

MAKING SENSE OF YOUNGER ONSET DEMENTIA: RE-AUTHORING LIFE STORIES DISRUPTED BY LOSS

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Abstract

Despite the recent dramatic growth in research into the subjective experiences of people with dementia, there has been less attention given to the ways that people with dementia find meaning in their illness experiences and the impact of that on their coping. In particular, there is still much to be said and understood about the meaning making of people with younger onset dementia. The purpose of this thesis is to explore the unique ways that younger people with dementia find meaning in their illness journey and how that impacts on the way that they understand and cope with dementia.

A constructivist narrative inquiry approach has informed the design and implementation of this study. Semi-structured interviews have been used to elicit narratives about the experiences of seven people with younger onset dementia in their daily quest to make sense of, and cope with, their illness. Neimeyer's model of meaning making (Gillies & Neimeyer, 2006) is used as a heuristic guide in the exploration of participants' narratives. Within this framework, meaning making comprises three aspects: making sense of losses experienced; identifying and understanding changes to sense of self; and finding benefit in experiences of loss (Gillies & Neimeyer, 2006).

Analysis of data comprises three phases: an initial thematic analysis, focusing on key events and experiences, and the use of metaphorical language and other narrative devices; structural analysis employing narrative concepts which reveal more nuanced aspects of participants' meaning making; concluding with the identification of key meta-themes in participants' narratives. These meta-themes draw on discourses that are familiar and meaningful for participants and include significant family narratives, narratives embedded in life long stories, stories of competence, and narratives of disconnection, trauma and struggle.

A full chapter focuses on key aspects of listening to the meaning making narratives of younger people with dementia. This includes following the movement from conventional narrative structures to more poetic expressions of meaning that occurred over time as an individual's capacities changed. This discussion points to the potential for listening for deeper meaning, which can reveal rich expressions of the storyteller's transitioning sense of self and important exceptions to more privileged self-narratives.

This thesis not only identifies important aspects of meaning making for participants, but points the way for counsellors and other helping professionals to create opportunities for exploration of meaning making with younger onset clients and their families. In this way, counsellors can provide powerful support as clients seek to understand the impact of their illness and potentially find the energy and motivation to live with a sense of hope and possibilities (Bryden, 2015, p. 229).

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Chapter One

Introduction

At diagnosis I faced the awful fear of ceasing to be; not just a physical death, but also a gradual emotional and psychological death, the long goodbye. But I reject this idea, and want to focus on who I am now and what I can still do. I can live a new life in the slow lane. The challenge is to live in a world of hope, alternatives, growth and possibility.

(Bryden, 2015, p. 229)

Prelude

Early in my community-based counselling work I had what I see now was a formative, even transformative experience. I agreed to see a client ('Matthew') who had just been diagnosed with younger onset dementia, a field that was new to me. Matthew was in his early fifties and had recently retired from a successful career in academia. He and his wife had been working overseas, and had cut short their posting because of Matthew's declining health. Our first appointment was in my office, in the company of his wife. It was a moving and emotional session where the couple openly grieved the emerging implications of this new diagnosis. In a poignant moment they clung together, supporting each other, as they reflected on this new vision of their future. Following this meeting, we all agreed that I would work with Matthew as he continued in his daily efforts to adjust to his diagnosis.

Our next couple of sessions were conducted in Matthew's home, while his wife was at work. We established a respectful, gradually evolving connection. In our fourth session it was clear from the outset that things had changed. Matthew greeted me at the door, but seemed confused about the purpose of my visit. Not long into our conversation, he became very agitated, leaving the room. He began to pace around the kitchen, checking doors and windows, watching me nervously. He was clearly distressed, but unable to communicate his anxieties to me, and I was deeply concerned about his rapidly growing agitation. I phoned a male colleague who

worked in the agency's behaviour management team. He arrived promptly and was able to gain Matthew's confidence and his agitation gradually subsided. Following this session, Matthew's partner and I discussed what had occurred in that session and assessed the potential for further counselling work with her husband. We agreed to end the therapeutic relationship with Matthew at that point, while Matthew's wife continued to receive support from another counsellor in the agency.

Reflecting on this experience at the time, and subsequently, raised important questions about my work with Matthew in the light of broader professional issues. As with all counselling clients, there were duty of care and ethical issues to consider, in terms of client autonomy; doing no harm; the right and capacity to give informed consent; and client confidentiality (Corey, Corey, Corey, & Callanan, 2015). As I reviewed my work with Matthew, it struck me like a lightning bolt that consultations regarding our future work did not include him. This was a clear violation of his rights and something that I would never contemplate with any other client. The decision to end our therapeutic relationship was based on my assumptions about Matthew's capacity to engage with and benefit from further counselling support. I began to realise that I needed to know more about providing support to a younger person living with dementia. In particular, I needed to understand what it might mean to receive this diagnosis, and the impact of the changes clients were facing in their lives.

As I progressed my clinical work with younger people with dementia, I became aware of significant conceptual developments in two key fields - bereavement and dementia care. Moving away from phase-stage-task approaches in bereavement therapy (see Rando, 1993; Worden, 2018), Neimeyer (2000, 2004) wrote about the unique quest for a personal narrative that individuals undertake in order to make sense of their lives in times of loss (Neimeyer, 2000, p. 261). He argued that our sense of self is fashioned through the stories that we tell about ourselves, that others tell about us and that we 'enact' in our lives (Neimeyer, 2004, p. 52). Key life events such

as significant loss presents a challenge to the coherence of our self narrative (p. 54). Life stories disrupted by the complex experience of loss must be deconstructed and 'rewritten' to find ways to bridge the past and present and to provide a more coherent sense of self (Neimeyer, 2000, p. 263). These narratives reflect an individual's previous experiences, personality and interactions with others. Telling those stories provides opportunities to articulate and assimilate the multiple meanings involved in losses, and to find ways to live with those losses.

In the field of dementia care, a separate movement associated with exploring the subjective experiences of living with dementia emerged in the 1990s. Some of the impetus for this originated from Kitwood's (1997a; 1997b) watershed work locating dementia within a psychological framework which focused on the needs and well-being of the person with dementia. In this context, valuing the unique experiences of individuals with dementia and their relatedness with others was foregrounded. This was articulated in his concept of 'personhood' which he described as 'the standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust' (1997a, p. 8). Kitwood argued that a person with dementia should not be subjected to depersonalised care practices and reduced solely to their neurobiology. Instead, a person's behaviour needed to be seen within the broader context of their unique temperament, history and the impact of their social and cultural setting, rather than interpreted through the lens of their diagnosis (1997b). Kitwood's notion of person-centred care fostered significant shifts in community and professional attitudes, and in time became integrated into public policy and practice (Baldwin & Capstick, 2007; Kaufman & Engel, 2016; Keady, Williams, & Hughes-Roberts, 2007; Tolhurst, Weicht, & Kingston, 2017).

These two conceptual frameworks offered initial guidance as I sought to provide more effective therapeutic support to people with dementia as they responded to the shifting landscape of their illness. The traditional bio-medical discourse that

Kitwood challenged, conceptualised dementia principally as a disease that brought inevitable decline determined by neurodegenerative changes, with scant reference to the lived experience of dementia (O'Connor et al., 2007, p. 122). Over the past two decades, changes in this field have gathered momentum (Keady et al., 2007). Current research perspectives have broadened and deepened ways of understanding dementia by acknowledging the interaction of biological, psychological, social, and cultural factors and their impact on the subjective experience of dementia (see Clemerson, Walsh, & Isaac, 2014; Keady et al., 2007; Sabat & Lee, 2012).

These developments have fostered a discourse that has moved away from a focus on individual 'symptoms' and their management to a more holistic, situated view of a person with dementia. Even within the life of this study, there have been noticeable shifts in the focus of research. There has been a growing move to qualitative, phenomenological studies which consider the more complex, contextual aspects of living with dementia (Keady et al., 2007).

In earlier research studies, the voices of the people living with dementia were silenced. It was assumed that individuals with dementia had limited insight into their illness experiences and reduced capacity to communicate those experiences in a meaningful way (O'Connor et al., 2007). A turning point has been a call for the inclusion of the perspectives of people with dementia, in particular in research, and associated advocacy and policy development (see Alzheimer's Australia, 2010, 2016; Bryden, 2016, 2018; Rees, 2010, 2015; Swaffer, 2015). In Australia, it is notable that this movement has been fostered by the strong work of younger people with dementia such as Christine Bryden and Kate Swaffer.¹ In addition, Consumer

¹ Christine Bryden is a recognised author, researcher and co-founder of Dementia Advocacy and Support Network International (DASNI). She was the first person with dementia to join the board of Alzheimer's Disease International. Kate Swaffer is the 2017 South Australian of the Year and co-founder and chair of Dementia Alliance International. She has published books and scholarly articles about her experiences with younger onset dementia.

Summits have garnered the views of people with dementia in order to inform submissions to government and guide policy development (see Alzheimer's Australia 2013, 2015, 2016). Despite these improvements, there is still a need to include more people with dementia in research (Swaffer, 2014) in ways that promote their autonomy and well-being (Novak & Wilkinson, 2017). This deepening focus on the subjective experiences of people with dementia is a central theme in this thesis.

Locating dementia

According to the National Centre for Social and Economic Modelling, dementia is a broad term used to describe a syndrome associated with more than a hundred diseases (NATSEM, 2017, p. 1). These diseases are characterised by changes in brain function such as loss of memory; mood changes; changes to reasoning and judgement; problems with communication and social skills; visual perception; and physical functioning (Alzheimer's Association, 2018; Dementia Australia, 2018; Dementia UK, 2018; NATSEM, 2017, p. 1). In 2015, dementia affected an estimated 47 million people worldwide and is seen as a major cause of disability in older adults (World Health Organization, 2017, p. 2). In Australia in 2016, there was an estimated 400,833 Australians living with dementia, of which 44% were men and 56% were women (NATSEM, 2017, p. viii). The number of people with dementia is projected to increase to 760,672 over the next 20 years (NATSEM, 2017, p. viii), unless there is a significant medical breakthrough.

The most common types of dementia include Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies (NATSEM, 2017, p. 1). Each type of dementia is characterised by a different constellation of symptoms. Causes of dementia include a number of conditions which lead to permanent damage to brain cells (Dementia Australia, 2018). People with dementia also have a shortage of some chemicals that are involved with the transmission of messages within the brain (Alzheimer Europe, 2013). Alzheimer's disease is the most

common form of dementia (MacKinlay & Trevitt, 2012, p. 34) accounting for between 50 to 70% of all dementia cases in Australia (Dementia Australia, 2018). Alzheimer's disease is commonly characterised by confusion and memory loss; changes in mood; struggles with the tasks of everyday living and problems with communication, including word finding (MacKinlay & Trevitt, 2012, p. 34). Dementia is progressive and ultimately terminal, although world-wide there is less awareness of this in the community (Alzheimer Europe, 2011; Andrews, McInerney, Toye, Parkinson, & Robinson, 2017).

Younger onset dementia refers to symptoms of dementia developed before the age of 65 (Melbourne Neuropsychiatry Centre, 2008). It is sometimes referred to as 'early onset dementia' or 'working age dementia' (Greenwood & Smith, 2016, p. 103). Nationwide there were an estimated 25,938 people living with younger onset dementia in 2017 (NATSEM, 2017, p. viii). The types of dementia diagnosed in younger people include Alzheimer's disease, which is the most common (Alzheimer Europe, 2013; Roach, Keady, Bee, & Williams, 2014, p. 1398); frontotemporal lobar degeneration; stroke; Parkinson's disease; dementia with Lewy bodies; Huntington's disease; multiple sclerosis; brain injury; HIV-Aids and alcohol-related dementia (Melbourne Neuropsychiatry Centre, 2008). It is more common for people diagnosed with younger onset dementia to move more rapidly through the stages of dementia than those with older onset dementia, which significantly shortens their lifespan (Roach et al., 2014, p. 1398). In keeping with worldwide trends, the majority of the participants in this study were living with younger onset Alzheimer's disease.

Social narratives about dementia

The above brief definitions offer a generalised, medically orientated guide to some aspects of dementia. Equally, it is important to acknowledge that they do not fully convey what having dementia means for individuals, who perceive and experience dementia very differently. As Kleinman (1988) noted, illness is 'multi-vocal' - and

can have many meanings which change over time (p. 8). Not everyone considers dementia as a medical condition. Explanatory models used in the community include seeing dementia as 'a natural part of ageing', and 'a disease of old age'; a 'biomedical condition'; a 'mental disorder'; a 'second childhood'; a 'hereditary condition'; a 'contagious condition'; a 'bio-psycho-social phenomenon'; a 'disability'; 'the result of possession by spirits' and 'a person's own fault' (Alzheimer Europe, 2013, pp. 21-42).

Perceptions about dementia are developed by people based on what they see and hear in the community and their past experiences, knowledge and beliefs. It is also formed by official discourses including government reports and research by other expert groups. These narratives are mediated by social and cultural systems, including popular and social media (Alzheimer Europe, 2013, p. 13).

The type of language used to describe dementia is particularly powerful in its impact on how the condition is experienced and understood. An example of this is the use of catastrophic terms such as 'global dementia epidemics' (George & Whitehouse, 2014, p. 121) and the 'dementia tsunami' which compare people with dementia to natural disasters, thereby increasing the sense of threat associated with the condition (McInerney, 2017, p. 409). In the United States, military metaphors associated with the US-led 'War on Terror' have been appropriated in the 'War on Alzheimer's disease' campaigns. The use of such militaristic terms has framed Alzheimer's disease as an enemy which 'attacks' and 'strikes' the brain of the 'victim' (George & Whitehouse, 2014, p. 122). In this context the only acceptable goal is 'victory' - that is, a cure. This potentially shifts public attention away from alternative ways of responding to the challenges of this condition, such as the provision of effective care and support (p. 121). In this context, fear and antipathy towards people with memory loss are engendered rather than a sense of inclusion and compassion (p. 122).

The development of constructive narratives regarding dementia is still unfolding. In response to the research on the stigmatising impact of negative dementia narratives, a number of associations nationally and internationally have released language guidelines in order to empower people living with dementia (Alzheimer Society of Canada, 2012; Alzheimer's Australia, 2014; Dementia Engagement and Empowerment Project (DEEP), 2014; The Alzheimer Society of Ireland, 2015). One current discourse which promotes the notion of 'living well' with dementia is a welcome development in the move to de-stigmatise dementia. It promotes the notion that people with dementia can have positive experiences, not in spite of, but 'because of dementia' (Wolverson, Clarke, & Moniz-Cook, 2016, p. 676). In addition, there have been increased messages in the media aimed at promoting constructive preventative approaches to dementia, such as 'good brain health' (Lawless & Augoustinos, 2017, p. 62). These new narratives are potentially very positive, and yet, they also risk establishing new expectations about health in older age (Lawless & Augoustinos, 2017, p. 62) and life with dementia that may not necessarily reflect the uncertainties and complexities that individuals experience (McParland, Kelly, & Innes, 2017).

From the above discussion it can be seen that there are complex issues at play when considering how to represent the experience of dementia. Despite increased public education and improved media coverage, dementia remains an illness that is still deeply misunderstood and socially isolating (Rees, 2010). In her early writing, Bryden captured the sense of personal dislocation and separation from others experienced by those with dementia. She observed that if she were to die from cancer she would still be the person she knew - a loving mother, friend and member of a church family. But she asked poignantly, 'When I die of Alzheimer's, who will I be when I die?' (Boden, 1998, p. 47). These are some of the issues still faced by younger people living with dementia today, which illustrate the need to understand

how individuals experience and make sense of their illness in their social and cultural contexts.

Younger onset dementia - a unique challenge

While older people diagnosed with dementia have much in common with younger people living with dementia (Reed, Cantley, Clarke, & Stanley, 2002), the experience of younger onset dementia has been characterised as significantly different from living with dementia in later life (Alzheimer's Australia, 2007, 2013; Cox & Keady, 1999b). The changes and challenges faced by younger people may feel 'out of time' (Greenwood & Smith, 2016, p. 102) as they adjust to a diagnosis that is typically linked with old age and steady decline (Clemerson et al., 2014). The impact of age-based factors such as sustained physical mobility; changing body image; the needs of younger families with dependent children or young adults living at home; and changes to employment and financial security are central to considering the impact of dementia for a younger person (Brown & Roach, 2010; Cox & Keady, 1999b; Greenwood & Smith, 2016; Roach et al., 2014; Roach, Drummond, & Keady, 2016; Tolhurst, Bhattacharyya, & Kingston, 2014). Yet the development of appropriate support services for younger people has been slow to emerge (Rees, 2015), with younger people feeling out of place in community support groups, respite and residential care facilities (Rimkeit & McIntosh, 2017).

The 'out of time' nature of this condition is evident when younger people seek an accurate diagnosis. Diagnosing any form of dementia is a complex process which may be confounded by high rates of co-morbidities such as depression, anxiety and other medical conditions (Bunn et al., 2012; Bunn et al., 2014). It is usual for at least three years to elapse before a firm diagnosis is made in later onset dementia (Phillips, Pond, & Goode, 2011, p. 7). Symptoms of younger onset dementia are frequently misunderstood by health professionals, perhaps because doctors often do not associate dementia with this age group and look to other explanations for

presenting symptoms. As a result, it commonly takes an additional one and a half years to be diagnosed with younger onset dementia (Greenwood & Smith, 2016, p. 102). Delays to diagnosis can mean that a person with dementia may be living with more advanced symptoms, without appropriate support. In addition, the impact of these delays has been linked to an increased burden of care and prolonged confusion, stress and anxiety (Johannessen & Möller, 2013).

A diagnosis of younger onset dementia represents a fundamental shift in how a person sees themselves and can be influenced strongly by the reactions of others (Beard, Knauss, & Moyer, 2009; Clemerson et al., 2014; Johannessen, Möller, Haugen, & Biong, 2014). Many younger people experience a transitioning as their daily sense of self is impacted by their condition. Central relationships and roles in the family change (Cox & Keady, 1999b; Harris & Keady, 2009). While older people with dementia may be retired with married children, younger people are more likely to have younger children, which may mean that a diagnosis of dementia poses a strong challenge for all of the family (Hutchinson, Roberts, Kurrle, & Daly, 2016).

The stigma relating to an illness associated with ageing and the lack of understanding from family and friends regarding the meaning of that diagnosis for a younger person can contribute to a deep sense of isolation and disempowerment (Alzheimer's Australia, 2007; Clemerson et al., 2014). People with dementia may experience persistent negative social positioning by formal and informal carers, where remaining strengths and capacities are overlooked or diminished (Sabat & Lee, 2012.) Some younger people cope with these changes by drawing on past strengths and strategies to re-engage with life (Beard et al., 2009), while others feel disconnected from themselves and the community (Alzheimer's Australia, 2017; Alzheimer's Disease International, 2012; Clemerson et al., 2014). This potential marginalisation comes at a time when younger people usually expect to remain actively engaged personally, socially and professionally and have purposeful, fulfilling lives (Greenwood & Smith, 2016).

Many people notice significant changes in their capacity whilst still employed (Chaplin & Davidson, 2016; Öhman, Nygård, & Borell, 2001). They are often diagnosed at points of active engagement in their careers, impacting workplace identities (Harris & Keady, 2009; Roach, 2017; Roach & Drummond, 2014). Stress and anxiety may fuel innovative strategies for coping with health-related changes (Chaplin & Davidson, 2016; Öhman et al., 2001), but this may delay diagnosis as people seek to disguise their illness.

Once diagnosed, younger people can feel excluded by workplace management from decision making regarding their future. They may be poorly treated by colleagues, resulting in humiliation and deep distress (Chaplin & Davidson, 2016). Despite some innovative workplace engagement programs (Robertson & Evans, 2015; Robertson, Evans, & Horsnell, 2014), there are still significant gaps. Loss of meaningful activity at a time of potentially strong career engagement, combined with financial losses and increased social isolation, can negatively impact a person's sense of self and their significant relationships (Greenwood & Smith, 2016).

The quest to find meaning - the focus of this thesis

In the field of psychology interest in meaning and meaning making has grown over recent years, with a particular focus on its role in coping with stressful life events (Park, 2010, p. 257). Definitions of meaning are often elusive and vary in the research literature depending on the context of the study. In her review of the meaning making literature, Park (2010, p. 257) offered Baumeister's definition (1991) as a reasonable starting point. Baumeister proposed that meaning is 'a mental representation of possible relationships among things, events, and relationships. Thus, meaning *connects* things' (p. 15). In addition, many researchers have emphasised that meaning is not forged in isolation. It is strongly relational and is impacted by a person's immediate social context and wider cultural influences (Bryden, 2018; MacKinlay, 2016; Neimeyer, 2004, 2016a; 2016b; Neimeyer, Prigerson,

& Davies, 2002; Park, 2010), often unfolding over a person's lifetime (MacKinlay, 2016; MacKinlay & Trevitt, 2012).

The seminal work of Viktor Frankl (1984) has been formative in this area of interest. Writing from an existential perspective, he theorised that the compelling human drive to find meaning is a unique quest that can foster hope, well-being and purpose in life. It enables people to face and transcend adversity and deeply challenging personal tragedies, including facing one's own mortality.

While meaning is typically connected with an individual's ideals and values, Frankl observed that it can be surprisingly concrete (p. 121, 122). It may be experienced through tasks and goals that are significant for a person at a particular time in their life (p. 133). Experiences encountered in life such as beauty, goodness and truth or a loving relationship may also create meaning and purpose (p. 133, 134).

Suffering has an important role to play in the search for meaning. When people face adverse life events that they cannot change, Frankl believed that those experiences can be an invitation for individuals to change themselves. If people open themselves to the possibility of meaning, the experience of suffering may be transformed, in some situations through acts of sacrifice (p. 135). In these cases, it is important to 'bear witness' to those human efforts to transcend adversity (p. 135). Listening to the stories of younger people with dementia as they face the deep challenges of their illness is one way to do that.

Even though there is still debate in the psychological literature regarding *how* finding meaning is helpful in adjusting to adversity, it has been acknowledged as an important factor in confronting distressing life experiences (Gillies & Neimeyer, 2006; Neimeyer et al., 2002; Park, 2010). Many researchers have found consensus in detailing key aspects of meaning making (Park, 2010, p. 257). These include that people have orienting frameworks - comprising beliefs, goals and subjective feelings - which are used to interpret their experiences. When life events challenge those

frameworks they appraise the situation and assign meaning to it. The extent to which that appraised meaning does not match their orienting framework impacts the extent to which they experience distress, which then begins a new process of meaning making. In this way, individuals attempt to reduce the differences between emerging appraised meanings and orienting frameworks. This re-establishes a sense of the world as meaningful and their own lives as worthwhile. When successful, this process helps people to cope with the stressful event (Park, 2010, pp. 257, 258).

In the field of loss and grief, meaning making has been seen as a key aspect of adjusting to loss and has been investigated using a range of theoretical lenses (Gillies & Neimeyer, 2006; Gillies, Neimeyer, & Milman, 2014; Neimeyer & Sands, 2011; Worden, 2018). A key contributor to this area of research is Robert Neimeyer, whose concept of meaning making is central to this thesis. His model was based on a review of cognitive, trauma, attachment, and constructivist theories relating to the re-affirming, finding² and reconstruction of meaning in times of loss (Gillies & Neimeyer, 2006, p. 32). The resulting integrated framework encompassed social, behavioural, psychological, and spiritual domains and was designed as a heuristic guide to meaning making. According to Neimeyer, a key aspect of this meaning making process is the reaffirming or reconstructing of self-narratives over the course of grieving a loss (Neimeyer, 2004; Gillies & Neimeyer, 2006). This all takes place within familial, community and cultural contexts, which significantly shape those interpersonal expressions of grief (Neimeyer, Klass, & Dennis, 2014).

In the dementia literature, the role of meaning making has been acknowledged as a significant aspect of coping with dementia (Bryden, 2016; Keady et al., 2007; MacKinlay, 2016; MacKinlay & Trevitt, 2012; MacQuarrie, 2005; Robertson, 2014) but has received less attention in research studies. It seems like a paradoxical question:

² Aligning with Frankl's (1984) notion of *'finding'* meaning.

can a person who is deemed to be 'losing their senses', make sense of life with dementia?

In more recent dementia research, the importance of meaning making has been conveyed in studies that explore how dementia is integrated into a person's sense of self (Robertson, 2014, p. 526). Meaning making has been linked to making sense of illness experiences (see Harland, Bath, Wainwright, & Seymour, 2017; Örvulv & Hydén, 2006), while some approaches have conceptualised meaning making using different theoretical models. An example is the 'meaning making coping' model developed by Park and Folkman (1997) which differentiates 'global meaning' from 'situational meaning' (Park, 2010, p. 258) and concentrates on problem and emotion focused coping strategies (Lee, Roen, & Thornton, 2014). Meaning making has also been explored in the context of life stories (Keady et al., 2007; MacKinlay & Trevitt, 2012; Robertson, 2014). In addition, an interest in meaning making has emerged from research which considers broader spiritual and pastoral care dimensions of living with dementia (Bryden, 2016, 2018; Bryden & MacKinlay, 2008; MacKinlay, 2016; MacKinlay & Trevitt, 2012; Zubrick, 2016). Aspects of meaning making associated with younger onset dementia as a distinct cohort have received less attention, with some notable exceptions (for example see Bryden, 2016, 2018; Swaffer, 2012, 2015).

Given that there has been more limited attention to the interplay between meaning making and younger people with dementia, this thesis explores the meaning making processes of this cohort. Neimeyer's conceptualisation of meaning making was chosen as a guiding framework in this exploration. Neimeyer posits that meaning making involves three discreet elements: making sense of the loss; changes in sense of self; and benefit finding or lessons learnt (Gillies & Neimeyer, 2006; Gillies et al., 2014). Aspects of meaning making addressed by other models employed in dementia research such as changes in identity and making sense of changes and losses are included in Neimeyer's framework. It also includes an intentional focus on benefit finding which involves re-building benevolent views of the world which can

provide motivation for finding positive new goals in life (Gillies & Neimeyer, 2006). Accordingly, opportunities for growth and resilience are highlighted, which resonates with the view that there is scope for positive changes in the experience of dementia (Kitwood, 1995; Wolverson et al., 2016).

Meaning making can be conveyed in many ways. In addition to the telling of stories, attending to the performance of narratives offers additional insights into how the narrator gives meaning to life experiences (McCormack, 2004, p. 223). Historically, a strong focus in the research literature has been on the problems associated with the way that people with dementia communicate (Goldsmith, 1996; Jones, 2015, p. 555). Attention to the richness of their communication has received less attention (Killick, 1999). Thus, this thesis examines the impact of dementia on key aspects of the performance of participant's narratives, the changes to their narrative structures over time and how that shaped and deepened their meaning making.

External influences that might shape a person's narratives are their familial, community, social and cultural connections and interactions (Chase, 2005; Neimeyer, 2000). In order to capture key relational elements that formed the context for participants' meaning making, I chose to interview the younger person's carer, seeking their perspectives on the cared for person. In this way we hear first-hand from the most immediate support that the younger person is experiencing and gain insights into the nature and impact of that support. The inclusion of the carer's stories is not intended to privilege the carer's perspectives or regard them as a more 'reliable' version of the younger person's narratives. Instead, it offers a context for the younger person's storylines using a narrative approach that is outlined below. It is also a response to the growing interest in more systemic approaches to dementia research (see for example Roach et al., 2014).

Against this background, the following research questions were developed:

1. What might the telling of stories reveal about the experience of having younger onset dementia?
2. How might a person construct narratives that contribute to making sense of their illness and changes in their sense of self; and enhance their well-being?
3. How might relevant concepts from the field of loss and grief shed light on this meaning making process?
4. How might the experience of dementia shape the narrative structure of these stories?
5. How might the responses of the younger person's carer impact on the younger person's meaning making?

Locating the methodology

In order to explore in depth how younger people with dementia found meaning in their illness experiences a qualitative approach, using narrative inquiry, was chosen. Narrative interviews were employed to elicit stories that might convey the complexity and iterative nature of meaning making processes.

The significance and function of storying lived experiences is a key concept in narrative inquiry and encompasses the personal, interpersonal and social domains (Neimeyer, 2004). Creating narratives about life events offers the scope to story and re-story experiences in order to understand those events and the role that others have played in the narrator's world. This process has the potential to transform the narrator and the narrative (Caine, Estefan, & Clandinin, 2013). In particular, telling stories helps individuals to make sense of the challenges and paradoxes of their lives in order to create a new narrative coherence and purpose in times of adversity and loss (Neimeyer, 2000, 2016b). This is particularly germane for younger people who are struggling to make sense of an illness that is associated with ageing and may take years to be diagnosed.

A key aspect of narrative interviews is the scope they offer for uninterrupted opportunities to hear in depth stories of loss, when individuals may be feeling marginalised and invalidated by others in the community (Gilbert, 2002). Younger

people with dementia report strong feelings of stigma and depersonalisation as they struggle to come to terms with an illness that is still widely misunderstood in the community (see Alzheimer's Australia, 2017; Alzheimer's Disease International, 2012; Burgener, Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu et al., 2015; Swaffer, 2014). Inviting participants to tell their stories offers the opportunity for them to explore their experiences on many levels and to reflect on, and recreate the rich personal meanings associated with their condition. In addition, the storying of experience over an extended period allows for the narrative sequencing of events over time (White & Epston, 1990), revealing the nuances of the meaning making processes that do not remain stable but are iterative and emergent (Neimeyer & Sands, 2011).

Locating the participants

Participants in this narrative study shared my Anglo socio-linguistic background, providing some initial points of connection when we met. Seven people (three women and four men) with early to mid-range younger onset dementia were recruited. Five had Alzheimer's disease, while one person had a mix of Alzheimer's disease and vascular dementia and another was given no specific diagnosis other than dementia. Their age at interview ranged from 59 to 67 years of age. All participants had been working at the time of their diagnosis, except for one person who had retired earlier due to a pre-existing chronic health condition. Some were professionals while others worked for government or in their own business. They had all accessed services provided by a local agency who supported people with dementia and were recruited through that agency.

Five participants had carers, four of whom were spouses, while one was cared for by her daughter.

Locating the researcher

As a counsellor, with a particular interest in loss and grief, my work has been principally informed by a 'person-centred' clinical framework. Person-centred work maintains a fundamental belief in the subjective perspective on human behaviour and focuses on the exploration and understanding of the personal experience of the client (Nelson-Jones, 2015, p. 93). Working within this framework, the meaning of experience is constructed by each client in their context (McLeod, 2013, pp. 171,172). As a person centred counsellor, I adopt the view that most people have at least some capacity to know and understand themselves and have the resources to identify the need for personal change on different levels, given the right therapeutic conditions (Nelson-Jones, 2015, p. 104).

My experiences in providing counselling support to people with dementia, in a community agency which privileged a bio-medical model, challenged these fundamental counselling beliefs. My own constructions of dementia were deeply influenced by strong early research discourses which promoted the view that people with dementia had limited insight into their experiences and were physically present but psychologically absent (Doka & Aber, 2002). This medical model emphasised support for carers, in particular, in managing the cared for person's 'difficult behaviours'. It is shocking, but not surprising in this therapeutic climate, that it was over a decade before I worked directly with the person with dementia. Apart from this professional experience, my very meaningful role in sharing the care of my father, who had dementia with Lewy Bodies and Parkinson's disease, made deep impressions. At that time, the assistance offered by community agencies focused on supporting me as a part-time carer. There was no direct engagement with my father who could have benefited from skilful professional support.

A major impetus for this study has been a search for counter narratives to the constructions of dementia care that informed my emerging practice. My clinical and

personal experiences were at the heart of my desire to understand and validate my participants' subjective experiences and meaning making, and to follow their storytelling processes as we co-constructed interview narratives.

Reading this thesis

This aim of this thesis is to raise important questions about the experience of younger onset dementia and in particular, to explore the process of meaning making in order to understand how that shapes a younger person's daily experiences of dementia. The intended readers for this study are the counselling and helping professionals who will be working with those people as they learn to live with their illness. In addition, I wish to share my own journey in making the radical shift from a medical model to respect for a person-centred approach to supporting people with dementia, with its attendant values. This is an area which has received less attention in the literature, with the notable exception of Lipinska (2009). I hope that other clinicians and helping professionals will be encouraged to take a similar path.

This chapter has introduced some key concepts and issues associated with the experience of younger onset dementia. The following chapter (Chapter Two) offers a context for this study by providing a synthesis of the research literature relating to the experience of dementia with a focus on younger onset. In particular, the role of meaning making and its impact on a person's well-being is explored. In this overview of the research, I outline some of the significant gaps in the literature that this thesis addresses. In Chapter Three, I trace the conceptual development and design of the study and describe key focal points and notable aspects of its implementation. This encompasses how the study design addresses specific issues associated with including people with dementia in research.

In Chapters Four to Ten we hear in depth the narratives of each study participant. The first section of the chapter stays close to the participant's story and is illustrative of person-centred research reporting. Each chapter begins with some background

information which contextualises the participant's narratives. Key themes from each participant are presented as they unfolded across the three interviews. Quotes from the interviews are included with the researcher's accompanying questions, so that the constructed nature of the narrative is more clearly conveyed.³ Where relevant, some of the participant's carer's responses are also presented in order to illustrate that contextual dynamic. The second part of the chapter moves the reader away from a close reading of the participant's responses to explore broader issues raised by the research questions outlined above. Hence discussion of the data is embedded in each chapter and comprises the researcher's analysis, which links key narrative themes with the relevant research literature.

Chapter Eleven deepens the discussion presented in the data chapters, by devoting an entire section to the challenging aspects of listening for meaning in the stories of dementia. It includes listening for narratives of self which convey meaning making in times of transition; finding ways to 'transcend the obvious', by going beyond the literal to meaning making conveyed through metaphor and 'oblique allusion' (Kitwood, 1997b, p. 15); and listening when words fail - exploring how different narrative forms and non-verbal communication can convey significant meaning.

Chapter Twelve concludes the thesis with a distillation of key aspects of meaning making that emerge from this study. The effectiveness of narrative inquiry as a methodological approach and the usefulness of Neimeyer's concept of meaning making as a heuristic lens are also assessed. In this chapter my own development as a researcher is plotted, particularly in relation to my capacity to hear the stories that I elicited. Finally, I outline the implications of this research for the provision of effective counselling support for people with younger onset dementia and their families, the limitations of this study and avenues for further inquiry.

³ Verbatim quotes from interviews are italicised.

Chapter Two

Missing voices, missing lives

Introduction

In Chapter One, I described a changing research and policy agenda which has begun to include the experiences and voices of people living with dementia. This has heralded a gradual movement away from bio-medical models and earlier notions of personhood (see Kitwood, 1990, 1995, 1997a, 1997b) to the embedding of dementia within broader socio-political and systemic discourses (Bartlett & O'Connor, 2010; O'Connor & Nedlund, 2016; Tolhurst et al., 2017). While Kitwood's concept of personhood continues to be critiqued for its particular focus on the significance of interpersonal relationships (Bryden, 2018; Swinton, 2008), his pioneering concepts and their attendant values remain influential in research and care practice (Baldwin & Capstick, 2007; Kaufman & Engel, 2016; Tolhurst et al., 2017).

Despite this shift to a more holistic, nuanced exploration of the subjective illness experience, research which highlights the role of meaning making in adjusting to living with dementia has been more limited. In addition, while earlier innovative research focused on younger people with dementia and the need for tailored service planning and provision (see for example Cox & Keady, 1999a), this group is still frequently overlooked as an area worthy of separate investigation (Clemerson et al., 2014; Roach et al., 2016).

In the context of these developing research trends this chapter provides a synthesis of more recent literature relevant to the study focus. The reviewed literature is primarily confined to qualitative, phenomenological studies from the last two decades, with the exception of earlier formative works. Significant aspects of the illness experience which may impact meaning making processes for younger people with dementia are highlighted, while important gaps in the research are noted.

Detailing these gaps provides a framework and rationale for this study and sets the scene for the methodological and data chapters that follow.

In the first chapter, I referred to the impact of traditional bio-medical paradigms and their role in shaping our understanding of dementia. This approach has privileged a focus on the impact of neurodegenerative changes, particularly in the later stages of the illness (Bryden & MacKinlay, 2008, p. 136), and the challenges of managing the symptoms associated with those changes (O'Connor et al., 2007). In the last few decades, the interplay between biological, psychological, social, and cultural factors and their impact on the subjective experience of dementia has been acknowledged (Clemerson et al., 2014; Sabat & Lee, 2012). In addition, a growing body of qualitative research has investigated contextual aspects of living with dementia (Keady et al., 2007). Some of this research has included the perspectives of the person with dementia as well as carers and, more recently, broader multi-generational, systemic and social contexts have been explored (see Kontos, Miller, & Kontos, 2017; O'Connor & Nedlund, 2016; Roach et al., 2016; Roach et al., 2014).

In Chapter One, I described how I had unwittingly disenfranchised my client with my assumptions about his capacity to engage with counselling processes. Similarly, the literature shows how suppositions about lack of insight and capacity to communicate have meant that the voices of people living with dementia have been slow to emerge in research discourses (O'Connor et al., 2007; Swaffer, 2014). Examples of people with dementia setting the research agenda are even rarer (for example see Bryden, 2018; Harris & Sterin, 1999; Swarbrick, Open Doors, EDUCATE, Davis, & Keady, 2016). However, a more complex, nuanced picture of the experience of living with dementia is beginning to emerge from research conveying the profound struggles people face daily, along with the 'beauty and lessons' learnt (Swaffer, 2012, p. 90).

Crossing the line - receiving a diagnosis of dementia

A strong theme in the literature is the initial impact of receiving a diagnosis of dementia (Bunn et al., 2014). Some of the challenges associated with diagnosis have been explored using bio-medical or systemic perspectives while other studies focus on the subjective meaning of receiving a diagnosis and its effect on an individual's coping and sense of self.

Obtaining an accurate diagnosis of dementia is a complex and stressful process which may be influenced by social and cultural beliefs about dementia; failings in the medical system (Bunn et al., 2014); and the confounding effects of co-morbid conditions (see Alzheimer Europe, 2011; Campbell et al., 2016; Perry-Young, Owen, Kelly, & Owens, 2018; Lee et al., 2014). As a result, people experience significant delays in confirming a diagnosis or, in some cases, remain undiagnosed (Alzheimer Europe, 2011; Phillips et al., 2011).

As noted in Chapter One, the entire diagnostic phase can be a time of disabling fear and uncertainty for individuals and families (Campbell et al., 2016; Roach et al., 2016) who often notice symptoms up to two years prior to the first consultation with a health professional (Phillips et al., 2011, p. 7). Notably, the person with dementia often identifies memory lapses first, while the carer may focus on more subtle changes in personality (Perry-Young et al., 2018). More recent research has pointed to the potential for an increased risk of suicide for the person with dementia, particularly in the first three months after diagnosis and where there is a pre-existing history of depression or suicidality. In their discussion Draper, Peisahab, Snowdonde and Brodaty (2010) note the need for counselling support at this critical time because of these escalated risks.

As individuals notice changes in their capacities and begin the process of seeking a diagnosis, reactions can vary. Some people move into a 'liminal' status of uncertainty and ambiguity. They can no longer return to their pre-diagnosis sense of

themselves, but may avoid the status of being known as the 'person with dementia' (Birt, Poland, Csipke, & Charlesworth, 2017, p. 201). Yet, dementia is not always perceived as a devastating disease, especially at first. Some people ignore or downplay the implications of a diagnosis, while others wait and see what the new landscape of dementia looks like (Alzheimer Europe, 2013).

On receiving a diagnosis, a confusing mix of emotions may be experienced, such as shock, fear about the future and acceptance (MacKinlay & Trevitt, 2012; Milby, Murphy, & Winthrop, 2017). In the midst of these powerful emotions, people can become defined by deficit narratives about their condition. Created by themselves and others, these negative narratives can lead to social exclusion and stigmatisation (Birt et al., 2017; Swaffer, 2015). Swaffer (2015) described this experience as 'prescribed disengagement' (p. 3). It occurs when the newly diagnosed are told by health professionals to give up the life they have been leading to date and to go home and prepare for the worst. Not surprisingly in this scenario, a crushing sense of defeat and 'anticipatory helplessness' can overwhelm pre-existing coping strategies as any hopes for the future evaporate (Bryden, 2015, p. 262).

Conversely, some people see the benefit of a diagnosis as they are now able to put a meaning to their experiences, even if that meaning is initially upsetting. Lee and colleagues (2014) argue that acceptance of a diagnosis can open opportunities for agency and embracing of a new identity. In some cases, dementia is not seen as a problem by the person diagnosed, but they may be concerned about its impact on their families (MacQuarrie, 2005).

Birt and colleagues (2017) posit that movement beyond this liminal diagnostic phase into a more constructive engagement with an individual's illness is contingent upon personal and cultural beliefs, the responses of others and pre-existing comorbidities (p. 199). In order to adjust to a diagnosis and move on with their lives some people employ both problem and emotion-focused coping strategies. Cognitive re-

appraisals, which involve re-assessing and restructuring beliefs and assumptions can be employed to accommodate the diagnosis and life changes (Lee et al., 2014). Practical strategies such as normalising the condition and using practical aids assist in positively adjusting to the diagnosis along with familial and social supports - such as attending community groups and involvement in a faith community (Harris & Sterin, 1999, p. 247). Notably, Lee and colleagues (2014) argue that people who are unable to make sense of their experiences have problems accommodating the diagnosis and its consequences, and may experience ongoing distress, even though they continue to use practical coping strategies.

As some people struggle to confront or maintain a psychological and emotional connection with the meaning of a diagnosis, they can adopt a range of protective responses. For example, people might seek out information about dementia but not a diagnosis that could position them in a stigmatised group (Milby et al., 2017, p. 612). With the newly diagnosed, avoidance of information from health professionals is more likely if people feel unable to change their situation. They may then turn instead to other explanations to normalise their memory loss. The stigma associated with dementia and lack of knowledge regarding how to access information can create further barriers to seeking help (Harland, Bath, Wainwright, & Seymour, 2017).

There is a growing view in the dementia literature that ambivalence, denial and avoidance throughout the diagnostic phase can be adaptive and form part of an individual's grieving responses as they integrate their diagnosis into their sense of self over time (Harman & Clare, 2006). Research has cited examples of coping strategies which include moving between loss-oriented responses and processes oriented to re-claiming normal living (Lee et al., 2014; Milby et al., 2017). This resonates with Stroebe and Schut's (2010) model for grieving responses (Lee et al., 2014). It is argued that these processes help to maintain emotional equilibrium and manage loss of sense of self and anxieties about the future (Milby et al., 2017;

Lishman, Cheston, & Smithson, 2016). Notably, there may be a ‘parallel process of avoidance’ in clinicians, specifically in relation to using explicit terminology to label the diagnosis (Milby et al., 2017, p. 615). Lishman and colleagues (2016) argue that social support is critical in providing a safe context within which to approach acceptance of a diagnosis, as people can withdraw from the judgement of others in more threatening environments.

The examples of research cited above illustrate the importance of understanding the varied, complex individual responses in this phase, in particular, the function of ambivalence and denial which may provide some respite from the shock of receiving a diagnosis. Each person’s familial, social and cultural context will impact on the meanings they attach to this change in their health. A range of adaptive responses can be employed that need to be recognised by helping professionals, along with the impact of significant relationships on the person’s coping responses over time.

The degenerating sense of ‘nobodiness’⁴ - selfhood and dementia

Am I now less human? Is my existence diminishing in lockstep and because of the progression of the disease? Is there still a ‘Richard’ who is mutually exclusive from the disease?

(Taylor, 2007, p. 117)

For the person diagnosed with dementia, there can be profound challenges to their sense of self. Richard Taylor’s moving questions (cited above), speak to the deep existential struggles of many people with dementia as they seek to understand their illness and find meaning in the context of their changing sense of self. Taylor was an American psychologist who was diagnosed with Alzheimer’s disease at age 58 and who died in 2015. He co-founded Dementia Alliance International and was widely known for his series of essays which afforded a deeply personal window into his daily struggles to understand the impact of his illness on his fluctuating sense of self.

⁴ Swaffer, 2012, p. 96.

People living with dementia have been described as being in a 'state of flux' (Harris & Sterin, 1999, p. 246). As people experience dramatic shifts in their sense of self due to illness, there can be a 'crumbling away of former self-images' without the simultaneous development of equally valued ones' (Charmaz, 1983, p. 168). For the person with dementia, this can feel like a relentless deconstruction of the self with no way back to wholeness (Lipinska, 2009, p. 48). In the wake of these feelings, there may be an urgent need to make sense of these changes and build valued new self-images. Several studies have indicated that the success of this process can depend on the individual's meaning making, and the nature of their social context (see Harris & Sterin, 1999; Lishman et al., 2016; Birt et al., 2017).

As individuals struggle to maintain their sense of self, they can experience a range of emotional reactions including frustration, humiliation and shame, anger, fear and disempowerment. In the wake of these powerful feelings, coping strategies aimed at maintaining a sense of self may include the adoption of varying storylines such as, 'I'll live until I die'; 'I accept what I have'; 'There is nothing wrong with me'; 'I'm just struggling to get through the day'; and 'I'm giving up' (Harris & Sterin, 1999, pp. 248-249).

There has been a long standing view in the literature regarding the impact of dementia, as being like a steady erosion of the person's sense of self until no 'person' remains, just an empty shell (Alzheimer Europe, 2013; Bryden, 2018; Bryden & MacKinlay, 2003; Downs, 1997; Kitwood & Benson, 1995; Kontos, 2003; Sabat, 2001; Sabat & Harré, 1992). Very early in my role as a counselling educator I subscribed to this view. Over time, the implications of this belief became clearer to me. The empty shell image is a legacy of Western conceptualisations of personhood, with its privileging of cognitive processes (Kontos, 2003, p. 152). From this perspective the physical body is seen simply as a container for the mind, where the 'real person' is to be found (Alzheimer Europe, 2013, p. 51). This notion leaves the door open for what Kitwood described as a 'malignant social psychology' (1997a, p. 45), where people

with dementia are positioned as less than fully human. By adopting this view, the feelings and concerns of those with dementia can be overlooked, resulting in disempowerment, intimidation, objectification and stigmatisation (Kitwood, 1997a, p. 46).

A counterpoint to this dualistic, de-humanising notion has emerged in research and has gained currency. Many studies have argued that, although there is a decline in capacity, people with dementia experience an enduring sense of self and most notably, in some cases, scope for growth (Bryden, 2018; Clark-McGhee & Castro, 2015; Hedman, Hansebo, Ternstedt, Hellström, & Norberg, 2013; Kitwood, 1995; MacKinlay, 2016; Sabat & Harré, 1992; Sabat, 2002).

In this debate regarding the nature of self, new paradigms for understanding how people with dementia experience their sense of self have emerged. This includes the concept of 'multiple components of identity' (Cadell & Clare, 2013, p. 319) or multiple selves, rather than a single, unified entity. From this postmodern perspective, the self is a more complex, shifting phenomenon that is shaped by the person's context and relationships (Sabat, 2002; Sabat & Harré, 1992). It is also embodied. The notion that people with dementia experience themselves through maintaining a sense of their embodied experiences in the world, even though they may not be able to fully articulate those experiences, has been largely overlooked, but is gaining recognition in the literature (Bryden, 2018; Kontos, 2003; Kontos & Martin, 2013; Kontos, Miller, & Kontos, 2017).

While there is consensus that aspects of the self are impacted by significant neurological changes to a person's mental and physical capacities as dementia progresses, some writers maintain that significant elements of these attributes remain (Sabat, 2002, p. 25). In addition, some people with dementia develop new skills over the course of their illness (Sabat, 2002; Hedman et al., 2013). Furthermore, features of the self that are publically presented in everyday, personal interactions

can be significantly impacted by the ways in which others perceive them once changes are noticed (Hedman et al., 2013; Sabat & Harré, 1992; Sabat & Lee, 2012).

From this perspective, while cognitive and behavioural problems may arise, there is no loss of self, and only an indirect loss of selves, even in the end stages of dementia (Sabat & Harré, 1992). This view of personhood and the impact of dementia on the self has important implications for how those with dementia are supported, particularly in formal care settings (Kelly, 2010). Loss of selves can be prevented if carers and significant others stop positioning the person with dementia as 'helpless' and 'confused' (Sabat & Harré, 1992, p. 460).

A more recent view has challenged this notion of 'malignant social positioning' (see Kitwood, 1997a; Sabat, 2001). It is argued that this approach could be seen as privileging the narrative of the person with dementia over the struggles of informal carers who have their own challenges and constraints in their caring role (Tolhurst et al., 2017). This cautionary note alerts us to important issues and I also see the need to guard against the negative positioning of people with dementia, which may frame 'successful adaptations' to their illness as 'symptoms' to be managed (Sabat & Harré, 1992, p. 448; Sabat & Lee, 2012).

Most recently, Bryden (2018) has contributed to this debate by bringing her perspectives as a person living with dementia. She passionately advocates for the view that people with dementia experience a continuing sense of self. She argues that over time she has experienced a relational, embodied sense of self, who has been able to find meaning in the present moment (p. 279). This concept of a continuing sense of self is fundamental to this thesis. Hence, exploration of the changes to each participant's sense of self over time is explored in the data chapters that follow.

As noted above, a significant aspect of the way a person with dementia experiences themselves is the impact of their social context and changes in their social identity (Robertson, 2014). As individuals struggle to maintain agency and preserve a sense

of self, a line can be crossed when relatives, carers and professionals treat the person differently, for example, excluding them from conversations and access to information about their illness (Harman & Clare, 2006, p. 495). Harman and Clare (2006) found that in order to cope, individuals may hold different feelings and beliefs in tension as they move between approaching and avoiding their illness and actively fighting or passively accepting their diagnosis. There can be a belief that 'it will get worse', along with a desire 'to be me' which speaks to maintaining a sense of self in the face of loss (p. 484).

The impact of social contexts on the person's sense of self is also explored by Clark-McGhee and Castro (2015), who challenge a tendency by significant others and/or health professionals to invalidate, and thereby limit, the capacity of the person with dementia to express their long-established, 'preferred self' (p. 12). The writers posit that telling unique life stories which convey past, highly valued skills expresses a yearning in participants for autonomy and agency amidst the painful process of being 'de-personed' (p. 15). Their research showed that persisting, powerful expressions of very human responses over the course of the illness can be heard through the evocative language of poetry – a form of communication that is afforded less attention in the dementia research. I will explore these issues further in the chapters that follow.

While self-doubt may build as people with dementia are disregarded and disempowered, some people can take unexpected actions to preserve their sense of self (Clark-McGhee & Castro p. 12). This includes falling in love again (p. 16) along with wanting to be a 'full person in the world'; and striving to maintain life-long values and resist the social constraints of dementia (p. 21). Highly valued social skills such as a capacity for caring relationships, emotional intelligence and values based behaviour (p. 21) remain in people with dementia, even though they are often overlooked in medically oriented assessments of a person (Clark-McGhee & Castro, 2015, p. 21; see also Sabat, 2001; Sabat & Lee, 2012).

The experience of a changing sense of self is revealed in more depth when looked at in the context of a person's whole life experience (Keady et al., 2007). This approach uncovers strengths and coping resources that have been developed in response to earlier adversity, potentially building resilience. An illustration of this is 'Janet', a participant in research by Angus and Bowen-Osborne (2014) who lived in a residential aged care facility and had moderate dementia – Alzheimer's type (p. 148). She chose to orient her experience of dementia within an overarching narrative of a life-long disability, caused by a serious injury to her arm that occurred as a baby. Despite her reduced language capacity, Janet generated a compelling self-narrative that opened the way to understanding important aspects of her resilience. This was built up over time within the context of her family and religious life, and the impact of her beliefs about disability, illness and well-being (p. 157).

Locating the behaviours and experiences of the individual within their family structures and dynamics offers a multi-layered context within which to understand the various factors at play in an individual's changing sense of self. Borley, Sixsmith and Church (2016) found that strong family narratives about providing care for others in the past, can shape the meaning of subsequently becoming a recipient of care for the person with dementia. While individuals might desire to continue to be useful in the family and not become a burden, a growing need for assistance may not alter a person's sense of self if these changes are linked with past successful efforts to face adversity.

Some researchers use the lens of gender to explore changes to identity for those living with dementia. Tolhurst and Weicht (2017) consider the impact of experiencing an illness that creates a sense of vulnerability and powerlessness, and the challenge this potentially poses for men. The writers suggest that this challenge is particularly strong for men who want to preserve their personhood in social contexts that privilege 'independence, resilience and instrumental competence' (2017, p. 30).

The researchers found that strategies to address these important issues included stoic acceptance of the constraints of the illness and using personal strengths to remain the same person in the face of adversity, thereby avoiding negative social positioning. Proactive 'fighting back' against the constraints of the illness involved adopting problem solving approaches to avoid being defined by the condition, in order to stay connected with former roles, status and autonomy. Some men stressed the positive social contributions that they were making in familial relationships, groups, employment and various social contexts, in order to avoid being positioned as passive. From this perspective, accepting help from health professionals in community groups was reframed as active social engagement; assisting caring partners by giving them a break; and offering practical assistance to others rather than receiving help (Tolhurst & Weicht, 2017).

Continuing the focus on gender, Borley and Hardy (2017) found that there are important individual differences in how women cope with transitioning into a cared-for role. In particular, this can involve acknowledging the impact of past life experiences and gender role expectations within differing social contexts. Being cared for may affect perceptions of self particularly in regards to past central roles in the family and the ways that a person has expressed intimacy (p. 1019). Negative feelings of self can be linked to a reduced capacity to undertake routine daily tasks or changes in positive attributes, such as decision making capacity, as others in the family assume those tasks and roles. Some women miss taking charge or fight to maintain their central position in the family, while others are able to adjust and accept change (p. 1020).

While these studies identify important issues for the person with dementia, such as the impact of negative social positioning and the need to retain a connection with former strengths and skills, it could be argued that many individuals with dementia experience aspects of these challenges, irrespective of gender. This may be the case particularly for younger people with dementia, whose gender roles might be more

fluid due to age related factors. For example, both the person with dementia and their carer may be in full time employment at the time of diagnosis and consequently sharing various roles in the family.

The notion of 'selfhood' in dementia is complex and dynamic and is shaped by the ways that people encounter daily life in their social and cultural contexts. Established and reassuring versions of self may disappear (Charmaz, 1983) while new adaptive aspects of self can emerge (Clark-McGhee & Castro, 2015; Hedman et al., 2013; Sabat & Harré, 1992; Tolhurst & Weicht, 2017). Connecting with the meaning of a diagnosis for a person's sense of self might be too difficult to sustain over time, so that fluctuating, contradictory feelings and beliefs are held in tension by the person with dementia (Harman & Clare, 2006). Understanding these experiences can be deepened by locating them within the context of family dynamics (Roach et al., 2016; Roach, Keady, Bee, & Hope, 2008; Roach et al., 2014) and the whole of a person's life experiences (Keady et al., 2007).

Adrift in the dark days - the loss and grief of dementia

Every day I live with the fear that everything I hold so dear ... will slip through my fingers like sand ... have I just gone on my last trip, read my last book, had my last meaningful conversation? ... I feel adrift and at a loss ...

(Bryden, 2015, p. 217)

As people navigate the often poignant changes associated with living with dementia, they experience a range of grieving responses that may be difficult to name and communicate. These grieving responses can include seeking to understand and articulate the meaning of these changes and losses as the person adapts to and creates new life narratives.

The psychological and social losses sustained by the person with dementia are encountered every day (Bryden, 2015; Harris & Sterin, 1999; Swaffer, 2012). As discussed earlier, diminishing cognitive capacity and decreasing independence

impact on a person's sense of autonomy and sense of self. Meaningful roles and responsibilities may disappear, while sustaining relationships are altered or lost. A changing capacity to complete tasks of daily living threatens the person's sense of self along with the erosion of valued memories (Harris & Sterin, 1999; Noyes, 2002).

While the range of losses associated with living with dementia have been broadly acknowledged in the grief and loss literature (Noyes, 2002; Beard et al., 2009), less attention has been given to finer grained, contextualised analysis of the nature of the grief experienced by the person with dementia; and how that grief might be expressed. This is surprising given that MacKinlay and Trevitt (2012) found that participants in their study involving older people with dementia, wanted to talk about their experiences of grief, even though they may have struggled to communicate those experiences. In contrast, there is a strong focus on the grief of informal care-givers and families (see for example Blandin & Pepin, 2017; Boss, 1999, 2010, 2011; Doka, 2004; Doka & Aber, 2002; Lindauer & Harvath, 2014; MacCourt, McLennan, Somers, & Krawczyk, 2017; Noyes et al., 2010).

In considering how people with dementia experience their grief, remnants of the bio-medical discourse are evident in questions about the capacity of a person with dementia to experience their grief at all. It has been posited that, although the person's suffering is real, the complex interrelationship between subjective experiencing and the neurological changes that are associated with the condition make it difficult to determine whether a person's responses are evidence of grief or other neurological changes (Rentz, Krikorian, & Keys, 2005). A counterpoint to this position is the observation by Doka (2004) who noted that people may assume that the person with dementia has no insight into their losses and consequently does not experience any grief (p. 145). He names this as the disenfranchised grief of people with dementia. This can be seen as another example of the 'de-personing' (Clark-McGhee & Castro, 2015) of those living with dementia.

Associated with these ideas is the notion in the loss and grief literature, that the self of a person with dementia 'dies'. This has been described as a psychosocial death (Doka & Aber, 2002) where the essence of the person gradually 'dies' over the course of their illness. From this perspective, family carers grieve the loss of their cared for relative, who they regard as having 'died' years ago (Boss, 1999, p. 45). A key theme in this discourse, which emerged principally from research on carers, is that people with dementia are physically present, but psychologically absent - creating a form of 'ambiguous loss' which is difficult to convey to others (Boss, 1999, 2010). It is surprising that this discourse has persisted, given the shifts in other research narratives discussed earlier in this chapter that supports the notion of an enduring sense of self in the person with dementia.

Notably, there are examples of challenging this, such as one family included in research by Boss (1999) who positively embraced the new self of their mother who had dementia. They focused on working constructively with the changes their mother experienced, emphasising the joyful aspects of their lives together. This enhanced the family's capacity to cope with the changes and losses experienced by the person with dementia (Boss, 1999, pp. 53-56).

A more recent notion has been suggested by Lindauer and Harvath (2014) that provides an important counterpoint to the picture of the person with dementia as physically present, but psychologically absent. They posit that caregivers may grieve the psychological loss of aspects of the person that the family has known over time, while at the same time, there are important aspects of the person that persist and are valued.

A distinction has been made in the literature between dementia grief and the anticipatory grief experienced with other terminal conditions (Blandin & Pepin, 2017). With dementia grief, there are changing communication skills and an altered awareness in the person with dementia. As a consequence of this, resolution of

conflict and meaningful sharing of feelings will be more difficult and this may impact on the carer's experience of bereavement. The concept of the 'receding of the known self' (p. 70) captures the psychological losses incurred by the person with dementia. This includes changes in the self, such as identifying personality characteristics, memories and abilities.

Blandin and Pepin propose a new model of dementia grief that echoes other research which focuses on the role of transitioning and liminality in the dementia experience (see Birt et al., 2017). They posit that grief cycles through three states: separation in the face of serial losses; liminality, a state of transition through uncertainty and change; and re-emergence to a state of acceptance and adaptation (pp. 72-74). Observations by younger people with dementia relating to their experiences of grief suggest that this process is iterative, and fluctuates between connecting with deep grief and seeking positive ways to live with the condition (Bryden, 2015, 2016; Swaffer, 2012).

The welcome move away from discourses relating to the notion of ambiguous loss and the psychosocial death of the person with dementia (Boss, 1999, 2010; Doka & Aber, 2002) has strengthened the idea that people with dementia can maintain a sense of their self, including in their grieving responses. The notion that people with dementia are able to articulate their grief and find meaning in their losses - and that that meaning can provide hope - is still emerging and will be explored further in the chapters that follow.

'Disappearing ghosts' - the social constructions of dementia

The stigmas of dementia incubate between the ears of most everyone walking the earth.

(Taylor, 2016, p. 9)

Living with dementia involves not just living with a terminal condition but also includes coping with the stigma associated with the condition (Alzheimer's

Australia, 2017; Alzheimer's Disease International, 2012; Burgener, Buckwalter, Perkhounkova, Liu et al., 2015; Burgener, Buckwalter, Perkhounkova, & Liu, 2015; MacKinlay & Trevitt, 2012). Stigma has been described as a complex individual experience where symptoms of diseases and social environments interact to affect a person's sense of self (Goffman, 1963, p. 591). In this process, negative stereotyping and shunning encountered in social contexts are internalised so that the person continues the process of marginalisation by isolating themselves (Goffman, 1963).

Social constructions of dementia vary, and prejudicial views and negative stereotypes include the beliefs that people with dementia cannot be expected to have meaningful conversations, or that one should avoid contact with a person with dementia (Alzheimer's Australia, 2012). Notably, some people report that they would feel humiliated if they were to be diagnosed with dementia and would delay seeking help for memory problems. By contrast, some people believe that individuals with dementia should be included in social activities, and acknowledge their value and capacity to participate (Alzheimer's Australia, 2012, p. 4).

As noted in Chapter One, language is a powerful tool in maintaining the stigma of dementia, which conveys the varied meanings associated with the illness. Metaphors that have been used to describe dementia have included referring to the condition as 'an epidemic' and its treatment as 'a crusade'. People with dementia have been characterised as 'away with the fairies'; 'zombies'; 'empty shells' and 'disappearing ghosts' (Alzheimer Europe, 2013, p. 5, pp. 51-53). Adopting military metaphors which liken a person's experience of their illness to a 'battle' can have a mixed impact. It may suggest solidarity and agency, but it can position the person as a helpless victim fighting a marauding attacker (Sontag, 1991; Alzheimer Europe, 2013, p. 51). These metaphors increase the anxiety associated with the condition, strongly shaping medical and social discourses (Alzheimer Europe, 2013; McInerney, 2017).

The effects of stigma may be felt over the course of the illness (Alzheimer's Australia, 2017). These may include financial insecurity due to premature retirement or changing capacity to manage finances; social rejection; internalized shame; and social isolation. Strong feelings of disconnection from the community, a reduced sense of competency and less contact with friends over time are frequently reported. People with dementia have a sense of becoming progressively 'invisible' as they are often ignored, or spoken about in their presence (Alzheimer's Australia, 2017; Alzheimer Europe, 2013, p. 51).

Seemingly in response to the corrosive effects of the stigma of dementia, a new narrative theme has emerged. This new discourse potentially reduces the complex experience of dementia into a dichotomy between 'tragedy', which emphasises the losses of dementia; and 'living well' with its focus on positive, active living (McParland et al., 2017). In 'living well' narratives, individuals preserve continuity in their sense of identity, re-evaluate meaning and even experience personal growth, as opposed to just 'coping' with their illness (see for example Wolverson et al., 2016). While 'living well' narratives offer a welcome and constructive counterpoint to the 'tragedy' discourse, it is important to continue to offer representations of dementia that convey the varied and unique nature of the illness journey.

An alternative could be a discourse that embraces the multiple realities of dementia, and which celebrates ageing as part of life with all its potentials and limitations (McParland et al., 2017, p. 266 citing Baars & Phillipson, 2014, p. 26). This could include employing the language of 'suffering' as it is understood in the field of palliative care, which aims to acknowledge and relieve the suffering of all conditions, including dementia (McInerney, 2017). This understanding of 'suffering' challenges the view argued by some dementia advocates that the use of terms such as 'sufferers of dementia' positions people as helpless victims of the disease (for example see Swaffer, 2014, p. 771).

The experience of younger onset dementia

For those of us who “caught” it relatively early in life ... we know what is going on ... We know we are off life’s track. We know that we are wandering farther and farther away from the crowd, our families and ourselves.

(Taylor, 2007, p. 19)

As noted in Chapter One, younger people with dementia have been identified as a distinct cohort whose needs require understanding and tailored support (Alzheimer’s Australia, 2007; 2013; Clemerson et al., 2014). While it has been argued that, support services need to be responsive to the individual needs of all people with dementia, irrespective of age (Reed, Cantley, Clarke, & Stanley, 2002, pp. 111), there are some potential differences with this group that should be noted. In particular, the influence of emergent age-based factors such as the needs of younger dependent families and changes to employment and finances make the experience of younger onset particularly challenging (Tolhurst et al., 2014, p. 204).

A key task for younger people with dementia is the difficult process of obtaining an accurate diagnosis. People may become aware of changes in their capacity long before a diagnosis – often in the context of struggles at work or failure to complete new tasks (Johannessen & Möller, 2013, p. 414). Younger onset dementia is a diagnostic challenge in that it may present with a wide variety of ‘subtle behavioural, cognitive, psychiatric, or neurological symptoms’ (Sampson, Warren, & Rosser, 2004, p. 125). In addition, specialist assessment may be needed due to the significant gaps in the knowledge of health professionals regarding younger onset dementia (Johannessen & Möller, 2013).

During the diagnostic phase, undergoing tests that make younger people ‘feel stupid’ can be stressful and confronting (p. 415). In addition, people with higher levels of cognitive functioning, such as well-educated professionals, may be more impacted by the perceived stigma of dementia (Burgener, Buckwalter,

Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu et al., 2015). This can be exacerbated by diagnostic processes which do not take into account a person's intelligence and background, so that the assessed degree of disability for the person could be under-represented by test scores (Swaffer, 2012, p. 92). Some people report feeling like 'second class citizens' when their diagnosis is confirmed and the support needed immediately following diagnosis is not readily accessed, as they seek to adjust to problems which can evoke deep grief (Johannessen & Möller, 2013, p. 415, 419).

Once diagnosed, younger people with dementia can experience a 'transition' in selfhood as many aspects of their daily sense of self are affected (Harris & Keady, 2009). Radical changes in sense of self need to be understood in the context of the younger person's life stage (Tolhurst et al., 2014, p. 204), while coping strategies may be different from older people due to the different psychological tasks they are facing at this point in their lives (Clemerson et al., 2014).

A range of responses to a diagnosis of younger onset dementia have been identified in the literature. People may re-define themselves, through identifying with their diagnosis and developing 'a more robust sense of self' (Clemerson et al., 2014, p. 459), while others respond with strategies for regaining control, such as re-adjusting expectations about the future (Clemerson et al., 2014; Harris & Keady, 2009). While some people stress the importance of re-engaging with life, others feel abandoned and disconnected from family and the wider community. In these instances, strong feelings of powerlessness and loss of control can emerge. Adjustment to a diagnosis can be compounded by the stigma relating to an illness associated with death and ageing (Clemerson et al., 2014), as well as a lack of understanding from others regarding the meaning of that diagnosis at this point in their lives (Greenwood & Smith, 2016).

At the same time, changes to a person's sense of self may be experienced in the context of a changing social identity. This can include family and work roles, and sexual identity (Cox & Keady, 1999b; Harris & Keady, 2009, pp. 439-441; Sampson et al., 2004). As people experience disruptions to their life-cycle, their sense of adult competency may be reduced as they begin to feel more 'childlike' (p. 457). This can affect the person's sense of autonomy and in turn, impact on significant social roles. In the midst of these changes, adjusting expectations include avoiding thinking about these issues as people take time to come to terms with their diagnosis (Clemerson et al., 2014, p. 457, 458).

It is important to acknowledge the considerable losses faced by younger people with dementia. However, there have been counterpoints to discourses of loss in the literature that have overlooked the complexity of socio-cultural contexts (Beard et al., 2009, p. 227). There is evidence of varied adaptive processes employed as people cope with their illness by using a range of behavioural, cognitive and affective strategies that draw on their mid-life skills. While responses from people in the community can be described as an obstacle and 'condescending' (p. 232), individuals may also be 'far more capable than is assumed' (p. 229) and seek help and accept changes as needed.

The impact of intergenerational family dynamics on the illness experience highlights the multi-layered, contextual influences at play, as both carers and people with the condition potentially cope with the complex needs of younger children (Gelman & Rhames, 2018; Sikes & Hall, 2018) and older parents. These distinctly different relational dynamics shape the younger person's identity and their adaptive responses (Roach et al., 2008; Roach et al., 2014; Roach et al., 2016). An illustration of this is Roach and colleagues' identification of family 'storylines' which represent the different ways families cope with their illness experiences (Roach et al., 2014, p. 1408). Their narrative research used a family systems approach that identified

dominant storylines embedded in the narratives of five families, including the person with younger onset dementia. The authors explored the impact of these storylines on the family dynamics and the way that the family adapted to the younger person's illness.

According to Roach and colleagues, 'agreeing' storylines indicates a strong narrative of 'togetherness', with open communication, shared experiences and negotiated roles (p. 1409). 'Colluding' storylines signify dissonance between family members, where two or more members 'plot' with one another to maintain a storyline to aid family functioning, effectively 'closing off' other family members (p. 1410). Strong disagreement in narratives, with evidence of some hostility, can be characteristic of 'conflicting' storylines (p. 1411) which may lead to significant family dysfunction. 'Fabricating' storylines may be used to consciously mislead and misinform, while 'protecting' storylines reduce stress and assist with identifying issues (pp. 1412, 1413).

The researchers argue that while these narratives can be an understandable response to the crisis of a new diagnosis, they may also be potentially disempowering to the younger person or other family members (p. 1413). While all families may use one or more of these storylines at various times, families that adopt an 'agreeing' storyline are more likely to find ways of positively adapting to the challenges of dementia over time. By contrast, families who present 'conflicting' and 'colluding' storylines are more likely to require assistance to understand those family positions and promote change. These ideas are touched on where relevant, in the chapters that follow.

In a similar vein, Roach and colleagues (2016) posit that positioning the person with dementia within the family system - rather than external to it or as a burden of care - amplifies the extent of the impact of the illness, as family members, including children, share many similar adaptive struggles. The difficulties and delays involved

in obtaining a diagnosis of younger onset can be a significant element in the way whole families accommodate the transitions in the illness pathway (p. 28). This goes hand in hand with struggles with finances and the stress of carers needing to continue in employment. Social isolation can be experienced by *all* family members. Moreover, the grief of noticing and coping with changes in the person with dementia, and anticipating the need to move out of the family home at this life stage will impact each person in different ways (Roach et al., 2016).

Given the age ranges of this population, disruptions to work roles due to changes in capacity are to be expected (see Harris & Keady, 2009; Tolhurst et al., 2014). The workplace is particularly significant in that it is often the first place where the person with dementia begins to notice changes, most usually memory loss - while colleagues may notice illness effects later (Öhman et al., 2001). People are often reluctant to acknowledge the signs of change in their capacity, and may consequently experience very high levels of stress and anxiety. This gives rise to creative strategies for coping, consequently masking the extent of their illness (Chaplin & Davidson, 2016).

Being forced to retire prematurely can lead to reduced self-worth and agency, and strong feelings of disempowerment and marginalisation. In this context, the person's sense of self is impacted as valued social and professional roles disappear (Greenwood & Smith, 2016, p. 107). Meaningful, purposeful activity which is paid or unpaid, can provide ways to positively adapt to the transitions experienced in order to provide a continuity of sense of self for the younger person with dementia (Roach & Drummond, 2014; Roach et al., 2016).

Some people with dementia can gain the skills needed to complete their work duties, although they may take longer than other staff (Robertson & Evans, 2015). Australian workplace engagement projects (for example see Robertson et al., 2014) have been able to model collaborative approaches to including younger people with

dementia in meaningful work which has improved their well-being, self-esteem and confidence. These projects also provide a chance for the person with dementia to give back to the community; and they offer opportunities for socialisation with other staff, customers and other younger onset people (Robertson & Evans, 2015).

While people have reported positive responses to inclusion in the workplace, there are still challenges for the person with dementia (Evans, Robertson, & Candy, 2015). Many still have difficulty coping and struggle with frustration, loneliness, loss of control and self-doubt as a result of their dementia. Concerns are often expressed about the impact of their illness on their families. In particular, changes to their relationship with their spouse due to the unexpected impact of dementia are highlighted - so that it felt like the spouse was just as much a 'victim' of the dementia (Evans et al., 2015).

Meaning making and dementia

It is hardly possible to take up one's residence in the kingdom of the ill unprejudiced by the lurid metaphors with which it has been landscaped.

(Sontag, 1991, p. 3)

There is an emerging picture in the literature that characterises the meaning making processes that people with dementia engage in as iterative, multi-layered and shaped by a range of complex processes. These processes can encompass individual constructions of dementia and the impact of social, cultural and spiritual influences on the person's sense of self, uniquely situated in the context of their illness (Bryden, 2018; Keady et al., 2007; MacKinlay & Trevitt, 2012; Robertson, 2014).

As we seek to understand the meaning of having a terminal illness like dementia the writing of Susan Sontag is salient. In her seminal work, 'Illness as metaphor and AIDS and its metaphors' (1991), Sontag explored the meanings that have been ascribed to TB, cancer and AIDS and the attendant psychological, social and cultural

impact of that meaning making. Sontag observed how public discourses powerfully shape the experience of those illnesses, including the dread created by the metaphorical language used to characterise those diseases. This potent language divides those diagnosed, from the rest of society - the inhabitants of the 'kingdom of the well' from the 'kingdom of the sick' (Sontag, 1991, p. 3). Deepening this divide are symptoms that instil fear and confront us with the unpredictability and uncertainty of the human condition (Kleinman, 1988, p. 20). In particular, diseases whose causes are not understood and where there have been unfulfilled promises of a cure, are generally viewed as 'morally contagious' (Sontag, 1991, p. 6). Contemporary understandings of dementia have been shaped by similar discourses in the 21st century (McInerney, 2017). As noted earlier, powerful language shapes the current narratives, with warnings of the imminent 'dementia tsunami' (p. 409), redolent of earlier forecasts of cancer 'epidemics'.

As Sontag has observed, meaning making processes relating to illness, are forged in social and cultural contexts (1991) and consequently have strong relational elements. As meaning is shaped by connections with others, (Bryden, 2018; MacKinlay & Trevitt, 2012; Robertson, 2014), a person's search for meaning as they live with dementia is impacted by their community in significant ways. While some aspects of community responses may be negative (Clemerson et al., 2014; Greenwood & Smith, 2016; Sabat & Lee, 2012), it can also support an individual's search for meaning in constructive ways. In particular, belonging to a community has the potential to help the person with dementia remain connected with their values, memories and sense of self (MacKinlay, 2016; MacKinlay & Trevitt, 2012).

Finding meaning can also be contingent upon maintaining connections with an earlier social identity (Robertson, 2014). 'Cynthia', an older woman with dementia, reflected on her changing social status following diagnosis and the impact of that on how she found meaning in everyday life (Robertson, 2014, p. 538). Cynthia

celebrated her efforts to maintain an 'ordinary life' (p. 539) and a valued social identity, which included continuity with past relationships and roles (pp. 538, 539). Deep insights emerge when meaning making is located in the context of whole life stories and an individual's on-going sense of self (MacKinlay & Trevitt, 2012; Robertson, 2014). As individuals with dementia recall significant life events, they are able to review important aspects of their lives in order to explore how they have found meaning over time and the impact of that meaning making. An illustration of this is 'Spiritual Reminiscence' work (MacKinlay & Trevitt, 2012). Using this approach, MacKinlay found that individuals challenged by disabilities like dementia may relinquish previously held life meanings and story new meanings that have the potential to foster self-transcendence and build positive approaches to the future (p. 87). In particular, when self-sufficiency declines and cognitive processes and memories fade, a person's continuing sense of connection with their spiritual beliefs may foster hope and well-being (MacKinlay & Trevitt, 2012, p. 43, 44). When people are not able to find new meanings, despair may become the focus of life (p. 87).

A complex and nuanced example of a younger person's struggle to find meaning over time is Bryden's comprehensive exploration of her long journey with dementia conveyed through autobiographical works (Boden, 1998; Bryden, 2005, 2015) and scholarly articles (for example see Bryden, 2016, 2018; Bryden & MacKinlay, 2003; Bryden & MacKinlay, 2008). Her work provides in-depth insights into her existential struggles, within a context of personal, professional and familial changes over many decades. Drawing on wilderness and exile metaphors to capture her sense of estrangement from her former life and sense of self as a high achieving, professional woman, Bryden's cry of 'Why me?' reflects a deep sense of abandonment to the 'desert of dementia' (Bryden, 2016, p. 8).

The stigma of dementia cast Bryden into a liminal space, outside of the normality and competence that society values. Yet in the midst of this deep sense of the loss of all that she was before her diagnosis, she describes finding a sense of identity by

simply being herself, a soul capable of finding love and hope (Bryden & MacKinlay, 2003, p. 72). Finding meaning as 'a transcendent being' (Bryden & MacKinlay, 2003, p. 72), free from the fears of loss of self, provided a safe, enduring place with God - even at the point when she lost the cohesion of a personal narrative to shape her sense of her future (Bryden, 2016, p. 11).

In a similar vein, 'Sarah', a 70 year old woman with Alzheimer's disease, used the metaphorical language of 'losing balance, finding balance and keeping balance' (Keady et al., 2007, p. 357), to describe how she had coped with her early diagnosis of Alzheimer's disease and her changing sense of self within the context of her whole life story. This process allowed Sarah to use a strengths-based approach and to find perspective in her current situation. In particular, she noted that having faced more challenging adversity in the past, she would be able to cope in the present.

There are some powerful examples of people with dementia finding meaning through advocacy, particularly younger people with dementia. Strong themes include the need to help others in the community to understand dementia and to promote living positively and compassionately with dementia at all stages of the illness (Bryden, 2016b; Bryden & MacKinlay, 2008; Bute, 2016; Swaffer, 2012, 2015, 2107; Taylor, 2007).

Some studies have investigated the meaning of activity in the daily life of a person with dementia (Menne, Kinney, & Morhardt, 2002; Phinney, Chaudhury, & O'Connor, 2006). Despite the various changes a person with dementia encounters, there can be a need to maintain continuity of lifestyle in the face of the impact of their illness. Maintaining established activities that were valued before receiving a diagnosis of dementia can provide a significant connection with former beliefs and practices which helps people to cope with change, particularly early in their illness when the future seems so uncertain (Menne, Kinney, & Morhardt, 2002, p. 372). In addition, having purposeful, meaningful activity can foster an on-going connection

with a person's sense of self, feelings of belonging and a sense of autonomy (Phinney, Chaudhury, & O'Connor, 2006).

Conclusion

The significance of meaning making in adjusting to a life with dementia has been acknowledged in the literature (Bryden, 2016; Keady et al., 2007; MacKinlay, 2016; MacKinlay & Trevitt, 2011; Robertson, 2014), and yet there is still more limited attention devoted to the role of meaning making in the subjective experience of dementia, particularly in relation to younger onset dementia. Even in the caregiver literature, the potential impact of meaning making on a person's experience of a caring role has received less attention. When the meaning making of carers is explored there is a consistent focus on the relational aspects of meaning or the links between meaning and values, beliefs, spirituality and personal growth (see for example Bergman, Graff, Eriksson, Fugl-Meyer, & Schuster, 2016; Quinn, Clare, & Woods, 2015).

A relatively small number of studies have explored meaning making by the person with dementia in the context of receiving a diagnosis (see for example Campbell et al., 2016; Lee et al., 2014). Recent research has included personal reflections on significant illness experiences and the impact of social and cultural elements on the person's sense of self in the context of their illness. Some studies have employed specific models such as the 'meaning making coping' model (Park & Folkman, 1997), which differentiates 'global meaning' from 'situational meaning' (Park, 2010, p. 258) and narrative meaning making (Robertson, 2014). These approaches were used to analyse how individuals made sense of their illness experiences, with limited examples of models and concepts from the field of loss and grief.

In addition, meaning making has been explored using the lens of sense making (see Harland, Bath, Wainwright, & Seymour, 2017; Örvulv & Hydén, 2006) or from the perspective of various spiritual frameworks (see Bryden, 2018; Bryden & MacKinlay,

2003; Finlay, 2015; MacKinlay, 2016; MacKinlay & Trevitt, 2012; Post, 2013; Zubrik, 2016). Finally, meaning making has been located in the context of whole life stories (Keady et al., 2007; MacKinlay & Trevitt, 2012; Robertson, 2014). With a few notable exceptions, scholarly accounts written by younger people with dementia, who explore their search for meaning, are small in number (see for example Bryden, 2016, 2018; Swaffer, 2012, 2015).

A clear area for further development is how younger people with dementia find meaning in their illness experience, in their unique social contexts; and the impact of that on their coping. In particular, there has been relatively limited attention paid to the exploration of meaning making, employing concepts and models from the field of loss and grief. This field offers additional lenses for understanding meaning making and the scope to explore how this process expresses a person's unique response to losses experienced in the course of their illness and the potential for post loss growth. Given these gaps, my research questions consider how younger people find meaning in the diminishing experience of dementia and how concepts from the field of loss and grief might shed light on these questions. The next chapter outlines the key processes involved in the design and development of this study which aims to explore these important issues.

Chapter Three

Tracing the theoretical and methodological journey

Introduction

The review of the literature in Chapter Two established that the role of meaning making has been acknowledged as an important aspect of coping with dementia (Bryden, 2016; Keady et al., 2007; MacKinlay, 2016; MacQuarrie, 2005); yet there is still a need to develop this area of research, most particularly in relation to younger onset dementia. Hence the focus of this thesis is to explore how people find meaning as they adapt to the experience of younger onset dementia, and the impact of that meaning making. In addition, there is a significant opportunity to examine how notions from the field of loss and grief might deepen our understanding of these experiences. In this exploration, relevant models and concepts from the loss and grief literature are therefore used as a heuristic guide.

In order to further explore the meaning making processes of younger people in their social and cultural contexts, I searched for methodological approaches that would offer the scope for meaningful reflection on each individual's lived experiences with dementia. This included reflection by participants and by the researcher. This chapter describes the theoretical and methodological approaches that were chosen in the design of this study, in order to create a space and process for those reflections.

It is a principle of research design that the methodological frameworks and research methods of a study should have an interconnection and coherence (McLeod, 2011, p. 42). I began with a deep interest in the subjective experiences of younger people as they lived with dementia, in particular in the earlier and middle phases of their illness. As described in Chapter One, this interest was fostered by my clinical work with people who had been recently diagnosed with dementia. As qualitative research represents a 'form of narrative knowing, grounded in the everyday

experience' (McLeod, 2011, p. 15), it was clear that a qualitative approach was appropriate for this study. The aim of this method of research is to study in depth, the unique perspectives of individuals, in particular, how people make meaning of lived experiences (Neimeyer & Hogan, 2001, p. 105) - a goal which aligned with the focus of this thesis.

My qualitative methodology is largely informed by constructivist philosophies and a phenomenological approach. Constructivist philosophies see knowledge as 'socially and personally constructed' and social realities are regarded as multiplistic (Neimeyer & Hogan, 2001, p. 105). As a counsellor I was familiar with the concept that counselling conversations are shaped by various social and cultural contexts and the skills and traits of both client and counsellor (McLeod, 2013, p. 8,9). From this vantage point, I decided that a constructivist and phenomenological framework aligned with my counselling beliefs and the goal of my study, which is to explore meaning making as it is shaped by each person's lived experience in their individual, social and cultural context.

Qualitative methodologies regard researchers as embedded in the phenomena to be studied, and provide an opportunity for adopting a collaborative partnership with research participants (Sarantakos, 2005). From this perspective, the subjectivity of the researcher is central to the research process and an important element in establishing rigour (Somekh & Lewin, 2005). As I became immersed in conducting the study interviews I came to see that what was being generated in research was clearly shaped by the participant and by myself, the researcher, using our own situated lenses. From my perspective those lenses included the formation of my counselling training and clinical experience with other clients with dementia, along with my personal experiences of loss and chronic illness. Therefore a further focus of this chapter is an explanation of the creation of the intersubjective space between myself and study participants.

The remainder of this chapter is presented in four sections. These discuss the relevance of narrative inquiry for this study; creating the intersubjective space; and the integration of narrative inquiry and grief research. The final section details various aspects of the processes and conduct of the research study. This includes issues to be considered when including people with dementia in research; background information about the research participants; conducting interviews with the person with dementia; and methods for data analysis.

The relevance of narrative inquiry for this study

Narrative inquiry, with its scope for in depth exploration of the way people organise and make sense of their lives, emerged as a clear choice for this study. Contemporary narrative inquiry revolves 'around an interest in biographical particulars as narrated by the one who lives them' (Chase, 2005, p. 651). This resonated with my desire to hear firsthand from the people with dementia, rather than through other lenses, such as bio-medical narratives.

The function of storytelling is central to narrative inquiry. Willis and Leeson (2012) distinguish between two different categories of stories (p. 7). Citing Baumeister and Newman (1994), they make the point that stories are either aimed at 'affecting' listeners in some manner or are used as a way to interpret and make sense of experience (p. 7). They argue that it is important for the narrative researcher to be aware of the various motivations of the storyteller and the type of knowledge that they are intending to build.

Current understandings of narrative forms which are concerned with making sense of experience have been strongly influenced by the foundational work of Bruner (1986, 1990) and Polkinghorne (1988, 1995). They have written at length about issues related to human behaviour, meaning making and narrative forms. In their body of work, narrative is identified as the linguistic form uniquely suited for representing

human existence, although life experience is richer and more complex than the storied accounts it represents (Bruner, 1986; Polkinghorne, 1995).

Narrative ways of constructing reality are particularly concerned with the ups and downs of life and contextualising lived experiences in order to understand them (Bruner, 1986). Narratives provide a way for those lived experiences to be storied and re-storied potentially resulting in changes to the narrators and others in their world (Caine et al., 2013). Thus, we tell stories about our lives, seeking to frame the complexity and paradoxes of our human condition and in turn, we are shaped by that story telling. These concepts resonated with my aim to understand how younger people with dementia might story their complex illness experiences in order to make sense of them.

An important concept that informed my work was the narrative idea of the ordering of events. The meaning of parts of a story can be conveyed by their place in the narrative (Bruner, 1990, p. 43). In this way stories connect events in a coherent form, creating meaningful sequences out of potentially random events. In addition, narrative structures can provide temporal constructs such as a beginning and an end, and provide criteria for the inclusion or exclusion of events. In these structures events are plotted, relating happenings by 'causally linking a prior choice ... to a later effect' (Polkinghorne, 1995, p. 8). In this form of retrospective meaning making, events are understood in terms of their outcomes. In this way, we create personal accounts of past actions, try to understand the behaviour of others and assess decisions by entertaining the 'what ifs' (p. 11). These concepts were particularly relevant to my exploration of the nature and impact of an individual's narrative constructions on meanings made in the stressful time of diagnosis and its aftermath.

A significant feature of narrative lies in its capacity to forge 'links between the exceptional and the ordinary' (Bruner, 1990, p. 47). Bruner argued that the viability of a culture depends on its capacity to create and contain shared understandings or

norms within a community and at the same time have processes that allow for explanations of deviations from those norms. Stories provide these vital processes. These narratives 'frame' and accommodate idiosyncratic experiences and at the same time may also convey important individual and communal values (Bruner, 1990, p. 56).

An important function of this storytelling relates to the way that individuals 'narrativise particular experiences in their lives, often where there has been a breach between ideal and real, self and society' (Riessman, 1993, p. 3). This is particularly germane, as receiving a diagnosis of a chronic condition like dementia, which is typically seen as an older person's illness, certainly represents a seismic shift in a younger person's sense of self, the future, beliefs about life, and their relationships. In addition, these dramatic changes take place within a social and cultural setting that shapes those experiences.

Creating the inter-subjective space

When considering the unique individual and their illness experiences, a complex mix of factors require attention. These include a person's abilities, temperament, interests, beliefs, values, lifestyle, biography, gender, class and culture (Kitwood, 1997a, p. 14). All of these elements shape their experience of dementia in combination with their neuropathology (Kitwood, 1990, p. 178). Researchers can gain access to this complex world of experiencing in various ways, including via interviews with individuals with dementia (Kitwood, 1997b). In this process of connecting with people with dementia, a broad range of sensibilities is needed (1997b, p. 16) in order to fully understand what is being communicated. In particular, attention needs to be paid to 'metaphor, oblique allusion as well as verbal and non-verbal registers' (1997b, p. 15).

Early in the study design I decided to employ semi-structured interviews. I considered that these could offer the scope for this more nuanced exploration of a

participant's illness experiences, conveyed using varied narrative structures and emotional registers. Mishler's (1986) ground breaking work on the use of interviews in research was formative in my thinking and fundamental to my narrative inquiry. While undertaking his research, Mishler became interested in the power imbalance between researchers and respondents. Very frequently, irrespective of the questions that were asked by researchers, respondents told the story that was most significant to them. In response to this, he noticed that most researchers worked to shape the response to more closely match what they were seeking from the respondent, overlooking what may have been conveyed by the seemingly 'irrelevant' stories. Mishler advocated reducing the structure and use of directive questions, so as to allow respondents to find their own 'voice' and tell their stories. Thus, he reframed the research agenda, arguing that the new question was concerned with how respondent's views and understandings of themselves and the world were shaped by the form and context of research interviews (1986, p. 121).

These ideas resonated with the challenges I encountered with my interview participants. While my strong intention was to hear first-hand the experiences of people with dementia and accounts of their meaning making, initially I made assumptions about what those stories would contain. My assumptions were quickly disrupted by participants' stories which did not appear to answer my questions. My persistent recourse to directive questions, diverting respondents from their preferred storylines, clearly needed to be modified. Reviews of transcripts and conversations with supervisors alerted me to this, setting in train a concerted process of intentionally calling on my counselling skills to help me carefully follow participant's narratives, clarifying and developing important themes.⁵

⁵ Further details regarding the challenges of listening to my respondents are provided in Chapter Eleven.

Attending in this way to respondents' stories provided the scope for them to narrativise their experience of their world and make sense of it. Particular stories, that appeared to be background to my questions, provided the material that I needed to comprehend how participants understood their life experiences (Chase, 2005). Over time, I was more able to hear narratives which were reflections on the meaning of a participant's illness in the context of their whole lives, including narratives of competence and growth as well as stories of loss.

My experiences illustrated the importance of openly hearing respondents' stories and appreciating them from the narrator's perspective - capacities that as a counsellor, trained in empathic listening, I was able to bring to the research experience. In addition to a conscious use of counselling skills to promote more effective listening, I came to see that a fundamental sustained belief in my participants' capacity to tell their story was required and that no story was 'irrelevant' (Mishler, 1986).

Following Gilbert (2002), I used a number of ways to foreground the narrator's 'voice', including transcribing my own data so that I was more able to hear the nuances of the narrator's emotional tone. Gilbert also recommends 'member checks'. However, not all of my participants opted for this, as some were no longer able to read and process their transcripts, and did not want their carers to read them either.

An important tool in creating a constructive space for reflection during interviews was the use of a reflective journal. The research process is a dialogue between the researcher and participant that shapes interviews and research data (McLeod, 2011). An important part of this dialogue is 'researcher reflexivity and openness ... and keeping a diary represents a practical way of harnessing these qualities' (p. 63). Reflective journals are at the heart of qualitative research and describe a 'continuum' of reflexive practice:

I understand researcher reflexivity as the capacity of the researcher to acknowledge how their own experiences and contexts (which might be fluid and changing) inform the process and outcomes of inquiry. If we can be aware of how our own thoughts, feelings, culture, environment and social and personal history inform us as we dialogue with our participants ... then perhaps we can come close to the rigour that is required of good qualitative research (Etherington, 2004, p. 32).

My reflective journal recorded personal, intuitive responses to each participant on meeting with them for the first time and during subsequent interviews. I also noted my sense of the sub-text of interviews (MacKay, 2008), as well as reflections on the researcher/participant intersubjective space and insights gained between interviews and while transcribing data. This provided a rich source of information and insight that proved invaluable in the data analysis phase of the study and in discussions with supervisors and colleagues about the project.

The integration of narrative inquiry and grief research

An important aspect of this study is exploring how the use of concepts from the field of loss and grief might shed new light on the meaning making experiences of younger people with dementia. Different theoretical constructions of the nature of loss and grieving will inform methodological approaches and vice versa. For example, if grief is seen as a predictable and stable trajectory of behavioural responses that can be reduced to a snapshot in time and generalised to a broader population, then quantitative measures may be appropriate (O'Hansson, Carpenter, & Fairchild, 1993). If however, as in my study, a complex process of individual adaptation to multi-dimensional stressors is being examined, important aspects of grief such as competency, improved functioning or the seemingly paradoxical experience of personal growth through loss may be missed in a quantitative approach (O'Hansson et al., 1993, p. 69). Commenting on his extensive experience with grief research, Jordan (2000) asked how can the use of standardised 'paper and pencil' measures of mental health or global measures of grief 'capture the heart of the matter' (p. 462) in these deeply personal encounters with loss?

Gilbert (2002) developed these sentiments, by pointing to narrative analysis as particularly relevant in qualitative grief research:

We need to create stories to make order of disorder and to find meaning in the meaningless. This “drive to story” seems particularly strong when one is confronted with death, loss and grief, and this makes narrative analysis particularly useful in thanatological studies (p. 236).

A major strength of narrative analysis lies in its scope for uninterrupted opportunities to hear in depth stories of loss. This is particularly relevant when individuals, such as younger people with dementia, may be feeling marginalised, invalidated or ‘disenfranchised’ (see Doka, 2002; Neimeyer & Jordan, 2002) by others in the community (Gilbert, 2002). In addition, Romanoff (2001) has argued that narrative approaches to grief research provide a potentially ‘therapeutic’ opportunity for the narrator to affirm the central meaning of losses in life by re-telling and re-constructing those stories. In some cases, this re-storying offers the chance to revise and re-build relationships with people that may have been lost, even though the aim of research is not therapy as such.

This discussion goes to the heart of key issues in this study. Narrative approaches offer the scope to explore in depth the very personal meanings associated with losses encountered in a journey with dementia; in particular, for those who have been socially marginalised because of their diagnosis (Gilbert, 2002). From this perspective, there is a powerful invitation in this research for participants to reconstruct stories in a way that may bring some benefit, such as articulation and validation of their unique illness experiences. In addition, narrative exploration opens up possibilities for the generation of alternatives to dominant discourses of loss - for example the opportunities for personal growth that illness may afford (Romanoff, 2001).

Grief, narrative coherence and identity

Ideas about the function of narratives have been explored not only in grief research, but also in the development of new approaches to grief therapy. These ideas provide a nexus between my choice of a research framework and my conceptualisation of fundamental grieving processes. The work of Neimeyer on the role of narratives as they shape our experience of loss and our sense of self (Neimeyer 2000; Neimeyer & Sands, 2011) is important in this context. He argued that significant loss presents a challenge to our 'narrative coherence' and 'identity' (2000, p. 263).

At this point it is important to locate what I mean by 'our sense of self' in this research context. Developing a satisfactory 'working definition' of self presents significant conceptual challenges (Meares, Butt, Henderson-Brooks, & Samir, 2005). Indeed, notions of self vary considerably across fields of inquiry and are uniquely shaped by the theoretical lens of the researcher (O'Hara, 2016). Established Western views strongly support the concept of a pre-existing 'essential self' which we endeavour to understand and potentially experience more fully. Examples of this approach include person-centred and psychodynamic theories. A counterpoint to essentialist approaches is the notion that our sense of self is entirely constructed through our life experiences (O'Hara, 2014, p. 67). Theorising from this constructivist perspective, commentators have argued that postmodern approaches have deconstructed concepts of the self as 'single, stable and knowable' to re-position it as a construction shaped by multiple realities, language and social and temporal factors (Neimeyer & Raskin, 2000, p. 5; Neimeyer & Hogan, 2001). This paradigmatic shift is also reflected in trends within the dementia literature (see for example Cadell & Clare, 2013; Sabat, 2002; Sabat & Harré, 1992).

A seminal notion which is relevant to this thesis, with its interest in subjective experiencing, is the concept of the introspective self. The work of James (1890) is important here (O'Hara, 2016). James regarded the self as a process, rather than a

structure⁶ or range of attributes. This process consists of a movement between ‘thoughts, images, memories, and imaginings’, that James termed a ‘stream of consciousness’ (Meares & Graham, 2008, p. 433, citing James, 1890). In this context, James argued that the self was made up of two poles, consisting of inner events and awareness of those events (Meares & Graham, 2008, p. 433). This capacity to experience and the associated awareness of experience is integral to the formation of self and denotes its reflective nature. In addition, Meares (1995) has posited that different forms of memory unite elements of our past and present experiences, which comprise this inner life.

Strong themes in the psychological literature, which align with the dementia literature,⁷ also stress the significance of regarding self as relational and embodied (O’Hara, 2016). Many commentators have asserted that the self is relational, in that it cannot be separated from its environment and various forms of relatedness with others (see for example Meares & Graham, 2008). In addition, new insights emerging from neuroscientific research have highlighted the embodied nature of key elements that contribute to the development of the self, such as the affective emotional system (see Panksepp, 2005).

In this thesis, I was guided by Neimeyer’s constructivist view (2004; 2016b) that the self is a narrative creation. In this way, my concept of self aligns with key narrative approaches adopted in this thesis. Neimeyer argued that the self is developed through ‘the stories that we tell about ourselves, stories that relevant others tell about us and the stories we enact in their presence’ (2004, p. 54). This ‘self narrative’ acts as an ‘orienting system’ that guides a person’s perception of themselves, their world, and the interactions between the two (Gillies et al., 2014, p. 208). Further, this self comprises an ‘overall cognitive-affective-behavioural structure’ that forms our

⁶ The term structure is used here in the Freudian and post-Freudian sense (see McLeod, 2013, pp. 81 ff).

⁷ See Chapter Two.

typical emotions and goals, and guides our social performance (Neimeyer, 2004, p. 53). Employing this narrative conceptualisation of self, the question arises regarding what happens to our sense of self when the telling and enacting of these narratives is disrupted by changes in memory, cognitive processing and the ability to communicate.

As noted above, language is a significant factor in the formation of self and how we experience life events. In particular Neimeyer (2000) argued that experiences of loss are expressed in various ways, and accorded meanings within different discursive frameworks. These formative frameworks are mediated and validated by cultural and social contexts (p. 264). This echoes Richardson and St Pierre's (2005) view that language shapes a person's sense of themselves and their way of making meaning, that in turn is subject to the discourses available to that person (p. 961). In this process, human beings construct a life story they can 'make sense of and that makes sense of them' (Neimeyer, 2016a, p. 11). It is this meaning making that may enable individuals to face and even transcend, the most challenging life events, such as receiving a diagnosis of dementia as a younger person.

An interesting counterpoint to Neimeyer's theory concerning the need for a coherent sense of self in times of adversity, is the notion that incoherence may be functional in different circumstances. Potentially incoherent forms of a story may be needed for different purposes and events (Gergen & Gergen, 2011, p. 378). Thus seeking a coherent story may be privileging singularity and judgments may be made about the 'incoherent' person who is seen as 'fragmented' (p. 378). This is an important consideration in relation to the potentially incoherent experience of living with dementia.

My way forward with these seemingly contradictory approaches was to hold these notions in tension, allowing coherence and lack of coherence to have their place and be seen as adaptive in different circumstances. One can see how constructing

meaningful narratives is an important way to make sense of and cope with life events that feel threatening to one's sense of self and the world. It also became evident, as I engaged with participants' narratives, that what my respondents were making sense of was inevitable decline due to the progress of their illness. This spoke to the question of what coherence might look like in the diminishing experience of dementia and how lack of coherence might also 'make sense' and play a part in a person's coping.

Including people with dementia in research

Significant ethical issues are raised by research into the experiences of a vulnerable population such as younger people with dementia (Novek & Wilkinson, 2017). There are serious concerns related to including people with dementia in research, such as assessing the participant's capacity to decide and give informed consent. The benefits however, outweigh the risks (Hellström, Nolan, Nordenfelt, & Lundh, 2007) and it has been argued that participation in research can be therapeutic (Gilbert, 2002). As previously noted, issues of equity and justice are also relevant here, since exclusion of people with dementia in research practices of the past, has added to their sense of marginalisation (Alzheimer's Australia, 2015, 2016; Hellström et al., 2007; Swaffer, 2014).

The steps taken in this project to address these issues, included processes informed by the recommendations of researchers from the Dementia Collaborative Research Centres⁸ (see Beattie, 2009; Beattie, Featherstonhaugh, & Moyle, 2009). One critical element of the study design was the method used to assess the capacity of participants to decide to take part. Formal assessment instruments such as the Mini Mental State Exam were not used to screen prospective participants as 'capacity assessments involve more than judging cognition and weighing objective scores of

⁸ The Dementia Collaborative Research Centres have been established around the nation as an Australian Government initiative to promote and facilitate research in the field of dementia.

memory, concentration, attention and orientation' (Darzins, Molloy, & Strang, 2000, p. 6). Similarly, aspects associated with dementia, such as cognitive decline, should not be used as criteria for exclusion from research (Wilkinson, 2002). Individual differences in the disease process mean that a more person-centred, holistic approach to assessing a person's capacity to be involved in research was needed.

Similar questions emerge when considering a person's capacity to give informed consent. Capacity is determined by whether individuals can understand and appreciate information and it should not be presumed that a diagnosis of dementia means that people lack capacity at all times and in all contexts (Darzins et al., 2000). In a similar vein, Beattie (2009) describes capacity as comprising four abilities: understanding; appreciation; reasoning and expressing a choice. Furthermore, she argues that we need to differentiate between 'acute' versus 'persistent impairment' and 'progressive' versus 'fluctuating impairment' (p. 95).

Methods to assess capacity to consent need to be linked to the level of risk for participants. In projects of higher than minimal risk, more formal assessment of decision capacity is warranted. While clinical interviews have traditionally been used to assess capacity to consent, they have been shown to be sometimes less reliable. Beattie advocates the use of a formal assessment tool, although there is still no agreed upon 'gold standard'.

One such tool is the 'Evaluation to Sign Consent' (ESC) (Beattie, 2009; Resnick et al., 2007). The ESC is:

... a five-item measure with an opening question that is not scored, which is used simply to indicate if an individual is alert and able to communicate. The five items reflect the participant's ability to name at least two potential risks incurred as a result of participating in the study; name two things that will be expected of him or her related to participation; explain what he or she would do if no longer interested in participating in the study, or if distress or discomfort was experienced associated with study participation.

This scale has a short administration time; has been evaluated in a randomised, controlled trial; and requires no additional training to deliver. It also assesses whether 'the person with dementia has sufficient factual understanding to provide ethically valid informed consent for a specific research study' (Beattie, 2009, p. 98).

In light of these issues, I employed the guidelines outlined by Beattie (2009) by attending to the following: careful reading of information forms (aloud if needed) to facilitate comprehension of the nature of the project; provision of adequate time for participants to ask questions; careful and accurate delineation of risks and benefits; discussion of the possible impact of participation in the project in concrete language; inviting a support person to attend all information sessions so that they could reinforce understanding of the project; regular checking throughout the project that the person still consented to participation, given that their capacity may fluctuate; and the use of the 'ESC' to formally assess capacity to consent given that there were higher than minimal risk for these participants.⁹

Recruitment

Potential research participants were contacted through a local community support service specialising in dementia care, with the agreement of its Executive Director. Purposive sampling (Babbie, 2005) was chosen as a way to recruit participants. In consultation with the researcher, participants were accessed via the agency counsellors and two 'Living With Memory Loss' program facilitators, who were nurses with experience in the mental health field.

Clients who were considered to be potentially able to engage with the interview process were given information about the project, via a 'Plain English Research Study Information Sheet'. Those interested in hearing more completed a form requesting contact with the researcher, and appointments were made by the

⁹ Permission to conduct this study was granted by the University of Canberra's Committee for Ethics in Human Research (Project Number: CEHR 11-45).

researcher to meet with potential participants. Meetings were held with participants in the company of their carers, if requested. Project information was reviewed and questions were asked by participants and the researcher to make sure that participants understood the nature of the study and its processes. Appointments for first interviews were then made with people who indicated an interest in participating in the research.

Timing of interviews

As noted earlier in this chapter, time is an important element in the meaningful construction of narratives, in particular because meaning making changes over time (Neimeyer & Sands, 2011). I saw the timing of interviews as critical in tracing shifts in participant's narratives and the impact of changing capacities due to their illness. This issue is even more pressing with this cohort because of the uncertainty of the progression of their illness. It can be seen from Table 1 below that the timing of interviews was not uniform across all participants. This was influenced by their availability and the need to be sensitive to an individual's capacity to participate, which varied markedly for each person.

The time range between a participant's diagnosis and their first interview ranged from one year to three and a half years. Despite this difference, participants were selected who were functionally similar for the first two interviews, perhaps reflecting a delay in the initial diagnosis in some cases. The time between first and second interview was approximately one month for all participants except Anne. Those interviews were conducted close together in order to retain continuity and a connection with the participants. Anne's second interview was delayed due to uncertainties about her diagnosis.

The timing of the third interview depended on the rate of each participant's decline. For example Julie was declining more quickly so her interview was conducted earlier than others. It should be noted that diagnosis is not always an indicator of

onset of the illness. For example, when Julie was diagnosed she was told that she was ‘mid-range’ and her family estimated that she had been displaying symptoms for three to four years before her diagnosis. As noted in Chapter One, this delay in diagnosis is a common problem, especially when symptoms are masked by other health issues.

The research participants

A total of three women and four men with younger onset dementia form the study cohort. All participants were aware of their diagnosis. As can be seen in Table 1, the most common type of dementia was Alzheimer’s disease, with most participants receiving their diagnosis in their late fifties to mid-sixties. All participants experienced significant delays in confirming their diagnosis, and reported onset of symptoms at least a year earlier. In discussing their diagnosis I employed the language used by each participant (Novek & Wilkinson, 2017), for example, Anne referred to her experiences with ‘memory loss,’ while all other participants used the term dementia.

Table 1: Participants’ profiles

Pseudonym for participant	Dementia – type	Year of diagnosis	Age at diagnosis	Age at interview	Initial interview	Time since diagnosis (years)	Final interview
Kathleen	Alzheimer’s	2008	64	67	July 2011	3.0	Dec 2013
John	Alzheimer’s	2007	56	60	July 2011	3.5	Aug 2011
Anne	Not determined	2016	64	59	Nov 2011	n/a	Jan 2014
Vowell	Alzheimer’s	2010	63	65	Sept 2012	2.0	Sept 2014
Warren	Alzheimer’s	2009	59	62	Aug 2011	2.0	Sept 2011
Arty	Alzheimer’s/ vascular	2010	63	64	July 2011	1.0	Feb 2014
Julie	Alzheimer’s	2012	59	60	Oct 2012	1.0	Aug 2013

The participants' carers

In order to capture some of the key influences on the participants' meaning making, their carers' narratives were also explored. As discussed in Chapter Two, meaning making is relational in that people construct their narratives using the discourses that are available to them, that are shaped by their social and cultural contexts (Chase, 2005, p. 657). Carers have the potential to contribute in a significant way to the development of a younger person's narratives. This includes the impact of the carer's meaning making on the experiences of the cared for person.

In recruiting family carers, I began by introducing the idea to my participants to gain their approval. If they agreed, I then spoke in person to the respective family carers, inviting them to participate. While all of the carers approached were familiar with the study, I re-iterated the nature of the research, supplying a 'Plain English Research Study Information Sheet for Carers' and then, if requested, a Consent form. Interviews were arranged and conducted at their homes.

Five carers were interviewed, each interview lasting one and a half to two hours. These interviews took place later in the journey, around the time of the third interview with the cared for person. The same questions that provided the structure for interviews with the younger person with dementia were used in the carer interviews, to gain a sense of their perspective on those issues. Two participants had no family carers.

Interviews and the person with dementia

As the design of this study evolved, important questions relating to the nature of the inquiry and the particular constraints that research participants may be managing highlighted key methodological concerns. These included creating a safe emotional and psychological environment for interviewees (Novek & Wilkinson, 2017) and adopting interview processes that took account of each individual's cognitive processing and physical well-being.

The interview process

In determining how to conduct interviews with my participants, I adopted a standard process for this cohort. Essential strategies in working with interviewees who have dementia have been clearly outlined in the literature (for example see Clarke & Keady, 2002). Researchers need to adopt flexible approaches to the duration and pacing of interviews, possibly using a more structured approach if open interviews prove unworkable.

Semi-structured, multiple interviews were chosen to allow for sufficient engagement with and by the participants over time, including the scope for revisiting important issues if needed. Conducting multiple interviews allowed me to accustom myself to participants' individual communication styles. This helped me to monitor signs of anxiety, agitation, distress or tiredness conveyed through participant's body language, tone of voice, and pacing of responses.

Interviews were conducted at a place and time of the participant's choosing. Family carers, who are potential 'gate keepers' (Clarke & Keady, 2002, p. 36) and a source of important information (Novek & Wilkinson, 2017, p. 6), were invited to attend interviews in order to reduce the anxiety of the interviewee, create a safe space for conversation and provide additional insights, if the interviewee agreed to this. This did of course, create a different dynamic than those interviews conducted without a carer present, an issue which will be discussed in more depth in the data chapters that follow.

Initially, it was intended that the first interview could be used to assess the quality of the data generated. This thinking was soon abandoned, as all aspects of each narrative were seen as 'grist for the mill' and as containing valuable insights. In addition, while there was some repetition of narrative themes in the second interview, overall, new themes or developments in participant's stories emerged, building on the rapport that had been established.

Four broad questions which could be a prompt and invitation to engage in a reflective conversation served as a guiding structure for interviews. I assumed that these questions might also be needed to assist participants as they recalled and reflected on important events, given the possible impact of their illness on their cognition, memory and processing capacity.

The interview questions were:

1. Can you tell me what it was like to receive this diagnosis?
2. How do you see this illness affecting your life?
3. What or who is providing or will provide support for you?
4. What sense do you make of these experiences?

While these questions were not always asked directly, they served as a guide while I used active listening skills to follow the lead of interviewees as they reconstructed their narratives. In this process, other storylines emerged, including participants' experiences with family carers, health professionals and the wider community. Researcher observation was an important adjunct to verbal communication, especially if/when the interviewee's communication skills were more limited (Clarke & Keady, 2002).

Constructing the research narrative

I transcribed most of the interviews verbatim to allow immersion in the data in order to identify and understand the layers of meaning contained in the text. In addition, I was concerned that some participant's word finding difficulties could make transcription by another person problematic, resulting in valuable aspects of the data being missed. As transcripts were completed I was also able to recall the body language, tone and the impact of the narrative on the participant and the listener at certain points in the interview, refreshing and deepening connections with the data. There was limited 'cleaning up' of the transcript, in order to convey a more complete picture of the narrator and maintain the integrity of their 'voice'.

A fundamental feature of conducting narrative inquiry is to negotiate the research relationship as researchers co-construct the research narrative (Clandinin, 2006, p. 47). As I met with most participants two or three times, I had the opportunity to revisit previous transcripts and invite respondents to suggest changes or corrections. Participants indicated that they were content with the record of our interviews, although levels of comprehension varied with each person. Some commented on how helpful it was to have their reflections in writing. One participant declined having transcripts returned, stating that his capacity to read and comprehend was very limited and he did not want his carer to see the transcripts. Some family carers reported being deeply moved by the younger person's stories and all expressed deep gratitude for the opportunity to engage in these conversations.

Data analysis

In keeping with narrative approaches, theorising emerged principally from each participant's narrative, rather than from component themes across all narratives (Riessman, 2008, p. 53). Within each data chapter, key elements of participant's narratives were drawn together into personal narrative themes.

The first level of analysis involved reviewing each transcript to identify key words and phrases that conveyed important experiences, relationships and events, staying close to the data by focusing on the narrator's unique use of language. Key quotes that represented important moments in the story were highlighted, along with movement in the plotline or dissonance when the narrative didn't seem 'to hold' or when there were interesting gaps. Chief characters and the absent or 'silent' voices were noted. In keeping with a constructivist approach (Neimeyer, 1993), the use of metaphorical language was noted, signalling how participants were engaged in their own meaning making. My clinical skills enabled me to listen to *how* stories were told as well as *what* was said. This included attending to silences, tone and pace of

delivery (McCormack, 2004). A preliminary organising structure of four broad themes which echoed the interview questions included:

- pathway to diagnosis
- the impact of the diagnosis – the inner journey; effect of symptoms
- life day to day
- visions of the future

The second analysis provided a finer grained exploration of participants' narratives. This took the form of structural analysis, using a model that I developed. This model was informed by a narrative approach and drew on narrative therapy concepts developed by White and Epston¹⁰ (see White, 2007) and the work of Riessman (2008). In developing this model, my aim was to use language and concepts that might be more familiar to counselling and helping professionals, providing an alternative to models from the fields of linguistics and sociology.

Structural analysis provides opportunities to listen for forms of storytelling that are less privileged in our society (Riessman, 2008, p. 77-87). This includes listening to the ways that people with dementia tell their stories. By amplifying the 'how' in addition to the 'what', this form of analysis helped me to see how having dementia shaped my participants' narrative structures. It revealed how participants came to construct their meaning making; shifts in self narratives over time; and how narratives were shaped by internal and external processes.

Using this process of analysis, I broke each interview down into discreet narratives, using McCormack (2004) as a guide. McCormack describes stories as bounded by a beginning, which provides an orientation to who, what, where and when and an end

¹⁰ Narrative therapy draws on the work of Bruner (1986, 1990) as a theoretical foundation, aligning with key narrative theory epistemologies.

which takes the form of a coda, bringing the story to a close (p. 223). The next step in analysis was based on Riessman's (2008) model of structural analysis, which was informed by Labov's seminal work (1972).

Using Riessman as a guide I developed the schema shown in Table 2.

Table 2: Research schema

Abstract	The point of the story, what the narrator wants the listener to know about them
Cultural context	Background, setting, characters, cultural resources. The cultural context has the sense of the entirety of the narrator's setting, which is broader than a popular understanding of 'culture', and includes supports and resources, as the person perceives them. This may include which people the narrator chooses to include in the narrative and who is missing. This term has the embedded notion that these resources potentially shape the narrator, as such reflecting a social constructionist stance. In this study the cultural context is being accessed more directly in that we also hear from family carers.
Action	Carries story forward, includes events; sequence; time; plot. It can involve a crisis or turning points. The action may not necessarily be linear, but could be conveyed in fragments, or have a more circular, repeated form.
Evaluation	Complications – feelings, 'influence' or impact of the event Conclusions – thinking, judgements about events, experiences and identities of self and others
Meaning making	How the narrator connects events and wants to be understood. This includes Gillies and Neimeyer's (2006) three key elements: sense making; changing sense of sense of self; and benefit finding.
Coda	The narrative is brought to an end, but may not be resolved

With regard to the coda, these narratives do not necessarily have a clear ending or resolution as such - there may be recurring threads or disruptions to the flow of

stories. Cognitive changes may impact on a person's capacity to find and form resolution to some narratives.

This schema was applied by breaking each sentence in a narrative into clauses which were then categorised using the model's terms. This analysis enabled me to identify interesting patterns in narratives and highlight different elements. This could include for example, a participant's focus on thinking and appraisals of events that might be predominantly negative. Alternatively, recurring feeling states and their impact could be identified more clearly.

In the loss and grief research, a distinction has been drawn between 'meaning making' and 'meaning made' (Gillies et al., 2014, p. 207). 'Meaning making' is a process which an individual 'encounters, searches for, finds and/or makes' meaning (p. 7). Meaning made is an outcome where a person 'has encountered, found and/or constructed' meaning (p. 7). I have adopted the term 'meaning making' as it implies an iterative, open-ended dynamic, aligning with constructivist approaches that underpin the methodology of this thesis.

In identifying instances of meaning making I was guided by, but not limited to, Gillies and Neimeyer's Codebook (2014). Even though the Codebook relates to bereavement, examples of meaning making in the data were compared and contrasted to those described in the Codebook as another point of reference.

The final analysis took the form of a 'coda' that is, my retrospective evaluation of what the research might mean (Kim, 2008, p. 260, citing Bruner, 2002), in particular for counsellors working with younger people with dementia. This analysis employed interpretive processes, where the voice of the researcher comes to the fore and is found in the Discussion section of each data chapter and in Chapter Eleven.

In summary, analysis of the data consisted of three phases: an initial focus on the participant's whole narrative, using thematic analysis; followed by identifying

important elements of the narrative through structural analysis; with a return to whole narratives via my interpretation and reflections on the data.

Analysis of carers' narratives

Analysis of the carers' interviews was undertaken in the same form as detailed for the younger people with dementia. While each narrative in the caring dyad was treated as an important context for the other, the narratives of the cared for person were foregrounded. This was done in order to differentiate from other studies that privilege the carers' narrative and what may be a more typical clinical focus. In this way, we avoid seeing the carer's narratives as more valuable or reliable.

Conclusion

The methodology outlined in this chapter emerged in response to sustained calls by younger people with dementia for increased attention to their perspectives on their illness experiences (Alzheimer's Australia, 2015, 2016). A narrative approach provided rich opportunities for deep exploration of those storied accounts of living with dementia. At the beginning of this project I was uncertain about my participants' capacity to find meaning in their illness journey and effectively communicate those experiences. In telling their own stories, the younger people in this study were able to maintain a narrative identity, despite the radical changes they were undergoing. Each participant surprised and moved me as they shared their meaningful search for ways to understand and cope with their illness. In the following chapters the reader will have the opportunity to meet these resourceful people who worked hard to make sense of their illness experiences in their own unique ways.

The development of this study has been an iterative process. Initial expectations and assumptions were challenged and my understandings deepened as the interviews unfolded. My own professional journey has been shaped by these experiences and a more complete account of this reflexive process is included in each of the seven data

analysis chapters that follow. In addition, I gleaned important insights into ways to listen for meaning over the course of my conversations with study participants. Consequently Chapter Eleven is devoted to analysing those insights and identifying implications for working with people with dementia in research and support services.

Chapter Four

Kathleen

Introduction

My first encounter with Kathleen was in 2007. She was a guest speaker at a course for people recently diagnosed with dementia, held in a local community agency specialising in dementia support. Kathleen presented as an articulate, passionate woman from an Irish Catholic background, with a lively spirit and a strong faith. A powerful narrative in that first address was her conviction that she and others could be a model for *living* with dementia with courage and a whole heart, so that the entire community could see what was possible.

Kathleen was diagnosed with Alzheimer's disease at 64 years old and was 67 when I first interviewed her. She had retired from the Public Service and lived alone. In our first interview, Kathleen furnished lengthy details about her current family. Kathleen was divorced with one son, although he did not appear as a prominent figure in her narratives. For day to day assistance, Kathleen relied on a very supportive neighbour. In addition, her brother and sister, who lived in Canberra, were her carers. She also had two sisters living interstate. Her brother saw her most often as he helped with her financial management and home maintenance, consequently visiting regularly.

When I met with her to discuss the research project, she was unequivocally enthusiastic about participating. Interviews were conducted in her small, cosy lounge room that was full of family photos and personal memorabilia, all neatly displayed. In our early interviews, Kathleen related her observations and reflections in clear, flowing prose, with a slight Irish lilt. In all of our encounters, I was impressed by her confident tone and comprehensive accounts of past events.

Family is sacred

A striking feature of Kathleen's narratives was the centrality and power of family relationships and the legacy of her extended family, past and present. She seemed to derive deep meaning from her family history and where she was located within those narratives. All three interviews generated stories deeply embedded in long, detailed and thoughtful accounts of several generations of her family history, including her mother, father, uncle, grandfather and great grandfather. Over the course of our time together, it was clear that Kathleen understood, accepted and lived with her diagnosis from within this strong family context. In this way there was a sense of the continuity and shared history through the generations.

In many ways, Kathleen's life story echoed those of many other immigrant families moving to Australia in the fifties and sixties. Kathleen was 15 when the whole family left Northern Ireland, in order to make a better life away from sectarian violence. She was clearly proud of her parents and the way that they had carved out a successful life for the family in their new home.

Kathleen related with deep affection that her mother was a *'lovely looking woman'* who had worked successfully as a *'tailoress'*, then subsequently became a devoted mother and homemaker. Her father was a builder and Kathleen described how he had *'made his print here'* by working on major bridges and key public buildings, including the National Gallery of Australia, while he successfully managed large teams of European migrant workers engaged in those capital works. It became apparent to me over our time together that Kathleen was working on her legacy too, in the form of service to the dementia community and advocacy for improved social and government policies for younger people with dementia.

Kathleen's parents both *'loved'* Canberra and the family happily settled into their new lives, albeit with a dawning consciousness of the distance that separated them from cherished family back home, particularly at times of loss. At one point early in

our time together Kathleen summed up the meaning of these relationships when she pointed to the group of family photos on the sideboard and said, *'I wouldn't know who I was if I didn't have these'*. This seemed to have meaning metaphorically and literally - these photos aided her unreliable memory in recalling important people and events and these family members were critical in her formation and on-going sense of herself.

Narratives relating to her mother and father reflected Kathleen's deep respect for their achievements and her compassion for their struggles in hard times. In particular, Kathleen's mother's experiences with dementia were clearly formative. She reiterated often that her depth of understanding about dementia flowed from wanting to understand what her mother had been through. Kathleen believed that her mother began experiencing symptoms of dementia in her early fifties. She recalled how her mother would become confused and fail to recognise close family members. These lapses were jokingly dismissed by Kathleen's siblings as a pretence. Kathleen witnessed early expressions of the stigma of dementia, through her own mother's secrecy about her own illness:

K: I started to remember things mum had spoken to me about years ago, that she hadn't spoken to the young ones about it because, I think she was embarrassed, but she wanted me to know, because in her days things like that in the family were an embarrassment and you would just cut off.

Kathleen's role of trusted confidante to her mother was very meaningful for her. Family secrets were divulged to Kathleen, who was the gatekeeper of the 'unspeakable' in the family, including deeply sensitive family stories:

K: So, I was the only person she talked to about anything in fact. My brothers and sisters knew nothing that my mother lost two babies and that they had names and I knew the names. They didn't want to believe it when I told them, because mum was just too sacred to us. It was just, 'No, that didn't happen to our mum'. But I discussed them with her.

Over time Kathleen came to understand the difficult decisions required as the person with dementia declined. She expressed her grief, regret and shock relating to her mother's move from the family home in Canberra to be cared for by Kathleen's sister in Queensland:

K: We didn't know, even I didn't know, that to move her on to some where she didn't know, people she didn't know, her everyday life totally changes, and her dementia just smacked her [makes loud smacking noise with her hands]. She deteriorated and was gone in two months.

The blessing

The sense of her special role in the family was developed early in the first interview when I asked Kathleen about her response to her diagnosis. Kathleen quietly reflected then replied:

K: I thought that if it would come to me, then my brothers and sisters might be free of it. [Kathleen smiles.] But that's me.

This powerful belief about the meaning of her illness was, for me, an unexpected alternative narrative. It was a clear move away from the more conventional medical discourse, which relates more obviously to stories of diagnosis and treatment. Seen within the context of Kathleen's life experiences and her deep Catholic spirituality, it became clear to me how this view transformed her illness into a type of spiritual quest and helped her make sense of, and live positively with, her illness. In this way, living with dementia appeared to have meaning on many levels, potentially transforming her suffering into a redemptive experience for her and her siblings, motivating Kathleen to be a 'blessing' to all. While the power of this narrative was clear, I wondered whether there were any aspects of this story that would cause difficulties for Kathleen.

Not with his family like he should have been

Kathleen returned many times to issues of providing support for people with dementia. Extended family members were referenced, as examples of the impact of

contrasting forms of providing care - in the 'village' and in the institution. The imperative for actively involved family caregivers was a persistent narrative, in contrast to the inherent pitfalls of institutional care. Kathleen detailed moving stories relating to how her great grandfather had been '*locked up*' as a younger man, in a '*mental hospital with big walls around them*', that were '*more like big jails*'. Her grandfather was also institutionalised when her mother was four years old. Tragically, over his lifetime he became a shadowy figure, being periodically re-admitted; a shameful secret that Kathleen's mother '*admitted*' to her alone.

Moving her focus into the present, Kathleen told a cautionary tale regarding 'Bill', a fellow participant in her dementia support group. His story amplified the need for people to be cared for at home, by those who really understood dementia. In a shocking example of the consequences of an incorrect diagnosis, Kathleen related how Bill had been put into a home for many years and '*not at home with his family like he should have been*'. When Bill did not follow the normal disease trajectory associated with Alzheimer's he was reassessed, and his diagnosis was changed to another condition. Kathleen's judgement of the situation was that his carer had put him in a home '*so young*' because she had been '*embarrassed*' by his illness. This seemingly paradoxical observation that family members didn't always understand or know what was best for the person with dementia was returned to at various points:

K: Umm, 'David' who died recently who was the teacher, his wife took him all over Australia, and yet David loved coming to our meetings, but she loved taking him everywhere on holidays ... and when he came back [to the support group], he didn't know hardly any of us ... that wasn't really what he wanted, because the last time he came he was so thrilled to be there.

Further powerful exceptions to positive narratives about family care were found in Kathleen's repeated emotional references to the lack of understanding she received from her siblings. In particular, Kathleen detailed how her sister angrily denied her diagnosis and put her memory problems down to normal ageing. When she reflected on this, Kathleen's performance of her story changed as she shifted into a

different emotional register. Throughout the interviews a consistent characteristic of Kathleen's narrative style was that of an even, well formed, flowing account; seemingly the result of much deep reflection and processing. In marked contrast, several references to her sister's reactions to her diagnosis were more emotionally charged and less controlled, uncharacteristically angry and openly frustrated.

These more spontaneous reactions culminated in a passionate outburst in the third interview:

K: ... she can sometimes be so insulting and that stresses me terribly and I feel like I want to say to her, 'Christ I hate you! ... May God forgive me but I hate you ...

In the midst of this righteous anger there were also moments when Kathleen was able to reflect more positively on her sister's acts of kindness.

I get upset because that's not really me

Despite the obvious signs of cognitive decline and changes in capacity that I witnessed over the period that I met with Kathleen, I had a strong sense of connecting with a person who maintained a continued presence and a deep self-awareness. At many points in interviews Kathleen demonstrated a determined belief in herself, in her capacity to make a difference in the world and a strong commitment to her values - familial and spiritual. While she did have times of troubling doubts and uncertainty, this belief persisted in the face of changing circumstances and capacity.

Her pathway to diagnosis exemplified her coherent sense of self, deeply embedded in her family history. Knowledge gained through family stories prompted her to seek medical help after experiencing uncharacteristic difficulties at work. Kathleen began to reflect on the strong prevalence of dementia in the family history and concluded that *'her memory loss problems were probably because of the family'*. Her GP

was sceptical about this possible diagnosis and sent her to a neurologist who also disagreed with that hypothesis. Kathleen persisted with her beliefs about her illness and was finally given a diagnosis of Alzheimer's disease by another specialist, several months later.

In addition to Kathleen's understanding of family history, her insight and self-awareness also played a vital role in detecting problems. She recalled how her meticulous work habits shifted, as she experienced memory lapses and made frequent mistakes that other colleagues would rectify for her:

K: I was really one of these people, that was, um, I had a very good memory, I was very into 'place for everything and everything in its place' ... it had to go into this box and I never overloaded ... and all of a sudden I realised the things I was forgetting ... and I used to be so proud of how well I remembered things.

It was notable that despite the discouraging scepticism of her siblings and some health professionals, she persisted in her convictions about her illness. Kathleen regarded the 'attitudes' of those doctors as 'their problem' and felt vindicated when a geriatrician finally confirmed her diagnosis.

Once diagnosed Kathleen worked hard to understand dementia, 'looking into so much of it' reading and 'taking notice' of advice to keep mentally active, doing puzzles and learning new computer skills. She also developed reassuring narratives about the progress of medical research in treating many formerly life threatening illnesses like polio and pneumonia; something equally positive could develop in the treatment of Alzheimer's disease.

Over the course of the interviews Kathleen showed that she knew that her capacities were changing, drawing on her clear sense of herself. She acknowledged her frustrations with 'losing track of things ... losing focus' and 'getting side tracked', so that important tasks no longer got done. Despite her evident distress over these changes,

her independent spirit and resilience remained, as was evident on our final interview:

E: So these core things that really matter, that made you, you, are not ...

K: With me any more ... well I don't let it upset me too much ... when you read about young people with depression, I think, no, no, you can't let that happen to you, you've got to um, er accept [sigh] the goodness of life and people ... the comfort of being able to enjoy people's company.

Kathleen, just 'got on doing everything and helping with everything ... that helps me with the Alzheimer's'. This active service to others was a consistent trait that seemed to give Kathleen purpose and renewed energy in dealing with her illness.

A strong aspect of Kathleen's sense of identity was her spiritual practice. It is clear that Kathleen's faith strongly shaped her experiences of her illness and her responses to it. It provided comfort when friends died, even though she knew that not everyone shared that view:

K: You know that the illness has taken them and they are better off, in another world. For me they are with the Lord and being looked after, but some people probably get annoyed with me for looking at it like that ... they probably think, 'It's only because she is an Irish Catholic' ... my brother, sister and son, they don't have the same meaning.

Kathleen observed regular prayers for the members of her support group, drawing comfort and strength from knowing that she was remembering them, asking for 'the Lord's care for this person or that person ...'

They last a lot longer by having their group

In contrast to other study participants, Kathleen strongly identified as a person with dementia and with others who had the condition. The psycho-educational support group which was run by a local community agency was an important reference group, which became 'another family' where they could 'talk about their whole lives' not

just their illness. Kathleen repeated strong endorsements of the group members and its leaders at many points:

K: ... the staff there are absolutely marvellous, and the people themselves get the caring and loving from one another, because they've got the problem too and um, we understand it ...

In the face of fear and anxiety about the future, group members found a place of belonging and support for each other, even when the inevitable happened, with group members dying:

K: And now the whole group know everything about one another and as each one has passed away, it has been something that has been much easier to take ... we know it and expect it and we know what's causing it to come sooner than it should in some cases.

Kathleen's strong sense of self that flowed from her deep connections with her own family extended to the support group. Not only did the group provide comfort in anxious times, but notable people attended, lending prestige and credibility to the gathering. Kathleen returned in all interviews to a 'famous lady' who came along and shared her published poetry. Kathleen was 'so extremely proud' of the fact that the Governor-General had read one of the poet's works in a public address and had invited her to Government House for a meal. In a later interview Kathleen expanded upon this theme by connecting her experiences of poetry reading in the support group with cherished family memories. She began by observing '*... poetry is for everybody, for anyone who has migrants in their family ...*'

When I asked what happened for Kathleen when she read that poetry she spoke about the 'comfort' and 'warmth' it gave her, linked to the fact that she could read poetry well, getting the 'gift out of the poetry', adding how important it was to read it with feeling. This prompted a deeper reflection on the special relationship she had developed with one of her grandfathers, a 'brilliant man', who used to read poetry to her:

K: ... he loved the Irish poets, and he used to read it to me when I was very young, so now I know how to read it for myself and that was very important.

We can't just sit here singing

One strong thread that emerged in Kathleen's stories was her passionate belief that the community should be more accurately informed about what people living with dementia were experiencing and their need for support. In all three interviews Kathleen returned to themes regarding the need for meaningful campaigns to promote community awareness and raise funds for research and improved support services. In particular, she was adamant that stories about younger people with dementia should be publicised, lamenting that:

K: People don't know it and people don't get out onto little street corners, the way that cancer people do.

In this vein, Kathleen outlined her fund raising plans in detail, which included small scale projects and larger publicity campaigns using national media. An important note was the need to do things *with* people living with dementia, as well as *for* them. This included involving them in education and publicity campaigns, so that members of the community can mix '*with the people with the problem*', so that they come to understand that '*it really isn't anything to be afraid of ...*' and that '*it's people's attitudes towards things that are ... problems ...*'

It's other people's futures too

Deep reflections on the fate of family and support group members who had been '*put into*' care appeared to produce a mixed response in Kathleen. At one point she observed that '*... people do some really nasty things to people with dementia ...*'

While in other moments she was more optimistic, acknowledging that there were some '*lovely places*' to go to now and that the future was potentially positive if you knew what you needed and what was available. What was unequivocal was Kathleen's resolute intention to plan for the future, in particular, using respite to

assess the options for permanent residential care, *'making her mind up'* to get used to the idea *'of going into a home.'* In this way Kathleen appeared to be taking charge of her future, preparing a path that would allow her to enter into residential care in a manner and time of her choosing, perhaps avoiding the tragic fate of her forbears who had suffered so much in institutional care.

Discussion – Then my brothers and sisters might be free

Spiritual narratives like Kathleen's can offer ways to make sense of an illness and connect with supportive resources outside of an individual's everyday experience. This was evident in Kathleen's meaning making, which was deeply immersed in her Irish Catholic faith and a powerful, positive sense of God's presence in her life. Kathleen perceived her illness as a spiritual vocation comprising a commanding redemptive role in her family. Her selfless acceptance of the suffering of her illness could, she believed, save her siblings from a similar fate:

K: If it [dementia] would come to me, then my brothers and sisters might be free ...

Kathleen was clearly proud of this role, which was visible in her face whenever she returned to that storyline. This notion, that sacrifice can transform suffering, is resonant with aspects of meaning making that Frankl described (1984, p. 135).

Much of the energy for Kathleen's 'sacred' work flowed from her strong sense of self, located within intergenerational stories of living with dementia. Intergenerational family dynamics can have a profound impact on the illness experience and participant's narratives can be enriched when understood from within those deeper systemic contexts (see Roach et al., 2008; Roach et al., 2014; Roach et al., 2016). Kathleen particularly identified with her mother's history; she looked like her, was her only confidante, and cared devotedly for her over many years. It made sense to Kathleen that she would suffer in the same way. In this manner, events from the past that aligned with and made sense of her present

experiences were privileged in her telling. Kathleen's family history provided a discourse that was familiar and meaningful to her as a way of understanding and coping with her illness experiences.

As noted above, on a deeper, existential level Kathleen considered her illness as a type of sacrifice for her siblings. Because of the perceived genetic likelihood that her siblings could also have this condition, Kathleen believed that she could save them from a similar fate by being the one to have this illness, to bear this cross for others. The depth of the meaning and importance of this was reflected in the righteous anger Kathleen demonstrated when discussing her sister, who stubbornly refused to accept that Kathleen had dementia, denying her this sacred role. Despite these difficulties, Kathleen's sense of a higher purpose appeared to be protective in the face of rejection by others, allowing her to transcend the negative social positioning experienced by so many with dementia (see Alzheimer's Disease International, 2012; Alzheimer's Australia 2017). It also appeared to support her when family disagreements or 'conflicting storylines'¹¹ relating to her illness experience emerged (see Roach et al., 2014, p. 50). This in turn helped her to maintain her sense of purpose and agency.

This is a radical departure from discourses that are more commonly anticipated and acceptable in a medical story. Yet as Frank (2013) argues, ill people realise that there is more involved in their experiences than the medical model can tell (p. 6). This aspect of Kathleen's narrative resonates with Frank's notion of illness stories that take the form of a 'quest'. 'Quest' stories reflect the narrator's capacity to accept and find a use for their illness (p. 115) thereby gaining something meaningful, resonating with aspects of Neimeyer's notion of meaning making. In this sense Kathleen found

¹¹ The notion of 'family storylines' and their function (Roach et al., 2014) are discussed in detail in Chapter Two.

a way to 'redeem' her illness and point the way to living positively with dementia, creating an alternative narrative to the tragic family stories from the past.

Across the three interviews, a transitioning sense of self was evident (see Harris & Keady, 2009), linked to her changing roles and capacity. In the first interview Kathleen described herself as having been a capable, organised person, with a good memory, who faithfully observed important social and familial practices. This was particularly evident in her previous work role. Kathleen described her long, successful career in the Australian Federal Police and subsequently in the Public Service, which she '*dearly loved*'. There was a strong sense of agency in Kathleen's narratives, with a clear focus on her uncompromising thinking and its powerful impact on her feelings and behaviour.

For individuals with a strong spiritual orientation, subtle, on-going changes can include a gradual disconnection from an immediate sense of God's benevolent presence and purpose (Cook, 2016; Bryden, 2016). This was partly the case with Kathleen, evidenced in the shifts in her emotional well-being over a long period. Kathleen's narratives traced declining capacity, as she found that she could no longer keep up with the demands of work or maintain her home. She was '*losing interest*', '*watching too much television*' and struggling to '*stay focused*'. In the final interview Kathleen became more pre-occupied with her changing sense of self and her day to day struggles reflected in her melancholy observation that her behaviours were '*not really me*'. Yet even then, her strong values linked to her faith buoyed her, as she described her resistance to feelings of despair:

K: ... you can't let that happen to you ... you've got to accept the goodness of life and people ...

Alongside her insights into those changes and what they might have meant, Kathleen still maintained a passionate commitment to family and friends. Her leadership and dedication to others with dementia was a broader expression of her

vocation as she compassionately joined with the suffering of others. Her passionate belief in her cause fuelled her activism in community groups where she worked for greater acknowledgement of the needs of people with dementia and more effective government policies and programs. Kathleen actively sought out information about dementia and resources for support, including community support groups which provided her with a unique reference point for understanding the needs of people with dementia. So despite shifts in capacities, personal values and roles that had been important remained. In this way, while her embodied experience shaped her illness narrative in an important way, yet internal reference points survived.

Clear instances of benefit finding could be found in Kathleen's reflections. Groups that Kathleen attended at a local community agency offered belonging and acceptance. In her support group for people with dementia, participants could talk about their whole lives and share their stories with valued friends in a spirit of mutuality and respect. In this way, her community could hold the valued memories of people who were no longer able to remember for themselves (MacKinlay, 2016, p. 34):

K: [long pause] Ok [strong emotion in her voice] ... you could always tell when it's getting serious when they stop talking, and singing, but they still want to be there, the people let them know they miss them and give them a big kiss on the cheek and they love it, because they know people care. They last a lot longer by having their group ... Mixing with the people with the problem, it gives you a separate family.

In addition to the provision of vital support, Kathleen also made particular mention of notable individuals in the group, returning to the narrative about the 'famous lady poet' in their group five times across the three interviews. These stories established the credibility and standing of the group by referencing the poet's national fame, the beauty of her writing and the historical importance of her works. For Kathleen, this was a powerful demonstration of the enduring capacity of people with dementia to achieve remarkable things.

The poetry of pain

The delivery of Kathleen's stories clearly conveyed a sense of her passion and deep beliefs about her illness. In the first two interviews there was a steady flow from topic to topic, with clear links and internal logic in the progression of ideas. The quality of Kathleen's voice was strong and there were few hesitations or breaks in dialogue, except in rare moments of word finding difficulties. The narratives formed a type of seamless commentary; deep emotion was conveyed through her evocative descriptions, rather than erupting in the interview. The flow of Kathleen's narratives could have been the result of deeper processing and reflection, possibly born of her faith, along with a lifetime of traditional Irish story telling.

As the interviews progressed, there was a movement from well-formed prose, with clear links and narrative structures to a different form. In this instance, the more disruptive form of poetry captures the rhythm and nature of her telling.¹² Narratives were less well formed, while raw emotion was more evident, expressed in sudden outbursts of strong feelings such as anger and frustration. Stories were fragmented, with more rapid movement between narrative strands like riffing on a jazz theme, resembling a stream of consciousness.

Key narrative themes were repeated, in particular references to her troubled relationship with her sister, which appears eight times, most frequently in the final interview. She also dwelt on her mother's illness experiences which conveyed Kathleen's growing concern over evidence of her own decline and uncharacteristic behaviours. Other strong themes included extensive details of family history; the positive care of the local community and key members of her support group; and the need for increased community awareness and acceptance of younger onset dementia.

¹² These concepts will be explored further in Chapter Eleven.

In our final interview, when Kathleen's decline was more obvious, repetition increased, former themes were not as prominent and there was a stronger focus on family now, and in the past. A notable narrative development was more explicit reflection on her spirituality. In particular, Kathleen reflected on its impact on the way she had managed her illness, fostering resilience in times when depression and despair could have taken hold.

The repetition of themes and the fragmentation of plotlines made following Kathleen harder at points. An illustration of this was the varied narratives Kathleen told about her father. Earlier stories portrayed her father as a devoted family man, full of praise for his skilful work and loving care of her mother. In the third interview, there was a dramatic account of her father's active involvement in the IRA before he immigrated to Australia. This was embedded in a long rambling account of her love of football and her enjoyment of singing Irish songs. Kathleen followed this narrative by seamlessly reverting to a more familiar narrative about her father's legacy in the development of the early infrastructure of Canberra, without seeming to skip a narrative beat.

In the IRA narrative, Kathleen described her father and grandfather's involvement, which included tending wounded soldiers in the field, and taking along the host and a crucifix for those in mortal peril. The perilous nature of their involvement demanded strict secrecy and eventually resulted in the whole family migrating to Australia. As this remarkable story was embedded in other, more prosaic themes, it would have been easy to miss its powerful emotional undertones. This story hinted at darker, more violent chapters of the family history, investing their migration story with different meanings. While the nature of her telling cloaked her father's activities in some mystery, Kathleen's pride in her family's achievements fighting for the freedom of the Irish was unmistakable and conveyed her deep beliefs about the justice of their cause. In this way, Kathleen presented this narrative on its own terms, with its own personal meaning.

Kathleen's narratives of living meaningfully with dementia were notable in their passionate embrace of all that this illness had meant for her. Her capacity to live and grow with her illness experience was very moving and resonates with Frank's (2013) notion of the 'ethics of inspiration' (p. 133). In this context, the storyteller does not hide the pain, but seeks to demonstrate what is possible in an impossible situation. In this way, Kathleen joined other well-known Australian women living with younger onset dementia, such as Kate Swaffer and Christine Bryden. These women continue to work hard to change community perceptions regarding the possibilities of actively living with the roller coaster of life with dementia.

Searching for the meaning of suffering by drawing on spiritual narratives can bring a sense of purpose and direction as people seek to understand and cope with their illness in ways which are congruent with their values and history. For some people, spirituality is central to the person's sense of self (MacKinlay & Trevitt, 2012) and their search for 'meaning, hope and transcendence' in difficult times (Finlay, 2015, p. 280). Connections with God can form part of meaningful relationships which provide a different, transcendent sense of self in moments of crisis (Bryden, 2016; MacKinlay & Trevitt, 2012). While some spiritual beliefs may create obstacles as individuals struggle with a crisis of faith, they can also offer release from the intensity and immediacy of daily struggles, providing larger perspectives and motivation to persist in the face of adversity (Bryden, 2016). In Kathleen's narratives a compelling sense of the spiritual vocation in her illness journey provided purpose, direction and vital connections that helped her to transcend her losses (MacKinlay & Trevitt, 2012) and maintain hope in the face of suffering. Kathleen's hope was grounded in the real struggles that she was encountering, which included moments of despair as her illness progressed. Nevertheless her hope enabled her to find meaningful goals and pathways to action (Snyder, 2000). In this way, Kathleen appeared to see herself as someone called to live out her deeply held values as she journeyed with her illness.

Chapter Five

John

Introduction

My first impression of John was that of a quiet, gentle man, who reflected on his illness experience from deep within. During our conversations, I was aware that I felt a strong interest in John's story that continued throughout the interviews. This may have emerged from our earlier therapeutic relationship, when John consulted me in my role as a counsellor at a local community agency, not long after receiving his diagnosis at the age of 56. At that time, John had just retired from his secondary teaching job and was living alone. Our subsequent re-connection was certainly strengthened by John's open, reflective, and at times, emotional responses as he carefully pondered my interview questions.

Our initial meeting to discuss participation in this research project was conducted in John's home, along with Kathy, his partner and carer. This was the second marriage for both John and Kathy, who each had grown up children living in Canberra. As we reviewed the study project, Kathy remained present to provide support for John and raise any questions or concerns about the project.

In this conversation I outlined my desire to create an open, accepting space that could be an invitation to John to reflect on and explore his experiences as he felt able. In response, Kathy stressed that she wanted these to be John's interviews and in this spirit, we all agreed that she would continue to attend interviews. Throughout both subsequent interviews Kathy stayed in the background, out of John's line of vision, intermittently providing some clarifying information. I conducted two interviews with John, whose rapid decline sadly prevented a third interview taking place.

Early in our conversations, John and Kathy made it clear that they were very motivated to be part of this and other research studies and were already actively

involved in national dementia consumer groups. Their desire was to *'improve things for others'* with this illness. Kathy confided that she thought that it was *'too late'* for John, as there would be no cure for him, but there might be for his children; in this way they could *'find some meaning in his illness'*. John teared up as he observed that three other family members had had dementia, and that he was very pre-occupied with his own children's future welfare.

I've got to do something about this, I've got to do the best

John did not begin with a chronological narrative when invited to describe his response to the news of his diagnosis. Instead, John and Kathy provided a partial history of his pathway to diagnosis, which described how John was initially diagnosed with depression after experiencing problems at work. Further tests were undertaken at Kathy's insistence and the diagnosis was subsequently amended to dementia.

This brief account was quickly overtaken by other preoccupations in John's narrative. For the remainder of the interview John became absorbed in a careful articulation of how he wanted to *be*, in response to his illness. After a few moments of quiet reflection, John began his first narrative, which developed into what could be seen as a meta-narrative for the two interviews that were conducted. After briefly describing his anger and grief in response to his diagnosis and his protest as yet another family member was *'gone'* to this terrible illness, he paused dramatically and revealed a critical turning point in the story:

J: ... but after that I er ... changed ... and I thought you know, I can't act like this, because what's the use of it. So um I sort of, the anger dissipated and I thought, well, I've got to make the most of this. You know, you can't just sit in a room and er ... just feel sorry for yourself ...

Out of this very conscious decision, ways of thinking about his illness, emotional responses and desired ways of being emerged for John. In this context, both of John's

interviews became a deeply interior space, a place to create and connect with narratives that elaborated on this over-arching theme.

As the interview progressed, John developed his thoughts about the impact of this intentional way of responding to his illness. He believed that he had been able to find a new approach to living that helped him to cope with his illness. In this process of change he was guided by his desire 'to do his best'. This included not going 'into his shell' but to meet the challenges of his illness head on. These were strong themes that he returned to later in both interviews.

John confronted the reality that this illness would lead to his death, and found perspective by thinking that:

J: Everyone has to die ... the best thing is to go with it and ... you know, be a decent person ... That was very high on my agenda. I thought well, I don't want to be thought of as a nasty person, or anything like that ...

The strong desire to be valued as a 'decent' person emerged at several points in both interviews. John elaborated upon this theme with a story about some negative behaviour that he had witnessed. He described how some men with dementia had kicked the van door when they were picked up for community activities. He understood that they were angry, but was critical of their behaviour, observing that 'you can't have everyone upset, things have to go along.' John admitted, rather sheepishly, that his current attitude was different than his younger days when he 'couldn't have cared less'. John concluded the narrative by describing how he wanted to take a stand and use this experience to 'do good things rather than bad.'

Come on, get on with it!

A strong inspiration for this mindset was his father. John's narratives relating to his memories of his father began with a portrait of a 'tough bloke', a merchant seaman with tattoos who always 'cracked hardy'. He seldom showed his feelings and didn't 'suffer fools', showing little outward signs of sympathy for other's weaknesses.

These story lines continued with John's brief outline of his father and mother's experiences with dementia. John had little involvement with his mother's illness, as his father kept it hidden. Indeed, his mother remained a shadowy figure, who was largely consigned to the background in all of John's narratives. When John's father was diagnosed with dementia he stoically '*battled*' on at home, refusing most help. The unexpected climax in this narrative came with an unequivocal declaration that John wanted to be like his father:

J: ... I think that when I had the diagnosis I thought of him a lot and what he would think, that he would say, "Come on get on with it!"

E: So that was important to you?

J: Yes, very important actually, yeah ... that was a very pivotal thing in my ... um, in my coming to grips with things ... if he wasn't around I might have struggled a bit.

This powerful positioning of his father as a key motivator and model was returned to at many points in both interviews. A moment that revealed the strength and nature of that connection occurred towards the end of the first interview. As a way of drawing the session to a close, I provided a summary of some key themes in our conversation that day. I referred to my impressions of some aspects of his father's behaviour with which John might have struggled. John immediately picked up on this characterisation and queried my meaning. I responded that I saw his father as a strong personality and imagined that that may have been hard for someone like John who was quiet. John immediately defended his father as someone who '*didn't yell or anything like that*'. At a later point John added that his father loved jokes and fun. Following a very long reflective pause, he recounted one of his father's favourite stories about a voyage to San Francisco Bay when another crew member had pointed out Alcatraz and the fact that Al Capone was '*up there*', a '*real bad egg, with no redeeming thoughts*.' John admitted that this story, which seemed to suggest toughness by association, was a favourite of his too, although he didn't elaborate further.

This narrative of how to be in the face of adversity was developed in the second interview when John introduced a story about an older man who had befriended him in one of the support groups. This man was also a *'tough bloke'* who had served in the Vietnam War. John specifically noted that this man had owned a gun and had shot someone whilst on military service. Like his father, this friend was able to help John *'get into the right frame of mind.'* His consistently positive attitude to life was a boon to John, a strong example of how to cope with challenging life events. His friendly support also helped John to settle into the men's group.

As John reflected on this desire to be *'tough'* like his father and his friend in the support group, John returned to reflections on this dramatic shift in his sense of himself. He noted that these changes began after his mother died and were strengthened following his own diagnosis. John observed that he had been a *'real quiet kid at school ... who wouldn't say boo'*. Around the time of his illness however, he decided that he had to *'take a stand'* and *'speak up for himself'*. This resonated with his memories of his father telling him to not be *'a shrinking violet'* and to *'get out there'*. John felt *'really good'* about this personal transformation and was sure that old friends would be surprised to see the *'new'* John in a group, comfortably mixing with others.

There's no pain

As the interviews progressed, I became curious about a particular feature of John's narratives that emerged when he considered his future. Several of the research participants expressed deep anxiety about the impact of their illness over time. I had assumed that this would be the case for John. Indeed when we had first met in a clinical setting, John had been overwhelmed and depressed about his recent diagnosis and struggled with fearful visions of his future. Perhaps in response to these initial impressions, I actively attempted to steer the direction of the interview

down similar paths, by persistently inviting him to tell me about the struggles and fears that he had been facing.

In response to this John traced a different narrative arc. He reflected on his initial fears and uncertainties when diagnosed, in particular fear of pain and needles. However, in the face of those fears, he decided that while his prognosis was bleak, everyone had to die, including him and that *'it might really be ... no problem'*. John returned to this narrative early in the second interview, declaring that he was not worried, that he didn't think *'anything was going to happen'*. He elaborated on how he had arrived at this belief:

J: What really happens is that we just go into a, you know, one phase which is, 'Oh my God, no, it's the end of life.' Well, now I have felt that, um, there's life outside and aah, and the aah, with the people that look after us, they are wonderful ... and I have no, no fear of anything, absolutely none.

John was consistently clear and emphatic about this transformation in his thinking. Towards the end of the second interview when I asked him if he had been frustrated by a lack of understanding from others regarding the nature and impact of dementia, John responded in a firm tone, that seemed to be demanding my attention, that he had *'turned that around'*, and that he was *'going to have fun.'*

In this way, what had begun as a time of deep uncertainty and anxiety about terrible times ahead, with unknown, imagined painful medical interventions, was transformed into feeling like he was *'in clover'*, a *'sham'* because it had not *'posed a big problem in his life'*. This narrative of release from the fear of pain and suffering to a life that was definitely worth living was returned to over a dozen times in the interviews.

Discussion – You've got to do your best

Illness narratives can be invitations to reframe an illness into a challenge or some form of heroic venture. In this genre of stories, life experience requires that the

protagonist transcends who they have been, to become a better person (Frank, 2013). This may involve engaging with existential questions such as how one chooses to be as a 'sick person'. John responded emphatically to the opportunity to be a different person which he believed his illness afforded him. He did not profess an explicitly spiritual approach to life, but he clearly articulated his new found intention to be '*a decent person*' who would be strong, '*do his best*', and make the most of his life.

John's dramatic search for meaning was at the heart of all of our conversations. His strong identification with his memory of his father's strength in adversity and his attachment to this 'heroic' figure who could lift him out of the fear and anxiety that he had experienced earlier, appeared to be a powerful source of motivation. His relationship with his father seemed to be inextricably linked with his relationship with his illness.

When faced with a chronic illness, some people yearn for the protection of a parent as they face their decline (Bruce & Schultz, 2001, p. 70). John's adoption of his father's tough approach to life's challenges could be seen as his way of accessing his father's support and protection in his absence. Furthermore, the legacy of positive parental beliefs have been found to be a significant factor in a person's capacity to respond more hopefully to their illness (Wolverson, Clarke, & Moniz-Cook, 2010). Adopting his father's positive beliefs about coping with adversity appeared to motivate John to change life goals and positively re-appraise his circumstances.

Even though I wondered about such a radical turn in John's narratives, I gradually became aware of positive aspects of his stories that threw light on his transformative experiences. John's circumstances had changed dramatically after confirmation of his diagnosis. He began to enjoy a range of social activities and supports that potentially contribute to a person's well-being as they age (Boerner & Jopp, 2010). This included maintaining constructive familial and social roles which can positively impact people with dementia (Robertson, 2014; Ryan, Bannister, & Anas, 2009). For

example, following initial reservations, he began to relate to individuals in the support groups that he attended, whom he admired and who were critical in helping him to adjust.

Another important aspect of John's narratives was that his overwhelming expectation of pain and suffering was not realised. This contributed to his radical decision to *'go with it'* and *'have fun'* with dementia. The impact of embodied experiences of dementia have received less attention in more recent research (Kontos, 2003). Yet this points to important aspects of living with an illness, including an individual's experiences of physical suffering (Snyder, 2002). John's fearful visions of his future gave way to optimism that nothing *'bad'* was going to happen, when the initial threat subsided. His appraisal of the impact of his illness was that he was *'in clover'*, there was *'no pain'* and he was being *'looked after beautifully.'* This allowed him to re-claim his future and act hopefully. In some ways, it could be argued that the illness acted as a catalyst for significant advances in John's life. His quality of life, with his partner Kathy, had improved in that he had a loving home, enjoyable, purposeful activities and little physical suffering to this point.

These features of John's narratives illustrate important aspects of how he coped with his illness. In this context, John seemed to be able to integrate the potentially profound losses he encountered initially and move forward with his life. It suggests that as Gillies and Neimeyer (2006) propose, the meaning making that is evident in John's narrative played a key role in this resilience. He was able to make sense of his illness by drawing on an established familial narrative which offered connections with strength in crisis. In this way, John's narrative about his hero father represented a new coherent narrative with which to move forward (Neimeyer, Burke, Mackay, & van Dyke Stringer, 2009) and embrace changes in his sense of self.

The challenges of listening

My struggles with John's narrative were expressed in the many moments of disjunct in the interviews where I moved away from the immediacy of the interaction and re-directed to my agenda - the potential losses and difficulties. I was aware that my scepticism was fuelling my form of 'reality' check as John's narrative seemed too good to be true and strikingly out of character.

I came to see that illness narratives may present us with multiple 'truths' told by multiple selves. In this way, truth telling may seem selective, as individuals privilege certain aspects of their narrative (Frank, 2013, p. 62). This echoes Polkinghorne's (1988, 1995) notion that narrative provides a way to include or order certain events, while others will be excluded. From this perspective, the issue becomes not speaking *the truth*, but finding a self that can speak with a voice that is recognisable as one's own (Frank, p. 70). It is possible that John's identification with his father was a way of finding that recognisable voice, the voice that John needed in order to live up to the illness narrative that he was creating for himself, to '*be a decent person and go with it, to do good things.*'

Over the course of our interviews, I became more conscious of what I was privileging as a researcher and counsellor that constituted my own narrative truths (Gilbert, 2002). I came to the interviews with an initial impression from previous clinical work with John, of his vulnerability and fragility immediately post diagnosis. As indicated earlier, from this vantage point I was expecting more of the same, a narrative of struggle and pain. My thinking was also shaped by the loss and grief research literature, which until the last few decades has maintained a strong focus on the individual, intrapersonal experiences of grief, including the deep vulnerabilities of grieving persons (Stroebe, Hansson, Schut, & Stroebe, 2008, p. 9). Because of these pre-occupations, there has been little attention paid by researchers to the concept that some people may experience considerably less distress and be

genuinely resilient to loss (Bonanno, 2004, 2008, 2010; Mancini & Bonnano, 2010) and significant changes to their health (Boerner & Jopp, 2010).

Reflecting on John's story and my response to it highlights the potential for counsellors and helping professionals to 'disenfranchise' clients if they do not hear all aspects of narratives of loss and adversity (Doka, 2002). Doka argues that this disenfranchising occurs when the helping community fails to hear, acknowledge and accept the various ways individuals experience and communicate their losses, including how they cope with those losses.

John's narratives clearly demonstrated a capacity for the development of new skills (see Hedman et al., 2013); positive experiences of living with dementia (Wolverson et al., 2016); and the post loss growth that Neimeyer argues is possible when individuals reconstruct their life narratives in times of adversity (2004, p. 58). It also resonates with the life affirming choices that some people with dementia make in defiance of the constraints of their illness (Clark-McGhee & Castro, 2015). From this perspective, John's narrative appeared to support his efforts to find a voice that would help him live his life as fully as he could. In this way, he seemed to remain engaged with himself and significant others in his life until his declining health interrupted that experience.

An interesting post script to John's 'toughness in adversity' narratives was the feedback from community agency staff who facilitated a support group where he was a member.¹³ They commented on John's gentle, sensitive and inclusive nature and described it as highly valued by the women in the group. This would suggest that new self-narratives that have emerged from meaningful life events can be held in tension with earlier ways of being, resonating with the findings of Clemerson and colleagues (2014, p. 459).

¹³ Personal communication with the researcher (4th February, 2013).

Kathy

There are many ways to love

As John's carer, Kathy was involved in and engaged with the interview process from the beginning. During our time together, I came to see that she was a thoughtful, articulate woman, who cared for John in a respectful, compassionate way. In our interview, she presented her story of caring for John in a detailed, orderly chronological account. Kathy's narrative unfolded as she traced the key events of their journey before and following John's diagnosis, with the climax of John's entry into permanent residential care. On one level it was a story that was echoed in other carer's narratives relating to younger onset dementia - the first inklings of a problem; the rocky road to diagnosis; informing family members and struggling to gain their support; early adjustments in life together; finding community support; and then gradual decline which resulted in a crisis that precipitated moving into care (see Alzheimer's Australia, 2007). On another level, it was a story about a practical love that achieved important things.

Early in our conversation Kathy's clear minded, independent appraisal of John's situation was evident. This emerged as a critical resource as Kathy and John battled to clarify John's diagnosis and come to terms with their dramatically altered future. This was particularly the case when John was initially diagnosed with depression. Kathy recounted how John was '*just so over the moon happy*' that it wasn't Alzheimer's disease, while she remained unconvinced. Part of the reason for her scepticism was her day to day observations of John. A consistent pattern was emerging which included problems caused by John's poor judgement; getting lost in the car; his trouble with word finding; confusion with everyday tasks that he would normally accomplish with ease; and his growing disorientation with time. She believed that John's problem was not a lack of motivation or energy, as you would expect with depression, but deep confusion about how to successfully complete tasks of daily living.

Kathy remained determined to clarify the nature of John's diagnosis, even in the face of strong family resistance to the notion that he may have dementia. Her insistence that John return to the neurologist resulted in more specialised tests that revealed the extent of the damage in his brain and resulted in a referral to a geriatrician and confirmation of his diagnosis. Kathy's practical, almost matter of fact reconstruction of these potentially stressful events was a strong characteristic of Kathy's narrative that re-emerged at several points, particularly when John's condition changed and new understandings and adjustments were needed.

If John had cancer I wouldn't be running

A strong new narrative thread was developed as Kathy reviewed details of her dawning comprehension regarding John's prognosis. At the time of diagnosis John had been living alone and was clearly not coping. He was '*afraid to be on his own*' and was finding functioning safely at home increasingly difficult. Kathy realised that she needed to make a critical decision. Kathy and John had known each other for three years and had made no long-term commitment to each other. They both had previous partners and commitments of their own. Life was becoming more complicated as Kathy divided her time between providing daily support for John and attending to the needs of her teenage daughter. When Kathy consulted her brothers about possible options they advised caution, arguing that it was '*not her responsibility*' as they were not in a formal partnership.

Resolution came for Kathy via a number of avenues. From the outset, Kathy had conducted extensive research on John's condition, using those insights to inform her decision making. Both John and Kathy were also processing their experiences with the support of counselling. John was beginning to understand his illness and that there was real scope for him to continue to enjoy life. Similarly, Kathy was able to gain clarity about her issues, coming to the conclusion that she loved John and that '*he had an illness and if he had cancer I wouldn't have been running ...*' Kathy believed

that the fact that John had dementia did not change her desire to make that commitment. In fact it became a moral imperative to stay and care for him, *'you wouldn't just drop somebody because they had cancer or heart disease ...'*

In recounting this sequence of events, Kathy raised the issue of managing expectations in caring relationships. Once Kathy resolved her indecision, she invited John to move in with her, outlining conditions that *'cleared things up'*. This gave Kathy a sense of control over the situation. If *'things got too difficult ... he would have to agree ... that he would go into care.'* Kathy saw this as an important positive, something that carers in other contexts may not have, such as those caring for a parent. Through her on-going research into dementia, Kathy realised what John's potential illness trajectory might be. This included also what that might mean for her in a support role. She believed however, that this was something that she wanted to do or *'should be doing'* and that John's agreement to her conditions gave her *'an out'*.

Kathy admitted that she couldn't know the full extent of John's understanding of this agreement and its implications. Nevertheless, it was important for her in that she *'wasn't pretending that I could care right to the bitter end'* or making promises that she couldn't keep regarding their future together. Kathy observed that a powerful consequence of this was that she did not feel guilty when John eventually needed permanent residential care as they had reached that understanding when he was well enough to agree.

The capacity to have a clear understanding about the future was possible, in part, because of the quality of their relationship. Kathy described their life together as very harmonious with many interests in common and rich shared experiences, including a love of travel. Their bond of mutual understanding was evidenced in their capacity to adjust as John's condition changed. This included a good humoured acceptance of the need to scale down unrealistically ambitious travel plans. Even when John was less able to help out at home and was becoming disoriented when

left alone, Kathy was philosophically pragmatic about leaving work, seeing it as an opportunity to *'escape'* an unhappy workplace.

More like a carer, less like a partner

The critical qualities of their relationship became more apparent as the dynamic between them began to change. As care needs intensified, the mutuality declined and Kathy assumed more responsibility and began to feel *'more like his carer and less like a partner'*. Kathy believed that she didn't *'cope all that well'* as her resentment grew with a deepening awareness of the *'burden'* of her caring role. This culminated in crisis when John became more volatile, as sleeplessness, disorientation and aggression took hold and Kathy began to feel unsafe with him. Even in the midst of this severe distress and sense of threat, Kathy held on to her sense of John's soft hearted nature, believing that it *'wasn't him'*, but the impact of dementia that caused these violent outbursts. In this way she was able to hold on to the notion of John's core qualities, which had guided their decisions to date.

Kathy returned at several points to the issue of access to support and appropriate medical care and a long narrative was devoted to this theme. Just as John's care needs increased most of his regular community supports were withdrawn *'all at once'*. Kathy persisted in raising these issues with doctors and support workers, but ultimately had to alleviate the pressure on them both by finding one on one care. To illustrate the impact of this, Kathy recounted how John was suddenly asked not to return to one group activity that he had really enjoyed, because his behaviour had changed. Kathy empathised with John's deep disappointment at this point and sought permission to accompany John to one last meeting in order for him to say goodbye to the other members and the facilitator, but she noted that many other members did not have that opportunity in similar circumstances. Kathy expressed the hope that this practice of abruptly removing people from activities would be changed out of respect for all of the group members.

Things go belly up

Gaps in services became acute when John's decline reached crisis point. Kathy described, in a manner that belied the intensity of the situation, how *'things then went really belly up.'* Following a week in residential respite care where John became highly agitated and violent towards staff and family, he was sent to the local hospital where he was finally admitted to an adult high dependency psychiatric ward following 27 hours in Emergency. As John's aggressive behaviour escalated his medications were increased further, to a point where he could *'hardly walk'*.

In the midst of this *'nightmare'*, Kathy's resourceful pragmatism found a solution as she managed to secure a permanent nursing home bed at a local residential aged care facility. Kathy explained that she had begun researching and ringing facilities months earlier. Once admitted, John began to *'recover'* from the trauma he had experienced and his violent episodes abated. His physical and emotional well-being improved and medications were reduced as John began to settle into life in residential care. Kathy found the care residence a *'confronting place,'* commenting that several residents had already passed away. She normalised things when visiting John by going to spaces that had more life in them, like the facility's coffee shop or the lounge, and she felt reassured that finally *'things were a lot better for him'*.

Getting on with life

Overall Kathy did not dwell in depth on her own internal responses to her experiences with John. Her desire to stay involved in John's care meant that she was still visiting most days, despite her doctor's advice *'to get out and get on with her life'*. In a more reflective moment towards the end of the interview however, Kathy observed that *'there's a big gap in my life now as well ...'* Kathy acknowledged that she felt a bit *'down and depressed'* and was unsure about what she was going to do with her life. Her professional and social life had radically changed because of her

intensive caring role. Kathy confessed that she didn't know how to *'get on with her life'* yet, needing more time to decide on next steps.

Towards the end of the interview Kathy also began to review some of the good things that had emerged over this time. This included a striking transformation in the involvement of John's children, who *'really picked up their game'*. Kathy described how they had built more of a connection with John, becoming more hands on in their caring role, despite how hard it had been for them to see their father in care and so unwell. In the early stages, when John had first received his diagnosis and had been asked to leave his teaching job, Kathy recounted how only one of the children, who were all living with him at the time, noticed that he was no longer employed. When John's condition reached crisis point the children were finally confronted with the stark reality of the impact of his terminal illness, and became involved in his care on a daily basis.

In this narrative, Kathy expressed growing admiration for John's daughter whom she described as having been *'high maintenance'* and *'a bit of a tearaway.'* Over the last couple of years, his daughter had begun reflecting on her priorities in life and clarifying what was really important for her. This had resulted in her ending a relationship with an unsupportive boyfriend who had treated her poorly. Kathy believed that all of the children had *'changed for the better'*, becoming more mature and less self-centred. Kathy observed that many people miss out on that opportunity to connect with their parents in such a meaningful way, particularly when parents are terminally ill.

Another instance of benefit finding was Kathy's positive evaluation of their involvement in local and national dementia organisations. Despite the later disappointment with the abrupt withdrawal of services, overall the support John and Kathy had received had been *'important'*. Kathy described how John had liked to think that he was helping many members of the groups he was attending, as he was

younger and more able. This resonated with the feedback from one group facilitator who described him as a gift to the group. This sense of providing mutual aid helped them both to feel that they were '*making a difference*', in small acts of kindness and involvement in more systemic, national issues like consumer advocacy.

Discussion

Kathy's narratives provide a rich window into the context for John's stories. In these narratives there was a strong focus on her relationship with John, her portrayal of her unwavering commitment to him, and her efforts to improve his life. Kathy is located in the centre of her narratives, which build a picture of her agency in the face of challenge. In this context, Kathy's actions in her role as partner, support, guide and strategic planner feature strongly, while the more emotional and existential aspects of her experience are less evident. In contrast, as noted earlier, John's narratives were deeply reflective and focused on how he wanted to be in response to his illness. In these stories Kathy was positioned on the margins by John, who made some heartfelt, passing references to her supportive role.

A key feature of Kathy's narratives was her pragmatic problem solving and strong focus on planning and information gathering. While Kathy's deep commitment to the telling of John's story was clear, her narratives did not elicit any sustained depth of feeling. A sense of loss and experiences of grief were implicit in some narratives, particularly when Kathy reflected on her future, but were not explicitly explored or elaborated on. This privileging of her thinking and actions created narratives of skilful, respectful caring and a sustained desire to provide the best support for John.

The power of Kathy's values was also striking. Ideals such as loyalty, tenacity, perseverance and a commitment to preserving John's rights and well-being were embedded in the narratives and shaped how events were plotted and given meaning. Implied in these narratives was the importance of doing the right thing and getting it right. This included her decision to invite John to live with her and

care for him; her desire to keep her promises; her advocacy for John when support systems failed; her unwavering belief in him when his behaviour became threatening; and her assessments of, and behaviour towards, John's children.

These values were important elements in the narratives of Kathy and John's relationship and appeared to shape John's illness experiences in a notably positive way. Aspects of Kathy's narratives echo the respectful, mutual partnerships that are discussed in the literature on couplehood (Davies & Gregory, 2007; Hellström, Nolan, & Lundh, 2005; Hellström, Nolan, & Lundh, 2007; Wadham, Simpson, Rust, & Murray, 2016). These studies found that open communication between the person with dementia and their partner/carer, combined with a capacity to make the best of things, along with a graduated transfer of roles, resulted in enhanced quality of life for the cared for person. In addition, the amicable, negotiated nature of Kathy and John's relationship align with families who adopt 'agreeing storylines', potentially resulting in more adaptive responses to the younger person's illness (Roach et al., 2014, p. 1409).

Towards the conclusion of the interview Kathy spent time finding perspective about her experiences. Meaning making, in Neimeyer's terms, featured at different points. Kathy alluded to her desire to make sense of things early on when we met to discuss the research project and she stressed the importance of improving things for the next generation of potential dementia sufferers, a sentiment shared by John. Kathy also discussed making a difference in terms of increasing current community understanding about the illness. Clear examples of benefit finding included Kathy's assessment of the personal transformation that John's children underwent as a result of their caring role. She also stressed how much she had learnt in her role as a carer advocate; following research developments; and tackling new tasks on committees with people with whom she clearly enjoyed working.

At the conclusion of our interview Kathy was still processing many aspects of her experiences with John and facing questions about future directions and her purpose in life. However, the many examples of meaning making and the well-formed nature of her narratives seemed to indicate that she had already gained important perspectives on key aspects of those experiences. Kathy's tenacity, commitment and skilful problem solving appeared to be instrumental in her capacity to adjust to, and accommodate, her experiences in her caring role. At the same time, it could be argued that these qualities helped provide a stable and caring environment for John, potentially supporting him in his search for a more positive, proactive stance towards his illness.

Chapter Six

Anne

Introduction

Anne's narratives dramatically illustrated how living with dementia may be shaped by other pre-existing chronic conditions. Anne's story was a tale of two journeys with chronic illness - dementia and Crohn's disease. A complex interplay between the two conditions shaped the impact and meaning of her illness experience and profoundly changed her life. Some of the effects of co-morbid conditions on the experience of dementia have been identified in the literature, including the challenges of obtaining an accurate diagnosis (see Alzheimer Europe, 2011; Lee et al., 2014; Campbell et al., 2016). In particular the confounding effects of depression and anxiety have been noted (Phillips et al., 2011). Experiences such as Anne's however, which relate to the psychological impact of living with more than one chronic condition, have received less attention.

Anne was 59 years old at the time of our interviews, and was diagnosed at 64, subsequent to our conversations together. Even though Anne did not have a formal diagnosis when we met, the staff who were assisting with the screening of study participants believed that Anne's symptoms were consistent with dementia. Anne's experiences included significant memory loss, confusion, problems with orientation to place and time and lapses in following social cues. When Anne was diagnosed the type of dementia was not specified but frontal lobe atrophy was noted.

From our first meeting Anne impressed me as an articulate, intelligent woman, who, despite being somewhat awkward socially, had great personal warmth. Her self-deprecating sense of humour was evident as she pointed out the ramshackle chaos in her house, describing her fruitless efforts to put things in order. Examples of how she managed the daily constraints of her illnesses illustrated her unusual approach

to problem solving. This included coping with the challenges of driving by travelling in the slow lane with her hazard lights flashing. Anne was divorced with no children and had no formal carers.

Anne's narratives were a bricolage of reminiscence and philosophising, which conveyed powerful insights into her embodied illness experiences. This philosophising did not form a coherent overall narrative but held competing or contradictory narratives in tension. In this way Anne moved between stories piecing together sometimes unconnected topics and ideas or shifting positions. Jones (2015) has noted that research into the ways that people with dementia communicate during interviews and conversations has revealed common 'deficits' such as 'inappropriate topic shifts' (p. 556). According to Jones, these 'language disabilities' are typically seen as problems associated with cognitive impairment and do not take account of the narrator's context. Like Jones, I was interested to explore what other factors may have shaped Anne's narratives.

Anne's dementia narratives were uniquely framed by her 30 years of living with Crohn's disease. For Anne this had been an extremely debilitating and life reducing condition. The challenges of extreme, unpredictable pain and confronting symptoms such as faecal vomiting had resulted in a prolonged self-imposed isolation. It became clear as we talked, that these deeply formative experiences prepared her for living with dementia in important ways. In particular, creating a determination to seek more support.

Two, two hour long interviews were conducted in Anne's home. The first interview was used to acquaint myself with Anne's story, while I returned for a second interview two years later to see how she was progressing and whether her symptoms had changed. Her deeply personal stories were conveyed in a sustained narrative flow, which was strongly associative, with few hesitations and limited word finding difficulties.

Swiss cheese

Our first obvious point of departure from the stories of other study participants was the inconclusive nature of Anne's diagnosis. As noted in the introduction to this chapter, the research literature has confirmed the challenges faced by younger people with dementia when seeking a definitive diagnosis. This is often due to the untimely nature of the illness and commonly pre-existing conditions that mask dementia, such as depression (Alzheimer Europe, 2011; Phillips et al., 2011). Anne's situation was complicated by having Crohn's disease. Anne described how the results of many neurological tests confirmed memory loss and some aspects of reduced cognitive capacity. In particular, her MRI showed that there was clear evidence of lesions on the brain. However, the cause of these lesions was not determined and an unequivocal diagnosis of dementia was not forthcoming from any of the medical professionals that she had consulted at that point.

Anne's meaningful reflections began with detailed accounts of her symptoms that she believed could have been related to having dementia, although she preferred to call it '*memory loss*' until she received an official diagnosis. Long narratives were devoted to making her case for dementia/memory loss, citing many examples of chronic, significant forgetfulness; getting lost in familiar places; being disoriented to time; and having major difficulties with driving and routine daily living tasks that required planning and self-care. Anne described her understanding of her situation:

A: ... the way I look at it, it's like Swiss cheese and if I happen to do anything while my brain is in the hole section, then I've got no recollection whatsoever.

While the cause of these symptoms was not easily discerned, the meaning Anne attributed to them was clear; *she* knew that there was something seriously wrong:

A: ... and he [the neurologist] said, "There is nothing wrong with you, don't worry about it," and I had had such difficulty getting there and remembering what day it was and how to get there, and I was on the verge of collapse ... I was so upset and I knew I wasn't right.

The signs of dementia seemed obvious to Anne, and the causes of her illness seemed equally clear. Anne attributed her Crohn's disease to a strong genetic link, while the memory loss appeared to make sense in the context of her Crohn's, which she believed may have contributed to her cognitive impairments.

Wading through treacle

A strong theme in Anne's stories which spoke to her sense of self, was her assessment of her intellectual aptitude. This was based on her high IQ (135) and results from a Mensa entry test that ranked Anne as brighter than 95% of the population. In this context, neuropsychological testing presented Anne with unfamiliar challenges:

A: I've always been very good with language ... it [completing the test] was like trying to wade through treacle ... I was really shocked ... amazed that I couldn't come up with the words.

While her neurological tests did not show anything clinically remarkable, to Anne they were devastating. Test results that represented her scores as average, meant a significant change to Anne and a dramatic shift in her sense of self, most particularly her cognitive competence. To her, these results represented compelling evidence that her condition had caused dramatic cognitive decline. This resonates with the critique by Kate Swaffer (2012), who wrote about the impact neuropsychological testing had on her, when her pre-diagnosis level of intelligence was not factored into her results. She described the distress caused by the 'gross underestimation of the level of my cognitive impairment and the disabilities caused by it' (p. 92).

This narrative could be seen as an example of the 'modern medical story', where the personal and particular is overlooked within a medical report, and an individual's suffering is reduced to an aggregated medical view (Frank, 2013, p. 6). Frank makes the point that individuals in postmodern times are resisting this generalisation of suffering that could be likened to a 'colonisation' by the dominant medical discourse

(p. 11). The impact of these processes for Anne was clearly stressful and depersonalising.

Despite the protracted and frustrating nature of Anne's pathway to diagnosis, ultimately a definitive diagnosis was not the most critical issue for her:

A: I know that there is something wrong ... other people can see there is something wrong and either it's going to get a lot worse or it's not and I'm prepared to just wait and see ...

This determined belief in her own assessments of her situation was formed in part by her previous experience of being diagnosed with Crohn's disease. While Anne was diagnosed relatively quickly, she recounted other examples she had witnessed where many people with Crohn's were '*just told to pull themselves together*' resulting in critical delays in diagnosis and treatment. These experiences were formative for Anne, who decided to trust in her own insights regarding her health.

I've come out of the closet

Consistent with her beliefs about her symptoms, Anne was a regular participant in the many activities offered by local dementia focused community agencies, whose staff didn't question her presentation and welcomed her attendance. Indeed, her acceptance into the dementia community was validation of her beliefs about her possible diagnosis and a meaningful narrative theme that Anne returned to in both interviews.

Unlike other study participants, for Anne there was no stigma attached to attending activities with older people with dementia. These community groups became a new respected reference group, offering shared values and inspirational friendships. Anne described '*feeling at home*' in the psychoeducational groups and social activities where she no longer needed to struggle to present an image of coping, but could just '*be*' with older people who seemed happy '*to just get through the day to day.*' Accessing community support had meant that her social life '*had blossomed*' as the crippling

social isolation caused by her Crohn's disease had been reduced. The challenge and discipline of following a more regularised routine with weekly activities also improved her well-being.

It might be contagious

In contrast to the relative comfort conveyed in Anne's dementia narratives, with her sense of finding a place to belong, Anne did raise other aspects of experiencing stigma. These emerged in her Crohn's narratives and included a range of dramatic familial and social reactions to her diagnosis. In a striking way, these narratives echoed similar stories from other study participants relating to their dementia diagnosis, where participants such as Kathleen, encountered first opposition, then misunderstanding and anger from family members and friends.

Anne related how, once diagnosed with Crohn's, the doctor's prognosis for her had been 'very dire'. She recounted that, while in hospital, the doctor came to confirm her diagnosis, at the time that her mother was visiting. Her normally robust, assertive mother became:

A: ... a terrified old lady, and that was the first time I'd seen her like that, and I thought then I could never let her know how bad it gets, because she'll blame herself because I was born prematurely ... if she had looked after herself I would have stayed longer in the womb ... and I thought if she knows that it's a genetic weakness, she will be devastated.

This narrative clearly conveyed the consequences of her complex meaning making. In Anne's storying, this event was potentially catastrophic for her and her mother. The layered meanings associated with premature birth and assuming responsibility for her mother's responses were striking.

The legacy of this early decision was tragic. Consequences included a lifetime of 'underplaying her symptoms', hiding her deterioration and subsequent incapacitation. Consequently, her father came to see her as 'incompetent' and her brother assumed that she was 'a drug addict' because her symptoms resulted in a steady decline in her

capacity to manage her affairs and maintain normal social roles and connections. It also led to years of under-reporting acute chronic pain, and a reluctance to accept support with pain management. Anne observed that her withdrawal from all social contact had been a *'big mistake'* and something that she was now seeking to rectify.

This life of isolation and misunderstanding led to deep reflections on the nature of illness and how it separates people from mainstream society. From this perspective, Anne reflected on the nature of the stigma associated with illness:

A: ... people don't know how to deal with illness. It's the same with dementia, you know that they are a bit scared, so it's easier to pass as normal. I guess that it makes biological sense to ostracize people who are ill ... they are still afraid, somehow elementally, that it might be contagious ... they don't want the reminder that it can happen to them ... It's like you are rotting food or something ...

The implied perspective taking in this observation presented a stark contrast. On the one hand the confronting, visceral language conveyed a shocking picture of suffering and abandonment. It also represented decades of hard work and contemplation as Anne sought to understand social and community responses to her illness and incapacity, and manage their impact on her well-being. This hard work bore fruit in her new found embrace of all forms of assistance with her dementia. This included community supports, but sometimes simply indicating to others that she was not able to complete a task on her own.

If I could live my life again

Reflecting on years of chronic illness, Anne concluded that she had not been sufficiently educated about her options for treatment that could have transformed her quality of life and given her more autonomy. Over the years she had *'forgotten'* how to make decisions and care for herself. She believed however, that on reflection, she now had more control than she thought, and she could choose to change things. Using the wisdom gained over many years, Anne was currently more actively

managing her illnesses. Seeking appropriate help included consulting a psychologist, something that she was openly engaged with at the time of the interview. Anne was also attending information sessions about dementia in order to understand more about this illness and its impact on her life. With these changes, Anne felt that '*she was taking more control*' of her life and her mood had become more positive.

If it was a card game sometimes I'd throw in the cards

While there had been important improvements in her life there were still times of depression and hopelessness. This was particularly the case when she contrasted her life before her illness when she was competent and successful to her current circumstances. Anne had held a '*prestigious job*' managing a large budget; then she became too ill to work and her income dropped to \$5,000 a year. Her work roles had included several decades spent producing educational videos in various workplaces in many cities. Her final role was a senior policy position in a Ministerial office which had been personally very meaningful. In all of these positions, Anne enjoyed working with people and having leadership responsibilities.

Since then there had been dark times when she had felt worthless and without hope, convinced that she contributed nothing to society:

A: If it was a card game I'd throw in the cards and it's only because it's against my religion and also I realise that it would upset too many people that I don't kill myself ... part of me feels definitely like I'm not worth bothering about ...

Anne's spiritual practice and beliefs were positioned in her narratives as strong protection in the face of her deep despair. Anne returned to these beliefs in several stories, stressing the notion that we are much more than our physical bodies and that there is more than one lifetime. Anne was reassured by the idea that this difficult life would not be her only experience of living. She also treasured earlier memories of a

'more active' 'adventurous' life, that helped her to connect with earlier versions of herself and feel comfort when reflecting on her later losses.

Another protective factor was Anne's keen awareness of her parent's love, which had fostered feelings of self-worth early in her childhood. Honouring that love was an important anchor in later desperate times and strengthened her commitment to never use suicide to escape her pain. Anne *'vowed'* that she would never be the cause of her mother losing another child, since she had lost two at birth. This powerful meaning making had been strong motivation to develop practices to improve her mental health. This involved managing her thinking and using strategies such as meditation and externalising destructive thoughts. This involved allowing negative thoughts to pass, believing that their influence would change with time.

I've got so many things to be grateful for

A strong element in Anne's spiritual practice was the discipline of gratitude. This helped her to find a more spacious perspective:

A: It's not just what is happening at the moment, it's putting it in context ... I need to appreciate, be more grateful for things. It's happening 30 years too early, but it's OK.

An example of that practice was Anne's view that she had learnt so much from her illnesses on so many levels. Through her contact with community groups Anne had relished the opportunity to attend courses and research dementia:

A: I love learning things, even if I've got to learn them the hard way ...

In addition to learning about dementia, Anne reflected that her experiences of living with dementia had expanded her capacity for social connectedness and understanding others. She believed that she would never have understood *'mental deterioration and sickness'* if she hadn't experienced that herself. This had fostered her capacity to connect more meaningfully with other people with dementia, creating opportunities for mutual support. As Anne helped some support group members

who were more advanced in their illness than her, respite from her worries came through mixing with older people, who modelled a grateful acceptance of life in the moment. This in turn reduced Anne's stress and sense of helplessness.

Included in her practice of gratitude was an appreciation of Australian social services and architects of schemes like Superannuation, providing protection for vulnerable people like her. Notably, Anne had been more able to take advantage of government services and to use them more effectively since her dementia diagnosis. In her earlier isolation and suffering these things had not been accessible or even considered. More recently, Anne had initiated a systematic process of accessing community help, such as Community Options and Meals on Wheels. She attributed reduction in hospitalisation and improved standards of living to these supports.

Other aspects of support that helped Anne deal with her times of despair included her love for, and commitment to, her two dogs. This was critically important, as she worked hard to provide them with high quality, reliable care, in spite of her fluctuating capacity. In addition, Anne observed that contact with professionals who valued her and who had '*put so much time into her*' had been very meaningful. Anne summed this up with her stark observation that it would be '*a real slap in the face*' for those who had worked with her over so many years, if she '*knocked herself off*'.

We need to be contributing

Anne's values strongly shaped many narratives, and spoke to her continuing sense of self. A strong work ethic was evident in the long narrative that outlined her work history, beginning with a description of the lengths Anne went to in order to remain employed, before being accepted for superannuation support.

These values were reflected in narratives that alluded to the importance of '*contributing*.' Anne's struggles with her suicidal thoughts appeared to have been fuelled by her thinking that she was no longer contributing to society in a

meaningful way. One long section in the second interview reflected Anne's conflicted thoughts about these issues. On the one hand she unequivocally stated that *'the measurement of a civilisation is the way they treat their vulnerable people'*. She then posed hard questions about the possible limits that should be imposed on spending for expensive community support services, which could be used on more worthwhile projects:

A: it would make a lot more sense if I was put down ... it would be more productive for society.

Yet in the face of these confronting questions, Anne advocated that health professionals should encourage people to accept help, even though they *'may feel like a parasite'*. In this way, Anne argued, people may be assisted to be more useful to society. Anne developed this position, expressing her own conviction that if she had sought help 30 years before, she may have been able to extend her working life and remain a productive member of society. However, all was not completely lost. Even at this point in her journey, when she felt so incapacitated, she acknowledged that the help she had received, allowed her to model *'a healthy psychological attitude to life.'*

As if to illustrate her point, these reflections were followed by a story about Anne's capacity to make a contribution to the recently formed Younger Onset Dementia Activity group that she attended. The group members, who were at various stages in their illness, expressed a strong desire to attend the cinema together, but were prevented by an agency policy that mandated the presence of *'a responsible adult'*. As there was no staff member to assist, Anne volunteered herself as the *'responsible adult'* and the group was able to enjoy two excursions. Anne described this as a wonderful thing that has:

A: helped my quality of life because I've felt useful ... anything that goes wrong, we just laugh about it. And I've improved the quality of their life ... just psychologically, there's so much... we're all so much better off.

In these later narratives, Anne's processing over the two interviews appeared to lead to a reframe of the notion of how a person may be '*productive*' to society. Moving from a focus on her incapacity and her failure to measure up to the more tangible societal markers of what constitutes a '*worthwhile life*', such as being fully employed, Anne shifted to a different perspective. In this space, less measurable, small acts of resistance in the face of her illnesses, were seen as having a profound impact on her sense of self and her value in the community.

Discussion – I *am* valued and worthwhile

Life themes associated with fragmentation, disconnection and reconnection may surface in illness narratives as people struggle with the impact of a chronic condition. In particular, living with chronic illness can disrupt a person's relationship with themselves and their social and spiritual connections. This fragmentation may occur when former '*selves*' disappear and new valued versions of the self have not yet developed (Charmaz, 1983). In response to this sense of disconnection, people with dementia may seek to reclaim recognisable, pre-diagnosis versions of themselves in order to re-establish well-being (Harman & Clare, 2006).

For Anne, experiences of disconnection from her sense of self and others emerged in the context of multiple interwoven illness narratives. In Anne's case a different sense of herself, that had been lost in her years of pain and struggle with Crohn's disease, emerged from opportunities to adopt different ways of responding to her experiences of dementia. In this way, she appeared to have created valuable new narratives for her life that helped her to accommodate profound changes and build a hopeful vision of the future, resonating with the findings of MacKinlay & Trevitt (2012).

The structure of Anne's narratives seemed to reflect the persistent interruptions that illness had wrought in Anne's life. Many narratives were fragments centred on

thoughts and ideas. They had their own internal coherence, and were interrupted by a rapid movement from topic to topic. This could have reflected the impact of dementia on Anne's processing and capacity to maintain a coherent train of thought. Another lens for Anne's performance of her narratives is to see it as the product of a rich interior life that did not often have opportunities for expression. As a result, stories were still being formed in our conversations and Anne had much to tell. This view would align with a constructivist understanding of narrative formation, in particular the impact of context in the shaping of narratives (Neimeyer, 2000). It was notable that even though Anne appeared to be forming her narratives for the first time, her telling was articulate and engaging, often revealing a playful sense of humour.

Some narratives addressed more personal matters such as the challenges of daily living and accessing supports. Other narratives were confronting in their graphic and raw details. Anne's reflections frequently tapped into larger existential themes, linked to spiritual beliefs and deep values. Some of these beliefs and values were embedded in stories; other fragments were more carefully articulated frameworks of belief or positions that Anne held and strove to defend.

In her telling, a dialectic appeared to emerge, as Anne presented and weighed up differing and sometimes opposing, views on her illness experiences, to arrive at a more balanced position. At various points it seemed like a strong, internalised, critical voice competed with a more compassionate understanding of her circumstances, conveying a complex and sometimes shifting sense of herself.

Deeply emotional incidents were mostly described in the same even tone used for more prosaic matters. This presentation of her narratives may have been a function of Anne's strongly cognitive way of being in the world, resulting in deep processing of these experiences, as she thought her way into her feelings. It could also have been the result of her well-established Buddhist practices, in particular the discipline

of meditation, which she described as central to her well-being (see Van Der Kolk, 2014, p. 63). The impact of her 'matter of fact' narration on me was to mask the depth of the suffering conveyed in her stories. As a result, I found it hard to stay connected to the emotional impact of Anne's remarkable experiences. As I struggled to accord Anne's narratives the weight and meaning that they deserved, I wondered what had contributed to this apparent sense of detachment from her stories.

Anne's disconnection from aspects of her narratives, in particular, from her feelings when recalling stories from the past, could be seen as the result of earlier childhood traumas (Herman, 1992, p. 51). Such traumas could also have contributed to a disconnection from her body, resulting in her chronic lack of pain management. Examples of narratives that amplified this disconnection included some striking stories drawn from her early history. Towards the end of the second interview, Anne shared an extraordinary childhood recollection of an incident which occurred when she was playing with her two brothers. She recalled how her brothers had lured her to a spot near a local creek, where they had discovered a beehive. They proceeded to throw stones at the hive in order to agitate the bees, in the hope that they would attack Anne. She sustained 33 stings, but was determined to '*be brave*' and not complain. Anne's dispassionate recounting of the story belied the violence of the attack and what could have been the impact on her physically and emotionally.

The themes of this narrative linked to another account detailing the '*excruciating*' pain of enduring Colonoscopies with a highly inflamed bowel. In this narrative, Anne conveyed a bemused incomprehension regarding her extraordinary degree of compliance at the time, and the length of time it took her to alert medical professionals to her acute distress. Following several agonising tests, Anne finally protested to her specialist and the procedure was changed. It was clear that despite some level of emotional distance, these were highly significant stories for Anne. She had continued to hold these stories and was looking for someone to be a witness to them.

Over the course of our interviews Anne's narratives conveyed shifting representations of her sense of self. Some storylines positioned Anne as powerless, betrayed by medical staff and family members as she tried to be the good patient and daughter. At other points she conveyed a contrasting sense of her agency and competence, particularly in her professional life. Anne described how many significant people in her life ignored her, or worse, took advantage of her open, generous nature. In response to these hardships, her spiritual practice, strong intellect and early formation provided important protective tools that enabled Anne to find perspective and cope with the deep challenges that she faced.

Despite the centrality of her cognitive capacity to her sense of self, Anne conveyed a certain ease with dementia which surprised me. I expected that an illness that was eroding her strong intellectual capacity would have caused a crisis of identity and deep anxiety about the future, aligning with other accounts of living with younger onset (for example see Boden, 1998; Bryden, 2015; Swaffer, 2012, 2016). Paradoxically, Anne's experience of dementia marked a turning point and opportunity for strengthening her sense of self. Her condition was positioned as affording her opportunities for connection and personal growth, in the midst of her daily challenges. This was largely due to the perspectives and practices that she had developed as a result of her painful journey with Crohn's disease.

Anne positioned many narratives to establish her stoic approach to life, and her strongly independent values around not complaining and managing her pain and distress alone. It was clear that this approach to her illness had taken her into the darkest places. Anne's conclusions about this way of being was unequivocal- she needed to change. Drawing on what she had learnt from living with Crohn's, she was developing a more sustainable way to respond to dementia. This marked a shift in her relationship with herself and her condition. Instead of ignoring or '*forgetting*' her illness she had begun to acknowledge her needs and seek help, particularly with pain relief. In addition, she declared that she intended to complain more and had

initiated this process by complaining to me in these interviews. This dramatic change potentially paved the way for her to reclaim parts of herself and her embodied illness experiences.

Some of Anne's narratives were deeply moving, as they brought into stark relief the very poignant losses that she had experienced. Sadness, longing and a palpable sense of a lonely life on the margins emerged, as Anne described her deep feelings of separation from 'normal' living. This included practical matters like more recent constraints on driving that curtailed her independence, along with a chaotic lifestyle, that made social connections less likely. The impact of medication was a powerful factor, as Anne detailed side-effects such as disinhibition and reduced capacity to manage finances, *'frittering money away.'*

Anne instanced many occasions when her lack of social connections had deeply negative consequences. This included gaps in her social skills when she crossed boundaries in conversation, moving into spaces that were too personal and confronting for others. Most recently she had become estranged from her siblings, who were all *'wealthy'* but who seemed uninterested in connecting with and supporting her. Their responses appeared to resonate with the notion of 'conflicting storylines' (Roach et al., 2014) in families who disagree about the nature of the younger person's disabilities, resulting in significant breakdowns in family communication. A notable exception to this sense of social isolation was the social support that Anne enjoyed in her community groups.

A fundamental aspect of Anne's coping with these losses in her life was her capacity to find benefits in even the most diminished circumstances. Anne deeply valued the acceptance and simplicity of her recently made connections with older people with dementia. Meaningful participation in support groups had created a new reference group, where she identified with the values of group members. Anne believed that group activities had improved her social skills and connected her with services

which helped her organise her disrupted life and improve her standard of living. Her unexpected immersion in community support activities *'helped my quality of life because I've felt useful.'* This belief opened the way for new meaning and purpose to emerge as she came to see her dementia as an opportunity to model positive *'attitudes to life'*, concluding that her life was worthwhile. Anne's growth resonates with Kitwood's observation that the experience of inclusion allows the person with dementia to *'expand in new and unexpected ways'* (1997b, p. 20).

The roller coaster experience of her daily life was a powerful challenge, but Anne had learnt to make the most of the good days and any positive change in her capacity:

A: I can't believe the swings ... I go up and down exactly like a roller coaster and the same thing happens with my memory ... I'm just really blissed out, being able to achieve things ... it's brilliant.

Anne cultivated an intentional practice of gratitude for her home, her parent's love, government financial supports and the engagement of staff at community agencies, who helped with practical advice and care. Anne spoke very lovingly about her life with her two dogs whose well-being motivated her to persevere on difficult days, resonating with studies of older people living with dementia (see for example Duane, Brascher, & Koch, 2013).

Anne deeply valued all that she had learnt through both of her illness experiences, including developing a capacity to see the humour in her circumstances and fostering an understanding and acceptance of human frailty. Even her participation in this study was a function of her love of learning and a way to fulfil a life-long dream to conduct her own research. Anne's deep interest in learning provided many ways to reframe adversity into opportunities to grow as a person.

The impact of these forms of meaning making were complex and not always consistently sustained. Anne still struggled with disconnection, in the form of

suicidal thoughts, feelings of worthlessness and confusion. Despite these movements into darker more uncertain places, connecting with others and her spiritual practice offered opportunities to re-establish a forgotten sense of herself as a valuable person with skills to offer to her new community. In addition, Anne's strong conviction that this life was not the only one, afforded her the perspective to see this current illness journey as a foundation for a better life in the future. In this way, Anne's meaning making became a lens for, and a comfort in, times of deeper suffering.

Chapter Seven

Vowell

Introduction

At the time of our interviews Vowell¹⁴ and his wife Sue had retired from their practice as lawyers, and were living in their family home, which was filled with beautiful art work and memorabilia from extensive overseas travel. Vowell and Sue had been married for over thirty years and had two married daughters who lived in Canberra. Their strong engagement with the study was clear from the outset. They both responded with thoughtful questions and keen observations about some of their experiences to date, although Vowell expressed some doubts about whether his responses would be *'useful to me'*. A striking hallmark of all their conversations was the respectful mutuality that I observed in all of my contacts with them. This dynamic is reflected in the structure of this chapter, with Sue's voice integrated throughout in order to represent the co-construction of their narratives.

As we all discussed the project at that initial visit, Vowell struggled to provide details of some background information regarding his diagnosis, as gaps in his memory interrupted his retelling. He politely enlisted Sue's help, who then provided her own chronological outline of Vowell's medical history. Sue described how Vowell had experienced many years of depression, then began to battle memory problems that culminated in a crisis at work, when he was not able to carry out his normal activities.

In the wake of these changes, Vowell consulted with his GP and a neuropsychologist, and a diagnosis of younger onset Alzheimer's disease was confirmed when he was 63. Sue described this as *'a relief to have a label'*, however

¹⁴ This unusual name was chosen by the participant because it was an important name in the extended family that had meaning for him.

other family members, including his mother and brother remained sceptical, both continuing to believe that his symptoms were part of his on-going depression. Subsequent to Vowell's diagnosis, Sue described how she had imagined that life would continue with *'more of the same'*. However, this was not the case for Vowell, whose emotional and psychological struggle with his diagnosis and his declining capacity deepened from that point.

I was cut off from everything ... it just 'sysed' (scythed)

A powerful narrative theme in our first interview was Vowell's grief stricken, angry reviews of past events in his life which he believed had directly contributed to his illness. These stories were filled with bitter self-recrimination and emerged as the meta-narrative for the first two of the three interviews. Vowell described how he believed that he had *'ruined his life'* as a young man and he spoke at length about the irredeemable consequences of this.

Three key events were instrumental in these stories, which were returned to at several points in the first two interviews¹⁵. The first event was a serious car accident where Vowell was driving, which resulted in significant injury for himself and two friends. The second, less emotive issue, was playing football and sustaining several concussions, as a student. The final and deeply wounding event was more recent surgery for an acoustic neuroma, which resulted in significant hearing loss in his right ear. Towards the end of the first interview Vowell made a clear causal link between these events and his illness:

V: I went into Law because er I wanted to ... but then I had this affliction [dementia], from all these things, my own fault.

E: Do you mean the car accident?

V: Car accident, football injuries and er doctor ...

¹⁵ Variations on these themes surfaced 16 times across the two interviews.

The power of this observation was intensified by Vowell's belief that all of these events could have been prevented and that he could have lived a richer, more successful life had he not been '*so foolish*'.

I was weak ... so weak

Key aspects of his sense of self emerged in Vowell's reconstruction of his traumatic car accident and its impact. He provided a coherent, detailed account of how, as a new driver at 18, he had collided with another driver on a busy major city road. Two friends were in the front seat, without seat belts and all three sustained serious injuries. In a familiar story of a young inexperienced driver showing off to friends, Vowell's remorse regarding his actions was palpable. In particular, he recalled his father's strict warnings against having extra passengers in the front seat without belts. He declared that he had ignored this caution because he was '*too weak*' to stand up to his friend, who insisted on riding in front with him and his other companion.

The meaning of these narratives was central in shaping Vowell's response to his experiences of dementia. Using graphic imagery he described the car accident as a '*scythe*' that had cut him off from everything that he valued in his life:

V: ... that [the accident] was the end of me really ... If I had known what I know now I would have just, you know, topped myself, really, couldn't be bothered. I shouldn't have ever gone on with anything ... because there was no life left ... my life was ruined [tears up] ... I just became a bit of a nothing really ... anyway ... and that's why I'm trying so hard with this [the dementia] and then this comes up, and I get this in the head ...

In this narrative, the accident, which had been so catastrophic, provided an impetus to Vowell, to '*try hard*' with this illness, because of the overwhelming guilt that he associated with those early events. Yet maintaining this motivation was difficult as having dementia felt like the final, overwhelming blow in a life tragically marred by setbacks.

He destroyed me

The second element comprising the meta-narrative of a *'ruined life'* was Vowell's representation of what happened when he had to have surgery on his right ear because of an acoustic neuroma. This was a particularly critical narrative, as Sue confirmed that Vowell saw this surgery as a direct cause of his dementia, despite independent advice to the contrary from a neurologist. This story was retold at four points across the two interviews and was saturated in vitriol for the doctor who performed the surgery:

V: ... and then because of that acoustic ... [the doctor] just decimated it and there was nothing there. So, I haven't got anything else now.

E: Is that how you think about it?

V: I have to – I am not a brave person.

Vowell went on to openly express the bitterness of his feelings about this loss:

V: I have a huge amount of hate and I don't talk to people about it and I shouldn't talk about it with you, but you are asking me ... I hate every single thing these people have done to me ... he's never, all I want him to do is say he is sorry, but he couldn't ... because he didn't have the guts ... I'm sorry, I don't think you need this, but I am really angry ... so anyway, now we get on, get the fuselage out of the way.

This heightened emotional telling was characteristic of each time Vowell revisited this narrative, with no noticeable shifts in his expression of raw anger, hate and despair across the first two interviews. At the same time, his apologetic tone seemed to represent another voice reflecting on his emotional state, revealing the power of his inner turmoil.

It could be worse

A counter narrative to the dominant theme of a *'ruined life'*, emerged in the first two interviews. At many points in our conversation, Vowell would pause, regroup and shift to another emotional register with comments like *'but I am not here for that'* and

'you don't want to hear about this, what else can I tell you?' This different voice offered what felt like a commentary on his stories of tragic personal loss. Vowell would then transition to a more positive reflection, although he soon returned to his brooding pre-occupations. At one point he poignantly observed:

V: ... and now I feel very sorry for myself, but still ... I am still alive thank God, I was very lucky – because it could be worse, so I am lucky, yeah, still here.

And later:

V: and I just feel sorry for myself, and you just don't feel sorry for yourself ... you know ... you can't say that, you've just got to get on.

This pattern of moving between these two orientations of a focus on his deep grief and more positive perspective finding formed the narrative structure of both interviews. At points, the movement seemed to represent some type of internal conflict as he struggled to articulate and accept his feelings:

V: And then they look at you, with a face which is normal, and they don't get any response. That's the nutshell for me, and I, and it's all me, me, me, me [strong censorial tone].

I'm inadequate ... I'm useless

The impact of his illness on Vowell's sense of self emerged strongly when he described his day to day experiences with dementia. These narratives detailed the devastating impact his illness and past events were having on his feeling states and his capacity to cope. This included several examples of strong negative self appraisal linked to changing capacity. At one point, Vowell launched into a tirade against himself which included his strong sense of perceived rejection by others:

V: I have a huge amount of stupidity.

E: What do you mean by that?

V: Well, that I feel inadequate, I'm useless, I can't do things I used to do ... I know people look at me in an odd fashion, and that I'm a fruit loop because I

stutter and I don't hear because I am deaf in this one, the other one's useless ... I'm just saying, I have not the capacity [sigh], I just haven't got the guts of the majority of other fellas.

E: In terms of?

*V: ... I've often thought ... I reckon it would have been better to be in a worse situation so that you don't have to know, how you know that you can do these things ... and be the same as all the rest of the people, but you **can't**.*

These themes that conveyed his deep feelings of marginalisation and powerlessness were repeated in the final interview, despite the fact that there were signs of a slowing of cognitive processes:

V: You can't use the word better, you can't say it's better... I just feel as though what I've got to do is just sit around ... stay out of the way ... I just haven't any capability to how to do anything ... I find that it's not fair. I shouldn't have this ... I'm a figure ... I think ... I would ... if you asked people around the place, I'd be a figure of ... what do you call them? Figure of ...

S: Fun, but you're not.

V: Yeah, no, it is.

Towards the end of the final interview Vowell reflected on the extent of his diminishing selfhood:

V: ... I'm sort of woe is me, yeah. I try not to ... so not very good things for myself. That's the thing ... You're not a ... I'm not a person, the others are all ... I just don't know what I am doing here ... what's the point of me, you know?

I have no confidence anymore

As Vowell processed these deep changes in his life he was prompted to draw on some powerful memories of his father, providing a brief snapshot of some significant boyhood experiences and their enduring legacy:

V: ... and – I have no confidence anymore and that comes from a father who was ... he didn't have a good time with malaria ... he was unfortunate and he

used to hit us across the head ... and Mum would say, 'Dad's had malaria' ... mmm ... yeah, but you know a crack across the head ...

E: It sounds like things with your dad were difficult?

V: Well ... it wasn't his fault ... he wasn't that bad, you know he went through hell and high water.

Vowell returned to this narrative twice in the first two interviews, as he processed his assessments of the impact of his father and his legacy. This ambivalence was not resolved as he moved between compassion for his father's suffering in the war and criticism of his behaviour towards Vowell and his brother. It was also notable that he returned to the issue of his father 'cracking' them across the head, an implied link to possible causes of his illness.

I went into the law because I wanted to

A counterpoint to narratives about his accidents was Vowell's reflections on his work life. These were bitter sweet. Work was a source of deep pride in hard won accomplishments. It was also the context for the first indications that something was seriously wrong and that life was about to change. Vowell's diagnosis narrative included his memory of the moment when he was unable to complete work on an important mediation matter. Reading and analysis of documents that should have been 'an absolute piece of cake' suddenly became impossible, as his mind became a complete blank and he had to abandon the project:

V: ... you are going along one way, and its X, Y, Z and then suddenly, the gate shut, and so that's- but- yes, I just couldn't do it ... I tried to do it at home, and it was still going bad ... well I was stuffed, I didn't have anywhere to go then.

At other points, references to work expressed the depth of his losses, as he struggled to find perspective and make sense of his situation:

E: So, there are these strong feelings ... deep anger and grief?

V: Yeah ... it is grief ... I could have been a pretty good barrister and I could have been – [deep sigh] ahh, healthy, but you know there are other people, a good mate of mine and that bloke did die.

In contrast, a clear shift in energy and narrative structure occurred when Vowell reflected on past successes in his work life. A strong narrative thread described his work establishing a new commercial mediation practice. He was extremely proud of the fact that he chose to leave more lucrative legal areas to forge his ground breaking approach to commercial mediation, which he saw as valuable pioneering work in the field. Vowell showcased his capacity to skilfully mediate, with examples from matters where he worked in a more nuanced way, rather than playing 'hard ball' like other lawyers:

S: That [the mediation practice] worked successfully on and off for 11 years ... he was very well thought of.

*V: Real mediation, this was the **real** [emphasis in speaker's tone] mediation, but all these other things in the Family Court is a load of rubbish. And later:*

V: I was in the Court, in the Supreme Court ... and I loved that, that's what I wanted to do all day. It was just like rolling in caramel!

Another example of these striking work narratives was the recounting of a visit to a remote Aboriginal community to conduct a mediation. This story clearly conveyed his values regarding respect for the people in the community and his outrage at what he regarded as the shocking treatment they had received from some large mining corporations. In the telling, another aspect of Vowell emerged as he shared some amusing anecdotes that struck a more playful, light hearted note and showed his capacity to laugh at himself. In this story, some Aboriginal colleagues talked him into going down some tunnels to document what was there.

After what seemed like hours of squeezing himself through stiflingly hot and impossibly narrow passages, he finally emerged with the sweat pouring off him, while his Aboriginal colleagues 'were rolling on their backs, in the sand, laughing and

laughing.' It then dawned on him that the whole episode was a joke at his expense. Vowell concluded the story by wryly observing:

*V: Well it's good to get back at the white man isn't it ... but I feel for those
Aboriginals, because of the owners of the land who wanted to kill the river.*

All of these narratives struck a confident, competent tone, in contrast to the desperate narratives of pain and loss.

An interesting moment, which amplified Vowell's values regarding his workplace success and career choices, featured in a story concerning his brother. After completing his law degree, Vowell described how his brother had joined a law firm where he had remained for his entire career, following a more conventional, less independent pathway. Even though he observed that his brother had done very well in his law practice, in his view, he had followed a less adventurous, less meaningful path, *'riding other's coat tails.'*

She must be at the end of her tether

Vowell's appraisal of the supports that he had received during his illness, focused strongly on family supports, with no references to community services, even though he was regularly attending several community based activities. He made several, unequivocally positive references to the daily care that he had received from Sue. Vowell's representation of Sue's caring role consistently positioned her as uncomplaining in dealing with his unreasonable demands, including his hot tempered outbursts. He expressed deep concern about the pressures she was having to contend with because of his difficult behaviour:

*V: She is just the same, but she can't be really the same because she has had to
shoulder everything, brickbats and all those sort of things and you know ...
there wouldn't be anybody else as nuisance than me ... she got the bad marble,
didn't she?*

The only other reference to family support was a brief mention of his mother who was a 'strong woman' and a 'magnificent lady' who was always there for him, despite her great age. This was consistent with her history, as she had always been 'solid as a rock', including in the aftermath of his car accident. A brief allusion was made to the negative impact of his 'manic behaviours' on his relationship with his brother following his diagnosis, and to friends 'dropping off' because of his illness.

Following this narrative thread, I widened the scope of our exploration, to ask what health professionals might do to provide more effective support. Vowell gave an unequivocal response:

V: That's the question. No.1, a person who has the capacity to understand what a person like me is living with ... they don't give a stuff ... you know, this dementia ... it's a bit like horse jumping ... you can see the gate ... but it's a bloody big hurdle. Let's just stop tippy toeing around, saying nice things and get onto it and say, 'You've got this,' 'Right, tell us what dementia is'. They say just read it, that's no good to me ... they don't listen to you ... When I was a lawyer, and I'm not a goody goody, all lawyers are ratbags and I am a ratbag, but I used to look after people ... but there's no humanity in this place.

Vowell clearly articulated that in order to support a younger person with dementia, professionals needed to listen to the person, provide clear, unambiguous information and bring a compassionate, more 'human' understanding to their patient relations.

My brain is not manufacturing a think

The narrative structure and themes of the third interview represented a striking shift from the previous discussions. In this interview, Sue was present for the whole time and her narratives were more closely interwoven with Vowell's narrative threads. There was a partial movement away from Vowell's intensely negative ruminating to more positive appraisals of Vowell's life from Sue. This was interwoven with Vowell's more confused, yet still deeply troubled reflections that re-iterated some

earlier themes. These two strands operated like parallel narrative tracks, with some empathic joining by Sue at points.

Sue's reflections shaped Vowell's narratives to some degree, although he returned to his thoughts and feelings from previous interviews at regular intervals, demonstrating the depth and power of his feelings. In particular he continued to struggle with his declining capacity and the unfairness of his condition:

V: ... it's pretty hard to know what to know, pretty hard to work out- because I don't know ... if I knew I would go and do it.

S: Vowell has to sort of wait to be told what's happening these days I think, don't you?

V: Yeah.

S: But in fact the days are quite busy.

V: I find it ... I find that it's not, it's not fair. I shouldn't have this ...

Changes in Vowell's capacity were evident in this interview with more fragmented sentences, and slower processing of the conversation as he searched for words and thoughts. There was frequent movement between narrative themes, which were more limited in their scope. However, they were still focused on angry reflections on the impact of his illness and his bleak thoughts about his current situation. While fluency was reduced, the raw energy of Vowell's despair was still strong.

As Vowell reviewed his loss of capacity, he sounded uncomprehending, lost in the illness experience, continuing his protest at the 'unfairness' of it all. His oscillation between a negative voice and a more positive perspective that had formed the narrative structure of the previous interviews had diminished, with a stronger focus on the negative discourse. He returned to familiar themes including the catastrophic damage suffered at the hands of others, although those references were more oblique:

V: ... it's not fair. I shouldn't have this.

S: No, it isn't.

V: Some bastard doing something and then, ah, and then I don't know, I don't know ...

S: Vowell and I talk a lot about how one of the awful things about getting to our age is that we know lots of people that unexpected and unfair things are happening to ... it's not to make you feel any better but it's just that time of life unfortunately.

V: Yes.

In contrast, Sue's narratives were constructed like a well-argued case for an alternative, more positive reframe of Vowell's thoughts and feelings. At many points she would respectfully put her view of Vowell's responses, along with additional suggestions that expanded the discussion and seemed to temporarily shift Vowell's thinking:

S: You enjoy your walks don't you, with M. and the boys?

V: I enjoy it in ... walks with other fellows.

S: ... and they, you know they sought Vowell out ... so that was just lovely.

V: Yeah, which is nice ... that's a good exercise for me. Not much to do for others but that's really good for me.

There were other moments in the discussion when Sue joined with Vowell in a more empathic response, which showed her understanding and support:

V: Ah, it's very hard. My brain is not manufacturing a think [participant's word] and that's not fair.

S: [Laughs] Yeah. Not fair that you have to live with that.

V: Well, it just doesn't work.

S: Mmm. Thinking is hard.

The overall impact of the shaping by Sue was a focus on more positive themes that highlighted pleasurable activities. These included visits from family members and grandchildren, shared activities like visits to the art gallery, a new friendship at a local community centre and spending some time drawing. In particular, Sue described a project shared between Vowell and one of his daughters which centred on collating all of his mother's recipes, providing a trigger for reminiscences about his childhood. While Sue described these activities Vowell listened and agreed but didn't elaborate on or develop any of her themes. Vowell's own, less positive, reflections were much briefer and were still very emotionally charged.

Discussion - I shouldn't have this; it's all my fault!

Vowell's stories offer a rich example of a search for meaning in the context of a whole life story (see MacKinlay & Trevitt, 2012; Robertson, 2014). In his storytelling, Vowell focused on key events which seemed to offer insights into the causes of his illness. Crafting an understanding of the causes of an illness can provide a meaningful focus in the narrative reconstruction of life events. This process may involve linking early life choices and episodes with later events, in order to make sense of those experiences (Polkinghorne, 1995, p. 8). In this way, people can potentially reclaim a sense of control, purpose and direction in life (Williams, 1984).

Vowell's meaning making amplified the potential pitfalls of this type of narrative reconstruction, when storylines generate ambiguous or negative meanings (Williams, 1984). Vowell's narratives involved complex acts of interpretation which created competing storylines comprising two themes: self-blame and angry protest. In his complex stories rich metaphorical language portrayed deep emotional and psychological turmoil. The strongest positive outcome of this meaning making was to motivate Vowell to '*try hard*' to cope with his illness in order to atone for his earlier mistakes. Tragically, this determination appeared to be frequently overcome by his persistent pessimistic ruminating.

A notable and consistent characteristic of Vowell's narratives was the linking of the three key events in his life with the onset of his illness, which were in his mind all preventable and *'his fault.'* The complicating impact of perceived preventable losses and their associated feelings of anger, protest and the need to assign blame and responsibility has been noted in the bereavement literature (Rando, 1993, pp. 9-10; Worden, 2018, p. 62). A dominant feature of Vowell's discourses was the frequent use of assessments and judgements about himself and others, which were negative and blaming. There were constant references to himself as *'having no guts'* being *'stupid'* *'useless'*; and *'not a real person'*. This self-denigration and blaming, along with feelings of grief and bitter regret, which were linked to those appraisals, did not shift in focus or intensity across all three of the interviews. In Vowell's mind, these events thwarted his opportunities to become a *'pretty good barrister ... in higher levels'* and build a long, successful career and happy life.

Grieving for what might have been is described by Machin (2014) as an example of thinking that long held ambitions in life can, and in some cases, should, be realised. This, she argued, is a belief based on more recent notions of individual control and autonomy. Unrealised ambitions may be carried over many years and feelings of grief may only emerge when another loss provides the trigger for previous disappointments to be acknowledged (p. 22). In this instance, the onset of Vowell's dementia could be seen as providing the impetus for a review of past choices and *'failures'* that tragically altered his life course:

V: It just cuts the rug from underneath – and then you've got, oh, I don't know. I did the job and so I should get the um, the um, what comes after it. So you just have to sit and take it.'

In times of adversity, individuals may be triggered into more childlike spaces, where earlier childhood beliefs and lessons from the past take hold, such as *'only bad behaviour deserves punishment'* (Bruce & Schultz, 2001, p. 4). These explanations could be childhood messages that may have been punishments for risks taken, such

as 'you brought it upon yourself' (p. 5). This would suggest that Vowell's bad behaviour in the car accident and the subsequent injuries that he '*brought upon himself*' because he was '*weak*' and didn't heed his father's warnings, could be seen as having some deeper resonance for him and made sense in the crisis of his illness.

This notion about a movement into a more childlike state resonates with my experience of the oscillations between the two 'voices' that characterised the narrative structure of the first two interviews. The voice of protest and despair that repeatedly expressed Vowell's grief over past incidents moved between anger and a more plaintive, childlike tone. This was countered by a seemingly more adult, possibly parental voice, where he admonished himself to stop his stories of '*woe is me*' and move on.

Vowell's sense of self was focused strongly on what he perceived as negative traits and behaviours. It centred on his perceptions of how others were seeing him, that is, as a '*figure of fun*' and his own critical appraisals of his reduced capacity and his '*stupid*' behaviour in the past. These judgements were expressed consistently over all three interviews and triggered strong negative emotions in our exchanges.

It is not clear whether a tendency to more negative self-appraisals was a well-established way of thinking and being for Vowell, or whether it could be argued that it emerged as a response to his current illness experience, as described by Machin (2014) and Bruce and Schultz (2001). However, Vowell's long history of depression could suggest a pre-existing tendency towards more negative thinking and appraisals of life events. In addition, individuals who are not able to meet their expectations of themselves, or accept that others may disappoint them, may be more vulnerable to depression (Geldard, 2009).

The major exception to this negative self-assessment was Vowell's retelling of stories relating to his work as a mediator. Here, the tone lightened and a real pride and pleasure in the recollecting was evident. In these narratives, Vowell represented his

work and by implication, himself, as innovative, intelligent and courageous, providing another version of himself. In this telling, Vowell's passion for his work was compelling and narratives flowed, with a clear organising structure, as action carried the story. Strong negative emotions did not disrupt the telling on these occasions, as Vowell seemed to be transported to another thinking and feeling state. The stark contrast between these storylines and other negative narratives suggests that Vowell's sense of his professional self was not generalised into other versions of himself. This appeared to limit the internal resources available for Vowell to draw upon in these times of crisis.

Benefit finding in Vowell's narratives was more limited. He did find perspective in some moments, when Vowell appeared to consciously shift his feeling states by moving to another thought, such as examples of friends his age who had recently died. This new perspective, *'but I am lucky ... still here ...'* seemed to short circuit that downward spiral into deeper despair and restore some emotional equilibrium. At another point, reflections on the hardships that his father had endured in the war appeared to provide some perspective and ground for a shift in feelings. While these shifts in thinking and feeling represented some capacity to access multiple perspectives, their value seemed to be limited, and the narrative thread soon moved back into more negative rumination.

Sue also introduced some benefit finding towards the end of interview three when she reflected on community attitudes to dementia. Sue picked up on Vowell's pre-occupation with the reactions of others which he characterised as stigmatising. Sue argued that community understanding of dementia had improved, resulting in more inclusive practices. She cited experiences with long-time friends, who knew Vowell well. In Sue's view, these valued friends were able to differentiate between Vowell as a person and the impact of his dementia. Consequently, they all continued to hold him in high regard. She maintained that any awkwardness from friends was due to not knowing how to communicate with an individual with memory problems, rather

than a rejection of Vowell. Vowell appeared to agree with these observations, and then added his own perspective, that in times spent with friends there was, *'Not much to do for others'* but that it was *'really good for me.'*

Vowell's responses to his illness appeared to draw upon the personal and interpersonal narratives available to him through the course of his life. Vowell's storylines positioned him as entirely responsible for his illness, re-constructed within a long term familial and professional context where success, excellence and getting things right was important. In this setting, deep beliefs about perceived life changing personal mistakes were powerful barriers to more adaptive responses. Deep sadness was a persistent note in all of Vowell's meaning making, which seemed to disconnect him from aspects of himself, his family and social supports, even in the midst of the love and support of his family.

Sue

It's like a shroud building up around him

Sue's opening observations about the impact of dementia on Vowell conveyed a powerful sense of an insidious process that was robbing him of all life. Sue described how *'horrible'* it had been to see the impact of this deadening process:

S: ... almost like a shroud building up around him where he sees himself as, well, quite cut off from what he sees as the real world.

This striking image resonated with Vowell's picture of dementia that had cut him off *'like a scythe'* from all of the aspects of living that he held as worthwhile. Sue expressed her deep grief in response to the changes they had experienced together, even though she tried not to dwell on them. She also reiterated and empathised with Vowell's sense of isolation and humiliation at the perceived injustice of his illness:

S: the hardest thing for Vowell has been accepting a diagnosis which in his eyes makes him very different ... and certainly less than everyone else. He sees

himself, well rightly I suppose, in one way, because he's intellectually compromised by this cognitive decline ...'

Part of Sue's meaning making was conveyed in her belief that an added layer of suffering came in the form of Vowell's beliefs about his situation, which she described as '*cruel for him*'. While Sue worked hard to maintain their normal social connections, she noted the impact of the stigma of dementia:

S: His good manners come to the fore and he's always extraordinarily gracious and polite and welcoming to people ... but his constant mantra at home is, 'I'm sick of everybody looking at me as if I am a nut case or crossing the road to avoid speaking to me.'

Reflecting on the depth of Vowell's distress, Sue '*wished fervently*' that he would come to some form of acceptance of his diagnosis, in order to alleviate some of his deep suffering and reduce the intensity of his reactions.

It is notable that Sue consistently moved away from a medical discourse in trying to understand dementia, to a more contextualised appraisal of Vowell's experiences and responses, locating it within his whole life story. Sue added her own meaning making as she observed that life had become more complicated for Vowell when he left his law practice to establish his work as a commercial mediator. Sue believed that even though Vowell had initiated this move, she thought that he had suffered a loss of status in leaving the mainstream of his professional body, from which he never recovered. This insecurity was exacerbated by his surgery for an acoustic neuroma seven years later, when memory and concentration difficulties began.

In Sue's view, these major events deepened Vowell's existing feelings of being '*a nobody*', which had now built into a major preoccupation with the onset of dementia. Vowell's persistently negative feelings were '*awful because it extends to everything ...*' including relationships with his family and herself. In this way Vowell appeared to be re-writing his life narrative, paradoxically using the new lens of dementia to bring some coherence.

He desperately needs it to be the same

All of Sue's narratives showed her highly developed self-awareness and capacity to connect empathically with Vowell in his grief; and her strong values around maintaining a loving, compassionate relationship. Sue acknowledged the relational nature of Vowell's sense of self, in his need for their relationship to remain unchanged. Yet, Sue believed that to maintain the pre-diagnosis dynamic between them was problematic and in some cases unrealistic. Sue described Vowell as someone who:

S: wants to feel that you see them as attractive and desirable and the protector.

Yet for Sue, this was no longer possible:

S: it just doesn't feel like that anymore ... and so there is a sense of well - a horrible thing to say but how much acting do I have to do?

This resonates with Kitwood's notion that the person with dementia's personhood (1997a) and their experience of their illness is largely impacted by their relationship with their principal carers. Vowell's sense of himself in the relationship was in flux and he needed constant reassurance.

However, on a practical level, the mutuality of the relationship was disappearing as Sue regarded herself as the person who '*needed to think for both of us and manage for both of us*'. In addition the quality of their relationship was changing as spontaneity and intimacy between them was reduced. Free flowing conversation had changed to a more '*guarded*' dynamic, where Vowell's sensitive introspection created a climate of self-doubt and morbid sensibilities:

S: We can be sitting in the cinema together and I might squeeze his arm and say, 'Isn't this a great film?' And he'll say, 'Yes' and then a minute later he'll whisper, 'Are you bored? I expect you wish you were here with someone else.' And I think oh, please [laughter] can't we just enjoy something for a minute without having to analyse it and reassure you.

In an effort to maintain some continuity with the threads of their pre-illness relationship and find a more constructive perspective, Sue encouraged Vowell to reflect with her on their shared history. Sue described how they spent time with old photographs that reminded her that while things were changing, it was in the context of many happy years of marriage. Maintaining these narrative threads has been promoted by commentators (see Bruce & Schultz, 2001) as a way of preserving links with some enduring aspects of self and maintaining valued life views from before the loss (Machin, 2014). This meaningful perspective finding seemed to comfort Sue but was not always positive for Vowell, as their reminiscing appeared to exacerbate his feelings of loss.

I am the person to vent to

Maintaining the equilibrium of the relationship was a challenge. Vowell's increasing struggle to feel in control, in the face of his diminishing autonomy posed problems for Sue:

S: I think I am being seen to be managing our lives. I'm therefore seen as being in control and he resents that, so he can be quite critical of me in that sense ...

This gave rise to Vowell showing feelings of 'jealousy and intrusion.' As a consequence, Sue had decided to limit her activities to times when he was away from home, to reduce stress for them both. Sue regarded his 'very watchful' behaviours as an understandable outcome of Vowell's 'vulnerable state of low self-esteem'. However the intensity of living with such a sensitive, critical person was taking its toll:

S: I think certainly the anger is hard to deal with because there's certainly an element where I find myself thinking this isn't fair, I'm trying really hard ... It isn't much fun for me either ... he can be quite harsh in his criticism ... that's probably the time I feel most stretched ... in the moment you do think, oh, I just want to run away.

Sue reflected on the meaning of Vowell's dementia for her. She grieved her lack of personal space, and yearned for times of solitude. At those moments it became *'very tough'* and felt more like dealing with a *'small child'* and the demanding immediacy of their needs. As a consequence she had begun to use respite to take breaks just *'to feel the silence for a minute'*, but the constant need for understanding, effort and careful management of the situation was exhausting and an on-going issue.

Family don't understand

While friends and colleagues had shown understanding of Vowell's illness, his immediate family were not seen as accepting of his diagnosis of dementia. With a strong family history of depression, both his mother and brother focused on this as a more probable diagnosis and urged Sue to find a *'good doctor'* in Sydney, in order to arrive at a more accurate assessment. Sue believed that misunderstanding and the family meaning making had had a very negative impact on Vowell. He felt cut off from the family, who in his mind did not really understand the nature of what he was experiencing. This caused him deep frustration, particularly with his brother who seemed to think that his illness could *'be fixed'*.

There were also examples of unrealistic expectations of family members who offered to involve Vowell in activities that he was no longer able to undertake, such as crewing on a yacht in a regatta. In these circumstances, Sue reported carefully navigating between Vowell's *'childish sense of ... you can't stop me doing everything'*, avoiding conflict with the family, and respecting his need for some independence within realistic limits. Sue also considered that Vowell was distressed by thoughts that he couldn't *'be a proper son'* as he was now limited in the support that he could offer his ageing mother.

It just robs you bit by bit

These reflections gave rise to Sue's observation that earlier in Vowell's illness, they had been able to avoid doing things that were too difficult, such as home

maintenance, but had still been able to share many pleasurable activities together. Sue's creative problem solving day to day delayed confrontation with the more stressful aspects of the illness, such as Vowell's awareness of declining capacities. However over time, activities that involved more complex processing had become too difficult, and were abandoned. Sue likened this to the illness '*just robbing you bit by bit of your sense of a normal life.*' More recently, in response to that steady erosion of their shared life together, Sue had decided to schedule something '*special*' to do together each week.

It feels like a long dark tunnel

While Sue's major focus in her narratives was on the current impact of the illness, she did reflect towards the end of the interview on what her future might look like as Vowell's capacity declined. She related a recent visit to their family doctor when Vowell had asked him for a realistic prognosis. The doctor reassured him that in light of the fact that he was currently '*doing well*' he could have another 15 to 20 years to live. Sue was momentarily overwhelmed by this picture of her future life:

S: There was an awful moment when I thought, 'Oh, my God' and then thought, 'What are you thinking Sue?', but it's not that I don't want to have him around for that period of time, of course at all, but just the thought of, 'Do I have to go on like this?'

While Sue was able to regain some perspective she added:

S: From what we know of the illness, it won't be like that, but ... yeah ... when things are really difficult it does feel like a long dark tunnel that we're travelling along and I suppose the not knowing how and when things will change ...

Sue also flagged that she could anticipate a time when she would need to take longer breaks alone, overnight. As Vowell's capacity to cope with travel even short distances was significantly diminishing, this would require the support of their daughters, to provide additional respite.

In the more immediate term, Sue was planning modifications to their home in case mobility for Vowell became more of an issue. Sue was clear that she wanted to avoid moving from an area that had excellent amenity and where they felt supported by neighbours. However, even those practical measures were proving difficult as Vowell had been very stressed by the planning process and was suspicious about Sue's motives for the proposed new arrangements. In spite of those barriers, Sue was determined to '*forge ahead*' with these changes.

Discussion

Sue's narratives centred primarily on her insightful and articulate assessment of the impact of dementia and previous life events on Vowell; her responses to their changing relationship; and thoughts about the future. Throughout her reflections Sue seemed to be making sense of Vowell's experiences, using the lens of their long history together. Sue clearly identified Vowell's negative meaning making as a critical factor in his struggles to accept his diagnosis and adjust to his illness. Her narratives were strongly focused on thoughtful appraisals of her experiences, including her feelings. However, it was notable given the intensity of those experiences that those emotions did not erupt in her telling.

In our conversation, Sue positioned herself as working hard to understand Vowell's deep struggles with his illness and provide effective support. Many of Sue's narratives amplified the high standards that she set for herself in this challenging relationship, as she sought to maintain a loving, open and respectful partnership. In this regard, Sue and Vowell's relationship resonated with the positive qualities discussed in the couplehood literature referred to in Chapter Five (see Davies & Gregory, 2007; Hellström et al., 2005; Hellström et al., 2007; Wadham, Simpson, Rust, & Murray, 2016). However, despite her best efforts, important aspects of their relationship that were clearly important to them both, such as mutuality, trust and

open communication, appeared to be steadily eroded by Vowell's struggle to find meaning that could shift his perspectives and sustain him.

In her valiant efforts to remain connected with Vowell, Sue demonstrated a strong sense of herself in recognising his needs *and* working to find a balance in her roles as a wife and carer. This often involved a complex process where Sue struggled to continue in the face of the relentless intensity of day to day living. At times the demands felt overwhelming. At the close of our interview Sue described her commitment to pressing on with changes that were needed for their future lives together. This quiet determination to meet the challenges of her caring role head on seemed to capture the essence of Sue's capacity to navigate the deep waters of their life together.

Chapter Eight

Warren

Introduction

Interviewing Warren posed considerable challenges for me as a listener and paradoxically provided unexpected insights into the impact of dementia on narrative forms. His storylines focused on themes that resonated with other study participants, however his use of language and mode of telling was strikingly different. This was principally due to the significant word finding difficulties caused by his dementia. Even though these word finding difficulties made it hard to follow Warren's train of thought, his particular style of telling with narrative highs and lows and dramatic turns was persuasive and engaging. His use of tone, pace, body language and invented words strongly conveyed his struggles and triumphs in living with his illness. At some points, making sense of Warren's stories involved deducing more obscure meanings from their context in the narrative. As I tuned in to Warren's language, I saw that his stories had a narrative logic of their own, which helped me to connect with him and his stories.

The process of connecting with the meaning of Warren's stories prompted me to frequently reflect what I had heard, in order to check for accuracy in my understanding. Warren responded to these reflections consistently with a clear and emphatic 'yes' or 'no'. As we engaged with each other, this process shaped the narrative. Since this was a critical element in the co-creation of Warren's stories, this dynamic is represented in this chapter by including my voice in the interview, demonstrating the interplay between us.

Information about Warren's performance of his narratives is provided throughout this chapter to provide clarity and meaning for the reader, including descriptions of body language. In order to demonstrate Warren's remarkable capacity to convey his

meaning, verbatim quotes have been included (represented phonetically when needed). However some 'translation' has been provided to aid understanding when meanings are more obscure. The forms of these stories provide a useful contrast to some of Warrens' more fluent narratives.

Two interviews were conducted in Warren's immaculate home, with his wife Clara nearby in the study, in case we needed any assistance. Clara, who was Warren's full time carer, had her own serious health issues, which included managing Multiple Sclerosis over several years. They had two sons, one of whom was living in Canberra (Chris), the other being overseas. Warren was 60 years old when he was diagnosed. We did not complete a third interview as Warren's dementia had progressed to the point where he was unable to participate comfortably in that process.

What am I going to do?

A topic that elicited strong energy early in our first interview related to events at Warren's workplace, which heralded a decline in his capacity to fulfil his duties and the beginnings of his pathway to diagnosis. Failure to complete standard tasks at work was the first indication of a serious problem, which was then investigated by a wide range of medical experts, eventually leading to a diagnosis of dementia. In describing these events, Warren wanted me to have a detailed, clear account of the tests that he underwent and all of the medical experts that he consulted - inviting me to see the paperwork that he had collected during that period. This included visits to a neurologist, a psychiatrist, a geriatrician and other expert specialists in younger onset dementia. Following months of inconclusive and exhaustive testing, Warren's diagnosis of younger onset dementia was finally confirmed by an expert in that field.

It was notable that an early narrative describing how his diagnosis was confirmed and his subsequent early retirement was preceded by a long story detailing how he had survived several heart attacks. This narrative involved accounts of multiple surgical procedures and extensive rehabilitation work. These stories positioned

Warren as a person who had stoically endured life threatening health crises and had survived. The climax of the story also set the context of an unsupportive workplace for the narrative that followed. Warren gave an emotional re-creation of a call from his boss while he was recovering in hospital, wanting to know when he was returning to work:

W: Yes, and he says, 'When are you going to get out of the room and come back to work?' Just like that! That's what he wanted!

E: What did you think about that?

W: I just dropped the phone and ... my 'p-choo' went up [motions upwards with hand, rising tone].

E: Oh, your heart rate?

W: Yeah ... yeah, he doesn't say, how ... [amazed look on his face].

E: How are you?

W: Yeah.

E: So pretty shocking?

W: Yeah, because the bells are going 'shwoo.'

E: Oh the heart monitor is going?

W: Yeah! It's going [motions with hands flying up, laughs].

This narrative is immediately followed by his retirement story detailing how Warren was moved out of his job. Once he had taken all of his sick leave, he was retired on medical grounds. This narrative described how devastating it was for him to leave a long term position without any formal acknowledgement of his services or farewells from colleagues:

W: ... If I um- through, I um, all the leave, sick leave, it comes up 'poof'. They take that out, 'Go!' That's it! Just like that! [Voice rising, emphatic, surprised look].

E: What was it like for you, just to be told to go?

W: Well, it's like, 'What am I going to do?' They said, 'Right' and that was it! What am I going to do ... just sitting at home ... [looks despondent].

In this telling, Warren's tone clearly conveyed his distress and despair at having been discarded by management and cut off from all workplace relationships without a chance to say goodbye.

I knew that!

Another strong focus of Warren's diagnosis narratives was the frustration of undergoing diagnostic testing, where he felt propelled through complex processes that were conducted in a way that showed little personal engagement by the health professionals:

W: ... they had bottles and apples and everything all over the place, books, follow this and follow that!

In particular, Warren felt a lack of orienting information and positive feedback from the people conducting the tests. While recounting these experiences, he took real pleasure in telling me about episodes in his encounters with medical staff, when the balance of power shifted. These were important moments when Warren believed that he possessed the specialist knowledge that they were lacking:

W: ... I can do that [identify pictures of different tools in a test], I can what they are. We had a cresa.¹⁶ That's a ... I've got one, in the shed. ... it's a thing, with a little bit [motions a curved shape]. And I said, 'A cresa' and he said, 'No a shifter,' and I said, 'No' and I had a go at him.

E: You knew the name of the tool and you were telling him.

W: Yes ... there's three of them.

¹⁶ Warren is referring to a specialised tool, a 'crescent spanner' which is an adjustable spanner or wrench (US and Canada) with more than one fastener size. It has a flat handle, at the end of which are jaws, one fixed and one that moves, which are nearly parallel to the handle in contrast to other spanners (<https://home.howstuffworks.com/what-does-crescent-wrench-look-like.htm>).

E: *Three different tools?*

W: *No, they're the same, in America and in England and in Australia [sudden increase in fluency] ... I knew that [emphatic tone].*

It's very hard and I don't understand why

A notable narrative thread which re-emerged eight times across the two interviews, was the impact of his diagnosis on everyday functioning. In particular, problems with word finding were described as extremely stressful and exhausting:

W: *... some days I can talk all day and on days I have, I can't get a word out ...*

E: *That must be very difficult to be constantly trying ...*

W: *Yes, the word, that's what it is, it's very hard ...*

At one point Warren elaborated on how he tackled his communication difficulties by targeting words with sounds that he knew he could say, such as words with 'v' or 'u'. When he was struggling he also began with the 'back' or end of the word. His difficulties also included problems with reading, where processing was slow and typically limited to a portion of a page at a time or material that was very simple and had visual cues:

W: *Sometimes I try because I know the words, by the time from the top to the bottom, I've lost... There was a couple of papers and I had, it was about three times down the column and I just [motions back again] and by the time, I'm thinking, 'Where am I?' Um I can [read] comics, but er little books and children's books, I can't do that.*

In the kitchen ... it's not the place for me

Observations about the impact of his illness on communication flowed into accounts of the conflict this had caused between himself and Clara. It was clear that dynamics in family relationships were a significant issue for them both, with positive and negative elements. 'In the kitchen' seemed to be a particularly difficult space, which was emblematic of daily struggles. Warren described how he had difficulties

following Clara's instructions when he was trying to help out at home, needing repeated clarification, which lead to frustration on both sides:

W: She, um, but she, Clara is sort of, if I, with her in the kitchen, I hear and it sort of drops off ... she will say a couple of words, flip, what was that? ... and um then she, her voice picks up, saying words.

E: She gets upset with you?

W: Yes.

E: And what do you do?

W: I just do it!

A related point of tension was Warren's perceived lack of autonomy and his belief that his carer curtailed his activities. There were many domestic tasks that Warren believed he was still capable of doing, but in his view, he was prevented by Clara, who 'made' him wait for others to supervise him:

W: The other day, oh what ... I got a trailer, I wanted to take around and put it the other side of the garage and Clara said, 'You wait for Sam to come' and I couldn't do it, it's not hard ... but she said, 'Wait'.

E: So did you wait?

W: Yeah, I did, I had to.

In contrast to these frustrations and stresses, Warren described his sons as having more understanding of what was happening for him, easing the dynamics between them and making conversation easier. These examples spoke to the nature of the different relationships that Warren had with each family member and the varied ways each person provided support and adapted to his changing capacity:

W: He, on Father's Day he just, he ... [Warren's son], he wanted to talk to me and we talked to him. And he knows, he's picked up that if I've, if words have been going across the phone and he says, 'No, no, no, slow down.'

No way

Concerns for the future were briefly referenced when Warren made some observations about another member of a walking group that he attended, who was living in a hostel. Warren observed that this man's wife was happy with the arrangement and that extended family did visit, however, he discounted this as an option for him:

W: ... I was talking to him and I asked him and he said she, his wife is happy with him there ...

E: And what do you think about that arrangement?

W: No, no [emphatic]. Mmm. No way ...

Warren concluded this narrative with another example of care, this time recounting his mother's experiences. In this telling, he focused on her need to go into care because of hip problems which surgery had failed to rectify, another negative medical narrative. This story included close attention to the technical problems the surgeon had adjusting her hip, resulting in an extremely restricted lifestyle and on-going problems post surgically. This narrative seemed to be speaking to Warren's fears of aged care and the unpredictable changes in a person's health that may lead to undesirable and irrevocable outcomes.

I know straight up

While Warren openly described many of the major aspects of his life that he found stressful, when I asked about his coping day to day, there was a notable emphasis on the tasks and activities that he could still do, and more significantly, could do well. These narratives were repeated in both interviews and consistently focused on his competence, either before the diagnosis, or at the time. This included still being able to drive; finding his way without maps; working skilfully with mechanical or electrical tools; and shopping on his own. These stories of mastery also included

information about his work history and the importance of skills that he had retained from his earlier training as an electrician.

One long narrative was devoted to a description of how he managed driving, in particular, finding his way over long distances without a map:

W: Yes, so I, one place to go, and it's the first time, I don't need a map, I know straight up, and Clara she says, 'Now choo, choo, choo, choo' [invented words to make up for lost words, meaning is not clear] 'Where are we?'

E: So you know where to go, but she doesn't?

W: Yeah. The other day, she says, where were we, um [long pause] oh ... we had to go to ... and I thought, 'Oh, I know that, but she's getting the map out.'

This topic held strong energy for Warren and at one point in the interview there seemed to be a reversal of roles when he set me a test, asking me to describe to him which bus I would take from his home into the city centre. He seemed pleased when I couldn't answer his question. Warren was proud of his capacity to navigate his way across the city or further afield, even though it didn't make sense to him that this capability remained, while others had vanished or at best fluctuated.

The Man Shed

Positive narratives that focused on his competence included several stories about a local community program for men with dementia. Warren described this as a place where he could use former work skills in a relaxed setting and talk with other men about the projects that he was working on. Attending this program did not appear to have any stigma for Warren, who identified with those who attended and who was proud of his work and his role in the program:

W: Yes, I being an electrician I do the te, te, te [motions working on something]. There's another who does things ... he's the boss in that part ... if there's anything electrical to do there's only two people, him and me [laughs].

Warren described in detail the projects that he had worked on, eagerly showing me pieces of wood working that he had completed. The work in the shed also included inviting younger people in to see demonstrations of the projects that the men were involved with:

W: At the moment, when we go to the timber time, I box, like that and there are three of them and in there it has a lash sort of thing. It's leather so you can carry it and when you sit down it's got a hot line and it's a thing you can do words in timber.

E: Oh... you can burn letters into the timber?

W: Yeah. So we've got three of those and er, the kids, the kids, they sit down there and it's on [warm, confiding tone].

Further references to positive supports included the local community walking group for individuals with younger onset dementia. Although his descriptions of the group were brief, they gave an affectionate impression of a welcoming group, where he was able to talk openly and was missed when he was unable to attend.

I knew what to do

Towards the conclusion of the second interview, Warren detailed a notable narrative of competence. It involved his part in a rescue mission in the Sydney to Hobart Yacht Race, when weather conditions had become very dangerous. He described how, while working on board a government aircraft, the crew managed to locate two yachts in distress and drop supplies to them. The narrative then took an unexpectedly dramatic turn, when Warren recounted how the pilot announced that there was a problem with the plane that might prevent them from landing. In addition, fuel was low, limiting their capacity to keep flying until they solved the problem.

As Warren became immersed in the story his fluency increased as he skilfully built the narrative tension, recalling the moment of crisis:

W: ... normally we're about 160 feet, because they say feet, its different in the plane, and we come in the dark, really dark and the wind and the next thing, the bloke says, 'We mightn't be able', he says, 'there's a part of the plane, to make the plane land' and in the area, I had to get inside, because we still had, and we were, the er, the fuel was coming down ...

Warren became very animated as he went on to explain how his problem solving saved the day:

W: ... then so what I had to do is, he said, 'We've just, when before on the land, we've got to dump it, then push it' ...

E: You had to make some kind of adjustment?

W: Yes, some adjustment and I had to go, push, push it in, and we went boom, beauty!

E: Wow! So it worked! [I am feeling Warren's excitement.]

W: Yeah, worked, otherwise ... [laughs]

E: Otherwise!

W: Yeah, it makes the plane to pull up, not on the wheels, on the, the wings.

E: Oh, something to do with the wing flaps?

W: Wing flaps.

E: ... if it wasn't working properly, you wouldn't have been able to land.

Warren proudly recounted how his willingness to go down into the part of the engine that needed adjustments to remove overheated bearings and problem solve in the crisis was a critical factor in their success:

W: I knew, I knew what to do and you could hear. I was in the bottom and I could hear 'Yay' ...

E: So you were down the bottom fixing things and you could hear everyone cheering because it was working.

W: Yeah working! [Very energised.]

E: ... You saved the day!

W: Yes, and that was, I was, my corporal and I was just, just, and I said, 'Oh, I will go down there' and he wouldn't go down!

In this way, Warren positioned himself as the quick thinking and courageous protagonist, the hero in the story. It was notable that Warren's fluency increased as he warmed to the story, suggesting that his pride and energy in the telling elicited a different level of capacity with cognitive processing and language. It may also have indicated competence in telling stories about the past, where narrative memories were still intact.

Discussion – I can do all those

Not all meaning making takes the form of deep existential struggles. Pragmatic problem solving in order to cope may be an expression of meaning making that maintains connections with earlier versions of a person's sense of self. In this process a person may draw on highly valued, established strengths and skills (Tolhurst & Weicht, 2017). This was evident in the grounded nature of Warren's storylines, which focused primarily on practical ways that he coped day to day and workplace stories from the past. Indeed, it became clear to me over our two meetings that making sense of his illness in that instrumental way was critical to his adjustment.

Despite his obvious difficulties with word finding, Warren was able to clearly relate stories of both mastery and struggle as he engaged with the considerable obstacles created by his illness. Most of his stories had a recognisable narrative structure as described by Riessman (2008, p. 84), with clear boundaries, including an orientation to the context and characters and a coda, that brought the story to a close. Finer grained analysis also revealed a strong emphasis on action in which he was often the primary agent. Warren used language economically, bringing an immediacy and engagement to the telling.

Meaning making for Warren was often implied or grounded in his stories of action. Warren's response to my questions was frequently very literal, with a strong focus on

the more functional adaptations. For example, when I asked how he coped with the frustration of his word finding difficulties, he gave a detailed account of how he thought about words and how he made a connection between the word in his mind and what he could articulate, which was remarkable in its level of problem solving. It is possible that Warren's word finding difficulties impacted on his train of meaning making, or that his normal modes of expression had always been more instrumental.

Expressions of feelings and deeper meanings were more evident through his use of body language and tone of voice, rather than the more complex language of metaphor. At critical moments Warren acted out his narrative, using his hands to indicate rapid movement, things rising and falling or facial expressions to convey disappointment, confusion or resignation. A rising tone often conveyed frustration, especially in regard to his word finding difficulties or lack of understanding from others. These emotions did not interrupt the flow of the narrative, but added emphasis and depth to his telling. This can be illustrated by Warren's brief reference to the moment when his diagnosis was confirmed and his stoic response:

W: Ohh, when he [the specialist] told, I said, 'Oh well I know now.' [lowered tone] Clara she, er cried [tears up], but I took it and I said, 'I've got it.' [emphatic tone] ... and earlier, in the first interview:

W: And I sort of, I said, 'Well I'm still going' [rising tone].

Invented words also conveyed clear meanings within the context of the narratives, such as 'I do the te, te, te' which explained how he used tools to work on projects which were important to him. In one instance, Warren gave an evocative account of his confidence in his driving skills and the dynamic between himself and his wife in the car:

W: ... And I go, shoo, shoo [making fast motions with his hands]. And she [Clara] goes, 'Stop, stop', but it's not a stop sign, it's a give way, she doesn't like, because there's two lanes, right and I just go zzt, zzt, around through.

The absence of any reflection on the causes of his illness in Warren's narratives was notable, when contrasted with those of other study participants. There was no mention of any other family members with dementia, or any other condition or event which might explain his illness. References to his extended family were restricted to a brief story about his mother's experience in residential care. In Warren's telling, the orientation of any diagnosis narrative was a detailed chronological account from the time that symptoms of dementia began emerging until confirmation of his illness. The 'truth' of this was accepted by Warren and he then moved on to talk about his day to day experiences of dementia. This response was interesting in that he did not act in such a compliant way in other medical narratives:

E: So when you were told that ... did that make sense to you?

W: Oh yes, he told me what was the thing and I thought, 'Oh well, that's it!'

E: So that made sense?

W: Yes and some days I can talk all day and on days I have, I can't get a word out.

Warren spent less time contextualising his illness with reflections on the past. When he did draw on earlier experiences his strong focus was on his work history and how that represented his sense of himself. In these narratives, he positioned himself as a skilful and competent worker, coping with unsupportive managers. The story of the rescue at sea is an interesting example of this. On one level, we could see this story as a moving account that was told mainly for its dramatic effect (see Willis & Leeson, 2012). However, the portrait that emerges of a brave, resourceful person who was able to respond in extreme circumstances is compelling. In contrast to his narratives describing his growing dependence, the depiction of his problem solving capabilities which were critical to the crew's safety portrayed him in a different light.

These stories of competence and fulfilment of important roles were also echoed in his description of his experiences in the community groups that he was currently

attending. In the '*Man Shed*' he did projects in which few other group members could participate. His workplace skills as an electrician were acknowledged as valuable and over time he moved from participant to co-leader. In these storylines, it could be argued that Warren was creating narratives that maintained a presentation of self that was consistent with his history. By using familiar discourses that focused on his work role and skills, he maintained stability and self-esteem in a changing landscape (Örulv & Hydén, 2006; Tolhurst & Weicht, 2017). In addition, meaningful group activities enhanced feelings of belonging and a sense of autonomy (Phinney, Chaudhury, & O'Connor, 2006).

The significance of grounded narratives like Warren's could easily be overlooked. In considering the meaning of these competence and problem solving narratives, Warren's response has elements of 'instrumental grieving' (Doka & Martin, 2010). This experience of grieving focuses on thinking and problem solving and engages less with feelings (p. 65). Warren did express some of his feelings about the impact of his illness, often made vivid through his body language. However, his strong focus was on his cognitive processes and how they supported his coping. According to Doka and Martin, instrumental griever operate with a different worldview. Their particular approach strengthens their confidence that they can master the crisis. Their success in this will depend on the adaptive strategies that they employ (p. 66). Warren believed that his processes succeeded in managing many of the operational challenges he faced daily, just as he had done in the past.

Warren's positive appraisal of the way he coped with his illness was not shared by his carer. Conflict frequently arose between them, when Warren attempted tasks that his wife believed were beyond his capacity. As discussed in Chapter Two, carers may misunderstand the coping behaviors of people with dementia, seeing them instead, as negative behaviors to be managed (Sabat & Lee, 2012). This approach can limit the cared for person's adaptive responses. Warren's experiences with his carer could be seen in this light. A counterpoint to this view is offered by Tolhurst and colleagues

(2017). They caution against privileging narratives that detail the struggles of the person with dementia, over the deep challenges faced by carers, creating in effect a new dominant discourse.

Despite the differences in the way that Warren and his carer assessed his capacity to cope day to day, his belief in his strengths provided an important sustaining connection with pre-diagnosis versions of himself. This was often conveyed through Warrens' meaning making which recreated consistent narratives of competence, pre and post diagnosis. The overall impact of these narratives was to convey a picture of someone who was actively engaging with his illness and who was very keen for others to know what he *could* do, rather than base their assessments of him on his changing capacity.

Clara

At the time of my interview with Clara, Warren had significantly changed since our interviews and was not engaging at the levels that he had demonstrated in our conversations together. Despite this rapid decline, Clara was still able to manage at home, with help from community services. Clara's narratives began with a list of the things that Warren could no longer do and her deep feelings of frustration and isolation. Clara's descriptions detailed Warren's increased word finding difficulties; marked changes in his memory and cognitive processing; and his social and emotional withdrawal from the family.

A strong focus of Clara's narratives was the impact of Warren's illness on their daily life and their relationship. In a reflective moment, Clara observed that life could be very challenging as a consequence of Warren's changing capacity, and that she had *'off days, when things just feel like a bit of a mountain.'* Clara's sense of loneliness and disconnection from Warren was pervasive as she described their life together:

C: ... he does tend not to try and communicate much, sits around a lot, not doing much, which I find frustrating. And yeah, there is a great sense of isolation, not just from the outside world but just here in the home.

E: Just between you two?

C: Just the two of us. Yeah. Yeah, because I like to be able to talk. I'm a female.

Clara went on to describe largely separate routines where Warren regularly retired to bed early, a time that she used to have long conversations with friends on the telephone. Even watching television and meal times were no longer a shared experience:

C: ... he can watch the news but he doesn't really comment on anything ... Sometimes he does tend to laugh at different things that I don't think is really appropriate ... so I just try to ignore it ... you can't really have a normal conversation with him now.

Immediately following this observation, Clara began a new narrative that illustrated how she adaptively coped with Warren's changing capacity. She described her concern about his driving and how she began to take charge of the situation by 'grabbing the keys and sending him around the passenger's side.' Although, at this point in the story she paused, to express uncertainty about the way that she had handled the issue. Her next step was to enlist their doctor's support. Following a letter from the Road Traffic Authority (RTA), Clara asked their doctor to confirm that Warren was not driving and his licence was cancelled. Clara expressed further doubt about her actions, wondering again whether she should have intervened. When Warren received a letter confirming that his licence had been revoked, Clara described his response:

C: ... it took quite some time for him to accept it. He kept it [the letter from the RTA] ... when he first got the letter he kept on reading it and reading it and then he went and got his medications out and I think he felt that he couldn't drive because of his medications.

Clara described how Warren had brought the letter out when family visited next, but their efforts to discuss it were rebuffed by Warren. The final blow was delivered by the geriatrician, who told Warren that he would no longer get insurance cover and that *'it was not a good idea'* for him to drive. The narrative concluded:

C: ... the look on his face. And the doctor said to him, he said, 'You're not happy with me are you?' He could see that. He came around eventually that day. So now I just have the car keys in my handbag all the time. I'm sure he knows where they are but he never goes looking for them.

During this long story my memory of Warren's pride in his driving and his capacity to find his way struck me. I reflected my impressions back to Clara, who responded:

C: That's right, so – ever since we've been married, he's virtually done all the driving, 'cause he's one of these people who doesn't like being a passenger. It's a male thing.

Clara concluded by observing that now she was able to have a car that was automatic, with cruise control, and that made life much easier for her.

This narrative was followed immediately by another long story, which outlined Warrens' growing incapacity to cope with family occasions. In this instance, it was Clara's birthday and Warren became confused and upset. One of the sons took his young daughter in to see Warren who had removed himself from the celebrations, but it took a long time for him to reconnect with the family and Clara:

C: He goes off, oh didn't want anything to do with anyone. Chris went in with the baby, he thought that it'd get him out. No. He came out eventually with a long face and after they all left he just sat down on the ground. I'm sorry I just left him on the ground ... it was a long time before he eventually came around.

When I asked Clara what she thought was happening for Warren at these times, Clara responded:

C: ... I think a lot of it's probably a bit of anxiety related, and when he's like that he gets teary ... sometimes ... you get the feeling he's probably frustrated, because he's probably not really aware of what's happening. Or why it's

happening ... and I know he does get frustrated when he wants to say something ... but just can't get it out. Sometimes I might be able to figure it out ... other times I've got no idea ... in those cases I tend to agree with whatever he's saying ... I know it's a cheat's way out for me.

Later in the interview, Clara introduced a related story about communication issues; in this instance elaborating more openly on the emotional impact of the incident for her. Clara described how she had asked Warren for help cleaning the car:

C: ... and in the end he just lost it. It's the first time I've ever seen him in tears. And I thought, what do I do here? Didn't want anything to do with me.

Clara telephoned her son who came around immediately:

C: ... so he [their son] came round and Warren just came inside, curled up like a little baby in one of the rooms and it took a bit of getting him to come around. I had to keep right out of it ... that was frightening ... I still don't know what that was about but I think basically I'd just overloaded his mind with too much.

These narratives all conveyed the struggle that Clara had in balancing her interests with an understanding of what was happening for Warren. At many points she editorialised by commenting on her reactions to Warren's behaviour with negative self appraisals. These included comments like '*it's a cheat's way out*' or describing some of Warren's responses as her fault, with comments such as '*I overloaded him.*'

Exceptions to the strong discourses in Clara's narratives of stress and isolation were two stories that involved family members. The first described Warren's joy in being with children, in particular with his granddaughter. In this narrative, Warren was represented as connecting happily and being '*besotted*' with her and '*different when she's around*'. This was born out by the frequent instances in Clara's stories when their granddaughter was brought around for a visit when Warren was distressed and uncommunicative.

The second example was a brief story about the time when Warren's mother became seriously ill 18 months earlier and subsequently died. In the re-creation of this story,

there was more light and shade and more emotion and engagement was evident. In Clara's telling, suspense was created when doubt was cast on Warrens' capacity to travel up to see his mother in time. Happily, he did arrive at the right moment and she was still able to recognise him. Clara, Warren and his mother were all 'teary' and they spent a 'happy time' together. Following that, Warren decided not to attend the funeral, but was able to travel interstate with Clara and their son to a scattering of his mother's ashes. When they arrived for the ceremony, Clara noted Warren's pre-occupation with joining other family members:

C: As soon as we got there, didn't matter about Chris or myself, Chris parked the car, he [Warren] was out of the car, looking for his sister ... but he hasn't really talked much about mum since.

Clara concluded that narrative by wistfully observing that Warrens' mother missed seeing their granddaughter, whom she would have loved.

Discussion

Themes of disconnection and struggle featured strongly in Clara's narratives. This included disconnections from Warren, conveyed in the many narratives about communication difficulties and frustrations with his behaviour. There was also a notable silence about their previous life together. Clara's focus on immediate concerns left no space for reminiscing about Warren when he was well, or thoughts about his life before dementia, positive or negative. Unlike other carers in the study, Clara did not reference any stories from their past shared life as a context for her narratives, or reflect on valued memories or significant moments in their relationship. For example, Clara did not reflect on the time of Warren's diagnosis and how she experienced that pivotal moment.

Similarly, Clara did not theorize about Warren's illness or share family narratives that might have provided a context for his dementia, in order to make sense of it. The exception to this was Clara's brief reference to a family belief that Warren had

undiagnosed dyslexia, and possibilities of a connection with his dementia. Given the nature of Clara's narratives, it seemed that many of her stories were reviews of her experiences and her responses to Warren's illness, even though it had been some time since his diagnosis.

Like Warren, Clara's narrative themes were more instrumental and confined to the daily struggle to cope with Warren's declining health and capacity; subsequent changing roles in their relationship; and her current need for support. Longer narratives were devoted to stories of crisis when Warren's illness created problems that needed to be managed, such as the driving licence story or examples of Warren disrupting family occasions. These narratives could be seen as representing one form of 'conflicting storylines',¹⁷ which are characterised by open disagreement between family members about the competence of the person with dementia. These disagreements can reduce the likelihood of effective communication in the family (Roach et al., 2014, p. 1411).

At many points in these crisis narratives, Clara expressed uncertainty about the way that she had responded to Warren, with comments like: *'I still don't really know what that was about'*; *'At other times I've got no idea ...'*; *'I am not sure if that's part of the process'*; and *'I probably could have come around it in a different way ...'* However, Clara did not elaborate on, or demonstrate any shifts in her appraisals of the way that she related to Warren. I wondered what that uncertainty and ambivalence was about, in particular whether it spoke to feelings of guilt about the ways she was responding to Warren in this phase of his illness.

A notable feature of much of Clara's story telling was her matter of fact, dispassionate tone which did not convey a felt sense of the losses and stresses that

¹⁷ As noted earlier, the notion of 'family storylines' and their function (see Roach et al., 2014) are discussed in detail in Chapter Two.

she was describing. This was despite the nature and scope of those changes, in the context of a long married life together. This may have reflected a relationship dynamic that existed before the onset of Warren's illness; the overwhelming nature of the demands of her current life, including her own health issues; her own way of coping with adversity; or some combination of each of these factors. I was aware in the interview that at times I responded to this by becoming an advocate for Warren. At points I suggested possible alternative interpretations of Warrens' behaviour, based on my impressions of him from our conversations. Clara did not connect with or comment on these observations, quickly moving on to other topics.

As Clara's narratives were so grounded in everyday experience her meaning making was often embedded in the action of the story. Clara did not explicitly elaborate on meaning making themes such as hopes, beliefs, values or lessons learnt (see Gillies et al., 2014, p. 211). Clara did describe in some detail how she coped practically with Warren's illness and to a lesser degree the emotional impact of that, including a brief reference to growing '*emotionally stronger.*' However, she did not reflect on her internal life to any great extent or comment on any significant changes in her own personal development. This raised a question for me, concerning whether this conveyed Clara's stoic approach to coping or her resignation in the face of the daily challenges of caring for Warren in the context of her own significant health issues.

Examples of benefit finding (Gillies & Neimeyer, 2006) strongly focused on appreciation for the support groups which Clara attended and her friendships with women who understood the loneliness and struggles of her caring role. These groups were clearly central to her capacity to cope with her daily life, as was the practical support from her two sons. She also spoke positively about the community groups that Warren attended, and detailed her efforts to maintain his involvement in those activities.

Chapter Nine

Arty

Introduction

As I reflected on my three interviews with Arty, contrasting scenes from my initial and final meetings came vividly to mind. My first contact with Arty, a year after his diagnosis at the age of 63, began with him greeting me at his front door and beckoning me into his lounge room. In our final interview Arty's carer and wife, Cilla, ushered me into a darkened lounge room, where all the drapes were closed, despite the brilliant sunshine of a Canberra winter's day. Here, a more tentative Arty was guided into the room and motioned to sit down.

In our initial contact Arty appeared to engage comfortably with the idea of the study and observed that it was 'O.K.' to talk about these things and to '*get things off his chest*'. Cilla also was deeply interested in the project - so much so that she chose to be present for, and actively participated in, two out of the three interviews. This strongly shaped the interview narratives as Cilla interjected at regular intervals, clarifying and elaborating on Arty's stories and adding information. Cilla's narratives included her perspectives on events in Arty's life; appraisals of available support systems; and longer stories, when she introduced her own topics. This included detailed examples of her research into the family tree which provided a context for her perspectives on Arty's response to his illness.

Having family members present in interviews can create problems, particularly if they dominate or cause distress to the participant (Novek & Wilkinson, 2017, p. 6). The interplay between Arty and Cilla created a challenging dynamic for me as I struggled to maintain a focus on Arty. At times, the atmosphere in the room became tense as sensitive topics were raised by them both and associated feelings emerged - such as anger and frustration. I was conscious of my ethical obligations in the

conduct of the interviews and felt concerned about the impact of this on them both. I addressed my concerns by re-directing the discussion to topics that I believed would be less contentious. This response proved unhelpful as it did not create an open space for Arty to explore his narratives but substituted one form of redirecting with another. I did note, however, that Arty eventually returned to the narratives that were significant for him, despite my well-intended efforts to deflect our discussion onto other issues. Over time it became clear that, while these tensions were uncomfortable for me, the participants were able to contain the situation by moving away from topics that caused distress. As this dynamic was such a significant factor in the co-construction of the interviews, I have included all three of our voices in verbatim quotes cited in this chapter.

In our early discussion, Cilla provided context for their stories by outlining some formative aspects of Arty's history. This included a brief family history relating to his early boyhood in a rural area; growing up in a large family with very modest means; and his limited educational opportunities. Both Arty and Cilla had been public servants and Arty had also run his own business, a key experience that he returned to at several points in the interviews. Arty was a Vietnam war veteran and early on, a diagnosis of post-traumatic stress disorder and severe depression had been considered, but not confirmed by a treating psychiatrist. Cilla made several references to Arty's history of heavy drinking and domestic violence over the forty years of their marriage. This had resulted, at a critical point, in Cilla calling the police and seeking support for herself. Arty and Cilla had adult children, but no details about them were given and Arty only made a passing reference to them in his third interview.

The arc of Arty's declining capacity was clearly traced across our three interviews. The initial interview had a more positive hopeful tone and Arty's ability to process and articulate his responses was similar to other study respondents in their early interviews, despite his word finding difficulties. The second interview was more

negative generally and pessimistic about the lack of change in his condition. Here, narratives were characterised by angry outbursts, deep ambivalence, and struggle - although there were lighter moments.

The third interview was conducted with Arty on his own, while Cilla sat in another room. His narratives were more fragmented and frequently emotional, with more pronounced word finding difficulties and muffled or inaudible speech in places. Here, Arty's language was more generalised with frequent use of personal pronouns such as 'he' and 'they' in place of specific names and generic terms like 'stuff' and 'things'. This reduced clarity of meaning, prompting me to check frequently for accuracy with clarifying questions and reflection of content. In this meeting, Arty seemed to have moved into a hopeless, helpless state of resignation and resentment with visions of a bleak future.

I still don't really reckon that I had it

Arty's pathway to diagnosis was similar to other study participants in that there were indications of problems at least a year before his diagnosis, that became more meaningful in retrospect. Arty's small business was suffering because he could no longer perform the tasks required, which included building pergolas and installing air conditioners. A turning point came when his apprentice alerted him to important mistakes that he was making and he openly acknowledged his struggles:

A: I used to go out and do a lot gardening and all that sort of thing ... or help blokes with the air conditioning ... and I would think, 'Oh I can do that tomorrow', but I couldn't, it all fell over ... I couldn't put two and two together ... I just couldn't get it to work out the way I wanted it.

As the year progressed, Cilla described how Arty was 'drinking a lot' and became 'depressed' and 'difficult to live with', culminating in a violent fight with her which resulted in her notifying the police and a temporary separation. As Cilla's anxiety about Arty's welfare increased, she decided to re-establish contact and arranged for him to be admitted to hospital. Arty remained in hospital for five weeks and

underwent extensive testing. However, a diagnosis was not confirmed until they consulted a geriatrician eight months later, who diagnosed a combination of Alzheimer's disease and vascular dementia.

Arty expressed deep frustration with diagnostic processes, particularly in hospital, where he felt confused, frustrated and ignored by the doctors. He felt '*well enough to go home*', and was '*left on his own for long periods*' with little guidance or support, yet was not released. When a diagnosis was finally confirmed by a geriatrician, Arty described his process of accommodating this life changing news:

A: ... I wasn't very impressed with her [the geriatrician], I felt like telling her it was all bullshit [angry tone] ... I think I'm coming through now, I'm starting to come to grips with it now, over the last couple of months.

E: But it's taken a while.

A: Yes, it's taken a long while to get down there [motioning down from his head], and I'm not much help getting it there [laughs].

C: Well you wouldn't have any help darling.

A: That's right ... I felt alright. I still do. It's just this bit up the back here [motions to the back of his head].

E: So you feel OK. So how can this be right?

A: Yes, how can this be happening to me, how can this be bugging me up?

In this narrative, Cilla resonated with Arty's description of the sense of confusion and isolation in the diagnosis process. Cilla positioned herself in this phase as the person who took charge and kept advocating for clear information and a confirmed diagnosis in the face of resistance from Arty and the doctors:

C: Once again, the psychiatrist wasn't giving us any feedback ... there wasn't any other diagnosis other than depression ... I had to keep pushing ...

A: I kept thinking that there was nothing wrong with me, so there was no point wasting money going back to them ...

C: *We were really up in the air. And he didn't help because he refused [emphatic tone] to go to the doctors and I would go to the doctors and say, 'Look, I can't get him here, I can't force him, he won't come'.*

A: *I couldn't see a problem, I was alright.*

C: *You were in denial.*

It was notable that this narrative was immediately followed by a confronting story about the distressing conditions that Arty had witnessed in a local aged care facility when he was working on installing air conditioners. Here he provided a vivid depiction of 'hospitals with old people':

A: *I used to think about going into hospitals with the old people ... and some of the people I seen in there ... that really put me off, and I thought, 'I'm never going to places like that. I'm staying at home'. You would have to drag me out ... it would be alright if they looked after them there, but they didn't ... they should be shutting this place down, instead of fixing it up.*

E: *Yes, so that was in your mind and you were thinking, 'Well, I'm not going there.'*

A: *No, I'm definitely not [emphatic tone]. I'd rather die out in the sticks somewhere, rather than go there!*

The sequencing of these narratives suggests that this story was important as it provided the cautionary tale, revealing his fears about the future, an important context for his resistance to further investigations by doctors.

Just to think what could have been

Arty made many references to his changing sense of self, within varied contexts. This included former work roles; recreational interests; and social connections. One strong narrative thread that was sustained across all three interviews was stories about his cars, which conveyed the practical implications of his illness and deeper meanings. The first reference to driving was made early on, in response to my probing about aspects of dementia that were most challenging for him. Arty immediately identified inability to drive as his biggest issue. Cilla provided context to this narrative by

detailing how the geriatrician had recently ruled out driving for Arty, because of his changing cognitive capacities. Arty acknowledged that he had been losing confidence in his capacity to deal with the complexities of driving and that he had experienced 'close calls' on the road:

E: So, what did you think about that, when you were told you couldn't drive?

A: I didn't pay ...

C: [Speaking over Arty] He wasn't happy! He yelled at her [the geriatrician].

E: You were very upset.

A: Yep [emphatic tone] ... It cut me out of doing anything virtually ... You can't go anywhere ... it's a kick in the bum really.

E: And so, do you miss it?

A: Yep. I still sit in it.

C: He still sits in the car! [Laughs]

E: What's it like to go and sit in the car?

A: It just reminds you. I used to do that, do that. Drive here and drive there. Just sit there and it makes you feel good. Just to think what could have been.

Of all the changes that Arty had to negotiate, this seemed to have the most impact and meaning. It provided a tangible indicator of the unavoidable consequences of his illness and completely eroded his autonomy. The car was linked to happy memories of recreational pursuits and his freedom to connect with valued friends. His response to driving was quite visceral, with loving descriptions of the design of his favourite cars and their ease of driving. It was clear that Arty had been devastated by this setback, but he concluded that he was 'getting used to it now.'

His final reference to this powerful symbol consisted of two narratives in the third interview. The first was a more light-hearted story about driving, which shifted to a notably different register than the cynical disengagement of most of that conversation. In this narrative, the energy increased as Arty reminisced about an

incident with some male friends, when he had risen to their challenge of driving his large truck over a big hole in the road, which had been created by flooding waters. Arty succeeded in crossing the gap in the road, even though he did some damage to his truck, which proved expensive to repair. Arty's nostalgic, wistful story provided a snapshot of 'good days' when he could show those 'city blokes what a bloke from the country could do'.

The second narrative returned to the dominant negative theme of losing all control over his life – in this instance because of his carer's interference. Arty bitterly recounted how Cilla had arranged for his car 'to be sold to some copper's daughter down the road.' Arty's voice rose and his tone became angry as he stated emphatically that he would refuse to sell that car 'to anyone'. In his attempt to reclaim his autonomy, Arty considered buying a bike, but concluded that that was not practical. He then toyed with the idea of moving to another country where 'his mate' had told him that he could still keep his licence and get some work. His concluding thoughts conveyed his painful dilemma in being caught between his yearning for freedom and his powerlessness:

A: We will see how we go with the copper's daughter, I'm not going to give her the car- she [Arty's wife] won't stop, won't stop ... it's like putting you in gaol ... just trapped ... I've got no say.

They had the same problems as me

Participation in community group activities for younger people with dementia precipitated crucial turning points in Arty's responses to his illness and his changing sense of self. His descriptions of the groups were positive at first, but shifted to a more negative appraisal over time. The first intimation of the role of the groups in Arty's adaptive processes was his observation early in the first interview that watching other group members provided a mirror for his own situation:

A: Yeah, meeting the people it was different ... I started looking around, I was looking at me and I was looking at them, there was nothing ... that I could see

wrong with them. The only thing, they were having trouble talking ... and I was having trouble talking. So I thought, 'There must be something about this ... maybe I have got something wrong with me ... maybe I have got dementia'. And I came home and I said to Cilla, 'Remember three or four years ago when I did this, I thought that I had something wrong with me then. But it wouldn't come up, I wouldn't let it go out, I was keeping a hold of it'.

In this regard, the group normalised dementia, and became a catalyst for Arty to begin to accept his diagnosis. The stigma of dementia and his fearful resistance lessened as his new insights became a lens for retrospective meaning making. Events from the past made more sense and Arty could begin to accommodate this new experience of himself, although this was a fluid, iterative process. The theme of 'looking' was returned to later in the same interview when Arty observed that since attending group activities he no longer worried whether people were looking at him or noticing that something was wrong, which made it easier to 'keep going'.

The community groups offered a place to experience mutuality as he helped others who were less able. Arty seemed pleased that he could assist other less confident members in the walking group, providing an exception to the dominant narrative of disability and loss of capacity that he was encountering in other contexts. An art group offered links to past competencies through drawing exercises, something that he had done as a student of technical drawing. A more playful tone emerged as Arty described the friendly rivalry of the participants as the facilitator guided the group through various exercises, yielding surprisingly positive results.

The psycho-educational groups that Arty attended afforded opportunities to learn more about dementia, in particular its causes and cures. It was notable that this was singled out in Arty's thinking as a compelling reason to attend this group and was linked with his beliefs about the causes of his illness:

A: I wanted to find what, how to find something to fix it [laughs]. I'd hit myself in the wrong place in the head, and [I thought] 'I'll fix it up and [the dementia will be] gone.'

At this point in the narrative Cilla interjected, explaining that this was a reference to an incident with friends years earlier. Arty had been drinking heavily and Cilla described how he *'panicked and couldn't find his way out of a glassed area and collapsed.'* The idea that this accident was a possible cause of his illness made sense in Arty's thinking as there was no known history of dementia in his family. The accident was a tenuous theory however, since at other points in the interviews Arty commented that he *'didn't have a clue ... that it [his illness] had just happened'* and that *'he was just stuck with it'*.

I just get sick of the same old thing

The positive impact of the groups as they were described in the first interview quickly gave way to the shifting sands of a more pessimistic appraisal in the second interview conducted two months later. At this point, Arty expressed a bored impatience with the walking group which had become repetitive, with the same participants and no *'real talking'*. Characteristics that had been so meaningful earlier, such as being with others who shared the same health challenges and opportunities for mutual aid had been transformed into a chore:

A: I don't like hanging around with people who are sick anyway and some are crooker than others ... I'm the one picking them up half the time, saying, 'Let's go this way'... if they leave their hat somewhere, I'll go and bring their hat to them. I don't mind doing it sometimes, it just feels like the same old thing again.

A very lengthy narrative was devoted to a reappraisal of the art group. Arty expressed disappointment with the lack of social connecting at each session, however it still provided opportunities for intellectual engagement and creative expression. Recently, it had become a source of unwelcome stress as the participants were now working to produce pieces for an exhibition. Cilla observed that Arty's perfectionism with this task had resulted in him spending many frustrating hours attempting to finalise his work:

C: And the more thought he puts into it, the more stressed out he gets ... he was a perfectionist, when he was doing drawings for houses or air conditioning units, he used to draw with pen and ink, then went to CAD¹⁸. He always took pride in his work and that's still kicking in ...

A: Yes, because it won't go ... I was getting a bit frustrated with it last week. I said to one of the girls who was bringing me home, 'I'm not, I'm not, don't really feel like I'm getting anything out of this'.

Arty showed thoughtful insight into the processes that he used to produce good results with his art work, yet was clearly critical of the results and disappointed that he couldn't draw as well as other group members:

A: I know what I want, I'll have this little square piece here, but by the time I finish it, this one comes out that way, and I'll screw that one out and I'll have all these things over it.

E: So, it doesn't connect?

A: It does in some ways, but it doesn't a lot ... and I look at it and think, 'It's not getting any better' ... but there's a couple of blokes there who look like they have done it all their life ...

C: Well, so do you too ...

He did conclude this narrative with a more hopeful observation that things might improve once the exhibition was over and that he would persevere because, while there were many things now that he couldn't do, there remained things that he could achieve in the group and that was '*alright*'.

At the time of the third interview, Arty had completely disconnected from the groups and gave an unequivocally negative appraisal of their activities. Elements of the group that had formerly given some pleasure were sources of irritation and were dismissed as childish:

¹⁸ Drawing software for architectural and engineering diagrams.

A: I went for a few months and it came out the same thing every bloody day, the same thing. I got sick of it, a stupid thing to be doing. You'd go out with them [the walking group], people going arse over head, had to pick them up, not there for that ... come out, give you a bit of paper [a reference to the art group], put something here, something there, what?! [Laughs]. I used to do that when I was ten! [Emphatic tone] I thought, 'Heck, I'm getting nothing out of this crap'.

Arty's withdrawal from all group activities reflected a new phase of his experience with his illness that was isolating and deeply dispiriting. A resigned, frustrated tone characterised most of his appraisals of his life at that point, with a strong focus on what he could no longer do:

A: ... nothing I can do, I just sit here, nothing I can do... I am just going to sit here till I die, bugger them ...

I've done my time, I've done life!

Narratives relating to Arty's work life represented another perspective on his evolving understanding of his illness and his changing sense of self. As noted earlier, the workplace was the setting for the first intimations of serious health issues, which eventually led to his diagnosis years later. When Arty decided to retire early, he acknowledged that this was a critical turning point, where he '*went downhill*' and began drinking more heavily.

As a counterpoint to this story of premature interruptions to life, a different work narrative emerged towards the end of the first interview where Arty described his experiences prior to his diagnosis, as the operator of a small business. Here his fluency and energy increased as he detailed the challenges he faced as he sought to grow his business. Arty reflected on issues around managing staff, bearing the start-up costs for new projects, and the responsibility of making a sustainable living from his work.

In this narrative he expressed satisfaction in his work and frustrations with the increasing pressures of competition from other firms:

A: It was good when I started, it was really good, I had some good people who I was working with. Towards the end of it, it was getting too much. I spent half my time looking through places and you get nothing for it ... you never got your paper work back, so the bloke up the road could get the job.

Cilla expressed disappointment that Arty didn't continue with a small part-time job after he folded his business, just to 'keep his mind going', nevertheless Arty's view was clear:

A: If you're on your own ... you can't beat them [larger firms], you can't beat the prices and if you do get a good one [a new job] you can't ask them to give you a hand if you need it, they say, you took my job, so I'm not going to give you a hand ... So, I said , 'No, that's it' ... I'd had enough of working, I'd done my time, I've done life I reckon!

Arty made a final reference to work in the third interview, when he confirmed his decision that he 'didn't want to go back into that, always hot, hard work, climbing around ... there's no money in that ...'. It was notable that this narrative shifted from more positive appraisals earlier on, to an unqualified, negative representation of his work experiences as unfulfilling drudgery. The exception to this was a wistful reference to the possibility that some work might 'come along' and liberate him from his current circumstances and bring longed for freedoms.

Sometimes it's a long walk

Key traits connected with Arty's sense of himself included his perceived capacity to problem solve and persevere in difficult circumstances. This was apparent in many contexts, including running his own business; participating in the community groups; and adjusting to changes in his capacity. Notable examples of this were the narratives relating to the time spent learning to navigate public transport on his own, after Arty reluctantly relinquished his driving licence. This drive to remain independent had mixed results that he related in detail.

The key focus of these narratives was his determination not to be constrained by his dementia, as he struggled to find his way, and process information, such as bus

timetables. It was clear that Cilla found Arty's bus trips very stressful, as Arty had been lost on two occasions, at night, while travelling across town after meeting with old friends. Arty admitted that he had become very anxious in these situations, particularly at an interchange when he felt *'intimidated'* by some teenage boys who had harassed him for money. Despite these challenges, he remained convinced that he was able to manage these activities alone.

You feel like you've been cut out of something

Family members did not feature strongly in Arty's narratives - in fact at first he stated that he did not have any extended family. Cilla provided a context for that response with observations about Arty's family of origin, including a brief medical history relating to his brother's diagnosis of bi-polar disorder and post-traumatic stress disorder. Cilla speculated about the possible connections between his brother's history and Arty's dementia. Cilla described Arty's family as *'not very close'*. In particular, his father was *'a very quiet man'*, and Arty responded with a long, reflective narrative about his early life at home with his father.

In this story Arty described a shy, reclusive man who led a solitary life driving graders in country Australia. His father's job removed him from the life of the family, to become an elusive figure who was only home on weekends. According to Cilla, he would always prepare his own meals and eat alone. Cilla characterised him as a *'bit backward, like he was living in the wrong era'*. Like many stories about fathers of that generation, Arty jokingly observed that his father's key role with the children was that of disciplinarian. Cilla explained how Arty preferred her family because *'everyone was together'*. With Cilla's encouragement, Arty began to sit with his father at meal times, precipitating an important dialogue, including sharing stories of his father's life history. Arty expressed real regret that this new perspective had emerged so late in their relationship:

A: You feel like you've been cut out of something, all these things he's been doing and he never talked about it, never talked about his family or anything. I never knew he had brothers or sisters, to be honest. He would just come home, get some more for next week and get going ... though, you're not going to hear all of it from our lot, you'll get some of it ... secret, don't want to talk about it.

Arty had maintained his interest in the family history by joining Cilla in her work on the family tree, striking a rare note of companionship. Recollecting this work prompted a re-telling of a vivid memory by Arty relating to a period in his teenage years when he had won some school swimming races, against the odds - a singular moment of pride in some of his boyhood achievements.

The good old times

Apart from his carer and the community groups that he attended, the remaining significant source of support came from old friends, whom Arty visited as regularly as his illness allowed. This support was mixed in its benefits. While they were initially accepting of his diagnosis, Arty did report in the second interview that friends were *'dropping off'* and that no allowances were made by them for the growing constraints of his illness. This meant that Arty still had to travel by bus across town to join with them and that the main focus of their time together was drinking. Arty admitted that this had resulted in some very stressful episodes, when fights broke out. While Arty agreed that this was not sustainable, he was very reluctant to relinquish those friendships and their links to his former life, before his diagnosis.

Discussion – There's nothing wrong with me; why don't they fix it?

For some people, making sense of their illness is a daily, sometimes bitter, struggle which brings no enduring resolution. In this context, meaning making statements may move between acceptance of changes and denial that anything is wrong (Lee et al., 2014; Milby et al., 2017). These fluctuations in confronting the realities of an illness can provide respite from the intensity of change and loss. Arty's narratives

could be considered from this perspective. His storylines represented shifting responses to his illness, marked by a complex mix of issues and emotional states, often expressed either in volatility or passivity.

Initially, Arty made sense by making a direct connection between an accident when he collapsed following a heavy drinking bout, and the onset of his dementia. In this narrative, Arty became more hopeful about the future, as in this case, he believed that a cure could be found and normal life could be resumed. At other points in the second interview, he declared that his diagnosis didn't make any sense because *'he felt alright'*, and there was no family history of dementia. Dementia was something that he was *'stuck with'* and as the doctors had abandoned him, there was no hope:

A: It's the same old thing since last time. Take this and go home, the doctors would come and see you and throw you some pills and away you go ... no-one has come to see me since we've been then, to say, 'You're looking good or you are getting better' ... I'm still waiting ...

C: I think he wants a miracle.

A: I want a miracle, yes, where am I going to be in three or four years' time? They say, 'You've got that and that's it', they know nothing else about it ... no-one's come along and said, 'Well we've found something, that's how we're going to fix that up!' I feel like I'm sitting on a bloody rock on the edge of something ... where the hell am I going to end up?

These moments of protest - *'How can this be happening to me, I feel alright, so how can anything be wrong with me?'* resonate with themes found in Harris and Sterin's study (1999). This ambiguous relationship with his illness resulted in what appeared to be frequently changing and contradictory states of mind and adaptive responses. At times Arty worked to accept his diagnosis and the help offered by community agencies and his wife. At other points, he expressed deep frustration and became dismissive and blaming of health professionals who weren't *'fixing it'* for him.

A new way of understanding how people cope with loss includes seeing 'denial' and ambivalence as adaptive. Some writers have argued that, for people with dementia,

periods of denial can help them manage anxieties about the future and stressful changes to one's sense of self (Lipinska, 2009; Lishman et al., 2016; Milby et al., 2017).

Stroebe and Schut's model (1999, 2010) of adapting to loss is a relevant lens in this context. The model describes a pendulum like movement between deep connection with a loss and moving away from that connection in order to resume 'normal' living. This process is seen as functional and more sustainable over time. This understanding could be applied to Arty's movements towards and away from confronting the realities of his illness. While denial does not necessarily indicate a problem that suggests the need for professional support, it is important to assess the impact of this way of coping on the person with dementia and their families. In Arty's case the outcomes of his adaptive responses were very mixed and a deep source of frustration for his carer.

The significant long term struggles of individuals who are not able to make sense of their diagnosis of dementia and their consequent anger and confusion has been noted by Lee and colleagues (2014). Meaning making (Gillies & Neimeyer, 2006) in Arty's narratives was marked by ambivalence, frustration, a poignant sense of loss and bitter resignation as he struggled to make sense of his illness. The impact of this meaning making appeared to contribute to a limited engagement with his illness, and a lack of agency that was captured by the exchange with his carer who observed that *'he was waiting for a miracle'*. Arty's retort that he was indeed waiting for someone to come along and tell him how they would fix it all up, captured his sense of being trapped with no way out, protesting that he was *'sitting on a bloody rock on the edge of something'*.

Arty did not explicitly link his illness with significant adversity in the past. His early history suggested a family life with a paucity of openly loving, nurturing relationships. His account of his father's isolation from the family was striking and Arty made no comments about his mother at all. There were also references to Arty's

years of drinking and its powerful impact on their relationship. Arty openly recognised that his drinking had not abated since his diagnosis, and had been an on-going focus of his social activities, leading to his increased confusion and volatility. In Cilla's view this had exacerbated Arty's 'depression' and the conflicted dynamic between them.

The trauma of serving as a Vietnam war veteran was touched upon with brief references to 'flashbacks', although they were not specifically linked to his wartime experiences:

C: ... he seems to go over the same things, over and over again. He doesn't know where it comes from and why it's so strong in his mind and he gets very upset.

A: Yes it just goes and goes and then it's alright again.

E: That must be hard, how do you manage that?

A: I talk to her [Cilla] and I get over it.

C: Well, not talking initially.

A: Not talking, yelling and carrying on, accusing of this and that. Once that's gone I feel better. I tell her I'm sorry I've done it again. It's just some bloody thing that turns up now and again.

Such experiences from the past were narrated as isolated memories, rather than expanded into meaningful bridges with his current condition. However Arty viewed those experiences, it could be argued that these aspects of his history tragically contributed to a lack of personal resources that may have supported him in the crisis of his illness.

Arty expressed sustained sadness for his loss of capacity and related changes to his daily life since his diagnosis. What began as more positive and hopeful responses to his illness soon gave way to powerful feelings of corrosive resentment and angry frustration as 'nothing changed.' In particular, he deeply grieved his loss of autonomy,

so evident in his evocative reminiscences about his cars. His sense of overwhelmed helplessness in the final interview was palpable. In an angry reference to his carer, whom he characterised as unreasonably controlling of his day to day life, Arty railed against his lost freedom. He likened his life to *'being put in a gaol'*, where all he could do was *'sit around until he died.'* In concluding, he observed that he had stopped doing things *'because I might do it wrong,'*

Despite the deep pain and suffering of his life with dementia, Arty did move into reflective moments when he expressed a more positive appreciation for life. Even though he struggled with the drawing group, he still engaged with and enjoyed the artworks in the gallery, which he continued to visit after he left the group. He valued the friendships of a few men in the walking group and despite his frustrations, showed kindness towards group members who were more disabled by their dementia. His use of humour to bring perspective on how much his life had diminished was a consistent coping mechanism that struck a different note than the depressed pessimism of other discourses.

Cilla

Introduction

Cilla's narratives focused on two interrelated areas of concern. These encompassed the practical aspects of caring for and living with Arty, and the deeply challenging aspects of his behaviour as they impacted on their relationship. Cilla positioned herself in these narratives as Arty's advocate, guide and support in the face of an intense struggle to cope day to day. This interview was conducted at the same time as Arty's third interview, providing further context for his final narratives.

I just don't know how I'm going to keep going

From the outset Cilla made the nature and intensity of her caring role clear. Her introductory story focused on Arty's mood swings and abusive behaviour, which she observed had not abated over several years. Their days together were characterised

by conflict and deep frustration with each other. By way of illustration, Cilla recounted a recent episode:

C: And now he's tried this ... last week he went for a walk, he had a fight with me, took off, away for four hours, police ring, he'd lost his wallet, he didn't know where he was ... so now I've got to look at getting a tracker for him, so if he goes missing, they can go and pick him up. To be honest I wish he'd just keep going.

Sometimes I think well, he could have helped it

Cilla's exasperation was compounded by what she saw as Arty's lack of agency in response to his illness, and his avoidant behaviour which she described in several narratives. Cilla saw this as characteristic of Arty's way of facing adversity. Her narratives established her case by detailing his various medical conditions which she believed could have been prevented. This included vascular problems caused by sustained heavy drinking, that had begun following his war service in Vietnam. Arty also had a history of high blood pressure and cholesterol that he had refused to have treated. Cilla argued that Arty's dementia could have been prevented if he had been prepared to seek medical help for these conditions at an earlier juncture.

In Cilla's view, this avoidance of 'reality' extended to his response to his diagnosis of dementia:

C: ... he has never accepted it. He refused to find out about it. I mean, I push, push, push to try and I said, 'Look we need to find out about it so we can try and make our life the best we can'. But no, no, don't want to know about it. Bury your head in the sand. And that's no good because I'd rather face things.

Cilla criticised the way that Arty had excluded himself from community supports, in particular the group activities for people with younger onset dementia. In Cilla's view this had increased pressure on their relationship by isolating them both, as Cilla found it difficult to take breaks when Arty was at home. Reflecting on the reasons for Arty's reluctance to join with others who also had dementia, Cilla observed:

C: I think it's always been him. ... It's like if you ignore it, it goes away. But that's not what happens.

Immediately following this narrative and by way of illustrating her beliefs about Arty's avoidant behaviours, Cilla confided a tragic story relating to the still birth of their first child. Here Cilla described how, following the birth, the baby had been removed and no further information had been provided to her:

C: ... when we first got married we had a stillborn baby and, this is '67, and they were very archaic and nobody told me what had happened to the baby. They told him and told him not to talk to me about it. Now that isolated me completely.

The emotion that was attached to this narrative was still evident as Cilla described her devastation when she discovered later that Arty and other family members had been told where the baby was buried:

C: He [the baby] was buried on top of Arty's grandfather. Well I hit the roof. Was not happy. But anyway I bided my time until we went home and we happened to go to a funeral. While we were there I thought, 'Here's my chance'. I said to him, 'Show me where the baby's buried'. He nearly died he didn't know what to do ... we had one hell of a barney ... and he told me what happened ... he does not like confrontation, he doesn't want to face things and I think this is the pattern all the way along. So it's not going to change now.

I've got to be here, I've got to look after you

Later in the interview Cilla shifted into a deeper reflective space as she wrestled with making sense of Arty's behaviour. This narrative came from a different register as she became lost in her thoughts. Cilla began by relating her anxieties about taking breaks that required her to leave Arty on his own. Apart from concern about his welfare, she also dreaded his angry reactions, confiding that *'when you're on the receiving end it's not much fun'*. Cilla objected to Arty's *'selfishness'* in this regard, yet she also maintained that while Arty expressed no need for her on-going care, she *'had to be there, looking after him'*.

In this context she went on to question what had led to the traumatic violence in their relationship:

C: See ... what I don't understand in the whole thing is ... I thought he had depression because he used to sit out the back, he would drink 12 drinks ... and he would just stare into space ... I kept saying, 'Go to the doctor, there's something wrong' ... so then he goes off, gets drunk that day and then comes home and tries to kill me ... I can't fathom what happened, what snapped ... it sounds to me like years of frustration and not talking about things ... and it's been out of control ever since.

This uncertainty and searching for answers was echoed at different points in Cilla's narratives, where her appraisal struck a different note. The dominant narratives of blaming Arty for his illness and behaviour and her clarity about the causes of these issues gave way to an alternative storyline where she expressed doubts:

C: I mean you keep saying to yourself, 'Well he can't help it'. But sometimes I think, well, I think he could've helped it if he had looked after himself better. Well anyway ...

At a later point:

C: He's just isolated himself. And I think its pigheadedness but probably it isn't, but anyway ...

Well it doesn't help me ... it means I've got to do it

A central theme that characterised several long narratives was Cilla's management of Arty's daily care, in particular her problem solving and strong decision making. In this regard, Cilla represented herself as doggedly advocating for Arty's needs in the face of limited assistance from health professionals and community services alike. Examples of Cilla's determined quest for improvements to their quality of life were evident in varied contexts. This included months of research work for a compensation claim with the Department of Veteran's Affairs, in light of Arty's chronic poor health and mental health issues. It was notable that some of Arty's narratives resonated with this. In an earlier interview, he jokingly referred to the fact

that he called her *'Doctor C'* and acknowledged that despite his strong desire for autonomy, he still consulted his wife on many matters. Although, it soon emerged that he did not consistently act on that advice.

Discussion

Cilla's narratives were characterised by a strong focus on the established dynamics of their marriage that predated Arty's experiences of dementia. Cilla described decades of marital hardship and lost opportunities, with all the attendant suffering created by alcohol fuelled violence and abuse. The interplay between their relationship dynamic and Arty's ability to manage his illness was a notable narrative theme. Stories which related years of open conflict over Arty's response to his health issues resonate with examples of *'conflicting storylines'* identified by Roach and her colleagues discussed earlier (Roach et al., 2014). These storylines can represent on-going disagreement and hostility in families that is played out in the context of the person's illness. This can lead to *'long term family dysfunction'* and a serious breakdown in familial relationships (p. 1411).

The significance and meaning of these narratives for Cilla emerged early in our conversations, as her stories shaped all of the interviews, with the exception of Arty's final interview. In Cilla's view, the impact of Arty's illness, with all of its challenges, was exacerbated by his refusal to face his situation and take positive action. Over the course of the interviews Cilla theorised about the reasons for Arty's reactions – with varying results.

A strong focus of Cilla's meaning making was the cause of Arty's illness and his violent behaviour towards her. Narratives of blame framed Cilla's understanding as she made sense of Arty's dementia. In this context, Cilla believed that his refusal to seek help for his health problems resulted in his own unsustainable and destructive solutions, which had powerful consequences for her. Her role in response to this situation was to *'do the best that we can'* by finding practical ways to address their

problems. This involved researching possible solutions for the obstacles that they faced and urging Arty to adopt a more proactive approach. In this way, Cilla's agency in the face of adversity was highlighted, in contrast to Arty's refusal to confront reality and act in his best interests.

A counterpoint to her compelling narratives regarding the causes of Arty's illness, were occasions when Cilla was less certain about the reasons for Arty's violent behaviour. While it seemed clear to Cilla that *'heavy drinking'* was responsible for his rages, she was at a loss to understand the function and meaning of his excessive drinking, unless viewed as a symptom of depression. Despite the emotional, physical and psychological cost for her, Cilla positioned herself as determined to continue in her role, and stay in charge of their life together.

Cilla's sense of self and the role of her values was conveyed through comments such as *'I'd rather face things'* and characterisations of her role as the active problem solver who steered a steady course. Her values around helping were evident in her tenacious insistence that she *'had to be there'*, to look after Arty in spite of his angry resistance to her support. Cilla's narratives featured a consistent focus on thinking, planning and action, with less open expression of feelings - with the exception of anger and frustration. While these emotions were often embedded in the story, they rarely disrupted the telling.

There was limited benefit finding in Cilla's narratives, with some expression of appreciation for the community group that they were currently attending and support from the police at times of crisis. At the heart of Cilla's narratives was her independent quest to improve their circumstances despite the lack of assistance from the medical profession, community supports and services and most significantly, Arty.

Chapter Ten

Julie

Introduction

As I came to know Julie across the course of our interviews, my sense of her courage and open hearted approach to life created a positive, empathic bond which shaped our interactions. This bond seemed to build trust and hold the space between us, allowing us to touch on issues that were sometimes painful for Julie, and formative in her life history. Returning to these narratives at various points in the interviews, Julie constructed accounts of significant life events, despite her considerable difficulties with cognitive processing.

Julie lived alone and had been diagnosed with younger onset Alzheimer's disease at 59 years old. She was divorced and had three children, including two daughters living in Canberra and one son in Western Australia. Six months before our first interview Carly, her daughter and principle carer, informed me that medical reports confirming her diagnosis described her mother as '*mid-range*'. This suggested that symptoms of dementia had been present for at least three to four years before confirmation of her illness. Julie reported a pre-existing history of depression, and an earlier history of abuse in her family of origin. Carly considered that these years of depression had complicated the diagnostic process, masking Julie's symptoms, so that the diagnosis of dementia came as a huge shock for all of the family.

The impact of her dementia was evident in Julie's word finding and thought processing difficulties. It was clear that she had difficulties with memory, speed of information processing, concentration and communication. Many narratives were fragmented and themes drifted across many topics that had no apparent connection, as she struggled to maintain her focus. Most narrative threads were truncated and repeated, while some narratives were longer, more fluent and elicited more energy.

In those instances, my engagement was evident and our discussion deepened. In addition to problems with accessing and processing thoughts and memories, Julie struggled with sensitive traumatic issues from her past. As a consequence, she recounted these narratives in a way that appeared to protect her from the more distressing nature of that material. This resulted in these storylines being more oblique, creating impressions rather than clearly articulating events.

The delivery of Julie's stories was slow, softly spoken and thoughtful - with many long pauses. I had to learn to wait as she composed her thinking, but I was not always successful in this. At times, I interrupted and introduced new topics in the long silences. Julie politely engaged with those changes in direction, then quickly returned to the themes that were deeply significant for her.

Everyone thought that I was an Alzheimer's patient already

In response to my initial inquiry regarding the impact of the news of her diagnosis, Julie joked that the family probably already saw her as an '*Alzheimer's patient*.' Her rather philosophical self-deprecating response was, I came to see, strongly characteristic of her way of coping with difficult life events. Julie described how for a long period, she had been struggling with retrieving words and forming them into sentences, until it came to a crisis point when she could barely communicate at all. Consequently, she spent five weeks in a psychiatric ward and was then moved into an older person's ward. In this period she underwent diagnostic testing with a neurologist and clinical psychologist.

In these early hospital narratives, two strong responses emerged. Aligning with observations from other study participants, Julie described the stressful impact of the diagnostic testing. She was shocked and confronted by her reduced capacity to complete basic tasks, in particular simple tests such as reading a clock face. Julie hastened to note however, that her scores had improved since then. This narrative stressed how returning to appointments day after day was '*the hardest thing that I had*

to do ... I felt stupid'. When the final report arrived the results were devastating, particularly one psychologist's observation about her lack of grooming, which made her feel 'like I was dirty'.

While Julie found hospital staff to be generally friendly and supportive, being with other patients in distressed states was confronting. She described feeling out of place in an older person's ward:

J: ... it took quite a bit of time to get around what was going on ... when you walk in and they are all whispering, 'What's she doing in here?' At the same time we had a patient come in, he was really stuffed up. He had Alzheimer's and he had to be locked into a room ... the nurses would have to go in and feed him and he was a bit agro ...

This stark image of the 'Alzheimer's patient' had remained with Julie and resonated with later references to patients who had to be locked up, possibly speaking to her own fears for the future. In the midst of this dislocating upheaval, Julie described how she managed her day by reading, cleaning, or helping other patients as the ward was short staffed.

In the end I just lost it

Julie returned to narratives relating to hospital visits in the third interview when she began her observations with a long story describing the trauma of a recent re-admittance. This narrative was notable in its length and the evocative descriptions of daily life on the ward - echoing some earlier themes. Julie set the scene by describing how she had deteriorated in her capacity to cope on her own at home and had become suicidal. Realising how desperate she felt, Julie contacted her daughters who arranged for her to be admitted. Her emotions were evident as she described several incidents that had been so deeply distressing that she eventually insisted on being discharged, in order to return home.

Julie detailed how she struggled to cope with the behaviours of other patients which included aggressive acts and abusive language; patients 'escaping' and harming

themselves; and the management of patients such as locking them in their rooms. Her anxiety was evident as she described patients who were there *'just to die'*, stating that *'once you get into there you can't get out.'* In fact, two patients did die in a ward close by. Her sense of safety was threatened by her door remaining open, allowing other patients to enter her room, including one male patient who came into her room at night. Julie described her horror in that setting, that was so difficult to convey to others:

J: ... my daughter said that, 'You know they can't help it' ... but there has to be something that's going to help it ... I don't think that you should have to live like that in there ... and I'm a mental person, so it was just, oh God ... I just hate to think of that.

Her fear and desperation reached crisis point when a male patient *'flashed her'*. The impact of the episode was clear as she struggled to put words to the memory:

J: But I found it just, just, just- so anyway, when he flashed me the last time I said, 'I'm going home', and they said, 'You can't go home, we can't' – whatever ... and anyway I said, 'I'm going home'. And I just stood my ground. I said, 'I can't stay in here anymore'.

E: ... so what happened then?

J: My son came and picked me up and I came back here, back home.

Remarkably, despite the level of distress that Julie experienced, she was still able to find benefit in the kindness of some staff, who she characterised as under resourced and unable to cope with the scale of the demands. Similarly, in the midst of this suffering, there were patients with whom she could connect who were *'really lovely people'*. Julie described how she talked to these patients as often as she was able, in order to cope and reduce her anxiety.

A striking example of resilience and compassion in the midst of this distress, was a short narrative recounting her relationship with one of the more difficult patients. At first Julie was intimidated by an *'obnoxious woman'* who would *'push people around'*

and who verbally abused her on many occasions. Julie went on to describe her decision to respond differently to this person:

J: Oh, she called me everything and nothing. And so then I realised that I'm a much better person than that, and so when I went to go home I kissed her and I said, 'I'm going to come back and see you again'. And I will ... I'm going to buy her something and send it to her. She loved pink and purple. She had red hair ... it all fell out.

E: So you had to go back [for a follow up with staff].

J: Yeah ... so I went in and I had a pink thing for her.

E: Did you have a chance to give it to her?

J: Yeah ... she was asleep ... so I sat on the bed and she said, 'Oh, you are so...' and gives me a big kiss ...

Hospitals are not safe places for people with dementia

By way of a coda to her hospital narratives, Julie invited me to read an article that she had found recently. The author argued that evidence was growing which suggested that hospitals were not safe places for people with dementia. The article provided research to demonstrate that half of the patients with dementia were not identified as such, and that the hospital stays of those identified as having dementia were longer than other patients. Julie used this as a bridge to make further observations about her time in hospital. This indicated careful thought about her future, as she outlined her ideas:

J: ... next time, and there will be a next time, I've got a few things going on ... I'm going to try somewhere else just to go - Carly said she should have done something to get respite for me.

E: So rather than getting to the point of crisis you and Carly work out a way of having a break, go into respite?

J: Hmm.

E: How do you feel about that?

J: Good ... because it's not going to be like [long pause]

E: Because it's not hospital?

J: Yes!

It just broke my heart

In common with other participants, illness precipitated retiring from work sooner than Julie had anticipated. In her case, however, chronic depression and not dementia was the catalyst for her premature retirement, although early symptoms of dementia may also have been at play. Strong emotion marked her telling, as Julie described how she returned from leave, ready to resume her duties, only to find that her services were no longer required by her managers. Julie recounted in clear strong language, how she was allowed a few days to finalise her work and handover to another colleague who eagerly took over her role:

J: Yes, he just told me I wasn't needed any more, 'You've had your holiday and you can go home now' ... it was horrible, one of the worst things I have had to do. To hear those words ... and nobody would look at me because they all knew – knew what was happening ... no-one would talk to me, nobody came and saw me ... I would go home crying ... I think I did three more days ... he didn't need to do that, and in front of other people ... I think he's gutless.

Julie contextualised this narrative by explaining that she had been employed in top legal firms for many years, working her way into a secretarial role. Julie stressed that she had been recruited into this position by her current manager, whom she had previously held in high regard. Subsequent to leaving her post, Julie suffered further setbacks as she was forced to sell her family home for financial reasons and go on to a pension. The final blow came when she began experiencing marked new symptoms relating to word finding and memory problems. This culminated in her diagnosis of dementia.

There is nothing here for you

Following her emotional review of the events leading up to her diagnosis of dementia, Julie moved into a deeper space of reflection. She made a tentative move

towards a new narrative by asking me whether medical reports that she had provided as background to the interviews included any references to ‘*anything in my youth?*’ Slowly, Julie recounted how she had been abused by her father over many years, while living at home. Her narrative was a guarded account of her experiences, in which she chose not to explicitly identify the nature of that abuse. However, later narratives suggested that it was sexual abuse:

J: My father was a POW in Changi and he wasn't a nice guy at all, he was very selfish ... he was on a farm and he was very um- you couldn't do anything ...

Julie finally left the family home when she was 17, and had left school in order to work. At this point her mother told her, ‘*Don't come back home; there is nothing here for you*’. Many years later, her mother became ill and she came to have some respite care with Julie. During that visit, Julie revealed what had been happening in the family home all those years. Her mother refused to believe her, but Julie stood firm and insisted that only her mother could come to stay during that period. While she received no support from family members, Julie was finally able to talk about the abuse with one of her treating psychiatrists:

J: We would meet every day ... and we would just talk about everything and it all came out – so I think I won that one, it's a nice feeling ... because he was so nice and there was no pressure or anything ...

As a result of her childhood experiences, Julie would not leave her children with anyone when they were younger, which meant that Julie did not go back to work for many years. When I asked whether she thought there were any connections between her childhood abuse, her depression and the dementia, she responded that she didn't know because she tried not to think about it, but that ‘*was the hard bit*’.

If you don't have to function, if you can find something you really like

Narratives of tragic loss faced with courage was a strong theme in our first interview. In the second interview, Julie introduced stories that moved to a different register. This included a new theme that created a lighter, more joyful picture of life. The energy and engagement increased as Julie described how she had run pottery classes for the children at her daughter's primary school. She clearly relished these opportunities to offer a creative space to all of the students, allowing them freedom for individual expression:

J: ... so the kids could go for their life ... and the ones that are quite 'out there' they just love it. You know they have the freedom to make all that ... they would all come in and – it was lovely ... they can just say, 'Look what I made'.

Julie was proud of the fact that staff trusted her to teach the classes unsupervised and that her work was celebrated with a mural in the school foyer. A strong focus of this narrative was her love of creativity and her passion for artwork that began with a degree from Art School.

It was notable that Julie's fluency increased and her language became technically more complex, as she detailed important aspects of her pottery work. Julie showcased her competence as she described how she experimented with new glazes in her work, conveying a rich time of developing skills and a more spacious experience of life. Sadly, the practicalities of life intervened and this phase ended with a move to working in law firms in order to support her family financially.

I hate it, but I am lucky

The most critical avenue of support for Julie was her family, in particular, her daughter Carly. It was clear that the dynamic between them was warm, loving and compassionate notwithstanding the usual frustrations and misunderstandings. Carly provided daily assistance with transport, shopping and inclusion in the broader

family life, including time with grandchildren. Julie also assisted by walking grandchildren to school and attending school functions. It was clear that Carly's advice and guidance, which appeared to be respectful of Julie's hopes and concerns, was highly valued and influential in her decision making. An example of this was Julie's unequivocal decision to give up driving because of her concerns about her capacity to keep her passengers safe. All of the family had strongly supported this change and Carly in particular had endorsed it:

J: I wouldn't go back to driving ... I just wouldn't. I just know that I've got dementia and if I was driving my own grandchildren around, that would be horrible, if anything went wrong.

There were costs however, in that Julie was keenly aware of her dependence on her daughter:

J: I'll say to Carly, can you pick me up after she has finished work ... and she comes and gets me, but they've all got their own lives and they don't want to have me relying on them.

E: So what's that like for you?

J: I hate it, it's not very nice at all. But, anyway, I am lucky that I have got the family that I have got here. Because they all care ...

This ambivalence was evident in many of Julie's narratives. A strong picture of her resolute independence emerged as she recounted the efforts she made to catch buses to community activities or walk to the local shops - even when this became problematic. One such instance was Julie's final narrative in the third interview, when she described how she had taken a taxi to a group activity and on the return trip had decided to detour via the shops to buy a gift for Carly, who was about to have a baby. Even though she knew that she was tired from the morning's activities she persisted with her plan. Julie completed her shopping and came home in the same taxi, discovering on her arrival that she had left all of her parcels behind. As she could not find her receipts she believed that she was unable to do anything about

the situation. Julie described her devastation when she realised what had happened, recalling how she had *'just cried and cried.'*

I try to be a good patient

Other storylines relating to Julie's access to and experience of support were varied. She characterised her relationship with her psychiatrists and geriatrician in positive terms generally, noting the level of trust that she invested in their treatment. In response to their perceived skill, she tried to be *'a good patient.'* However, she did struggle with some of the side effects of her medications and expressed frustration with the process of resolving these on-going problems. Julie conveyed appreciation for the kindness of community and medical staff at various points and understood their constraints in challenging environments such as hospitals.

Notably, difficulties finding appropriate support appeared to emerge more from Julie's own sense of herself. She began the second interview with the strong observation that *'her kids had no idea'* about how difficult it was for her to *'just get out and be with people'*. Julie insisted that she had never felt comfortable socialising and that attending groups and meeting people was *'very difficult'*:

J: I'm happy to be on my own, I talk to myself and the dog. I go for a walk ... I've got a sewing machine and I play around. I know it's probably not healthy and I probably should be doing a lot more, but I can only do what I can do.

In this regard, she had resisted attending a group for younger people with dementia run by a local community agency, even though her daughter had urged her to join. However, later in our conversations, it emerged that she planned to attend a community group that focused on coping with stress, which did not have a dementia context. In addition, Julie finally did attend a new group for younger people with dementia. It was notable that in this instance, the facilitator invited the participants to determine its format and Julie had enthusiastically offered to teach the group members pottery making, an activity that was meaningful for her. At the conclusion

of this narrative Julie became very focused on locating her pottery gear in preparation for the upcoming group.

I don't like to be talked about

Towards the end of our third interview, a long narrative emerged reviving the theme of Julie's capacity to care for herself. She confided that her doctor had recently expressed deep concern about her persistently poor health. As I clarified the setting for this conversation, it emerged that this exchange took place in a family meeting with her doctor, which had been convened in order to decide on Julie's future care. She expressed strong resistance in the face of these discussions, where she felt less visible, and more like a child:

E: And what did Carly and the doctor say about all of that?

J: I went out of the room ... I don't like to be talked about [Laughs]. I don't care.

E: Don't care?

J: Hmm [pause].

E: So you left the room?

J: Yeah. I thought I'd sit in there with them, but when they started to – you know going around the room in the chairs and ...

E: Yes and talking about –

J: Me ... and what we can do

E: About you

J: [Laughs] Naughty Julie [laughs]

E: Oh! So – naughty?

J: Hmm ... [long pause] I went back into the other room ... I didn't want to hear...

E: Too hard?

J: Carly will look after me. She's a really soft little girl, she always was.

E: So talking about it all?

J: Would I go into a home? They just floated things around.

E: What do you think about that?

J: I think I'm OK ... OK to stay here ...

As if to strengthen her case, Julie went on to describe all of the practical support that she received from family members each day, which was working effectively. She also showed me a new flyer from a local community agency detailing new services available for younger people with dementia aimed at keeping them at home. Julie believed that support workers had drawn that to her attention because of her most recent traumatic admission to hospital. This narrative revived themes from an earlier story, where Julie had stressed how happy she was to be home and that she was very capable of finding meaningful activities to occupy her during the day.

Discussion – Life goes on even when you don't want it to

The nature of Julie's storylines illustrates how narrating illness experiences provides scope for reflecting on aspects of a person's whole life in a more complex way (for example, see Keady et al., 2007). Strengths forged in times of crisis may fashion a stoic acceptance of 'what life deals you.' This way of making meaning applies to Julie who did not look to causes to make sense of dementia, but located her illness within the context of her life story that seemed full of unexpected setbacks and adversity. The gentle, weary sadness of her observations that '*it's a funny old world*' and that '*life continues even when you don't want it to*', expressed a quiet resignation that characterised much of Julie's responses to her illness and past traumas. A wry sense of humour about the absurdities of the human condition were also strong notes in her narratives that afforded her perspective on her current struggles.

The simple directness of Julie's stories conveyed a power and pathos that drew me into her world and often belied the depth of her suffering. Her struggles, so simply

related, spoke to deep pain and times of despair. The context of Julie's experience of dementia was complex, and included the impact of trauma and abuse; deep grief and depression. Towards the conclusion of our first interview after Julie had reviewed some key aspects of her history, she reflected on this deeply challenging context for her current illness and observed how it helped her to find perspective:

J: There's probably plenty of times that I wouldn't have been - I went through a lot in that way [tears up] ... so I don't think I will be very worried about Alzheimer's!

Julie's slow and deliberate delivery appeared to speak to the care that she took to review important episodes in her life, in addition to the constraints imposed by her cognitive processing issues. Key stories were repeated, in particular, the narratives detailing her traumatic experiences in hospital; retiring from work; and varying levels of support from her doctors. In the recurring narratives, important themes were elaborated upon, indicating some development in her thinking. In some cases it was deepened, where the exceptions to her dominant theme emerged. This was evident in Julie's description of her hospital visits. The emotions triggered by these narratives surfaced and shaped her telling, sometimes disrupting her train of thought. Once those deep feelings subsided, Julie connected with another memory, that of her evolving relationship with the 'obnoxious' woman who she eventually befriended.

Notably, in these narratives of suffering, Julie did not convey a sense of victimhood, despite moments when she would seem lost, 'not knowing who she was'. At crucial moments when her world seemed to be so reduced, she was able to persist and find joy in the simple things of daily living. These included her visits with family and her love for her dog. This capacity for agency was evident in Julie's on-going struggle to reclaim some autonomy by using public transport and seeking information on support services which met her needs. Her narrative about losing the gifts that she

had purchased for Carly's new baby was poignant in this context, as she struggled to overcome her limitations in order to be a loving mother and grandmother.

Other narratives illustrated her determination to stand her ground, such as stories regarding early abuse and her desire to stay in her own home. Julie's compassionate connection with the '*obnoxious*' woman in hospital also spoke to the strength of her values in determining her responses. In this context, Julie '*decided that she [the other patient] was the one who was really sick*' and that she [Julie] '*was a better person than that*'. These beliefs enabled her to reach out to another suffering human being in a highly stressful context.

Complex narratives that capture experiences over time may hold many storylines in tension. Seemingly conflicting stories and fluctuating emotions can impact on the sense of narrative coherence (Gergen & Gergen, 2011). This could suggest that, there are internal, relational and environmental sources of incoherence which result in the fragmentation of narratives (McLean, 2006, p. 14). Illness narratives like Julie's - embedded in life stories encompassing trauma and battles with mental health - may convey disrupted meaning making processes or evoke layers of contradictory meaning making. For example, a gentle acceptance of her tough life was not the whole story. At other times, angry protests that the family did not understand her and that dementia was rendering her invisible to those she loved created a counterpoint in her narratives. Julie expressed deep ambivalence about family supports that were essential day to day, yet diminished her sense of self:

J: I am lucky and I hate it ...

Taylor (2007) captured a similar sense of de-personalisation beautifully, characterising his experience as moving from a 'Thou' to an 'it'¹⁹ (p. 150). Felt

¹⁹ A reference to Martin Buber's concept of 'I-Thou' relationships where people relate to each other authentically and humanly (Buber, 1937).

experiences of 'invisibility' were identified by Harman and Clare (2006) who found that people with dementia felt equally marginalised by health professionals and family members. Similarly, Clark-McGhee and Castro (2015) described the 'de-personing' of their respondents (p. 15), echoing observations by participants in this study.

In addition, there was a strong thread in Julie's stories that presented a counter narrative to those of being overlooked and not validated. These included the success of her art work with the primary school students, and her pathway into the law firm where she was encouraged to take on a more demanding role. It was notable how Julie faced the devastating changes that followed her retirement from the law firm, which included uprooting from her family home and making a new life for herself in adverse circumstances.

Julie's meaning making appeared to support her in moments of crisis in her illness, forging a determination to take charge of her fate. Exceptions to the dominant narrative that Julie was chronically dependent upon others for her welfare emerged in storylines representing moments of agency and independence, when she consciously chose to be the '*better person*' or '*stood her ground*' in settings where she felt alone and afraid. These movements surprised her daughter and expressed an aspect of Julie's selfhood that was strongly represented in her memories of earlier times; a sense of self that was becoming lost in the dementia narratives.

Carly

Introduction

My interview with Carly took place six months after my initial interview with Julie. We sat in her kitchen at the end of the work day, in the midst of bustling family activity. Her husband and youngest daughter listened in the background, while Carly recalled key experiences in her mother's illness journey. At times the flow of our conversation was interrupted by various family members seeking her assistance.

Carly's narratives about her mother's illness were thoughtful and articulate, conveying a warm and affectionate relationship. Her reflections focused on the practical demands of her daily caring role, as well as deeper themes relating to her understanding of the changes and losses brought by Julie's dementia and its impact on their relationship.

I don't think anyone thought of Alzheimer's

A strong narrative theme focused on the lead up to Julie's diagnosis of dementia and its impact. Five narratives described the pathway to diagnosis and the complexity of her mother's history. Carly emphasised the difficulties of arriving at a definitive diagnosis, due to Julie's long history of depression and earlier abuse:

C: There are some times in the year when she is not so good, and that comes from things that have happened previously to her ... times when those anniversaries come around. So I imagine that they would have had a very hard time trying to distinguish the ups and downs.

In contrast to Julie's perceptions, when the diagnosis was confirmed it was a shock for the family, even though Carly had identified significant changes in her mother over a long period. These included obvious word finding difficulties and problems forming her ideas into fluent sentences. Carly also noticed that the '*spark*' she had always associated with her mother was gone. While the diagnosis was completely unanticipated, it was also '*more upsetting*' in the meanings Carly ascribed to depression as '*treatable*' and dementia as '*not so much*'. In addition, Julie was diagnosed as '*mid-range*' and given a prognosis of approximately four more years to live, which was deeply confronting for all the family.

Carly described Julie's reaction to the diagnosis as putting on a '*brave front*', that she was '*OK*' with it, and that her mother was relieved because she had previously believed that she was dying. This flowed into a notable narrative concerning Carly's perceptions of the impact of the illness on Julie:

C: I guess in a sense part of her is dying, not her body, her mind is dying, so you are not going to be who you are, well you are not going to recognise me – in her essence she is dying ... she would say to me, 'I am going to die soon.' I actually found that really hard, it's probably easier if you are going to die soon, but I had to say, 'No, you are not going to die soon ... you're just not going to remember'. I found it really confronting having to say to her ... you are not dying, you are going to be here, but you are not going to know us ... I think that she will be happier when she gets to the stage that she doesn't know that something's not right ... she will be more content and we will just carry on, but it will be the hardest part for me, when that happens.

So much was conveyed in this insightful reflection, including Carly's belief that Julie's essence - all that her mother meant to her- would be irrevocably lost. In this regard, Julie's not remembering would be like a death. Carly's reflections also spoke to the meaning of a mother no longer recognising her children's faces, evident in her deep grief that her mother would no longer recognise *her*.

She was always there for you

Reflecting on the meaning of the 'essence' of her mother, Carly recalled important aspects of Julie's personality and fond memories associated with those qualities. This included her 'easy going' nature and her 'quirky' sense of humour. Carly reiterated Julie's positive traits as a mother - a 'reliable' person, who went to great lengths to support her children. Julie was a bright, active, fun loving person who liked socialising and playing with the children. She was also tough when needed, enforcing discipline at home. Looking to the future, Carly anticipated what would be lost as Julie's illness progressed:

C: Knowing that she's not going to be there for me ... not going to have that connection anymore ... I haven't really had a Nan, I had hoped that my girls would have had that ... not having her there to talk to, to have fun with ... it was like having a sister. She used to do some embarrassing things when I was a kid, it was hilarious.

Carly followed these observations with a long narrative detailing an example of Julie's quirky behaviour, when she dropped a group of Carly's friends off at an

under-aged disco at a local club. Julie mistakenly drove the wrong way up an exit and parked in the middle of two statues on a lawn, in front of a large crowd of surprised on-lookers. Carly's retelling celebrated her mother's unconventional behaviour, combined with her capacity to stay calm and problem solve when things went wrong:

C: You know, she didn't get upset about it, she'd have a laugh and keep going ... 'Oh, well, we got there didn't we? That's OK!' Everyone out the front getting picked up. Big station wagon ... that was mum ...

A second narrative that highlighted Julie's tenacity and competence related to how difficult it had been for her to give up her large family home and divest herself of treasured belongings. Amongst her most valued possessions was all of her pottery making equipment, including two large kilns. Carly proudly described how talented her mother had been at Art School, and how she pioneered the development of a particular purple glaze for pots. In later years, Julie successfully supplemented her income with earnings from her craft work, in order to provide for the family. Carly also briefly referred to the classes that Julie ran at the local school and colleges. In this context, disposing of the pottery kilns and related equipment was very meaningful for her mother, so Carly arranged for some of them to be donated to the Art School, while Carly kept her pottery wheel. By way of a coda to this story, Carly concluded with a wistful reflection on her sense of loss:

C: That was mum and now, well we can still have a good time, we can still be silly together, but she tends to have a lot of things wrong ...

I don't want to sound uncaring

In all of the narratives relating to her relationship with Julie, Carly positioned herself as closest to her mother and most involved in her care. At one point Carly declared that she would '*do anything*' for her mother and that she could not understand why her siblings were not more involved:

C: How hard is it, she's your mother, she raised you, always there for you, you know, a lovely mother ...

Carly's narratives also traced the fluctuating nature of their relationship. One story described a comfortable companionship which Carly noted was more evident when they took time out in a more spacious context. This included enjoying activities together, such as going for walks or roaming through trash and treasure markets in a more leisurely way. At other points, Carly expressed frustration with Julie's expectations of her, in particular in regard to balancing her caring role with her own family's needs:

C: ... with mum if she can't do it she gets cranky. So if I can't do something she gets cranky ... it's hard, it's hard trying to balance that [her caring role] with kids and work, household chores and all the other things ... I find it hard to meet everyone's expectations of me. In between a rock and a hard place.

Carly elaborated on this theme with examples of her responsibilities, including accompanying her mother to all of her appointments and trouble-shooting when things went wrong. This flowed into a long narrative devoted to Julie's vulnerability to aggressive telephone marketing that often resulted in her purchasing something that she didn't need, such as a new mobile phone. In this narrative, Carly struck a strongly protective note, expressing deep frustration that more wasn't done to shield people with dementia from this type of exploitation.

There were times when Carly's expectations of Julie were disappointed. However, she tried to understand the impact of her mother's illness. By way of illustration, Carly described the family's approach to managing Christmas. This period had always been a challenging time for Julie because of unhappy memories. For Carly, it had become important to make the most of special occasions, particularly for the grandchildren. As a way of creating important memories for her two daughters, Carly always invited her mother to stay over on Christmas Eve, so that she could be there in the early morning to watch the family open presents. Carly described their

last Christmas, when Julie slept over as usual, but did not stay beyond opening of gifts:

C: She watched the girls in the morning ... she did that and went home, that was it, she didn't stick around for breakfast ... she didn't really, you know. It's just a bad time of year, so I thought, 'Well OK', you know. So those sort of things can cause confusion, when she gets anxious, her ability to take in information is harder. Er, noise, too much noise around her, gets her really disorientated, it really gets too hard.

Following this theme of creating memories for her children, Carly added that despite Julie's constraints, she still allowed her oldest daughter to sleep over with her grandmother and walk to school together:

C: I just want her to have as much time with her grandmother as she can and she loves her, absolutely adores her. This one [gesturing to her younger daughter] this one loves her, but she won't go, she won't have any memories of her, but she loves her ...

She wants it to be over

Carly made several appraisals of Julie's responses to her illness since her diagnosis, which conveyed a changing landscape. This included the ways that her mother coped with her growing incapacity, such as problems handling money; frequent short term memory loss; repeated and fragmented conversations; and lack of motivation. An early narrative focused strongly on Julie's adaptive processes, and their impact on Carly's caring role:

C: I find that really hard, she is her own worst enemy, she won't help herself, she's very self-defeating. I tried to get her involved with lots of Alzheimer's groups ... not so much for the social, you know to keep her mind going ... but yeah, 'too hard', 'I give in', 'don't want to talk about it', 'don't want to do it'...

Carly's narrative foregrounded her concerns about Julie's growing isolation, and her efforts to problem solve with options that would be more sensitive to Julie's self-conscious struggles in new groups. Carly reasoned that a group where all members had dementia would be less marginalising for Julie and was clearly disappointed in

her mother's apparent refusal to participate. As if to support her case, Carly went on to describe Julie's subsequent behaviour as a *'bit funny'*, and that her *'whole comprehension was dwindling'*, making Carly's support and guidance even more critical.

Carly deepened this theme when she confided that Julie *'wanted it all to be over'*, that she wanted the daily struggle to end. Reflecting on the meaning of this, she observed:

C: She doesn't want to forget, she doesn't want to become that person that doesn't know herself anymore. She hasn't asked me, but I know she has asked someone else if when she got to the point when she couldn't remember anything, they would 'take her out'. She doesn't ask me because she knows my answer, but she could do it herself, she has enough medication.

Carly weighed up the likelihood of her mother taking her own life and did not believe that it was a serious risk. She did however, conclude that it would be easier when Julie lost insight into her illness, and that she could see a time when she *'will start getting stranger ... sooner rather than later ...'*

A notable counterpoint to these narratives emerged towards the end of the interview when Carly summed up her thoughts about her mother's current situation and observed, with a surprised note, that *'she's doing well'*. In fact, Carly observed that there had been a shift in the dynamic, where Julie *'had backed off a bit'* and hadn't made as many calls on her time:

C: She doesn't seem to want me to do as many things for her. And in saying that, I was happily amazed that she managed to organise some things herself ... I think she realised that I couldn't be there at a drop of a hat and that she does have the ability to arrange meetings and you know she tapped into resources ... most impressed I was, I thought well, 'Good on you' and I thought well, maybe I should step back a bit more, just to give her, you know, I think that makes her feel better – but at the same time she didn't invite me to her doctor's appointment ...

This more upbeat, positive reflection was quickly followed by a movement into a darker space. Carly observed that in the midst of the constructive changes that she had noticed in Julie, there had been a marked 'regression' into memories from her mother's childhood. This had become difficult for Carly, as Julie was sharing memories about her early history which Carly found uncomfortable, yet she wanted to continue to offer her mother support. Carly observed that this movement into connecting with earlier, previously avoided memories, was something that had alerted her to important changes in her mother before she received her diagnosis:

C: I began to notice, it was a bit of a twig, I noticed that she would go further back ... and I would wonder why ... what was going on. So that's why when they said 'Alzheimer's' I thought, 'Oh, so that's why you are doing that'. That was one of the triggers. It was so strange ...

When I asked how it was for Carly to hear these stories from a past that her mother had worked so hard to forget and bury, she responded:

C: I don't like it really ... she didn't have a very nice upbringing ... so when she talks about how things were, ehrr, I'm not looking forward to hearing about it ... It must be hard for her to think about them, she hasn't thought about them for so long, but for her to have them in front of her face again ... potentially that may be why she just wants it all to be over, that's a hard thing to go back through.

Carly described her strategies for supporting Julie as she reviewed her life in the context of earlier abuse. At those moments, Carly would listen to her reminiscences, and then move her on, by re-orienting her to the present, and reassuring her that all of those experiences were in the past. However, Carly worried that there could come a time when the lines between Julie's perceptions of the present reality and memories of the past might become blurred, increasing her mother's distress.

Discussion

Carly's narratives represented an open and compassionate portrait of her mother as she lived with her illness. This affectionate picture conveyed the meaning of Julie's

illness for Carly, in the context of their past and current relationship. It was notable that in her telling, Carly moved between different registers that signalled her shifts in roles - from daughter to parent/carer and friend. Many stories were underpinned by a loving concern, even when Carly reflected on aspects of Julie's behaviours that she found difficult and exhausting. In these narratives, she worked hard to be even handed in her appraisals of her mother, showing a sensitive and intelligent appreciation of her deep struggles with dementia and other painful life experiences.

In making sense of Julie's diagnosis of dementia, Carly did not create a family narrative that drew on significant history or speculate about the causes of her mother's illness. She was accepting of Julie's prognosis, however, she acknowledged what a shock the diagnosis had been. It was particularly confronting to be given such a short time frame for Julie's life expectancy.

Strong values relating to helping her mother in gratitude for her own upbringing were evident. At times when the burden of her role was clear, Carly still wanted to maintain a close connection and remain involved with important aspects of Julie's daily life, such as visits to the doctor. Many narratives focused on Carly's thinking and action as she detailed the pains she took, to be understanding and appropriate in her responses to Julie.

An 'inner critic' seemed to surface at points, when Carly assumed responsibility for Julie and blamed herself for her mother's difficulties. This was evident in her response to Julie's breakdown and hospitalisation when she expressed regret that she hadn't organised respite for Julie that could have averted the crisis. In this regard Carly's alignment with her mother was strong, and her lack of sympathy with her sibling's less engaged responses, was obvious. Despite Carly's efforts to help them understand their mother's needs, neither sibling had taken on the same level of caring.

While Carly often focused on the daily problem-solving required in her caring role, she was also able to articulate and reflect on the meaning of Julie's illness. Key narratives described Carly's deep grief in the face of the changes and losses that her mother was experiencing. Julie's love and constancy had clearly been a mainstay to Carly over her formative years, and she made several references to life without this critical touchstone. The essential qualities that represented her mother were dying and her *'spark'* and active engagement, were diminishing. Anticipating a time when Julie would no longer know her, or *'be there for her'* and her children brought deep sadness. In those moments, the depth and meaning of her attachment was clear. Carly's sense of herself as the loved daughter and fun loving companion was already changing and would soon be lost. Carly would need to find new ways to integrate Julie's legacy into her sense of self.

Chapter Eleven

Listening for meaning – Deepening the discussion

It is too easy for health professionals to stay at a safe distance from people with dementia and to allow the theoretical to overpower the experience. It is easier to think you know than to listen. If we perceive people with dementia as unable to understand, communicate, and participate meaningfully in their care, then we have no real reason to listen.

(MacKinlay, 2016, p. 25)

Introduction

As can be seen from the rich stories shared by study participants, finding meaning in times of dramatic change or adverse circumstances can be a complex, iterative process which emerges from each person's unique lived experience. This process may develop over time and might be undertaken retrospectively. It takes place in a variety of settings including our families, community, institutional settings and broader social networks (MacKinlay, 2016; Neimeyer, 2000; Neimeyer et al., 2002). For the person with dementia, the contexts shaping those meaningful thoughts and feelings might include conversations with family members amidst familiar daily routines; time spent with friends and carers; or in moments of solitary reflection. It might also include more formal settings such as clinical conversations and research interviews (Jones, 2015). An important aspect of this whole process is the way that the person with dementia communicates their meaning making to others and how those communications are heard and understood.

While there has been a large body of research dedicated to how people with dementia communicate (Lipinska, 2009), earlier clinical investigations into these processes have typically focused on the impact of language disorders associated with the condition (Jones, 2015). These investigations have generally located communication deficits within the context of the individual's cognitive and semantic

impairments, without reference to the impact of their social and cultural settings (Jones, 2015, p. 555). As in other areas of dementia research, significant shifts in the field are gradually transforming established views on how people with dementia communicate, and are beginning to locate this issue within more complex social contexts (see for example the study cited above by Jones, 2015, which explores the impact of family relationships on communication).

It is now increasingly acknowledged that people with dementia can call on a wide range of verbal and nonverbal behaviours that can help them stay connected with themselves and their social worlds in meaningful ways (Haberstroh, Neumeyer, Krause, Franzmann, & Pantel, 2011; MacKinlay & Trevitt, 2012; Sabat & Harré, 1992; Sabat, 2002). In addition, there has been growing interest in more nuanced aspects of communication, such as the use of metaphor and symbol in the narratives of people with dementia, as they express deeply personal aspects of their illness journey (Cheston, 1996; Killick, 1999, 2005; Killick & Allan, 2001).

In my early struggles to understand how to listen to a person with dementia, I expected that each participant's embodied illness experience would significantly shape the way that they communicated. In particular, I assumed that over time their capacity to express the ways that they found meaning in their experiences would decline. The growing body of research which argues that all forms of communication should be seen as potentially meaningful prompted me to interrogate my assumptions. I became aware that I was privileging coherent, integrated narratives over those that were multiple and incoherent (Gergen & Gergen, 2011). Over the course of the interviews, it became clear that all forms of narrative could convey expressions of meaning making that needed to be valued and explored. In addition, as I became more accustomed to the participants' narrative forms and patterns of communication, I learnt to hold coherence and incoherence in tension, and see both as functional in different narrative contexts.

So, what brought me to that change in perspective? This chapter focuses on three important aspects of listening for meaning that emerged for me as I attended to my participants' stories. These include listening for narratives of self which convey meaning making in times of transition; finding ways to 'transcend the obvious', that is, going beyond literal meaning to meaning making conveyed through metaphor and 'oblique allusion' (Kitwood, 1997b, p. 15); and listening when words fail, that is, exploring how changes in narrative structures yielded different forms of meaning making.

Listening for narratives of self - meaning making in transition

A central tenet in this thesis is that an important aspect of meaning making is the way that individuals experience changes in their sense of self (Gillies & Neimeyer, 2006). Participants in this study frequently told stories that conveyed their sense of self before and following diagnosis, and over time in different interviews. These self-narratives took varied forms and involved 're-presenting' key events, people and ideas; and reviewing uncertainties and hopes (see Cheston, 1996). This included long narratives detailing earlier triumphs, such as Vowell's workplace successes; embedded examples of deeply held values, such as Julie's moving story about the *'obnoxious woman'* in hospital; or Arty's more oblique references to his car. Some narratives were implicit in the storyline and conveyed aspects of self that were threatened by illness, such as Anne's struggle to feel loved and worthwhile, or Vowell's desperate battle to reclaim a sense of himself as a *'real person'*.

The dramatic changes that each person experienced in their illness seemed to represent a 'transitioning' in selfhood (Harris & Keady, 2009), often expressed in changes to a person's social identity, experienced in relationships with family and friends, work and daily living. Participants' self-narratives represented connections with old and new versions of self in a fluid process that moved between the two as needed, rather than in some form of linear progression. This movement was often

influenced by the responses of others at critical moments. They included positive themes such as *'being the better person'*; *'making the most of things'*; *'I wouldn't know who I was if I didn't have these [photos]'*; ²⁰ *'you can't be a shrinking violet'*; *'I'm trying hard'*; *'I like to be brave'*. They also included more negative expressions of self, conveyed through moments of resignation and lack of meaning and purpose in life, *'all I can do is sit around until I die'*; and *'I'm useless, not a real person.'*

These varied themes resonate with the changes to self identified in the dementia literature (Clemerson et al., 2014; Harris & Sterin, 1999; Lee et al., 2014). This includes participants identifying with their diagnosis in order to find 'a more robust sense of self' (Clemerson et al., 2014, p. 459), similar to aspects of Kathleen and John's storylines. In contrast, some studies reported participants feeling isolated and disconnected from family and the wider community (Clemerson et al., 2014; Greenwood & Smith, 2016). In these instances, strong feelings of powerlessness and loss of control emerged echoing Vowell and Arty's experiences. Their negative expressions of self and sustained failure to find new meaning in their illness experiences appeared to result in a relentless focus on despair (see MacKinlay & Trevitt, 2012).

Age based factors and their impact for younger people with dementia, particularly in regard to experiences of self, have received less attention in the research and warrant a stronger focus (Tolhurst et al., 2014, p. 204). An example of a strong narrative theme, which reflects the ages of this study cohort and priorities at their stage of life, was the function of professional roles in the experiencing of self. This was amplified in the workplace competence storylines told by all participants, except John.

²⁰ A reference to family photographs.

Workplace stories were frequently located within diagnosis narratives which amplified the profound disruptions to participants' lives caused by their illness. In re-storying these aspects of their selves in the interview space, participants were potentially re-claiming pre-diagnosis parts of themselves that may have become disconnected in the overwhelming dementia narrative of loss (Bruce & Schultz, 2001, p. 191). This provided a narrative sense of continuity that White and Epston (1990) have argued is functional in these contexts and maintains a recognisable sense of self in times of stressful changes (see also Harris & Sterin, 1999; Tolhurst & Weicht, 2017). Striking examples included Warren's sea rescue story or Julie's narrative relating her innovations in pottery making. These important self-narratives included examples of valuable skills and qualities such as problem solving, innovation, creativity, dedication, determination and responsibility and were capacities that often made a significant difference in the participant's life.

In contrast, a notable unexpected outcome of Vowell's competence narrative was to bring into sharp relief the profound impact of his negative meaning making. Deep pride and satisfaction was conveyed by his increased energy and fluency as Vowell detailed his professional successes as a barrister and his ground breaking work as a mediator. Yet, this was not sufficient to counterbalance his self-narratives of being '*weak and foolish*', and making life changing mistakes in his past. These earlier losses appeared to assume deeper, overwhelmingly negative meaning seen through the lens of his current dementia diagnosis.

As noted in Chapters One and Two, some writers have cautioned against establishing narratives about dementia that do not reflect the very varied ways that people live with their illness (McParland et al., 2017). In order to elicit more nuanced narratives, I discovered that listening for alternative stories to the dominant narratives privileged by participants (White & Epston, 1990) revealed more complex, multiple aspects of a person's sense of self which could have been overlooked.

Participants' narratives offered many illustrations of these often unexpected, glimpses into other aspects of that person. A surprising picture of Arty's creativity and appreciation of beauty was conveyed as he described his engagement with the community art classes and his on-going interest in visiting galleries. This was in stark contrast to the negativity and anger that characterised his stories of denial and bitter resentment about his illness experiences. Kathleen's proud narrative about her father's involvement in the IRA represented a different, darker quest story than her accounts of being an advocate who championed the rights of those living with dementia. A counterpoint to Vowell's *'weak and foolish'* risk taking as a young driver was his obvious pride in his entrepreneurial risk taking in his work life. Vowell characterised his move to mediation work as courageous, unlike his brother who had stayed in the same law firm all his working life, *'riding the coat tails'* of others in the firm. Similarly, embedded in Warren's frequent references to what *'he knew'* and his problem solving expertise, were fleeting but powerful moments of self-doubt and bewilderment, where he *'just didn't know'* why he had so many problems with communicating.

Listening to stories over time offered the scope to identify persistent images that conveyed significant meaning making for participants, particularly in relation to changes in self. An illustration of this was the sustained reference made by some participants to *'looking'* and *'being looked at'* which conveyed a pervasive sense of being judged and marginalised – of being seen as somehow defective. This included Vowell's perceptions of others in social settings *'looking'* at him *'oddly, like he was a fruitloop'*. These are reminiscent of popular references to *'senility'* and *'losing your marbles'*. Arty recounted looking at others in a community group he had begun to attend. Initially, this was positive and helped Arty accept his diagnosis. Group participants *'looked like him'*, so it might not be so unthinkable that he too had dementia. Later Arty expressed exasperation with the behaviours of group members as he watched them on walks and he stopped identifying with other younger people

with dementia. Julie recalled her time of hospitalisation and feeling discomfort when patients in an older person's ward were *'looking at her'* and wondering aloud *'what she was doing there'*. She was visibly distressed as she recounted feeling *'dirty'* in response to a psychologist's report which criticised her appearance, describing her as *'unkempt'*.

This sense of marginalisation was also evident in stories relating to scrutiny by medical professionals, as participants underwent diagnostic and clinical assessments. Confrontations with a changing sense of self was amplified by devastating test results delivered by staff who seemed unaware of its impact. Warren re-asserted his sense of technical competence by debating the answers to questions in the testing he underwent, while Anne expressed deep *'shock'* in changes to her literacy skills that represented a strong sense of her intellectual capacity. Arty complained about the depersonalising impact of tests that were administered with limited support and feedback from staff. These responses are consistent with Johannessen and Möller's study (2013) where participants related feeling *'stupid'* undergoing testing and like *'second class citizens'* when their diagnosis was confirmed (p. 415).

This strong narrative conveying participants' convictions that normal people in society were looking at them and judging them to be different and lesser as human beings, resonates with themes from the work of Foucault (1979). He described the phenomenon of the ever present *'gaze'* of certain groups and individuals within society and the impact on those living under the gaze. He argued that this gaze was used as a form of social control, where people experienced on-going evaluation by others, often in the guise of institutional norms. In this process, individuals became isolated and eventually took that normalising judgement upon themselves.

The impact of the stigma of dementia for younger people has been well documented (Alzheimer's Australia, 2017; Alzheimer's Disease International, 2012; Burgener,

Buckwalter, Perkhounkova, & Liu, 2015; Burgener, Buckwalter, Perkhounkova, Liu et al., 2015; Swaffer, 2014). A strong focus in the literature has been on the deleterious effects on individuals who have struggled with this corrosive experience. It was notable that participants in this study responded in surprisingly varied ways to these experiences of marginalisation and depersonalisation.

In some instances, participants found pathways to transcend feelings of isolation and disconnection. For example, new reference groups and roles created fresh narratives that provided a sense of reconnection for some participants. Warren and Julie looked to community groups for belonging and acceptance, notably in Julie's case, a group that was not specifically for people with dementia. Warren was clearly proud of his role in the men's group where he believed that his expertise as an electrician was valued by the manager of the program. John initially struggled with a community group of men who were older than him, until he found the role of helper.

Kathleen adopted an agentic, systemic approach as she worked for increased community and political recognition of the nature and impact of younger onset dementia. For Anne, perspectives gained through years of struggle with chronic illness shaped her response. Dementia seemed to be a much more socially acceptable illness, compared to living with Crohn's disease. She embraced a support group of older people with dementia, where she felt at home with their values and slower pace of life.

In other, less positive instances, social connections amplified a sense of life on the margins. Arty's friends seemed unable to understand and accommodate the changes he was experiencing due to his illness, which exacerbated his feelings of loneliness. Vowell continued to meet with old friends, but these occasions became a stressful trigger for wary hypervigilance. Reflecting on his embodied illness experience Vowell observed, *'We don't look different but when we speak up it's all over ...'*

In her deeply personal reflection, Bryden (2016a), a woman living with younger onset dementia, has articulated that sense of separation, judgement and loneliness, as people with dementia live under the 'gaze'. Using Judaeo/Christian imagery she described the 'desert of dementia' that took her into a liminal space of disconnection from the mainstream of life (p. 8).

Many moving narratives portrayed participants' experiences of personal dislocation and loneliness. These narrative themes represent powerful aspects of the negative social positioning that is associated with having dementia and the reductionism of many dementia narratives in the literature (Harman & Clare, 2006; Milby et al., 2017). Yet, remarkably, at times, participants were also able to move beyond those feelings of isolation and marginalisation to find new ways to re-connect with themselves and others.

'Transcending the obvious'²¹ - metaphor and meaning making

Many of my participants' narratives employed metaphorical language which conveyed their meaning through powerful visual imagery and the evocation of strong feelings. By these means they were able to dramatically represent the deeper experiences of living with dementia. Looking beyond the literal meaning of a person's communication has slowly gained currency over the past few decades (see for example Feil's Validation Therapy, 1993). Kitwood (1997b) argued that researchers and clinicians needed to employ imaginative and intuitive sensibilities in their work in order to understand important and often overlooked aspects of a person's communication. This he maintained, would be possible when we paid attention to 'metaphor, oblique allusion as well as verbal and non-verbal registers' (p. 15). In this way we can move beyond neurological issues and literal meanings to a more complex understanding of the person's experiences with dementia.

²¹ A reference by Neimeyer (2012, p. 8, citing Kelly, 1997) to the need for counsellors to move to a less literal more 'imagistic depiction' of a client's story.

Metaphorical language is an important part of all communication. Metaphors can sometimes be the only way to express experience that is too complex or vague for other forms of expression (Cheston, 1996, p. 582, citing Lakoff & Johnson, 1980). Metaphorical expressions impact on our conceptions of reality and guide our thinking and actions. As such they provide a rich insight into key aspects of our individual and cultural processes (Johannessen et al., 2014, p. 3, citing Lakoff & Johnson, 2003). This is also the case for the person with dementia (Johannessen et al., 2014). Metaphorical language conveys feelings that are 'authentic' and 'raw' in moments when insight and powers of expression converge (Killick, 2005, p. 22). Highly visual language which is often embedded in metaphor may also come to the fore when memories for words fade (Lipinska, 2009, p. 91). Paying attention to different forms of expression, such as symbolic language which is the product of the senses and the imagination, can provide insights that go beyond more prosaic explanations (Killick, 2005, p. 22). In other words, metaphors serve an important meaning making function.

For my participants, there were evocative metaphorical references to the nature of dementia, such as: *'I was cut off from everything... it just sysed (scythed), what's the word, just cutting you in half'; 'then suddenly, the gate shut'; 'I feel like I'm sitting on a bloody rock on the edge of something...'; 'it's like Swiss cheese and if I happen to do anything while my brain is in the hole section, then I've got no recollection whatsoever'; and 'it's like being put in a gaol.'*

These powerful images conveyed a deep sense of life as they knew it being abruptly and irrevocably severed, with descriptions that evoked the grim reaper. The yearning for freedom is palpable in references to life lived in captivity, while the randomness of the *'swiss cheese'* metaphor conveys the unpredictability of life, as capacities fluctuated. A strong theme is the deadly sense of finality and powerlessness. A surprising counterpoint to this is John's reference to *'being in clover'*

which referenced his optimistic sense of a future where he could still enjoy life to the full.

Metaphorical language conveyed rich descriptions of some participant's sense of self. Anne's visceral descriptions, which were a notable echo of Sontag's work (1991), expressed the stigma attached to dementia with phrases such as *'it's like you are rotting food or something ...'* and that people may think *'that it might be contagious'*. Kathleen crystallised the centrality of her family in locating herself when she stated that, *'I wouldn't know who I was if I didn't have these'*, pointing to a group of family photos. Vowell conveyed pure joy when he likened his ground breaking mediation work to *'rolling in caramel'*; a powerful expression of his professional sense of self and the meaning of his innovative work.

In other instances, responses were more ambiguous and complex and *'entertained multiple possibilities for interpretation and response'* (Allan, 2001, p. 43). In this case, whole narratives suggested deeper meanings about a participant's lived experiences with dementia. An illustration of this is Kathleen's narrative about a piece of coal which she had brought home from Ireland, which she had been giving to friends to share *'the warmth and luck it brought'*. On a symbolic level, this story appeared to position Kathleen as a person who gave unstintingly of herself to others through her faithful service to the dementia community.

Telling stories about the past can also provide opportunities to communicate and explore the experiences of dementia (Cheston, 1996, p. 581). In these instances, people with dementia may be seeking symbolic descriptions of earlier life events in order to make sense of their current illness experiences (p. 588). An illustration of this is Warren's dramatic sea plane rescue story, which amplified important aspects of his approach to life's challenges and could be seen as a metaphor for the way he coped with dementia. In this context, Warren's narrative achieves two functions. First, by showcasing his courage and ingenuity; and secondly by saying that, in

facing an unpredictable, life threatening situation, such as a diagnosis of dementia, he was bringing the same qualities to bear. In the face of overwhelming odds, he was surviving and coping. On the other hand, his stories about episodes with his carer '*in the kitchen*' which was '*not the place for him*' seemed to speak more generally to his search for belonging in a strange and bewildering world.

Arty's remarkable references to his car was a sustained image that emerged in all three interviews and offered possibilities for deeper interpretations. His description of being back in the 'driver's seat' of his life, as he sat in his car in the garage and thought about '*what could have been*', could be seen as a poignant portrayal of his struggle to take charge and reconnect with all that was slipping from his grasp, not just driving. This imagery re-surfaced in the third interview, in his story about driving through a flooded road in order to show those '*city blokes what a bloke from the country could do*', revisiting a picture of Arty as a person who was able to take dangerous challenges, like a life threatening illness, head on. The final reference to his car being sold, without his permission, which was like '*putting you in gaol ... just trapped ...*' continued the image of his battle to stay in control of his life as dementia eroded what was left of his freedom.

In another vein, I was struck by Anne's dramatic story describing how her brothers deliberately disturbed a bee hive in order to cause her harm. This story emerged in the immediate context of other narratives concerned with her years of struggle with pain and suggested a possible reference to her experience of her body, under attack from her chronic illnesses. Her observation in this narrative that '*she liked to be brave*' and '*didn't complain*' was a recurring reference to her stoicism in the face of all adversity. Similarly, Vowell's humorous work story, describing how he had crawled through labyrinthine underground tunnels, sweating and exhausted, while those above ground laughed at his suffering, brought to mind his struggles with dementia. While friends and family might see him as a '*figure of fun*', Vowell saw himself as making heroic efforts to transcend the constraints of his illness.

This more interpretive approach to listening to an individual as they seek to find meaning in their narratives, through symbolism and metaphor, can yield a richer picture of a person's illness experiences. However, this form of communication has its limits (Cheston, p. 598). It is only useful if the listener is able to apprehend how the story acts as a metaphor and the meaning of those metaphors. Stories need to be understood within their contexts and attention needs to be paid to repeated themes. It is important to note that any analysis by listeners should be tentative and guided by the narrator and their sense of their experiences so that it is a truly shared act of meaning making (Cheston, 1996, p. 598).

When words fail - finding meaning in form

Participants in this study employed a range of communication behaviours in our conversations which expressed a rich repertoire of narrative skills. Many of these communication processes contributed to moments of significant meaning making. In considering how people with dementia communicate their meaningful insights, such *performance* of narratives conveys potential information and additional meanings that are important to note and interrogate (Hyden, 2013; McCormack, 2004). Even though verbal communication may alter over time, there are enduring aspects of communication that emerge from a 'pre-symbolic' self (Lipinska, 2009, p. 50), including the use of tone, sounds and body language.

While these forms of communication are evident in all populations, they were particularly significant for these participants as their memory for words failed. Even when narrative coherence and word finding was significantly reduced, participants conveyed moments of crisis when their sense of self was under threat; the tragedy of loss that should have been avoided; the passion of resistance to their illness; existential struggle and fearful visions of the future. Important mechanisms in this process included the use of tone to convey more nuanced feelings; movements to a different emotional register; evocative body language, including changes in facial

expression and pallor; deliberate pacing of speech; varied fluency; and changing levels of language and narrative structures.

Strong emotions erupted at critical turning points in the narrative, shaping story directions and emphasis - helping the listener to understand what was important. This form of expression was evident in Warren's rising, emphatic tone conveying his sense of betrayal at the hands of his managers when forced to 'retire' prematurely. Similarly, Arty's barely audible, whispering rage expressed his outraged sense of growing powerlessness as he described his carer's interference in his life and what it meant for him at this stage of his illness.

A different tone, along with the use of noticeably more complex language, frequently conveyed significant aspects of self, including valued strengths and skills. Energy and fluency increased, particularly in storylines associated with competence in the workplace or formative family narratives. This was evident in Warren's technical expertise when describing tools and Vowell's gripping, articulate account of ingenuity and courage when tested by workplace challenges. Kathleen's strong Irish lilt deepened when speaking of her father. In her intonation, Kathleen conveyed deep pride in her father's hard work in establishing the infrastructure of early Canberra, and strong identification with his part in the Irish sectarian struggles.

For other participants, narratives gave way to thoughtful reveries. John's reflective processing of his memories in response to my questions, embedded in long silences, pointed to moments of deep meaning making. Julie's often hesitant, tentative delivery appeared to speak to the painful feelings some memories evoked for her, as she ranged across seemingly unrelated topics. Her long silences would often presage a movement into recounting personal memories of abuse and suffering that provided an important context for the meanings she ascribed to her experience of dementia. Anne painstakingly re-constructed appraisals of her life in fragments

centred on thoughts and ideas that reflected her position on key existential issues. Over time, I learnt to wait for participants to collect their thoughts, correct my misunderstandings or to create space for the introduction of more sensitive topics. These typically included emotionally charged issues, such as past traumatic events or fears about the future.

Repetition of phrases or whole narratives occurred over the course of interviews. In these repeated narratives, former themes and characters re-emerged, sometimes seen through a different lens; or narrative themes were deepened. As a listener, the repetition and fragmentation made following harder. It is easy to discount or ignore repeated stories, conflating them into one story or seeing them solely as evidence of perseverance (Godwin & Waters, 2009, p. 270). Yet, repetition may signal a story that holds deep significance (Lipinska, 2009). A more attentive listener can detect differences, more emotion in the telling, or another character introduced that could modify the meaning. Similarly, incomplete narrative fragments might be overlooked, or appear to hold less weight for the narrator. Yet they may reveal deeply personal, life shaping experiences and reflections, such as Kathleen's references to her father's history with the IRA. Reviewing transcripts of interviews in between meetings with participants alerted me to the richness of these repeated or incomplete stories, so that I learnt to pay close attention when they re-emerged at a later point.

A strong challenge lay in the use of language that did not conform to normal linguistic forms, such as Warren's frequent use of onomatopoeic words like '*te, te, te*'; (hammering), '*choo, choo, choo, choo*' (going fast) and '*zzt, zzt*' (cornering roundabouts in his car). A lack of clarity at times certainly made apprehending his intended meaning more difficult. However, even when communication is impaired meaningful exchanges can take place (Kontos, 2003). Developing an ear for Warren's unfamiliar and economic language required patience and alertness to contextual clues. Warren's facial expressions and varied tones were compelling and evocative

of the high drama he was seeking to convey. In addition, the use of strongly visual language, succeeded in painting the scene. Illustrative of this was his description of the stressful diagnostic testing that he had to undergo, where he felt overwhelmed and unsupported by staff: *'they had bottles and apples and everything all over the place, books, follow this and follow that!'*

The use of counselling skills such as reflection of the narrator's content and feelings²² and regular summary of longer stories assisted in checking the accuracy of my understanding and built my confidence in responding to Warren.

When decline in memory and cognitive capacity was more evident, narratives became more fragmented and it was harder to elicit meaning at a deeper level. In Arty's case, his use of language became more generalised and unclear by the third interview. Similarly, Julie's word finding and thought processing difficulties were more apparent in the final interview when feelings associated with painful childhood memories intruded. This shift in communication patterns, such as naming and word finding difficulties, could be regarded as the result of neurological changes and typical in a person with Alzheimer's at a particular stage in their illness (Goldsmith, 1996, p. 54). Conflating time and using words which may be associated with something else can be confusing for the listener (Goldsmith, 1996, p. 60). In addition, problems with episodic memory may increase as an individual's ability to retrieve past experiences become more limited. This can lead to significant misalignments in shared understandings between the narrator and listener (Jones, 2015, p. 557).

Despite these constraints, there was no mistaking the significance of the despair and powerlessness that Arty struggled with in his stories about his car or Julie's anger

²² Reflecting or paraphrasing involves saying back to the speaker what the listener has heard, in the listener's own words, and aims to capture the main points of the speaker's message (Crago & Gardner, 2012, pp. 31, 32).

over past abuses and their continuing impact on her current life. When narratives lacked clarity and coherence, it was tempting to regard participant's stories as less 'reliable' or meaningful. One might think that participants were confabulating, in order to make up gaps in their memory. Yet even confabulation can convey its own form of emotional 'truth' for individuals as they seek to relate important events (Meares, 2000, p. 78). It may also offer an opportunity to make sense of a current situation by drawing on past experiences that feel more familiar and reassuring (Örnlv & Hydén, 2006, p. 647).

The movement into the poetic

Over time some participants' narrative structures shifted away from stories with a clear beginning, middle and end and a coherent plotline. In these instances more associative thinking seemed to emerge. Strong energy and emotion were evident, even though the processing of memories may have been changing. The degree of control over the telling appeared to be shifting, revealing the power and significance of the story for the speaker. This more associative narration may have represented deeper, intuitive responses, so that I was hearing and joining with a less edited version of events which was emerging from another level of experience.

It may be tempting to think that it is at this point, when cognitive processes are collapsing, that the more complex process of meaning making disappears. However, in psychodynamic terms, this may be the time when the person's 'truth' is unconsciously emerging (McLeod, 2013, p. 89), bringing the potential for deeper, more meaningful stories. In this process, the shift into associative language and ideas resembles the more compressed poetic language of our inner life (Meares, 2000).

Movement into more poetic forms of communication has been observed in older people with dementia (Barnett, 2000; Goldsmith, 1996; Killick & Allan, 2001). The idea that the deeper meanings of people with dementia may be expressed and understood more effectively through the use of the poetic imagination has also been

explored by Killick (1999, 2005, 2008, 2010) and Kitwood (1997b). Killick's poetry crystallised and intensified narrative themes he found in his conversations with people with dementia living in residential care. Among the myriad themes explored in Killick's work, his poetry captured feelings about personhood, self-worth and the impact of the negative positioning by others (Clark-McGhee & Castro, 2015, pp. 10-11). This is illustrated here in an excerpt from 'All Singing' based on a conversation with an older woman with Alzheimer's disease (2003, p. 19):

*I was always singing at school,
and singing before the rest of the school.
Sometimes I'd stand in the lounge
and start singing at the top of my voice.
Perhaps the day will come when you'll hear me.*

This simple narrative conveys the emotional power of cherished childhood memories and younger versions of the narrator, linked with a desire for others to still 'hear' her. It is interesting to compare this poem with the negative stories related by my participants that describe being 'looked at' and judged by others, discussed earlier in this chapter. It would suggest that people with dementia need to be seen and heard, but not subject to the critical gaze.

In this study, it is notable that the movement into poetic forms revealed significant exceptions to the dominant narratives privileged by participants. These alternative narratives emerged from deep feelings. An example of this different form of expression emerged in the third interview with Kathleen. In this fragment we hear an unusually vitriolic outburst about her sister and more pessimistic warnings about people with Alzheimer's 'giving up'. I have set out the following narrative fragment using a poetic structure, in order to illustrate how this form of communication captures the meaning and power of Kathleen's words:

K: And she can sometimes be so insulting

And that stresses me terribly

And sometimes I feel

Like I want to say to her

'Christ I hate you!'

May God forgive me

But I hate you

Because it stresses me terribly

And if I go to Alzheimer's

You've got nothing to worry about

We all know one another

Have the same problem

And people say

'You don't die of Alzheimer's!'

You do, people do

People give up!

Picking up on strong themes from earlier interviews, Kathleen's feelings about her heroic struggles with her illness are laid bare. She reveals her deep anger about her sister's failure to understand and support her; the joy of belonging to a group of people who do understand, concluding with a caution, that people with Alzheimer's can give up – perhaps without that supportive understanding.

Some poetic expressions conveyed emotions embedded in the everyday, domestic scene, for example, this fragment from Warren:

W: With her in the kitchen,

I hear and it sort of drops off

She will say a couple of words,

Flip, what was that?

Then she, her voice picks up,

Saying words.

I just do it!

In the kitchen,

Is not the place for me.

Warren's spare, simple language conveyed his deep sense of frustration and bewilderment as he struggled to understand his wife's instructions as he helped her in the kitchen. It also suggested deeper feelings of not belonging – of finding no place in her life or possibly in the wider world. This posed a strong counterpoint to earlier dominant narratives of confidently finding his way in other contexts.

As participant's cognitive processes declined, clarity and meaning was not always immediately apparent, yet significant expressions of meaning making endured for all participants. Tuning in to the different forms of narrative structure that emerged at these points uncovered layers of meaning and alternative storylines that might otherwise have been missed. This was not unlike learning a new language (Goldsmith, 1996, p. 56) with the need for careful listening, observation, developing a familiarity with speech patterns (Godwin & Waters, 2009) and repeated exposure. It called for less privileging of conventional narrative structures in order to hear the obscure and fragmented storylines that revealed much more than was initially apparent.

Conclusion

It is clear from the examples discussed in this chapter, that over time, participants' meaning making took varied forms. Some participants reviewed illness experiences in light of reflections on the past or re-wrote the past in light of the present in order

to create a form of coherence that resonated for the storyteller (Bruner, 1990). In some notable instances, that meaning making was consistently life giving, offering the opportunity to 'reclaim the narrative wreckage' (Frank, 2013, p. 68) from illness experiences and build a sense of hope (MacKinlay & Trevitt, 2012). For others, meaning making was elusive and at times, destructive. In these instances old stories and painful feelings disrupted attempts to find sustainable stories to live by.

Strong threads within meaning making narratives comprised enduring struggles to stay connected with a sense of self that was recognisable and reassuring, even when words began to fail. In some cases this self emerged from formative past memories, while for others a new self seemed to be called for. In many cases, there was a movement between different versions of self as was needed and sustainable at the time. This process was idiosyncratic, yet the strong urge to remain attached to masterful versions of oneself was notable.

Important aspects of this narrative 're-membering' was expressed in metaphorical and symbolic language that invited the listener to transcend the literal, in order to discover deeper meaning. This included the less privileged storylines embedded within the narrative layers. At times, structures and forms of language were employed that were not typical of ordinary forms of communication. It became clear to me that, as Riessman notes (2008, p. 80), researchers need to develop the capacity to listen for alternative narrative forms, so that these voices are not silenced. Indeed, companioning a person with dementia calls for deep listening, including a capacity to listen for the poetic and symbolic. It also requires a strong ethic of presence, of simply being with the person (Kitwood, 1997a) and a belief in the value of each person's story as a significant expression of themselves and their endeavours to find meaning in the most challenging circumstances.

Chapter Twelve

Conclusion - Discover the person, not the disease

As we discover the person who has dementia we also discover something of ourselves. For what we ultimately have to offer is not technical expertise but ordinary faculties raised to a higher level: our power to feel, to give, to stand in the shoes (or sit in the chair) of another, through the use of our imagination.

(Kitwood, 1993, p. 17)

Introduction

This thesis began with a strong commitment to two ways of knowing: narrative inquiry, which has an interest in how narratives are used to organise and understand human experiences (see Bruner, 1986, 1990; Polkinghorne, 1988, 1995); and the person-centred approach to counselling which privileges the subjective experience and insights of the client (McLeod, 2013). The challenge has been to enact these different ways of knowing. During the interview phase of this study, barriers to honouring these approaches soon emerged. These roadblocks were partly the result of my early formation in clinical contexts, where the bio-medical model held sway. Yet the struggle to hold these competing voices in balance has yielded a richer research narrative and a more holistic, compassionate sense of my participants' journeys. Importantly, it opened the way for participants to explore how their meaning making shaped their lived experiences with younger onset dementia. That process of exploration enabled me to hear the voices of those who had been previously silenced in other contexts.

Stories of meaning and the transitioning self

Initially, I had low expectations about the likelihood that participants would engage in meaning making processes, and had planned to ask questions that would elicit this. This proved unnecessary. From the beginning, participants engaged in meaningful reflections which took a variety of forms and often involved a whole of

life perspective. Indeed, meaning making emerged as a significant element in each participant's narrative and had a notable impact on their way of coping with their illness. For some participants this included providing powerful motivation to transcend the constraints of dementia and adopt a hopeful vision of their lives (MacKinlay & Trevitt, 2012), while for others, negative meaning making undermined almost every effort to cope on a daily basis.

Participants' narratives did not form a singular and uniform discourse. Rather, the stories reflected the unique ways in which individuals understood, experienced and coped with their illness. Some participant's stories resonated with the 'living well with dementia' (Clemerson et al., 2014; Wolverson et al., 2016) narratives discussed in earlier chapters. Other storylines reflected unresolved struggles, while for some there was a dynamic interplay between times of despair and a more hopeful openness to new possibilities. It was notable that even repeated narratives held varied meanings at different times. In these instances, the same life event was accorded different meanings as they were interpreted through the lens of changing illness experiences.

Strong links to a sense of self informed all participants' meaning making. Family history provided a significant context for one participant's self-narrative, where meaning making drew on intergenerational stories of living with dementia. These narratives provided the ground for a redemptive quest which called for courageous acceptance of illness experiences. For another participant, a heroic father figure provided the energy to take charge of his illness and concentrate on building a positive future in line with newly adopted beliefs. For some, positive narratives provided a counterpoint to other familial and social narratives which focused on participants' declining capacity. In one instance, meaning making was very instrumental and focused on solving the problems of daily living. This involved working hard to maintain pre-existing strengths and skills.

Most participants' self narratives conveyed a transitioning (see Harris & Keady, 2009) between old and new versions of themselves. Earlier versions of self and related activities were referenced in order to provide a vital sense of continuity in participants' lives (Menne et al., 2002). This perceived continuity brought coherence and meaning to life stories in times of loss (Neimeyer, 2000). In some cases a sense of self emerged from early parental messages about how to be in times of crisis. For others, formative negative views of self persisted and undermined individual efforts to adjust to their illness, adding to their sense of dislocation and powerlessness.

Strong expressions of self were conveyed in the competence stories that featured in the narratives of all but one of the participants. These competence storylines contextualised each person's response to their illness, foregrounding aspects of self that either helped them to make sense of and cope with their situation or provided a poignant counterpoint to their current daily life, amplifying their losses. These narratives had a strong workplace focus, reflecting the age related factors of this cohort (Tolhurst et al., 2014). A change in meticulous work practices signalled the beginnings of a health problem, while those same disciplined habits informed approaches to help-seeking post diagnosis. A capacity to problem solve at work was generalised into tackling the everyday challenges of dementia. Work histories which showcased skills of leadership and responsibility re-emerged in later engagement with community activities. Stories of personal strength and courage re-surfaced at times of crisis in the illness journey. Passionate accounts of work successes provided a moving contrast to accounts of despairing struggles with dementia.

For some participants, formative life events and co-morbid conditions offered critical perspectives on their experience of dementia. This shaped participants' meaning making and their understanding of their illness in powerful ways. In these instances, dementia was seen as part of a person's complex, whole of life experience - *a* diagnosis, not *the* diagnosis. For one participant with a pre-existing chronic illness, dementia provided a positive opportunity to resolve a decade's long struggle to feel

valued and worthwhile. In some cases dementia was not perceived to *'be as bad'* as traumatic experiences from the past. This perspective enabled one participant to reclaim her capacity to cope with the tough experiences that life dealt her.

Several participants embedded their meaning making in the context of their whole life story, in order to build coherence with previous life narratives (see Keady et al., 2007). An illustration of this was the way that participants looked to causes, in order to make sense of and accept their diagnosis. This approach was mixed in its impact. Beliefs about dementia which were deeply intertwined with life histories provided powerful motivation to live well with dementia and advocate for improved services. In contrast, perceptions that dementia had been caused by earlier, preventable accidents had a tragic impact. The bitterness and regret associated with these events appeared to subsume every other positive narrative which might have helped the person to cope with their illness.

Participants who failed to make any sense of their illness appeared to gradually give up on attempts to adapt to their diagnosis (see Lee et al., 2014), moving between acceptance and denial. This ambivalence, while potentially adaptive in the sense that it can provide respite from the intensity of struggles with dementia (see for example Lishman et al., 2016; Milby et al., 2017), disconnected individuals from aspects of themselves that could have helped them to find meaning and adjust over time. This appeared to result in loss of hope (see MacKinlay & Trevitt, 2012) and deep periods of resignation and despair.

It is clear that the way that participants found meaning in their illness experiences was a significant factor in their adjustment to their condition. This reflected participants' individual ways of being in the world, their familial and social context, history and stage of life. Meaning making processes were fluid and iterative, emerging from a shifting sense of self over time. For some participants, locating their meaning making within their life stories, offered constructive perspectives and

connections with earlier, valued versions of self. Those who struggled to find meaning appeared to find less ground from which to meet the daily challenges of their illness.

Methodological lessons

Adopting a narrative inquiry approach offered the scope for a deeper exploration of participants' experiences in ways that I had not anticipated. The openness of the interview format afforded the space for reflection and development of ideas for participants and myself, despite the constraints imposed by their changing cognitive capacity. Over time, I was able to engage with and revisit significant themes in participant's narratives that were very powerful and deeply moving. By following this 'affect trail' (Neimeyer, 2012, p. 8), dementia faded into the background and the person came steadily into view.

Exploring narrative structures and devices revealed each person's meaning making in a number of important ways. This included the development of gripping plots that foregrounded key actors, who shaped the action and often appeared in the guise of heroes or villains. Events were carefully sequenced to provide an explanation for their outcomes, while others were ignored (Bruner, 1990; Polkinghorne, 1995). Some participants looked to causes in order to construct a narrative which made sense in their familial and social context, albeit with mixed consequences. Re-creating stories from the past offered opportunities to re-story key episodes (Caine et al., 2013) and in some cases provide symbolic representations of significant illness events (Cheston, 1996). All of these elements built a meaningful picture of each participant's experiences, in particular, how they understood and coped with younger onset dementia.

As participants' cognitive capacities changed, privileging narrative form became less useful. Listening for the poetic form enabled me to value a different structure and hear the meaningful expressions of pain and struggle that some participants were

relating. In particular, it foregrounded meaning making which provided an important counterpoint to the narrative themes more typically privileged by the participant. An illustration of this is one participant's poignant search for a place to belong – *'in the kitchen is no place for me'* - which contrasted to other narratives devoted to confidently finding his way.

Valuing the poetic form required a fundamental conceptual shift for me which provided rich new insights expressed in fragments and opaque allusions. Notably, the structural analysis that I employed to interrogate the data was useful in providing a bridge between the narrative and poetic forms. By breaking down each narrative into sentences and their constituent clauses, the nature and impact of participant's thoughts, feelings and actions were identified and highlighted. In this way the value of those fragments became clearer.

The principal conceptual framework which guided my exploration of participants' narratives was Neimeyer's model of meaning making (Gillies & Neimeyer, 2006). This model proved a useful tool in its clear delineation of specific elements in the meaning making process which develop and deepen approaches employed in other models, such as Park and Folkman (1997) 'meaning making coping' model. This highlighted the complexity and paradoxes of the meaning making process for participants which involved making sense of their illness; adapting to changes to their sense of self; and benefit finding (Gillies & Neimeyer, 2006).

In the bereavement literature, Neimeyer's model has been criticised for its emphasis on meaning making as central to coping with loss. Research is cited which posits that some people adjust to loss without embarking on meaning making and that, of those who do search for meaning, fewer than half found it a year after their loss (Worden, 2018, p. 6). Neimeyer has responded to these criticisms by arguing that the research studies cited featured people who were struggling with meaning making and

needed help with this process. However, he does caution, that these processes should not be explored if they are not initiated by the client (Worden, 2018, p. 6).

I have already noted in this chapter that participants in this study embarked on meaning making processes without my prompting and sustained that process over time. In addition, even though Neimeyer's model is located within the bereavement literature, I found the focal points of Neimeyer's model to be very relevant to key aspects that challenge a person with dementia. They reflect fundamental questions that people encounter regarding who they are as the illness erodes cognitive capacity and lifelong memories; how they can make sense of what is happening in that context; and how they can reclaim positive aspects of their experiences.

It is clear that not all of the elements in Neimeyer's model were experienced in the same way by each participant. However, all participants reflected on their shifting sense of self and struggled to make sense of what was happening for them. A surprising outcome was evidence of unsolicited benefit-finding (Gillies & Neimeyer, 2006) by all participants. Even the most negative narratives had moments where the participant could identify some benefit which brought a modicum of relief or a more positive perspective for the narrator.

Adopting a narrative approach to this research afforded an effective theoretical framework and scope for participant and researcher reflection, which was critical in the exploration of each participant's narratives. In addition, interviewing participants over time offered opportunities to review and revisit themes from earlier interviews. Paying attention to notable narrative devices and structures also revealed significant moments of meaning making, particularly when narrative forms shifted into more poetic expressions. Neimeyer's model aided this process of identifying important aspects of meaning making which powerfully shaped how people experienced and coped with their illness.

Encountering the person

As MacKinlay discovered in her 'spiritual reminiscence' work (MacKinlay, 2016; MacKinlay & Trevitt, 2012), listening to the narratives of people with dementia was a transformative process. Indeed, MacKinlay argues that the storyteller and the story listener journey together, and it is not possible to take that journey without being part of it (MacKinlay, 2016, p. 29, citing Henri Nouen, 1981). While I assented to the belief that the 'person came first' (Kitwood, 1997) and strongly resisted the dehumanising impact of categorising and responding to people according to their neuropathology, the legacy of the bio-medical model was strong for me. Its influence was evident in my directive responses in early interviews. Gradually adjusting that formative lens and acting as if participants' stories were meaningful opened the way to hearing on a new level. This required reclaiming my person-centred roots and being open to my narrators, following them and trusting that their stories were much more than an expression of symptoms and challenging behaviours. From this perspective, their powerful stories surprised and moved me, with their warm honesty and complex paradoxes. Participants conveyed times of struggle, despair, boredom, alienation, hope, yearning, love, joy and pride in the space of an hour together.

Listening deeply, for meaning beyond the literal, required being present and reflexive in my practice, in order to become aware of my own internal narratives. I needed to suspend the search for the 'truth' and a focus on factual content, in order to acknowledge different ways of knowing (MacKinlay, 2016, p. 35) which would enable me to encounter the person (Kitwood, 1993). Often this involved relinquishing the search for coherent plotlines that made sense to me, in order to follow strong expressions of feelings, or 'quality terms' (Neimeyer, 2012, p. 8) that conveyed the narrator's position with more clarity. In turn, connecting with deep emotions helped me to tune into the language of 'sensory images, metaphors and symbols' (Gershman, 2012, p. 205). This shifted my awareness to a different level. In

this way attending to the various elements of participant's narratives that were significant and meaningful for them brought new insights into life with dementia.

As a counsellor, I was aware that developing empathic connections with my participants deepened listening. While it was clear that in many ways I was joining with another experience altogether, it was also apparent that I was witness to experiences that might befall any person struggling to live with a chronic illness. Kitwood's (1997b) notion of mining our own stock of emotional memories to create an 'inner narrative' (p. 17) which has at least some resemblance to living with dementia was relevant here and assisted in creating that empathic bond.

Building trust is a critical element in creating these deeper connections (Goldsmith, 1996) and was a key concern which I addressed in a number of ways. Holding the interview space was enabled by my person-centred stance, which fostered a more collaborative approach, and built a growing trust in the emerging process. This person-centred process allowed participants to stay in charge of their material, moving into more sensitive areas when they felt able to do so, such as moments when Julie revealed traumatic stories of past abuse. Kitwood (1997b) drew attention to the need to 'hold' the space for people with dementia, enabling them to remain 'in one piece' when they are in danger of 'falling apart' (p. 19), as they encounter the fear and uncertainty of daily life. In addition, meeting over time created the opportunities to get to know participants in more depth, and establish trust as their narratives unfolded. On a more practical level, the space where we met was familiar and free from noise and distraction. Inviting family carers to be available for support worked well overall, although most participants only called on carers when they wanted to confirm factual information such as timelines leading up to diagnosis.

Adopting a person-centred approach to this study was central to its implementation. Engaging with participants and being open to their unique narratives was genuinely transformative and required fundamental conceptual shifts that impacted on all

aspects of my listening, which has had implications for my current clinical practice. This level of connection involved letting go of my assumptions and agenda in order to join empathically with participants, building trust and allowing my 'not knowing' to open the way for deeper exploration of participant's narratives. While I was not always successful in this endeavour, my capacity to join with participants deepened over time.

Implications for counsellors

Inviting counselling clients with younger onset dementia to articulate and explore the meaning of their illness experiences offers scope to gain insight into how people understand and cope with their illness and opportunities for change where needed. Research supports the central idea in this thesis that people with dementia can engage in meaning making (Bryden, 2016; Keady et al., 2007; MacKinlay, 2016; MacKinlay & Trevitt, 2012) or reacquire capacities for meaning-giving that may have been lost (Kitwood, 1997b, p. 18). Counselling can build on this process, by helping people to develop insight into their coping styles early in their illness (Kitwood, 1997b, p. 14) and develop new ways of responding (Lipinska, 2009). In addition, it is becoming clear that some people with dementia can acquire new forms of 'feeling language' and that it may be possible to 'work through' some of the experiences of pain, at different stages in their illness journey (Kitwood, 1995; 1997b, p. 18).

An important focus for counselling can be making sense of and accommodating changes to self when needed or learning to value new versions of self (Lipinska, 2009) as younger people engage with the losses they are facing (Clemerson et al., 2014; Greenwood & Smith, 2016). As I discovered with my participants, telling stories of self potentially enables clients to establish, remain connected with, or re-connect with, important aspects of their identity that seem to be disappearing (Cheston, 1996; Clark-McGhee & Castro, 2015; Kitwood, 1997b). In addition, creating new narratives of self offers the scope to develop different ways of coping (Hedman

et al., 2013; Kitwood, 1995; Wolverson et al., 2016). For the person with dementia, this process of adapting to such significant change, could well involve movements between hope and despair as they engage with the realities of their daily life. The counsellor can accompany the person in this process 'until a genuine hope can be discovered and fostered' (O' Hara, 2011, p. 325).

The notion of listening for layers of meaning that are conveyed in different forms, including through symbolic language, is an important aspect of working with meaning making in research and therapeutic settings. A pathway into recognising these meaning making moments is through attending to 'quality terms' in a client's narrative which may reveal their experience with a clarity and precision not found in everyday speech. Quality terms are typically signalled by the use of non-verbal and coverbal language and the use of metaphor and symbol (Neimeyer, 2012, p. 8).

As discussed in Chapter Eleven, these elements are strongly present in the communication of people with dementia, particularly as narrative forms disappear (Killick & Allan, 2001; Lipinska, 2009). Paying attention to the language of symbol and metaphor used by clients can provide a pathway into therapeutic work as it conveys the interplay between our inner and outer life, out of which our sense of self emerges (Meares et al., 2005). In addition, metaphorical language can be used by the clinician to represent significant issues which the narrator is struggling to articulate (McLeod, 2013, p. 451), thereby deepening the therapeutic encounter.

As I learnt with my participants, eliciting stories of meaning making from a younger person with dementia requires the listener to be able to hear incoherent narratives and hold them in tension with other more coherent storylines. In this way, valuing incoherence as potentially meaningful offers the scope for more nuanced and/or less privileged, alternative narratives to emerge. In a counselling setting, this approach can provide rich opportunities to acknowledge and explore events, feelings,

thoughts and actions that more dominant stories cannot accommodate (White & Epston, 1990, p. 16).

Listening to these less well formed stories can pose a challenge for the counsellor who may have been trained to privilege coherent narratives. It requires significant conceptual shifts regarding the person with dementia and their capacity for meaning making, such as those outlined in this thesis. This suggests the need for professional support for counsellors to embark on and sustain this more challenging work. Some of this support could take the form of post counselling reflections and analysis with colleagues, along with regular clinical supervision.

It is important that the therapeutic relationship is collaborative and respectful of the unique ways that clients create meaning (Cheston, 1996; MacKinlay, 2016; Neimeyer, 2012). In addition, clinicians need to acknowledge that clients can take the lead in evaluating their meaning making and what changes might be needed if any (Neimeyer, 2012). In order to build that respectful relationship, an open and accepting stance by the counsellor can engender trust and pave the way for self-acceptance by the client. This is particularly important for younger people with dementia, who may be struggling with negative changes to their sense of self or lack of understanding from others (Lipinska, 2009; Sabat & Lee, 2012). As MacKinlay discovered in her work with Christine Bryden (2016), the task of the helper is to forego their expert stance and companion the younger person with dementia, into the unknown. In this way the counsellor will be more able to hear from, and within, the client's own meaning making framework, from and within their own experiencing (Lipinska, 2009).

In addition to working with individual meaning making, there is scope for counsellors to explore meaning making located within broader family dynamics. Keady and colleagues (Roach et al., 2008; Roach et al., 2014; Roach et al., 2016) have pointed to the possibilities for deepening understanding of meaning making by

exploring how family dynamics shape these processes. In this context, a systemic approach offers scope for counsellors who may be working with whole families, including the person with dementia. Adopting a systemic approach is particularly important in assisting younger people with dementia, who may be parents of younger families with dependent children or young adults living at home (Brown & Roach, 2010; Greenwood & Smith, 2016; Tolhurst et al., 2014). In this context the family unit may become the only available support that is able to be maintained. In approaching this work, the family's capacity to be open to meaning making with each other is an important factor in the therapeutic process (Nadeau, 2000, p. 99).

Nadeau (2000) suggests principles for fostering shared understandings of changes and losses within families and their meaning for each person. While her model concerns the impact of bereavement on family meaning making, her discussion articulates important family processes that impact on responses to changes and loss, which could include a diagnosis of dementia. These complex processes take place within the context of pre-existing family dynamics and structures, where perceived losses may be impacting on established roles, family rules and boundaries (p. 109).

Supporting people with younger onset dementia requires the counsellor to relinquish pre-conceived notions about what that client may bring to the therapeutic encounter and to embrace their unique stories and narrative processes. This is not different to counselling any other client, but the remnants of bio-medical models would tell us otherwise. If we accept that people with dementia have as much to tell as any other counselling client, then we can truly discover the person, rather than seeing them solely through the lens of their illness (MacKinlay & Trevitt, 2012).

Limitations of this study and implications for further research

This small scale study provides us with a better understanding of the unique ways that younger people with dementia find meaning in their illness journey and how that impacts on their experience of their illness. Given the number of participants,

this research adopted a more focused, in-depth approach to study design. The majority of participants were living with Alzheimer's disease, with the exception of Anne. In addition, the participants represented a relatively homogenous socio-linguistic group, who resided in urban settings in the ACT.

The next steps in this research clearly point to broadening the scope of inquiry. Increasing sample size would offer opportunities to identify, compare and contrast themes across participants' narratives. In addition, recruiting a younger, more diverse cultural, linguistic and geographical group may elicit notably different meaning making narratives and insights into adaptive processes. In particular, employing narrative approaches to interrogate the stories of younger Aboriginal people with dementia, could offer a culturally appropriate avenue for further research (see Merritt, 2016). Exploring the experience of other forms of dementia could also reveal important insights into the effect of each illness on the participants' sense of self.

While there is a strong focus in this study on the person with dementia, there is growing interest in the literature regarding broader systemic approaches (see for example Roach et al., 2014). Hence there is scope for research which investigates the meaning making of the whole family, including the younger person with dementia.

Conclusion

This thesis concludes where it began, with my client 'Matthew'. I imagine that if we had continued to work together, like other younger people with dementia, Matthew might have grieved his many profound losses as his illness took hold. He may have also shared stories about his successes, inviting me into other aspects of his life that were deeply valued and meaningful. Such an invitation could have opened the way for Matthew to understand more about the impact of the illness on his transitioning sense of self and to create possibilities for living more positively with dementia.

This research has been undertaken to help the Matthews of the future and the families and counsellors who walk alongside them. It offers a number of important findings relating to the struggle to find meaning in the illness journey and deepens our understanding of the experience of the self in dementia, including the following:

1. Early life experiences and self-narratives can have a powerful impact on a person's meaning making and sense of self post diagnosis.
2. Telling one's 'normal' life story as individuals seek to find meaning has the potential to provide a sense of coherence in the midst of a changing self.
3. Movement between different 'versions' of self persists over time in a non-linear, iterative process in response to changing needs.
4. 'Re-storying' various life experiences by privileging parts of an individual's history shapes sense of self and influences how the narrator adapts to change.
5. Telling stories of competence and mastery reconnects the person with forgotten aspects of self and provides the ground for future coping.
6. Listening to and valuing varied forms of verbal and non-verbal communications offers insights into the person's experience of self, in particular when memory and verbal communication is failing.
7. The use of metaphor is a significant narrative device which conveys meaning making and potentially maintains a sense of self. Notably, it may reveal exceptions to dominant self narratives.

In light of these findings I believe that supporting a younger person with dementia is not about imposing new narratives relating to how that person should experience their illness. Rather, it requires being truly present and open, attentive to the varied narratives that each person might share, thereby validating those experiences as they move through the different stages of their illness. In this way, exploring those meaning making narratives can have a profound effect, potentially providing the energy and motivation to transcend daily struggles enough to find ways to live 'a new life in the slow lane' (Bryden, 2015, p. 229) - to find realistic hope in an uncertain future.

References

- Alzheimer Society of Canada. (2012). *Person centred language*. Retrieved from http://www.alzheimer.ca//media/Files/national/Culture-change/culture_person_centred_language_2012_e.pdf
- Alzheimer's Association. (2018). *What is dementia?* Retrieved from <https://www.alz.org/what-is-dementia.asp>
- Alzheimer's Australia. (2007). *Exploring the needs of younger people in Australia: Report to the Australian Government Department of Health and Ageing*. Retrieved from <https://www.fightdementia.org.au/files/20101027-Nat-YOD-Exploring-needs-Australia.pdf>
- Alzheimer's Australia. (2010). *Consumer involvement in dementia research: Alzheimer's Australia's consumer dementia research network: A report for Alzheimer's Australia*. Paper 22 September 2010. Retrieved from <https://www.fightdementia.org.au/files/20100906-NAT-NP-Alzheimers-Australia-Consumer-Involvement-in-Dementia-Research-Paper-22-final.pdf>
- Alzheimer's Australia. (2012). *Exploring dementia and stigma beliefs. A pilot study of Australian adults aged 40 to 65 yrs*. Retrieved from https://www.fightdementia.org.au/files/20120712_US_28_Stigma_Report.pdf
- Alzheimer's Australia. (2013). *Younger onset dementia: A new horizon?* Paper presented at the National Consumer Summit March 2013. Retrieved from https://www.fightdementia.org.au/sites/default/files/NATIONAL_CONSUMER_SUMMIT_-_FINAL_March_2013.pdf
- Alzheimer's Australia. (2014). *Dementia language guidelines*. Retrieved from <https://www.fightdementia.org.au/resources/dementia-language-guidelines>
- Alzheimer's Australia. (2015). *Consumer summit*. Retrieved from <https://www.fightdementia.org.au/research-and-publications/conferences/consumer-summit-2015>
- Alzheimer's Australia. (2016). *Consumer summit*. Retrieved from <https://www.fightdementia.org.au/conferences/consumer-summit-2016>
- Alzheimer's Australia. (2017). *Dementia and the impact of stigma*. Retrieved from <https://www.fightdementia.org.au/files/NATIONAL/documents/dementia-and-stigma-2017.pdf>
- Alzheimer's Disease International. (2012). *World Alzheimer Report 2012: Overcoming the stigma of dementia*. Retrieved from <https://www.alz.co.uk/sites/default/files/pdfs/world-report-2012-summary-sheet.pdf>

- Alzheimer Europe. (2011). *The value of knowing. Findings of Alzheimer Europe's five country survey on public perceptions of Alzheimer's Disease and views on the value of diagnosis*. Retrieved from <http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports>.
- Alzheimer Europe. (2013). *The ethical issues linked to the perceptions and portrayal of dementia and people with dementia*. Retrieved from <http://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports>.
- Andrews, S., McInerney, F., Toye, C., Parkinson, C-A., Robinson, A. (2017). Knowledge of dementia: Do family members understand dementia as a terminal condition? *Dementia: the international journal of social research and practice*, 16(5), 556–575. doi:10.1177/1471301215605630
- Angus, J., & Bowen-Osborne, S. (2014). A self-narrative of life-long disability: A reflection on resilience and living with dementia. *Dementia: the international journal of social research and practice*, 13(2), 147–159. doi:10.1177/1471301212455121
- American Psychiatric Association. (2013). *Desk reference to the diagnostic criteria from DSM-5*. Arlington, VA: American Psychiatric Publishing.
- Babbie, E. (2005). *The basics of social research* (3rd ed.). Belmont, CA: Thomson/Wadsworth Learning.
- Baldwin, C., & Capstick, A. (Eds.). (2007). *Tom Kitwood on dementia: A reader and critical commentary*. Maidenhead: McGraw-Hill/Open University Press.
- Barnett, E. (2000). *Including the person with dementia in designing and delivering care: 'I need to be me!'* London: Jessica Kingsley Publishers.
- Bartlett, R., & O'Connor, D. (2010). *Broadening the dementia debate: Towards social citizenship*. Bristol: The Policy Press.
- Baumeister, R. F. (1991). *Meanings in life*. New York, NY: Guilford.
- Beard, R., Knauss, J., & Moyer, D. (2009). Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies*, 23(4), 227–235. doi:10.1016/j.jaging.2008.01.002
- Beattie, E. (2009). Research participation of individuals with dementia: Decisional capacity, informed consent, and considerations for nurse investigators. *Research in Gerontological Nursing*, 2(2), 94–102. doi:10.3928/19404921-20090401-01
- Beattie, E., Fetherstonhaugh, D., & Moyle, W. (2009, September). *Research involving persons with mental disorders which may affect decision-making capacity*. Paper presented at the Decisional Capacity Forum, Sydney.
- Bergman, M., Graff, C., Eriksson, M., Fugl-Meyer, K.S., & Schuster, M. (2016). The meaning of living close to a person with Alzheimer disease. *Medicine, Health Care and Philosophy*, 19(3), 341–349. doi:10.1007/s11019-016-9696-3

- Birt, L., Poland, F., Csipke, E., & Charlesworth, G. (2017). Shifting dementia discourses from deficit to active citizenship. *Sociology of Health & Illness*, 39(2), 199–211. doi:10.1111/1467-9566.12530
- Blandin, K., & Pepin, R. (2017). Dementia grief: A theoretical model of a unique grief experience. *Dementia: the international journal of social research and practice*, 16(1), 67–78. doi:10.1177/1471301215581081
- Boden, C. (1998). *Who will I be when I die?* East Melbourne, Victoria: HarperCollins.
- Boerner, K., & Jopp, D. (2010). Resilience in response to loss. In J. W. Reich, A. J. Zautra, & J. S. Hall. (Eds.), *Handbook of adult resilience* (pp. 126–145). New York, NY: The Guilford Press.
- Bonanno, G. A. (2004). Loss, trauma and human resilience: Have we underestimated the human capacity to thrive after extremely aversive events? *American Psychologist*, 59, 20–28. doi:10.1037/0003-066X.59.1.20
- Bonanno, G. A. (2008). Grief, trauma and resilience. *The Australian Journal of Grief and Bereavement*, 11(1), 11–17.
- Borley, G., & Hardy, S. (2017). A qualitative study on becoming cared for in Alzheimer's disease: The effects to women's sense of identity. *Ageing & Mental Health*, 21(10), 1017–1022. doi:10.1080/13607863.2016.1200535
- Borley, G., Sixsmith, J., & Church, S. (2016). How does a woman with Alzheimer's disease make sense of becoming cared for? *Dementia: the international journal of social research and practice*, 15(6), 1405–1421. doi:10.1177/1471301214561647
- Boss, P. (1999). *Ambiguous loss: Learning to live with unresolved grief*. Cambridge, MA: Harvard University Press.
- Boss, P. (2010). The trauma and complicated grief of ambiguous loss. *Pastoral Psychology*, 59(2), 137–145. doi:10.1007/s11089-009-0264-0
- Boss, P. (2011). *Loving someone who has dementia: How to find hope while coping with stress and grief*. New York, NY: Jossey-Bass.
- Brown, A., & Roach, P. (2010). My husband has young-onset dementia: A daughter, wife and mother's story. *Dementia: the international journal of social research and practice*, 9(4), 451–453. doi: 10.1177/1471301210381778
- Bruce, E. J., & Schultz, C.L. (2001). *Nonfinite loss and grief: A psychoeducational approach*. Baltimore, MD: Paul. H. Brookes.
- Bruner, J. (1986). *Actual minds, possible worlds*. Cambridge, MA: Harvard University Press.
- Bruner, J. (1990). *Acts of meaning*. Cambridge, MA: Harvard University Press.
- Bruner, J. (2002). *Making stories: Law, literature, life*. New York: Farrar, Straus and Giroux.

- Bryden, C. (2005). *Dancing with dementia*. London: Jessica Kingsley Publishers.
- Bryden, C. (2015). *Before I forget*. Hawthorn, Australia: Penguin Books.
- Bryden, C. (2016a). A spiritual journey into the I-Thou relationship: A personal reflection on living with dementia. *Journal of Religion, Spirituality & Aging*, 28(1–2), 7–14. doi:10.1080/15528030.2015.1047294
- Bryden, C. (2016b). *Nothing about us, without us! 20 years of dementia advocacy*. London, England: Jessica Kingsley Publishers.
- Bryden, C. (2018). A continuing sense of self in the lived experience of dementia. *Journal of Religion, Spirituality & Aging*, 30(3), 279-290. doi: 10.1080/15528030.2018.1462290
- Bryden, C., & MacKinlay, E. (2003). Dementia – A spiritual journey towards the divine: A personal view of dementia. *Journal of Religious Gerontology*, 13(3/4), 69–75. doi: 10.1300/J078v13n03_05
- Bryden, C., & MacKinlay, E. (2008). Dementia: A journey inwards to a spiritual self. In E. B. MacKinlay (Ed.), *Ageing, disability & spirituality: Addressing the challenge of disability in later life* (pp. 134–144). London, UK: Jessica Kingsley Publishers.
- Buber, M. (1970). *I and thou* (W. Kaufmann, Trans.). New York, NY: Simon & Schuster.
- Bunn, F., Burn, A-M., Goodman, C., Rait, G., Norton, S., Robinson, L., ... Brayne, C. (2014). Comorbidity and dementia: A scoping review of the literature. *BMC Medicine*, 12(1), 1-28. doi:10.1186/s12916-014-0192-4.
- Bunn, F., Goodman, C., Sworn, K., Rait, G., Brayne, C., Robinson, L., ... Iliffe, S. (2012). Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: A systematic review of qualitative studies. *Plos Medicine*, 9(10), 1–12. doi:10.1371/journal.pmed.1001331.
- Burgener, S. C., Buckwalter, K., Perkhounkova, Y., & Liu, M. F. (2015). Perceived stigma in persons with early stage dementia: Longitudinal findings: Part 2. *Dementia: the international journal of social research and practice*, 14(5), 609–632. doi:10.1177/1471301213504202
- Burgener, S. C., Buckwalter, K., Perkhounkova, Y., Liu, M. F., Carol, R. R. Einhorn, J., ... Hahn-Swanson, C. (2015). Perceived stigma in persons with early-stage dementia: Longitudinal findings: Part 1. *Dementia: the international journal of social research and practice*, 14(5), 589–608. doi:10.1177/1471301213508399.
- Bute, J. (2016). My glorious opportunity: How my dementia has been a gift. *Journal of Religion, Spirituality and Aging*, 28(1–2), 15–23. doi:10.1080/15528030.2015.1047295

- Cadell, L.S., & Clare, L. (2013). A profile of identity in early-stage dementia and a comparison with healthy older people. *Aging & Mental Health, 17*(3), 319–327. doi:10.1080/13607863.2012.742489
- Caine, V., Estefan, A., & Clandinin, D. J. (2013). A return to methodological commitment: Reflections on narrative inquiry. *Scandinavian Journal of Educational Research, 57*(6), 574–586. doi:10.1080/00313831.2013.798833
- Campbell, S., Manthorpe, J., Samsi, K., Abley, C., Robinson, L., Watts, S., ... Keady, J. (2016). Living with uncertainty: Mapping the transition to a diagnosis of dementia. *Journal of Ageing Studies, 37*, 40–47. doi:10.1016/j.jaging.2016.03.001
- Chaplin, R., & Davidson, I. (2016). What are the experiences of people with dementia in employment? *Dementia: the international journal of social research and practice, 15*(2), 147–161. doi:10.1177/1471301213519252
- Charmaz, K. (1983). Loss of self: A fundamental form of suffering in the chronically ill. *Sociology of Health & Illness, 5*(2), 168–195. doi:10.1111/1467-9566.ep10491512
- Chase, S. E. (2005). Narrative inquiry: Multiple lenses, approaches, voices. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage book of qualitative research* (3rd ed., pp. 651–679). Thousand Oaks, CA: Sage.
- Cheston, R. (1996). Stories and metaphors. *Ageing & Society, 16*, 579–602. Retrieved from <http://eprints.uwe.ac.uk/id/eprint/26301>
- Clandinin, D.J. (2006). Narrative inquiry: A methodology for studying lived experience. *Research Studies in Music Education, 27*, 44–54. doi:10.1177/1321103X060270010301
- Clarke, C. L., & Keady, J. (2002). Getting down to brass tacks: A discussion of data collection with people with dementia. In H. Wilkinson (Ed.), *The perspectives of people with dementia* (pp. 25–46). London: Jessica Kingsley Publishers.
- Clark-McGhee, K., & Castro, M. (2015). A narrative analysis of poetry written from the words of people given a diagnosis of dementia. *Dementia: the international journal of social research and practice, 14*(1), 9–26. doi:10.1177/1471301213488116
- Clemerson, G., Walsh, S., & Isaac, C. (2014). Towards living well with young onset dementia: An exploration of coping from the perspective of those diagnosed. *Dementia: the international journal of social research and practice, 13*(4), 451–466. doi:10.1177/1471301212474149
- Cook, C. C. H. (2016). The lived experience of dementia: Developing a contextual theology. *Journal of Religion, Spirituality & Aging, 28*(1–2), 84–97. doi:10.1080/15528030.2015.1046631
- Corey, G., Corey, M. S., Corey, C., & Callanan, P. (2015). *Issues and ethics in the helping professions* (9th ed.). Stanford, CT: Cengage Learning.

- Cox, S., & Keady, J. (Eds.). (1999a). *Younger people with dementia. Planning, practice and development*. London, UK: Jessica Kingsley Publishers.
- Cox, S., & Keady, J. (1999b). Changing the mind-set. Developing an agenda for change. In S. Cox, & J. Keady (Eds.), *Younger people with dementia. Planning, practice and development* (pp. 292-304). London, UK: Jessica Kingsley Publishers.
- Crago, H., & Gardiner, P. (2012). *A safe place for change. Skills and capacities for counselling and therapy*. Melbourne, Australia: IP Communications.
- Darzins, P., Molloy, D. W., & Strang, D. (Eds.) (2000). *Who can decide? The six step capacity assessment process*. Glenside, SA: Memory Australia Press Alzheimer's Association (SA).
- Davies, J., & Gregory, D. (2007). Entering the dialogue: Marriage biographies and dementia care. *Dementia: the international journal of social research and practice*, 6(4), 481–488. doi:10.1177/1471301207084366
- Dementia Australia. (2018). *What is dementia?* Retrieved from <https://dementia-australia.org/wp-content/uploads/2018/09/What-is-dementia.pdf>
- Dementia Engagement and Empowerment Project (DEEP). (2014). *Dementia words matter: Guidelines on language about dementia*. Retrieved from <http://dementivoices.org.uk/wp-content/uploads/2015/03/DEEP-Guide-Language.pdf>.
- Dementia UK. (2018). *What is dementia?* Retrieved from <https://www.dementiauk.org/understanding-dementia/advice-and-information/dementia-first-steps>
- Doka, K. J. (2002). Introduction. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges and strategies for practice* (pp. 5–22). Champaign, Ill: Research Press.
- Doka, K. J. (2004). Grief and dementia. In K. J. Doka (Ed.), *Living with grief: Alzheimer's disease* (pp. 139–153). Washington, DC: Hospice Foundation of America.
- Doka, K. J., & Aber, R. A. (2002). Psycho social loss and grief. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges, and strategies for practice* (pp. 217–231). Champaign, IL: Research Press.
- Doka, K. J., & Martin. T .L. (2010). *Grieving beyond gender: Understanding the ways men and women mourn*. (Revised ed.). New York, NY: Routledge.
- Downs, M. (1997). The emergence of the person in dementia research. *Ageing and Society*, 17(5), 597–607.
- Draper, B., Peisahab, P., Snowdonde, S., & Brodaty, H. (2010). Early dementia diagnosis and the risk of suicide and euthanasia. *Alzheimer's and Dementia*, 6(1), 75–82. doi:10.1016/j.jalz.2009.04.1229

- Duane, F., Brascher, S., & Koch, S. (2013). Living alone with dementia. *Dementia: the international journal of social research and practice*, 12(11), 123–136. doi:10.1177/1471301211420331
- Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research*. London: Jessica Kingsley Publishers.
- Evans, D., Robertson, J., & Candy, A. (2015). Use of photovoice with people with younger onset dementia. *Dementia: the international journal of social research and practice*, 15(4), 798–813. doi:10.1177/1471301214539955
- Evans, J., Frank, B., Oliffe, J.L., & Gregory, D. (2011). Health, illness, men and masculinities (HIMM): A theoretical framework for understanding men and their health. *Journal of Men's Health*, 8(1), 7–15. doi:10.1016/j.jomh.2010.09.227
- Feil, N. (1993). *The validation breakthrough: Simple techniques for communicating with people with 'Alzheimer's type dementia'*. Baltimore, MD: Health Professions Press.
- Finlay, M. (2015). Righteousness in the land of forgetfulness. *Journal of Religion & Health*, 54(1), 279–286. doi:10.1007/s10943-013-9813-z
- Foucault, M. (1979). *Discipline and punish: The birth of the prison*. Middlesex, UK: Peregrine Books.
- Frank, A. W. (2013). *The wounded storyteller: Body, illness and ethics*. (2nd ed.). Chicago, IL: The University of Chicago Press.
- Frankl, V. E. (1984). *Man's search for meaning*. New York, NY: Simon & Schuster.
- Geldard, D. (2009). *Basic personal counselling: A training manual for counsellors*. (6th ed.). French's Forest, NSW: Pearson Education Australia.
- Gelman, C. R., & Rhames, K. (2018). In their own words: The experience and needs of children in younger-onset Alzheimer's disease and other dementias families. *Dementia: the international journal of social research and practice*, 17(3), 337–358. doi:10.1177/1471301216647097
- George, D. R., & Whitehouse P. J. (2014). The war (on terror) on Alzheimer's. *Dementia: the international journal of social research and practice*, 13(1), 120–130. doi:10.1177/1471301214548143
- Gergen, K. J., & Gergen, M. M. (2011). Narrative tensions: Perilous and productive. *Narrative Inquiry*, 21(2), 347–381. doi:10.1075/ni.21.2.17ger
- Gershman, N. (2012). Prescriptive photomontage. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counselling the bereaved* (pp. 205–210). New York, N.Y.: Routledge.
- Gilbert, K. R. (2002). Taking a narrative approach to grief research: Finding meaning in stories. *Death Studies*, 26(3), 223–239. doi:10.1080/07481180211274

- Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology, 19*(1), 31–65. doi:10.1080/10720530500311182
- Gillies, J., Neimeyer, R. A., & Milman, E. (2014). The meaning of loss codebook: Construction of a system for analyzing meanings made in bereavement. *Death Studies, 38*(4), 207–216. doi:10.1080/07481187.2013.829367
- Godwin, B., & Waters, H. (2009). 'In solitary confinement': Planning end-of-life well-being with people with advanced dementia, their family and professional carers. *Mortality, 14*(3), 265–285. doi:10.1080/13576270903056840
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Harmondsworth, England: Penguin Books.
- Goldsmith, M. (1996). *Hearing the voice of people with dementia*. London, UK: Jessica Kingsley Publishers.
- Greenwood, N., & Smith, R. (2016). The experience of people with young-onset dementia: A meta-ethnographic review of the qualitative literature. *Maturitas, 92*, 102–109. doi:10.1016/j.maturitas.2016.07.019
- Haberstroh, J., Neumeyer, K., Krause, K., Franzmann, J., & Pantel, J. (2011). TANDEM: Communication training for informal caregivers of people with dementia. *Aging & Mental Health, 15*(3), 405–413. doi:10.1080/13607863.2010.536135
- Hansson, R. O., Carpenter, B. N., & Fairchild, S. K. (1993). Measurement issues in bereavement. In M. S. Stroebe, W. Stroebe., & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 62–74). New York, NY: Cambridge University Press.
- Harland, J., Bath, P. A., Wainwright, A., & Seymour, J. (2017). Making sense of dementia. *Aslib Journal of Information Management, 69*(3), 261–277. doi:10.1108/AJIM-08-2016-0141
- Harman, G., & Clare, L. (2006). Illness representations and lived experience in early-stage dementia. *Qualitative Health Research, 16*(4), 484–502. doi:10.1177/1049732306286851
- Harris, P. B., & Keady, J. (2009). Selfhood in younger onset dementia: Transitions and testimonies. *Aging and Mental Health, 13*(3), 437–444. doi:10.1080/13607860802534609
- Harris, P. B., & Sterin, G. J. (1999). Defining self and preserving the self of dementia. *Journal of Mental Health and Aging, 5*(3), 241–256. Retrieved from https://www.researchgate.net/publication/290781882_Insider's_perspective_Defining_and_preserving_the_self_of_dementia

- Hedman, R., Hansebo, G., Ternstedt, B-M., Hellström, I., & Norberg, A. (2013). How people with Alzheimer's disease express their sense of self: Analysis using Rom Harré's theory of selfhood. *Dementia: the international journal of social research and practice*, 12(6), 713–733. doi:10.1177/1471301212444053
- Hellström, I., Nolan, M., & Lundh, U. (2005). 'We do things together'. *Dementia: the international journal of social research and practice*, 4(1), 7-22. doi: 10.1177/1471301205049188
- Hellström, I., Nolan, M., & Lundh, U. (2007). Sustaining 'couplehood': Spouses' strategies for living positively with dementia. *Dementia: the international journal of social research and practice*, 6(3), 383–409. doi:10.1177/1471301207081571
- Hellström, I., Nolan, M., Nordenfelt, L., & Lundh, U. (2007). Ethical and methodological issues in interviewing persons with dementia. *Nursing Ethics*, 14, 608–619. doi:10.1177/0969733007080206
- Herman, J. L. (1992). *Trauma and recovery*. New York, NY: Basic Books.
- HowStuffWorks.com Contributors. (2011, 24 July). *What does a crescent wrench look like?* Retrieved from <https://home.howstuffworks.com/what-does-crescent-wrench-look-like.htm>> 3 February 2019
- Hutchinson, K., Roberts, C., Kurrle, S., & Daly, M. (2016). The emotional well-being of younger people having a parent with younger dementia. *Dementia: the international journal of social research and practice*, 15(4), 609–628. doi:10.1177/1471301214532111
- Hyden, L.- C. (2013). Storytelling in dementia: Embodiment as a resource. *Dementia: the international journal of social research and practice*, 12(3), 359–367. doi:10.1177/1471301213476290
- James, W. (1890). *Principles of Psychology, Vols. I and II*. New York: Holt.
- Johannessen, A., & Möller, A. (2013). Experiences of persons with early-onset dementia in everyday life: A qualitative study. *Dementia: the international journal of social research and practice*, 12(4), 410–424. doi:10.1177/1471301211430647
- Johannessen, A., Möller, A., Haugen, P.K., & Biong, S. (2014). A shifting sense of being: A secondary analysis and comparison of two qualitative studies on young-onset dementia. *International Journal of Qualitative Studies on Health and Well-being*, 9(1), 24756. doi:10.3402/qhw.v9.24756
- Jones, D. (2015). A family living with Alzheimer's disease: The communicative challenges. *Dementia: the international journal of social research and practice*, 14(5), 555–573. doi:10.1177/1471301213502213
- Jordan, J. (2000). Introduction. Research that matters: Bridging the gap between research and practice in thanatology. *Death Studies*, 24(6), 457–467. doi:10.1080/07481180050121444

- Kaufman, E. G., & Engel, S.A. (2016). Dementia and well-being: A conceptual framework based on Tom Kitwood's model of needs. *Dementia: the international journal of social research and practice*, 15(4), 774–788.
doi:10.1177/1471301214539690
- Keady, J., Williams, S., & Hughes-Roberts, J. (2007). 'Making mistakes': Using co-constructed inquiry to illuminate meaning and relationships in the early adjustment to Alzheimer's disease – A single case study approach. *Dementia: the international journal of social research and practice*, 6(3), 343–364.
doi:10.1177/1471301207081569
- Kelly, F. (2010). Recognising and supporting self in dementia: a new way to facilitate a person-centred approach to dementia care. *Ageing and Society*, 30(1),
doi:10.1017/S0144686X09008708
- Killick, J. (1999). 'Dark head amongst the grey': Experiencing the worlds of younger persons with dementia. In S. Cox, & J. Keady (Eds.), *Younger people with dementia. Planning, practice and development* (pp. 292-304). London, UK: Jessica Kingsley Publishers.
- Killick, J. (2005). Making sense of dementia through metaphor. *Journal of Dementia Care*, 13(1), 22–23.
- Killick, J. (2008). *Dementia diary: Poems and prose*. London, UK: Hawker publications.
- Killick, J. (Ed.). (2010). *The elephant in the room: Poems by people with memory loss in Cambridgeshire*. Cambridge, MA: Cambridgeshire County Council.
- Killick, J., & Allan, K. (2001). *Communication and the care of people with dementia*. Buckingham, UK: Open University Press.
- Kim, J-H. (2008). A romance with narrative inquiry. Toward an act of narrative theorising. *Curriculum and Teaching Dialogue*, 10(1 & 2), 251-267. Retrieved from <http://ezproxy.canberra.edu.au/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=a9h&AN=35829158>.
- Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society*, 10(2), 177–196.
doi:10.1017/S0144686X00008060
- Kitwood, T. (1993). Discover the person not the disease. *Journal of Dementia Care*, 1(6), 16–17.
- Kitwood, T. (1995). Positive long-term changes in dementia: Some preliminary observations. *Journal of Mental Health*, 4(2), 133–144.
doi:10.1080/09638239550037677
- Kitwood, T. (1997a). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.

- Kitwood, T. (1997b). The experience of dementia. *Aging & Mental Health*, 1(1), 13–22. doi:10.1080/13607869757344
- Kitwood, T., & Benson, S. (1995). *The new culture of dementia care*. London, UK: Hawker.
- Kleinman, A. (1988). *The illness narratives: Suffering, healing and the human condition*. New York, NY: Basic Books.
- Kontos, P. C. (2003). 'The painterly hand': Embodied consciousness and Alzheimer's disease. *Journal of Aging Studies*, 17(2), 151–170. doi:10.1016/S0890-4065(03)00006-9
- Kontos, P. C., & Martin, W. (2013). Embodiment and dementia: Exploring critical narratives of selfhood, surveillance and dementia care. *Dementia: the international journal of social research and practice*, 12(3), 288–302. doi:10.1177/1471301213479787
- Kontos, P. C., Miller, K-L., & Kontos, A. (2017). Relational citizenship: Supporting embodied selfhood and relationality in dementia care. *Sociology of Health & Illness*, 39(2), 182–198. doi:10.1177/1467-9566.12453.
- Labov, W. (1972). *Language in the inner city: Studies in the black English vernacular*. Philadelphia: University of Pennsylvania Press.
- Lakoff, G., & Johnson, M. (1980). *Metaphors we live by*. Chicago, IL: University of Chicago Press.
- Lakoff, G., & Johnson, M. (2003). *Metaphors we live by*. Chicago, IL: University of Chicago Press.
- Lawless, M., & Augoustinos, M. (2017). Brain health advice in the news: managing notions of individual responsibility in media discourse on cognitive decline and dementia. *Qualitative Research in Psychology*, 14(1), 62–80. doi:10.1080/14780887.2016.1236866
- Lee, S. M., Roen, K. & Thornton, A. (2014). The psychological impact of a diagnosis of Alzheimer's disease. *Dementia: the international journal of social research and practice*, 13(13), 289–305. doi:10.1177/1471301213497080
- Lindauer, A., & Harvath, T. A. (2014). Pre-death grief in the context of dementia caregiving: A concept analysis. *Journal of Advanced Nursing*, 70(10), 2196–2207. doi:10.1111/jan.12411
- Lipinska, D. (2009). *Person-centred counselling for people with dementia: Making sense of self*. London, UK: Jessica Kingsley Publishers.
- Lishman, E., Cheston, R., & Smithson, J. (2016). The paradox of dementia: Changes in assimilation after receiving a diagnosis of dementia. *Dementia: the international journal of social research and practice*, 15(2), 181–203. doi:10.1177/1471301214520781

- MacCourt, P., McLennan, M., Somers, S., & Krawczyk, M. (2017). Effectiveness of a grief intervention for caregivers of people with dementia. *Omega: Journal of Death & Dying*, 75(3), 230–247. doi:10.1177/0030222816652802
- Machin, L. (2014). *Working with loss and grief: A theoretical and practical approach*. (2nd ed.). Thousand Oaks, CA: Sage.
- MacKay, F. (2008). A perilous and passionate calling: The development of counsellor spirituality. *Psychotherapy in Australia*, 14(2), 56–63.
- MacKinlay, E. (2016). Journeys with people who have dementia: Connecting and finding meaning in the journey. *Journal of Religion, Spirituality & Aging*, 28(1–2), 24–36. doi:10.1080/15528030.2015.1046632
- MacKinlay, E., & Trevitt, C. (2012). *Finding meaning in the experience of dementia: The place of spiritual reminiscence work*. London, England: Jessica Kingsley Publishers.
- MacQuarrie, C. R. (2005). Experiences in early stage Alzheimer's disease: Understanding the paradox of acceptance and denial. *Aging and Mental Health*, 9(5), 430–441. doi:10.1080/13607860500142853
- Mancini, A. D., & Bonanno, G. A. (2010). Resilience to potential trauma. In J. W. Reich, A. J. Zautra, & J. S. Hall (Eds.), *Handbook of adult resilience* (pp. 258–280). New York, NY: The Guilford Press.
- McCormack, C. (2004). Storying stories: A narrative approach to in-depth interview conversations. *International Journal of Social Research Methodology*, 7(3), 219–236. doi:10.1080/13645570210166382
- McInerney, F. (2017). Dementia discourse: A rethink? *Dementia: the international journal of social research and practice*, 16(4), 409–412. doi:10.1177/1471301217700535.
- McLean, A. (2006). Coherence without facticity in dementia: The case of Mrs Fine. In A. Leibing, & L. Cohen (Eds.), *Thinking about dementia: Culture, loss and the anthropology of senility* (pp. 157–179). Piscataway, NJ: Rutgers University Press.
- McLeod, J. (2011). *Qualitative research in counselling and psychotherapy* (2nd ed.). Thousand Oaks, CA: Sage.
- McLeod, J. (2013). *An introduction to counselling* (5th ed.). Maidenhead, Berkshire: Open University Press.
- McParland, P., Kelly, F., & Innes, A. (2017). Dichotomising dementia: Is there another way? *Sociology of Health & Illness*, 39(2), 258–269. doi:10.1111/1467-9566.12438
- Meares, R. (1995). Episodic memory, trauma, and the narrative of self. *Contemporary Psychoanalysis*, 31(4), 541–556. doi:10.1080/00107530.1995.10746923

- Meares, R. (2000). *Intimacy & alienation: Memory, trauma and personal being*. East Sussex, UK: Brunner-Routledge.
- Meares, R., Butt, D., Henderson-Brooks, C., & Samir, H. (2005). A poetics of change. *Psychoanalytic Dialogues*, 15(5), 661–680. doi:10.1080/10481881509348858
- Meares, R., & Graham, P. (2008). Recognition and the duality of self. *International Journal of Psychoanalytic Self Psychology*, 3, 432–446. doi:10.1080/15551020802337484
- Melbourne Neuropsychiatry Centre (2008). *Quality dementia care: Understanding younger onset dementia*. Melbourne: Alzheimer's Australia.
- Merritt, F. (2016). First nations healing: Indigenous approaches to counselling. In C. Noble, & E. Day (Eds.), *Psychotherapy and counselling* (pp. 28–40). South Melbourne, Victoria: Oxford University Press.
- Menne, H. L., Kinney, J. M., & Morhardt, D. J. (2002). 'Trying to continue to do as much as they can do': Theoretical insights regarding continuity and meaning making in the face of dementia. *Dementia: the international journal of social research and practice*, 1(3), 367–382. doi:10.1177/147130120200100308
- Milby, E., Murphy, G., & Winthrop, A. (2017). Diagnosis disclosure in dementia: Understanding the experience of clinicians and patients who have recently given or received a diagnosis. *Dementia: the international journal of social research and practice*, 16(5), 611–628. doi:10.1177/1471301215612676
- Mishler, E. G. (1986). *Research interviewing: Context and narrative*. Cambridge, MA: Harvard University Press.
- Nadeau, J. W. (2000). Family construction of meaning. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 95–111). Washington, DC: American Psychological Association.
- National Centre for Social and Economic Modelling (NATSEM). (2017). *Economic cost of dementia in Australia 2016–2056*. Canberra, ACT: IGPA, University of Canberra.
- Neimeyer, R. A. (1993). An appraisal of constructivist psychotherapies. *Journal of Consulting and Clinical Psychology*, 61(2), 221–234. doi:10.1037/0022-006X.61.2.221
- Neimeyer, R. A. (2000). The language of loss: Grief therapy as a process of meaning reconstruction. In R. A. Neimeyer (Ed.), *Meaning reconstruction and the experience of loss* (pp. 261–292). Washington DC: American Psychological Association.
- Neimeyer, R. A. (2004). Fostering posttraumatic growth: A narrative contribution. *Psychological Inquiry*, 15(1), 53–59. Retrieved from <http://www.jstor.org/stable/20447202>

- Neimeyer, R. A. (2012). Presence, process and procedure: A relational frame for technical proficiency in grief therapy. In R. A. Neimeyer (Ed.), *Techniques of grief therapy: Creative practices for counseling the bereaved* (pp. 3–11). New York, NY: Routledge.
- Neimeyer, R. A. (2016a). Reconstructing meaning in mourning: Evolution of a research program. *The Australian Journal of Grief and Bereavement*, *19*(1), 10–13.
- Neimeyer, R. A. (2016b). Meaning reconstruction in the wake of loss: Evolution of a research program. *Behaviour Change*, 1–15. doi:10.1017/bec.2016.4
- Neimeyer, R. A., Burke, L. A., Mackay, M. M., & van Dyke Stringer, J. G. (2009). Grief therapy and the reconstruction of meaning: From principles to practice. *Journal of Contemporary Psychotherapy*, *40*, 73–83. doi:10.1007/s10879-009-9135-3
- Neimeyer, R. A., & Hogan, N. S. (2001). Quantitative or qualitative? Measurement issues in the study of grief. In M. S. Stroebe, R. O. Hansson, H. Schut & W. Stroebe (Eds.), *Handbook of bereavement research: Consequences, coping, and care* (pp. 89–118). Washington, DC: American Psychological Association.
- Neimeyer, R. A., & Jordan, J. R. (2002). Disenfranchisement as empathic failure. In K. J. Doka (Ed.), *Disenfranchised grief: New directions, challenges and strategies for practice* (pp. 95–117). Champaign, IL: Research Press.
- Neimeyer, R.A., Klass, D., & Dennis, M.R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies*, *38*, 485–498. doi: 10.1080/07481187.2014.913454
- Neimeyer, R. A., Prigerson, H. G., & Davies, B. (2002). Mourning and meaning. *American Behavioural Scientist*, *46*(2), 235–251. doi: 10.1177/000276402236676
- Neimeyer, R. A., & Raskin, J. (2000). On practising postmodern therapy in modern times. In R. A. Neimeyer, & J. Raskin (Eds.), *Constructions of disorder* (pp. 3–14). Washington, DC: American Psychological Association.
- Neimeyer, R. A., & Sands, D. C. (2011). Meaning reconstruction in bereavement: From principles to practice. In R. A. Neimeyer, D. L. Harris, H. R. Winokuer, & G. F. Thornton (Eds.), *Grief and bereavement in contemporary society: Bridging research and practice* (pp. 9–22). New York, NY: Routledge.
- Nelson-Jones, R. (2015). *Theory and practice of counselling and therapy* (6th ed.). London, UK: Sage.
- Novek, S., & Wilkinson, H. (2017). Safe and inclusive research practices for qualitative research involving people with dementia: A review of key issues and strategies. *Dementia: the international journal of social research and practice*, *0*(0), 1–18. doi: 10.1177/1471301217701274

- Noyes, L. E. (2002). Loss and Alzheimer's disease. In K. J. Doka (Ed.), *Living with grief: Loss in later life* (pp. 59–70). Washington, DC: Hospice Foundation of America.
- Noyes, B. B., Hill, R. D., Hicken, B. L., Luptak, M., Rupper, R., Dailey, N. K.,...Bair, B. D. (2010). The role of grief in dementia caregiving. *American Journal of Alzheimer's Disease & Other Dementias*, 25(1), 9–17. doi: 10.1177/1533317509333902
- O'Connor, D., & Nedlund, A-C. (2016). Editorial introduction: Special issue on citizenship and dementia. *Dementia: the international journal of social research and practice*, 15(3), 285–288. doi:10.1177/1471301216647150
- O'Connor, D., Phinney, A., Smith, A., Small, J., Purves, B., Perry, J., ... Beattie, L. (2007). Personhood in dementia care: Developing a research agenda for broadening the vision. *Dementia: the international journal of social research and practice*, 6(1), 121–142. doi:10.1177/1471301207075648
- O'Hansson, R. O., Carpenter, B. N., & Fairchild, S. K. (1993). Measurement issues in bereavement. In M. S. Stroebe, W. Stroebe, & R. O. Hansson (Eds.), *Handbook of bereavement: Theory, research and intervention* (pp. 62–74). Cambridge, MA: Cambridge University Press.
- O'Hara, D.J. (2011). Psychotherapy and the dialectics of hope and despair. *Counselling Psychology Quarterly*, 24(4), 323–329. doi:10.1080/09515070.2011.623542
- O'Hara, D.J. (2014). The question of the self. *Counselling Psychology Review*, 29(2), 67–69. Retrieved from <http://search.ebscohost.com.ezproxy.canberra.edu.au/login.aspx?direct=true&db=asn&AN=97266024>
- O'Hara, D.J. (2016). The self: reflective, relational, and embodied. *PACJA*, 4(1). Retrieved from <http://pacja.org.au/?p=3207>
- Öhman, A., Nygård, L., & Borell, L. (2001). The vocational situation in cases of memory deficits or younger-onset dementia. *Scandinavian Journal of Caring Sciences*, 15(1), 34–43. doi:10.1046/j.1471-6712.2001.1510034.x
- Örulv, L., & Hydén, L-C. (2006). Confabulation: sense-making, self-making and world making in dementia. *Discourse Studies*, 8(5), 647–673. doi:10.1177/1461445606067333
- Panksepp, J. (2005). On the embodied neural nature of core emotional affects. *Journal of Consciousness Studies*, 12(8–10), 158–84. Retrieved from <https://pdfs.semanticscholar.org/1914/192e4a27bdf153aeb422347461c7690fb044.pdf>
- Park, C. L. (2010). Making sense of the meaning literature. *Psychological Bulletin*, 136(2), 257–301. doi: 10.1037/a001830

- Park, C. L., & Folkman, S. (1997). Meaning in the context of stress and coping. *General Review of Psychology*, 1(2), 115–144. doi:10.1037%2F1089-2680.1.2.115
- Perry-Young, L., Owen, G., Kelly, S., & Owens, C. (2018). How people come to recognise a problem and seek medical help for a person showing early signs of dementia: A systematic review and meta-ethnography. *Dementia: the international journal of social research and practice*, 17(1), 34–60. doi:10.1177/1471301215626889
- Phillips, J., Pond, D., & Goode, S. (2011). *Timely diagnosis of dementia: Can we do better?* A report for Alzheimer's Australia. Paper 24. Retrieved from https://www.fightdementia.org.au/files/Timely_Diagnosis_Can_we_do_better.pdf
- Phinney, A., Chaudhury, H., & O'Connor, D.L. (2006). Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health*, 11(4), 384-393. doi: 10.1080/13607860601086470
- Polkinghorne, D. F. (1988). *Narrative knowing and the human sciences*. Albany, NY: State University of New York Press.
- Polkinghorne, D. F. (1995). Narrative configuration in qualitative analysis. *Qualitative Studies in Education*, 8(1), 5–23. doi:10.1080/0951839950080103
- Post, S. G. (2013). Hope in caring for the deeply forgetful: Enduring selfhood and being open to surprises. *Bulletin of the Menninger Clinic*, 77(4), 349–368. doi:10.1521/bumc.2013.77.4.349
- Quinn, C., Clare, L., & Woods, R. (2015). Balancing needs: The role of motivations, meanings and relationship dynamics in the experience of informal caregivers of people with dementia. *Dementia: the international journal of social research and practice*, 14(2), 220–237. doi:10.1177/1471301213495863
- Rando, T. A. (1993). *Treatment of complicated mourning*. Champaign, IL: Research Press.
- Reed, J., Cantley, C., Clarke, C.L., & Stanley, D. (2002). Services for younger people with dementia. Problems with differentiating needs on the basis of age. *Dementia: the international journal of social research and practice*, 1(1), 95-112. doi: 10.1177/147130120200100105
- Rees, G. (June, 2010). *Dementia evolution or revolution?* Alzheimer's Australia Paper 19. Retrieved from https://www.fightdementia.org.au/files/20100600_Nat_NP_19ReesDemEvolRev.pdf
- Rees, G. (2015, March). *Making reform work for consumers*. Paper presented at the Consumer Summit. Retrieved from <https://www.fightdementia.org.au/files/NATIONAL/documents/Consumer-Summit-2015-speeches-Glenn-Rees.pdf>

- Rentz, C., Krikorian, R., & Keys, M. (2005). Grief and mourning from the perspective of the person with a dementing illness: Beginning the dialogue. *Omega: Journal of Death & Dying*, 50(3), 165–179. doi:10.2190/XBH0-0XR1-H2KA-H0JT
- Resnick, B., Gruber-Baldini, A.L., Pretzer-Aboff, I., Galik, E., Custis-Buie, V., Russ, K., & Zimmerman, S. (2007). Reliability and validity of the evaluation to consent measure. *The Gerontologist*, 47, 69-77. doi:10.1093/geront/47.1.69
- Richardson, L., & St Pierre, E. A. (2005). Writing: A method of inquiry. In N. K. Denzin, & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed., pp. 651–679). Thousand Oaks, CA: Sage.
- Riessman, C. K. (1993). *Qualitative research methods* (Vol. 30. Narrative analysis). Newbury Park, CA: Sage Publications.
- Riessman, C. K. (2008). *Narrative methods for the human sciences*. Thousand Oaks, CA: Sage.
- Rimkeit, S., & McIntosh, J. (2017). The voices of people with younger onset dementia as they face aged care. *International Journal of Health, Wellness & Society*, 7(3), 43–52. doi:10.1177/1039856217706821
- Roach, P. (2017). Younger onset dementia: Negotiating future workplace roles and identities. *Dementia: the international journal of social research and practice*, 16(1), 5–8. doi:10.1177/1471301216674420
- Roach, P., & Drummond, N. (2014). 'It's nice to have something to do': Early-onset dementia and maintaining purposeful activity. *Journal of Psychiatric and Mental Health Nursing*, 21(10), 889–895. doi:10.1111/jpm.12154.
- Roach, P., Drummond, N., & Keady, J. (2016). 'Nobody would say that it is Alzheimer's or dementia at this age': Family adjustment following a diagnosis of early-onset dementia. *Journal of Aging Studies*, 36, 26–32. doi:10.1016/j.jaging.2015.12.001
- Roach, P., Keady, J., Bee, P., & Hope, K. (2008). Subjective experiences of younger people with dementia and their families: Implications for UK research, policy and practice. *Reviews in Clinical Gerontology*, 18, 165–172. doi:10.1017/S0959259809002779
- Roach, P., Keady, J., Bee, P., & Williams, S. (2014). 'We can't keep going on like this': Identifying family storylines in young onset dementia. *Ageing & Society*, 34(8), 1397–1426. doi:10.1017/S0144686X13000202
- Robertson, J., & Evans, D. (2015). Evaluation of a workplace engagement project for people with younger onset dementia. *Journal of Clinical Nursing*, 24(15–16), 2331–2339. doi:10.1111/jocn.12852
- Robertson, J., Evans, D., & Horsnell, T. (2014). Side by side: A workplace engagement program for people with younger onset dementia. *Dementia: the*

- international journal of social research and practice*, 12(5), 666–674.
doi:10.1177/1471301212473881
- Robertson, M. (2014). Finding meaning in everyday life with dementia: A case study. *Dementia: the international journal of social research and practice*, 13(4), 525–543.
doi:10.1177/1471301213479357
- Romanoff, B. D. (2001). Research as therapy: The power of narrative to effect change. In R. A. Neimeyer (Ed.), *Meaning reconstruction & the experience of loss* (pp. 245–257). Washington, DC: American Psychological Association.
- Ryan, E. B., Bannister, K. A., & Anas, A. P. (2009). The dementia narrative: Writing to reclaim social identity. *Journal of Ageing Studies*, 23(3), 145–157.
doi:10.1016/j.jaging.2007.12.018
- Sabat, S. R. (2001). *The experience of Alzheimer's Disease: Life through a tangled veil*. Oxford: Blackwood Publishers.
- Sabat, S. R. (2002). Surviving manifestations of selfhood in Alzheimer's disease. *Dementia: the international journal of social research and practice*, 1(1), 25–36.
doi:10.1177/147130120200100101
- Sabat, S. R., & Harré, R. (1992). The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society*, 12(4), 443–461.
doi:10.1017/S0144686X00005262
- Sabat, S. R., & Lee, J. M. (2012). Relatedness among people diagnosed with dementia: Social cognition and the possibility of friendship. *Dementia: the international journal of social research and practice*, 11(3), 315–327.
doi:10.1177/1471301211421069
- Sampson, E. L., Warren, J. D., & Rosser, M. N. (2004). Young onset dementia. *Postgraduate Medical Journal*, 80, 125–139. doi:10.1136/pgmj.2003.011171
- Sarantakos, S. (2005). *Social research*. Basingstoke, Hampshire: Palgrave Macmillan.
- Sikes, P., & Hall, M. (2018). 'It was then that I thought "What? This is not my Dad"': The implications of the 'still the same person' narrative for children and young people who have a parent with dementia. *Dementia: the international journal of social research and practice*, 17(2), 180–198. doi:10.1177/1471301216637204
- Snyder, C. (2002). Hope theory: Rainbows in the mind. *Psychological Inquiry*, 13(4), 249–275. doi:10.1207/S15327965PLI1304_01
- Somekh, B., & Lewin, C. (2005). *Research methods in the social sciences*. London: Sage Publications.
- Sontag, S. (1991). *Illness as metaphor and AIDS and its metaphors*. London: Penguin Books.

- Stroebe, M. S., Hansson, R. O., Schut, H., & Stroebe, W. (2008). Bereavement research: Contemporary perspectives. In M. S. Stroebe, R. O. Hansson, H. Schut, & W. Stroebe (Eds.), *Handbook of bereavement research and practice: Advances in theory and intervention* (pp. 3–25). Washington, DC: American Psychological Association.
- Stroebe, M., & Schut, H. (1999). The dual process model of coping with bereavement: Rationale and description. *Death Studies*, 23(3), 197–224.
doi:10.1080/074811899201046
- Stroebe, M., & Schut, H. (2010). The dual process model of coping with bereavement: A decade on. *Omega: Journal of Death & Dying*, 61(4), 273–289.
doi:10.2190/OM.61.4.b
- Swaffer, K. (2012). You live until you die. In P. Willis & K. Leeson (Eds.), *Learning life from illness stories* (pp. 90–101). Mt Gravatt, Queensland: Post Pressed.
- Swaffer, K. (2014). Dementia: Stigma, language and dementia-friendly. *Dementia: the international journal of social research and practice*, 13(6), 709–716.
doi:10.1177/1471301214548143
- Swaffer, K. (2015). Dementia and prescribed disengagement. *Dementia: the international journal of social research and practice*, 14(1), 3–6.
doi:10.1177/1471301214548136
- Swaffer, K. (2016). *What the hell happened to my brain? Living beyond dementia*. London, UK: Jessica Kingsley Publishers.
- Swaffer, K. (2017). *Being bold: Living with dementia*. Retrieved from <http://www.dementiaallianceinternational.org/bold-living-dementia>
- Swarbrick, C.M., Open Doors, EDUCATE, Davis, K. & Keady, J. (2016). Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice). *Dementia: the international journal of social research and practice*, 0(0), 1-8. doi: 10.1177/1471301216674559
- Swinton, J. (2008). Remembering the person: Theological reflections on God, personhood and dementia. In E. MacKinlay, *Ageing, disability and spirituality* (pp. 22-35). London, UK: Jessica Kingsley Publishers.
- Taylor, R. (2007). *Alzheimer's from the inside out*. Baltimore, MA: Health Professions Press.
- Taylor, R. (2016). Foreword by Dr Richard Taylor. In S. Swaffer, *What the hell happened to my brain? Living beyond dementia*. London, UK: Jessica Kingsley Publishers.
- The Alzheimer Society of Ireland. (2015). *Dementia friendly language*. Retrieved from https://www.alzheimer.ie/Alzheimer/media/SiteMedia/Fundraising/Camino/2014/Dementia-FriendlyLanguage-Final-for-Web-Aug-15_2.pdf

- Tolhurst, E., Bhattacharyya, S., & Kingston, P. (2014). Young onset dementia: The impact of emergent age-based factors upon personhood. *Dementia: the international journal of social research and practice*, 13(2), 193–206. doi:10.1177/1471301212456278
- Tolhurst, E., & Weicht, B. (2017). Preserving personhood: The strategies of men negotiating the experience of dementia. *Journal of Aging Studies*, 40, 29–35. doi:10.1016/j.jaging.2016.12.005
- Tolhurst, E., Weicht, B., & Kingston, P. (2017). Narrative collisions, sociocultural pressures and dementia: The relational basis of personhood reconsidered. *Sociology of Health & Illness*, 39(2), 212–226. doi:10.1111/1467-9566.12523
- Van Der Kolk, B. (2014). *The body keeps the score*. London, UK: Penguin Books.
- Wadham, O., Simpson, J., Rust, J., & Murray, C. (2016). Couple's shared experiences of dementia: A meta-synthesis of the impact upon relationships and couplehood. *Ageing & Mental Health*, 20(5), 463–473. doi:10.1080/13607863.2015.1023769
- White, M. (2007). *Maps of narrative practice*. New York, NY: W. W. Norton & Company.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. Adelaide, SA: W. W. Norton.
- Wilkinson, H. (2002). Including people with dementia in research. In H. Wilkinson (Ed.), *The perspective of people with dementia: Research methods and motivations* (pp. 9–24). London: Jessica Kingsley Publishers.
- Williams, G. (1984). The genesis of chronic illness: Narrative re-construction. *Sociology of Health & Illness*, 6(2), 175–200. doi:10.1111/1467-9566.ep10778250
- Willis, P., & Leeson, K. (2012). Introduction: Learning, reading and storytelling in times of illness. In P. Willis, & K. Leeson (Eds.), *Learning life from illness stories* (pp. 1–13). Mt Gravatt, Queensland: Post Pressed.
- Wolverson, E. L., Clarke, C., & Moniz-Cook, E. D. (2010). Remaining hopeful in early-stage dementia: A qualitative study. *Ageing & Mental Health*, 14(4), 450–460. doi: 10.1080/13607860903483110
- Wolverson, E. L., Clarke, C., & Moniz-Cook, E. D. (2016). Living positively with dementia: A systematic review and synthesis of the qualitative literature. *Ageing & Mental Health*, 20(7), 676–699. doi:10.1080/13607863.2015.1052777
- Worden, J. W. (2018). *Grief counselling and grief therapy: A handbook for the mental health practitioner* (5th ed.). New York, NY: Springer Publishing.
- World Health Organization. (2017). *Global action plan on the public health response to dementia 2017–2025*. Retrieved from

http://www.who.int/mental_health/neurology/dementia/action_plan_2017_2025/en/

Zubrick, A. (2016). Epiphanies: Small miracles in everyday experiences of dementia. *Journal of Religion, Spirituality & Aging*, 28(1-2), 15-23.
doi:10.1080/15528030.2015.1046636