigma and discrimination towards them made people feel that they no longer belonged among ‘normals’ in society. The stigma and discrimination often forced these people to hide their mental illness from family, friends and others. When people made a public disclosure that they had an anxiety disorder it often led to social embarrassment which led to the avoidance of further public disclosure.

Hidden Agoraphobia
The findings have shown that by research participants’ fear of the public disclosure of their mental illness and their fear of negative value judgements often forced them to hide their agoraphobia from others. In the study, people reported that they were fearful that public disclosure would lead to them being treated differently following the disclosure. In the study,
people hid their agoraphobia from others by shifting the focus of attention from themselves to other family members’ problems, putting on an ‘act’ to mask their agoraphobia, making excuses to avoid places/situations, and by selecting public places/situations where they felt safe from having panic attacks. This strategy of non-disclosure and avoidance often led individuals to deliberately distance themselves from family members with resulting increased social isolation and alienation.

Making Excuses
The study shows that research participants often felt ashamed of having panic attacks, and feared negative value judgements and social embarrassment, and felt the need to protect their privacy by regularly making excuses to others to hide their agoraphobia. Therefore, people’s self-interaction (e.g. feelings of shame and embarrassment) was interwoven with, and influenced their social interaction. In the study, people were shown to use lies and deception as a normalised part of their life as a form of social survival which they may not have otherwise developed during their life. People regularly made excuses to avoid doing things and to manipulate others into doing things that they could not do themselves, which enabled the individual to survive everyday life (e.g. supermarket shopping, paying bills, etc). However, people reported that the regular usage of lies and deception often damaged their self-image and feelings of self-worth. People often experienced an internal conflict between the desire to be a truthful individual while needing to be a dishonest person to socially survive. In addition, people reported that the regular making of excuses and avoidance behaviour led to social distancing from others and that when family members and friends learnt about the lies and deception they often distanced themselves from the individual.

In summary, the study has shown that most research participants regularly made excuses to avoid places and situations where they fear having a panic attack. Also, people lied to protect their privacy and to avoid the social stigma and discrimination associated with mental illness. However, research participants often suffered a crisis of conscience about their lying and deceiving of others. These people would not have had to hide their agoraphobia if mental illness was more socially understood and accepted.
Coming Out about Agoraphobia

The findings have shown that research participants often experienced the need to tell others that agoraphobia is a part of their identity and life experience, to gain acceptance and understanding from family and friends. The study has shown that people often struggled between telling the truth about themselves or hiding their mental illness to avoid negative value judgements and discrimination. These people were careful to tell others that they knew they could trust to be understanding and supportive, while continuing to hide the truth from strangers. Unfortunately, some people who did tell family, friends and others encountered ignorance, lack of understanding, and disbelief that they had panic attacks due to the lack of visible symptoms. People often felt uncomfortable and emotionally distressed when telling others, due to the fear of making a fool of themselves, being seen as a mentally unstable person and the possibility of social isolation and alienation from their families and friends. In some cases, people made a partial disclosure to others about having a mental illness by claiming to have claustrophobia, which is more readily accepted and understood by the general population. In addition, the person’s claim of claustrophobia allowed them to escape the panic attack and feeling of entrapment in the public places/situations without the social stigmatisation attached to revealing to others a more serious mental illness (i.e. agoraphobia). In summary, the study has shown that research participants often struggled to come out about their mental illness due to the fear of negative reactions from others. Hopefully, as public awareness increases about agoraphobia and stigma and discrimination reduces to mental illness, people will be more willing and able to disclose their mental health disabilities.

Public Reaction to Disclosure

In the study, people who made a public disclosure of their panic attacks often experienced trauma when describing and discussing their panic attack symptoms due to negative reactions from others. These negative reactions included: lack of understanding about panic attacks, disbelief that they were having panic attacks, trivialisation of their effect on everyday life and their mental health condition, and/or being treated as abnormal. In some cases, family members, friends and others told the person with agoraphobia to simply ‘snap out’ of their panic attacks or insisted that the person should simply assert control over their thoughts and
feelings. Some people lost a large number of friends following the disclosure of having agoraphobia.

However, some people reported that the public disclosure led to positive experiences such as family members and friends becoming more understanding and supportive. The study shows that people often found it easier to tell others after successfully learning to manage their panic attacks as they had acquired the confidence and knowledge to deal with any problems that arose from telling people about their mental illness. In addition, people were more comfortable making a public disclosure to others who were themselves knowledgeable and/or experienced about panic attacks. In summary, research participants had both positive and negative reactions from public disclosure, which sometimes lead to close and supportive relationships and other times to social devaluation and social isolation.

Marriage/Intimate Relationships

In the study, research participants were shown to struggle to form intimate relationships, due to their internalised feelings (i.e. self-interaction) of low confidence, shyness and feelings of worthlessness that affected their ability to form and retain intimate relationships. For example, in the study 16% of research participants stated that their low confidence, shyness and anxiety (due to their agoraphobia) severely restricted their ability to socialise in public places/situations to meet a wide range of potential partners.

In the literature review, some social scientists believed that women with agoraphobia who tended to have low levels of confidence entered dependent-orientated relationships with male partners (Fodor 1974, Chambless, 1983). The social scientists argued that these women often sought a partner whom they felt would compensate their lack of confidence in public places and situations (Fodor, 1974). This study supports this argument as most female research participants reported that they sought partners who were more confident, assertive, protective and supportive than them. In addition, the study has shown that female research participants regularly relied on their partner as their ‘safe’ person in public places and situations. However, these partners sometimes became resentful towards their partner with agoraphobia, due to the development of dependency issues within the marriage/intimate relationship.
In the literature review, clinical studies have shown that people with agoraphobia often (involuntarily) place considerable strain on their marriage/intimate relationships (Dumont, 1997, Kleinknecht, 1986). These people with agoraphobia often adopted a reclusive lifestyle that required them to manipulate their partners and other family members into taking a greater share of the roles and responsibilities in the family, especially beyond the family home (Dumont, 1997). In addition, the person’s reclusive lifestyle disrupted familial, social and recreational activities in public places/situations (Kleinknecht, 1986). This study supports these studies as 14% of research participants reported that they regularly manipulated their partners and family members to do activities in public places/situations for them to avoid panic attacks. In addition, research participants would either avoid family-related events or force themselves to attend these family-related events to appease their partner (and family members), to meet social obligations, and/or to avoid damaging their relationships with other family members. Those research participants who did attend family-related events often struggled to socialise with their partner (and family members) in those public places/situations. While research participants often forced themselves to attend family-related events most simply endured the event and hid their agoraphobia from their partner and family members to avoid social embarrassment to themselves and others.

In the literature review a greater percentage of women were shown to have concerns about disharmony in their marriages/intimate relationships (Thorpe & Burns, 1983, Greist, et al. 1986). The literature review argues that women as the emotional caretakers in marriages/intimate relationships are more aware and concerned about disharmony in the marriage/intimate relationship, compared to their male partners. This study challenge’s that view as 93% of men, compared to 75% of women reported that agoraphobia affected their marriage/intimate relationship. In the study, male research participants reported that they were more dependent on the support of their partner than female research participants, who had the physical and emotional support of companions (family, friends, neighbours, etc). However, female research participants were more financially dependent on their partner, due to their role as unpaid housewives and mothers and the higher incidence of homebound agoraphobia among these women.
In the literature review, people with agoraphobia were shown to suffer a significant
deterioration in their panic attack symptoms due to stress occurring in their marriages/intimate
relationships (Mathews, et al. 1981, Jansson, et al. 1984). This study supports this viewpoint by
showing that research participants often endured stress in the relationship due to their partners’
unwillingness to acknowledge that their panic attacks were happening, partners’ indifference
towards the panic attacks, and partners’ unwillingness to talk about mental health issues. The
partners’ unwillingness to acknowledge or talk to their partner about their panic attacks was due
to the invisibility of the panic attacks, which meant that partners could not ‘see’ a problem. In
the literature review, studies showed that a source of relationship dysfunction was that people
with agoraphobia often suffered a loss of sexual arousal, which contributed to stress between
partners (Gournay, 1989). In the study, several female research participants were shown to
suffer impaired sexual performance due to their lack of self-confidence, feelings of
unhappiness, depression, side effects of anti-depressant medication, anxiety, tiredness, and/or
the belief that sexual arousal was a sign of an impending panic attack.

In the study, research participants reported that relationship conflicts occurred due to their
inability to overcome their anxiety and socialise with their partner in public places/situations.
Some research participants reported that their partners became impatient, resentful and angry
towards them, due to their avoidance of social outings. In some cases, the stressful nature of the
marriage/intimate relationship spiralled downwards into conflict and mental and emotional
abuse. This study revealed that 9% of research participants (all of them women) suffered abuse
following the development of their agoraphobia. In the study, female research participants who
were trapped in abusive relationships suffered a dramatic loss of confidence and self-esteem,
which contributed to their panic and avoidance symptoms. These research participants became
trapped in unsatisfactory and/or abusive relationships, possibly due to their mental illness
undermining their confidence to assert themselves in the relationship, as well as undermining
their ability to function in public places independent from their unsatisfactory/abusive partner,
who was often their support person. While the literature review showed that people with
agoraphobia often contributed to stress in the marriage/intimate relationship, this study shows
that the reaction of partners and/or family members to the panic attacks also creates stress in the
family relationships.
In the literature review, clinicians argued that partners (and family members) often play a positive and supportive role in helping the person with agoraphobia to manage their panic attacks by changing their role with the marriage/intimate relationship (Greist, et al. 1986, Saul, 2001). This study supports those clinicians’ statements as 48% of research participants reported that their partners appreciated the seriousness of their panic attacks and encouraged, as well as supported, their seeking of medical treatment. In addition, 35% of research participants stated that their partner acted as their support person during their agoraphobia. However, the study shows that some partners struggled to support their partners due to their lack understanding about panic attacks and lack of practical skills to provide appropriate support during the person’s panic attack. It seems that the research participants required their partners’ to be knowledgeable about panic attacks, as well as cognitive behavioural techniques to effectively support them during a panic attack. In summary, the study has shown that research participants had problems in their marriages/intimate relationships due to agoraphobia. However, those research participants who had a partner who was accepting, understanding, and able to provide practical support had a much closer and stronger marriage/intimate relationship.

Parenting Experience

The findings have shown that agoraphobia had a major effect on the parenting/childcare skills, abilities and experiences of research participants. The study has shown that some people believed that they have a genetic predisposition towards anxiety disorders, and decided not to have children due to their fear that their mental illness would be passed onto their children. People who had children often felt guilty about their decision to have children; their inability to do things with their children, letting their children down and burdening their children with adult responsibilities (e.g. doing out-of-home activities). In addition, parents were often fearful that they were role-modelling anxiety to their children, that there was an ongoing effect of anxiety on their developing children, and that their children may then develop agoraphobia. These parents with agoraphobia often struggled to participate in everyday activities with their children including: pre-school and kindergarten sessions, school trips, school sport events and performances, school camps, out-door recreation programmes, socialising with peer groups, visiting extended family, church attendance, doctor and/or dental appointments, swimming sessions, music and dance classes, long distance travelling, etc. In addition, these parents often
struggled to participate in family related activities including family holidays and formal family functions.

The study shows that these parents often used family members and sometimes their children as ‘safe’ persons when they entered public places and situations. These parents sometimes used the caregiver role (i.e. concern about others needs) as a distraction from their anxiety in public places. In addition, some parents used their children to do out-of-home activities to enable them to avoid public places and situations where they feared the occurrence of a panic attack. In some cases, parents who regularly used their children as a ‘safe’ person, distraction or a means to avoid, developed a dependency on their children.

The study has shown that female research participants often withdrew into the family home to avoid panic attacks in public places and situations. However, these mothers often had to force themselves to endure panic attacks in public places/situations, as other family members could not or would not undertake family-related activities in those public places/situations. However, some mothers were able to transfer their responsibilities on to friends and neighbours such as arranging for others to transport their children to pre-school, which allowed the mother to maintain her avoidance of public places and situations.

The study shows that a large number of research participants as parents hide their mental illness from their children, to protect their children from developing the fear that they would develop agoraphobia. These parents often decided to delay telling their children until they were older, so that they were more mature and more understanding and supportive of their parent’s mental illness.

In summary, the study has shown that research participants’ agoraphobia had a major effect on their parenting skills, abilities and experiences.
Post-Secondary School Education

In the literature review, the United Kingdom’s National Survey showed that people with agoraphobia often struggled to attain post-secondary qualifications compared to the general population (Canino, et al. 1987). In the survey of 963 people with agoraphobia, only 11.9% undertook post-secondary education (e.g. trades) and merely 0.7% completed University studies (Thorpe & Burns, 1983). This study shows that 55% of research participants reported that their post-secondary school education was adversely affected by agoraphobia. As students, these people were unable to concentrate, follow instructions, retain and recall information due to their high levels of anxiety and panic attacks. In addition, these people struggled to travel long distances to attend polytechnics and universities, participate in lecture auditoriums, classrooms, class activities and field trips, or sit tests and examinations. Some people feared the public embarrassment of having a panic attack in the physical and social environment. In addition, the tendency of lecturers and teachers to speak for long periods of time without breaks meant that students often focused on their anxious thoughts and feelings, increasing the likelihood of panic attacks. These people often endured panic attacks, or dropped out of post-secondary education. In some cases, people undertook correspondence courses to complete their post-secondary education. In summary, the study has shown that research participants’ agoraphobia often had an adverse effect on their post-secondary education and undermined their confidence, educational performance, which affected their employment chances, income-earning potential, and future lifestyle choices.

Employment

In the literature review, the United Kingdom’s National Survey of Agoraphobics, showed that people were reluctant to travel long distances to work, accept promotions, engage in public speaking roles or accept work-related responsibilities due to their agoraphobia (Marks & Hearst, 1970, Burns & Thorpe, 1977). In addition, people were fearful that any work-related absence due to panic attacks would endanger their employment (Marks & Hearst, 1970, Burns & Thorpe, 1977). This study contributes to those studies by showing that 60% of research participants had their work performance significantly impaired by agoraphobia. In the study, people struggled to travel to their workplace, settle into the workplace, learn work skills and deal with stress in the workplace environment. People were often fearful of having panic
attacks and suffering social embarrassment. These people often struggled to suppress their panic attacks, to relax and to stop themselves from constant worrying about impending panic attacks. These people regularly avoided perceived anxiety-inducing situations, public speaking, handling of customer relations, conflict situations and extra work-related responsibilities. In addition, people would avoid seeking other (i.e. better) employment if it required leaving the safety of their current workplace. The research participants would often suffer impaired work performance due to these problems and became trapped in unsatisfying workplaces, had less employment choices and low income earning potential compared to able-bodied workers. In addition, research participants were often unwilling and unable to report their ‘problems’ to their employers and/or colleagues due to possible stigma, discrimination and social embarrassment towards mental illness. Those people who chose to inform their managers, supervisors and/or co-workers of their condition often reported negative reactions including: lack of acceptance and understanding, gossip, confrontations, ostracism, harassment and victimisation. However in some cases, people had a positive reaction from others in the workplace, including encouragement, understanding and acceptance.

In the study, research participants often developed strategies to cope with their anxiety including: the usage of prescription medication and/or alcohol to suppress their panic attack symptoms as well as the avoidance of workplace situations that they believed would trigger a panic attack. However, people who continued to struggle in their workplace often lost their confidence and left their employment. These people often became trapped in a downward spiral of panic attacks, loss of confidence, unemployment, welfare benefit dependency or financial dependence on a partner.

In the literature review, the ‘United Kingdom National Survey of Agoraphobics’ showed that 41.96% of men expressed a concern about their inability to acquire work compared to 14% of women (Thorpe & Burns, 1983, Greist, et al. 1986). In this study, 87% of male research participants, compared to 55% women reported that agoraphobia affected their employment. In the study, female research participants were more willing to leave their paid employment to become financially dependent on their partner than male research participants, who were less willing to become financially dependent on their partner, due to the concern that this would
damage their self-esteem as men (i.e. breadwinner role). In summary, this study has shown that agoraphobia had a major effect on the employment experiences of research participants.

**Welfare Beneficiaries**

In the literature review, the United Kingdom’s National Survey of Agoraphobics, reported that 60% of its respondents were registered as unemployed and that 83% of the respondents had stated that their anxiety disorder prevented them from seeking employment (Burns & Thorpe, 1977). In this study, 22% of research participants reported being forced to leave their employment and registering on a state welfare benefit due to their agoraphobia. This level of unemployment was significantly higher than the able-bodied population. In the study, people were registered on different types of welfare benefits such as unemployment, sickness, invalid, and domestic purposes benefit. These people often suffered the double stigma and discrimination of being labelled, categorised and devalued as being both mentally ill and welfare beneficiaries. In the study, the majority of research participants stated that they wished to get off the welfare benefit and return to employment to achieve financial independence and to improve their socioeconomic status and life chances. However, these people required effective coping mechanisms (e.g. cognitive behavioural techniques) to manage their panic attacks to seek and retain employment.

**Homebound**

In the literature review, Dr Green, the author of ‘Living Fear Free: Overcoming Agoraphobia’ argued that people would normally endure their panic attacks and continue functioning in public places/situations, while others would withdraw into the perceived safety of their homes to live a very restricted life (Green, 1985). In this study, 70% of research participants reported that they initially withdrew into their homes for various periods of time, and then returned to public places/situation and endured their panic attack symptoms. The study has shown that the initial panic attack was often an overwhelming and terrifying experience that caused people to immediately withdraw into their home. In the study, research participants reported an increased sense of personal wellbeing by withdrawing into the home. These people saw their home as a safe haven, where they could relax and have a sense of wellbeing as well as escape the fear of having panic attacks in public place/situation. However, the person’s withdrawal into the home
required the manipulation of family members to undertake tasks in public places/situations (e.g. supermarket shopping). In some cases, people attempted to draw others (e.g. hairdresser) into their home to avoid venturing out into public places/situations (e.g. hair salon) where they feared having a panic attack. The research participants would return to public places/situations several days, weeks, months or years later using various coping mechanisms (e.g. alcohol, distraction, companions, etc), that helped them endure the panic attacks in public places/situations.

In the literature review, studies stated that more women than men became homebound (Thorpe & Burns, 1983). These studies argued that the patriarchal society’s expectation that men ought to be engaged in paid employment, forced them to continue working and enduring panic attacks in public places and situations. In contrast these studies argued that the patriarchal society often pressured women into working in the private space of the family home, which meant that women were more able to retreat to the perceived safety of their homes (Clarke & Wardman, 1985). Therefore, patriarchal expectations and pressures were seen to influence women to develop homebound agoraphobia (Clarke & Wardman, 1985). This study challenges the view that a larger percentage of women become homebound. In the study, 54% of female research participants and 46% of male research participants became homebound. The female research participants spent longer periods homebound than did the male research participants. These female research participants stated that they felt that it was socially acceptable for them to leave the workforce and withdraw into the home as housewives and mothers. The male research participants spent several days or weeks homebound and then returned to the workforce to be the provider. This study suggests that a roughly equal number women and men initially became homebound, but that men who return immediately to the workforce may not count themselves as having been homebound. Therefore, the literature review studies can be challenged on the argument that a greater number of women become homebound.

In the literature review, social scientists argued that men tend to drink more alcohol, which allows them to ‘self-medicate’ themselves sufficiently to suppress their panic attack symptoms to enable them to continue functioning at their work in public places (Clarke & Wardmen, 1985). This study supports that argument, as a greater proportion of male research participants
reported regularly using alcohol as a form of self-medication to enable them to function in public places and situations. In summary, the study has shown that research participants often become homebound in the early stages of their agoraphobia and that some force themselves immediately to return to those public places and situations to resume social obligations such as employment.

**Personal Coping Mechanisms**

The findings have shown how research participants used personal coping mechanisms in an attempt to suppress their panic attacks. The study shows that research participants’ initial coping mechanism for panic attacks was avoidance of the public places/situations where the panic attacks were happening to them. Those people who had to force themselves (e.g. work obligations) into public places and situations, often developed safe routes to avoid panic attacks occurring in places and situations where previous panic attacks had happened. Also, people often had safe places/situations (e.g. public toilets) on the route and in the place/situation that allowed them to take time out from the panic attack. In addition, people regularly used a companion to provide reassurances and support during their ventures into public places and situations. Those people who ventured out alone often used a wide range of distraction techniques including counting, writing and reciting affirmations. The personal coping mechanisms helped to disrupt the person’s anxiety-inducing thoughts that preceded the panic attack. However, the personal coping mechanisms failed to control the panic attack’s physical systems (e.g. hyperventilation) which fuelled the panic attack. Some research participants reported that they regularly used prescription medications, cigarettes, alcohol and/or cannabis to suppress the physiological symptoms of their panic attack.

The study has shown that research participants’ usage of personal coping mechanisms often hindered the usage of medically approved treatment techniques (i.e. cognitive behavioural therapy). These people often developed a reliance on their personalised coping mechanism and were reluctant to use a new, unfamiliar, and untried coping mechanism in a crisis situation such as a overwhelming and terrifying panic attack. The study has shown that research participants preferred to use a partially effective personalised coping mechanism that was known and
trusted by them to have some effect on suppressing their panic attack, than use a medically approved coping mechanisms that simply promised more effective management.

In summary, the study has shown that research participants often developed personalised coping mechanisms to help suppress their panic attacks. However, these coping mechanisms often failed to properly manage the panic attack symptoms and sometimes hindered the person’s usage of medically approved techniques.

Alcohol

In the literature review, studies have shown that people with agoraphobia often use alcohol to suppress their panic attack symptoms. This study supports those studies by showing that 36% of research participants used alcohol, as a form of self-medication, to suppress their panic attack symptoms. In the study, people reported using alcohol prior to entering places and situations where they feared having a panic attack, and/or to settle their nerves when feeling anxiety in public places/situations.

In the literature review, studies argued that people with anxiety disorders often develop alcohol dependency problems more rapidly than the general population (Mullaney & Trippett, 1979, Gold, 1989). This study shows that the majority of research participants were responsible users of alcohol, and only a small number developed a dependency problem. In the study, 23% of people reported occasionally using alcohol to suppress their agoraphobia, 8% regularly used alcohol to suppress their agoraphobia, and 5% reported excessive usage of alcohol to suppress their agoraphobia, which led to dependency problems.

In the literature review a greater number of men than women were seen to use alcohol to suppress their panic attack symptoms (Saul, 2001). This study has shown that 60% of the male research participants, compared to 32% of female research respondents used alcohol to suppress their panic attacks/anxiety symptoms. In the literature review, a Canadian study argued that men believed it was more socially acceptable for them to drink in public places/situations, compared to women (Saul, 2001). This study lends support to that argument
as more male research participants reported that they believed it was socially acceptable for them to drink in order to suppress their panic attacks, than female research participants.

In the literature review, some social scientists argued that women preferred prescription medication, to alcohol, as a coping mechanism compared to men, which is the reason for the lower number of women using alcohol to suppress their panic attack symptoms. (Gournay, 1989). This study tends to support that view as more female research participants reported using prescription medication to manage their panic attacks, than male research participants.

In the literature review, studies argued that the usage of alcohol had a negative effect by prolonging and worsening the panic attack symptoms, as well as affecting the effectiveness of prescription medication being used to suppress the panic attack symptoms (Gold, 1989). The findings have shown that research participants often saw a benefit from the usage of alcohol in the management of their panic attack symptoms. These people spoke of alcohol as equipping them with the confidence to manage their panic attacks, which allowed them time-out from their panic attacks, as well as allowing them to hide their panic attacks from others and continue their participation in public places and situations (e.g. education, employment, etc).

In the study, people argued that alcohol had several major advantages over the usage of prescription medication as a coping mechanism.

- People could purchase alcohol more readily than prescription medication (e.g. local supermarket purchase compared to GP appointment, waiting room, consultation and chemist).
- People could purchase alcohol at their supermarket as a ‘normalised’ everyday transaction, while people had to present themselves as mentally unstable to a GP or other health professional to acquire a prescription for anti-depressant medications.
- People believed that there was less social stigma attached to social drinking to suppress anxiety, than using anti-depressants.
- People felt more comfortable being seen socially drinking that being seen taking anti-depressant medication.
• People felt that the usage of alcohol and the social interaction with others enabled them to feel more relaxed in social situations.
• People could use alcohol at short notice as and when required, while anti-depressant medication often required weeks to take effect.
• People had more confidence and feeling of control in their figuring out of the amount of alcohol required to effectively suppress their anxiety, while people often felt uncomfortable relying on a health professional’s guesswork of the dosage of prescription medication required to suppress the panic attack symptoms.
• People were less worried about the side effects of alcohol compared to prescription medication.
• Finally, the physical presence of, and the regular intake of anti-depressants acted as a constant reminder that the person had a mental illness, while a bottle of wine in the fridge allowed the person to forget about having a mental illness and allowed them to feel more ‘normal’.

However, the study shows that alcohol was only partially effective in suppressing panic attack symptoms, which returned when the effects of the alcohol decreased. It could be that people’s reliance on alcohol delayed and hindered their usage of cognitive behavioural therapy and prescription medication. In addition, research participants’ excessive usage of alcohol without proper external monitoring processes (e.g. health professionals) sometimes led to other health problems (e.g. alcoholism, liver damage). In some cases, people who attempted to cease using alcohol felt that they did not have an effective coping mechanism to manage their panic attacks, and returned to using alcohol. In summary, the study has shown that a significant number of research participants responsibly used alcohol to suppress their panic attacks, however the excessive usage of alcohol could lead to health and dependency problems.

Labelling and Learning
The study has shown that research participants usually did not learn the name for their ‘strange thoughts and feelings’ for many weeks, months or years. These people often believed that the ‘strange thoughts and feelings’ were a unique personal weakness, social inadequacy, physiological problem or mental illness. In the study, people were shown to struggle to identify
and understand their problem, and most learnt that their problem had a label - agoraphobia - by chance social interaction with others. These chance encounters included television and radio programmes, women’s magazines, newspaper articles and advertisements, leaflets, books, libraries, Citizens Advice Bureau, Internet, family members, friends, co-workers and strangers. People often struggled to relate their ‘problem’ to the description of panic attacks in literature, due to the overuse of scientific jargon, instead of everyday language, while people readily connected with personal accounts of others who had similar experiences. These personal accounts helped people to attach meaning to their thoughts and feelings. Generally, the personal accounts gave research participants reassurance that they were not going ‘crazy’ or that they were suffering alone. In addition, people were able to use these personal accounts to place a name on their problem, identify a cause for their panic attacks, correct misinformation about agoraphobia, as well as learn about practical coping mechanisms and treatment programmes. When people had ‘figured out’ that their strange thoughts and feelings were a medical problem that affected others they would then visit a health professional to be diagnosed with a mental illness, which enabled them to access treatment programmes and/or prescription medications. The study has shown that people who acquired knowledge, diagnosis and treatment for panic attacks in the earlier stages were less likely to suffer family breakdown, educational and employment disruption, social isolation, alcoholism, etc. In summary, the study has shown that research participants often struggled to label and learn about their agoraphobia, that labelling and learning about agoraphobia is often through a chance encounter and the information comes from a multitude of sources. The study shows that labelling and learning about panic attacks/agoraphobia can have a positive effect on the individual from diagnosis and treatment to support.

Usage of the Internet

The literature review has shown that there is a lack of information on the usage of the Internet by people with agoraphobia. The findings have shown that 25% of research participants regularly used the Internet to acquire information about agoraphobia. In the study, research participants in the 20 to 30 age groups regularly used the Internet to search for information on panic attacks and treatment programmes and/or medications. In addition, some research participants were able to use the Internet to confirm health professionals’ diagnosis of their agoraphobia. In the study, the Internet was seen to provide a large volume of information
accessible in less time, compared to other public providers of information such as public libraries. Also, people who were homebound were able to access information within the safety of their home. While some people would use the Internet to access information, others used it as a means of social interaction with others (e.g. chat-rooms, on-line support groups) which reduced their sense of social isolation. In addition, people often sought out other people similarly affected with panic attacks for understanding, empathy and support. Also, people searched the Internet for other people’s personal stories about agoraphobia as a source of encouragement to help them overcome their panic attacks. These personal stories often provided a source of inspiration for people who were socially isolated and struggling with the daily life of panic attacks.

The study has shown that the long-term usage of Internet chat-rooms and on-line support groups for social interaction could sometimes undermine people’s willingness to venture from their home into public places. However, in some cases the social interaction occurring in the Internet chat-room or on-line support group enabled people to form friendships that led to social interaction in public places. Also, people would often encourage and emotionally support each other on-line in completing exposure tasks in public places/situations.

In summary, the study has shown that research participants used the Internet to acquire meaning (e.g. information) and social interaction (e.g. friendships), which often helped in their daily struggle with of agoraphobia.

Medical Intervention
In the literature review, studies showed that people with agoraphobia normally sought orthodox medical treatment for their panic attacks in the 20 to 40 age group (Marks, 1969, Shafar, 1976, Breier, et al. 1986, Marks, 1987, Craske, et al. 1990). This study extends that age range by showing that of the 93 research participants, 15% of people sought treatment under the age of twenty, 37% between 21 and 30 years, 27% between 31 and 40 years, 15% between 41 and 50 years, and 6% between 51 and 60 years. Therefore, this study has shown that people were seeking medical treatment for agoraphobia in younger and older age groups, compared to other studies.
The study has shown that the majority of research participants did not immediately seek medical treatment for their agoraphobia. For example, 1/3 of people sought immediate medical treatment within one year of the onset of agoraphobia, while 2/3 of people acquired medical treatment one year following the development of agoraphobia. The study suggests that the reason these research participants did not immediately seek medical treatment was their view that the strange thoughts and feelings were a personal weakness rather than a medical problem that affected others. In addition, some research participants were unaware that treatment programmes existed for agoraphobia.

In the literature review, studies showed that about 80% of people who report agoraphobia are women, which implies a higher incidence of agoraphobia among women, (Thorpe & Burns). However, some clinicians argue that men under-report panic attack symptoms and that men may actually have a similar rate to women of agoraphobia (Voss, 1980). These clinicians argue that men are often unwilling to report panic attack symptoms to their health professional due to their gender socialisation, that teaches men that it is not “masculine” to show or admit to weakness to others, especially mental or emotional weakness (Voss, 1980, Goldstein & Stainback, 1987). Therefore, the clinicians argue that men are less likely to report panic attacks/agoraphobia, which skews the statistical data on the incidence of agoraphobia between men and women. This study supports those arguments as 67% of male research participants, compared to 39% of female research participants reported that they did not want to appear mentally unstable to a health professional. In addition, 47% of male research participants, compared to 18% of female research participants reported that they did not want to show emotional weakness to a health professional.

The findings show that other factors contributed to the lower reportage of agoraphobia among male research participants, these factors include:

- 47% of male research participants (31% of female research participants) believed that their panic attacks were a personal weakness, which did not require medical intervention. The study suggests that male research participants believed that anxiety was a personal weakness due their gender socialisation (e.g. kiwi macho culture).
• 33% of male research participants (22% of female research participants) did not know that a health professional could be helpful, and 20% of male research participants (11% of female research participants) felt unable to describe their ‘problem’ to a health professional. The study suggests that male research participants had less contact with health professionals, which meant that they are less experienced in describing their symptoms to a doctor.

• 66% of male research participants (36% of female research participants) were unaware that treatment programmes existed to treat their panic attacks, which led to them not seeking medical intervention. The study suggests that the male research participant’s lack of interaction with health professionals’ would have lessened their chance of coming into contact with information about treatment programmes.

• 40% of male research participants (20% of female research participants) did not want to be pressured by a health professional into using medication, and 47% of male research participants (24% of female research participants) feared possible side-effects from medication. The study suggests that male research participants may have had a preference for the usage of alcohol with their previous experience of its side-effects.

The findings have shown that a major contributory factor in male research participants’ under-reportage of the incidence of agoraphobia is their lack of regular social interaction with health professionals. The study argues that male research participants tended to limit their contact with health professionals to serious accidents and illness, while women regularly used health professionals (e.g. contraception, anti-natal and post-natal check-ups, breast cancer screening, accompanying children for visits and vaccinations, etc). It could be that the male research participants’ lack of regular interaction with health professionals meant that they lacked knowledge and experience in reporting health issues and using health professionals and treatment programmes.

In the literature review, a clinician argued that the higher usage of alcohol by males to suppress their panic attack symptoms reduced their need to seek orthodox medical treatment (Goldstein & Stainback, 1987). This study supports that argument, as 47% of male research participants (compared to 19% of female research participants) occasionally used alcohol to suppress panic attack symptoms, and 13% of male research participants (compared to 4% of female research
participants) regularly used alcohol to suppress panic attack symptoms. In summary, the study has shown that most research participants struggled with panic attacks for a significant period of time before seeking medical intervention. In addition, the study casts doubt on whether studies that claim that the higher reportage of panic attacks/agoraphobia among women is evidence of a higher incidence of agoraphobia among women.

Health Professionals

In the study, 76% of the research participants initially had problems informing their health professional of their panic attacks, 19% of research respondents had no problems and 5% of research participants did not comment. The study shows that some people struggled to inform their health professional about their anxiety due to the belief that the thoughts and feelings were a personal weakness unique to themselves, which did not require consultation and treatment from a health professional. In addition, people who sought medical intervention often believed that they had a physical problem (e.g. heart problem). These people were unaware that a mental health professional could provide Cognitive Behavioural Therapy and/or medications to assist in the management of their panic attacks. In summary, research participants’ failure to inform their health professional (and mental health professionals) was often due to the incorrect meanings that they attached to their panic attacks.

In the study, the majority of research participants consulted their General Practitioner (GP) to identify a physical cause for their panic attacks. These people often believed that their panic attacks symptoms were a symptom of a rapidly deteriorating physical condition, and contacted emergency services for diagnosis and treatment. People often struggled to provide an accurate description of their panic attack symptoms and some people believed that the health professional would not believe them due to the lack of physiological symptoms. In addition, research participants reported that some health professionals were ignorant about panic attacks and treatment programmes. Also, some people who had other mental illnesses (e.g. depression) believed that these masked the presence of panic attacks. The study argues that health professionals’ diagnosis of panic attacks was often reliant on their medical knowledge and their interpretation of patients self-reports, which could be vague and confusing if the person was struggling to make sense of their panic attack symptoms themselves. In summary, health
professionals’ accurate diagnosis of panic attacks and agoraphobia involved a complex interpretative process between doctor and patient. The research participants had to engage in this complex interpretative process to impress upon the health professional the seriousness of their ‘problem’ to acquire medical treatment. The study has shown that research participants sought to hide their panic attacks from health professionals and family members, to avoid stigmatisation and embarrassment. These people saw the stigmatisation, discrimination and embarrassment of mental illness as a threat to their social survival (e.g. person seen as unfit caregiver for their children).

In the study, some health professionals were seen to take longer than necessary to diagnose panic attacks/agoraphobia, misdiagnosed the mental illness or dismissed the panic attack symptoms as simply ‘nerves’. Some health professionals prescribed anti-depressants to suppress the anxiety problem, without specifically identifying the anxiety disorder. Unfortunately, health professionals’ ignorance meant that people’s diagnosis and appropriate treatment were delayed, which caused them to suffer longer with panic attacks. In summary, the study has shown that a large number of research participants had negative experiences with health professionals. However, these people usually continued searching for a health professional that was knowledgeable about agoraphobia and was able to provide appropriate and effective treatment.

In the study, research participants saw the Anxiety Disorders Unit (ADU) as the major community mental health service provider for people with agoraphobia. The ADU provides people with cognitive/behavioural therapy and/or medication to manage their anxiety disorder. The study shows that the ADU often has long waiting lists for assessments and treatment programmes, which placed people at risk of suffering a further deterioration in their mental health (i.e. more panic attacks and avoidance). In addition, people on long waiting lists had more difficulty in learning to use cognitive/behavioural techniques due to their established reliance on flawed personal coping mechanisms (e.g. alcohol). Also people on long waiting lists were more adversely affected by the social consequence of agoraphobia (e.g. marriage/relationship problems, parenting problems, disrupted education and employment, etc). The study concludes that research participants who had their panic attacks and agoraphobia treated earlier suffered less adverse effects on their personal and social wellbeing.
The study has shown that the successful treatment of panic attacks/agoraphobia required a joint act, in that clinicians had to be friendly, approachable, empathic and good communicators to effectively teach cognitive behavioural techniques and clients had to be open, trusting and responsive to learning cognitive behavioural techniques. A major part of the ADU treatment programme involves joint acts between people similarly affected by agoraphobia. The ADU regularly provides cognitive/behavioural treatment programmes to small groups of similarly affected individuals. These small group sessions allow people to share thoughts and feelings with others who are empathic, understanding and non-judgemental. The study shows that people often acquire a feeling of confidence and reassurance about managing their agoraphobia, by seeing other people successfully using the cognitive/behavioural techniques. In addition, people were able to feel normalised through socialising with other people who had agoraphobia and appeared to them as ‘normal’ individuals. Therefore, small group sessions enable social interaction that reduces stigma, feelings of helplessness and social isolation. While some people were shown to enjoy the small social environment, other people sometimes struggled to manage their anxiety disorder to participate in the small group environment. In these cases, the ADU’s provision of one-to-one sessions (e.g. clinician and service user) enabled people to acquire the cognitive/behavioural techniques required to return to social interaction.

In the study, some research participants struggled to access ADU treatment programmes due to their inability to travel to the treatment programme (i.e. homebound). However, ADU clinicians were able to provide home visits for initial assessment and arrange support for individuals to travel to the treatment programme.

The study has shown that research participants who participated in treatment programmes sometimes lacked confidence in the appropriateness and effectiveness of cognitive behavioural therapy (CBT) to manage their panic attacks. These people often struggled to properly use the CBT, which undermined their confidence in using CBT to control their panic attacks. In some cases, people’s attempts to use CBT techniques contributed to an increased awareness of the panic attack symptoms. The study argues that research participants required confidence, commitment, perseverance as well as trust in CBT to work during a panic attack to successfully use CBT techniques. People who did not successfully complete the ADU treatment programme
sometimes developed feelings of hopelessness about their long-term management of agoraphobia. In some cases people chose to use anti-depressants, instead of CBT, to control their panic attacks, as it required very little effort on the part of the patient.

The study shows that ADU patients often had relapses due to poor stress management and irregular usage of CBT techniques. However, people could successfully maintain their mental health by participating in relapse prevention programmes.

In the study, some research participants chose to use private psychologists or counselling services due to the ADU waiting lists for assessments and treatments. Private psychologist and/or counselling services were able to provide CBT as well as address other ‘issues’ (e.g. relationship problems) that could be hindering the management of their agoraphobia. The study argues that people who resolve traumatic and/or stressful issues in their lives are more likely to successfully manage their anxiety than people who are constantly being exposed to high levels of trauma and/or stress that could trigger panic attacks. However, the study shows that some private counsellors lacked knowledge and understanding about agoraphobia and some counsellors offered treatment programmes that were inappropriate, due to their lack of understanding of agoraphobia.

The professional fees of private psychologists were often prohibitive for research participants on low incomes, which created unfairness as research participants on higher incomes were able to access (private) treatment sooner than people on low incomes waiting for public treatment programmes. The study argues that research participants on low incomes on long waiting lists are at more risk from suffering a significant deterioration in their mental health and having more difficulty in learning to use CBT due to their long-term reliance on flawed personal coping mechanisms. In addition, research participants with low incomes on long waiting lists for publicly funded treatment programmes could be more adversely affected by the social consequences of agoraphobia (e.g. marriage/relationship and parenting problems, education failure and unemployment, etc).
Medications
The literature review and this study have shown that some research participants who socially struggled in everyday interactions were able to use anti-depressant medication to allow them to suppress their panic attacks symptoms and continue social interaction with family members, friends and others. In the study, research participants reported that simply having access to anti-depressant medication was sufficient to reduce their anxiety and the incidence of panic attacks. Therefore, the study suggests that the psychological properties of anti-depressants (e.g. people feeling more confidence about their ability to manage their panic attacks) may be as important as the physiological effects of the medication.

While the study shows that some research participants benefited from anti-depressant medication, other people experienced unpleasant side effects (e.g. feeling of illness, stomach upset and queasiness, intoxication, heart palpitations, loss of concentration), which impaired their functioning in everyday activities. In the study, people reported worrying that their health professional would pressure them into using medication with its possible side effects. One research participant argued that the taking of prescription medication reinforced her self-image that she was not normal, since a normal person didn’t need to take medication to do everyday activities. In some cases, people discontinued taking their medication due to its failure to suppress their panic attacks, to avoid unpleasantness side effects, or to resume a normalised life. In some cases, health professionals’ over-prescription of medication, and/or failure to adequately monitor their patient’s usage of medication led to drug dependency problems.

In the study some research participants were shown to prefer the use of homeopathic remedies, rather than prescription anti-depressant medication. These people usually learnt about homeopathic remedies from trusted family members and friends. The commonest homeopathic remedy was rescue remedy, which was seen to be less harsh to the body’s system than orthodox medications. In summary, the study has shown that research participants often used prescription medication to successfully suppress their panic attacks. However, some research participants’ usage of anti-depressant medication hindered their willingness to learn and use cognitive and behavioural therapy, which did not have the possible side effects of anti-depressant medication.
Companions

In the literature review, studies have shown that people with agoraphobia often use a companion to accompany them into public places/situations where they are fearful of having panic attacks (Clarke & Wardman, 1985). This study has shown that 78% of research participants required a companion to accompany them into a place and/or situation. The study argues that research participants’ self-interaction (e.g. fear of panic attacks) was interwoven with their social interaction (e.g. requiring companions) and influenced that social interaction (e.g. person accompanied by companion into public places/situations) and that social life consists of joint acts between individuals that are formed and carried out by its members (e.g. person with agoraphobia and companion).

In the literature review, people with agoraphobia were seen to develop a personal attachment to a companion who regularly accompanied them into public places and situations (Clarke & Wardman, 1985). In the study, a large number of research participants had a pre-existing trusting relationship with the person who they had selected to be their companion. These companions included partners, family members, friends, neighbours, family pets, health professionals, social worker and volunteers.

The study has shown that research participants sometimes would often use their companion to help them flee public places/situations. These research participants sometimes asked their companion to make an excuse for their sudden ‘flight’ from the public place/situation, which enabled them to avoid the social embarrassment of having a panic attack in that place/situation. In addition, research participants often used a companion to help them avoid panic attacks in public places by getting the companion to do the out-of-home activities for them (e.g. shopping). The study suggests that research participants’ usage of a companion to help them to avoid panic attacks could undermine their willingness and ability to use CBT to manage their panic attacks/agoraphobia.

The study has shown that research participants would often use their companion as a ‘safe person’ when entering a public place/situation. The companion as a safe person provided the person with a source of confidence, comfort, protection, safety, dependability, stability,
strength and support. In addition, research participants often allowed their companion to take over roles, responsibilities and decision-making, so they could minimise their participation in the public place/situation. Also, research participants, would often use a companion as practical support to escape panic attacks occurring in public places/situations (e.g. safe person drives them home).

In the study, research participants reported that they feared that their companion would be upset, frightened and/or socially embarrassed if they had a noticeable panic attack in a public place/situation. Some people had an increase in their anxiety as they struggled to suppress a potentially embarrassing panic attack.

In the study, some research participants reported that a companion could be unhelpful and hurtful due to their lack of knowledge and empathy, inappropriate comments, lack of understanding and support during a panic attack. Sometimes a companion would force the person to stay in the public place/situation where they feared having a panic attack, which heightened their anxiety and the likelihood of having a panic attack. Some research participants complained that they had to fit their excursions around their companion’s timetable, which restricted their ability to act spontaneously in their daily life. In addition, some people became overly dependent on their companion for everyday excursions into public places, which placed considerable strain on their relationship.

In the study, some research participants would engage their companion in conversations to disrupt their panic-inducing thinking. However, the companion’s comments could sometimes be inappropriate and cause more upset to the person with agoraphobia.

The study shows that research participants wanted a companion who was understanding of the seriousness of their panic attacks, a calming influence, regularly offered reassurances, and inspired confidence in their ability to overcome their panic attacks. Some research participants who were worried that their panic attack would cause them physical harm, often felt safer knowing that a companion could provide practical support should they have a panic attack in a public place and/or situation.
The study has shown that a large number of research participants hid their panic attack symptoms and tried to continue to act ‘normal’ when accompanied by a companion into public places and situations. In these cases, research participants reported that the ignorance, lack of understanding and discrimination towards mental illness forced them to hide their anxiety from their companions. Therefore, companions were often unaware that they were actually acting as a support person for a person with agoraphobia.

The study identified a gender difference in the usage of companions. The study shows that 81% of women, compared to 60% of men indicated that a companion accompanied them into public places/situations. The study argues that female research participants were more socially skilled (e.g. networking) in selecting and using a companion to accompany them into public places/situations for activities such as shopping.

In summary, the study has shown that research participants initially used companions as a ‘safe’ person who allowed them to avoid panic attacks in public places and situations. In addition, some companions unconsciously reinforced safety and avoidance behaviours by assisting the person to escape places and situations where they feared having a panic attack. However, a companion could be a positive influence by providing encouragement and practical support for the person with agoraphobia to live their everyday life.

Support Groups

The findings have shown that support group membership empowered research participants to form supportive relationships and attach new meanings to their agoraphobia. The study has shown that support groups enabled people to meet, talk, share and learn from other people with agoraphobia. Also, support group membership meant that people were able to receive encouragement and support as well as becoming informed on panic attacks and the effective management of agoraphobia through other people experiences. Generally, research participants felt less distressed about their panic attacks following meeting other people similarly affected by panic attacks. In some cases, people felt more confidence about their ability to manage their panic attacks after meeting people who were less able to control their own panic attacks and avoidance behaviours. Support groups members often developed a sense of belonging and
feelings of being normal, which reduced their social alienation. Also, support group membership was a catalyst for research participants forming friendships that sustained them during their recovery from the unmanaged symptoms stage of agoraphobia.

The study has shown that some barriers existed for research participants’ attendance and participation in support group meetings. A large number of people lacked the confidence to socially interact and were reliant on the availability of transportation and the accompaniment of a companion. In addition, some people worried about having a panic attack travelling to, and participating in the support group meetings. In most cases, people had to be successfully (or sufficiently) managing their panic attacks to enable them to travel to, and participate in support group meetings. Support group members tended to be diverse with people having panic attacks in different places and situations with different panic attack symptoms and avoidance behaviours, which made it difficult for some people to relate to others in the support group. Therefore, support group members sometimes struggled to participate in support group meetings, which reinforced their social disconnection from the community.

The study shows that some support group members continued participation in the support group, hindered their ‘moving on’ with their lives and people who were successfully managing their agoraphobia could sometimes ‘slide-back’ due to over-exposure to the thoughts and feelings of people who were struggling to manage their agoraphobia.

In summary, the study shows that support groups play a positive role in helping people construct supportive social networks that encourage and support their management of agoraphobia. Support group membership enables people to attach new meanings to their mental illness and obtain information that enables effective management of their panic attacks. However, the study shows that some barriers do exist to support group participation and that it may be appropriate for people who have begun to successfully manage their panic attacks/agoraphobia to leave the support group and move on with their life.
Faith and Spiritual Experiences

The study has shown that research participants were often suffering stress prior to the initial panic attack, and became socially isolated due to their avoidance of panic attacks in public places/situations. The study argues that people who lack social interaction and are searching for a meaning for their panic attacks are more ‘open’ to a spiritual experience (e.g. companionship and guidance) from a supernatural force than others.

In the study, Christians spoke of their ‘person relationship’ with Jesus Christ as central to the spiritual experience, which reduced their sense of social isolation and enabled them to attach meaning to their panic attacks. Some Christian respondents believed that “God’s Plan” was to use trials and tribulations (e.g. panic attacks and deteriorating mental health) to force them to search for God’s intervention, which lead to spiritual healing and salvation. Therefore, panic attacks had a spiritual role, purpose and meaning to the believer. In some cases, Christians saw their panic attacks as the manifestation of demonic entities in their lives, and believed that they had to wage a spiritual battle (i.e. faith, bible study, prayer) to overcome them and free themselves from the demon of fear.

In the study, Christians spoke of their overwhelming sense of God’s unconditional love and validation that displaced the secular thoughts and feelings (e.g. fear) that triggered panic attacks. The Christians’ ‘born-again’ spiritual experience includes the old self (e.g. a person with anxious thoughts and feelings) who is re-born into a new self that is modelled on the teaching of Jesus Christ. These Christians felt confident in using Christian coping mechanisms (e.g. bible reading, prayer) to rid themselves of the anxious thoughts that contributed to their anxiety and panic attacks. In addition, born again Christians who believed that they had had an initial spiritual encounter (e.g. Holy Spirit visitation) tried to embed their faith (e.g. the Holy Spirit’s habitation of the believer), by reading inspirational scripture from the bible. The study argues that people’s reading and embedding of scripture in their conscious mind suppressed anxious thoughts that triggered panic attacks.

The study shows that some Christians believe that their faith alone will help them to overcome their panic attacks, while other Christians believe that God has given health professionals the
knowledge to help them overcome their agoraphobia. While the study has shown that some people with agoraphobia benefit from faith, religious practices and church attendance; other people report that their religion had no effect on their management of their mental illness. In some cases, the church environment was seen to be similar to other public places (e.g. supermarket, shopping mall, etc), where people often struggle with panic attacks and develop avoidance behaviours.

While the study has focused on the Christian spiritual experience some research participants’ have had a non-Christian spiritual experience that was helpful in the management of their agoraphobia. In these cases people have sought a spiritual counsellor to help them heal past stressful and traumatic experiences that have contributed to their high level of stress and panic attacks. It seems that some people with agoraphobia who have had a traumatic experience require a spiritual/ emotional healing (both Christian and non-Christian) to achieve closure, which allows them to reduce their stress that triggered their panic attacks. In addition, both Christian and non-Christian spiritual healing, which includes personal growth, appears to reduce stress, anxiety and panic attacks. It appears that the Christian and non-Christian spiritual experiences create an internal dialogue (i.e. self-talk of healing) that is more powerful than the anxious thoughts that triggered panic attacks.

In summary, the study has shown that faith and spiritual experience often had a positive effect on research participants’ management of their agoraphobia. The success of faith and spiritual experience involves spiritual meaning being attached to the panic attacks, the emergence and embedding of a powerful ‘religious’ internal dialogue and religious coping mechanisms which suppress the anxiety-inducing internal dialogue that contributes to panic attacks. In addition, church attendance often reduces social isolation and facilitates desensitising exposure for the person with agoraphobia. Unfortunately, the study shows that when people’s faith and religious internal dialogue is weakened due to secular distractions there is often a resurgence of the anxiety-inducing internal dialogue that contributes to panic attacks.
Successful Management of Agoraphobia

In the literature review, health professionals believed that people with agoraphobia could live a normal life, with the usage of cognitive/behavioural therapy, medication, supportive family members, friends and/or support groups, with some experiencing periodic relapses of panic attacks symptoms over their lifetime (Hand, et al. 1974, Sinnott, et al. 1981, Mathews, et al. 1977, Clarke & Wardman, 1985). The health professionals believed that relapses of panic attack symptoms occurred due to stress, fatigue, physical ill health and/or a return to anxiety-inducing cognitive/behavioural patterns (Clarke & Wardman, 1985).

The study shows that the effective management of agoraphobia required prompt diagnosis and referral to a cognitive/behavioural therapy programme. The study has shown that people who made a serious commitment to, and believed in the effectiveness of the treatment programme, had more chance of a successful outcome. Those research participants who had successfully completed cognitive/behavioural therapy stated that the most important skills and experiences acquired included: self-awareness, rationalism, critical thinking, accurate information, breathing and relaxation techniques, achievement of graduated exposure tasks and the support of others.

In the literature review, studies showed that people who participated in short-term intensive CBT treatment programmes often had relationship problems, as personal changes often altered the power balance in marriages/relationships (Barlow, et al. 1983). Also, the lack of preparation for rapid and dramatic change in roles and responsibilities created serious marital problems (Barlow, et al. 1983). This study argues that the successful treatment of people with agoraphobia would benefit from partners undertaking relationship counselling with their spouse/partner, to enable adjustment during and following completion of the treatment programme.

In the study, research participants’ successful management of agoraphobia benefited from social interaction with other people with agoraphobia. These social interactions included listening to other people’s personal accounts through ASG support group participation and Internet on-line support groups and chat-rooms. In addition, research participants benefited
from reading inspirational life stories in newspapers, magazines, and library books of other people overcoming their panic attacks and leading a normal life. The personal accounts and inspirational life stories modified people’s meanings towards their agoraphobia by challenging misinformation (e.g. fear of open spaces). Unfortunately, the study shows that stigma and discrimination towards mental illness often prevented people from informing and asking for help from others, which robbed them of valuable social support.

The study has shown that research participants who increased their personal confidence by achieving in other parts of their lives were more confident in managing their panic attacks. In addition, people benefited from building strong social networks among family, friends and colleagues. Also, research participants who resolved other issues in their life often reduced the stress that could contribute to their relapse into panic attacks and agoraphobia. In some cases, these were the same stressful issues that originally contributed to the onset of the panic attacks and the development of their agoraphobia.

In the literature review, family system theorists saw the family group as a self-balancing system of relationships, where changes in one family member threaten to disturb the family balance which caused other family members to take measures to re-establish the balance within the family group (Agras, 1985). For example, a husband may do out-of-home activities that their partner with agoraphobia can no longer do, in order to maintain family functioning and balance. This study argues that the successful treatment of research participants required partners and family members to change those behaviours that contributed to and/or reinforced the panic attacks and/or avoidance behaviours of the family member with agoraphobia. This included partners and family members resisting the urge to take over roles and responsibilities for the family member with agoraphobia in public places and situations, and instead supporting the family member to use CBT to complete those tasks in public places and situations. The study has shown that research participants’ management of their panic attacks benefited from the accompaniment of a support person into public places and situations where they feared having a panic attack. Therefore, the ideal support person should support the usage of CBT during those outings into public places and situations.
The study has shown that research participants’ relapse prevention required a positive internal dialogue and deconstruction of negative thoughts and feelings that triggered a cognitive downward spiral into panic attacks and avoidance behaviours. Also, research participants had to view mental and/or physical stress as a ‘early warning system’ to warn them of the risk of a relapse into panic attacks and agoraphobia. Therefore, research participants had to learn to take ‘time out’ to relax and reduce the stress, which made them more susceptible to panic attacks.

In summary, the study argues that the successful management of agoraphobia requires a holistic approach that improves the mental, physical and social health of individuals. While health professionals focus on the mental and physical health of people with agoraphobia, the social factors are often neglected. These social factors include; people developing confidence through participating and achieving in socially valued activities (i.e. education, employment, recreation, etc), building supportive social networks (i.e. family, friends, colleagues, etc), and developing a post-agoraphobic identity (i.e. discovering and valuing one’s true self).

Emergence of the Post-Agoraphobic Identity

The findings have shown the effect that agoraphobia has had on shaping the identity of research participants. The study shows that research participants often had low levels of (or loss of) confidence, low feelings of self-worth, and a sense of dependence. In addition, these people often had their creativity and talent suppressed due to their agoraphobia. Also, the panic attacks and avoidance behaviours disrupted people’s everyday actions, social interaction and forced withdrawal from public places/situations, which undermined their sense of identity as ‘social’ human beings.

The study shows that stigma and discrimination towards research participants affected their sense of identity. In some instances, people withdrew from social interactions to avoid real and/or perceived social embarrassment, while other people used lies and deception to hide their agoraphobia from others to avoid stigma, discrimination and social embarrassment. Research participants who used lies and deception to hide their agoraphobia often suffered a crisis of identity about being an honest and trustworthy person.
While the study has shown that the unmanaged symptoms stage of agoraphobia had a negative effect on shaping people’s identity, those research participants who were managing their panic attacks often developed a post-agoraphobic identity that was more confident and stronger through having overcome the fear of fear. These people were more confident, assertive, self-aware, compassionate, caring, giving, attentive, empathic, understanding, and have a sense of inner strength and tolerance towards others. The emergence of the post-agoraphobic identity often enabled these people to develop (or rediscover) their true selves and get on with their lives. In summary, the study has shown that research participants’ identity is often negatively shaped by agoraphobia, while the successful management of agoraphobia is sometimes the catalyst for the emergence of a positive post-agoraphobic identity.

In conclusion, this chapter has shown that research participants believed that their family upbringing, familial stress, one-off and clusters of traumatic events and/or accumulated stressful events contributed to a pre-disposition to the onset of agoraphobia. In addition, the chapter has explored how research participant’s self-interaction and social interaction proceeding, during and following an initial panic attack contributed to the development of their agoraphobia. The chapter has showed how research participants’ had their primary and secondary school years, youth, social interactions and movement affected during the emerging symptoms of agoraphobia. In addition, the chapter has explored how public perception and stigma towards mental illness forced some research participants’ to make excuses, or hide their agoraphobia, to socially survive interactions with others. Also, the chapter discussed how some research participants experienced ‘coming out’ about their agoraphobia to family members, friends and others. The chapter has showed how research participants believed their marriages/intimate relationships, parenting, post-secondary education, and employment had been affected by agoraphobia. Also, the chapter has shown how some research participants became homebound with agoraphobia, while other people were shown to use personal coping mechanisms and alcohol to suppress their panic attacks sufficiently to function in public places and situations. The chapter has showed how labelling, learning, Internet, and medical interventions helped research participants to start to manage their agoraphobia. In addition, the chapter showed how research participants’ interaction with health professionals and medication affected their medical management of their agoraphobia. The chapter showed how research
participants’ usage of companions, support groups and spiritual experiences affected their social management of agoraphobia. The chapter concluded by showing how research participants were successfully managing their agoraphobia and that a post-agoraphobic identity often developed among research participants.
Chapter 8 Discussion - Themes

This chapter will use the three Interactionist theoretical frameworks that were presented in the theory chapter to analyse four major themes emerging from the summary of findings. In the first theme, Agoraphobia as Interaction, Blumer’s theoretical framework will be used to analyse the self-interactions and social interactions involved at the onset of agoraphobia. In the second theme, Stigma, Goffman’s theoretical discourse will be used in the analysis of the relationship between the stigmatised (research participants) and normals (partners, companions, etc) in mixed contact situations during the unmanaged and managed symptoms stages of agoraphobia. In the third theme, Normalness, Goffman’s theoretical framework will be used to analyse research participants’ concepts of the boundaries of normalness in both the unmanaged and managed symptoms stage of agoraphobia. Finally, in the fourth theme, Therapists and Therapy, Schur’s revision of the labelling approach will be used to analyse the interactions occurring between therapists and patients (research participants) during the managed symptoms stage of agoraphobia.
Agoraphobia as Interaction

In this first essay Blumer’s Interactionist theoretical framework will be used to explore the internalised social processes involved in the creation of the framework of self-interactions that contribute to the onset of agoraphobia. These social processes include meanings, things, interactions and interpretative processes. In addition, Blumer’s theoretical framework will be used to analyse the social interactions happening around the framework of self-interactions, which affect the person experiencing agoraphobia. These social interactions include actions, interactions with others, objects, indications, and lines of actions. The summary of findings will be the source of material for this thematic analysis of self-interactions and social interactions related to agoraphobia.

Self-Interaction (Meanings)

In Blumer’s theoretical framework there are three premises about human interaction. The first premise is that people act towards things on the basis of the meanings that the things have for them (Blumer 1969). In human society, the family group (parents/caregivers) normally teaches (formally and informally) their children to attach appropriate meaning to things and instruct them in the appropriate response to the meanings attached to those things. For example, parents/caregivers will normally teach their children that fire is potentially harmful and that they must treat it with respect and be safety conscious. This primary socialisation process enables the developing child to learn how to safely interact with the natural and social environment. In the study, some families had parents/caregivers with agoraphobia, who were anxious about having ‘panic attacks’ about things (e.g. shopping malls) in their environment. These parents/caregivers regularly modelled this anxiety and accompanying avoidance behaviour towards things, in the presence of their children in the environment. The parents/caregivers attachment of the meaning of fear (e.g. anxiety and avoidance) towards these things in the environment instilled in their developing children a “framework of meanings of fear”. For example, a parent who regularly modelled anxiety and avoidance of supermarkets, shopping malls, tunnels, etc… to their developing child instilled in them a framework of meanings of fear towards these things in the environment. The parents/caregivers’ interaction with the child through this process of socialisation created and
reinforced a “framework of transferable meanings of fear” where the developing child expanded this framework by transferring and applying the meaning of fear towards more and more things they encountered in their environment. As one research participant recounts:

*I think there are a lot of things I have learnt from her, including panic and avoidance. One comes to mind is lifts, now I’ve always been scared of being in a lift on my own and I think I learnt that from my mother because she was scared of lifts also, because I can remember we once went into a lift and I really picked it up off her that she was so scared by the way she acted and I think I probably picked that up off her (Code 63).*

In addition to the parents/caregivers primary socialisation of the child creating within them a “framework of transferable meanings of fear” to things in their environment, the parents/caregivers neglected to instil in the developing child the confidence and personal coping mechanisms to respond effectively to the meaning of fear attached to things in their environment. This lack of confidence and personal coping mechanisms combined to create a “framework of transferable responses of flight” to the meaning of fear attached to things in the environment. When humans attach the meaning of fear to things in their natural environment, their response is to either fight or flee from the fear. In humans, the fight response requires a reasonable level of confidence and personal coping mechanisms to deal with the meaning of fear attached to things, while humans who lack confidence and personal coping mechanisms normally flee from the situation. The “framework of responses of flight” refers to the developing child who develops a framework of flight responses from the meaning of fear that they have attached to things in the environment. The “framework of transferable responses of flight” develops as the child creates a framework of flight responses that are transferred and applied to more and more meanings of fear that are attached to things that they encounter in their environment. As one research participants comments:

*Girls were raised to be very passive, don’t take risks, avoid conflict…so I think women often developed much less personal confidence and had lower self esteem, and were more likely to develop feelings of anxiousness. While boys were more encouraged to climb the tree and fall out of it, and take more risks and of course their confidence was a lot higher. I’ve noticed with people I’ve talked to in the support group, one of the things that seems to come over is the lack of confidence in the family upbringing and of course when they go into these different situations and they are having this anxiousness it just takes over because they haven’t learnt how to manage it (Code 67).*
Self-Interaction (Things)

In Blumer’s Interactionist theoretical framework, humans are seen to attach meaning to things including physical objects, other individuals, categories of people, institutions, guiding ideals, activities of others, and any other situations that a person may encounter in their everyday life. In the study, the research participants (as children) during their family upbringing attached the meaning of fear to things that were happening to them and/or significant others in their home environment. These individuals attached the meaning of fear to those things that threatened their wellbeing or that of a significant other in their social environment. These things included major accidents or illness, divorce, abandonment, suicide, mental, emotional, physical, or sexual abuse, depression, alcoholism, anxiety disorders, an undiagnosed mental illness or financial problems. As individuals experienced an increasing number of these things happening in their social interactions it created a “framework of harmful things”. The “framework of harmful things” refers to individuals experiencing a number of things that threatened to harm them or significant others in their social environment. As one research participant recounts:

The home environment was so screwy… I grew up with fear… fear became enormous and there were a whole lot of other sort of clusters of things that went with that. I would think the world is a very scary place that we couldn’t trust, you know, that was the message we got from our mother, you couldn’t trust anyone, people were after me, this was what she would project on us. Everybody was dangerous, life was pretty scary out there, and at the time… I would think of not having the ability and not valuing anything about myself, or not being able to do things (Code 281).

Since humans act towards a thing on the basis of the meaning that the thing has for them, these individuals applied their “framework of meanings of fear” and the accompanying “framework of responses of flight” to the “framework of harmful things” happening in their social environment. For example, an individual could attach feelings of grief, anger and loss of enjoyment of life (framework of meanings) and become socially withdrawn and isolated (framework of responses) following a major accident causing permanent disability or death to a significant other (framework of harmful things). In addition, individuals then developed a “framework of transferable harmful things” as the meanings and responses to harmful things were transferred and applied to other harmful things encountered in the environment.
To summarise, the research participants’ primary socialisation led them to adopt their parents/caregivers meanings of fear towards ordinary things in their natural and social environment. In addition, the research participants’ attached the meaning of fear to things seen as harmful to the wellbeing of them or significant others in their home environment. The research participants’ attribution of the meaning of fear to an ever-expanding range of things created a “framework of self-perpetuating attachment of the meaning of fear to things”. Those research participants who developed agoraphobia as children applied this “framework” to ordinary things in their school environment. These ordinary things included: travelling to school, classroom and playground activities, assemblies, performances, sports teams, field trips, social events, and school responsibilities. The research participants, as school children having established the “framework” within the family home unconsciously expanded its coverage into their school environment. While research participants experiencing the meaning of fear attached to things could engage in avoidance behaviour in other environments, state regulations about school attendance restricted their usage of avoidance behaviours. These research participants were able to continue functioning and enduring the meanings of fear attached to things, due to their inability to use the response of flight in the school environment. However, as research participants emerged from their school years the “framework of meanings of fear” and the “frameworks of responses of flight” re-connected to enable the individual to avoid things in the community environment.

I went to a country school, I was shy and for some reason the headmaster singled me out. If I didn’t finish my maths or couldn’t do something, he hauled me out in front of the class and put me down saying how stupid I was, and he used to ring my parents and say how spoilt I was and I was a horrible little girl. The teacher was wanting to set up a school choir…I couldn’t sing, but that was another excuse to get me out in front of the class and say how useless I was that I couldn’t even sing properly, and that went on every day for two years…I can always remember it, he had a daughter in the same class, and she had done something, and he said, “Right, over to the office” and he got the strap out and went over and administered his punishment and came back and was whacking the strap on his hand and I was absolutely totally terrified of him and I felt all this fear….On the weekends I would come right because he wasn’t around, but when it was time for school, then the fear and terror of going to school and being constantly mentally abused by this man would came back…Then I left school and for years and years later the panic attacks still kept coming whenever I got stressed or depressed (Code 289).
Self-Interaction (Interaction)

In Blumer’s theoretical framework, the second premise is that the meaning of things is derived from, or arises out of social interaction with others in everyday interactions (Blumer 1969). In the previous section, the individual was seen to develop a “framework of self-perpetuating attachment of the meaning of fear to things” from their primary socialisation and social interactions with others. In research participants’ accounts of their first major panic attack in adult life, this “framework” was readily applied in their search for the meanings of events happening to them or others during social interactions. These events included; the abrupt onset of a major illness or accident affecting them or a significant other; moving and adapting to a new social environment, conflict with others in a social environment; travel-related stress involving others; workplace stress resulting from the actions of others; and victimisation by others. The research participants’ application of the “framework” meant that the meaning of fear was attached to these events. As one research participant indicates:

\[\text{The main thing that provoked me into panic attacks is that an elderly guy about three years ago was hanging around town and he’s well known for abusing women and getting hold of them sexually no matter what age group, and he was beginning to approach me too much even when I was with a partner. He asked me to go around to cook and clean for him, and then he began following me around town for a number of weeks. I found he was hanging near Burger King behind one of the big stone pillars there, and it was really frightening me, and I began noticing bad tremors going through my body, and I was really freaking out all over the place and I didn’t know what was happening to me at the time, and when he approached me near a shopping spot and asked me if I would go away with him for a dirty weekend, that gave me – just like it is now - the cold shivers, and I didn’t know what the heck was happening to my body, and I just had a feeling of fear (Code 88).}\]

In addition to the individual searching for the meaning of fear to things happening within events during social interaction with others, and then attaching the meaning of fear to these things, they then transferred the meaning of fear from these things on to other things happening within events in similar social interactions. As one research participant indicates in the death of her mother on a bus:

\[\text{My mother was waiting in the square (Christchurch) to catch the bus home and she collapsed and died of a heart attack...I had my first major panic attack on a bus following that event (Code 1).}\]
The individual’s search and attachment of the meaning of fear towards things, happening within events during social interaction with others, then triggered the flight response. In humans the flight response is a valuable coping mechanism that enables the individual and group to ensure their safety by fleeing things that have had the meaning of fear attached to them by the individual and/or others. Therefore, the individual’s search and attachment of the meaning of fear to things and their flight response from those things is derived from, or arises out of social interaction with others in social interactions. In the case of people with agoraphobia who develop the “framework of self-perpetuating attachment of the meaning of fear to things”, this is accompanied by the “framework of self-perpetuating flight from the meaning of fear attached to things”. As the person with agoraphobia applies these socially constructed “frameworks” to more and more things happening within events during social interaction with others, they become trapped in their self-perpetuating attachment of the meaning of fear to things and flight from the meaning of fear towards those things in social situations.

Self-Interaction (Interpretative Processes)

In Blumer’s theoretical framework the third premise is that meanings are handled, and modified, through an interpretative process that the person uses in dealing with the things they encounter in their daily life (Blumer 1969). In the study, research participants’ attachment of the meaning of fear to things and the accompanying flight response from the meaning attached to those things, triggered the psychological and physiological symptoms of a panic attack. The panic attack’s psychological symptoms included: an overwhelming fear of being unable to escape, de-realisation, depersonalisation, fear of fainting/collapsing, fear of losing control, fear of going crazy, fear of physical illness, endurance or dread of situations, fear of social embarrassment, feared loss of consciousness and incapacitation and the fear of imminent death (Weekes, 1977, Craske & Barlow, 1993). The physiological symptoms included: palpitations, paraesthesia, sweating, chills or hot flushes, trembling or shaking, shortness of breath and feelings of being unable to breathe, difficulty in swallowing food and feelings of choking, chest pain or discomfort, bladder or bowel incontinence, nausea, feelings of unsteadiness, blurred vision, faintness, and hyperventilation (Chambless & Goldstein, 1982, Read, 1996). The research participant’s application of the “framework of self-perpetuating attachment of the
meaning of fear to things” meant that their interpretation of these psychological and physiological symptoms was a seemingly impending life threatening crisis. As individuals interpreted these meanings of fear as indicating their impending death, they interpreted other panic attacks symptoms as reinforcing their rationale of the worse case scenario. As one research participants recounts:

*I felt that I couldn’t breathe, and then I felt like my heart was pounding. I made it worse by reacting the way I did instead of dealing with it. I thought I was having a heart attack, and that I was going to die in seconds* (Code 105).

The research participants’ attachment and interpretation of the meaning of fear to their panic attack symptoms, with the resulting escalating fear of those panic attack symptoms created a “framework of self-perpetuating and escalating attachment of the meaning of fear to the meaning of fear”. In the findings, the research participants framed this simply as the “fear of fear”. The individual’s internal dialogue of the attachment of the meaning of fear to the meaning of fear (fear of fear) created an overwhelming and terrifying experience. These individuals became trapped in this powerful, compulsive, overwhelming and terrifying internal dialogue and struggled to attach other interpretations to their panic attack symptoms. As one research participants recounts:

*When I have a panic attack one thought will come into my brain and it just keeps clicking over and over, its very compulsive. This compulsion of thinking a certain thought all the time just kind of gets a hold and takes over my thinking and I start to feel panicky about what I think is about to happen to me. I lose control of my thinking and all the physical symptoms tell me that the thinking is right - I’m going to go crazy or die...then I have a full panic attack* (Code 274).

The research participant’s entrapment in this powerful, compulsive, overwhelming and terrifying internal dialogue and their inability to assert other meanings and interpretations to their panic attack symptoms meant that they struggled to understand what was actually happening to them. As another research participant recounts of their experience:

*My first panic attack - I didn’t realise it was a panic attack, I didn’t know what it was, I felt totally out of control, and really scared. I couldn’t breathe, I thought that I was going to die. I believed I was on the verge of a breakdown, I didn’t know what was going on really...* (Code 93).
The research participant’s interpretation of their panic attack symptoms as a sign of an impending life threatening crisis and their struggle to comprehend what was actually happening to them, caused them to seek medical assistance or to flee to their home. The individual fled towards medical assistance or their home, due to their pre-existing attachment of the meaning of safety to hospitals and/or their home. As the research participants fled the situation, their panic attack symptoms subsided as the bodily movement used the surplus chemicals (oxygen and adrenaline) fuelling the panic attack symptoms. The research participant’s flight from the panic attack, with the resulting reduction in the intensity of the panic attack symptoms, caused them to interpret the ‘flight’ response as an effective coping mechanism for panic attacks.

The research participant’s attachment of the meaning of fear towards their panic attack symptoms was usually accompanied by the fear of social embarrassment in social interactions. In these cases, the individual concern was that that others would negatively interpret any appearance of their panic attack symptoms in the social situation. The individuals concern about others interpretations of their behaviour, led to their avoidance of public places and situations where others could see their behaviour and/or undignified flight from the social situation.

To summarise, the research participants’ interpretative processes involved them indicating to themselves that their thoughts; feelings and bodily sensations (i.e. panic attack symptoms) are the things that they ought to be acting towards in the social situation. The individual’s attachment of meanings and interpretations of these things is an internalised social process involving a process of internal communication with themselves. This individual’s process of internal communication enables them to make guide and form their actions in the social situation (e.g. avoidance). Therefore, research participants’ application of meaning and interpretative processing is embedded in the process of self-interaction and affects their social interactions in the situation.
Social-Interaction (Actions)

In Blumer’s theoretical analysis of society and the function of its members, he addresses the following social interactions; actions, interaction with others, objects, indications, actors and lines of actions and the interconnection of the lines of actions. These social interactions are referred to as “root images” The first root image is that human society consists of individuals engaging in actions, and that the individual performs a multitude of activities as they encounter others to deal with situations. The individual may at times act singly, collectively, on behalf of, as representative of, or as part of a group. These activities belong to the acting individual and are carried out by them in relation to the situation in which they have to act (Blumer 1969).

The research participants’ attachment of the meaning of fear towards their panic attack symptoms, and the accompanying attachment of the meaning of fear to encounters with others (e.g. social embarrassment) in social interactions, led them to avoid a multitude of activities in public places and situations. These public places and situations included; shopping malls, movies, churches, sitting in a hairdresser’s chair, lifts, riding on a bus, travelling on the motorway or stopped at road works etc. The individual’s attempt to act singly in public places was restricted by the occurrence of panic attacks in a wide range of situations. Those individuals who singly engaged in actions in public places and situations were often reluctant to spend too much time or travel too far from the safety of their home. The individual acting singly often planned their activities in advance, including establishing safe routes and venturing out during quiet times of the day. In addition, the individual often became reliant on coping mechanisms such as distraction techniques to enable them to function in public places and situations. In the findings, the research participants reported feeling the loss of freedom and spontaneity in engaging in actions in public places and situations. As one research participant states:

I couldn’t be spontaneous and do something like go to the movies during the holidays, like I couldn’t just say let’s go and do something (Code 148).

In the study a large number of research participants experienced a “boundary” forming around their actions in everyday life. The individual’s struggle to act singly meant that a
boundary formed around their actions affecting their ability to act on behalf of, as representative of, or as part of a group. As a research participant indicates:

I would have loved to have had done modelling, and dancing - ballroom dancing. I always watched it if it was on telly and I think you tend to dream away a bit and imagine yourself doing it or something. I would have loved to travel as well, that is something else I would have loved to done. I would have loved to have had travelled overseas. I have never been out of Christchurch, I’ve been stuck here...There are other things that come into it as well, but the agoraphobia is the biggest reason that I haven’t done these things (Code 156).

While the research participants struggled to act singly, most were able to act collectively with a companion in public places and situations.

Social-Interaction (Interaction with Others)

The second root image is that society consists of individuals interacting with others and that activities between individuals arise predominantly out of interaction between one another. The individual, during their interacting with others, must take into account the actions (or intended actions) of others and direct (or redirect) their own conduct in those activities according to the actions (or intended actions) of others (Blumer 1969). In the literature review, the research participants were seen to regularly act collectively with an “other” (a companion) to enable them to complete a multitude of activities in public places and situations (Clarke & Wardman, 1985). The individual normally sought a companion who was trustworthy, in the sense that they would ensure their safety by providing confidence, comfort, protection, dependability, stability, strength and support in public places and situations. However, the individual, during their interacting with the companion, had to take into account the actions of the companion. The companion’s actions included the taking over of roles, responsibilities and decision-making, which enabled the completion of activities in the public place/situation. Thereupon, the individual had to direct (or redirect) their own conduct in those activities according to the actions of the companion. This meant that individuals often had to fit their activities around their companion’s availability and timetable, which restricted the individual’s ability to act spontaneously in their daily life. As one research participant recounts:
The individual interacting with their companion, often required the individual to take into account the inappropriateness of the companion’s actions, which included unhelpful and hurtful remarks, and lack of understanding and support during a panic attack. To the individual the companion’s inappropriate actions was due to their ignorance and lack of understanding towards agoraphobia. The companion’s inappropriate actions then forced the individual to redirect their own conduct during activities, which normally meant suppressing and hiding their panic attack symptoms from the companion in the public place and situation. In addition, some individuals during their interaction with the companion feared that their companion would be upset, frightened and/or socially embarrassed if they had a noticeable panic attack in a public place/situation. Therefore, these individuals masked their panic attack symptoms, to avoid a negative reaction from the companion.

Social-Interaction (Objects)

The third root image is that human “worlds” consist of objects and that these objects are the product of the process of social interaction. An object is anything that can be indicated or referred to and are usually classified into three categories (1) physical objects, (2) social objects and (3) abstract objects. The nature of an object consists of the meaning that it has for the individual for whom it is an object. The meaning attached to the object shapes how the object is seen, is acted towards, and is spoken about by the individual. An object may have different meanings to individuals, due to individuals attaching different meanings to the object through their interaction with others towards that object. However, individuals often develop similar meanings towards an object through interacting with others that share a common meaning towards the object. This social process of interacting between individuals means that objects are created, affirmed, transformed and dismissed (Blumer, 1969).

In the study, the research participants’ perception of their panic attacks and agoraphobia was as physical objects, social objects and as abstract objects. Some individuals’ perception of panic attacks was a physical object, which was derived from the meanings placed upon the
physiological symptoms occurring during the panic attack to the individual (e.g. rapid heartbeat being the sign of an impending heart attack). Most individuals saw agoraphobia as a social object, due to their attachment of social embarrassment to the panic attack symptoms occurring in a public place/situation. To some individual’s their panic attacks and agoraphobia were an abstract object, existing only as a mental concept (e.g. going crazy) as opposed to an concrete (physical) object.

In the findings, the nature of agoraphobia consisted of the meaning that it had for the individual for whom it was an object. The meaning attached to agoraphobia shaped how it was seen, acted towards, and spoken about by the individual. Initially, some individuals’ saw their panic attacks as physical object (a set of physiological symptoms), which lead them to seek medical intervention and to speak about it in medical terms to general practitioners. Some individuals who saw agoraphobia as a social object sought to hide it from others, and only spoke about it to others whom they trusted. Those individuals’ who saw the panic attacks and agoraphobia as an abstract object (internal dialogue) sought psychotherapy and spoke about it in cognitive/behavioural terms to therapists and/or counsellors. While research participants initially saw their agoraphobia as a physical object, social object and/or abstract object the interaction with health general practitioners, trusted others and mental health professionals either confirmed or dismissed the meaning that they had attached to their panic attack/agoraphobia.

While agoraphobia could have different meanings to individuals due to individuals attaching different meanings to their agoraphobia through their interaction with others towards agoraphobia, individuals often developed similar meanings towards agoraphobia through interacting with others that shared a common meaning towards the object. In support groups, individuals often met others similarly affected who have attached similar meanings to their agoraphobia. As one research participant recounts:

> At the open meetings it was good to able to meet twenty other people that had some understanding of how I felt at times. I know everybody is different, but that was good to see that there were other people out there – its like a AA meeting where there are other people with similar stories. Yes, that side of it was good, knowing that there were other people the same (Code 56).
In summary, the creation, affirmation, transformation and/or dismissal of agoraphobia as an object is produced through the social process of interaction between the individual and others.

Social-Interaction (Indications)

The fourth root image is that humans are acting organisms that make indications to others and interpret the indications of others. According to Mead, the ability of humans to be an acting organism required them to possess a concept of Self, which simply means that a human sees themselves as an object in their own actions and act towards themselves and are guided in their action towards others on the basis of being that object (Blumer, 1969). In the study, research participants initially recognised themselves as a weak person (an object of weakness) in their experience of agoraphobia. For example, these individuals often described themselves as ashamed, weak, scared, silly, frightened, ridiculous, fearful, unstable, out of control, overwhelmed, terrified, weird, etc. The research participants’ self-conception as an object of weakness meant that they acted passively towards themselves in dealing with their panic attacks. These individuals guided their actions (e.g. avoidance) towards their panic attacks in public places and situations on the basis of being an object of weakness.

In Mead’s discourse, the individual’s self-conception as an object is seen to emerge out of the process of social interaction with others that defines the individual as that object (Blumer, 1969). While research participants initially recognised themselves as weak persons, they re-conceptualised themselves as agoraphobic following social interaction with others. As one research participant recounts:

I was at a bar one night and I met a guy who started talking to me. He spoke about having these ‘symptoms’ and I was like wow! - He sounds exactly like me, yeah! (Code 93).

To Mead the individual’s development of their concept of Self involved them role-playing the other and then viewing or acting towards themselves from that position. This role-playing allowed the individual to define themselves as an object through others. The research participants’ re-conceptualisation as agoraphobic often involved them taking on (listening to)
the role of the agoraphobic from “others” and viewing it from their position. As one research participant states, her conceptualisation of being agoraphobic arose through her taking on that role following her reading of an account from an “other” in the newspaper.

I didn’t know what agoraphobia was until one day we got the Wellington paper and there was a write-up by this lady and she was at Massey University doing some course, and it said how she panicked going shopping and different places. She said that every so often when she was like this she had to take antidepressants to allow her to lead a full life and when I read it then, that is when I first heard about agoraphobia. I’d never heard about it before then, and that was the first time – I’ve still got the cutting – I read it and said to my husband this is what I’ve got (Code 33).

To conclude, the research participants’ self-interaction enabled them to make indications to themselves of the meaning of agoraphobia and its relevance and importance to their actions. The research participants making of these indications to themselves and their response to those indications enabled them to make sense of the object, to give it meaning and to allow that meaning to form the basis for them to direct actions.

Social Interaction (Lines of Actions)

In the fifth root image the individual, to be able to make indications to themselves, has to interpret in order to act in their environment. Also, the individual must construct and guide their actions to handle situations where action is required by ascertaining the meaning of the actions of others and undertake actions based on those interpretations (Blumer, 1969). In the findings, the research participant’s re-conceptualisation of their panic attack’s symptoms as indicating an agoraphobic condition (instead of weakness) enabled them to act differently towards their panic attacks occurring in the public places and situations. These individuals were able to construct effective coping mechanisms to handle their panic attacks through ascertaining the actions undertaken by others in dealing with panic attacks, and then applying those actions to their own situation. A large number of individuals ascertained the meaning and actions of others through reading their personal accounts written in books, magazines, etc. As one research participant states, the reading the accounts of others helped her confirm the meaning of her actions:
I went and bought books, I borrowed them, I got them out of the library, all about panic, anxiety, stress, the whole lot, and I had to fill my mind up to reassure myself that was what I had (Code 108).

Blumer states that human interaction involves individuals engaging in activities occurring in a flow of situations in which the individual has to act, and that the action is based on what the individual notes, how they assess and interpret what they note and the lines of actions that are mapped out from those notes (Blumer, 1969). In the findings, the research participants would use the coping mechanism acquired from the “other” in a range of public places and situations where the panic attacks were happening to them. These individuals’ choice of coping mechanisms was based on their notes on the actions of others, their assessment and interpretation of those notes, and the lines of actions that those notes mapped out for the individual.

The final root image is that group life consists of, and exists in, the fitting of individual lines of action to the group. When these lines of action come together they create and constitute “joint action” - a societal organisation (Blumer 1969). In the study, the Agoraphobic Support Group’s provided a group life consisting of members fitting their individual lines of action together. Therefore, the Agoraphobic Support Group bringing together of these individual lines of action created “join actions” between the group members. While the Agoraphobic Support Group role involved the fitting together of individual lines of action (personal coping mechanisms) its promotion of cognitive behavioural therapy (CBT) as “joint action” made it different from any one individual line of action, as well as from their aggregation.

Blumer states that in human societies the majority of joint actions are stable and repetitive, where people act towards each other on a shared understanding of how to act and how the other will act (Blumer 1969). As a societal organisation the Agoraphobic Support Group’s promotion of common meanings (DSMIV diagnosis) and pre-established joint actions (CBT) enables the individual to support others on the basis of their shared understanding of panic attacks and how to deal with them in the group and wider environment. However, Blumer argues that common meanings and pre-established joint actions are constantly threatened by new and emerging problematic situations that give rise to new meanings and lines of actions, which lead to the formation of new joint actions. In the Agoraphobic Support Group, the
shared meanings and established joint actions could be threatened by the arrival of new individuals who had attached different meanings to panic attacks (e.g. spiritual causation) and different lines of action (e.g. prayer), which could lead to the formation of new joint actions (e.g. spiritual healing). As Blumer suggests, the group’s stable and repetitive joint action is continuously vulnerable to the pressures placed on meanings from these new social processes (Blumer 1969).

In Blumer’s discourse, he argues that people participating in a system occupy different points in the system and engage in actions at those points on the basis of the meanings they have developed through interaction with others at that point in the system (Blumer 1969). In the Agoraphobic Support Group, the clinicians’ occupation of the “advisor” point in the group system, and their instruction of CBT derived from the DSMIV allows them to influence the joint actions (coping mechanisms) of members. The Agoraphobic Support Group’s ability to function (promote joint lines of action) is dependent on clinicians instructing members in the usage of CBT in the group situation when required. Therefore, Agoraphobic Support Group members’ meanings (DMSIV definitions) and lines of action (CBT) are produced through the process of social interaction with clinicians in the group environment. In addition, the Agoraphobic Support Group as a social system is dependent on the processes of interpretation that occurs among clinicians and group members.

Blumer concludes his analysis by observing that any new joint action emerges from, and is connected to previous joint actions, and those joint actions by necessity have arisen out of a background of previous actions of individuals. In the Agoraphobic Support Group, the clinicians promotion of new (refined) CBT techniques to members, emerged from, and was connected to trials of the previous version of CBT, and that version of CBT had been by necessity formed from an earlier version of CBT in clinical practice. Therefore, joint action represents both a linkage of activities of individuals and a linkage to previous joint actions (Blumer 1969).
Conclusion

In conclusion, Blumer’s Interactionist theoretical framework and its application to the findings data has shown that micro-level social processes create and maintain individual’s attachment of meanings and interpretations of their panic attack symptoms. The individual’s attachment of meaning to their panic attacks involves internalised communication that attaches meaning to thoughts, feelings and bodily sensations influenced by the interpretations of others in social interaction. The individual’s engagement in self-interaction and social interaction leads to lines of actions that continually recreate the lived experience of agoraphobia in everyday life. The essay concludes that individuals who want to overcome their panic attacks and avoidance behaviours must deconstruct their current self-interactions and social interactions and create new non-agoraphobic meanings, interpretations and lines of action towards their thoughts, feelings and bodily sensations to live a more normal life.
Agoraphobia and Stigma

This essay will explore how the research participants as people with agoraphobia were stigmatised by normals and the strategies used to manage their spoiled identity. In Goffman’s book ‘Stigma - Notes on the Management of Spoiled Identity’ he provides an Interactionist theoretical framework that will used to explore this theme – stigmatisation and identity management. The Interactionist framework will enable the writer to outline the Western medicalisation of thoughts and behaviours, which has created a list of discreditable attributes (symptoms) and a medicalised identity of agoraphobia. Also, the Interactionist approach will reveal that people with agoraphobia must attempt to hide their actual personal identity (agoraphobic) and maintain a virtual social identity to be accepted as normal. The Interactionist perspective will enable the writer to explore the relationship between people with agoraphobia and ‘normals’ in mixed contact situations. Also, the Interactionist approach enables the writer to investigate the research participants “agoraphobic career” in the management of their identity information as discreditable individuals’ and/or tension as discredited individuals. This will include an analysis of how research participants manage their social information, visibility, personal identity, and biography. Also, the analysis will include the research participants’ usage of passing and covering techniques in the management of their spoiled identity. The essay’s major advantage in using Goffmans’ Interactionist theoretical framework to analyse research participants’ lived experiences of stigma is that it specifically focuses on the formation and management of stigma. Goffmans’ theoretical framework is readily applicable to people with agoraphobia, as shown by the regular citing of the lived experiences of people with mental illness in his book. Therefore, this theoretical framework provides an excellent tool to analyse the research participants’ lived experiences as members of the stigmatised category of people with mental illness.
Identity

In Goffman’s theoretical framework the basic premise is that human societies establish a means to place people into categories where their attributes are seen as natural and ordinary in those categories (Goffman, 1973). In Western societies, the medicalisation of patterns of thoughts and behaviours has lead to some collectives of thoughts and behaviours being classified as undesirable attributes among society members. This Western medicalisation of thoughts and behaviours has created a division between desirable collectives of thoughts and behaviours (rational) and undesirable collectives of thoughts and behaviours (irrational). The collectives of rational thoughts and behaviours are seen as normal, while the irrational collectives of thoughts and behaviours are seen as abnormal. This Western medicalisation of thoughts and behaviours has seeped into social life where normals are seen to naturally and ordinarily to have desirable collectives of thoughts and behaviours while individuals labelled as abnormal are seen to have naturally and ordinarily have undesirable collectives of thoughts and behaviours. Those individuals who are seen as having undesirable collectives of thoughts and behaviours belonging to the category of the mentally ill often suffer social ridicule, embarrassment, isolation and alienation.

In the study, research participants were aware of the importance of how their collectives of thoughts and behaviours were seen by others in social interactions. These individuals realised that the appearance of undesirable collectives of thoughts and behaviours, linked to the category of mental illness, in social interactions would lead to social rejection and alienation. Therefore, these individuals had to create and maintain a socially valued identity in their interactions with others to avoid stigma and discrimination.

In Goffman’s theoretical discourse he states that the person’s ascribed membership to a category arises from their day-to-day social interactions with others. In these social interactions the other identifies desirable and undesirable attributes which allow the categorisation of the individual. The individual’s categorisation of their attributes establishes their ‘social identity’. In subsequent social interactions the individual is expected to conform to the attributes of their category (Goffman, 1973). In this study, some research participants were fearful that the public appearance of their panic attacks and/or avoidance during social interactions would lead to their being socially ascribed to the category of the mentally ill.
These research participants worried that the establishing of their ‘social identity’ as mentally ill, would create social expectations of them as conforming to the stereotype of the category of the mentally ill, and would lead to social embarrassment, devaluation and exclusion. As one research participant indicates:

*I don’t tell everybody about this, because people think, oh God, he’s nuts. I mean, this year Christmas day came and we were going to someone’s house...I walked in on Christmas day and had a major panic attack. I don’t know why, and I had to come running home to get something to calm me down which was tablets... They actually saw me have a panic attack and I know they can’t see anything physically, they just think what the hell’s wrong with him, he’s a nut, because that is what people assume, they think you’re nuts. I am quite intelligent I think, I’ve got a nice home, I’ve worked hard for it, but if people see that side of you, they think what a nut. It is just a worry about how other people are going to react and whether they’ve shut you out (Code 56).*

Goffman states that when others ascribe a person as belonging to a specific category this characterisation creates a ‘virtual social identity’, while the person’s actual category of attributes is their ‘actual social identity’. When a person is seen to possess an attribute that makes them different to others in their category and when this attribute is less desirable, the person’s status is reduced among others. When this less desirable attribute has a significant discrediting effect it is referred to as stigma. This stigmatised identity is a special discrepancy that exists between virtual and actual social identity. Therefore, stigma is more than an attribute, it is the relationship between the attribute and its stereotype (Goffman, 1973). In the findings, the research participants who did not visibly have panic attacks during social interactions with others, were ascribed as belonging in the ‘normal’ category, this became their ‘virtual social identity’. However, research participants who were seen to have panic attacks during social interaction were recognised as being different by others and were seen as having an undesirable attribute. The recognition of the panic attack and avoidance behaviour as an undesirable trait, and its discrediting effect created the feeling of stigma. Therefore, the individual’s stigma is the relationship between the attribute (i.e. panic attacks and avoidance behaviours) and their stereotyping as a mental illness. As one research participant recounts of their stereotyping of being labelled “mental”:

*When I say to people that…I just have panic attacks, they think you are not normal and people sort of joke about it, thinking it is not normal. People think*
In Goffman’s discourse on stigma, he identified two groups of stigmatised individuals, the ‘discreditable’ and the ‘discredited’. In everyday life the discreditable individual tried to pass as an ordinary person within their category, which required the managing of information about themselves to avoid their discrediting attribute being recognised by others. In contrast, the discredited individual whose discrediting attribute was recognised by others had to manage tension with others in social interactions (Goffman, 1973). In this study, the research participants who were ‘discreditable’ were those who could be discredited should their panic attacks and/or avoidance behaviour become known or perceivable to others during social interactions, while the research participants who were ‘discredited’ were those whose panic attacks were known or perceivable to others in social settings. The findings suggest that research participants usually began their “agoraphobic career”, as discreditable individuals who were fearful that public disclosure of their discrediting attribute (e.g. panic attacks) would lead to stigmatisation and discrimination. The research participant’s “agoraphobic career” would then advance to the stage of being a discredited individual following the voluntarily disclosure of their panic attacks or the perceiving of their discrediting attribute to others. Therefore, the research participants had to manage their information as discreditable individuals and then manage tension as a discredited individual in mixed contact situations. As one research participant indicates:

I haven’t told many people about the panic attacks, because of the fear of discrimination. I’ve really got to know them very well before I say anything, so that they won’t treat me differently afterwards. I have to know that person and know whether it is safe to tell them. I am very selective about who I tell, otherwise I hide it (Code 22).

In Goffman’s theorising he states that normals’ attitudes and actions towards the stigmatised often lead to various acts of discrimination, which reduce the life chances of the stigmatised individual. The normals’ theorising, and adopting of an ideology to explain the inferiority of the stigmatised individual, as well as using specific terms in their daily discourses to impute undesirable attributes to the individual leads to the construction of the stigma (Goffman, 1973). In the study, research participants believed that the public theorising towards mental illness and their adoption of devaluing philosophies (e.g. institutionalisation), which was
socially constructed through the negative images of people with mental illness in the mass media, reduced their enjoyment of everyday life. As one research participant recounts of the devaluing portrayal of people with mental illness on a television programme:

I watched a television documentary the other day and this guy was mumbling incoherently, and was chained to the wall. The interviewer asked what was wrong with this person, and someone said he’s mental, he’s sick, he’s got a mental illness. The interviewer said why don’t you have him in a proper place, and they said we don’t have the facilities for that, so they had him chained up and he’d been there for about 10 years and was sitting in his own faeces and urine, and was just babbling away. I think this is what people are going to think of me when I mention mental illness. This is the picture they are going to have, of people babbling away, living in filth in mental institutions (Code 274).

In the findings, some research participants believed that socially constructed mis-information contributed to normals’ ignorance and misinformation towards agoraphobia. This public ignorance and misinformation often leads to the dismissal, ridicule or minimisation of people’s claim that panic attacks were a very distressing and disabling experience. As one research participant recounts:

A lot of people look at what it says in the dictionary and it says a fear of open spaces, so sometimes when you talk to someone who doesn’t understand, you’ve actually got to address the misinformation first, before you can have a more accurate understanding (Code 148).

Goffman states that the stigmatised person’s regular contact with normals creates and maintains an awareness of others’ perspectives and discourses on the stigmatised person’s failings. The stigmatised person’s awareness of these perceived failings often induces feelings of shame, self-hate and self-derogation. In addition, the stigmatised person often has to accept the loss of respect from others towards unstigmatised attributes of his/her social identity (Goffman, 1973). In the study, some research participants experienced negative attitudes and value judgements following the disclosure of their discrediting attribute (panic attacks) to family, friends, colleagues and others. These negative attitudes and value judgements included: lack of understanding and support, and having to endure a disbelieving response to their claims of the negative effect of panic attacks on their lives. Individuals often felt socially devalued and social isolated and felt that they no longer belonged among ‘normals’ in society. In addition, some individuals felt that others transferred the loss of
respect from their stigmatised attribute to their unstigmatised attributes. As one research participant indicates, her partner transferred his intolerance and frustration from her mental illness to her role as a travelling companion:

**Mixed Contact Situations**

In Goffman’s book he theorised on the relationship between the stigmatised and normal in ‘mixed contact’ situations. The stigmatised person was seen to feel unsure about how they were thought of, identified, categorised and received by normals in mixed contact situations (Goffman, 1973). In the study, research participants’ spoke about their loss of confidence to socially interact with normals in mixed contact situations. These individuals believed that the public disclosure of their panic attacks and avoidance behaviour would lead normals to identify, categorised and receive them as mentally unstable, which caused their stigmatisation. As one research participant states:

I didn’t want to be seen as being mentally unstable, because there is still stigma attached to mental illness (Code 41).

Goffman believed that the stigmatised person would feel self-conscious about the impression that they were making about themselves to normals (Goffman, 1973). In the findings, some research participants felt self-conscious about normals witnessing their panic attacks and/or avoidance behaviours. In addition, individuals often felt different and apart from normals in these mixed contact situations. As one research participant states:

I can go to the supermarket one day and get around, get everything, get up to the checkout and out and the next day because I am feeling a little bit crazy, so-called crazy, going to the supermarket is just a daunting task. I don’t feel like I fit in and I feel everyone is looking at me, and I do feel different. I don’t feel like I belong. I feel different from others who I think are normal you do feel different, you don’t feel part of everything (Code 56).

Goffman postulated that the stigmatised person would believe that the sighting of any of their failings by normals would be interpreted as an attribute of their stigmatised difference (Goffman, 1973). In the findings, individuals believed that the sighting of their panic attacks would be interpreted by normals as a sign of their being mentally unstable and lead to their stigmatisation as mentally ill.
According, to Goffman the stigmatised person’s response to these encounters with normals could be defensive and cowering or undertaken with hostile bravado, which would lead to negative repercussions. The stigmatised person could appear too ashamed or too aggressive and be seen as too willing to read unintended meanings into normals actions. Due to the problems in the mixed contact situation the stigmatised person and normals could feel anxiety, self-consciousness and experience interaction-uneasiness. Ultimately, the problems in mixed contact situations lead to normals acting towards the stigmatised person as a non-person (Goffman 1973). In the study, research participants’ response to encounter in mixed contact situations was defensive and cowering in the senses that they felt ashamed, socially embarrassed and feared negative value judgements. These individuals would often use lies and deception to mask their panic attack symptoms and would regularly make excuses to avoid doing things or manipulate others into doing things that they could not do themselves, in order to survive in everyday life. As one research participant states:

I hid my agoraphobia by not telling family, I had to make excuses for not doing things, and I got really good at it (Code 22).

However, the individual’s usage of lies, deception, and making of excuses made them feel dishonest and uncomfortable among normals, which caused them to experience interaction-uneasiness in mixed contact situations.

In Goffman’s theoretical discourse he states that the discredited person will attempt to manage tension related to their stigma during social interaction, while the discreditable person will attempt to control information about their stigma in mixed contact situations. The discreditable individual’s concealment of information about their stigma enables them to be accepted by others, who are normally prejudiced against that stigma category. In the study, research participants were often fearful that information about their panic attacks would lead to negative value judgements and social rejections from normals. These individuals regularly hid information about their panic attacks from others, by lying and using deceptions in mixed contact situations. The individual often experienced a crisis of conscience due to the desire to be truthful, while having to lie to others to be socially accepted.
Goffman concludes that when the discreditable person decides to reveal their actual social identity they must decide to whom, how, when and where to tell or not to tell; to let on or not to let on; to lie or not to lie; to display or not to display; and so on (Goffman, 1973). In the findings, research participants often felt the need to tell others about their panic attacks and agoraphobia. These individuals felt that agoraphobia was a part of their personal identity and life experience, and wished to share the information with close family members, friends and others. These individuals were careful to tell others they knew to be trustworthy, accepting, understanding and supportive, while continuing to hide the truth from strangers. The individual could feel uncomfortable and emotionally distressed when telling others, due to the fear of making a fool of themselves, being seen as a mentally unstable person and risk of social isolation and alienation from others. As one research participant indicates in their ‘coming out’ about agoraphobia:

*Coming out as having agoraphobia was bigger than anything, bigger than gay, gay is nothing, it’s just life, being gay is just what I am and who I enjoy. But being agoraphobic is definitely a bigger hurdle, to come out and say to everybody I’m agoraphobic, I feel like they think I’m nuts. So I wouldn’t tell them and I would become creative and wouldn’t tell them, I would do anything but tell them. Coming out as agoraphobic is definitely a bigger thing (Code 56).*

Goffman theorises that the stigmatised person will attempt to remove his/her stigma by attempting to correct their undesirable attribute by taking direct action to correct its objective basis (Goffman, 1973). In the study, most research participants tried to use personal coping mechanisms to correct (control) their panic attacks. Initially, the personal coping mechanism was the direct avoidance of the public place/situation where the panic attacks were happening. The individual’s direct avoidance of specific public places and situations led to their developing safe routes to avoid these specific public places and situations. In some cases, the individual’s increasing avoidance of more and more public places and situations led them to become homebound. While some individuals could use the personal coping mechanism of direct avoidance, other individuals had to venture into public places and situations (e.g. work obligations). These individuals then had to develop other personal coping mechanisms to control their panic attacks and avoid social embarrassment. These personal coping mechanisms included the usage of distraction techniques (e.g. counting, writing and reciting affirmations), prescription medication, alcohol and/or cannabis and self-help books (e.g. cognitive
behavioural therapy) to correct (control) their panic attacks in public places/situation. The successful usage of these personal coping mechanisms reduced the incidence of panic attacks, as well as the risk of the accompanying social embarrassment of their undesirable attribute (panic attacks) being seen by others in of public places and situations.

Goffman states that the stigmatised individual will sometimes respond indirectly through mastering activities that are seen to be beyond the reach of the person in their stigma category (Goffman, 1973). In the study, the majority of research participants participated in Anxiety Disorders Unit treatment programmes and/or the Agoraphobic Support Group meetings to acquire more effective coping mechanisms to control their panic attacks and allow them to master activities in public places/situations. In some cases, some individuals felt that their ability to master activities made them feel more normal than the individuals that were less able to participate in activities in public places/situations. These individuals who felt more ‘normal’, then struggled to relate to those in their stigma category. As one research participant, who had mastered doing activities be beyond the reach of other group members states:

_I went to the support group for a wee while, but I didn’t find that terribly helpful because people there seemed to be such a lot worse than me...There were people who couldn’t even go out to the letterbox and they’d talk about things that were really bad. I thought that I’d never been that bad and that I couldn’t mix with these people... (Code 37)._

In Goffman’s theoretical discourse he suggests that the stigmatised person will develop an unconventional interpretation of their stigma, or will use their stigma as an excuse for failure, or see the undesirable attribute as a blessing if it is felt that a lesson has been learnt. In addition, the stigmatised person may develop an awareness of the undesirable attributes of normals, such as their ignorance and intolerance towards people in stigmatised categories (Goffman, 1973). In the study, some research participants’ search for the meaning of their panic attacks led them to make the unconventional interpretation that the manifestation of their panic attacks was part of a spiritual experience. These individuals believed that their panic attacks led to their experiencing trials and tribulations which made them search for God’s intervention to acquire spiritual healing leading to eternal salvation. As one research participant states:
I’m beginning to think that’s God had me have these panic attacks as part of his plan to make me seek his help. I do believe that, I really do. That to me is a reassurance, it is a comforting thought really to think that God cared that much to bring it, to make me seek him out and to be saved. I knew there was a God, but he wanted a personal relationship with me. That is the most empowering thing when I think wow, he loves me and we have to come to know him and open up the door as he says, and he’ll come in (Code 108).

To some individuals the panic attacks were seen as a blessing that had saved them from an extremely self-destructive secular lifestyle among normals (unbelievers). The individual’s placement of a spiritual meaning and interpretation to their panic attacks and the recognition of their secular lifestyle as the source of their self-destruction, led them to seek and adopt a spiritually oriented lifestyle. The individual’s new spiritual orientated character as a “born again” Christian, then enabled them to present the desirable attributes of having “Christian love” towards others in their social interaction with them. Therefore, these individuals were able to use an internalised social process to deconstruct their “old self” with its undesirable attributes, and adopt a “new self” with desirable attributes that enabled their acceptance by others. As one research participant reveals in her account of the spiritual experience:

My husband was a volatile man and it was a violent relationship and he is a druggie too, so it wasn’t a good mixture. I think the stress in that relationship started the panic attacks… Then I started to get suicidal, that was the lowest point in my life. I can look back and see a vision of myself in a dark black place and I was on my own and I was in a foetal position and my spirit was dying. I asked God, to help me leave this body and in that moment something unusual happened. There was a light and then there was God’s voice and I just felt calm, I felt unconditional love coming from him, and how do I know it is God, because I could feel his spirit and knowing this, that someone great was with me, and I thought wow! You know. I thought to myself I don’t need a priest, I don’t need a doctor, I don’t need anybody, I have found God, and I found him here in my house, and I was really happy… This was a real turning point…I had no more panic attacks, absolutely none. I was normal and back to my old self. There was a new love of human kind, more love, more understanding, more patience; I was more loving towards my children, a real personality change (Code 274).

However, the individuals’ “born again” Christian experience often lead them to develop an awareness of the undesirable attributes of normals (non-believers), such as their ignorance and intolerance towards people in stigmatised categories (Christians). Therefore, the individual’s
means to escape one stigmatised category (mentally ill) can lead them to fall into another stigmatised category (born again Christians).

The Agoraphobic’s and Normals

In Goffman’s book, he theorised that when a stigmatised person experienced problems in mixed contact situations they would develop strategies to manage their spoiled identity. In addition, the stigmatised person would use a sympathetic other to assist in the management of their spoiled identity. The sympathetic other could be a person with the same stigma and who could instruct the stigmatised person how to manage their stigma and provide acceptance and moral support as required (Goffman 1973). In the study, the majority of research participants sought a sympathetic other (companion) to accompany them into public places and situations where they feared having panic attacks and experiencing the accompanying social embarrassment. The individual normally had a pre-existing trusting relationship with their sympathetic other (trusted companion). The individual’s pre-existing trusting relationship enabled them to inform the sympathetic other about their discrediting attribute (panic attacks). These sympathetic others were normally partners, family members, friends, or neighbours. The individual would normally use the sympathetic other to help them manage their discrediting attribute in social situations and settings. The sympathetic other would often assist the individual to use their personal coping mechanisms in the social situation. Also, the sympathetic other would often instruct the individual on how to use CBT to manage their panic attacks in social settings. In some cases, the sympathetic other would take over roles, responsibilities and decision-making, so the individual could concentrate on managing there panic attacks. In all of these roles the sympathetic other became a “safe” person who could provide a source of confidence, comfort, protection, safety, dependability, stability, strength and support to the individual. As one research participant indicates:

*When I feel anxious, especially on the bus, having a companion with me makes me feel safe (Code 3).*

In the study, some research participants reported that an unsympathetic other would accompany them into social settings. The individual normally had a pre-existing relationship with their unsympathetic other. These unsympathetic others included partners and family members, who were usually aware of the discrediting attribute. According to the research
participants, these unsympathetic others lacked understanding of the seriousness of the panic attacks which often hindered their management of their spoiled identity in social settings. For example, some unsympathetic others made the individual participate in social interactions to meet social obligations which increased the risk of panic attacks occurring and spoiling the identity of the individual. According to the research participants, the unsympathetic others often appeared to see their panic attacks as a source of social embarrassment and inconvenience to them in social situations. The unsympathetic other would then provide unsolicited, unhelpful and hurtful advice to the individual on how to deal with their panic attacks (e.g. snap out of it). Therefore, these unsympathetic others failed to provide acceptance and moral support as required by the individual. As one research participant states about her relationship with an unsympathetic other:

*I did have one friend who had a “snap out of it” attitude and this made her more of a hindrance, than help, as a companion. She wasn’t very reassuring and having her with me tended to increase my anxiety, because of her attitude and lack of understanding (Code 104).*

In the findings, some individuals hid their discrediting attribute from both the sympathetic and unsympathetic other and tried to continue to act ‘normal’ when accompanied by them into social situations and settings. In these cases, the individual’s used the strategy of “masking” their discrediting attribute from all others to manage their spoiled identity in mixed contact situations.

In Goffman’s book he states that the stigmatised person would sometimes acquire active support from a ‘wise’ person to manage his/her stigma. The wise person is a normal, who as a sympathetic other has an intimate knowledge of the stigmatised person’s life experience (Goffman 1973). In the study, the research participants identified parents, partners, family members, friends, therapists, and counsellors as ‘wise’ persons who were normal, sympathetic and had an intimate knowledge of their agoraphobic experience. Goffman theorised that the ‘wise’ person often adopted that position following a heart-changing personal experience involving the stigmatised individual and/or category. In addition, the wise person would seek validation and acceptance by the stigmatised person (Goffman, 1973). In the findings, the research participants discovered that ‘coming out’ about their personal experience of agoraphobia to normals’ was often the catalyst for the normal becoming a ‘wise’ person who
was sympathetic and whose intimate knowledge meant that the research participants no longer had to hide their stigma. As one research participant acknowledges:

*I did tell my sister-in-law and my brother, I wrote them a letter, because I knew that I couldn’t just say all the things I wanted to say in a sentence that would be coherent... I didn’t want to freak them out, and I didn’t want to paint myself as a ridiculous fool. They came around and said thanks for the letter, it was really good, anything we can do kind of thing, and it was so low key that I knew that they understood and there was no big drama, which was really good. I definitely had a big sense of relief, like when the phone rang I could say to my brother, “No, that is just not going to happen” and I didn’t need to lie any more about it* (Code 31).

In the findings, some research participants often struggled to accept a normal as a ‘wise’ person, due to their lack of personal experience of agoraphobia. These research participants believed that normals had to have a personal experience of the type of panic attacks that lead to agoraphobia to fully understand and sympathise with the individual. This creates a ‘Catch 22’ situation, as the stigmatised person’s requirement that a normal must have a personal experience of agoraphobia to be accepted as a ‘wise’ person, meant that the normal had to be, or become a stigmatised person (e.g. personal experience of agoraphobia) to then become a ‘wise’ person. Therefore, these research participants saw the ‘wise’ person as actually having to be a stigmatised person who was sympathetic and had an intimate knowledge of their shared stigma. This writer suggests that these individuals are actually “personally experienced” persons who are both stigmatised persons (personal experience) and ‘wise’ persons (shared knowledge). In addition, this writer suggests that some individuals can be categorised as “previously personally experienced” persons who are normals whose previous personal experience of the stigma means that they are sympathetic and have intimate knowledge of the stigmatised persons’ experience of stigma. This description is applicable to people who have personally experienced agoraphobia (and stigmatisation), and who have then had a ‘recovery’ and identify themselves as non-agoraphobic (and normal), while continuing to be sympathetic towards people with agoraphobia. As one research participant indicates:

*I was a Lifeline counsellor last year for the year, and it [the agoraphobic experience] gave me all the qualities to get through that to have the compassion and understanding for people who were calling and having panic attacks* (Code 93).
Goffman states that the ‘wise’ person’s appearance of carrying the burden of the stigma, can be a source of annoyance to the stigmatised person, and the ‘wise’ person’s continuing acceptance by the stigmatised was often in doubt (Goffman 1973). In the findings, some research participants believed that the ‘wise’ person (e.g. parents, partners, family members, friends, etc) presented to them and others the appearance of carrying the burden of the agoraphobia, which caused annoyance and undermined the relationship between the research participant and the ‘wise’ person. As one research participants states in her parent’s taking on of the blame for her panic attacks:

*I rang my mum, and told her that I had been having panic attacks and that I had been to a therapist because I felt that I was going crazy, and she said, “Oh, did they blame it on the parents? They always do” and that was all that she said, so I was like OK, I am definitely alone. It was like trying to reach out, but no that was it, I am not going to talk to anyone about this. Because that is what people say, you’ve just got to deal with it yourself (Code 93).*

In Goffman’s discourse he states that the ‘wise’ person can often be the relative of the stigmatised person. In addition, the apparent closeness of the relationship between the stigmatised person and the wise person means that they are sometimes seen as the same by normals. The relative’s experience of the stigma can cause strain and lead to termination of their relationship with the stigmatised person (Goffman, 1973). In the study, the research participant’s partners and/or family members appeared to fulfil the role and responsibilities of the ‘wise’ person. In some cases, the partners and family members became socially embarrassed when the person had a panic attack in a public place/situation, which was seen by other normals. On occasions, the partner or family member became angry and frustrated with the agoraphobic person due to the social embarrassment, which placed strain on the relationship between the person with agoraphobia and their partner or family member. As one research participants states:

*He doesn’t really want to know, he thinks I’m stupid, he wants me to shut up about it and get on with it and never cause him embarrassment (e.g. running out of somewhere in public (Code 31).* 

However, Goffman states that some relatives’ response to their de-facto stigmatisation was to embrace and live alongside those in the stigmatised category (Goffman, 1973). In the findings, some partners and family members appreciated the seriousness of the panic attacks and
provided positive support to the person with agoraphobia in managing both their panic attacks and any accompanying social embarrassment in public places and situations. As one individual reports:

*My partner is very supportive when we are in these situations (Code 287).*

Goffman believed that stigmatised persons particularly struggled to manage their identity information in intimate relationships due to the long periods of time spent together, which increased the chance of discrediting information being revealed. (Goffman, 1973). In the study, some research participants struggled to manage their identity information in their intimate relationships, due to having panic attacks in the presence of their partner in public places and situations. These research participants would attempt to hide their panic attacks, due to the fear that this discrediting information would lead to negative value judgements (stigmatisation). As one research participant indicates in her statement about hiding her panic attacks to avoid the disclosure of discrediting information:

*I didn’t reveal my true self to any partner in case they judged me or didn’t understand me. My relationships were pretty much a lie, pretty worthless (Code 93).*

Goffman states that the stigmatised person will often feel obliged to share an appropriate amount of intimate facts about themselves as part of the trust and mutual commitment required in building a close relationship (Goffman, 1973). In the findings, some research participants were obligated to share their personal identity information with their partners in order to acquire the trust and commitment required to use their partner as a support person to assist in the management of their panic attacks in public places and situations.

Goffman concludes that the stigmatised person begins the relationship concealing information, which is then compromised and becomes deficient when the parties exchange personal information (Goffman, 1973). The research participants normally had a lack of confidence at the beginning of the relationship, which made them conceal their personal identity information from their partners. However, the research participant’s increase in confidence eventually led them to reveal their personal identity information to their partners with mixed results. Some research participants had positive and supportive experiences of
disclosing their information, while others had negative and damaging experiences following their revealing of their personal identity information.

Goffman states that intimates were a major source of assistance and support for the discreditable person in enabling them to mask their stigma from others. In addition, the intimate could assist and support the discreditable person to function without others becoming aware of their discrediting attribute (Goffman, 1973). In the study, some research participants used their intimates to assist and support them to manage their panic attacks, which enabled them to continue functioning and mask their stigma from others in public places and situations. In some cases, the research participants would use intimates to make excuses to enable them to avoid doing things in social settings and/or manipulate intimates into doing out-of-home activities for them, which allowed them to prevent others becoming aware of their discrediting attribute.

Goffman states that a group of intimates may form a protective circle around the discreditable individual, allowing them to think they have been fully accepted as normal, which may be untrue (Goffman, 1973). In the study, some research participants had partners, family members and friends who simply accepted them as normal individuals, following the voluntary disclosure of their panic attacks and agoraphobia. These intimates would then provide protection and support for the research participant to manage their panic attacks in mixed contact situations.

My new partner has been more protective, more helpful, and more considerate. He has helped me to be more confident by being amazed that I can cope at all during a bad attack and he gets very concerned during times when the panic attacks are more frequent or intense (Code 86).

Goffman theorises that the stigmatised person will rely more on the intimates who share their stigma to help them in passing as normal more than other intimates (Goffman, 1973). In the findings, some research participants who shared their personal information learnt that the parent, partner, family member of friend had had panic attacks and agoraphobia too. These intimates were more knowledgeable, understanding, empathic and supportive than other intimates due to their personal experience of agoraphobia. Therefore, these intimates were more knowledgeable about passing techniques, which would allow the research participant
to pass as normal. However, Goffman concludes that in mixed contact situations the stigmatised person may continue their strategy of passing as normal by deliberately failing to acknowledge an intimate or handling any greeting or interaction with the intimate discreetly in the presence of the normal (Goffman, 1973).

Goffman states that both the discreditable and discredited will voluntarily maintain distance to avoid intimacy with others, which require the divulging of information. The physical distancing ensures that the discreditable or discredited person will not spend time with the other, this reduces the chance of unanticipated events that force the disclose information. In addition, the physical distancing restricts the ability of the other constructing a personal identification of them. The stigmatised person’s avoidance of contact with others reduces the chance that their stigma will be established as part of the biography that others have towards them (Goffman, 1973).

The Agoraphobic’s Moral Career

In Goffman’s book, he states that stigmatised individuals who have the same stigma will have a similar ‘moral career’ that will cause and affect their commitment to a similar sequence of personal adjustments (Goffman, 1973). In the study, research participants were shown to have had a similar ‘moral career’ as seen in their experience of personal adjustments to agoraphobia. Goffman states that stigmatised individuals will have a similar conception of Self and the socialisation experience around their condition (Goffman, 1973). In the study, all of the research participants’ experience of panic attacks and agoraphobia involved a similar sequence of personal adjustments. These individuals had a similar conception of Self, in the sense that they initially saw their panic attacks as a unique personal weakness. These individuals then learnt that the strange thoughts, feelings and physiological symptoms were actually a mental illness called agoraphobia, following a chance encounter with others who had been medically diagnosed and treated for agoraphobia. Goffman believed that the socialisation process involved the stigmatised individual learning and adopting the point of view of normals towards the stigmatised category, which taught the individual what it was like to possess that stigma in society (Goffman, 1973). The research participants’ contact with others, who had been subjected to the medicalisation of their ‘personal weakness’, led to their learning and adopting the normals’ (medical profession’s) point of view towards agoraphobia.
Also, the research participants’ shift of point of view from seeing their panic attacks as a weakness to a mental illness led to the attachment of stigma. As Goffman states, the stigmatised person learns that they have a stigma, as well as the consequences of possessing that stigma (Goffman, 1973). In Goffman’s theorising, he believed that the timing and interplay between these two parts of the socialisation process was important in forming patterns and establishing the foundations for the future moral careers of the stigmatised in normal society (Goffman, 1973).

In Goffman’s theoretical discourse he states that the stigmatised person conveys their ‘social’ information through the bodily expression of their characteristics in the presence of others (Goffman, 1973). In the study, the research participants tended to convey their ‘social’ information of agoraphobia, through their panic attack symptoms (e.g. people who appeared anxious to others) and avoidance behaviours in mixed contact situations. When the social information is routinely and steadily conveyed it is referred to as a ‘symbol’. A symbol that conveys a desirable characteristic is called a ‘status symbol’ or ‘prestige symbol’. However, a symbol that conveys an undesirable characteristic is referred to as a ‘stigma symbol’ (Goffman, 1973). In the findings, some research participants routinely conveyed their social information (panic attacks and avoidance behaviours) to partners, family members, friends, and others in public places and situations. The research participants’ panic attacks and avoidance behaviours became seen as a stigma symbol (undesirable characteristic) by some partners, family members, friends, and others in mixed contact situations. Goffman states that the challenge for the stigmatised person is the management of social information when dealing with being seen ‘with’ others. However, the stigmatised persons’ ability to manage their social information is heavily influenced by the visibility (or perceptibility) of their stigma, and the presentation of these signs in social interaction, which informs others of their social identity (Goffman, 1973). In the case of the research participants, the challenge was to manage the visible appearance of their panic attacks and avoidance behaviour in mixed contact situations. These individuals would attempt to hide the outward appearance of their anxiety to reduce the visibility of the panic attacks to others. Also, these individuals would make excuses to hide their avoidant behaviour in mixed contact situations. Goffman states that the stigmatised person will develop strategies to reduce the visibility of their stigma in interactions with others. However, the stigmatised person’s successful management of their information is
dependent on the decoding abilities of the normals in the mixed contact situation (Goffman, 1973). In this case, the research participants’ success in hiding the visibility of their panic attack and ability to make excuses was dependent on the decoding abilities of partners, family members, friends and others. As one research participant indicates, people with agoraphobia become ‘masters of disguise’ in hiding the visibility of their stigma from others who failed to decode their making of excuses and avoidance behaviour:

I remember reading in a book where the author said that people with agoraphobia are masters of disguise, because they hide it from their family, from work colleagues and are very good at making excuses to get out of situations without coming across as being abnormal (Code 45).

While most stigmatised individuals hide their stigma from others, some individuals made a private disclosure to normals, especially to intimates in close contact situations. These intimates were expected to show sympathy, empathy and understanding towards the stigmatised individual. This positive and supportive approach was expected to arise from the intimate’s positive evaluation of the personal qualities of the stigmatised person (Goffman, 1973). In the study, some research participants had positive and supportive experiences following the disclosure of their stigma to intimates in mixed contact situations. However, these individuals tended to make their private disclosure to ‘trusted’ intimates, who were seen to have made a positive evaluation of the personal qualities of the individual. As one research participant indicates in telling her ‘true friends’:

True friends will be there through thick and thin, and we support one another. When I’m down the best thing really is to talk about it and they will listen and then tell me about somebody else who has gone through the same thing and that reassures me that there is a way out (Code 108).

However, Goffman argues that the intimate’s familiarity with the stigmatised person may not actually reduce their contempt for them. Instead, the normal may continue to retain their societal formed perceptions of persons in that stigma category (Goffman, 1973). In the findings, the research participants’ familiarity with the normal did not protect them from the normal’s negative stereotyping of people with mental illness. As one individual indicates in the response of a colleague to their disclosure about having a mental illness:
When I explained to a working colleague that I had had a breakdown she didn’t understand it. She took it like I was a leper and she stood right back and gave me an eyes wide open, and oh my God, keep away from you look, and I thought I’m not a leper, I just wanted someone to understand (Code 274).

Therefore, the stigmatised person may be required to manage their social information with strangers and intimates (Goffman, 1973).

Goffman states that when the discreditable person’s stigma symbol (undesirable characteristic) is known only to them, and is invisible to others the role of ‘passing’ arises. The discreditable person will attempt to pass as normal in mixed contact situations to secure the higher social status of being seen as a normal (Goffman, 1973). In the study, most research participants saw their panic attacks as a stigma symbol which was invisible to others, and hid their panic attacks from others in mixed contact situations. These research participants became ‘passers’ who attempted to hide their panic attacks to enable themselves to be accepted as normal among other normals in public places and situations.

Goffman suggests that the discreditable person as a passer can feel torn between their stigma group and the normal group, as the passer may experience feelings of disloyalty and self-contempt when unable to take action against ‘offensive’ remarks against the category they are passing out of, by the members of the new group, at the same time the passer may struggle to identify with the normal group they are passing into as new members (Goffman, 1973). In the findings, Agoraphobic Support Group (ASG) members (research participants) often struggled to pass out of the support group and pass into normal groups in society. Some ASG members may have felt disloyalty to other group members, as the reason for their “passing out” of the ASG membership was their feeling that continuing contact with other support group members would lead to a set-back in the management of their agoraphobia. As one research participant indicates in her decision to pass out of the support group:

I didn’t want to go to the (support group) meetings any more because you are hearing everybody else’s problems and what they are feeling. I was like that when I started and that is when I needed the support from them, but I got to a stage where I wanted to go on and get away from that, and that is when we all did our own kind of thing. I still see them, but that is why I kind of never carried on with the group (Code 33).
In addition, the ASG member may experience feelings of self-contempt due to their inaction towards any ‘offensive’ remarks made against people with mental illness by normals. However, ASG members who do attempt to take action against devaluing comments by normals, risk being identified and discredited.

Goffman suggests that the passer will need to develop strategies to manage identity issues that are simply routine for normals, and the passer will need to have a place and time where they can refurbish their disguise, and rest from the passing without losing control over their personal information (Goffman, 1973). In the findings, the ASG members’ strategy to hide their identity involved the avoidance of commenting on mental health issues in social settings. However, the ASG member could take time-out from masking their identity and control their personal information by discussing mental health-related issues with sympathetic others. The thesis writer regularly uses this strategy in his place of employment.

In Goffman’s discourse he states that the individual’s attempt to pass as normal can be uncovered and exposed by those who have personal identification of them, and have biographical details that are incompatible with their passing as normal (Goffman, 1973). In the findings, some research participants were unsuccessful in their attempt to pass as normal, due to public disclosure of their mental illness by others, as one research participant indicates happened in the form of gossiping that occurred in her employment situation:

I talked to my manager about the panic attacks and she seemed to be trying to be an understanding employer. I said to her please don’t tell anyone about this illness. But she told the staff… the gossip it went right around, it was a vicious cycle, and of course it just made my anxiety worse. I went to the senior manager and said that there is one person in particular who is making my life really hard – she spreads vicious rumours about me, and everybody ostracises me and if this continues I will go further… I’ve tried to speak to the people, who were making my life hell, and they denied the whole thing and they kept denying it, even my manager denied the whole thing. But in the end I was forced to change managers, and I don’t trust anyone now, I don’t say much to anybody. I just needed help, why didn’t someone try to understand and just be kind and just let me be… (Code 274).

Goffman states that the stigmatised person was often forced to live a double-life of attempting to pass as normal, while attempting to conceal information about their stigma (Goffman,
In the findings, some research participants lived a double life by attempting to pass as normal to family members, friends and others while hiding the panic attacks from them. These research participants often lied and deceived family members, friends and others to avoid mixed contact situations where the exposure of their panic attacks could lead to social embarrassment. As one research participant indicates in their account of lies and deception:

*I told a lot of lies to get out of going to family occasions. I used to tell family that I had the flu to avoid having to go to family wedding and funerals. It was easier to lie and possibly hurt people’s feelings than face the danger of having a panic attack in a place where I couldn’t escape without making a scene (Code 31).*

However, the individual’s need to act normal often contributed to the already existing burden of feeling anxious and having panic attack symptoms in mixed contact situations. As one person indicates:

*I hated having to act so called ‘normal’ in front of them when I felt anxious out in public (Code 56).*

Some individuals would invite a companion to accompany them into public places and situations to make themselves feel safe, while concealing information about their panic attacks from the companion. Also, some individuals would make excuses so that the companion would complete out-of-home activities for them.

Goffman states that the stigmatised person risks inadvertent disclosure when those who know the biography of their real stigmatised identity come into contact with those who know the socially constructed biography of their normalised identity (Goffman, 1973). In the findings, some research participants had their socially constructed biography of being a normal deconstructed when a sympathetic other (partner, family member, friend, etc) spoke about their panic attacks to others in mixed contact situations. In the case of one research participant, their socially constructed biography of being a normal was ruined when a family member told other family members about their real stigmatised identity:

*I confided in my husband’s older son’s wife that I suffer a mental illness and panic attacks and that went right around the family, they treated me differently after that. I could tell that, when I was around his daughter she would give me a really scowled look, which said, “You’re sick (Code 274).*
Goffman states that the negative consequences of passing include the unanticipated need to disclose discrediting information to others, such as the disclosure of discrediting information to receive some form of benefit (Goffman, 1973). In the findings, some research participants who had to pass as normal (e.g. tenants) in mixed contact situations (e.g. landlords) had to disclose their discrediting information to agencies (WINZ) to receive a benefit (e.g. sickness benefit) to meet the expectation of others (e.g. landlords expectation of rent payments). However, the individual often felt the socially constructed stigma of being labelled a ‘welfare beneficiary’, which made them extend their lying to prevent disclosure of the new discrediting information to others.

Goffman states that stigmatised individuals’ who successfully pass as normal are often open to learning what normals ‘really’ think of people in that stigmatised category. In addition, the stigmatised individual often does not know how much information is known about them by others, which means that the individual is at risk of exposure through failing to successfully hide their failing, or by their failing being revealed by others during social interactions. (Goffman, 1973). In the findings, the research participants who initially passed as normal developed an awareness of the public perception of normals towards their stigma categories. The public perception towards people with agoraphobia was that they had a fear of open spaces. Alternatively, the public perception of mental illness was that people were mentally abnormal, unstable, and dangerous. While these research participants passed as normal, they often did not know whether their panic attacks were visible to others, and often felt at risk of being exposed through their failing to successfully hide their panic attacks or by their panic attacks being revealed by others during social interactions. As one research participant summarises in his account:

I don’t tell everybody about this, because people think, oh God, he’s nuts. I mean, this year Christmas day came and we were going to someone’s house who I’ve known for years and years – they’ve seen me through marriage, divorce, coming out of the closet, and I walked in on Christmas day and had a major panic attack. I don’t know why, and I had to come running home to get something to calm me down which was tablets… They actually saw me have a panic attack and I know they can’t see anything physically, they just think what the hell’s wrong with him, he’s a nut, because that is what people assume, they think you’re nuts (Code 56).
Goffman concludes that the stigmatised person’s attempt to pass may be complicated by the presence of people who share the stigma, who are aware of the techniques being used to conceal that stigma, and who tell others of the persons stigma and their tricks to hide it. Therefore, the stigmatised person may be confronted by others who have learnt about their secret and their falsehood (Goffman, 1973).

In Goffman’s theorising, he suggests that the stigmatised person’s passing is dependent on whether or not others are aware of his/her ‘identity peg’ and ‘set of facts’, which distinguished them from others (Goffman, 1973). In the study, some research participants’ would use identity pegs to assist in their passing as normal. For example, a person having a panic attack may use a paper bag to control their breathing during a panic attack in public place/situation. However, the persons’ attempt at passing as normal would be dependent on whether or not others saw the usage of the paper bag. Also, some research participants would manage their set of facts by making excuses, lying and deceiving others to hide information about their agoraphobia. Goffman states that the person’s use of identity pegs and set of facts, which are attached to an individual, establishes their personal identity. This personal identity is then built into a single continuous record of social facts to which other biographical facts can be attached (Goffman, 1973).

In Goffman’s theoretical discourse, he states that the stigmatised persons biographical facts are maintained in the minds of intimates and/or the personnel files of an organisation (Goffman, 1973). In the study, some research participants had their biographical facts maintained in the minds and case notes of social agents and their respectively agencies (WINZ). Goffman states that this means that the person becomes an object for biographical recording. The stigmatised person can attempt to present in these biographies a social role, which is different from their role in the stigmatised category (Goffman, 1973). In the findings, research participants who were WINZ beneficiaries had to present a social role (e.g. job seeker), which was different from their role as a mentally ill person, to access employment services. While the research participant’s social role of job seeker created a desirable biography (e.g. knowledge, skills, and employment experiences) for seeking employment, the unmasking of their other role as a mentally ill person hindered their access to employment services (e.g. job seeker seen as
mentally unstable). As one research participant indicates when enrolling as a WINZ job seeker:

*The Social Welfare department put down on the computer that was I was mentally incompetent, I was incapable of doing a job (Code 201).*

Goffman states that the stigmatised person’s ability to manage social facts about themselves is dependent on the knowledge that the different audiences have on the ‘informational connectedness’ of facts within the stigmatised person’s biography. The stigmatised person’s management of their biography can enable them to socially misrepresented themselves and mask their personal identity. The persons stigma and their concealment of this stigma often become a ‘fixed part of their personal identity. When the discreditable stigma and the social misrepresentation are discovered, the stigmatised person is discredited and their reputation is damaged (Goffman, 1973). As WINZ beneficiaries, the research participants had to manage their social facts (e.g. job seeker) by withholding health professionals’ knowledge about them, from WINZ case managers during enrolment (e.g. health status on enrolment form) to prevent informational connectedness of facts that would reveal their personal identity (e.g. mentally ill), which would discredit their social identity (e.g. job seeker). As one research participant indicates her WINZ case manager placed her in the “too hard basket” following her disclosure as a person with a mental illness:

> At WINZ, they kept jabbing me about mental health issues, my body is tightening and I just try and relax, but the case manager begins to taunt me and taunt me with no, we’re not doing that, no, we’re not doing this, you’re good for nothing…. At WINZ they sort you into those who are the easiest to place in real jobs and those in the too hard basket. Then they send you to the jobs that are the easiest to fill with hard basket cases and this makes it easy for them to meet their quota. In other words, crap jobs! If you’re been placed in the too hard basket they basically don’t spend much time on you (Code 201).

As Goffman concludes, the stigmatised person’s management of their personal identity creates a division among others, into the knowing and the unknowing. The knowing have the personal biographical facts of the individual, while the unknowing do not have the personal biography of the individual (Goffman, 1973). To this writer, the research participant is seen to create a division between the knowing health professional with the medical biography and the unknowing WINZ case manager without the medicalised biography. Therefore, the key difference is seen to be ‘how much’ is or is not known about the stigmatised person (research
participant) by others (agents and agencies), whether others (agents and agencies) know about them, and whether the stigmatised person (research participant) knows that they know about them. The key point is that different individuals (health professionals, WINZ case managers, employers, family members, etc) have different amounts of information about the stigmatised person (research participant), which affects their perception of the personal and social identity of the stigmatised (research participant) (Goffman, 1973).

Goffman states that the discredible person may voluntarily disclose their personal information to end the need to manage their social identity (Goffman, 1973). In the study, some research participants voluntarily disclosed their agoraphobia to overcome feelings of shame and to end the need to attempt to pass in mixed contact situations. As one research participant states, the voluntary disclosure of her personal information about mental illness was important in managing (normalising) her social identity in mixed contact situations:

> I’ve learnt to speak out. What is there to be ashamed about in having a panic attack? You know, I’ve got a gallstone, well I’ve got a gallstone, so what? People have mental problems, well let’s try and help them. Why cover it up, you know, that is why I like the world now, in a way it is opening up. No, speak out; definitely speak out (Code 108).

When the discredited individual become discredited, they then have to manage the resulting tension with others in mixed contact situations. The discredited individual may feel that they should accepted and respected as themselves and should no longer be required to conceal their failing to others (Goffman, 1973). In the findings, some research participants following their voluntary disclosure felt accepted and respected and no longer needed to pass as normal to others. As one research participant indicates, her friends were supportive following her voluntary disclosure:

> I have told some people about the panic attacks and they have become really true friends. Telling people the truth about who you really are does help to sort out true friends from people who don’t really care about you (Code 31).

While some research participants had positive experiences following their voluntary disclosure of personal information, other people who involuntarily disclosed their personal information had to mask their discredited social identity. According to Goffman, when the individual is
discredited they must use a strategy of concealing or obliterating the signs that are seen as stigma symbols, or present the signs of their stigma as the sign of some other attribute, which has less stigma attached (Goffman, 1973). In the study, most research participants sought to pass as normal by hiding their personal identity as people with agoraphobia from others in mixed contact situations. However, some individuals who showed a noticeable level of anxiety, which was recognised by others, were discredited in these mixed contact situations. While these discredited individuals could no longer pass as normal, some attempted to mask their panic attacks as an attribute of claustrophobia, which was seen to have less attached stigma. As one research participant indicates, the masking of her panic attacks and avoidance behaviour as claustrophobia enabled her to maintain her personal identity (agoraphobic) while creating a social identity (claustrophobic), which allowed her actions to be accepted as normal by others:

People don’t understand about agoraphobia, so I tell them I have claustrophobia as people know straight away that claustrophobia is being a fear of being closed in, so it allows me to get out of places without having to explain about agoraphobia (Code 35).

While the discredited must manage the tensions in mixed contact situations and the discreditable must manage information in mixed contact situations, both of these techniques come together in managing the visibility and obtrusiveness of the stigma. The stigmatised person’s objective is to reduce the tension by managing information, which reduces the size of the stigma in mixed contact situations. This process is referred to as covering, which includes an individual restricting the display of a failing centrally identified with that stigma, and anything associated with the organisation of social situations (Goffman, 1973). In the study, whether the research participants were discreditable or discredited they had to manage information and tension in mixed contact situations. These individuals regularly sought to cover the visibility and obtrusiveness of their panic attacks through attempting to suppress the outward appearance of their anxiety to others.
Conclusion

The Interactionist theoretical perspective’s application to the findings material has shown that research participants regularly experienced stigma and discrimination towards their agoraphobia from intimates, as well as experiencing stigma and discrimination towards mental illness from normals in mixed contact situations. Some research participants experienced stigma and discrimination from partners and family members through disrespectful, disempowering, and devaluing attitudes and behaviours directed towards them, due to their apparent deviance from the normative expectations of other family members. In addition, the person with agoraphobia often experienced a lack of knowledge, understanding, and empathy from other societal members due to mis-information about panic attacks. When research participants made a public disclosure about their thoughts, feelings and actions they were routinely labelled and placed in the stigma category of the mentally ill by intimates and others. In some cases, the research participants attempted to manage their personal information and social identity to hide their stigma from with normals in mixed contact situations to avoid being discredited, while other research participants who chose to reveal their actual identity to sympathetic others sought to manage tension in close contact situations. The research participants were seen to use sympathetic others to accompany them into public places and situations to assist in the management of their panic attacks, and wise persons to assist in the management of information and tension in mixed contact situations. Some research participants were shown to use passing and covering techniques to manage information, visibility and biographical histories of their panic attacks. The essay concludes that research participants’ experience of stigma towards agoraphobia and mental illness evolved from the need to manage their spoiled identity in a society that treats the mentally ill as second-class citizens.
Normalness

This essay will explore whether research participants saw themselves as normal when interacting with other people with agoraphobia. The essay will use Goffman’s theoretical framework on ambivalence, professional presentations, in-group alignments and out-group alignments and the politics of identity to explore the research participants’ concept of normalness. The Agoraphobic Support Group (ASG) members as research participants will be shown to have experienced ambivalence towards other people with agoraphobia. Also, clinicians will be seen through professional presentations to contribute to the support group members’ ambivalence towards identifying as normal or agoraphobic. The essay will show the formation of in-group alignments. In addition, the ASG members’ shift to out-group alignments will be revealed. Finally, the ASG members will show to be involved in the politics of identity in their interaction with normals’ society. Therefore, this Interactionist framework promises to provide an excellent tool to analyse the research participants’ experience on the theme of normalness.

Ambivalence

In Goffman’s theoretical discourse he states that the stigmatised person will often feel some ambivalence towards their stigma category (Goffman, 1973). In the study, some ASG members experienced ambivalence towards their interaction with other support group members. Initially, these ASG members felt positive about meeting, talking, and sharing with other people with agoraphobia. The ASG members often formed positive and supportive relationships and received encouragement and support to effectively manage their agoraphobia through their interactions with other support group members. Also, ASG membership was a catalyst for some research participants forming friendships that sustained them during their recovery from the unmanaged symptoms stage of agoraphobia. In addition, some ASG members experienced a sense of acceptance, inclusion and belonging in the support group environment. These ASG members often felt “normal” being among other people similarly affected by panic attacks and agoraphobia. In these cases, the ASG members could relate to a shared identity, lived experiences and the stigma and discrimination of others in the wider community. As one ASG member states, she didn’t feel negatively judged in the support group environment.
I felt like I was sitting in a room where for once I wasn’t a freak (Code 93).

Goffman states that the stigmatised individual will tend to stratify his/her ‘own’ according to the degree that their stigma is apparent and obtrusive to them (Goffman, 1973). In the study, some ASG members experienced ambivalence towards interacting with other support group members due to stratification among the support group members. The ASG membership stratification was formed on the basis of support group members’ experience of panic attacks and avoidance behaviours. The ASG membership stratification is divided into the layers of ASG members with a few panic attack symptoms and avoidance behaviours to those with a large number of panic attack symptoms and avoidance behaviours. Also, the ASG membership stratification is layered into those successfully managing their agoraphobia to those in the unmanaged stage of agoraphobia. The ASG stratification means that members often relate to and accept other support group members in the same stratum, while struggling to relate and accept members in different strata in the support group. Therefore, ASG members tend to feel a sense of “agoraphobic normalcy” with others in their stratum, while seeing others on a different stratum as a different experience of agoraphobia.

Goffman suggests that when stigmatised persons stratify their ‘own’ on the basis of the apparentness and obtrusiveness of their stigma they will then adopt the attitudes of normals towards the more evidently stigmatised individual (Goffman, 1973). In the findings, the ASG members who successfully managed their agoraphobia often adopted the attitudes of normals towards ASG members who had apparent and obtrusive panic attack symptoms and avoidance behaviours. These ASG members’ normative judgements included feelings of pity towards those ASG members less normal than themselves. As one ASG member indicates in her account of feeling different from those she saw as more anxious:

*I went to the support group for a wee while, but I didn’t find that terribly helpful because people there seemed to be such a lot worse than me...They didn’t seem to have the same sort of things that I kind of thought I had. They seemed to have different sort of anxieties to me...There were people who couldn’t even go out to the letterbox and they’d talk about things that were really bad. I thought that I’d never been that bad and that I couldn’t mix with these people...(Code 37).*
Goffman states that the stigmatised person’s separation from the more evidently stigmatised individual shows a sharply marked oscillation in their identification. The stigmatised person’s self-betrayal and betrayal of the more evidently stigmatised person is the development of social alliances with normals. As the stigmatised person increases their social alliances with normals, the possibility exists that they will see themselves as no longer having a stigma (Goffman, 1973). In the findings, the ASG members who saw themselves as more normal than those ASG members who were more evidently agoraphobic, reduced their attendance at ASG open meetings and increased their interaction with normals in other social settings. As one ASG member indicates in her comments, she began to reduce her interaction with ASG who were more agoraphobic, to avoid reminders of her stigma:

I found the support group good for a time, but when you are getting better, and living your life, listening to people going through what you went through in the early days brings it all back (Code 33).

In addition, the stigmatised person may exhibit identity ambivalence when seeing a person sharing the stigma acting in a stereotypically manner in social situations. The stigmatised person may feel repelled and then shamed having seen these stereotypical behaviours. In addition, the stigmatised person may feel acute ambivalence when caught in the process of ‘nearing’, that is, when the person comes into close contact with an undesirable instance of their stigma category while in the company of a normal (Goffman, 1973). Therefore, ASG members sought to distance themselves from ASG members who were apparent and obtrusive in their agoraphobia and would have felt socially uncomfortable nearing the ASG member and witnessing their panic attacks and/or avoidance behaviours in the company of normals.

Goffman’s states that the stigmatised individual would often oscillate between identifying, participating with and supporting members of their stigmatised category and the members of the normal category. The stigmatised individuals would often go through ‘affiliation cycles’ where the special opportunities for the different in-group participation was accepted or rejected (Goffman, 1973). In the study, former ASG members who were successfully managing their struggling panic attacks and agoraphobia felt more comfortable supporting, identifying, and participating with normals. In addition, these former ASG members enjoyed the special opportunities of accepting the identity of normal, such as higher social status among normals.
However, former ASG members who had relapses of panic attacks and agoraphobia often sought to be re-identified as ASG members and participated in support group activities to access the special opportunities provided to support group members. These special opportunities included acceptance, empathy, understanding and support from other support group members.

Professional Presentations
In Goffman’s theoretical discourse, he states that professionals who are present in in-groups (e.g. support groups) often teach the stigmatised individual how to reveal or conceal their stigma. The professional will teach the individual how to deal with tricky situations; the support that should be given to their own stigma category; the type of social contact with normals that ought to maintained; the types of prejudice against his/her own stigma category that ought to be ignored and the types of prejudice that should be challenged; the extent he/she should present as normal to others; the extent he/she should receive different treatment; the facts about his/her stigma category that they should be proud of; and the ‘facing up to’ his/her differences (Goffman, 1973). In the study, the Anxiety Disorders Unit (ADU) provided clinicians on a rotation basis to provide instruction to ASG members on how to manage their agoraphobia. At the ASG monthly chat groups the ADU clinicians would address ASG members’ concerns on dealing with potentially socially embarrassing panic attacks during interactions with normals. The ADU clinicians would instruct ASG members on how to support each other during social group outings and activities with each other. In some cases, the ADU clinicians would suggest how the ASG member ought to handle regular social interactions with normals such as family members, friends, and work colleagues. In addition, the ASG committee regularly invited other professionals to talk at open meetings to assist ASG members to address issues. The Mental Health Foundation and Human Rights Commission speakers advised ASG members on how to address stigma and discrimination towards people with mental illness. These professionals advised ASG members on the different types of prejudice, the different types of treatment and consumer rights. In most presentations these professionals encouraged and supported ASG members to be proud of their recovery from mental illness and to ‘face up’ to stigma and discrimination in their social interactions with normals.
Goffman states that the professional will provide the stigmatised person with a code of conduct that includes a list of appropriate attitudes regarding the self. The stigmatised individual’s success in the usage of these codes of conduct is seen as real and worthy, which combined produce ‘authenticity’. The professional who advocates these codes of personal conduct can make the stigmatised person become a critic of their social situation which creates a social consciousness absent in normals in the same social situation. In addition, the professional’s advice to the stigmatised individual often deals with a private and shameful part of their life (Goffman, 1973). In the findings, the ADU clinicians provide a code of conduct that evolved around ASG members’ usage of cognitive behavioural therapy (CBT) to manage their panic attacks. A key component to CBT was “straight thinking” where the individual had to challenge their reasoning and actions towards their panic attacks. The ASG members’ successful adoption and usage of CBT was seen as a worthy course of action, which promised to enable the individual to live a more normalised life. The ADU clinician’s advocacy of CBT meant that the individual became a critic of their attitudes and actions in social situations, creating an awareness of the need to act normal that was absent in normals in the same social situation. In addition, the ADU clinicians’ advice lead the individual to feel more comfortable towards their dealing with the social embarrassment of their agoraphobia.

In Goffman’s discourse he argues that professionals often require the stigmatised person to make a ‘good adjustment’ by acknowledging and accepting that they are essentially normal, while at the same time instructing them on how to manage their stigma in mixed contact situations. The professionals’ encouragement of this good-adjustment means that the stigmatised individual’s stigma is never presented to the normal audience, and normals will never have to admit to their lack of tactfulness and tolerance; and normals can remain relatively uncontaminated by intimate contact with the stigmatised and unthreatened by the identity beliefs of the stigmatised category (Goffman, 1973). At ASG open meetings and chat groups, professionals often encouraged ASG members to see themselves as essentially ‘normal’, while instructing them on how to manage their panic attacks in mixed contact situations. In essence, the ASG members learnt to present themselves as normals, a social identity that was acceptable to normals, while suppressing the presentation of their actual personal identity – as an agoraphobic – in mixed contact situations. The ASG members’ presentation of the normalised identity, coupled with the suppression of their actual personal
identity, to normal audiences (e.g. family, friends, and work colleagues), meant that normals did not have to address their ignorance and intolerance. Also, the family members, friends, and work colleagues could remain relatively uncontaminated by intimate contact with the individual and unthreatened by their actual personal identity – as an agoraphobic.

In-Group Alignments

In Goffman’s theoretical discourse he states that stigmatised individuals often formed into small-organised social groups, which provided organised support for their members. These small-organised groups enabled members to share their stories and to form friendships (Goffman 1973). The Agoraphobic Support Group (Canterbury) (ASG) is a small-organised group formed by people with agoraphobia who sought to form mutually supportive relationships with others in their stigma category. The ASG enables individuals to receive encouragement and support as well as informing them on the nature of panic attacks and various treatment programmes. Also, the ASG empowers people to meet, talk, share and learn from other people with agoraphobia. As one research participants reports:

*It was helpful just talking about it and sharing with people who had the same sort of problems (Code 256).*

The ASG helped group members to feel more confidence about managing their panic attacks following their interaction with others who appeared able to control their agoraphobia. Also, ASG group members experienced a sense of belonging and being “normal” among those in their stigma category, which reduced their feelings of social isolation and alienation. In addition, ASG group membership was a catalyst for group members forming the friendships that sustained them during their recovery process from agoraphobia.

According to Goffman, the small-organised groups advocate for the rights of the stigmatised person to various audiences of normals. The group speakers would present the case of the stigmatised to these audiences and many stigmatised speakers acted as role models who had been successfully “normalised” through group interaction. The ASG regularly advocates for the rights of people with agoraphobia in public meetings and workshops presented to both audiences of professionals, ordinary persons, and group members. In addition, group speakers (committee members) regularly acted as role models to other members, by showing that they
had successfully learnt to manage their panic attacks through group activities (e.g. workshops, chat-groups, etc).

Goffman states that these groups often publish material to give voice to their members, to disseminate success and atrocity stories, create a sense of belonging among members and identity enemies of their group. These publications may include the advertisement of resources required by the stigmatised person to successfully cope in their daily life (Goffman 1973). The ASG publishes a newsletter each month, which enables group members to contribute their “voice” in the form of articles about their personal experience of panic attacks. These personal stories provide inspiration and assurances to the reader that panic attacks can be overcome. The newsletter presents professionals’ articles on new treatment programmes and medications for the successful management of agoraphobia. Also, the newsletter includes advertisements for various self-help books and tapes that help group members to cope with their panic attacks and a calendar of events that will provide information and support to group members in their everyday life. Also, the newsletter provides the lifestyle corner (recipes and puzzles), which allow group members to engage in normalised activities. Finally, newsletter provided a service to set up supportive networks between group members to help them manage their agoraphobia. As one research participant reports:

_In the ASG newsletters they send out and I still get them, they set up a Buddy Support System and it said there are people in these areas if you want to contact them, contact us, and they put me on to this lady. She lived just around the corner, so I used to go and visit her once a fortnight. I would have been about 26 and she was probably in her early 40s, but that didn’t matter. We got on really well. She is a very open person, which allowed me to be open. I kind of just talked a lot about what I had suppressed all those years and it was quite exciting. It was like finding a best friend (Code 93)._

In Goffman’s discourse, he states that the leaders of these groups often develop a career through their attainment of political, financial or occupational position in the group. These leaders in making a profession of their stigma are obliged to deal with representatives of other categories, which means that they socialised beyond their stigma category. The leaders’ interaction with representatives of other categories may then undermine their social interaction with and their representation of members. Also, the leaders’ representation of the stigma to others may simply reflect their personal experience of the stigma, which may be
unrepresentative of members’ experiences (Goffman 1973). The ASG leaders have developed their “agoraphobic careers” through attaining positions of power on the committee, which include the roles of chairperson, treasury and secretary. These ASG leaders are regularly obligated to deal with the representatives of other categories, such as the Canterbury District Health Board (funder) and the Anxiety Disorders Unit (service provider). The ASG leaders’ tendency to deal with these representatives for funds and services reduces the time and effort spent in social interactions with group members. The ASG leaders’ representation of group members often reflects instead their own personal experiences, which are more familiar to them than the personal experiences of group members, which undermines their role as the representatives of group members.

While Goffman identifies the empowering role of small-organised social groups’ in providing organised support for their members, the findings show that the ASG sometimes struggled to provide organised support for its members. Some ASG members struggled to attend and participate in social interactions at open meetings due to their agoraphobia. In these cases, the ASG committee would attempt to organise a support person to accompany the individual to open meetings. However, some ASG members still struggled to attend these open meeting when accompanied by a support person. The ASG members, who could not attend open meetings, often experienced social disconnection from both their stigmatised category and normals.

Those ASG members, who did attend the open meetings and social groups, often struggled to socially interact with others due to differences in age, gender, class, culture, and life experiences with panic attacks. In addition, some ASG members believed that their continuing participation in the support group would hinder their attempt to return to the status of the normal category. These individuals believed that their over-exposure to the anxiety-related thoughts and feelings of other ASG members would cause them to ‘slide-back’ into the undesirable attributes (e.g. panic attacks) of the stigma group. As ASG members began to recover from their panic attacks, some individuals felt that their continuing identification with, and participation with other support group members would undermine their return to a normalised life. As one former ASG member indicates in her reason for leaving the support group:
I got to the stage where I didn’t want to go to the meetings any more because you are hearing everybody else’s problems and what they are feeling. I was like that when I started and that is when I needed the support from them, but I got to a stage where I wanted to go on and get away from that, and that is when we all did our own kind of thing. I still see them, but that is why I kind of never carried on with the group (Code 33).

Therefore, as the ASG members recovered from their panic attacks, this reduced their willingness and ability to identify with, and participate with support group members.

Out-Group Alignments

In Goffman’s theoretical discourse, he states that stigmatised individuals are normally required to see themselves from the perspective of a second grouping, which comprises normals from the wider society. This group uses psychiatric discourse inspired by normals, which advocates that people who adhere to their discourse are mature and adjusted, while people who don’t are impaired, rigid, defensive and lacking in inner resources (Goffman, 1973). In the study, health professional groups (e.g. general practitioners and ADU clinicians) regularly used their medical discourses to diagnose and treat patients presenting with panic attack symptoms. The health professionals’ usage of these medical discourses meant that patients came to see their panic attack symptoms as either a medical or mental health issue, which required medical treatment. Therefore, some research participants’ initial perception of their ‘problem’, as a personal weakness, was altered by the health professionals’ usage of medicalised discourses. In the case of some general practitioners, their knowledge and experience in physical medicine led them to frame (diagnose) the patient’s presentation of panic attack symptoms as having a physiological root which required medical treatment (e.g. heart condition requiring medication). In other cases, the general practitioners identified the panic attack symptoms as a mental health problem and framed (treated) their patient using physiological approaches (anxiety requiring anti-depressants). In a large number of cases, the patient would advocate and support the general practitioner’s perception that their condition required a medical diagnosis and/or treatment. As one research participant indicates in her account of her perception of her condition:

I didn’t realise for a long time, that my panic attacks/agoraphobic symptoms were a mental health issue, thought that it was a physical problem (Code 27).
In contrast, the ADU clinicians and other mental health professionals used the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) as the psychiatric discourse which framed their perspective of patients panic attack symptoms. The ADU clinicians and mental health professional’s usage of the psychiatric discourse led patients to see their condition as a cognitive and behavioural issue, rather than a personal weakness and/or physiological problem (e.g. heart condition).

In the writer’s personal experience of general practitioners, ADU clinicians and mental health professionals the patient is seen to become mature and well-adjusted following their acceptance of a medicalised diagnosis and medical treatment, while a patient who resists the medical framing of their condition is seen by some health professionals as cognitively impaired, rigid, defensive and lacking in inner resources to deal appropriately with their medical condition.

Goffman states that this second group normally advises the stigmatised person to see themselves as fully human like normals. The group argues that the stigma is nothing in itself, that the stigma should not cause shame, and that the person should not try to conceal the stigma. In addition, the secondary group argues that hard work and persistence will enable the person to achieve ordinary standards (Goffman, 1973). In the findings, most general practitioners, ADU clinicians and mental health professionals advised their patients to see themselves as fully human (The Health and Disability Code of Consumers Rights appropriately displayed in medical establishments) and to accept that they were no different from other individuals. Some health professionals’ lack of knowledge about panic attack symptoms lead them to be dismissive of both the panic attack symptoms and the patients’ experience of shame and social embarrassment in everyday life, which required passing and covering of their agoraphobic identity. Also, most health professionals advocated to their patients that hard work and persistence would enable them to achieve a recovery to a normalised standard of living among others in the wider community.

Goffman states that the group will propose a strategy for the stigmatised individual to deal with normals based on the assumption that stigma arises from normals’ ignorance towards the stigmatised category. Also, the group will advocate a strategy for the stigmatised person to
tactfully handle normals in mixed contact situations. This strategy involves the education of the normal to make them accept that the stigmatised person is fully human (Goffman, 1973). In the findings, research participants identified the Mental Health Foundation’s usage of the ‘Like Minds Like Mine’ strategies as challenging normals’ ignorance towards people with mental illness, which helped people with agoraphobia to deal with normals’ attitudes in everyday life. This strategy of challenging normals’ ignorance towards people with mental illness was central to the Like Minds Like Mine campaign which research participants believed had had a positive affect on their dealing with negative attitudes in everyday life.

These strategies often involve the stigmatised individual modelling normalised behaviours to normals in an attempt to alter how normals see individuals in the stigmatised category (Goffman, 1973). In the Like Minds Like Mine campaign, people with mental illness (including a person with agoraphobia) were shown in socially valued roles, such as politician, professional, family member, parent, worker, etc. However, when the stigmatised person encounters normals who struggle to ignore his/her failing, then the person will try to help the normal through making a conscious effort using matter-of-factness and detachment to ease the tension in mixed contact situations. In addition, the stigmatised individual may introduce their stigma as a topic for serious discussion in an attempt to reduce its significance as a topic of suppressed concern (Goffman, 1973). In the study, several ASG members believed that the Like Minds Like Mine campaign’s matter-of-factness helped to de-mystify and ease tension with normals in mixed contact situations. In the writer’s experience the Like Minds Like Mine advertisements have been valuable in opening up the subject of mental illness for serious discussion in conversations with normals, without the writer having to reveal his identity or lived experiences at that time. Goffman concludes that the stigmatised individual may inform normals that their efforts to reduce concern was effective and appreciated, while the stigmatised person will tactfully accept unsolicited offers of interest, sympathy and help from normals (Goffman, 1973).

The Politics of Identity

In Goffman’s theoretical framework he states that the in-group and out-group both present an ego identity for the stigmatised person; the in-group through political phrasings and the out-group through psychiatric phrases (Goffman, 1973). The ASG committee’s political phrasing
of consumer rights, influenced ASG members to see themselves as consumers of mental health services, while the health professionals’ psychiatric discourse contributed to ASG members seeing themselves as patients of mental health services.

Goffman states that the stigmatised person is promised that both of these lines will lead to an acceptance of self, dignity and self-respect. In reality, the stigmatised persons’ politically or psychiatrically framed self is simply a voice for the respective group that talks for them and through them (Goffman, 1973). As the ASG Chairperson, the writer acknowledges that his political discourse (e.g. consumer rights and human rights) sought to encourage ASG members to accept themselves as deserving of dignity and respect in interactions with normals in mixed contact situations. Also, as the ASG committee’s spokesperson the writer has regularly acted as a voice for the ASG members in public forums (e.g. university and polytechnic presentations), which means that the writer has a major role in shaping the social identity of ASG members. In the case of the ADU clinicians, their medical discourse appeared to encourage ASG members development of self-respect and dignity, while expecting the ASG member to accept the clinician “as an expert” voice able to talk for them in the public forum of ASG open meetings.

Goffman states that in the political and psychiatric discourses the stigmatised person is told that they are normal and belong in the wider group (Goffman, 1973). In the study, the ASG leaders and ADU clinicians’ discourses combined to instruct the person with agoraphobia to see themselves as normal, and belonging among other normals in the wider community. However, the stigmatised person is then told that they are ‘different’ and it would be foolish to deny their difference, this defining of difference derives from the viewpoint of normals in society (Goffman, 1973). In the case of the ASG leaders, the political discourse of consumer and human rights informs ASG members that they are actually different (i.e. mental health consumers), while the ADU clinicians medical discourse informs them that they are different (i.e. patients), which is a view derived from the medical experts (i.e. normals) in society. Therefore, the stigmatised person is told that they are normal and that they are not normal. The stigmatised individual is then trapped into an argument concerning how he/she ought to think about themselves, that is, their ego identity.
Goffman argues that the professionals in these two groups will simultaneously push the stigmatised person in different directions by telling them what they should do and feel about what they are and are not, and all of this is advocated as being in their best interests (Goffman, 1973). In this case, the ASG leaders as professionals (moral career) and ADU clinicians and other health professionals push the person with agoraphobia in a political and medical direction at the same time, seemingly in their best interests.

In Goffman’s theoretical discourse he states that stigma and normalness is a social process that involves the construction of a perspective about an individual (Goffman, 1973). In the study, the ASG socialisation process involved ADU clinicians and ASG leaders constructing a medical and political perspective towards people experiencing agoraphobia. Thereupon, the ASG members’ perception of agoraphobia evolved from a personal weakness to include the identification of having a mental illness (medical discourse) and being oppressed by normals (political discourse). The ADU clinicians and ASG leaders medical and political perspectives dominated ASG members’ discourses in the chat groups, open meetings and social groups.

In Goffman’s discourse, he states that a group of normals can subject any individual to the social process of stigmatisation at any place or time in their life. Also, the stigma management happens when a group asserts identity norms which individuals fail to acquire or achieve in their life. Therefore, all social actors can play the role of normal and the stigmatised depending on the identity norm (Goffman, 1973). In the ASG, the ADU clinicians, ASG leaders and ASG members’ roles as normals (expert or recovered agoraphobic) or the stigmatised (mentally ill) was dependent on the individual acquiring or achieving the identity norm of a person who can successfully manage panic attacks in social situations.

Goffman concludes that in society, all human beings share the same psychological framework and are mentally equipped to play either of the roles of normal or the stigmatised. The individual can be placed and participate in either the normal category or the stigmatised category. However, the individual in the stigmatised category will have to manage tension (as the discredited) and control information about their personal and social identity (as the discreditable) to effectively manage their spoiled identity (Goffman, 1973). While, the ASG leaders’ successful management of their agoraphobia secured their position in the normal
category (recovered agoraphobic), a relapse of panic attack symptoms could readily lead to their placement in the stigmatised category (mentally ill). In the case of ADU clinicians the onset and development of panic symptoms and avoidance behaviours, could shift them from the normal category (experts) to the stigmatised category (mentally ill). Also, the ASG members’ successful management of their panic attacks and agoraphobia as well as their election on to the ASG committee could lead to their shifting from the stigmatised category (mentally ill) to the normal category (recovered agoraphobic). In all of these cases, the ADU clinician, ASG leader, or ASG member who were placed in the stigmatised category would have to manage tension (as the discredited) or control information (as the discreditable) to effectively manage their stigma.

In conclusion, the general practitioners’ medical discourse played a major role in shaping ASG members’ perceptions of their agoraphobia as a mental illness, which pushed them towards the medicalised group of the mentally ill. In contrast, the ADU clinicians’ CBT discourse encouraged ASG members to see themselves as potential normals (recovering agoraphobics), who had to adopt normalised patterns of cognitions and behaviours. The Mental Health Foundation’s Like Minds Like Mine campaign influenced ASG members towards seeing themselves as normals who ought to be socially valued, while ASG leaders’ political discourse promoted ASG members’ perception of themselves as consumers with normal rights (human and consumer) Finally, the ASG members’ stratification on the basis of the degree of stigma shaped their perception of themselves as being more or less normal than other ASG members.
Therapists and Therapy

This essay will use Schur’s theoretical framework, derived from the labelling approach, to explore the relationship between therapists and patients with agoraphobia. The writer will explore the role of therapists as expert “audiences”, who use collective rule making to assess patients with agoraphobia. Also, the essay will examine therapists’ interpersonal interactions with, and organisational processing of patients with agoraphobia. This will include therapists’ stereotyping of, retrospective interpretations of, and negotiations with patients who have agoraphobia. The writer will investigate therapists’ tendency to contribute to the role engulfment of patients with agoraphobia. Also, the patient’s attempts to de-label and re-label themselves as normal will be explored. The essay will use the writer’s personal observations, as an Anxiety Disorder’s Unit patient, as well as Agoraphobic Support Group members’ observations as the sources of data.

In Schur’s theoretical discourse he states that social agents and social agencies use social interactions to define and shape the identity of the individual. The individual’s actions are seen as deviant when the actions are seen as a discreditable departure from the social agents and social agencies’ normative expectations. The social agents and social agencies’ response to this discreditable departure is to use collective rule making and social control processes to change the actions of the individual. In Schur’s definition he implies that deviance is dependent upon the extent that the human behaviour is seen and responded too, also that deviance and control are interrelated, and the understanding of one requires an understanding of the other (Schur, 1971). In the study, the majority of Agoraphobic Support Group (ASG) members (research participants) initially went to their general practitioner for diagnosis and treatment for their anxiety-related thoughts, feelings and behaviours. In some cases, the general practitioners’ lack of knowledge and understanding led to trivialisation, mis-diagnosis or even dismissal of the patient’s report of anxiety-related symptoms. These research participants often had to search for other general practitioners to properly assess their panic attack symptoms or endure the mis-diagnosis and mis-treatment of their anxiety disorder. In most cases, the research participants eventually came into contact with a general practitioner who properly diagnosed their thoughts, feelings and behaviours as an anxiety disorder. Some of these general practitioners then referred their patient to the Anxiety Disorders Unit (ADU)
for assessment and treatment, while others continued to treat their patient with anti-depressants. The ADU is a publicly funded social agency which employs trained therapists (agents) who define (diagnose) and treat (control) people experiencing anxiety-related thoughts, feelings and behaviours. The ADU therapists’ assessment involves using the Diagnostic Standards Manual (DSM-IV), which identifies and labels clusters of thoughts and behaviours as abnormal. The DSM-IV is derived from the collective rule-making of the medical profession. The ADU therapists’ use the DSM-IV to determine whether their patients have made a discreditable departure from the normative expectations of society.

In Schur’s discourse he states that deviance and social control involve processes of social definition. The societal definition of ‘normal’ and ‘abnormal’ are socially defined within the context of specific periods of time, cultures and subcultures. Those thoughts, feelings and behaviours which by definition are normal in one social setting, may be defined as abnormal in a different setting. It is the social processes that shape social definitions of thoughts, feelings and behaviours as normal or abnormal, not the individual who actually commits these actions. In addition, the individuals’ defining of their actions as being normal or abnormal is the product of these social processes (Schur, 1971). In this study, the ADU therapists’ diagnosis of patients is seen as a social process, where the patient’s anxiety-related thoughts, feelings and behaviours were medically defined as abnormal (e.g. agoraphobic), which then required “fixing” through the social process of small group cognitive behavioural therapy (CBT) programmes. The ADU therapists’ usage of social processing (e.g. therapist diagnosis and CBT group therapy) meant that the patients’ initial personal definition of their thoughts, feelings and behaviours as a personal weakness of unknown origin and/or a physical problem was socially re-defined as a mental illness requiring treatment. Therefore, the ADU therapists’ social processing contributed to the patient adopting the self-definition of “abnormal”, rather than the adoption of that label resulting from the actions of the individual.

Schur states that the social definitions of behaviour are continuously shaped and reshaped by social processes occurring within social interactions. The social processes involve formal and/or informal responses and counter-responses, which enable social definitions of deviance to be attached to individuals’ thoughts, feelings and behaviours, as well as shaping the individuals’ self-conception, role and actions as being that of the deviant. The individuals’
development of a self-conception, role and actions of deviance leads to their “commitment” and “career” as a deviant (Schur, 1971). In the study, the ADU therapists’ regularly used the DSM-IV as a medicalised diagnostic tool to define their patient’s thoughts, feelings and behaviours as a category of mental illness. The therapist’s diagnostic process involved one-to-one interaction with the patient in the form of an assessment. The therapist’s assessment involved their patients’ responses to a formalised diagnostic questionnaire. In the diagnostic questionnaire, the patient would report the level of anxiety and avoidance they had experienced in different public places and situations. In the writer’s experience of completing the ADU diagnostic questionnaire, the self-report of frequent and high levels of anxiety and avoidance, inevitably led to my medical definition as a person with agoraphobia. In addition to the formal assessment of the diagnostic questionnaire, the therapist and patient would engage in informal responses and counter-responses, where the therapist would attempt to gather information about the patient’s anxiety-related thoughts, feelings and behaviours. This therapist’s usage of this informal process enabled them to confirm the medical diagnosis drawn from the formal process of the diagnostic questionnaire. The therapist’s medical processing of the patient, using formal and informal assessment tools, shaped the patients self-conception, role and action as a mental health consumer. The ADU patient’s medical processing meant that their initial self-conception of their thoughts, feelings and behaviours as a personal weakness was re-defined as a category of mental illness, which required them to perform the role of a mental health consumer and to commit to the action of small group cognitive behavioural therapy. As one ADU patient states her medical processing involved informal (interview) and formal (questionnaire) assessment which lead to her placement on a CBT programme that confirmed her self-conception, role and actions as a mental health consumer:

*I went to the Anxiety Clinic when it was at Princess Margaret Hospital...I went in and I had the interview, there were heaps and heaps of paper tests to fill out. I saw a counsellor who put my name down for a course, which I did. That was a three week course – it was very intense, it was extremely intense, and I was quite hard because a lot of the other people were really, really bad, but some of them weren’t too bad... I think it was the second day we went into this department store and got into the lift. I thought I’m not getting in that, but everyone had got in the lift and I thought I’ve got to do it, everyone else is doing it, so we got in and went up to the next floor and got out and we’d all survived. We had to go back down, and that was the first thing that I’d ever done and I felt really relieved afterwards, but as we went through the course we were*
taught how to cope with our fears and stuff... It takes a long, long time, it really does, but I did everything I had to do and I even drove out to Birdlings Flat on my own and stayed there for while and then came back – that was one of my tasks I had to do – that was in the last week, and by the time I finished the course I felt really good (Code 41).

Schur’s theoretical framework involves an exploration of the several processes involved in the labelling and control of deviance behaviour. The labelling process include collective rule-making, interpersonal reactions, and organisational processing, which are undertaken by several “audiences”. The first “audience” is the large and complex network of groups and interests, which label (e.g. collective rule-making) various forms of behaviour. The second “audience” comprises those people with whom a person has regular interaction (e.g. interpersonal reactions), and by whom he/she is positively or negatively “labelled”. The third “audience” includes the agents of social control for official organisations (e.g. organisational processing) (Schur, 1971). The ADU acts as the first audience, as a publicly funded service provider engaging in collective rule-making through its labelling and treatment of deviance behaviour, such as panic attacks and agoraphobia. In the ADU, therapists regularly use the DSM-IV as a diagnostic tool to label deviant behaviour and CBT as its treatment programme for the deviant behaviour. The ADU therapists act as the second audience through their interpersonal reactions with patients during small group programmes and one-to-one sessions. The therapists’ interpersonal reactions with their patients enable them to label their thoughts, feelings and behaviours as either deviant or as normal. The ADU management team and the therapists act as the third audience through their role as official agents, who internally process (case management) the patient through the organisation.

In Schur’s theoretical framework he focuses on the interpersonal reactions between the deviant and other social actors. These interpersonal reactions involve stereotyping, retrospective interpretation and negotiation. In stereotyping, the social actor is seen to construct their expectations of the deviant from selective and stereotypical images of their group, which enable the social actor to predict the actions of the deviant, to the extent that it is sufficient for the social actor to organise their own behaviour. However, the social actor’s perception of the deviant, formed from the stereotypical images, often leads to an inaccurate assessment of the deviant. Therefore, the social actor’s interpersonal reaction (stereotyping) significantly influences their expectations of others, and creates serious response problems for the person.
defined as deviant (Schur, 1971). In the writer’s observations of ADU clinical assessments, the therapists appeared to construct their expectations of the patient from their selective and stereotypical images of their representative group (e.g. agoraphobic). The therapist’s selective and stereotypical image seemed to stem from the DSM-IV list of thoughts, feelings and behaviours, which had been categorised into deviant groups. The therapist’s usage of the DSM-IV then enabled them to predict the actions of the patient, to the extent that it was sufficient for the therapist to organise their treatment approach towards their patients. Schur states that the social actor’s perception of the deviant, formed from the stereotypical images, often leads to an inaccurate assessment of the deviant. Therefore, the social actor’s interpersonal reaction (stereotyping) significantly influences their expectations of others, and creates serious response problems for the person defined as deviant. In this study, the ADU therapists’ usage of clinical assessments created a perception of the patient that formed a medicalised (instead of holistic) representation of the individual.

The concept of retrospective interpretation involves mechanisms where other social actors view the deviant in a “new light” (Schur, 1971). In the ADU, the therapists’ usage of case notes acted as a mechanism that created a medicalised identity of the patient. The therapists’ usage, updating and reflection on these case records then influenced their expectations and response to the behaviour of the patient.

The concept of negotiation involves agents of social control who use their discretionary power to negotiate with those labelled as deviant. This negotiation normally involves direct bargaining between the parties, where the agent of control usage of discretion is influenced by their stereotyping and retrospective interpretations of the deviant, as well as any organisational imperatives to produce an outcome to manage the deviant. In the writer’s experience, the ADU therapists are seen to use their discretionary powers to negotiate a “label” during the diagnosis phase of their assessment for an anxiety disorder. The therapist’s negotiation with the writer involved my reporting of anxiety-related thoughts, feelings and behaviours and the therapists usage of stereotyping (DSM-IV) and retrospective interpretations (case notes) to determine whether my anxiety was a personal weakness or an anxiety disorder (and which type of anxiety disorder). The therapist’s negotiation with the writer involved their “offer” of a diagnosis for my anxiety symptoms, which then required my acceptance to enable a mutually
accepted diagnosis to be reached for both parties. This negotiation process involves the therapist medically defining my self-report and offering medical labels and solutions as is seen appropriate to the situation. Therefore, the therapist and patient have unequal power in defining the situation, with the doctor’s definition having considerable influence in determining the outcome (Scheff, 1968). Finally, the ADU organisational imperatives of diagnosing and treating anxiety disorders meant that the assessment and treatment phases produced a managed outcome for the individual. In the findings, an ADU patient reported that initially the ADU therapist’s case management led to the successful management of her panic attack symptoms. However, when the ADU therapist’s case management was completed the patient’s lack of self-management led to the relapse of her panic attack symptoms.

The Anxiety Disorders course taught me a lot of skills and was very useful in managing my anxiety. But I began to stop doing the breathing and relaxation, I never seemed to have the time and then stressful things would happen and I would be back to square one - panic attacks. I think it would be really valuable if people could redo the course, and have a second chance of getting all the information deeply ingrained in their minds. I feel that just doing the course once teaches you skills and gives you the information, but it doesn’t really get programmed deep inside of you and that’s where it has to be because that’s where the panic thoughts live (Code 31).

The concept of organisational processing involves agents and agencies of control using political power and economic resources to define and control the individual who is officially labelled as deviant. In organisational processing; policies, procedures and practices of organisations define and control deviants. (Schur, 1971). The Canterbury District Health Board (CDHB) uses its political power and economic resources to fund and resource the ADU, which defines (diagnostic assessments) and controls (CBT treatment programmes) patients who have been officially (DSM-IV) labelled as mentally ill. Also, organisational processing involves deviants experiencing loss of status and their prior identity as non-deviants (Schur, 1971). In the ADU, the person experiencing panic attacks is officially processed through case management that leads to their official status as a mental patient and their loss of social status as a normal.

In Schur’s theoretical framework he states that social agents and agencies that define and control individuals labelled as deviant can cause them to experience role engulfment. Those
individuals who are labelled as deviant will have their other roles taken over by their role of deviant. Also, the individual’s role of deviant will eventually dominate their concept of self. The individual will organise their actions around the role of deviant, and attempt to meet the social expectations linked to the role of deviant. As an individual assumes more of the roles of the deviant, the more likely they will develop a conception of self as defined by others. Thereupon, the individual’s role of deviant will becomes increasingly present in their everyday activities and lifestyle (Schur, 1971). In the study, the ADU therapists’ diagnoses and treatment programmes led to research participants’ role engulfment as patients with agoraphobia. The therapists’ diagnostic assessment (defining) of the research participants experiencing anxiety, produced their label as a patient with agoraphobia. In addition, the therapists’ enrolment of their patients in CBT treatment (control) programmes established their role as patients with agoraphobia. The ADU patients’ immersion into the CBT small group programme with other agoraphobics meant that their other social roles were taken over by their role as a CBT group member. The CBT group member would develop the self-conception of a recovering agoraphobic, which required the individual to organise their actions (e.g. management of their panic attacks) to meet the therapists and other CBT group members’ expectations of them in the role of recovering agoraphobics (e.g. using breathing and relaxation exercises). As the CBT group member assumes more of the roles of the recovering agoraphobic (e.g. successfully completing exposure assignments), the more likely they will develop the conception of self as a recovered agoraphobic as defined by the therapists and other CBT group members. Thereupon, the CBT group member’s new role as a recovering agoraphobic becomes increasingly present in their everyday activities and lifestyle. As one ADU patient comments the successful completion of the CBT course led to a better future:

When the Anxiety Disorders course finished my horizons kind of broadened then, because I started going further afield and staying away from home for longer amounts of time. I got back that feeling that I could do anything and go anywhere, and that I was making progress and I was doing OK (Code 269).

Schur states that at the heart of role engulfment is “master status”, where the deviant role dominates all other roles belonging to the individual. The individual’s response to the acquisition of the “master status” involves deviance disavowal (de-labelling and re-labelling). In the deviance disavowal process these individuals have to distance themselves from the deviant labelling processes that are attached towards their behaviour, and participate in
processes that re-label their behaviour as normal. In addition, the individual has to participate in behaviours that are seen and relabelled as normal by others (Schur, 1971). In the writer’s experience my “master status” as a recovering agoraphobic has determined my other roles and actions as a “normal”, especially as a student (studying agoraphobia) as a paid worker (disability-related) and as a volunteer (ASG committee member). The writer’s deviance disavowal processes have involved separation from the de-labelling process (e.g. treatment programmes) and participation in re-labelling processes. The writer’s participation in normalised behaviours with others, include social and sporting activities with others in normal settings. In the study, some research participants on completion of the ADU treatment programme attempted to distance themselves from other CBT group members. These individuals normally sought to participate in normalised behaviour which was seen by others as normal. However, most research participants accepted that the occasional relapse of panic attack symptoms would be a part of their normal life.

I guess that agoraphobia will always be a part of my life. It’s like an acceptance that I will always be an agoraphobic. I found it quite hard when I thought I had sort of come right, and then it would all of a sudden just flare up again. I tried fighting it all the time, and it really took me a long time to accept this is my life. I accept that there could be times in my life when it does flare up but I have the knowledge and skills now to deal with it (Code 148).

In conclusion, Schur’s labelling approach has shown that ADU therapists act as expert “audiences” in the assessment and treatment of people with agoraphobia. The ADU therapists act as an expert audience through listening to and then defining the meaning of patients self-reports of seemingly abnormal anxiety-related thoughts, feelings and behaviours in different social contexts (e.g. panic attack in supermarket). The ADU therapists’ collective rule-making was seen in their universal adherence to the DSM-IV as in the assessment method to diagnose patients with suspected anxiety disorders. The ADU therapists’ usage of the DSM-IV enables them to stereotype the patients’ self-reports of thoughts, feelings and behaviours into specific categories of mental illness. In addition to the ADU therapists’ usage of the DSM-IV as a formalised from of diagnostic assessment, therapist’s informal interpersonal interactions with the patient enable them to acquire information to assist in their diagnostic assessment. The ADU therapists’ organisational processing (e.g. case management) of the patient creates a medicalised experience of agoraphobia. In this case, the person’s experience of agoraphobia
becomes a medicalised experience shared with other patients on CBT small group programmes. The ADU therapists and other CBT small group members’ negotiations with the individual leads to them learning and being engulfed in the role of a recovering agoraphobic. The essay concludes that ADU therapists and CBT small group members can have a valuable role in encouraging and supporting the recovering agoraphobic. However, the person will eventually have to leave this medicalised process (ADU assessment and CBT treatment programmes) to escape the role of the recovering agoraphobic. In most cases, ASG members who sought to distance themselves from the agoraphobic identity and experience had to engage in deviance disavowal processes that enabled them to establish new and socially valued identities among normals in the wider community.
Chapter 9

Conclusion

The Ph.D. study concludes with a summary of the major findings and recommendations for further research on social interactions that shape, and are shaped by, agoraphobia. The study concludes that a large number of research participants who had agoraphobia as children had a lack of confidence, high levels of familial stress, over-protective parents, parental modelling of anxiety, poor anxiety-coping mechanisms and suffered a one-off or cluster of traumatic events. Those research participants who developed agoraphobia in adult life had a significant loss of confidence and a high level of stress, due to a one-off or cluster of traumatic events, and/or accumulated stressful events, as well as a lack of effective anxiety-coping mechanisms to manage their panic attack symptoms. The research has shown that a cognitive, behavioural and physiological sequence came together prior to and during the research participants’ initial panic attack and accompanying avoidance behaviour. The study recommends that further research investigates whether, and how, other social interactions contribute to the onset and development of agoraphobia.

The study has reached the conclusion that a significant number of research participants had panic attacks and avoidance behaviour in a wide range of primary and secondary school places and situations. The research has shown that research participants as school children normally believed that their panic attack symptoms were a personal weakness and that they simply endured the panic attacks, which led to under-reportage to parents/caregivers, school authorities and health professionals. The major finding that research participants had a high incidence of agoraphobia as school children, which contributed to social and academic disadvantage, prompts the recommendation that future research should focus on the statistical prevalence of agoraphobia among primary and secondary school children.

The study has determined that research participants as youths missed out on a wide range of youth-related experiences including: youthful spontaneity, the forming of relationships, social drinking, socialising in public places, participating with friends in public entertainment (e.g. concerts) and travelling overseas. The study recommends that future studies explore the social
interactions of youth with agoraphobia in relation to their parents, peer group and significant others.

The study has resolved that research participants had their everyday interactions in different public places and situations severely affected by agoraphobia. Some research participants had to plan activities in advance (e.g. safe routes), venture out during quiet times of the day, and/or manipulate others to undertake tasks for them and/or use a companion to accompany them into various public places and situations. However, the research participants planning and organisation robbed them of a sense of freedom and spontaneity in their daily life, and often a single panic attack could disrupt a day of activities, which often undermined their willingness to do those the activities again and led to less participation in out-of-home activities. The research participants’ excessive worrying about recurring panic attacks and a lack of effective personal coping mechanism often contributed to a downward spiral that weakened resolve and energy to continue functioning in everyday life.

The study has concluded that research participants often felt fearful travelling through and being trapped in a large range of traffic situations including: travelling to the supermarket, school or employment, traffic lights, multiple lanes of traffic, road works, travelling over long-spanned bridges, on the motorway, cities, towns, and the countryside. The research participants would often develop strategies to enable them to travel, including the accompaniment of a companion, distraction techniques, regular breaks and a safe route. The study recommends that future studies investigate the effects that travel restrictions have on restricting social interactions for people with agoraphobia.

The study has deduced from its findings that research participants often lost their confidence and social skills to participate in social interactions, became increasingly socially isolated and were economically disconnected due to their inability to interact in public places/situations due to the fear of panic attacks. The research participants often struggled to attend major family events, which contributed to estrangement with offended family members. Those research participants who out of social obligation and to maintain family relationships and friendships, forced themselves to participate in family events, often felt anxiety ridden and trapped, which
ruined their enjoyment of the family event. These research participants often formulated strategies to avoid family events (e.g. making excuses, and escapes routes). Unfortunately, a large number of research participants were seen to miss out on doing the things that they would have loved to do, miss out on pursuing their dreams, while becoming increasingly trapped in an unwanted and unfulfilling lifestyle.

The study has reached the conclusion that some research participants who had the initial panic attack continued to function in public places/situations, until the frequency and intensity of panic attacks forced them to withdraw into their homes, while other research participants who had the initial panic attack immediately withdrew into their home. The research participants would often force themselves to return to public places/situations, to meet social and employment obligations, by using various coping mechanisms to endure the panic attacks. The study has shown that female research participants often left the workforce and withdrew into the home as housewives and mothers, while male research participants continued working in the paid workforce. This study recommends that future research explore whether changing gender roles (e.g. women as providers and men as caregivers) has had any effect on the gender experience of functional and homebound agoraphobia.

The study has deduced from research participants’ reports that the ‘normal’ population was often ignorant and misinformed about agoraphobia, and that they believed that it was simply an unpleasant experience (i.e. fear of open spaces). However, a large number of research participants were often ignorant themselves about agoraphobia until they acquired information or came into contact with others similarly affected by agoraphobia. The research participants often feared negative value judgements, labels, and ridicule from family, friends, colleagues and others due to negative attitudes towards mental illness. The research participants’ fear of stigma and discrimination often forced them to hide their mental illness from family, friends and others. However, the study recognises that public education programmes such as the Like Minds Like Mine campaign have promoted positive images of people with mental illness. The study recommends that future studies on mental illness explore public perceptions and discrimination suffered by people with specific mental illness such as agoraphobia.
The study has reached the conclusion that research participants often had to manipulate their social interactions to socially survive among others. The research participants’ manipulations of others included: making excuses to others to manipulate them into doing things, avoiding entering places and/or situations where they feared having panic attacks, and protecting their privacy to prevent negative value judgements and social embarrassment. A few research participants lied to others by claiming that they had claustrophobia, which is less socially stigmatised, and more readily accepted and understood, than agoraphobia. Some research participants who regularly made excuses as a form of social survival often suffered a crisis of conscience about their lying to and deceiving of others, as well as a crisis of identity as they became a dishonest and untrustworthy person. The study recommends that future research examine the role that manipulation of social interactions has in changing the identity of people with agoraphobia.

The study has revealed that research participants would tell others about their ‘problem’ in an attempt to gain acceptance and understanding from their family, friends and significant others. Some people felt uncomfortable and emotionally distressed telling others, and were fearful that they would be seen as mentally unstable and would suffer social rejection. In some cases, the stress of public disclosure and the fear of negative reactions triggered panic attacks. Those research participants who told others about their ‘problem’ were careful to tell those whom they trusted, while continuing to hide their ‘problem’ from strangers. The research participants who disclosed their ‘problem’ often encountered ignorance, indifference, lack of understanding and empathy, ridicule and negative value judgements. People often treated the person differently following their disclosure, often insisted that they simply ‘snap out of it’ or simply assert control over their thoughts and feelings. However, some research participants had positive experiences following disclosure that led to their identifying understanding and supportive family members, friends and others. The study concludes that research participants had the choice to hide their agoraphobia and avoid possible negative reactions or tell others the truth. The study recommends that future research should investigate the strategies that would enable safe and effective disclosure of mental illness.
The study has determined that research participants’ formation of intimate relationships was often affected by agoraphobia. Single research participants often struggled to socialise with a wide range of potential partners, due to a lack of confidence, low self-esteem, panic attacks and avoidance behaviours. The single research participants often sought partners that were seen as confident, assertive, protective, and supportive in public places and situations. Those research participants who entered intimate relationships often hid their agoraphobia from their partner, due to a fear that they would not understand and/or that they would make a negative judgement towards them, which would damage the developing relationship. The male research participants in intimate relationships and marriages were more likely to become dependent on the practical and emotional support of their partner than female research participants who had wider circles of social support including family members, friends, neighbours and others. However, female research participants were normally more financially dependent on their partner, due to their role as unpaid housewives and mothers. Some research participants regularly manipulated their partners into undertaking a greater share of roles and responsibilities and do out-of-home activities that allowed them to avoid panic attacks. The partner was often forced to accommodate the reclusive lifestyle of the partner with agoraphobia, including the avoidance of family-related events. However, some research participants forced themselves to attend family-related events to appease and avoid damaging their relationship with their partner. The research participants’ unwillingness to go out with their partner and that partner’s impatience, resentfulness and anger towards their ability to go out together sometimes led to conflict and abuse within the marriage/intimate relationship. These research participants’ lost confidence and self-esteem and became trapped in unsatisfactory relationships, due to their mental illness undermining their confidence to assert themselves in the relationship, and ability to function in public places/situations independent from their abusive partner. Some research participants suffered impaired sexual performance due to a lack of self-confidence, feelings of unhappiness, side effects of anti-depressant medication, and/or the perception that sexual arousal was a sign of panic attack symptoms. While some research participants had problems in their marriage/intimate relationships, other people had a positive and supportive partner who encouraged and supported their seeking of medical treatment as well as acting as their support person. The study recommends that future research explore the partners’ experience of having a partner with agoraphobia.
The study has reached the conclusion that research participants were often fearful that they would role model anxiety and avoidance behaviour and pass on their lack of confidence to their developing children. These parents often felt guilty about having children due to their inability to do things with their children and the burdening of their children with out-of-home roles and responsibilities. The parents often struggled to participate with their children in out-of-home activities (e.g. family visits, school, church, recreation, doctor appointments, etc) which they believed impeded the children’s social integration into the community. Some parents passed their roles and responsibilities on to other family members, such as arranging for family members to transport their children to public places and situations. Some parents who went into public places and situations with their children would often use the caregiver role to distract themselves from their panic attacks, while other parents used the caregiver role as an excuse to withdraw into the home. Some parents hid their mental illness to protect their children from developing the fear that they would develop agoraphobia, while other parents delayed telling their children until they were more mature, understanding and supportive towards mental illness.

The study has shown that research participants’ post-secondary school education was often adversely affected by panic attacks, which led to difficulty in participating in class activities, impaired educational performance and reduced career choices and income-earning potential. A large number of research participants reported that their panic attacks interfered with their ability to concentrate, follow instructions, learn, retain and recall information. The research participants’ fear of panic attacks and possible public embarrassment of having the panic attack meant that many research participants simply endured the panic attacks, dropped out, or engaged in correspondence courses to complete their post-secondary education. The study recommends that future research examine the effect of agoraphobia on different forms of post-secondary education (e.g. trade courses, tertiary studies, etc).

The study has determined that some research participants suffered impaired work performance, became trapped in unsatisfying workplaces, had low income earning potential and lower employment status compared to their (able-bodied) colleagues. A large number of research participants struggled to secure employment as their panic attacks had led to a high turnover of
jobs and sub-standard work histories that made them unattractive to potential employers. Those people who were able to acquire employment often struggled with travelling to their workplace, settling into the workplace, managing the workplace environment, learning new skills, accepting responsibilities in the workplace, public speaking, handling customer relations and resolving conflict situations in the workplace. In addition, people struggled with the fear of having panic attacks and the ongoing suppression of panic attacks, public embarrassment of having panic attacks, stigma and discrimination towards mental illness, and their impaired work performance due to constant worrying about anxiety and the avoidance of perceived anxiety-inducing work-related places/situations. Also, people struggled with the feeling of entrapment in the perceived safety of the workplace and the resulting avoidance of seeking alternative employment that required travelling a long distance from their home. Those people who informed their managers, and/or supervisors and/or co-workers of their condition often had to endure negative reactions that included, lack of acceptance and understanding, gossip, ostracism, harassment and victimisation. Some research participants developed coping mechanisms in the workplace to manage these problems including avoidance of employers and co-workers, avoidance of specific situations that were perceived as triggering anxiety and in some cases using alcohol to suppress panic attacks. In addition, some research participants’ coping mechanisms included fleeing from the workplace to their homes. Some research participants who lost their confidence and ability to remain in employment became unemployed, welfare dependent and/or financially dependent on a partner/family member. The confidence of research participants often went into a downward spiral as they were labelled, categorised and stigmatised as devalued citizens - dole bludgers. Those research participants on sickness benefits often suffered the double social stigma of being mentally ill and welfare beneficiaries. The study recommends that future research should investigate employers and co-workers views on people with agoraphobia in the workplace.

The study has made known that research participants regularly used personal coping mechanisms to suppress their panic attacks in public places and situations for their personal and social survival. The personal coping mechanisms included the usage of safe routes, companions, distraction techniques, drugs (i.e. anti-depressants, cigarettes, cannabis, and alcohol), breathing and relaxation techniques, and stress management. The research
participants’ reliance on a partially effective personal coping mechanism in a crisis situation often hindered the usage of Cognitive Behavioural Therapy (CBT) that promised more effective management.

The study has demonstrated that some research participants used alcohol to manage their panic attacks, to mask their panic attacks from others, to take time-out from their panic attacks, to continue their education and/or employment and to enable themselves to enjoy public places and situations where they feared having panic attacks. However, the research participants’ usage of alcohol was normally only partially effective in suppressing their panic attacks. In addition, some people worried that their excessive usage of alcohol would lead into alcoholism, while ceasing to use alcohol would leave them without a coping mechanism for their panic attacks. The study has shown that that alcohol had several major advantages over the usage of prescription medication. The research participants could access alcohol more readily than prescription medication (e.g. supermarket purchase compared to GP appointment, waiting room, consultation and chemist). People could purchase alcohol at the supermarket as a ‘normal’ transaction, while people had to present themselves as mentally unstable and emotionally weak to gain a prescription for anti-depressants from a GP or other health professional. There was less social stigma attached to drinking around family members, than being seen taking anti-depressants around other family members. The person could use alcohol at short notice, while anti-depressants required several weeks to take effect (i.e. 4 to 6 weeks). Also, people had more knowledge about the amount of alcohol required to suppress their anxiety, while working out the correct dosage of prescription medication relied heavily on guesswork. In addition, people were more aware of the side effects of alcohol compared to prescription medication. The research participants reported that the usage of alcohol enabled them to relax and socialise with others. In addition, the presence and regular usage of anti-depressants was a constant reminder that the person had a mental illness, while a bottle of wine in the fridge allowed the person to dismiss their mental illness as a personal weakness. However, the some research participants usage of alcohol had several major disadvantages that included the lack of independent (i.e. health professional) monitoring of their alcohol usage which could lead to dependency on the usage of alcohol and hindered the seeking of CBT treatment, the possible effect of alcohol on anti-depressant medication, and the health
consequences of prolonged alcohol usage (e.g. liver damage). The study recommends that future research explores whether and how people with agoraphobia use cannabis as an alternative coping mechanism to alcohol and prescription medications (e.g. anti-depressants).

The study has shown how research participants’ labelling and learning about their anxiety-inducing thoughts and feelings was an important step towards the management of their agoraphobia. Generally, research participants believed that their anxiety-inducing thoughts and feelings were a unique personal weakness, social inadequacy, and/or physiological problem, and most struggled for weeks, months or years to identify and understand their problem. The research participants identified their strange thoughts and feelings through television programmes, radio talk-back, women’s magazines, newspaper articles and advertisements, leaflets, books, libraries, Citizens Advice Bureau, Internet and conversations with family, friends, co-workers and strangers who have had similar panic-like symptoms and avoidance behaviour. When research participants had labelled their ‘problem’ as a mental illness most visited a health professional to access a proper diagnosis, treatment programmes and/or prescription medications. The people who visited health professionals usually wanted information on the cause of their problem, an understanding of agoraphobia, assurances that they were not alone or going crazy and how to control (e.g. cure or manage) their panic attacks. The study recommends that future research examines the role that public education and interaction has in the labelling and learning about mental illness.

The study has reached the conclusion that research participants’ usage of the Internet helped in securing information on panic attacks/agoraphobia, treatment and medications. In addition, people were able to acquire understanding, empathy, encouragement, inspiration and support from others through the usage of web-sites, chat-rooms and on-line support groups. Those people who were homebound were able to use the Internet to reduce their social isolation. The study argues that the short-term usage of the Internet is often highly beneficial for users, as people can form friendships that lead to mutual encouragement and support in completing social interactions in public places/situations. However, the long-term usage of the Internet for social interaction has the potential to undermine people’s willingness to leave their home to engage in social interaction in public places/situations. The study recommends that further
research should investigate whether long-term usage of the Internet chat-rooms helps or hinders the social interaction in public places/situations.

The study has shown that research participants sometimes contacted emergency services due to belief that their panic attack symptoms were a sign of a rapidly deteriorating physical condition that required urgent medical attention. The research participants often confused the panic attack symptoms with a physical illness, due to the similarity between panic attacks and other medical conditions, such as heart attacks. The emergency service, personal and/or family doctor normally provided comfort to the individual and reassurance that the panic symptoms would not lead to a medical crisis. Some people would continue to use emergency services to assure themselves that medical intervention would be instantly accessible if the ‘worse scenario’ should happen. A significant number of research participants struggled to inform their health professional (GP) due to the fear of leaving their home, using public transport, and fear of being in public places and situations where a panic attacks could happen. Also, people struggled to describe their symptoms, believed that they would not be believed due to the lack of physiological symptoms, were unwilling to appear mentally unstable or show emotional weakness and feared social embarrassment. In addition, people were unaware that a health professional could be helpful, were worried about being pressured into using medication, and possible side effects of taking medication. According to research participants, health professionals (GPs) often started their medical investigation by eliminating a physical cause for the ‘problem’, which some patients struggled to accept, due to their belief that the physical symptoms (e.g. heart palpitations, breathlessness) were a sign of an underlying physical health problem. Also, some health professionals appeared to struggle to make an accurate diagnosis due to the patient’s difficulty in accurately describing their panic attack symptoms. In addition, some health professionals seemed to lack knowledge about panic attacks, CBT programmes, and simply prescribed anti-depressants to suppress anxiety without specifically identifying the anxiety disorder. The study concludes that research participants often struggled to inform and impress upon their health professional the seriousness of their problem, which affected their ability to access treatment programmes and/or medication. The study recommends that future studies explore health professionals’ perspective on their interaction with patients who have agoraphobia.
The study has demonstrated that research participants on long waiting lists for medically approved assessment and treatment programmes often suffered deterioration in their mental health, and damage to their marriages/relationships, education and employment, etc. Some people struggled to access treatment programmes due to being severely restricted in their ability to travel or being homebound. In addition, people often developed a reliance on their personal coping mechanisms, which increased their difficulty in learning and using CBT to manage their agoraphobia. The study has shown that CBT taught in small groups enabled people to share their thoughts and feelings with others in a understanding, non-judgemental social environment and acquire a feeling of reassurance, by seeing others successfully use the CBT to manage their agoraphobia. However, some research participants with social phobia and agoraphobia struggled to participate in the small group environment. The study has shown that CBT was often effective in people’s management of panic attacks and would reduce dependency on anti-depressant medication. The successful teaching of CBT required clinicians that were friendly, approachable, empathic and who were able to communicate effectively to a wide range of people. However, the research participants reported that a person had to believe in the effectiveness of CBT, and regularly practise CBT skills to effectively manage their panic attack symptoms. In addition, research participants believed that stress management was important to prevent relapses of panic attacks and agoraphobia. The study has shown that some people preferred to use private psychologists or counselling services that addressed other ‘issues’ (e.g. stressful factors) at the same time as learning to manage their agoraphobia. However, private psychologists/counsellors were usually unaffordable for research participants on low incomes, who often suffered a deterioration in their mental health waiting for publicly funded treatment, increasing their difficulty in learning CBT due to their established reliance on flawed personal coping mechanisms. In addition, research participants on low incomes with deteriorating mental health, often suffered more disruption to their marriages, education and employment, etc. The study recommends that future studies further explore peoples’ experiences of private and publicly funded CBT programmes.

The study has reached the conclusion that some research participants used anti-depressant medication to feel more confident about managing their panic attacks, which enabled them to resume everyday social interactions. However, some people had unpleasant side effects such as feelings of illness, stomach upset and queasiness, intoxication, heart palpitations and loss of
concentration. Also, some research participants believed that health professional’s overprescribed anti-depressant medication, which led to dependency problems for those patients. In addition, some people believed that the taking of anti-depressants reinforced their self-image of being abnormal, as a normal person would not need to take anti-depressants to do everyday activities. Some research participants stopped taking their prescription medication to avoid the unpleasant side effects and its social effect on their everyday lives. The study concludes that some research participants used prescription medication to successfully manage their anxiety, while some people attained the same results using CBT without the exposing themselves to side-effects of prescription medication. The study recommends that future research explore whether the usage of anti-depressants by people with agoraphobia undermines their usage of CBT programmes.

The study has revealed how research participants regularly used companions in public places and situations where they feared having panic attacks and suffering social embarrassment. The research participants would often use the companion as a ‘safe person’ to provide confidence, comfort, protection, safety, dependability, strength, stability and support in the public place/situation. The research participants often became dependent on the companion to accompany them into public places/situations, which placed considerable strain on the relationship. The research participants’ reliance on their companion and the requirement to fit their outings around the companion’s timetable often restricted their spontaneity in everyday interactions and created dependency on the companion. Some research participants were fearful of upsetting their companion, causing them embarrassment, and/or frightening them when they had a panic attack that was noticeable to the companion. The research participants reported that they usually hid their panic attack symptoms from their companion and they believed that the companion was normally unaware that they were acting as a support person for them. Some research participants reported that the companion took over roles, responsibilities and decision-making in the public places/situations, while the research participant concentrated on conversing with the companion to distract themselves from their panic attack. When research participants suffered major panic attacks they would use the companion to help them physically leave the public place/situation and sometimes arranged for the companion to do out-of-home activities for them so they could avoid recurring panic attacks in that public place/situation. In
some cases, the companions unconsciously reinforced safety behaviours by assisting the person to escape places and situations where they feared having a panic attack. Generally, research participants had a pre-existing relationship with the companion who could be a partner, family member, friend, neighbour, family pet, health professional, social worker or volunteer. This companion could make excuses or enable the person to make excuses in order to leave the public place/situation. Some research participants reported that their companions were unhelpful, due to their lack of knowledge and understanding, inappropriate comments and their applying of pressure on the individual to stay in the place/situation during a panic attack. In the study, research participants believed that the ideal companion should be knowledgeable about panic attacks and a calming influence that could provide encouragement, reassurance and practical support in their usage of CBT to manage their panic attacks. Therefore, research participants believed that companions could be a positive influence by providing encouragement and practical support for people with agoraphobia to manage their panic attacks in everyday life.

The study has determined that some research participants used support groups to receive encouragement and support from others, to enjoy the company of others and to be informed on subjects relevant to the effective management of their agoraphobia. The support group often acted as catalyst for research participants forming friendships that sustained them during their unmanaged symptoms stage of agoraphobia. In addition, research participants’ believed that support groups created a sense of belonging among others, which reduced their feelings of social disconnection from the community. While research participants had similar panic attack experiences to other support group members, the places and situations they avoided were often different from other members, which made it difficult to relate to their experiences of agoraphobia. Generally, research participants felt more confident about their ability to manage their own panic attacks, and felt less distressed about their panic attacks after meeting people more severely affected by panic attacks. While a support group has many positive aspects, some research participants were anxious about travelling and participating in the support group meetings, especially without a companion. In addition, those research participants who were homebound were unable to travel to and participate in support group meetings, which reinforced their social disconnection from others. Also, support group participation had
negative aspects including support group members who developed a dependence on support group meetings, who struggled to ‘move on’ in their lives, and ‘slid back’ into panic attacks due to their over-exposure to other support group members’ accounts of struggling with panic attacks. The study concludes that support groups that are properly used by support group members can play a major role in helping them in construct social networks that provide encouragement and support to manage their agoraphobia.

The study has reached the conclusion that research participants who were suffering high levels of stress, anxiety, depression and social isolation were often open to having a spiritual experience that included human (e.g. evangelists/missionaries) and supernatural interaction (e.g. Jesus Christ). In the study, some Christians believed that God used the trials and tribulations of panic attacks to make them search for God’s intervention that led to their personal and spiritual salvation. The Christian spiritual experience was normally experienced as unconditional love and validation of the individual with the accompaniment of powerful thoughts and emotions that displaced the anxiety-inducing thoughts and feelings that triggered their panic attack symptoms and avoidance behaviour. The Christian spiritual experience normally involved the research participant being ‘born-again’ where the former self (i.e. person with panic attacks) was ‘born-again’ into a new self (i.e. person free of panic attacks). Alternatively, some Christians who were ‘born again’ still had panic attacks, but had been equipped with religious coping mechanisms (e.g. faith, bible, prayer). The Christian spiritual experience often led to regular church attendance and fellowship, which reduced social isolation. In addition, research participants’ church attendance enabled them to participate in spiritual healing, such as slaying of the spirit that often lowered the stress levels that could contribute to panic attacks. While some research participants benefited from faith, spiritual experiences, religious practices and church attendance, other people reported that their religion had no effect on their management of agoraphobia. In some cases, the church environment was seen to be to stressful and similar to other places (e.g. supermarket, shopping mall, etc), where they had had panic attacks. In the study, non-Christian spiritual experiences (e.g. spiritual counsellors) were seen to be helpful by research participants who believed that personal growth and the healing for past stressful experiences would reduce the incidence of panic attacks. The study concludes that research participants’ spiritual experiences were normally positive towards
their management of agoraphobia and recommends that future research explores the role of other religious experiences on people with agoraphobia.

The study has shown that research participants’ successful management of agoraphobia required prompt diagnosis, accurate information, referral to a CBT programme, other counselling programmes (i.e. relationship counselling), stress management, effective support systems and relapse prevention programmes. Those research participants who made a serious commitment to a CBT programme and had a support system that encouraged the usage of CBT in public places and situations were more likely to have a successful outcome, compared to others. Also, research participants who sought to resolve stress and took time-out to relax were less susceptible to panic attacks. The study argues that research participants whose personal confidence increased through achieving in other parts of their lives were more likely to overcome their panic attacks, than other people who focused exclusively on the maintenance of their mental health. Therefore, the successful management of agoraphobia requires a holistic approach that addresses the mental, physical and social health of individuals. While health professionals have focused on the mental and physical health of people with agoraphobia, the social factors are often neglected. These social factors include confidence through participating in social interactions (e.g. education, employment, recreation, etc), and establishing supportive social networks (e.g. family, friends, colleagues, etc).

The study concludes with the observation that a significant number of research participants who developed a post-agoraphobic identity were more confident, assertive, self-aware, compassionate, caring, giving, attentive, empathic, understanding and tolerant towards others. The emergence of the post-agoraphobic identity meant that these people were able to develop (or rediscover) their true selves having emerged from the shadow of the fear of fear.

The End
References


Gingrich, P., (2000). Lecture Notes: Symbolic Interactionism, February 1, 2000, Department of Sociology and Social Studies, University of Regina.


Appendices

Agoraphobic Support Group (Canterbury) Approval for Research

To
Secretary
Human Ethics Committee
University of Canterbury
Private Bag 4800
Christchurch
New Zealand

Re: David Lemon’s Research Proposal

The Agoraphobic Support Group (Canterbury) committee has reviewed the research proposal entitled “The Sociological Study of Agoraphobia” and the accompanying University of Canterbury Human Ethics Application form. The ASG committee has given David Lemon approval to use the Agoraphobic Support Group’s database and membership mailing list to enable this research to proceed.

For any additional information, please contact
Agoraphobic Support Group contact person

Paula Rountree
Tel: 374-9893
Fax: 365-5345
E-mail: agoraphobic.support@xtra.co.nz

Signed_________________________ Date________________________
Letter to Agoraphobia Support Group members

Dear Sir/Madam

This letter is to introduce myself - David Lemon - a University of Canterbury Ph.D. student. I have been preparing a major research project on people’s experience of agoraphobia. The purpose of the research is to investigate the social factors how agoraphobia effects peoples’ life experiences. I am hopeful that this Ph.D. research will make a valuable contribution to knowledge on agoraphobia.

It is my intention to use the research data to assist in the development of ASG information services, which will directly contribute to the development of support for people with agoraphobia. An example, is the Agoraphobic Support Group Committee current application for COGS funding to develop a Support Person Guide pamphlet to provide useful information for partners and families who are beginning to support a person with agoraphobia. I am also hopeful that the research questionnaire data on education, employment, etc… will be useful to the Agoraphobic Support Group committee in other advocacy and information projects.

Research Participants Needed

To successfully undertake this research I need people with agoraphobia who are willing to complete the accompanying questionnaire. The attachment information sheet provides detailed information on the questionnaire.

IMPORTANT: You have the right to decline my invitation to volunteer to complete this questionnaire. Should you decide to decline to volunteer then please return the uncompleted questionnaire in the postage paid reply-envelope.

Yours Faithfully

David Lemon
Survey Information Sheet

• The questionnaire should take about 45 minutes to complete.

• Should a question not allow sufficient lines for your comments, then continue writing your answer on a spare sheet of paper and attach to the questionnaire. Please write the question number on the sheet of paper and then continue writing your answer. For example: Q12 __________

• You can have a support person present to assist you during the completion of the questionnaire.

• You should be able to complete this questionnaire at your home. Please contact me if this causes a problem - Phone (03) 3242285 evenings to make arrangements for an alternative place.

• Should you feel any distress when attempting to answer any question, then you have the right to decline to answer that specific question in the questionnaire.

• The questionnaire’s data will be included in the results of the research and will be published in a Ph.D. thesis document.

• You are assured of complete anonymity and confidentiality of all personal information in this research project. All questionnaires have a research participant (identification) code number on the first page that hides the identity of the volunteer. The research data published in the thesis or any other publications will not include volunteers’ names or any identifying information.

• All questionnaires will be stored in a locked filing cabinet in my office and shall be destroyed when no longer required for research purposes.
• Please note that this study has the approval of the University of Canterbury Human Ethics Committee.

• Volunteers are required to sign the consent form below, following the reading of this information sheet and should return the consent form with the completed questionnaire.

Research Participants Consent Form

‘The Sociological Study of Agoraphobia’
I have read and understood the information sheet on the above-named project. On this basis I agree to participate as a subject in the project, and I consent to publication of the results of the project with the understanding that anonymity will be preserved. I understand also that I may at any time withdraw from the project, including withdrawal of any information I have provided.

Signed__________________________________________ Date / /
Survey Questionnaire

Research Participants Code Number

Research Participants Information Section:
In the survey questionnaire, you may circle as many of the small squares (next to your answers) as required to completely answer the question.

Question 1: Date of Birth

Question 2: Gender

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Family Section:
Question 3: What type of family were you raised in for the majority of your time as a child (5 to 12 years)?

- Single Parent (Mother)
- Single Parent (Father)
- Both Biological Parents (Mother & Father)
- One Biological Parent & One Step Parent (Step-Mother)
- One Biological Parent & One Step Parent (Step-Father)
- Welfare Guardian
- Foster parents
- Adoptive parents
- Grandparent(s)
- Whanau
- Institution (Orphanage, boarding school, etc)
- Other

Please state __________________________

Question 4: What type of family were you raised in for the majority of your time as a youth (13 to 18 years)?

- Single Parent (Mother)
- Single Parent (Father)
- Both Biological Parents (Mother & Father)
- One Biological Parent & One Step Parent (Step-Mother)
- One Biological Parent & One Step Parent (Step-Father)
- Welfare Guardian
- Foster parents
- Adoptive parents
- Grandparent(s)
- Whanau
- Institution (Orphanage, boarding school, etc)
- Other

Please state __________________________
**Female Caregiver Section:**

**Definition:** Your primary female caregiver was the person who had the major role and responsibility for your upbringing in your family group. For example: your mother, stepmother, grandmother, female welfare guardian or any other significant female person.

Question 5: What personality traits did your primary female caregiver have when you were a child/youth (Birth to 18 years).

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<tr>
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<tbody>
<tr>
<td>□ She was a critical person.</td>
<td>□ She was a strict person.</td>
<td>□ She was an affectionate person.</td>
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<tr>
<td>□ She was a protective person.</td>
<td>□ She was a dominant person.</td>
<td>□ She was an anxious (worried) person.</td>
</tr>
<tr>
<td>□ She was an angry person.</td>
<td>□ She was an emotionally distant person.</td>
<td>□ She was unwilling to show physical affection (hugs)</td>
</tr>
<tr>
<td>□ She was a uncommunicative person.</td>
<td>□ She was a kind person.</td>
<td>□ She was a passive person.</td>
</tr>
<tr>
<td>□ She was an intolerant person.</td>
<td>□ She was a manipulative person.</td>
<td>□ I don’t know.</td>
</tr>
</tbody>
</table>

Please state any other personality traits of your primary female caregiver.

---

**Male Caregiver Section:**

**Definition:** Your primary male caregiver is the person who had the major role and responsibility for your upbringing in your family group. For example: your father, stepfather, grandfather, male welfare guardian or any other significant male person.

Question 6: What personality traits did your primary male caregiver have when you were a child/youth (Birth to 18 years).

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<tbody>
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</tr>
<tr>
<td>□ He was an intolerant person.</td>
<td>□ He was a manipulative person.</td>
<td>□ I don’t know.</td>
</tr>
</tbody>
</table>

Please state any other personality traits of your primary male caregiver.
**Family Stressful Events:**

**Definition:** Close family members can include biological and step-parents, siblings, cousins, aunts, uncles and grandparents, as well as any other person who you would describe as a close family member during your family upbringing.

**Question 7:** What stressful events occurred to one or more of your close family members during your family upbringing?

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<tbody>
<tr>
<td>□</td>
<td>One or more close family members suffered a chronic physical illness.</td>
<td>□</td>
</tr>
<tr>
<td>□</td>
<td>One or more close family members suffered from an anxiety disorder.</td>
<td>□</td>
</tr>
<tr>
<td>□</td>
<td>One or more close family members suffered from bankruptcy.</td>
<td>□</td>
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<tr>
<td>□</td>
<td>One or more close family members were mentally abusive.</td>
<td>□</td>
</tr>
<tr>
<td>□</td>
<td>One or more close family members were emotionally abusive.</td>
<td>□</td>
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<tr>
<td>□</td>
<td>One or more close family members had a significant disability.</td>
<td>□</td>
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</table>

Please describe any major stressful event that occurred during your family upbringing to either one or more close family members?

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**Primary School:**

**Question 8:** At primary school did you have panic attacks (or panic-like symptoms) and avoid the following places or situations?

<table>
<thead>
<tr>
<th>Travelling on the school bus.</th>
<th>School classroom.</th>
<th>School assemblies.</th>
</tr>
</thead>
<tbody>
<tr>
<td>School field trips.</td>
<td>School performances.</td>
<td>School sports events.</td>
</tr>
<tr>
<td>School social events.</td>
<td>School playground.</td>
<td>School library.</td>
</tr>
<tr>
<td>School choir</td>
<td>School sports teams</td>
<td>School responsibilities such as librarian, council, etc…</td>
</tr>
<tr>
<td>School sick room.</td>
<td>I did not have panic attacks or avoid any of the above situations.</td>
<td>I can not accurately remember my primary school years to comment.</td>
</tr>
</tbody>
</table>

Please describe any other primary school activities where you had panic attacks (or panic-like symptoms) and avoided the situation?

______________________________________________________________________________

______________________________________________________________________________

**Secondary School:**

**Question 9:** At secondary school did you have panic attacks (or panic-like symptoms) and avoid the following places and situations?

<table>
<thead>
<tr>
<th>Travelling on the school bus.</th>
<th>School classroom.</th>
<th>School assemblies.</th>
</tr>
</thead>
<tbody>
<tr>
<td>School field trips.</td>
<td>School performances.</td>
<td>School sports events.</td>
</tr>
<tr>
<td>School social events.</td>
<td>School playground.</td>
<td>School library.</td>
</tr>
<tr>
<td>School choir</td>
<td>School sports teams</td>
<td>School responsibilities such as librarian, council, etc…</td>
</tr>
<tr>
<td>School sick room.</td>
<td>I did not have panic attacks or avoid any of the above situations.</td>
<td>I can not accurately remember my secondary school years to comment.</td>
</tr>
</tbody>
</table>

Please describe any other secondary school activities where you had panic attacks (or panic like symptoms) and avoided the situation?

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______________________________________________________________________________
**Traumatic Event:**
*Question 10: Had any of the following events, occurred within six months of your first panic attack?*

| ☐ I had a major conflict with my parent(s). | ☐ I had been the victim of school bullying. | ☐ I had been separated from one or both parents. |
| ☐ I had ended a relationship with a girlfriend or boyfriend. | ☐ I had become engaged or married. | ☐ My partner or I had become pregnant. |
| ☐ My partner or I had a child. | ☐ My partner or I had a miscarriage. | ☐ I had recently had a major conflict (fight) with my partner. |
| ☐ I had separated from or divorced my partner. | ☐ A close family member or friend had died. | ☐ My partner had died. |
| ☐ I had suffered a major illness. | ☐ I had suffered a long-term illness. | ☐ I had suffered a major accident |
| ☐ I had recently had a very bad travel experience (aircraft, train, ship, etc). | ☐ I had a bad drug experience. | ☐ I had recently had a very bad social experience (party, family gathering, etc). |
| ☐ My partner had a major illness. | ☐ My partner had suffered a long-term illness. | ☐ My partner had suffered a major accident. |
| ☐ I had been made redundant. | ☐ I had suffered a large number of job applications (interview) rejections. | ☐ I had a near-death experience. |
| ☐ I had experienced a traumatic event out of my home. | ☐ I had witnessed a traumatic event occurring to another person. | ☐ I had been the victim of crime. |
| ☐ I had been under major work-related stress. | ☐ I had been involved in a fire. | ☐ I had been involved in a flood. |
| ☐ I had been involved in an earthquake. | ☐ I had been involved in an accident at sea. | ☐ I had a major financial crisis. |
| ☐ None of the above. | | |

Please describe any traumatic event(s) that preceded your first panic attack.
Medical Diagnosis:

Question 11: What was your approximate age when you had your first panic attack?
Age: ___________________

Question 12: What was your age when you sought a GP or mental health professional’s intervention for your agoraphobic symptoms?
Age: ___________________

Question 13: Have you been medically diagnosed with the following?

- Agoraphobia
- Social Phobia
- Specific phobia
- Generalised Anxiety
- OCD (Obsessive Compulsive Disorder)
- Post-traumatic disorder
- Separation Anxiety Disorder
- None of the above.

Question 14: Please circle the panic attack symptoms, which you have suffered in a period of intense fear or discomfort, which developed abruptly and reached a peak within 10 minutes?

- Palpitations, pounding heart (or accelerated heart rate).
- Sweating.
- Trembling or shaking.
- Sensations of shortness of breath or smothering.
- Feelings of choking.
- Chest pain or discomfort.
- Nausea or abdominal distress.
- Feeling dizzy, unsteady, lightheaded, or faint.
- Feelings of unreality.
- Feelings of being detached from oneself.
- Fear of losing control or going crazy.
- Fear of dying.
- Numbness or tingling sensations.
- Chills or hot flushes.
- Muscle Tension
- Hyperventilation
- Blurred Vision
- None of the above.

Question 15: Have you ever had the following agoraphobic symptoms?

- Anxiety about being trapped in places or situations from which escape might be difficult (or embarrassing).
- Anxiety about being beyond the help of others in the event of having an unexpected panic attack or panic-like symptoms.
- Avoidance of a cluster of places or situations. (Such as being away from home, being in a crowd, travelling on a bus, etc…)
- Avoidance or endurance with marked distress of places or situations, where the fear of having panic-like symptoms exits.
- The requirement to be sometimes accompanied by a companion into situations where you fear having panic-like symptoms.
- None of the above.
**Homebound:**
**Question 16:** Has agoraphobia caused you to become homebound at any time?

- Yes
  Please state the length of time below:
  __________________________

- No
  (Please go to next question)

**Alcohol Usage:**
**Question 17:** Please indicate if you have used alcohol to suppress your symptoms of agoraphobia.

- I occasionally used alcohol to suppress my symptoms.
- I regularly used alcohol to suppress my symptoms.
- I excessively used alcohol to suppress my symptoms.
- I developed a dependency on alcohol to suppress my symptoms.
- I have been on an alcohol treatment programme.
- I have never used alcohol to suppress my symptoms.

**Medical Intervention:**
**Question 18:** Have any of the following factors ever affected your willingness or ability to seek medical treatment for agoraphobia.

- I had no problems in informing my health professional.
- I didn’t think my health professional would believe me.
- I didn’t want to show emotional weakness to my health professional.
- I didn’t know that a health professional could be helpful.
- I didn’t know that my symptoms also affected other people.
- I didn’t want to be pressured into using medication.
- I was concerned about the possible side effects of medication.
- I did not want to appear to be a mentally unstable person.
- My panic attack symptoms would not let me visit a health professional (i.e. fear of leaving home, public transport, public places, etc)
- I did not want my parents to know about my anxiety problems by my arranging to visit a family health professional.
- I believed that my panic attack symptoms were simply a personal weakness, not a medically treatable mental health problem.
- I do not want my family (i.e. children) to become aware of my anxiety problems by my arranging to visit a family health professional.
- I believed that my panic attack symptoms were simply a personal weakness, not a medically treatable mental health problem.

Describe any other reasons that caused you to avoid your health professional.

____________________________________________________________________________

____________________________________________________________________________

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Companion - Support Person:

Question 19: Have you required a companion to accompany you into situations where you have feared having a panic attack?

☐ Yes (Go to next question) ☐ No (Go to the next section: Marriage and Intimate Relationships)

Question 20: Have you required any of the following companions when entering situations where you feared having a panic attack.

☐ I have required my partner to accompany me into situations.
☐ I have required my children to accompany me into situations.
☐ I have required other family members to accompany me into situations.
☐ I have required a volunteer to accompany me into situations.
☐ I have required a social worker to accompany me into situations.
☐ I have required a health professional to accompany me into situations.
☐ I have required friends and/or neighbours to accompany me into situations.
☐ I have required my pet to accompany me into situations.
☐ Please state any other type of ‘companion’.

Question 21: Have you ever depended on your companion to have any of the following personality traits in situations where you would normally have agoraphobic symptoms?

☐ I depended on my companion to be assertive and confident.
☐ I depended on my companion to be dependable and supportive.
☐ I depended on my companion to be protective and comforting.
☐ I depended on companion to do out-of-home activities (i.e. shopping, doctor visits).
☐ I have never depended on a companion in any situations.

Question 22: Please describe the benefits of having a companion in situations where you have feared having a panic attack.

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Question 23: Please describe the problems caused by having a companion in situations where you have feared having a panic attack.

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Marriage/Intimate Relationships:

Question 24: Has agoraphobia had any of the following effects on your relationship(s)?

| ☐ I have not been in a relationship during my agoraphobia. | ☐ My agoraphobic symptoms have adversely affected my ability to go out on dates. | ☐ My agoraphobic symptoms have adversely affected my ability to have long-term relationships. |
| ☐ My agoraphobic symptoms have undermined my confidence and feelings of worth to be in a relationship. | ☐ My partner was less willing to attend social events with me. | ☐ My partner was resentful about assuming the extra out-of-home responsibilities that I was unable to do. |
| ☐ My partner was unwilling to acknowledge that I had a mental health problem. | ☐ My partner was unwilling to talk to me about my problem. | ☐ My partner was indifferent towards my agoraphobic symptoms. |
| ☐ My partner became abusive. Please state type of abuse: ☐ | ☐ My partner was unwilling to commit to the relationship due to my agoraphobia. | ☐ My partner left the relationship. |
| ☐ My partner was more protective and comforting of me. | ☐ My partner was more willing to do out-of-home activities for me. | ☐ My partner was more dependable and supportive in our relationship. |
| ☐ My partner encouraged and supported me to seek medical treatment. | ☐ My partner acted as my support person during my agoraphobia. | ☐ None of the above. |

Please describe how agoraphobia has affected your relationship(s).

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Parenting Section:

Question 25: Has agoraphobia had any of the following effects on your parenting?

<table>
<thead>
<tr>
<th>Effect</th>
<th>Effect</th>
<th>Effect</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have not been actively involved in parenting during my agoraphobia.</td>
<td>I was unable to form a relationship to have children because of my agoraphobia.</td>
<td>I decided not to have children, due to the fear that the child would inherit agoraphobia.</td>
</tr>
<tr>
<td>I was unable to attend my child or children’s pre-school or kindergarten sessions due to agoraphobia.</td>
<td>I was unable to attend my child or children’s school performances due to agoraphobia.</td>
<td>I was unable to attend my child or children’s birth (as partner of birth mother), due to agoraphobia.</td>
</tr>
<tr>
<td>I was unable to accompany my child or children on school trips, due to agoraphobia.</td>
<td>I was unable to take my child or children on outdoor recreational activities, due to agoraphobia.</td>
<td>I was unable to take my child or children to visit extended family.</td>
</tr>
<tr>
<td>I was unable to take my child or children to visit his/her friends.</td>
<td>I was unable to travel with my child or children over long distances, due to agoraphobia.</td>
<td>I was unable to take my child or children to after school sport events, due to agoraphobia.</td>
</tr>
<tr>
<td>I was unable to take my child or children to the doctor and/or dentist due to agoraphobia.</td>
<td>I was unable to take my child or children to church, due to agoraphobia.</td>
<td>None of the above.</td>
</tr>
</tbody>
</table>

Please describe how agoraphobia has affected your parenting.

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**Education Section:**

**Question 26: Has agoraphobia caused any of the following effects on your education (Post-Secondary School Education)?**

- I have been not been engaged in post secondary school education.
- I believe that agoraphobia has adversely affected my educational performance.
- I have missed lectures, tutorials, and classes due to agoraphobia.
- I have completely dropped out of the school, college, university, etc.
- I have avoided attending exams.
- I have been unable to engage in education and/or training that required public speaking or performances.
- Agoraphobia has prevented me from using education and/or training to up-skill in my employment.
- I have dropped out of classes, courses, and/or programmes, etc.
- I have been unable to engage in education that involves travelling a long distance from home.
- I have been unable to engage in education or training.
- I have avoided attending exams.
- I have completely dropped out of the school, college, university, etc.
- I have been unable to engage in education and/or training that required public speaking or performances.
- I have been unable to engage in work-related training programmes.
- Agoraphobia has caused me to drop out of work-related training programmes.
- I have been unable to engage in work-related training.
- Agoraphobia has caused me to lose my confidence to be able to engage in education or training.
- I have felt that my lack of educational achievement due to agoraphobia has adversely affected my life.
- Agoraphobia has had none of these effects.

Please describe how agoraphobia has affected your education.

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**Question 27: Since the effective management (or recovery) of your agoraphobic symptoms have you had any problems in returning to, or continuing your adult education?**

- Yes (Please describe those problems below).
- No (Go to next question).
- I don’t know (Go to next question).
**Disruption to Employment:**

**Question 28: Has agoraphobia had any of the following effects on your employment?**

| ☐ I have not sought employment during my agoraphobia. | ☐ I have been forced to leave employment. | ☐ I have avoided job interviews. |
| ☐ I have been unable to accept employment (or promotion) that would have required travelling a long distance from home. | ☐ I have been unable to seek employment (or promotion) that would have required public speaking. | ☐ I have been forced to go onto a welfare benefit. Please state type(s). |
| ☐ Agoraphobia caused me to lose confidence in my ability to gain employment. | ☐ I have had a high turnover of jobs due to agoraphobic symptoms occurring in the workplace. | ☐ I have been unable to accept employment (promotions) that would have increased my responsibilities. |
| ☐ I have been prevented from changing my employment. | ☐ Agoraphobia has caused me to develop a poor work history. | ☐ None of the above. |

Please describe how agoraphobia has affected your employment and/or promotions.

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**Question 29: Since the effective management (or recovery) of your agoraphobic symptoms have you had any problems in returning to, or continuing your adult employment?**

| ☐ Yes (Please describe those problems below). | ☐ No (Go to next question) | ☐ I don’t know (Go to next question). |
| | | |
| | | |
| | | |
Technology:

Question 30: Has computer technology affected your daily life with agoraphobia?

- I use the Internet to search for information on agoraphobia.
- I use the Internet to access on-line support groups for people with agoraphobia.
- I use the Internet to access chat-rooms to talk to other people with agoraphobia.
- I use the Internet to locate information on medications.
- I use the Internet to reduce social isolation.
- I do not use the Internet for any of the stated reasons.
- I do not use the Internet at all.

Please describe any other usage of computer technology that assists you with your agoraphobia?
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Final Comments:

Please make any final comments you want to about your personal and/or social experience of agoraphobia?
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Thank you for completing the survey questionnaire.
Letter Attached to Survey Questionnaire - Interview Request

Please complete the panel below, if you are willing to be interviewed on your experience of agoraphobia.

I shall specifically ask for you, when phoning to arrange a date and time for the interview.

Full Name____________________________________________________________

Telephone number_____________________________________________________

Address_______________________________________________________________________
______________________________________________________________________________
______________________________________________________________________________

Please return this sheet with your completed survey questionnaires.

Important:

Research participants, who do not wish to be interviewed should ignore this sheet and proceed to the survey questionnaires.

Thank you
Interview Guidelines

Purpose of Interview:
1. The purpose of this interview is to gather information on:
   ➢ Your experience of the onset and development of your agoraphobia,
   ➢ The affect of agoraphobia on you,
   ➢ Your management or recovery from agoraphobia

Research Participants Rights:
1. The interview will normally take no longer than one hour.
2. If you need to have a break, just let me know.
3. You stop the interview at any time for any reason.
4. You can choose to answer none, some or all of the questions.

Recording:
1. The interview will be tape-recorded to ensure the accuracy of the research material.

Data Usage:
1. A verbatim transcription of the tape cassette will be made and used in the thesis.

Confidential:
1. All tapes and written material will be stored in a locked filing cabinet
2. Your name and any identifying information will not be included in the transcript.
3. Your information will not be used for any other purposes and when the thesis is submitted, all tapes and written material will be destroyed.
4. You may request a copy of your tape-recording and the verbatim transcription prior to submission of the thesis.

Questions:
Do you have any questions before we start?
Interview Schedule

The personal interviews were structured around a range of topics within the three stages of agoraphobia, the social factors occurring prior to the onset of agoraphobia, the social factors attributable to the unmanaged symptom’s stage of agoraphobia and the social factors that affect the successful management of agoraphobic symptoms.

All interviews included the following questions

• How did your agoraphobia start?
• What did you think was happening to you?
• How did you try to cope with the onset of your agoraphobic symptoms?
• How did you learn that you had an anxiety disorder called agoraphobia?
• Why do you think you developed agoraphobia?
• How did (or does) agoraphobia effect your day-to-day life?
• What have been the major effects of agoraphobia on your life?
• What life goals (or experiences) have you been unable to fulfil due to agoraphobia?
• How did ‘other’ people respond to the knowledge that you had a mental health problem?
• What was your experience of GPs mental health clinicians, or alternative medicine in treating your agoraphobia?
• What do you believe was the key to successfully managing (or recovering) from your agoraphobic symptoms?
• How do you think the experience of agoraphobia has shaped you as a person?
• Is there anything else that you would like to say about your experience of agoraphobia that I have not asked about in the survey or this interview?