

**A HOME AWAY FROM HOME? : THE TRANSITIONS  
OF OLDER PEOPLE WITHIN TWO NEW ZEALAND  
RETIREMENT VILLAGES.**

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## Abstract

This study explores the experiences of retirement village residents as they move from an independent to a supported living environment within a retirement village. It focuses on residents' perceptions of their transitions and adopts a qualitative approach to understand the nature of their transitions and the way in which they are experienced. A grounded theory framework is used in order to capture the meanings that participants apply to concepts such as home, and to the physical, social, personal and veiled spaces in which they live.

The findings from the study reveal that as residents' health fails, the impact of increasing dependence is such that their sense of social and personal autonomy is gradually eroded. The research also provides insights into residents' expectations and fears surrounding end of life. In many ways the experiences of the residents in supported living environments do not differ greatly from those of residents in any aged care facility. One major finding of this research, however, is the debilitating impact on well-being that occurs as a consequence of these transitions from independent to supported living, taking place within one physical location – the retirement village – a physical space which promises prospective residents the opportunity for active and positive ageing.

*Supported living within Retirement Villages – A home away from home?*

This research focuses on the transition experiences of residents who relocate from independent living to supported living environments within large retirement villages in New Zealand. It focuses on the way in which residents make meaning in their social world; on the transitions they have experienced within their village; the impact this has on their sense of independence and autonomy and their expectations for the future, including any consideration they may have given to preferences and preparations for end-of-life.

Theories and demographic studies of ageing have pointed to the rise in life expectancy and a recognition that lifespan is increasing throughout the world (Magnus, 2008). This has clear implications for people facing retirement and the prospect of perhaps thirty or so years of non-productive life. A number of studies have demonstrated that there is a fear of poverty and failing health in later life that has effectively stigmatised elderly people and created a social distance between the young and the old (Hockey & James, 1993; Arber & Ginn, 1991; Markides & Miranda, 1997). In twenty-first century postmodern societies life is characterised by social fragmentation, increased choice and individuality (Giddens, 1991). Retirement village literature emphasises aspects of individuality and choice through the concept of *positive ageism* (Palmore, 1999: 13) and promotes the notion of a leisure society which includes early retirement and engagement with active lifestyles in later life (Leonard, 2002; Simpson, 2007) perhaps involving travel, sporting activities, gardening and hobbies. In line with this emphasis on active ageing, the New Zealand Department of Housing and Building, along with the New Zealand Government and private sector stakeholders, continue to search for new and

appropriate models of living for older people that encourage physical activity and social engagement. One such model is the retirement village.

*‘A retirement village offers a fantastic lifestyle to those who want to live independently in their own home whilst enjoying the benefits that a retirement village can provide. People can enjoy a retirement village lifestyle whether they are 55 or 90 years of age. Retirement villages are located in prime areas which may be beside the sea, near a golf course or in the heart of the city.’* (Retirement Villages Association of New Zealand, 2012: Further description is available from the New Zealand Retirement Villages Association web site at [www.retirementvillages.org.nz](http://www.retirementvillages.org.nz)).

The retirement village model is a relatively new housing concept that first emerged in New Zealand in the 1990s. Grant (2006:4) cites the New Zealand Law Commission’s (1999) description of a retirement village as, *‘a purpose-built complex of residential units with access to a range of ancillary facilities planned specifically for the comfort and convenience of the residents’*. There are currently over 300 registered retirement villages in New Zealand (Ministry of Economic Development, 2011). Retirement villages allow people, usually over the age of sixty, to live in independent apartments or houses and smaller semi-independent apartments where hands-on support may be provided, and in more intimate levels of supported living where every assistance is on hand for daily living tasks, often coupled with a higher degree of contact and dependency on retirement village staff. All these living spaces are encapsulated within a single retirement village complex. Retirement villages are predominantly owned by large companies that promote them to potential purchasers as fully independent living arrangements backed up by peace of mind security, higher levels of care, and care packages available as and when their needs change over time. Services such as hairdressing, a

library, bar, swimming pool, gym and regular social activities are not uncommon, particularly in the larger establishments (Retirement Villages Association of New Zealand, 2012). Most retirement villages offer support services to their residents at some level but this varies widely from village to village. Some provide a significant support function in the form of a rest home facility and hospital wing within the larger retirement village structures. Retirement villages have become an established housing model for older people in New Zealand and there are indications that they will continue as a growth sector in the future (Williamson, 2009).

There are various purchase models available in New Zealand and a common entry method utilises a licence to occupy. The majority of retirement villages provide the resident with occupation rights only. It is usual for intending residents to pay a capital sum to the retirement village owners in order to live in a retirement village and this can include periodic payments for the services they will receive. The capital sum gives the resident a licence to occupy their specific living accommodation and it is a form of tenancy. When the resident vacates the accommodation or dies, the village owner returns the capital sum to the resident or to their estate. A fee is often deducted from this amount, normally between fifteen and twenty-five per cent of the sum they originally paid, calculated over the first five years of their occupation. For this reason, paying a capital sum to live in a retirement village with a licence to occupy does not give the resident a market-linked property investment. Their money is returned without interest and with the fee deduction noted above. Retirement village owners retain the right to force an end to the agreement if they can no longer provide an appropriate level of care or if the resident presents a nuisance or risk to the retirement village facility or to other residents. The resident may move to alternative accommodation offering a higher level of care within the same village if that is available. The New Zealand Department of Building and Housing



assumed responsibility for the Retirement Villages Act 2003, on 1 July 2005, which stipulates the legal requirements for this form of housing. This is supported by the Retirement Villages Code of Practice 2008, which sets minimum standards for retirement village owners and endeavours to protect the rights of intending and existing retirement village residents when they enter into agreements (Age Concern, 2012). These agreements are complex and they vary widely between retirement village owners (Department of Building and Housing, 2012).

Retirement villages primarily attract people who owned their own homes before seeking out the village living environment, where they expect to receive a degree of living support if needed in the future and a greater degree of security than in their privately owned residential home (Leonard, 2002). Retirement village promotional images (for example, The Yellow Guide to Retirement Living, 2010) project the idea of active lifestyles for older people by placing emphasis on positive ageing. This is characterised by individuality, private living space, social connections and freedom of choice with the added expectation of professional support services that are accessible to those who need them (Simpson, 2007).

A retirement village is not a microcosm of the wider postmodern world because it restricts its occupancy to older people who move into an age-based, walled community. The village is promoted as home to each resident, whether they are active and independent or receiving higher levels of supported living services. The village community does not, therefore, reflect the demographic or socially experienced transitions of the wider community population. Furthermore, the transitions that residents experience as their ability to remain independent gradually or suddenly diminishes, may require them to move through transitory living situations within their village environment or to vacate and relocate elsewhere until their death. This poses significant questions relating to those who reside in supported living areas who may,

to some degree, be disconnected from the wider community and thus be limited in their opportunity to assert their individuality or to experience significant aspects of positive ageing (Greenbrook, 2005). While the overall village environment may continue to be perceived as their home, it is reasonable to expect that when people physically relocate into supported units, they have different experiences to their counterparts in the independent living units. The catalysts for these transitions and the residents' subsequent opportunities to age positively and to retain their autonomy in relation to their end-of-life choices forms the focus for this study.

Previous studies have considered the retirement village model in New Zealand from the perspective of lifestyle choice (Leonard, 2002; Simpson, 2007; Mansvelt, 2003) and the role that retirement villages play in the lives of older people (Greenbrook, 2005; Grant, 2003). These studies have explored the notions of lifestyle and worry free living and have considered the advertising used to attract potential residents (Leonard, 2002). An active lifestyle is promoted as synonymous with well-being and thus counters the idea of declining health in old age (Jolanki, 2009). Many of the studies suggest that the primary motivation to live in a retirement village relates to the anticipation of leading a more active life and as a reaction to the life span transitions of declining health, widowhood and the older person's perception of security within their own residential locale (Gardner, 2008). There is a perception that the retirement village model will simplify the manner in which older people's practical needs will be met in the future. This is generally interpreted as a sensible choice by the independent 'leisured lifestylers' within the villages (Simpson, 2007: 347).

The retirement village lifestyle is also chosen by those who have the means to pay a significant amount of money, approximating the amount that would be paid to purchase a small freehold home in a similar geographic area to the village itself (The New Zealand Retirement Guide,

2012). This is further born out by Leonard (2002) who found that retirement village residents were previously financially secure home-owners who had commonly acquired their homes in the 1950s to 1960s. There have been moves in the UK to experiment with retirement village models that are available to people from lower socio-economic groups and they include a number of occupancy structures, including title ownership and rentals (Evans & Means, 2007). In the New Zealand context, Leonard (2002), Simpson (2007) and Gardner (2008) have also indicated that the appeal of retirement village living relates to the positive lifestyle choice, the anticipation of future support needs being met and the security that the village is perceived to provide when residents have sold their owner occupied home and relocated.

To a large extent the studies that have been undertaken in retirement villages have considered the experiences and expectations of people who are post-retirement but not in need of high levels of support. The literature on aged care demonstrates that there is a significant distinction to be made between the day-to-day living environments of what have been termed the *young old* in contrast to the *old old* and the *oldest old* (Garfein & Herzog, 1995). As the need for support increases, older people find themselves having to make choices that impact on their sense of independence and autonomy (Cheek, et al., 2007). It is at this stage that decisions have to be made, either by the older person or by their family, that may involve moving into residential care or receiving a care package within their own home. In the context of a possible move from a private home to a nursing or residential home, the experience of the transition and the impact this has on the individual has been well researched (Kane, 2001).

In the context of the retirement village, the relocation into supported living takes place within one setting. Moving into a supported living environment within the village entails receiving additional support interventions that are purportedly blended into residents' daily lives (Age

Concern, NZ, 2010). These residents are portrayed as equal members of the village community living alongside the independent residents, though their breadth of village experience, combined with their relocation experiences and associated transitions and adjustments may be quite different. Further, it is reasonable to assume that their practical daily support needs mirror the needs of other people with similar physical and mental capability, who receive living support in their own homes, within a classic rest home facility, or whilst living with their family.

There is little or no research that focuses on the transitions surrounding the relocation into the supported living units of the village and the impact that the move has on residents' lifestyle, independence and autonomy, sense of well-being and end-of-life considerations. Whilst the retirement village concept incorporates the security that is offered by a move into supported living, the village emphasis on active living promotes an ethos of independence and autonomy which runs contrary to the dependence on support services and may therefore impact significantly on the experiences and well-being of those who make these relocations.

This study will examine the impacts that these relocations and transitions have on retirement village residents. The next chapter provides a review of the relevant literature on the experience of ageing in western societies. It considers older people's attachment to place and examines the concepts of *home* and *care*, placing these in the context of ageing in New Zealand, and then, more specifically in retirement villages. Chapter Three discusses the methodology used for the study and outlines the specific research questions. This chapter includes a discussion of grounded theory and a detailed account of the research methods and ethical considerations. Chapter Four presents a discussion of the findings from the study, and the final chapter considers these findings in their broader social context.

*Overview*

This study is specifically concerned with the way in which residents experience their relocations and subsequent transitions from independent to supported living within their retirement village setting. This chapter utilises theoretical and empirical research on ageing to position the study within its wider social context.

The chapter begins by considering current literature on ageing, social attitudes to ageing and the experiences associated with ageing. It goes on to examine transitions in the context of the meaning of home, expectations and understandings of care in later life, and the impact that declining health and increasing support with daily living may have on a person's sense of independence and autonomy. In so doing, it presents an in depth review of the literature that informs and supports the research questions that underpin this study.

*Ageing in western societies*

Studies of ageing have become a significant focus for sociology, largely due to the global trend towards increased longevity (Population Division, United Nations, 2012). Demographic evidence in New Zealand signals an increase in the number of older people surviving to become octogenarians, nonagenarians and centenarians (Department of Statistics, New Zealand 2011). In the political sphere, ageing has become framed as an impending economic crisis and both international and New Zealand Government funded social agencies wrestle with the planning and development of services to cater for an aged population.

The need for western governments to respond to the predicted growth in ageing populations appears to detract from any notion of ageing as a natural, inevitable and socially acceptable human state. Instead, ageing is increasingly portrayed as a condition that presents various challenges for the future of humankind, including attempts to postpone the ageing process and to seek out ways to keep people healthy and economically active deeper into later life. This approach to ageing is far removed from past expectations of later life, when retirement was portrayed as an entrance into a well-earned period of rest to pursue relaxing pastimes. Now, older people are frequently perceived as patients to be managed, invited to annual medical screenings and encouraged to undertake health assessments as a measure of their right to receive support services. As such, ageing has become a pathological condition rather than a normal human process (Arber & Evandrou, 1993).

Similarly, the sociological literature indicates negative social images of ageing accompanied by mental or physical decline or both (Comfort, 1977; Arber & Ginn, 1991a, 1991b; Featherstone & Hepworth, 1993; Gibson, 1993; Hockey & James, 1993). It has also come to be conceptualised by western societies as a form of disability within that pathology, rather than a natural condition (Oliver, 1990). The manner in which western societies perceive this decline and respond to those who live into old age is pivotal to understanding the transitions of retirement village residents whose end-of-life years are spent within a walled community that separates the over sixties from their younger counterparts.

Outside the realms of political strategy and academic enquiry, public interest in ageing commonly focuses on sensational news stories in which crime or violence targets an older person. Media coverage appears to show vulnerability in old age as an accepted social norm, encompassing both violence and poor quality care in residential homes. The latter has become

increasingly topical in Australia, the UK, and New Zealand. Residents in aged care facilities have died as a result of various shortcomings including the withdrawal of fluids, falls occurring under staff supervision and a lack of adequate medical attention (Coronial Services of New Zealand, 2012). The profile of such cases has increased in many countries over recent years with Coroners, among others, questioning the quality of service provision. Within New Zealand, these concerns are reflected in, *A Report into Aged Care: What does the future hold for older New Zealanders* (2010).

From an individual perspective, the daily lives of older people may present personal challenges that are tangible and noticeable, whilst alongside this there appears to be a significant reduction in engagement with older populations by the general population and in the older person's local community (Shanas, et al 2007; Townsend, 2010). Social isolation and loneliness are purported to be increasing in New Zealand (3 News, 2011). This reduction in social participation has been considered as a form of *social death* (Sudnow, 1967), and exacerbated isolation to a level that has moved beyond the socio-medical arena (Timmermans, 1998). This socially hidden population is sometimes the result of sequestration (Mellor & Shilling, 1993; Howarth, 2007) where the ageing individual has come to represent the frail world of our own mortality; removal from public view serves to maintain the ageless comfort of the general population.

### *The ageing individual*

Bodily ageing occurs regardless of any effort to retain youthful looks, muscle definition, mobility, or general health. In western societies, until relatively recently, it was a generally accepted norm that people will retire in their early sixties, commonly engaging in social

celebrations and positive acknowledgement, even though often forcibly disenfranchised from the opportunity to work. This rite of passage was socially constructed as a reward for previous hard work (Dittmann-Kohli, 2005). Thus the transitions associated with ageing are framed within the context of perceived levels of social and economic value and the aged person's contribution to society as a whole. Furthermore, with increased longevity, the social category of aged has been unpacked to incorporate a more subtle and layered categorisation system that labels people into biological subcategories that range from the young old to the oldest old (Baltes & Smith 2003). These artificial classifications serve a segmenting purpose for the researcher or the policymaker but they never-the-less have implications for older people themselves. The social value and quality of life associated with transiting through these stages may impact on the individual's sense of identity and self-worth. To use Giddens' (1991) work on age and identity, where a person is located in this categorisation is likely to influence the way in which self-identity is reworked and reconstituted.

Giddens (1994) suggests that the characteristics of globalisation and the influences of high modernity have led institutions to take on reflexive characteristics that enable them to control their transformation towards the needs of the future. For Giddens (1994), these conditions have created a direct link between personal connections and the wider sphere of global social connections. He describes a reflexivity between the core of the self and the many influential aspects of social interaction that lead individuals to adopt the reflexive project of self where the individual is constantly defining and re-defining their self-identity in the context of wider globalised expectations and definitions of meaning. Giddens' reflexive project of self is also underpinned by the past because it requires a reconstruction of the past in order to provide a narrative that explains the present and project a meaningful narrative towards the future, where



late modern society focuses (Giddens, 1993). In this way, individuals take on a sense of mastery of their perceived place amongst the fast changing institutions of late modern society. Giddens sees this process of constant personal redefinition to be transforming day-to-day social activities, as the individual's self-meaning is reflected back and then modified in ways that fit with the current and changing expectations of society.

Oswald & Wahl (2003) build on Giddens' approach and note that throughout the life course people interact with their physical and social environment in ways that lead to a meaningful representation of the self within their environment. Examples of these influences can be seen in corporate advertising media that reflect norms and social expectations that embody a risk-averse global culture, one that Giddens sees as unquantifiable, having gradual and intangible effects on the subtle transitions in social and personal identity. Giddens (1992) also notes the way in which the body itself, within a process of reflexive self-identity, has become integral to an individual's lifestyle decisions. This is particularly pertinent in the context of ageing where declining health may force individuals to change their day-to-day practices requiring them to make significant lifestyle decisions according to their need to access appropriate support systems.

Given that the context in which self-identity is conceived, created and reworked occurs within the organisational, political and social environments that are external to the individual, Hockey and James (2003) suggest that in ageing, a disjunction occurs between the individual's self-conceived identity and the external environment. Irrespective of an individual's self perception, ageing has become likened to a fixed cultural category where wrinkles and weakened bodies are manifested as visible signs of difference that set elderly people apart from younger people,

who are deemed to be more able to maintain their project of self improvement (Hockey & James, 2003).

Mellor & Shilling (1993) support this by drawing on Giddens (1991) proposition that the body has become a private and personal aspect of self-identity, reified in consumer culture and central to self-identity. This focus on the body as central to the reflexive project adds further threats to self-identity in later life. ‘After all, what could more effectively signal to the body conscious individual their limitations on their reflexive ordering of self than the brute facts of their thickening waistlines, sagging breasts, ageing bodies and inevitable deaths?’ (Mellor & Shilling, 1993: 413). Mellor and Shilling further argue that the reflexive project of self operates within a cultural environment where death has become a hidden and private affair, such that the very presence of death in western societies challenges our day-to-day beliefs that our fluid self-identity will somehow be immortal. Instead, at death, the seemingly on-going reflexivity of the project of self comes to an end. Death is glimpsed only on rare occasions and is no longer a public or social ritual. The private nature of death and its’ sequestration serves to threaten the individual’s ontological security and beliefs about the existence of one’s own self-identified core, causing self-identity to be threatened and seemingly unreliable. Societal perceptions of ageing incorporate an unspoken awareness of proximity to end-of-life and raise the spectre of the inevitability of death. It can be argued that societal norms create an imaginary line or finishing post across the life trajectory. When economic value and health diminish, policy makers and medics may work to recover and maintain health but when an older person crosses that line, or is pulled across it by natural ageing processes, society tends to place them into a virtual compartment that is symbolic of a waiting room for impending death.

In late modern societies, the social and cultural construction of later life is also noted by Holstein & Gubrium (2000) who posit that retirement is reflected in advertising media as a lifestyle of active health and youthful looks as if people may somehow defeat old age and death. Retirement village advertising depicts residents as youthful and active (Featherstone & Hepworth, 1995) enjoying security and peace-of-mind whilst living independent lives in their retirement village homes (Yellow Guide To Retirement Living, 2010). Retirement villages portray their accommodation as the entry point to a new lease of life, framed around the opportunity for outings and activities, new social connections and a security that might reasonably be interpreted as somehow shielding the resident from any worries about ageing; worries that may otherwise become an intrinsic part of the ageing process. By relocating and establishing home within a retirement village an older person may reasonably see an avenue to avoid the negative aspects of ageing where the threat to ontological security is diminished, along with the threat of sequestration in old age. As such, the inevitability of dying and death may seem more distant as residents retain a positive self-identity and extended well-being.

This notion of well-being is a central element of ontological security and studies have shown the importance of one's home to a sense of security that contributes to self-identity. Home holds 'emotional meaning that can bring to mind one's roots as well as the security of a private place' (Fitzgerald and Robertson, 2006: 51-2) and as such carries with it a fundamental sense of well-being. Home is, however, an ambiguous concept that can hold several meanings, reflecting cultural distinctions and the individual's relationship to physical, social and personal space.

### *The meaning of home in later life*

A wide body of literature addresses the concept of home and its meaning from both theoretical and empirical perspectives (Giddens, 1989, Hockey, 1999, Saunders, 1990; Mansvelt, 1997; Pain et al, 2000; Dupuis & Thorns, 1996; Gurney & Means, 1993; Gurney, 1997; Keeling, 1999; Boston & Davey, 2006; Davey, 2006a, 2006b). These varied perspectives encompass social, individual and environmental factors that construct a sense of place and human connection that is home. The conceptualisation of home is overlaid by the actual living arrangements that the notion of home evokes, engendering a personal sense of autonomy for an individual in that particular place (Arber et al., 1993). Children, elderly people and other vulnerable groups within society may personally redefine the meaning of home over time to incorporate a sense of well-being, encompassing their need for security and maintaining their emotional connections.

Within much of the literature home is characterised as a *physical* site where people want to construct a personally meaningful place in which they can identify with people or objects as well as a place that encompasses the intangible and complex concepts that are constructed from their social values and personal experiences. Definitions that place emphasis on meanings constructed through emotional connections, possessions, and personal autonomy usually view home as a positive place that people seek to make meaningful. In the context of western societies, however, the assumption that home is necessarily a positive place can be questioned. For example, young people, particularly those who have become displaced from their family home, may perceive late night street gatherings as their home (Perkins, et al, 2002). Others may experience a more nomadic lifestyle in which a dwelling contains no special meaning.

Similarly, with an increased incidence of domestic violence, child abuse, and neglect and abuse of elderly people (Age Concern, 2011), home may not provide positive connections or a secure and safe haven in which people lead autonomous lives.

In the New Zealand context, the concept of home sits against a fractious political and social landscape that has witnessed the reclaiming of physical places that hold deep spiritual and religious meaning for Maori on one hand, and represent areas of natural beauty and leisure enjoyment for New Zealand Europeans on the other. The meaning of home in New Zealand, therefore, needs to be framed within a historical, economic and cultural context that has shaped the nature and meaning of home for its citizens and is bound up by notions of land ownership. New Zealand experienced relatively sparse colonisation by Polynesians in the thirteenth century and Maori remained undisturbed by western influences until European settlement in the late eighteenth century. The subsequent signing of the Treaty of Waitangi in 1840 enabled predominantly British settlers to colonise and apportion the majority of the land for development by the incoming migrant population. This reduced the geographic spread of Maori settlements through various land treaties and the subsequent Maori Wars (Kingi, K.R., 2006). New Zealand culture became underpinned by two distinct political, social and cultural systems living side by side. The signing of the Treaty of Waitangi led to further on-going political unrest and was the catalyst for subsequent land claims by Iwi seeking to redress the inequalities born out of the Treaty. A political struggle spanning over one hundred and fifty years culminated in the settlement of one of these claims with Ngai Tahu in 1998 and various other claims have since come to fruition. These land claims reached their peak in the first few years of the twenty-first century and avenues for foreshore and seabed claims by Iwi have been opened up by the Marine and Coastal Area (Takutai Moana) Act 2011 which replaced the

Foreshore and Seabed Act 2004 (Parliamentary Council Office, 2011). This presents an opportunity for claims to be lodged for exclusive rights to foreshore areas that are *Waitapu* (places sacred to Maori).

European settlement and land development in New Zealand has resulted in an overarching culture that reflects the development of the land in a modern economy of farming, tourism and resource development (New Zealand Ministry for Culture and Heritage, 2011) yet this may be a superficial portrayal of New Zealand that is promoted in tourism advertising. The loss of access to areas of land and a perception of lost foreshore for New Zealand Europeans, compounded by Maori land claims<sup>1</sup> suggests a constantly changing landscape.

When this history is considered in conjunction with the need for mobility of labour across a relatively new and emerging country, the cultural norm of temporary migration for New Zealanders seeking work and experience overseas, along with the relatively high level of non-indigenous New Zealanders, the concept of home may have to be considered in a more adaptive and fluid light than in many other western societies. New Zealand also has a history of earthquakes and volcanic eruptions with some recently experienced earthquake damage in the city of Christchurch, resulting in many deaths and the demolition of over ten thousand homes (Brook, 2011).

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<sup>1</sup> The degree to which New Zealand's political and social culture has been influenced by long term immigration from the Pacific Island nations, Australia and the United Kingdom and now increasingly from China and India (Department of Labour, 2011) raises additional complex theoretical and empirical questions about the rapid evolution of an overarching 'social culture' which lies beyond the scope of this study. Yet it is interesting to note that the purported uniqueness of New Zealand's culture has been challenged academically by Fairburn (2008) who theorised that New Zealand remains largely dominated in a cultural and political sense by the influences of the UK immigrant population as well as New Zealand's geographic proximity to Australia and its political, economic and media alliances with Australia, the USA and the UK, in addition to its cultural heritage.

These factors may well influence public and social perceptions of home and may have influenced ontological security and societal assumptions about permanency and predictability in New Zealand.

### *Ageing and home*

As noted above, the notion of home contributes to a sense of well-being and research has indicated that older people place more emphasis on the social connectedness of their home than on the physical dwelling that houses them. In an empirical study of owner occupation and ontological security in the UK, Saunders (1990) asked participants what home meant to them. He found that home was widely associated with family life. He also found that homeowners placed an emphasis on their house as their home along with the personal possessions that surrounded them, while public housing tenants placed a greater emphasis on their neighbours and their social connectedness to place within their local communities. The concept of place incorporates the notion of community as structure but also the notion of community as lived experience. An important inter-dependency therefore exists between the two when considering where a person may choose to live their life and the manner in which they want to live it. For Mesch (1998) belonging to a place is linked directly to social connectedness and is significant to the process of growing older as well as being inextricably linked with the concept of home. In a study conducted by Fitzgerald and Robertson (2006) of older people in New Zealand, participants' depictions of home incorporated a geographical location (e.g. place of birth), their physical environment (e.g. the countryside), their capacity to be creative (e.g., having space in which to paint, garden, cook), and, perhaps most significantly, home was 'understood as a place of privacy and autonomy' (Fitzgerald and Robertson, 2006: 53).

Numerous studies have attempted to conceptualise the relationship between place and home. Some suggest that a sense of attachment to place increases with age (Fried 1982; Sampson 1988; Cuba and Hummon 1993). For example, McHugh & Mings (1996) used the notion of place affinity to describe the degree of attachment and sense of belonging to a local area. Fitzgerald and Robertson (2006) have theorised the concept of places and non-places to address the sense of alienation and social isolation that people may experience living in residential institutions. Wiles, et al (2009) adopted the concepts of physical space and social space to assist in understanding the nature of an older person's attachment to place. Physical and social spaces are often constructed and interpreted at both an individual and social level and are likely to be dependent on the actual living space that an older person inhabits and their experiences of that space. As health deteriorates, the availability of physical space and the way in which this is experienced will be influenced by, and will influence the older person's autonomy and independence. This, in turn, is likely to impact on their emotional well-being and their sense of having the right amount of space to meet their physical and emotional needs. The adequacy of space at both a personal and a social level is therefore likely to differ from one individual to the next and from one life stage to the next.

For example, in a study of older people living in the community Wiles, et. al. (2009) explored how they experienced their social and physical space and how this contributed to the meaning they placed on home. They found that most participants had a central place of focus within their living environment and obtained a sense of comfort from the familiarity of their home and their ease of routine tasks. Adaptation to smaller physical living space was compensated by a complexity of factors that contributed to satisfaction including a focus on *beyond spaces*, a term the researchers used to represent both temporal and spatial experiences gained through



participants own geographic imaginations, by reminiscing, and by hearing accounts of the experiences of family members.

Gilleard, et al (2007) examined the influence that age, place and ageing in place has on attachment to place. They used quantitative techniques to measure citizens' needs and satisfactions across the domains of quality of life, control, autonomy, self-realisation, and pleasure, all of which were chosen as quality-of-life indicators for people living in the third age. The aim was to determine whether these domains contributed to a sense of well-being in later life. The results indicated that those who were 80 – 89 years of age reported slightly less attachment to place than those who were in their seventies, although this may have been a consequence of people in the higher age group becoming disconnected from their local community due to lack of mobility or social isolation. The findings also revealed that age and ageing in place do contribute to a sense of belonging but that this attachment to place does not necessarily evoke feelings of well-being. They suggested that the feeling of well-being itself may be the driver that contributes to a sense of belonging and connectedness, rather than the other way around.

Turning now to consider policy in relation to this issue, the strength of cultural assumptions about the positive nature of home, coupled with research that suggests that elderly people are reluctant to relocate into aged care facilities (Davey, 2006b), has led many western governments to consider the human and economic benefits of *ageing in place* and the delivery of support services within the older person's home in the community. The *New Zealand Positive Ageing Strategy* (2001) aims to encourage and assist older people to remain in their own homes as a way of enhancing their sense of independence and self-reliance. *The Health of Older People Strategy* (2002) proposes an integrated approach to health and disability support

services which is responsive to varied and changing needs, supporting older people to remain in their own homes and reducing the need for institutional care (Davey, 2006b). Ageing in place has come to be viewed positively by the New Zealand government as a preferred option for older people.

This policy might appear to contradict the notion of retirement villages as ideal organisations in which people can enjoy positive ageing, given the relocations that occur into retirement villages from local communities. However, it should be noted that for many older people choosing retirement village living, their independent unit may become their home and therefore provide them with a sense of well-being that is associated with ageing in place. The initial relocation into the village provides people with a community of similar minded others and the prospect of an active and enjoyable lifestyle (Leonard, 2002; Simpson, 2007). Of relevance to the current study, however, is the impact of a further relocation into the supported living environment of a retirement village and the extent to which residents are able to retain a sense of attachment to place. This potential further relocation is most commonly undertaken as a consequence of the need for a higher level of care and it is the meaning of care that we turn to next.

### *The meaning of care*

The conceptualisation of care lies at the heart of this study because it is pivotal to the quality of the transitions that older people experience within retirement villages. Through their advertising, retirement villages assert that they care for their residents. It is unclear whether the resident's expectation is that they will receive *care with feeling* that may assist in supporting

their emotional well being, or whether retirement villages are promising that they will provide care that focuses predominantly on the their physical needs.

The concept of *care* is open to misinterpretation between a researcher and respondents and the word therefore carries a high risk of miscommunication. As a noun, care can mean ‘the provision of what is necessary for the health, welfare, maintenance, and protection of someone or something’ (Oxford English Dictionary, 1989). As a verb, it can mean ‘to feel affection or liking’ (Oxford English Dictionary, 1989) as well as to provide for someone’s needs. Care can also be defined by context and by the many conceptual and practical purposes it serves in different arenas whether these are culturally, politically, clinically, socially or individually defined. At a policy level, the World Health Organization recognises a gap between policy intent and the practical application of care by promoting an integrated strategy to encapsulate both clinical and social aspects of care provision. This refers to a need for four levels of integration: functional, organisational, professional and clinical. Identifying these four elements aims to integrate the work of policy makers and service providers in an attempt to minimise the risk of people falling through the net between health and social care (Lloyd & Wait, 2005). Research in New Zealand has added to the body of literature that endeavours to predict the level of need for care in the future (Broad, et al, 2011) and the way in which equitable care might be provided (Ministry of Social Development, 2001).

Formal institutionalised care has evolved from the medicalisation of care in a society where the need to prolong life is a widely accepted norm. Care tasks that might previously have been performed at home by the family (Clark, 2002) are now embraced by New Zealand government policy as a component part of ageing in place and as such, the two paradigms can no longer be seen to be mutually exclusive. Social workers now play a greater role in the provision of home

care services and Kellehear (2005) includes social workers, along with a range of health professionals and clinicians as central to the care of dying people. 'Social workers and counsellors, like doctors and nurses in palliative care are face-to-face clinical workers for whom community, citizenship or self-help are but distant or absent dimensions of health care' (Kellehear, 2005: 22). Similarly, some researchers have challenged the focus on policy and the language of care that lead to the objectification of the care recipient (Oldman, 2002). Typologies of care are therefore shifting.

Like many other western societies, New Zealand is positioned against this backdrop as a country that promotes ageing in place at a policy level, driving social, economic and service reforms that promote positive ageing within the wider community. In New Zealand agendas, family input into care is emphasised, supporting the provision of home-based services delivered through public, private or voluntary sector agencies. This policy approach recognises the contribution of family members in the process of care and indicates that kinship networks underpin the concept of care in New Zealand.

One might expect that New Zealand's indigenous Maori culture would provide a cultural and social role model of kinship-based care that reflects family *whanau* values and holistic forms of support for elderly people, extending beyond Maori culture to European New Zealanders. Yet despite the norms of Maori culture which value older citizens as a source of wisdom, cultural continuity and hope, elderly Maori are also reported to be vulnerable and at risk of isolation (Kêpa, M. 2006). Those with strong financial means are predominantly New Zealand Europeans who choose their place of care to a greater extent, with Government subsidies available for all who meet a means test and who are medically assessed as requiring services. A mix of market demand and welfare intervention largely determines the availability and choice

of living establishment. A neo-liberal mixed economy approach promotes consumer participation in the provision of services along with family involvement in living support and all this within a policy environment that supports the maintenance of individual rights on the one hand and citizens' responsibility for their own health on the other (Esping-Anderson, 2002). However, this approach cannot, as yet, address issues of inequality in the provision of care services or the unpaid care roles commonly performed by women. Informal care thus becomes an underlying requirement that maintains the prevailing system of care without considering the suitability of the carer, whether professional or family (Milligan, 2009).

The practice of ageing in place removes any distinct conceptual boundaries between institutional care and the informal home care traditionally undertaken by family members. This blurring of roles between family care and institutional care becomes more profound as home visits by care professionals increase and the private nature of the home, which has been shown to be important in making a dwelling place meaningful, is gradually eroded. Mahmood and Martin-Matthews (2008) note the way in which newer forms of service provision in the home allow care professionals to move into private residential space. Keeling & Davey (2008: 130) propose the concept of a *gap*, rather than a *boundary*, to describe the interface between informal care provided by family and the formalised care provided by public or community services. Kane (2001) suggests that quality of life indicators are important in the provision of care services but that these are largely ignored when agencies monitor their services to the elderly and instead, focus on the absence of negative outcomes as an indicator of high quality care. This use of the absence of negative outcomes as positive evidence suggests it is difficult to adequately measure or quantify satisfaction or to gauge quality of life for care recipients. Phillipson (2005) raises pertinent questions about the relationship between older people and

professional providers within institutional settings and asks whether service professionals challenge low expectations of service provision or whether they reinforce old age as a period of decline<sup>2</sup>.

Having explored the meaning of home and the meaning of care, it is important to consider the nature of transitions in ageing because these impact and are impacted upon by the nature of home and of care.

### *Transitions in ageing*

This study seeks to identify the changes that the research participants described as significant to them both in the past and present, having moved from one living environment to another. Some studies (Shippee, 2008; Cheek, 2006, Reed & Stanley, 2006) that consider the transitions of older people relocating from independent living to supported living environments have focused on the relocation event itself. It is important to emphasise, however, that this study does not make the assumption that transitions are static, end-state events. The Oxford English Dictionary (1989) defines a transition as ‘the process or a period of changing from one state or condition to another’. Thus, a transition may represent a set of inter-related changes rather than a set of event-based adaptations. In the context of this research the term *transition* does not refer to the act of *transiting* from one living area to another, nor does it refer to the period of time over which an actual physical relocation occurred. Human transitions are commonly experienced over long periods of personal and social change throughout the life course. Building on the

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<sup>2</sup> This question may be significant to the decision that older people make when they choose to enter a retirement village.

concepts of cumulative advantage and cumulative inequality (Ferraro, Shippee & Schafer 2009; Dannefer, 2003; O’Rand, 2003; DiPrete and Eirich, 2006), Marshall and Bengtson (2011) argue that advantages and inequalities across the life course are cumulative and may impact on self-efficacy, mental health and physical health in later life. This can be taken further by suggesting that long-term causal links and compounding factors may result in life course transitions that are multi-dimensional and not easily unravelled or separated by a beginning and an end. In transiting from one living environment to another, the cumulative effect of residents’ prior understanding of home and care is likely to impact on the way in which they experience the move from independent to supported living<sup>3</sup>.

Cheek (2006) notes a difficulty in identifying where the process of transition begins and ends. It is perhaps reasonable to assert that older people experience their transitions in a recursive pattern that continues for as long as those changes in their living environment impact upon them. This supports the notion that relocation events are most likely to be the catalysts that create the personal and social changes that residents identify and describe. Indeed, Heinz and Marshall (2003) suggest that transitions in older age (as at any age) are influenced by socially constructed expectations, social controls and individual experiences that are shaped by historical and social contexts. ‘Every society has a system of social expectations regarding age-appropriate behaviour. The individual passes through a socially-regulated cycle from birth to death... a succession of socially-delineated age-status, each with its recognized rights, duties, and obligations.... This normative pattern is adhered to, more or less consistently, by most persons’ (Neugarten, 1970: 8).

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<sup>3</sup> This was born out by the participants in this study who identified their transitions as dynamic periods of significant change that were brought about by the inter-relationship between various personal and social factors that were significant to them.

The suggestion that historical change, earlier life experiences and their meanings are carried forward into new situations has been posited by Mannheim (1952). The concept of the life course in sociological literature represents a paradigm that emerged after WW11 when social research focused predominantly on cross-sectional surveys that provided snapshots of a persons' life without contextual considerations. Elder (1975) advanced the theoretical construct of life course, suggesting that a sequence of roles and events, social transitions and turning points overlay family relationships and socio-cultural perspectives of the social meaning of age. Elder posited a link between historical time and lifetime, noting that social change and historical change also influence life course patterns. The contextualisation of lived experiences adds further dimensions to the study of transitions occurring within retirement villages.

The concept of status passages put forward by Glaser & Strauss (1971: 30) recognises the potential to analyse 'the reversible and irreversible events' that are experienced throughout life. Their notion of *agents* and *passagees* within these life-changing events indicates that some aspects of transitions may be either accepted or resisted by the individual and those around them as a means of social adaptation to a given change in circumstance. Whether the inevitability of life changes that Glaser and Strauss suggest may or may not be usefully resisted remains a reflective testament to the way in which social and cultural values might manage and maintain normative behaviours throughout the life course. The concept of life course has developed into a major theme for sociological research incorporating Elder's four paradigmatic factors of geographic/historical location, social ties to others, human agency in the construction of one's life course, and variations in the timing of events (Elder & Giele, 2009). Each provides useful prompts for this study.



Two further elements that are central to the lives and well-being of older people experiencing transitions are understandings of independence and autonomy. These concepts will now be considered.

### *Independence and autonomy*

Common sense definitions suggest that independence refers to the ability to function without relying on others for support. Whilst this definition of independence would appear clear and relatively uncontentious, there are variations in the way in which it is adopted within the literature. Peel, et al. (2004) examined a number of healthy ageing studies to assess the degree of variation in the defining terminology and Asquith (2009) noted that there is no common agreement between studies that use indicators of independence. Some literature has focused on biological well-being, often measured by a lack of morbidity and others use various psychosocial indicators of well-being, such as life satisfaction. Peel, et al. (2004) also found that many of these studies adopted definitions that used the maintenance of functional independence as a measure of well-being. This is perhaps not surprising because the loss of functional ability is a pronounced characteristic of ageing that commonly prompts the introduction of support services.

The concept of autonomy is less related to functional capacity and more concerned with the right to self-govern. The word itself derives from the Greek word *autonomia* meaning freedom to live by one's own laws and it has been used to refer to the right of self-determination for both States and individuals. If the concept of independence requires clarification, the notion of autonomy is fraught with ambiguity. Darab and Hartman (2011: 795) draw on Kant's definition of autonomy as the basis of dignity, seeing it as 'the capacity of human beings to establish universal law by means of their will and its orientation to reason'. Agich (2004: 6) adds depth

to this definition by asserting that autonomy refers to ‘self-rule, self-determination, freedom of will, dignity, integrity, individuality, independence, responsibility, and self-knowledge; it is also identified with the qualities of self-assertion, critical reflection, freedom from obligation, absence of external causation and knowledge of one’s own interest.’ Such an all-embracing definition needs to be refined according to the context in which it is being used and Beauchamp and Childress (1994: 58) suggest a more concise definition stating, simply, that ‘autonomy typically refers to what makes a life one’s own; viz. that it is shaped by personal preferences and choices’. From the perspective of chronic illness, Mars et al (2008: 333) suggest that the concept of autonomy offers useful insights into the ‘correspondence’ between ‘what people want their lives to be’ and ‘what their lives are actually like’.

In a thorough discussion of personal autonomy for older people in residential care in New Zealand, Rogers and Neville (2007) point out that whilst residents may lose functional independence, if they receive individualised care that takes account of their personal routines and preferences they are able to retain their autonomy. This is reminiscent of an assertion by Illich (2003) who argued that autonomy includes the self-management of one’s own intimacy. Illich viewed this in terms of the individual’s physical and emotional well-being, claiming that in becoming ‘dependent on the management of his intimacy he renounces his autonomy and his health must decline’ (2003: 922). Rogers and Neville (2007) go on to suggest that individualised care of older people which is self-managed by the recipient, is unusual in that it is undertaken against a backdrop of ageism within society ‘that reinforce(s) discriminatory practices, for example promoting dependency and infantilization of the older person. As a result, older adults are marginalized through being placed in institutions such as residential care facilities. They are stigmatized, disempowered, treated like children and objectified’ (2007: 33).

They conclude that, ‘Ageism is therefore a direct threat to personal autonomy in older people’ (2007: 33).

Prior to discussing the methodology and findings from the current study it is pertinent to examine previous studies of retirement village living, many of which consider the reasons why older people may choose to relocate into a retirement village.

#### *Ageing in a retirement village*

Research in New Zealand retirement villages has provided insights into retirement village living and addressed the question of why people choose to relocate (Leonard, 2002; Graham and Tuffin, 2004; Greenbrook, 2005; Grant, 2006; Simpson, 2007, Wilson, 2005). Leonard’s (2002) study of older people’s decision to relocate to a retirement village was prompted in part by the increasing popularity of retirement village living and the high profile advertising proliferating within New Zealand society. She suggests that retirement villages in New Zealand appear to promise people the opportunity to maintain an active lifestyle and social connections, and a small section of older people who can afford to pay, enter these retirement villages to enjoy active lives, independence and security.

Wilson (2005) studied the decision-making strategies of people moving into retirement villages and looked at their satisfaction levels within three months of their relocation. She found that residents who made the relocation at a relatively young age tended to be attracted by the lifestyle and amenities of their village, while those who were older tended to be seeking

increased social interaction and a supportive living environment. Graham and Tuffin (2004) also found that companionship and privacy were important aspects of daily life for potential retirement village residents.

Simpson's (2007) findings suggest that retirement village residents identified with images of freedom and choice and acted out roles that reinforced these images when they became active participants in village life. This was a self-identity that Simpson indicates they emanated and protected via their personal involvement in village activities. At the same time, these independent residents, who Simpson describes as *leisured lifestylers*, created a distance between themselves and those village residents who were less able to participate.

In this regard, Simpson's findings are similar to those of Leonard (2002) who found that residents' anxieties were reduced and their sense of belonging and attachment heightened by a greater participation in village life, both within and external to the retirement village itself. Similarly, Grant (2006: 109) found a strong sense of community and self-identity within retirement villages because residents perceived their village as one community: 'The residents find comfort knowing that in a retirement village they can depend on others who share similar values as well as be depended on – they become somebody'.

Both Leonard (2002) and Simpson (2007) found that residents living in independent units had a negative perception of those residents who had higher-level support needs. They also indicated that independent villagers valued their group identity as lifestylers and maintained their persona of independence through their social interactions within and beyond the village environment. If independent villagers perceive themselves differently to villagers who have high-level supported needs, then a social barrier would appear to exist between those who are

independent, active and ageing positively and those who are deemed to be older in outlook or less able to participate in activities. These two studies indicate this sense of a divide between active participators and non-participators.

In a study of a retirement village in the UK, Evans & Means (2007) found that some residents exhibited intolerance towards those who appeared frail and they were perceived by the more active residents to represent a barrier to the development of a community atmosphere. This finding suggests a lack of integration between active residents and those with significant support needs, as revealed in the studies by Leonard (2002) and Simpson (2007).

The studies above raise questions about the degree of inclusion experienced by supported living residents in retirement villages and the way in which these residents may experience their transitions over time; from being leisured lifestylers to becoming less able residents requiring a higher degree of support services. Although people may choose to relocate from the wider community to a retirement village they do so primarily for the promise of an active lifestyle as they age. A disjunction may, therefore, exist between residents' expectations and the realities of longer-term village life that is likely to require a move into a supported living environment. This in turn indicates that transitions occur down the line that may well have a significant effect on residents' quality of life and sense of well-being as their care needs increase, along with the likelihood that they will have to make a further relocation into supported living accommodation.

The aim of this study is to explore how retirement village residents' experience these transitions. The effects of the retirement village model on an ageing resident population are also significant as an increasing number of independent village lifestylers can be expected to make

the relocation into a supported living environment. Some of the New Zealand studies reviewed in this chapter have specifically considered residents motives for moving into a retirement village from the wider community and their subsequent experiences, but a gap remains in the research that this study seeks to address. This gap relates to the experiences of those retirement village residents who come to need significant supported living services when their health declines and who, as a consequence need to relocate. Although this move frequently takes place within the same retirement village it can be described as similar to a move from a home in the community into an aged care institution. These residents may be active when they enter a retirement village but despite active lifestyles, healthy eating, in-house hairdressers and targeted fitness programmes, they cannot resist the ageing process indefinitely.

In essence, this study focuses on the transitions associated with retirement village living both before and after the residents move from independent accommodation into supported living accommodation within the same village. The aim is to examine what these residents consider to be the significant transitions associated with these changes and to explore how they are experienced within the retirement village environment. Much of the literature on aged care demonstrates that there is a significant distinction between the day-to-day living environments of those who have been termed the young old in contrast to the old old and the oldest old (Garfein & Herzog, 1995). Although no comprehensive statistics are currently available, in New Zealand retirement villages those moving into supported living units tend to be over the age of seventy-five<sup>4</sup>. Retirement village residents who move from independent units into supported living units commonly experience a significant relocation event, usually involving a

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<sup>4</sup> This study initially misjudged the likely age of the supported living research population who were found to be mainly over eighty years old in the villages studied.

quick and definitive move from one physical dwelling space to another. The independent unit has often been the resident's private living space for many years before making this move and although relocation usually occurs within the confines of one retirement village, the additional support from retirement village staff is portrayed in the advertising literature as a smooth blending into the resident's daily life and routine (Age Concern New Zealand, 2011).

Whilst a move to higher levels of supported living may seem an obvious consequence of ageing in a retirement village, it occurs in an environment that maintains a community of largely separated and categorised dwelling places within one enclosed and serviced establishment encompassing the independent dwellings and the supported living dwellings. Whether relocating from their private home in the community or from an independent retirement unit, the move into supported living is likely to impact on the resident's quality of life, prompted, as it usually is, by increasing support needs and resulting in the introduction of fundamental changes to their living environment. It is the way in which these transitions are experienced that forms the focus of the current research.

This study sought to discover how retirement village residents perceived and experienced the living transitions they encountered as they moved into and between different levels of supported living accommodation. It also aimed to examine how they made meaning from those experiences and to place their accounts and interpretations firmly at the forefront of the study.

To capture the experiences of residents transitioning from independent living to supported living within retirement villages a number of research questions were formulated, intended to explore their perceptions in the context of their social networks, living environments, support needs and end-of-life preferences. This also hoped to provide an account of any expectations they had of the future and to provide insight into their sense of independence and autonomy.

#### *The research questions*

The specific research questions that set the scope for the study were:

What prompts the move from independent living into supported living? How is the decision made and who makes it?

How do residents make sense of, and experience this transition? What are the short and long term effects of the transition from independent to dependent living (particularly in terms of the resident's self-identity and relationships with others) and how does this impact on their opportunity to age positively and retain their autonomy, for example, in relation to their end-of-life choices?



How do residents in supported living environments define, experience and value their personal space in terms of their new 'home' environment, personal belongings and privacy?

Do residents in supported living environments perceive themselves to be close to their end-of-life and if so, have they indicated their end-of-life preferences to family or staff, and have these preferences been recorded?

### *A qualitative approach*

The appropriateness of using objective or interpretative methodological perspectives was considered. Given the study was aimed at residents' narratives of retirement village living that were significant to them, an interpretivist perspective was adopted as this was expected to generate rich, detailed personal accounts that would facilitate understanding of the complex inter-relationships between various actions, events, experiences, environments, people, values and beliefs that were significant to the residents. Bengtson et al. (2005: 7) note 'The interpretivist perspective is premised on the notion that individuals are active agents and can change the nature of their social environments'. An open-ended, semi-structured qualitative interview based data gathering strategy was chosen to provide the depth of detail necessary to focus on the way in which residents made sense of their perceived transitions, their significant living experiences, and the factors that impacted on those experiences. As Hatch (2002: 8) notes, 'Qualitative studies try to capture the perspectives that actors use as a basis for their actions in specific social settings.' Quantitative methods would not capture the residents' meanings within the context of their accounts or allow topics to be generated from their perspective because these methods tend to focus on general trends. A survey of their experiences or attitudes would have required the construction of a series of questions and pre-determined measures, thus requiring residents to respond solely to the research agenda without

the opportunity to provide their own accounts of the nature of their transition experiences. As Kellehear (1993: 1) asserts, ‘Questionnaire surveys, then, are often viewed as the most blunt instrument to record the complexity of human drama. Although often relying on fewer people, in-depth interviews and the detailed analysis of their “texts” are seen to penetrate more deeply and sensitively into the subtle world of social and personal meaning.’

### *Adopting a grounded theory approach*

Having no knowledge of retirement village residents’ experiences, perceptions or their interpretation of their transitions, I was unable to develop a theoretical framework with a series of pre-determined categories that drove both the collection and analysis of the data. Moreover, the research needed to understand the experiences of residents and the meanings they attached to those experiences. It was, therefore, appropriate to analyse the interview data and apply theoretical models on an on-going basis. To achieve this the study adopted a grounded theory approach. Grounded theory was originally developed by Glaser and Strauss (1967) in a terminal care setting as a means of generating the narratives of dying people and their carers that were grounded in the participants own experiences, understandings and cultural knowledge. This approach uses inductive strategies to generate and collect data and to allow key themes to arise from the data rather than manipulating the data into preconceived categories. Grounded theory does not impose a theoretical model on the data but allows the overall themes to emerge as the data are collected. This analytical process identifies *the saturation point* (Glaser and Strauss, 1967) when new themes or issues are no longer occurring and, therefore, when sufficient data have been collected.

Grounded theory facilitated the analysis of residents' experiences in terms of their own social construction, that is, how their accounts and responses related to the norms, beliefs, social values and expectations about the way in which this type of living should be handled (Berger & Luckmann, 1967). These norms impact on the social, financial, psychological and emotional well-being of residents. They are based on social expectations, are co-constructed with significant others, and are continually evolving across time. This was particularly important to the study as a means of discovering how residents experienced their living transitions. As a research strategy grounded theory would enable the study to build rich accounts of residents experiences by capturing accounts of their significant relocation events and resulting living environments that had unfolded and evolved over time. It would also acknowledge the complex relationships between individual and social processes and highlight the way in which meaning is generated, defined and redefined through social interaction and changing circumstances. Employing grounded theory would provide a focus on the experience of supported living environments as integral to the residents' understandings of independence and autonomy, their social interactions, quality of life, views on end-of-life and on those aspects that mattered most to them.

To adhere to the principles of grounded theory, an interview process was required that would encourage participants to fully articulate the experiences that were significance to them from their own perspective. It was hoped that this would allow the data and the subsequent generation of theory to emerge from the research process – from the ground up – rather than constraining it by investigating specific, hypothetical causal factors that might have been presumed to be relevant. 'This distinction between "emergence and forcing", as Glaser frames it, is fundamental to understanding the methodology' (Dick, 2005: 17).

### *Semi-structured interviews*

‘Interviewing can be a powerful way to assist people in making explicit their perceptions and understandings that up to the time of interviewing may have been implicit’ (Arksey and Knight, 1999: 32). It is also a way to access the perspective of the person being interviewed and to find out things that we cannot directly observe and can facilitate the exploration of the meaning of individual experience (Patton, 1990). Payne and Langley-Evans (1996) have advocated in-depth interviewing as the most appropriate method when the well-being of participants is paramount; this seemed particularly appropriate for interviews with older residents in supported living environments.

In-depth, semi-structured qualitative interviewing was the method of data gathering chosen for this study. Rather than asking residents to respond to a set of rigidly defined questions, interviewees would be able to set the detailed agenda for discussion within a framework of questions designed to explore broad topics and encourage a logical flow of conversation within the parameters of the study. This interview approach enabled respondents to place emphasis on the questions that were most relevant to them and to respond briefly, or not at all, to those that were not. Respondents would have the opportunity to cover each topic in as much or as little depth as they wished and also to introduce new topics that they considered relevant. This interview process enabled the major themes that were pertinent to research participants to be captured within their accounts. Participants were free to interpret the interview questions from a past, present or future focused perspective and this aimed to mitigate any constraints or assumptions that might have inadvertently been applied by pre-setting the contexts that may be relevant to them. It also ensured that the interview method guided, rather than forced the

respondents' discussions and gave them the opportunity to express the experiences of retirement village living from their own perspective.

### *The interview questions*

In constructing an interview schedule previous studies of retirement village living that used qualitative methods were consulted (Evans & Means, 2007; Greenbrook, 2005; Leonard, 2002; Simpson, 2007) to assess whether aspects of their research techniques might be useful for this study. All of these studies used either structured or semi structured interviews to elicit data from their respondents. Their interviewing methods ranged from requiring interviewees to respond to a series of pre-determined questions to more open-ended forms of questioning. In order to attain residents' accounts and recollections of their retirement village transitions and to apply their own meaning and interpretations to their experiences, this study utilised a semi-structured interview schedule (see Appendix 1.1) that included a number of specific open-ended questions to enable data to be gathered about the issues that were considered to be relevant to the study. These encompassed the following:

1. The event prompting the move into the retirement village.
2. The event prompting the move into their specific living area within the retirement village.
3. The resident's opinions about their living environment.
4. Changes in the degree of living support the resident received.
5. Changes to the resident's immediate living environment and lifestyle.
6. Changes the resident made in order to feel 'at home' in their living environment.

7. Perceptions of independence and the degree of independence experienced.
8. Perceptions of the degree of mental stimulation available to the resident.
9. Perceptions of the degree of social and physical stimulation available to the resident.
10. Advice the resident would give to someone else considering moving to their living environment.
11. Plans and expectations the resident had for their future.
12. Expectations of living support that the resident thought they might need in the future.
13. Expectations the resident may have about nearing the end of their life.
14. Plans and expectations associated with end-of-life matters.
15. The meaning of 'home' and 'care' from the respondent's perspective.
16. Changes in the degree of privacy the resident experienced.
17. The resident's degree of satisfaction or dissatisfaction with the physical living environment.
18. The resident's degree of socialisation within the village.

These prompts were written as supporting questions to set the scope for the interview discussion and were incorporated into the interview sheet (see Appendix 1.1). Open-ended questioning allowed respondents to reply briefly and move to the next topic if they did not find a particular issue relevant to them.

### *Selecting the retirement villages*

The intention was to conduct the study within two retirement villages based on the rationale that researching within one village may not provide adequate respondents and researching within three villages may increase the disparity in retirement village characteristics. Following

a comprehensive search of retirement villages in New Zealand using the *Yellow Guide to Retirement Living* (2010), web sites and media reports, a decision was made to conduct the research within large private sector, profit-making retirement village organisations. The Retirement Village Association of New Zealand web site provided information about the types of facilities, accommodation and levels of support that were available within the various establishments. Companies and charitable trusts appeared to predominate. A search of the New Zealand Charitable Trusts Register and the Companies Register revealed that private sector companies had the strongest presence among the large establishments and offered their residents the most extensive choice of independent and supported living facilities. The decision to conduct the study within private sector retirement villages was based on the following rationale. First, given the extensive choice of accommodation available, it was likely that large retirement villages housed a greater number of residents who had made relocations from independent to supported living and therefore provided the best opportunity to locate the residents that the study sought to capture. Second, private sector villages had been the focus of previous New Zealand studies and this would provide additional background knowledge and information for this study. Third, business-owned retirement village organisations are particularly significant to the New Zealand economy because they make significant profit and continue to expand (Gibson, 2005). These profits are generated from the residents who buy a licence to occupy their homes within the villages. These commercial transactions add another dimension with potential relevance to the transitions that private sector village residents' experience. Residents who are able to pay large sums of money for retirement village housing and services may be assumed to have the highest expectations about the living support they will receive and the experiences they will have within their village, thus researching this population provided an opportunity to discover whether this would be reflected in the findings. Finally, it

was hoped that the findings from this study might provide groundwork for future comparative studies of living transitions, comparing transitions within privately owned retirement villages with transitions occurring within those owned by charitable trusts.

In choosing to conduct the research in privately owned retirement villages it was important to find out more about the senior management of the villages who would effectively be acting as gatekeepers for the research. Moreover, it was important to aim for some commonality in management style as widely different foci would impact on the characteristics of the villages being studied and possibly affect residents' transition experiences. For example, some villages had one or more directors on their board who were property developers; others had directors with medical and/or management-focused backgrounds. Three large retirement villages were initially selected based on their urban locations, with the intention of conducting the study within the first two villages that responded positively to the research request. These villages were located in Wellington and Christchurch and were selected because seventy eight per cent of New Zealanders live in urban areas (Statistics New Zealand, June 2010) and the estimated urban populations of Christchurch and Wellington are similar at 390,300 and 389,700 respectively (Statistics New Zealand, June 2010).

#### *Establishing contact with potential retirement village participants*

A number of methods were considered to invite the participation of retirement village residents and approaching retirement villages directly to gain their assistance was considered to be the most appropriate way to obtain the population sample. Apart from gaining the organisation's permission to conduct the study, this method provided the opportunity to obtain multiple



contacts with residents without impinging on the privacy of their personal information. Acquiring the assistance of retirement village managers meant that they would fully understand the nature of the study and be able to make the initial contact with residents in a friendly and informal manner, avoiding any reliance on residents opening and reading an initial letter which may have caused them concern and may have created difficulties for those with eyesight impairment.

On receipt of ethics approval from the University of Canterbury Ethics Committee, an introductory email was sent to the Operations Manager of each of the three selected villages. Making contact by letter offered the opportunity to fully explain the aims of the research and its potential value within the field. As noted above, the first two villages that responded positively to the request were selected to participate. The third village did respond positively at a later date and was thanked for their interest in the study.

The study did not seek input from retirement village managers or other employees, nor from the relatives of research participants as this would have changed the nature and purpose of the study and have overlain a further set of perceptions from people who were not experiencing the transitions or events personally. For this reason the views of people with whom residents interacted remained beyond the scope of the study.

### *The research sample*

Twelve people residing in either the independent units or supported living areas of two separate retirement villages were selected to participate. This was an appropriate number for a Masters thesis as a larger number of participants would have created difficulties in managing the

volume of data and a smaller number of participants could have resulted in insufficient data being collected to achieve meaningful results. The intention was to interview six people within each village. If possible, in order to address potential gender differences and capture any dynamics that might be specific to those who were living as a couple, the interviews would include two men and two women living alone and at least one married couple. The age range of residents targeted within each village was initially set between seventy and eighty-five years; ideally including one man and one woman aged between seventy and seventy eight years old, one man and one woman aged between seventy-eight years old and eighty-five years old and one couple aged between seventy and eighty-five years old. This was designed to provide an opportunity to capture respondents within two age groupings to obtain resident perspectives from those who were likely to be at different stages of transition and likely to be receiving different levels of daily living support. The purpose of placing a lower limit on the age range was to avoid a situation where retirement village management staff might identify potential participants but may either intentionally or inadvertently approach their youngest or most recently relocated residents. Although these residents may have been foremost in the mind of the staff member they may not have been typical of the supported living population.

#### *Selecting, interviewing and debriefing respondents*

Each retirement village manager was asked to nominate a member of staff who would pass a letter of invitation to residents they considered suitable for the study. Managers were provided with a process chart (see Appendix 1.2) and a set of written guidelines noting criteria for suitability (see Appendix 1.3) The criteria acted as a checklist to ensure that only residents who were able to give informed consent and who were capable of participating in the study were

approached. The guidelines outlined the process to be followed between the retirement village manager, the nominated member of staff, the resident and the researcher. The process chart (See Appendix 1.1) provided a visual flow chart to aid clarity for the staff. One wholly unexpected outcome of this arrangement was that the villages did not have many residents young enough to meet the lower pre-determined age range so approval was obtained from the University of Canterbury Ethics Committee to adjust the age range upwards. This was granted and the final pool of participants was aged between 68 and 93 years of age. These residents were provided with an invitation to participate in the study. (See Appendix 1.4.a & 1.4.b)

All of the potential participants selected in this way by the village managers agreed to meet with me to find out more about the research. I telephoned each resident, introduced myself and met with them individually to describe the research aims and process and to ensure that they understood the implications of their involvement and their rights, whether or not they subsequently decided to participate. Residents were provided with an information sheet at this meeting (see Appendix 1.5) and a copy of the consent form (see Appendix 1.7). The information sheet provided details about the study and the consent form included a description of their rights and responsibilities if they chose to participate. Prior to each meeting I used an observation sheet that I had designed (see Appendix 1.6) to prompt my own awareness of any resident behaviour that might indicate unease or concern. This was not carried with me into the meeting as its purpose was not to assess the resident or to cause any distraction but to ensure that I remained fully mindful of any indicators of stress or unease that should be taken into account. A subsequent meeting was arranged to allow potential participants to make an informed and unpressured decision about their participation in the study. During this second

meeting those who were happy to participate signed the consent form and we arranged a time for the interview that suited them and fitted in with their usual routine.

It was not possible to find twelve participants who exactly matched the sample characteristics originally specified. The participant sample consisted of two couples who were living in independent units (aged 73 & 79 and 83 & 88 respectively), one man (aged 87) who lived in an independent unit separate from his partner who was in the retirement village hospital wing, one man (aged 88) who lived in a supported unit separate from his partner who lived in a different supported unit, one man (aged 84) and five women (aged between 68<sup>5</sup> and 93) who all lived alone in supported units. This created a sample size of twelve people including the two couples, and ten interviews. The characteristics of the participants are included in Appendix 2.

### *The interview process*

Ten interviews were conducted over a period of two months. Each interview was expected to take up to ninety minutes although respondents were aware that they were free to end the interview at any point. Two small unobtrusive dicta-phone recorders were positioned, with the respondent's permission, to record the interview. Interviews commenced with a period of rapport building using spontaneous, open discussion. A statement was then made indicating that the interview would start, having checked that the respondent was comfortably positioned and ready and that the dicta-phones were in place and then switched on. Topics were raised in sequential order. If the respondent introduced a new topic this was discussed until they

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<sup>5</sup> The 68 year old participant was included because she was reported to have experienced significant relocations. First, from her home in the wider community into a public sector hospital environment and then into a retirement village supported living unit.

appeared to have completed their contribution. Open-ended exploratory questions were used alongside closed questions designed only for clarification when needed. I had planned to use reflective listening techniques throughout the interviews. This is a communication strategy involving two key steps: seeking to understand a speaker's idea, then offering the idea back to the speaker to confirm that it has been understood correctly. However, reflective listening was used sparingly during these interviews because it could equally steer respondents away from their intended meanings, especially if, as a result of clarifying too deeply, they lost confidence in their own descriptive account. The majority of interviewer comments were brief, such as encouraging *hmmms* to indicate attention and active listening. Exploratory questions were asked purposefully, keeping to the prompt questions provided on the interview sheet unless the participant moved to an unexpected topic. When a participant generated a new topic the interviewer questioning needed to be spontaneous. Throughout the interviews I drew on my prior counselling skills to ensure that the participant felt comfortable and at ease and was not suffering any distress as a consequence of our conversation.

At the end of the interview the respondent was thanked and their well-being checked informally. For example, *How did you find the interview?* A suitable time within the following seven days was arranged for a further visit to enable the respondent to check the content of their interview transcript. A debriefing sheet (see Appendix 1.8) was used that was explained verbally and then left with the resident. The debriefing sheet provided guidance and information in the event that the resident may feel stressed or may have questions following the interview. The resident was then handed a small *Thank You* card as a final gesture of appreciation. All written material was prepared using a reasonably large font size to assist those with vision impairment.

An overview of the discussion was written immediately following each interview noting the content that the respondent had made their predominant focus and indicating the general flow of the interview. A note was also made of any specific events or observations that might otherwise have been forgotten, such as staff entering without knocking or noting any possessions that the participant specifically pointed out, such as photos or ornaments. Each interview recording was transcribed by the researcher within two days of the completion of the interview and the interviews were well spaced to avoid time pressures. When typing up the transcript notes were made indicating any excessive pauses in the respondent's reply and any remarkable tone of voice. The transcript itself was either given to the participant to read or, alternatively, it was read to them if they had sight problems and were happy for it to be read aloud. Participants were thus able to check for accuracy, state their comfort level and acceptance of the resulting transcript. All respondents found the transcripts acceptable. I received a minimal number of clarifying questions and reflective or light-hearted comments.

### *Method of analysis*

The grounded theory analysis process required the development of concepts, categories and properties (Corbin & Strauss, 1990). Connections were developed between each category, and sub-categories and links were identified across the categories that were integrated and tested to build the resulting theoretical framework. As Hatch (2002:11) describes '*as patterns or relationships are discovered [inductively] in the data, hypothetical categories are formed and the data are then read deductively*'. Replication and patterns became evident as the process continued until saturation was reached and no new data was forthcoming.

In adhering to this process each transcript was given a unique numerical identifier rather than a fictitious name. This provided the basis for a numerical referencing system that was expanded to include page numbers within the transcript. For example, transcript one, page five was referenced as 1.5. The transcripts were studied repeatedly to enable familiarity with the content and the flow of each interview. A number of common themes and concepts emerged across the transcripts and re-emerge within single transcripts (Ryan, et al. 2006). These themes and concepts formed the basis for the development of a coding system that used alphabetical characters to represent each broad category. As each category was identified in the data it was noted on the transcript using the assigned alphabetical code and this code was also transposed onto a list. This resulted in a list of primary categories that were each transcribed onto an index card, again using the assigned alphabetic character. Following this process, additional index cards were added, but initially held separately, each representing an aspect of a transcript that was identified to be a commonality between all respondents.

The transcripts were then re-read a number of times and more discrete categories were assigned sub-codes within the broad categories and noted on each transcript alongside the relevant text. Each unique category code was similarly transposed onto an index card along with the numerical identifier referencing the transcript and page with a note on the card describing the specific comment from the respondent. Where practical, this comment was quoted directly from the text to assist in retaining the original meaning. Each additional index card was then either filed within the relevant index card set that represented that broad category or kept separately if it did not readily fit an existing category. When a topic was repeated in the same or in a different transcript, the appropriate index card was accessed and the comment was noted, again referenced to the transcript page numerical identifier and the alphabetic code that

represented the specific category. The category list was continually updated as new categories and sub-categories emerged. This made cross-referencing relatively easy between the index cards, transcript location and category list. This process resulted in a number of sets of indexed categories representing broad topics and eighty-five detailed topic cards, some of which contained in excess of thirty comments and others which contained only one or two.

The index cards were then grouped by broad category headings and sub-categories were reconsidered within those headings. The detailed comments were studied to check for inconsistency and any mismatch of categorisation. The inter-relationships were then considered carefully, looking for themes, concepts and topics within and across the categories. Mind maps were created from the index cards based on potential relationships and links (Bazeley, 2007). This process was repeated a number of times commencing with different aspects of the content and with differing levels of detail to identify consistency and to analyse any inconsistencies as well as checking for similarities and variations in context (Bazeley, 2009). This was undertaken whilst referring back to the transcripts so that the comments were reviewed within the context of the original interviews. This resulted in multi-dimensional maps that indicated multiple links, patterns within patterns, as well as distinctive differences in a few cases.

From this analytical process, the distinctive patterns and links were tested against theoretical constructs to enable existing theory to be applied and new theory to emerge. This provided a greater depth of understanding of the ways in which the residents who participated in this study experience their daily lives and associated living transitions, as well as the factors that may have, or may in the future, influence those experiences.



### *Ethical Considerations*

New Zealand has a small population of around 4.5 million people of whom 600,000 are over the age of 65 (Statistics New Zealand, 2011). Approximately 3% of these people live in retirement villages and this trend is expected to increase (Simpson 2007). There was a risk that participants may have been personally identified unless additional steps were taken to ensure anonymity. For this reason the specific locations of the retirement villages have not been cited. The names of participants were separated from the descriptions of their living circumstances, the transcripts had a unique number so fictitious names were applied later to the presented findings. All names and geographical references disclosed by the participants were also removed.

Arrangements to interview in Christchurch were thwarted by the strong earthquake of September 2010 and subsequent aftershocks. I revisited all the Christchurch participants a few weeks after an initial meeting to check their well-being and comfort levels for interview. One person who had previously agreed to participate appeared anxious so a decision was made not to include him in the study. A retirement village manager also advised that one potential participant had become unwell. This resulted in the selection of two further participants from the Wellington retirement village.

Confidentiality was important within each retirement village environment being a small community of residents who were living in close proximity to each other. Residents observed comings and goings and some talked to each other on a daily basis. This confidentiality issue was addressed by ensuring that I carried only small, discrete papers with me rather than an

official looking briefcase or a conspicuous folder so that I blended in with other visitors. When a resident asked informally if I was interviewing someone they knew, I provided no indication of whether that was the case. Similarly, if a resident suggested the name of another resident who I may like to include or who wanted to be included in the study, I offered my thanks and explained that I had reached a full quota of participants. This was a common occurrence, indicating a strong interest in the study but also indicating the possibility that information about the study was circulating informally.

A number of factors contributed to ensuring the well-being of residents from the first point of contact through to the end of the research process. It was especially important to ensure that residents who accepted the invitation to participate in the study were capable of providing their informed consent. A number of simple daily life factors that indicate this ability were incorporated into the guidelines provided to retirement village managers who made the initial selection. The documents used to communicate with residents were consistently supplemented with verbal explanations demonstrating the logical flow used throughout the process to mitigate the risk of any negative impacts (See Appendix 1). The information sheets and associated documents were also designed to emphasise residents' free choice in accepting or declining the invitation to participate and their on-going opportunity to cease their involvement at any time before, during or after the interview. To provide them with the opportunity to seek advice and clarification residents were given a minimum of seven days to make all decisions. To mitigate any sense of obligation or fear of negative consequences if they chose not to participate, the researcher's independence from the retirement village was emphasised and confidentiality of the interview content assured. Residents who accepted the invitation to participate were reminded that the study could not actively address any issues they might raise relating to their

daily living, although any safety issues would be relayed to the village at the resident's request. Within the interview process I endeavoured to enable the residents to retain a realistic level of control by enabling them to make their own choices. These included choosing the interview location within their village, choosing where I should sit within the interview and choosing where the dicta-phone should be placed (with minimal prompting to choose a close and noise-free location).

### *Methodological reflections*

Establishing contact with suitable research participants was a challenge from the outset. In the context of a retirement village the concept of a gatekeeper is particularly relevant. Whilst residents own a licence to occupy they do not own the bricks and mortar of their living spaces. As such, a researcher does not have any right of access or any acknowledged right to promote an upcoming study within a retirement village. Given this significant challenge I felt that the strategy used to enrol participants worked well and presented some thought provoking issues for future researchers. Legitimate access to this type of research population through their accommodation provider may always be largely dependent on the owners of the retirement village, despite the fact that residents have paid for a licence to occupy their living spaces freely within the village. This raises an interesting potential tension with a lens of security represented on the one hand and a lens of possible sequestration on the other.

The recruitment process relied heavily on the co-operation of retirement village managers and staff. This meant relying on their decisions regarding who would and would not be approached and raised the potential for bias in the selection process. For example, it was possible that

approaches were only made to those residents who were believed to be most likely to provide favourable reports of their transition experiences. This may have been reduced to some extent by my assurances that the research was driven by the residents' perceptions rather than a focus on the village's quality of care. Bias was further mitigated by my opportunity to decline potential participants when I initially met with the manager to discuss the residents' profiles anonymously. I also needed to remain aware of any negative bias that I might apply. Utilising a third party remained a limitation in the selection process but it was necessary because it ensured that I made contact with an appropriate number of residents in supported living environments who were capable of making an informed choice and within a limited time frame.

#### *Confidentiality and the involvement of relatives*

Some relatives of retirement village participants demonstrated an interest in the study and were particularly keen to see the findings. Many residents' accounts, however, included comments about their relatives and associated matters. This presented another reason to protect the anonymity of participants within the subsequent analysis as relatives would have a greater familiarity with the life of the participant and therefore have a greater likelihood of identifying the person concerned.

#### *Considering the reliability of the residents accounts*

The limitations of semi-structured interviews on the reliability of the resulting data included a reliance on 'a language of variables' (Silverman, 2000: 102) thus making assumptions that the variables utilised do in fact exist. This omits any investigation of how, in different situations

and contexts, some concepts may themselves have been defined by the respondents (Silverman, 2000). In the current study, for example, the concept of *transition* is one example of a pre-determined process that I have assumed exists. There was a risk that the respondents may not narrate, or even perceive of their experiences in a way that indicated any transition had occurred. Similarly, variables presented by the respondents would be based on their own unique set of assumptions. Further, the resulting analysis could be problematic if there were no commonalities in the data generated between residents' accounts, thus producing a high number of disparate themes. If this had occurred, it may have suggested that resident perceptions and experiences are unique to the individual with little influence from common external factors. If that had been the case, the grounded theory approach that was employed would have allowed this finding to emerge from the data.

The study intended to record, capture and analyse residents accounts of their living transitions based on their own recollections of events, their current opinions and thoughts, and any future focused expectations they may have regarding their living situations, including any end-of-life matters that may be relevant to them. This required a data collection approach that would enable participants to provide information about their transitions across broad topic areas and at the same time discover what was significant to them. Most methods that capture accounts of events rely on the respondent's memory recall. Given that some research participants would be over ninety years old, their mental acuity may be less keen in some areas than that of younger research populations. It is interesting to note that there are various recognised types of memory, including episodic memory, the conscious recollection of experienced events; semantic memory, the storing of factual knowledge; autobiographical memory, of one's own life events; flashbulb memory, a type of episodic memory that relates to emotionally salient events;

familiarity, recognising a person without recalling their specific details; and false memory, when there is an inability to recall specific episodic detail (Tulving, 2002). Whilst many types of memory decline significantly in old age, some types of memory function do remain constant or even increase with age. For example, it has been suggested that episodic memory declines with age yet semantic memory increases until very old age, and flashbulb memory remains relatively unaffected throughout the lifespan (Drag and Bieliauskas, 2010). These differences in memory capacity do not, however, negate the perceptions and experiences of retirement village residents who participated in this study although it does pose an interesting hypothesis that certain types of information could potentially be recounted more readily when the research participant is given the freedom to provide their own interpretation and account of their experiences. Any investigation of this suggestion lies beyond the scope of this study. The data collected in the research interviews was based on residents' current beliefs, recollection and perceptions of past events that have contributed to shaping their present world. The findings, therefore, retain their reliability in part because they reflect the way in which the residents interpreted their own experiences and made meaning from them. As Thomas and Thomas (1928) assert, when a situation is defined as real, it becomes real in its consequences.

*Introduction*

This study began as an interest in transitions and, more specifically, the transitions that older people living in retirement villages experience when they make the physical move from an independent unit and active lifestyle to a supported living environment within the village. Transitions tend to be viewed as events with a clear beginning and end. In the context of the retirement village and for participants in this study, relocating from one living environment to another was not a bounded event even though it may have been prompted by a crisis or a sharp decline in health. The move is usually prompted by failing health and the need for a package of care that can only be provided to residents in the supported living areas of the retirement village. The physical move into new accommodation can be a traumatic event for the general population and may be expected to be even more so when, in later life, the move is accompanied by an increased dependency on retirement village service providers. The gradual erosion or shrinking of residents' physical capacities and social worlds means that their subsequent living experience is comprised of a series of further transitions at the heart of which are changes to their status in respect of their degree of independence and autonomy.

Moving into supported living accommodation requires the resident to adjust not only to a new, more limited living space but also to a new social culture that brings with it a series of organisational rules and expectations that have consequences for functional independence, social, and personal autonomy. The nature of these relocations, together with the resident's shifting autonomy status, means that transitions are overlaid by additional changes that combine to form a complex mix of adjustments that have long-term consequences for their

living experience and well-being. For example, residents find themselves needing to physically adjust to a new living space that is, in the majority of cases, smaller than their previous accommodation and therefore requires them to refine their material possessions to fit that space. They are also required to adapt to organisational rules for their lives (Retirement Villages Association, 2008) and to adapt daily timetables that include set meal times and menus. For those requiring higher levels of support this involves adjusting to times and procedures in relation to when they get up, when they go to bed and when they might expect to receive personal services (such as bathing and toileting). These practical requirements inevitably affect their sense of self and their degree of social and personal autonomy.

The discussion here will, therefore, consider the impact that residents' transitions and living experiences had on their sense of independence and autonomy. For the purpose of this study, the term *independence* refers to the residents' functional capacity to execute their wishes whether in terms of their mobility or their ability to undertake self-care tasks such as dressing, preparing meals, bathing and toileting; that is, the ability to undertake practical tasks and activities without reliance on others. Given the study focus on retirement village residents' transitions involving increasing degrees of supported living intervention, *autonomy* is defined as self-determinism, including residents' ability and opportunity to manage their own intimacy and to initiate self-driven choices that come together to enable self-management towards the way one wishes one's life, and death, to be. The nature and extent of independence and autonomy are, therefore, likely to be central to residents' experiences of their transitions. For example, as they become more reliant on support services their independence, and subsequently their social and personal autonomy, is likely to be increasingly eroded. The way in which this



attrition is experienced is influenced by their relationship with the physical, social and personal spaces they inhabit.

The findings are organised via an exploration of their living experiences using the concept of different forms of space: physical space, social space, personal space and veiled space. *Physical space* refers to their material living environment; the actual bricks and mortar in which they reside, their attachment to this space and the extent to which they consider it to be their home. *Social space* refers to their social relationships; their sense of connectedness with family and friends and their attachments to social networks both within and external to the retirement village. *Personal space* is related to their level of personal privacy, particularly in terms of their adjustment (or otherwise) to a reliance on support for some of the most intimate activities of daily living (such as bathing and toileting). A further concept, original to this study, is that of *veiled space* which refers to residents' end-of-life concerns and, for supported living residents, what they perceive to be their likely future transition into the rest home or hospital area of their retirement village - a physical location that they viewed as the doorway to the very end of life. In order to reflect the chronology of their transitions each of these discussions of space will begin by considering the experiences of interviewees from the independent units of the villages and go on to discuss those of residents in the supported living areas.

This discussion begins with a brief note about the residents who took part in the study and a description of the physical environments in which they lived.

### *The residents*

As explained in the previous chapter, twelve residents from two retirement villages were interviewed for this study: five in independent living accommodation (two couples and one man who lived alone because his wife was in the hospital wing of the retirement village) and seven in supported living accommodation, all of whom lived alone. A table of residents interviewed, together with information about each of their circumstances can be found in Appendix 2. Given that the purpose of this research is to understand residents' perceptions of life in their retirement village, the two villages are not differentiated (other than the descriptions of their physical spaces below) and information that interviewees offered, for example, about staff and resources (the accuracy of which was not clarified with either village organisation). This is not a comparative study of life in two distinct retirement villages but a study of how residents in retirement villages more generally experience the transitions associated with decreased mobility and failing health that might reasonably be expected to occur within a retirement community.

### *Physical space*

Physical space usually has material boundaries such as windows, walls, doors and fencing and, in the retirement village context, may include roads and pathways and non-material but generally accepted boundaries that delineate and separate the village from the external community. The physical spaces in which the research was carried out were two retirement villages that have been assigned the names Hill Crest and Larch View<sup>6</sup>. Both villages were built

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<sup>6</sup> Pseudonyms have been assigned to these retirement villages in order to retain their anonymity.

around 1999 – 2001, were of similar size, covering an area of a few hectares, and both were located in residential suburbs approximately five kilometres from New Zealand cities.

### *The retirement village physical environment*

The villages were similar to look at in most respects except that Larch View's building layout had a more elongated shape than Hill Crest. Each village had the appearance of a walled community with an entrance gate and high walls enclosing the village residences within, surrounded by lawns, trees and flower borders. The grounds of both villages were maintained by retirement village staff. Hill Crest had a light, bright and welcoming entrance. Staff attended to visitors at the reception desk. There was an open, light, spacious area at the entrance foyer and plush seating and fresh flowers adorning the main public area, providing an atmosphere that was akin to a private hospital or a modern hotel. Activity was evident and there was a sense of animation with residents, staff and members of the public coming and going. Residents were active in the corridors, some with walking frames to move around the building despite their slow pace, while other residents used the armchairs in the public areas, appearing to watch the world go by. Larch View had a darker, smaller entrance foyer, though still modern and the reception desk was more prominent, enclosed by walls and glass. Staff were visible working behind the desk. The residents were less frequently seen in corridors or public areas of the building except before and after meals when supported living residents moved to and from the dining areas, also using walking frames in some cases. There was less space for armchairs because the corridors were narrower but there were one or two sofas placed within the corridor recesses. In comparison with Hill Crest, the public seating facilities at Larch View were significantly more limited and the outlook was less open. Hill Crest therefore presented as a

more buoyant environment suggestive of a greater level of connection with its residents than the initial impression of Larch View.

These villages offered both independent and supported living accommodation. According to their advertising material independent living areas provided a choice of independent townhouses, villas and apartments. These accommodations offered residents one, two or three bedroomed houses and a high level of independence in conjunction with a number of property maintenance services including lawn mowing and window cleaning as well as the opportunity to purchase personal items and cooked meals. Both advertised a degree of security, companionship and organised recreational activities. In both villages, the detached independent dwellings were spread over an area up to four hundred metres from the main facilities and were geographically separated from the smaller dwellings where higher levels of support services were provided. The independent detached houses had plenty of natural light and a pleasant outlook onto greenery and pathways. They were equivalent to a small, modern two bedroomed house or apartment of approximately 60 – 70 square metres with light coloured internal walls and large glass lounge windows, often with two bedrooms and an attached, internal access, garage. The houses did not have individual boundary fences or gates defining the front of each property but some had fenced rear gardens. Walking into these homes was a similar experience to that of any compact, modern, middle-income home.

For those needing supported living services both Larch View and Hill Crest offered serviced apartments and care apartments that provided services on a user-pays basis and ranging from assistance with housekeeping, laundry and linen, to comprehensive packages of assistance termed ‘care packages’ and described as being tailored to suit the resident’s individual requirements. In both villages the supported living units were set within the main buildings of

the village, closer to staff, service areas and dining rooms. These units were generally small apartments, approximately thirty to forty square metres in size with a single bedroom, a bathroom and in some cases a separate lounge and kitchenette. Some had open access to the communal grounds and others were located on a first floor level of the building, occasionally with a balcony included. Some of the residents who received a higher degree of living support, (such as daily assistance with washing, dressing and toileting) lived in a single room approximately sixteen to twenty square metres that had space for a single bed, one small armchair and an en-suite bathroom or alternatively, shared bathroom facilities situated down a main corridor. Walking into these supported living dwellings presented varied impressions. The units with a separate lounge appeared similar in look to a small middle-income city apartment. The units that comprised one room only, or a room with an en-suite bathroom, were more typical of a rest home bedroom. Some presented a sense of confined space, emphasised by the furniture that had been fitted tightly into the available space. These rooms were never-the-less light and bright, sometimes with a window view onto the surrounding grounds or shrubbery.

The independent living residents interviewed in this study used the official terminology adopted by their retirement village, such as *villa*, *townhouse* and *independent* when referring to their accommodation. By contrast, supported living residents tended to describe the various supported living areas as *rest home*, *in here*, or *hospital*, rather than the retirement village advertised terminology of premium level care, comprehensive care or care apartment. For the purpose of clarity this study uses the term *independent living* to describe those living in independent accommodation and *supported living* to describe those participants receiving any form of living assistance that was provided to residents living in any of the non-independent

accommodations<sup>7</sup> are noted in Appendix 2. Their own descriptive terminology is used within quotes. The term *unit* is used to refer to the dwelling where they lived.

### *Residents' perceptions of physical space*

As discussed in the literature review chapter, a number of studies have examined the attachment that older people may have to the physical spaces in which they reside. Studies have considered the physical environment surrounding a dwelling and also the dwelling itself and whether or not residents view their accommodation as home (Fitzgerald and Robertson, 2006; Gitlin, 2003; Golant, 1984; Rowles, 1978; 2006; Rowles & Chaudhury, 2005, Rubinstein, 1989; Shenk, et al., 2004; Wiles, et al., 2009). This literature has demonstrated that in order to be perceived as home and, therefore, to be invested with the personal and social meaning that enhances well-being, older people have to feel that they have significant, often long-term ties with their physical surroundings, enough space for household objects that are important to them, and a sense of being in control and feeling secure in their environment. To a great extent this suggests that people become attached to physical space if they are socially connected to their environment and their accommodation and their possessions, whether these connections are current or through past events.

This study asked retirement village residents living in both independent and supported units what they thought about their accommodation in terms of the extent of space they enjoyed, their personal possessions and whether or not they viewed their physical space in the village as home. Some residents framed descriptions of their physical space in terms of its impact on their

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<sup>7</sup>The support services that each interviewee reported receiving are noted in Appendix 2.

social space and this underlines the point that notions of space are complex and interwoven. As Wiles, et, al, (2009) assert, there is a complexity of factors that contribute to satisfaction or acceptance of living spaces.

*The significance of physical space for independent lifestylers*

Participants living independently had made self-initiated choices to relocate into the village, usually prompted by the promise of an attractive lifestyle (Leonard, 2002), desire for security associated with living in a gated community, and assurance that support was at hand if their health should fail. Many recalled their move into the village, making a significant financial outlay for their licence to occupy; Yet the village had offered them a new sense of freedom and a greater opportunity to retain their independence. **‘And the houses we sold are now worth more than double what we sold them for [meaning the houses they had sold prior to moving to the Retirement Village] so it’s swings and roundabouts’** (Alan). Their previous owner-occupied homes were described as unwanted personal responsibilities that would have required high maintenance, though they had lost their capital investment. Interviewees spoke of the village as a worry free environment given that the village took responsibility for home maintenance and gardening and these costs were all covered by one monthly payment. They noted that the facilities offered by the retirement village had grown over time and saw this as a positive attribute, demonstrating that their retirement village was continuing to provide up-to-date and useful facilities for its independent residents. **‘You’ve got to accept what they can fit in. They’re doing a little bit of jiggling around now to do different things. On the whole, as I say, it suits us. We’re in it for us’** (David).

The independent residents were generally happy with their accommodation and although some commented that the space was small, the challenges that presented in terms of relocating their possessions had been solved either by storing belongings with relatives or by hiring storage space elsewhere. One couple, Barbara and Alan, commented that they were pleased to have enough parking space to keep more than one vehicle and Carol and David mentioned the positive aspects of having a spare bedroom for visitors and a garage for the car. Retaining a car was significant to these residents' sense of independence and well-being hence the importance of being able to house and maintain their car in what they considered to be an appropriate manner. One resident, John, was particularly attached to his car and saw it not only as a prized possession but also as a source of independence. **'I can still get up and go anywhere. I still have my car'**.

Interviewees spoke positively about their physical space being large enough to enable them to retain their most significant personal and household possessions such as furniture, paintings and crockery. Whilst describing his independent living space in positive terms, John also noted his concern that any adaptations he made would have to be removed and the unit returned to its original condition when he vacated. **'The biggest thing that stands out was, when we moved into the village, getting anything done that we wanted to, like, put a fireplace in. It took three months to get permission to put a fireplace in, ridiculous'** (John).

Respondents' reflections on their physical space strongly suggest that they felt positively about it. The house fulfilled their functional needs and also gave them a sense of connection with their village and with the independent living neighbourhood. Although there was little mention of the physical environment of the retirement village outside of the confines of their own units, the residents spoke of the area in terms of a community with communal spaces (such as grassed



areas) that were well maintained by the village organisation and where neighbourliness added to the sense of attachment to place. They had retained their ability to come and go as they pleased and, if anything, their capacity for life satisfaction had been increased in that they were able to continue with their external facing lives (such as inviting guests for dinner and to stay overnight) whilst also enjoying enhanced social activities through the new relationships available to them in the retirement village community. Most of these research participants thought of their houses as homes implying a sense of meaningful attachment to place and neighbourhood. The exception to this was John who lived in an independent unit but whose wife had become increasingly frail and had moved into the hospital area of the village. Although still satisfied with his house and the fact that it could accommodate all his possessions, since his wife's relocation he no longer thought of the house as a home. **'It isn't a home. It's a house to live in, now. ... I've got two full wardrobes ... but we have enough room for everything we want. ... it's not a home, its a house. It's a place to live. It's not a place to.... I can't say I enjoy living here. I can ... I don't enjoy it.. but I accept it.'**

*Physical space: supported living residents*

Four of the seven supported living interviewees, Emma, Brian, Diana and Marion, had relocated from independent units within their retirement village. Alex, Susan and Janet had moved directly into a supported living unit from their own homes within the wider community. They all recalled their initial entry into the village but in their interviews focused more fully on their relocation into the supported living environment. For most of the respondents the relocation to units offering higher levels of support had been due to deteriorating physical mobility or a significant life event, such as an illness or a fall, that had created an event-driven,

acute or urgent need. Bereavements and sudden illness that resulted in a hospital stay were the most common event-driven relocations and others included falls resulting in lost mobility and chronic decline in physical faculties, such as eyesight impairment or hearing loss that had created increased dependency on family or friends. It was noticeable that many of the changes that created negative transitions were described as on-going and unresolved matters rather than being framed as a one-off event. Positive comments about their relocations tended to be focused on features of their physical space.

Talking of her physical environment, Diana made positive comments about the amount of sunlight in her living area and Janet valued her view of the hills and the birds. Emma reminisced about her independent unit and the sunlight she remembered in the communal building where 'happy hours' had been held. Although Diana had a balcony in her supported living unit, which was not common within her village, she missed having a garden of her own and being able to check on her plants each morning and evening. **'I'm very fortunate to have the balcony 'cos it does give you somewhere to open the door and get a bit of fresh air.'** These were the only comments made by these interviewees that related to their natural environment.

Brian and Marion were the only supported living residents who had actively pursued their own relocation to receive additional support services. Marion talked about her choice of unit. **'I put my name down quite a bit ahead and I said I wanted a sunny one and she showed me one upstairs that was very sunny but it was so small. I didn't think I could stand that and I thought, 'no, I'll wait', and I thought I'd see what comes up. I really wanted the one next door but the man didn't die so I've got this one which was very nice. Being able to look out the front and see what's going on is very nice.'**

Supported living participants also indicated a difficulty in adjusting to living in closer proximity to other residents in the same corridor. **‘I think people do notice the closeness and not so much individuality as what you’ve got in your own place’** (Marion). Alex spoke negatively about his unit being located too close to the dining room and his resulting sense of a loss of privacy. Emma had the opposite problem in that her unit was much further away from the dining room, which meant that she needed to walk a long way and required assistance. **‘I’m as slow as a snail’** (Emma). For Brian proximity to the dining area was a positive feature of his unit location, **‘You just fall out of here and into there.’** Some residents commented on the noisiness of living so close to others and the distraction that caused them. **‘I had a man next door to me once, he was making a terrible noise, it was just constant, it was dreadful’** (Emma). Emma also described how, despite her hearing impairment, she could hear the staff talking and laughing at their work station at night, which she found annoying.

Most respondents found the overall living space cramped or confining. Janet was not satisfied with the amount of storage space available for her possessions and Emma (who had a smaller room than the other participants) said that she had found it difficult to adjust to the small space that had only room for a chest of drawers and a small armchair squeezed in between the end of her bed and the wall. Marion complained of inadequate space to store her craft materials that prevented her from completing her craft work as she was unable to easily locate the items she needed.

Having only one bedroom or, alternatively, living within a single room, many interviewees found the lack of space precluded them from inviting friends to stay or from entertaining visitors. Janet had wanted a friend to stay but was unable to accommodate her. She described the value of this visit saying that the friend had added immensely to her increased level of

confidence and regretted the fact that her lack of space had prevented her from hosting her friend personally.

Whether living in units with a separate bedroom or living in a single room, respondents commented that it had not been possible for them to bring some of their important possessions with them when they had relocated. Downsizing had meant parting with some of their treasured possessions but had also left some feeling fortunate that they had been able to retain others including dining suites, paintings, cabinets and other furniture and display items. Diana compared the physical space in which she now resided to that of her previous independent unit. **‘I had an alcove for a dining room so I was able to have my table and that. [After moving into a supported living unit] I lost some ornaments and things although I was very lucky to be able to keep my china cabinet and err, but I was very sorry to lose my dining room table and chairs and that was something my parents had given to us as a wedding present, but there was just no room. That’s the thing you can’t have here, but I think that was sentimental value, wanting to keep it.’** Alex was attached to his paintings and his model ships that he had brought from his owner-occupied home in the local community. Janet (the only interviewee in the supported living area who was becoming more physically able as time passed) discussed her possessions from a functional perspective. For example, she was able to have a washing machine plumbed into her unit even though this was not common practice in the surrounding units. In addition to a loss of other possessions the loss of a car was, for many residents, linked to lost independence and a sense of social isolation. They were no longer able to make what Davey (2007) refers to as the discretionary trips that contribute significantly to their quality of life. Janet, Emma, Diana, Marion and Brian all reflected on losing their car.

Diana commented, **‘Well, I haven’t got my car. I miss that very, very much, and all of us do.’**

Although Brian did not focus on furniture or other objects he did comment on the loss of his collection of alcoholic beverages that he had kept in a drinks cabinet brought with him from his independent unit. He explained that he had gone away one weekend to see his family and had returned to discover that his alcohol had been removed by the retirement village staff. **‘They couldn’t take the booze off me in the independent units, that was my home. But they tell me I shouldn’t be having it here and they took everything out of my cabinet. It was just the way it was done really. That was an instance there a while ago, nothing nasty but we argued about that a bit. Nothing nasty, but if it was a boarding school I’d get a belt up the backside. It’s close enough to that structure that sometimes you think you might be in a boarding school.’** Although he had no choice in the matter, the most significant aspect of his narrative was that he explained this lack of autonomy as being a consequence of his physical location, i.e., in a supported living unit, in contrast to when he had lived in an independent unit where he was clear that the staff would have no authority to remove his alcohol because **‘... that was my home.’** Brian was not alone in differentiating between his previous home and the unit he now occupied. Susan remarked, **‘I try and make the best of it. I mean, nobody likes leaving their own home.’** And Emma reported, **‘Well, I’ve just accepted it. I’m making the best of it because I know I can never go to my own home again. I think you’ve just got to learn to accept it if you can’t do anything for yourself. I mean, I’ve been talking to my daughter many times and saying, Oh, I hate it here, I just want to go home. But I know I can’t’** (Emma).

### *Social space*

Physical locations become social spaces when there is a social connection. Wiles et al. (2009: 670) describe social spaces as ‘the elastic physical, imaginative, emotional and symbolic experiences of and connections to people and place across time and in scope’. Social space can be defined as those areas within or outside the retirement village where residents connect with one or more others. These social exchanges and points of connection may occur within the residents own unit but also in any other location. Social spaces may include spaces set aside for formal social activities, such as lounges and dining rooms, as well as informal spaces such as corridors, entranceways, gardens and grounds, libraries, reception areas and so on. Beyond the retirement village, social spaces may include bus stops, the village minibus, shops, park seats and even pavements.

Social spaces within a retirement village may change over time as the resident population changes. Residents become less mobile, or unwell, or die, leading to the loss of long-standing social connections for those who remain. Individual routines also change and the physical space that once served as a social space may be used differently and no longer be a space where social connections occur. Residents’ social space may expand when they make new social connections or decrease when friends become less active or die (Wyles, et al, 2009). Places that constitute social spaces can, therefore, fluctuate within a retirement village and only continue to be social spaces when the social connections that occur within those spaces are maintained.

*Social space: independent lifestylers*

Independent residents enjoyed the village social life, their retirement village friends, and the activities organised by village staff. They had functions to attend and interest groups that stimulated and maintained them both mentally and physically. **'We're a lot more active than we were'** (Barbara). A full social calendar appeared to be a symbol of freedom, good health, and social status. **'I used to say to her, [his wife] you're back then you're going! We're away next year from February to April! We can just shut the door'** (Alan), **'Set the alarm...'** (Barbara) **'... and we're away then'** (Alan).

Four of the five interviewees who lived in independent units reported enjoying a positive lifestyle enhanced by the social activities of independent living within their villages. **'Oh, we've got a better lifestyle [now] .... We're busier ... there's functions for the home, pantomimes and music halls and there's games in there. I go every Wednesday night and play cards. [Barbara] goes across to Thai Chi. There's something on every day'** (Alan). **'I like it. It's great. It's great'** (Carol). **'Well, it suits me very well . . . I think it's the social life that particularly has come as ... I mean I knew it existed because I'd found out a little bit. I think that for me has been sort of probably the major thing really'** (David).

John, the remaining participant who lived in an independent unit, referenced his enjoyment of social activities and lifestyle in the past tense. **'We were quite happy, we could come and go when we wanted, the people are nice, eh, nice people to live with, nice people to work with, everything like that. I wouldn't say we were unhappy here, not at all. ... But when A [his wife] had to move I had to change dramatically, but not too bad. We're a hundred**

**yards apart, I spend every afternoon and every evening with [her]. It is quite different. We're not married any more, for that kind of life.'**

Establishing new social networks was significant and this too was described in positive terms. Residents appeared to be accepted by the wider group of independent residents when they were visible within their independent living community. Barbara and Alan described the majority of independent residents as sociable. **'There are people within the village, we don't see them get out and we don't see them at the functions and that's their prerogative. But the biggest majority [are sociable]. We have happy hour every Friday you see, anything from fifty to eighty there, about fifty to sixty of them and you talk and chat and have a drink.'**

A willingness to be self-sufficient and to project an appearance of helping themselves was valued, rather than conveying messages of dependency or incapacity. Displays of independence were rewarded within the community by offers of practical help from the other residents. For example, David recalled a fully mobile resident who had assisted another independent living resident who was confined to a wheelchair during outings. By contrast, if a resident was not visibly engaging with the community they were not viewed by other residents to be part of the social network of the village. **'Some people don't make the effort. They stay in and they don't join in or they're looking after someone so we don't see them'** (Carol). If a resident had become less sociable because their partner needed more living support at home, the independent participants were aware but at the same time, they did not mention visiting or offering support beyond their immediate neighbours.

The length of time in the village was perceived as a measure of social standing. Long-standing residents were not 'new members' they were 'old hands'. They had experienced the past events



and changes within the village; they knew the system and they talked of knowing many of the independent people who had come into the village subsequent to their own arrival. However, none of these interviewees made reference to the residents who lived in the supported living accommodation areas of their retirement villages; neither did they make reference to them when talking about social activities that took place in the village. This suggested a clear division between the two types of living. This was a division that was confirmed by supported living residents (discussed below).

*Social space: supported living residents*

In contrast to the independent residents, the supported living interviewees made few references to ‘belonging’ to the retirement village community. There was no discussion of positive social networks within their living environments and only two spoke of interacting with neighbours living along the same corridor, both of which were negative comments. The first was a complaint about a neighbour’s failure to acknowledge a gift and the other was a description of a neighbour’s over zealous presence and their lack of common interests. **‘She’s cottoned on to me, and she talks and talks and talks about everything that I’m not interested in’** (Emma). Both Alex and Susan were clear that supported living was a necessity and not a choice. **‘Um, all I can say is I accept that this is not my mode of living or never would be ... it’s so different from my previous existence’** (Alex). Brian commented that his mobility affected his ability to take part in social outings that were organised by the retirement village. **‘If my health improves a little bit I’ll start to use the [retirement village] buses again. In the meantime I just can’t be bothered, in so far as you’re inconveniencing other people because you’ve taken up a bit more room than you should have done.’**

Coupled with the problems of declining health was the loss of social connections: **'... it's very lonely, it's very difficult to make friends when you come to a place like this because you very seldom have any contact with many people. I don't. You don't make any close friends'** (Susan). None of these interviewees projected a sense of belonging to the retirement village community. The social environment was a focus for many, including Alex, Susan, Emma, Diana and Marion. Rather than perceiving a social life within his village, Alex reflected on his past social life in the independent area and the role his late wife had played in his social world. **'Well, first of all I miss my sports, sport's high on the list. I used to enjoy my golf on my days off and through golf you meet an awful lot of friends. One thing I do miss is my late wife. She was a very sociable person, we used to do a tremendous amount together but she was the organiser, she was the very sociable person in my life.'** Like Brian, Emma, reflected on her enjoyment of the social activities when she had lived in an independent unit and reminisced about those times with a sense of enjoyment and community atmosphere. **'It was really lovely and they were a nice crowd of people and we used to get on very well. Every Friday night we had 'happy hour'. We didn't have a hall at that stage but we had one of the buildings, which had a lovely little sunny room that we used to have our meetings in and the "happy hour". . . People are still very nice [in the supported living area] but it's different. The village is separate, separate activities and things, their [residents in the independent living area] activities are more flexible because they can get around and things'** (Emma).

A number of respondents talked about the lack of social interaction between those in the independent units and those in the supported living units. **'I think the amount I've been here, two years, I've lost touch. I've got my own particular friends that I used to live beside and**

**they're still good friends and they see me and I can go for a walk and see them, but being interested in them, they're not so interested in us now, because we're supposed to be the lesser of the interesting people, I think. Well, I mean, we're not so much out in the world as we used to be' (Diana).**

The social culture was a particular focus for Marion, who described the changes she had experienced in greater detail. She found the residents in the supported living area to be less sociable than those in the independent units. She described the residents who she considered to have dementia. **'They all seem to sit together and they talk a lot [those with dementia talk amongst themselves]. That was something I found here, nobody talks much, especially the people that are able to talk. I'm finding that quite hard, that's why I spend so much time in my room I think.'**

When asked whether she had been aware that there would be fewer social activities prior to her move into the supported living unit, Marion continued, **'Yes, I was aware of it 'cos there's a very strict code between the townhouses and here, because, I don't know why. For instance, they go out for their own happy hour and we're invited to it but not made welcome. At least people come in here to see me but it's just, there just doesn't seem to be any connection unless they make it.'**

Marion had occasional visitors from the independent units. **'One or two people see me sitting here and just pop in. No, they seem to forget you.'** She also described what she considered to be the social rules when talking to other residents. **'It's completely different here and there are a few people you can talk to but you think you've made the wrong decision if you talk to them and they take exception here that you talk to them. There's a bit of that goes on.'**

**It's very difficult, very difficult to break into it [the social groups]. I didn't realise there were so many people who are not with it in the serviced apartments but it didn't use to be that. It was more like I thought it would be, that you progressed here because you were physically disabled rather than mentally. But they've since started taking these people in and they don't wander, so they keep them here.'**

Janet was the only interviewee who used public transport and was still active within the community. She was distinct from the other interviewees because she was recovering from illness and her health was improving rather than deteriorating. She reported that her daughter had said, "Mum, you're in backwards land", believing that Janet could move into an independent unit at a later stage. Janet did not mention feeling lonely within her village. She visited residents in the independent units and had joined a number of interest groups since her health had improved. She also maintained her social network outside the retirement village. **'I was starting on the back foot because so many people within the village have come from the local area, for many years. They've got families, background, networking, everything and that was another reason I felt I couldn't afford to just sit back. I had to get out there and become part of the community which to me was very important, it is very important and it's amazing, a wide range of people, ages, included.'**

Interestingly, Janet was careful to keep a degree of separation from her supported living area even though her unit was in that part of the village. She described her need for privacy and her desire to retain her sense of independence. **'I never talk about myself to other people here. They don't know where I came from, what I did, or what my life was before I came here and that's the way I prefer it to be. The fact that these apartments are now care apartments and can come under the rest home umbrella, I am quite conscious. I don't**

**like using that corridor. Psychologically, I don't know why, I don't like it. Err.. because I have a feeling perhaps... the word institution is a wee bit strong but I don't like to feel that, I like to feel that I'm independent.'** A further example of her attempt to remain separate from other supported living residents was that instead of using the front door, she treated her glass sliding door (which gave access to her unit from the grounds), as her front door and only used the actual front door into the rest home corridor when she needed to collect her paper or mail. Friends who called on her were instructed to use the glass sliding door in her lounge area. **'The door that represents the institutionalised side, the front door, the cat won't go outside that way at all. She stands at the door but never crosses over into the corridor. Usually, I go out at 6am to collect my newspaper, I leave the door open and she has never gone out, never stepped over that door, just her little face will be waiting for me in the opening part of the door.'**

#### *Loss of social activities*

The loss of active pursuits and social activities was noted by the participants and appeared to have occurred at the point they relocated into their supported living unit. After this time, activities were described as sedentary in physical terms. Alex commented on his loss of physical access to ski lifts, golf courses and restaurants in relation to his limited mobility and regretted that he had not travelled overseas more frequently when he was more able. Brian recalled his enjoyment of golf and bowls but was now too immobile to play. Susan also mentioned her loss of access to golf and had enjoyed cooking but her eyesight was now too poor. Emma also missed cooking and although some cooking demonstrations had been held in her village, she complained that she was expected to watch passively, rather than being actively

involved. **‘They had two ladies come and show us cake decorating. We didn’t actually do anything though. They showed us pictures and models of things.’** Susan also missed sewing, having made tapestries all her life, but could no longer see to thread her needles.

Many of these interviewees said that they could get to activities if they had help from a staff member but that this assistance was not always available. **‘Some of the staff are really good and helpful and do anything for you. Mind you, there’s some that don’t. But some of them have said they’d take me down, but it’s not the same without my husband there, although they’re always nice to me. . . . I usually wait for the nurses because I can’t get in or out of the car. It’s frightening to think you might fall over. They should be aware of me falling over because I’ve done it so often. I used to play indoor bowls sitting down but I haven’t done that lately because they do it first thing in the morning and I’m not up. I’ve got to wait for them [the nurses], there’s nothing I can do about it’** (Emma). Diana also spoke of the problems of having to wait for the nurses to help her to dress in the mornings. **‘Sometimes they’re very late and I need to get my breakfast as we have to be at morning tea at ten... and that doesn’t give you a lot of time.’**

Alex was less interested in village activities but enjoyed getting out beyond the village environment. **‘It’s a lot of activities happening outside, that’s what I do. A lot of people do things within the village, bridge or songs and dances but that’s not quite my thing but they certainly do their utmost to keep you occupied.’** A loss of both physical exertion and intellectual stimulation within the retirement village was a common theme. Some interviewees made up for the lack of mental stimulation by keeping their brain active within their own living environment. **‘We have this sort of entertainment in the afternoon, but most of it has to be geared towards them, [residents with dementia] so we sit around walls and bowl balls into**

**the middle and some of them say, “what are we supposed to be doing?” I find that very trying. ... I try to keep my brain active (Marion). As long as you can keep up your interest and listen to what’s going on in the world, keep your mental stimulation going. For as long as my head works, I’ll be fine. If I lose that, they’ll lose me!’ (Diana).**

Eyesight or hearing loss prevented some residents from participating in activities. Interestingly, some reported having requested more mentally stimulating activities, though there were no reports of their retirement village having responded to these requests. Diana explained that she had regularly used the internet to communicate with her family overseas but the computer room had been closed to make way for a beauty salon. As a consequence she was unable to contact her family by email and had lost the mental stimulation of using the internet. She had approached the village management and requested an alternative location for the computer room but felt that she would be seen to be an annoyance if she persisted. At the time of interview she was considering asking the village staff if she and another resident could go by taxi to a shopping centre but did not know whether this would be allowed. Her discussion of this suggested a sense of adventure that had been stifled. **‘I’d like to ask if we can get a taxi and go to [a local city store]. I’m not sure if they’d let us both go ... She’d love to go and so would I! I’ve never asked. I don’t know if they’ll say you can or you can’t.’**

#### *A sense of social isolation*

Diana, Susan, Marion, Emma and Alex spoke of feeling socially isolated. Social isolation was described in relation to failing health and mobility, loss of suitable transport, lost social contacts, and a village environment where links with socially active people were minimal.

Diana and Emma felt isolated due to their inability to walk without assistance and, for Diana, a lack of energy to go out for any length of time. She commented on this in terms of her transport difficulties. **'If you can't have family with you, well you can't [ go out ].'**

Susan explained her lack of social interaction inside her village environment as exacerbated by difficulty in remembering people's names. **'It's very difficult to make friends when you come to a place like this because you very seldom have any contact with many people. I don't, you don't make close friends. In vegetative terms, your memory slips, people, names are very hard to remember.'** Marion described herself as socially isolated even though she attended coffee mornings with other residents. By choice, she spent much of her time in her own unit to avoid the social dynamics that she experienced when she had made an effort to meet people. **'It amazes me that people can just sit and yet some of them talk to each other and some of the addled brain ones, they carry on a big conversation. You say good morning to people and that's just about the conversation. I usually come back and do my puzzles or read a book.'**

Alex described his isolation as being a consequence of moving into the village. **'Quite truthfully the main reason for accepting it [living in the village] is that it's a family thing. They wanted me to be well looked after and happy, and I was brought up, being eighty four now, like my mother was brought up, that the eldest daughter was the one that looked after the father if he was ill. But that has not happened in our family and it's in modern families that it doesn't seem to be the accepted thing at all. Um, so I just seem, being totally isolated, that's not quite the word. I'm not totally isolated because I have three children. They've given me support, don't put me wrong, but it's not the support of**



**close family there might have been in the old days. .. I feel quite isolated in a retirement village like this. ‘**

For those with family living locally, it was the daughters who were described as the primary source of social interaction and that was where most interviewees placed their reliance and social focus.

*Supported Living: dining experiences and daily routines*

Food and dining room facilities were not a pre-determined focus for the study yet these topics were raised by all of the interviewees living in the supported living areas. Diana described the number of meals eaten in the dining room as a marker of her level of support need. **‘We have this rest home care which is full care like I have. I have breakfast brought to me. Everyone has their lunch there [in the dining room] but I have to go for tea... so I’m on full care.’** Many interviewees identified meal times as their main social activity, although not in positive terms. Alex recognised that even though he did not describe himself as a sociable person, his meal times provided his main social contact with other residents. **‘I don’t get very many [visitors] actually. When it comes to meal times, people can socialise. I mean, I’m not terribly good at that. Part of an elderly person’s life is adapting to a totally different life situation, understanding facilities is very difficult for older people. Talking to residents here is a must almost, must come down to meet people. They try and get you to socialise as much as you can and my family are pushing me like mad to do a lot more socialising. I don’t do enough and I accept that.’**

Alex also described changes that were occurring to the dining area which were designed to combine supported living residents with those from the 'hospital' area of his village. **'We've just moved, the other week, into all dining together, we used to have three dining rooms.** 'Diana described being appalled when staff placed a bib around her neck before she ate her meal. **'One thing, you go into the dining room and you automatically get a bib. I hated that and there was no, or very little, chatter, and I think there are about seventy people in the rest home.'** Diana, Emma and Marion also spoke of the different degrees of social skills in the dining room and reported that residents were allocated a specific seat that was changed every few months. This led to negative social dynamics for some participants at meal times and the level of social stimulation appeared to depend on the particular seating allocation at any given time. **'I was put in the dining room, corridor there, and a lot of people were sitting around at one table... about six old ladies and they started throwing things, throwing things at each other from each end of the table. There was china and all sorts of things, and I thought "my God, what have I come to?"'** (Emma). **'Sometimes you're quite compatible and sometimes you're not. Some people want to talk, some people sit and just hang their heads and don't want to talk. A lot of that goes on. We change tables every few months. It's just bedlam when they do that'** (Diana).

Interviewees also described their dislike for stew and other 'soft' food that they reported as a frequent menu item. They made similar derogatory comments about cold or overcooked food that was described by one interviewee as 'rubberised'. Janet described every food item in her very first meal at the village and said that after that experience she had asked her son-in-law to deliver her lunch from a local cafe each day. In conjunction with her fellow residents, Susan was making a formal, written complaint. **'The food is terrible. I've written up a screed about**

**it. A few of us are going to complain about it. As for whether it goes anywhere or not ...'**  
(Susan).

### *The influence of family*

Interviewees looked forward to family visits or outings and many described their family as their primary social focus. With one exception, the significant family member they mentioned was a daughter. As Janet commented, **'[if you didn't have a family] I can't imagine what you'd do. I've said to my daughter "it seems to me that everyone has a daughter", and it's true'**. Interviewees also said that family members played a social role in their lives, although the level of contact varied from an annual visit for one interviewee to monthly or weekly visits for others. Some family members also played a positive role in advocating on behalf of the resident when issues related to quality of service needed to be raised with retirement village staff.

All of these supported living participants said that their relatives were happy that they were living in the retirement village and receiving village services. Apart from Marion and Brian, the respondents' relatives had been instrumental in choosing the supported living unit. **'I think they're happy that I'm settled in and not being a nuisance. What would I do? I mean, I couldn't live with anybody. There's no-one I can live with. I've only got one daughter and so, I know she's happy I'm here'** (Susan).

Diana, who had a particularly attractive room with additional features, commented that the retirement village sales person used her unit as part of the retirement village sales process, to show to the families of prospective purchasers. **'Often, their family will come around and**

they often bring people to look at my place when they're showing them around. And if I'm here, or if I come back while they're showing them, they'll say, "Mum or Dad needs some support but she doesn't want to leave home or doesn't want to do anything about it but we think she's ready for it". Well, I think it makes all the difference if you've made the decision yourself and it's not out of your own hands. Of course, I didn't make the decision myself.'

Marion and Janet were clear, however, about their desire to retain control over the decisions they made and each spoke of refusing to conform to their daughters' wishes. 'I've done all these things [moving into the village] for myself because I want to be in charge of my life. My daughters are very good but none of them bosses me. Well, one tries, but I don't take any notice of her (Marion). I think she [daughter] looked on me as a mature student I would say. I used to get up in the morning and there would be a little list, "Mum, today you might like to" ...MIGHT LIKE TO.. de dum, de dum, de dum, de dum and when the lists stopped, she did say to me "Mum, did those lists upset you?" and I said, "yes, they did"' (Janet). At the same time, Janet went on to say that her daughter's support was helpful and it encouraged her towards greater independence, '...because, I knew that I don't want that list.'

Susan described a strong sense of family control when she moved into her supported living unit. Her family chose the unit while she was in hospital and had not been considered well enough to return to her independent unit. Her grandchildren had decided what possessions should be moved into the smaller living space of the supported living unit and she said that she occasionally saw some of her possessions in their homes when she visited them. 'My family only had two days and it was a case of "that goes into the skip" and somebody else got

**everything that, and lots of things I look around for and see, “Oh, I haven’t got my knife sharpener”... and of course I go to my grandchildren’s occasionally and I see they’ve got things.. but it’s a really funny feeling to think that you didn’t really have any control over what was happening’ (Susan).**

Over half the interviewees spoke of their family members being involved in the management of their finances and their personal matters. For example, Diana mentioned having limited access to her own money and was unable to visit an automated teller machine or a bank. She reported that retirement village staff provided her with a limited amount of spending money for her own personal needs such as toiletries or biscuits. This suggests that they were managing her finances beyond the payment of the monthly service fees.

When residents moved from an independent unit to a supported living unit they not only moved from one physical space to another but they relocated from one social space to another. A major factor in this long term transition was the loss of independence that was associated with declining mobility and the increasing inability to function in order to engage in social activities and to perform the personal tasks of daily living. As their health deteriorated and they relied more heavily on staff support they also experienced the gradual erosion of their autonomy in that they were no longer able to control the timing and nature of their social and personal life worlds. Those residents who required the highest levels of care within their supported living unit also needed to adapt to the loss of their personal space. This is discussed below.

### *Personal space*

The notion of personal space was formulated by Hall (1966) who used it to describe the social rules that define the appropriate physical distances that people try to keep from others; it is the space that a person regards as *belonging to them*. This space varies according to the significance of the relationship with others and Hall suggested four zones of personal space: an intimate zone reserved for lovers and close family members; a zone for friends, associates and group discussions; a zone for strangers and new acquaintances; and a public zone used during public events such as visits to the theatre. Personal space is relevant in a retirement village where residents engage in relationships with others that range across each of these zones.

### *Personal space: independent lifestylers*

Although they were in close physical proximity to their neighbours' homes and there were no fences, residents living in independent units did not view this as a loss of privacy or invasion of personal space. On the contrary this proximity was described positively in the context of greater security and a sense of being connected to the village community. They described an informal security network operating, watching over each others dwellings, and informal watching events; for example, checking that their neighbours' curtains were opened each day by 9am. They took holidays, reassured that neighbours would informally keep an eye on things. At the same time, their sense of belonging to a lifestyle community was combined with a sense of valued privacy, having their own private space and sense of independence from other residents.

*Personal space: supported living residents*

For supported living residents the issues of personal space largely related to the intimate levels of care they received, for some this involved help with dressing, bathing and toileting. These high levels of intimate care breached the social norms that would be accepted in the external community and if mapped onto Hall's (1966) personal space zones would ordinarily have been reserved for lovers or close family members. Brian spoke of his bathing experiences in terms of a loss of privacy. **'I've thrown all my privacy out the backdoor and let the wind blow it away. You get to my age and you have a girl, twenty five years old showering you, get you up in the morning, put you to bed at night, you've got no privacy, you've got no secrets from her. There's about twelve of them. You've got no privacy.'**

The difficulty of adapting to what was clearly experienced as an invasion of personal space was coupled with the problem of having little control over when and how this care was delivered. Interviewees spoke of their preferred daily living routines and the lack of concurrence with the routines of the retirement village organisation which timetabled basic activities such as washing, dressing, bathing and bedtimes. Those who were early risers found it unsettling to wait in bed to be assisted with dressing whilst staff were occupied elsewhere. Similarly, some had no wish to adapt their often life long routines to fit those of village staff. **'They wanted to shower me in the afternoon. I refused that. I said "I don't want to go down for tea in my nightie or get dressed and undressed again". So I said "No". So sometimes I get it around seven o'clock, occasionally it's about eight... and then I just have my nightie and dressing gown on and I just sit in my chair, like that, until when I go to bed'** (Emma). Emma was bathed on three days each week and had night sweats but she was not bathed over the weekends

and commented that this was uncomfortable for her. She also experienced distress when sometimes left sitting on the toilet for '**half an hour or more**' after using her buzzer to call for assistance.

### *Veiled space*

Veiled space is a concept original to this study and refers to the residents' preparations, thoughts, expectations and fears concerning their anticipated end of life experiences. It is termed veiled space because of what may be construed as either the residents' reluctance to consider their end of life, or, in the case of supported living residents, their lack of knowledge about what the experience might entail when they move into the highest level of care within the retirement village hospital.

### *Veiled space: independent residents*

End of life concerns for independent residents largely centred around financial issues and questions of their economic ability to purchase a care package in a supported living unit 'if' needed at some point in the future. Interestingly, physical deterioration and failing health, factors that commonly prompt the transition into supported living, were not viewed as inevitable. Most did not openly acknowledge any significant likelihood that they would need to transfer to the supported living areas of the village yet their awareness of this possibility was indicated in their comments about the issues associated with the affordability of supported living accommodations. John, whose wife was in the hospital wing, commented that he would not be going there himself.



Residents described the retirement village supported living services as a safety net and were reassured by the knowledge that help was at hand in the event of an emergency, along with first priority access to relocate to the supported living areas if their needs increased. When asked whether they had considered what would happen if their health deteriorated, Alan and Barbara said, **‘Not really, not really, don’t really think about it’** (Alan). **‘As long as we keep mobile and moving, there’s no reason for it to change’** (Barbara).

These independent residents appeared to see no need to address future support until the time came when it was needed. When asked what they thought they might be doing in a few years time, they either suggested they would be living the same social lifestyle in the same independent unit, or that they would be dead. For example, David, who was already experiencing deteriorating mobility, responded with, **‘I’ll be pushing up the daisies by then.’** If residents were thinking ahead about potential declining health and mobility and what this might mean for their end of life process, they chose not to share this with the researcher. Only John indicated he was planning for his future by keeping a wheelchair handy but he appeared to see the wheelchair as his means of independence if he became less mobile. **‘No, it doesn't worry me [deteriorating health] because I know I will be taken care of. As long as I can stay at home, in my own home, I'll be reasonably happy. I can manage on my own, I've always been independent since I was eighteen and I'm eighty seven now.. so... be a big thing to go into a retirement home full time. I'm still lucky, I've still got the electric wheelchair we bought for A [his wife]. I'm keeping that back now, for myself’** (John).

The only other indication that independent residents thought of a possible future relocation into a supported living unit was in terms of their financial situation. All of the respondents

mentioned the licence to occupy they had purchased when they first moved into the village<sup>8</sup>. This licence gave them the right to remain in their current accommodation type but any future move would require a new contract. They pointed out that their licence to occupy had lost parity with market rates over time and they expected that, by the time they might need to consider moving into a supported living unit, the value of their independent unit would have depreciated further. At the same time, they knew that the cost of a supported living unit would have gone up to the current market price. This meant that residents might not be able to afford to move to the next level of support especially if they had used all their savings to purchase the original licence. When asked in interview if they had any advice for people considering moving to a retirement village, they wanted newcomers to know that any future move into a supported living unit could not be assumed without a sound degree of financial awareness. **‘I would advise anybody that wants to come in, read it [the contract] and understand it. The fine print, understand it. If you don’t understand it, then get somebody that does’** (Alan).

#### *Veiled space: supported living residents*

Having already made the transition into supported living, these residents were more forthcoming in their discussion of end of life issues. Like the independent residents, many of the interviewees commented on the financial model of the retirement village and urged caution or suggested that people consider the licence to occupy contract carefully. Some also spoke of the financial model depleting their financial resources over time, particularly after moving into a supported living unit and having already lost further parity with current housing prices.

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<sup>8</sup> Interestingly, this was the only aspect of retirement village living that was raised in some way by all of the respondents within this study.

**‘They’ve [the retirement village] given me an interest free loan for the difference in the price; that’s all still invested I suppose, which is ridiculous. I think they also kept my money from my house so I haven’t got that back and I won’t get that back till I sell this place and move on to the rest home’ (Marion). ‘I got the whole amount that my townhouse was and that went into here, and then they take it all off at the end when you’re totally finished’ (Diana).**

It was, however, the fear of having to relocate to the retirement village hospital – the next and possibly last major transition - that caused supported living residents the greatest concern. They tended to view the hospital as a place of total dependence and lost autonomy; a place of no return. As such, it was a place to be avoided as it signified that they were close to the end of their lives. **‘I’d hate it because you’ve got nobody to, [pause]. I guess it wouldn’t matter if something happened to your brain or something. You see, a lot of them [people in the hospital] have bad legs, bandaged and all that sort of thing. Some of them fall out of bed and have problems or their arms are hurt’ (Diana).** The need for more intensive support was seen by most as inevitable, particularly if they had a fall or if an existing health condition deteriorated. **‘It’s a funny feeling not knowing what’s going to happen. I’ve still got the fear of falling, that’s what worries me more than anything’ (Marion).** Higher levels of support were perceived as a staged process that residents would pass through if they did not die unexpectedly in their current living environment. **‘If they find you’ve got something they didn’t know you had before, they’ll see that it gets treated. You progress from houses [independent living], to this [serviced unit], to the rest home and then to the hospital, the “final resting place” as they call it’ (Brian).**

In contrast with the independent interviewees, these respondents were all aware that they were close to the end of their lives. A particularly sharp awareness of being closer to death came from those who had lost relatives and friends in the recent past and those who had already experienced serious health events such as heart attacks. Emma commented that she had lost many friends and was saddened by her inability to attend the funerals because there was no-one to take her. Marion had lost relatives recently and commented, **‘I know how quickly things can happen.’** When asked what she might be doing in the future she replied, **‘I’ll be dead, I want to be.’** With reference to her own health she felt that she was due to die suddenly and very soon. Some had indicated their end-of-life preferences to their family and others said that they intended to do so. This was explained by Marion as a preference to remain in control of the situation. **‘I wanted to arrange my own funeral but my family wouldn’t hear of it. If I say, “I want to make a list of things for people”, they say, “Oh Mum, no, no, you don’t need to do that”. I will, I will do it anyway because, you know, because I don’t want to happen what happened when I had to give up my townhouse. You know, what I’ve got, still, I want it to go to the people I decide. I keep the control. Absolutely in control, yes’** (Marion ).

Although he did not share his thoughts in any depth, rather than focusing on his end-of-life preferences, Alex spoke of how he might cope when dying. **‘Just wondering how one copes when one gets to the bitter end. Like how one is in a retirement village. I suppose one would call that the bitter end. The end demise is going to be the big thing here in retirement villages.’**

Interviewees also related anecdotes of residents who had been *taken* into the hospital and who had *not been seen again*. The hospital stood in stark contrast to the physical, personal and

social spaces enjoyed by the independent residents and to a much more limited extent by the supported living residents. The architecture of these retirement villages meant that there was close physical proximity between the supported living residents and the hospital. Despite this, supported living residents appeared to have little information about how the hospital functioned and they repeated anecdotes that strongly suggested that they viewed the hospital wing as a place where people resided for only a short time before dying.

To some extent, the hospital could be interpreted as a *beyond space* (Wiles, et al, 2009) in that it loomed large in the residents' imagination. Beyond space is not a good fit, however, in that whilst residents imaginatively constructed what happened in the hospital, the physical space of the hospital itself did exist – it had a real physical presence and one that most assumed they would have to experience if they did not die suddenly. Most residents had not ventured into the hospital, or been encouraged to do so. Their descriptions portrayed the hospital as an unknown but significant space within the retirement village complex that was the last step before death. As such, a metaphorical veil hung over the hospital that symbolically separated it from the supported living units yet was framed within residents' imaginations as an unknown space for dying - one entered and did not return. Passing through the veiled space of the hospital suggested that there was only one further step to take, behind the final curtain to death.

### *Summary*

This chapter has presented the research findings and focused on both independent and supported living residents experiences of transitions in the context of their physical, social,

personal and veiled space. The next and final chapter will discuss the wider implications of these findings.

This study, with its focus on retirement village residents' transitions, has generated a wealth of data on their experiences of change as a consequence of failing health, the impact of increasing dependence on support systems, the gradual erosion of their social and personal autonomy, and the meanings they associate with home and care. It has also provided insights into residents' expectations and fears surrounding end-of-life and, a major finding has been the unique nature of these experiences, occurring as they do within one physical location – the retirement village. These findings have been discussed in detail in the last chapter. The wider implications of residents' transitions; physical space and the meaning of home; independence and autonomy; their end-of-life expectations; and the retirement village as a place of divide are discussed below.

### *Transitions*

This study aimed to gain insight into the transitions experienced by retirement village residents as they relocated through various levels of support available when living within a retirement village and onward to end-of-life. The expectation was that these transitions would be prompted by events such as failing health and mobility that would have necessitated a move from independent living in one physical space into a more supported living environment in another. A further expectation was that the transitions would predominantly involve big step changes that mirrored the significant changes in health and mobility that are likely to occur as

people age, coupled with indications of adaptation to a new physical living environment where additional support services were provided.

What the findings of this study actually suggest is a more complex set of inter-related transitions. Rather than big-step changes, followed by a period of adjustment or non-adjustment, the transitions that residents experienced followed along a continuum. At one end of the continuum was independent, active, autonomous living; at the other end was dependent living and lost autonomy. In utilising the framework of a continuum it is important to be aware of the gradual and on-going impact of losses along the way, and to highlight the multifaceted nature of residents' losses in an environment in which one change in living circumstances may overlay another, without any signs of adjustment being reached. Residents' accounts of their life-worlds indicated a number of concurrent, inter-related transitions, many of which appeared to be on-going, without reaching a point of adjustment or conclusion other than a sense of being resigned to the inevitability of the changes, and only in this respect accepting them. The transitions they were experiencing were not simply a consequence of the change to their physical dwelling space but also to their social and personal space, each of which was impacted by the organisational structure of the retirement village in which they lived and which, in turn, presented a *veiled* space of imagined but unknown experiences ahead of them.

For the participants in this study, their experience of physical, social, and personal space impacted significantly on their transitions. What was particularly striking in the on-going nature of the transitions was that once they were on the care pathway there was no turning back and, although there might be time to stop for a short while along the way, their journey of decreased mobility, functional capacity, and social and personal autonomy would inevitably continue until they reached the end of their lives.



Thus the findings from the study demonstrate that transitions are not one-off events to which residents adapt (or not) but have an on-going impact on their lives and are multi-layered. Some supported living residents had been taken by surprise by their health problems and changing environment and were clearly ill-prepared emotionally to adapt to new and limiting routines or to a transformation in self-identity from an active lifestyler to an image of themselves as unhealthy and in need of living support in a sheltered environment. For example, in interview, one person summed this up with the exclamation, ‘**I didn’t think it would happen to me!**’ Despite limited or no contact with their former friends and neighbours in the independent area of their village, some residents appeared to continue to identify with the independent living residents and most reminisced about those times when they enjoyed independent lifestyles. Supported living was not how they had expected their lives to be.

#### *Physical space and the meaning of home*

As noted in the review of the literature, attachment to physical space is, to a large extent, reliant on social connections. Unlike the independent residents who spoke positively about their physical environment and considered their unit to be home, the supported living residents demonstrated little attachment to their physical space whether it was their individual unit or the communal areas of the supported living environment. The only independent living resident who spoke of his house not being a home was John who explained this as due to the relocation of his wife into a high-level support area of the village. This finding demonstrates the significance of social connections to the way in which residents give meaning to the physical spaces in which they live. The independent participants who continued to enjoy active and fulfilling lives felt a

strong attachment to their houses which they referred to as home. In contrast, the supported living residents felt that they had lost something that was fundamental to their definition of home. Studies have shown that personal histories are important in the relationship between an individual and their physical space (Peace, et al, 2006; Rowles, 1978) and also that positive connections to place enhance older people's well-being (Wiles, et al, 2009). The transformation of a physical space into a significant place, a house into a home, involves a complex range of factors that draw from personal values and experiences and include social connectedness, autonomy, privacy and so on (Dupuis and Thorns, 1996: Gurney and Means, 1993; Mansvelt, 1997). Conversely, physical space that holds no sense of attachment or which has lost its meaning, 'may be linked to negative feelings such as isolation or loneliness, physical difficulties ... and social frustrations in dealing with other household occupants (or the lack of them) and neighbours' (Wiles, et al, 2009: 665).

For the supported living residents in this study, their current physical location was associated primarily with experiences of loss and failing health and the physical environments of the retirement village that they now inhabited held no memories of happier times when they had enjoyed better health and the pleasures of an active lifestyle.

This sense of discomfort in their physical space was common among the residents in the supported living areas, none of whom referred to their units as home. The units in which they now resided were compared unfavourably with their previous dwellings, not only in terms of limited space and reduced autonomy but, importantly, by the way in which they described their attachment to place. For them, home was used to refer to an earlier dwelling (whether in the independent area of the retirement village or in the wider community); a place they had given up reluctantly.

### *Independence and autonomy*

When residents moved from an independent unit to a supported living unit they not only moved from one physical space to another but they relocated from one social space to another. A major factor in this transition was the loss of independence that was associated with declining mobility and the increasing inability to function in order to engage in social activities and to perform the personal tasks of daily living. As their health deteriorated and they relied more heavily on staff support they also experienced the gradual erosion of their autonomy (defined as the right to self-govern) in that they were no longer able to control the timing and nature of their social and personal life-worlds. Those residents who required the highest levels of care within their supported living unit also needed to adapt to the loss of their personal space.

In terms of independence, the supported living respondents were saddened by the loss of independence they experienced, evidenced by failing mobility, and for many, the loss of their car that symbolised their freedom to come and go as they pleased. In addition to downsizing their physical space, the compounding limitations to their mobility and deteriorating health status, coupled with the need for increasing support services, impacted negatively on their social and physical activities, eroding or curtailing their social networks and dramatically reducing their lifestyle choices. In the context of the supported living areas of the retirement village, residents' autonomy was compromised together with their experiences of privacy and loss of personal space that was connected with the need for intimate care. Residents in the supported living areas were keen to enjoy social activities, viewing them as a mechanism for

maintaining social interaction and mental acuity, but these tended to be designed to encompass the needs of all supported living residents including those with the highest level of support need and reduced mental functioning. This was experienced as a problem by the participants in this study who reported that many of the activities lacked adequate stimulation, were sedentary and commonly failed to actively engage them either socially, physically or mentally. This highlights an unexpected plunge into a lifestyle that is limiting and inappropriate for many residents who had not anticipated the resulting loss of enjoyment.

Retirement village organisation rules, practices and services are created to enable the smooth functioning of their care systems. The need to adapt to organisational rules, designed to suit the functional needs of the village care system, that exerted considerable influence over when they woke, dressed, bathed, dined, and slept, had long-term, on-going implications for their sense of self and for their personal and emotional well-being and autonomy. This was compounded by the frequent failure of staff to respect their privacy, for example, entering residents' accommodation without permission and sometimes without even knocking first. Indeed, much of the practice of care echoed the findings of the UK report *Counsel and Care* (1991) that noted that whilst such practices may facilitate the work of staff, they invade residents' privacy unnecessarily and further erode their sense of well-being.

Whilst for independent residents issues of personal space hinged on privacy and proximity to neighbours, supported living residents focused their descriptions on their reliance on staff to perform the most intimate tasks of daily living. As Rogers and Neville (2007: 33) assert, these tasks 'set the boundaries of the older resident's moral universe'. Not only is there a deep sense of having lost their privacy but coupled with this is the loss of autonomy that comes when residents personal, long-held routines are disrupted and they are forced to compromise or adapt

their needs to meet the organisational structures of the institution, for example, being bathed at a time convenient to staff and helped from the toilet when there are no other tasks deemed more pressing to perform. Nolan et al. (1995) refer to this as the *routinisation* of care that is task-oriented and devalues the social and emotional needs of residents.

Rogers and Neville (2007) assert that this loss of privacy and autonomy is a consequence of organisational rules that fail to respect residents' preferences and long-held personal routines. They argue that it is possible for aged care facilities to enhance the personal autonomy of their residents by respecting their rights to privacy and their need to have some control over the nature and timing of intimate care tasks. Involving residents themselves in discussions of how this might be achieved whilst retaining the functional capacity of the organisation, they believe to be fundamental to the process.

For the supported living residents, the loss of their social networks within and beyond the village, coupled with their loss of choice in most areas of their lives, including their most personal care, had led to a transition that was not appearing to find resolution. It is fair to say that many supported living residents saw their future as the *bitter end* but did not understand or know how this would be managed within a retirement village. They lived in a community where illness and death were commonplace yet, although not totally hidden and sequestered, the boundary these participants perceived between themselves and hospital residents suggested a level of sequestration that may have assisted the independent residents to avoid the signals of their own mortality, thus retaining their ontological security, but was clearly a source of anxiety for those who were emotionally closest to its doors.

### *End-of-Life*

As residents age and journey through the retirement village they become increasingly aware of their proximity to the end-of-life. A fear of what the next stage might entail manifests in the need to perform in order to avoid, or at least stave off, being obliged to move into even higher-level support accommodation in the hospital wing of the village. To some extent it could be argued that this was also true for the independent residents who, when asked about the potential need to relocate into the supported living areas, responded that if they stayed well and active they would not need to move. Supported living residents feared major deterioration or a serious fall that they believed would put them at risk of being transferred to the hospital. The devolvement of responsibility enabling retirement villages to undertake regular assessments of their residents<sup>9</sup> enables a strong emphasis on the surveillance of residents. This includes changed assessment practices (Campbell, 2004) for the health and care professionals of the village and reduces residents' self-governance, potentially creating more resident anxiety regarding the need to produce a healthy performance.

As other studies have demonstrated it is common for people to only consider their end-of-life when, because of serious illness, they feel they have no option to do otherwise or when life dissatisfaction reaches a point where death may be seen as preferable. Even though many of the residents who were receiving relatively high levels of support services spoke of being resigned to death, the manner and location of their dying continued to hold fear for them as they had little or no information (other than shared anecdotes) about the transition experiences involved

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<sup>9</sup> See New Zealand Ministry of Health 'National contract for age-related residential care between district health boards and aged residential-care providers'.

in a move to the hospital wing of their retirement village; a place that symbolised their final demise.

For independent residents, for whom the hospital was largely out of sight, the availability of the hospital facility provided reassurance and security, but for the supported living residents, located in the same building as the hospital wing, it represented further loss. In the interviews with residents in the supported living areas references were made to people (unknown to the respondents) in the village hospital. These people were described as extremely frail or unable to communicate because they were suffering from dementia. As Marion declared, ‘.. **you would need to lose your mind before such a place could be bearable.**’ Some residents said they knew of people who had “been placed” in the hospital and had died shortly afterwards. Others described the hospital as the last location on a downward trajectory, or, as one resident described it, ‘**the last resting place**’. None of the interviewees spoke of the hospital as a place of healing; a place where people received medical treatment and then returned to their own accommodation. In the wider community, the meaning of hospital is constructed around regaining health. From respondents’ narratives and perceptions it would appear that the retirement village hospital is inappropriately titled *hospital* as its function was perceived closer to that of a hospice. Renaming the facility as a hospice or high care facility is, however, unlikely to be adopted by retirement villages as it would not complement the marketing strategies that emphasise health and active lifestyles.

### *The retirement village as a place of divide*

It may appear that the supported living areas of retirement villages are no different from any other aged care facility in New Zealand. Yet, whilst the experience of transitions involving the erosion of independence and autonomy might have been expected, a major finding of this study is the impact that placing all these features of ageing within one physical location (marketed as a positive aspect of choosing to live in a retirement village) has on the well-being of residents. All these levels of ageing and aged care support are located within close geographical proximity to independent residents and those requiring higher level support are located on each others doorstep. While prospective independent residents are attracted to the safety net of knowing that care is available if needed, when they initially sign up and are enjoying good health their lifestyle is far removed from the worry of needing daily support and it would appear from this study that they have no desire to become familiar with the high-level care areas of the village. The architectural and social divide between the living areas of independent residents and those in supported living accommodation certainly appeared to create additional social isolation for the supported living residents and this was compounded by the lack of opportunity they had to mix with more able-bodied people. This supports the findings of previous studies conducted by Leonard (2002), Simpson (2007), and Evans and Means (2007) , each of which found either a social barrier or a sense of intolerance between independent and supported living residents.

This study also found a distinctive social divide between the independent residents and the supported living resident beyond the physical separation of their living areas. Supported living residents reported this separation in terms of feeling unwelcome at the independent living



events as well as being the ‘**lesser interesting**’ residents in the village. On the face of it this appears to be a form of discrimination with independent residents choosing to snub those who are forced to make the move into supported living areas. Yet, the supported living residents, in turn, were reluctant to have any contact with residents experiencing even higher levels of care, such as those in the hospital; as one resident characterised them, ‘**the doolallies**’. It could be argued, then, that there is also a divide between the supported living residents and those residing in the hospital. Supported living residents had little information about the hospital wing but this did not appear to be because they had been refused information and, had they wanted to, they could probably have wandered into the physical spaces of the hospital or at least close by. Instead, they colluded with staff in masking the hospital function and did not appear to want to breach the boundaries or the divide that separated the two areas and groups of residents.

These divides within the village are suggestive of a form of sequestration which is practiced by the residents themselves – each group of residents sequestering those requiring higher levels of support. If, as a continual reminder of what is likely to come, the hospital holds a degree of fear or trepidation for supported living residents, it is not unreasonable to suggest that the supported living area holds similar fears for those living active lives in independent units. Unlike the supported living residents who were affected by the physical proximity of the hospital, the independent residents had greater independence and autonomy to choose to have only limited contact with supported living residents. Whilst it is probable that there were also organisational factors that made engagement unlikely, the lack of contact between the independent and supported living residents was not viewed as problematic for the active lifestyle. Likewise,

the supported living residents did not choose to have contact, or even information, about residents living and dying in the hospital wing of the village.

Retirement villages are designed to enable efficiencies in service provision by locating those with support needs close to the support service base and associated staff. It may also be the case that the promotional materials that influence people to buy a licence to occupy an independent unit would not be successful in promoting a lifestyle of independence and freedom if those who are clearly ageing and declining in health become more visible within the retirement village environment. However, supported living residents did reside in close proximity to the reception areas and some could be seen moving along the corridors with their 'walkers'. Thus, they were not all physically sequestered. Only the hospital residents appeared to be hidden from view. The experiences of village hospital residents and the care that they receive in the hospital as they approach their end-of-life would be an important study for the future and might serve to allay some of the fears of supported living residents.

Despite retirement village literature that markets an active lifestyle for older people with the safety net of packages of care if needed, these villages are clearly places of transition; a feature that is reflected in both the business model and the architecture of the villages. The business model succeeds if, within a few years of entering the village, independent residents relocate to the supported living area thus relinquishing their monies at a relatively reduced value that has no parity with the housing market. The license to occupy is just that, and is not the same as a market-linked purchase of a house or unit. When failing health necessitates a move to the supported living area of the village the resident must sell the licence back to the village (at a price that has not kept pace with market value) in order to relocate into a supported living unit and purchase increasing levels of packages of care. The supported living areas of the village

are, in all likelihood, subsidised in part by the income generated from the sale of the occupation licences for the independent accommodation. By the time they are in need of living support most residents' ability to buy out of the village has been seriously damaged by the economic commitment they made when they purchased the original licence (as evidenced by the concern of residents in this study to warn prospective purchasers to seek legal advice and to think very carefully before signing a contract with a retirement village).

In terms of architecture, whatever their level of support, retirement village residents reside within the boundaries of one physical location. The independent residents tend to be external facing and other than occasional visits to the village shop or services (such as the beauty salon) they enjoy lifestyles that draw on village activities, such as the happy hour, but are relatively independent. They tend to have little, if any, social interaction with the supported living residents, arguably preferring not to confront what they may well see as an unwelcome future. Likewise, supported living residents choose not to look at the hospital wing of the village, preferring instead to look back towards the independent areas of the village where their past and their memories are held, albeit that the proximity of this area serves as a continual reminder of a series of losses. Their separation from the healthy, mobile, independent residents created an environment where the supported living residents felt isolated within their own portion of the village, bounded by the walls of large blocks of accommodation with the reception areas, dining rooms and hospital enclosed within.

This suggests a social divide that is, arguably, created by the physical and organisational structure of the village with its separation of living areas based on the level of a resident's functional independence. From this study, independent residents appeared to view supported residents as embodying the very essence of ageing and decline that they did not themselves

wish to face. Supported living residents had no desire to spend time with residents who demonstrated extremely high-level care needs and they feared becoming a part of the hospital resident population.

### *Summary*

The findings from this study have revealed that relocation from independent living into supported living accommodation is a catalyst for a number of resident transitions. The initial transition requiring adjustment to a new and more sheltered (restricted) environment, is overlaid by additional discrete transitions that combine to create complex, often inter-dependent transitions across their social and private spaces. This increases the degree of adaptation and acceptance residents need to make within the village environment which, for some, is overpowering, exposing them to experiences associated with lost autonomy and independence that they are perhaps expected to adjust to (particularly by family and the retirement village staff).

Findings suggest that residents do not easily adapt, if at all, eventually becoming resigned to their impending death when their health is failing further and they believe they have nothing to look forward to in their future. While the resident's physical relocation into a supported living area indicates an immediate and pronounced change in environment and loss of established social connections, it is possibly better tolerated when residents have made their own choice to relocate, often having visited the supported living areas beforehand. The majority of participants in this study, however, were not in a position to make the choice for themselves,

being obliged to relocate as a result of decisions made by family, medical practitioners or the retirement village organisation.

Within each village studied, residents appeared to transition from a sense of well-being, independence and social connectedness at one end of a continuum, to a state where they lacked the independence and autonomy, social connections and personal space that are associated with well-being at the other. The physical spaces of the retirement villages, which co-locate independent lifestylers, supported living residents and hospital residents within one geographical location, means that these retirement villages were not microcosms of the wider society. Independent residents lived with the stages of decline being played out in close proximity to their own living spaces. Supported living residents were accommodated alongside the village hospital catching only anecdotal glimpses of life within, which led them to construct negative impressions of veiled accommodation that represented the place where they expected they would die.

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## Appendix 1 Field Research Materials and Supporting Documentation

### *Appendix 1.1 Semi- Structured interview guide*

List of topics to be covered and *examples* of supporting prompt questions.

Notes:

*i.) The prompt questions are for the researcher to pick up from the descriptions presented by the participant and they will not all be asked directly. This will be a matter for spontaneous discretion. It is expected that many of the questions noted below may be covered by the participant's account and replies to previous questions, and will therefore not need to be asked. The level of detail provided below ensures that significant broad areas of the study will not be missed. Also, to assist the Ethics Committee to assess the content in detail. This document will be drafted and formatted into an interview plan with associated guidelines for the interviewer.*

*ii.) If the participant takes a question in a different or unexpected direction, the researcher will explore that direction but will endeavour to avoid any prompting that might alter the participant' direction, or disturb their confidence and/or flow, but the discussion will subsequently be linked through to the next question..*

*iii) There will be an introductory "chat" to assist the participant to settle into the discussion, after the description of the process and after consent is reconfirmed and after the tape recorder is set up (whatever appears to be most appropriate at the time for the participant's comfort). e.g.: Light rapport building conversation and a recap of the previous meeting.*

#### *Research Question One*

1. What prompts the move from independent living into supported living? How is the decision made and who makes it?

**What are your memories of the time when you first moved into the retirement village?**

What was the presenting situation?

Who were the significant people mentioned?

What was the predominant reason for the move?

Did the resident want to move into the village? If yes, why?

**How did you come to live in this particular part of the retirement village? (For those in supported living only)**



What was the presenting situation?  
Who were the significant people mentioned?  
What was the predominant reason for the move?  
Did the resident want to move into supported living? If yes, why? If no, why not?

### *Research Question Two*

2. How do residents make sense of, and experience this transition? What are the short, and long term effects of the transition from independent to dependent living (particularly in terms of the resident's self-identity, and relationships with others) and how does this impact on their opportunity to age positively and retain their autonomy, for example, in relation to their end-of-life choices?

**What do you think about living here?** (*body language - gesture gently to the living area*)

**What help do you get now that you didn't have in your last place?**

Who are the significant people involved in the support?  
What is the nature of the support?

**Are there things in your life that have changed since you moved into this (unit)(room)?**

How does the extra support affect the residents' quality of life?  
How does the extra support affect the resident's perception of self?  
(Prompt questions if needed:  
What was life like before this!?  
Do you have friends and acquaintances in the village?  
Are you involved in the village's organised activities?)

**Do you think you have the same lifestyle since you moved in here?**

Do you see as many people as you used to, in terms of other residents?  
What are the differences living here and living in another part of the village?  
What are your thoughts now that you are getting more help living here?

**Have you had to *change* in any way, in order to feel at home (right here)(your unit)?**

**What do you think of, when you think about the word "independence"?**

What type of things does this bring to mind for the resident?

**How independent do you feel here?**

Does this feel more or less independent than your previous unit / room / house?  
Is it the right amount of independence for you? In an ideal world, would you like more independence, less independence or is this situation just right?

Does the participant feel “shut away” or kept out of the mainstream village activities?

**Do you have all the freedom that you want? Can you come and go as you like  
Do you ever get bored or do you find your days are full?**

How do you keep yourself occupied?

Can I ask what sort of things you do in a “typical” day?

Does the resident see many people in a typical day?

Activities (external to living space) Activities (within living space) Activities (in the village)?

**In an ideal world, is there anything you'd like to do that you can't or don't do since you lived here?**

**What advice would you give to someone else who was thinking of getting more support and (coming to live)(living in) in this part of the village as you do?**

**Have you got any particular plans for the immediate future?**

What do you think you'll do next? Would you like to live here in this unit/room indefinitely?

**What about in the longer term?**

**Do you expect anything to change in the future?** If yes, what does the resident expect to change?

Why does the resident expect that to change?

What or who might cause things to change?

### *Research Question Three*

3. Do residents in supported living environments perceive themselves to be close to their end-of-life and if so, have they indicated their end-of-life preferences to family, staff, and have these preferences been recorded?

**What do you think you'll be doing in (one), (ten), (twenty) years time?** (strong discretion)

**Do you think you'll live here for the rest of your life or would you like to live elsewhere later on?**

**Do you ever think about being ill or needing more support for your daily living?**

Is there any particular situation you'd like to be living in then? What would be your ideal situation, say for example, if you were ill.

**What does the term 'care' mean to you?**

Does the resident think of nurses and care staff, or family members and personal things?

**What do you think is an “ideal situation”, when you need to be cared for?**

**Do you ever think about being closer to the end of your life, than say, a 21 year old is!**

If yes, what things are important to the participant?

If yes, what things are significant to the participant and why?

**Have you ever wanted to talk to anyone about (this)(these)?**

If yes, has the resident done so?

Who does the resident talk to about these things?

Broadly (only) what types of matters or concerns are discussed by the participant and with whom? (*Note - If the participant moves into detail of private matters the researcher will redirect the discussion gently, back to general terms*) eg: “We need to stop for a moment, you can't tell me that, its your private business!.. Let's talk about.....  
“

**Do you think that your end-of-life wishes /requests are written down / recorded satisfactorily for you? Do you think that your needs and wishes are known?**

Does the resident believe that all their wishes would be known and met.

*Research Question Four*

4. How do residents in supported living environments define, experience and value their personal space in terms of their new ‘home’ environment, personal belongings, privacy, etc.?

**When you think of the term “home”, what sorts of things come to mind?**

**Do you think you have any more or less privacy, living in this space, than you had living in your last (unit)(room)(house)?**

Physical location / accessibility? Light? Noise? Smells? Comfort? Bedding? Furniture?

**How does that suit you?**

**Are you satisfied with the amount of space you have for your belongings?**

**Has this changed since your move into this (room) (unit) (house)?** If yes, how has the resident adjusted to that?

How did you deal with that?

**Would you like to have any more room, (or a smaller place) or is this just right for you?**

**Do you have anything you can think of that you'd like to see changed here?**

Does the resident feel any sense of annoyance, disturbance or dissatisfaction with their living space (i.e.: physical living space) ?

**What are the best things about your living space?**

**Would you recommend this particular living area to someone moving in?** (Partial repeat question but asked within a different context).

**What advice would you give to someone thinking of moving in where you live, in terms of the space and general living environment?**

**Is there anything you'd suggest they need to think about first, before they finally decide to move here?**

**Do you feel good about living here?** If no, then realistically, what would your ideal place be?

Does this living arrangement meet the resident's expectations?

**What do other people think about you living here? (Your friends, family etc.)**

**Do you get many visitors?**

Is this a good thing or a bad thing to the participant?

*Note: The interview concludes by moving into a more general discussion about people, either friends and relatives mentioned by the participant in the interview or if this not forthcoming in the question above, by the researcher talking about the friendliness of the staff or some other positive comments she's noticed about the general environment.*

**Is there anything else you'd like to talk about before we end our interview?**

Note: The researcher will then recap on the process that will occur from this point on, as follows:

The researcher will thank the resident verbally and express gratitude for the contribution the participant has made to the study.

The researcher will ask the resident how he/she found the interview and check their comfort level. This will include handing the resident a handwritten card of thanks,

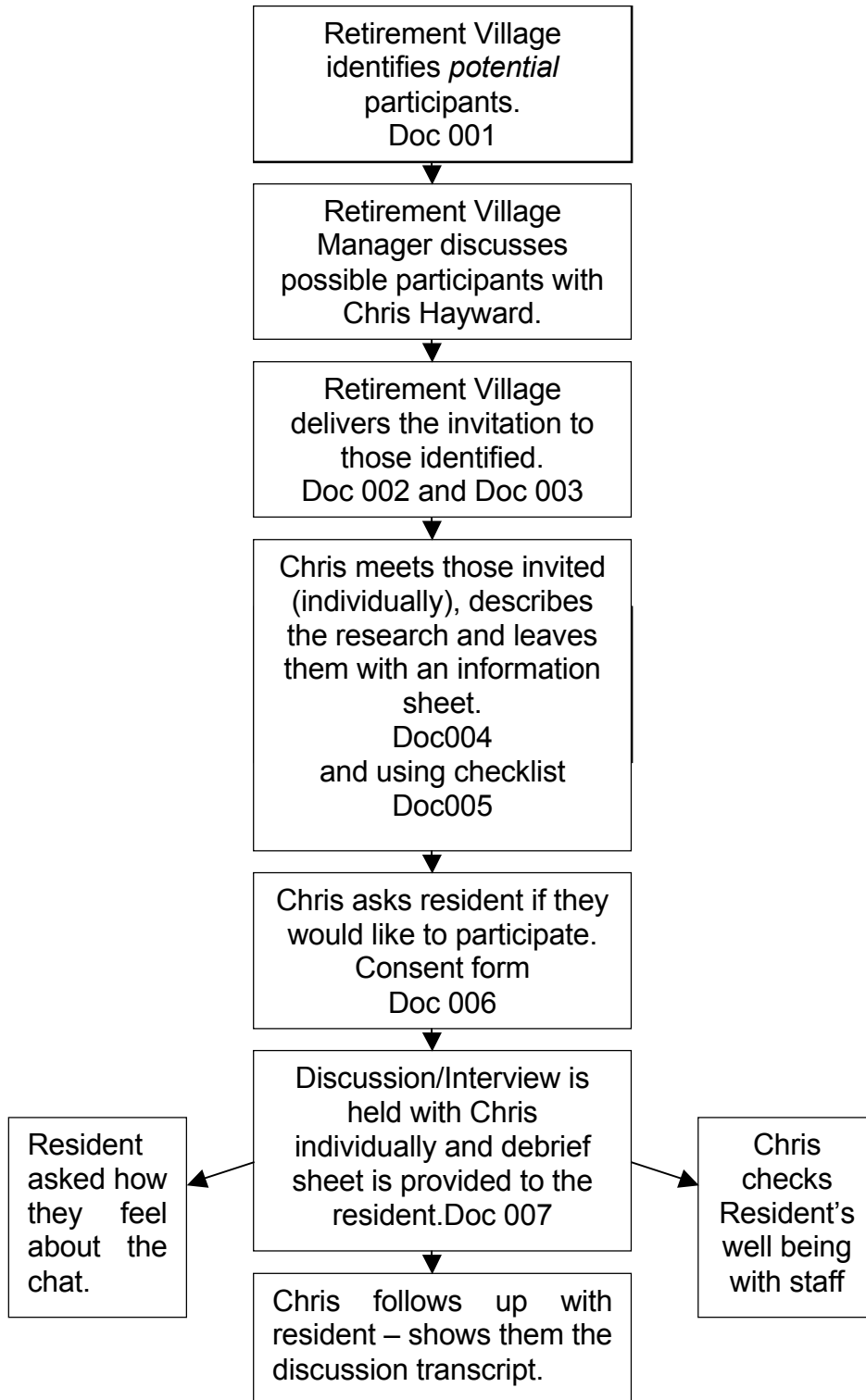
containing the researcher's contact details (and the supervisor's) and a verbal comment that it would be helpful if they tell the researcher or talk with someone else if they feel upset or worried by the discussion. The researcher will further advise the resident that an arrangement can easily be made if the resident would like to talk to someone else or have some assistance such as counselling and the researcher will *briefly* explain the benefits of this if it should be needed.

The researcher will write up the transcript from the interview and will arrange a time to return, show it to the resident and give the resident time to change /add anything that they wish to.

The researcher will ring the resident the following day (but not after 6pm), or at a time convenient to the resident, to see that they are still comfortable with the process and the event.

Appendix 1.2

Figure 0-1 - Retirement Village Transitions – Process Chart



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### Doc 001

**Study:** Supported living within retirement villages  
**Researcher:** Chris Hayward

#### **Steps required to ensure that all potential research subjects living in a fully serviced environment are competent to give their informed consent.**

Potential research subjects need to be freely able and competent to give their informed consent to their participation in the study if they so choose. To ensure that any resident showing an interest in the study is competent to give their informed consent, consideration **MUST** be given to each of the following factors when deciding which residents will be approached within a supported living environment.

*For the purposes of this study, a “supported living environment” is a living space where a resident requires on-going daily and active support or intervention to manage their daily living tasks, such as bathing, meal preparation, toileting and / or food shopping.*

In broad terms, the resident must have the ability to understand the request to participate in the study, they must have the ability to read and understand what is being asked of them and they must have the ability to make a sound decision that is based on an understanding of the potential risks involved in a research study such as this. Talking about one's experiences, transitions and lifestyle changes presents a slight risk of emotional concern, stress or distress. All participants must have a reasonable degree of “robustness” (similar to that of any other independent person) to participate in this study.

Specifically:

1. The resident must have consistently indicated the ability to use their own reasoning to make sound decisions about participating in other activities and/or any significant matters that may be likely to impact on their own well being.

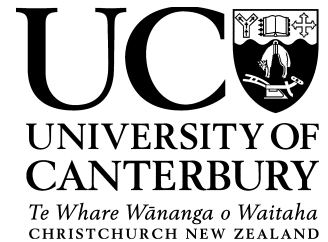
2. The resident must have indicated an ability to read, comprehend and assimilate written material such as letters, newspapers and/or books and to hear, understand and respond independently in verbal communication.
3. The resident must have shown that they are able to consistently make reasonable choices for themselves.

*Thank you very much for applying the above criteria carefully before approaching residents.*



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Doc 002 Invite to those in Independent Living

(Date)

Dear Sir/Madam,

My name is Chris Hayward and I'm carrying out a study of retirement village living. This is a research project for my Master of Arts Degree at The University of Canterbury.

I am inviting you to help me with my study, by giving me an hour or so of your time to talk with me about your experiences of retirement village living and any changes that you've experienced personally, relating to your home and daily living, during the time you've lived within the village.

This may include things to do with your living environment and village life, any support or input you have had from other people in order to carry out your daily tasks, like getting around and any other things about your home environment that are important to you personally, in your daily life.

To do this, I'm inviting you to have an initial chat to see whether you'd be willing to get together and go through a research interview with me. I can tell you more about my study at this initial meeting and then find out if you'd like to participate in the interview.

If you'd like to accept this invitation to have an informative chat about the study, our discussion would be strictly confidential, so your name and contact details, including your address, would not be given to anyone.

This means your information is not disclosed to any other resident within the retirement village or any of the staff and management team of the retirement village.

Thanks for letting me know whether you are able to accept my invitation to chat with me about this and I hope to meet with you soon at your convenience. I can be contacted at the phone number below or by email.

Kind regards,

Christine Hayward    [Tel: 0226591523](tel:0226591523)    [Email: chris\\_hayward@xtra.co.nz](mailto:chris_hayward@xtra.co.nz)

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(Date)

**Doc 003**

Dear Sir/Madam,

My name is Chris Hayward and I'm carrying out a study of retirement village living. This is a research project for my Master of Arts Degree at the University of Canterbury.

I am inviting you to help me with my study, by giving me an hour or so of your time to talk with me about your experiences of retirement village living and any changes that you've experienced personally, relating to your home and daily living, during the time you've lived within the village. I'm also interested to find out about any moves you have had between different living areas or from an apartment into another part of the village where you may receive more help with your daily living tasks.

This interview may include things to do with your living environment and village life, any support or input you have had from other people in order to carry out your daily tasks, like getting around and any other things about your home environment that are important to you personally, in your daily life.

To do this, I'm inviting you to have an initial chat to see whether you'd be willing to get together and go through a research interview with me. I can tell you more about my study at this initial meeting and then find out if you'd like to participate in the interview.

I have asked your Retirement Village Organization to pass this letter to you, but any discussions you have with me will be strictly confidential, so your name and contact details, including your address, would not be given to anyone. This means your information is not disclosed to any other resident within the retirement village or any of the staff and management team of the retirement village.

If you'd like to accept this invitation to have an informative chat about the study, you would tell XXXXXXXX (staff name). With your agreement, they will let me know whether you are able to accept my invitation to chat about this and I hope to meet with you soon at your convenience. Alternatively, I can be contacted at the phone number below or by email.

Kind regards,

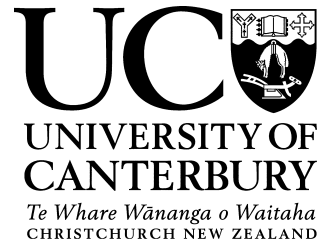
Christine Hayward

Phone: 0226591523

Email: [chris\\_hayward@xtra.co.nz](mailto:chris_hayward@xtra.co.nz)

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*Verbal prompt description of the study for the researcher's use when describing the project to residents. This document will be left with the resident after an initial meeting and verbal description of the research.*

### Doc 004

Information about my study of supported living in retirement villages.

My name is Chris Hayward and I sent you an invitation asking if you'd like to participate in a study I'm carrying out. This is looking at retirement village living which is my research project for a Masters Degree I'm undertaking at the University of Canterbury.

I am inviting you to help me with my study by asking you to give me an hour or so of your time to talk about some of your experiences and any changes that you've noticed in your quality of life over the recent years. I am specifically looking at the changes and transitions that people experience in retirement villages and this can also include end-of-life matters.

I would like to know your opinions and thoughts so that I can understand more about any changes in your quality of life and living arrangements since the time you moved into the retirement village. There are no "right" or "wrong" answers to the questions I will ask you. The study is seeking to gather information on various aspects of village life. This includes your home environment, any support you may want or need and to find out what you think of living in the village. The study also asks questions about the future to learn more about your perspectives on any future needs.

Unfortunately, the research can't help individual residents, personally, to obtain extra help if that is needed. This is because it is a confidential study about your personal experiences, so the content of the interview isn't disclosed to anyone. Yet, the research may help retirement village residents in the longer term by describing some of the good things and some of the less helpful things about living in a retirement village.

The discussion and interview will be held with me and it will take approximately one to one and a half hours but you will be able to end the interview at any stage and leave

out any questions that you may not wish to answer. I will have a set of broad questions in front of me and will record your opinions and experiences. I may ask additional questions that are small prompts, to help me to understand your point of view more clearly. With your permission, the interview will be tape recorded and then I will go away and type up our discussion. You will then have the opportunity to read through it and make any changes that you want.

You would be able to say as little or as much as you like to me and I would ask the questions in an informal, relaxed and friendly manner and with the greatest respect for your experiences.

Most interviews are comfortable experiences, but occasionally, talking about personal experiences with a researcher can cause unexpected feelings of distress or concern. If you find that any part of the interview has been upsetting to you or if you find it becomes a worry in the future, there will be someone available who can talk with you about it. Counselling can also be offered if you decide you would like to talk through your thoughts or feelings after the interview experience.

If you are willing to take part in this study we will hold the interview in a place of your choice in the retirement village. You might choose to meet with me in your own living area or in a public area of the retirement village.

The research is being undertaken independently from any Retirement Village Organisation and your input would be strictly confidential, so your name and contact details, including your address would not be given to anyone else. After the interview, I remove your name and use a number to identify the information and the written thesis uses a fictitious name for your information, so that you cannot be identified.

If you mention particular places or people or such-like, they will also be renamed so that none of the information can identify you.

Thank you for taking the time to meet with me and to consider participating in my study. I really appreciate you taking the time to do this. With your agreement I will get in touch in a couple of days time to find out if you would be willing to go ahead with the interview.

With all best wishes,

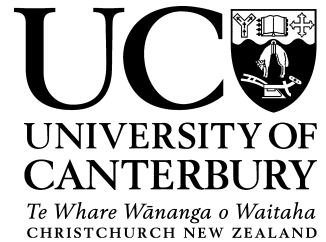
Chris Hayward`

Tel: 0226591523

Email: [chris\\_hayward@xtra.co.nz](mailto:chris_hayward@xtra.co.nz)

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**Note: This is a prompt sheet for the researcher. It is not a form for completion.**  
**DOC 005**

**Study:** Supported Living Within Retirement Villages  
**Researcher:** Chris Hayward

### Researcher's Checklist

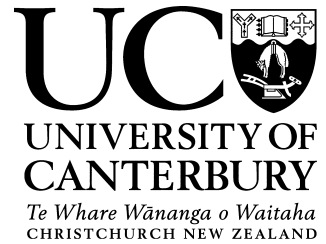
#### Indicators of competence to give informed consent.

1. The resident showed no indicators of nervousness or unease after the initial introduction.
2. The resident did not appear overly willing to participate in a manner that appeared ill considered.
3. The resident read the information sheet and was able to reflect back the information under discussion.
4. The resident asked questions that appeared positive and did not indicate concern.

*If the researcher has any reservations, the resident will not be chosen to participate.*

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**Doc 006**

### **CONSENT FORM**

**Study:** Supported Living Within Retirement Villages.

**Researcher:** Chris Hayward

**Contact Address:** School of Social and Political Sciences,  
College of Arts,  
University of Canterbury,  
Private Bag 4800  
Christchurch 8140

**Date:**

I have read and understood the description of the above named study. I agree to participate in this research and I consent to the publication of the results of the study on the understanding that my anonymity will be preserved. None of the information that I have given will have my name attached to it once the interview notes are written up.

I understand that sometimes, talking about personal experiences can bring up unexpected feelings or concerns. If the research interview causes me any concerns or distress, I will be able to talk with someone about this, including a counsellor if I request this service.

I understand that I may withdraw from the study at any time and that I may withdraw any information that I have provided if I chose to do so.



**I have noted that the study has been reviewed and approved by the University of Canterbury Human Ethics Committee.**

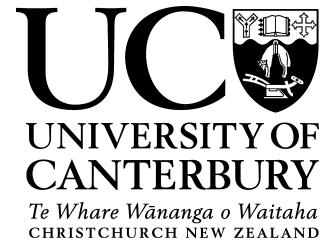
**Name: (Please Print):**.....

**Signature:**.....

**Date:**.....

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DOC 007

### Supported Living Within Retirement Villages : Debriefing Information Sheet

Thank you very much for taking part in my research into supported living in retirement village.

The main objective of the study in which you just participated is to explore the nature of retirement living changes and transitions and to gather the views and experiences of residents who move into supported living environments within retirement villages. This includes finding out about social networks, home living environments, any associated support needs and can include end-of-life preferences and decisions.

Most interview experiences are enjoyable and interesting, but occasionally, people can become worried or upset after talking about some things that are personal to them. If you find that any part of the interview has been upsetting to you or if you find it becomes a worry in the future, please will you let me or a staff member know? There will be someone available who can talk with you about any upset the interview caused you or any concerns it raised for you. Counselling can be offered if you would like to talk through your thoughts or feelings about the interview experience.

I hope the interview was a pleasant experience for you and thank you again for participating in this project. Without you, my research project would not be possible. Your involvement will help me to better understand the experiences of retirement village residents.

Kind regards,

Chris Hayward

Masters Research Student, University of Canterbury. Tel: 0226591523

## Appendix 2

### *The Research Participants - Characteristics*

<b>Name</b>	<b>Living Situation</b>	<b>Age</b>	<b>Years in Residence</b>	<b>Gender</b>	<b>Relationship Status</b>
Barbara & Alan	Independent Unit	73 & 79	10 yrs. & 10 yrs.	Female & Male	Couple
Carol & David	Independent Unit	83 & 88	6 yrs. & 7 yrs.	Female & Male	Couple
John	Independent Unit (his partner lived in the retirement village hospital)	87	6 yrs.	Male	Couple
Alex	Supported Living Unit	84	8 yrs.	Male	Single Widower
Susan	Supported Living Unit	93	2 yrs.	Female	Single Widow
Janet	Supported Living Unit	68	1 yr.	Female	Single Widow
Emma	Supported Living Unit	90	10 yrs.	Female	Single Widow
Brian	Supported Living Unit	88	11 yrs.	Male	One of a Couple, living in separate Supported Living Units
Diana	Supported Living Unit	89	12 yrs.	Female	Single Widow
Marion	Supported Living Unit	87	11.5 yrs.	Female	Single Widow

**Figure 0-2 - The Research Participants**

## *The Research Participants*<sup>10</sup>

### **Barbara & Alan**

Barbara and Alan moved to their independent unit from their house in the local community. They had lived in their retirement village for ten years and still enjoyed an active lifestyle, noting a full calendar of social events and many travel plans. They described two circles of friends, those within the village and those in the wider community who were members of their local interest groups. Both Barbara and Alan were fully mobile and active with no mention of physical limitations.

### **Carol & David**

Carol and David had met each other within the retirement village and each had their own independent unit. They preferred to live in each unit seasonally, choosing the unit that afforded the greatest warmth and sunlight in the summer and winter months. They had many friends and a strong social circle within their retirement village, some of whom they had known since they moved there. They were both physically mobile, though David walked slowly with a walking stick. Carol was still fully mobile and assisted David with his mobility when needed.

### **John**

John had lived in his independent unit for eight years, and up until the last two years had lived there with his wife, until she was relocated into the retirement village hospital due to her failing health. Together they had an active social life within the village but John now spent much of his time visiting his wife in the hospital, a few hundred yards from their independent unit. He walked with a stick but was able to visit the hospital independently, usually three times a day. He received four hours of home help each week from an external provider, mainly to assist him with his housework. He was able to manage his own cooking and shopping and said he had now learned how to prepare his own meals.

### **Alex**

Alex lived on his own, having moved into the retirement village from his own home in the local community when his wife died eight years earlier. He had not experienced independent apartment living within his retirement village but had relocated directly into a supported living unit due to his increased support needs and his family considered this to be the best choice for him. He did not have a social life within the village and described his situation as 'isolated', seeing his grandchildren occasionally and going to stay with his family once a year for the Christmas period. He was mobile with a walker, and had suffered two strokes that had affected his short-term memory. He received his meals in the dining room and received help with showering, toileting and other personal needs.

### **Susan**

Susan moved directly into her supported living unit two years after she was widowed having had a number of falls in her own home. She had relocated between hospitals and rest homes a number of times before moving into the current retirement village where she had spent a month in their hospital following a fall. Her daughter had found the accommodation for her. She did not have an active social life and spoke of herself as lonely, although she did have one friend who visited her

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<sup>10</sup> The names of residents are pseudonyms in order to retain anonymity.

occasionally from the local community. She also went out with her daughter once a week. She described herself as 'very handicapped' but was able to walk slowly with the aid of a walker and a support person. Her hearing was impaired but she reported that her hearing aids did assist when the batteries were charged. Susan took her meals in the dining room and had assistance with most daily living tasks, although she was able feed herself.

### **Janet**

Janet was at an earlier stage of life to the other study participants because she was sixty-eight years old and had moved directly to a rest home unit within her retirement village following a significant illness. She had previously lived in her own home but illness had prompted an urgent need for daily living support when she was discharged from hospital. Her daughter had found the accommodation for her. Janet did not participate in the structured social activities within the village but she did visit friends, both within the village and in the wider community, using the retirement village mini-bus to visit the shops. Although she said she was close to her daughter but reported a wish to retain her independence, having been dependent on her daughter throughout the period of her illness. She had recovered her health to a level where she could now go about her day relatively independently and her daily living support needs had reduced to three mornings each week (provided by the District Health Board rather than the retirement village) for showering, dressing and medical nursing.

### **Emma**

Emma and her husband had moved from their own home into an independent unit within the retirement village where they had lived for two years. She was one of the first residents to move to her village when it opened. They had enjoyed an active social life within the village community but after her husband died she had relocated into a supported living unit on medical advice. She had spent a further eight years there during which time her hearing and eyesight had deteriorated. Her social activities had largely ceased and she had very few remaining friends, although she attended presentations occasionally when visiting speakers came to the village. She relied largely on her daughter who managed any issues that arose regarding her care, and she went for outings with her daughter occasionally. She received support for all of her daily living needs, including showering, dressing and toileting.

### **Brian**

Brian had lived with his first wife in his own home until the year after she died. He then moved a few hundred kilometres away to assist a female friend whose health was deteriorating. The two of them subsequently returned to his local area where they lived together in his community. After a number of years they relocated to an independent unit in the retirement village where they remained for five years. Brian's health had begun to deteriorate and they had both received living support three days a week. It was Brian's own choice to move into a supported living unit where, at the time of interview, he had lived for six years. His unit was within sight of their original independent unit. His partner had also moved into her own supported living unit in the same area of the village, so they were now living 'down the corridor' from one another. Brian had enjoyed an active social life in the independent unit but his hearing and mobility had gradually diminished and he no longer used the village mini-bus, although he continued to go out once a week to have dinner with his family. He also had friends who came to visit him occasionally from their independent units. The support he received with his daily living included showering, dressing and toileting, and he took his meals in the dining room.

**Diana**

Diana had resided in the retirement village for twelve years after relocating from her own detached home in the community. She had initially lived for ten years in a 'townhouse' but due to illness and a short period in the retirement village hospital, she was told she should not return to her independent unit. She moved directly into a supported living unit from the village hospital and had been there for two years. She had experienced an active social life in her independent unit and now attended some of the activities available for those in the supported living units. She occasionally visited some of her friends in the independent units although she had lost touch with others. Her grandchildren came to see her infrequently and her remaining family members lived overseas. Her mobility had declined and she had significant eyesight impairment, which also limited her ability to socialise. She received daily living support to wash, shower and dress and she had her meals in the dining room, except for breakfast which she could make for herself in her own unit.

**Marion**

Following the death of her husband eighteen years ago, Marion had continued to live in her own home, eventually making her own decision to move into the retirement village. She had lived in an independent unit for eleven years until, again, by her own choice, she had relocated into a supported living unit where she had been living for six months. The relocation into her supported unit was prompted by two heart attacks and a number of falls, and her need for greater support and staff around to assist her. She had enjoyed socialising with her neighbours when she lived in the independent unit but now had few visitors. She did occasionally visit one of her previous neighbours who still lived in an independent unit, but had found it difficult to make friends in the supported living area of the village. Although her mobility had reduced, Marion was still able to walk using her walking frame. She prepared her own breakfast and dinner in her unit but attended the dining room for the cooked lunchtime meal. Marion undertook her own bathing and was relatively independent on a day-to-day basis.