

# Strengths of Family Carers:

Looking After A Terminally Ill Adult

Under 65 years of Age



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By

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## Dedication

This research thesis is dedicated to my mother,

*Keri Patricia Coutts*

*1939- 2013.*

Keri was the lynchpin for our family, highly organised, extremely creative and engaged in a wide range of interests. Her top priorities were her faith, her family and her friends.

She keenly supported her children in their pursuits, was an amazing wife, mother and grandmother, an active member of her community.

She was my father's caregiver for the last six years of her life and through her final illness, taught us how to die, tended by the team at Arohanui Hospice, loved and cared for by her family, and cradled in the love and prayers of her faith community.

*Ad Dei Glorium.*

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Firstly, I would like to give thanks to my parents, Keri and Colin, who always expressed their support for the value of education. They were my first teachers, always encouraging me in my chosen career. They modelled the value of a support team and working alongside others to achieve one's aspirations and goals. Although they are no longer living, I know they would be delighted to see this piece of work reach completion. Thank you.

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Special thanks to my dear friend, Kate Bell for the photo on the cover page. The Caritas lamp was lit and kept vigil with the family as her husband was dying. Since mid-2018, they have been living the experience that I have been researching.

Finally, thanks go to Tim, my husband, and Joseph, Rachel and Lauren, the young adults of our life. Reciprocity in any relationship is always important and I have appreciated the myriad of ways you have accommodated my research in our lives. Thank you for all your support and encouragement for the duration of this research project.

## Abstract

Learning of a potentially terminal illness is devastating at any age. How much more so when in early or mid-adulthood, busy with dreams of family and career goals. This research project investigates the experiences of bereaved family carers who companioned their husband/ wife through their illness and dying. Each spouse was under 65 years of age, a time at which people are eligible to retire from the paid workforce in Aotearoa New Zealand. This is an age group whose voice is virtually invisible in the palliative caregiving literature. Yet, one in every five people die in New Zealand before 65 years of age. For Māori, almost half will die under the age of 65 years. There is a story to be told.

This research sought to explore the strengths that underpinned and sustained family carers through the illness and death of their husband/ wife. It utilises a social construction methodology which fits well with a social work perspective. Through thematic analysis of the narratives, themes emerged of the medical circle of care, the home circle of care, saying goodbye and picking up the threads. Further analysis revealed strengths of love, hope, family, teamwork and resilience. Finally, some suggestions are made to develop palliative care services in order to better meet the needs of family carers.

Key words: family carers, palliative care, under 65, social work, strengths

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## Key to Transcripts

*‘Italics’* ..... Voice of the family carer

(...) ..... Text has been left out of the narrative

[...] ..... Text has been inserted to give context to what is being read

## A Note about Terminology

Throughout much of the caregiving literature, both the terminally ill person and their carer are referred to as the patient and caregiver, thus locating them firmly in the medical world. In this research project, a conscious decision was made to locate the unwell person and the family carer within the context of their world. It is a reminder that they are people first and foremost, with interests and experiences well beyond that of the medical domain. It is only as a consequence of ill health that their identity and being is changed and they become known as patient and caregiver.

## Chapter 1: Introduction

Caring for someone we love at home during serious illness is something many people might anticipate as they grow into their senior years. This may come with romanticised notions of adult children, grandchildren and an assortment of close friends supporting and being present, fondly recalling memories of times past and a life well lived. Sadness intermingled with the knowledge that the person we love has 'had a good innings' and 'we all have to go sometime.' Some will have thoughts of companioning a loved one through their final days as they become increasingly frail; gently letting go of this world and all that has made up the fabric of their life on earth. This image evokes warmth, a cushioning of love and laughter, a knowing of the anticipation of loss, and a continuation of a legacy of memories saturated in love that will last long through the generations of family bonds.

But what if ... what if the news of terminal illness comes visiting a family long before they are ready. What if this occurs as a young person embarks on life independently from living at home with their parents, experimenting with ideas of who they are and their place in the world? What if this occurs in early adulthood as milestones of career, marriage, family and a mortgage are in their infancy? What if this occurs in mid adulthood as attention is focused on the busyness of family life and striving to attain long held dreams and career aspirations? What if this occurs in the years between raising a family and retiring? What then? What are the images that appear in one's mind as each of the above scenarios are contemplated?

For this is the reality that many people face as they traverse through adulthood in Aotearoa New Zealand. McLeod (2016) identified that 22% of all deaths between the years of 2000 and 2013 occurred to those under 65 years of age. Ministry of Health (2014) data highlights that 48% of Māori die under 65 years of age. For this group of people, there is no retirement, there is no imagining of a long life fondly remembered through the mists of time. For this group of people, there is the immediacy of illness intruding, interrupting and disrupting the plans of their lives, their hopes and dreams of the present and the future. For this group of people, a new reality has entered both their lives and the lives of those whom they hold dear, as they work to adapt, accommodate and accept the news of serious and terminal illness and all its attendant implications.

My earliest memory of death was just before my third birthday in the late 1960s. My sister died of meningitis at six months of age. Her death is the silver thread of sorrow that traverses through the months and years of our family memory, always a silent yet never forgotten presence at family gatherings and celebrations. Her death was the catalyst for my own entry into the social work profession as a young adult and on into palliative care in 2007, where I continue to work. The legacy of her death carried with it the hope and intention that support is available for families who lose a

family member, no matter their age and stage of life. Her death is the thread that continues to silently echo into our lives, the rawness of loss and bereavement again exposed during the illness and death of our parents over the past six years.

As a palliative care Social Worker, there have been times when it seemed that every other week a person under the age of 65 years was referred to Nelson Tasman Hospice for palliative care support. In working alongside this cohort, I became increasingly aware of some of their needs, some of which I considered were specific to their age and stage in life. It was only when listening to a presentation by Heather McLeod (2016) at a University of Canterbury block course and seeing her statistics on the number of people who died before the age of retirement, that I began to think maybe there was a much bigger picture to the deaths of this age group than that which I saw in my day to day work. Thus, began an exploration of delving into the lived stories of those who cared for a family member who died under the age of 65 years.

This research will explore the strengths that underpin and sustain family carers who are looking after a terminally ill adult under 65 years of age. It is intended to primarily focus on the experience of bereaved carers who have lived the experience of caring for their unwell spouse/ partner/ ex-partner. It is an opportunity to gain an understanding of their experience of living with a spouse/ partner who is terminally ill. Through this, new insight into the needs of family carers may be revealed. It is hoped that these insights will guide the development and provision of palliative care services that support and maintain the ability of family carers to continue to operate from a place of strength.

While those who work in palliative care 'bear witness' to the experience of those we meet in a professional capacity, companioning the families we work with; in the fullness of the experiences encountered by those who are unwell and their carer, we are merely the traffic conductors signalling possible paths to travel. Rather, it is the family carers who 'bear witness' to the experience of their husband/ wife throughout their illness. They are the ones who hold onto the fullness of the personhood of the one whom they live with, even when this is masked by illness induced behaviours. They are the ones who are relied upon to be the primary carers, holding and juggling a multiplicity of information, roles and responsibilities that were once shared between the couple. They are the key cheerleaders in times of good news and a source of consolation on the tough days. The family carers in this research are the constant figures who choose to be present to support and care for their unwell husband/ wife. They are the ones who have a ringside seat to the inner world of their unwell spouse and all they are going through. They are the ones negotiating their own wellbeing and knowing that only one party will come out of this experience alive.

Historically much of the focus on research with family carers has focused on the difficult aspects of caregiving and terms such as 'caregiver burden', 'caregiver distress', 'personal costs', 'stigma', and 'vulnerability' abound. (Hong & Harrington, 2016; Stajduhar et al., 2010; Tanco et al., 2017; Unson, Flynn, Haymes, Sancho, & Glendon, 2016). Whilst these factors are real and do occur, an emerging voice is calling for the positive aspects of caregiving at end of life to be researched, arguing this provides a more comprehensive and nuanced description to the actions of family carers. This research adds to that voice through the identification of strengths that underpin and sustain the actions of family carers engaged in looking after their terminally ill spouse/ partner.

### Overview of research

This thesis consists of five chapters. Chapter 1 sets the scene introducing the research topic and gives an overview of the research itself. For those who are unfamiliar with social work, some background to the concepts of the social construction of social work, strengths-based practice, the ecological perspective and health and welfare policy in Aotearoa New Zealand is provided, setting the scene for the research.

Chapter 2 delves into the literature reviewed in relation to caregiving. The themes identified in this chapter are the politics of caregiving which covers two subthemes; the ownership of end of life care and perspectives in caregiving. Family caregiving as a research priority, interpersonal aspects of the family carer role and home-based caregiving of people who are terminally ill round out the themes within the literature. Given the breadth of literature available, a decision was made to primarily focus on literature published after 2010, unless there was a compelling reason to include data published prior to that date.

Chapter 3 provides an outline of the methodology and method that underpins the research. This is qualitative research using a social construction methodology and life story interviewing. Ethical considerations are addressed in this chapter as well as the process of recruiting participants, data collection, and the process of analysing the data via thematic analysis.

Chapter 4 presents the key findings from the research analysis. The key themes in this chapter are the medical circle of care, the home circle of care, saying goodbye, and picking up the threads. Each theme has a series of subthemes which build a more comprehensive narrative from the individual narratives of each of the carers interviewed. The image that pulls these themes together is that of a river with each person having their own experience of traversing the nuances and idiosyncrasies of the river.

Chapter 5 leads with a discussion of ideas that underpin the themes from Chapter 4. These ideas are the circles of care, support for family carers, the experience of bereaved family carers, change in personhood, caregiving as a spiritual act, a model of bereavement, carer resilience and the strengths of family carers. The chapter continues with a discussion of implications for practice for palliative care social work, as well as acknowledging limitations of the research, and offering suggestions for further research and development.

### Background Information on Social Work

Palliative care Social Workers bring a different perspective to the end of life conversation from that of their medical and nursing colleagues. In order for the reader to understand this difference, this section aims to give a brief overview of the social construction of social work followed by a description of a strengths-based perspective for social work. This is a mode of practice that deliberately positions itself focusing on the capabilities and resources held by the parties involved. It demands collaboration with people, drawing out their stories, their truth, and their understanding of the world as they see it. This sets a foundation on which to build a pathway for positive outcomes that all parties are able to commit to.

The ecological perspective is presented as a framework for understanding the contexts of people's lived experience. Social Workers engage with people in their environment, and changes in one part of the environment affect other parts of the environment. An important skill for any Social Worker is to have a knowledge and understanding of the broader environment in which the people they work with live. To this end a brief history of health and welfare policy in New Zealand from the 1980s is presented. This illustrates a change from the universal provision of health and social security by the Government to a more market driven approach in the provision of these services. The impact of the reforms initiated in the 1980s has continued into the present day.

### The Social Construction of Social Work

Social work is a dynamic field of practice, constantly evolving as it seeks to meet the needs of the people practitioners engage with. There is no 'one size fits all' measure to address the many and varied needs of the people social work seeks to support and assist. The issues Social Workers are asked to address are often the same issues that arise in the wider community. Thus, the social construction of the profession gives emphasis to enabling people to making meaning of the world around them through storytelling and narrative. These stories are shaped by the norms and beliefs of

the culture storytellers find themselves in. Language, common understandings, and patterns of behaviour all contribute to the understanding of culture at any point in time. Individuals and society are constantly evolving and exerting influence upon one another, thus nothing is 'set in stone.' Rather it is a 'work in progress.'

Where the story of an individual or community does not fit with the mainstream narrative of a culture, they may develop their own counter story, which over time has the ability to shape and cause modification of the central narrative of a particular culture. As a profession, social work has the malleability to respond to change as it often aligns itself with those who are vulnerable and at the margins of society. (Parton, 2003; M. Payne, 2016; Saleebey, 1996)

Borgmeyer (2011) describes palliative care Social Workers as:

"Observant and inquisitive participants in the helping process, demonstrating both a knowledge of ethical principles as well as skills that help to identify and integrate spiritual beliefs, practices, and needs of individual patients, families, and intimate networks into the decision-making process." (Borgmeyer, 2011. p.615)

She places emphasis on the palliative care Social Worker being a 'humble learner' with each unwell person and family they encounter in order to enable them to provide appropriate support and assistance.

### Strengths Based Practice

The strengths perspective in social work is a way of honouring the people with whom Social Workers engage. It is based in Social Workers actively listening and learning from the stories they hear from those they work with. Through listening and hearing the accounts of individuals, families, groups and communities, Social Workers are able to learn what is important to them; what abilities and resources people bring to their narrative; what people may want to change; and more importantly, what strategies people may be willing to engage in.

This perspective in no way ignores or diminishes the challenging circumstances people may find themselves in. It is predicated on the premise that all people bring a valuable contribution to the interaction and through engaging in a collaborative process, outcomes beyond each person's expectations can be achieved. (Cadell, Shermack, & Johnston, 2011; Saleebey, 1996; Sullivan, 2012)

In order to achieve holistic helping, Saleebey (as cited in Cadell et al., 2011. p.219) draws the Social Workers attention to the CPR of strengths as shown in Figure 1. Through engaging in a strengths approach to social work practice in palliative care, this positions social work apart from the medical model which pathologises and medicalises what is occurring for many of the people Social Workers

meet. It is in the embracing of strengths-based practice in palliative care that the potential to support and encourage growth emerges. By asking questions that seek to identify critical moments or turning points which have helped people in their lives, attention is given to the wisdom and knowledge of the person telling their story. It is in the holding of space for people grappling with change that opportunities for growth can occur.

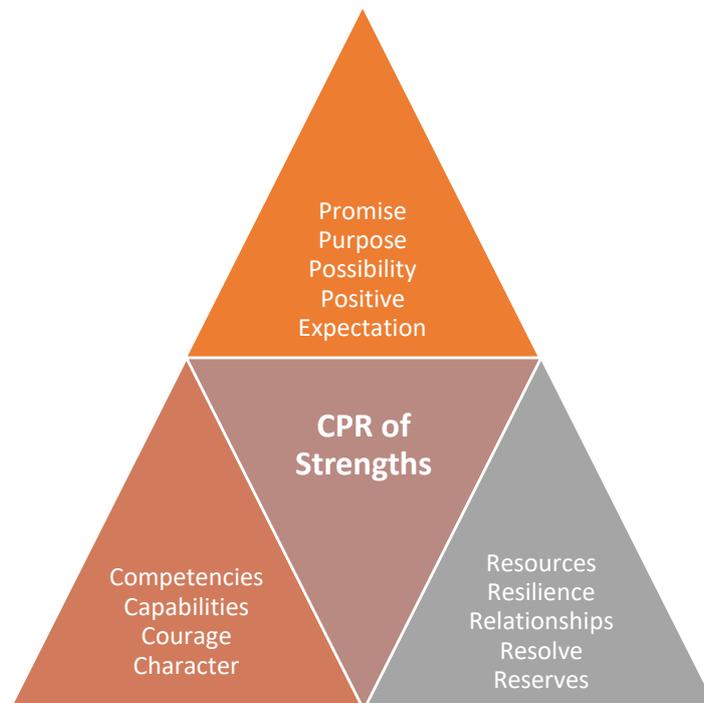


Figure 1: CPR of strengths

Madsen and Gillespie (2014) simplify conversations that help to identify strengths into three areas of inquiry:

- i) Enquiries regarding the activities that sustain people in their lives as a means to identify strengths as practices.
- ii) Searching to gain understanding of the intentions that underpin the activities people engage in. This includes gaining knowledge of their commitments, values, beliefs, hopes and dreams.
- iii) Establishing connections within the community to support people in maintaining and sustaining their strengths as intentional practices.

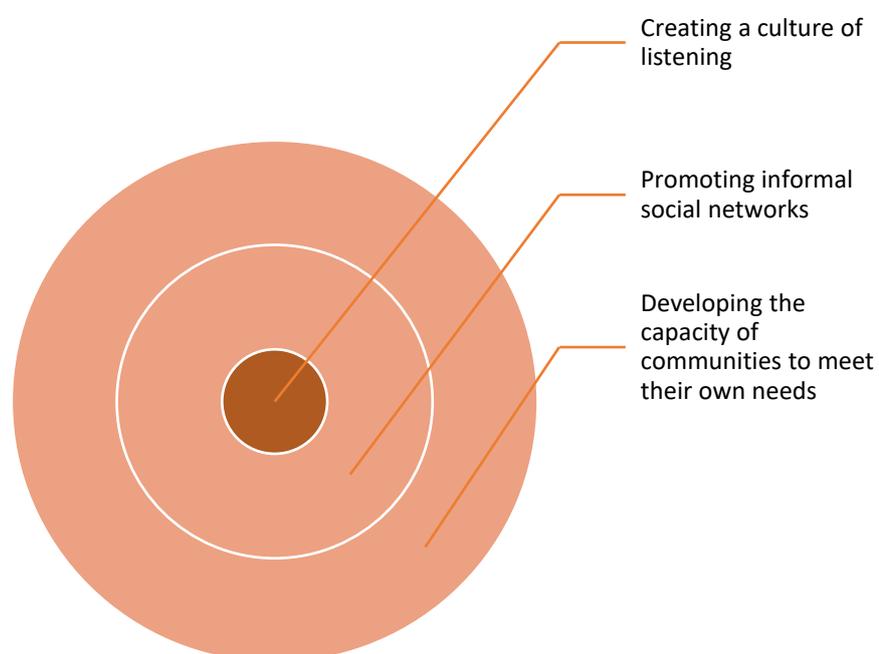
Research in the area of strengths in palliative care is an emerging field. In their research into post traumatic growth in a population of bereaved parents who had lost a child, Cadell, Janzen and Fletcher (as cited in Cadell et al., 2011) identified themes of new possibilities, a new way of relating to others, an increase in personal strength, greater appreciation of life, and the experience of spiritual change.

Nelson Becker (as cited in Cadell et al., 2011) examined strengths and resilience in older adults at end of life and identified themes of self, spirituality, social investment and independence. Continuity of care and the ability of professionals to be fully present with participants was seen as critical to nurturing growth.

Hughes (2015) explored the strengths caregivers brought to their role of caring for a terminally ill person. She identified themes of courage, determination, acceptance, humour and empathy. She found that as carers took ownership of their role and gave meaning to the choices they made, whilst respecting the cultural and structural dynamics of their own situation, they were able to navigate the transformation from being weighed down by caregiving to operating from their strengths.

### Ecological Perspective

For social work, an ecological perspective sets a framework whereby individuals and their environment are interconnected, so that the processes taking place within and between them all are interconnected (Bronfenbrenner as cited in Jack, 2012). In seeking to develop ecological social work practice Gill and Jack (as cited in Jack, 2012) propose intervention at three distinct steps.



*Figure 2: Ecological perspective of social work*

The first step involves listening to the stories of the people we work with. As people talk of the issues impacting them, many people include in their description an image of people, community and societal actions and influences they consider to be significant, and the connections between them.

The second step is to recognise and give attention to the personal sources of support people identified in their narrative. A useful way to graphically portray the relationships described is by way of eco-maps. This helps to visually identify strengths and weaknesses that exist within a person's social network indicating where specific intervention may be targeted.

The third step is to move to meet self-defined needs, wishes and hopes of individual people and groups through building on existing strengths. Associated with this for the Social Worker is an awareness of the social, economic, and demographic norms and policies and how they can impact on individual people and groups. (Adamson, 2005; Jack, 2012; Payne, 2016)

### Health and Welfare Policy in New Zealand

In order to have an understanding of the environment that palliative care Social Workers operate within, it is helpful to have an awareness of the changes that have occurred in both health and welfare policy in Aotearoa New Zealand since the 1980s. This background knowledge forms a foundation that reminds Social Workers that there are broader political issues that can and do have an impact on the individuals and families they work alongside. This knowledge underpins the efforts Social Workers make to address the issues they encounter every day.

Since the 1980s in New Zealand, government approaches to policy have taken a more market driven approach than previously. Hanson (as cited in Cheyne, Belgrave, & O'Brien, 2008) identified that during the establishment of the welfare state, a strong underlying assumption underpinned health care policy, recognising that all people were at risk of accident, illness or early death, so that social security was universally available to all.

However, during the market reforms that began in the 1980s and have continued into the current era, this assumption has been challenged and reshaped by various governments of the day. Cheyne et al., (2008) identify ongoing themes in health reform focus as cost savings, reorganisation of services provided, and a desire for community participation in planning health services. Some of the ideology behind the provision of health care shifted from the universal provision of healthcare for all, to focus on individual behaviour as a contributing factor to ill health; that includes smoking, obesity, alcohol consumption, lack of exercise and poor diet.

For those who view health care through the lens of structural inequality within society, health cannot be separated from the welfare of the people who live in that nation. Issues such as gender, ethnicity, poverty, employment, and the impact of poor housing on health, all have a consequent flow on impact to the access and use of health resources.

“Greater equality in health outcomes is seen ... as the consequence of better housing, better nutrition, and greater equality of income, and not just achieved through more equitable or more universal access to medical technology.” (Cheyne et al., 2008, p.216)

Easton (2008) identified the largest cohort of those who were unwell tended to have an average household income level. Through further analysis, those over 65 years of age were found to experience the poorest health across all household incomes levels. He argued that age was a more important determinant than income for poor health. Across all age groups, greater numbers of people with poor health were found to have low income homes.

These findings are supported by Pearce et al., (as cited in Hill, 2008) who found that:

“Occupational class and ethnicity were each independently related to risk of death: within the same occupational group there were clear mortality differences between Māori and non-Māori men, while a social class gradient was apparent amongst both Māori and non-Māori.” (Pearce et al., as cited in Hill, 2008. p.37)

Other policies that have impacted New Zealand over the past three decades include the drive towards ‘deinstitutionalisation’ and transferring the responsibility of caring for people with varying health needs to individuals and communities. ‘Community care’ has been a buzzword of the time epitomising the desire for more patient driven choice. The Cartwright Report (New Zealand Committee of Inquiry and National Women’s Hospital Auckland, 1988) continued to drive the issue of patient rights. By 1994, New Zealand had appointed a Health and Disability Commissioner; and by 1996 a Code of Rights for Consumers of Health and Disability Services had been developed. Issues of informed consent by patients undergoing treatment, and systems for greater transparency and accountability by medical practitioners for their actions, were instituted. The Community Services Card was introduced to assist those on low incomes and/ or with long-term health issues. Cheyne et al., (2008) described the impact these reforms had on the health system as experiencing a ‘managerial revolution’; and they continued on through the 1990s and beyond.

According to Cheyne et al., (2008) one area in which the health reforms were considered to be successful was in the development and provision of health services for Māori and Pacifica people. One of the ingredients that enabled this success to occur was the engagement of iwi providers who were able to advocate for their needs of their own community. As Cheyne et al., (2008, p.233) note, “To some extent, the language of competition is often, as in the social service sector, softened with the rhetoric of partnership.”

Cheyne et al., (2008) identify that health technology has increased in sophistication over the past few decades. This brings greater choice when considering treatment options for various illnesses, including greater options for relieving symptoms and improving quality of life. People are often

articulate and expect a level of treatment and health care management that is greater than the ideologues behind the reforms of the 1980s ever anticipated.

It is useful to take a brief look at social policy over the same time period.

“Issues of inequality and poverty (as) central themes in the development of social policy and in promoting well-being, and are closely related to access to health care, education access and outcomes, housing availability and affordability and social services.” (Cheyne et al., 2008, p.163)

‘Inequality’ is defined as the difference between the highest and lowest levels of income distribution within the population they (Cheyne et al., 2008) are writing about. It can be described as a measure of relative difference. By comparison, poverty is a measure of the inability of income to meet a socially identified and agreed living standard. Townsend (as cited in Cheyne et al., 2008) developed the concepts of ‘relative deprivation’ and ‘relative poverty’. These terms refer to poverty research that is specific to a particular time and place in society which enable the term relative to be attached to definitions of a particular historical period.

When using a structural approach to poverty, attention is drawn to the structures of society (laws and policies) that contribute to the way in which they create and sustain inequality and poverty in the community. This can be demonstrated in income support levels are set by the government for those who need financial assistance and are not in paid employment. In contrast, an individual approach to poverty clearly locates both the causes of poverty and solutions to poverty as result of individual failure to thrive or survive in their particular circumstances.

The work of Easton (2008) adds another layer to understanding the relationship between socio-economic status and poor health, concluding that a direct correlation between these two items was not always readily made. It seems the connecting factor to people’s circumstances and poor health is affected by their perception and the impact of stress in their lives. Wilkinson and Marmot (as cited by Easton, 2008. p.98) argue “early life experiences, social exclusion, work, and lack of social support as well as unemployment have all been identified as sources of health-damaging stress.”

A fundamental change in the policy direction of those who are dependent on income support from the government can be seen by the language that came to be used to describe those who received income support – as having to be in ‘genuine need’ in order to be eligible to apply for a benefit. This was later supplemented with a requirement that those receiving benefits were expected to be ‘work ready’ and needed to meet minimum requirements in order to maintain their eligibility for income assistance. The cost of housing is identified as having a significant impact on poverty and living standards. Although an Accommodation Supplement is available for those on low incomes,

“overcrowding and poor housing conditions are major factors in diseases such as rheumatic fever and meningococcal disease.” (Cheyne et al., 2008, p.188)

Cheyne et al., (2008) recognise that while the number of non-Māori living in poverty in New Zealand is high; when the total population of each group is taken into account, the percentage of Māori living in poverty is higher than non-Māori. Research has shown that households where members are in paid work are better able to adapt to a financial emergency or crisis than households where there are already significant financial stresses. Easton (2008) cautions against the tendency to generalise and focus on who is living in poverty i.e. single parent households, ethnic minorities, renters, and those who receive benefits. Rather, he claims, “if there is a typical poor household, it is one which contains children.” (Easton, 2008. p.104). This has implications for families who have major health crises.

It seems that despite the health reforms of the past decades, many of the major issues New Zealand has been attempting to address through various health reforms of the 1980s remain:

“The country’s performance in children’s health remains poor. Diseases of poverty have increased. Mental-health expenditure is still well below what is required. The problems of maintaining services for declining rural and provincial populations are even more pressing. Responsiveness to the health delivery needs of Māori and Pacifica peoples is unlikely to improve the health status of these populations dramatically, unless it is accompanied by major improvements in housing, education, incomes and employment.” (Cheyne et al., 2008, p.228)

Taking the above information into account, and that this research intends to explore the strengths that underpin and sustain family carers looking after a terminally ill adult, consideration turns to asking the following questions: What impact might the unwell person’s life stage have on their ability to adapt to and accommodate the illness they face? What strengths do families who are socio-economically disadvantaged draw on as they navigate the illness of their family member? What impact does health and welfare policies have on the ability of the unwell person and their carer to access healthcare and manage the complexities of negotiating their illness, as well as maintaining other family responsibilities? The literature review, to which we turn next, might offer some insight into these questions.

## Chapter 2: Conducting the Literature Review

Early in 2017, a literature search was conducted focusing on palliative care and caregiving at the end of life via the University of Canterbury library search engine. This search engine was used to access a wide range of databases including CINAHL, EBSCOHost, Elsevier Science Direct Journals, ERIC, JSTOR Arts and Sciences, ProQuest Central, PsychINFO, PubMed, SagePub, Springer Standard Collection, Taylor and Francis Social Sciences and Humanities Library, and Wiley On-Line Library. Key words included: palliative or end stage, psychosocial support, under 65, effects of family support, social work, financial stress, gaps in social work support, middle age, New Zealand, young people, factors impacting families, family distress, socioeconomic, caregiver stress, financial stress, social impact on caregivers, social support, caregiver and strengths.

Throughout the literature search much of the research available focused on caregiving at the end of life. Very little research was age-specific or targeted those under 65. (This is the age of retirement from paid employment in New Zealand.) Only one article directly addressing the experiences of family members of middle adult family members as a consequence of cancer was found (Agnew, Manktelow, & Donaghy, 2008). This was a Northern Ireland qualitative study retrospectively exploring pre- and post-bereavement experiences of partners bereaved through cancer.

Due to the quantity of research focused on caregivers, a decision was made to focus primarily on research published after 2010, unless there was a compelling reason to include research published prior to this date.

A second literature search was conducted nine months later. It included a broad focus on the sociological databases accessed via the University of Canterbury library search engine and used many of the first set of key words. It yielded a different set of research and highlighted an additional theme of politics relating to caregiving. Two further articles were found focusing on the wellbeing of young people caring for a dependent relative, both located in England (Baulkwill, Dechamps, Manning, van der Kroft, & Payne, 2012; Bolas, Wersch, & Flynn, 2007). A third article focused on the experience of younger adults with advanced cancer in Canada (Knox, et al., 2017).

Thus, from both international literature searches the following four themes were identified:

- i) The politics of caregiving;
- ii) Family caregiving as a research priority;
- iii) Interpersonal aspects of the family carer role; and
- iv) Home based caregiving of people who are terminally ill.

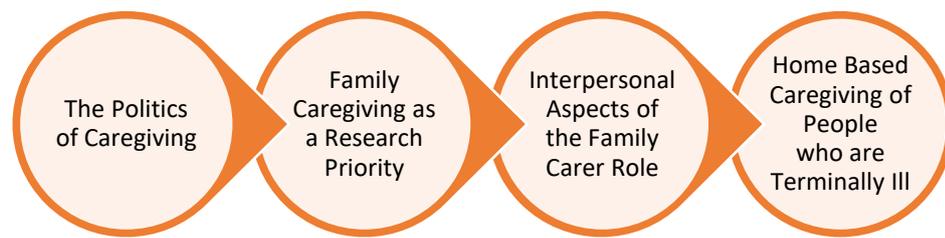


Figure 3: Themes from the literature search

## The Politics of Caregiving

### i) Ownership of End of Life Care

A core challenge in the caregiving literature is around the concept of who ‘owns’ end of life care. Blum and Sherman (2010) describe removal of core knowledge about dying from the community in the following way:

“When once upon a time, death was not hidden, and, because it was out in the open, it was not dark and mysterious. People spoke openly of death and it was connected to life. When death moved into the seclusion of intensive care units and social and family connections were replaced with professional caregivers, it gradually moved out of conversation and out of people’s lives.” (Blum & Sherman, 2010. p.256)

These same ideas are reflected by other writers who challenge the biomedical knowledge and ownership of dying calling for a relinquishing of that ownership; redirecting support for the responsibility to the communities where people who are dying usually live. In their research, Horsfall, Noonan, and Leonard (2012) found that when informal support networks supported people who were terminally ill as well as carers throughout illness and death, those networks were often strengthened by the experiences people had gone through thus forging stronger links between group members. This positive bond permeated into other aspects of people’s lives.

It is acknowledged there is a delicate balance between health care professionals supporting social networks and taking over the role of ‘expert’. Whilst those engaged in palliative care are seen to have a role in supporting the terminally ill, their carers and their social networks, perhaps the greatest challenge for health providers is to step back from wanting to be the ‘key player’ to one of being on the ‘support team’. Inherent with this tension is the search for legitimacy and recognition by those seen to be providing the professional care as a source of generating financial income. As Rosenberg, (2011) states:

“Paradoxically ... the systemisation of hospice into the healthcare specialty now called ‘palliative care’ has again disenfranchised the very groups the palliative care professional community must rely on for its survival.” (Rosenberg, 2011. p.18)

Figure 4 depicts the community support network as identified in the research of Horsfall et al., (2012, p.376).

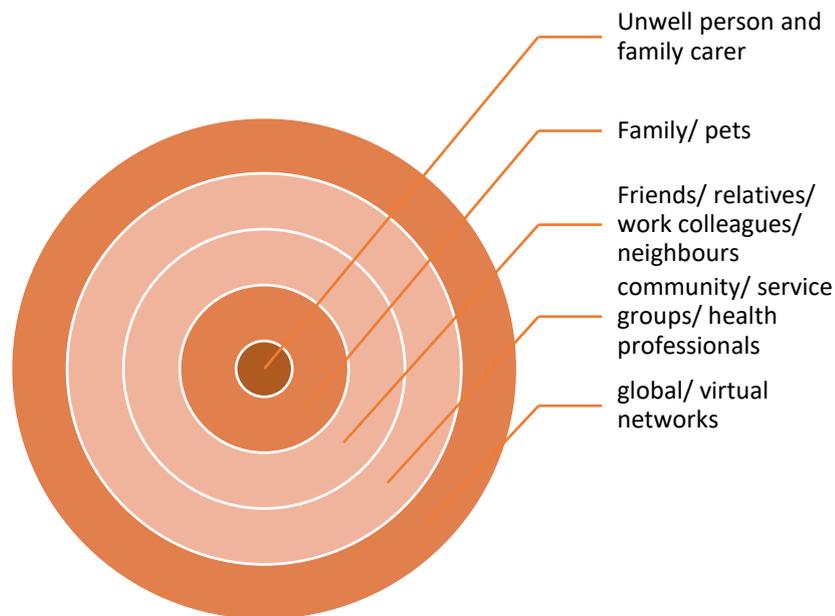


Figure 4: Community support network

Ray, Brown, and Street (2014) develop this position further arguing that debates about euthanasia and patient assisted suicide are a consequence of the removal of familial and community knowledge about dying, and the desire for control over the process of dying. They support the development of Advanced Care Planning (ACP) describing this as one of the tools which families and healthcare professionals can and do use to return decision making to the unwell person. It allows for conversations between people who are unwell, carers, and their social networks around preferences for care, and what is important to consider at the end of life.

Given and Reinhard (2017) advocate that public education about supportive care at the end of life is vital in moving death from a ‘medically treatable condition’ to a normal aspect of life for all. Inherent in this position is an expansion of resources and services being available to support carers caring for a dying family member at home. They argue that prioritising attention on supportive and comfort care has the potential to “result in more constructive and compassionate ways to respond to the social,

psychological, and spiritual needs of both the patient and family members.” (Given & Reinhard, 2017. p.55)

## ii) Perspectives on Caregiving

Another tension around palliative care is that of upskilling carers. Whilst in and of itself, this is a useful and beneficial task and is seen as important in supporting carers in their role; from a Foucauldian perspective it also can be viewed as an example of the state monitoring the activities of the home environment. Attention is drawn to the:

“Moral codes and values embedded in ... manuals that serve to shape the moral and ethical character required of caregivers, and the role of health-care professionals ... in upholding these values by monitoring their conduct.” (Sadler & McKeivitt, 2013. p.50)

Within the sociological and anthropological caregiving literature is an acknowledgment of the presence of kinship and social networks, “with normative expectations of reciprocity and obligation, which sometimes, ... require negotiation and may also be contested.” (Sadler & McKeivitt, 2013. p.53). Twigg (as cited in Sadler and McKeivitt, 2013) describes this perspective as the state assuming and expecting family carers to be resources willing and able to take on the caregiver role. Following an examination of gender norms in the provision of palliative care, Williams, Giddings, Bellamy, and Gott (2017) issued a challenge to those involved in driving palliative care policy and practice to examine the impact of their policies and programmes on women, who are the main providers of family care in the home.

A small study of teenage carers highlighted those providing care to a dependent family member feeling as if they had no choice but to take on the caregiving role which created its own tensions. They tended to be almost secretive in their personal relationships about the role they held at home for fear of social judgment and rejection from their peers. Whilst they became competent and skilled in the tasks and responsibilities of caregiving, they often had difficulty finding an identity beyond their family unit and missed out on social support and inclusion with their peers (Bolas et al., 2007).

According to Alpass, Keeling, Allen, Stevenson, and Stephens (2017):

“Informal family-based care is an essential part of the health system and provides many benefits including improved patient outcomes, reduced unnecessary re-hospitalisations and residential care placements, and considerable savings in health care expenditure.” (Alpass et al., 2017. p.323)

Morris, King, Turner, and Payne (2015) draw attention to the geographic mobility of families being one factor that may preclude supportive end of life care occurring in the family home. A corollary to this is the number of people living alone in small apartments at an older age. They also highlight that some ethnic communities lack familiarity with medical terminology. Combined with language barriers

and anxieties about access to travel visas, housing, and dying away from their country of origin, the ability of palliative care providers to give quality end of life care may be hindered. It may then be that the intended recipients neither accept nor understand the support being offered.

Rosenthal Gelman, Sokoloff, Graziani, Arias, and Peralta (2014) reviewed an American programme specifically designed to support adults in an ethnically-diverse and underprivileged area in New York. Poverty, unstable housing, immigration issues, poor physical and/or mental health, substance abuse and other issues impacted on the ability of family to care for their terminally ill family member. A key finding of the programme was that rather than seeking support to care for their family member, carers were most keen to obtain alternate care provision for their unwell family member. As carers were most interested in respite for their unwell family member, Rosenthal Gelman et al., (2014) argue ethically and economically for programmes and resources to support the needs of family carers.

Gott et al., (2013) caution against making assumptions regarding the place of dying for those in New Zealand, citing carer exhaustion, cultural considerations, inability to contact palliative care support out of hours, and the desire to be seen to be doing something as contributing factors to people who are unwell being admitted to hospital at the end of life. They contend the need to “acknowledge... that understandings of a ‘good death’ are culturally rooted and, as such, differ between New Zealand’s different population groups.” (Gott et al., 2013, p.753). There is no ‘one size fits all’ approach to death and dying.

This is a theme repeated throughout the international literature. Whilst at face value it does appear to uphold and respect family and cultural norms, it can also come at a high cost to the families themselves which will be discussed further in the following section.

### Family Caregiving as a Research Priority

As far back as 2006, family caregiving was identified as an international research priority in end of life care. This was partly in acknowledgement of the estimated large numbers of family carers providing care to those in their own home. Recognition was made of the cost of providing care in the home, shifting from the state on to individual people who are unwell and their families (or support network). (Chai, Guirriere, Zagorski, Kennedy, & Coyte, 2013; Funk et al., 2010, Williams et al., 2017)

Gott, Allen, Moeke-Maxwell, Gardiner, and Robinson, (2015) have explored the financial costs incurred by carers within a palliative care context in New Zealand. They found the costs borne by families were high, with some participants incurring significant debt or even bankruptcy. The family’s financial circumstances prior to illness had a flow on effect in how they managed the costs of

caregiving. Those with limited financial means were found to be disproportionately impacted by the costs involved in caregiving. “Low income Māori families accrued debt at a time when cultural and familial imperatives to care were at their greatest.” (Gott et al., 2015, p.525)

Internationally, a number of studies have taken place focusing on the economic impact of having a terminally ill family member. What they have in common is an acknowledgement that high numbers of women take the role of primary carer. This can impact their employment and social connectivity. By way of example, in Canada, approximately 70% of family carers are 45 years and older; around 25% of carers are over 65 years of age (Stajduhar, 2013). A growing number of carers juggle multiple roles – that of paid employment, and caring for their own families, as well as providing support and care for older family members. It may not be surprising to find that many family carers suffer detrimental effects to their health as the person they are caring for declines in health. (Emanuel et al., 2010; Funk et al., 2010; Keesing, Rosenwax, & McNamara, 2011; Mendes & Palmer, 2016; Stajduhar, 2013; Stajduhar et al., 2010; Stenberg, Ekstedt, Olsson, & Ruland, 2014; Williams et al., 2017)

In their research, Cagle, Carr, Hong, and Zimmerman (2016) found end-stage care was financially crippling for many families in the United States. Households identified as particularly vulnerable for financial distress often had terminally ill family members who were young or from a minority ethnicity. The authors identify three areas of financial stress which occur for working age people who are unwell and their families: the reduced ability of the unwell person to earn income; the need for other family members to take time off from work to provide care; and additional out-of-pocket expenses related to care. The work of Unson et al., (2016) support these findings.

Whilst these studies are located in different countries and cultures to New Zealand, a theme does emerge of the cost of home-based caregiving to the family of a terminally ill person, which to some extent, also resonates with the New Zealand findings of Gott et al., (2015).

In a Canadian study of family carers across three carer groupings, Williams, Wang, and Kitchen, (2014) found end of life carers experienced a higher proportion of negative impacts than their counterparts involved in long-term and short-term caregiving. Given their research explored socio-demographic characteristics among carers, they were able to isolate the impact on working men and women involved in caregiving, as well as identifying commonalities and differences as to how carers navigated their role and accessed additional support.

These studies raise questions as to where people are dying, how they are dying, and the impact on their family or social network as they traverse the news of their illness, the dying journey and its

aftermath. Furthermore, what is the language used to describe their experience – both by family carers themselves and by professionals?

### Interpersonal Aspects of the Family Carer Role

A growing body of literature exists that explores the impact of providing care for people with a terminal illness. Increasingly, this includes acknowledgement of the expanding nature of the caregiving role. The traditional role of caregiving may have involved assistance with daily activities (e.g. washing and dressing) and household activities (e.g. shopping and meal preparation). In contrast, the role of family carers to the terminally ill has expanded and comes with high expectations. It can include management of medications and health related assistance products (ranging from continence products through to technological communication devices). The home environment of the unwell person as well as the family are affected by the introduction of home support aids (e.g. wheelchairs and hospital beds). Furthermore, the quality of the relationship between the carer and the terminally ill family member is identified as having an impact on how the family negotiates the provision of home-based care and ongoing decision making. (Blum & Sherman, 2010; Morris et al., 2015; Sheets, Black, and Kaye, 2014; Stajduhar et al., 2010; Tanco et al., 2017)

According to Morris et al., (2015) a good formal care team is essential to support the unwell person receiving end of life care, irrespective of setting.

“A good care team is defined as one having a positive attitude, providing holistic ‘around the clock’ patient care, giving clear, timely information about the patient’s condition and acknowledging the significance of the family carers role.” (Morris et al., 2015. p.491)

Where this was found to be missing, family carers had more difficulty in providing ongoing care for their family member at home. Support aimed at meeting the personal, social and spiritual needs of carers, as well as the engagement of outside resources and knowledge is critical. Most importantly, when carers felt excluded and left out of communication and decision making, it had a negative impact on their wellbeing.

Wittenberg, Kravits, Goldsmith, Ferrell, and Fujinami (2017) sought to assess the effectiveness of a model of family communication in identifying how the primary carer communicated within the family, and how this might impact on caregiving outcomes. Four communication types were defined – Manager, Carrier, Partner and Lone. Each had a unique style of communication, and each was found to experience a tendency towards a specific type of distress. Whilst this research is still in its formative stages, it has the potential to give direction to targeting support that may be best for carers.

## Home-based Caregiving of People who are Terminally Ill

For those who become terminally ill prior to the time of retirement from the paid workforce, Ray et al., (2014) describe this as a:

“Socially unacceptable time of life... A time of life when people in western societies expect to have independent children and be at the peak of their working life, perhaps contemplating an active retirement.” (Ray et al., 2014. p.472)

For those who become terminally ill at a younger age, the concept of this occurring at a socially unacceptable time of life may be compounded.

In their research with people who were terminally ill during early adulthood, Knox et al., (2017) identified isolation from their peers as a key theme. This included those who were recovering from serious illness. The young adults further identified themselves as distinct from the older people whom they also saw in clinical visits to their Medical Specialists. Disbelief at their circumstances and a high level of distress at the possibility of leaving young children behind who may not remember them had a huge impact on those who were parents. For those who were single, parents became default caregivers which created tensions with the loss of independence and the life each party had planned for themselves. Making meaning of their lives came to focus on living a meaningful life for however long or short that might be. Whilst this group expressed the importance of having peer support and access to psychotherapy available, each person in this study indicated they would personally not be interested in accessing it for their own benefit.

Those interviewed by Ray et al., (2014) and Knox et al., (2017) spoke of how the value of interests shared with individuals and groups outside the realm of their illness, brought a strong sense of normality to their lives. The timing of these interactions could be either hurtful or helpful depending on the circumstances surrounding the interactions. Similarly, Morris et al., (2015) echoed the importance of carers having a sense of normality in their lives when they had a terminally ill family member being cared for at home. When carers were able to maintain daily routines, hobbies and social connection, this enhanced their ability to manage.

Given the interconnectedness of the person who is unwell and their carer, as well as the dynamic and evolving nature of caregiving within the context of a terminal illness, Blum and Sherman (2010) advocate that there is a need to assess the carer separately to the patient.

“This journey is fraught with uncertainty and potential danger. Unexplored beliefs, expectations, and resources, as well as family dynamics affect the challenges and successes of the journey.” (Blum & Sherman. 2010, p.248)

They present a Stress Process Model (Pearlin et al., as cited in Blum and Sherman, 2010) as one tool which could assist with this process.

MacArtney, Broom, Kirby, Good, and Wootton (2017) explored the relationship of terminally ill people living in the present moment as well as projecting into the future simultaneously as a way to grapple with the complexities of their immediate circumstances whilst holding onto hope for a positive outcome. A strong theme that emerged out of this research was the desire unwell people had to maintain a normal life, whilst recognizing the impact their health concerns had on them. They displayed an ability to frame and reframe whatever circumstances they were in to make it manageable, yet at the same time were aware their preferred outcome might not eventuate. They were able to move between, and make sense of, seemingly contradictory understandings of their health and wellbeing without difficulty.

Exploring the strengths family carers bring to their role brings a different perspective to that of the medical and nursing literature which has commonly explored areas of caregiving focusing, at times, on the health impacts experienced by the carer. Terms such as 'caregiver burden', 'caregiver distress', 'comorbidities', 'personal costs', 'stigma', and 'vulnerability' are evident. (Hong & Harrington, 2016; Stajduhar et al., 2010; Tanco et al., 2017; Unson et al., 2016). Whilst all these factors are real and do occur, there is a need to bring a different lens into the caregiving conversation. Funk et al., (2010) contend the positive features of caregiving at the end of life assist in giving a more comprehensive and nuanced description as to why people engage in caregiving, and the benefits they may personally gain through the process. They recognise this as being a gap in the research literature in caregiving at the end of life.

In her research, Bowden-Tucker (2012) sought to identify what supports were required to sustain family carers providing end of life care in the home in New Zealand. She argued that recognition of the significant contribution a family carer made during their family member's illness was crucial; as was the availability of appropriate support and information from both the health care professionals and service providers; as well as the role kinship and social networks made to meeting non-medical support needs.

In their research into post traumatic growth in a population of bereaved parents who had lost a child, Cadell, Janzen and Fletcher (as cited in Cadell et al., 2011) identified themes of new possibilities, a new way of relating to others, an increase in personal strength, greater appreciation of life, and the experience of spiritual change.

Nelson Becker (as cited in Cadell et al., 2011) examined strengths and resilience in older adults at end of life and identified themes of self, spirituality, social investment and independence. Continuity of care and the ability of professionals to be fully present with participants was seen as critical to nurturing growth.

Given and Reinhard (2017) support the provision of timely care coordination as crucial to supporting unwell people and carers at the end of life. They see communication between all parties as a key factor in supporting families. This includes acknowledging the cultural and spiritual needs of the unwell person, carer and family. Advanced Care Planning is one tool that is able to grant the family leverage when working with health professionals.

Throughout the literature search only one article, from Australia, was found that directly explored the strengths family carers brought to their role of caring for a terminally ill person (Hughes, 2015). A second article, based in Canada, exploring the socio-economic context of resilient carers, was able to broaden the strengths identified in contributing to positive carer functioning (Giesbrecht, Wolse, Crooks, & Stajduhar, 2015).

Both authors identify “the ‘opportunities that exist’ for carers to take to overcome challenges and develop coping strategies, which ultimately are influenced by their socio-economic contexts.” (Giesbrecht et al., 2015. p.562). They describe the impact of this as transformational in the life of the family carers. It is in owning their role as carers, giving meaning to the choices they make, and respecting the cultural and structural dynamics that influence the decisions they make, that carers engage in this transformation from being weighed down by caregiving to operating from their strengths. Carers with positive mental health were found to have higher self-esteem and positive perceptions of caregiving (Bowden-Tucker, 2012; Unson et al., 2016).

The strengths identified by Hughes (2015) might best be described as personal qualities i.e., courage, determination, acceptance, humour and empathy. Horsfall et al., (2012) add gratitude, love, privilege, intimacy and personal fulfilment to the qualities that are transformative in the caregiving relationship. In contrast, the factors Giesbrecht et al., (2015) identified were more structural i.e., access to social networks, education/ knowledge/ awareness, employment status, geographic location of residence, housing status, and life-course status. Both sets of factors are able to complement one another and are influenced by the cultural norms of people who are unwell and their carers. Figure 5 provides a diagrammatic representation of this relationship.

“People’s strengths were not clearly apparent, obscured beneath stories of struggle, adversity, and irreplaceable loss, as well as the chaos generated by grief, and a widespread

propensity to direct attention towards the negative aspects of caregiving and bereavement.” (Hughes, 2015. p.161)

This is supported by Giesbrecht et al., (2015) who are careful to note that research devoted to carer burden and vulnerabilities is inextricably linked to research devoted to resilience. They are two sides of the same coin. Building resilience is an active dynamic process whereby individuals need the ability to acknowledge the circumstances they are experiencing, in order to adapt and find a solution, on their way to overcoming challenges.

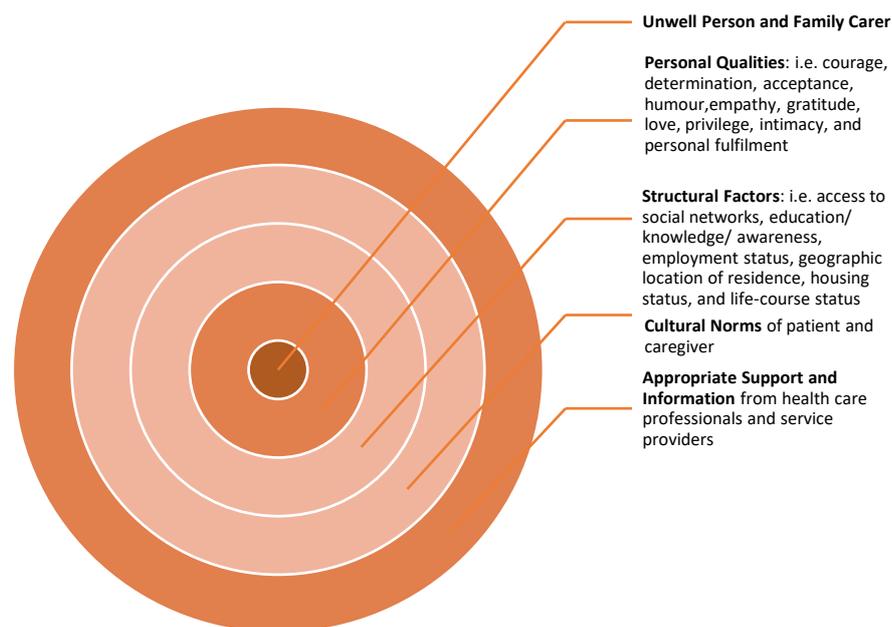


Figure 5: Strengths of caregivers as identified in the literature review

Stenberg et al., (2014) have called for:

“Research on family caregivers to be more focused on the positive aspects of caregiving, family caregiver’s strengths and health assets, coping strategies to prevent burden, and ways to prevent distress.” (Stenberg et al., 2014, p.543)

The authors reinforce the importance of the unwell person and their carer being viewed as a unit and placed at the centre of health and care planning decisions. (Stenberg et al., 2014)

The consequences of not doing this can result in a deterioration in the quality of care provided and the health of both the unwell person and their carer. Consequences of carer depression could result in the inability of the carer to provide ‘respectful care’ demonstrated in a range of behaviour from ignoring the needs of the unwell person through to yelling, screaming and threatening actions, and on

through to physical abuse. Unson et al., (2016) identified carers most likely to be struggling tended to be those providing care who were young and/ or lacking additional support.

## Conclusion

The literature review undertaken has revealed four broad themes: the politics of caregiving, family caregiving as a research priority, the interpersonal aspects of the family carer role, and home-based caregiving of people who are terminally ill.

Within this review into family carers, four specific gaps in the literature have emerged. These are: international research into family carers is predominantly focused on carer burden, there is a scarcity of information concerning the experiences of spouses/ partners of those who die under 65 years of age, limited information exists about the experiences of family carers in New Zealand, and there are very clear differences in life expectancy for New Zealand Māori and non-Māori adults.

In recent years, the Te Arai Research Group at the University of Auckland, New Zealand, has published extensively from their research in the field of palliative and end of life care. Notwithstanding the growing body of literature the group has published which includes the needs of family carers, some of which has already been referred to during the literature review (Gott et al., 2015, 2013; Williams et al., 2017), their research has yet to specifically focus on the experiences of those caring for family members under the age of 65 years.

Thus, the focus of this research project is to investigate the strengths that underpin and sustain family carers looking after a terminally ill adult under 65 years of age. This is an emerging field of research and it is hoped that the findings of this research will complement the findings of Bowden-Tucker (2012); Cadell et al., (2011); Giesbrecht et al., (2015); Horsfall et al., (2012); and Hughes, (2015). It is anticipated that some of the experiences carers have will be as a direct consequence of their age of their unwell family member, their stage of family life, and their access to social support within their community.

## Chapter 3: Methodology and Method

The aim of this research project is to explore the strengths that underpin and sustain family carers looking after a terminally ill adult under the age of 65 years. This chapter sets the framework for the research project using a social construction methodology and life story interviewing. It will address the broader ethical considerations that underpin interviewing people who have been bereaved. From here, the method used in undertaking the research is described.

### Social Constructionism

Social constructionism is a methodology that aligns well with a social work perspective allowing individuals to give meaning to their lived experiences, taking into account the wider interpersonal, social, cultural and political context in which it occurs. (Butler-Kisber, 2010; Creswell & Poth, 2018; Esin, Fathi, & Squire, 2013; Gergen, 2011; Gergen & Gergen, 2017; O’Dowd, 2011; O’Leary, 2011; Shotter, 2014; Vall Castelló, 2016)

“The idea of the professional encounter as a situation of ‘reflective solidarity’ that attempts to take account of the idea that all participants, including the professionals, shift their positions, enlarge their perspectives, value the words and offerings of others and come to see the world in a slightly different way in order to negotiate and identify solutions.” (Parton, 2003. p.13)

Constructionist research is socially oriented. It has as its focus the ongoing, active interrelationships between people, their environment and their understanding of the world they live in. All this is located in everyday life, and while it may be possible to retrospectively identify key points, they are not always readily discernible in a flow of daily activity and unrelated minutiae. Thus, as people’s ideas change and evolve, so, too, do their understandings of the world they live in. (Esin et al., 2013; O’Dowd, 2011; Shotter, 2014)

During the research process, the researcher is engaged in the social world being studied, variously acting as an interpreter, mediator or commentator. Social construction pays attention to the ‘positioning’ of the tellers and the listeners. It is less concerned with factual reality, than the self-generated meanings of the person telling their story. It allows room for the narrative to change over time dependent on the storyteller, the audience, and the context in which the narrative is being delivered (Riessman, 2008).

Esin et al., (2013) encourage researchers using a constructionist methodology to keep a keen awareness and analyse their own personal, social and cultural positioning, especially in the power

relationship that occurs with participants, the research data and its interpretation. They argue that from this analysis, a creative approach to the 'story' may emerge that is deeper and more critical than that occurring at face value within the research data.

### Life Story Interviewing

An important aspect of this research is to interview bereaved family carers to learn of their experience of caring for a family member who was terminally ill, their death, and how they learned to pick up the threads of their life again, without their significant other. The purpose of the life story interview is to enable the person being interviewed to tell of his/ her lived experience, in the way that best works for them, to enable others to learn from "their voice, their words, and their subjective meaning of life." (Atkinson, 2012. p.12)

A key factor when interviewing participants is bearing witness to their story. According to Atkinson (2012, p.14) "just witnessing – really hearing, understanding, and accepting, without judgement – another's story can be transforming." (Atkinson, 2012; Riessman, 2008). For those who are interviewed, the opportunity to tell their story enables them to revisit a specific time in their lives. In doing this, they, too, may discover new learnings and insights about their experience and themselves.

According to Esin et al., (2013):

"Confidentiality and anonymity may be such high priorities as to be met for some research participants; for others, extremely 'difficult' topics may be readily engaged with in a non-judgmental research context which they will never have to revisit." (Esin et al., 2013. p.12)

Constructionist research takes place within an environment of specific historical and cultural contexts. The stories presented by the bereaved carers is impacted upon, and created by, these very processes both at an interpersonal, and broader social level. Through analysis of the participants individual story, the researcher is able to articulate and convey the most meaning.

According to Elliot (2011, p.5) "the aim of analysing an individual biography is ... to use it to develop an understanding of social groups, classes, and cultures and the structural relationships between them." Bertaux and Bertaux-Wiame (as cited in Elliot, 2011, p.6) reinforce this position emphasising the necessity to move from one life story to another, checking for common experiences which are able to explain the structural features that underpin each person's experience. This enables a collective narrative to be discovered, that is built from a wide diversity of individual narratives. (Riessman, 2008; Robson, 2011)

## Ethical Considerations

In conducting this research, two sets of ethical parameters will guide the project. The first is an overarching consideration for the entire project, more commonly known as the feminist ethics of care. The second relates specifically to the ethics of research with people who have been bereaved.

### i) Ethics of Care

The feminist ethics of care acknowledges interdependency within relationships as a defining feature of human existence. It has the power to both transform and challenge traditional notions of how society functions. As a generalisation, Featherstone and Morris (2012) describe male thinking operating within an ethic of justice which stresses rights and regulations. In comparison, they describe female thinking operating within an ethic of care, which revolves around relationships and responsibilities.

“Feminist ‘ethics of care’ recognise that ‘care work’ is usually devalued as a social activity or practice, and is also devalued conceptually through its assumed connection with privacy, with emotion and with the ‘needy’. It is far broader than a simple definition of ‘women’s work.’” (Parton, 2003. p.10)

It raises issues of vulnerability, something we all experience at some time in our lives; and become acutely aware of when we are a recipient of care-giving. It questions how social policy addresses matters of wellbeing and social justice for all people. It challenges the idea of care being only for those considered to be most in need by asking what type of environment is required for good care for all to flourish. It critiques social policies that are developed from a market perspective that ignores the social realities of the people for whom they are intended.

Ethics of care is considered to be an ongoing process made up of four interconnected phases: caring about, taking care of, caregiving, and care receiving. From these phases arise four ethical elements of care: attentiveness, responsibility, competence, and responsiveness. (Tronto, cited in Featherstone and Morris, 2012) From their work, Ward and Barnes (2016) flesh out these ethical elements of care in action:

“In practice this meant being attentive to individual differences within the team, being flexible to accommodate uninvited disruptions, taking responsibility and adopting different roles, both taking the lead and stepping back, paying attention to detail and of practicalities and noticing how people are responding to being involved and how they can contribute to the process.” (Ward & Barnes, 2016. p.18)

## ii) Research with those who have been bereaved

Ethical considerations	Practical strategies
<b>Participant identification and recruitment</b>	
Access, confidentiality	Formally obtain the support of a key person to undertake the role of identifying potential participants and disseminating pre-prepared recruitment packs on behalf of the research team.
Regard	Recruit potential participants in a serial manner, for example, send out a maximum of five recruitment packs at any one time so that participants are not kept waiting for long periods before the research interview.
Respect, relevance	Consider participant inclusion criteria of bereaved no less than 3 months and no more than 12 months at the time of recruitment to the study.
Compassion	Include a covering letter that introduces the study in a personalised way by taking familiarity into consideration.
Informed choice	Provide clear written and web-based information about the researchers and the study. Include an invitation to contact the researcher. Demonstrate timely responsiveness to any potential questions or queries.
Non-coercion	Provide a minimum of 10 days for participants to decide about joining the study.
<b>The research interview</b>	
Choice, respect	Agree a convenient date, time and venue for the research interview. Avoid dates that coincide with any significant family events or anniversaries.
Safety	Implement a study site policy for researchers working alone in advance of the interview encounter.
Safety, support	Competent researcher with experience of conducting sensitive research interviews and supporting the bereaved.
Choice, privacy	Provide the option of an interview face to face or remotely, for example, via telephone.
Informed consent	Provide an overview of the study and present opportunity for participants to ask questions. Explain how the interview will proceed. Obtain written agreement to audio-record the interview and to use anonymous quotes in any presentation of the research. Provide participants with a copy of the signed consent form to keep.
Support	Discuss and agree avenues of post-interview support prior to the interview commencing.
Support	Observe/listen for signs of distress during the interview. Discuss the option of pausing the recording or stopping the interview. Plan a natural break for refreshments.
Confidentiality, anonymity	Ensure audio-recordings and transcripts are securely stored and electronic data are password protected. Assign a study code at the point of transcription.
<b>Post-interview follow-up care</b>	
Support	Arrange a convenient time to telephone the participant (normally in 24–48 h) to check on any issues the interview may have raised and to answer any questions.
Support	Compile information about local support organisations. Offer this to participants if they consider it helpful and/or direct them to appropriate professionals to discuss any issues of concern.
Support	Establish if participants wish their general practitioner (GP) to be informed about their participation in the study and obtain written consent to proceed. Provide GP with information about the study at the time of notification.
Appreciation	Send participants a personal thank-you letter and offer an executive summary of the research findings.
Involvement	Provide participants with an opportunity to evaluate their experience of participating in bereavement research.
Support	Determine support for the researcher from an individual with whom they feel comfortable and who is suitably qualified to provide support. Plan a debriefing session after each interview encounter. Utilise reflexive notes to guide the discussion.

Figure 6: Table for ethical decision making by Sque et al., (2014)

An Australian study (Bentley & O'Connor, 2015) into the timing when bereaved carers might be approached for conducting research interviews found that whilst some carers are willing to be approached as early as weeks after their family member's death; others prefer a period of time to pass enabling for 'reflection rather than distress'. These findings echoed those of Hynson et al., (as cited in Bentley & O'Connor, 2015) whose stated preference for timing of research interviews spanned from a minimum of six months to two years post bereavement. The most important factor to be

considered when inviting bereaved carers to participate in research interviews was not if they were asked, but how they were asked. (Bentley & O'Connor, 2015)

Sque, Walker, and Long-Sutehall (2014, p.948) developed a framework for ethical decision making which identified practical strategies to address ethical concerns at three specific stages throughout the process of conducting research with people who have been bereaved. These are person identification and recruitment, the research interview, and post-interview follow up care. Consent was been sought from the authors of this research to include their framework in this research. The framework will be used to guide the ethical concerns at each step of this research project (see Figure 6).

In their framework, Sque et al., (2014) recommend that people being included in research shall be no less than three months and no more than twelve months from bereavement at the time of recruitment. Taking heed of the recommendations made by Bentley and O'Connor (2015), this research will only consider carers who had been bereaved for a minimum of six months but extend to carers who have been bereaved for a maximum of five years to enable a greater opportunity for reflection following the death of their family member.

### Reliability/ Validity

Kronick (as cited in Rubin and Babbie, 2015) proposed four criteria for evaluation of the validity of qualitative data. These are:

- i) The analysis of separate parts of the data should be consistent with other parts of the data, including the data as a whole;
- ii) The analysis of the data should be complete when all the data is included;
- iii) The analysis of the data should be 'compelling' within the context of all the data available; and
- iv) The analysis of the data should be meaningful, as it seeks to make sense of the data and extend the researcher's understanding of it.

Ways to achieve consistency of the analysis include asking those interviewed to review the written transcription of the interview data, and give feedback for the purpose of editing or clarification of information. Reviewing transcriptions along with fieldnotes written after each interview will assist the understanding of aspects of the data that may be overlooked at the time of interview.

As a Social Worker, supervision is an essential component of our profession. Supervision will be used throughout the research process; both as an aid to debrief from interviews and to gain further insight

into the data that has been obtained. It will provide an opportunity to further reflect on what is, and is not, spoken within each interview.

## Method

### Aim of Research

The aim of this research project is to explore the strengths that underpin and sustain family carers looking after a terminally ill adult under the age of 65 years. This will be achieved through data collection of information gathered from semi-structured interviews with eight bereaved carers.

### Participants

Potential participants are adults who had a family member (spouse/partner/ex-partner) they had cared for die under the age of 65 years. All will have used the Hospice service within the previous six months to five years in the Nelson Tasman region at the time of applying for ethical consent. Anyone with a known mental health diagnosis will be excluded. Participants need to be fluent English speakers and familiar with the cultural norms of living in New Zealand. For this reason, they need to have been living in New Zealand for a minimum of 15 years. A kaumātua from a local Māori health agency has agreed to support Māori participants in this research.

The names of all people under 65 years who had died at Nelson Tasman Hospice (NTH) within the recruitment period will be sourced from the NTH database. A preliminary search has identified 337 people. For every person who died under the age of 55 years, two people died between the ages of 55 and 64 years. From this, those who meet the recruitment criteria of having a spouse/partner/ex-partner as a carer will be identified. Where the information is insufficient to determine people's eligibility (e.g. no longer living at address on the NTH database, or the primary carer is known to have died) those people will be excluded. This refining has reduced the number of potential participants down to 180 people. In order to have an opportunity for equal representation between each cohort, every second person identified who is under 55 years, and every fourth person identified aged 55 - 64 years will be sent a letter by the NTH Bereavement Coordinator inviting them to participate in the research (Refer to Appendix 1).

From the postal drop of sixty invitations, twelve replies were received. Six letters were returned due to change of address from that held on the NTH database. Following the receipt of replies from interested people; ethnicity and the number of years living in New Zealand were used to provide a secondary level of screening. By using this process, there was no selective or purposive recruitment

of participants. For each person who wished to proceed with an interview, an information sheet with written details about the research and consent form was sent to them (Refer to Appendix 2). Within one week, each person was contacted again to confirm their wish to proceed. As everyone did, an appointment time was made to meet and interview them.

From the first eight respondents, interviews were arranged over the course of six weeks. Most people preferred to be interviewed in their own home, with two people being interviewed at NTH. One person with whom an interview had been arranged, died suddenly prior to the interview taking place. As a consequence, an interview was arranged with another respondent.

### Ethical Approvals

Ethical consent for the research was granted by four separate parties:

- i) Frans Dellebeke, Chief Executive Officer of Nelson Tasman Hospice.  
This was granted on 20 November 2017.
- ii) Rangiriri Kohe, Alcohol and Drug Clinician for Te Piki Oranga and a Kaumātua for Ngāti Koata, Ngāti Toa Rangitira and Ngāti Kuia.  
This was granted on 13 December 2017.
- iii) Ngāi Tahu Consultation and Engagement Group, University of Canterbury.  
This was granted on 28 February 2018.
- iv) Human Ethics Committee, University of Canterbury.  
This was granted on 10 May 2018. Ref: HEC 2018/20.

Please refer to Appendix 3 for copies of the ethical approval given.

### Data Collection

Data collection was by way of semi-structured interviews with each person which lasted approximately sixty to ninety minutes. (Refer to Appendix 4 for interview questions). The interview questions served as a guide enabling me as an interviewer to hold the focus of the interview. Rubin and Babbie (2017) describe this type of interview as “essentially a conversation in which the interviewer establishes a general direction for the conversation and pursues specific topics raised by the respondent.” I found that following receipt of the letter inviting them to participate in the research, most people had semi-prepared what they wanted to say. The interviews gave people permission to tell their story, one that was often kept in the storehouse of their heart, and often no longer retold.

Prior to the formal interview beginning, time was spent talking through the purpose of the research, and getting the consent form signed. Each interview was recorded on two digital devices, to ensure there was no loss of the interview material. As the researcher, I later transcribed each interview, before sending it back to each person to review and edit as they preferred. People were free to stop the interview at any point, or to exclude any information they did not want included in the analysis. The editing of the interviews was generally done to maintain the anonymity of the person interviewed by broadening some details e.g. from a specific professional identity to the more generic industry.

Some of the people interviewed saw their involvement in the research as a way of 'giving back' for all the support they had received during the time of their husband / wife's illness. Others valued the perceived neutrality of a 'researcher from the University' taking the time to hear their story. Two people, due to their profile within the wider community, expressed concerns regarding the confidentiality of their information. Their concerns were allayed in the preliminary discussion prior to embarking on the formal interview.

The interviews were intensely personal as each person spoke of their husband/ wife, the life they had shared over many years and the story of the illness that had taken the person they most loved from their life. During each interview, it was as if the treasure house in each person's heart was opened and as they felt comfortable and accepted in sharing information, more treasures were brought out into the open. A tear in the eye, a clenching of the body holding grief, a moment of weeping; these were present in the interviews especially when each person spoke of the death of their husband/ wife. This was accompanied by a silence and waiting until people were ready to continue. This was their time, their story, and it needed to be honoured.

Conducting the interviews demanded that I, as the researcher, be fully present and attentive as required by the feminist ethics of care (Featherstone & Morris, 2012; Parton, 2003; Ward & Barnes, 2016). In practice, this meant only one interview per day. It also required attending to the recommendations of Sque et al., (2014), and ensuring people who agreed to be interviewed were feeling safe emotionally, both during and after their interview. One person who felt vulnerable in the days following the interview took up the offer of follow up support via the NTH counsellor who was already known to them.

### Data Analysis

Data analysis was by way of thematic analysis. From the interview narratives, analysis focused on how each person made sense of their experiences so that a "dense, detailed, and contextualised description" could be obtained (Elliot, 2011. p.3). The analysis focused on identifying common themes

from each narrative which represented a collective story, highlighting the strengths underpinning each person's experience. The specific steps involved in this process were:

- i) Familiarisation with the narrative data through the transcription process as well as reading and rereading the narratives to gain a sense of initial codes.
- ii) Generation of codes to collate similar data across the narratives.
- iii) Grouping of data codes to develop themes. It was intended that whilst a collective story may emerge, attention also needed to be given to aspects of the narratives that did not fit neatly into a collective narrative.
- iv) Construction of thematic networks that gave an image of how the data fitted into a specific theme.
- v) Integration and interpretation of the data to give a deeper understanding of the research findings to answer the research question.

(Riessman, 2008; Robson, 2011)

“Extracts need to be embedded within an analytic narrative that compellingly illustrates the story you are telling about your data, and your analytic narrative needs to go *beyond* description of the data, and make an *argument* in relation to your research question.” (Braun & Clarke, 2006. p.93)

The process of interviewing widowed carers, transcribing the interviews into narrative text, reading and re-reading the narratives during the coding and arranging the codes into thematic networks, involved immersing myself into the data again and again. Each immersion stripped away another level of ‘professional veneer’ and I found myself responding to the details of the narratives at a personal level. In order to attend to my own wellbeing throughout this process, and maintain an ability to respond and work with the data, professional supervision was a valuable and necessary aid. As stated earlier, both of my parents have died within the past six years, and there were times when the sorrow and pain of loss and bereavement that the carers recounted touched the sorrow and pain of loss and bereavement in my own life. Professional supervision enabled me to acknowledge my own grief, and process different aspects of it. Through engaging in this process and reflecting on what was happening, new insights were revealed, and freedom to attend to the details of the research I was analysing ensued. Thomas and Davis (2005) describe this as strength-based supervision in action, where supervisees bring the fullness of themselves to supervision and reflect on what they notice about the work they are engaged in.

Figure 7 gives a brief overview of the bereaved carers and their spouse/ partner. All family carers had been married and six out of the eight carers were in their first marriage when their husband/ wife

became unwell. Two carers were acutely aware of the importance of their spouse's relationship with children from their previous marriage and included them in the care of their husband. Most of the carers identified as New Zealand European with one person being of both New Zealand Māori and European origin (this information was disclosed after the interview concluded). Another carer had migrated from Europe over twenty years earlier and now called New Zealand home.

Name of family carer (pseudonym)	Age at time of unwell person's death	Name of unwell person (pseudonym)	Age at time of death	Length of time together	Time from diagnosis to death	Time since bereavement at date of interview Years/ months
Penny	54	Jake	58	33 years married	4 years	3 / 7
Sally	55	Luke	64	14 years married	18 months	3 / 5
Kirsten	57	Caleb	46	12 years together	5 years	3
Grace	58	Josh	62	27 years married	8 years	2
Mark	59	Rose	57	37 years married	2 months	2 / 4
Harry	64	Beth	63	40 years married	15 years	3 / 7
Matt	66	Isla	59	37 years married	3 months	3 / 7
George	71	Ruth	63	40 years married	3 years	5

Figure 7: Table of bereaved carer demographics

All carers had been bereaved for a minimum of two years bereaved, with half being bereaved around three and a half years. Most of the interviews were between one and one and a half hours duration. Each person gave their version of what had occurred with their unwell husband/ wife, noting symptoms leading to the time of diagnosis, through the period of treatment with surgery, chemotherapy and/or radiotherapy. The stories traversed travelling to other cities for treatment, and the complexities of negotiating family communication and work commitments whilst dealing with a world of medical changes. They were stories of love and devotion in the face of an illness with the ability to be tenacious. They were stories of courage under fire illuminated with moments of tenderness, humour and raw gut-wrenching pain. They were stories of striving to adapt to a new normal as illness continued its relentless march into the lives of men and women who were not ready for death to invade their lives. They were stories of accepting the truth of treatment no longer being effective, of receiving palliative care, of the death of their spouse, and somehow finding a way to

continue living and rebuilding their lives. To the men and women who willingly and generously shared their stories in an effort to give back and help others; to them I am truly grateful.

As the bereaved carers shared their stories, I noted that they were given either in broad brush strokes, or in fine detail. After consideration, I came to appreciate that this was a further reflection of the way each person saw the world. Those who had careers that operated at the level of painting a broad canvas exhibited the same skills when telling their story. For those whose careers dealt in details, this was reflected in the way they told their story. No matter which approach each person took, they were well able to incorporate the subtleties and nuances that were required.

In seeking to pull the narratives together, I came to think of them as part of a flowing river with differing entry and exit points for each person. Each couple joined the river during the time of having their illness diagnosed. Their journey down river might be filled with rockpools, eddies, exploratory detours and picnics on the riverbank. It might be a time of exploring the beauty of nature above and below the water, or it might be one of hurtling through rapids bumping over rocks and rapids, hanging on until calm waters appear once again. Whichever experience people had, generally they were all travelling in a similar direction albeit at different rates. Bateson (as cited in Clandinin, 2007, p. 266) used the metaphor of “weaving separate skeins of memory into a single fabric” to convey this same idea of pulling narratives together.

From analysing the data four main themes were identified: the medical circle of care, the home circle of care, saying goodbye and picking up the threads. Each theme is made up of a series of smaller subthemes that build the narrative. They are discussed and expanded upon in the following chapter.

## Chapter 4: Research Findings

This research is aimed at identifying the strengths that underpin and sustain carers looking after a terminally ill family member. Eight bereaved carers were involved in semi-structured interviews to learn from their accounts of caring for their unwell husband/ wife, and so gain an understanding of their experiences. The research utilises a social construction methodology which encompasses the relationships between the person being interviewed as well as the relationships between people, their environment and their understanding of the world they live in (Esin et al., 2013; O'Dowd, 2011; Shotter, 2014). The interview data has been analysed via coding, and grouped into themes that give a sense of the experience of family carers.

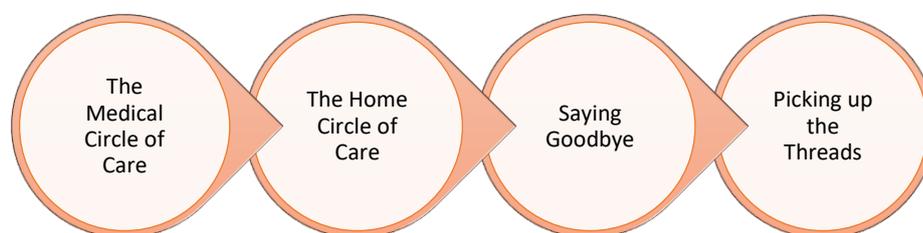


Figure 8: Themes from research findings

Four main themes have been identified: The Medical Circle of Care, the Home Circle of Care, Saying Goodbye and Picking up the Threads. Each theme is broken into a series of smaller subthemes that build the narrative. There is not a generic narrative because each person's story is unique to their personal circumstances. But every interview began with the story of diagnosis and the treatment options that were available, so, that is where this section will begin.

### Theme 1: The Medical Circle of Care

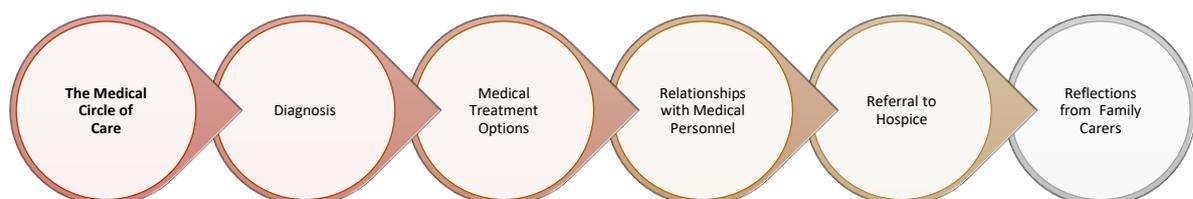


Figure 9: Subthemes for the Medical Circle of Care

i) Diagnosis

Each person had a vivid recollection of the events surrounding diagnosis and the impact of the news. For some couples, the diagnosis seemed to come out of nowhere.

*'One morning, in the summer, just before Christmas, Josh collapsed - in the house and I had to do a 111 call to get the ambulance. So, to me, it started from there. And he was rushed to hospital and that very day they did lots of scans and testing and that day they found that he had a tumour on his kidney. And, so he was in hospital for three weeks, that was over Christmas 2008, he came out on the 31st of December 2008. And, they were going to operate, they were going to send him home and operate on the fifth of January but- they couldn't stabilize him so they operated on the 27th of December 2008 and removed a two-kilogram tumour and one of his kidneys. And then he was sent home to recover.'* (Grace, p.1)

For other couples, there was a background of investigating various symptoms prior to a diagnosis being confirmed.

*'By that time, she was becoming a bit restricted in swallowing. But she was still doing stuff like going for runs and she went water skiing, for example, on the 29th of June which is pretty cold. (...) she also went water skiing in early September as well and her ability to swallow was restricted by then. Then she went to the Doctor and the Doctor gave her some antacid stuff to suppress (...) but that hadn't done any good. She went back to the Doctor three weeks later and (...) that Doctor sent her immediately for an ultrasound scan and they found some mass in her stomach. And based on that she went for a CT scan on the 25th of October and that showed cancer in the middle of her oesophagus and some more in the bottom of her oesophagus. So, they immediately admitted her to hospital. She had a gastroscopy in there as well. The 21st of October. Immediately they admitted her into Hospital as a result of that and then they put a stent in her throat on the 23rd of October which enabled her to swallow a bit better and after that she was allowed to come home.'* (Matt, p.1)

The news of the diagnosis had an impact on everyone:

*'The day he was diagnosed with cancer, I was so distraught.'* (Kirsten, p.2)

*'It was really quick and our life just stopped. I was trying to juggle all my life. That was so significant. If somebody has a road accident or whatever, people often have said, so different to have cancer because it's long and slow and you kind of have time to get your head around it and plan and prepare. But I think actually it was quite, not similar to a road accident, but certainly was like stopped. Right. That day really.'* (Sally, p.2)

*'So, when he was diagnosed it was, 'Okay gosh we've got something we can work on.'* (Penny, p.1)

The language people used to describe their entry into dealing with ill health was noteworthy:

*'So, the rollercoaster started and through that period we're still fairly optimistic but we would (...) battle this thing. I read in the paper all the time now about people battling cancer and I keep thinking you shouldn't say that, cos it's not really a battle, it's trying to get better over a period, but I suppose a battle is (...) rather like the difference between passing away and dying isn't it. I don't like the term passing away. I prefer dying. People die. So, we thought we would get through this and we changed; did lots of things to change the way we lived. We changed our diets and we did exercise and we cut down on alcohol and (...) we were particularly positive right through the initial period and little did I know this would go on for fifteen years.'* (Harry, p.1)

*'We were in the kinda cancer continuum really after that.'* (Sally, p.2)

*'I found (...) you get what I call battle-hardened. You get initially problems and information that's very upsetting and then as time goes on and you have more visits to the Oncologist and more specialists and more people telling you things that are not good that you get battle hardened. You seem to be able to deal with them or ride through them relatively okay. You get really toughened to hard decisions and bad news.'* (George, p.1)

Even when people had had a time of remission, learning of a return of the disease seemed to be even more difficult than the initial hearing of the diagnosis.

*'The initial shock was bad enough but to get through all that and then think you were in the clear and then to be hit at the end with, 'No, it wasn't all clear. It had spread to other areas.' The second shock was worse than the first one if you know what I mean. You think you've done and you've put all the work in to overcome it over three years and then at the end of it, it's all been in vain. It's quite devastating that second hit.'* (George, p.1)

*'I pushed his wheelchair into ED and we spoke to the triage nurse and we were both in tears because of the amount of pain he was in and we went straight in and they pumped him full of morphine. And kept him in overnight and did a whole lot of testing and the next day, they found that he was riddled with cancer in his bones. I was at home, I was at home and the Specialist, who's a Surgeon, so I guess he doesn't have to do this too much – he phoned me up and told me. It was just crushing. It was just awful and I remember thinking I just want to go and hide. And then he said you need to come up and see Josh now. I thought, 'God, I've got to*

*drive up to the hospital.’ But I did. I drove up to the hospital and they’d cleared the - bless them, I don’t know whether you are familiar with the surgical ward but they’re just so crowded and horrible and they’d cleared this room for us. So, we could sit in this room and oh, it was, it was just hideous. Josh was terribly upset. I was terribly upset. It was just the most mind-blowing thing to know that someone suddenly got a terminal illness. Actually, this is it, ‘Where am I going to get the strength to keep going?’ (Grace, p.2)*

The following is a reflection on presenting symptoms. Most of the carers acknowledged this is one way or another during their interview:

*‘Looking back, if I had’ve known then what I do now, she could’ve pursued that a bit more. She did have a history of hemorrhoids, but when they started bleeding, it would have been better, I think, to have checked it out more thoroughly than what we did at the time. Probably, it’s like a lot of things, you get the warning signs, but it’s what you do with them that’s important, not just reading them. Anybody can read them, and understand them. It’s what you do about them that’s the important thing.’ (George, p.17)*

## ii) Medical Treatment Options

Couples varied in their approach to treatment options. Most stuck with conventional treatments as recommended by their Specialist.

*‘During that period (...) this is a fact I’ll never forget; sixteen different chemo materials, a couple of Docetaxel – it’s one that nearly killed her and put her in hospital. She had numerous tests and blood tests and visits to see the Oncologist and hair falling out, and days in bed and days up and so our life really changed then.’ (Harry, p.2)*

*‘We were both pretty sharp (...) on picking up the information cos I went to all the appointments with the Oncologist. I think anything you needed to know we got the information straight away and we were able to question them straight away or they would tell us. I was pretty aware of what was going on and who with. (...) you’re getting pamphlets, you’re getting information, you’re getting Cancer Society stuff, you’re getting feedback all the way along from different people.’ (George, p.15)*

*‘We went to see the Oncologist and he said, ‘Okay, so that you know, this is the situation. It’s terminal. What we can do is we can try and delay it as long as possible with this new drug which is a blocker that blocks and it’s like a chem, not even chemotherapy; it sort of is and it isn’t. It’s one that you take orally (...) and funding from Pharmac is about 10,000 bucks. (...) The idea is it stops all the DNA of the cancer spreading. So, it won’t take away, it’s too late for that cos it was everywhere. But it stops or slows down its growing.’ So we started on that and (...) just trying to get the blood pressure under control because I found out since all this, what*

*happens with kidney cancer is that your kidneys produce proteins which bugger up your blood pressure and so it's why it was so hard for the Doctor to get the blood pressure under control (...) So [the Oncologist] did the same thing with all the (...) different drugs for the blood pressure as well as all the drugs, you know, the steroids and everything. (Mark, p.3)*

Family carers were acutely aware of the need to be alert and organised when managing medications at home. This was particularly the case when calibrating the timing of taking medication.

*'As time went on, she was put on more and more medications particularly near the end when the pain medications come in, so I used to put on a shelf six or seven egg cups. I used to put in them the pills that she had to take. I had little bits of cardboard on them for the times that she had to take pills. I think that it was important to be well organized as a carer as to what medications they're taking and supervising the taking of them cos they were so important. Those medications were quite critical in keeping her going and keeping her quality of life up, as good as it could be, even though it wasn't great. As soon as the medications wore off you knew the symptoms of pain and discomfort came back in again pretty quickly.'* (George, p.3)

*'We just had pills so you weren't allowed to touch them, they're so disgustingly toxic. You have to shake them into the thing and it said on the jar and it said on the stuff not to touch them. I did wonder about how people that aren't competent would manage. Like they just give you all these drugs, masses of drugs and I had to sit down and work out. Okay, so I'd have the alarm on at six, and then give him the anti-nausea that had to be in an hour before the one you had to have at seven and that had to be two hours before the one that you had at nine. You kind of had to work it all out on your own which I didn't have any trouble with, but I did wonder how some people might sort it out.'* (Sally, p.5)

Half the couples investigated complementary therapies, and participated in these for a time. Of all those interviewed, Kirsten pursued this option the most. Common elements explored included Vitamin C infusions, acupuncture, oxygen therapy, and changes to diet and lifestyle.

*'Caleb [was] trying acupuncture. (...) Then he said it doesn't help him that much anymore. He had something else, what is it called – NIS [Neurological Integration System] (...) that helped him more. The Vitamin C went on for maybe a year or so three times a week. But that helped him too. And then I think they forbade food acid and alkaline, that we eat far too much acid. I then tried to find food which is more alkaline. And then maybe all together helped. And being in a loving relationship.'* (Kirsten, p.5)

*'I remember I said to him, 'What about diet? What I can do at home?' And he said, 'This is way beyond diet.' Which I think is not right, now. We're learning more and more about how much diet can affect cancer cells and the ketogenic diet's really quite interesting and researched.*

*There's not a lot done, but the stuff that I've read was really interesting around feeding those cancer cells or not. (...) He was just totally closed to anything like that.'* (Sally, p.17)

Of those who explored this option, Kirsten continued with this throughout the duration of Caleb's illness.

*'Because I have a bit of money and I supported him the whole way through. I paid \$25,000 for his acupuncture, he went four times a week. I could've saved that money. I could've made my best for him and I know I did all that.'* (Kirsten, p.9)

A key aspect of living in a regional community requires travel to Auckland, Christchurch or Wellington in order to access more specialised treatment including some surgeries and radiotherapy. For seven of the couples, treatment away from home often meant staying in accommodation provided by the Cancer Society and regular visits to the radiotherapy suite. Being away from home often meant being away from the support of family and friends, unless they were able to visit.

*'Then they said, 'The next thing we've gotta get the pressure off the brain.' That sounds worse when I tell it. So, they gave her huge amounts of steroids and they started what they had to do, radio treatment. (...) So, we went down to Christchurch and stayed at Daffodil House. That was fantastic what they do, and we went in there along with everyone else. Then you start [to] get your head around it; you start realising. Have you ever been down the end of the radiation area? It's like a big bunker down underneath the Christchurch Hospital. And it's quite a long-winded way to go down there. And they say there, 'Follow the yellow path.' You know, and it's all yellow, Cancer Society. And it's just everyday its traipsing, people traipsing down there, people traipsing back, all getting zapped. They've got five big treatment rooms and Rose was having that bloody mask put over her and all this sort of stuff.'* (Mark, p.2)

Even in the midst of difficult times, Grace was able to reflect back on travelling in the air ambulance and, with humour, recalling their flight.

*'We went down to Christchurch for him to have more radiotherapy on his arm. I thought he was completely mad but he wanted to do it. He made the decision and he had so little control of anything at that point that, 'Just a minute,' I thought, 'he's made a decision. It's something he's got control over. Let's do it.' So off we went to Christchurch in the air ambulance plane. I was terrified. I'm not good on planes. This plane is too small and we took off, and it sort of, you travel in the ambulance, you get there and you lower the patient into the plane and then they must wait for a gap in the planes coming in, cos we suddenly shot out onto the runway, we're up in the air and I was just so scared. After about quarter of an hour sort of relaxed enough to look out and thought, – 'This is quite pretty, I can look down on either side – it's like being in an executive jet.' And then I thought, 'Hold on, there's only one pilot. What if the pilot*

*has a heart attack?’ And I sat there, hands clenched onto the seat on either side of me for the rest of the flight looking at the pilot to be sure he wasn’t having a heart attack.’ (Grace, p.5)*

For three couples, surgery took place at a tertiary centre. Kirsten and Caleb accessed private health care to do this. For Sally and Luke, the surgery he required was not available in Nelson.

*‘We went up to Wellington. (...) The nurses were really kind (...) so I was feeding Luke good food and they let me put soups and stuff like that in their fridge. I kinda just settled in and was part of the ward. They were very good. And then we came back here and just got on with life and Luke had this massive scar with staples tuk tuk tuk tuk tuk tuk he looked like something out of Dracula.’ (Sally, p.5)*

As well as going to Christchurch, Penny and Jake went to Auckland for assessment for a lung transplant.

*‘We thought we’d go down to Christchurch to see the Specialist down there (...) who said, ‘Well, there’s probably not a lot we can do, but maybe we could have a look at you and at a lung transplant place up in Greenlane.’ So, we thought right, and we packed our bags and they sent us up to Auckland for about four days. I thought that might have been the turning point for him, where he could see people that are going through his journey that he was having. We could see people that were struggling with their health, with lung conditions and heart conditions, and then you could see people who had gone through their surgery. Cos where we stayed it was an amazing place and you could see people that’d just come out of surgery and just recovering. You’d see people that’ve come out the other side, that come back in and have checkups and things. Then we went through counselling sessions. We had various tests up there, a psych eval and that, (...) anyway we passed the first lot, I think. They didn’t really say very much. They sent us home again.’ (Penny, p.2)*

Some carers could identify a rhythm in their daily or weekly routines. This enabled them to go with the flow of appointments and all that was required to meet the needs of their unwell husband/ wife.

*‘It became a cycle of blood test, Oncologist, oncology ward, scan, blood test, see [the] Oncologist every week. Then into the pharmacy, pick up the drugs, go down there and get him to organize some laxative or something to stop her being crook – tighten her up a bit, or you know Panadol’s. (...) It was just full time. I was pretty much full time for four years looking after Beth.’ (Harry, p.3)*

*‘I found that when we were going through it you get into a special zone of time. Time, that is not something that you register on a clock. That sort of clock time goes out the window because time becomes a nonentity because you have so many hospital appointments where*

*you're sitting there for long periods and you can't afford to dwell on what time it is or how long you've been there. As I've said you forget about time. You just wait until the next thing happens which is an appointment like in an hour or hour and a half or two hours late and it sort of goes on so you get into that zone.'* (George, p.1)

*'We were trying to get her off steroids cos the radiotherapy worked. But then you got this big problem coming off steroids. (...) She'd be awake at five o'clock and hungry. All she wanted was a Vogel's really thin toast with marmalade that her friend had made. So, we'd be Hoovering through it by eight o'clock. Anyway, and she was quite up because of the steroids.'* (Mark, p.3)

### iii) Relationships with Medical Personnel

This was an area where positive relationships were critical. Where it went well, couples were positive and able to relax, engage in banter and develop a useful working relationship.

*'The Oncologist – we had a really good relationship. He's fantastic. Beth and [the Oncologist] were able to joke and laugh about things and he'd give her a bit of stick when she came in looking a bit frail. She was always interested in what was happening (...) so it was good conversation there. Always a few tears obviously when things weren't going right. And when things were going right it was good news. So, we never ask him about bad news. We'd only ask about the good news because if it was something like things weren't going right, we had to go back on chemo. Well, sometimes we were tense and frustrated. But by and by, you really just got to suck it up. There's nothing else you can do. You either do it or you don't.'* (Harry, p.12)

*'[The Specialist] said, 'You are a champion' because they didn't give him that long and he was still alive. It made a difference, a whole lot.'* (Kirsten, p.2)

*'My daughter had a colleague in America who was a cancer expert. He was one of the top people in America. What would happen was that we would get the information from [the local Oncologist] as to what the chemotherapy was going to be, and we would send it to him for consideration. So, we did have that input of another Oncologist offering help on what chemotherapy things might work or how they'd work, so we did make a bit of an effort, but nothing way out.'* (George, p.18)

During an inpatient admission to hospital, Mark observed the commitment of medical practitioners to the wellbeing of his wife, Rose. Such was the care and attention given, that he was still able to recall specific details of the experience.

*'We had this fantastic little Registrar, she looked about 13 and she was a short Irish girl and she was down there when I first went in and then at nine o'clock that night, I remember she was still there. And then I saw her wandering around that night and I saw her leave about 11 o'clock and then next morning she was there at seven. That day we were all just around and them saying, 'Well, we don't, you know, we're not too sure what we're gonna do here.' And then we all went home and then she finished about nine o'clock and then, unbeknown to us, she had had a thought about it and she did some research when she went home. She came back the next morning and she said, what did she say? She went and saw [the Oncologist] and she said, 'I think I know what Rose's got and it's a press..., which is: women who get pregnant have high blood pressure get it and they go into a coma because their brain expands and its reverse, its posterior or reversible, I can't remember, it's something.' And now we had, everything changed. All of a sudden, they started putting back in the drugs and started treating her like there were some signs, but over the next ten days, (...) [the Oncologist] had the hard job to tell us that it's not reversing, it's not looking that good. And we have to see what we are going to do.'* (Matt, p.4-5)

However, when it did not go well, tension developed and dissatisfaction tainted the professional relationship.

*'I think he was arrogant in that he knew best. Then I said I wanted to change Oncologists and [the Oncologist] rang me up at home, which I think was absolutely appalling – on the home line so I didn't know it was him ringing. I just answered the phone and he was angry and said, 'Why are you changing Consultant's? I have given you the most incredible care.' It was just so shocking, cos you should be able to change if you want to change. And [another Oncologist] was so much better, so much more open and yes, she was much better. But [the initial Oncologist] found me very difficult.'* (Sally, p.8)

Missed opportunities occurred both in the hospital and in the community. This included an error in correctly diagnosing the illness; for another couple it was feeling ignored and having their needs disregarded by their GP. Three families laid complaints following the death of their family member.

*'We got rid of the Doctor. The Doctor was a chapter in our life that we never liked. (...) We got another Doctor from the same practice. It was a completely different kettle of fish and she was absolutely fantastic. Beth's Doctor would never come and see her and she lived in [town]. We were on the way to [town] and so she wouldn't, she never came up. Not once. But when we got the new Doctor, (...) she was fantastic and she'd pop in any time. She'd pop in because she was interested in Beth. I laid a complaint with [the medical practice] when Beth died and I did get a response from them. I had a response, not a written response, from a couple of practitioners there, and they weren't happy with what went on. (...) It was unsatisfactory. (...) I rang her one day. I wanted her to come and do something and she insisted I take Beth there. I couldn't have got Beth there, you know. It was really just prescribing something. She needed something prescribed, which she needed to get from her GP. But she wouldn't do that. [Dr \_]*

*was the one that ended up coming out and she was bloody awesome. (...) She's a really good practitioner. (...) She was so lovely; to have her take such an interest in Beth was really good. When you need someone, you need someone. And I've never been in that situation before of actually needing a house call. And it was only one house call. It wasn't like it was a major. And she could have done it. She could have done it.'* (Harry, p.5-6)

*'We would have liked to have avoided all those so-called errors of judgment that different Doctor's made who were involved. That was a bit disheartening cos there was a chance that had it been picked up earlier, you know, the outcome might have been better. That's what you tend to think. Like months can go by when you're being treated for hemorrhoids – probably six months went by. Then of course the cancer was inside growing and spreading. So that was not good. That Doctor did apologise and so on but anyway it's a small consolation. The Radiologist wrote us a nice personal letter which I appreciate. The fact is that he apologized for not reading it properly and making that mistake, and so that was good to get that. (...) My son is (...) very capable with written documentation (...) so he set out all the complaints and sent them away.'* (George, p.16)

*'Luke had a lump in his groin and [the Oncologist] just said 'That's the least of your problems. (...) This is what we have to worry about.' But actually, we should've been referred across and when we got over there, the Surgeon, he was like beside himself. (...) He went 'WOW! Why have you not been sent over here?' So, then we had to go to Hutt [Hospital] and Luke had this thing removed and then he had trouble with drainage, and it did really make quite an effect on his quality of life towards the end. (...) [The Oncologist] was just dismissive of it. But it turned into a massive (...) it was a cancer, obviously, and then that's the one that went through his liver and his other organs. Then he had another, he had another tumour in his brain that was all connected to that. And that could have been surgically removed really early on before it was anything. Luke was still running and it was this great thing, and the guy, when we got over there, this really top Surgeon, said it was about to burst. He said, 'Holy shit, where have you been?' It was like we come from the provinces.'* (Sally, p.7)

Rather than make a formal complaint, Sally decided to take a different approach to dealing with health professionals she was unhappy with. When sending thank you letters, she chose not to include the names of people whom she considered to be unhelpful in caring for her husband.

*'We did have one nurse that [we] had problems with. After the surgery, Luke was in the ICU and she was from overseas (...) and I called her the weetbix nurse cos she got her qualification in a weetbix box. But she and I had words because she, first of all, she – the first time she did something, she moved the bed that Luke was connected to. (...) He had the drip in his arms and the things up his nose, and she was moving the bed and it was (...) pulling on the things and I said 'STOP!' and she was just oblivious. (...) I said, 'He doesn't need to move. What are you doing?' And she's moving the bed somewhere else or something. And I said, 'But he's attached.'*

*You can't move.' Cos he's attached to these things in the ICU. The next time, which was shortly afterwards, she took the thing out of his nose; I don't know if she was going to move his bed still, and she put it down on the bed linen and then she did whatever she did, and then she picked it up without gloves or anything like that on her hands, and she was going to put it back in. And I said, 'You can't put that anywhere near him. You need a new one, surely.' I said, 'You and I are going to get on really well if you – see that line around this bed. Don't ever come back in here. I don't know how you shift your shifts, I don't know how you'll manage it. And I won't make a complaint about you. You just don't come near us again. Go away.' She scuttled away. The rest were really, really good; brilliant, some brilliant nurses we came across. So instead of writing a complaint about her, I can't remember all the other things she did but she was incompetent. So instead, I listed all the people so that someone would be able to look at all the people that had had contact with us and see that her name wasn't included. So, I did it by omission.'* (Sally, p.2-3)

For each person, the decision to stop seeking curative treatment occurred when they came to a place of saying 'Enough, I'm done.' In some instances, this was as a result of a negative reaction to chemotherapy or being advised by the attending Specialist that their lifespan was decreasing.

*'Probably about the June, our Specialist was away and there was this UK Doctor that came up to [hospital] and he wanted to see Jake. He was respiratory and he more or less said to Jake, 'No, you haven't got long.' Jake and I looked at each other and said, 'What do you mean, haven't got long?' He said, 'Well, I think it's probably time that you did your bucket list.' That was a gift. The June or July, so I thought, 'Really, are you saying that he's gonna die soon or what are you saying?' That was quite hard because he was 58 and I was 54 and kids were quite young still. I thought, 'This is terrible.' And so, came home and cried about it. We told the boys and thought, 'What's happening?' That was really hard cos we couldn't work out how long he had. We didn't know whether he had one week or whether he had two months or whether he had six months or twelve months. It was the hardest thing. So, we had to make the most of everything that you had, so we did.'* (Penny, p.3)

*'We did everything. (...) really at the end of the day we probably knew that the writing was on the wall because the liver was so badly affected.'* (Harry, p.13)

*'We were told that Isla's health professionals couldn't really do anything to heal. All they could do was make her swallow a bit better and give her drugs to suppress the pain and the nausea she was subject to. (...) When they told us what the implications were of putting a stent further up her throat and it would cause her possibly discomfort because of some nerves there, that was a big factor that meant she'd have a constant sensation of something blocking her throat all the time. So, in the end we decided it wasn't worth going ahead with the second stent.'* (Matt, p.2)

*'Josh tried some drugs which (...) had a chance of increasing his life but neither of them was successful so (...) that was another big down real big down was him saying, 'I don't want to keep going with the treatment.' He made that decision. I mean it was a sort of forced choice in a way because he reacted so badly to the drugs, but there was a definite point where he said to [the Oncologist], 'I don't want to do this anymore. I don't want to do the treatment' and that was very hard.'* (Grace, p.2)

#### iv) Referral to Hospice

Being referred to hospice was not always an easy transition, partially because families were comfortable with their existing health care providers, and partially because of people's own understandings of what hospice was.

*'We didn't come to the hospice because Luke had a thing about the hospice. We just live up there and he used to say every time we came down and across the ford, he'd say, 'Those poor bastards in there.' So, he just had that thing about it.'* (Sally, p.12)

However, as couples became familiar with the role of hospice in their lives their concerns faded.

*'When I said to people, 'We're going to get referred to hospice,' some people looked at me and said, 'But he's not dying.' I said, 'No, it may not be time, but I need the help.' Jake's sister, the one who's sick now, she used to really, just simply we were close to her, said, 'Why do you want to do that? Why do you want to bring hospice in?' I said, 'Because I need some help. You know, I really need that help. I need some agencies to help us get through some of these times cos they're really hard.' And it's probably now she actually gets it.'* (Penny, p.25)

Along with appreciating the support that came from hospice in the home, came moments of profound realisation.

*'That was another horror – I mean, I think the day when your partner goes into the hospice is a real reality. I can remember sitting there, and I was shaking. My teeth were chattering because it was such a, 'Here we are. This is it. We're here. This is going to be it.' It was a real reality. 'This is really happening. I'm really sitting; I'm really sitting in a hospice bedroom.' Yeah, it was amazing. (...) But he didn't come out of the hospice again.'* (Grace, p.5)

For half the families, the expertise of hospice care was especially helpful for assessing and making changes to medication as new symptoms and changes were occurring.

*'The hospice was a great institution for people in my situation, no doubt about that. (...) Like, I think that was the longest night I've ever had (...) trying to regulate the pain. (...) It was just unbearable for me. (...) Trying to get through that night and so when that's taken off your*

*hands, I just remember her being wheeled out down the path and thinking, 'Thank goodness someone's helping her out cos I'd done all I could do.' So that was good.'* (George, p.18)

Providing care at home to one's husband/ wife was something that everyone embraced. During the interviews, memories of time spent together illustrated the ordinariness of daily activities combined with pragmatism of getting on with what needed to be done.

*'We were getting a lady coming in about three times a week to shower him which was really good because I found it hard because he would get angry with me and I didn't want him to get angry. He didn't want to get angry with me, so we would get Access in to help us shower three times a week. They would come in while I'm at work and they would do that. And that was the best thing I ever did because he wouldn't argue with them and they were briefed on what his condition was. The condition was that they had to make him the last of the day because by the time he finally got out of bed and he had to have time. It took ages to shower or to even shave. It was just the energy.'* (Penny, p.6)

The very ordinariness of daily living and functioning with an unwell spouse had the ability to test the bonds of marriage. Despite this, spouses continued on with providing care and support at home.

*'It's a really long haul and (...) because Beth wanted to be alive (...) and because of the health situation (...) she got quite angry at times. (...) She also got quite picky, especially at me. (...) I got so frustrated. Just about so many things that were so frustrating. (...) having the tap going too large in the bathroom when you were actually cleaning your teeth or clacking the cupboard doors closed when you weren't actually. She was becoming more sensitive to things, you see. You'd sort of close the cupboards quietly and she'd sit and you'd take a cup of tea out to her in bed and she'd say, 'Stop clacking those cupboard doors all the time.' And you weren't. Later on, probably only three or four months before she died, um her snoring. (...) She'd be zonked out on material, she'd snore like crazy. (...) And two o'clock in the morning, I'd just have to go and sleep in another room. She got grumpy and that sort of thing, because we'd spent 40 years sleeping together, so it was frustrating. Got bloody frustrating.'* (Harry, p.3)

Half the carers were able to recall a specific crisis situation that marked a definite turning point in their ability to continue caring for their spouse at home. In these situations, the transition from 'business as usual' to responding and acting at a more critical level occurred within a short space of time.

*'I woke up one morning and got ready, looked over at Rose and she was nice and asleep, so I thought I'll leave her. Got up and had a shower and stuff, came out here and went to work, and went and checked how she was still breathing. About nine o'clock I checked her again and thought, 'She hasn't really moved.' So, I tried to wake her and I couldn't wake her. I thought, 'She's still breathing. She's just passed out or something.' She had earplugs in, so I took her earplugs out and said, 'Rose, Rose!' and I shook her. She sort of looked at me and I said, 'Rose'*

*and she said, 'No, no.' So, (...) I called 111. (...) We finally got her into hospital and her blood pressure was through the roof. (...) They said, 'We'll boost up the steroids.' They did that and it wasn't working and she's like, 'I think we're gonna lose her.' And I thought, 'What?' (...) That was weird, that was awful. (...) And they said, 'Oh well, you better ring your family.' So, I had to ring the boys again and said, 'Looks like Mum's going.' That was terrible too. (...) So, they, course they said, 'We'll come over right now.' (...) They flew overnight and drove up and then they got - the following morning, they got there. Rose was still alive. I said, 'She's still alive.' That was really good. That was fantastic. But she was hardly responsive. (...) But when the kids came home, she'd open her eyes and I said, 'Rose, the kids are here.' (...) And she loved that. Wherever they went, she just followed them.' (Matt, p.4)*

#### v) Reflections

Drawing from their experience as spouses who had cared for their husband/ wife throughout their illness, some reflections were made about the healthcare journey.

*'Diagnosis and the correct diagnosis of these issues is something that I believe is quite critical and as a result in a lot of cases have quite averagey feelings about medical practitioners. I do believe that anyone that suspects there's something wrong with them should be advised from more than one person. I think that's absolutely critical.'* (Harry, p.1)

*'There's nothing you can do in your diet, change your diet, or the way you live that will extend your life. I don't believe there is. I don't believe it, cos everyone says, 'Oh, it must be the dairy' and you cut out the dairy. 'We're gonna do this. We're gonna eat lots of nuts. We're going to have only greens and broccoli and we're going to' – we did all that. Beth still died. (...) They did it, they said it because of, you know. And it doesn't work. You may as well keep going the way you were. But you might want to change. You might think the change isn't going to do you any harm. But I don't think those things work.'* (Harry, p.13)

*'I believe all of this medicine is really, it's just a big financial thing. I'm really convinced of that. The drug companies do well out of cancer. They do really, really well, and their shareholders get a fantastic return. Some of the materials [the Oncologist] told us what some of the materials were and some of these single or two treatments of some of these materials are like two, three or four thousand dollars. Just incredible cost, incredible. (...) The whole health thing is just a big numbers game really. It's just incredible.'* (Harry, p.14)

*'The treatment was all in vain. All the bloody chemo – it's all for nothing in the finish (...) that's the way it is.'* (George, p.19)

*'The hospital oncology department, I just regard it as the seventh circle of hell. It's very noisy, its rooms are antique – five people in a room – mixed rooms, so there's men and women in the same room. I thought it was cruel and it was noisy. Josh was in there twice. One time the police had to be called to take away relatives who were fighting. (...) They were continually noisy. There were people everywhere, the television was blaring. There was a woman in his room who wouldn't stop talking; shouting. It's just, it's just such a horrible place.'* (Grace, p.6)

*'I went to see (...) Josh's Oncologist. He writes a letter to the bereaved spouses, which is very sweet, and he says, 'If you'd like to come and see me to talk anything over, make an appointment.' So, I did. I don't know how many people do it (...) cos it's horrible going back into that environment where you sat for so long. I said to him, 'If they'd found the cancer in Josh's bones earlier, would it have made a difference? Could you have done anything?' And he said, 'No.' So I said, 'I'm glad we didn't know.' Because Josh had that really good six years of his retirement where he was enjoying himself and I'm really glad he didn't know, really glad he didn't know, glad none of us didn't know.'* (Grace, p.10)

*'I kinda worked on lime chutney and fruit cake, right through the process so that the Surgeon would distinguish which person Luke was. He was the fruit cake and chutney man, not just another person. One of the Oncologists over there was like, 'Can I keep the fruit cake. My parents are coming from overseas.' I remember thinking this was quite weird really. She said, 'They won't be here for another week. Will it keep?' I said, 'Yeah, yeah. It will be good.' So, it must be special to have home baking, cos they work so hard and they see you at seven in the morning and ten at night. Amazing, those Consultants anyway. (...) They were pretty amazing really. Yeah, so I just made fruitcakes all the way through and lime chutney.'* (Sally, p.7)

## Theme 2: The Home Circle of Care

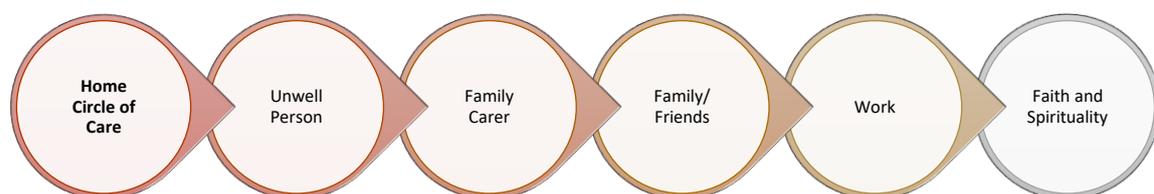


Figure 10: Subthemes for the Home Circle of Care

## i) Unwell Person

During each interview each person gave vivid descriptions of their husband/ wife that honoured them. The descriptions were full of action-oriented words and portraying men and women actively involved with their families, their interests, their workplaces and the world around them. As well as acknowledging their wives' careers, husbands complemented their wives as creative homemakers and their roles in raising their children. Wives acknowledged their husbands' responsibilities in providing for their families, their values and their personal characteristics. The following is a selection of words used:

*'He was a beekeeper and he was an artist and he was everything.'* (Sally, p.16)

*'Josh, my husband, was a very, very optimistic person, hugely optimistic. He was always looking on the sunny side of life which is hugely refreshing.'* (Grace, p.19)

*'He went every single Saturday to visit his sons the whole day.'* (Kirsten, p.4)

*'He was always a hard worker. So, he always wanted to feel that he could support the family, always.'* (Penny, p.2)

*'She was a clever person, so she was a great nurse, well liked as a nurse and then well liked as a Plunket Nurse and good homemaker, brought up great kids – taught them good ways and (...) we had a really good relationship and probably a life that lots of other um – we were hard workers though.'* (Harry, p.9)

*'When our daughter came back from overseas (...) Ruth gave up her jobs and took the responsibility of looking after the two kids so [our daughter] could do a full-time job. She became like a de facto mother during the week.'* (George, p.14)

*'Rose was an avid gymmie. She loved to go to the gym and she was pretty healthy and fit. (...) She still instructed aerobics.'* (Mark, p.1)

Within each relationship was a picture of contentment, a committed relationship with good communication, coupled with the freedom for each person to pursue their own interests and careers. None of the couples had children at home; most were either away studying or working. It was a time of life where the couples were looking forward to the next chapter of their lives after raising children.

Six of the couples were in their first marriage. Six of the carers were still actively engaged in the workforce.

*'He, at that point decided he wanted to retire. So, he took early retirement in 2009, and he had six years of retirement. So, it was a really good move. He took a long time to recover from the operation. But he did lots of fishing and biking and he had a little part time job that he did to earn the money to pay for his hobbies.'* (Grace, p.1)

*'So, we'd each had a previous partner and then fourteen years together as a second relationship. Yeah, which doesn't sound like that long. Fourteen years. But it was pretty action packed because we didn't have any children really. They'd all gone and were at university and doing their own things. So yeah, we did lots of travelling and lots of stuff together. Probably more than a lot of people would fit into longer.'* (Sally, p.20)

*'We were both looking forward to the years of our retirement and Isla kept on saying to me, 'When I'm a little old lady, I'm going to do this.' This, implying that I wouldn't be here, sort of thing. (...) We had retired and we were living here and Isla was pretty keen on gardening and this is why we chose this place. (...) so we were enjoying living here and we often went for walks (...) up the hills and that. She was keeping herself quite fit. She'd go for a run in the morning quite often. And she went to the Doctor for an assessment on her general health. And the result came back that I think she was in the top five percent as far as heart health went.'* (Matt, p.1)

Once illness became a feature of their lives, people still had that strong urge to maintain a life that was as normal as possible.

*'It was always a highlight when he says he feels better and he went to work again.'* (Kirsten, p.2)

*'He was so strong and so determined that you had to keep an eye on him, so people came up to the house while I went to work. Cos otherwise, he was told not to drive right from diagnosis; he wasn't allowed to. He was on his bike which was okay. He used to bike up to the hospital for his oncology appointments and we went to Wellington for seven weeks for (...) radiotherapy; and Luke booked a trip on the Tongariro Crossing for the last weekend. So, we went away most weekends from Wellington. We went up to these friends that are on a farm (...) in the Hawkes Bay. You know, we went to all sorts of places and had a nice holiday really. (...) Luke romped up there and back after seven weeks of radiotherapy.'* (Sally, p.16)

*'We did what he wanted cos his body was sick but his mind wasn't.'* (Penny, p.18)

*'When we started doing the music, she became the leader and I made a big effort to be in the background playing the guitar and providing the accompaniment and she was the one that led the kids. Ruth and I felt really good about that. It was as I was saying, she had forty years of doing my bidding and now here was I putting her at the front. She got dressed up in nice clothes, going out doing this, and I made a conscious effort to try and elevate her, making her the head person in the team. I felt good about that.'* (George, p.12)

*'We got to see a different country in those years when Beth was in remission. Even after that we still could travel, so we did. We had an interest in going up to holiday in Thailand too, so it's good up there. (...) Beth went there not long before she died. (...) I just had a gutsful of it all and wouldn't go. So, I paid for her and a friend to go and they had a ball. (...). Beth was pretty bald and pretty scrawny at that stage. She was quite pleased to see a bit of weight loss but she didn't look that great. When she got dressed up, she did look quite good (...) but, the weight loss thing was one of the bonuses that she saw.'* (Harry, p.11)

When it came to decision making around pursuing treatment options, carers were really clear that this was not their role. Jenny and Harry described their role in supporting their spouses' decisions.

*'I made sure that he did what he wanted. I always made sure I didn't put my opinions in too much because that would cause too much friction I would think. I would support him whatever he wanted. He decided he didn't want the lung transplant. (...) He didn't and then he did. When he decided he did, it was too late. I supported him through that. And that was really hard. (...) I really wanted him to have it in 2012, but he didn't want it then. He was probably well enough to have it then. But once he got to 2014, he wasn't well enough; his lungs had deteriorated more. (...) That was his decision. (...) And I think that's really important too, cos you can't change their journey. They've got to decide what their journeys are.'* (Jenny, p.22)

*'People will say, 'If I was getting in that situation, I would stop. I would stop. There's no way.' Course they're not sick, are they? The drive when people get sick and I'm the same myself; I'd want to go through that. And you won't really know until you're in that position, will you? There's no way that Beth wouldn't have; so, it was never up to me to say whether she should do it or not. We never even discussed it. (...) Beth would have said if she wanted to do it or not. So, it's up to the individual. Beth was there. It's her life (...) and this goes back to the fact that we were quite open about what's happening. We didn't discuss it all the time but we knew what was happening.'* (Harry, p.14)

*'Rose said to me when she was diagnosed (...) we used to sit down and have these great talks. (...) She'd say, 'Okay now, the only thing I don't want you to do is – don't get another woman for two months after I've gone.' Two months. I think knowing full well that, cos she reckons, 'I don't know how you're going to cope. You need another woman.' (...) Which I suppose is a natural thing for her to say because I hadn't done any of the household stuff.'* (Mark, p.13)

Accompanying ill health over a period of time, family carers did notice a change in the personhood of their spouse.

*'It was amazingly tough what she actually went through. Especially when she's had chemo's that reacted badly with her. (...) Then there's the diarrhoea, there's the not liking all sorts of foods, not knowing which foods can be taken and which can't. She wanted to look better, so she spent a lot of money on clothes. Oh, it's completely irrational. In my case, her rationality was no longer the issue I suppose. But then, you'd have periods where she was really, really good. Just depending on where she was at the time. So, (...) for four years I cobbled and cooked every meal. Cos, she couldn't stand the smell of food cooking. I don't know whether all the cancer patients were like this because I never bothered to find out. So, food was an issue. Everything was an issue actually. Even the dog shaking was an issue. And her moods, quite - I got to the stage that I thought, 'Right, I'm going to write down everything that Beth doesn't like just to see how many things that Beth doesn't like and that fill in my day.' I think I got to 80 - 80 things that niggled her on a regular basis. But I ripped that long list up long before she died and I threw it away. She just got crooker and crooker and crooker and we realized that she wasn't ever going to get better.'* (Harry, p.4)

*'I think we sort of did lose him along the way anyway. It's really hard to explain. He wasn't the Jake we had. He wasn't the father or the husband we had because he was so sick. (...) He wasn't this guy that bowled in the door at night and said, 'Come on, guys. We're going out.' Or, 'Let's go and have a game of cricket' or something like that. He couldn't do that. He lost that, lost the energy. He had no energy. Worked, hard worker; always outside doing something.'* (Penny, p.21)

## ii) Family Carer

In reflecting on their role as a family carer, everyone made it very clear how important it was for them to be able to provide the support and care at home, companionship their spouse during their illness.

*'I never thought about walking away. (...) I remember Josh saying, 'This isn't something that's supposed to happen.' (...) I said, 'Ah, but it does, in the marriage it says, 'for richer, for poorer; in sickness and in health' so it does say. It is something that happens.' But no, I didn't, I never contemplated not being with Josh (...) You just don't do that and I never even thought about it. (...) You can't take any of the suffering away. You can't take anyone's suffering away. All you can do is walk beside them. (...) They've far worse to face than you have. You walk alongside, but you don't suffer the way that they suffer; I mean you suffer but you don't have it the way that they suffer.'* (Grace, p.14)

*'I would never have left Caleb. (...) I always said he was the love of my life.'* (Kirsten, p.4)

*'We really just worked together on this and (...) I found that quite easy. I'm quite a do anything sort of a bloke and we'd worked well for 30 years before that so it was just a matter of carrying on.'* (Harry, p.1)

*'There's no second thought. There's not a second thought.'* (Mark, p.29)

Life together during their spouse's illness had times of busyness, times of quietness, and times of realisation that changes were coming, if not already there.

*'I can't stand sitting around and that's probably why I didn't mind looking after Beth so much. (...) It's quite a busy, it's a big job (...) You gotta buy a lot of groceries and do all the washing and keep the beds made and clean them. Some days I was having to change the sheets twice. (...) Going through, I think she went through about four or five or maybe six stages where she lost her hair, so every time she lost her hair - it would get to a stage where it was on the verge of starting to fall, seriously fall out and then one morning she'd have a shower and she'd start washing her hair and all this hair. (...) But just hair everywhere – and the bottom of the shower. That would be the day we'd have to go off down to the hairdresser (...) and get it taken off. It's a long haul and if someone had said it was gonna last sort of 15 years, but it did, right from woe to go, it was about 14-15 years.'* (Harry, p.9-10)

*'When she was sick, we had our 37th wedding anniversary and I remember we were here. It was still a bit cold. (...) We had the fire going and she wasn't very mobile by then, so I remember we just sat here and we'd been sent a lovely CD of Christian music so we listened to that and enjoyed that. I remember Isla sending an email to the people that were praying for us and our family and everyone saying how much we enjoyed doing that.'* (Matt, p.7)

All the carers had to find a way to be present and supportive during their spouses' illness. Sometimes this required rethinking everyday activities. Other times it required searching out 'tips and tricks' or options that might provide hope for a different future.

*'You've got to survive. You've got to survive these sorts of things in the best way you can.'* (Grace, p.18)

*'As far as caring for Isla, she didn't eat much so I didn't have to cook much. So that wasn't an issue. I washed her clothes in the washing machine and made a few meals like soup and (...) made her jellies and got her some special food from the chemist that you mixed up with water. (...) My daughter and her husband, (...) came up from Christchurch and stayed with us during the last couple of weeks, and my son and daughter-in-law lived over here. Our sections are joined so you can just walk through to, and they had one little girl at the time, so we had one*

*grandchild at that stage. So, they came and visited Isla quite often in the hospice and my daughter and her husband (...) came and stayed here and we went in and visited every day. We prayed with her, we sang hymns and that sort of thing. That was sort of good family times.'* (Matt, p.3)

*'I think people just soldier on as much as they can and they do. They do. Financially it was really hard. I used to find it quite hard to do things but if we needed to do things, I'd just pull some money out and if we needed some tyres for the car, or something like that. Keeping up the insurance was hard to keep up because (...) his insurance was quite high in the end.'* (Penny, p.17)

*'It was tough, but it was kinda enjoyable. It was kinda enjoyable to be able to do it cos I'd want it done for me, if you know what I mean?'* (Harry, p.6)

*'As far as the looking after side of it, I found that very easy because I'd been a very demanding person for probably 35-40 years as a husband because of my career. (...) It was all about me (...) and my wife had been very supportive of all that and took very much a back seat in what was going on. When it came time to care for her in a bigger way, I just realised it was a real small payback for 30 or 40 years of her supporting me. So that was very easy as far as the caring goes.'* (George, p.1)

*'It was so intense. There wasn't time to (...) think about anything but looking after Rose. There was nothing else.'* (Mark, p.8)

Searching out knowledge and options was important for most of the participants. This was certainly one way that family carers felt able to sustain their role as an advocate in the search for hope. This endured into the bereavement phase as well, with carers commenting on breakthroughs and updates in medical thinking.

*'There must be blogs where people have kept really good notes and helpful things. I never really looked for one. It would be good to have some that people had written, or something that would be useful, maybe. I don't know. I wish I'd kept a blog, cos I think I learned a lot of stuff that would have been quite handy to other people.'* (Sally, p.6)

*'The Cancer Society have one travelling lecture a year, every year. That year it was brain tumours. So, Luke and I went to that and this woman was amazing and she was at Brisbane Hospital and her thing was brain tumours and glioblastoma multiform and she was just on fire. (...) So, I contacted [the Manager] and said, 'Is it okay (...) if you ask her if I could email her and*

*be in touch with her?’ (...) So, (...) I sent her a whole pile of questions (...) and she answered all of them. Like pages and pages of work – amazing. And wasn’t that amazing that that was the cancer that they did that year?’ (Sally, p.10)*

*‘There’s these guys at the Malaghan Institute in Wellington. They’re doing some amazing stuff. (...) I think they’ve developed something now that’s (...) looking at enzymes and helping the (...) I think it’s more like one of those things that keep you going. It builds that up instead of wiping everything out, like with the chemo.’ (Sally, p.11)*

All of the family carers developed strategies for self-care. Most of these involved some form of exercise, although not exclusively. This provided an important opportunity for time away from their role at home.

*‘I found I was acutely aware of how healthy I was. (...) I did actually keep going to exercise, that was really important, so I swam. Doing swimming and that sort of thing, I remember thinking, ‘You’re so healthy cos this poor man is getting sicker and sicker and I feel so healthy.’ It was most likely guilt.’ (Grace, p.14)*

*‘I think one of the important things is taking care of your own health and maintaining your own fitness and health through it all, so you were in pretty good shape to help the one that is sick. You couldn’t afford both of you to be down, both of you in a bad place, that would be very difficult. I was fit and healthy and strong and had interests outside of the house that I maintained just to keep myself in good shape, in a good frame of mind.’ (George, p.2)*

*‘Beth and I had other interests as well. I was involved in an international club and so I was able to go to those meetings around the place which Beth generally came with me too. I think I only went to a couple without her and every year they were in a different country in the world. So, we got to see a different country in those years and when Beth was in remission. Even after that we could still travel, so we did. We had an interest in going up to holiday in Thailand, too; so, it’s good up there. It’s sort of an escape up there. (...) Really it was just a matter of muddling on, you know.’ (Harry, p.11)*

*‘A couple of Beth’s friends or one particular friend who lived away would visit her (...) and I could ring her up every now and again and have a grumble about Beth and her manner. (...) But it didn’t stop me doing the job that needed to be done and I actually quite enjoyed it to be honest.’ (Harry, p.3)*

iii) Family and friends

Keeping adult children involved in current information affecting their parent's wellbeing was important to everyone. Most had adult children who lived remotely from their parents, so travelling in and out of Nelson to provide support was important to those families. For the couples who had children living in Nelson, the constancy of that support was gratefully appreciated.

*'It was all like bang! Ringing the boys up, jeez, that was horrible. It was the most horrible thing; (...) most worst thing you can do.'* (Mark, p.2)

*'We had to tell our sons. (...) I remember ringing [one son] up and he was just a mess on the other end of the phone and I was in a mess here, and so we booked him to come to fly up to Nelson the next day. (...) It was just, it was terrible for our sons. They were in their 20s, so they're quite young. They were just completely devastated. The other son was going to travel overseas for a competition, so we decided not to tell him until after he'd done this. We thought we'd give him one more nice experience before he's in this hell. So, we didn't tell him for three weeks. It was very hard not to tell him. (...) But telling our sons was one of the ghastly experiences.'* (Grace, p.2)

*'After that first meeting, one of the kids thought (...) we weren't telling her everything. And I went away and thought about it. (...) So, I rang them both up and said, 'I want you to come to all the oncology appointments.' (...) Then I rang [the Oncologist's] nurse who's amazing. That whole system was really, really excellent and said, '[The Oncologist] has a small office. Can you please let him know we're all coming, the whole whānau is going to come? There's going to be this many people and two babies.'* (Sally, p.8)

*'One of the nice things that happened when we first went down to Christchurch was that Josh's brother and his wife, my brother-in-law and sister-in-law, they actually flew over from Australia and joined us in Christchurch for a weekend. So, it was amazing. So, I was staying at the Cancer Society place and they were staying in a motel but it meant we could take Josh out for walks in the park with the wheelchair cos I couldn't do it by myself cos it was too heavy. But my brother-in-law could push the wheelchair. So, we did things like take Josh out of the oncology ward and take him (...) [for] coffee in the boatshed café and walked in the park and all that sort of thing. So, we got some normalish time.'* (Grace, p.2)

An important aspect of maintaining family communication and caring was finding ways to involve and include everyone at a level that was appropriate for their circumstances.

*'I've got a daughter that lives out at Richmond with a couple of grandchildren and towards the end my son came from the UK for probably two or three months. Ruth had a couple of sisters*

*and a brother that were very good. And I have a sister. My sister is very good in these sorts of situations when a family member is going through problems, cos there's one thing, she always brings around things to eat. She used to bring our lunch almost every day at the hospice. She's still the same. She likes helping people in a real sense, like bringing cooked meals, bringing lunch, so that was good. So, I had her, and then my son and I used to share sleeping at the hospice. We'd do night about, so you get a night back in your own bed. And those sorts of things, so that was very good having him here.'* (George, p.7)

*'[Our older son] decided to come home. (...) He moved back home. That winter things really hit the fan. [Jake] struggled and if I didn't have [our son] to support us at home. So, for us it was trying to get him, to keep him well – having the oxygen, keeping the tablets going. It was really hard and working as well. I worked four days a week and had Fridays off. (...) Then [our son] was home during the day to look after him through the other days, just to try and get through.'* (Penny, p.3)

*'I think we're close because we've experienced a lot. (...) They step up in a way that they have to, not because they want to, but because it's in them. (...) They said to me, 'Tell him he can go.' Cos he was hanging. 'Tell him he can go. Give him permission.' So, I said to him, 'It's okay, the boys can take care of me now. You've done a great job.' That's what I said, 'You've done your job. You've done a great job.' I said, 'Look, the boys are here. I just give you permission to go now.' And they stepped up.'* (Penny, p.27)

Friends were also a key part of the support team. They helped fill the gaps and gave a perspective of life away from illness. Distraction is a great therapy.

*'There were a lot of people praying. There was a Christian nurse and she promised to pray for Isla. In the meantime, she moved to the United Kingdom and she was still praying for her. We had a nephew and his wife and family in Indonesia there and they were praying, and a niece and her husband and family in Australia, they were praying. And some missionary people in South America. Lots of our friends in Christchurch (...) were praying as well. And our relations. So, we felt really well supported and although we did think God had perhaps started to heal Isla, it was only a week (...) that the dryness in her mouth came back again and she continued to get weaker and weaker. There were some people, a group of people who had been through a course (...) and they were taught to minister to people and pray for people (...) so they came and prayed for her, at least twice in the hospice. The elders from [our] Church came and prayed for Isla at least once here and probably twice in the hospice.'* (Matt, p.3)

*'We had people that would come in if I wanted to go out. There would be people looking in. I have to say another source of support was there was just some really faithful friends of Josh's that visited very regularly. (...) So, someone would come every Sunday to bring him communion. I think that was just really very impressive – they never missed. (...) The Parish*

*Priest came every week. So, it was nice for me because I knew those people were coming because I think (...) it could be enormously difficult if your ill spouse wasn't getting support from anyone except you. I think you'd just die under the – collapse under the strain. I think it's really important that he was getting to see other people and having them visit and that was enormously positive for him.'* (Grace, p.4)

*'Beth and I had a really, really good network of friends. (...) They were really supportive, so they'd come around. (...) The thought of people coming around for people that are chronically or terminally ill like Beth is probably not great, but when the support people do get there, it generally does cheer them up. I haven't ever seen an instance where that didn't happen. So, she had a few girlfriends that would come around on a regular basis and see her and that was good.'* (Harry, p.6)

*'I had [support] from my mates as much as many boys can do. They were bloody good; (...) they've all kicked in after which is fantastic. But Rose, all Rose's gym friends, there was food being dropped off and there [were] people coming to visit. (...) But everybody was very conscious, it was such an intense thing. (...) Everybody was very respectful. But all her friends were really lovely, really nice through that. (...) But it was so intense (...) There wasn't time to (...) think about anything but looking after Rose. (...) There was nothing else.'* (Mark, p.8)

Family life doesn't go on hold simply because one's spouse is terminally ill. The following is a list of events that occurred and impacted couples living with terminal illness:

- \* witness to a murder (Kirsten, p.7)
- \* mother diagnosed with dementia (Grace, p.9)
- \* received a diagnosis of terminal illness whilst in the midst of house renovations (Mark, p.3)
- \* sons diagnosed with illnesses that have a genetic link to their father's illness (Penny, p.20)
- \* other deaths in the wider family (Penny, p.13)
- \* daughter getting married (Harry, p.15; Matt, p.5)

#### iv) Work

For all of the people who were unwell, returning to full time work following a diagnosis was not possible. Luke and Josh took early retirement (Sally, p.2; Grace, p.1).

*'Josh, at that point, decided he wanted to retire, so he took early retirement in 2009 and he had six years of retirement and I think he, Josh just loved being retired. So, it was a really good move. He took a long time to recover from the operation, but he did lots of fishing and biking*

*and he had a little part time job that he did to earn the money to pay for his hobbies.’ (Grace, p.1)*

Jake and Caleb had periods when they were sufficiently well to return to work for periods of time (Penny, p.2; Kirsten, p.4). Isla and Ruth had not been in paid employment at the time of becoming unwell (Matt, p.1; George, p.9). Following her initial recovery from her illness Beth returned to work. However, once she and Harry began travelling, she resigned from paid work (Harry, p.2). Rose’s illness progressed so quickly there was not an opportunity to even think about work (Mark, p.8).

For the carers, there were distinct differences in their financial circumstances which enabled them to make different choices. Two of the men were retired (George, p.12; Matt, p.1). The other two were self-employed and able to take time from their business to attend to the needs of their wives (Harry, p.2; Mark, p.2). Notwithstanding having his own business, Harry valued the opportunity to go to work in a reduced capacity to attend to his own wellbeing.

*‘Our life really changed then and I was fortunate that I had a company big enough that it could run on its own. My daughter was running it anyway. (...) Both of them were working for me at that stage in the company and I was able to spend a lot of time at home. So that’s how I was able to keep Beth at home the whole time and basically meet every appointment, take every chemical, give her all the treatment that needed to be done and keep going. (...) It was full time. I was pretty much full time for four years looking after Beth. I’d still go out there maybe in the mornings about 9.00, stay till lunchtime, stay till 11.30 or something, go home for three hours, maybe go back to work. She was quite happy cruising. I mean, she wasn’t laid up in bed all the time.’ (Harry, p.2)*

*‘[Work] was an escape, a great escape for me. I could get out and go to work. It was good. Yeah, yeah. I really liked that. I liked getting away. I liked getting in the car and driving away. Beth got a bit cross with me at times, but I always had an excuse to get to work because I thought I was indispensable at work. I had to be there. But it was a period when the company was doing really, really well. We had ambitious plans and we had to go through those plans and keep things going. We were employing more and more people and making more and more product. (...) So, it was always a good excuse to go to work.’ (Harry, p.10)*

Kirsten also worked from home and was able to accommodate her employment with attending to Caleb’s needs (Kirsten, p.4). Grace, Sally and Penny made changes to their work routines in order to still be able to bring in an income, maintain their employment and be available to support their husbands.

*'You just lose one whole salary. You've got two salaries coming in and suddenly you've got one and you've got all the same outgoings pretty much. Then I worked part time for a year. I run the practice out there. (...) I don't know how I did that and I had relief counsellors. Those people were there to cover for me and take on clients. (...) Both Colleges were extraordinarily good. Very adaptable to me and letting me do what I did, which was probably just survive for a year.'* (Sally, p.19)

*'Work was so important to me (...) because I needed somewhere, an outlet, because it was so hard at home. I would get up five o'clock cos I had to start work at seven. So, I'd get up and have a shower, have my breakfast, and I'd make sure that his medication [was attended to]. (...) He would stay in bed, cos it was just so hard to get out of bed. So, I'd just leave him in bed and he would just get out of bed when he can and would make his way. (...) I think work probably was good for me cos I could actually be up and be someone else outside. No one had to know what I was experiencing at home having a sick husband.'* (Penny, p.12)

*'Work (...) to take you away from where you are at, just to give you that release and then you come back refreshed and you come back and deal with the pain that you're experiencing at home and coping with at home.'* (Penny, p.24)

Of the people interviewed, Penny was perhaps the least able to reduce her hours or give up work altogether because of her modest income.

*'The only regret is probably that I didn't stay at home. I was working probably a lot, but he supported me going out and I think he felt that I needed to go out. He'd say, 'I'm okay. I'm alright.' And so, I took that. It was always in the back of my mind. I did feel guilty at times having to go to work, that he was so sick. The guilt was probably really hard in the last year, but what made it easier was having someone else at home to help, you know, family.'* (Penny, p.18)

The women spoke of being aware that their lives would continue on following the deaths of their husbands and they still needed a career to return to.

*'At the other end, I still had to do something at the other end. I had to have a beginning and I had to have a middle and I had to have an end as well to keep me going.'* (Penny, p.23)

*'I kept working but I reduced my hours a lot, so I did keep working but often I needed half days. I also kept some of my normal hobby things going so I still went to my French classes. I did a couple of things every week that kept me in touch with my normal life. I think that was a good thing to do because also it meant that after Josh had died that was intact and I could just keep*

*going. (...) I think it would be quite hard to have to restart things again when I didn't have the energy, because I'd been doing it all the time.'* (Grace, p.3)

#### v) Faith and Spirituality

For two of the unwell spouses, God was an important component of their lives. Matt and Isla had a network of people praying for a miracle, equally accepting that God might choose not to heal her here on earth.

*'We do believe in miracles (...) we believe that God does heal and we were praying for his desire for that sort of outcome. So (...) we had the hope that the Lord might heal Isla. But we sort of were aware that God doesn't always heal and that the other possibility is quite on the cards as well. So that's how we looked at it.'* (Matt, p.2)

*'You know when you're complying with what it says in the Bible in James Chapter five: 'If there are any sick people, they should call for the elders of the church, and they will pray for them and anoint them with oil and they will be healed.' (...) Isla said to me, that she wasn't worried whatever the outcome because she knew that if she died, she'd go to heaven, and that if she was healed that would be good too. She said she was more worried about me because I'd have to deal with losing her, which was true of course; so that's basically how we dealt with it.'* (Matt, p.2-3)

*'He was a man of faith and he was on his trajectory. He knew (...) and his faith was very strong.'* (Grace, p.8)

For Jake, nearing the end of his life opened up an opportunity to reconnect with God. He spent time with the Hospice Chaplain. It was important to the two wives that their Christian husbands had their spiritual needs met.

*'He wanted [the Chaplain] and they talked about that. [The Chaplain] did his funeral. He was lovely. He talked to the boys and that sort of thing. They had that time together and I think that was really important because I wasn't a Christian. I didn't know what he wanted. What I did know, he always used to recite the Lord's prayer. When he was really sick, he would just recite it (...) 'My Father, who art in heaven, hallowed be thy name' would come up all the time, so we actually put that in his service because it obviously meant and gave him comfort. It gave him comfort. (...) Even though he wasn't very religious but obviously he felt it was in there and it was good that [the Chaplain] was there when he was there. We were just so blessed to have him because shortly after that time, he helped us with the ashes and we had a thing here on his birthday on the next year 2015 and then [the Chaplain] left hospice. It was like Wow. [He] was a massive part of Jake's journey and now he's gone. How lucky was I to have him? How lucky was Jake to have him in that journey? What would we have done if he wasn't there?'*

*Would there have been someone else that Jake would have had that attachment with? I don't know. That was something that I'm really very grateful for. Very, very grateful.'* (Penny, p.25)

For others, the mere mention of God was anathema to them. Two wives gave strict instructions on this issue.

*'The other connected thing was she didn't want God mentioned at the funeral either. She's an atheist.'* (Mark, p.5)

*'We're not religious people. She didn't believe in God; Beth's mother and father are very religious, but Beth was not religious. (...) She was a nurse so she knew the consequences. She knew the path she was on.'* (Harry, p.11)

Another carer spoke about the importance of spiritual practices that helped her.

*'The strength – it's probably just believing (...) is that I saw this happening, if it's good or bad. That helped me a lot because then you look and its day and night and those belong together. Good and bad things belong together for all people. If it was always good, we wouldn't even know that it was good. (...) Love is kind of like a power. No, it's not gone.'* (Kirsten, p.8)

Two of the women spoke of their house being blessed following the death of their husband. This was a cultural practice for one of the women.

*'The school came and blessed the house. (...) [Our neighbor] said it was the most moving thing she's ever been part of. So [Mātua], he teaches Māori at Nelson College. He came with some boys and they went right through the house and told Luke's spirit that it wasn't to stay there. It needed to move on. (...) We were at the funeral when he did that.'* (Sally, p.22)

### Theme 3: Saying Goodbye

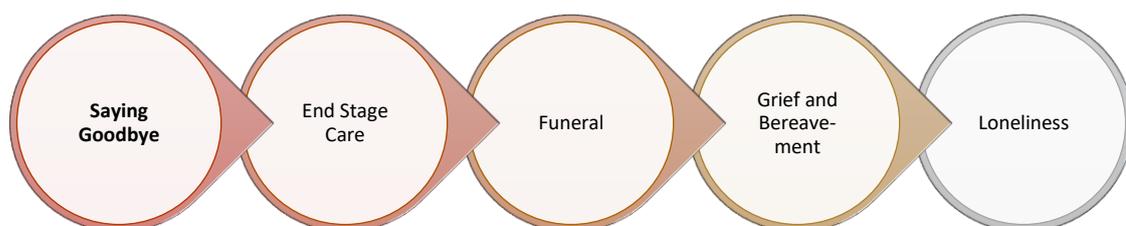


Figure 11: Subthemes for Saying Goodbye

i) End Stage Care

All of those interviewed were aware when their husband/ wife was nearing the end of their life. All were present at the time of death. Whether at home or in the hospice, a network of support was an important feature of how well this was managed.

*'She gradually got weaker and weaker and there was a time when we thought it would be best that one of us slept in the room with her. So, we did that the last few days and [my son] and I took turns. (...) Isla had some little notebook that her mother had given her with lots of encouraging verses from the Bible in it and so I was reading (...) John Chapter 14, that's a very encouraging chapter and I got to verse 27 which is about peace. 'My peace I leave with you, Jesus said to his disciples, not as the world gives. Let not your heart be troubled.' I was just writing the verse down in her little pad when she breathed her last.'* (Matt, p.3)

*'On the Wednesday, 'No more visitors.' It was really hard because there were some. This is the hardest thing, because there were people waiting in the little wee lounge that wanted to see him (...) cos the message had gone out that Jake is not very well. Some of it was family. I just said, 'Look, I'm sorry. You're too late. He just wants (...) the kids and I there.' They said, 'Really?' and I said, 'At the moment he does.' I said, 'I'm so sorry. He's just too tired, you know. Just can't.' My mother was there. My brother was there. We have to accept his wishes. (...) He was really low (...) and he passed away that day. (...) It was really funny because when he did go, the kids and I were there and it was such a long drawn out thing. (...) He's got such a funny sense of humour. When he did pass, they said, 'Look, we'll count it as such and such a time.' And then he promptly started breathing again. We said, 'Jake, what's going on? End it.' And we always laugh about that. He wasn't quite ready and then five minutes later he took his last breath. He had us on the edge of our feet from the word go. But that was him.'* (Penny, p.6)

*'She eventually died one night. The girls had been round to see her in the day, that day and had just gone home and Beth had gone to sleep. (...) I went to bed and I woke up at two o'clock in the morning and Beth was dead.'* (Harry, p.7)

*'We had fifteen people staying at home. (...) So, it brought us together a lot really. (...) We were all living up there together and just had [the hospice nurse] come in once a day which was really cool. Then [our Doctor] said to me, 'You don't have to rush when he dies. (...) You can just enjoy and have the time together.' And the hospice nurse (...) I went out on the Saturday, out to the car, and thanked this woman. I said to her, 'Thank you so much. You've been marvellous.' (...) He slipped away at 2.20 in the morning and so I'd sent my son to go and wake everyone up and he died and then they all came in and we were all there together.'* (Sally, p.14)

### i) Funeral

Four of the family carers spoke about the funeral arrangements for their deceased husband/ wife. Each arrangement reflected the person who had died, their views and their perspectives regarding how to farewell a loved one.

*'I left [our sons] to do a lot of stuff like doing the coffin they wanted. We had a really good friend who was the undertaker and he came up and spoke to the to the boys and they worked it out.'* (Penny, p.21)

*Beth had already arranged all the funeral and all her post dying, what she wanted done. She'd already gifted some money to her Godchildren and set up a Grandchildren's Trust to put her Superannuation money in and she had an insurance policy as well. We decided that we'd put it into a Grandchildren's Trust in case they needed anything done before they reach 21, urgent money. She'd planned her letter that went in the newspaper and she's planned what she was going to do. We'd already prepaid her cremation. (...) So, the plan was that she wanted to just be cremated and no one, no family, nothing. So that's what happened. (...) We didn't go to the cremation. We didn't need to. We stayed in the gardens and as I recall, we took some bubbles and some baguettes and it was really good. It was so awesome. Yeah, it was good. (...) We got the ashes back and (...) it was right at the end of the summer, she wanted to be spread sprinkled into [her favourite] River. (...) A couple of weeks after Beth died, we had a celebration in the garden.'* (Harry, p.7)

*'We had a good service for her and then kids stayed round for another week or so, and then (...) they went back and I carried on. And I continue to carry on.'* (Mark, p.6)

### ii) Grief and Bereavement

The grief experienced when one loses a spouse in the prime of life is huge. It can be messy and leak into all areas of one's life, and is not easily contained. The following sections are an attempt to make some sense of what the people who were interviewed experienced. It is not as discrete an entity as might be indicated, more of a blending and merging of grief and bereavement into every part of one's being and the world that is encountered.

As each carer embarked on the process of learning to live a life without the person they had lived with and loved for many years, there was a stark rawness to their sense of being.

*'The next day I thought, 'I'm not worth anymore to anyone.' I was loved and I was here for him the whole day really helping him to wash and eat and things. He could pretty much eat himself but I was loved.'* (Kirsten, p.3)

*'From going along like life's normal to nothing's ever normal anymore.'* (Mark, p.7)

*'There was the incredible weekend when people were coming and there was a funeral to arrange. And then it all goes quiet. My sons flew off and I sat here thinking, 'Oh, here's the first day of the rest of your life, sitting in a house by yourself.' (...) Just everything turned upside down, everything. (...) All the plans you have got for the future, everything's changed; nothing's the same anymore. (...) Nothing is the same, nothing. I suppose some things are still the same. I still go to work still, but in terms of your aspirations I don't like thinking too far into the future now cos I can only see a lonely old age and I don't want to look at that. I think one of the things about being a young widow which is really useful is that you've still got work. So, you've still got structure to my life.'* (Grace, p.9)

Trying to navigate through the days and establish a family routine that included memories of their deceased spouse was important.

*'The first year was pretty shitty I'd have to say, trying to juggle everything. It's pretty good now. So, first year wasn't great. It was terrible. (...) We have had a trip up Mt Arthur every year at the time when he died, cos that's where we put his ashes the next year. (...) I haven't yet got a seat. We looked at getting a seat. I haven't really decided where to put it yet. So, that's probably the last bit of the kind of memorially stuff.'* (Sally, p.15)

When close family are not around, this can compound the sense of loss that is felt.

*'You've got this layer of skin over the grief because you've learned to sort of cope but underneath is a huge hole. That's my metaphor about where I am now. There's this layer of skin and I put up a good pretence and people say, 'You're so cheerful.' I'm not. I'm just having a really good pretence at it but underneath there's this huge gaping hole. So, that's what my life's like now. It is quite lonely because my family are a long way away and that's as it should be. Your sons and daughters grow up and get on with their own lives. I just wish they weren't quite so far away sometimes. But my son needs to be going to do his PhD. It's what should be happening. My older son's got a lovely partner now. That's all the things that should be happening now. It is a bit lonely and there's things that happen and I just think, 'Oh why isn't Josh here?' I had to meet my son's partner, meet the parents. 'Why am I doing this alone?' So, there's lots I feel sorry for Josh because there's so much he's missed. He's already missed a whole lot of life.'* (Grace, p.12)

As time passes, people who have provided support begin to move on with their lives, yet those who are bereaved might not be able to do this so easily.

*'I've been devastated by cancer and my whole life has changed. And yet people stop thinking about you quite quickly; stop thinking about you in that way.'* (Grace, p.12)

*'I presume, most of us [are] conscious of not (...) badgering our buddy our friends about woes and how we feel and that. You've got to be really careful who you talk to about it.'* (Mark, p.35)

Alongside recognition of the pain of losing a husband/ wife came an acknowledgement, that in some way, people did need to find a way forward.

*'Everyone talks about two years; but as my mate said, 'That's bullshit, it's not two years. It can be different for so many people.' Generally. I'm sort of like it's a plateau. I still feel the same way, in a lot of ways, as I did two months into it. (...) There's a big black hole and that's the grief (...) and what you do is you work your way round it but it's always there. And so, you sort of get used to that hole being there. It's always there, but you just get on with your life. (...) I don't want to be defined by my grief about Rose because I don't want to be defined as I was only known as a husband and a son. (...) I want to live my life now. I want to live it even in honour of Rose, cos she used to [say], – 'You just live your life and look after the boys.'* (Mark, p.35)

### iii) Loneliness

In the process of navigating a new life without a loved husband or wife, the bereaved person becomes aware that although life has changed, there is still living to be done. Two bereaved carers, who do not have family living close by for support, offered the following thoughts.

*'What's my life now? So, I've got my work. I'm thinking about moving house because this house is too big for me and it's got too many memories. I have an elderly mother with dementia that I have to (...) at least see, visit regularly. It's a different sort of life. It's sad, lonely. (...) It's really different not having a partner so you haven't got someone to talk things over with. You spend a lot of time on your own. I guess [it's] about valuing what you've got. In fact, sometimes when I'm feeling really miserable, I tell myself, 'You're healthy, you have a house, you have a job, you have enough to eat, you live in a safe country. Stop moaning.' Because I think it's about counting your blessings because we take things for granted.'* (Grace, p.9)

*'I found my confidence took a bit hit actually. I'm not as confident. (...) I think I've lost my belief in happy endings. So, I expect things to go badly and not go well. (...) Josh, my husband, was a very, very optimistic person, hugely optimistic. He was always looking on the sunny side which was very refreshing because my own family are intensely pessimistic. And I think I acquired a lot of that but it's very hard to keep that up. I tend to think about things going wrong rather than things going right.'* (Grace, p.19)

*'Even though I'm incredibly lonely every day, I'm not lonely cos it's a different way. I feel okay about the guys, a really cool network and [my colleague] she's worked for me for 20 years. (...) I've got lots of cool friends and people who care about me and that. Both Rose and I went from*

*home to marriage, neither of us flatted. (...) I say to people [when] we're talking about it; I say, 'I'm flatted for the first time in my life. At age 58 I started flatted when Rose died, and I'm still flatted.' And the thing about that is that you really, it's the first time - the first time in my life I've never been a son or a husband, I'm just me. I'm a father as first and foremost, that's good. But from when we were talking about just living here, cos the boys are over in Australia, so, there's none of this, 'Come and call round for tea' and that sort of stuff. That just doesn't happen, which I'd love, but that's just the way it is. So, I'm just me now. And I'm fine with it. I've found out so much about myself that I'm surprised. I'm really surprised.'* (Mark, p.12)

One person had tried dating, but found it wasn't for him.

*'They're always trying to jack me up with other women. They are surprised how it's been so long and I haven't got another partner. (...) If you've been with someone for all of your adult life and it's been a good marriage, a loving you know, a nice marriage, a good marriage, there's this I don't know that its respect, but it's this feeling that there's honour that you don't want to shack up with someone else too soon.'* (Mark, p.12)

Two people have established new relationships. In both instances, they had known the person before they were bereaved.

*'I got friendly with a [woman]. (...) I said, 'I'm going (...) overseas for four months and do you want to come?' Cos she'd been talking about having a holiday. She'd been working for 35 years and never had a holiday, never been overseas. So, she said, 'I'll come.' (...) Then came back home and after that got married. (...) So that's where we're at. Sold the family home. 19 years and I built a new home which we thoroughly enjoy and are cracking on. But the thought of being married for all that time doesn't go away; still living with a lot of furniture in the house that was Beth's and mine. Beth and I collected artworks. (...) All of that's still hanging up in the house, in our new home. So, those memories don't go away.'* (Harry, p.8)

#### Theme 4: Picking up the Threads

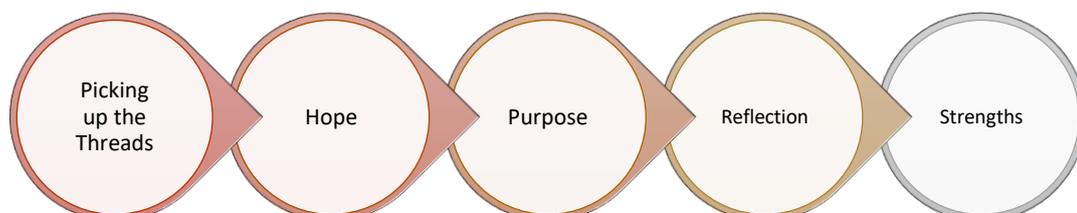


Figure 12: Subthemes for Picking up the Threads

For all of the bereaved carers, picking up the threads of life as a widow/ widower had an impact on how they saw themselves and their relationships. It challenged them to find hope for their future, and some were actively grappling with this. It required a change of thinking about how they filled in their day, their week, their month, their year. For those who had been planning for forty years towards a retirement plan that was no longer possible, how did they make sense of their future?

i) Hope

In searching for hope, bereaved carers looked to their own personal resources, their family and their friends for support. It also came from books, and from encounters with unexpected sources.

*'Where did I get the support from? I got support from my work colleagues. I got support from my friends. I got a lot of support from Josh's family, particularly my sister-in-law, Josh's brother's wife. She was really good at keeping really good contact. They came over several times. They were here the day he died, from Australia. Which is pretty good. (...) I think my sons and I have provided a certain amount of support for each other. I don't know if I've been as supportive to them as I should have been. It's quite difficult to support other people when you're feeling unsupported yourself. I didn't want them to feel that they had to look after me because that changes the relationship. When my own father died, my mother collapsed and it just changed our relationship so much and I didn't really want that. I wanted us to still have a relationship (...) I didn't want them to feel that they had to look after me. I wanted them to see me as someone who was strong, (...) who they were able to leave. I didn't want them to worry. I wanted them to be able to go and get back into their lives without worrying about me.'* (Grace, p.13)

*'Since her death, I've shifted to another church now. (...) I was sitting in the chair waiting for the service to start and someone slapped me on the shoulder and said, 'Hello, Matt' and it was the senior pastor there. (...) I knew him from way back. And that was a really good welcome. (...) He phoned me up a couple of days later and said, 'Would you like to join a small group?' I said, 'Yes, that would be lovely.' So, he invited me to join the small group that he goes to. That's really great. We can pray together and support one another and there's members of the group like me who've lost their husband or wife. One of them lost their husband recently. She hasn't come back to the homegroup yet, but presumably she will. Another chap who's quite a bit older than me, he lost his wife going on three years ago as well, so you know, people in the same situation as me. So that's been quite a help.'* (Matt, p.4)

*'I tell what's something else that was really, really good for me, was really good for me. (...) Lucy Hone (Hone, 2016) wrote 'What Abi Taught Us.' I bought and read it about three times. I'm not a good reader at all. (...) I read this book, I've read it about four to five times. I bought about five, six copies and gave it to the sons, and some other people that were going through some crap and it's really, really good. (...) It gave me affirmation of things I had been doing.*

*(...) If I could tell anybody, suggest something to do for anybody who's going through it, it would be that. Particularly that book's really good cos its written so nicely from someone (...) whose gone through it.' (Mark, p.21)*

Having an interest in their family is enormously satisfying for everyone. A sense of humour also helps.

*'I am happy in my own space. I think probably my best thing now is to make sure my children, our children are okay. (...) My ambition is to get [my son] through his studies and then I'm free. Then I can go and do some holidays.' (Penny, p.10)*

*'It really mattered to me that the stepchildren – I was really shocked at that thing, some of them had already ditched their stepchildren. (...) I thought woo. That was a really useful learning from that hospice thing, from the bereavement group. And I thought, 'I have to make that a focus (...) keeping the family together.' (...) So, I had big family lunches on Sundays for that whole year. Now it's really well established and the kids are good and again the three grandchildren, two of them are five and [the youngest] who wasn't born is now three. She was three, two or three months ago. So, I'm definitely the grandmother even though I'm not related. (...) That was really important. They were all on the journey. We were all on the journey together.' (Sally, p.20)*

*'They can talk really freely now about their father and stuff like that. The other night was quite funny. [My son] came for tea with his girlfriend and (...) I was doing something for [him]. I said, 'What did your last slave die of?' sort of thing. And he said, 'Actually, Mum, he died of lung disease.' Well if you can laugh, I said, 'You're right.' You can laugh about things like that now. You can get, that will be the sort of thing that Jake would want to hear. (...) We don't have to sugarcoat anything now, like we used to. We used to be a little bit more reserved. We can be, 'You know, it's alright.' We give ourselves permission now, which is really good to say a few things.' (Penny, p.20)*

*'I went to Australia thirteen times cos the boys were saying, 'Okay, it's Easter, you're not staying home. Come over.' 'It's this, you're not staying at home. Come over.' Cos the weekends are (...) the hardest, you know, times when you're not working.' (Mark, p.10)*

*'I have a pretty good relationship with my kids and they trust me with talking about a lot of things – business and the company. When I sold the family home, I was able to distribute some of that money out to the kids.' (Harry, p.16)*

*'I've got the freedom that's probably about the nicest thing that's come out of it. I've got the freedom you know to get up when I want, eat when I want and do what I want. But you've lost so much for that freedom, you've lost so much.'* (Penny, p.13)

*'I like tramping, quite often go tramping with my two sisters and their husbands. [The] last tramp I went on (...) my 2 sisters and I were talking about what preparation we had done for this tramp. So, they said, 'Oh yeah, we've done a bit of bike riding and walking. What have you been doing?' And I said, 'Oh, mowed the lawns.' But mind you this is half an acre section almost so it's a reasonable amount of exercise to mow the lawns and when we were walking up some of the steep places. I was doing reasonably well when one of my sisters said to me, 'You sure that's all you've been doing – just mowing the lawns?' I don't carry much weight so that probably helps.'* (Matt, p.7-8)

Not all family relationships go smoothly following a bereavement. Two people spoke of tension between family members.

*'It puts a huge strain on families. To my great grief my sons aren't really talking to each other. (...) There's something that was said at the time Josh died, around that time when everyone is so tense and uptight.'* (Grace, p.18)

*'[My daughter] and my new wife don't hit it off that well, for what reason I don't know. (...) So, there's a little bit of tension there which I'm trying to smooth out. Whether I'm able to try convince everyone that we're going to have Christmas together. (...) We did the first year. But it was all a bit tense. Last year they went to Golden Bay but [my wife] and I decided to go up to Waiheke Island for Christmas. It was great. No tension. No family. It was good, but I missed the grandkids, so I want to have Christmas back with them this year. So, [my wife's] okay with that.'* (Harry, p.15)

Friends help to bridge the gap that opens with loss of a spouse.

*'It's surprising because what I found is that there's a whole bunch of people around you (...) that I would class as acquaintances. They live their life and you live yours (...) not real mates, not real friends. (...) I always thought there were only ever five friends in life. (...) Now, that's different. (...) What these people are, they're good people. (...) We only ever see the goodness in people. If the shit hits the fan, they just come in, they go from being acquaintance to supporter. Then as they see you getting better, they go back out again, so it then goes back to normal, but it's really, really interesting. They're just waiting to help. (...) That's what everybody said to me. I said, 'You guys.' 'Well, we're just giving you back what you give out.'* (Mark, p.9)

*'I don't have sort of much social life. I like going to the pictures and stuff like that. And going with a few friends from work. We go to that or to the theatre if there's a show or something on. (...) I'm just a very quiet simple person really.'* (Penny, p.11)

ii) Purpose

Work, retirement and finances were discussed by everyone to varying degrees. Work gave people a means of structuring their day and gave them a sense of purpose.

*'Work keeps me going which is really good. I have my ups and downs at work. But they're very, very supportive because of the work that I do there.'* (Penny, p.10)

*'I think one of the things about being a young widow which is really useful is that you've still got work, so you've still got structure to my life. It's an important anchor and it gives you a reason, it gives your life structure and (...) I think that's easier than if you're older and you haven't got that structure because although work drives me nuts sometimes, at least I've got people around me and someone to talk to.'* (Grace, p.9)

For the two men who were officially of retirement age, part time work helped to give them some sense of purpose.

*'You need those structures. (...) I also work for [a monthly publication]. I'm the deputy editor but that only commits me to about three days towards the end of the month just before publication. I do all the proof reading of that. I also write an article for it. I kept it going all the time when Ruth was sick. I kept it going because I've been doing that for over ten years.'* (George, p.11)

*'While I was at [the] Bay, I met a friend (...) and I told him about Isla's death. He said to me, 'I could give you a job if you like to keep your mind off things.' He owns a business that rents out property. He said, 'I need someone to put the rental signs in place and put a rented sticker on them when the property's been rented and take the sign away after the tenants have moved in. I could pay you to do that. Would you like to do that?' I said, 'Yeah, that'd be alright.' (...) So that keeps me occupied and gives me a source of income as well. They are a good company to work for. Pretty much all of them are Christians I think, so I really enjoy doing that. So that's another thing which helps me to do other things and put some of my sadness behind me. But as you can see, it's a long process.'* (Matt, p.6)

For the two men who owned their own business they had a differing approach to work. Harry decided to retire from his business, whereas Mark found the people he met in his business a valuable source of support.

*'One of the things that really never interested me after that was going back to work. I just lost interest in work after that. (...) I'm 68 this year (...) I decided I wasn't going to go back to work.'* (Harry, p.8)

*'I have my own business and I have a client base here, and now I've bought one close by as well (...) basically 90% are retired. So, I've got quite a few widows (...) I can't believe how supportive they've been. We're on a professional basis but they've been clients for 15 years or more, all that sort of stuff. They have been fantastic. The women (...) really understand and they talk about it and they always give me a big hug (...) which is really nice from a business perspective. (...) That's another discussion about the grief hole; they have that hole, this grief hole and the whole of their life. Whereas I've got a business. I'm busy working every day with people five days a week. And that's interestingly what the widows have told me (...) that when their husbands died and they were working, their jobs kept them sane, kept them busy. It kept them sane, helped them through it.'* (Mark, p.10-11)

For those who were still in the midst of careers and looking towards retirement, losing their husband/wife scuppered plans they had been working towards.

*'I look at couples now, you know four years on and they've got grandchildren and they're starting to look at retiring cos some of them are a lot older than us. (...) I'm not even thinking about retiring, you know. I'm still working, yeah. It's just, it's really quite strange. My journey, that journey's changed for me. Yeah. What I thought we were going to do, can't do.'* (Penny, p.10)

*'Our big plan which we were heading towards the year Rose got diagnosed (...) we were going to sell this, buy an apartment and then buy a small apartment in Australia and I was going to spend three months here, one month over there, or we were. That was our big plan cos [our family] they're camped there, our sons might come back, but I don't know when. That was our plan so there's – all gone. (...) So, what I did was I had the chance to buy another business. (...) It's about keeping busy. (...) Then, that's another bizarre thing that life throws at you. When you stop worrying about the money, more of it seems to come in. I don't know how, that's another whole story.'* (Mark, p.24)

The women interviewed were all in their 50s when they lost their husbands. For them, finances were a concern. Some had to unravel financial affairs that had not been discussed due to the nature of the illness. Others had to contend with real estate agents.

*'Financially it's a real issue isn't it. I had three real estate agents ring me up. I don't know how they do it or how they sleep at night, but I won't be going anywhere near the three of them. They were thinking like vultures that I'd have to sell. 'So sorry Sally, that's Luke's died. We just wanted to touch base and were wondering if you'd like to sell, if you'd like to ...' It was quite upsetting.'* (Sally, p.19)

*'You've got to survive these sorts of things in the best way you can. Losing your husband so early (...) but there's an awful lotta life left. (...) We had a vision about what we were going to do in our retirement. (...) When Josh retired early, we had to change. It was a bit of a loss then because typically a couple, when the children leave home, and then you have some real income earning years which you can salt away some money to fund your retirement later. I remember having grief about that, what we weren't going to have (...) a little stockpile which would let us have a comfortable (...) retirement. (...) I needn't have worried but (...) you just worried about money. (...) We had lots of plans and they've just gone.'* (Grace, p.19)

*'For Jake's anniversary (...) we went over there. I took the kids over there. (...) I paid off the house. He was very good. (...) I was earning an income and just trying to pay the bills and stuff. I still managed to. And he had some insurance money and he sort of said to me, 'Right, pay your mortgage off, get yourself a nice little car, take the kids for a holiday.' So, we decided that on the first anniversary that we would go away. Went over two weeks to Australia, but it was without him.'* (Penny, p.9)

### iii) Reflections

In reflecting back on their experiences, some thoughtful comments were offered.

*'I think everyone's got their own life and I don't think other people can interfere in other people's lives too much either, you know. I, we hear it all the time. Someone will say, 'Oh, God knows why they are doing that.' Who cares, you know? Let 'em do it. It's what they do. How can anyone dictate or call shot on someone else? (...) [On getting married] I don't think my kids are annoyed. I think they probably thought I'd maybe should've given it another couple of years. My reasoning was that I'm getting a lot older, and I've only got one more crack at building another house and getting moved and getting settled down again, you know, so with someone that would look after me, so yeah. We have, I have a fantastic relationship compared to where I was with Beth at the end of that relationship. This new relationship, I'm thinking, 'My God, yes this is what it was like. This is fantastic.'* (Harry, p.16)

*'I never plan that much anymore because what was the point? (...) I'm just que será, será, a bit. (...) That's why if someone says, 'Do this.' I'll do it, I'll go here, I'll go there, because why not? Cos that's what it does to you, you know. This changes everything, how you think. Yeah and you're finding yourself, more and more of yourself.'* (Mark, p.25)

*'I get this too now. I look at people gosh, especially poor refugees and that; they've lost bloody the whole family and extended family and they're still living. I get that now though. Never could, never got it, never got it – 'Why didn't you just top yourself? What's the point of living?' But the human spirit, just you go on living cos you go through that. Why, I don't know. (...) They've lost absolutely everything, there's nothing to go back to – no country, no family, no extended family. The whole village is gone, but they keep on going, cos there's just – it's what we do.'* (Mark, p.22)

*'Being positive including not taking life for granted, make family close, do the things that you want to do, and just try and be happy. (...) I think I am pretty happy. (...) I'm debt free and I think that's really great. I've got the freedom to do what I like. I've got lovely children. I've got a lovely mother and brother – family, so I'm really, really lucky. Jake's sister, on the side. I think I am very lucky. (...) I really would love to travel. I think I've got that in the back of my mind, and I'm still young. I'm going to be 58 in a couple of months, so I know I've still got plenty of time. That's probably enough, I just feel that I've got time on my, I like to think I've got time on my side. You never know whether you've got time on your side. (...) We were very young when. We were very young. He was not long after turning 22. (...) We had a really good marriage, and like we didn't have a lot. But what we did have was ours. We worked for it. We worked blimmin hard. He worked hard. He worked six days a week. He worked six days a week to support the family. He was always really good, I really, really appreciated that.'* (Penny, p.15)

*'I didn't have a clue what she had written about me until I read it in the paper and I was oh, oh mmm. Cos it was quite amazing what she wrote. So, it was rewarding. I think it was quite rewarding. I wouldn't change that either. It's good. (...) I'm sure that there are a lot of other cases out there that are just like it. I think she had pretty good care too.'* (Harry, p.18)

*'Good and bad things belong together for all people. If it was always good, we wouldn't even know that it was good.'* (Kirsten, p.8)

*'Why fret about that I have fretted about all my life cos it's actually meaningless? Yeah, the same thing I [thought] I'd never survive this. (...) but you do and you go, 'Well, why worry about what other people think? Why worry about [a] whole lot of other stuff?''* (Mark, p.22)

#### iv) Strengths (as identified by family carers)

During each interview, people were asked if they could identify any strengths that had helped them throughout their caregiving experience. The following is a summary of their responses.

*'They were all on the journey. We were all on the journey together.'* (Sally, p.20)

*'I think his friends were most important to him. You know ringing his friends, they would come, sometimes it used to drive me nuts. They'd come at different times. I was trying to get the meal or we had to go somewhere. We'd have to say, 'Look, I'm sorry. We've got to go.' He would look at me and I'd say, 'You've got an appointment you've got to keep.' That would be the thing. And probably the strengths just being able to manage your day.'* (Penny, p.22)

*'One of the strengths that I have is that I've never been one to get upset if things aren't going right, I've never been one to get totally devastated. I always seem to be able to stay in control of the situation, but on the other hand, when things are going great, I haven't been one to do great celebrations either. I'm a person that's more in the middle range of emotion. I don't really get upset. In fact, I can only remember one instance of breaking down and crying in public over the whole episode which is pretty good when you think of three years. There's only once when I just reached a breaking point. I thought that was quite an achievement really. And as I say always being able to work with a problem, around a problem, I guess it might come from my school teaching days when I always used to reckon that you're better off facing up to a problem than trying to put it off or steer clear of it. I find you're always better to meet it head on and then deal with it, cos then it's done rather than going to custard.'* (George, p.8)

*'When you're part of a network of a supportive family and some good friends. If you've all that, you can do anything.'* (Harry, p.12)

## Summary

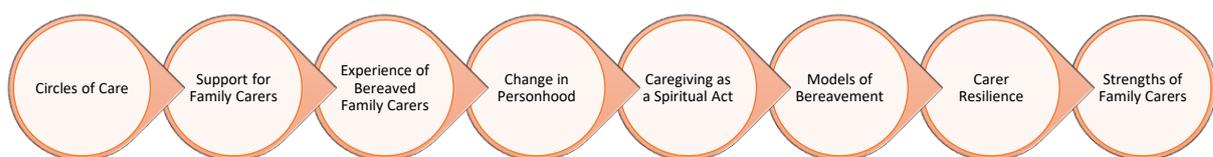
Through exploring the narratives, a powerful story has emerged full of poignancy, filled with love and devotion, complete with determination and the desire of carers who have done their utmost in caring for the husband/ wife during their illness and death. The narratives add a richness and depth that belies the simplicity of the term 'family carers.' The themes that were generated from the narratives are the medical circle of care, the home circle of care, saying goodbye and picking up the threads. The following chapter turns to a discussion of the ideas that underpin these themes. Some links are drawn with the initial literature review, as well as exploring a new understanding of palliative care. All this leads to the identification of strengths that underpin and sustain family carers in their role. Some suggestions are offered for providers of palliative care to enhance their ability to support those family carers who are supporting a terminally ill family member.

## Chapter 5: Discussion

In seeking to identify the strengths that underpin and sustain family carers looking after a terminally ill adult under 65 years, four themes reflected the findings of the research interviews. These were the medical circle of care, the home circle of care, saying goodbye and picking up the threads. This chapter presents some thoughts that emerged following a time of reflecting on the research findings that underpin the family carers narratives. Some of these cross over thematic areas and give a different perspective depending on which position they are viewed. These ideas permeate the lived experience of the bereaved spouses, drawing back to themes identified in the literature search and, in some cases, expanding on ideas that were previously held by the writer. These are Circles of Care, Support for Family Carers, the Experience of Bereaved Family Carers, Change in Personhood, Caregiving as a Spiritual Act, Models of Bereavement, Carer Resilience, and Strengths of Family Carers.

This chapter rounds off with a discussion on implications for social work practice. Four areas for the growth and development of palliative care in regard to family carers are presented. These are the need to prioritise support for family carers, the protection of the sacred spaces in people's lives, access to social work and pastoral care, and targeted support for bereaved carers. Within this section, some practical suggestions are offered to enable this to occur.

The chapter concludes with acknowledging the limitations of this research project and offers suggestions for further research to build the body of knowledge around strengths of family carers.



*Figure 13: Concepts that underpin the research findings*

### Circles of Care

Prior to engaging in this research, as a Social Worker, whenever I thought about models of palliative care that placed the patient at the centre of care, I envisaged an ecological model similar to that described by Horsfall et al., (2012) with the palliative care entering in and out of this environment. Whenever I met with people who were unwell it was always my intention to gain a sense of what their world looked like, including their support network which might be made up of spouse/ carer, family,

and friends as well as their broader social connections. This was always an effective way to gain a sense of their place in the world and assess what additional support might be necessary to aid in their ability to maintain themselves in the community. While it was not as neat and tidy as Rosenberg et al., (2015) it looked similar to that portrayed in Figure 14.

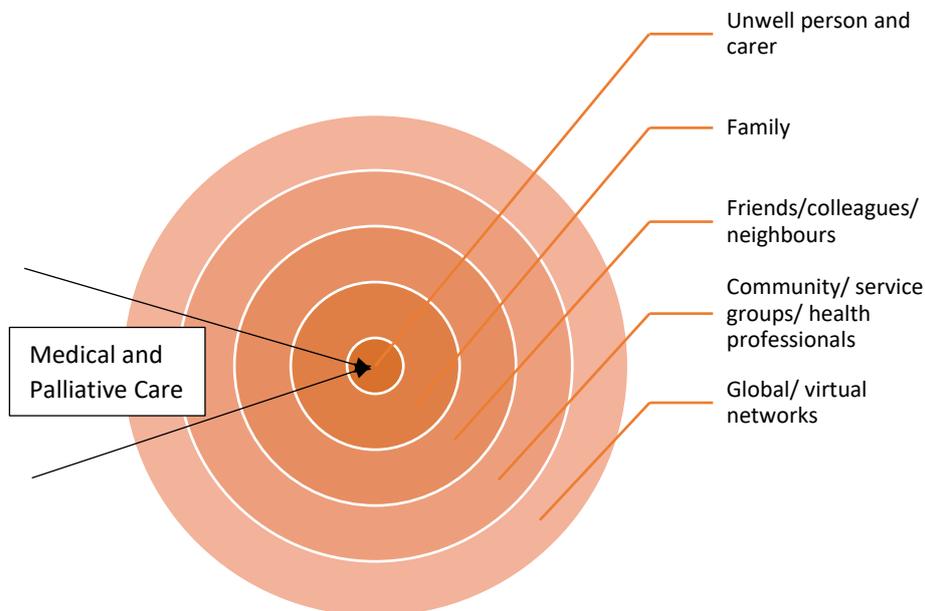
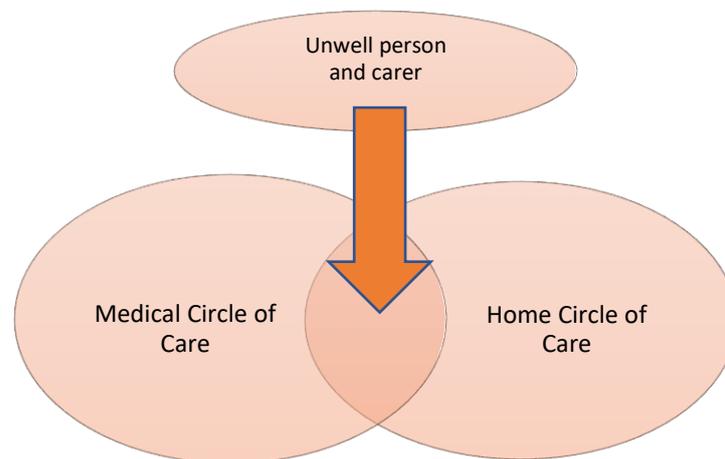


Figure 14: Understanding of palliative care held prior to undertaking the research

As a consequence of engaging in this research I have a greater appreciation of the value unwell people and their carers have for the role of the entire medical side of their care. This has changed my view on the provision of palliative care. From the research, it appears that what is described as the medical circle of care and the home circle of care carry equal value for the unwell person and their carer throughout the entirety of the illness. Yet, for those in the medical world and the home world, this is only one aspect of the worlds they each inhabit. It is at the intersection of these two circles of care that the unwell person and their carer meet with different members of the medical team who are involved in their health and welfare. There is a fluidity to both circles of care, enabling parties from both sides of the care circle to step in and step out depending on the need, expertise and place of care. The constant within the circles of care is the unwell person and their carer.

Figure 15 is an attempt to illustrate the relationship between the unwell person, their carer and the networks of social and medical support. This is different from models proposed within the literature espousing patient circles of care. What these have in common is that they place the unwell person as the patient at the epicentre of care within a medically or palliatively defined framework. Each of these models contribute to the circle of care, yet each fails to locate the broader social environment the

unwell person lives in, and the influence that environment might have on the decisions, actions and experiences of the unwell person and their carer. There appears to be a mismatch between the models of care as documented in the literature and that voiced by the carers in this research.



*Figure 15: Updated understanding of palliative care*

For those who inhabit the medical circle of care, the unwell person is their focus of attention during the time the parties spend together. However, they are also subject to policies, procedures and resource constraints that all influence what services may be offered and how these are provided. For example, The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand (Ministry of Health, 2013) details three levels of need for those who eligible for palliative care and who is best to respond to those needs.

Lee et al., (2013) developed a patient circle of care as a resource to assist an array of medical professionals who were working with an unwell person to keep that person at the centre of care making decisions. This was an attempt to reinforce communication and collaborative teamwork among the multidisciplinary team to coordinate the support of unwell people transitioning between different care environments, whether at home, in the community, or in a hospital setting. A perceived benefit of this model was the ability to include both hospital, general practice and community resources as well as the unwell person, carer, family and friends in the care planning process (Please see Figure 16).

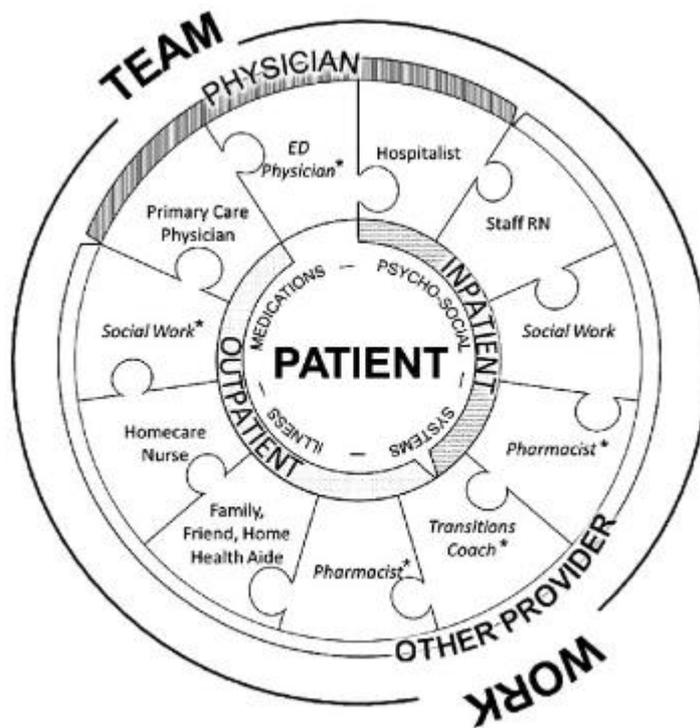


Figure 16: Patient care circle as developed by Lee et al., (2013)

The work of Price (2016) extended ideas such as those developed by Lee et al., (2013) into a circle of care model that used a digital resource to graphically illustrate the care interactions of the unwell person with healthcare professionals. This model took a systems approach, and was able to operate both across health providers and above the level of direct interaction between health care professionals, and the unwell person and their caregiver. Essentially, it has the potential to be used as a tool to influence changes in the healthcare system so that is more responsive to the needs of the unwell person.

In contrast, McKinlay (2001) developed a patient circle of care which originated from the perspective of the unwell person. This model acknowledges the agency of the unwell person in their environment, and their ability to engage or disengage from what was occurring around them. It also acknowledges the ability of unwell people to notice and assess the actions of those involved in providing care for them. At the core of McKinlay's (2001) model is the identity the unwell person has of themselves, beyond the confines of illness and the palliative world they currently inhabit (Please see Figure 17).

A further school of literature regarding circles of care has emerged. Abel et al., (2013) recognise models such as those above have limitations when social policy, social infrastructure, community coordination and resources are not available to maintain and sustain people who are unwell in the community and in their own home until end of life, if this is their preference. In response to this, they propose an ecological model of care with the patient at the centre, supported by inner and outer

networks, as well as the wider community and social and health care organisations. All of this is supported by policy at a local, regional and national level to support different aspects of care. The model is designed to enhance the lives of those who have the weakest support networks in communities that are under resourced. “Good end of life care not only requires community development but can actually assist it.” (Abel et al., 2013, p. 387)

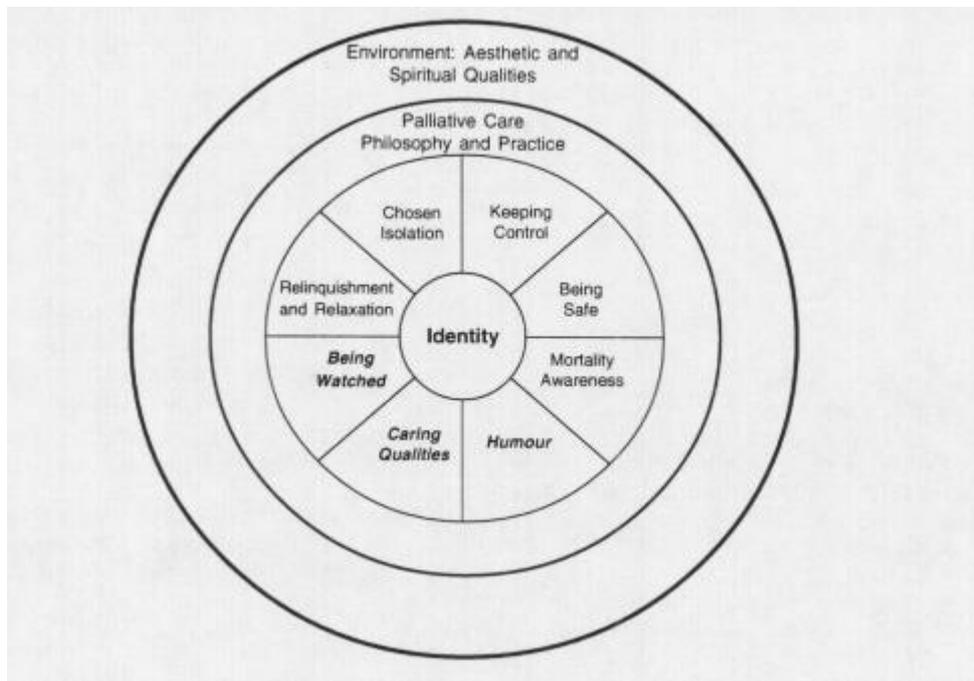


Figure 17: Patient Circle of Care as developed by McKinlay (2001)

This alternative does have some challenges for implementation. Abel et al., (2013) identify the following as some areas for exploration and negotiation in the development of circles of care:

- i) What capacity do communities have to become more intimately involved in circles of care?
- ii) What willingness do health professionals have to relinquish their power and position as experts in palliative care?
- iii) How will coordination and communication of care needs occur when members of the community are not subject to the same regulatory requirements for provision of service as their professional colleagues?

These concerns echo those raised by Horsfall et al., (2012) and Rosenberg et al., (2015) in the earlier literature review.

Within the literature, two examples of circles of care in action are provided. Hanson et al., (2014) described a coordinated volunteer project set up to provide support in two locations to African Americans who had serious illness. This was a community-academic partnership that provided training and coordination for volunteers assigned to seriously ill people over a two-month period. After the trial period it was found that those who benefited from the project reported their practical, emotional and spiritual needs were better met, and they had a greater knowledge of hospice services. The researchers contended that those who declined to participate in the research had existing support networks which already met their needs. For a community to successfully engage with circles of care, Hanson et al., (2014) found the key was to identify the unique strengths of a particular community, and/ or to develop a charismatic leadership group to run the project.

Carpenter, Phipps, and Finn (2013) reported on a care circle promoted by the local Department of Senior Services and Programmes in New York. This model placed value on the interdependence of individuals who supported each other through a shared purpose for mutual benefit. It encouraged the value of 'stepping forward and giving back' within the community. Through being involved in circles of care, people within the community were able to build social capital. This occurred as they built social connections with others which, in turn, enhanced their own sense of wellbeing and purpose. The authors found that involvement in circles of care promoted the social, physical and emotional wellbeing of all involved as it was seen as a community initiative open to all.

It appears the circles of care models are precursors to the movement that is now known as Compassionate Communities. Within this research (Carpenter et al., 2013), the caregivers were able to clearly articulate and access the support provided to them by their family and friends. They were not people who would necessarily have benefited from support provided by a circle of care.

### Support for Family Carers

Despite the passage of time since the death of their husband/ wife, in this research, carers were able to clearly remember details that were important to them during their spouse's illness. Two of the women expressed a desire and need for information provided by other family carers who had been through a similar experience to them, written in an easily accessible way. This information needed to be separate and distinct from that which addressed caregiving in a more clinical manner, whether by electronic media (e.g. blogs and internet) or via libraries (e.g. personal journals and books). In addition to information provided by their Medical Specialists, most people interviewed spoke of going online to search for information that was specific to their personal circumstances.

Living intimately with a person who became unwell had an impact on the relationship between husband and wife. For some couples, this was a short intense period of ill health; for others it could last for a number of months or years. Where couples lived within the shadow of potentially further ill health returning, they reported periods of stable health away from the routines and rhythms of medical appointments and treatments. They also reported there were decisions to be made regarding living and working. All parties acknowledged figuring things out as they went along without a lot of guidance from those who had previously lived a similar experience.

As a response to her own experience of this particular issue, Capper (2017) wrote *The Accidental Carer* following the death of her husband. Her book is a 'tips and tricks' style of book, giving practical suggestions as to how carers might approach different situations they encounter during their experience of family caregiving in the home. It is a simple, easy to read book written with the acknowledgement that those involved in the activities of caregiving are busy people, often juggling multiple tasks at once. At the forefront of the book's design is an important message to each and every family carer that "You matter." (Capper, 2017, p.10)

Following her experience as a carer to a husband who experienced ill health over a number of years, Sheehy (2011) drew from her personal journals and embarked on a writing a book of her experiences. Her research included the experiences of other family carers. Sheehy (2011) developed a model of the caregiving journey, describing the caregiving experience as a pilgrimage, and depicted this pilgrimage as walking a labyrinth with eight distinct turnings.

These turnings are Shock and Mobilization, the New Normal, Boomerang, Playing God, I Can't Do This Anymore, Coming Back, the In-Between Stage, and the Long Goodbye.

"Most of us will go through what I call 'turnings' – significant changes in the condition of our loved one that demand new coping strategies. Each new turning requires a shift in attitude, different tools, and more help. We caregivers also have our own turnings, bombarded by conflicting emotions that force us to question our motives and reshape our attitudes. We have so much to learn, not only how to become fearless advocates for our loved one but also how to care for ourselves at the same time." (Sheehy, 2011, p.22)

The family carer has needs and concerns of his/her own, independent from that of their unwell spouse. There is a need to acknowledge and give visibility to the role so the distinct needs of carers can be recognised and met. It cannot be assumed that carers are willing participants in the care of their unwell spouse. Notwithstanding that, every person interviewed willingly embraced this role, and to consider otherwise was anathema to them; at a broader level there is a growing call for policies at a local, regional and national level that attend to the specific concerns and needs of caregivers. (Abel

et al., 2013; Lee & Zurlo, 2014) These research findings support those made in the initial literature review. (Alpass et al., 2017; Sadler & McKeivitt, 2013; Williams et al., 2017)

### The Experience of Bereaved Family Carers

The initial literature review did provide some insights in to the experience of family carers. It appeared that those who cared for an unwell person under 65 years of age are an under-represented research cohort. The literature search identified that the family's financial circumstances prior to illness had a flow on effect as to how they negotiated the costs involved in caregiving.

In this research there were distinct differences between how the men and the women managed the tasks and the experience of caring for their unwell husband/ wife. The men were generally financially in a more comfortable position than the women. Some of this is directly attributable to age as two of the men were retired. The other two men were able to take time away from their businesses to tend to the needs of their wives, trusting others to keep the business running. The women, who were all in their 50s, needed to juggle work and home life, as well as learn to take on the full financial responsibility of their relationship. Losing the income earning capacity of a husband had a dramatic impact on the couple, causing a rethink of financial priorities at a time when they also needed to focus on adapting to new information regarding the husband's health.

Most parties spoke of the loss of many years of dreams and plans for their joint future, and the process of coming to accept that those dreams were disappearing fast. Some couples prioritised time to do the things that were on their 'bucket list.'

*'We did what he wanted cos his body was sick but his mind wasn't.'* (Penny, p.18).

Others tended to get through each day, dependent on the health and wellbeing of their husband/ wife as to what might be possible.

These findings are supported in the bereavement literature. In their work, Lee and Zurlo (2014) found spousal carers had greater difficulty in meeting the basic expenses compared with non-spousal carers. Women were found to have more difficulty in meeting expenses than men. This was also found to be true for those aged in the 45-54 age group, compared with their older counterparts. The financial strain of caregiving was found to be associated with socio-economic status and the age of family carers. Maintaining employment was seen as a protective factor for family carers as it offered a place for social interaction outside the home. It also enabled the person working to have some agency in their ability to meet living expenses at home. The work of Corden, Hirst, and Nice (2010) and Roulston

et al., (2017) support these findings, adding that women's perceptions of financial distress could reverberate for two years or longer following the loss of their spouse.

The process of beginning to find a way to live as a newly widowed person following the death of their spouse was difficult for everyone. Feelings of lack of value, being lost, a sense of loneliness stretching out before them and being raw with grief abounded. Just trying to make it through each day was a challenge for some participants in the early days of days of learning to live without their husband/ wife of many years.

For everyone, returning to employment, whether full or part-time, helped to give structure to people's days. Generally, people felt supported by their workplace colleagues in their grief. However, as time passed, due to changes in workplaces, some people found those around them 'forgot' about their loss, moving on with their lives, yet unaware that the person they had once supported was still emotionally close to the memory of their lost spouse. Their life had not moved on in the same way; it might be stalled as they were still trying to adapt to their new life as a widow/ widower.

Two people described their loss with metaphor. They spoke of making an attempt at life and those around them saw these attempts, yet underneath there was still a raw gaping wound that had yet to heal. Widowed men and women felt after a period of time, they needed to be careful whom they shared their story of loss with. More than half those interviewed spoke of other people's expectation that they were over the loss of their life long companion, and the pain this continued to cause them.

*'Everyone talks about two years, but as my mate said, 'That's bullshit, it's not two years. It can be different for so many people.' Generally, it's sort of like a plateau. I still feel the same way, as I did two months into it.'* (Mark, p.35).

Whilst there was limited literature on caregiving specifically targeting those under 65 years, this cohort is subject to an increasing body of research as widowed carers. All of the issues identified in this research project are acknowledged in the bereavement literature.

In their research with bereaved spouses aged between 20 and 50 years at the time of death, Tomarken et al., (2012) found:

*"Young prolonged grievers likely feel that the loss of their young spouse invalidates all their previously held constructions of their pre-death reality. With this invalidation, previously used life narratives and personal meanings are obsolete. Without a basic foundation of how to view the world and one's self in it, the process of working through the grief is stalled, leading to the unintegrated traumatic experience of prolonged grief."* (Tomarken et al., 2012. p.776)

Following their investigation into the similarities and differences between spousal and non-spousal caregivers, DiGiacomo et al., (2017) found younger spousal carers had greater need for emotional and

bereavement support than their older counterparts. They recommend that support services need a flexible approach to addressing these needs due to the competing demands of the life stage of each carer.

Thus, while carers spoke of the change in personhood of their husband/ wife during his/her illness, so too, did those who were bereaved experience a change in their personhood.

### Change in Personhood

For everyone, their sense of identity is connected to how they see themselves as well as how they perceive the world around them and perceive the world sees them. The carers noticed numerous changes in the identity of their unwell spouse as their health declined. This resulted from the disengagement from paid employment, changes in sociability, and required a readjustment of priorities to focus more on family. It entailed coming to a place of accepting assistance with washing and dressing themselves, as well as letting go of attending to tasks that had been a part of their functioning within their marital and other personal relationships. People who struggled to accept help from outside the relationship were more willing to accept it from their spouse.

There were times when making a decision about their health and their immediate environment was the only aspect of their lives, they may have felt they had control over. This had the potential to cause tension. Most carers spoke of times where this did cause upset in the relationship. They also spoke of supporting and upholding their husband/ wife in whatever decisions they wished to make in regard to their healthcare, recognising how important that autonomy was. Many could still see the person whom they had lived with and loved for many years underneath the mask of illness induced behavioural traits that emerged at various times. It was this knowing that enabled family carers to continue on in their chosen role, learning new tasks and taking over responsibilities that had previously belonged to their spouse.

The impact of seeing the one they loved become increasingly unwell and unable to participate in the fullness of their lives together, also caused a change in the identity of the family carers. Dreams and visions long held, planned and pursued, had to be modified and eventually discarded as carers companioned their husband/ wife through the ongoing changes in their health.

Each and every carer came to the realisation that their life would continue after the death of their husband/ wife and this had a profound effect on how they saw themselves and how they might begin to walk into a new future without the one person who had been a constant through the years of marriage, raising a family and seeking a future for their lives. This dream was cut short and required

major readjustment for each carer as they worked out how to continue living. The metaphors for grief and making a way through each day, highlighted a new reality of a life alone that most would have preferred not to embrace. Perhaps the most significant aspect of rebuilding a life without one's life companion was the absence of sustaining emotional support and encouragement from this most intimate of relationships. That gulf was keenly felt.

*'I think my sons and I have provided a certain amount of support for each other. I don't know if I've been as supportive to them as I should have been. It's quite difficult to support other people when you're feeling unsupported yourself.'* (Grace, p.12).

For couples, especially those who have been married a long time, whilst they may maintain separate hobbies and interests, much of their "well-being is bound up with the web of relationships to which they belong." (McCarthy, 2012, p.79). Thus, their personhood is encapsulated and intimately entwined within the connections and relationships of marriage and family. When this is broken as a consequence of death, the surviving party can struggle to find a new sense of identity beyond that which is so familiar to them. Their new state of being is not chosen; rather it is forced upon them by circumstances beyond their control.

During the research interviews, carers spoke eloquently of the gifts, talents, skills and attributes they admired in their spouse including how this contributed to their relationship, their family and their community. Corden et al., (2010, p.27) described this as 'economic personhood'. It appears that carers continue to be the keepers of the memories of the full personhood of their husband/ wife even after their death, and this continues to sustain them emotionally.

All of these themes are represented within in the literature (Bach, 2012; Broady, 2017; Corden et al., 2010; Kong, Fang, & Lou, 2017; Leeming, Murray, & Kendall, 2014; Swinton, 2017). Kong et al., (2017) found that as people became increasingly unwell and unable to communicate, their personhood continued to be upheld and maintained by those with whom they were in relationship. Broady (2017) identified an important task in supporting family carers is to assist them to develop a sense of personhood beyond the current role they are in, to begin to envisage a future life and what that might look like.

### Caregiving as a Spiritual Act

A common thread to all couples was their desire to support and assist each other throughout the entirety of the illness trajectory. For each couple it was important that they share this experience together – from the uncertainties and initial concerns, through to diagnosis and consequent treatment options, through to receiving palliative care and dying. More important than the medical experiences

they encounter, was negotiating the care and welfare of each other; as well as negotiating the inclusion of their significant others throughout this time.

Amongst the minutiae of keeping a family home running as well as juggling work commitments and medical appointments, was the commitment to attending to one another's needs, reassuring and providing comfort; a listening ear; a sounding board for 'what if's' and 'if only's.' Carers are cheerleaders when things are going well, and a source of consolation on the tough days. Couples have a ringside presence to all that is going on in the life of the other. They have the ability to read the almost indiscernible language of the other, an ability garnered through years of living, working and loving each other. For either to choose to walk away when presented with the news of serious illness was simply not a consideration.

*'There's no second thought. There's not a second thought.'* (Mark, p.29)

And so, they traversed the rapids of illness and treatment options, of successes and failures together. Carers willingly picked up what their husband/ wife was unable to manage, secure in the bonds of their togetherness. Together they negotiated the rocky terrain ahead of them, helping one another, confident in their unity as a team that had experience in meeting and overcoming challenges.

Along this journey, a point of divergence occurred. Once it became known in their inner being that whilst couples were in this together there were two distinct destination points, a new reality entered their relationship. Again, and again family carers chose to be present. Just as they had witnessed each other's living, now carers were witness to the decline of their loved one, knowing that at some point an ending would come. For some couples this meant opening their lives and homes to new people who would accompany them on their travels, sharing the caring, and helping to smooth the path ahead. It brought a new vulnerability to couples as they negotiated deep inner knowing's of changes ahead, yet the shape and form in which that was to come, remained largely unknown.

The love and intimacy that flourished between couples throughout the illness, nourished by a supportive network of family and friends; aided and abetted by medical professionals, was valued and appreciated. All of this was a deeply spiritual action. It was love with gumboots on, entering new terrain on a regular basis, committed to the other, loving one another, laughing with one another, honouring one another, trusting one another, and knowing that decisions made were for the best interests of one another. It was in the tiny gestures: a look, a smile, a whispered 'thank you'; it was in the companionship, the quiet moments, the being present, the knowing and being known. It was choosing to look heartbreak in the eye and continuing on step by step. It may be couched in words of love, care, and affection. Yet it is the work of the soul and spirit, the essence of who people are, that drives their desire to engage in caring for one another.

According to Nowitz (2005. p.191), “Spiritual care means care that responds that encompasses the person as a whole and responds to what is meaningful in that person’s life.” Thus, every act of being present, caring and attending to the needs of their husband/wife is an inherently spiritual act. This is supported in the literature as written by Adams, Mosher, Cannady, Lucette, and Kim (2014); Doka (2003); Griffin (2005); and Stanworth (2003).

### Models of Bereavement

Whether it was a tear in the eye, quiet weeping, speaking with a tremulous voice, or the clenching of the body bowed over; these were all physical signs that occurred as carers spoke of the loss of their loved one. Just as this was a turning point in the lives of the couples, so too, it was a turning point in the narrative. Each person touched on some of the details of this time. For most it appeared to still carry a lot of tenderness. Half the carers spoke eloquently of arrangements made following death that were personalised to the preferences of their loved one; others simply moved on to the next part of their narrative.



Figure 18: Melancolie by György (2014)

It was profoundly moving to listen to those who were able to speak of the impact of the loss of their loved one and the consequent devastation they experienced in their lives. Throughout the interviews, we had entered the sacred vault of people’s hearts and treasured memories and while other treasures may have been shared, this one was mostly kept in the ‘holy of holies.’

As (Tonkin, 1999. p.3) describes, “Grief is like a fingerprint: it is unique to you and to that loss.” This, too, was the experience of listening to bereaved carers. She further articulates that coping with grief is not so much a matter of getting *over* a loss, but finding a way to live with it. Much as the sculpture by György (2014) in Figure 18 illustrates, it is not that the loss of a spouse dissipates, rather, over time the loss becomes a part of the fabric of the life of the bereaved person. (Tonkin, 2001)

The pragmatics of living were easier to articulate and have been referred to earlier. It was important to hear, notice and recognise the progression of those widowed between actions that were sustaining, enabling them to make positive forward movement and actions that held them in their sorrow. Thus

the projections of social functioning in the carer's professional world could comfortably sit with the protection and nurturing of self in the privacy of one's home.

*'You've got this layer of skin over the grief because you've learned to sort of cope but underneath is a huge hole. That's my metaphor about where I am now. There's this layer of skin and I put up a good pretence and people say, 'You're so cheerful'. I'm not. I'm just having a really good pretence at it but underneath there's this huge gaping hole.'* (Grace, p.12)

This resonates with the Dual Process Model of Coping as developed by Stroebe and Schut (2010, p.276) and illustrated in Figure 19.

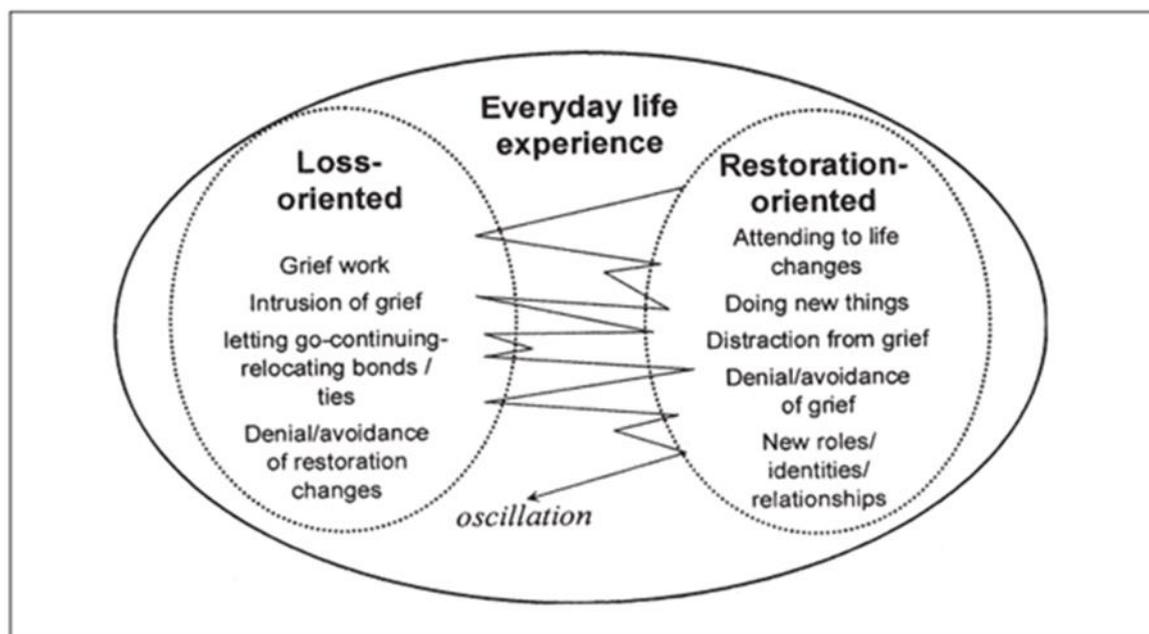


Figure 19: Dual Process Model by Stroebe and Schut (2010)

The Dual Process Model is predicated on stress and coping theories. It posits that those who are grieving oscillate between two different types of stressors – loss-orientation and restoration-orientation stressors. The loss-oriented stressors are acknowledged to be at the heart of grieving, occurring as the bereaved person gives attention to the loss they have experienced, reviews and processes events that have occurred, and dwells on the loss they are experiencing. In contrast, the restoration-oriented stressors reflect the efforts and decisions the bereaved person makes to reorient themselves to their new life without their loved one. This is a process with movement in both directions allowing people to be where they are, comfortable in the knowledge that the existence of both orientations is necessary. The loss-orientated activities can serve as a springboard to evaluate actions taken in the restoration-orientated part of one's life.

This model is frequently referred to within the wider body of bereavement literature. (Baddeley & Singer, 2009; Bar-Nadav & Rubin, 2016; Malkinson, Rubin, & Witztum, 2006; McManus, Walter, & Claridge, 2018; Newsom, Schut, Stroebe, Wilson, & Birrell, 2016; Rubin, Witztum, & Malkinson, 2017)

According to Payne, Lloyd-Williams, and Kennedy (2008), models to address bereavement such as Kübler-Ross (1997, 2001) which identify stages of grief, and Worden (1991, 2009, 2018) who focuses on the tasks of mourning, are built on developmental theories. These are based on the assumption that bereavement is a process in which there is an outcome. This process is often expressed as phases, stages or tasks to be completed.

Another type of bereavement model based on continuity theories assume people wish to maintain continuity with those they have lost through death. It is in remembering that relationships are transformed and continue to have importance to individuals and in some instances the wider community. The work of Neimeyer and Burke (2017); Neimeyer, Burke, Mackay, and van Dyke Stringer, (2010); and Neimeyer, Prigerson, and Davies, (2002) is based on continuity theories.

### Carer Resilience

Throughout the interview process, it became apparent that the men and women who participated were resourceful. Two women had experienced rebuilding intimate relationships following the breakdown of their first marriage. They, and others had experienced building and developing teams in their chosen employment – whether that was people, skills, or business. Most people had been or were currently in roles where communication was a key skill. Everyone had raised children and reframed their lives following their children leaving home and establishing their lives independently of their parents. Most people had interests outside of their immediate relationship that gave balance to their lives. During the course of their husband/ wife's illness, everyone interviewed had a network of family, friends and colleagues whom they could draw on for practical and emotional support. They also welcomed the support offered by friends of their husband/ wife as this helped to share the care, and maintain the wellbeing of the couple.

It was these skills, and others, that gave depth to their ability to sustain themselves during the course of caring for their husband/ wife. These skills enabled bereaved carers to begin the process of figuring out how to live separate from the identity of being a couple. For them, it was minute by minute, hour by hour, day by day; each moment of living building on the previous one. From moments of intense bleakness and not knowing which way to turn, to utilising the structure provided by employment to frame the day, each person began to carve out a different life for themselves, holding the memory of their loved one close to their heart.

Recognition grew that even as people mourned the loss of the one they had lived with and loved for many years, deep within each person was a tiny kernel of desire to keep living and find a way to rediscover hope and a purpose for their lives. In the learning of new skills, and in the adapting to life as a widowed person, the routine of one day passed into another. With each new day the widowed carers stepped into their own future finding it undiscovered and unknown.

*'I'm flattening for the first time in my life. At age 58 I started flattening when Rose died, and I'm still flattening. And the thing about that is that you really, it's the first time - the first time in my life I've never been a son or a husband, I'm just me. I'm a father as first and foremost, that's good. (...) So, I'm just me now. And I'm fine with it. I've found out so much about myself that I'm surprised. I'm really surprised.'* (Mark, p.12)

These qualities fit with the literature about resilience. Payne (2016, p. 185) describes resilience as "the capacity to bounce back from adversity." Factors associated with resilience following the loss of a spouse include an ability to cultivate interests; identifying benefits such as pursuing interests without needing to consider the needs of a husband/ wife; recognition that in spite of the loss, life does continue on; cultivating a positive outlook; being resource rich; and an ability to build a new life for oneself. Those who had close meaningful emotional relationships prior to their loss, recognised that those were a significant ongoing source of support. Another important demonstration of resilience was shown by the two carers who had established new relationships. (Hwang et al., 2018; Koren, 2016; Mancini, Sinan, & Bonanno, 2015; Palacio, Krikorian, & Limonero, 2018)

In their work, Infurna and Luthar (2016) questioned the likelihood of resiliency following personal loss, and found that this did not always occur. They suggest that further research should focus on learning from those people who seem to thrive in adverse circumstance and using those findings to assist those who wilt in adversity.

Hone<sup>1</sup> (2018) has developed strategies that can be taught to assist and support resilience. These are:

- i) Choosing to focus attention on what is good in one's life. This can include practicing an attitude of gratitude.
- ii) Accept struggle is part of life.
- iii) Asking 'Is this helping/ harming me?' to guide decision making. In all circumstances, encouragement is made to make decisions that are helpful not harmful.
- iv) Find positive emotions and activities to top up our emotional tank.
- v) Ask 'Given what is happening, what are you hoping for now?' to discover a series of sub hopes and find a way to move forward.

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<sup>1</sup> Hone (2018). These strategies are from notes taken during her presentation at the Hospice New Zealand Conference in Auckland, New Zealand.

## Strengths of Family Carers

When considering the strengths of family carers, it is important to recall the three areas Madsen and Gillespie (2014) considered when identifying strengths. They asked:

- i) What activities sustain people in their lives?
- ii) What are the intentions, commitments, values, beliefs, hopes and dreams that underpin people's actions? and
- iii) What community connections maintain and sustain people when they operate from their strengths?

Reflection on these questions has led to the identification of the strengths of carers. These strengths have emerged out of the words of the bereaved carers during the research interviews. They are love, hope, family, teamwork and resilience.

Early on in the interviews, I was struck by the **love**, care and attention that carers bestowed upon their unwell husband/ wife during their illness. The descriptor that came to mind again and again was 'steadfast love', demonstrating their constancy in companionship and supporting their loved one through the duration of the illness. Whilst earlier I called this 'love with gumboots on' (p.97), Swinton (2017) fills out this description:

"It is absolutely crucial to remember that love remains love even if its shape shifts and changes. Caring for the bodily needs of a person is a deep expression of love, but it isn't the same as sharing in his/her emotional life, planning together for the future, or sharing dreams. What we need to remember is that love isn't always romantic. Love is more than a feeling; it is a way of being in the world. Sometimes it is hard, willful, intentional, and deeply disappointing. ... But even if we can recognise the way that our love remains real even if it has to adapt to the rhythm of the disease process, we need not feel guilty when our feelings shift, change, and oscillate. Freed in this way, we might just be able to discover new and hopeful ways to love as the old and tested ways move on." (Swinton, 2017, p.285)

The companion to love is **hope**. Hope holds the promise of outcomes that will satisfy the desires of those who hold it. In the midst of difficulty, hope sticks out a wee tendril, seeking out a pathway of promise. Hope is fluid, adapting and responding to the circumstances people find themselves in. It is not fixed in time. It is rooted in the present, forging links with the past and the future. It has threads that connect and reconnect to leverage an ongoing ability to maintain caring and caregiving.

Folkman (2010) holds the position that hope is essential for people living with serious ongoing stress. She recognises hope and coping as mutually dependent upon one another. She argues that as hope traverses the hills and valleys of human experience it is not static. Feudtner (2014) describes hope as hard wired into our being as humans:

“In every story of hope, there is longing, and within that longing a sense of pain. ... To be a master of hope, one has to be well acquainted with the fear of darkness that hope helps us to surmount, to be comfortable and capable of confronting this darkness directly.” (Feudtner, 2014. p.556)

The **family** is a key component of the wellbeing of couples where ill health permeates their lives. They are the immediate group of people couples turn to for support in times of trouble. For all of the couples involved in this research - variously parents, siblings, adult children and grandchildren – family members made up the social fabric of how they saw themselves. These relationships nurtured and sustained the couple throughout the time of illness. The support of families was essential in maintaining the fullness of personhood for both the unwell person and the carer. The myriad of tasks and inconsequential details that they could assist with was invaluable to the wellbeing of the couple, and assisted their ability to manage the ongoing realities of living with an unwell person in the family home.

Families also provided opportunities for celebration, as family milestones rolled around. They were active participants and cheerleaders in the accomplishment of ‘bucket list’ goals, reveling in the opportunity to be together and to share memories during a time when the endpoint of their family member was unknown. Time together was precious, consciously chosen as a priority.

*‘That was really important. They were all on the journey. We were all on the journey together.’  
(Sally, p.20)*

For the adult children of the family, the pull to return home to spend time with their parents was vitally important. This could be more difficult when those adult children lived some distance away from the parental home. There was the tension of balancing responsibilities between the needs of parents, study/ employment, international travel (for those who lived overseas), and in some cases, their own relationships and/ or families.

Throughout the illness of their husband/ wife, an important feature was **teamwork**, whether with those the couple met through the medical circle of care, or those already known to them through the home circle of care. What was most valuable about teamwork was sharing the load and allowing others into this intimate circle. Throughout the illness, both husband and wife came to rely on others for knowledge, information, skills and expertise. They learned to assimilate a vast body of information in order to make health decisions. They learned to effectively communicate with health professionals as well as relay key information to family. They learned to adapt to changing environments and an array of people being introduced into their world.

*‘When you’re part of a network of a supportive family and some good friends. If you’ve all that, you can do anything.’ (Harry, p.12)*

According to Hayes et al., (2014, p.78) the “key to true integration is coordination of a holistic, person-centred assessment where all services communicate and work together for identified needs.”

Throughout the entirety of the illness, the couples needed to exhibit **resilience**. They did this in abundance, accommodating, adapting and adjusting their lives each step along the way. The research interviews had a dual benefit; for me, as the researcher to obtain narrative data, and for them as the family carer to recall, remember and review their personal experience of caring for their much loved husband/ wife. In doing this, with the benefit of a little distance between the illness and death of their spouse, as well as a time of reflection, they brought a freshness to all they had experienced as a carer at the centre of a complex interpersonal health induced drama.

Recounting their stories, and seeing their stories in a new context, contributed to carers having a renewed sense of themselves and their role in caring for their loved one during their illness and death. It was an opportunity to reflect on their relationships and abilities, and how the love they had for their husband/ wife underpinned and sustained every action both great and small. That love shown throughout that important journey is not gone, it has merely changed in form, as each carer builds on the foundation of their married life and moved to create a life without they one they lived with and loved over many years.



Figure 20: Word cloud of strengths

The strengths identified in this research - love, hope, family, teamwork and resilience - add to the knowledge base of strengths already identified in the literature. Cadell et al., (2011); Horsfall et al., (2012); and Hughes (2015) have previously identified self, spirituality, social investment, independence, greater appreciation of life, courage, determination, acceptance, humour, empathy, gratitude, love, privilege, intimacy and personal fulfilment, as the strengths that are transformative in

the caregiving relationship. So easily the strengths identified could lean one way or another within the collection of words used. As an example, courage, determination and an attitude of gratitude contribute to resilience; just as empathy, intimacy and personal fulfilment are all aspects of love. Rather than trying to limit the words used to describe identified strengths, it is in the growing collaboration of descriptive strengths that carers see themselves reflected, thus enabling them to adopt and own the strengths that best suit their personality and character.

## Implications for Practice

Following reflection on the findings of this research it is considered that there are four areas of development which could enhance the delivery of palliative care to the unwell person and their family carer. These are to Prioritise Support for Family Carers, the Protection of Sacred Spaces in People's Lives, Access to Social Work and Pastoral Care, and Targeted Support for Bereaved Carers. I acknowledge that some of these services already exist, however I do believe it is imperative that opportunity is given for further growth and development.

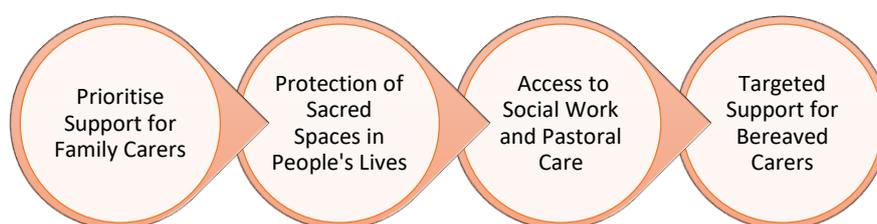


Figure 21: Themes for implications for practice

### i) Prioritise Support for Family Carers

In both the literature review and the bereavement literature, acknowledgement is given to the large numbers of men and women involved in providing care in the community for family members. (Alpass et al., 2017; Blum & Sherman, 2010; Bolas et al., 2007; Broady, 2017; Cadell et al., 2011; Cagle et al., 2016; Chai et al., 2013; Corden et al., 2010; Emanuel et al., 2010; Feudtner, 2014; Funk et al., 2010; Giesbrecht et al., 2015; Given & Reinhard, 2017; Gott et al., 2015, 2013; Hone, 2016; Horsfall et al., 2012; Hughes, 2015; Hwang et al., 2018; Infurna & Luthar, 2016; Keesing et al., 2011; Knox et al., 2017; Leeming et al., 2014; Mancini et al., 2015; McCarthy, 2012; Mendes & Palmer, 2016; Morris et al., 2015; Palacio et al., 2018; Ray et al., 2014; Rosenthal Gelman et al., 2014; Sadler & McKeivitt, 2013;

Sheehy, 2011; Sheets et al., 2014; Stajduhar, 2013; Stajduhar et al., 2010; Stenberg et al., 2014; Swinton, 2017; Tanco et al., 2017; Unson et al., 2016; Williams et al., 2014; Williams et al., 2017; Wittenberg et al., 2017)

From the range of issues raised within the literature and in this research three key areas to support family carers have emerged. Firstly, there is a clearly expressed need for palliative care services to have systems and procedures in place for assessing and providing support to all family carers. One way to achieve this is to have a process of automatic referral to Social Work and the Allied Health team for each and every person who is admitted to the Hospice service. In doing this, the unwell person and their carer are immediately introduced to the holistic support team provided by Hospice. This meets Standards Four of the Standards for Palliative Care which states:

“The person’s family, whānau and carers holistic needs are assessed, and they are provided with culturally appropriate support, guidance and resources, according to identify their needs, capacity, cultural context and preferences.” (Hospice New Zealand, 2018. p.10)

Through being proactive with the referral to Social Work and the Allied Health team, all parties are better positioned to act in the event of a crisis.

Secondly, palliative care services need to ensure they have processes in place to assist family carers to meet their own needs independently of providing care and support to their unwell family member. One way to achieve this could be to draw from the work of Hone (2018) to develop and provide a Resilience Programme from a social work perspective that supports family carers to develop and maintain strategies to look after themselves. Through attending to their own needs, carers are then better able to attend to the needs of their unwell family member. This is a programme that could run parallel to family carer courses that palliative care services offer that primarily focus on education and practical skills to provide care in the home for their unwell family member.

Thirdly, palliative care services need to join the voice of those who advocate at a governmental level for the extension of policies and programmes that support the needs of family carers. This has been discussed earlier on pages 24 and 93. (Abel et al., 2013; Alpass et al., 2017; Lee & Zurlo, 2014; Sadler & McKeivitt, 2013; Williams et al., 2017)

## ii) Protection of Sacred Spaces in People’s Lives

Through giving priority to assessing, creating, supporting and maintaining the wellbeing of family carers, they are then better able to operate from a position of strength. Very often it can be an accumulation of small matters that hinder the ability of family carers to continue providing the support and care in the home, or community that they wish to provide. A key role of Social Workers is to help

people identify others who make up their support network, including how to access that support if it is not readily identifiable.

Social work takes into account the broader social environment of the unwell person and their carer, when working alongside families to enable them to consider what is/ is not possible. It acknowledges the values, beliefs and cultural considerations that undergird the couple's relationship, and how these guide and influence the decisions that are made.

Through attending to these matters and empowering the unwell person and their carer to make decisions regarding the ongoing wellbeing of both parties, the environment in the home is better able to be maintained and sustained. (Beresford, Croft, & Adshead, 2008; Capper, 2017; Golden, 2019; O'Connor & Fisher, 2011)

### iii) Access to Social Work and Pastoral Care

This research has focused on the experiences of bereaved family carers. Aside from family, the health professionals most commonly referred to throughout narratives were Specialists, Doctors, and Nurses. Pastoral care was accessed by half the couples. Throughout the entirety of the research, only one mention was made of social work.

*'So, we never got tied up with social work. They never sort of knocked on our door. You know, we had to find things for ourselves and that was a really hard thing to be referred to hospice. I would've thought our Doctor would've referred us to hospice. (...) I found that and maybe our Doctor should've referred us to social work or something like that or somebody to come in and say, 'Look, how are you guys doing?' We didn't actually have that.'* (Penny, p.17)

The absence of the presence of social work in the research data questions the idea of holistic palliative care and interprofessional collaboration offered by the interprofessional palliative care team. If a palliative care service is structured in such a way that access to Social Workers and other Allied Health staff is via our medical and nursing colleagues, this raises the question of whether interprofessional gatekeeping is occurring. Both social work and pastoral care need to be repositioned from a 'nice to have' to a fully included component of palliative care service provision.

The lack of inclusion of these disciplines is recognised within the wider international palliative care social work literature. Meier and Beresford (2008, p.679) state the need to acknowledge the "historical imbalance in power and responsibility between physicians and psycho-social-spiritual professionals." They quote Stadler, the Programme Director of Clinical Services in Hanover, New Hampshire:

“Our pastoral care and social work colleagues are integral members of the interdisciplinary team. However it has been a challenge to get medical palliative care providers to let go of certain things and to pass the baton to other professionals.” (Meier & Beresford, 2008. p. 679)

James (2012) conducted a snapshot survey of referrals to social work in Hospices within Aotearoa New Zealand. The results of the audit revealed some striking commonalities as well as variations which were thought to reflect the communities, and model of service provision the Hospices operate within. She suggested that to enable social work to be better incorporated as part of the palliative care interdisciplinary team, a review as to how this service is currently provided within each Hospice was required. Any changes to the provision of social work may also require change at an organisational level (in terms of resourcing as well as how it is structured). Associated with this is a need for a clearer understanding for interprofessional team regarding the value and purpose of palliative care social work and pastoral care. (Beresford et al., 2008; Golden, 2019)

Access to all members of the interprofessional team is explicit in Standards One and Two of the Hospice New Zealand Standards for Palliative Care that make reference to:

“A qualified multidisciplinary team (who) carry out the initial and ongoing holistic assessment ... in partnership with the person, their family, whānau and carers ... (which) provides the foundation for care planning.” (Hospice New Zealand, 2018. p.6-7)

Without a commitment to the full inclusion of specialist social work and pastoral care to all who receive palliative care; can providers of palliative care truly say they are providing holistic care if the care provided rests primarily on the skills of our medical and nursing colleagues? Just as it takes a village to raise a child, so too, does it take an interdisciplinary team to provide holistic palliative care.

#### iv) Targeted Support for Bereaved Family Carers

Standard Six of the Standards for Palliative Care (Hospice New Zealand, 2018) focuses on grief support and bereavement care. A challenge for any bereavement team operating within a palliative care service is the ability to effectively meet the needs of the bereaved carers within their community. To this end, two strategies are offered for consideration. These are seen as complementary to bereavement care support that may already on offer.

Within the literature was clear information regarding the specific bereavement needs of young carers, and women (Corden et al., 2010; DiGiacomo et al., 2017; Roulston et al., 2017; Tomarken et al., 2012). All this lends strength to the need to develop specific strategies to reach this population. Wittenberg-Lyles et al., (2015) trialled an online closed bereavement group. This was moderated by a Bereavement

Team for the nine months duration of the group. Findings demonstrated the potential of this as a means of supporting bereaved carers.

Another option to support bereaved carers is to offer a service where bereaved carers are able to record the story of their caregiving experience. Following this, the Social Worker is able to analyse the narrative, identifying strengths and skills specific to each carer. It is anticipated that this might be a useful tool to assist bereaved carers as they reorient their life following the death of their family member. Drawing from the experience of the carers who took part in this research, this is a service which could be offered between two and five years following the death of their spouse.

## Limitations of the Research and Suggestions for Further Research

This research is a snapshot of the experiences of bereaved carers in a couple relationship. It is a stepping stone into the emerging research on caregiver strengths. It is difficult to make generalisations beyond the experiences of this group as there are other population groups whose voices are not present in the research. Further research into the strengths of caregivers could focus specifically on the experiences of bereaved carers under 55 years of age, the experiences of Māori carers, the experiences of Pacifica carers, the experiences of carers from migrant (CALD) communities, and the experiences of carers in the rainbow (LGBTI) community. Whilst this research has focused on those in couple relationships, the voices of sibling carers and/ or adult children carers of unwell parents are other potential areas for inquiry. In essence, research into the strengths of family carers of the terminally unwell under 65 years of age is a field open for exploration.

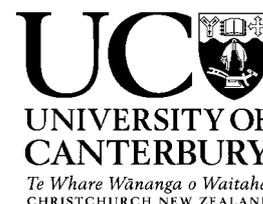
## Conclusion

This research has focused on those whose husband/ wife has died prior to the age of 65 years. It has delved into the lives of eight bereaved men and women who were intimately involved in the experience of their spouse's illness, medical care and later death. All this occurred within the context of an established network of familial and social relationships. It is their stories that give voice to a cohort of people who are largely invisible within the research literature. This is a poignant story that holds much richness. It is a story of love lived and love that continues beyond the death of a spouse. It serves as a reminder that whilst family carers willingly embrace their role, they also have needs of their own. It is when these needs are attended to that they are empowered to operate out of their strengths when caring for the one they have lived with and loved for many years.

The themes that came from the research interviews are the medical circle of care, the home circle of care, saying goodbye and picking up the threads. Underpinning these themes were a range of concepts that carried the actions, values and motivations of the couples. These were the circles of care, support for family carers, the experience of family carers, change in personhood, caregiving as a spiritual act, models of bereavement, carer resilience and strengths of family caregivers. It was in the exploration of these concepts that clarity began to emerge. Historically, models of care have primarily been medically focused, perhaps unable to fully appreciate how much/ little the social environment the unwell person and their carer inhabit can contribute in the care equation. Through further exploration of the social environment of the unwell person and their carer, and giving attention to the supporting and maintaining of both parties, it is possible for carers to be sustained in their role.

In this research, the strengths that underpin and sustain family carers are identified as **love, hope, family, teamwork** and **resilience**. These strengths add to the emerging research field into caregiver strengths. Whilst these qualities may come as no surprise, the challenge that accompanies them is for palliative care services to recognise strengths do not operate in a vacuum. They need to be nurtured and maintained in order for carers to be able to sustain the emotional, physical and spiritual demands of caring for their unwell spouse. Hence, this research offers four strategies for palliative care services to embrace as their desire to provide holistic care to the unwell person and their family carer. These are to prioritise support for family carers, to protect the sacred spaces in people's lives, to provide open access to social work and pastoral care, and to provide targeted support for bereaved carers supplementary to that which already exists in palliative care services.

## Appendix 1: Participant Invitation and Information Sheet



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 15 May 2018

### **Research Project: What are the strengths that underpin and sustain family caregivers caring for a terminally ill adult under 65 years of age?**

#### **Information Sheet for participants**

##### **Introduction**

You are invited to take part in the above research study. Before you take part, it is important to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss with others if you wish. Please do ask if anything is not clear or if you would like more information.

Thank you for reading this.

##### **Why have I been invited to participate?**

In this study family caregivers are identified as the main person who provided ongoing care and support to terminally ill patients and were in contact with the palliative care team. This project will require 6 voluntary participants who have been the primary caregiver for a terminally ill family member under 65 years of age, to share and describe their experience of providing care, seeking to identify the skills, gifts, talents and strengths that underpinned and sustained them during their family member's illness.

The Nelson Tasman Hospice database has identified patients who died under 65 years of age within the past five years. As a spouse/ partner/ or ex-partner who cared for a terminally ill family member, you are invited to participate in this research if you meet the following criteria. Participants are required to be over 18 years of age, between six months and five years' post bereavement, sufficiently well physically and mentally to participate, and able to give written informed consent to participate. You will also need to have lived in New Zealand for a minimum of fifteen years.

##### **What is the purpose of this study?**

This project is designed to explore and obtain understanding of how caregivers manage the illness trajectory of a family member who is terminally ill and under 65 years of age. It seeks to present a perspective of family-based caregiving that honours the lived experience of those who choose to care for a family member who is terminally ill.

There are no right or wrong answers to the questions that will be asked and will broadly

cover the following areas:

- i) Information regarding your family member whom you cared for during his/ her illness
- ii) Information around how you managed during your family member's illness
- iii) Information as to how your life has changed as a result of having a family member who was terminally ill
- iv) Information as to how your life is now

It is anticipated that this research will give greater understanding among palliative care professionals of the experiences of family caregivers supporting a terminally ill family member under 65 years of age. It is hoped that the information received will help contribute to the resources of palliative care Social Workers enabling them to boost the caregiver toolkit/ kete for caregiver wellbeing.

### **Do I have to take part?**

Your participation is entirely voluntary and you have the right to withdraw at any stage without penalty. You may ask for your raw data to be returned to you or destroyed at any point. If you withdraw, I will remove information relating to you. However, once analysis of raw data starts it will become increasingly difficult to remove the influence of your data on the results.

### **What will happen during the study?**

If you wish to participate in this project, please contact the researcher, Mary James, by email ([mary.james@pg.canterbury.ac.nz](mailto:mary.james@pg.canterbury.ac.nz)) to confirm your desire to participate with your contact details. At this time, you may wish to discuss the aims of the study and/ or talk through this information sheet and clarify any questions or queries you may have. At this point, Mary will also discuss informed consent. You may wish to consider these discussions for a further 2-3 days to reach your final decision. If you agree to participate, a date and time will be negotiated with you to participate in an interview of 1 to 1 1/2 hours duration, in a location of mutual agreement. This may be in your home, at Nelson Tasman Hospice, or another venue of mutual agreement.

### **What are the possible benefits of taking part?**

The potential benefits of taking part in this research include:

- i) An opportunity to reflect on your experience as a caregiver to a loved family member and perhaps gain fresh insights into the benefits of that experience.
- ii) An opportunity to contribute to the emerging body of knowledge and experience of family caregivers who care for a terminally ill family member under 65 years of age.
- iii) An opportunity to contribute to an emerging area of research knowledge exploring the strengths of family caregivers who care for a terminally ill family member under 65 years of age.

### **What are the possible risks of taking part?**

The potential risks of being involved in this research are anticipated to be minimal, however it is important that you be aware of them and what processes are put in place to support participants. These include:

- i) Some people may become upset when talking about the illness and death of a loved family member. You are welcome to have a support person with you during

the interview. You are able to ask for the interview to be stopped at any point during the interview if you are feeling upset or uncomfortable and you need a moment to recover. Our Nelson Tasman Hospice bereavement team are available on request for additional support.

- ii) With a small number of participants being interviewed for this research from the Nelson Tasman region, there is always a risk that people's identities will become public. To prevent this occurring, specific protocols around keeping your information secure and confidential are required by the researcher and her supervisor. These will be strictly followed by the researcher (Mary) and are designed to protect the privacy and identity of each research participant.
- iii) This research has been approved by four separate parties:
  - the Human Ethics Committee at Canterbury University,
  - the Ngāi Tahu Consultation and Engagement Group at Canterbury University,
  - Frans Dellebeke, the Chief Executive Officer at Nelson Tasman Hospice, and
  - Rangiriri Kohe, kaumātua for Ngāti Koata, Ngāti Toa Rangitira, and Ngāti Kuia. He is also the Cultural Advisor for the MNZAC Nelson/ Whakatū and the Alcohol and Drug Clinician at Te Piki Oranga.
 These parties have agreed the privacy and identity of each participant is protected.
- iv) It is important that your information is accurately reported. For this reason, you will be asked to give written consent for your interview to be audiotaped. Later your information will be transcribed to ensure accurate recording of the interview. You will have the opportunity to review the transcription of the interview and make any amendments you wish.
- v) It is anticipated that each interview will take between 1 to 1 ½ hours. The date, time and location of each interview will be agreed in advance with each participant.

#### **Will my taking part in this study be kept confidential?**

Yes. No material which could personally identify you will be used in any reports or presentations on this project. Throughout the research project collected data will be securely stored in accordance with the ethics approval granted in order to maintain confidentiality and protect your identity and privacy. As audio taped interviews are transcribed, your name will be replaced by a false name. Both the researcher and the transcriber are bound by confidentiality requirements. Upon completion of the research project, any personal information including audio tapes will be destroyed in keeping with the ethics approval granted for this project.

#### **What will happen to the results of this research study?**

The research findings will form part of a Master's thesis. It will also be used through presentations to palliative care professionals, both locally and nationally. The duration of this study is anticipated to be approximately 18 months. There will be some delay between when the interviews are conducted and publication of all findings. In any presentation of

findings, there will be no identifiable link to the identity of any participant.

If you have any concerns or questions regarding this research project, please contact the researcher or her supervisor, whose details are written below.

Researcher: Mary James  
Social Worker  
Masters of Health Science student  
Email: [mary.james@pg.canterbury.ac.nz](mailto:mary.james@pg.canterbury.ac.nz)

Research Supervisor: Kate Reid  
Department of Health Sciences  
Canterbury University  
Ph: 03 369 3575 xtn 93 575  
Email: [kate.reid@canterbury.ac.nz](mailto:kate.reid@canterbury.ac.nz)

## Appendix 2: Participant Consent Form

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Department of Health Sciences

Email:

[mary.james@pg.canterbury.ac.nz](mailto:mary.james@pg.canterbury.ac.nz)

**Research Project: What are the strengths that underpin and sustain family caregivers caring for a terminally ill adult under 65 years of age?**

### Consent Form for participants

- I have been given a full explanation of this project and have had the opportunity to ask questions.
- I understand what is required of me if I agree to take part in the research.
- I understand that participation is voluntary and I may withdraw at any time without penalty. Withdrawal of participation will also include the withdrawal of any information I have provided should this remain practically achievable.
- I understand that any information or opinions I provide will be kept confidential to the researcher and transcriber and that any published or reported results will not identify the participants. I understand that a thesis is a public document and will be available through the UC Library.
- I understand that all data collected for the study will be kept in locked and secure facilities and/or in password protected electronic form and will be destroyed after five years.
- I understand the risks associated with taking part and how they will be managed.
- I understand that I can contact the researcher, Mary James ([mary.james@pg.canterbury.ac.nz](mailto:mary.james@pg.canterbury.ac.nz)) or supervisor Kate Reid ([kate.reid@canterbury.ac.nz](mailto:kate.reid@canterbury.ac.nz)) ph: 03 366 7001 xtn 93575 for further information.
- If I have any complaints, I can contact the Chair of the University of Canterbury Human Ethics Committee, Private Bag 4800, Christchurch ([human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz))
- I would like a summary of the results of the project.
- By signing below, I agree to participate in this research project.

If you wish to talk to someone who isn't involved with this study, you can contact an independent health and disability advocate on:

Ph: 0800 555 050

Fax: 0800 2 Support (0800 2787 7678)

Email: [advocacy@hdc.org.nz](mailto:advocacy@hdc.org.nz)

My contact details are Mary James

Email: [mary.james@pg.canterbury.ac.nz](mailto:mary.james@pg.canterbury.ac.nz)

Participant's name: \_\_\_\_\_

Signed: \_\_\_\_\_

Date: \_\_\_\_\_

Email address (*for reporting of findings, if applicable*): \_\_\_\_\_

**Declaration by researcher:**

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: \_\_\_\_\_

Signature: \_\_\_\_\_

Date: \_\_\_\_\_

## Appendix 3: Ethical Approval Letters

- i) Site Consent from Frans Dellebeke, CEO, NTH

# **Nelson Tasman Hospice**

*to care always*

Human Ethics Committee  
University of Canterbury  
Te Whare Wananga o Waitaha  
Christchurch

20 November 2017

To Whom It May Concern:

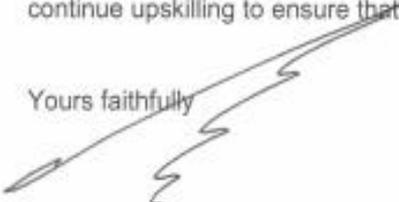
This letter is to advise that as the Chief Executive Officer of Nelson Tasman Hospice I have read Mary's research proposal and am willing to endorse and allow her to source participants once approval from the Human Ethics Committee is granted.

By doing the research, Mary will share her learnings with the rest of the team, as is normal practice at the Nelson Tasman Hospice. Therefore, not only does Mary benefit from this study, but so do her colleagues and more importantly the patients and their family members and carers who come under our care

Mary has been with Nelson Tasman Region Hospice since February 2007 is integral member of our specialist palliative care multi-disciplinary team.

I believe that Mary is motivated enough to fulfil the rigours of study that will be required of her. She will also have the support of her Supervisor and the other Hospice team members who are also studying. We have a learning culture within the organisation and must continue upskilling to ensure that we are the "specialist" in palliative care in our region.

Yours faithfully



Frans Dellebeke  
CEO

ii) Cultural consent from Rangiriri Kohe, Kaumātua

13th December 2017

Rangiriri Kohe  
38 Chamboard Place  
Nelson

Mary James  
46 Manuka Street  
P O Box 203  
Nelson 7040

Kia Ora Mary

This letter is to confirm that over the past two years I have been giving Cultural support to Nelson Tasman Hospice. I am the Alcohol and Drug Clinician for Te Piki Oranga and a Kaumātua for Ngāti Koata, Ngāti Toa Rangatira and Ngāti Kuia.

I am also the Cultural Advisor for MNZAC Nelson/Whakatū and my role is to assess the cultural component of the registration of new counsellors into full membership. I am currently facilitating two monthly/two hourly education sessions on Tikanga Mauri.

Te Piki Oranga nurses have been involved in the care of Māori whānau residing in the Nelson Tasman Hospice and this is how I became involved in supporting Māori who reside there.

During the past two years I have been involved in facilitating cultural processes for Māori residence at the Nelson Tasman Hospice i.e. Karakia, Waiata, Mihi/Whakataua, Pōwhiri, Poroporoaki, Matariki and other occasions.

I have read and considered Mary's research proposal and appreciate that she has requested cultural support. Her acknowledgement of cultural considerations for her research regarding Māori in Hospice care is commendable. I approve of this research and I am pleased to offer my support as a cultural advisor, especially because this research involves Māori participants.

I appreciate the care that Nelson Tasman Hospice gives to all those who spend time there and I am more than willing to share cultural processes with others. However, I believe my role with the Nelson Tasman Hospice is to ensure Māori are well supported by having cultural processes in place and it is my view that Mary's research proposal will enhance the wellbeing of Māori.

Naku noa na

Rangiriri Kohe  
AOD Clinician  
Clinical Supervisor MNZAC

## iii) Cultural Consent from Ngāi Tahu Consultation and Engagement Group

## Ngāi Tahu Consultation and Engagement Group



28 February 2018

Tēnā koe Mary

RE: What are the strengths that underpin and sustain family caregivers caring for a terminally ill adult under 65 years of age?

This letter is on behalf of the Ngāi Tahu Consultation and Engagement Group (NTCEG). The NTCEG considered your proposal and acknowledge it is a worthwhile and interesting project and especially relevant to Māori as almost half Māori die before the age of 65.

Given the scope of your project, no issues have been identified and further consultation with Māori is not required. However, the NTCEG have made the following comments/suggestions for you to consider:

- It is great to see local kaumātua and Māori health provider support
- How will UC be supporting/acknowledging the support of Rangiriri Kohe, for example, will we be offering a koha?
- It would be beneficial to have a UC Māori staff mentor to support you, preferably an academic from the School of Health Sciences, or your Kaiārahi, Jeanine Tamati-Elliffe
- Add macrons to Māori words with macrons – you can use this tool to identify words that should have macrons <http://community.nzdl.org/macron-restoration/jsp/servlet/DirectInput>

Thank you for engaging with the Māori consultation process. This will strengthen your research proposal, support the University's Strategy for Māori Development, and increase the likelihood of success with external engagement. It will also increase the likelihood that the outcomes of your research will be of benefit to Māori communities. We wish you all the best with your current project and look forward to hearing about future research plans.

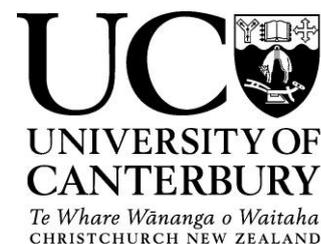
The Ngāi Tahu Consultation and Engagement Group would appreciate a summary of your findings on completion of the current project. Please feel free to contact me if you have any questions.

Ngā mihi  
Maxine Bryant (on behalf of the NTCEG)

A handwritten signature in cursive script that reads 'Maxine Bryant'.

Director Research Services | Kaihautū, Research & Innovation | Te Rōpū Rangahau  
University of Canterbury | Te Whare Wānanga o Waitaha  
Phone +64 3 369 5791, Private Bag 4800, Ōtautahi | Christchurch  
[maxine.bryant@canterbury.ac.nz](mailto:maxine.bryant@canterbury.ac.nz)  
<http://www.research.canterbury.ac.nz>

## iv) Ethical Consent from Human Ethics Committee, University of Canterbury



HUMAN ETHICS COMMITTEE  
Secretary, Rebecca Robinson  
Telephone: +64 03 369 4588, Extn 94588  
Email: [human-ethics@canterbury.ac.nz](mailto:human-ethics@canterbury.ac.nz)

Ref: HEC 2018/20

10 May 2018

Mary James  
Health Sciences  
UNIVERSITY OF CANTERBURY

Dear Mary

The Human Ethics Committee advises that your research proposal "What are the Strengths that Underpin and Sustain Family Caregivers Caring for a Terminally Ill Adult Under 65 Years of Age?" has been considered and approved.

Please note that this approval is subject to the incorporation of the amendments you have provided in your emails of 17<sup>th</sup> and 24<sup>th</sup> April 2018.

Best wishes for your project.

Yours sincerely

*R. Robinson*  
pp.

Professor Jane Maidment  
Chair University of Canterbury Human Ethics Committee

## Appendix 4: Interview Questions

Can you tell me the story of your experience of caring for ..... including the ups and downs and how you managed them, moving to how your life is now?

Where did you get your support from? How did that work?

How did your life change as a result of this illness?

What is your life like now?

What do you wish you had known prior to this occurring?

Given all you have experienced, what do you consider to be the strength that enabled you to get to where you are now?

How might this be evident in your life?

Is there anything else you would like me to know?

- You can interrupt at any time
- You can stop at any time
- You can ask for information to be removed from the recording if you do not wish me to use that in my research

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