‘TORN APART’: INVOLUNTARY SEPARATION AND THE SEARCH FOR CONNECTION

by

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ABSTRACT

Placing a loved one in care does not relieve informal caregivers’ physical and emotional stresses, yet the experience of caregivers during the long process of separation has not been fully explored, especially in Canada. This study sought to identify the social processes of involuntary separation for caregiving spouses. Participants were 17 spouse-caregivers (12 women and 5 men) with a mean age of 84 years who had been involuntarily separated for an average of 20 months. All participants lived in or near Medicine Hat, Alberta, and were of Western European descent. Data were comprised of 12 individual interviews and one focus group.

Using Charmaz’s (2006) model of grounded theory, this study found that the basic social process of spouse-caregiver involuntary separation was connecting, which had three distinct stages: 1) Initial news and coping, 2) Adjusting to new situation, and 3) Moving forward. There were also four additional categories: 1) Adjustment to separation, 2) Significant Helping Roles, 3) Family, and 4) Social world. Movement through the three stages was influenced by individuals’ willingness to reach out for connection and by the abilities of others to extend accurate empathy and practical help.

This study’s Canada-specific contributions include the polarized responses to the government’s required change in marital status to “involuntarily separated.” Additionally, weather conditions during harsh prairie winters had a negative impact on some participants’ abilities to spend time with their spouses in care. The implications of this study highlight spouse-caregivers’ needs for connection and support not only during the crisis of separation, but in the following months and years.
Keywords: Grounded theory; medical separation; involuntary separation; qualitative; basic social process; older adults; connecting
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CHAPTER 1: Introduction

According to the 2015 census by Statistics Canada (2015), the number of individuals over the age of 65 is 5.8 million. Recent estimates state that Canada now has more people age 65 years and older than age 0-14 years (Statistics Canada, 2015). Seniors are the most rapidly growing age group; it is predicted that Canada’s senior population will double to more than 10 million by 2036, and that seniors will make up 25% of the total Canadian population by 2051 (Employment and Social Development Canada; Statistics Canada, 2015). The Canadian Institute of Health Information (CIHI, 2010) states that there are more than two million informal caregivers involved in caring for our aging populace. In a study of 131,000 home care clients age 65 and older, CIHI found that approximately 40% of informal caregivers were assisting with basic activities of daily living, such as toileting and bathing, in addition to instrumental tasks like housework and food preparation. Statistics Canada (2012) reported that 83.5% of care recipients required long-term caretaking, and 10.5% received care from a spouse or common-law partner at home. Caregivers, themselves seniors and often with health issues of their own, are frequently left with no choice but to admit their spouse into a care facility. Statistics Canada (2012) and The Organisation for Economic Co-operation and Development (OECD, 2011) reported that approximately 12% of care recipients, representing 0.7% (250,000 individuals) of the Canadian population, live in a health care facility.

In spite of the increasing recognition of medical separation’s impact within the senior population, few research studies addressed this issue. Many studies have noted the impact of medical separation on caregiving spouses (Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Lieberman & Fisher, 2001; McLennon, Habermann, & Davis, 2010; Reuss, Dupuis, & Whitfield, 2005; Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001; Zarit & Whitlatch, 1993). Some
studies have experimented with various forms of interventions (Davis, Tremont, Bishop, & Fortinsky, 2011; Freeman & Ward, 1998; Gaugler, Leitsch, Zarit, & Pearlin, 2000; Givens, Prigerson, Kiely, Shaffer, & Mitchell, 2011; Kilbourn et al., 2011; Morris & Morris, 2012; Wang, Chien, & Lee, 2012), but there remains a lack of cohesion and breadth of understanding of what social processes are engaged during medical separation, and how this understanding should inform the interventions offered to caregivers and the appropriate healthcare policies. In Canada, the existence of research into this population is markedly scarce.

In response to this research gap, I examined in this study the social processes involved in the medical separation between caregivers and their spouses or partners who had been moved into long-term care. Specifically, my study aimed to answer the following research question: what are the social processes involved in medical separation from the caregiving spouses' perspective? I approached my research question using the grounded theory method as delineated by Charmaz (2006). Grounded theory is particularly suited for my research project because it seeks to unveil and understand the social processes involved in our experiences and daily interactions with our world. It emphasizes immersion into the data in order to develop a theory that is ‘grounded’ entirely in what the participants have shared. This study makes an important contribution to the field of spousal medical separation by identifying the social processes involved in the shift from being a caregiver to being medically separated in the context of the Canadian healthcare system.
CHAPTER 2: Literature Review

In this review of the literature, I will begin by defining key terms. I will then explore existing literature beginning with studies about caregivers in general, then narrowing more specifically to spousal caregivers. From there, I will identify some gaps in the existing research in general as well as gaps that may be unique to the Canadian context of spouse-caregiver medical separation. My rationale and personal connection to this topic will be outlined briefly, as well as the purpose of my study. I will touch on what I see as the implications for this project, and will end this chapter by restating my research question. Following Fassinger’s (2005) example, I will use first person language as appropriate to locate myself within this work. This is in harmony with the researcher reflexivity embraced in qualitative research.

**Key Terms**

Long-term care (LTC) refers to facilities which provide living accommodation for people who require on-site delivery of supervised care 24 hours a day, seven days a week. Care includes professional health services and personal care and services such as meals, laundry and housekeeping (HRSDC, 2014).

Involuntary separation (also referred to as medical or legal separation) is a provisional change in marital status that allows each member of the dyad to receive the Guaranteed Income Supplement (GIS)—part of the Old Age Security (OAS) benefits—at a single’s rate if they are “living apart for reasons beyond your control” (Service Canada, http://www.servicecanada.gc.ca).

Caregiver burden has numerous definitions depending on the researcher. Majerovitz (2007) defines it as “distress specifically related to caregiving” (p. 324). Phillips, Gallagher, Hunt, Der, and Carroll (2009) define it more precisely as “embarrassment, guilt, overload,
feelings of entrapment, resentment, isolation from society, and loss of control” (p. 336). I will borrow the more encompassing definition used by Gaugler, Roth, Haley, and Mittelman (2008), which is the “emotional, psychological, physical, and emotional ‘load’ of care provision” (p. 422).

**Informal Caregivers in the Existing Literature**

**General caregivers.** For most people, admitting a loved one into LTC is a difficult time both mentally and emotionally (Gaugler, Mittelman, Hepburn, & Newcomer, 2009; Gaugler, Pot, & Zarit, 2007; Gaugler et al., 2008; Lieberman & Fisher, 2001; Majerovitz, 2007; McLennon, Habermann, & Davis, 2010; Nolan & Dellasega, 1999; Stone & Clements, 2009; Tornatore & Grant, 2002). This decision is one of the hardest ones a caregiver can make (Nolan & Dellasega, 2000; Stadnyk, 2006). Caregivers have reported myriad sources for their difficulties, such as feelings of guilt and failure (Gaugler et al., 2007; McLennon, et al., 2010; Nolan & Dellasega, 2000; Penrod, Dellasega, Strang, Neufeld, & Nolan, 1998; Reuss, Dupuis, & Whitfield, 2005; Tornatore & Grant, 2002), relief and anger (Nolan & Dellasega, 2000; Reuss et al., 2005; Stone & Clements, 2009), helplessness or uselessness (Majerovitz, 2007; Reuss et al., 2005), grief and loss (McLennon et al., 2010; Reuss et al., 2005), sadness and shame (Nolan & Dellasega, 2000; Reuss et al., 2005), resentment, (Gaugler et al., 2007; Reuss et al., 2005), and loneliness and regret (Nolan & Dellasega, 1999; Nolan & Dellasega, 2000).

While caregivers tend to respond with recovery and resilience after a spouse dies, the institutionalization of a spouse appears to lead to a less positive experience overall regarding mental and physical health and recovery of caregivers (Schulz et al., 2004). Each individual’s experience is intricate and unique, but the literature suggests that caregiver burden and stress do not end after care facility admission (CFA) and are likely to increase (Gaugler et al., 2009;
Majerovitz, 2007; Reuss et al., 2005; Tornatore & Grant, 2002). Zarit and Whitlatch (1993), Gaugler et al. (2007), and Whitlatch, Schur, Noelker, Ejaz, and Looman (2001) found that caregivers often felt relief after the initial placement of their loved one, but overall stress remained long-term for years following admission. Reuss et al. (2005) noted the simultaneous emotions of relief and peace of mind during the process, followed by loneliness (Nolan & Dellasega, 2000; Stadnyk, 2006), a heavy sense of loss, overwhelming responsibility, and feeling isolated and alone. Participants in the 2010 study by McLennon et al. reported feelings of depression and anxiety, while Williams, Morrison, and Robinson (2014), Gaugler et al. (2007), and Majerovitz (2007) added that tensions between the caregiver and resident and general familial conflict may all affect caregiver stress post-CFA.

Majerovitz (2007) argues that caregiver stress and burden post-CFA shifts from a physical burden where the caregiver was responsible for all aspects of care for their loved one, to an emotional burden that is primarily psychological (Stone & Clements, 2009). After having been in control of their loved ones’ care, possibly for years, caregivers suddenly become visitors in their loved ones’ care facilities (Nolan & Dellasega, 1999). Nolan and Dellasega (1999) and Reuss et al. (2005) commented that this loss of control or disempowerment can leave caregivers feeling unrecognized and isolated (Elmståhl, Ingvad, & Annerstedt, 1998). Reuss et al. (2005) also observed that a large part of the difficulty with transitioning a loved one into care stemmed from guilt over placement, the stigma of institutionalizing a family member, and feeling like failures in their familial responsibility.

Contrary to the stigma that family members ‘dump’ their loved ones in care homes, most caregivers do not abandon their relatives after CFA (Gaugler, Anderson, & Leach, 2004; Keefe & Fancey, 2000; Nolan & Dellasega, 2000; Whitlatch et al., 2001). Rather, their role is altered;
many continue with some caring tasks while taking on new responsibilities such as maintaining vigilance and advocating for their loved one within the facility (Mullin, Simpson, & Froggatt, 2011; Schulz et al., 2004; Stadnyk, 2006; Zarit & Whitlatch, 1993). Many visit their loved ones faithfully, lending emotional support and helping with more minor aspects of physical care like assisting at mealtimes or doing their laundry in addition to regular at-home tasks like dealing with finances (Gaugler et al., 2007; Majerovitz, 2007; Stone & Clements, 2009). With the continued flurry of often conflicting emotions and feelings of burden and distress, caregiver needs continue long after CFA (Nolan & Dellasega, 1999). Caregivers must also cope with the emotional difficulty of watching their loved ones’ failing physical or mental health (Majerovitz, 2007). Lieberman and Fisher (2001) suggest that distress is possibly due to the “impending ‘psychological’ and physical death” (p. 824) of their loved one, otherwise known as anticipatory grief (Almberg, Grafström, & Winblad, 2000; Casarett, Kutner, & Abrahm, 2001; Garand et al., 2012; Gilliland & Fleming, 1998). This is supported by Mullin et al. (2011) and Nolan and Dellasega (1999) who found that caregivers struggle with feelings of emptiness and the finality of their loved ones’ inevitable deterioration.

Impact of medical separation on caregivers. Caregiving can be very demanding and caregivers often endanger their own health (Stone & Clements, 2009). With stressors continuing post-CFA, caregivers generally do not experience improvement in their psychological well-being over the long-term (Lieberman & Fisher 2001; McLennon et al., 2010; Zarit & Whitlatch, 1993). Numerous studies have found that older caregivers especially, and those with poorer physical health and lower incomes are at highest risk for health problems, most notably for depression (Gaugler et al., 2009; Majerovitz, 2007; Schulz et al., 2004). Caregivers tend to be less tired and feel less overwhelmed after the admission process, but new stressors often arise in their stead.
(Gaugler et al., 2009; Whitlatch et al., 2001), such as the already-mentioned vigilance, advocacy, visitation, and financial responsibilities. In addition, their loved ones’ difficult adjustment to the CFA is another factor that can lead to increased stress (Whitlatch et al., 2001), particularly when the caregiver is already feeling conflicted over their decision to seek placement (McLennon et al., 2010). Thus, most caregivers play an active role in their loved ones’ lives after CFA and continue to have stress and psychological distress, sometimes increasingly as time passes (Gaugler et al., 2000). The relationship of the caregiver and their loved one can have significant emotional impact (Stone & Clements, 2009); the stronger the emotional bond, the greater the emotional distress and sense of loss (Lieberman & Fisher, 2001). Gaugler et al. (2009) found that both older and female caregivers reported more feelings of burden and depression after a loved one’s admission, as did caregivers who reported hospital use during the transition (Whitlatch et al., 2001). Thus, it is unsurprising that the literature affirms that feelings of burden, distress, and depression post-CFA were greatest for spouses who admitted their husband or wife (CIHI, 2010; Elmståhl et al., 1998; Gaugler et al., 2007; Gaugler et al., 2009; Lieberman & Fisher, 2001). Stadnyk (2006) wrote that “the move of a spouse to a nursing home is often described as one of the most difficult transitions, aside from death, that a married person can face in North American society” (p. 283).

**Spouse caregivers.** Of course, all family members must make adjustments when a loved one is admitted to long-term care, but spouses face the greatest demands. They must transition to a new situation, but often provide support for the resident and other family members in addition to facing familial tensions and potential financial hardships (Sidell, 2000; Stadnyk, 2006). Schulz et al. (2004) have argued that the institutionalization of a spouse can be more difficult than the death of a spouse; while the general emotional recovery of the survivor is increasingly
noticeable with the passing of time, similar improvement is not typically seen with spousal institutionalization. Compared to non-spouses, spouses “were significantly more depressed before placement and more depressed and anxious after placement” (Schulz et al., 2004, p. 965).

For many caregivers, placing their spouse in care can feel like an abandonment of their marriage vows (Sidell, 2000; Stone & Clements, 2009). The uniqueness of their situation as a couple makes it hard for family and friends to understand what the caregiver is going through, leading to heavy feelings of isolation from people who were normally sources of social support (Sidell, 2000). Stadnyk (2006) noted that married caregivers often experience a kind of “married widowhood” (p. 284) where they live in “limbo” (p. 290). Though still part of a marital dyad, the caregiver lives alone like a widow or widower (Sidell, 2000). This limbo can be awkward socially and can discourage caregivers from engaging in social activities outside their spouses’ care facility (Stadnyk, 2006).

**Transitioning factors of care facility admission.** Numerous factors have been identified as making the CFA and post-CFA transition more difficult. Lack of confidence in the quality of care in nursing homes may make caregivers extra vigilant, feeling like they need to be around to ensure sufficient care for their loved one while adding extra burden onto themselves (Majerovitz, 2007; Tornatore & Grant, 2002). The constant commute to and from the nursing home, managing administrative and financial issues, and decreased control over their loved ones’ care have also been shown to increase caregiver stress along with questioning their placement decision and feelings of failure in spousal commitment (Majerovitz, 2007; Schulz et al., 2004).

The decision to admit a loved one can be extremely difficult for caregivers and is often precipitated by a crisis or series of crises (McLennon et al., 2010). A major factor is declining caregiver health as their loved ones’ care becomes too overwhelming to maintain a level of
sufficiency (McLennon et al., 2010). The decision to place can also be ‘expert-driven’ with physicians and health professionals making the final call to move a loved one into a care facility (Nolan & Dellasega, 2000). Families in the Reuss et al. (2005) study in Ontario, Canada, reported feeling especially powerless when the decision to place their relative was taken out of their hands, and when a placement opened up, the family felt that “we had no choice. The government makes you go there” (p. 28). Participants commented frequently on feeling rushed through the admission process which resulted in increased burden and stress (Nolan & Dellasega 1999; Reuss et al., 2005). With the abruptness of an available placement, there was no time to plan the move to the care home, to get paperwork in order, to organize logistics, or to pack, arrange for a moving vehicle, or even begin to emotionally prepare the loved one for the move (Reuss et al., 2005).

Reuss et al. (2005) noted the importance of a welcoming environment upon arrival at the care home, while Mullin et al. (2011) specifically highlighted good communication between care workers and families, warm and friendly staff, and cleanliness. Conversely, an introduction to the care home that was perceived as cold or apathetic increased the difficulty of transition. Perceptions of poor quality of care made for a more negative transition for families as it became harder to reconcile the decision to place their loved one into care, though the opposite is also true—when they felt their loved one was well cared for, families felt comfort and relief (Reuss et al., 2005). Along similar lines, Whitlatch et al. (2001) and Reuss et al. (2005) linked caregiver depression to the level of CFA adjustment of the caregiver and their loved one; when the loved one fought the placement, caregivers experienced increased feelings of guilt and failure. Acceptance of the move made the overall process more positive for the whole family.
Visiting is considered by caregivers as one of the most important things they can do to support their institutionalized spouse (Stadnyk, 2006). The commute from the caregiver’s house to the care home can therefore be another stressor, particularly when the caregiver has difficulty with driving or cannot drive at all (Majerovitz, 2007). With spousal caregivers, the geographic proximity of their children eased the transition as the closer the family lives to the care facility, the more frequent and more involved they tend to be in their loved ones’ lives (Gaugler et al., 2004; Stone & Clements, 2009).

The transition to the nursing home was more positive when staff made a deliberate effort to welcome the family on moving day (Reuss et al., 2005). Families with previous familiarity with the care home experienced a smoother process, and higher satisfaction with the quality of care was correlated with lower caregiver burden (Gaugler, Leitsch, Zarit, & Pearlin, 2000; Reuss et al., 2005). Nolan and Dellasega (2000) emphasized the importance of the formulation of trust between the care home and caregivers in order to promote positive interactions in the future. Adjustment also improved when caregivers acknowledged their personal limitations in their ability to care for their loved one (Reuss et al., 2005). Numerous caregivers have expressed relief and reduced fear and anxiety in knowing their loved ones were receiving quality care around-the-clock (Reuss et al., 2005; Stone & Clements, 2009).

Respondents also noted the helpfulness of social workers in dealing with emotional difficulties and as a communication link in the admission process (Stone & Clements, 2009). Support from physicians, case managers, clergy, local support groups, and care home staff made a big difference, as did having one central person they could call to ask questions (Reuss et al., 2005). Zarit, Lee, Barrineau, Whitlatch, and Femia (2013) did not include discussion of caregivers’ spirituality in their study and commented that some of their participants wished they
had. Gaugler et al. (2000) found that caregivers who received emotional support prior to CFA reported fewer problems with nursing home staff and increased satisfaction with overall care.

In summary, numerous studies have noted that the emotional impact of placing someone into care was higher when there were stronger emotional bonds between them, such as with husbands and wives (CIHI, 2010; Elmstáhl et al., 1998; Gaugler, Pot, & Zarit, 2007; Gaugler et al., 2009; Lieberman & Fisher, 2001; Stadnyk, 2006; Stone & Clements, 2009). Participants in Reuss et al.’s (2005) study in Ontario, Canada, reported feelings of powerlessness, especially surrounding the placement process itself. Caregivers reported feeling overwhelmed by the logistics of the transition and the abruptness of everything that suddenly had to be accomplished in a very short amount of time. Whitlatch et al. (2001) and Reuss et al. (2005) noted the negative impact on caregivers when their spouses fought placement or did not adjust well. These caregivers reported more feelings of guilt and failure. In contrast, they also found that caregivers adjusted more quickly and smoothly when the spouse admitted into care accepted the move. The positive impact of previous familiarity with the care facilities was observed by Gaugler et al. (2000) and Reuss et al. (2005), as was the valuable role of trust between spouse-caregivers and professional care workers (see also Stone & Clements, 2009; Nolan & Dellasega, 2000). The importance of miscellaneous helpers such as social workers, physicians, chaplains, support groups, case managers, and care workers have been highlighted by Reuss et al. (2005) and Stone and Clements (2009).

Much has been noted about the continuing responsibilities, stressors, guilt, and negative anticipation toward the future among separating spouse-caregivers. The anticipation of loss as caregivers looked ahead to their spouses’ inevitable deterioration and eventual death has also been well-documented by Lieberman and Fisher (2001), Nolan and Dellasega (1999), Casarett,
Kutner, and Abrahm (2001), Garand et al. (2012), Almberg, Grafström, and Winblad (2000), and Gilliland and Fleming (1998). Additionally, Stadnyk (2006) and Sidell (2000) reiterate the sense of social limbo that arises when caregivers feel they no longer fit with the couples or the widows and widowers in their social circles. In short, caregivers’ needs shift after their spouses are placed into LTC, but it is clear that their needs do not end.

**Existing Theoretical Frameworks**

The purpose of grounded theory is to examine a phenomenon and develop a theory that is based firmly in the data. However, researchers approach data with their own prior experiences and knowledge, which include other theoretical frameworks. Rather than viewing these frameworks as competition for the researcher’s new theory, Charmaz (2006) and Stern (2007) embrace their value for grounded theory. Charmaz (2006) recommends using them “to provide an anchor for your reader and to demonstrate how your grounded theory refines, extends, challenges, or supersedes extant concepts” (p. 169). Acknowledging preferred theories is also an act of researcher transparency. With this in mind, I have briefly outlined Bowlby’s attachment theory below, which is my own primary theoretical framework. During the conceptualizing phase of this project, I also borrowed from Erikson’s stages of psychosocial development, and Lazarus and Folkman’s theory of stress and coping. I will attempt to locate this study’s new, grounded theory among these theoretical frameworks in my discussion chapter.

**Bowlby’s attachment theory.** Attachment theory states that a stable relationship with at least one reliable attachment figure beginning in infancy is the foundation of psychological health. For adults, Bowlby (1979/1980, as cited in Mikulincer & Shaver, 2008) saw adult romantic relationships as the major source of attachment bonds. Chopik, Edelstein, and Fraley (2013) cited Edelstein and Gillath’s (2008) findings that individuals in romantic relationships
demonstrated more secure attachments than those who were single. As individuals age, more focus and energy is directed toward the health of intimate relationships, “making such relationships increasingly central to personality development and functioning” (Chopik, Edelstein, & Fraley, 2013).

For this study, the question becomes: What happens to the caregiving spouse when they are separated from their romantic attachment figure? According to Mikulincer and Shaver (2008), the reaction is similar to those of infants who have lost or been separated from their primary attachment figure. Adults in grief or separation go through states of protest, despair, and reorganization. In protest, individuals show their adamant resistance to the separation through crying, clinging to their attachment partner, and usually experience feelings of anger and anxiety. The next stage is despair, which includes “depressed mood, pained expressions, decreased appetite, and disturbed sleep” (Mikulincer & Shaver, 2008, p. 93).

The third stage for adults is reorganization, which involves seeking new attachment figures to at least partially take over the role of a new “safe haven and secure base” (Mikulincer & Shaver, 2008, p. 94). Rather than detaching from the previous attachment figure, that person can instead continue to be “a symbolic source of protection, comfort, and love while life with other people continues, perhaps on new foundations” (Mikulincer & Shaver, 2008, p. 94). This stage harkens back somewhat toward the individuation of late adolescence. Instead of developing one’s own identity apart from a parental attachment figure, the spouse-caregivers begin to shift their identities away from their husbands or wives. Former partnerships of co-attachment become unequal relationships of parent-like caregiving for a care-recipient.

**Erikson’s stages of psychosocial development.** Erikson’s eighth and final stage of psychosocial development is ego integrity vs. despair. It is typically thought to begin roughly
around age 65 upon retirement from the workforce and continuing until death. Each of Erikson’s eight stages involves a crisis between two opposing fields that must be resolved at least somewhat in order to continue to the next stage of development. In this sense, crises are not seen as entirely negative but are rather opportunities for growth. Svetina (2014) defined a crisis as “facing uncertainty and threat in attaining [an] important need or life goal, being associated with a particular event, long-lasting life circumstances, or [a] particular developmental period” (p. 393). Hamachek (1990) describes integrity as “a sense of personal completeness and positive worth,” and despair as “a sense of incompleteness and feelings of disappointment” (p. 681). However, Kivnick and Wells (2013) argue that the integrity vs. despair stage includes “unique efforts around renewing, re-experiencing, and ‘reresolving’ all eight themes” (p. 44). Previous crises of trust vs. distrust, autonomy vs. shame, initiative vs. guilt, industry vs. inferiority, identity vs. confusion, intimacy vs. isolation, and generativity vs. stagnation are naturally revisited in light of life’s experiences, and are reintegrated from a more mature perspective (Glover, 1998).

Weismann and Hannich (2011) noted that this re-evaluation could be challenging for individuals in the midst of transition. Though they specifically highlighted the shift from the workforce to retirement, we can extrapolate that any kind of major life transition—including involuntary separation—could be disruptive to the resolution of integrity vs. despair; “In the face of this upheaval, ‘one is dramatically faced with the question of how one is to go about (or even whether one can or wishes to) reconstructing a new social world’” (Antonovsky & Sagy, 1990, p. 365, as cited in Weismann & Hannich, 2011, p. 354). I will not explore all the previous stages, but stages six (intimacy vs. isolation) and seven (generativity vs. stagnation) have particular relevance. Some highlights of Hamachek’s (1990) description of both sides of intimacy vs.
isolation include the following: Struggling to form a firm sense of their own identity; not trusting themselves easily; and willingness to commit to relationships that involve sacrifice. General attitudes could be that life is difficult and everyone needs to look after themselves (isolation) vs. life is difficult but we can get through it by working together (intimacy), or “I’m okay but others are not okay” (isolation) vs. “I’m okay and others are too” (intimacy) (Hamachek, 1990, p. 678).

Lazarus and Folkman’s stress and coping. The theory of stress and coping as set forth by Lazarus and Folkman (1984) supports the hypothesis that an individual’s health and wellbeing are affected more by how people cope with stress than by the stress itself (Folkman, Lazarus, Pimley, & Novacek, 1987). Coping is impacted by the type of stressful events being faced and, as Folkman et al. (1987) noted, can change across contexts as individuals age. They defined stressful events as “person-environment transactions that are appraised by the person as relevant to well-being and as taxing or exceeding coping resources” (Folkman et al., 1987, p. 172). Coping strategies are either problem-focused, such as seeking information and exploring solutions, or emotion-focused, which attend to the emotional and psychological consequences of the stressful event (Ben-Zur, 2005). Most people use a combination of both during stress, but tend to lean more heavily on one over the other (Folkman et al., 1987).

In any stressful situation, there is a primary appraisal, which looks at what is at stake for the individual. In the secondary appraisal, individuals look for options in how to change their relationship to their current environments (Folkman et al., 1987). According to Folkman et al. (1987), “effective coping fits the possibilities or lack of possibilities for action in a specific context” (p. 182). When a situation was deemed personally relevant (primary appraisal) and changeable (secondary appraisal), individuals tended to be more problem-focused. This included planning, problem solving, confronting, accepting responsibility, and attending selectively to
positive facets of their situations. When the situation was deemed unchangeable (secondary appraisal), individuals turned more toward emotion-focused coping, such as emotional distancing and escape-avoidance in order to distract from the unavoidable outcome of the event (Folkman, Lazarus, Dunkel-Schetter, DeLongis, & Gruen, 1986).

Folkman et al.’s (1987) study suggested that younger people tended to use more problem-focused coping, while older groups generally used more emotion-focused coping. The researchers noted that this could have been due to contextual factors.

**Rationale of the Present Study**

Though studies are starting to look more into the long-term effect of spousal institutionalization on caregivers, most do not go beyond three or four years (Gaugler et al., 2007). Sidell (2000) is an exception whose study extended 15 years after care facility admission and still found evidence of burden and distress. Gaugler et al. (2009) note the potential in exploring how the placement decision came about, while Nolan and Dellasega (2000) and Gaugler et al. (2008) emphasize the need to investigate the specific needs of caregivers during and after the admission process. Though it is no longer assumed that care home placement will relieve all caregiver physical and emotional stress, the experience of caregivers during the long process of transition has not been fully explored (Gaugler et al., 2007; Lieberman & Fisher, 2001; Mullin et al., 2011; Whitlatch et al., 2001). It has been noted that there may be distinctive factors for caregivers in Canada as health care and government policies differ from country to country (Reuss et al., 2005). Gaugler et al. (2007) have noted the potential value in researching specific subgroups of caregivers, such as by gender or relationship to the institutionalized loved one.
Given that spouses appear to experience more burden, distress, and depression after admission into care, the literature suggests that research which focuses specifically on the social processes of transition for the in-community spouse is needed. Additionally, there is a current lack of literature that emphasizes the Canadian context which includes our unique system of public healthcare. It was my goal to develop a fuller understanding of the general social processes involved in the spousal shift from informal caregiver to being medically separated. This was the next step in being able to better equip mental, medical, and spiritual health professionals as they endeavour to support spouse-caregivers through this transition. Furthermore, the literature supports the idea that practical information can help reduce stress in individuals who are facing life change (Gaugler et al., 2008; Gaugler et al., 2009; Majerovitz, 2007; Mullin et al., 2011; Stone & Clements, 2009; Tornatore & Grant, 2002).

**Research Question and Implications**

This study addressed the following question: What are the social processes involved in medical separation for caregiving spouses? I desire to see the results of this study disseminated to the population of medically separating or separated caregivers in order to normalize their overall experiences while offering practical suggestions. Suggestions stemming from this study may also extend to care professionals and others who interact with individuals who are involuntarily separating.
CHAPTER 3: Method

In this chapter, I will begin by outlining my research design and will note how my method fits within the constructivist paradigm. I will make brief mention of my personal interest in this topic and population before describing my participants and recruitment strategy. Some ethical implications will be discussed before delving into the process of analysis and the rigour and validation of grounded theory.

Paradigm

Grounded theory has undergone many transformations since its initial development by Glaser and Strauss (1967), and it continues to branch into multiple paradigms depending on the form and the researcher. Charmaz’s (2006) framework that I adopted for this project is decidedly situated in the constructivist paradigm, which also fits my chosen research design. My method of data gathering was comprised of semi-structured interviews both with individuals and focus groups. This is a personal and interactive way of acquiring data. Inherent within this method and the overarching paradigm is the assumption that the data and subsequent analysis are created within the relationship of shared experiences between participants and researchers (Charmaz, 2006; Mertens, 2010). In short, “constructivists study how—and sometimes why—participants construct meanings and actions in specific situations” (Charmaz, 2006, p. 130). This includes exploring “how, when, and to what extent the studied experience is imbedded in larger and, often, hidden positions, networks, situations, and relationships” (p. 130).

The constructivist paradigm takes a reflexive stance by considering how I, as the researcher, affect the research process. Within the constructive framework, grounded theory seeks to be transparent in the processes and influences of the researcher and attempts to make them explicit. These are tracked through auditing and memo-writing, “which involve monitoring
the researcher’s analytic decisions and documenting the researcher’s emerging theoretical ideas” (Fassinger, 2005, p. 157). During analysis, the aim is to clearly document how categories and interpretations are evolving. In this way, researcher assumptions and biases can be more readily identified.

My personal adherence to the constructivist paradigm does not encompass the existence of literal multiple realities, but this facet of constructivism is of negligible importance for the context of my study (Fassinger, 2005). Whether or not they are different realities or, as I understand them, unique perceptions of a single reality, my approach with grounded theory remained the same—to understand how my participants uniquely experience reality, while recognizing that my presence in the midst of data gathering and analysis influenced each part of the process.

My attraction to grounded theory is well-summarized by Charmaz (2006):

Neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and interactions with people, perspectives, and research practices. My approach explicitly assumes that any theoretical rendering offers an interpretive portrayal of the studied world, not an exact picture of it. (p. 19)

Grounded theory assumes an inherent connection between researchers, participants, and data. The makeup of an individual’s experience is unique, but there remain elements common to the human experience through our interactions with others and the world around us. Grounded theory endeavours to minimize the distance between the researcher and the data by openly
acknowledging and documenting the assumptions involved in the processes of data interpretation.

**Personal Interest**

My personal interest in the social processes of medical separation took root during my time as a chaplain’s aide in a multi-level care facility in the summers of 2010 and 2011. During this time, I came face-to-face with the emotional experiences many caregivers have during and after admit-ting their spouses into LTC. One person in particular made such an impact on me that, when given the opportunity to do an undergraduate research project, I immediately knew which topic I wanted to study. With invaluable support and encouragement from my former boss, the chaplain, and my project supervisor, I set out to explore the experiences of individuals who had been informal caregivers for their husbands or wives, and whose spouses had subsequently been admitted into LTC. My experience with this population has piqued more curiosity in the processes involved in medical separation. Additionally, it has fanned my passion to not only gain insight, but to figure out ways of disseminating this information to care facilities, frontline care workers, and spouse-caregivers.

**Research Design**

**Timeline.** This study took place over three main phases: (1) individual interviews, (2) focus group interviews, and (3) follow-up interviews. The initial grounded theory categories emerged from the individual interviews and were further refined via theoretical sampling through a focus group and follow-up interviews.

**Individual interviews.** In the initial phase of this study, I used the existing data of 10 semi-structured interviews which had been transcribed verbatim from the original audio
recordings. These transcripts were analyzed using the grounded theory method as outlined by Charmaz (2006). The coding scheme is presented in Appendix I and Appendix J.

**Focus group.** Partway through the analysis process and consistent with the theoretical sampling requirement of grounded theory (Bryant & Charmaz, 2007; Charmaz, 2006; Fassinger, 2005), I conducted two new interviews and a focus group with participants from the same geographical area as the original data to maintain homogeneity of the research participants. This group consisted of participants with the same criteria as the existing data (Table 3.1). In our focus group meeting, I presented the findings from my initial data analysis. Group members were then invited to reflect and respond with feedback from their own experiences. This served as a credibility check as recommended by grounded theory, and also as theoretical sampling geared at gathering more data to refine the theoretical categories of the grounded theory. The audio recordings of the two interviews and the focus group were transcribed verbatim by a professional transcriptionist. These transcripts were then analyzed in the same manner as the initial 10 transcripts.

**Follow-up interviews.** Charmaz (2006) encourages returning to participants during analysis to confirm researcher interpretations, gain clarity, or pursue specific topics in greater depth. Given that more than three years had passed since I gathered the original 10 interviews, some participants were no longer accessible or appropriate for me to contact due to their changed life circumstances. However, I approached my previous third-party contacts from the original study and asked them to use their discernment in passing on my invitation (Appendix A) to previous participants for a follow-up telephone call. I used these follow-up interviews and my focus group to check my interpretations, invite feedback, and explore specific categories that bore fleshing out. Informed consent and debriefing were done verbally over the telephone for
the follow-up calls, and I used a semi-structured interview script to guide the discussion as needed (Appendix B).

**Participants**

**Recruitment.** For this research project, I used data previously gathered from 10 semi-structured interviews (Appendix C) as well as new data collected via two new interviews and the focus group. My recruitment criteria were the same as those I used in finding the previous 10 participants (Table 3.1). Since my research question was examining the social processes of medical separation, my target population was individuals who had previously been in a caregiving role to their spouse but whose spouse had been admitted to a long-term care facility. I anticipated that the new data would augment my initial interviews to the point where I would no longer discover new categories, and existing categories would be of acceptable depth. This is typically referred to as “saturation” in grounded theory, but Dey (1999) uses the more realistic term “theoretical sufficiency” (p. 257; as cited in Charmaz, 2006, p. 114).

Table 3.1

<table>
<thead>
<tr>
<th>Spouse-Caregiver Inclusion and Exclusion Criteria</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Inclusion criteria</strong></td>
</tr>
<tr>
<td>• Former caregiver for their spouse for at least one month prior to care facility admission</td>
</tr>
<tr>
<td>• Have admitted their spouse into long-term care, or are in the process of doing so</td>
</tr>
<tr>
<td>• Must be located in or around the Medicine Hat, AB, area</td>
</tr>
<tr>
<td>• Must be willing to speak about their experiences in front of me and a small group of peers</td>
</tr>
<tr>
<td>• Any ethnicity</td>
</tr>
<tr>
<td>• Any faith, no professed faith</td>
</tr>
<tr>
<td>• Both genders welcome</td>
</tr>
<tr>
<td>• Must be willing to be audio recorded</td>
</tr>
</tbody>
</table>

Table 3.1

Spouse-Caregiver Inclusion and Exclusion Criteria
For my focus group, I recruited five participants (one male, four female) located in or around Medicine Hat, Alberta. This location was selected with the intention of maintaining participant homogeneity, as it was where the existing data were gathered. The main care facilities I approached were built—and continue to be maintained—by various Christian denominations. Many residents profess a Christian faith, but this was not required for admittance to the facilities. Participants of all ages, faiths, and ethnicities qualified for my study as I was not seeking to focus on any specifics in these areas other than geographical location and fluency in spoken English. Fluency in English was necessary as my research design relied on spoken interviews and spoken interactions in a focus group setting. Participants were required to understand what was happening, to communicate their own ideas with relative clarity, and to engage to a moderate extent on the levels of meaning which words can possess. To be included, the participants had to: be married or previously married, have been in a caregiving role for their spouses for a minimum of one month, and their spouses must have been admitted—or be in the process of admission—into LTC (Table 3.1). This time frame was chosen as it follows the clearly demarcated shift from informally giving care at home to actively becoming involuntarily separated. Exclusion criteria included: lack of fluency in spoken English, being divorced from their care-recipient spouse, being diagnosed with or showing symptoms of dementia or other significant cognitive limitations, being in a romantic relationship with someone new (e.g., after spousal death), and having a prior friendship (more than an acquaintanceship) with the researcher.

To recruit for the focus group and new interviews, I used intensive and theoretical sampling. I used my prior connections with administrators at two large care facilities in Medicine Hat, Alberta. After gaining permission from the managing entities, I gave invitation
letters to the chaplains and care workers (Appendices D and E). They were asked to distribute these letters at their discretion to individuals who seemed to fit my criteria. My invitation included my contact information but interested individuals were also welcome to ask the chaplains or care workers to contact me on their behalf. This was intended to make it easier for participants with impairments to reach me, and also to ensure potential participants were not burdened with the cost of a long distance telephone call.

**Ethical considerations.** The experience of LTC admission and medical separation is a heavy topic to ask participants to explore. In my informed consent, I emphasized the voluntary nature of their involvement and that they could withdraw at any time during or after the interview without any consequences. My original interviews were held wherever participants felt comfortable and were conducive to confidentiality. One chose to meet with me in the chaplain’s office, while the other nine invited me to their homes where we shared tea or coffee and cookies as we talked. If participants became emotional, they were gently offered a break or to discontinue the interview. For both the previous and current studies, the two chaplains involved in my study volunteered their free services to any participants who wished to receive pastoral support post-interview. Their contact information was included in the informed consent and was highlighted in my short debriefing handout after each interview and focus group. Participants were offered a copy of our final report at the study’s anticipated completion.

For the focus group, I included all of the above with the exception of meeting in someone’s home. Given the group nature, I used a meeting room with a comfortable family dining room set up at one of the care facilities. My informed consent for the focus group (Appendix F) was nearly identical to the interview consent except that it also included an emphasis on the confidential nature of what was discussed in our meeting. I verbally
emphasized that they were free to share about their own experiences in the group and any of the general information mentioned by the researcher; however, sharing anything related to another group member’s experience was a breach of confidentiality. At the completion of the focus group meeting, all group participants were debriefed and received a debriefing handout (Appendix G). In it, I expressed my gratitude for their willingness to share their knowledge and experiences with me and with each other. It had a gentle reminder to respect the confidentiality of their fellow group members, and included my contact information and an encouragement to get in touch with me if they had any questions or concerns. I also gave them the contact information for the chaplains in the event that they found themselves in need of support beyond our focus group setting.

The focus group session was audio recorded and given to a professional transcriptionist. The transcript was anonymized and all potentially identifying information was redacted. The audio recordings were stored on a password-protected computer for the duration of the study and will be destroyed at its completion. Participant names and contact information were stored in a separate file and were also encrypted and password-protected. The anonymized transcripts are stored in a locked briefcase or filing cabinet.

Potential risks and benefits. Individuals who took part in my study were warned that they may find it difficult or upsetting to talk about parts of their journeys of medical separation. They could be disturbed by memories and intense emotions that could arise, and they may feel overwhelmed. They did not have to talk about anything with me that they preferred not to, and an experienced chaplain was available to them in the days and weeks after our meetings at no cost to the participants. Conversely, many participants expressed feeling therapeutic relief in sharing pieces of their experiences with a nonjudgmental listener. Other possible benefits
included: feeling like they were part of something that would help shed new light on the processes of medical separation; potentially being able to indirectly help professional care providers; and indirectly helping other individuals in the future who are going through medical separation.

Data Collection

As mentioned earlier, this research project began with existing data. I had already conducted 10 exploratory and semi-structured interviews with participants in this population under the approval of the Research Ethics Board (REB) of The King’s University College (now The King’s University) in Edmonton, Alberta. With approval from the Trinity Western University REB, I reanalyzed these transcripts using grounded theory. The existing data consisted of 10 participants (7 female, 3 male) with age M = 88.9 years (range 70-95 years). They had been married an average of 51.8 years (range 20-66 years), and one participant was on her second marriage. The average length of time since their spouses’ admissions into LTC was M = 14 months (range 2-48 months). One spouse had been in the hospital for one month while awaiting placement into LTC. All participants lived in or near Medicine Hat, Alberta, at the time of the interviews. Their spouses had been admitted into one of four LTC facilities in Medicine Hat, with the one exception who was awaiting placement. Most, but not all, professed a Christian faith. All were of Western European origin, and several had immigrated to Canada during the WWII era. Most participants were from blue collar backgrounds, such as agriculture, trade, or had been otherwise self-employed. One had worked in the school district as a principal. Nine of the participants’ spouses were still alive at the time of the interviews, and the tenth had passed away approximately nine months prior.
The new data were gathered from two additional interviews and one focus group, all of which also took place in Medicine Hat, Alberta, and followed the same recruitment criteria as the previous data. As before, these meetings were audio recorded and later transcribed verbatim. The two interviews took place not long into the process of analysis. With these two participants, I outlined the purpose of my study, asked them some new questions, shared my initial findings thus far, and asked for their feedback (Appendix G). This was intended to be an early credibility check as my analysis began to take shape. I conducted the focus group roughly eight months later as I neared analysis completion. The purpose of this group was twofold; it was an in-depth credibility check on my emerging results and it garnered more data to ensure I had attained theoretical sufficiency.

Focus groups can be used for a variety of purposes; Morgan (1996) observed that they are often used in combination with in-depth interviews as a way to delve deeper into specific areas. He also cites Irwin (1970) in commenting on the value of focus groups as a way to check analyses of individual interviews. According to Morgan (1996) and Stewart, Shamdasani, and Rook’s (2013) definition, I chose a more structured moderating style; I asked specific questions, directed discussion away from other topics, and I made sure each person had opportunity to respond to each question. Participants were able to interact with each other in their responses to my questions with minimal intervention as long as they stayed on topic. Given the emotionally vulnerable nature of my questions, the small group of five participants was appropriate to encourage higher levels of participation and a sense of safety (Morgan, 1996).

Including the two interviews, there were a total of seven new participants (5 female, 2 male) with age M = 79.6 years (range 73-87 years) with two ages unknown. The participants had been married an average of 59.1 years (range 53-69 years). The average time since they had
been separated from their spouses was $M = 26$ months (range 9-48 months). All participants’ spouses were alive at the time of our meeting, with one exception from the focus group whose husband had died some months earlier.

After going through informed consent with the focus group, I began the discussion by outlining the main purposes of my study and the specific role I was asking them to play. I did not prepare a script beforehand, choosing instead to share what stood out from my data analysis, particularly the categories that appeared most significant from my preliminary mapping. I then asked the group to discuss and share their perspectives on my findings. Each section served as discussion aids (Stewart et al., 2013) to direct the conversation. Nearly all the findings I shared were met with heartfelt agreement and were frequently followed by brief, yet meaningful examples from group members’ own experiences. At the end, I went through a short debriefing and gave each person a copy of the debriefing document (Appendix H). The transcripts from the focus group and the two additional interviews were analyzed in the same manner as the previous data (Webb & Kevern, 2000).

**Data Analysis**

Remaining open only to the theory contained within the data can be challenging for researchers using the grounded theory method (Holton, 2007). Though it is impossible to enter into analysis without any preconceived notions, efforts should be made to minimize this tendency as much as possible. Because of this, studying potentially relevant theories prior to data analysis is discouraged as it may unduly influence the analytical process.

Grounded theory is not about description, but about “conceptual abstraction” (Holton, 2007, p. 172). The goal is to take concepts from the data, leaving the details behind, and to
integrate them “into a theory that explains the latent social pattern underlying the behaviour in a substantive area” (Holton, 2007, p. 273).

**Initial coding.** As delineated by Charmaz (2006), grounded theory uses primarily two phases of coding—initial and focused. Initial coding is used to define what is happening in the data and focused coding is to wrestle with what it means. I used the line-by-line technique of initial coding to reduce my risk of overlooking seemingly inconsequential sections and to avoid becoming caught up in narrative or engaging descriptions (Bryant & Charmaz, 2007b; Fassinger, 2005; Holton, 2007). This facilitated challenging my own assumptions of what might otherwise constitute a unit of meaning. Initial coding stays close to the data with minimal deviation. There is some interpretation inherent in this process because of every individual’s linguistic lens and prior assumptions, but the goal is to concretely identify the action of each line. Glaser (1998, as cited by Holton, 2007) proposed a series of queries to ask each line, such as, ‘What is this data about?’, ‘Does this incident suggest a certain category?’, ‘What is happening in the data?’, ‘What is the participant’s main concern?’, and ‘How is this concern being resolved?’ Charmaz (2006) recommends doing initial coding quickly to minimize the risk of overthinking each code, but she includes the caveat that these codes are provisional – they can be changed or shifted at any point during analysis. I attempted to follow her recommendations to “Remain open; stay close to the data; keep your codes simple and precise; construct short codes; preserve actions; compare data with data; move quickly through the data” (p. 49). The goal of initial coding is to create codes that reflect the action of the data rather than forcing the data to fit the codes or getting too distracted by descriptions (Holton, 2007). Fassinger (2005) succinctly describes the process as follows: breaking the data down into units of meaning, also known as concepts (line-by-line, in this case); labelling each unit or concept while attempting to use words similar to those of the
participants; and interrogating each concept for conditions surrounding it, for alternative meanings, and for any remaining gaps.

Charmaz (2006) cautions extra care regarding language during the coding process. *In vivo* codes can include general terms that are commonly used to refer to deceptively significant meanings, terms that are unique to the participant and describe a specific incident or meaning, and “insider shorthand terms” that are used among select groups (p. 55). I tried to maintain a curious attitude toward the language used by the participants in order to be more aware of and sensitive toward implicit meanings. It is normal for coding to feel awkward at first (Holton, 2007), and my experience was no exception; however, I cycled through the phases of coding while constantly returning to the data and reflecting on its content. It was through the coding, reflecting, and mapping of concepts that the categories began to appear.

**Focused coding.** Focused coding is more “directed, selective, and conceptual” than the steps involved with initial coding (Charmaz, 2006, p. 57). It requires “using the most significant and/or frequent earlier codes to sift through large amounts of data. Focused coding requires decisions about which initial codes make the most analytic sense to categorize your data incisively and completely” (Charmaz, 2006, p. 57). It is not necessarily linear as the construction of certain categories may shed new light on previous codes or other existing categories. In grounded theory, however, it is entirely appropriate—and expected—that the researcher will constantly return to the data in order to discard, clarify, or identify new categories that more accurately reflect their understanding of the data. It is necessary in the identification of “underlying uniformity and varying conditions of generated concepts and hypotheses” (Holton, 2007, p. 278).
For individuals who prefer to work within a solid pre-set structure, Charmaz (2006) notes that a third level of coding—axial coding—can be used, and some researchers insist on its necessity (e.g., Holton, 2007). However, Charmaz (2006) prefers “simple, flexible guidelines” of creating subcategories; she warns that this approach requires the ability to tolerate ambiguity (p. 60). I followed her example of identifying main categories, shifting the smaller categories into subcategories, and showing how they were all linked together. As I made connections and developed insights, I returned constantly to the data while being open to new interpretations and codes that did not previously stand out. I compared categories and subcategories across the data to detect subtle similarities and differences of action and meaning, and endeavoured to adjust accordingly. As practiced by Fassinger (2005), I noted and explored variations where the data began to disconfirm existing categories, and reconceptualized categories and their relationships. I made extensive use of concept maps to visually show how categories and subcategories were interconnected. It was through this mapping process—similar to Stern’s (2007) practice of hand-sorting her codes—that the core category, general categories, and subcategories began to take shape.

**Process of analysis.** I began analysis by reading through all the transcripts several times in order gain general familiarity with each one. Using Atlas.ti Qualitative Data Analysis (http://atlasti.com/), I began the process of initial coding as described by Charmaz (2006). As per her recommendation, I summarized each line by highlighting the action being described. By the end of the initial coding process, I had 2126 individual codes with many of them used multiple times. I have included several examples in Table 3.2 below, and readers are encouraged to turn to Appendix I for a comprehensive list of all initial codes.
Table 3.2.  
*Initial Coding*

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Initial code</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because it was more, you take care of somebody … you know. It’s not a partnership in that sense anymore. It’s just that somebody you can take care of.</td>
<td>Caretaking role, not partners</td>
</tr>
<tr>
<td>Like I say, at first they, they were quite supportive, but now I feel like the one son that’s here is quite supportive, but the others, they have kinda shied away.</td>
<td>Family less supportive after crisis</td>
</tr>
<tr>
<td>I’m not sure what to say. You just … sometimes you just feel like, when you get so overwhelmed, you have to find a place to … like, you’ve got to open up a valve so the pressure kinda can escape</td>
<td>Goes away when feeling overwhelmed</td>
</tr>
<tr>
<td>You know, like I say, I sit and I look at four empty walls… so… [Son] has made 25 visits from [town] to here in that period of time.</td>
<td>Home feels empty</td>
</tr>
<tr>
<td>She phones some mornings and says, “Auntie, would you like to go for coffee?”</td>
<td>Family invites her out for coffee</td>
</tr>
</tbody>
</table>

From there, I began focused coding. This was a lengthy process that involved looking at each code, revisiting its context in the transcript, and moving it into the most appropriate category.

Table 3.3 offers a small taste of the categorization process; readers are invited to turn to Appendix J for a full list of focused codes and their respective initial codes. Most categories evolved as I found them too restrictive or insufficiently representative. For example, one of my first categories was “Importance of Family.” It began to feel too positively oriented and lacked the nuances I was seeing in the data. I renamed it “Family: Helpful/Not Helpful” to be more reflective of the broader experiences participants shared of having with their families.

Memoing is a core tenet of grounded theory (see Bryant & Charmaz, 2007b; Charmaz, 2006; Stern, 2007). I wrote memos throughout the study and I also used internal memoing as a form of sustained reflective engagement with the topic. After going through all the codes and
Table 3.3.
Focused Coding

<table>
<thead>
<tr>
<th>Transcript</th>
<th>Initial code</th>
<th>Focused code (category)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Because it was more, you take care of somebody … you know. It’s not a</td>
<td>Caretaking role, not partners</td>
<td>Adjusting</td>
</tr>
<tr>
<td>partnership in that sense anymore. It’s just that somebody you can take</td>
<td></td>
<td></td>
</tr>
<tr>
<td>care of.</td>
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Like I say, at first they, they were quite supportive, but now I feel</td>
<td>Family less supportive after crisis</td>
<td>Family: Helpful/Hurtful</td>
</tr>
<tr>
<td>like the one son that’s here is quite supportive, but the others, they</td>
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<td>have kinda shied away.</td>
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<td>And I know he’s well taken care of out there and he enjoys being out</td>
<td>Helps to know spouse is well cared for</td>
<td>Comfort in spouse’s care</td>
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<td>there, which helps me.</td>
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<tr>
<td>She phones some mornings and says, “Auntie, would you like to go for</td>
<td>Family invites her out for coffee</td>
<td>Family: Helpful/Hurtful</td>
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<tr>
<td>coffee?”</td>
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placing the relevant ones in categories, I was left with 28 categories (Appendix K). I used CmapTools (http://cmap.ihmc.us/) to map the 28 categories to help identify which ones were primary categories and which could be moved into secondary or subcategories. I reviewed the initial codes in each potential subcategory, returning to the quotes and their contexts as necessary to refresh my memory. My first Cmap was valuable to me in enabling a better understanding of how all these categories tied together, but as the reader can plainly see, it was still a confusion of data (Appendix L, Fig. L1). To evaluate these categorizations, I again went through all the codes in all the categories and subcategories, reviewing each code and its originating quote, along with its context within the transcript. The more I returned to the data and reflected on it, I began to see that relationships were threaded throughout the 28 categories. After further reflecting on the categories and reviewing the central tenets of grounded theory, I identified connecting as the project’s core category and basic social process. From there, I returned to my Cmap and, in the
end, finished with connecting as the core category and the following four main categories: 1) Adjustment to separation, 2) Significant Helping Roles, 3) Family, and 4) Social world (Appendix L, Fig. L2).

For the sake of clarity moving forward, the term codes refers to initial and focused codes (Appendices I, J, and K), the core category is the basic social process of connecting, categories are the four main categories outlined immediately above (Appendix L, Fig. L2), and subcategories refers to the more specific outworkings of the main categories (e.g., the category of ‘Adjustment to Separation’ and its subcategory of ‘being involved in spouse’s life’) (Figure 3.1).

The core category of connecting is a basic social process, which Glaser and Holton (2005) argue requires a minimum of two identifiable and distinct stages. In this case, I have identified three stages: 1) Initial news and coping, 2) Adjusting to new situation, and 3) Moving forward (Figure 3.2). From participants awaiting placement for their spouses to ones who were four years post-separation, my participants ran the gamut between these three stages. The timeline for moving from one stage to the next was fluid with some seeming stuck in the second stage years after separation, while others were clearly in the third stage by 26 months. In Table 3.4, I highlighted which stages are the most tangible across the various categories. This is not to say that areas crucial in Stage 1 are no longer important in Stage 3, but rather that these categories are most likely to be encountered and somewhat resolved in these specific stages. The
Figure 3.2. The three stages of core category: connecting.

Four categories are represented across the stages with several elements crossing into all three stages. I have attempted to show how the needs and actions of the participants were different in each stage across these areas. For example, participants wrestled with their senses of identity in all three stages, but it often began as seeing themselves as failures in their roles of husbands or wives (Stage 1). Many struggled in their new roles after their spouses were placed in care, and this struggle was frequently impacted by their sense of social “limbo” (Stage 2). Finally, they began to not only accept the reality of their separations, they were also able to confidently

Table 3.4

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
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<tbody>
<tr>
<td>Initial news and coping</td>
<td>Adjusting to new situation</td>
<td>Moving forward</td>
</tr>
<tr>
<td>-Relinquishing control</td>
<td>-The work of separating</td>
<td>-Identity: confident</td>
</tr>
<tr>
<td>-Moving spouse to facility</td>
<td>-Life at home (aftershocks)</td>
<td>-Faith: peaceful, content</td>
</tr>
<tr>
<td>-Involuntarily separating</td>
<td>-Involved in spouse’s life</td>
<td>-Family: reciprocity of engagement</td>
</tr>
<tr>
<td>-Preparing &amp; learning</td>
<td>-Comfort in good care</td>
<td>-Social world: meaningful</td>
</tr>
<tr>
<td>-Filing paperwork</td>
<td>-Advocacy &amp; concern for care</td>
<td></td>
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<tr>
<td>-Identity: failure</td>
<td>-Financial shift</td>
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<tr>
<td>-Family: needing support</td>
<td>-Identity: struggling</td>
<td></td>
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<tr>
<td>-Social world: needing support</td>
<td>-Faith: tension, coping</td>
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<tr>
<td>-Social world: needing support</td>
<td>-Family: engaging vs. distancing</td>
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<td>-Social world: empathy vs. insensitivity</td>
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continue their bonds with their spouses while also investing in their own individual, social, and spiritual wellbeing (Stage 3). These broader categories and subcategories of family, identity, social world, and faith threaded and evolved throughout the stages. Most subcategories—while crucial at the time—tended to resolve reasonably well with more distinct endpoints, such as relinquishing control of their spouses’ physical care (Stage 1) and finding a new financial equilibrium amid a major financial shift (Stage 2).

**Rigour and Validation**

There are numerous forms of grounded theory that fall under the general umbrella of “grounded theory” and these should not all be viewed as having equal rigour and validity. However, the variant defined by Charmaz (2006) performs well on both. The purpose of grounded theory is to develop understanding about the social processes of a specific phenomenon or experience. The emphasis on constantly being immersed in the data provides a safeguard against straying from participants’ experiences by getting caught up in external theories or personal assumptions. Grounded theory recognizes that the researcher is personally involved in creating and identifying meaning with the participants through the data, however, so it is possible—and expected—that the researcher may stray from the data unintentionally. Charmaz (2006) recommends returning to the participants as a way to confirm current analyses, gain clarity, and allow the participants to disagree with the researcher’s interpretation. My follow-up telephone interviews with three of my original participants mid-way through analysis and the focus group held near the end of my analysis all served as credibility checks. I also gave a copy of an early draft of my results to a nursing manager and a chaplain at one of the care facilities as an additional credibility check and opportunity for feedback. With the follow-up
calls, focus group, and feedback from care professionals, I believe that the rigour and validity of this study is high.

**Memoing.** Memoing is highly emphasized in grounded theory. According to grounded theory’s co-founder, “The writing of theoretical memos is the core stage in the process of generating grounded theory. If the researcher skips this stage by going directly to sorting or writing up, after coding, she is not doing grounded theory” (Glaser, 1978, p. 83, as cited in Holton, 2007, p. 281). Memos are the written record of the researcher’s process of analysis and should be used extensively after the first initial coding step. They are a way to “catch your thoughts, capture the comparisons and connections you make, and crystallize questions and directions for you to pursue” (Charmaz, 2006, p. 72). They are helpful in developing focused codes and they are crucial in making connections of depth between subcategories. Memos also force the researcher to state their personal processes, making it easier to identify possible erroneous assumptions.

In the constructivist paradigm, it is assumed that the researcher is involved in identifying and constructing meaning (Mertens, 2010). It was not my goal to maintain an entirely objective view of the data, nor is it possible within the assumptions of grounded theory or constructivism. However, it is possible to allow personal experiences and assumptions to influence the data to the point where it is coloured over to an extent that is not justified (i.e., grounded) in the data. I practiced memoing during my analysis, along with extensive reflecting and sporadic discussions with care professionals who are fully competent on this topic.
CHAPTER 4: Results

The heart of grounded theory is the core category (Figure 3.1). It is the lens through which the main categories and subcategories are understood. The core category and basic social process of spousal involuntary separation is connecting. This need to connect is evident both when it is met and when it is left unmet. The process evolves through three distinct stages (Figure 4.1). I began to see evidence of these stages during my initial interviews as subsections of participants expressed similar concerns and observations about their situations. The stages began to take shape after my follow-up interviews over the telephone. Something had clearly shifted for these participants in the three years since our first meetings, yet what they shared continued to have similarities. It was the focus group that crystalized my conceptualization of the three stages. Though several of the participants in the focus group were solidly in stage 3, the examples they shared about their experiences of their initial separations and their ensuing months and years all followed similar arcs. Their concerns, frustrations, challenges, hopes, and the impact of connection and their abilities to accept and reciprocate connection evolved in identifiable ways over time. These shifts became the distinct basic social process of connecting.

**Figure 4.1.** The three stages of core category: connecting.

**STAGE 1**
- **Initial news & coping**
  - News of separation, moving spouse
  - Shock, grief, relief, guilt, failure, overwhelmed
  - Rushed – no time to prepare
  - Sorting finances and paperwork

**STAGE 2**
- **Adjusting to new situation**
  - Becoming resigned to new reality
  - Developing new routines
  - Physical rest
  - Grief, guilt, sadness, loneliness
  - Empathy vs. insensitivity of others

**STAGE 3**
- **Moving forward**
  - Acceptance of separation
  - Grief and gratitude
  - Permission to adjust routine for personal wellbeing
  - Continuing the bond with spouse
  - Continuing with life
In the first stage, individuals received the news of imminent separation and were left scrambling to get ready for their spouses’ physical move and all the associated details. They were often in a crisis or near-crisis state of overwhelming shock, grief, guilt, and a sense of failure, while also feeling relieved that they were no longer responsible for their spouses’ care on their own. The crucial drive for connecting at this stage was seen in either, A) a stalwart, indomitable resolution that their relationship and love for each other would be unaffected by the separation, B) a heartrending sense of brokenness that their relationship would never be the same, often coupled with the caregiver’s sense of failure for not having been able to meet their spouses’ needs, or C) a general comfort with the new arrangement. The latter was present only when the separation did not include geographical distance or significant changes in routine, such as when individuals moved into a different level of care while staying in the same multi-level care facility as their spouses.

Stage two shifted from the immediate shock into adjusting to life apart from their spouses. During this stage, individuals worked to develop new routines for staying connected to their spouses in care. Feelings of failure decreased but many still felt guilty for having had to place their spouses in care. They grieved the loss of their lives together, and doubly so for those whose spouses were mentally deteriorating. Feelings of loneliness were massively present during this stage. The impact of loneliness was attenuated when others made the effort to connect to the individuals in empathic or at least neutral ways. The loneliness and a deeper sense of isolation were intensified when individuals were left alone or were approached with insensitivity even if it was well-intended.

In stage three, individuals began to move forward. They accepted the reality and necessity of their separations. They continued to grieve their lives with their spouses and
anticipated their future losses, but the grief was mixed with a sense of gratitude for what they had and for the people around them. Individuals began to allow themselves personal time away from visiting their spouses in order to look after their own wellbeing. They continued their bonds with their loved ones whether or not their spouses were mentally cognizant. They formed new friendships and let go of others that were unsupportive, traveled to visit friends and family, and gave themselves permission to embrace their lives beyond their relationships and routines with their spouses.

The thirst for connection with others is present from the onset of separation and continues years later. Initially the focus is likely to be on their desire for closeness with their spouses and it is doubtful that this ever goes away. However, there are opportunities for connection with others threaded throughout these three steps, and these opportunities—where they have succeeded and where they have failed—are what I have attempted to explicate above through the categories and subcategories. Medical separation is a complex and lengthy event that is experienced uniquely by each individual, with several essential overarching findings. At innumerable points along each individual’s process, they make a choice to either reach toward care and support or to pull away. This is greatly impacted by the people around them and their choices to either reach out in supportive ways to individuals in crisis or to distance themselves from them. Spouse-caregivers who pull away from others—or who do not have significant people in their lives—feel more isolated in their experiences and may struggle more intensely with feelings of doubt and sadness. They may feel like burdens to their loved ones. They may have greater difficulty and resistance toward shifting their personal identities to allow for their increasing independence. If they have spiritual beliefs, they may also struggle more to reconcile them with their ongoing painful experiences.
People who tend to resist connecting may have supportive people in their lives who are limited by factors such as geographical distance or ignorance of how to effectively show support. Many are likely unwilling to put aside their own perceptions of the situation and instead behave judgementally toward spouse-caregivers. These unsupportive actions—whether willful or well-intended—are especially painful to spouse-caregivers and can be significant factors in spouse-caregivers giving up on receiving helpful support from family members or social circles.

Individuals who frequently seek contact and connection with others do not necessarily experience less pain than those who are disconnecting, but they are able to walk in their suffering with the felt support of others. They are more effectively able to combat their feelings of guilt for having to move their spouses (Stage 2), they tend to have support in the long-term rather than only in the initial stage of crisis (Stage 1), and they are more likely to reflect on positives (Stage 3). They are also more likely to express their feelings and have more self-awareness and acceptance of their conflicting emotions.

In the following explication, I will go through each of the four categories (1. Adjustment to Separation, 2. Significant Helping Roles, 3. Family, and 4. Social World) and their subcategories. Threaded throughout each category and subcategory is the core category and basic social process of connecting and its three stages (Table 4.1). Please note that with the exception of removing pieces for the sake of brevity, I have taken the quotes directly from the transcripts and have retained the verbal stumbles and fillers. I have done this intentionally to portray the words of my participants with as much accuracy as possible, and also to prevent the loss of rigour by cleaning up their grammar. At times, the very presence of these verbal stumbles was meaningful. Ellipses (…) are used to denote a pause in the participants’ speech or, less frequently, to show that a portion of the text has been removed for conciseness while
retaining as much of the overall meaning as possible. All participant names have been changed to protect their confidentiality. I chose names that were common for their generation. Generic pseudonyms like Participant 1 or Participant A felt detached, while using personal—albeit different—names helped me maintain more of a connection that honoured their humanness. It is my hope that the reader will experience a similar closeness to these individuals who have allowed me to share their stories.

**Adjustment to Separation**

**Relinquishing control.**

*And you know, I think that’s the hardest thing I had to, that decision to say, “Okay, I can’t keep him at home anymore.” That was the hardest thing I did.* (Faye)

*It was the hardest thing I ever did in my whole life. ... So I signed the papers and [date] was the worst day of my life.* (Richard)

Though there was often extensive time and complex issues that came earlier, the process of medical separation began with the decision to place their loved ones in care. Some caregivers recognized the inevitability and had looked into long-term care (LTC) admission beforehand. Others had the decision made for them by their doctors, by healthcare workers at the hospital or through Home Care, or by their adult children. In Jean’s case, her husband was admitted into care by her friends after Jean was hospitalized. No matter who made the final decision, many participants struggled with relinquishing control over their loved ones’ care. After months or years of being the primary caregivers day and night, looking after activities of daily living such as laundry, preparing food, keeping track of medications, and helping with personal hygiene, the shift into separation was abrupt. Some participants continued to help however they could, such
as doing their spouses’ laundry or staying as informed as possible about their spouses’ care.

Hilda told of:

*Trying to keep on top of his health issues with the nurses. Because I was so used to doing that, that’s something I just couldn’t relinquish. I just … ’cause I had looked after him all those years, and I just … I was probably a pest. I don’t know, but they were always kind. They didn’t tell me to scram or get lost or anything.* (Hilda)

All participants mentioned feeling varying levels of relief after their spouses were placed. However, when the caregivers made the decision to move their spouses, they often mentioned having more doubts about their decision, such as second-guessing the necessity to place them in care at that time. When someone else made the decision for them, feelings of powerlessness were more prevalent.

*I cried and cried all the time there in the hospital. I just cried. I just couldn’t see it, you know, that I wasn’t there and he was gone. You know, he was just gone … and that was so hard to do. I would have a hard time putting him in when I am still home because I kept postponing it too, but when all of a sudden he is gone and next time you come out of the hospital, you have to visit (at the facility) and he is not here anymore, that was devastating.* (Jean)

Gladys’s husband was cognitively well, but the tasks of daily life shifted to Gladys after his move. There was an interesting power conflict evident in her interview after his care shifted to the care facility. She was no longer responsible for his immediate care, but she acquired new, unwanted responsibilities.

*My husband said it, one day he was upset and he said, ‘Well, you’re the boss, you decide.’ And I thought, yeah, I am but I don’t want to be. I don’t want to be but I have to*
be. (tearful) ...Yeah, all of a sudden everything from gassing up the car to paying
insurance and doing the banking, all of it’s my responsibility. All of the major decisions
are, are mine. (Gladys)

The work of separating.

How would I say... you have to go through what is best for him. You have to accept what
they can do for him. You really haven’t got a choice. And you hope for the best. As, as
far as I mean, uh, it was difficult to think that I am moving him out there because I knew
that he wouldn’t be back home anymore. That was difficult. And when you’re together
that many years, and we had a wonderful marriage... and then all of sudden you’re torn
apart. Nobody can, can feel what you feel. (Rita)

The adjustment to separation was uniquely impacted by each participant’s situation.

When asked about the time shortly after her husband was moved to LTC, Sarah said, “Some
people they’re so sad they can’t see, and, and to me it doesn’t bother.” Elsewhere during our
interview, she stately plainly that she and her husband were not close and that this marriage—her
second—had not been what she expected after her good relationship with her first husband of 49
years. For Lily, the separation was difficult but she commented that, after decades of dealing
with her husband’s mental illness, “When you’ve gone through all that, then something like this
is probably not even the worst.” She did not specify which mental illness her husband had, but
said that she had often felt like a single parent even though she was not, so when it came to
adjusting to being separated, “It wasn’t... that hard to adjust when you ... you were just about
like you were alone then anyway, eh.”

For others whose spouses were cognitively deteriorating due to various forms of
dementia, the shift to LTC was another step in the ongoing process of losing their spouses. Jean
spoke of how caregiving for her husband changed their marriage well before he was admitted into care, saying, “You take care of somebody ... you know. It’s not a partnership in that sense anymore. It’s just that somebody you can take care of.” For George, the move made little difference in his daily life. They had already moved to a community with multiple levels of care prior to her admittance. George’s wife had dementia but was still physically fit at the time of our interview. Her admittance into a secured unit meant he walked upstairs to fetch her every morning and brought her back every night for bed; “She sort of accepts the fact that she goes up to sleep up there and to me, it doesn’t make much difference one way or the other.”

Some spouses with dementia struggled—understandably—with being moved into care. In addition to their own emotional conflict over the shift, these participants bore the brunt of their spouses’ confusion and anger. Faye’s husband blamed her for his move; “When I walked in, he just said, ‘She put me here,’ and he started to cry. ... So I, I walked away ... you know, I had to walk away.” Mae’s husband’s frustration was not directed at her, but it wrung her heart; “He’s looked at me very frustrated and bewildered and said, ‘Why am I here? What am I doing here? Am I going to have to die before I can get out of here?’ And what do you say? ‘Yeah’?”

Participants whose spouses retained good cognitive functioning but had to be placed due to physical limitations expressed a powerful sense of relief and gratitude when their spouses accepted and agreed with the decision to move them into care. These sentiments were similarly echoed when the couple was able to live in separate areas of the same community (i.e., a multi-level facility with everything from independent living to LTC). “I’m glad that I’m here, that I can go over there. I go over and help him with all his meals ... And I feel that way if I’m over there then he doesn’t think I just... uh... put him over there, wanted to get rid of him or something, know what I mean?” (Lily). The emphasis on continued living proximity will be
explored in more detail elsewhere, but I will note here that geographical closeness appeared to help participants adjust to the separation in several ways: Ease of visitation, accessibility of the spouse, nursing staff, and physician; knowing they were accessible to the nursing staff in the event of an emergency; and feeling comfort in knowing they lived in the same community even if their rooms were in separate areas.

Several participants whose families had lived in the area for multiple generations spoke warmly of a sense of comfort in the generational presence at their spouses’ care facility. They spoke of what the buildings had been like decades ago and tied meaningful historical events to their own memories of their parents and other family members at the facility. Rita found comfort not only in the memories of deceased family members, but in familial connections to current residents and care workers: “Dad, his mom, brothers, sisters, and have passed away at [care facility]. So... and when we took [my husband] to [care facility] my sister was on one side of the wall of him, his sister-in-law was around the corner, and my other sister-in-law, she was his night nurse. So he was surrounded by his family when we moved him in.” It was similar with Gertrude who expressed deep gratitude that her husband and another close family member were placed in the same facility and that she lived in a different area of the same community.

Most participants expressed that their initial focus was doing all they could to make their spouses’ moves as smooth as possible. They tried to make their spouses’ rooms look as homelike as they could and were busy sorting through all the details of LTC admission. Concern for their spouses’ adjustment was especially an issue for caregivers whose spouses had diminished cognitive function, which added an element of unpredictability. Eventually, the chaos settled enough for the new reality to settle in at home. “The adjustment, I was far more worried about her than I was about myself, but it kicks in after a while. You say, ‘You know, this
is final. She is not coming back”’” (Richard). It was especially difficult for Jean whose close friends admitted her husband into LTC after Jean was temporarily hospitalized; “I just couldn’t see it, you know, that I wasn’t there and he was gone. You know, he was just gone.” Wallace made the decision to admit his wife into the hospital for assessment and said, “The day I had to put her in the hospital, I cried for weeks. (tears up) It was so hard.” In contrast, Sarah was ever the pragmatist, saying, “Why should I feel bad? I know he’s taken good care of. … Well, I’m not like he is, I can walk yet. But the way he gets looked after, I think he’s just as good off as I am, with me helping myself, you know.”

Aftershocks – life at home. After decades of marriage followed by months or years of caring for their spouses, adjusting to living alone was tough for most participants. Days that used to revolve around their spouses’ care are now completely changed; “Even if she’s here … I’d get up, go look, oh, watch her for a while, see how she is breathing, and I can’t do that now. She’s not there” (Jacob). Rita’s husband’s cognitive functioning was intact, so they spent many hours talking on the phone every day. She treasured these calls, but they were sometimes bittersweet; “We’ll have a nice conversation and I hang up [tearful] and I sit and I look around, and I’m looking at empty walls. I’m alone. … So … it’s one day at a time. … It’s getting easier. But yet the loneliness is there.” Several women admitted that they no longer enjoyed cooking, saying “I love cooking and he loved to eat. Well now, anything’s good enough. You know, you don’t fuss for one person” (Rita). For Leonard, it is dancing. He used to love dancing with his wife, but “I couldn’t dance now; I consider it disloyal to her.”

Some participants found that they could finally sleep well again after their spouses’ move without being awoken multiple times a night, but others found bedtime unsettling. When asked what the toughest parts of her days are, Faye said, “Going home and sleeping alone.”
Similarly, Leonard said, “I find sleep eludes me, uh. I read more than I read in the rest of my life. Sometimes at 12:30 I’m still reading.” For Rita and Richard, the house itself became disquieting; “You know, like I say, I sit and I look at four empty walls” (Rita), “And you sit here and ... the house is quiet” (Richard). Mae’s husband had been in care more than four years at the time of our interview. When asked to reflect on her overall experience, she responded with, “Well, it doesn’t get any easier. You just push on.”

**Comfort in good care.** When it came to participants’ peace of mind after moving their spouses, nothing was as comforting as knowing their loved ones were receiving good care. There was a learning curve in adjusting to care workers and the practices of each individual care facility, but the confidence that their spouses were constantly in good hands was of utmost importance. This thread of comfort was sewn throughout many participants’ narratives. Sometimes it seemed like a counter-argument to their own feelings of guilt or failure for not being able to care for their loved ones on their own; “I know he’s well taken care of out there and he enjoys being out there, which helps me” (Rita), “It made it so much easier when you seen that they were so good.” (Lily). For others, the words came with sighs of relief and a sense of gratitude:

> “When I saw how good care they’re taking of him, and then... it wasn’t that hard then. And they’re taking good care of him out there” (Sarah);
>
> “But he is well taken of and that makes a lot of difference, you know” (Jean);
>
> “He gets good care. I don’t have to worry” (Rita).

Hilda spoke specifically of her appreciation for a male nurse at her husband’s facility, adding that, especially at the beginning, her husband felt much more comfortable with a male helping him in the bathroom. This nurse’s kindness eased many of Hilda’s concerns; “Well, there’s a lot
of them that were good, but the, but [nurse] ... was, was very considerate, very good. ...

Compassionate, caring. So he would make it easier for me to leave to go home in the evenings.

... [Husband] was in good hands.”

Mae commented appreciatively that her husband’s second care facility offered onsite church services every week. She could not take him to church with her anymore, and she was glad he still had access to spiritual care; “For the residents that live here, it’s great to have a facility with a sanctuary right there. It’s convenient and it’s good for them.”

**Advocacy and concern for care.** As much as it comforted participants when they felt their spouses were in good hands, the absence of this confidence left them feeling haunted by guilt and fear.

*I think anyone putting their loved one in care needs to be there. And you need to not just be there; you have to choose your battles (laughs lightly). Choose your battles, but also um... let it be known that this is your loved one, this is your husband or your father, your mother and you are going to be there for them. And uh, don’t ignore me ‘cause I’m not going to go away. (Gladys)*

Jacob expressed frustration with the nurses in the hospital for not understanding his wife’s limitations; “She will say, ‘Oh, I’m fine. I don’t need any help,’ and this is what she says to the nurses, and the nurses take her word for that. They don’t realize that she has had several strokes.” Gladys described the first six months of her husband’s placement as “a nightmare.” She described the care workers as secretive and evasive about injuries her husband received in care and she worried for his physical safety. She talked about a nurse who behaved apathetically at best toward her husband, and antagonistically at worst with his insistence that her husband should be moved to another town’s institution because of his dementia. “I was broken-
hearted. I said, you know, he worked all his life. I’m here in a nice apartment with everything and... (tearful) he has to be in this hellhole” (Gladys). Rita’s experience was not as severe as Gladys’s, but she also worried for her husband’s wellbeing; “You’re fearful of what’s happening to him out there, how long am I still going to have him?”

Numerous participants emphasized their important shifts from their roles as caregivers to that of advocates for their loved ones. Ida made her position clear at the time of placement; 

And especially when I first placed him, I said to them, “This is my husband. Now you’ve got to remember this is my husband and I want him treated with respect and I want him treated kindly even if he doesn’t know what he’s doing because he can’t help that.” (Ida)

Gladys and Hilda learned the hard way of their importance as advocates. They documented incidents, stood up to care workers who did not appear to prioritize their husbands’ wellbeing, and brought their concerns to the managers. Gladys’s documentation of neglectful behaviour resulted in one nurse being fired. She also pushed against facility policy and insisted that her husband be given his medication on schedule even if he was having a behavioural episode due to his dementia. Hilda’s astute tracking of her husband’s medications led her to stand against what she believed was an example of overmedicating; “Like that one time when he was in the hospital and then they put him on the ... that I just can’t agree with. They put him on this psycho pill ... (big sigh). Lord, forbid that they do that to people so that they can handle them.”

Gladys and Hilda eventually got on good terms with their husbands’ care workers but for Gladys, it took months. “It took a while to kind of... um... to get them to accept me, I guess. And for me to, perhaps, probably be a little more patient with them” (Gladys). Ida alluded to her own process of balancing advocacy with relinquishing control and added,

“That was definitely really a journey for me and it still is to this day. I can come in and I feel
that he’s not cleaned up like he should be. I always think, ‘Oh, if I had him at home, he wouldn’t be looking like that.’” Gladys emphasized the importance of advocating for loved ones in care but noted that she had to learn how to advocate wisely. She spoke of “finding the line where you’re not invading um, the territory of staff, but still accomplishing what you see that needs to be done for your loved one.” Though she admitted to having more than her share of negative experiences, Hilda acknowledged her personal growth through her interactions with care workers; “It opened my eyes to the fact that there are a lot of hurting people and that there are a lot of good healthcare people working in those facilities.”

**Financial adjustment.** With one exception, every participant talked about the financial difficulties of having their spouses move into LTC. Most struggled to stay afloat with the sudden increase of expenses. Two participants explicitly stated that they had saved enough money over their lives that they did not have to worry, but acknowledged that they were fortunate and unusual among many of their peers in this regard. Id said,

> I’m paying almost $2000 here a month for [husband] and nothing has changed at home. I still have all the bills coming in the same as we always did. When we were living together, we had no problem paying everything, but now I do. (Id)

Richard echoed her sentiment; “Because I’ve got taxes and utilities to pay here. I’ve still got my car to drive. I’ve got food to buy, and then to put her in there, my, and my cost of living doubled.” Most participants had little notice before their spouses’ moves—typically a few days—and did not have financial safety nets set in place beforehand. Participants talked about having to file new paperwork for pensions, veteran’s benefits, and medical coverage. In the meantime, some caregivers had to pay out-of-pocket for their spouses’ medications in addition to the monthly fee for their care. When the first available bed was in a private care facility, the
financial burden was even higher, and left some participants scraping by until they could transfer their spouses into a more affordable facility. Such was the case with Jean whose husband had been in a private facility for one month; “As long as I know if everything is settled and he is in the other home and everything is settled and my finances are settled and all that more, then I would feel a lot better.”

Sarah was the one exception who said she was not particularly affected financially by her husband’s move. They had always kept their finances separate, so her husband paid for his own care and she for hers. She later noted that her daughter paid for most of her living costs, and expressed gratitude for what additional help she got from the government; “I’m happy with the, with what I get. We could get nothing. Our parents, they got nothing.”

**Involuntary separation.**

*It was like a bomb dropped. Um, I couldn’t believe what I was hearing. I mean, all of the documentation and the medical reports and everything were there, of course, and I was aware, um, of his problems. And, but when, when this came up it was just, I was in shock. I was just in shock, I couldn’t believe... that this was necessary. And of course, I can’t remember who the, um, person was that we were working with. My son was with me. And... I thought this, this can’t be happening. It was just... like... on top of everything else, now you’re telling me that I have to be legally separated from my husband? ... Oh it was, it was like a bomb! It was just... an emotional bomb on top of everything else that was happening. And maybe there is no other way of doing it, but... because I recognize that, you know, for taxation and financial... it has to be, but... isn’t there a better way? (Gladys)*
Part of the logistics of admitting a spouse into LTC involves signing government documents stating that the couple are involuntarily separated. This allows the government to treat each member of the couple as a separate person when it comes to taxes and government subsidies. The couple remains legally married, but their status shifts to involuntarily separated. Among the 17 people I spoke with individually and in a group, their responses to the topic of involuntary or medical separation were dichotomous. Gladys and Hilda seemed to have the most difficult time with it personally, while Mae’s son had a strong aversive reaction as well. For Gladys, it felt like she was being forced to divorce her husband in exchange for more money; “The finality of it. ... just knowing that ... (crying) just knowing that after sixty years of marriage, it has to be like this” (Gladys). She was reminded by her children and care workers that the document did not mean anything, but she seemed to recoil from their “logical” perspective, saying, “It’s different because I’ve said to them, ‘You know, until it’s your spouse, you don’t know, you don’t understand. And you won’t until it’s you.’” It seemed like the more people tried to logically minimize the importance of the separation, the more Gladys struggled. Another factor to keep in mind with Gladys was her fear for her husband’s wellbeing in his facility – not only did she bear the common guilt of no longer being enough when it came to his care, but he had been put in a place where she did not feel he was safe. While not all participants had complete confidence in their spouse’s care, Gladys was the only participant who expressed fear on his behalf.

*I was broken-hearted. I said, you know, he worked all his life. I’m here in a nice apartment with everything and... (tearful) he has to be in this hellhole. Um... and then on top of that, then it’s being given the news that, you know, um, a medical separation, a*
*legal separation is in everybody’s best interest. Well, um, I don’t have to enlarge on it, it was absolutely devastating. It was just one blow after the other.* (Gladys)

Hilda seemed to struggle more with a feeling of powerlessness in being forced to sign a document that did not represent her reality.

*I’ll tell you what, I held up my income tax paper till the very last minute because I did not want to mark I was separated. ... I said it’s not right. There should be a different term, but I wasn’t separated. I was still there every day for him and, sure, we were living under different roofs, so we were separated, but we weren’t separated.* (Hilda)

She later expressed feeling angry at the vexing terminology and appeared insulted by the inaccuracy. “*Well, yeah, when I was supposed to think that I am separated and I’m not separated, it made me mad.*” For years, her life had revolved around caring for her husband and her family, and she continued to do so after he was admitted into care. Her priorities had not changed, and she resented the implication that she was distancing herself from her husband because he was in professional care.

The document was not of great concern to Mae, but she spoke about one of her sons who reacted strongly against it.

*Our oldest son was very much against it because he says, “Well, that’s divorce”, and of course the caregiver said, “No, no, no, it’s not divorce, it’s involuntary separation”, exactly what we said it was, you know, and ... the only way that we could get assistance for it from the government, and ... and it wasn’t easy, but [I] cried lots.* (Mae)

Mae’s experience highlighted again that caregivers are often struggling not only with their own burdens and emotional distress and those of their spouses who are being admitted into care, but there can be the additional hardship of trying to navigate their children’s reactions. They have
not yet had the time to show that they are not following the common stigma of ‘dumping their spouse into care’ and abandoning them. Signing a document that can—for some—be loosely interpreted as a divorce can be fodder for disruption and upset within the family.

We have looked at a few examples where involuntary separation led to turmoil and anguish for caregivers or their families. In contrast, many of the other participants did not seem particularly bothered by it. Richard was more saddened by the distance created between them because of his wife’s progressing Alzheimer’s. He added that, “She’s still my wife and until one of us passes on ... I think that will, that relationship will always be strong” (Richard). Rita’s husband’s illness is physical in nature rather than cognitive, so the two of them were able to talk about it together. Rita commented numerous times that her husband’s gratitude toward everyone who helped him made all the difference for her, and the involuntary separation was no different; “He is so grateful for that, that I don’t think that has... I don’t, I don’t feel that that has made a rift in our marriage. We still love each other, and I don’t think that’ll ever change” (Rita).

The remaining seven of the 12 participants I interviewed individually did not mention the involuntary separation component of LTC placement. When I brought up the topic with my focus group, the responses were surprisingly unanimous. Ida recalled that her sister had struggled with the idea several years ago when she had been going through the process with her own husband, but Ida was not bothered by it. She talked about how the Home Care nurses had explained the whole process to her when her husband was still living at home. Later when he was awaiting placement at the hospital, a social worker went through it with her again; “She said, you know, ‘It doesn’t mean to say that you’re separating or ... it’s called involuntary separation, is what it’s called and you’re doing it because you are legally living in different residences now,’ and I thought okay, you know, that’s okay” (Ida). After that, Ida referred to the
document as “just a piece of paper” that changed nothing in her relationship with her husband. Tracy and Wallace focused on the fact that the involuntary separation meant they got some extra money from the government:

*But as far as signing that, I had no problem because it didn’t, to me it didn’t mean anything except the fact that I might get a few bucks from the government to help, yeah.* (Tracy)

*I didn’t mind signing it. When I did my income tax, it sure made a big difference on it, on my income tax, so I wasn’t worried.* (Wallace)

Surprisingly, Gertrude did not even remember signing that particular document—“[It] probably was done at the hospital and I don’t even remember it.” She said she had filled out so much paperwork at the time that it must not have stood out to her. Surrounded by supportive peers who were unfazed by their own involuntary separations, Gertrude did not seem at all bothered in our focus group when she realized she must have signed one as well. Her only response was curiosity to make sure she had signed it.

**Staying involved in spouse’s life.**

*I’m grateful that I can still talk to him, that I can still see him. And I’ll be going out tomorrow morning again ... and I’ll spend the day with him ... those are special moments.* (Rita)

Whether it was Sarah getting a lift with her daughter once a week or Ida going multiple times a day, 29 days out of 30, staying involved and visiting with their spouses was an important part of daily life for every participant. For most, their entire days revolved around it. Lily walked over several times a day from her area of the MLCF. It was more than simply spending time with him—she helped him with feeding at mealtimes and kept a watchful eye on his mental
health status. After a lifetime with him, Lily knew no one else was as good as she was at
catching his mental shifts; “Whereas they wouldn’t notice. I mean, it could get out of hand and
they wouldn’t notice what’s wrong, whereas I notice it right away” (Lily). Gladys spoke sadly of
the many residents in the facility who did not have anyone visiting them regularly. Her husband
had since passed away, but she took comfort in knowing that she had been there for him every
day. “But at least [husband] knew I was going to be there two, two and a half hours every day. I
fed him his lunch. And I fed him his lunch because that’s a personal interaction” (Gladys).

Rita was not able to drive to the facility every day, but her husband’s limitations were
physical, not cognitive, so they made good use of their telephones. “We phone each other three
times a day. We talk at 10:00, we talk at 4:00, and we talk at 8:00. And uh, we do a lot of
sharing, sometimes we’re on the telephone a whole hour just visiting” (Rita). After her husband
died, Gladys was met with insensitive comments about how easy it must have been for her to
adjust to widowhood since they had already been separated for so long, but it was wholly untrue.
“When people say, you haven’t had him for four years so you don’t miss him. When he dies, I
said, I was there every day. He’s, was a part of my life every day. He was my focus. And when
he’s gone, then your focus is gone” (Gladys). George’s life remained relatively unchanged after
his wife moved upstairs in their MLCF. At the time of our interview, she spent almost all day at
home with George and only went upstairs for night.

The struggle for many caregivers was to visit less frequently so they could get more rest
and see to their other commitments at home or with their family or friends. Richard shared
freely about wanting to spend less time at the facility particularly as his wife’s Alzheimer’s
progressed, but then he would be haunted by feelings of guilt. “Usually, when I don’t go, I don’t
sleep well that night. ... I just don’t. No matter how much exercise I’ve had or how much fresh
air I’ve had, you say. ‘Well, I should have, I could have gone,’ you know, ‘I could have gone’” (Richard). Ida’s husband does not always recognize her anymore, so now she visits him for herself and for her own peace of mind; “I go to see him for me because right now it’s not me that he knows a lot of times. I’m many people sometimes, and that’s okay. As long as he’s content. If I go and he’s content, then I feel good about it” (Ida).

All the caregivers visited their spouses. For some it was a joy, some did it for their own peace of mind, and some found it a struggle that they chose anew every time out of love for their spouses. Some of the spouses who had cognitive decline from dementia were unpredictable. Richard said that, “The worst part is wondering what kind of reception I’m going to get.” Mae described being bored at times; “Sometimes you wish there was a little more to do, uh, other than just ... like, he does not contribute a lot to conversation and that, so I ... I read a fair bit to him and watch way too much TV.” Hilda’s husband had very poor long-term memory but good short-term, so they were able to talk about a broad range of subjects, but he could not remember conversations from one day to the next. Richard seemed sad and a bit frustrated about his visits, saying “You come home in the evening after visiting your wife, if you call it a visit. You really don’t visit. You sit there with her and try to make conversation. When she tries to tell you something, you, you sort of fill in the blanks, try to, try to help her.” After admission into LTC, the caregivers’ roles shift from their spouses’ physical wellbeing to being advocates and providing their spouses with love and emotional support. In the absence of partners who were cognitively present, these participants stood with their marriage vows and their decades of life together.

Leaving the care facility after the day’s visit was sometimes the most difficult part. Richard had a routine—complete with hand signals—with the care workers at his wife’s facility.
At his signal, the care worker would distract his wife so that Richard could leave without her noticing. “And then when you leave, I feel like a ... I, I feel like a man who’s let his wife down because I don’t dare say good bye because she, she thinks goodbyes are final. She has been afraid that I will leave her for about the last couple of years” (Richard). Several other caregivers spoke of their spouses being confused, sad, and sometimes upset that the participants did not spend the night with them in their rooms. Hilda’s husband did not like that she left every night, but he dealt with it well. Still, it was heartbreaking for Hilda; “I would sit out in the car after visiting [husband] and would cry (teary). Because I felt probably sorry for him, sorry for me (teary). But I would wipe my tears and say, smarten up (laughs) and ... leave. Yeah. But that part was, was hard ... to, um, to leave him there” (Hilda). In our group discussion, Leonard and Faye stumbled their words together to echo Hilda’s sentiment from years earlier:

Leonard: Well, she would love to come home ...

Faye: Yeah, well, that’s right, so would mine.

Leonard: And it’s just ... it, um ... it ...

Faye: Tears you apart.

Leonard: ... every time I leave, it bothers me.

Faith.

“The thought came, ‘God, you tell us that we call upon you, you meet all our needs. Why can’t you answer my prayer that my husband doesn’t have to leave me?’ You know? Because I, I am a Christian and prayer has... I don’t know what I would do if I couldn’t do that. And yet, at the time, there was an anger to think that now why does he have to be that sick, that I can’t look after him?” (Rita)
Spiritual faith was a foundational source of strength for many participants though they did not choose to speak on it at length. Nine of them stated that they did not know what they would do without their faith. The four ladies in the focus group added that they had a strong sense of belonging in their faith communities and felt supported. Others from the individual interviews showed more elements of internal struggle or outright anger amid their faith. Even in the interview, Rita’s plea to God was heartfelt and raw. There were hints of their struggles to reconcile their emotional pain and distress with their spiritual beliefs. Rita was clear about her confusion and anger at God, adding that “As time goes on, you accept and try to make the best of what there is.”

I find it’s still hard to deal with at times, you know, yeah, yeah ... worried about, yeah ... well, yeah, and it’s not ... supposed to rely on the Lord more too, you know. I mean, he guides my ways and ... but, yeah, it’s just that if I ... we have no children or anything and then you think, you know, nobody to help you in that way, you know, and say, well, if something happens to me, a child would take over or whatever. There is no such thing and ... that makes it awfully hard for me too, yeah. I shouldn’t worry about it because the Lord will provide that way too. ... but you can’t help it sometime and ... yeah, I still find it hard to deal with, yeah, and ... so many things to arrange, you know ... the money-wise, pension-wise, this and that. Oh boy, back and forth to Home Care and that, it ... it drags you down ... drags you down. (Jean)

With several participants, there was a sense that very little in life was within their abilities to control, which left them feeling helpless. Amid that helplessness was an anchor of prayer and faith which, unlike most everything else, was within their grasp. They gained strength by knowing that God had their situations under control even if he was not directing it in the ways
they wished or could even necessarily understand. Jean was clearly continuing to wrestle with an internal conflict between faith and worry. Hers was rawer than most which was understandable considering her husband had been placed in care only four weeks earlier. Still, she was not alone in her conflict. There seemed to be tension between, on one side, knowing that God had it in hand and, on the other, a sense of feeling that their lives have become unmoored from their former sense of familiarity and stability.

**Significant Helping Roles**

Within each participant’s narrative, there were always mentions of miscellaneous people who were notable either for their help and compassion or for their lack thereof – I call these the helpers and the hinderers. Some of these will be brought up again in the section on involuntary separation, but they merit mention here as well.

*Preparation and information.* Several participants expressed finding value in seeking information about their spouses’ diagnoses and in preparing for the inevitable. Richard cared for his wife for eight years before her Alzheimer’s led to her LTC admission. Richard spoke of a book for caregivers that helped him better understand his wife’s behaviour and wished he had read it sooner. Leonard mentioned a helpful video about his wife’s illness that he watched on the internet. Jean’s husband reverted to speaking solely in his native language and spoke only about his life as a young man in his country of origin. Jean said she did not understand the shift until the care workers in his facility explained that this was common with her husband’s diagnosis. (Thankfully, Jean also spoke her husband’s native language and was able to understand him, though she had to make a list of basic words so the care workers could communicate with him.)

Some participants had looked into what was involved in admitting someone into LTC before it became necessary. These individuals said there was no way they could have been fully
prepared for what it was like to separate, but they found some comfort in familiarity with the overall process.

The kind of preparation with the greatest impact seemed to be moving onsite before it became necessary. After her husband was diagnosed with Parkinson’s, his doctor recommended that Lily and her husband consider moving to a multi-level care facility so that it would be easier for Lily’s husband to move up the levels of care as needed. Though his move to LTC happened years sooner than Lily expected, the transition was, indeed, made smoother by moving onsite before it became necessary. This type of early preparation was also mentioned by George, Wallace, Tracy, and Gertrude, who all expressed appreciation for the ready accessibility of their spouses onsite after their moves to LTC. In George’s case, he said that his day-to-day life changed very little after his wife’s move to LTC because she still spent the day with him every day.

Jacob’s wife was in the hospital awaiting placement during our interview, and Jacob spoke about how he hoped she would be placed at a specific facility so he could move into independent living in the same facility; “That would be the best way because then, then we would be under the same roof and, you know, we could have a cup of tea together whenever we felt like it without getting in a car and driving somewhere” (Jacob).

**Help with paperwork.** Paperwork was mentioned by numerous individuals as a significant source of stress. In addition to documents for admission, there are also government documents to change a couple’s status from “married” to “involuntarily separated” which allows them to receive more government funding. Helpers such as managing nurses at the care facilities, placement workers at the hospital, social workers, and Home Care nurses were repeatedly mentioned as playing an invaluable role in sorting through all the paperwork for the
caregivers and explaining it to them. Mae added her appreciation for the fact that her husband’s care facility had free notary services on site so she did not have to go elsewhere and pay to get her documents notarized.

*When it was coming time for the ... to make out the papers for the involuntary separation, uh, the people, [name], I think was his name in [town 1] there, helped me tremendously. He, he made sure the papers got made out right and so forth, you know, that kept on top of everything. If I had any questions, I could go to him anytime and that, so I mean, uh, workers in that area were just great.* (Mae)

Though the majority of participants noted that they had received help with their paperwork, several seemed to fall through the cracks. On further exploration, it became clearer that these few struggled with applying for additional subsidies and in sorting through nongovernment pensions. This time of transition was already stressful for the caregivers and the mandatory use of the internet or working through a chain of menu options on the telephone only exacerbated the hardship and confusion.

*I can get a little bit extra pension, I think, some subsidies, and that will help, but it all has to be arranged again and it takes so long, and then they need this paper and they need that paper and ... you get on the phone and that confuses you too, and then that punch this number and punch that number, and if you want this, you know ... get in contact that or use our website and all the more, and I am not good on the computer, I just use it for email ... and it, it’s confusing when you get old, you know. You just wish that somebody answer the phone and say, “How can I help you?”* (Jean)

**Moving spouse to the facility.** The physical move from home or the hospital to the care facility was mentioned by a handful of participants. The majority of participants struggled with
the abruptness of the move, typically having only two or three days’ notice. Some were fortunate enough to have their spouses transported via ambulance, or had family who could take them. Several participants noted that they themselves did not drive, or were too upset and overwhelmed at the time to drive safely. Gladys’s unexpected helper in this case ended up being the lady who cleaned her home.

Well, I don’t have any kids here. I have a young lady who does cleaning for me and vacuuming, she does the heavy things, and she helped me get [husband] moved because all of a sudden, this morning, “We’re moving [husband] now”, I’ve got to clean out his room, I’ve got to get a wheelchair, I’ve got to get a cab or a bus or something, and it’s going to be here at 10:30 in the morning in the wintertime and I, I said, ‘I can’t do this, I’m only one person.” (Gladys)

Those who were already living in the multi-level care facility had experiences that contrasted with Gladys’s. When asked about the move, Lily first seemed confused by the question, then said simply, “I got a wheelchair and took him over there. They, they helped me, you know, I didn’t have to (laughs). They were really good with me, you know, to help me.”

Social workers. Social workers played a key role in explaining the situation for several caregivers, beginning before placement and for some, continuing weeks after their spouses were admitted into care.

The social worker explained everything and ... and how, how the system works and put before us all what the, what help there would be available in the home and that it would be very, very difficult and that the best, from her opinion, the best decision would be to ... to put him into long-term care. (Mae)
Richard mentioned several times his gratitude for a social worker who followed up with him in the weeks after his wife’s placement. “Well, I appreciated the call from the social worker. [Name] is her, I never did meet her, but she phoned me very faithfully ... every couple of weeks ... to see how I was doing and so forth.”

**Home Care.** Home Care was a source of stress and frustration for a couple participants when their spouses were still at home (which falls outside the limits of this study), but many others spoke about Home Care nurses pointing out the caregivers’ exhaustion leading up to placement, helping them with paperwork, and explaining what options were available to them. “[Homecare nurse] convinced me that it would be better for myself, which I knew a long time ago, because everybody used to say, ‘Oh, you look so tired’” (Hilda).

**Caregiver/Peer groups.** There were a few participants who resisted the idea of joining a peer group, but Leonard spoke positively about his experience in the local Alzheimer Society from when he was caring for his wife in their home and after she was placed in LTC. When Leonard realized he could no longer care for his wife, it was a nurse from the Alzheimer Society who immediately came through for him.

> I had to get a mutual friend and he went with us and ... but it was the Alzheimer Society, when I told her what happened, she says, she was a nurse, and she says, I’m going to send a message to your doctor, go there and he’ll have a letter. ... If it hadn’t of been for the, the professional help, I wouldn’t have ... you’re lost. (Leonard)

Not only did Leonard have access to healthcare professionals through the Society, but he spoke of meeting regularly with a handful of men who were all in a similar situation. He said that, “If you can talk to somebody with a little authority or even if they’re kinda guessing, but if they’ve been there, done that, or they’ve seen this, then it kinda stabilizes you” (Leonard). Wallace
realized the value of his MS caregivers group when it came time to admit his wife into care. As he was struggling with the decision, a member of the group came to him and said, “[Name], you know, you’ve got to; you can’t look after her anymore.’ And that’s how I found out the caregivers’ groups were really very, very helpful.”

The majority of the participants in the individual interviews seemed to either shy away from or shrug off the idea of meeting with a peer group, but most of the focus group participants went the opposite direction. Though they were not all involved in an official society or peer group like Leonard and Wallace, they spoke openly about visiting every evening with fellow caregivers in their spouses’ facility. Laura talked about her retirement villa where “We’re all sister and brothers. We all, everyone cares for each other, whatever, whoever it is.”

Richard and Gladys were the most vocal against joining a support group. Richard’s resistance seemed more toward the potential assumptions that he feared would result; “…and yet if I were to try to organize a group, say, for people who are alone, some people would get the wrong ideas, that [I’m] looking for a partner” (Richard). This concern was salient to him as he knew another man in his social circles who had gone with a new partner after his wife’s dementia progressed. Gladys’s hesitance stemmed from her desire for privacy and respect;

You know when, they found out [husband] had gone into care, well, “You should talk to so-and-so,” and everybody wanted to know everything. And at one point I said to a lady, “You know, my husband’s condition is personal. It’s not something I want to be a topic of conversation—dare I say, gossip?” (Gladys)

Hilda did not mention anything specific about focus groups, but I wondered if her situation was similar to Gladys’s. Hilda admitted that one thing she would like to have done differently was to have told more people that her husband had been placed in care. Though she would have had
access to social supports such as her church community, Hilda shared only with her closest confidants.

These two extremes create a tension between one subsection of participants who experienced feeling normalized and receiving comfort and validation from a supportive peer group, contrasted with the subsection who felt isolated in their experiences, but feared being the focus of judgement and gossip among peers.

**Facility care workers.** Care workers at the facilities have already been mentioned, including the negative influence of several nurses in the advocacy and concern for quality of care section. However, the positive impact of care workers warrants a return to the topic. Sometimes the relationship between participants and care workers did not begin smoothly, but nearly all caregivers expressed appreciation and even affection for the care workers after some time had passed. Of the participants whose spouses had died, some even continued to visit the facilities sporadically to say hello to the care workers. Gladys was clearly touched by the welcome she and her husband received during his move; “They made a point of this... we are family. Um, you are important to us, as well as our uh, your spouse, your husband. And we’re here to help you both” (Gladys). Several at the same facility commented on the comfort and convenience of having a doctor available onsite to all LTC residents. The facility chaplains were a valuable resource for some as well. When Lily was contemplating moving her husband into care, she sought the advice of a trusted friend who directed her to the facility’s managing nurse, the doctor, and the chaplain. Hilda had a similar story, and added that, “And then, of course, [chaplain] was priceless (teary).”

**Administrators.** Administrators at care facilities, Home Care, and the hospital were mentioned almost entirely in a very positive light, from their straightforward conversations that
helped assuage some of the guilt caregivers felt about admitting their spouses, to their part in streamlining the paperwork of admission, and their diligence in finding appropriate placement for participants’ spouses. One participant expressed some frustration because her husband needed placement when the primary person in charge of placement was on summer holidays, delaying his placement by several weeks. The clearest exception to this positive impact occurred with Richard in one instance that Richard returned to over and over in his interview.

*I wish, I do wish this: I do wish that the person who phoned me had been a little more gentle in breaking the news that a room was available. ... It was such an abrupt introduction to ‘Hey, got a room for your wife; will you ....’ Well, the conversation was this: ‘Hello, [Richard]. I have a room for [wife]. Will you take it?’ That’s exactly the conversation, word for word. ... I wish, I wish they’d been a little bit more, more gentle. [If] they had said, ‘Look, this is [name] calling.’ And she wouldn’t have had to say much more. (Richard)*

Being so suddenly tossed into a decision that he described as “the hardest thing I ever did in my whole life” came across as rude and abrupt. Richard said repeatedly that he wished he had been shown more social etiquette to soften the emotional blow.

**Others.** There are undoubtedly more people who could be mentioned among the helpers and hinderers, but one in particular stands out. Laura’s husband had passed away in care almost a year before our focus group took place. As the group talked about how often they visited their spouses in care, Laura shared that she had continued to take the bus to her husband’s care facility multiple times a week for months after he died. Clearly well-known to the bus drivers, one of them began to firmly, but gently, interrupt her habit. “And still, after he passed away, I was still taking the bus, going up there ... ‘cause that was my day, to visit him, then the bus driver would
say, ‘[Laura], not today.’” This quote has ruminated in my mind since Laura first said it in my focus group. Though it refers to a timeline that is outside the parameters of this study, after deliberation, I have chosen to include it. It speaks to the unexpected and perhaps underestimated connections that were being made along Laura’s journey—both literally and figuratively—of being medically separated.

Family

Connecting.

*Family were always so good to stand behind me and help, you know, if I needed any help or someone to cry on, a shoulder.* (Lily)

*They’re just there for me. They’re always there for me.* (Jacob)

*My kids always say, ‘We’ll look after you,’ you know. And they do.* (Sarah)

*I’m so lucky I got good kids. Oh, am I lucky! Today I get phone call from them, all three.* (Sarah)

Family was a powerful source of connection, support, and meaning when present and ready to engage. It was often family members who recognized that the caregivers were in over their heads in caring for their spouses. These are the ones who contacted physicians, initiated the process of placement into a care facility, helped with the practical elements of moving the spouse into the facility, and provided emotional support and affirmation throughout the process. After care facility admission (CFA), these family members continued to visit the loved one in care, regularly initiated contact with the caregiver with frequent—sometimes multiple times a day—phone calls, invitations to coffee and family events, attending church together, and overall simply making it clear that though they were busy with their own lives, they were open and ready to engage with and support the caregivers in whatever ways they could.
[Son] made sure the gas was put in the car. That might be just a small thing, but, you know ... I had no idea how to put gas in the car, getting that cap off, so at first I ... I would, when the car was getting near empty, I would call one of the boys over and ask them if they could, could put gas in the car for me. But, you know, it’s not always convenient and ... so eventually I did learn how to do that myself, you know. (Mae)

Family was a key support in practical ways around the caregiver’s home as well. For some caregivers, these needs arose before their spouses’ CFA as his or her functioning decreased. Mae needed her son to fuel her car for her until she eventually learned how to do it herself at the age of 70. She also learned how to use a mobile phone so she could text with family members. Others spoke about light bulbs needing replacing, the car needing oil changes, and learning how to pay bills and look after the household finances.

_I don’t know what women do who aren’t equipped to do it. ... Hopefully they have family to pick up the pieces, because uh, just simple little everyday things sometimes like getting new tires on the car, getting oil changed, or changing a light bulb or... yeah._ (Gladys)

For those who still lived in their own free-standing home, they had yards to care for, homes to maintain, and sidewalks to shovel in winter. Daughters, sons, and sometimes grandchildren were gratefully mentioned as family members who made special effort to help. This help took the form of emotional support, but also practical in helping participants learn new skills, or in some cases, looking after finances, day-to-day bookkeeping duties, and basic home and yard maintenance. Sarah also received extensive financial support from her children. Married for 20 years in what was a second marriage for both of them, this 95 year old shared that her husband kept his finances separate from hers. She survived by living frugally and with
financial help especially from her daughter who paid for her groceries and nearly all of her housing costs.

Adult children were often involved in making medical decisions about the spouse in care, and sometimes provided practical help such as joining the caregiver at medical appointments relating to the caregivers themselves or to the spouse in care. Driving was also an issue for some individuals whether due to visual impairment or a lack of comfort driving on icy roads during the long prairie winters. They often made do with public transit or taxis, but financial limitations usually impacted how often these participants were able to visit their spouses or to simply get out of the house without help from their families.

_They can sense when I am down. They know by my voice. And [son] will phone me two and three times during the day, “Mom, are you fine?”, “Mom, how are you doing?” And I don’t want to be a burden to my children but it’s certainly nice that they are that concerned._ (Rita)

Whether their children were geographically near or far, many made ready use of the telephone. Other family members such as siblings, nieces, nephews, and grandchildren were also mentioned frequently, though not as often as children. Coming over to visit or going out for coffee, phoning, and emailing were appreciated by caregivers. Hilda spoke gratefully of her son and grandson who kept her computer in good running condition so she could stay in daily contact with her siblings via email.

For many participants, family was a great source of pride. They took pride in their children’s successes and strengths, and enjoyed watching their grandchildren grow up. Hilda had helped raise three of her grandchildren since they were young and clearly felt connected to
them. Participants also gave off a sense of pride and seemed encouraged when their family members continued to phone or visit their spouses in care.

“And [granddaughter] was so good with him, you know. ...And even the other day she phoned me, and she said, ‘Wow, I hope I can get down to [town] to see Grandpa before I go back to school,’ you know (laughs).” (Lily)

Disconnecting.

The kids always say, “Dad, phone me anytime.” Well, they’re so busy with their own lives, you try not to bother them, but ... yeah, it’s just ... that’s something I think that, as she deteriorates, I think the stress level is just going to get higher. (Richard)

Sometimes you wish that they would maybe make a little more room for you. They went away here, went to the States, and I wanted to go to the States so bad, but ... [Son] said, “No, this is family time, we are going by ourselves.” So I had to stay home. (Mae)

Family was the most frequently mentioned source of support and strength, but for some it was also a source of disconnection. Sometimes the participants precipitated the distance themselves with their reluctance to reach out because they felt like an inconvenience. Other times it was due to geographical distance, emotional absence or conflict, or simply not having any family or children. Some participants who were a few years post-admission commented that though they felt supported by family during the initial crisis of transition, it tended to decrease as time went on. “The kids ... like I say, at first they were quite supportive, but now I feel like the one son that’s here is quite supportive, but the others, they have kinda shied away” (Mae). Two of the participants moved to a different city to be closer to immediate family members after their spouses began to need extensive care. Faye seemed content with her choice more than two years later, but Leonard spoke regretfully of his deteriorated relationship with his daughter after his
move. His attempt to plan ahead so he would have family nearby as his wife’s health inevitably declined ended up backfiring on him. At the time of our interview, his daughter was not speaking to him and was refusing to visit her mother in care. “It’s just like kicking your legs out from under you, you know, for me, because ... that’s why I came here” (Leonard). For Richard, part of the difficulty was his daughters’ hesitance in supporting his decision to place his wife. “The girls, of course, were very, very hesitant. ‘Why, bring somebody in, Dad. We’ve been telling you this for a long time, bring somebody in’; that’s not the kind of help I needed” (Richard).

With Richard and others, there was a sense that some family members placed a level of faith in the caregivers’ abilities that were no longer realistic given the care recipients’ needs. These caregivers spoke of having augmented feelings of guilt for failing their spouses and, less directly, their children. They spoke of having to navigate their children’s lack of understanding and sometimes even anger on top of the already overwhelming process of their spouses’ LTC admission. Most family members eventually understood or at least accepted the participants’ decisions to place their loved ones in care; however, many family members did not visit their parents in care. Richard said, “My son avoids that place [care facility] like the plague” because he found it too discouraging and difficult to see his mom in that environment. Others felt that their children tried to be supportive, but sometimes were not able to be there in the way the caregiver needed them to be; “Sometimes I might try to talk to the kids about it, but sometimes, you know, kids are not the right person to talk to” (Mae).

Social World

After family, the social world of friends and acquaintances was the second most frequent category mentioned by participants. Here again, the contrast of connection and disconnection
was clear. Some participants spoke of their own efforts to reach out and be involved with others, while others shared about their own reluctance and barriers to bridging the gap between themselves and their social worlds. They spoke about friends who stood by them and worked to stay engaged in the participants’ lives, while others told stories of friendships that stagnated, became awkward, and eventually disappeared.

**Connecting – by self.** The value of telephones and email cannot be over exaggerated for many of the participants. Whether their friends were nearby or far, phone calls were a common way for participants to keep in touch with friends and family.

> I talk a lot on the phone at night when I go home. My son thinks I should let my landline go and just go with the cell phone, and I, I ... you know, the technology that is so rapidly changing all the time, us older folk find it a little difficult to keep up with that, and so this new way of communicating, uh ... is strange to us (laughs). ... But, I mean he sent me a text the other day and I, I do the text thing. I’ve gotten onto that. If you want to communicate with the kids, you have to (laughs). (Mae)

Mae noted that she regularly spent several hours on the phone every day talking with friends and family across Western Canada. Hilda exchanged daily emails with her siblings and waited eagerly for their replies. Leonard, having moved away from his hometown, kept in contact with his friends through email and laughed as he spoke about the jokes and funny stories they sent each other. He appreciated having laughter in his life and added that his friends sometimes sent him useful information, specifically noting a short video on Alzheimer’s that had helped him better understand his wife’s behaviour.

Participants mentioned other proactive behaviours—Rita calling her son for help with paperwork and miscellaneous tasks; Mae asking her son to fill her car with gas, and later getting
him to teach her how to do it; Rita inviting her niece over for a visit; Gladys striking up conversations and friendships with fellow spouse-caregivers at her husband’s care facility; and Lily seeking advice from multiple people including a trusted friend, the head nurse of a care facility, and the care facility’s chaplain. I could list many more, but each of these examples shows participants choosing to reach out and inviting others to engage with them. Richard volunteered partly because, “This is what, this is when I get to talk to people. That’s why almost, well, I volunteer because I said, ‘It’s a chance to talk to somebody’” (Richard). Leonard joined a casual group of six men and often joined them for meals; “They’re all older than me and many of them have been through kind of the same thing” (Leonard). Mae continued her relationships with friends from her previous hometown by staying with them for a few days whenever she began to feel overwhelmed with stress over her husband’s situation.

Some participants formed connections with others by reaching out to others in similar circumstances. When he found out that a friend’s wife had been diagnosed with dementia, Richard contacted him and told him all the things Richard wishes someone had told him years earlier. He also talked about inviting another man, a widower, out for meals at a restaurant or for a home-cooked meal at Richard’s house. Mae spoke about feeling compassion for others at her husband’s care facility; “We see others come into the home, uh … maybe not quite the same situation as you’re in, but similar, and you feel for them, you know.” Leonard had several social groups that he spent time with but sometimes it was enough to simply be around people with minimal interaction on his part; “I find sometimes I go do exercise and I come back and there’s a half a dozen women sitting there, so I’ll sit there and listen and it is, it helps.” When it came to peer groups, he was able to embrace elements of humour in their common experiences; “But that’s where talking to other people helps in that, uh … you find where they’ve been and done
that, uh, you know, and ... so it gives you ... like, I guess it’s just the case, you find out, well, I might be stupid but I sure got lots of company. (laughs)” (Leonard).

**Disconnecting – by self.** While some participants made deliberate efforts to engage and connect with others, others—intentionally or unintentionally—behaved in ways that were more likely to result in disconnection.

*Usually I’m fairly sociable, not always, but usually I’m fairly sociable ... and I don’t even want to talk to anybody. I get in the car, I go for a drive, she is not there. She has been there for 62 years. (Jacob)*

This distancing was often twofold: a) caregivers turned away from others by choosing not to initiate contact or by shying away from others’ invitations, and b) they turned away from themselves and their own internal experiences. In both cases, it looked a lot like keeping themselves distracted. When asked about the good parts of her days, Faye laughed and replied, “I don’t know if I have any good parts. I’m ... you know, you’re busy doing this, you’re doing his laundry, you’re getting this ready for him, you don’t have too much time to think.” Hilda kept herself occupied too, saying, “Like I say, I keep myself busy and ... don’t think into things too much. Why ... how would I do that? I’m not that kind of person to get myself upset about things that I can’t change.” Leonard found that projects requiring physical work made his days better and helped him sleep better at night; “So ... it makes the day go. It kinda fills the head up and ... if you do things with your hands and that, you know, you come home and then you can sleep at night.”

Some of the participants seemed to have little interest in investing in their social lives or in developing new friendships. They may have felt too overwhelmed or physically and mentally exhausted to exert such an effort, but some came across as turning away from a life apart from
their spouses. Several individuals mentioned that their social lives had diminished during their years of caregiving for the spouses because their spouses required all their time and energy. After their spouses’ placements, most continued to prioritize spending time with their husbands and wives. However, several admitted that, though they felt isolated and lonely, they could not bring themselves to rekindle old friendships or expend the energy to develop new ones.

Her husband had since passed away, but when he was in care, Hilda had told only a few people what was happening – “Maybe I, I should have told more people what was going on so people would have been more understanding, but I never thought of that at the time” (Hilda). Rita spoke several times about feeling lonely, with only one person whom she would call a friend. This friend was not very accessible with her schedule, however, which seemed to reiterate Rita’s feeling of isolation. She wished for opportunities to meet other people but added that her area of the retirement community did not plan activities for its residents. In Rita, there seemed to be a tension between wanting to connect with others and feeling helpless to initiate it. Gladys maintained relationships with her existing friends but, similar to Rita, lamented the lack of structured social activities for residents in her retirement community. In her day to day life, Mae felt tension between wanting a close friend and feeling like that role belonged to her husband; “You kinda feel like you should be side by side and do things together and share the ... share the joys and the sorrows and ... and so consequently, because of my husband’s condition [dementia], I lot of times feel I have nobody to share things with, you know” (Mae). Ida and Leonard observed in themselves the desire to avoid certain people whom they knew would treat them with compassion; “Some, some people you kind of avoid because you know they’re going to make you cry (laughter)” (Ida). They did not avoid these people all the time, but there was a sense that sometimes they felt especially vulnerable and overwhelmed but felt they needed to
hold themselves together. Their last vestiges of self-containment would fall away if they were met with genuine kindness in those times.

Richard spoke at length about his previously active social life and how much he enjoyed being with people. An admittedly high energy person, one of the reasons he often held himself back from engaging socially was his fear of being misjudged. As mentioned earlier, he worried that others might think he was looking for a new partner. He sometimes brought his wife to their home during the day. His friends used to come visit when she was there, but it became an uncomfortable experience for Richard because of her Alzheimer’s – “I’m very sensitive about the whole thing, you know. Because sometimes when my friends will come over and chat, they know, too, what ... and she will make comments that just absolutely don’t make any sense” (Richard). He could have spent time with empathetic peers who were going through similar experiences as spouses of people with Alzheimer’s, but Richard resisted following up on the invitation.

_I don’t need any more reinforcement. I don’t need to hear somebody else’s problems, and when I hear people say, “[interviewee], it’s going to get worse,” I’ve heard that quite a few times. I don’t need to hear that. I don’t need to hear that. I know it’s going to get worse. It’s not going to get better._ (Richard)

**Connecting – by others.** Relationships are a two-way street. Caregivers retain a certain element of responsibility for their own attempts to foster or neglect relationships, and the same is true for those around them. Jean said her friends call her all the time, “and then they take me out for coffee, all of them take me out and we go out for coffee and that helps.” Ida spoke fondly of her friends who do not even ask, they inform her that she is going out with them. Mae called her friends often and they returned the gesture and called her too. Rita felt isolated in her experience
of involuntary separation, but had friends who reached out to her and listened to her pain and frustration even though they could not empathize from personal experience.

Jean’s friends went above and beyond the call of friendship when Jean was hospitalized; they cared for her husband and, when they saw how much work it involved, they made the tough call on Jean’s behalf and admitted him into care when a space became available during Jean’s hospital stay. In a similar vein, Ida did not have family nearby when her husband was being moved, so her friends stepped in to help; “I am very blessed, I have friends, and they helped with the placement and with moving him from one place to the other” (Ida). Jean lived in a retirement community and found connection with fellow residents, “It’s not that I’m totally alone, that I feel totally alone here, you know ... very good neighbours and very nice people here.” Gertrude and Tracy from the focus group were friends who met at their husbands’ care facility. Theirs was a mutual turning toward connection that involved visiting together “every night and that helps an awful lot” (Gertrude).

Disconnecting – by others. Peoples’ attempts to connect with participants were generally greatly valued. Invitations to go for coffee or a game of golf, eating meals together, or just phoning to visit were instrumental in caregivers’ emotional wellbeing. However, acquaintances and even friends sometimes said or did things that, though they seemed to be actions intended to facilitate connection, ended up having the opposite effect. “But, but then coming home to this big house that is DEAD QUIET. First thing you do when you walk in the door is to check the answering machine. Did somebody call?” (Richard). Most participants were on a limited budget and could not afford to go out for meals or to join in on their retirement community’s paid activities. Rita commented that her community had a weekly fellowship supper but the $13 cost was beyond her limit no matter how much she wanted to attend. Some
caregivers noted that they themselves were not in the best health and had limited mobility. Others were socially limited because they depended on taxis, public transit, or family for transportation. A common thread was one of no longer feeling they belonged in their social circles.

*This is, this is, this is a crucial thing. You just don’t fit. You go to a funeral, someone’s funeral and there’s reception afterwards, you look around ... well, where am I going to sit? There is a couple here, a couple there. I know all these people. Where am I going to sit ... at the reception table, like in, in the gymnasium. You finally say, “Is it okay if I sit down?” “Sure.” So I sit down and I, but there you are again. You’re the 5th wheel.* (Richard)

Sometimes people invited participants to couple events which the caregivers likely would have enjoyed when their spouses were well. However, numerous participants spoke about feeling like the odd one out—*“And I mean... when this happens, you don’t fit in with married people, you don’t fit in with widows”* (Rita). Their social status shifted to a strange state of limbo where, as Gladys described, *“You’re not a couple, I’m not a widow. And it’s like a death because our friends were couples and you’re not a couple anymore and you’re not part of that social scene.”* Tracy added that though some friends had stuck with her, some had not—*“Once you can’t join into everything, well, they just forget about you”* (Tracy). Previously socially active and highly energetic, the shift in his social status disrupted his sense of belonging among his social circles; *“They don’t invite you out ... again, because you don’t fit. You’re alone. You’re not a widower. You’re not a divorcee. You’re not married. Where are you?”* (Richard).
When caregivers have to place their spouses into care, they know it is one more step toward their inevitable continued deterioration. Whether the spouse has dementia or an illness that limits their physical abilities, these caregivers know that their spouses are not going to move out of care and they are not going to recover. Friends and acquaintances often do not know what to say to the caregiver after the separation. An easy default question to ask when attempting to initiate conversations with caregivers is the dreaded, “How is your wife/husband doing?”

_I find people are always asking me, ‘So how is he doing?’ And it’s not a question that can be answered when somebody has dementia. I mean, how do you answer that? I can’t say, ‘Oh, he’s fine.’ He’s not fine. …A lot of times I’ll say, ‘You know he has dementia and it doesn’t get better.’ That’s what I … because I don’t know what to tell them. Like, he’s been in care for two-and-a-half years. He’s not as good as he was when I placed him, but he’s still okay…_ (Ida)

Most people probably ask out of a sense of genuine care and a desire to connect with the caregiver without realizing that this question is painful and difficult to answer. “You know, they say hi, and with, the part they say is, ‘How is your wife doing?’ And you see, that kinda hurts because you answer the same question over and over and over and over” (Richard). At church or social events, caregivers may be asked this same question a dozen times or more in a single day. Participants’ spouses have some days that are better than others, but their deterioration is inevitable and each time the question is asked, caregivers are reminded of this inevitability.

Sometimes people go even further and offer clichés and unsolicited advice. When I asked him what had made his process of medical separation more difficult, Richard responded with the following:
What’s made it more difficult, that’s exactly if people say, “Well, it’s going to get worse, [Richard]. Adapt, do the best you can, live with it.” What else have I heard? “It is what it is.” These are flippant answers. People ... people, people should just say nothing.

(Richard)

But then there were the people who stopped calling. Perhaps they recognized that they did not know what to say to the caregiver so they literally said nothing. Maybe having someone who did not fit at the usual events oriented toward couples was too complicated to include, so they become excluded. When old friends and acquaintances fell away, some caregivers felt powerless to form new ones. Other caregivers pressed into their existing relationships and reached out to others with whom they felt a kinship. Richard was a curious case in that he did both – he was constantly reaching for—and in many ways, receiving—connection, but he also felt the painful stings of every pinprick of rejection and insensitive comments.

You get to the point where you say, ‘Well, you know, nobody calls, nobody comes, and you start to believe nobody cares.’ ... I don’t think that’s quite true. I think that people do care, but they ... I don’t think they mean to distance themselves, but they just don’t know, maybe they just don’t know what to do, what to say. Well, just treat me normally.

(Richard)

Ida expressed frustration for peoples’ lack of compassion and sensitivity during her process of involuntary separation. However, having watched her sister go through it several years before her, Ida recognized that it was not fair of her to expect people to understand what she was going through.

A lot of people don’t understand when you talk about what’s going on and I was the same way. I don’t fault anybody for that because I didn’t have a clue what somebody would go
through on a journey. So I didn’t, I didn’t understand. I couldn’t understand. Nobody can understand this unless they’re walking it. (Ida)

**Identity.** This subcategory technically belongs with the Adjustment to Separation category. I have left it to the end to retain its chronicity as one of the last processes to come to light. I was curious if the process of involuntary separation would have an impact on how participants viewed themselves. Near the end of each interview, I asked participants if their experience of separation had changed the way they thought about themselves, a) as people, and b) as spouses. Not everyone chose to answer, but the responses were mixed. Jean commented that she felt she had been “going into widowhood” for some time already and that their marriage was “not a partnership in that sense anymore. It’s just that somebody you can take care of” (Jean). Mae’s answer was similar to Jean’s. She said she felt more like a caregiver than a wife, and spoke sadly at the loss of feeling like she and her husband were a team. Gladys, too, noted that she was “not a couple, I’m not a widow. And it’s like a social death.” The way she viewed herself as a wife was notably impacted because of the resulting social exclusion. She also echoed the loss of partnership shared by Mae and Jean; “…one day [husband] was upset and he said, ‘Well, you’re the boss, you decide.’ And I thought, ‘Yeah, I am but I don’t want to be. I don’t want to be but I have to be’ (tearful).” As a husband, Jacob felt he had changed too; “Well, yeah, I feel like a failure, like a failure most of the time.”

Richard described himself as still feeling like his old self as a person and as a husband, but that he had grown more self-reflective. “You try very, very hard not to be selfish. I mean, every time I say, ‘Hey, you know, tonight I, I just, I’m just too tired. I, I just can’t go.’ And you say to yourself, ‘Well, are you starting to make excuses?’” He added that he re-evaluates his life more often and, a year later, he still second-guessed his decision to place his wife in care. In our
interview and subsequent phone calls, Richard usually came across as confident and articulate. Still, there were echoes peppered throughout that hinted at feelings of failure when it came to his wife’s care. He also seemed to have an internal tug-of-war between his own needs and wishes for rest and social activity and his powerful feelings of love and obligation toward his wife.

Rita said she did not think differently about herself as a person, but the rest of her reply spoke of creating an identity for herself apart from her husband. It was clear in our discussion that Rita was entirely committed to her husband and was continually orienting herself toward him, yet she was simultaneously developing the awareness that she also needed to turn positively toward herself. “I know that I have to make a life for myself. And whatever I put into it is what, how would I say, it’s going to either tear me down or it’s going to lift me up” (Rita). As a wife, Rita felt confident that she had done her best. “I feel within myself, I gave [husband] 100% of myself as a wife. And he has done the same. ... We still love each other, and I don’t think that’ll ever change.” Lily’s thoughts toward her marriage were also unchanged; “…because, um, when you get married, it’s for life, eh? I mean, you have to... I wouldn’t think of it any other way.” Sarah’s response was, “Nah... why should I think different?” In George’s perception of himself as a husband, he did not think he had changed either, nor would he do anything differently if he had the chance.

Summary of Results

The process of medical separation is complex and unique for each individual, but for all of them, connecting was at the heart of it. Each of the three stages (Figure 4.1 and Table 3.4) involved some form of connecting, whether it was turning toward others or turning away—or most often, a combination of both. The reactions of the people around the separating caregiver
involved a similar mixture of those who empathized and supported and those who avoided or responded insensitively.

Within the participants’ experiences are stories of their perceived failures as husbands and wives in having to place their spouses in LTC. For some, relinquishing control came more readily, especially for those who had prepared for the shift of their own volition, a) by moving to a MLCF, b) by initiating the placement process in advance, or c) for those whose spouses were cognitively able to understand what was happening and were able to give their own assent to the decision. The ensuing adjustment to separation in both the short and long term illuminated and, in a sense, exaggerated the kind of relationships the participants had built with their spouses over their previous decades of marriage. When participants spoke of working through unusual hardships in their marriages (e.g., mental illness) or of their extremely strong relationships, the adjustment in some ways seemed smoother if still painful; long histories of turning toward each other were transposed into a new situation where they continued to work on their connections, albeit in new settings.

The smoothness of transition was complicated when the spouses receiving care had illnesses such as dementia that led to loss of cognitive functioning. These caregiving spouses told of constantly seeking connection with their husbands and wives, and of the agony they felt when their loved ones, through the veil of dementia, interpreted their actions as turning away. As their spouses’ dementia progressed, caregivers spoke of emotional fatigue coupled with dedication and loyalty as they singlehandedly continued their bonds with their loved ones long after their loved ones could no long reciprocate or even understand their devotion. Among some of these participants, there was a sense that they were no longer turning toward who their
spouses were in the present, but were connecting with—or honouring—the meaningful memories of who these people had been in the past.

As participants worked to adjust to living in community while their spouses lived in care, some felt overwhelmed by feelings of helplessness over their situations and their spouses’ care. Some felt guilt, but also relief and comfort that their spouses were being safely cared for around the clock. Others saw areas where the quality care was lacking and took up the mantle of advocacy for their spouses’ wellbeing. Many participants immersed themselves in their spouses’ lives. For several, they seemed to reject entirely the idea of having a social life or hobbies outside of their spouses—in a sense, turning away from the notion of an individual identity and, instead, revolving their lives and identities around their relationships with their spouses. Others shared that they believed it would be healthy to take more time for themselves, but every one of these participants noted that this was a struggle, and that they usually felt guilty doing so. In contrast, the participant who freely shared that she and her husband were not close spoke about looking after herself and spending time with her family, whereas her husband was taken care of by the professional care workers and his own children.

Every participant noted the financial cost involved in having a spouse in care. Of those whose spouses had already been placed (as opposed to awaiting placement), only two stated clearly that they were financially secure. However, they added their voices to the rest in emphasizing the sudden financial strain involved in essentially paying for two households on limited budgets. Those with sufficient savings were not bothered by it beyond one noting that it meant his children would receive less inheritance. Finances became a limiting factor in participants’ social worlds, with some rejecting opportunities for social engagement due to no longer being able to afford activities that cost money. For a few, financial strain became a cause
of others connecting with them in more intentional ways. Whether it was paying for housing, helping with groceries, or coming over for coffee instead of going out, others reached out and these participants embraced it.

During the time of transition and in the months following, participants spoke of nonfamily individuals in significant helping roles whom I refer to as helpers or hinderers. The helpers were those who, in big or small ways, helped the participants by offering comfort or aid in ways that lessened their experience of stress. The paperwork involved with LTC admission was the most frequently mentioned, along with help during spouses’ physical moves into care. These helpers were often social workers, Home Care nurses, administrators and transition workers from the hospital and care facilities, professional care workers and chaplains at the care facilities, and caregiver or peer support groups. Mentioned less frequently were the hinderers. Specifically, a transition administrator was repeatedly brought up by one participant for her abrupt and insensitive interaction with him, and her husband’s poor quality of care observed by another participant was echoed throughout her interview.

From the decision-making prior to placement to the subsequent months and years, families had the most critical roles through either connecting or disconnecting actions. When there was mutual turning toward each other, participants spoke warmly and with a sense of gratitude for the practical and emotional support they received. Many had children who lived elsewhere and these participants noted their sadness at the distance, but spoke appreciatively of phone calls, emails, and visits. With some participants, the distance was of their own—usually inadvertent—creation. They shared of family members who offered to help in whatever ways needed, but the participants felt uncomfortable sharing certain feelings with their children, or they felt like a burden and withheld themselves from embracing the offers. Still others spoke of
the opposite—asking to be included more in their families’ lives but being painfully rebuffed. One individual spoke of his daughter’s hostility toward him and alluded to his perception that she punished him by refusing to visit her mother—his wife—in care. One lady and her husband were older when they married and did not have children. She noted several times how she felt her struggle was different than most because she had no children to support her. Friends stepped in to partially fill the void but she was intentional about not asking too much of them, adding that she did not want to be a burden on friends who had their own families that should have priority.

The social world of friends and acquaintances was the second most frequently mentioned category. I divided it into four kinds of approaches: a) participants seeking connection with others, b) participants turning away or disconnecting from others, c) others offering connection with participants, and d) others disconnecting from participants. In the first, this included an attitude of openness that allowed them to embrace coffee time with friends, meeting new people at caregiver or peer support groups, volunteering in the community, attending social activities, and more. Participants who disconnected from their social world did not make the effort to rekindle previous friendships, were afraid of judgment, were unwilling to form new social lives without their spouses, grew tired of insensitive questions, or were too tired after long days spent with their spouses. Several also noted their inability to financially afford any kind of social outings. Friends connected with caregivers by regularly initiating contact in person, on the telephone, or through email. They were empathetic and nonjudgmental toward the caregivers’ struggles and, at times, gave helpful advice or directed them toward others who could help. Friends who turned away from the caregivers—usually unintentionally—did things like invite them to events that were oriented toward couples, or events where everyone else in attendance was there with their spouse or partner, asked about the participants’ spouses’ wellbeing instead
of the participants’, gave unsolicited advice and warnings about the prognoses for their spouses’ illnesses, and decreased or eventually stopped contacting the caregivers.

Many participants made brief mentions of their reliance on their spiritual faith. One was clear about her anger at God and her feelings of abandonment. She struggled to reconcile her anger and sense of abandonment with her faith and her continued reliance on prayer. Many caregivers expressed that they could not have managed without their faith, the ability to pray, and for some, their faith communities. Still there was a sense that many were wrestling with the tension between trusting God and feeling like their lives were reeling out of control.

The process of separation had a notable impact on personal identity for many participants. When asked if they felt they had changed in how they saw themselves as people or as spouses, responses were varied. Several expressed that they felt more like caregivers than partners in their marriages, and had for a long time. Others observed that they were in a status of “limbo” – not widowed, but not part of a couple either. This was felt both internally for the participants but also socially in that they did not feel like they fit in anywhere. Numerous participants stated outright that they felt they had failed in their roles as husbands or wives. Some observed that they had become more self-reflective, but also that they were often hard on themselves for times where they felt that their wishes (such as wanting an evening at home instead of at their spouses’ care facility) meant they were selfish spouses.

The shift in relationship to self was felt more positively for a few individuals. One continued to care for her husband and viewed herself as a loyal wife, but she was transitioning into someone who also recognized her identity as someone who was becoming increasingly independent. There were those who did not feel their perceptions of themselves had changed, but added that they had done as well as they could have and that the separation had not changed
the love they had for their spouses. Their views of themselves as husbands or wives were still 
the same and they found comfort in that knowledge.

I have devoted much time in this chapter to describe in detail the many forms that 
connecting—and disconnecting—can take, but the message to take away is this: connecting is 
the heart of involuntary separation. The main categories and numerous subcategories are held 
together by this lens of connection. The outworking of connecting vs. disconnecting is unique 
for each individual, but the need for connection is common to all. Those who were extended—
and allowed themselves to receive—offers of practical help and emotional support were more 
readily able to go from the shock and raw coping of stage one, into the work of adjusting to their 
new reality in stage two, and finally to moving forward with acceptance in stage three (Figure 
4.1).
CHAPTER 5: Discussion

When the categories and subcategories are overlapped with the three stages of connecting (Table 3.4), four are distinctly present in each stage (Figure 5.1). These four factors should neither be viewed solely out of context from each other nor from the other elements in Table 3.4 as they are all inextricably interconnected. With the understanding that these four are part of a greater whole, however, it is worth exploring their unique roles throughout the process of involuntary separation.

![Figure 5.1. The four categories and subcategories that are uniquely present in each stage of core category: connecting.](image)

**Stages of Identity**

Participants often saw themselves initially as failures for no longer being able to meet the needs of their spouses. As they began to accept their limitations and the natural consequences thereof, many wrestled with formulating new identities that integrated the significant impact of involuntary separation (stage two). By stage three, participants had either resolved or made peace with their new senses of personal identity. What this looked like varied for each person. For some, they identified more strongly and more broadly in their roles as wives or husbands.
Others’ identities as wives or husbands shifted to include new senses of individuality and growing autonomy while still nurturing their bonds with their spouses.

**Stages of Family Interaction**

Interactions with family shifted depending on the stage. In the beginning, individuals were often in a state of crisis and need of support; their personal resources were exhausted and they had little left to offer their families. They often felt overwhelmed by the new tasks suddenly placed on them and they relied heavily on family to help sort through the chaos and to lend emotional support. Once the initial crisis had passed, there was a noticeable dichotomous shift where some participants’ families continued to offer support and empathy while others who had been helpful at first tapered away and became distancing (stage two). Participants also began to more clearly choose to engage or disengage with their families. Predictably, having supportive family members geographically nearby helped individuals feel the most supported overall. However, geographically distant family members who were intentional about staying in regular contact were also effective in meeting individuals’ needs for familial connection. As individuals’ needs for connection with family continued to be met, most also became increasingly able and willing to respond in kind. In these instances, they reached the third stage which involves reciprocity. Here, individuals spoke of mutual give-and-take in their relationships with family; participants felt loved and supported and enjoyed being able to actively show their love and support in return.

**Stages of Interaction with Social World**

Participants’ contacts with their social worlds were somewhat similar to family initially. During the first stage of crisis, individuals needed practical support and nonjudgmental understanding without obligations in return. In the second stage, individuals spoke repeatedly
about receiving either empathy or well-intentioned but insensitive comments from their social circles. Understandably, insensitive comments resulted in participants disengaging from their peers and having heightened feelings of isolation and loneliness. Conversely, the consistent kindness of even a small number of peers made a huge positive impact. Of those who were in the third stage, most participants noted having fewer people in their inner circle of friends than before becoming involuntarily separated, but they emphasized their closeness and deeply meaningful relationships.

**Stages of Connecting to Faith**

Not all participants chose to speak about their spiritual faith but of those who did, the three stages of connecting were evident. In the first stage, individuals seemed either rocked with uncertainty and shock over how God could let this happen, or their faith was like a rock, providing them with a sense of stability in chaos. Whether they experienced the shock or the stability, there always seemed to be some tension in the second stage. This was likely due, in large part, to the massive personal shifts occurring concurrently in their senses of identity and family and social relationships. At the same time, they were left wrestling with how to resolve the tension between their faith and their current suffering. A small number appeared to use their faith as a coping strategy but did not seem ready or interested in integrating their faith with their new, usually painful reality. Others were clearly active in wrestling with how to make sense of their shifting life in light of their spiritual beliefs. It was the latter who seemed to move into stage three; even if they readily admitted to still having feelings of frustration or tension within their faith, these participants had found a sense of peace and contentment in their faith. Several noted the invaluable influences of close friends and clergy in helping them wrestle through their faith-related questions and doubts.
Longitudinal Component

The results of this study were greatly enriched by including participants at various stages of involuntary separation—from those whose spouses were in hospital awaiting placement to individuals whose spouses had been in care for several years. While many participants referred back to the early days of becoming separated in their interviews, being able to speak with individuals who were currently in the midst of crisis and emotional devastation brought immeasurable depth to the data. Without these individuals, understanding of stage 1 would have been far less extensive and the value of the overall framework for involuntary separation would have been lessened.

Additionally, three of the original participants were contacted three years after their interviews as a credibility check (Chapter 3). This also allowed me to check in with these individuals and to inquire about what had changed for them since we had last spoken. In the initial interviews, one was in stage 1 and the remaining two were in stage 2. Three years later, it was clear that each had experienced dramatic shifts in their own unique ways. Those who were initially in stage 2 showed strong signs of movement into stage 3. Both stated that they were very lonely, but added that they had good relationships with family and a select group of friends. The one who was initially in stage 1 appeared to have stalled in stage 2. Even in our first interview, this participant repeatedly stated that she did not have children and that neither she nor her husband had family nearby. In our conversation later, she reiterated her lack of family. Though she acknowledged having a couple good friends, she spoke of continuing to hold herself back from them out of her fear of being a burden to them. To sum up, this longitudinal element confirmed what was already becoming evident in the data, which was that individuals are
capable of moving through the three stages over time, and reciprocal connections are necessary to facilitate movement.

Novelty

During the process of analysis, there were several instances where some participants’ responses were unusual. While most expressed positive sentiments toward their marriages over the years and usually in the present as well despite some difficulties adjusting to the separation, there was one participant for whom the opposite seemed to be the case. Her and her husband’s apparent lack of marital cohesion in the previous decades continued after separation; married in their 70s in what was a second marriage for both, they seemed to lack a genuine connection with each other. After separation, each focused on their own respective children. This participant spoke of a genial friendship between her and her husband, but her heart was clearly oriented primarily toward her children.

Another exception was in regard to signing the government documents stating that they were involuntarily separated, which is required by everyone who admits their spouse into long-term care (LTC). This allows them to receive more funding from the Canadian government, but participants’ reactions to the wording “involuntary separation” were mixed. Several individuals from the original interviews were utterly devastated by it, feeling like they had been forced to move their spouses into care and then to essentially divorce them after decades of marriage. One participant was fine with it, but her son misunderstood the document and accused her of divorcing his father. This led to strained familial dynamics for some time and increased the participant’s feelings of guilt and stress. Interestingly, this document was the only topic where the focus group participants unanimously disagreed. They understood why the change in status was necessary and it meant very little to them personally. I can only speculate on the reasons for
this difference, but it should be noted that the original interviews and the focus group took place nearly three-and-a-half years apart. It is possible that the participant pool was anomalous, or perhaps health care professionals (e.g., social workers, Home Care, hospital or care facility workers) in the area implemented changes in the intervening years that better prepared the focus group participants for that particular part of the process.

The third exception has been briefly noted in the previous chapter, but it involves moving a spouse from one area of a multi-level care facility (MLCF) to another—for example, from independent living where they live as a couple, to one of them moving into LTC or a secured unit on the same property. All participants living in MLCFs expressed feelings of gratitude for their abilities to remain close to their spouses—typically only a two or three minute walk away. One participant stated that he did not feel his life had changed much since his wife was moved. He fetched his wife from the secured unit upstairs in his own building every morning, brought her home for the day, and then brought her back upstairs in the evening. He was the only participant who was still able to bring his spouse home during the day; it is unfortunate that I was unable to contact him for a follow-up interview for this study as I am curious to know if his response would have changed as his wife’s abilities decreased to the extent that she had to remain on her unit.

Contributions

**Generational context.** While this study’s main contribution is its theory of involuntary separation centred on the basic social process of connecting, this study makes several additional contributions that should be noted. It gives voice to the lived experience of a significant portion of society and acts as a window into this elderly population. To give some context, with ages ranging from 70 to 95, most of these individuals would clearly recall World War II, and some
immigrated to Canada during the war or shortly thereafter. One participant mentioned that she and her husband delayed marrying because he was leaving to fight in the war and he refused to risk making her a widow so young. A couple of the older participants remembered the Great Depression in the 1930s. One spoke of what it was like to watch her husband struggle with mental illness since the 1950s, long before their town had a psychiatrist or any kind of mental health resources. Several participants had farmed for decades before retiring in town, and most of these grew up in rural areas. They likely would have grown up without electricity or running water, and probably used horses for work and transportation during their younger years.

Whether the individuals in this study moved more toward connecting or disconnecting, they all showed a strong sense of resilience. With a general appreciation of this cohort’s historical context, it is understandable that they would be able to weather an onslaught even if it was gut-wrenching. Perhaps even more so in the rural and small town setting of southeast Alberta, there is a strong sense of independence and self-reliance that, for many, was necessary for survival. Marriage also tends to be viewed more as a permanent commitment. Given this context, the difficulty that most participants experienced in relinquishing control and accepting their limitations makes sense. Both sides of the connecting vs. disconnecting spectrum experienced heartache that several said they would not wish on their worst enemies. Those who were more disconnecting came across as being held up internally by their sheer force of will, while those who were more connecting were bolstered by the people in their world. I posit that the participants who leaned toward disconnecting (i.e., emotional avoidance and extreme independence) were no less resilient than those who more readily inclined toward connecting; however, those who sought—and received—connection were able to experience moments of sweetness within their pain.
Canadian context. In addition to offering a window into the experiences of our older generation, this study also speaks specifically to its Canadian context. As mentioned earlier, spouse caregivers in Canada are required to sign a document stating their change in status from “married” to “involuntarily separated” after admitting their spouses into a care facility. In this study, this was met with polarized responses from participants. For some it was a perfunctory step that simply allowed them to receive more financial assistance from the government, but for others it was a devastatingly meaningful act. Being intentional about preparing and educating individuals about what this status change does—and most importantly, does not—mean was clearly valuable and effective for many participants, but it still left some utterly distraught. This could be remedied by a relatively simple policy change by the Canadian government. For example, instead of the current “involuntarily separated,” it could be “married, involuntarily separated”. With the addition of one word, the government’s terminology could validate that the couple continues to be married while acknowledging that their living arrangements have changed.

Weather conditions also had a notably negative impact for some participants. Like most of Canada, southern Alberta has its share of extreme weather during much of the year. Some participants noted that even though they were healthy and physically independent, they chose not to drive in bad weather or poor road conditions. One participant mentioned taking the bus, but this was not a viable option for everyone. This meant they were unable to visit their spouses as frequently as they wanted unless someone was available to drive them.

Dialogue with existing theoretical frameworks. Though this study presents a new theory of involuntary separation, there is potential value in attempting to locate this work within the existing theoretical frameworks briefly touched on in Chapter Two.
**Bowlby’s attachment theory.** Mikulincer and Shaver (2008) described the three-part response to grief or separation from an attachment figure as protest, despair, and reorganization. These three states have clear overlap with this study’s stages of connecting:

- Protest → Stage 1: Initial news and coping
- Despair → Stage 2: Adjusting to new situation
- Reorganization → Stage 3: Moving forward

The protest state was often alluded to by this study’s participants when they spoke about delaying admitting their spouses, and it continued after the decision was made and their spouses were moved into care. For the despair state, most participants spoke about their conflicted feelings of relief vs. guilt and failure for placing their spouses. The work of adjusting to their new reality was hard. Many participants shared about their struggles with depression after their spouses’ moves, and several specifically mentioned that they no longer took pleasure in cooking good food for themselves. In reorganization, the third state, individuals seek new attachment figures and seek to crystallize their new identities. In this study, former partnerships of co-attachment became unequal relationships of parent-like caregiving for a care-recipient. However, this was less noticeable in participants whose spouses were mentally cognizant as they seemed to retain the mental and emotional connections with each other. For participants whose spouses were cognitively deteriorating, the inequality was pronounced. There was no longer a sense of security or co-caring for each other, and sometimes there seemed to be internal conflict because of the one-sided nature of the love and commitment in the relationship. For these participants, it was a complex breach of attachment; their co-attachment figures were increasingly no longer mentally present, leaving the participants to reorganize their identities as husbands or wives, as individual people, and as individuals within their worlds of family and friends. In other words, their lives had changed drastically and the outworking of this change
took time and effort. Those who had strong family, church, or social connections were able to transfer their attachments more smoothly onto new safe havens in order to feel secure. Participants without these support structures were more likely to feel untethered and struggled longer to reorganize and find their new stability.

Erikson’s stages of psychosocial development. Borrowing from Kivnick and Wells’ (2013) argument that integrity vs. despair, the eighth and final crisis requiring resolution, involves a mature re-working through all of the previous crises (i.e., 1. Trust vs. distrust, 2. Autonomy vs. shame, 3. Initiative vs. guilt, 4. Industry vs. inferiority, 5. Identity vs. confusion, 6. Intimacy vs. isolation, and 7. Generativity vs. stagnation).

The stage of generativity vs. stagnation is centered on concern for others and a desire to care for them vs. concern for self. While this understanding of it is likely still relevant for spouse-caregivers in their overall re-evaluation of the developmental stages, their situations are unique in this area. Instead of being pulled between self-centeredness and other-centeredness, many of the participants seemed to be in a moderately healthy balance between the two polarities. The difficulty was the changing needs of the person on whom they had placed most of their energy. Most would likely have been gauged as passing through the crisis of intimacy vs isolation well or very well, and in their older ages, their energy and daily focus was on the safety and wellbeing of their physically or cognitively impaired spouses. For most, it had been years since they were in the workforce and decades since they had been responsible for raising children. As their husbands’ or wives’ health began to fail, caregivers spent increasing amounts of energy caring for them. After their spouses were placed in care, the outworking of their daily focus suddenly shifted. Some had been taking care of their spouses for years and did not know what to do with themselves without the responsibilities. Most shifted their focus into
emotionally supporting their spouses by visiting regularly and advocating for their wellbeing. However, this shift did not usually occur painlessly; there was a new struggle to reconcile what they wanted or felt they needed to do to care for their spouses (generativity) vs. what they needed or felt able to do for themselves (stagnation).

Stagnation may come across as negative, but there is value in each of the competing behavioural expressions. In this case, many spouse-caregivers suddenly found themselves with free time. Some continued to feel like they needed to dedicate all their energy toward caring for their spouses. They struggled to find balance between nurturing their connection with their spouses and taking care of their own needs, or the ‘other-centeredness’ of the stagnation designation. Several participants noted a decreasing sense of mutuality in their relationships with their spouses, which was especially true for those whose spouses were cognitively deteriorating. After their spouses were admitted into LTC, they began a new formulation of no longer identifying as caregivers (or not as strongly), and still being husbands or wives but at the same time, not really. Erikson’s theory can be helpful in shedding light on some of the elements contained in the earlier exploration of identity (Figure 5.1). If resolving the crisis of integrity vs. despair is largely brought about by revisiting and re-evaluating the previous psychosocial stages of development, then it makes sense that the stages that involved their spouses the first time around could potentially be more difficult to restructure.

Most participants had been married for forty to sixty or more years. The crises of development of their adult lives had most likely been resolved as part of a husband-wife team. As the caregiving spouse became more immersed in the role of caregiving, they may once again have stepped into their generative or nurturing behavioural expression. This seemed to occur less naturally for men than for women, all but one of whom had been primary caregivers for their
children and, in another case, for her grandchildren as well. After placing their spouses in LTC, caregiving was no longer the focus of their every moment, but their previous resolutions to the crisis of intimacy vs. isolation no longer fit their current realities of separation. For some the separation was only physical—their spouses were physically limited. For others the separation was psychological or both—dementia was robbing their spouses of their memories, their identities, and robbing the participants of their loved ones. Participants were left with the task of re-evaluating their own shifting identities as spouses and as caregivers. Part of the reformation of identity involved examining their old schemas (e.g., their lives as wives, husbands, companions, parents, social roles, etc.), retaining and protecting what was meaningful, and making room for new facets of their identities to emerge. The word “stagnation” in the generativity vs. stagnation crisis may come across as negative, but it is worth repeating that each behavioural polarity has value. This makes it complicated to clearly and concisely compare these crises with this study’s theory of involuntary separation without going into lengthy detail. However, it is worth noting that when the generativity vs. stagnation crisis is resolved, it bears a great deal of resemblance to Stage 3: Moving forward (Figure 4.1).

Kivnick and Wells (2013) emphasized that this real-life process of resolving integrity vs. despair does not typically take place in quiet self-reflection. Instead, it is “fundamentally grounded in their engagement, their vital involvement, with life’s people, materials, activities, ideas, institutions, and so forth” (p. 44). In other words, it is a psychosocial process that requires connecting. In the end, Hamachek (1990) posits that “Integrity, it would seem, is an ego quality that allows one to express the feeling that, ‘Yes, I have made mistakes, but given the circumstances and who I was at the time, the mistakes were inevitable. I accept responsibility
for them, along with the good things that have happened in my life”” (p. 681). This could easily be a description of the balance of grief and gratitude in this study’s third stage of connecting.

*Lazarus and Folkman: Stress and Coping.* Folkman et al.’s (1987) study observed that older individuals used more emotion-focused coping than younger people and posited that this difference may have been due to contextual factors. In this study, participants typically had exhausted their problem-focused options except for one – finally admitting their spouses into care. For most, their primary appraisal of this situation was that yes, the ramifications of this decision impacted them greatly. A couple of the individuals appraised it as less impactful—one because she and her husband were not emotionally close to begin with, and the other because his wife was still able to spend all day with him in their home at the time of our interview. The secondary appraisal always seemed initially that their situations were unchangeable. In other words, the participants were no longer able to care for their spouses at home, which meant they needed to be placed in a facility. With the unavoidable outcome of placement, problem-focused coping was no longer effective as a primary coping strategy, leaving participants to deal with the emotional and psychological consequences of their new realities via emotion-focused coping.

The shifts between problem-focused and emotion-focused can be seen in this study’s three stages of connecting (Figure 5.2). Part of the difficulty for many participants was their frequent reappraisals (stage one). Though this was an emotionally painful time, these feelings were pushed aside in order to deal with the tangible problems in their current crisis (e.g., moving spouse into facility, making them comfortable, dealing with paperwork, etc.). They did not have the energy to focus on anyone except their spouses and therefore needed others to step up and offer support and connection to them. Feelings of powerlessness frequently crept in because they simply could not continue taking care of their spouses, but emotion-focused strategies of
avoidance allowed them to disconnect from their feelings of pain, guilt, failure, and loss so they could cope with their immediate, solvable problems.

At various stages throughout the process of admitting their spouses into care and the following adjustment period (stage two), many doubted their decisions. These doubts—believing that maybe their situation was changeable after all—led them again down the paths of problem-focused coping. These thought processes of believing they could have done more or could still do better typically landed them back at the realization that the situation was, indeed, beyond their control. From there, they had no option but to resort to emotion-focused coping. In this stage, they either engaged with their emotional pain via connecting and confiding with others, or they continued with disconnecting strategies which Folkman et al. (1986) described as emotional distancing or escape-avoidance. Though they were able to begin pursuing connection with some people, they demonstrated low tolerance for others’ insensitivity. Continued avoidant emotion-focused coping kept individuals stuck in stage two, while working through their emotional turmoil with trusted others allowed them to move into stage three.
In stage three, participants were securely positioned in emotion-focused coping strategies. With little-to-no solvable problems in their day-to-day, they worked on embracing life in the midst of their unchangeable circumstances. They developed emotional resilience that was earned through continued vulnerability and genuine connections with family and their social worlds, and through wrestling through their own evolving personal identities and spiritual beliefs. They still struggled now and then with frustration, sadness, and grief, but they also experienced internal change that allowed them to accept their overall place in life and to once again find moments of joy within it.

**Contributions to counselling psychology.** Implications for counselling include increased understanding for therapists and other care professionals. With this knowledge, they will be better prepared to provide empathy and offer support to spouse-caregivers during their transitions and in the following years. In accordance with medical separation’s basic social process of connecting, therapists should endeavour to foster clients’ connections with others. This study highlights the importance of knowledgeable and empathetic support during the often crisis-like experience of medical separation. A basic understanding of the core category (connecting), the four categories (1. Adjustment to Separation, 2. Significant Helping Roles, 3. Family, and 4. Social World; see Appendix L, Fig. L2) and the three stages of connecting (1. Initial news and coping, 2. Adjusting to new situation, and 3. Moving forward; see Figure 4.1) offers therapists a valuable framework to work from when working with clients who are involuntarily separated or separating. For example, if a client appears to be in stage 1, therapists can quickly recognize that interventions that are more existentially oriented such as exploring meaning or inner consent are inappropriate and are likely to be ineffective and possibly harmful. Rather, interventions should resemble crisis management – what do they need to get through the
day? How about to get through the week? Do they need help organizing transportation? Are they eating regularly and getting enough fluids? Who do they have that can help them with paperwork? What contacts within the community can the therapist refer them to if these needs are not being met? Would it be helpful if the therapist—or a social worker, if relevant—spoke to the client’s family about ways they could actively support their loved one?

If the client is in stage 2, do they seem to be stuck on a particular point? Are they struggling with their sense of identity? Do they engage with others or do they disengage? If they express that they have no one left in their social circle, it may be helpful to brainstorm ideas on how they could meet others that are not oriented primarily toward couples. Given participants’ sensitivity toward trite or thoughtless comments from others no matter how well-intentioned, peer support groups—formal or informal—of fellow involuntarily separated spouse caregivers should be highly recommended if available.

By stage 3, clients will have worked through most of the practical concerns such as filling out paperwork and settling into life as a separated couple. Still, after the interviews and the focus group, participants in this study who were in stage 3 expressed deep appreciation for a nonjudgmental listener who validated their experiences. They continued to need support as they lived with the daily awareness that their spouses were continuing to deteriorate. This was especially salient for those whose spouses no longer recognized them at each visit.

The ability to normalize their experiences is also significant, and this research can itself be a resource for clients and their families. The older adult population is often neglected in psychotherapeutic work. Individuals in the realm of counselling psychology should have a basic understanding of crisis management work with the elderly, and should be aware that medical separation is a reality for many of them and should work appropriately with this framework in
mind. With many living on a fixed income, even those who could most benefit from therapy often cannot afford it. Low-cost services for seniors should be considered. As well, counsellors have an obligation to serve the community. They are well equipped to enact many of the recommendations just mentioned, including teaching workshops on listening and showing empathic support, educating others about the processes of medical separation, and leading support groups for caregivers and their families.

**Contributions for care professionals.** It appears that some care facilities are doing well in their attempts to offer support to their spouse-caregivers. However, this was clearly not the experience for all participants. Most care workers demonstrated kindness, compassion, and competent care for their residents and their spouses, but other workers showed disregard to spouse-caregiver concerns, were secretive about elements of their residents’ care, and did not welcome spouse-caregivers’ involvement. Sometimes care workers and administrators involved in placement did not behave sensitively to the utterly devastating impact the prospect of separation had on these individuals. Participants expressed appreciation for the care workers and miscellaneous helpers who spoke plainly, yet with kindness, about their situations.

It is also worth noting that overall, care facilities and Alberta Health Services seem to be doing well with their public awareness and education around dementia.

**Strengths and Limitations**

Qualitative research is valuable for its potential to uncover greater depths of a given topic, but generally speaking, extreme caution should be used before making broad generalizations from a small sampling of the population. However, grounded theory is a bold methodology that endeavours to identify the processes of a phenomenon to the extent that it does, in fact, become generalizable beyond the sampled population (Bryant & Charmaz, 2007a).
According to Mills, Bonner, and Francis (2006), grounded theory “illuminates common issues for people in a way that allows them to identify with theory and use it in their own lives” (p. 32). The participant sample in this study was homogenous; the voices within this demographic were well represented, and I expect much of the findings to bridge to other demographics. The participants mentioned time and again that their experiences were unique from others who were separating; in their minutiae, they are not even generalizable from one participant to the next. Still, I argue that the basic human experiences contained within the core category of connecting and the four main categories of adjusting to one’s new reality, interacting with significant helpers, the role of family, and the connecting or disconnecting actions of one’s social circles are, in fact, highly generalizable. The details will undoubtedly change as they did even for this study’s participants at the level of the subcategories, but the general elements of the three stages of connecting (initial news and coping, adjusting to life apart, and moving forward) can be transposed onto people from other demographics and scenarios with relative ease. Additionally, many of these findings are supported by existing literature from elsewhere in Canada, the United States, and internationally. Thus, this study merits a high level of confidence for its value as a general starting point in conceptualizing the process of involuntary separation and is likely to be helpful in a variety of contexts.

**Recommendations**

Based on these findings and on suggestions put forward by the participants, I have compiled some recommendations. Some are more labour intensive over time and require the commitment and involvement of appropriate individuals, while other ideas would require significant effort at the outset but little in the long term.
**Education and preparation.** The participants who expressed feeling the most psychological turmoil and emotional conflict were those who had done little in advance to prepare themselves for medical separation. Multiple avenues of education are recommended both in the general community and in specific groups.

*In peer groups.* Some participants resisted the idea of peer groups, but those who tried them found them valuable as sources of both information and emotional support. The town where the study took place has various caregiver support groups for spouses of people with specific illnesses such as multiple sclerosis, Alzheimer’s, other forms of dementia, and more. One of the care facilities has also started running a general support group for former spouse-caregivers. The participants who resisted these groups had a misperception that they would involve—to paraphrase—a bunch of seniors sitting around and complaining. There was also an element of not wanting to hear about someone else’s spouse who was further deteriorated than their own. These kinds of peer group opportunities should be highlighted for their multiple purposes of emotional support, informational resources, and no-cost social engagement.

*In retirement communities.* Retirement communities should offer straightforward, easy-to-understand resources to residents currently caring for their spouses or undergoing medical separation. This information packet should include the follow: a) the steps involved in admitting someone into care, b) a checklist of tasks that need to be completed in order of priority, c) names and contact info of people they can contact such as specific care facilities, financial advisors, caregiver support groups, clergy, etc., d) a brief description of common emotions experienced by spouse-caregivers during this process, and normalization of all of it, and e) the contact info for the Crisis Line and local psychotherapists competent in this area. As part of the two care facilities’ agreements to help recruit participants for my studies, I will be creating a handout
covering all these areas upon completion of this study. This resource will be available free of charge to care facilities and other relevant organizations in the community.

*In community.* In many participants’ faith communities and social circles, people often reacted to their medical separation with awkwardness and unintentional hurtfulness. Participants said they believed most people simply did not know what to say so either said the wrong things or pulled away entirely. Informational seminars and workshops should be offered to family, friends, and the general community. The purposes of these presentations would be to talk about the basics of what is involved in involuntary separation and the ways in which it can impact spouse-caregivers. Extra attention should be given to teaching good listening skills and how to show empathy in a supportive manner. These presentations could be given by knowledgeable professional care workers, clergy, or therapists in the community, and should be advertised especially in care facilities, retirement communities, and churches.

**Supporting spouse-caregivers.** There was a polarity of experiences when it came to caregivers feeling supported at various stages of their transitions. The contrast was valuable in highlighting the importance of several supportive roles.

**One contact person.** While most participants marked their appreciation for having one person who looked after the paperwork involved in admitting their spouses, not everyone seemed to have had someone in this role. Of those who did, they were either from their spouses’ care facility or social services at the hospital. I recommend that care facilities set up a primary contact person for spouse-caregivers if they do not already have one (see also CLHIA, 2012; Reuss et al., 2005). This person should look after the paperwork, keep the caregiver informed of what needs to be done, and prepare them as much as possible for difficulties they may encounter in the future. Simply being the caregivers’ primary contact person for the first month or two of
transition would likely be a relief for caregivers and would lend a much-needed sense of stability in a chaotic situation.

**Screening for support networks.** The majority of the participants in my study had some kind of support network either through family for good friends, but this was not the case for everyone. I would like to see spouse-caregivers being asked about their social support networks. If they revealed that they had little or none, support persons such as social workers, clergy, or others should make extra efforts to check in with these individuals. This could be as simple as telephoning once or twice a week in the first month, then once every week or two for several months.

**One-on-one peer support.** Participants told stories about reaching out to others who were in the midst of being separated. Spouse-caregivers who have reached relative stability in their situation and widows and widowers who went through it before their spouses died are valuable resources for the newly separating. I recommend that care facilities recruit volunteers who have gone through the experience themselves and who feel ready to walk along someone else who is just starting their own process. If the newly separating individuals agreed, they would be invited to have coffee or tea with the volunteer at least a handful of times in the first couple of months. They could talk specifically about their experiences of being separated or could simply visit with someone who knows from personal experience how difficult the process can be.

**Directions for Future Research**

It seems many separating spouse-caregivers are willing and eager to talk about their experiences. More focus groups would be useful to not only glean more information, but to observe and reflect on the immediate peer interactions. Other interventions that are likely worth
exploring are therapist-led support groups, therapist-led group therapy, individual and family therapy, and peer-led caregiver support groups. More generally, studies should be broadened across Canada in various-sized centres, including rural areas. Focus could also be placed on further exploration of differences between male and female spouse-caregivers or the unique impact of different spiritual faiths. This study has put forward a new framework for understanding and conceptualizing this topic, but there is room to explore how this framework may be adapted or transformed within other cultures and subcultures.

**Conclusion**

Involuntary separation is experienced uniquely by each individual, but an element common to everyone is connecting. For most, being involuntarily separated is a crisis with traumatic consequences that can echo for years after the initial move. Movement through the three identified stages of this basic social process is influenced twofold: by the individual’s willingness to reach out for connection and to accept the support that is offered; by the ability and readiness of others (family, social circles, and professionals) to extend accurate empathy, help with problem-solving, and educate caregivers and the general community. When all these components are aligned at least reasonably well, spouse-caregivers are able to work through the three stages. Here they nurture their bonds with their spouses, they continue to grieve their losses, and they simultaneously embrace life, family, friendship, and faith with gratitude.
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APPENDIX A: Invitation – Telephone Follow-Up

From: Willow Glasier
[mailing address]

Dear _____,

Hello again! It’s Willow Glasier. You may remember me from my research study that you helped me with back in the summer of 2012. My study was about caregivers whose spouses have been moved into long-term care. At the time, I was an undergraduate student at ***. I’m now finishing my second year of my master’s degree in counselling psychology at Trinity Western University in Langley, BC, and my research continues!

As part of my master’s research thesis, I’m looking to go deeper into the topic of caregiving spouses who have been medically separated from their husbands or wives. Part of this involves getting back in touch with a few of the people who allowed me the privilege of hearing a piece of their story of being separated from their spouses for medical reasons – in other words, people like you! This letter is my invitation to you to share with me some of what the last three years have been like for you.

Though this is a continuation of the same theme as our conversation in 2012, this is a separate study. Your participation is 100% your choice; you are under no obligation to say yes.

If you would like to be involved, you and I will have a 30-45 minute conversation over the telephone. I’ll briefly share some themes that came up in my previous study and in my current study, and I’ll ask you for your thoughts. I’ll also ask you a few questions about the three years since we last spoke. With the time that has passed, I know much may have changed – your spouse may even have passed away. However, if you feel that you are able and willing to talk about it, I would still like to talk with you.

If you’d like to be involved or would like more information about this study or the previous one in 2012, please contact me at:

  **Phone:** ***
  **Email:** ***

Alternatively, you may simply let Pastor *** know that you’re interested and he will pass on your response and your telephone number to me. After that, I’ll telephone you to set up a time that’s convenient for you to talk sometime early this month.

Thank you again for being part of my previous study, and for considering this invitation to be involved in my new one.

Respectfully yours, Willow Glasier
APPENDIX B: Script – Telephone Follow-up

Greetings
Go through verbal Informed Consent

Longitudinal Component

- It has been almost three years since we last spoke; what has happened since then? What has changed? What has stayed the same?
- What have been the longer-term impacts from your spouse’s admission into long-term care?
- What are some things that stand out in your mind about your spouse’s first admission into long-term care? How did these impact you?
  o How are you doing now?
- Is there anything that weighs heavily on your mind these days?
  o If yes, is there anything that you do or that anyone else does that helps take some of that weight off?
- Is there anything else you’d like to mention about the whole experience of your spouse being in long-term care?

Credibility Check (2012 study)
Thank you so much for answering these questions. As I mentioned earlier and in my letter given to you by Pastor ***, I’m eager to briefly go through the themes that came up in that first study I did in 2012. These are themes I noticed by analyzing what everyone in the study had to say about their experience. Are you okay if I go through them with you now? I’m happy to hear what you think about them, so please feel free to be honest! (You’re not going to hurt my feelings if you disagree.)

Go through main themes from previous study, querying for feedback between each

- After hearing about our results, do you have any thoughts or reflections on your life now several years after that data was gathered?
  o Is there anything that stands out to you from these four themes?

Credibility Check (2015 study)
- Thank you for sharing with me how you’re doing and some of your thoughts on my previous study. Are you feeling ready to move on to the last part? Or would you like to finish this up another day? (If they wish to have a break, we will arrange a date and time to resume our telephone conversation.)
- The last thing I wanted to run by you is my preliminary results from my current study. This will be very similar to what we just did before with the 2012 study, where I will share what
I’ve seen in the data, and you are invited to ask questions, agree, disagree, or comment however you like. Do you have any questions before I start?

*Go through preliminary findings from current study, querying for feedback after each section*

- That’s it for my questions! Do you have any questions or comments for me?
- I have just a couple things to confirm with you, okay?

*Go through debriefing document*

*Confirm*
  - Mailing address for mailing Informed Consent, Debriefing document, and a copy of the results for 2012 study upon completion (or, confirm that they would prefer to have the documents sent to the facility’s chaplain).
  - Ask if they would like a copy of the new study (thesis, or summary of results)
APPENDIX C: Guideline for Original Interviews

1. To get us started, can you tell me a bit about you and your wife/husband?
   a. How long have you been married?
   b. Would you be willing to share with me what year you were born in?
2. Tell me about when your spouse started needing some help.
   a. Did you become the caretaker for your spouse?
   b. **If needed:** And how long did you provide care before s/he was admitted to long-term care?
3. Did others take part in the caregiving?
4. And how long ago did your spouse move into [care facility]?
5. Who was involved in the decision to move spouse into [care facility]?
   a. **(If their decision):** What led to this decision?
      i. How did you feel about making that decision?
      ii. Did input from your family or friends affect your decision?
         1. How?
   b. **(If someone else’s decision):** How did you feel about the changing situation?
6. Was there something about the process of your spouse moving to [care facility] that stands out for you?
   a. Prompt, if needed, either positively or negatively
7. How did you feel in the time before the move?
   a. During?
   b. Immediately after?
   c. Now?
8. (If there’s been mention of difficulty): was there anything that helped you during the difficult times?
   a. Was there anything that made it more difficult?
   b. [Note: possible topics like social support, family support, speaking with others with similar experiences, church, prayer, faith in general]
9. **If living on-site:** Has living in [care facility] impacted your experience?
10. **If living off-site:** Has being connected to [care facility] impacted your experience?
11. Have these changes in your life changed how you think about yourself?
   a. If yes, how?
12. Have these changes in your marriage changed how you think about yourself as a wife/husband?
   a. If yes, how?
13. Complete the sentence: when I was in the middle of moving [spouse] over into [care facility] and in the time immediately afterwards, what I wish someone had told me was _______ (fill in the blank)
14. Is there anything that we haven't talked about that you would like to share/say?
   • Thank you so much for taking the time to talk with me. I’m going to turn the recorder off now.
   *turn recorder off*
   • Is there anything you would like to say without it being recorded? **(If Yes, request permission to include in my self-debrief)**
APPENDIX D: Interview Invitation Letter

Willow Glasier
[Mailing address]

Dear Sir or Madam,

My name is Willow Glasier. I am a graduate student in the Master of Arts of Counselling Psychology at Trinity Western University in Langley, BC. As part of my thesis research project, I am looking for people who have had a spouse admitted into continuing or long-term care.

I am writing to invite you to take part in a research study on what it’s like for individuals who have a spouse living in a long-term care facility. Involvement entails a one-time meeting with me where I will ask for your feedback on specific topics in an informal setting. You will be invited to share pieces of your personal experience as you feel comfortable.

Why am I interested in this topic? I want to understand the experiences of people who, like you, are the spouse of a person living in a care facility. I believe that it is important to document your perspective on what the journey of medical separation is like. An understanding of your experience and how you were—and still are—impacted by those around you may help other spouses facing a medical separation, as well as health care providers and pastoral care providers. Any information you share with me will be treated with the utmost confidentiality and respect.

If you are interested in participating, or if you would like more information, please contact me at:
Phone: ***
Email: ***

The meetings will take place in Medicine Hat between DATE and DATE. The exact location, date, and time are to be determined.

This study has been approved by the Research Ethics Board at Trinity Western University. I have been welcomed by [care facility 1] and [care facility 2] to carry out this project.

Thank you for your time. I hope to hear from you soon.

Respectfully,

Willow Glasier
APPENDIX E: Focus Group Invitation Letter

Willow Glasier
[Mailing address]

Dear Sir or Madam,

My name is Willow Glasier. I am a graduate student in the Master of Arts of Counselling Psychology at Trinity Western University in Langley, BC. As part of my thesis research project, I am looking for people who have had a spouse admitted into continuing or long-term care.

I am writing to invite you to take part in a research study on what it’s like for individuals who have a spouse living in a long-term care facility. Involvement entails a one-time meeting as part of a focus group of individuals who have also had their spouses admitted into continuing or long-term care. I will lead the meeting and will ask for your feedback on specific topics in a discussion setting. You, along with each member of the group, will be invited to share pieces of your personal experience as you feel comfortable.

Why am I interested in this topic? I want to understand the experiences of people who, like you, are the spouse of a person living in a care facility. I believe that it is important to document your perspective on what the journey of medical separation is like. An understanding of your experience and how you were—and still are—impacted by those around you may help other spouses facing a medical separation, as well as health care providers and pastoral care providers. Any information you share with me will be treated with the utmost confidentiality and respect.

If you are interested in participating, or if you would like more information, please contact me at:
Phone: *** *** ****
Email: ***

The focus group is taking place on [DATE] at 2:00pm at [CARE FACILITY], Medicine Hat.

This study has been approved by the Research Ethics Board at Trinity Western University. I have been welcomed by [care facility 1] and [care facility 2] to carry out this project.

Thank you for your time. I hope to hear from you soon.

Respectfully,

Willow Glasier
APPENDIX F: Focus Group Informed Consent

Mrs. Willow Glasier (Master of Arts in Counselling Psychology student)
Mihaela Launeanu (supervisor, Ph.D. cand.)

Thank you for meeting with me today. This letter is intended to help you decide if you will take part in our study, and describes its purpose and procedure. The letter also describes your right to decide not to take part, as well as your right to withdraw from the study at any time.

Study Purpose
I would like to understand the experiences of people who, like you, are the spouse of a person living in a care facility. I believe that it is important to document your perspective on what the journey of medical separation is like. This information may help other spouses facing a medical separation, as well as people who work at long-term care facilities.

Study Procedures
If you agree to take part in my study, we will have a conversation as a group about your journey as the spouse of a person living in a care facility. I will share preliminary findings from my study and will ask for your feedback from your own experience. What is said during our meeting is confidential, but please don’t feel pressured to share more than you feel comfortable. I will be audio recording the meeting. The meeting will last anywhere between 1-3 hours, with time for a break.

Risks and Discomforts
If you decide to take part in my study, you may find it difficult or upsetting to talk about parts of your journey of medical separation. You do not have to talk about difficult topics if you would prefer not to. If you would like to talk with someone afterwards, Pastor *** or Pastor *** would be glad to offer a listening ear, pastoral counselling, or further support.

Benefits
You may find it helpful to talk about your journey of medical separation from your spouse, and to hear about others’ experiences. As well, sharing your story will help us understand what it is like to be medically separated. The results of this study might be helpful to others who face a medical separation, and to people who work at long-term care facilities.

Confidentiality
You are free to talk about your experience in this study with whomever you wish, but everything said by other members of the group is confidential. Please do not repeat anything they say without their expressed permission.

No one other than the researchers involved in this study (Willow Glasier and Mihaela Launeanu) and a professional transcriptionist will have access to the recording of your interview. Your name will not be on any of the interview transcripts. Anything identifying you—such as your contact information and audio recording—will be kept in a locked container. The recordings will be destroyed when the study is done. Your name and any other identifying details will never
be given in any publication of the results of this study. The results of the study may be published in a professional journal or presented at professional meetings.

Choosing Not to Take Part
You can freely decide whether or not to take part in this study. You can decline to answer any of the questions. You can also change your mind and withdraw from the study at any time.

Follow-Up
You are welcome to ask questions if you have them. You can ask questions in person today or contact me later. I will be providing you with my contact information.

This study has been approved by the Research Ethics Board at Trinity Western University. If you have questions or concerns about our study ethics, please contact ***, chair of Trinity Western University’s Research Ethics Board at *** or ***.

I, ____________________________ (please print) understand that I am being asked to take part in a research study looking at the experience of spouses of persons living in a care facility. The study has been explained to me by Willow Glasier. I agree to take part in this study. I know that I can choose not to answer any questions and that I can withdraw from this study at any time. I understand that my responses will be kept anonymous. I acknowledge that anything said by my peers in this meeting is also confidential.

____________________________________________  _________________________
Participant Signature                              Date

____________________________________________  _________________________
Researcher Signature                               Date
APPENDIX G: New Interview Script

- What did you and your husband/wife do before retiring?
- How long have you and your husband/wife been married?
- How long ago did they move into long-term care?
- What was your reaction after it became clear your spouses had to move into long-term care?
- What did you do that helped you get through the process of moving your spouses into care?
  - Was there something you did—or didn’t do—that made the adjustment harder?
- What are the good parts of your day?
  - What do you do that helps make your day better?
- What are the tough parts of your day?
  - What do you do that helps you get through the tough stuff?
- What would you say to someone else whose spouse was going to be moved into long-term care soon?
- Summarize results that have arisen – main commonalities and differences between participants
- Does this summary seem accurate? Am I missing anything?
- To quickly review our goals in meeting here today, I'm looking at your experiences of being medically separated from your husbands or wives. What things you have done that have helped you manage the transition, what you’re doing now that you’re medically separated, and how you make sense of this shift in your life.
  - With this review, does anything else come to mind that we haven’t already talked about?
- That’s it for my questions! Do you have any questions or comments for me?
- I’m going to turn my recorder off now, and then I have just a couple things to go through with you, okay?

- Go through debriefing document; give a copy to each, query if participants want a copy of the study’s results upon completion (if so, confirm mailing addresses OR confirm that they would prefer to have the results sent c/o the facility’s chaplain). Do one final check-in to see if participants have questions or concerns about the process.
APPENDIX H: Interview and Focus Group Debriefing Document

Thank you for participating in my study. Your involvement is vital as I seek to gain a clearer understanding of what it is like for a caregiver whose spouse is admitted into a care facility. My goal is to learn more about the journeys of people who are medically separated. I hope that the results of this study will help others as they, too, make the major adjustment of being separated from their spouse because of medical reasons.

If you would like to speak with someone about thoughts or feelings that you had during or after our meeting, or if you would like pastoral counselling, please do not hesitate to contact either of the following:

Rev. ***
Cell: ***
Email: ***

Rev. ***
Cell: ***
Email: ***

If you have any further questions or comments about the study or if you would like me to send you the results of this study, please contact me at:

Willow Glasier
Cell: ***
Email: ***

If you would like to speak directly with the Research Ethics Board at Trinity Western University, you can reach ***, chairman of the board, at *** or ***.

Thank you for your willingness to be involved in my study!
APPENDIX I: All Initial Codes

Code-Filter: All

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a friend helped IE get wife to hospital
a sense of cynicism toward placement administrators
a sense of dread after moving spouse to new care facility
a sense of existential acceptance
a sense of feeling in limbo
a sense of feeling life is unstable
a sense of God's guidance
a sense of guilt for not relying enough on God
a sense of helplessness for spouse's safety
a sense of IE feeling guilty for not knowing about variety of symptoms
a sense of powerlessness - don't think about things IE can't change
a sense of purposelessness after spouse's death
a sense of sadness for residents whose loved ones don't visit
a sense that people weren't understanding of IE's situation
a sense that spouse's experience is improved when IE is there
a year and a half since spouse moved
accepting the situation
activity helps relieve stress
admits he gets turned around at the complex sometimes too
admitted spouse to hospital's assessment unit
admitting husband was hard
advocated for spouse in hospital ER
advocated for spouse long before spouse's LTCA
advocated for spouse to get better pureed food
advocating for enjoyable food for residents
afraid of falling
after 2 months since LTCA, the pain is still fresh
after initial separation, feelings of separation

anxiety, guilt, worry
after injury, spouse couldn't stay in AL
after LTCA, social worker called IE every week
after move, heartbreaking walking into spouse's room and seeing him cry
after spouse's move, IE was exhausted
after spouse's outburst, waited a day to visit again
after wife's admission, IE's brothers took him on a trip
all hours
all she and spouse can do is think about each other
always lots of tough stuff for IE to deal with
angry at the behaviour of another resident
angry at the lack of privacy because of a certain resident
angry that spouse was sick
anticipating future abilities
anticipating hardship of spouse's roommate dying
anticipating IE's decline if she moved to LTC too soon
anticipating more stress
anticipating spouse's condition worsening
appreciated the people who put in the alarm system
appreciates being invited for lunch, coffee
appreciates comradery of people in similar situations
appreciates encouragement
appreciates facility chaplain
appreciates spouse's easygoing care workers
appreciates the animals for their accepting natures
appreciates the helpers who brought spouse to on-site church services
appreciates their concern
appreciates their friends' help
arranged power of attorney
as a couple, moved to town and gradually downsized over many years
as a man, IE is outnumbered by women in retirement facility
asked for explanation for spouse's attitude shift
asked friends why they distanced themselves
asking family for help with tasks
asking questions and feeling supported by facility workers
asserted boundaries of respect with fellow retirement community residents
at 95, IE is slower but still active
at beginning, was confused by lack of structure at mealtimes at care facility
attended social activity at retirement facility once
attending church services
attending church services with family
attending church services with son
avoiding people who will make IE cry
baking seems pointless
balancing new expenses on limited income
battled care facility policies to advocate for spouse's wellbeing
becoming more compassionate
before retiring, drove logging truck
being informed about care options
being separated hasn't changed IE as a wife
being separated was hard
believes IE would still be lonely in a condo
believes people were stealing from spouse in hospital
believes their love will stay strong
blamed self for spouse's behaviour
blaming IE for limitations
blending two families wasn't the smoothest
both accepted the separation
both moved to multi-level retirement community
both were very active
bothered by abrupt manner of placement facilitator's phone call
bothers IE that IE is the only one to visit spouse
brings spouse to spend time with animals
brought bedding from home to LTC
brought food for animals at care facility
bus driver told her "not today"
But the place where I'm in, I ..
called ambulance
called and talked to nurses while on trip
called daughters during health scare
called son for help
calling ambulance again for frightening health emergency
calling ambulance for health emergency
calling on God for help
calling paramedics in middle of the night
calls building maintenance for some tasks
calls spouse three times a day
can't accept that medical separation is necessary
can't afford taxis to see spouse
can't be with spouse non-stop
can't believe how expensive groceries are
can't bus to spouse because of visual impairment
can't care about negative experiences
can't let spouse have combination to doors
can't make plans until spouse has been placed in LTC
can't transport her walker to spouse's care facility
can't walk much with spouse without her walker
care facility atmosphere improved over time
care facility didn't do anything particularly helpful after LTCA
care facility emphasized closeness and support
care facility emphasized support for both IE and spouse
care facility had animals nearby
care facility has big rooms for residents
care facility looks after all spouse's needs
care facility made no effort to make move feel home-like
care facility personnel were accommodating
care facility social worker was very helpful with paperwork during admission process
care facility staff initiated spouse's move to
LTC care facility staff were kind to IE. The care facility was helpful overall during the move. The care staff helped IE with daily care. The care worker's honesty with IE helped with decision making. The care worker stood up for IE. The care worker told IE he wouldn't last with the spouse at home. Care workers and other family members couldn't speak Dutch with the spouse. Care workers didn't listen to IE's input for the spouse's care. Care workers normalized the spouse's return to first language. Care workers say the spouse is easy to care for. Caring about rude people would make her the same as them. Caring for the spouse gave IE something to do. Caring for the spouse was a risk for IE's wellbeing. Caring for the spouse was stressful. Cautious about weather in wintertime. Changes are tough because IE is visually impaired - the neighbour helped her. Checking in on the spouse's behaviour at home. Checks answering machine to see if someone called. Church programs start up after summer. Closing of the first care facility. Committed to the spouse. Compares self to others in similar situations. Compares self to others who have been married multiple times. Compares the spouse's symptoms with typical disease progression. Concern that the spouse could live a long time yet. Concerned about the spouse's wellbeing. Concerned for spiritual growth of grandchildren. Concerned that savings will run out. Conflicting feelings about separation. Confronted the resident's spouse about resident's behaviour. Confusing process of getting financial subsidies. Connecting to other residents. Connections to people in the care facility. Considered hiring a foreign worker as a caregiver at home. Contact with the spouse sometimes makes IE feel more lonely. Continued as usual after the spouse's fall. Convenience of the first care facility. Cooks with minimal effort. Could leave the spouse alone for short periods of time. Couldn't believe the spouse wasn't home. Couldn't converse much because of the spouse's dementia. Couldn't live without the wife's big smile. Couldn't talk with the spouse, but was helpful to talk with nurses. Crying over involuntary separation. Current care facility is expensive. Current care facility isn't a home-like setting. Dating for a long time. Daughter and IE took the spouse to hospital. Daughter and son-in-law saw IE needed help. Daughter buys IE's groceries. Daughter came to see IE after the spouse was hospitalized. Daughter doesn't visit the spouse. Daughter drives IE. Daughter gets angry easily. Daughter got angry at IE over miscommunication. Daughter has health issues. Daughter helped IE financially after IE's husband moved. Daughter is aloof. Daughter is only relative nearby. Daughter looking after the spouse so IE can have a break. Daughter takes IE's BP. Daughter told IE he should be in hospital too. Daughter visits the spouse regularly. Daughter went with IE to admit the spouse into the assessment unit.
daughter went with spouse and IE to hospital
daughter went with spouse to hospital
daughter wrote hurtful things about IE on internet
daughters agreed with facility workers
daughters and facility workers looked after spouse's move
daughters have their own families
daughters helped with spouse's care
daughters took charge of spouse's medical care
daughters took spouse to LTC
daughters visit spouse in hospital
day program would help spouse be more active
day revolves around visiting spouse
days are long
dealing with spouse's mental illness was worse than LTCA
deciding to move closer to son
decision was made for IE
delayed admitted spouse because didn't want to be separated
delayed admitting spouse to LTC
delayed filing income tax to avoid marking that IE was "separated"
demanded spouse be treated with respect
dementia study doing drug trials
describes his marriage as "normal"
describes spouse as a perfectionist
describing spouse as positive
describing spouse with fondness
despite differences of opinion, tried to be on good terms with the care workers
despite everything, IE feels blessed
despite short term memory loss, spouse was good to talk with
devastating feelings of guilt for putting spouse into bad situation
devastating not being able to bring spouse home
developed good rapport with care workers
did what she had to care for spouse
didn't blame spouse for his illness
didn't cry the day of spouse's LTCA
didn't feel judged by others for spouse's LTCA
didn't feel like care workers wanted family and visitors around residents
didn't feel retirement community residents were supportive
didn't feel sorry for herself when spouse moved to LTC
didn't feel spouse got proper care in hospital
didn't feel strongly either way about spouse's move
didn't feel supported by care facility staff
didn't feel supported during move to second care facility
didn't feel welcomed at new care facility
didn't get first choice of care facility
didn't get sad when spouse moved to LTC
didn't have help
didn't have kids nearby to help with practical issues of moving spouse from hospital to care facility
didn't have much say in spouse's move to LTC
didn't have to move furniture - care facility supplied it
didn't know spouse was being moved to LTC
didn't know what to do except accept it
didn't like that spouse's room temperature was cold
didn't like that spouse was moved to LTC
didn't like when spouse first moved to AL
didn't mind taking care of their home
didn't realize how badly she needed a break
didn't see that spouse's wellbeing was nurse's priority
didn't sleep well around spouse
didn't spend much time with other visitors because of different schedules
didn't tell many people about spouse's LTCA
didn't think it would be possible to get away for a break
didn't trust care workers to take proper care of spouse
didn't want to be responsible for fixing house
didn't want to be the boss, but had to be
didn't want to risk own health
difficulty dealing with spouse's anger
difficulty seeing spouse's loss of cognitive function
difficulty talking about negative emotions
 disagreed with some of spouse's medications
disagrees with physician's opinion
discouraged knowing spouse will decline
discouraged with spouse's unpredictable symptoms
distracts self so doesn't think about emotional struggle
distracts self with TV during mealtimes
doctor asked IE what IE was going to do about spouse after hospital
doctor communicated clearly
doctor decided IE couldn't take care of spouse
doctors did the best they could with spouse's diagnosis
documented her interactions with difficult nurse
does everything himself now
does spouse's laundry
doesn't always get all her day-to-day home and yard tasks done
doesn't dance anymore because it feels disloyal to spouse
doesn't enjoy cooking anymore
doesn't fault people for not understanding what this is like
doesn't feel active, but walks regularly
doesn't feel bad about spouse being in LTC
doesn't feel he/she has changed much
doesn't feel supported except by family
doesn't have a plan
doesn't have family in town
doesn't have kids to help IE with computer
doesn't have time to think
doesn't have to pay extra for supper delivery if she's sick
doesn't know how she copes, she just does
doesn't know if she has any good parts to her days
doesn't know if spouse getting care she needs

doesn't know what he thought after spouse was moved
doesn't know what he would change
doesn't know what she'd do without her faith community
doesn't know what someone else would do in same situation
doesn't know what to expect when visits spouse
doesn't like relying on friends
doesn't like spending time around other residents
doesn't like to ask for help
doesn't like to see people suffer
doesn't like to think about the possible future
doesn't need much because two meals/day are provided
doesn't often get asked how IE is doing
doesn't pay attention to her emotional struggle
doesn't put effort into cooking anymore
doesn't remember signing separation paperwork
doesn't run around with her grandkids
doesn't say goodbye to spouse
doesn't sleep well anymore
doesn't sleep well if doesn't visit spouse every day
doesn't think about things too much
doesn't think caregivers realize how much work they do
doesn't think caregivers should feel guilty for admitting loved ones
doesn't think IE would be strong enough to work in a care facility
doesn't think she could work in a care facility
doesn't think spouse would notice if IE visited less
doesn't understand much of what spouse says anymore
doesn't understand need for spouse's high level of care
doesn't understand the social distancing
doesn't understand why spouse is high risk
doesn't want her geo distant kids to feel
guilty
doesn't want others to think IE is abandoning spouse
doesn't want spouse to think IE abandoned him
doesn't want to bother his kids with his problems
doesn't want to handle everything on his own
doesn't want to hear about how spouse will get worse
doesn't want to hear other people's problems
doesn't want to live much longer
doesn't want to place responsibilities on friends
doesn't want to put the effort into learning computers
doesn't want to suffer before dying
doing tasks at home made her too tired to visit spouse
doing the tasks of two people
doing things alone but not liking it
downsized before moving to retirement facility
drastic shift from living at home to being involuntarily separated
drove to care facility for spouse's admission during spouse's LTCA, his short term memory loss made it hard for IE who had to repeatedly explain what was happening during spouse's move to LTC, people were kind to IE each are looked after. IE doesn't care after that.
early years are still painful
easier to leave after spouse is distracted
easier to skip visits now that husband doesn't know her
easier to visit spouse after spouse's sudden 180 degree attitude shift
eating together
eats out to be around other people
eats together with fellow widower
emotional burden significantly worsened by spouse's rude roommate and poor conditions
emotional pain and heaviness still present
below surface 2+ years after LTCA
empathic relationship with sister in similar situation
enjoying life together before transition
enjoying spending time with spouse
enjoys music but finds it overwhelming to choose what album to play
enjoys music programs at retirement facility
enjoys other resident who is better contained
enjoys visiting with spouse
escorted out of the hospital
especially appreciates specific male nurse at care facility
eventually accepted medical separation
exercises at care facility
exhaustion and stress put IE in hospital
expected marriage to have ups and downs
expected second marriage to be good, but it isn't
expected to take spouse home after assessment
expected to take spouse home in a few days
expects polite etiquette
experiences women as natural caregivers
expresses appreciation for care equipment
eyes were opened to the hurting people around IE
facility eventually fired disruptive nurse
faith community is helpful
familiarity of care facility
family busy with their lives
family came to visit
family didn't know the needs
family didn't understand at first, but quickly recognized need for placement
family don't like to visit spouse
family don't visit often
family going for coffee with IE
family have their own health concerns
family helped IE see her limits
family helped with care
family helped with paperwork
family history at care facility
family invites her out for coffee
family less supportive after crisis
family made IE take a holiday
family members living at same facility as spouse
family phones
family phones and visits often
family pushes IE to rest
family pushes IE to take regular day off
family reluctant to move spouse into care
family supported decision to place spouse
family tell IE she did the right thing
family took care of spouse in care facility
family visits as often as possible
farmed through a lot of changes
fears others would judge IE for seeking friendships
fears spouse will give up once she needs diapers
fed spouse lunch everyday
feeling afraid to lose spouse
feeling angry at IE's helplessness to care for spouse
feeling antisocial
feeling comforted knowing spouse is only a short walk away if IE's needed
feeling conflicted over decision to admit spouse
feeling connection through loneliness
feeling displaced with palliative roommate
feeling dragged down by all the paperwork
feeling emotional heaviness
feeling emotionally devastated after spouse's LTCA
feeling empathy for others in similar situations
feeling excluded from family sometimes
feeling God's help before spouse's passing
feeling guilty - wanting spouse's struggle to be over
feeling guilty about IE's own health
feeling guilty when not with spouse
feeling inconvenient to family
feeling involved in spouse's care
feeling isolated in her pain
feeling like God isn't answering her prayer
feeling like God isn't stopping spouse from leaving her
feeling like LTCA was a failed end to 60 yrs marriage
feeling lonely
feeling obligated to family
feeling overwhelmed by short notice of spouse's move
feeling pressure to complete tasks in timely manner
feeling stuck with obligations
feeling supported by family
feeling supported by neighbours in practical ways
feeling threat of financial punishment for not doing tasks
feeling trapped
feeling uncertain how long he could stay nearby
feeling unsettled
feeling upset about being excluded
feelings of guilt for much nicer living quarters than spouse
feelings of guilt for not noticing spouse's symptoms
feelings of loneliness remain
feels a long connection to care facility
feels awkward finding places to sit at social events
feels both gave 100% in their marriage
feels conflicted about visiting spouse
feels empathy for others in similar situations
feels empty
feels fortunate that spouse responded gracefully to increased limitations
feels good about spouse's move because he's taken care of
feels guilty if doesn't visit spouse every day
feels guilty when leaving after visits
feels he can relax at supper when talking with his men friends
feels helpless to change it
feels her help is appreciated by care staff
feels her kids would know more about how she's changed than she does
feels high amount of stress
feels less alone because of retirement community residents
feels less guilty now about taking time for
herself feels like a failure as a husband
feels like a failure because he can't take care of his spouse
feels like daughter has kicked legs out from under IE
feels like he's killing time
feels like he's waiting to die
feels like he doesn't belong
feels like no one cares
feels like their marriage is still strong
feels lucky
feels lucky to have such good kids
feels old and limited
feels selfish if doesn't visit spouse every day
feels sense of value in her unique role in spouse's care
feels she's doing okay most of the time
feels she carries the burden for both self and spouse
feels sorry for self sometimes, but doesn't allow self to linger on it
feels spouse should be grateful he's getting good care
feels stronger after a day away from care facility
feels sympathy from women that makes him get teary
feels the government doesn't understand their financial struggles
feels there must be a better way than formal medical separation
feels they did their best with God's help
fellow retirement facility resident was rude to IE
felt fortunate to get spouse connected quickly with doctor
felt he had no option but to care for spouse on his own
felt heartrending to leave spouse on other side of locked door
felt kitchen workers weren't being truthful
felt like a cold reception at new care facility
felt like a failure as a spouse
felt like a rapid digression
felt like a weight was lifted off IE's shoulders
felt like her struggle with medical separation wasn't acknowledged
felt like IE had no choice
felt like IE was abandoning spouse at end of every visit
felt like IE was dealing with battle after battle for spouse's care
felt like IE was hit with one thing after another
felt like IE was letting spouse down
felt like moving spouse was 'giving him up'
felt like nursing staff were okay with IE's involvement in spouse's care
felt like she'd been vetoed
felt like slow progression into widowhood before move
felt like spouse was taken away
felt like their happy marriage was torn apart
felt lost after spouse's Alzheimer diagnosis
felt more at ease with alarm system to keep tabs on spouse at home
felt more equipped than others to pick up her new responsibilities
felt powerless
felt relief after physician called
felt sorry for spouse and self
felt spouse's condition was a topic of gossip at retirement community
felt spouse was overmedicated
felt stronger and rested after holiday
felt supported at first care facility
felt supported by family
felt supported by kids during spouse's move
felt the study was too much for spouse's
abilities
felt very supported by family
felt welcomed at facility
fetches spouse during the day then brings her back to LTC for night
fights feelings of depression
figures IE will get used to sitting at table alone eventually
figures she was a pest to the nursing staff
figures spouse losing sense of taste is good for the care facility
figuring out the right way to do it financially
finding balance between advocating for spouse and allowing care workers to do their jobs
finding placement was difficult
finding refreshment away from care facility environment
finding strength in prayer
finds animals therapeutic
finds comfort in faith
finds it upsetting when spouse deviates from typical Alzheimer's progression
finds the meals at retirement facility too expensive
first care facility was a nightmare
first facility had good care
first facility had poor conditions but excellent staff
first husband was better to her than second husband
first noticed spouse's forgetfulness
first six months after LTCA were a difficult adjustment
first six months after LTCA were a nightmare
focus on what's best for spouse
focuses on one day at a time in her loneliness
focusing on family
formed some close relationships with care facility staff
found out later that spouse's minor fall was serious
found spouse on floor one morning
friend's family is big and rallies around her
friend dying around spouse's LTCA
friend supported IE and whole family
friends' efforts are supportive
friends admitted spouse into LTC while IE in hospital
friends are helpful
friends aren't good on computers either
friends aren't in the best health either
friends brought spouse to first available care facility
friends don't know how to interact with IE anymore
friends email jokes to each other
friends emailed IE a short video about Alzheimer's
friends gave up on spouse
friends have distanced themselves
friends have their own families and own lives
friends looked after spouse while IE in hospital
friends phone IE regularly
friends take IE out for coffee
frustrated at patients misusing ER services
frustrated by equipment
frustrated by general population regarding spouse's limitations
frustrated with a fellow patient at hospital who was a bully
frustrated with hospital management
frustrated with patient priorities in ER
frustrated with people asking about spouse's wellbeing
frustrating when equipment not working full of doubts about decision
gave her husband love and care
gave son financial authority
gets angry easily
gets bouts of depression
gets encouragement from retirement facility nurse and chaplain
gets frustrated visiting spouse in hospital
gets own health checked up on
gets teary talking about spouse's rapid decline
getting away is refreshing
gotten married after coming home
given options of which care facility to go to
glad he was able to keep spouse at home a while longer
glad spouse is in the care facility that he's in
glad spouse isn't in diapers
glad to see that his wife is doing better now
glad when spouse responds positively to IE's presence
God gave IE strength to get through spouse's LTCA
God played an active role in getting her through the difficulties
God was a big support
goes along with spouse's cognitive dysfunction
goes for supper regularly with group of men
goes to patient conferences to learn more about spouse
goes to see friends/family when feeling overwhelmed
go for coffee by herself
going home and sleeping alone is toughest part of day
going home is hard for IE
going out for coffee together
going to church away from care facility environment
going to church off-site
going to on-site special events
going to Sunday church off-site
got annoyed at spouse
got spouse a new chair
grandchildren not engaging at on-site church
granddaughter is intentional about phoning and visiting
granddaughter lived with IE during practicum
granddaughter visited spouse daily during practicum
granddaughter was very helpful
grandkids stayed overnight
grateful for her mental functioning
grateful for his good memory
grateful for how well spouse is doing compared to others
grateful for IE's health and that she can visit regularly
grateful for spouse's rapid admission to LTC
grateful for the help she gets
grateful for what she gets from the government
grateful spouse still had his critical thinking
grateful to not have to drive; to be able to visit multiple times a day
gratitude for care facilities
had a good time reminiscing with spouse about the good times
had a hard time adjusting to living alone
had a hard time moving into master bedroom after spouse left
had a hard time not having spouse in good pants like he liked
had all necessary safety equipment for spouse's bath
had already marked some of spouse's clothes for respite care
had bad experience with home care
had caregiving practice with his mom
had daily personal interactions with spouse
had good years and bad years with spouse
had help putting up safety equipment
had help taking care of house
had laundry mixups at facility
had lots to do to move spouse with little notice
had never been separated
had phone set up for spouse's easy use at home
had power of attorney in place before separation
had spouse assessed several times
had surgery, then more health issues
had sympathy for other caregiver husband
had to be convinced to move spouse to LTC
had to be watchful as spouse's hallucinations made her unpredictable
had to deal with police after spouse called them
had to hospitalize spouse
had to look for spouse
had to move spouse into care
had to move to a different pharmacy
had to return spouse's home equipment
had to start thinking of where spouse would be the safest
had to take the first available bed
had to tough it out
had to walk away when spouse cried
had to work with lawyers
had worked outside of her home for years
handed personal business over to sons
handling paperwork responsibilities on own
happy that spouse likes his roommate
hard coming home to empty house
hard getting spouse's clothes ready for LTCA
hard seeing spouse decline so rapidly
hard to hear spouse say he wants to die
hard to leave spouse after visits
hard to not feel guilty
hard to see other residents in worse condition
hard to take breaks, but knows it's good to do
hard to think about 2 months later
hard watching son's struggle with spouse
harder losing child than spouse
harder to skip visits when spouses still recognize IE
has 2 for 1 meal coupons
has a long history in this town
has a system with care facility workers
has been dealing with spouse's narcolepsy and cataplexy for 15 years
has been invited out for meals a few times
has been using their savings
has coffee and visits with fellow retirement community residents
has connections to lots of people in town
has gone through complexities of adjusting social life
has grandkids at her place to visit
has group of men who have experienced similar situations
has her own bills to pay
has learned how to handle stress
has learned to look after self
has learned to take some time off visiting
has lived in Canada for 60 years, but no longer speaks English
has lots of energy
has negative self-talk
has only been in one marriage
has someone who helps keep her computer running
has stepped down from being head of the family
has to accept the situation
has to deal with deaths of other family members
hasn't been very involved in social activities
hasn't eaten at home kitchen table since spouse moved
hates dementia
have an evening ritual
have to cope
have to think differently when you're old
haven't felt as supportive by daughter as hoped
having family around was the most helpful
having people around made it a bit easier
having to cope, but not being able to define how
having to do tasks on her own
health is impacted by IE's stress
heavy inevitability of spouse's deterioration
help with paperwork made transition smoother
helped around the house at daughter's
helped each other
helpful nature is deeply ingrained - consistent
helpful to have family nearby
helpfulness of care facility workers
helping in practical ways
helping other residents
helping spouse in the bathroom
helping spouse was hard
helps IE to know spouse is well taken care of
helps keep spouse calm
helps monitor spouse's health
helps raise grandkids since daughter-in-law left
helps spouse at mealtimes in LTC
her choices can be building or destructive
her family was happy to receive her gifts
her kids don't want to hear about the difficult stuff
her kids phone her
her retirement community is always transitioning too
hesitant about support groups
hid car keys from spouse
history of being independent
history of hard work
holds resident's spouse responsible for
resident's lack of containment
home care wouldn't have been enough
home is lonely despite visits
homecare assessed IE's wife
homecare educated IE on the process
homecare got husband to talk
homecare helped with paperwork
homecare prepared IE for involuntary separation
homecare told IE to place spouse
homecare worker was good
hope for the best in a tough situation
hopes activity would help spouse be more responsive
hopes her involvement improved spouse's care at facility
hopes IE never needs lift equipment herself
hopes spouse would still like other care facility programs
hoping spouse could come home
horrible watching spouse's dementia rob him of his mind
hospital and facility care workers were supportive
hospital found LTC space for spouse
humour relaxes
hurts to answer questions about spouse's wellbeing
husband didn't object to care facility
husband enjoys second facility but still wants to go home
husband fought homecare
husband hated first care facility
husband realizes he needs care
husband stayed in hospital until placed in care
husband struggled with females helping him in washroom
husband thought IE should take care of him
husband wanted to go home but IE couldn't look after him
husband was angry about being placed
husband was satisfied with placement, but knew he was failing
husband was too much for homecare
I just take about one night a ..
identifies as Christian
IE's cleaning lady helped move spouse
IE's daughter was better to second spouse than his own kids were
IE's day used to revolve around spouse's care
IE's family are in another province
IE's feelings of guilt, worry, and frustration
IE's first marriage was good
IE's first marriage was much better than her second
IE's health wasn't the best
IE's home feels empty
IE's husband and son are in the same facility
IE's kids are all retired
IE's kids are critical supports
IE's kids take care of her
IE's limited mobility limited their walking
IE's mind blanking on details
IE's parents supported current care facility
IE's son brings food
IE's son called medical personnel to ask what they should do
IE's visual impairment made her spouse's behaviour harder to manage
IE's wife got their first choice of facility
IE's years of responsibility caring for four children and mentally unstable husband
IE acted as peacemaker in family
IE admires son's care for his wife
IE agreed with daughters if they were
willing to get less inheritance
IE and daughters decided spouse needed LTC
IE and friend leave notes for each other in buddy system
IE and her husband were never apart
IE and other visitors didn't visit much with each other
IE and spouse both visually impaired
IE and spouse had full life together
IE and spouse have a long history together
IE and spouse moved into AL soon after IE broke his hip
IE and spouse would look after grandkids
IE and wife mostly kept to themselves
IE appreciated care facility staff
IE appreciates her kids treating step-dad well
IE asked family for help
IE asked for help from resident at retirement facility and was treated rudely
IE asked what she could do, but nurse looked after it for her
IE attends church
IE attends facility's weekday church events
IE battled care facility policy on medication for spouse's wellbeing
IE became the boss in the relationship
IE believing she could handle spouse's health issues
IE blown away by how much some people get from CPP
IE broke his leg before moving to retirement facility
IE brought spouse home and then he had another medical emergency
IE calls son when she gets stuck
IE can't afford more provided meals
IE can't do much for spouse
IE can't go out with longtime friend
IE can't help spouse - both are 95 ys/o
IE can't partake in costly social activities
IE can't visit spouse regularly
IE can't walk as much as she used to
IE can cope with anything
IE can only help in certain ways
IE can speak Dutch with spouse
IE cares for the safety of the care staff
IE chose to put spouse on waitlist for LTCA
IE cleans her place mostly on her own
IE comforted knowing spouse had care 24/7
IE compensating for mobility decline
IE cooked differently to accommodate spouse's limitations
IE cooks for herself
IE could calm spouse's outbursts easily and quickly
IE could have moved to AL in spouse's new facility
IE could rely on care staff to meet spouse's needs
IE could visit spouse easily in AL
IE couldn't afford to move closer to spouse
IE couldn't manage all the responsibilities
IE couldn't rest properly
IE couldn't take care of spouse
IE couldn't take him in car anymore
IE couldn't take spouse home
IE cried a lot during move
IE cried for weeks after putting wife in hospital
IE did what she had to do - accept the situation
IE didn't ask for the help she needed
IE didn't have a say in spouse's move to AL
IE didn't interact much with other visitors
IE didn't know about the variety of Parkinson’s symptoms
IE didn't like being excluded from spouse's move to AL
IE didn't recognize spouse's symptoms because of his preexisting mental issues
IE didn't recognize spouse's symptoms for a while
IE didn't sense compassion in workers at second care facility
IE didn't want to go out without wife
IE disagreed with daughters' decisions for spouse
IE does her best despite visual impairment
IE doesn't contact friend because of differing sleep/awake schedules
IE doesn't enjoy cooking anymore - joy has gone out of it
IE doesn't fit with couples or widows
IE doesn't get CPP
IE doesn't get fazed like other people
IE doesn't have to worry about spouse's well-being
IE doesn't qualify for the same assistance because doesn't need as much care
IE doesn't take much money from the government
IE doesn't want to burden her sons
IE doesn't want to cause friction in spouse's family
IE doing all driving
IE downsizing home and possessions alone
IE encouraged spouse to contact family
IE enjoys her rare visits with friend
IE excluded from activities in other area of retirement community
IE exercises
IE feels alone when going out
IE feels fortunate to have an even-tempered spouse
IE feels isolated
IE feels isolated in her experience
IE feels isolated, keeps to herself
IE feels jealous sometimes
IE feels she's been a good wife
IE feels supported by son
IE felt afraid to leave spouse alone
IE felt care staff listened to her opinion on spouse's care
IE felt care workers were lying to her
IE felt comfortable talking with doctor
IE felt comforted knowing spouse was in capable hands at facility
IE felt grateful spouse was moved to familiar care facility
IE felt guilty about putting spouse into care
IE felt isolated from her supports
IE felt like a widow for years before spouse's LTCA
IE felt lonely and didn't know what to do
IE felt overwhelmed
IE felt peace of mind after move
understood it
IE invites family over to her house
IE is 84 years old
IE is committed to her husband and their marriage
IE is grateful for family's understanding
IE is happy spouse is happy
IE is used to living frugally
IE is very independent
IE is visually impaired
IE isn't helpless
IE jokes with her family
IE keeps a sense of humour
IE keeps mind active
IE kept busy
IE kept spouse's dementia symptoms from family for several years
IE knew he was getting older
IE knew she/he couldn't keep taking care of spouse at home
IE knew something was wrong
IE knew spouse loved her
IE knows spouse is checked on regularly
IE likes her current place
IE lives in same community as husband and son
IE looked after spouse's hygiene
IE looked after yard when spouse admitted to LTC
IE looked into getting spouse into care facility
IE looking out for the grandchildren
IE looks after herself, spouse looks after himself
IE making tough decisions for spouse's care
IE misses spouse despite the difficulties
IE misses spouse even more because they had a good marriage
IE more mobile than spouse
IE moved spouse's items over gradually
IE not able to help enough
IE not confident in all aspects of care
IE not feeling fulfilled at on-site church
IE not ready for LTC
IE not very happy in her second marriage
IE noticed spouse's unusual behaviour
IE now gets home care
IE pays for one meal/day at facility cafeteria
IE picked herself up and kept going
IE prays to help get through each day
IE providing for spouse's needs in care facility
IE questioned her decision to move spouse to new facility
IE reaching out for help in the past
IE realized she didn't pay attention to spouse's symptoms for a long time
IE recognizing own limits
IE remembers exact date
IE remembers exact date spouse transferred to care facility
IE researched spouse's diagnosis
IE resenting family lack of involvement
IE responding to spouse's medical emergencies
IE risking own health as caregiver
IE second guessing his/her care decisions
IE selfishly wanted spouse at home as long as possible
IE separated spouse's mental illness behaviours from who she knew he was
IE sought advice from friend, head nurse
IE sought help for spouse
IE spends time with extended family
IE standing up to her husband for safety reasons
IE still feels overwhelmed
IE still involved in spouse's day-to-to life
IE still looks after paperwork
IE struggled with basics like eating and sleeping
IE surprised at spouse's graceful acceptance
IE takes spouse to specialist
IE talked to chaplain
IE talks to others but doesn't find their advice helpful
IE talks with doctor
IE talks with longtime friend in building
IE thanks God she can look after her home
IE the only advocate for spouse - no one else listens to dementia patient
IE thinks she and spouse are equally cared
for, him with care staff and her with taking care of herself
IE thinks spouse gets good care in LTC, but isn't sure
IE told not to help spouse for his own good
IE took care of spouse
IE took spouse for medical care
IE took spouse home
IE took spouse to hospital
IE took spouse to hospital in middle of night
IE took spouse to hospital when he started falling
IE took spouse to second doctor
IE tried to help, but made it worse
IE tries to make spouse comfortable
IE trying her best to protect spouse and seeming to fail
IE uses her insight to help care workers with spouse's care
IE walks around the courtyard
IE walks in her retirement facility
IE walks quickly - prides herself on this
IE wanted help with cooking - AL
IE wanted to support husband as best she could
IE was admitted into hospital
IE was afraid spouse would be hurt beyond what she could manage
IE was alone a lot because of spouse's former job
IE was completely exhausted
IE was grateful that her son and his wife were around
IE was heartbroken at spouse's placement situation
IE was in shock about medical separation
IE was informed abruptly that his wife needed LTC
IE was nervous how spouse would react to increased limitations
IE was persistent in insisting on spouse's care at facility
IE was raised to be helpful
IE was raised to be helpful, and still is
IE was the oldest in his group of friends at retirement facility
IE was up after spouse went to bed
IE wasn't ready for spouse to need LTC so soon
IE went to family for emotional support
IE worried about her spouse
IE worried about losing her spouse
IE worries about her children
IE worries about her son
IE wouldn't last in a condo
IE's visiting their spouses as they themselves would hope to be visited
if IE were to get sick, she'd go to the same care facility for the quality of care
imagines it will get easier with time
in good health
in hindsight, IE wouldn't have lasted
in hindsight, knows IE made the right decision
in short amount of time, spouse had heart surgery
information session location didn't work with IE's hearing loss
initially feeling lost - no longer responsible for spouse's care
initially lots of tears, but they worked it out initially, a sense of feeling lost at mealtimes without set seating arrangements
injured himself caring for spouse
insufficient support finding placement
intentionally moving where some meals can be provided
internal conflict and dialogue
investing time in their relationship
involuntary separation
involuntary separation didn't bother IE
involving family in decision
irony of spouse being active and happy while IE is home alone
is afraid
is alone
is amazed at how much spouse reads and makes plans in care facility
is bothered by old-time music because it reminds him of spouse
is financially stable
is fine with spouse being in LTC
is frequently asked when he'll downsize to a condo
is glad spouse has calmed down
is intentional about reaching out to others in similar situations
is now a widow
is now better informed about care facilities
is stressed
is well educated
isn't anti-medication, but knows they're not the easy answer
isn't content with condo coffee times as his social life
it's good to have family
it's hard to talk about missing spouse
it's hard whether spouse is angry or wanting to be close
it's still hard 2+ years later
it was hard leaving care facility after visiting
it was hard watching spouse's health deteriorate
It's a hard row
joins and listens to the groups of women at retirement facility
jokes about her age and appearance
jokes around with fellow residents at retirement facility
keeping busy helps distract and make day pass faster
keeping husband involved in paperwork
keeping routine together
keeping sidewalks clear in winter was hard
keeps busy with hobbies
keeps in touch through email
kept in touch with siblings regularly via email
kept sons out of personal business
kids are active in IE's life
kids didn't understand IE's struggle with being termed "separated"
kids don't always get along with each other
kids encouraged IE to admit spouse
kids live nearby
kids tried to support, but didn't understand her struggle
kids visited spouse in LTC
kids were involved in spouse's move
to
kind, caring, compassionate care workers
knew all about spouse's condition, but didn't expect medical separation
knew each other since childhood
knew hiring someone wouldn't be enough help
knew placement administrator for years
knew she couldn't take care of spouse
knew someone who left spouse with dementia
knew spouse's health would deteriorate eventually
knew spouse would have been difficult in the study
knew spouse would have to move eventually
knew their relationship would change after spouse's LTCA
knowing that spouse was too far gone to be helped
knows a lot of people in town
knows an injury could happen at any time
knows caregivers have to take care of themselves
knows he's fortunate financially
knows he can't do this alone
knows hospital can't give full care to all patients
knows IE will die of something eventually - feels a semblance of choice
knows most care staff are good
knows other care facilities aren't as good as spouse's
knows others are struggling financially
knows others are struggling with similar hardships
knows others have to deal with worse
knows people still care
knows she has to take care of herself
knows spouse couldn't help his behaviour
knows spouse is upset when IE leaves
knows spouse isn't a good source of accurate information
knows spouse isn't going to get better
knows spouse would leave if he could
knows there are lots of good people working
in care facilities
knows what she thinks, but struggles to
make decisions for her spouse
lack of human contact in getting paperwork
completed
last summer, took spouse to park and did
flights of steps
laughing helps
learned how to cook
learning about spouse's illness brings a sense
of stability to IE
learning cell tech to keep in touch with
family
learning new skills
learns about dementia from others
leaving old friends behind
legal separation was hard
legal separation was like adding insult to
injury
let daughters look after spouse's medical
care
letting doctor make final decision
letting go of enjoyable activities
letting herself worry would harm her health
letting herself worry would leave her a
nervous wreck
liked having spouse nearby
likes an active social life
likes gardening
likes having tasks to do
likes her retirement facility
likes on-site church services
likes on-site church services for residents
likes retirement facility's guest rooms
likes that spouse still has music
likes to be frugal
likes to dance
likes to get her tasks done on her days off
likes to see spouse
likes working with his hands
liking the facility
limited access to spouse because of
transportation
listened to sons' suggestions
listens to the music
little family support structure

little opportunity for spouse to be active
lived in same house for 47 years
lived together in retirement area for short
amount of time
lives cheaply at home
lives one day at a time
living geographically far from family is hard
living in retirement community didn't help
after husband lost mobility
long ago, had no support with spouse's
mental health problems
longtime friend only goes out with family
looked after spouse for a year after IE's own
health scare
looking after her house by herself is a
challenge
looking for a cheaper care facility for spouse
looking for LTC placement was a nightmare
looking forward to time with son
looks forward to spending time with spouse
losing daughter-in-law was very hard
lost contact with friends and acquaintances
lost several family members prior to moving
to retirement community
lots of paperwork to do on short notice
lots of people asking IE how spouse was
injured in care facility
low expectations of son-in-law on farm
LTC to IE is no privacy, no mobility, and
needing lots of help
made a chart of tv shows for people with
dementia
made bad decisions because IE was
preoccupied
made decision to move spouse
made one very supportive friend (fellow
visitor) at care facility
made several trips between home and care
facility
maintains some independence
making a life for herself
making decisions after care facility closed
making decisions like change of address for
spouse
making effort to be closer to family
making financial arrangements
CONNECTION

making sacrifices for govt assistance
making the best of the situation
making tough decisions on her own
married 56 years
married 56 years. it was her and I.
moved quickly to retirement facility
married 59 years
married 62 years
married 64 years
married almost 39 years, married later
may not visit daily in winter
medical separation felt like invalidation of their marriage
medical separation was devastating
medical separation was like a bomb dropped
mental separation between them because of spouse's dementia
met a man who took care of spouse with Alzheimer's for six years
might not see spouse daily if spouse stops recognizing IE
missed feeling welcomed during move to care facility
missed making meals for spouse
missed talking with spouse
misses her sister
misses out on some conversations because of hearing loss
misses out on some music elements because of hearing loss
misses spending time as a couple
misses spouse
misses spouse terribly
missing taking care of house and a yard
moving amid health complications
more difficult finding a spot in dementia units
more women than men at retirement community
most fellow visitors at care facility didn't make much effort to be friendly
most people didn't visit their loved ones during lunchtime
most people have family support
most residents have been kind to IE at retirement facility
moving around
moving to LTC quickly
moved spouse to LTC quickly
moved spouse to more appropriate level of care
moved to current town to be closer to daughter
moved with spouse to retirement facility
moving closer to their kids
moving from home to LTC
moving from one care home/town to another
moving spouse into care was life-changing
moving spouse into new care facility was difficult
moving spouse into new care facility was unsettling
moving spouse to a different care facility was another nightmare
moving spouse to care was easy
moving spouse was hard because he wasn't coming home
moving spouse was hardest decision IE ever made
moving spouse where he would get good care
moving to LTC would quickly make IE helpless
mutual support between IE and son who lost his wife
My home from another home, my ..
necessity of being parted
needed distance from spouse to sleep
needed help at night at home
needing to reprioritize to spend time with spouse
needs to get away when feeling overwhelmed
neighbours helped shovel sidewalks for her
never voiced her complaints about the unhealthy food
new place would cost more
new responsibilities like car maintenance or changing light bulbs
niece contacted nursing home
niece helped look for affordable placement
no family that could help
no one could have made the move easier
not a couple, not a widow
not always happy with care workers' treatment of spouse
not always happy with the food
not attending on-site church service
not being burden on IE
not enjoying being separated from spouse
not enough places for people with dementia
not feeling connected to kids in certain issues
not feeling like partners
not feeling supported
not finding space at nursing homes
not fun being visually impaired but IE manages
not getting tasks done quickly
not given much notice to decide
not happy with home care's management
not impressed with unhealthy food at care facility
not prepared for spouse to move to LTC
not proud of how he acted
not used to the amount of sunshine in new province
not welcome on family holiday
nothing to complain about at spouse's facility
numerous retirement facility residents go walking in the same area
nurse behaved insensitively toward IE
nurse called 2 days later with room for spouse
nurse checked on IE once a month at his home
nurse comes around sometimes to check IE's BP
nurse from Alzheimer Society interceded for spouse's health
nurse tried to have spouse moved out of town to mental facility
nursing home called IE
often told to visit spouse less frequently
on-site church service feels overwhelming for IE
on-site church services were too early for IE
on a recent bad day, IE felt purposeless
Once you can’t join into every..
one friend phoned faithfully
one son is supportive
optimistic outlook turns devastating
other care facility has activities spouse could do
other care facility is more of a home-like setting
other care facility would be cheaper
other care facility would be good for spouse
other parts of retirement community have activities
other residents enjoy music
other residents show appreciation
other residents were disturbing for IE
other son visits too
others tell him to take more initiative
others tell IE not to visit spouse so often
over Christmas, kids saw how tired IE was
overwhelming stress put IE in hospital
paces herself so she can make her walking distance goal
paramedics said spouse wouldn't be coming home anymore
parking mishap on day of spouse's admission
participated in activities when spouse was mobile
paying double for housing
paying for own medication
paying lots for respite
people were insensitive in what they said
phones a friend to take IE shopping
physical relationship hasn't changed
physician called IE to tell her to bring spouse in for hospital admittance
physician comes to care facility to check on spouse
physician confirmed spouse's need for LTC
physician decided spouse needed to be assessed for LTC
physician validated IE’s frustration with care workers’ evasiveness
physician was proactive in getting spouse help
picked spouse up after she ran away from hospital
picked up each other’s slack when needed
picky about who he spends time with
places responsibility of spouse on his children
planning ahead
planning in case IE can’t look after basic responsibilities
post-LTCA, hasn't gotten easier
praying that spouse's situation will go well
prays to stay healthy
prided himself on caring for his family
prioritized time with family
prioritizing family
private care facility had room first
professionals helped facilitate spouse's move
protective of spouse
public perception that IE wasn't active in spouse's life after LTCA
pulled spouse out of dementia study
pushing forward
put off separation
putting on music sometimes helps
putting spouse in care is different than putting parent in care
questioned his decision for months
questioned if being closer to family would help spouse
questioned if they should move back to hometown
questioning why
quotes movie saying cooking isn't as hard as grocery shopping
reaching out for connection via phone
read up on spouse's dementia prognosis
reads more than ever before
realized how much IE was compensating for spouse
realizes most older people struggle with modern technology
recalls family members who lived a long time with dementia
received some mixed messages from care facilities that was disappointing
receiving special help from care facility recognizes financial reasons for medical separation
recognizes that daughter is busy too
recognizes that nurses have lots of patients to care for
recognizes that the facility has lots of laundry to look after
recognizing IE's depression helps IE get through it
recognizing limits of on-site church
recurring emergencies that progressively weakened spouse
reevaluating priorities
reflecting fondly on good-natured spouse
refused commitment during war
regret at downsizing alone
regrets how he treated spouse as caregiver relies on friends to help
relocated to be closer to daughter after wife's diagnosis
remembers spouse's great sense of humour
remembers the locked door of assessment unit
reported difficult nurse to head nurse
reprimanded for not hiding car keys from spouse
request for equipment wasn't fulfilled
requested equipment for spouse
resentment for having to downsize alone
resentment for having to make decisions alone
resistant to preparing for spouse to die
respects that others might have handled it differently
respite care workers got home care involved
responsibilities pushed on her last-minute
responsible for all decisions
responsible for all decisions before spouse's move
retirement community is close-knit - like
family

retirement community residents are nice to IE

retirement facility has various activities

retirement facility isn't perfect, but feels like home to IE

retirement facility worker comes when IE doesn't feel well

retirement facility worker sends meal to IE's room when she doesn't go down for supper

retirement facility workers kept spouse nearby as long as they could

retirement facility workers told IE's daughters that spouse needed more care

rushed move to current town

sad to think about spouse having no one

sad to watch spouse's mind go downhill

saddening to watch spouse lose basic mental abilities

sadness at spouse's mental loss

sat in car and cried after visiting spouse

saw risk to spouse's help through pilot alarm system study

saw son and spouse have good rapport

saw the financial benefit of involuntary separation

says men are different than women

scheduling time to talk

second spouse didn't pay attention to IE or her kids

second spouse wanted to move to retirement community

second spouse wasn't kind to IE

seeing friend develop health problems

seeing husband's unhappiness with faulty equipment

seeing husband's unhappiness with some equipment

seeing needs of others and trying to meet them

seeing other residents in worse condition

seeing poorer quality of care

seeing spouse's gradual decline

seeing spouse's health deteriorate

seeing spouse get good care made the move easier for IE

seeing temporary relief

seeing the animals lightens the weight

seems confused about spouse's deviation from typical Alzheimer's progression

sees brother-in-law's decline since moving to condo

sees guilt as unavoidable as the caregiver

sees her grandkids having fun

sees his friend in condo is lonely surrounded by people

sees spouse sometimes

sees that daughter's aloofness bothers spouse

sense of feeling lost

sense of feeling overwhelmed

sense of feeling powerless

sense of feeling unprepared, destabilized

sense of finality

sense of guilt

sense of helplessness

sense of helplessness conflicting with autonomy

sense of hope that a familiar place would bring back some of spouse's mental functioning

sense of not knowing what to do

sense of pride for daughters

sense of pride for grandkids

sense of pride in spouse's strong will to live

sense of relief that care workers aren't bothered by spouse speaking only Dutch

sense of sadness over spouse losing wedding rings

sense of sadness that spouse doesn't remember their life together

sense of unfairness

separation paperwork done at hospital

serious consecutive stressors

serious consecutive stressors before IE's hospitalization

shifting of role from wife into caregiver

shocked that spouse needed to stay on assessment unit for weeks

siblings encouraged IE to admit spouse to LTC

similar experiences among retirement community residents
sister has family to get back to
sister helped IE during transition
sister lives in England
sister stayed with IE for a month
sister was bothered by involuntary
separation from her husband, but IE wasn't
sits at table only with company
sitting in existential uncertainty
sleep helps IE feel better, but doesn't often
sleep well
sleeps better if he's physically active
sleeps better now
slept apart
slowly making new connections in current
town
So I look after both
social death
social death - can't socialize with couple
friends anymore
social peers judged decision to place spouse
social worker explained involuntary
separation
socially alienating having spouse in LTC
sold house
sold house in previous town after 51 years
sold house quickly
some care workers stood out as excellent
some days enjoys spending time with spouse
Some days it just gets to you
some friends stuck with them, others didn't
some people like to complain
sometimes brings spouse home
sometimes doubts spouse's diagnosis
sometimes the loneliness feels hopeless
somewhat shrugs difficulty off as part of life
son's arrival relieved some of the stress
son's strong resistance to parents'
 involuntary separation
son's struggle with medical separation was
very difficult for IE
son's visits help IE with feelings of
loneliness
son-in-law did better than expected
son-in-law farming through more changes
son-in-law found place for IE and spouse
son-in-law saw IE's responsibilities were too
much
son asks about IE's needs
son calls IE every night
son comes to on-site family events
son doesn't visit spouse on-site
son has good rapport with spouse
son helped move spouse
son helps IE
son is grieving his wife's death
son jokes with IE
son moved to nearby town
son phones spouse regularly
son supported IE in dispute with daughter
son took care of wife at home
son took husband to the hospital
son took over finances
son visits frequently
son visits from out of town
sons are too far away to help with day-to-
day tasks
sons attune to IE's emotional state
sons call multiple times a day to check on
her
sons have different skills
sons were emotionally supportive but
geographically distant
sought information and advice
speaks from the heart with researcher
speaks to spouse in English but he doesn't
respond
specific care worker made it easier for IE to
go home
spending many years together
spending time in care facility is discouraging
spending time with family
spending time with family helps the
loneliness
spending time with spouse helps IE feel
useful
spends lots of time with spouse
spends time with spouse
spent 4 days sitting in chairs because spouse
couldn't lay down
spent a lot of time alone before spouse's
move
spent lots of time together
spent time with other men in similar situation
spoke to nurses about spouse's overmedications
spouse's behaviour was disturbing for IE
spouse's behaviour was unpredictable for years because of mental illness
spouse's care is cheaper because of government assistance
spouse's care is very costly
spouse's continual health decline until he died
spouse's death was a difficult adjustment
spouse's decline happened faster than expected
spouse's decline has been relatively slow
spouse's declining abilities
spouse's declining mobility
spouse's deteriorating health
spouse's diagnosis prior to LTCA was wrong
spouse's difficulty adjusting to declining mobility
spouse's doctor is easily accessible
spouse's family isn't close like IE's
spouse's form of dementia is rampant throughout his family
Spouse's frightening injury
spouse's frustration at being in LTC
spouse's functioning was unpredictable
spouse's gratitude helps IE
spouse's health improved in LTC
spouse's history of mental illness has always impacted their social life
spouse's illness began 3.5 yrs earlier
spouse's illness presented with symptoms that were unexpected
spouse's illness was initially misdiagnosed
spouse's kids moved him to LTC
spouse's lack of good care adds to IE's emotional burden
spouse's living at home was hard for IE
spouse's loss of cognitive function
spouse's lungs filling with fluid
spouse's mental function has decreased rapidly since LTCA
spouse's move put extra strain on IE's finances
spouse's move to LTC wasn't hard
spouse's needs are taken care of
spouse's needs increased
spouse's nocturnal behaviour disturbed IE
spouse's rapid decline could be related to his medication
spouse's room wasn't big enough for comfort
spouse's roommate was rude
spouse's serious injury
spouse's son checks on him ~once a month
spouse's son looks after spouse
spouse's symptoms got too severe to hide
spouse's treatment not fair
spouse's treatment was tiring for spouse
spouse's unpredictable longevity
spouse's walking ability decreasing
spouse 3 yrs in AL, 2 years in LTC
spouse accepting move made it easier on IE
spouse accused IE of being disloyal
spouse acted strangely at night
spouse admitted into LTC one year ago
spouse admitted to hospital's assessment unit at Christmas
spouse admitted to LTC but IE took her back home after 1 month
spouse alienated family members
spouse asks IE to stay
spouse asks to go back to family's old grocery store
spouse asks to go home to boyhood town in Holland
spouse attended on-site church services
spouse back in hospital
spouse became difficult to work with
spouse behaved strangely
spouse behaving strangely, IE querying it
spouse bothered by fellow residents
spouse can't have a phone
spouse can't read or work stereo
spouse cooperated better at respite care than at home
spouse could get physician care on-site
spouse couldn't do anything without help
spouse couldn't do basic home maintenance
CONNECTION

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Tasks

Spouse couldn't do basic hygiene tasks
Spouse couldn't eat properly
Spouse couldn't speak, but still understood IE
Spouse couldn't use a phone
Spouse decided to move to assisted living
Spouse diagnosed with dementia
Spouse didn't do well sharing a room
Spouse didn't exercise with IE
Spouse didn't have after-effects from his stroke
Spouse didn't need a lot of help before AL
Spouse didn't visit IE unless he needed something
Spouse doesn't call IE by name
Spouse doesn't complain
Spouse doesn't get enough exercise in care
Spouse doesn't hallucinate as much as she used to
Spouse doesn't have good short-term memory
Spouse doesn't help IE
Spouse doesn't help IE financially
Spouse doesn't help much with IE's finances
Spouse doesn't recognize family
Spouse doesn't recognize her - she visits
Spouse because she wants to
Spouse doesn't recognize own house
Spouse doesn't talk about their shared home
Spouse doesn't talk much with IE
Spouse doesn't want her life prolonged at end
Spouse doesn't worry
Spouse doing chores and caught on fire
Spouse easily got new doctor
Spouse enjoys animals
Spouse enjoys music at care facility
Spouse enjoys young people
Spouse falling at home
Spouse falling down in public
Spouse fell at home and they thought it was nothing serious
Spouse fell in public places while doing day-to-day activities
Spouse fell multiple times while in hospital

Spouse felt unwell, IE responded to all his requests
Spouse fought tooth and nail in the assessment unit
Spouse gained a lot of weight at care facility
Spouse gets care he needs
Spouse gets care he needs 24/7
Spouse gets government funding
Spouse gets more food than he needs
Spouse getting better care at care facility
Spouse getting up numerous times at night
Spouse given dementia diagnosis shortly before LTCA
Spouse got diagnosed with COPD
Spouse had a few regular visitors
Spouse had a long history of mental health problems
Spouse had been offered a room earlier but IE couldn't do it
Spouse had had numerous medical emergencies
Spouse had medical emergency within hours of coming home
Spouse had multiple health issues
Spouse had prostate surgery, non-cancerous
Spouse had symptoms long before diagnosis
Spouse had to leave hospital and was admitted to LTC
Spouse has a nice room at LTC
Spouse has adjusted to LTC
Spouse has already been to day program at other facility
Spouse has been in hospital for 1 month
Spouse has been in LTC/at hospital for more than a year
Spouse has dementia
Spouse has furniture and space for what he needs
Spouse has good bone density
Spouse has mostly adapted
Spouse has narcolepsy, cataplexy
Spouse has some family nearby
Spouse has struggles with mental health
Spouse has to cope in LTC without IE
Spouse hasn't completely adjusted to LTC
Spouse having a heart attack
spouse in care facility 5 months before dying
spouse in hospital for a long time for treatment
spouse in hospital for one month before LTC
spouse in LTC for 2 months - has gone downhill fast
spouse in respite care
spouse initially living in higher care than needed
spouse injured by another resident
spouse injured himself in AL
spouse injured in a fall
spouse injured while in care facility
spouse is afraid IE is abandoning them
spouse is around people all the time
spouse is constantly on IE's mind
spouse is happy to see her, sad when she leaves
spouse is happy to see IE
spouse is hearing impaired
spouse is helpless now
spouse is involved in activities at care facility
spouse is out of town, IE still at retirement facility
spouse is physically healthy but his mind is gone
spouse is protective of IE
spouse is special to IE
spouse is still very nearby - in same building
spouse is very attentive to money
spouse isn't active in care facility
spouse isn't content with separation
spouse kind of understands IE can't stay constantly
spouse knew he going to be cared for
spouse knew IE couldn't take care of him anymore
spouse less active at care facility
spouse liked good pants
spouse liked the day program
spouse lives in his boyhood past in Holland
spouse living in a hellhole
spouse living with residents with more advanced illnesses

spouse looked after IE during IE's cancer
spouse looking unwell
spouse loved cooking
spouse loved sitting outside at home
spouse loved to dance
spouse loved walking
spouse loves music
spouse loves to sing
spouse may need higher level of care eventually
spouse may not like LTC, but he has to cope with it
spouse missed freedom of motorized wheelchair
spouse mixes up their kids
spouse mostly took care of himself before going to AL
spouse moved to AL next to IE
spouse moved to LTC about 6 months ago
spouse moved to LTC two years ago
spouse moved to same facility as other family members
spouse nearly immobile when moved
spouse needed care 24/7
spouse needed care for 10 years
spouse needed constant supervision
spouse needed help for a while
spouse needed help sooner than IE
spouse needing help for several years
spouse needs help eating
spouse needs to adjust to IE visiting less often
spouse never broke any bones
spouse not cooperating well
spouse not safe in care facility
spouse paid extra for AL
spouse received good care
Spouse recovering at home, then returning to work
spouse refusing medical care
spouse resenting IE
spouse retains some sense of humour
spouse saved money
spouse says IE moved spouse into care to wait for her to die
spouse seen by on-site doctor
spouse sees on-site physician - much less work for IE
spouse shovelling snow
spouse sometimes cries when IE visits
spouse speaks only in his first language (Dutch)
spouse spent time with grandkids
spouse stayed in hospital
spouse still does tasks when home during the day, though not always well
spouse still has good cognitive function
spouse still knows daughters
spouse still knows who IE is
spouse still mentally sharp in some ways
spouse stopped cooking
spouse stopped doing his exercises
spouse suddenly rolling on ground
spouse suddenly stopped asking for walks
spouse surrounded by family in care
spouse temporarily regained mobility
spouse told IE not to visit anymore
spouse understands some English
spouse upset by home care worker
spouse used to enjoy hobbies at home
spouse used to get lost walking around their retirement complex
spouse used to hug IE during visits
spouse used to put music on all the time
spouse used to take care of their home
spouse very weak when they moved him
spouse walked with walker and IE's help
spouse walks IE to the bus every night
spouse was 13 years IE's senior
spouse was a fussy eater at home, but not at care facility
spouse was a good conversationalist
spouse was active at home
spouse was brought to on-site church service until shortly before he died
spouse was calm
spouse was confrontational
spouse was confrontational for many years
spouse was considerate of IE
spouse was content in his room
spouse was demanding of IE
spouse was difficult to care for
spouse was happier after IE got him off so many pills
spouse was heading to LTC until IE stopped it
spouse was her daily focus
spouse was loving and kind
spouse was often upset and lashing out in care facility
spouse was on lots of medications
spouse was placed outside of town
spouse was quickly moved to another facility
spouse was strong-willed
spouse was stubborn with IE
spouse was up all hours
spouse was very active at home
spouse was very assertive
spouse was very smart
spouse wasn't bothered by bruise from fall
spouse weakening from multiple factors
spouse went from hospital to respite care
spouse went in ambulance, never returned
spouse will have no one if IE gets very sick
spouse worked with father
spouse worries about IE
spouse worries about IE living alone
spouse would wander away from home
stands out that her son was so good to his wife
stands up to care workers for what IE wants
stayed close by spouse
stayed with daughter when first moved to current town
staying with spouse all the time would be counter-intuitive
stays active
stays up late reading
still adjusting to separation
still enjoying physical relationship
still getting used to spouse being gone
still got a big smile from wife when he got back from vacation
still hard one year later
still went to care facility after spouse died
still wonders about possible consequences of medical separation though spouse has since
died
stood up for her and spouse's privacy
stood up for spouse in hospital
stopped going to church after spouse fell 8x in 2yrs
strain on relationship roles
stress adds to health issues
stressed by paperwork
stresses advocating for wellbeing of loved ones in care
stresses importance of visiting spouse regularly
struggled in marriage because of spouse's mental illness
struggled to let care workers take care of spouse
struggled to make sense of his role as spouse and caregiver
struggled with chores
struggled with looking after their car
struggled with short notice of spouse's move
struggled with some elements of spouse's care
struggles paying for two places
struggles seeing spouse upset
struggles sometimes with feeling spouse not getting proper care
struggles to describe perception as wife
struggles to manage her worries
struggles to understand how spouse could forget English
struggles with dry climate in new province
struggles with hearing loss
struggles with modern technology
struggles with whether or not to move spouse to other care facility
struggling to adjust to new independence, new responsibilities
struggling to make sense of life and death
struggling to make sense of suffering
struggling to take care of spouse
suddenly responsible for all household tasks
support smoothed the transition
supportive caregiver peers
surprised by spouse's illness
surrounded by people with declining mobility at on-site church service
suspecting that advocating for change with loved one doesn't positively impact other residents
suspecting that residents without an advocate don't get the best care
suspects her kids called physician
suspects she'll eventually visit spouse less often
takes breaks from visiting
takes care of her basic needs
takes care of herself because no one else will
takes care of his yard
takes care of house on own
takes comfort knowing the care staff find spouse easy to take care of
takes spouse around town
takes spouse out for coffee
takes spouse out for lunch
takes spouse out to visit family
takes spouse to watch animals
takes spouse upstairs to LTC for night
takes the bus
taking breaks from spouse's frustration
taking care of spouse's needs at home
taking charge of their walks together
taking it one day at a time
taking over finances
taking spouse to hospital for injury
talked in advance about end-of-life wishes
talking on phone a lot
talking on phone with daughter
talking on phone with son
talking on phone with spouse and sons helps get through each day
talking openly about the separation was therapeutic still
talking with dog was very helpful
talking with friends regularly on phone
talking with kids
talking with men is a good distraction from what he feels
talking with others in similar situations helped
talking with social worker
talks about grandkids growing up quickly
tells friend to take more time for self
taxi companies wouldn't tell IE they picked up spouse
tears IE apart to leave spouse
tells friend to take more time for self
thankful homecare had a male worker
thankful she can still have meaningful visits with spouse
thankful spouse didn't realize he was in a secured unit
thankful spouse had his own room
thankful transition didn't happen in winter
thanks God for her health and for her kids' help
thanks God for their years together
thanks God for what vision she has left
thanks God that grandkids are good students
thanks God that IE's kids help so much
the care staff rotate between areas
the finality of moving spouse to LTC
the good days and bad days feel unpredictable
the pain is still fresh
they have no kids
they were on their own before spouse moved to AL
thinks care staff do a great job
thinks separation is different for husband caregiver
thinks she would be too sympathetic working in a care facility
thinks spouse's overmedication damaged his kidneys
thinks spouse likes his LTC facility
thinks the move was a big shock to spouse - led to rapid deterioration of mind and body
thinks there must be a better way than medical separation
though her caregiving changed, identity as wife didn't
thought spouse's unusual behaviour were from preexisting health issue
thought spouse would be coming back home time with spouse is difficult
timing of paperwork was overwhelming
timing of spouse's LTCA was out of IE's hands
told families what was happening with spouse
took a vacation this year
took care of all their finances for years
took care of business as a couple
took care of wife at home for 20 years
took dog for walks
took spouse a month or two to adjust to LTC
took spouse on brief trips but they were terrible
took spouse on errands
took spouse to eye doctor
took spouse to hospital in middle of night
took time for IE to learn to be more patient with care workers
took time to feel like care workers accepted her input
transitioning in summer - people IE needs to talk to are on holidays
travelled to watch grandsons play lacrosse
treasures the good memories
treasures time with spouse
treasuring times of humour with husband and staff
tried to prepare spouse for move instead of thinking about self
tries new ways to spend time with spouse
tries to engage with spouse
tries to help friend financially
tries to keep busy
tries to make spouse's room feel like home
tries to reconnect with daughter now and then
tries to shrug off the pain
tries to take spouse away from other residents
tries to walk with spouse, but IE is physically limited
troubled by what spouse said sometimes
trying to accept family's need for boundaries
trying to figure out a way to bring spouse back home
trying to get more pension
trying to take more time for self
turns on spouse's favourite music for him
uncomfortable spending time with friends
when spouse is around
understanding spouse's medications and his medical situation
understands the need for the equipment, but wishes it was better
understands the nurses can't control behaviour of residents all the time
unhappy with spouse's location
updated house for resale value
upset at home care worker's treatment of spouse
used to dance with spouse
used to dealing with tough situations
uses a computer regularly
uses care facility's wood room
uses the retirement facility guest rooms for visitors
values people trying to understand her experience
values the empathy from women and the distraction from men
verbalizes that they're not bad for taking holidays
very glad to have easy access to spouse in care facility
very hard for IE when spouse was moved
very thankful for friends to help with husband's placement
Veteran's came to check on spouse's status
Veteran's stopped paying for spouse's medication
view of being a wife shifted
visited spouse every day
visited spouse regularly when he was nearby
visiting care facility after spouse's death, care workers give IE hugs
visiting spouse
visiting spouse helps fill her days
visiting spouse is hard
visits spouse every day
visits spouse multiple times a day
visits spouse regularly
visits with fellow resident and his in-community wife every night
visits with fellow residents at retirement facility
volunteers for the social interaction
waited a long time for spouse to be placed
waiting for space at other care facility
waiting until the next boot drops
walker helps IE not be scared of falling while walking
walking out of house taking spouse to LTC was incredibly hard
walking to church on nice days
walking together at a beautiful location
walking together for spouse's health
walking together on a beautiful day
walking together regularly
walks carefully so she doesn't fall
walks every day
walks over to spouse's multiple times a day
wanting access to church service
wanting family-oriented on-site church services
wanting someone to help in practical ways with paperwork
wants the struggle to be over - tired of feeling overwhelmed and like a burden
wants to clean up spouse's stuff because he's never coming back
wants to die before reaching 100
wants to move to same facility as spouse
wants to spend time with spouse
was able to look forward to his trip
was afraid for spouse's safety
was afraid leaving would make spouse angrier
was angry at medical separation
was determined to care for spouse longer than IE should have
was distracted on day of spouse's LTCA
was easier to walk with spouse when he was at home
was forced to be medically separated
was gone for two weeks
was hard to let go of looking after spouse's health
was helped by the professionals' help and
advice
was helped with paperwork
was helped with paperwork for involuntary separation
was in denial about spouse's condition
was invited to casual support group but never went
was planning to move already before he broke his leg
was right about spouse being overmedicated
was stubborn about resisting medical separation
was the only one who could see what was happening with spouse
was the only one who knew how to handle spouse's symptoms
was told he shouldn't bring spouse back home
was told to bring scrub-like pants for spouse
was told to stop risking her own health caring for spouse
was told to take a break from visiting spouse
was too close to recognize spouse's decline
wasn't active in retirement community during separation
wasn't allowed to take spouse to LTC
wasn't as comfortable with female homecare worker
wasn't getting any sleep when spouse at home
wasn't hard to adjust to being alone after spouse's move
wasn't offered any help to move spouse from hospital to care
wasn't prepared for financial complications
wasn't prepared for separation
wasn't ready to move to LTC with him
wasn't used to being a caregiver
watched video about typical prognosis for Alzheimer's
caring for spouse
wishes she couldn't speak without crying
wishes she had been warned how difficult it would be to see other residents in worse condition
wishes she/he had been warned how hard the shift would be
wishes someone could live in his shoes and come back and explain what's happening
wishes someone had gently prepared IE
wishes someone would invent better equipment
wishes spouse's attitude would have shifted years ago
wishes spouse weren't in hospital

we have to be strong for them
We’re high maintenance
got back to bed and accepted that spouse wasn't coming home
got on a trip alone
got on a trip to visit their families
got to daughter's every day
got to meeting at Alzheimer Society
when spouse got to need help, his kids put him in AL
when spouse was moved to LTC, IE was used to being alone
wintertime made moving spouse more complicated
wishes care facility had palliative room
wishes for more family-oriented events
wishes he had read about spouse's condition sooner
wishes IE had known more about spouse's disease sooner
wishes IE had the energy to advocate against overmedicating seniors
wishes IE knew more about spouse's condition
wishes independent living area had organized events like assisted living and congregate
wishes Alzheimer's symptoms
wishes people would treat IE normally
wishes she could speak without crying
wishes she had been warned how difficult it would be to see other residents in worse condition
wishes she/he had been warned how hard the shift would be
wishes someone could live in his shoes and come back and explain what's happening
wishes someone had gently prepared IE
wishes someone would invent better equipment
wishes spouse's attitude would have shifted years ago
wishes spouse weren't in hospital
wishes there were better equipment  
wishes there were casual opportunities for activities  
wishes there were more male nurses  
wishes there were younger people at on-site church service  
wishing the situation was different  
with spouse's care cost, will be less money for daughters' inheritance  
with time, accepted situation  
with time, feels less overwhelming  
wonders about care workers' legal liability if spouse was harmed before LTCA  
wonders about the legal ramifications of medical separation in medical decision-making  
wonders if care workers felt responsible for spouse's safety  
wonders if God hastened spouse's rapid decline  
wonders if his perceptions of spouse's care are accurate  
wonders if IE will need LTC eventually too  
wonders if putting spouse in LTC led to his rapid decline  
wonders if spouse's dementia is harder on her than on him  
wonders if spouse gave up  
word of spouse's condition spread quickly  
worked through doubts  
worked to keep spouse home  
worked with seniors when her kids were young  
workers at first care facility were supportive  
workers avoided spouse during his disturbed outbursts  
working out details in short amount of time  
working through recurring conflicting emotions  
worried about family and friends' support  
worried about spouse's adjustment  
worried about spouse's adjustment to LTC  
worried more about spouse's adjustment than IE's  
worried other resident will harm someone  
worries about spouse if she doesn't see him regularly  
worries about what would happen to spouse if something happened to IE  
would feel better if spouse was in other care facility  
would have had immediate surgery if not for eating first  
would help in any way IE could if someone else going through similar situation  
would prefer life to look different, but takes it as it comes  
wouldn't have known what to do on his own  
wouldn't wish her experience of separation on anyone  
wrote a log of her visits  
years ago, decided spouse needed to be home more for raising a family  
years ago, spouse used to be gone a lot for work  
younger generation not always willing to help
APPENDIX J: 28 Focused Codes (Categories) with Initial Codes

**Code Family: Activities - keeping busy**
Codes (89):  
[a sense of purposelessness after spouse's death]  [activity helps relieve stress]  
[attended social activity at retirement facility once]  [attending church services]  [baking seems pointless]  
[caring for spouse gave IE something to do]  [church programs start up after summer]  
[cooks with minimal effort]  [days are long]  [did what she had to to care for spouse]  
[doesn't mind taking care of their home]  [distracts self so doesn't think about emotional struggle]  
[distracts self with TV during mealtimes]  [doesn't always get all her day-to-day home and yard tasks done]  
[doesn't dance anymore because it feels disloyal to spouse]  [doesn't enjoy cooking anymore]  
[doesn't feel active, but walks regularly]  [doesn't have time to think]  [doesn't put effort into cooking anymore]  
[doesn't think about things too much]  [doesn't want to put the effort into learning computers]  
[enjoys music but finds it overwhelming to choose what album to play]  
[enjoys music programs at retirement facility]  [exercises at care facility]  
[feeling pressure to complete tasks in timely manner]  [feels like he's killing time]  
[finding refreshment away from care facility environment]  [going for coffee by herself]  
[going to church away from care facility environment]  [going to church off-site]  
[going to on-site special events]  [going to Sunday church off-site]  [has lots of energy]  
[helped around the house at daughter's]  [IE attends church]  
[IE attends facility's weekday church events]  [IE cooks for herself]  
[IE keeps busy with hobbies]  [learning how to cook]  
[letting go of enjoyable activities]  [likes gardening]  [likes having tasks to do]  
[likes to dance]  [likes to get her tasks done on her days off]  [likes working with his hands]  
[looks after her house by herself is a challenge]  [made a chart of tv shows for people with dementia]  
[missed making meals for spouse]  [missing taking care of house and a yard]  
[not attending on-site church service]  [not getting tasks done quickly]  
[on-site church service feels overwhelming for IE]  
[on-site church services were too early for IE]  
[paces herself so she can make her walking distance goal]  
[quotes movie saying cooking isn't as hard as grocery shopping]  
[reads more than ever before]  [recognizing limits of on-site church]  
[retirement facility has various activities]  [seeing the animals lightens the weight]  
[sleeps better if he's physically active]  [spouse was her daily focus]  [stays active]  
[stays up late reading]  [takes care of his yard]  
[tries to keep busy]  [used to dance with spouse]  
[visiting spouse helps fill her days]  [walking to church on nice days]  
[walks carefully so she doesn't fall]  [walks every day]  [wanting access to church service]  
[was easier to walk with spouse when he was at home]  [was gone for two weeks]  
[watches tv alone or with someone]  [went on a trip alone]  [wishes for more family-oriented events]  
[wishes there were casual opportunities for activities]  

Quotation(s): 121

**Code Family: Adjusting**
Codes (100):  
[a sense of feeling in limbo]  [a sense of feeling life is unstable]  
[after 2 months since LTCA, the pain is still fresh]  [caretaking role, not partners]  
[changed entire lifestyle because of move]  [couldn't believe spouse wasn't home]  
[dealing with spouse's mental illness]
Connection was worse than LTCA) [didn't feel welcomed at new care facility] [didn't get sad when spouse moved to LTC] [didn't want to be the boss, but had to be] [does everything himself now] [doesn't put effort into cooking anymore] [doesn't sleep well anymore] [doing tasks at home made her too tired to visit spouse] [doing the tasks of two people] [doing things alone but not liking it] [emotional pain and heaviness still present below surface 2+ years after LTCA] [feeling stuck with obligations] [feeling unsettled] [feels sense of value in her unique role in spouse's care] [felt comforted knowing spouse knew she would be there everyday] [felt more equipped than others to pick up her new responsibilities] [felt sorry for spouse and self] [figures IE will get used to sitting at table alone eventually] [first six months after LTCA were a difficult adjustment] [first six months after LTCA were a nightmare] [focus on what's best for spouse] [God gave IE strength to get through spouse's LTCA] [God played an active role in getting her through the difficulties] [had a hard time adjusting to living alone] [had to move to a different pharmacy] [had to return spouse's home equipment] [had to take the first available bed] [has learned to look after self] [hasn't eaten at home kitchen table since spouse moved] [having to do tasks on her own] [history of being independent] [identifies as Christian] [IE's day used to revolve around spouse's care] [IE's home feels empty] [IE's husband and son are in the same facility] [IE cried for weeks after putting wife in hospital] [IE downsizing home and possessions alone] [IE felt like a widow for years before spouse's LTCA] [IE has his own issues] [IE is very independent] [IE lives in same community as husband and son] [IE misses spouse even more because they had a good marriage] [IE pays for one meal/day at facility cafeteria] [IE prays to help get through each day] [IE thinks she and spouse are equally cared for, him with care staff and her with taking care of herself] [initially lots of tears, but they worked it out] [is fine with spouse being in LTC] [it's still hard 2+ years later] [knew their relationship would change after spouse's LTCA] [learning new skills] [liked having spouse nearby] [LTC to IE is no privacy, no mobility, and needing lots of help] [making a life for herself] [moving spouse into care was life-changing] [new responsibilities like car maintenance or changing light bulbs] [no one could have made the move easier] [not feeling like partners] [not prepared for spouse to move to LTC] [not used to the amount of sunshine in new province] [post-LTCA, hasn't gotten easier] [realized how much IE was compensating for spouse] [reevaluating priorities] [shifting of role from wife into caregiver] [sits at table only with company] [sleeps better now] [sold house] [sold house in previous town after 51 years] [sold house quickly] [spouse's death was a difficult adjustment] [spouse moved to same facility as other family members] [still getting used to spouse being gone] [strain on relationship roles] [struggled to let care workers take care of spouse] [struggled with chores] [struggled with looking after their car] [struggles with dry climate in new province] [struggles with modern technology] [struggling to adjust to new independence, new responsibilities] [suddenly responsible for all household tasks] [takes care of her basic needs] [takes care of herself because no one else will] [takes care of house on own] [talks to self] [though her caregiving changed, identity as wife didn't] [took care of all their finances for years] [took care of business as a couple] [took time for IE to learn to be more patient with care workers] [view of being a wife shifted] [was hard to let go of looking after spouse's health] [wasn't hard to adjust to being alone after spouse's move] [wasn't used to being a caregiver] [with time, feels less overwhelming] [worried about spouse's adjustment] [worried more about spouse's adjustment than IE's]

Quotation(s): 136
**Code Family: Adjusting - Spouse**

Codes (59):

- [after move, heartbreaking walking into spouse's room and seeing him cry]
- [doesn't want spouse to think IE abandoned him] [feels spouse should be grateful he's getting good care] [glad to see that his wife is doing better now] [had to walk away when spouse cried] [happy that spouse likes his roommate] [hopes spouse would still like other care facility programs] [husband didn't object to care facility] [husband enjoys second facility but still wants to go home] [husband hated first care facility] [husband realizes he needs care] [husband struggled with females helping him in washroom] [husband thought IE should take care of him] [husband wanted to go home but IE couldn't look after him] [husband was angry about being placed] [husband was satisfied with placement, but knew he was failing] [IE became the boss in the relationship] [IE grateful another facility became available before spouse settled in] [IE surprised at spouse's graceful acceptance] [IE tries to make spouse comfortable] [is amazed at how much spouse reads and makes plans in care facility] [is glad spouse has calmed down] [knows spouse would leave if he could] [move was hard because spouse rebelled against it] [moving spouse into new care facility was unsettling] [received some mixed messages from care facilities that was disappointing] [spouse's frustration at being in LTC] [spouse's gratitude helps IE] [spouse accused IE of being disloyal] [spouse didn't do well sharing a room] [spouse doesn't worry] [spouse fought tooth and nail in the assessment unit] [spouse has adjusted to LTC] [spouse has mostly adapted] [spouse has to cope in LTC without IE] [spouse hasn't completely adjusted to LTC] [spouse isn't content with separation] [spouse kind of understands IE can't stay constantly] [spouse knew he going to be care for] [spouse knew IE couldn't take care of him anymore] [spouse may not like LTC, but he has to cope with it] [spouse missed freedom of motorized wheelchair] [spouse moved to same facility as other family members] [spouse needs to adjust to IE visiting less often] [spouse not cooperating well] [spouse says IE moved spouse into care to wait for her to die] [spouse was a fussy eater at home, but not at care facility] [spouse was calm] [spouse was considerate of IE] [spouse was content in his room] [spouse was often upset and lashing out in care facility] [thankful spouse didn't realize he was in a secured unit] [thinks spouse likes his LTC facility] [took spouse a month or two to adjust to LTC] [tried to prepare spouse for move instead of thinking about self] [tries to make spouse's room feel like home] [was afraid leaving would make spouse angrier] [wonders if spouse's dementia is harder on her than on him] [wonders if spouse gave up]

Quotation(s): 80

**Code Family: Anticipating the future**

Codes (37):

- [anticipating hardship of spouse's roommate dying] [anticipating more stress] [anticipating spouse's condition worsening] [concern that spouse could live a long time yet] [discouraged knowing spouse will decline] [doesn't like spending time around other residents] [doesn't like to think about the possible future] [doesn't want to hear about how spouse will get worse] [doesn't want to live much longer] [doesn't want to suffer before dying] [fears spouse will give up once she needs diapers] [feels like he's waiting to die] [hard to see other residents in worse condition] [have to think differently when you're old] [heavy inevitability of spouse's deterioration] [hopes IE never needs lift equipment herself] [IE worried about losing her spouse] [if IE were to get sick, she'd go to the same care facility for the quality of care] [imagines it will get easier with time] [is afraid] [knew spouse's health would deteriorate eventually] [knows spouse isn't going to get better] [recalls family members who lived a long time with dementia]
[resistant to preparing for spouse to die] [sad to think about spouse having no one] [seeing other residents in worse condition] [spouse doesn't want her life prolonged at end] [spouse initially living in higher care than needed] [spouse living with residents with more advanced illnesses] [spouse may need higher level of care eventually] [surrounded by people with declining mobility at on-site church service] [suspects she'll eventually visit spouse less often] [waiting until the next boot drops] [wants the struggle to be over - tired of feeling overwhelmed and like a burden] [watched video about typical prognosis for Alzheimer's] [wishes she had been warned how difficult it would be to see other residents in worse condition] [worries about what would happen to spouse if something happened to IE]

Quotation(s): 68

**Code Family: Comfort in spouse's good care**

Codes (59): [care facility has big rooms for residents] [care facility looks after all spouse's needs] [care staff help spouse with daily care] [care workers say spouse is easy to care for] [convenience of first care facility] [doctor communicated clearly] [doesn't feel bad about spouse being in LTC] [each are looked after. IE doesn't care about that.] [especially appreciates specific male nurse at care facility] [expresses appreciation for care equipment] [family history at care facility] [feels a long connection to care facility] [feels good about spouse's move because he's taken care of] [felt like nursing staff were okay with IE's involvement in spouse's care] [felt supported at first care facility] [felt welcomed at facility] [first facility had good care] [first facility had poor conditions but excellent staff] [glad spouse is in the care facility that he's in] [helps IE to know spouse is well taken care of] [IE cares for the safety of the care staff] [IE comforted knowing spouse had care 24/7] [IE could rely on care staff to meet spouse's needs] [IE doesn't have to worry about spouse's well-being] [IE felt comforted knowing spouse was in capable hands at facility] [IE felt grateful spouse was moved to familiar care facility] [IE is happy spouse is happy] [IE knows spouse is checked on regularly] [IE thinks spouse gets good care in LTC, but isn't sure] [knows most care staff are good] [knows other care facilities aren't as good as spouse's] [likes on-site church services] [likes on-site church services for residents] [moving spouse where he would get good care] [nothing to complain about at spouse's facility] [other residents enjoy music] [physician comes to care facility to check on spouse] [seeing spouse get good care made the move easier for IE] [sense of relief that care workers aren't bothered by spouse speaking only Dutch] [spouse's needs are taken care of] [spouse attended on-site church services] [spouse easily got new doctor] [spouse enjoys animals] [spouse enjoys music at care facility] [spouse gets care he needs] [spouse gets care he needs 24/7] [spouse getting better care at care facility] [spouse has furniture and space for what he needs] [spouse is involved in activities at care facility] [spouse received good care] [spouse seen by on-site doctor] [spouse sees on-site physician - much less work for IE] [spouse was brought to on-site church service until shortly before he died] [spouse was content in his room] [takes comfort knowing the care staff find spouse easy to take care of] [thankful spouse had his own room] [thinks care staff do a great job] [took time to feel like care workers accepted her input] [workers at first care facility were supportive]

Quotation(s): 115
Code Family: Concerned about spouse's care
Codes (71):  [a sense of helplessness for spouse's safety] [advocated for spouse in hospital ER] [battled care facility policies to advocate for spouse's wellbeing] [believes people were stealing from spouse in hospital] [care workers didn't listen to IE's input for spouse's care] [current care facility isn't a home-like setting] [day program would help spouse be more active] [demanded spouse be treated with respect] [devastating feelings of guilt for putting spouse into bad situation] [didn't feel spouse got proper care in hospital] [didn't like that spouse's room temperature was cold] [didn't see that spouse's wellbeing was nurse's priority] [didn't trust care workers to take proper care of spouse] [disagreed with some of spouse's medications] [doesn't know if spouse getting care she needs] [doesn't understand need for spouse's high level of care] [emotional burden significantly worsened by spouse's rude roommate and poor conditions] [facility eventually fired disruptive nurse] [felt like IE was dealing with battle after battle for spouse's care] [felt spouse was overmedicated] [first care facility was a nightmare] [frustrated with hospital management] [frustrating when equipment not working] [hopes activity would help spouse be more responsive] [IE battled care facility policy on medication for spouse's wellbeing] [IE didn't sense compassion in workers at second care facility] [IE felt care workers were lying to her] [IE felt spouse deserved much better] [IE not confident in all aspects of care] [IE trying her best to protect spouse and seeming to fail] [IE was heartbroken at spouse's placement situation] [IE was persistent in insisting on spouse's care at facility] [IE worried about her spouse] [isn't anti-medication, but knows they're not the easy answer] [knows hospital can't give full care to all patients] [knows spouse isn't a good source of accurate information] [little opportunity for spouse to be active] [lots of people asking IE how spouse was injured in care facility] [moving spouse to a different care facility was another nightmare] [not always happy with care workers' treatment of spouse] [not happy with home care's management] [nurse tried to have spouse moved out of town to mental facility] [recognizes that nurses have lots of patients to care for] [request for equipment wasn't fulfilled] [seeing husband's unhappiness with faulty equipment] [seeing husband's unhappiness with some equipment] [seeing poorer quality of care] [spouse's lack of good care adds to IE's emotional burden] [spouse's room wasn't big enough for comfort] [spouse's treatment not fair] [spouse doesn't get enough exercise in care] [spouse fell multiple times while in hospital] [spouse gained a lot of weight at care facility] [spouse injured by another resident] [spouse injured while in care facility] [spouse isn't active in care facility] [spouse less active at care facility] [spouse living in a hellhole] [spouse not safe in care facility] [spouse was difficult to care for] [struggled with some elements of spouse's care] [struggles sometimes with feeling spouse not getting proper care] [troubled by what spouse said sometimes] [upset at home care worker's treatment of spouse] [walking together for spouse's health] [was afraid for spouse's safety] [wishes there were better equipment] [wonders if care workers felt responsible for spouse's safety] [wonders if his perceptions of spouse's care are accurate] [workers avoided spouse during his disturbed outbursts] [would feel better if spouse was in other care facility] Quotation(s): 127

Code Family: Coping - nonspecific
Codes (47):  [a sense of existential acceptance] [a sense of God's guidance] [a sense of powerlessness - don't think about things IE can't change] [accepting the situation] [both accepted the separation] [calling on God for help] [can't care about negative experiences] [didn't feel sorry for herself when spouse moved to LTC] [didn't know what to do except accept it] [doesn't know
how she copes, she just does] [doesn't know what she'd do without her faith community] [doesn't pay attention to her emotional struggle] [doesn't think about things too much] [faith community is helpful] [feels she's doing okay most of the time] [feels sorry for self sometimes, but doesn't allow self to linger on it] [focuses on one day at a time in her loneliness] [had to tough it out] [has learned how to handle stress] [has to accept the situation] [have to cope] [having to cope, but not being able to define how] [IE's wife got their first choice of facility] [IE can cope with anything] [IE did what she had to do - accept the situation] [IE doesn't get phased like other people] [IE picked herself up and kept going] [knows IE will die of something eventually - feels a semblance of choice] [letting herself worry would harm her health] [letting herself worry would leave her a nervous wreck] [lives one day at a time] [making the best of the situation] [praying that spouse's situation will go well] [prays to stay healthy] [pushing forward] [putting on music sometimes helps] [recognizing IE's depression helps IE get through it] [Some days it just gets to you] [somewhat shrugs difficulty off as part of life] [taking it one day at a time] [tries to shrug off the pain] [we have to be strong for them] [went back to bed and accepted that spouse wasn't coming home] [wishing the situation was different] [with time, accepted situation] [wonders if God hastened spouse's rapid decline] [would prefer life to look different, but takes it as it comes]

Quotation(s): 74
doesn't help IE] [spouse is around people all the time] [spouse is out of town, IE still at retirement facility] [spouse was confrontational] [spouse was confrontational for many years] [spouse worries about IE] [spouse worries about IE living alone] [suspecting that advocating for change with loved one doesn't positively impact other residents] [suspecting that residents without an advocate don't get the best care] [understands the need for the equipment, but wishes it was better] [understands the nurses can't control behaviour of residents all the time] [unhappy with spouse's location] [watching spouse lose roommates] [wishes he had read about spouse's condition sooner] [wishes IE had known more about spouse's disease sooner] [wishes IE had the energy to advocate against overmedicating seniors] [wishes IE knew more about spouse's condition] [wishes other resident would be contained] [wishes someone had gently prepared IE] [wishes someone would invent better equipment] [wishes spouse weren't in hospital] [wishes there were more male nurses] [wishes there were younger people at on-site church service] [wonders if putting spouse in LTC led to his rapid decline] [worried other resident will harm someone]  

Quotation(s): 107

**Code Family: Family - helpful/hurtful**

Codes (242):  [after wife's admission, IE's brothers took him on a trip] [appreciates their concern] [asking family for help with tasks] [attending church services with family] [attending church services with son] [bothers IE that IE is the only one to visit spouse] [called daughters during health scare] [called son for help] [concerned for spiritual growth of grandchildren] [daughter and son-in-law saw IE needed help] [daughter buys IE's groceries] [daughter came to see IE after spouse hospitalized] [daughter doesn't visit spouse] [daughter drives IE] [daughter gets angry easily] [daughter got angry at IE over miscommunication] [daughter helped IE financially after IE's husband moved] [daughter is aloof] [daughter is only relative nearby] [daughter looking after spouse so IE can have a break] [daughter takes IE's BP] [daughter told IE he should be in hospital too] [daughter visits spouse regularly] [daughter went with IE to admit spouse into assessment unit] [daughter went with spouse and IE to hospital] [daughter went with spouse to hospital] [daughter wrote hurtful things about IE on internet] [daughters agreed with facility workers] [daughters and facility workers looked after spouse's move] [daughters have their own families] [daughters helped with spouse's care] [daughters took charge of spouse's medical care] [daughters took spouse to LTC] [daughters visit spouse in hospital] [deciding to move closer to son] [didn't have kids nearby to help with practical issues of moving spouse from hospital to care facility] [doesn't feel supported except by family] [doesn't have family in town] [doesn't have kids to help IE with computer] [doesn't run around with her grandkids] [doesn't want her geo distant kids to feel guilty] [doesn't want to bother his kids with his problems] [empathic relationship with sister in similar situation] [family comes to visit] [family didn't know the needs] [family didn't understand at first, but quickly recognized need for placement] [family don't like to visit spouse] [family don't visit often] [family going for coffee with IE] [family have their own health concerns] [family helped IE see her limits] [family helped with care] [family helped with paperwork] [family history at care facility] [family invites her out for coffee] [family less supportive after crisis] [family made IE take a holiday] [family members living at same facility as spouse] [family phones] [family phones and visits often] [family pushes IE to rest] [family pushes IE to take regular day off] [family reluctant to move spouse into care] [family supported decision to place spouse] [family tell IE she did the right thing] [family took care of
spouse in care facility] [family visits as often as possible] [feeling excluded from family sometimes] [feeling inconvenient to family] [feeling obligated to family] [feeling supported by family] [feeling upset about being excluded] [feels like daughter has kicked legs out from under IE] [feels lucky to have such good kids] [felt like a weight was lifted off IE's shoulders] [felt supported by family] [felt supported by kids during spouse's move] [felt very supported by family] [focusing on family] [friend's family is big and rallies around her] [gave son financial authority] [getting away is refreshing] [goes to see friends/family when feeling overwhelmed] [grandchildren not engaging at on-site church] [granddaughter is intentional about phoning and visiting] [granddaughter lived with IE during practicum] [granddaughter visited spouse daily during practicum] [granddaughter was very helpful] [grandkids stayed overnight] [handed personal business over to sons] [has grandkids at her place to visit] [has stepped down from being head of the family] [has to deal with deaths of other family members] [haven't felt as supportive by daughter as hoped] [having family around was the most helpful] [having people around made it a bit easier] [helped around the house at daughter's] [helpful to have family nearby] [helps raise grandkids since daughter-in-law left] [her family was happy to receive her gifts] [her kids don't want to hear about the difficult stuff] [her kids phone her] [IE's family are in another province] [IE's kids are all retired] [IE's kids are critical supports] [IE's kids take care of her] [IE's parents supported current care facility] [IE's son brings food] [IE's son called medical personnel to ask what they should do] [IE admires son's care for his wife] [IE agreed with daughters if they were willing to get less inheritance] [IE and daughters decided spouse needed LTC] [IE appreciates her kids treating step-dad well] [IE asked family for help] [IE calls son when she gets stuck] [IE didn't ask for the help she needed] [IE didn't like being excluded from spouse's move to AL] [IE disagreed with daughters' decisions for spouse] [IE doesn't want to burden her sons] [IE doesn't want to cause friction in spouse's family] [IE feels supported by son] [IE felt isolated from her supports] [IE gave most of her things to her kids and grandchildren] [IE gets picked up by family member for meal] [IE goes out with family instead of staying home alone] [IE invites family over to her house] [IE is grateful for family's understanding] [IE kept spouse's dementia symptoms from family for several years] [IE looking out for the grandchildren] [IE resenting family lack of involvement] [IE spends time with extended family] [IE was grateful that her son and his wife were around] [IE went to family for emotional support] [IE worries about her children] [IE worries about her son] [involving family in decision] [it's good to have family] [kept in touch with siblings regularly via email] [kids are active in IE's life] [kids didn't understand IE's struggle with being termed "separated"] [kids don't allow get along with each other] [kids encouraged IE to admit spouse] [kids live nearby] [kids tried to support, but didn't understand her struggle] [kids visited spouse in LTC] [kids were involved in spouse's move] [knows he can't do this alone] [learning cell tech to keep in touch with family] [let daughters look after spouse's medical care] [likes retirement facility's guest rooms] [listened to sons' suggestions] [little family support structure] [living geographically far from family is hard] [looking forward to time with son] [losing daughter-in-law was very hard] [making effort to be closer to family] [misses her sister] [most people have family support] [moved to current town to be closer to daughter] [moving closer to their kids] [mutual support between IE and son who lost his wife] [niece contacted nursing home] [niece helped look for affordable placement] [no family that could help] [not feeling connected to kids in certain issues] [not feeling supported] [not welcome on family holiday] [one friend phoned faithfully] [one son is supportive] [other son visits too] [over Christmas, kids saw how tired IE was] [places responsibility of spouse on his children] [prided himself on caring for his family] [prioritized time with family] [prioritizing
family] [recognizes that daughter is busy too] [relocated to be closer to daughter after wife's diagnosis] [saw son and spouse have good rapport] [sees her grandkids having fun] [sees that daughter's aloofness bothers spouse] [sense of pride for daughters] [sense of pride for grandkids] [serious consecutive stressors] [sister has family to get back to] [sister helped IE during transition] [sister lives in England] [sister stayed with IE for a month] [son's arrival relieved some of the stress] [son's visits help IE with feelings of loneliness] [son-in-law found place for IE and spouse] [son-in-law saw IE's responsibilities were too much] [son asks about IE's needs] [son calls IE every night] [son comes to on-site family events] [son doesn't visit spouse on-site] [son has good rapport with spouse] [son helps move spouse] [son helps IE] [son jokes with IE] [son moved to nearby town] [son phones spouse regularly] [son supported IE in dispute with daughter] [son took care of wife at home] [son took husband to the hospital] [son took over finances] [son visits frequently] [son visits from out of town] [sons are too far away to help with day-to-day tasks] [sons attune to IE's emotional state] [sons call multiple times a day to check on her] [sons have different skills] [sons were emotionally supportive but geographically distant] [spending time with family] [spending time with family helps the loneliness] [spouse's family isn't close like IE's] [spouse's son checks on him ~once a month] [spouse's son looks after spouse] [spouse alienated family members] [spouse has some family nearby] [spouse surrounded by family in care] [stands out that her son was so good to his wife] [stayed with daughter when first moved to current town] [suspects her kids called physician] [talking on phone with daughter] [talking on phone with son] [talking on phone with spouse and sons helps get through each day] [talking with kids] [talks about grandkids growing up quickly] [talks on phone with kids] [thanks God for her health and for her kids' help] [thanks God that IE's kids help so much] [they have no kids] [told families what was happening with spouse] [took dog for walks] [travelled to watch grandsons play lacrosse] [tries to reconnect with daughter now and then] [trying to accept family's need for boundaries] [wanting family-oriented on-site church services] [went on a trip to visit their families] [went to daughter's every day] [when spouse got to need help, his kids put him in AL] [worried about family and friends' support]

Quotation(s): 314

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Code Family: Finances
Codes (45): [balancing new expenses on limited income] [can't afford taxis to see spouse] [can't believe how expensive groceries are] [concerned that savings will run out] [current care facility is expensive] [daughter helped IE financially after IE's husband moved] [feeling threat of financial punishment for not doing tasks] [feeling unsettled] [feels the government doesn't understand their financial struggles] [financial limitations] [gave son financial authority] [grateful for what she gets from the government] [has been using their savings] [has her own bills to pay] [IE can't afford more provided meals] [IE can't partake in costly social activities] [IE couldn't afford to move closer to spouse] [IE doesn't get CPP] [IE doesn't qualify for the same assistance because doesn't need as much care] [IE is used to living frugally] [is financially stable] [knows he's fortunate financially] [knows others are struggling financially] [likes to be frugal] [lives cheaply at home] [looking for a cheaper care facility for spouse] [making financial arrangements] [new place would cost more] [other care facility would be cheaper] [paying double for housing] [paying for own medication] [spouse's care is cheaper because of government assistance] [spouse's care is very costly] [spouse's move put extra strain on IE's finances] [spouse doesn't help IE financially] [spouse doesn't help much with IE's finances]
CONNECTION

[spouse gets government funding] [spouse is very attentive to money] [spouse saved money] [struggles paying for two places] [taking over finances] [trying to get more pension] [Veteran's stopped paying for spouse's medication] [wasn't prepared for financial complications] [with spouse's care cost, will be less money for daughters' inheritance]

Quotation(s): 68

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**Code Family: Humour - keeping sense of**

Codes (10): [humour relaxes] [IE jokes with her family] [IE keeps a sense of humour] [jokes about her age and appearance] [jokes around with fellow residents at retirement facility] [laughing helps] [remembers spouse's great sense of humour] [son jokes with IE] [spouse retains some sense of humour] [treasuring times of humour with husband and staff]

Quotation(s): 18

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**Code Family: IE's own health**

Codes (42): [anticipating IE's decline if she moved to LTC too soon] [can't bus to spouse because of visual impairment] [can't walk much with spouse without her walker] [care worker told IE he wouldn't last with spouse at home] [caring for spouse was a risk for IE's wellbeing] [changes are tough because IE is visually impaired - neighbour helped her] [didn't want to risk own health] [exhaustion and stress put IE in hospital] [gets own health checked up on] [grateful for his good memory] [had never been separated] [health is impacted by IE's stress] [hopes IE never needs lift equipment herself] [IE's health wasn't the best] [IE's limited mobility limited their walking] [IE and spouse both visually impaired] [IE can't walk as much as she used to] [IE couldn't rest properly] [IE has health issues] [IE is visually impaired] [IE more mobile than spouse] [IE not ready for LTC] [IE risking own health as caregiver] [IE was admitted into hospital] [IE wouldn't last in a condo] [in good health] [in hindsight, IE wouldn't have lasted] [information session location didn't work with IE's hearing loss] [letting herself worry would harm her health] [misses out on some conversations because of hearing loss] [misses out on some music elements because of hearing loss] [moving to LTC would quickly make IE helpless] [not fun being visually impaired but IE manages] [overwhelming stress put IE in hospital] [spouse will have no one if IE gets very sick] [stressed adds to health issues] [struggles with hearing loss] [tries to walk with spouse, but IE is physically limited] [trying to take more time for self] [wants to die before reaching 100] [was told to stop risking her own health caring for spouse] [wonders if IE will need LTC eventually too]

Quotation(s): 94

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**Code Family: Internal turmoil**

Codes (135): [a sense of dread after moving spouse to new care facility] [a sense of guilt for not relying enough on God] [a sense of helplessness for spouse's safety] [a sense of IE feeling guilty for not knowing about variety of symptoms] [after initial separation, feelings of separation anxiety, guilt, worry] [blamed self for spouse's behaviour] [can't be with spouse non-stop] [contact with spouse sometimes makes IE feel more lonely] [devastating feelings of guilt for putting spouse into bad situation] [difficulty talking about negative emotions] [doesn't sleep well if doesn't visit spouse every day] [doesn't think caregivers should feel guilty for admitting loved
ones] [easier to leave after spouse is distracted] [emotional burden significantly worsened by spouse's rude roommate and poor conditions] [feeling conflicted over decision to admit spouse] [feeling emotional heaviness] [feeling emotionally devastated after spouse's LTCA] [feeling guilty - wanting spouse's struggle to be over] [feeling guilty about IE's own health] [feeling guilty when not with spouse] [feeling isolated in her pain] [feeling like God isn't answering her prayer] [feeling like God isn't stopping spouse from leaving her] [feeling trapped] [feelings of guilt for much nicer living quarters than spouse] [feelings of guilt for not noticing spouse's symptoms] [feelings of loneliness remain] [feels conflicted about visiting spouse] [feels empty] [feels guilty if doesn't visit spouse every day] [feels helpless to change it] [feels like a failure as a husband] [feels like a failure because he can't take care of his spouse] [feels old and limited] [feels selfish if doesn't visit spouse every day] [feels she carries the burden for both self and spouse] [felt alone before spouse moved] [felt heartrending to leave spouse on other side of locked door] [felt like a failure as a spouse] [felt IE had no choice] [felt IE was abandoning spouse at end of every visit] [felt like IE was letting spouse down] [felt like moving spouse was 'giving him up'] [felt like she'd been vetoed] [felt like slow progression into widowhood before move] [felt lost after spouse's Alzheimer diagnosis] [felt powerless] [felt sorry for spouse and self] [full of doubts about decision] [friend dying around spouse's LTCA] [going home is hard for IE] [got annoyed at spouse] [had never been separated] [had to walk away when spouse cried] [hard coming home to empty house] [hard to hear spouse say he wants to die] [hard to leave spouse after visits] [hard to not feel guilty] [hard to think about 2 months later] [home is lonely despite visits] [IE’s feelings of guilt, worry, and frustration] [IE and her husband were never apart] [IE cried for weeks after putting wife in hospital] [IE feels jealous sometimes] [IE felt guilty about putting spouse into care] [IE felt overwhelmed] [IE felt spouse deserved much better] [IE had no choice] [IE questioned her decision to move spouse to new facility] [IE second guessing his/her care decisions] [IE still feels overwhelmed] [IE struggled with basics like eating and sleeping] [IE was completely exhausted] [IE was heartbroken at spouse's placement situation] [IE was咀ansified with dialogue] [it's hard to talk about missing spouse] [it's hard whether spouse is angry or wanting to be close] [it's still hard 2+ years later] [medical separation was like a bomb dropped] [misses spouse] [misses spouse terribly] [missing their routine together] [mournning daughter-in-law's death] [move was one blow after the other] [moving spouse was hard because he wasn't coming home] [necessity of being parted] [needs to get away when feeling overwhelmed] [on a recent bad day, IE felt purposeless] [putting spouse in care is different than putting parent in care] [questioning why] [recognizing IE's depression helps IE get through it] [regrets how he treated spouse as caregiver] [remembers the locked door of assessment unit] [resentment for having to downsize alone] [sat in car and cried after visiting spouse] [sees guilt as unavoidable as the caregiver] [sense of feeling lost] [sense of feeling overwhelmed] [sense of feeling powerless] [sense of finality] [sense of guilt] [sense of helplessness] [sense of helplessness conflicting with autonomy] [sense of not knowing what to do] [sense of unfairness] [sitting in existential uncertainty] [Some days it just gets to you] [sometimes the loneliness feels hopeless] [spouse's treatment not fair] [spouse asks IE to stay] [spouse doesn't talk about their shared home] [spouse is afraid IE is abandoning them] [spouse is constantly on IE's mind] [spouse resenting IE] [spouse says IE moved spouse into care to wait for her to die] [still adjusting to separation] [still hard one year later] [struggled to make sense of his role as spouse and caregiver] [struggles seeing spouse upset] [struggles to manage her worries] [struggles with whether or not to move spouse to other care facility] [struggling to make
sense of life and death] [struggling to make sense of suffering] [taking breaks from spouse's frustration] [tears IE apart to leave spouse] [the finality of moving spouse to LTC] [the pain is still fresh] [wants the struggle to be over - tired of feeling overwhelmed and like a burden] [wishes she could speak without crying] [wishes she/he had been warned how hard the shift would be] [wishes someone could live in his shoes and come back and explain what's happening] [working through recurring conflicting emotions]

Quotation(s): 253

Code Family: Making tough decisions
Codes (44): [considered hiring foreign worker as caregiver at home] [didn't get first choice of care facility] [doctor asked IE what IE was going to do about spouse after hospital] [familiarity of care facility] [feels high amount of stress] [figuring out the right way to do it] [finding placement was difficult] [given options of which care facility to go to] [had to start thinking of where spouse would be the safest] [her choices can be building or destructive] [hope for the best in a tough situation] [IE became the boss in the relationship] [IE given choice of which care facility] [IE making tough decisions for spouse's care] [IE selfishly wanted spouse at home as long as possible] [knows what she thinks, but struggles to make decisions for her spouse] [letting doctor make final decision] [listened to sons' suggestions] [made bad decisions because IE was preoccupied] [making decisions after care facility closed] [making decisions like change of address for spouse] [making tough decisions on her own] [moved spouse for convenience of access] [moving from one care home/town to another] [moving spouse to a different care facility was another nightmare] [moving spouse was hardest decision IE ever made] [not given much notice to decide] [nurse called 2 days later with room for spouse] [other care facility has activities spouse could do] [other care facility is more of a home-like setting] [questioned his decision for months] [questioned if being closer to family would help spouse] [questioned if they should move back to hometown] [resentment for having to make decisions alone] [responsibilities pushed on her last-minute] [responsible for all decisions] [responsible for all decisions before spouse's move] [stressed by paperwork] [struggles with whether or not to move spouse to other care facility] [tells friend to take more time for self] [used to dealing with tough situations] [waiting for space at other care facility] [was too close to recognize spouse's decline] [worked through doubts]

Quotation(s): 82

Code Family: Medical separation
Codes (42): [being separated hasn't changed IE as a wife] [being separated was hard] [can't accept that medical separation is necessary] [crying over involuntary separation] [delayed filing income tax to avoid marking that IE was "separated"] [doesn't remember signing separation paperwork] [drastic shift from living at home to being involuntary separated] [eventually accepted medical separation] [feeling like LTCA was a failed end to 60 yrs marriage] [feels like their marriage is still strong] [feels there must be a better way than formal medical separation] [felt like her struggle with medical separation wasn't acknowledged] [felt like their happy marriage was torn apart] [homecare prepared IE for involuntary separation] [IE was in shock about medical separation] [involuntary separation] [involuntary separation didn't bother IE] [kids didn't understand IE’s struggle with being termed "separated"] [knew all about spouse's
condition, but didn't expect medical separation] [legal separation was hard] [legal separation was like adding insult to injury] [making sacrifices for govt assistance] [medical separation felt like invalidation of their marriage] [medical separation was devastating] [not enjoying being separated from spouse] [put off separation] [recognizes financial reasons for medical separation] [saw the financial benefit of involuntary separation] [separation paperwork done at hospital] [sister was bothered by involuntary separation from her husband, but IE wasn't] [social worker explained involuntary separation] [son's strong resistance to parents' involuntary separation] [son's struggle with medical separation was very difficult for IE] [still wonders about possible consequences of medical separation though spouse has since died] [thinks there must be a better way than medical separation] [was angry at medical separation] [was forced to be medically separated] [was stubborn about resisting medical separation] [wasn't prepared for separation] [wonders about care workers' legal liability if spouse was harmed before LTCA] [wonders about the legal ramifications of medical separation in medical decision-making] [wouldn't wish her experience of separation on anyone]

Quotation(s): 62

Code Family: Miscellaneous helpers

Codes (88):  [a friend helped IE get wife to hospital] [a sense of cynicism toward placement administrators] [after LTCA, social worker called IE every week] [appreciated the people who put in the alarm system] [appreciates facility chaplain] [appreciates spouse's easygoing care workers] [appreciates the helpers who brought spouse to on-site church services] [appreciates their friends' help] [asking questions and feeling supported by facility workers] [being informed about care options] [bus driver told her "not today"] [called and talked to nurses while on trip] [care facility emphasized closeness and support] [care facility emphasized support for both IE and spouse] [care facility personnel were accommodating] [care facility staff were kind to IE] [care worker's honesty with IE helped with decision] [care worker standing up for IE] [care workers normalized spouse's return to first language] [changes are tough because IE is visually impaired - neighbour helped her] [couldn't talk with spouse, but was helpful to talk with nurses] [daughters and facility workers looked after spouse's move] [despite differences of opinion, tried to be on good terms with the care workers] [developed good rapport with care workers] [didn't feel supported by care facility staff] [doesn't like relying on friends] [doesn't want to place responsibilities on friends] [during spouse's move to LTC, people were kind to IE] [expects polite etiquette] [eyes were opened to the hurting people around IE] [feeling supported by neighbours in practical ways] [feels her help is appreciated by care staff] [felt more at ease with alarm system to keep tabs on spouse at home] [formed some close relationships with care facility staff] [friends' efforts are supportive] [friends admitted spouse into LTC while IE in hospital] [friends looked after spouse while IE in hospital] [gets encouragement from retirement facility nurse and chaplain] [had bad experience with home care] [had help taking care of house] [has a system with care facility workers] [has someone who helps keep her computer running] [helpfulness of care facility workers] [homecare assessed IE's wife] [homecare educated IE on the process] [homecare got husband to talk] [homecare helped with paperwork] [homecare prepared IE for involuntary separation] [homecare worker was good] [hospital and facility care workers were supportive] [IE's cleaning lady helped move spouse] [IE appreciated care facility staff] [IE asked what she could do, but nurse looked after it for her] [IE felt comfortable talking with doctor] [IE felt supported] [IE felt supported by care facility workers] [IE got help from
care staff] [IE had homecare help] [IE now gets home care] [IE talked to chaplain] [IE was
informed abruptly that his wife needed LTC] [kind, caring, compassionate care workers] [knew
placement administrator for years] [knows there are lots of good people working in care
facilities] [learns about dementia from others] [neighbours helped shovel sidewalks for her] [not
feeling supported] [nurse behaved insensitively toward IE] [nurse checked on IE once a month at
his home] [nurse from Alzheimer Society interceded for spouse's health] [nursing home called
IE] [often told to visit spouse less frequently] [physician validated IE's frustration with care
workers' evasiveness] [professionals helped facilitate spouse's move] [saw risk to spouse's help
through pilot alarm system study] [social worker explained involuntary separation] [some care
workers stood out as excellent] [specific care worker made it easier for IE to go home] [spouse's
doctor is easily accessible] [spouse upset by home care worker] [struggled with chores] [support
smoothed the transition] [talking with social worker] [thankful homecare had a male worker]
[very thankful for friends to help with husband's placement] [was helped with paperwork for
involuntary separation] [wasn't as comfortable with female homecare worker] [wouldn't have
known what to do on his own]

Quotation(s): 140

Code Family: Moving spouse

Codes (44):  
[after spouse's move, IE was exhausted] [brought bedding from home to LTC]  
[care facility didn't do anything particularly helpful after LTCA] [care facility made no effort to
make move feel home-like] [care facility was helpful overall during move] [didn't cry the day of
spouse's LTCA] [didn't feel supported during move to second care facility] [didn't have to move
furniture - care facility supplied it] [drove to care facility for spouse's admission] [during
spouse's LTCA, his short term memory loss made it hard for IE who had to repeatedly explain
what was happening] [grateful for spouse's rapid admission to LTC] [had lots to do to move
spouse with little notice] [hard getting spouse's clothes ready for LTCA] [hospital found LTC
space for spouse] [IE's cleaning lady helped move spouse] [IE couldn't manage all the
responsibilities] [IE cried a lot during move] [IE felt peace of mind after move] [IE felt relief
after spouse's move into care] [IE moved spouse's items over gradually] [IE providing for
spouse's needs in care facility] [IE remembers exact date] [IE remembers exact date spouse
transferred to care facility] [initially, a sense of feeling lost at mealtimes without set seating
arrangements] [insufficient support finding placement] [kids were involved in spouse's move]
[made several trips between home and care facility] [missed feeling welcomed during move to
care facility] [more difficult finding a spot in dementia units] [moving spouse into new care
facility was difficult] [moving spouse to care was easy] [private care facility had room first]
[professionals helped facilitate spouse's move] [shocked that spouse needed to stay on
assessment unit for weeks] [spouse's move happened quickly] [spouse's move to LTC wasn't
hard] [spouse in hospital for one month before LTCA] [spouse was placed outside of town]
[transitioning in summer - people IE needs to talk to are on holidays] [waited a long time for
spouse to be placed] [walking out of house taking spouse to LTC was incredibly hard] [wasn't
allowed to take spouse to LTC] [wasn't offered any help to move spouse from hospital to care]
[wintertime made moving spouse more complicated]

Quotation(s): 45
**Code Family: Others in similar situation**

Codes (21):  [appreciates comradery of people in similar situations] [compares self to others in similar situation] [doesn't know what someone else would do in same situation] [doesn't think caregivers realize how much work they do] [feeling empathy for others in similar situations] [feels empathy for others in similar situations] [had sympathy for other caregiver husband] [has group of men who have experienced similar situations] [IE feels isolated in her experience] [is now better informed about care facilities] [knows others are struggling with similar hardships] [knows others have to deal with worse] [met a man who took care of spouse with Alzheimer's for six years] [respects that others might have handled it differently] [says men are different than women] [seeing friend develop health problems] [similar experiences among retirement community residents] [spent time with other men in similar situation] [talking with others in similar situations helped] [thinks separation is different for husband caregiver] [would help in any way IE could if someone else going through similar situation]

Quotation(s): 33

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**Code Family: Paperwork**

Codes (22):  [care facility social worker was very helpful with paperwork during admission process] [confusing process of getting financial subsidies] [family helped with paperwork] [feeling dragged down by all the paperwork] [had to work with lawyers] [handling paperwork responsibilities on own] [help with paperwork made transition smoother] [homecare helped with paperwork] [IE couldn't manage all the responsibilities] [IE felt supported] [IE still looks after paperwork] [kept sons out of personal business] [lack of human contact in getting paperwork completed] [lots of paperwork to do on short notice] [receiving special help from care facility] [timing of paperwork was overwhelming] [trying to get more pension] [Veteran's came to check on spouse's status] [was helped with paperwork] [was helped with paperwork for involuntary separation] [working out details in short amount of time]

Quotation(s): 31

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**Code Family: Planning/Preparing**

Codes (28):  [arranged power of attorney] [as a couple, moved to town and gradually downsized over many years] [both moved to multi-level retirement community] [can't make plans until spouse has been placed in LTC] [didn't want to be responsible for fixing house] [doesn't have a plan] [doesn't want to handle everything on his own] [downsized before moving to retirement facility] [feeling uncertain how long he could stay nearby] [had power of attorney in place before separation] [IE chose to put spouse on waitlist for LTCA] [IE knew he was getting older] [IE wanted help with cooking - AL] [intentionally moving where some meals can be provided] [knew spouse would have to move eventually] [liking the facility] [maintains some independence] [moved quickly to retirement facility] [moved with spouse to retirement facility] [planning ahead] [planning in case IE can't look after basic responsibilities] [read up on spouse's dementia prognosis] [second spouse wanted to move to retirement community] [sense of feeling unprepared, destabilized] [spouse doesn't want her life prolonged at end] [talked in advance about end-of-life wishes] [wants to move to same facility as spouse] [was planning to move already before he broke his leg]
**Code Family: Reaching out**

Codes (23):
- [asked for explanation for spouse's attitude shift]
- [asking family for help with tasks]
- [doesn't like to ask for help]
- [goes to patient conferences to learn more about spouse]
- [helping other residents]
- [IE asked for help from resident at retirement facility and was treated rudely]
- [IE calls son when she gets stuck]
- [IE invites family over to her house]
- [IE researched spouse's diagnosis]
- [IE sought advice from friend, head nurse]
- [is intentional about reaching out to others in similar situations]
- [joins and listens to the groups of women at retirement facility]
- [keeps in touch through email]
- [learning about spouse's illness brings a sense of stability to IE]
- [likes an active social life]
- [phones a friend to take IE shopping]
- [reaching out for connection via phone]
- [sought information and advice]
- [talking on phone a lot]
- [tries to help friend financially]
- [uses a computer regularly]
- [was helped by the professionals' help and advice]
- [went to meeting at Alzheimer Society]

Quotation(s): 54

**Code Family: Reflections - positive**

Codes (55):
- [appreciates the animals for their accepting natures]
- [becoming more compassionate]
- [believes their love will stay strong]
- [brings spouse to spend time with animals]
- [brought food for animals at care facility]
- [care facility atmosphere improved over time]
- [care facility had animals nearby]
- [despite everything, IE feels blessed]
- [doesn't feel he/she has changed much]
- [enjoys other resident who is better contained]
- [feeling God's help before spouse's passing]
- [feels both gave 100% in their marriage]
- [feels lucky]
- [feels they did their best with God's help]
- [felt fortunate to get spouse connected quickly with doctor]
- [finding strength in prayer]
- [finds animals therapeutic]
- [finds comfort in faith]
- [gave her husband love and care]
- [glad he was able to keep spouse at home a while longer]
- [God was a big support]
- [grateful for her mental functioning]
- [grateful for the help she gets]
- [had a good time reminiscing with spouse about the good times]
- [history of hard work]
- [IE and spouse had full life together]
- [IE and spouse have a long history together]
- [IE feels fortunate to have an even-tempered spouse]
- [IE feels she's been a good wife]
- [IE knew spouse loved her]
- [likes her retirement facility]
- [likes that spouse still has music]
- [looks forward to spending time with spouse]
- [married 56 years]
- [married 62 years]
- [other residents show appreciation]
- [reflecting fondly on good-natured spouse]
- [retirement community residents are nice to IE]
- [retirement facility isn't perfect, but feels like home to IE]
- [spending many years together]
- [spouse enjoys young people]
- [spouse had a few regular visitors]
- [spouse was a good conversationalist]
- [spouse was loving and kind]
- [still enjoying physical relationship]
- [talking with dog was very helpful]
- [thankful transition didn't happen in winter]
- [thanks God for their years together]
- [thanks God for what vision she has left]
- [thanks God that grandkids are good students]
- [treasures the good memories]
- [uses the retirement facility guest rooms for visitors]
- [visiting care facility after spouse's death, care workers give IE hugs]

Quotation(s): 83
**Code Family: Relinquishing care of spouse**

Codes (76):  [admitted spouse to hospital's assessment unit] [admitting husband was hard] [being informed about care options] [bothered by abrupt manner of placement facilitator's phone call] [care facility staff initiated spouse's move to LTC] [care worker's honesty with IE helped with decision] [decision was made for IE] [delayed admitted spouse because didn't want to be separated] [delayed admitting spouse to LTC] [devastating not being able to bring spouse home] [didn't feel strongly either way about spouse's move] [didn't have much say in spouse's move to LTC] [didn't know spouse was being moved to LTC] [didn't like that spouse was moved to LTC] [doctor decided IE couldn't take care of spouse] [escorted out of the hospital] [expected to take spouse home after assessment] [feeling overwhelmed by short notice of spouse's move] [felt comforted knowing others recognized IE's limitations] [felt didn't have much choice] [felt like she'd been vetoed] [felt like spouse was taken away] [felt relief after physician called] [friends brought spouse to first available care facility] [had to be convinced to move spouse to LTC] [had to move spouse into care] [home care wouldn't have been enough] [homecare told IE to place spouse] [hoping spouse could come home] [husband wanted to go home but IE couldn't look after him] [IE agreed with daughters if they were willing to get less inheritance] [IE and daughters decided spouse needed LTC] [IE can't do much for spouse] [IE couldn't take care of spouse] [IE didn't have a say in spouse's move to AL] [IE felt she couldn't afford to keep spouse at home] [IE had no choice] [IE had to accept she couldn't care for spouse] [IE had to accept that they could take better care of spouse] [IE helpless to care for spouse] [IE knew she/he couldn't keep taking care of spouse at home] [IE recognizing own limits] [IE wasn't ready for spouse to need LTC so soon] [in hindsight, knows IE made the right decision] [knew hiring someone wouldn't be enough help] [knew she couldn't take care of spouse] [letting doctor make final decision] [lived together in retirement area for short amount of time] [looking for LTC placement was a nightmare] [made decision to move spouse] [married 56 years. it was her and I.] [moved spouse to LTC quickly] [moving from home to LTC] [not finding space at nursing homes] [not given much notice to decide] [nurse called 2 days later with room for spouse] [paramedics said spouse wouldn't be coming home anymore] [physician confirmed spouse's need for LTC] [physician decided spouse needed to be assessed for LTC] [retirement facility workers told IE's daughters that spouse needed more care] [siblings encouraged IE to admit spouse to LTC] [spouse's kids moved him to LTC] [spouse accepting move made it easier on IE] [spouse admitted into LTC one year ago] [spouse admitted to LTC but IE took her back home after 1 month] [spouse had been offered a room earlier but IE couldn't do it] [spouse was heading to LTC until IE stopped it] [spouse went in ambulance, never returned] [struggled with short notice of spouse's move] [thought spouse would be coming back home] [timing of spouse's LTC was out of IE's hands] [trying to figure out a way to bring spouse back home] [very hard for IE when spouse was moved] [waited a long time for spouse to be placed] [was told he shouldn't bring spouse back home] [was told to stop risking her own health caring for spouse]

Quotation(s): 148

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**Code Family: Social world - connect/disconnect**

Codes (153):  [a sense that people weren't understanding of IE's situation] [appreciates being invited for lunch, coffee] [appreciates encouragement] [as a man, IE is outnumbered by women in retirement facility] [asked friends why they distanced themselves] [asserted boundaries of respect with fellow retirement community residents] [avoiding people who will make IE cry]
believes IE would still be lonely in a condo] [But the place where I’m in, I ..] [caring about rude people would make her the same as them] [checks answering machine to see if someone called] [conflicting feelings about separation] [connecting to other residents] [connections to people in care facility] [didn't feel judged by others for spouse's LTCA] [didn't feel retirement community residents were supportive] [didn't spend much time with other visitors because of different schedules] [didn't tell many people about spouse's LTCA] [doesn't fault people for not understanding what this is like] [doesn't feel supported except by family] [doesn't often get asked how IE is doing] [doesn't understand the social distancing] [doesn't want others to think IE is abandoning spouse] [doesn't want to hear other people's problems] [eats out to be around other people] [eats together with fellow widower] [experiences women as natural caregivers] [family busy with their lives] [fears others would judge IE for seeking friendships] [feeling antisocial] [feeling connection through loneliness] [feeling lonely] [feels awkward finding places to sit at social events] [feels he can relax at supper when talking with his men friends] [feels less alone because of retirement community residents] [feels like he doesn't belong] [feels like no one cares] [feels sympathy from women that makes him get teary] [fellow retirement facility resident was rude to IE] [fellow visitors weren't an important factor positively or negatively] [fellowship opportunity one day a week] [felt fellow retirement community residents were too nosy about spouse's condition] [felt spouse's condition was a topic of gossip at retirement community] [friend supported IE and whole family] [friends are helpful] [friends aren't good on computers either] [friends aren't in the best health either] [friends don't know how to interact with IE anymore] [friends email jokes to each other] [friends emailed IE a short video about Alzheimer's] [friends gave up on spouse] [friends have distanced themselves] [friends have their own families and own lives] [friends phone IE regularly] [friends take IE out for coffee] [frustrated with people asking about spouse's wellbeing] [eats out to be around other people] [has coffee and visits with fellow retirement community residents] [has gone through complexities of adjusting social life] [has group of men who have experienced similar situations] [hasn't been very involved in social activities] [her retirement community is always transitioning too] [hurts to answer questions about spouse's wellbeing] [IE and friend leave notes for each other in buddy system] [IE and other visitors didn't visit much with each other] [IE and wife mostly kept to themselves] [IE asked for help from resident at retirement facility and was treated rudely] [IE can't go out with longtime friend] [IE can't partake in costly social activities] [IE didn't interact much with other visitors] [IE didn't want to go out without wife] [IE doesn't contact friend because of differing sleep/awake schedules] [IE doesn't fit with couples or widows] [IE enjoys her rare visits with friend] [IE excluded from activities in other area of retirement community] [IE feels alone when going out] [IE feels isolated] [IE feels isolated in her experience] [IE feels isolated, keeps to herself] [IE felt lonely and didn't know what to do] [IE had some men friends] [IE has no family nearby] [IE has one friend she turns to] [IE talks to others but doesn't find their advice helpful] [IE talks with longtime friend in building] [IE was the oldest in his group of friends at retirement facility] [irony of spouse being active and happy while IE is home alone] [is alone] [isn't content with condo coffee times as his social life] [jokes around with fellow residents at retirement facility] [keeps in touch through email] [knew someone who left spouse with dementia] [knows a lot of people in town] [knows people still care] [leaving old friends behind] [likes an active social life] [longtime friend only goes out with family] [lost contact with friends and acquaintances] [made one very supportive friend (fellow visitor) at care facility]
[misses out on some conversations because of hearing loss] [more women than men at retirement community] [most fellow visitors at care facility didn't make much effort to be friendly] [most people didn't visit their loved ones during luncheon] [most residents have been kind to IE at retirement facility] [My home from another home, my ...] [not a couple, not a widow] [Once you can’t join into every...] [other parts of retirement community have activities] [others tell him to take more initiative] [people were insensitive in what they said] [phones a friend to take IE shopping] [picky about who he spends time with] [public perception that IE wasn't active in spouse's life after LTCA] [relies on friends to help] [retirement community is close-knit - like family] [seeing needs of others and trying to meet them] [sees his friend in condo is lonely surrounded by people] [slowly making new connections in current town] [social death] [social death - can't socialize with couple friends anymore] [social peers judged decision to place spouse] [socially alienating having spouse in LTC] [some friends stuck with them, others didn't] [sometimes the loneliness feels hopeless] [speaks from the heart with researcher] [spent a lot of time alone before spouse's move] [spouse's history of mental illness has always impacted their social life] [stopped going to church after spouse fell 8x in 2yrs] [supportive caregiver peers] [talking openly about the separation was therapeutic still] [talking with friends regularly on phone] [talking with men is a good distraction from what he feels] [uncomfortable spending time with friends when spouse is around] [values people trying to understand her experience] [values the empathy from women and the distraction from men] [very thankful for friends to help with husband's placement] [visits with fellow resident and his in-community wife every night] [visits with fellow residents at retirement facility] [volunteers for the social interaction] [was invited to casual support group but never went] [wasn't active in retirement community during separation] [went to meeting at Alzheimer Society] [when spouse was moved to LTC, IE was used to being alone] [wishes independent living area had organized events like assisted living and congregate] [wishes others would be intentional with him] [wishes people would treat IE normally] [word of spouse's condition spread quickly] [worried about family and friends' support]

Quotation(s): 215

Code Family: Spouse's declining health
Codes (67): [angry that spouse was sick] [care workers and other family members can't speak Dutch with spouse] [couldn't converse much because of spouse's dementia] [didn't blame spouse for his illness] [difficulty seeing spouse's loss of cognitive function] [doesn't think spouse would notice if IE visited less] [doesn't understand much of what spouse says anymore] [doesn't understand why spouse is high risk] [feels fortunate that spouse responded gracefully to increased limitations] [felt like a rapid digression] [gets teary talking about spouse's rapid decline] [glad spouse isn't in diapers] [grateful for how well spouse is doing compared to others] [grateful spouse still had his critical thinking] [hard seeing spouse decline so rapidly] [has lived in Canada for 60 years, but no longer speaks English] [horrible watching spouse's dementia rob him of his mind] [IE looked after spouse's hygiene] [IE separated spouse's mental illness behaviours from who she knew he was] [IE took care of spouse] [it was hard watching spouse's health deteriorate] [knowing that spouse was too far gone to be helped] [mental separation between them because of spouse's dementia] [sad to watch spouse's mind go downhill] [saddening to watch spouse lose basic mental abilities] [sadness at spouse's mental loss] [seeing spouse's gradual decline] [seeing spouse's health deteriorate] [sense of hope that a familiar place would bring back some of spouse's mental functioning] [sense of sadness that spouse doesn't
remember their life together] [spouse's decline happened faster than expected] [spouse's decline has been relatively slow] [spouse's declining abilities] [spouse's declining mobility] [spouse's deteriorating health] [spouse's difficulty adjusting to declining mobility] [spouse's loss of cognitive function] [spouse's lungs filling with fluid] [spouse's mental function has decreased rapidly since LTCA] [spouse became difficult to work with] [spouse couldn't do basic hygiene tasks] [spouse doesn't call IE by name] [spouse doesn't have good short-term memory] [spouse doesn't recognize family] [spouse doesn't recognize own house] [spouse doesn't talk much with IE] [spouse in LTC for 2 months - has gone downhill fast] [spouse is helpless now] [spouse is physically healthy but his mind is gone] [spouse lives in his boyhood past in Holland] [spouse mixes up their kids] [spouse nearly immobile when moved] [spouse needed care 24/7] [spouse resenting IE] [spouse sometimes cries when IE visits] [spouse speaks only in his first language (Dutch)] [spouse still has good cognitive function] [spouse still knows daughters] [spouse still mentally sharp in some ways] [spouse was very active at home] [spouse weakening from multiple factors] [spouse would wander away from home] [struggles to understand how spouse could forget English] [watching spouse's declining mobility was discouraging] [watching spouse's dementia is awful] [watching spouse's physical decline] [wishes spouse's attitude would have shifted years ago]

Quotation(s): 192

**Code Family: Staying involved in spouse's life**

Codes (174): 
[a sense that spouse's experience is improved when IE is there] [after spouse's outburst, waited a day to visit again] [all she and spouse can do is think about each other] [brings spouse to spend time with animals] [calls spouse three times a day] [can't be with spouse non-stop] [can't let spouse have combination to doors] [committed to spouse] [confronted resident's spouse about resident's behaviour] [contact with spouse sometimes makes IE feel more lonely] [couldn't live without wife's big smile] [day program would help spouse be more active] [day revolves around visiting spouse] [despite short term memory loss, spouse was good to talk with] [didn't realize how badly she needed a break] [didn't think it would be possible to get away for a break] [disagrees with physician's opinion] [documented her interactions with difficult nurse] [does spouse's laundry] [doesn't say goodbye to spouse] [doesn't think spouse would notice if IE visited less] [easier to skip visits now that husband doesn't know her] [easier to visit spouse after spouse's sudden 180 degree attitude shift] [eating together] [enjoying spending time with spouse] [enjoys visiting with spouse] [family made IE take a holiday] [family pushes IE to rest] [family pushes IE to take regular day off] [feeling comforted knowing spouse is only a short walk away if IE's needed] [feeling involved in spouse's care] [feels guilty when leaving after visits] [feels less guilty now about taking time for herself] [feels selfish if doesn't visit spouse every day] [feels stronger after a day away from care facility] [felt stronger and rested after holiday] [fetches spouse during the day then brings her back to LTC for night] [figures she was a pest to the nursing staff] [finding balance between advocating for spouse and allowing care workers to do their jobs] [gets frustrated visiting spouse in hospital] [glad when spouse responds positively to IE's presence] [goes along with spouse's cognitive dysfunction] [got spouse a new chair] [grateful for IE's health and that she can visit regularly] [grateful to not have to drive; to be able to visit multiple times a day] [had daily personal interactions with spouse] [hard to take breaks, but knows it's good to do] [harder to skip visits when spouse's still recognize IE] [has learned to take some time off visiting] [have a evening ritual] [helps keep spouse calm] [helps monitor
spouse's health] [helps spouse at mealtimes in LTC] [hopes her involvement improved spouse's care at facility] [I just take about one night a .] [IE can't visit spouse regularly] [IE can speak Dutch with spouse] [IE could calm spouse's outbursts easily and quickly] [IE felt care staff listened to her opinion on spouse's care] [IE gets bored at care facility] [IE goes to visit spouse once a week] [IE had a say in spouse's care at facility] [IE has a hard time not being there every day] [IE has unique insight into spouse's mental state] [IE is committed to her husband and their marriage] [IE sought help for spouse] [IE still involved in spouse's day-to-day life] [IE talks with doctor] [IE the only advocate for spouse - no one else listens to dementia patient] [IE uses her insight to help care workers with spouse's care] [IE wanted to support husband as best she could] [IE was persistent in insisting on spouse's care at facility] [IEs visiting their spouses as they themselves would hope to be visited] [initially feeling lost - no longer responsible for spouse's care] [investing time in their relationship] [it was hard leaving care facility after visiting] [keeping husband involved in paperwork] [knows caregivers have to take care of themselves] [knows she has to take care of herself] [likes to see spouse] [limited access to spouse because of transportation] [looks forward to spending time with spouse] [may not visit daily in winter] [might not see spouse daily if spouse stops recognizing IE] [misses spending time as a couple] [moved spouse for convenience of access] [moved spouse from old facility into nice new one] [moved spouse to more appropriate level of care] [need to reprioritize to spend time with spouse] [not being burden on IE] [often told to visit spouse less frequently] [other care facility would be good for spouse] [others tell IE not to visit spouse so often] [physical relationship hasn't changed] [places responsibility of spouse on his children] [protective of spouse] [report difficult nurse to head nurse] [requested equipment for spouse] [scheduling time to talk] [sees spouse sometimes] [So I look after both] [some days enjoys spending time with spouse] [sometimes brings spouse home] [speaks to spouse in English but he doesn't respond] [spending time in care facility is discouraging] [spending time with spouse helps IE feel useful] [spends lots of time with spouse] [spoke to nurses about spouse's overmedications] [spouse couldn't speak, but still understood IE] [spouse doesn't complain] [spouse doesn't recognize her - she visits spouse because she wants to] [spouse is happy to see her, sad when she leaves] [spouse is happy to see IE] [spouse is special to IE] [spouse is still very nearby - in same building] [spouse needs help eating] [spouse needs to adjust to IE visiting less often] [spouse still does tasks when home during the day, though not always well] [spouse still knows who IE is] [spouse told IE not to visit anymore] [spouse used to hug IE during visits] [spouse was happier after IE got him off so many pills] [spouse was stubborn with IE] [stands up to care workers for what IE wants] [stayed close by spouse] [staying with spouse all the time would be counter-intuitive] [still enjoying physical relationship] [still got a big smile from wife when he got back from vacation] [still went to care facility after spouse died] [stood up for her and spouse's privacy] [stood up for spouse in hospital] [stresses advocating for wellbeing of loved ones in care] [stresses importance of visiting spouse regularly] [takes breaks from visiting] [takes spouse around town] [takes spouse out for coffee] [takes spouse out for lunch] [takes spouse out to visit family] [takes spouse to watch animals] [takes spouse upstairs to LTC for night] [takes the bus] [talks with spouse outside] [thankful she can still have meaningful visits with spouse] [time with spouse is difficult] [took a vacation this year] [took spouse on brief trips but they were terrible] [treasures time with spouse] [tries new ways to spend time with spouse] [tries to engage with spouse] [tries to make spouse's room feel like home] [tries to take spouse away from other residents] [turns on spouse's favourite music for him] [understanding spouse's medications and his medical situation] [verbalizes that they're not bad for taking holidays] [very
glad to have easy access to spouse in care facility] [visited spouse every day] [visited spouse regularly when he was nearby] [visiting spouse] [visiting spouse is hard] [visits spouse every day] [visits spouse multiple times a day] [visits spouse regularly] [walking together regularly] [walks over to spouse's multiple times a day] [wants to spend time with spouse] [was able to look forward to his trip] [was the only one who could see what was happening with spouse] [was the only one who knew how to handle spouse's symptoms] [was told to take a break from visiting spouse] [wasn't ready to move to LTC with him] [wishes care facility had palliative room] [worries about spouse if she doesn't see him regularly] [wrote a log of her visits]

Quotation(s): 250

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**Code Family: Unhappy with food at facility**

Codes (8):

- [advocated for spouse to get better pureed food]
- [advocating for enjoyable food for residents]
- [felt kitchen workers weren't being truthful]
- [figures spouse losing sense of taste is good for the care facility]
- [never voiced her complaints about the unhealthy food]
- [not always happy with the food]
- [not impressed with unhealthy food at care facility]
- [spouse gets more food than he needs]

Quotation(s): 21

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**Code Family: Unpredictability**

Codes (15):

- [after spouse's outburst, waited a day to visit again]
- [asked for explanation for spouse's attitude shift]
- [compares spouse's symptoms with typical disease progression]
- [discouraged with spouse's unpredictable symptoms]
- [doesn't know what to expect when visits spouse]
- [finds it upsetting when spouse deviates from typical Alzheimer's progression]
- [had to be watchful as spouse's hallucinations made her unpredictable]
- [learning about spouse's illness brings a sense of stability to IE]
- [seems confused about spouse's deviation from typical Alzheimer's progression]
- [sense of feeling unprepared, destabilized]
- [spouse's functioning was unpredictable]
- [spouse's unpredictable longevity]
- [the good days and bad days feel unpredictable]
- [wishes people could better predict Alzheimer's symptoms]
- [worried about spouse's adjustment to LTC]

Quotation(s): 30
APPENDIX K: 28 Code Families

Activities - keeping busy
Adjusting
Adjusting - Spouse
Anticipating the future
Comfort in spouse's good care
Concerned about spouse's care
Coping - nonspecific
Daily difficulties
Family - helpful/hurtful
Finances
Humour - keeping sense of
IE's own health
Internal turmoil
Making tough decisions
Medical separation
Miscellaneous helpers
Moving spouse
Others in similar situation
Paperwork
Planning/Preparing
Reaching out
Reflections - positive
Relinquishing care of spouse
Social world - connect/disconnect
Spouse's declining health
Staying involved in spouse's life
Unhappy with food at facility
Unpredictability
APPENDIX L: Concept Maps

Fig. L1. Concept map 1
Fig. L2. Concept map 2.