

# Alzheimer's Disease

## A Caregiver's Story

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### Abstract

Recent research suggests that Alzheimer's disease (AD) and related dementias (ADRD) are reaching epidemic proportions worldwide and that those who care for family members are at high risk of experiencing stress, depression, and anxiety. The numbers of caregivers who seek the services of counsellors will surely continue to grow along with the increasing number of ADRD sufferers. This article investigates issues experienced by family caregivers, and explores a variety of approaches available to counsellors to assist them. The author, a counsellor, employs an autoethnographic approach to this research, drawing on her own caregiving experiences. Findings indicate that caregiving for an ADRD family member has a significant effect on the caregiver's wellbeing. Despite the paucity of research into the effectiveness of counselling interventions, a variety of approaches appear to have the potential to assist ADRD caregivers. Appendix 1 offers a selection of psychoeducational materials and useful resources.

**Keywords:** autoethnography, Alzheimer's disease, dementia, caregiving, counselling

"Give sorrow words: the grief that does not speak  
Whispers the o'er-fraught heart, and bids it break."

(William Shakespeare, *Macbeth*, 1V, iii)

"One only understands the things that one tames."

(Antoine de Saint-Exupéry, *The Little Prince*, 1993, p. 69)

"I don't know where I'm going. I think I am a little lost"—words to be understood on a variety of levels, words inspired by a brain that undoubtedly has clusters of amyloid plaques and neurofibrillary tangles strangling its neurons, rendering unfamiliar the

familiar, making the ordinary confusing and frightening. A diagnosis of Alzheimer's disease or a related dementia<sup>1</sup> thrusts the person diagnosed and the family members closest to them into a realm of "not knowing." This research is an attempt to impose academic structure on the personal journey into unknown territory that I am still navigating. It is an attempt to "tame" the thing and give the sorrow words. I explore the challenges facing caregivers, and offer a variety of approaches that may assist counsellors to help clients "tame" their own experiences, and enable them to give words to their sorrow.

### **Research Questions**

The research questions that formed the focus of my autoethnographic exploration included the following:

1. What are the issues facing caregivers of people with dementia?
2. Which approaches may enable counsellors to work effectively with caregivers?
3. In what ways might autoethnographic writing be of value to the reader?
4. How might autoethnographic research be of value to the writer?

### **Methodology**

Regarded by some as a self-indulgent exercise in navel-gazing (A. Baker, personal communication, August, 2009), the use of the self as something to write about can also be regarded as "one of the most ancient Western traditions" (Foucault, 1997, p. 233). With its focus on personal experience, autoethnography is gaining popularity in the field of counselling research (Etherington, 2004). It offers the potential to transform both the writer and the reader, and the opportunity for readers to learn about the general from the specific (Ellis, 2004; Etherington, 2004; Wright, 2009). Traditionally, ethnographic researchers have been concerned with observing culture as if from an omniscient perspective, paying little attention to the researcher's experience (Etherington, 2004). More recently, reflexive field researchers, feminist writers, and postmodernists have challenged positivist approaches and an increasing number of researchers are engaging in self-reflective writing or autoethnography (Berg, 2004). In counselling and psychotherapy, the idea that practice involves the use of the self is generally accepted, but this same concept is more recently emerging in the field of research (McLeod, 2003).

Autoethnography—a form of self-narrative, and a blend of ethnography and autobiographical writing—has its roots in the fields of anthropological and sociological

ethnology. Like ethnographers, autoethnographers follow a process of collecting data or field texts, which are then analysed and interpreted to produce a form of writing designed to enhance the understanding of others (Chang, 2008). Although autoethnographers, unlike ethnographers, use their personal experiences as the essential source of data, Chang (2008) asserts that the framing of the individual's story within a larger context of understanding makes autoethnography essentially ethnographic.

Chang (2008) urges researchers to define their use of the term autoethnography clearly, due to the existence of a mixed bag of self-narratives to which the term is sometimes applied. Autoethnography is distinctive in its reflection on "the interconnectivity of self and others" and its emphasis on "the cultural context of individual stories commingled with others" (Chang, 2008, p. 54). I intend to situate my personal narrative within the culture of a body of people popularly termed "caregivers," people whose lives are changed irreversibly when they take on the responsibility of caring for a family member with dementia, either in their own home or from a distance.

In my discussion of caregiver issues, I propose weaving my story with others' stories, moving between a focus inward on my own vulnerable self and outward on the cultural context (Ellis, 2004). I hope to achieve this "balancing act" (Jones, 2005, p. 764) by employing a "layered text" approach, as described by Ellis (2004, p. 198). This involves juxtaposing references to literature, or "traditional theorizing segments" with my personal situation and its related emotions, or "story segments" (Ellis), as well as the written stories of others. For ease of recognition, my personal story vignettes are presented in italics and others' story fragments are recorded in a contrasting script.

In the second part of the article, I consider a range of possible counselling interventions for caregivers. I review relevant literature and comment on my related personal experience. My aim here is not to provide an in-depth analysis of any one approach, but rather to open windows onto a variety of pathways worthy of practitioners' further reflection, exploration, or future research.

## **Ethics**

The ethical principles I aspired to in this research are very similar to those I adhere to professionally in following the Code of Ethics of the New Zealand Association of Counsellors (2002). These include informed consent, voluntary participation, avoiding doing harm, beneficence, confidentiality, and authenticity/transparency. As a member of a dominant culture group in Aotearoa New Zealand, I also wish to respect kaupapa Māori research frameworks. I embrace Smith's (1997) key ethical considerations (as

cited in Matairea, 2003, p. 6), with their focus on respect, care for others, and humility. The ethical considerations of writing about myself and involving others in my story are indeed “complex” (Wright, 2009, p. 630). The matter of informed consent is paramount in my mind.

*I contact an Australian academic undertaking dementia research. She assures me that as long as the person with dementia consistently says “yes,” even if she does not remember, then it is deemed ethically appropriate to continue with the research (C. Peisah, personal communication, 22 May, 2010). I remain unconvinced. How can I ask for consent to expose this cognitive decline, this loss of self? I procrastinate. My mother gives her blessing. I ask for reassurance from others. I know this research is deemed “low risk.” I wonder if anything is ever “low risk.” I proceed, as I am becoming accustomed to “not knowing.”*

### Issues for Caregivers

*Ah, grief, my chameleon, how many faces you have!*

*A stabbing pain, a stifling heat*

*A chronic sorrow*

*A white-faced ice goddess, you whisper the future in all its horror.*

### Grief at Diagnosis

*Three days after flying to Australia to help arrange my father’s funeral, I first hear the term Alzheimer’s disease mentioned in relation to my mother. My first days in Australia are a flurry of activity, numbness, and constant scrutinising of my mother for signs of memory loss. I attempt to separate out her grief from her memory confusion. I frantically try to recall recent conversations with my father about visits to a specialist, about Mum’s decreasing social confidence and inability to remember day-to-day matters. I know I was reassuring. I sent parcels of Gingko tablets.*

*I see my mother’s doctor. She is adamant that with no family in Australia, Mum cannot stay. She has Alzheimer’s disease. The term slips in gently, quietly. The doctor looks at me compassionately. She says the worst thing for a person with AD is to move to a new environment. We book flights. I sell her house.*

Lindgren, Connelly, and Gaspar’s (1999) quantitative, US-based study involving 33 participants sought to determine patterns of grief for family caregivers of dementia sufferers and the relationship of those patterns to their experiences as caregivers. Their findings indicated the presence of “disastrous emotional feelings at the time of diagnosis” (p. 532). These feelings include “anger, fear, panic, sadness, and uncertainty”

(p. 527), and were shown to continue throughout the caregiving experience with little abatement of the grief over time. The authors postulated that, in contrast to individuals who are grieving over the death of loved ones, caregivers are unable to move on to new and different experiences and therefore the intensity of the initial feelings experienced at the time of diagnosis remains throughout the caregiving experience.

Finally admitting my dad had Alzheimer's Disease was admitting all the things it will eventually do to him. (Van Dyck, 2007, p. 91)

Within a week of the diagnosis, I felt as if I had already lost my spouse. (Carrubba, 2007, p. 142)

### *Latent Grief*

*Five minutes in my counsellor's warm office,  
She names the grief she notices in me,  
Now it cannot hide and turn its knife in secret.*

*I am dreaming in a half-awake state. I suddenly realise that my dad is there. I am so excited. I wanted him to come. I reach out and hug him. I notice that I can't smell his jersey. It doesn't smell of smoke anymore. He has given up at last! My mind races and I seem to know he won't be here for long. I feel the effort he is making to be here. I want to ask him: are you happy with what I've done for Mum? Is it for the best? Is there anything else you want me to do? I don't ask this, but instead I ask: "Is it alright where you are?" He replies that it is fine. He fades. He is gone. I feel the familiar ache of loss.*

Grief in caregivers can frequently be mistaken for depression and has tended to be underacknowledged (Sanders, Ott, Kelber, & Noonan, 2008). Dempsey and Baago (1998) make a convincing case for latent grief as a major factor in caregiver stress and burnout, referring to it as the "unique and hidden grief experience of family caregivers" (p. 91). The authors highlight the very real losses involved in caregiving for a person whose condition can change each day. The authors' experiences working for the Alzheimer Society of Niagara, Canada have taught them that many caregivers are not even aware they are grieving. As counsellors, they assist caregivers to identify and deal with the multiplicity of losses due to slow cognitive decline, and the ambiguity of the losses involved when the individual is physically present but psychologically absent.

That gut-wrenching, deep sadness takes over. (Newman, 2010, p. 149)

We tried the best we could to deal with something so unbearable. (Jeffery, 2010, p. 121)

### *Anticipatory Grief*

*I dream I am on a large ship and I am taking Mum home to Scotland. The journey will take six weeks. I wonder why I once thought this would be a good idea. I am constantly vigilant. I am scared she will fall overboard. She can't find her clothes to get dressed. Urine dribbles down her stockings. I wake telling myself we aren't there yet, but I know this is to come.*

Over the past two decades, researchers have become increasingly interested in the concept of anticipatory or pre-death grief and how it applies to the dementia caregiver. In her doctoral thesis, Sweeting (1991) provided an extensive literature review in the area of anticipatory grief, exploring the differences between anticipatory grief and conventional post-death grief, pointing out that caregivers experience a multitude of different losses related to the deteriorating health of the AD family member. Holley and Mast (2009) defined anticipatory grief as a “complex concept that encompasses grief in anticipation of the future loss of a loved one” (p. 388). Reporting on the findings of their quantitative US-based study of 80 dementia caregivers, they concluded that anticipatory grief is a significant and understudied part of the caregiving experience and that it contributes considerably to caregiver burden. It is largely acknowledged now that grief as a reaction to the non-death losses is a large part of the caregiving experience (Lindgren, Connelly, & Gasper, 1999).

My feelings...were of unease, uncertainty, a sense of impending loss, a constant and generalized anxiety. (Jackson, 2010, p. 53)

I am already mourning him and he is still alive. But he is just a shell of his former self. That is what Alzheimer's does. I don't consider this the long goodbye...It is the stolen goodbye. (Williams, 2007, p. 14)

### *Caregivers' Grief for Self*

*I escape to Wellington for two nights. I long to feel carefree, to forget, to have fun. I have a call on my mobile. My mother has burnt a pot and she has been angry with a support worker. It is my problem. I feel trapped. AD is omnipresent. My other roles are subsumed by this new role of caregiver. This is my loss.*

*A friend has given me a book voucher. I am excited. I anticipate a visit to my favourite bookshop. I contemplate buying the latest Barbara Kingsolver novel, or maybe a book for my counselling library. I find myself yet again in front of the dementia books. They are magnetic. I leave with two and feel strangely content.*

A phenomenological study by Butcher, Holkup, and Buckwalter (2001) described the experience of caring for a family member with ADRD. The study involved a secondary analysis of in-depth transcribed interviews with 103 family caregivers. The authors included one interviewee's words, claiming that they captured the essence of caregivers' suffering: "It makes you a prisoner. You know the slogan 'living death'? That's what it is for the caregiver" (p. 45).

Alzheimer's Disease is an octopus. Its tentacles stretch out through the ether, strangling the lives of those within its reach. The aftermath of dementia leaves survivors weaving the frayed threads of their lives into lessons colored in grief, anger, fear, sadness and human frailty. (Nation, 2007, p. 87)

### *The Caregiver's Burden*

*My husband and I are co-conspirators. We have murdered my aunt and hidden her body. In my dream I am talking to my husband about mundane things and I suddenly remember that we have murdered someone. I remind him. He says he doesn't remember. I recount our actions. He doesn't believe me. I think maybe I did it myself. I am horrified, stressed and anxious beyond belief. How could I have committed murder and barely remember that I did it? How easily I have betrayed my family—done the unthinkable.*

*Today I take Mum to an appointment with the doctor in order to enact a power of attorney. The doctor talks with Mum and, as we leave the room, she slips me the necessary letter. I have not told Mum this is the reason for our visit. I feel like a coward, guilty of treachery and betrayal.*

Recent studies suggest that caregiving for a person with AD can drastically impact on both the physiological and mental wellbeing of the carer. Caregivers are at risk of increased levels of stress, anxiety, and depression (Magai & Cohen, 1998; Waelde, Thompson, & Gallagher-Thompson, 2004). Family caregivers may experience considerable levels of anger, resentment, and guilt (Pillemer & Sutor, 1992, as cited in Magai & Cohen, 1998, p. 147). Feelings of guilt often increase the caregiver's burden (Perkins, 2004). "Guilt is frequently assessed in caregivers, and can be crippling, especially around obtaining caregiving relief and nursing home placement" (Silverberg, 2007, p. 223).

I know you: I know when your mother dies, you're going to feel guilty. You're going to think that you should have been kinder, not in a rush, that you should have done more with her, taken her more places, insisted the kids be nicer. (O'Dell, 2007, p. 3)

Jackson (2010) describes:

a constant and generalised anxiety, and—yes—sometimes uncontrollable irritation, particularly at the repetitive questions. (Naturally this irritation led to an inevitable sense of guilt felt by all carers in this situation.) (pp. 53–54)

### *Fear*

*I am overwhelmed, haunted. I sob and want to keep sobbing. I have read so much about dementia in the last two weeks. I feel horrified. I worry about the genetic link. I am scared for my children, my husband, myself. I wonder if this research is too much, brings me too close. I feel the need to run, to swim, to meditate, to do anything that is not associated with dementia, anything that is life-affirming, anything that makes me feel alive.*

Alzheimer's disease has a genetic component. First-degree relatives of a simplex case of AD (one person in the family with AD) have a cumulative lifetime risk of developing AD of approximately 15 to 30% (Bird, 1998). Children caring for parents with dementia may fear both developing it themselves, and passing it on to their children. Recent research indicates that dementia stirs in caregivers “their worst fears of growing old” (Terry, 2010, p. 21).

Rom (2007) writes:

While I fantasize about forming Dementia Worriers Anonymous or Daughters of Dementia, I'm a sucker for any possible connections between the disease and lecithin, aluminium, even dental amalgam. Shouldn't I be eating more flax oil or fish for brain food? (p. 233).

### **Counselling Strategies to Support Caregivers**

Grappling with such challenges, caregivers are therefore likely to bring myriad complex issues and emotions to counselling. Studies of therapeutic effectiveness have produced conflicting results. One American meta-analysis of interventions with caregivers (Acton & Kang, 2001) found that none of the methods evaluated (support group, psychoeducation, and counselling) had any effect on caregiver burden. A British systematic review of similar interventions (Cooke, McNally, Mulligan, Harrison, & Newman, 2001) showed that they were ineffective in two-thirds of cases. Conversely, a later American review by Sörenson, Pinquart, and Duberstein (2002) indicated that caregivers receiving psychoeducational input and counselling enjoyed greater general wellbeing than those who did not receive them. It is hard to determine the exact reason for these conflicting results, but it would seem that researchers have found it



very difficult to accurately measure a subjective component such as “caregiver burden,” and that there have been insufficient studies conducted with standardised intervention components and adequate sample sizes (Cooke et al., 2001).

An analysis of the relative worth of psychoeducational resources, group support, and counselling is outside the scope of this article. However, Appendix 1 provides a guide to relevant psychoeducational material and resources for Aotearoa New Zealand. Given the paucity of research nationally or internationally dealing specifically with preferred counselling approaches for working with dementia caregivers, it is not possible to promote any specific approach as the most effective. My review instead focuses on a variety of approaches that have potential to “help caregivers find meaning in the experience or transcend the negativity” (Acton & Kang, 2001, p. 358).

### *Grief Counselling*

Counsellors need to be person-centred in their approach to the caregiver's current grief. They need to validate the caregiver's experience of grief, acknowledge it, normalise it, and address it (Dempsey & Baago, 1998; Hodgson, 1998; Sanders et al., 2008, Silverberg, 2007). The relief and healing I experienced in hearing the word “grief” named in the counselling room is testimony to the therapeutic value of the counsellor simply bearing witness to the client's present grief.

Roos (2002) offered an insightful analysis of the unique impact of non-death losses, and of what she termed “chronic sorrow.” She provided clear guidelines for therapists working with clients, including family caregivers who were experiencing living losses, who were “in the throes of a human condition that is draining and inevitable and normal” (p. xvi).

A variety of other approaches to working with these living losses exists. Peller and Walter (1993) offered a solution-focused model aimed at assisting clients to stay “on track” with their own normal grieving process. Kumar (2005), in a self-help guide entitled *Grieving Mindfully*, dealt well with relevant issues of gradual loss and guilt, and offered specific tools for coping with grief and related depression. These included radical acceptance, mindfulness, spiritual meaning-making, CBT techniques, diet, and exercise. Similarly pragmatic, Hodgson (1998) suggested keeping a log of grief triggers, and advocated evaluating the grief through depicting the losses on a continuum or graph.

Counsellors will also undoubtedly find useful the writings of Attig (1996) and Neimeyer (1998). Both have conceptualised grief as a centrally important human

experience in the sense that it challenges our understanding of the world and causes us to search for and make meaning from our experiences. Both authors have offered practical guidance for those who are suffering losses and for those who bear witness to the stories of grief.

### *Spirituality*

The practice of caregiving itself, then, may offer opportunities for spiritual growth, for meaning-making, or for “self-transcendence” (Acton, 2002, p. 23). In recognition of the unique and diverse nature of such meaning-making processes, it may be useful for counsellors to adopt “an attitude of wonder” (Penwarden, 2009, p. 4), so that in therapy, caregivers have the opportunity to explore and revise their view of the world in response to their experiences of grief. A few such possibilities are outlined here.

Dreams have been significant in my own grieving and meaning-making processes and I have been drawn to the work of Margaret Bowater. Bowater (2009) offers inspiration for counsellors interested in harnessing the therapeutic, healing potential of dreams, particularly in grief work. Both Bowater (2009) and Shenk (2003) have presented extracts from clients’ dream accounts, the healing aspects of which are most evident. Waelde et al. (2004) reported a significant reduction in caregiver stress and depression following a pilot study introducing a yoga and meditation programme to 12 female, stressed dementia caregivers in the United States. While Hodgson (1998) wrote of the solace she found personally through learning meditation and relaxation skills, Kapleau (1998) provided practical guidance on how to meditate and relax using breathing techniques. A strong Christian faith and sense of humour provided strength for Boden (1998) and her family as they dealt with her early-onset AD.

### *Postmodern Approaches*

Counsellors wishing to foster hope in their clients might consider postmodern approaches. Weingarten (2010) believed interventions that help clients to perceive themselves as resilient were likely to increase their hope. She encouraged counsellors to look for “the gaps in the stories people tell” and for evidence of “courage” (p. 10), advice that accords with narrative and solution-focused approaches. Coping questions, and looking for exceptions, which are common in solution-focused practice (de Jong & Berg, 2008), can build up the client’s appreciation of their strengths. I have been challenged and encouraged by Weingarten’s ideas and have benefited from applying a strengths-based approach both to the way I view my mother’s remaining capacities and to the ways I evaluate my input into her care and wellbeing.

This two-fold benefit of a shift from deficit thinking is evidenced in the following caregiver's comment:

When her abilities were gradually waning, I felt my heart was being chipped away bit by bit, and I became distraught. But now, when I am able to recognise her remaining abilities, however minute, it renews my determination to look after her (Htay, 2010, p. 59).

Caregivers may derive benefit from working with counsellors who create "conversational spaces in which reasonable hope rather than hopelessness is more likely to arise" (Weingarten, 2010, p. 7). Narrative and expressive arts therapies with older people and their families offer similar hope. Caldwell (2005) described a life review process with huge therapeutic potential for both dementia sufferers and their caregivers. In a similar vein, Andrews (2007) outlined a unique project undertaken by counselling students who engaged with elders in "non-pathologising and non-hierarchical conversations" (p. 150). This intervention is inspirational in the way it empowers older people and their families, and involves a wider community in their care. The demand for these types of collaborative, creative interventions will undoubtedly increase as ADRD numbers grow.

### *Writing Therapy*

They can be like sun, words  
They can do for the heart  
What light can  
For a field.

(St John of the Cross, 2002, as cited in Hartman-Stein, 2010, p. 13)

Writing about traumatic experiences can lead to significant improvements in physical and mental health (Pennebaker, 1993). Bolton (2004) claims, and my personal experiences concur, that writing "can allow an exploration of cognitive, emotional and spiritual areas otherwise not accessible and an expression of elements otherwise inexpressible" (p. 1). Wright (2009) and Bowater (2009) both evocatively demonstrate the potential for self-healing in their use of writing as part of their own grieving processes.

While a large number of studies have demonstrated its health benefits among the general population, the exploration of the use of writing as a support tool for caregivers is still in its infancy, and studies have produced equivocal results. Promisingly, a

project in Pennsylvania that introduced narrative writing to a caregiver support group showed that participants' mental and physical health improved significantly (Dellasega & Haagen, 2004). An initial study by Mackenzie, Wiprzycka, Hasher and Goldstein (2007) found that, contrary to their own expectations, expressive writing did not improve caregivers' mental or physical wellbeing. In a follow-up study, the same authors, searching for an explanation for this initial finding, suggested that expressive writing, most effective following trauma, may not be so effective in reducing caregivers' stress because the caregivers are still in the midst of turmoil. Nevertheless, this second study by Mackenzie, Wiprzycka, Hasher, and Goldstein (2008) offered more positive findings, showing that caregivers who "wrote about their difficult situation with increasing honesty and complexity benefited from doing so" (p. 75). Importantly, the authors postulated that future research should consider modifying expressive writing instructions "to target hope and optimism" (p.76). This suggestion fits well with postmodern therapies, which avoid focusing on the problem-saturated story and related emotions. The study indicates that potential exists for using writing interventions effectively with caregivers and that further research is needed in this area.

#### *Others' Narratives: A Therapeutic Connection*

Sharing others' written stories may also have therapeutic value for caregivers. Nicholson (2009) offered a useful review of caregivers' narratives, claiming that they provide a helpful guide for individuals and families trying to negotiate the experience themselves. Two collections, *Voices of Alzheimer's: The Healing Companion: Stories for Courage, Comfort and Strength* (2007) and *Telling Tales about Dementia: Experiences of Caring* (2010), present stories written by those suffering from the disease and by caregivers. These poignant narratives are testimony to the capacity of humans to be courageous in the most challenging of situations, and to the fact that healing can be found in sharing others' stories. Mahy (2002) and Genova (2007) offer works of fiction that I have found immensely valuable in the way that they portray and normalise the rich kaleidoscope of human emotions evoked by this illness.

#### *Attachment Theory*

On a more theoretical level, attachment theory can provide a valuable framework for working with caregivers. Early on in my research, I hosted a TAG (The Attachment Group) meeting at my home and I was fascinated when a couple of the group members began discussing the centrality of attachment issues when caring for older parents. One group member spoke of the way in which the old patterns of attachment are amplified

in this new caregiver/cared-for relationship. This had not previously occurred to me, but I have now begun to consider my interactions with my mother and the way in which our respective attachment styles impact on our own and each other's wellbeing.

Surprisingly, there are a relatively limited number of studies in the area of attachment and dementia caregiving, and few data exist about "how differential attachment styles of dementia patients or relationship histories between carers and patients may affect the current caregiving relationship" (Magai & Cohen, 1998, p. 148). A small British study, which administered the Adult Attachment Interview (AAI) to 17 daughter caregivers of mothers with dementia, found that behaviours by daughters with insecure attachment styles and unresolved feelings concerning the past impacted negatively on their mothers (Steele, Phibbs, & Woods, 2004). Despite limitations, this study highlights the significance of attachment issues in the caregiving relationship and suggests the need for future research in this area. Other studies indicate that adult children caregivers with a secure attachment style demonstrate the most resilience in the face of the burden of caregiving (Crispi, Schiaffino, & Berman, 1997; Daire, 2002; Magai & Cohen, 1998).

Terry (2010) underlined the importance of considering attachment issues in the caregiving role, pointing out that if caregivers' fears are not expressed and managed, they can be devastating for both the caregiver and the dementia sufferer. For caregivers who have not had satisfactory relationships with their parents as children, the anticipation of becoming dependent again in old age, triggered by the caregiving experience, can bring "apprehension that dependency needs will once again not be met" (Terry, 2010, p. 21). Therapists may notice that caregiver clients engage in "projective identification," splitting off "deep-seated unmanageable feelings" and believing them to reside in the dementia patient (p. 23). Watching the decline of a close attachment figure with dementia has been a terrifying experience in many respects, and I am very conscious of how easy it is for me to transfer my own fears, anxieties, and anger onto my mother. Helping clients to understand and explore this dynamic could be immensely beneficial for both caregivers and parents.

## **Conclusion**

It is evident that caregivers may experience a wide variety of challenges and emotions, including grief, stress, anxiety, panic, depression, sadness, anger, resentment, uncertainty, guilt, and fear. They may also suffer due to deep-seated attachment issues and unconscious fears amplified by their caregiving role.

Counsellors need to consider a variety of interventions when working with caregivers, guiding them to appropriate sources of psychoeducational material, literature, online resources, and support groups. They need to acknowledge grief, support clients in their natural grieving processes, be aware of clients' meaning-making processes, and be open to exploring spiritual dimensions. While little empirical research exists as to the effectiveness of specific counselling interventions with caregivers, a number of approaches offer potential. These include client-centred and postmodern collaborative approaches focusing on client resilience, expressive arts therapies, writing activities, sharing others' narratives, and the understandings offered by attachment theory.

Autoethnography challenges familiar rules for judging research (Etherington, 2004). The five criteria for evaluating ethnography suggested by Richardson (2000a) are: "substantive contribution, aesthetic merit, reflexivity, impact, and expression of a reality" (p. 253). The value of my research is not for me but rather for the reader to determine. I can claim without hesitation, however, that this study truly reflects the expression of my reality, and that I have attempted to be consciously reflexive and self-aware throughout the research process.

The final research question is the easiest for me to address. Macaskie (2010) claimed that practitioner-based research can be transformative for the researcher. The process has indeed been "cathartic" (Ellis, 2004, p. 236), and I feel "transformed by the experience" (p. 254). Clichéd though it may seem, the research process has been one of agony and ecstasy. It has given me cognitive, emotional, and spiritual insights; it has challenged my integrity and my ethical codes, forcing me to examine the consequences of my writing (Medford, 2006). It has loaned me the luxury of self-indulgence in the form of time to read, contemplate the meaning of dreams, dabble in poetry writing, and correspond with overseas "gurus" in the field. It has connected me with a community of people I may never meet, but who grieve as I do.

### *Limitations*

Word and time constraints for this research have required me to be selective. The legitimacy and validity of research using one person's subjective experience is often called into question (Holt, 2003; Wall, 2008). Ideally, I might have conducted reflexive dyadic interviews with other caregivers, as proposed by Ellis (2004), to "provide external data that give contextual information to confirm, complement, or reject introspectively generated data" (Chang, 2008, p. 104). My inclusion of others'

perspectives from the literature has perhaps gone some way to mitigate this limitation. Parts of my own story have not been told for ethical reasons, and so certain emotions and issues are missing from my narrative. I have not differentiated between spousal and adult children caregivers in reviewing the intervention literature, nor have I distinguished between family caregivers who live in and those who provide care from further afield. Despite these omissions, and in harmony with postmodern beliefs about the impossibility of complete knowledge, I hope to have produced a “complex, thoroughly partial understanding of the topic” (Richardson, 2000b, p. 934). I hope to have demonstrated that it is possible to learn about the general from the particular (Wright, 2009) and to have provided some signposts for practitioners to draw upon in their future work with caregivers.

### *Future Directions*

By 2051, it is estimated there will be over 50,000 people in New Zealand with dementia (Perkins, 2004). It is crucial that we identify ways to help caregivers find healing and acceptance, and to reduce the negative effects of caregiving on family members (Acton, 2002). Research into the following areas could be enormously beneficial:

- The specific issues for caregivers among Māori, Pasifika, and Asian peoples, as well as new immigrants and Pākehā in Aotearoa New Zealand (Perkins, 2004). These might be best conveyed through personal narratives.
- The role of attachment in caregiving (Carpenter, 2001). It would be useful to determine whether caregivers who develop a deep understanding of their own attachment style and that of the AD sufferer experience reduced stress as a result.
- The effectiveness of using narrative or expressive writing interventions combined with future-focused, strengths-based, collaborative approaches to foster resilience in caregivers.

On completion of my own research, I read with interest that the British Association for Counselling and Psychotherapy has recently funded Dr Ruth Elvish, of the University of Manchester, to conduct a review of counselling and psychotherapy interventions with dementia caregivers, along with a qualitative project investigating caregivers' experiences (“Winners of research funding” 2010). These future research projects align well with the priorities I have already identified.

Above all, I hope my research will “generate stories from others” (Ellis, 2004, p. 310). Those who deal with the “exploding reality of how this disease unravels actual lives” (Shenk, 2007, p. ix) have much wisdom to share. A collection of narratives from

caregivers in Aotearoa New Zealand would undoubtedly contribute enormously to our understanding of the ways in which caregivers might be supported and sustained in their resilience, as well as to our sociological, cultural, psychological, and spiritual understanding of the shocks and aftershocks created by this disease.

### *Acknowledgement*

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### **Note**

1 Although not medically accurate, the terms Alzheimer's disease and dementia are used interchangeably in this work. For medical definitions of dementia and Alzheimer's disease, please refer to the work of Dr Chris Perkins, listed in the reference section.

### **References**

- Acton, G. J. (2002). Self-transcendent views and behaviours. Exploring growth in caregivers of adults with dementia. *Journal of Gerontological Nursing*, 28(12), 23–30.
- Acton, G. J., & Kang, J. (2001). Interventions to reduce the burden of caregiving for an adult with dementia: A meta-analysis. *Research in Nursing and Health*, 24, 349–360.
- Andrews, J. (2007). Honoring elders through conversations about their lives. In H. Anderson & D. Gehart (Eds.), *Collaborative therapy: Relationships and conversations that make a difference* (pp. 149–166). New York: Routledge.
- Attig, T. (1996). *How we grieve: Relearning the world*. New York: Oxford University Press.
- Berg, B. L. (2004). *Qualitative research methods for the social sciences*. Boston: Pearson.
- Bird, T. D. (1998). Genetic counseling. In *Alzheimer disease overview*. Retrieved April 22, 2010, from <http://www.ncbi.nlm.nih.gov/bookshelf/br.fcgi?book=gene&part=alzheimer>
- Boden, C. (1998). *Who will I be when I die?* Melbourne: Harper Collins Religious.
- Bolton, G. (2004). Introduction: Writing cures. In G. Bolton, S. Howlett, C. Lago & J. K. Wright (Eds.), *Writing cures: An introductory handbook of writing in counselling and therapy* (pp. 1–3). Hove: Brunner-Routledge.
- Bowater, M. (2009). Dreams as a source of creativity. *Counselling Today: Newsletter of the New Zealand Association of Counsellors*, 29(4), 33–36.
- Butcher, H., Holkup, P., & Buckwalter, I. (2001). The experience of caring for a family member with Alzheimer's disease. *Western Journal of Nursing Research*, 23(1), 33–55.
- Caldwell, R. L. (2005). At the confluence of memory and meaning: Life review with older adults and families: Using narrative therapy and the expressive arts to re-member and re-author stories of resilience. *The Family Journal*, 13(2), 172–175.



- Carpenter, B. D. (2001). Attachment bonds between adult daughters and their older mothers: Associations with contemporary caregiving. *Journal of Gerontology: Psychological Sciences*, 56B(5), 257–266.
- Carrubba, S. M. (2007). Teacher's pet. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 141–146). New York: LaChance Publishing.
- Chang, H. (2008). *Autoethnography as method*. Walnut Creek, CA: Left Coast Press.
- Cooke, D. D., McNally, L., Mulligan, K. T., Harrison, M. J. G., & Newman, S. P. (2001). Psychosocial interventions for caregivers of people with dementia: A systematic review. *Aging and Mental Health*, 5(2), 120–135.
- Crispi, E. L., Schiaffino, K., & Berman, W. H. (1997). The contribution of attachment to burden in adult children of institutionalized parents with dementia. *The Gerontologist*, 37(1), 52–60.
- Daire, A. (2002). The influence of parental bonding on emotional distress in caregiving sons for a parent with dementia. *The Gerontologist*, 42(6), 766–771.
- de Jong, P., & Berg, I. K. (2008). *Interviewing for solutions* (3rd ed.). Belmont, MA: Thomson Brooks/Cole.
- Dellasega, C., & Haagen, B. (2004). A different kind of caregiving support group. *Journal of Psychosocial Nursing and Mental Health Services*, 42(8), 46–55.
- Dempsey, M., & Baago, S. (1998). Latent grief: The unique and hidden grief of carers of loved ones with dementia. *American Journal of Alzheimer's Disease and Other Dementias*, 13, 84–91.
- Ellis, C. (2004). *The ethnographic I: A methodological novel about autoethnography*. Walnut Creek, CA: Altamira Press.
- Etherington, K. (2004). *Becoming a reflexive researcher: Using ourselves in research*. London: Jessica Kingsley.
- Foucault, M. (1997). Technologies of the self. In P. Rainbow (Ed.), *Ethics: Subjectivity and truth* (pp. 223–252). London: Penguin.
- Genova, L. (2007). *Still Alice*. New York: Pocket Books.
- Hartman-Stein, P. E. (2010). They can be like a sun. *PLTC Newsletter*, 24(2), 13–16.
- Hodgson, H. (1998). *The Alzheimer's caregiver: Dealing with the realities of dementia*. Minneapolis, MN: Chronimed Publishing.
- Holley, C. K., & Mast, B. T. (2009). The impact of anticipatory grief on caregiver burden in dementia caregivers. *The Gerontologist*, 49(3), 388–389.
- Holt, N. L. (2003). Representation, legitimation, and autoethnography: An autoethnographic writing story. *International Journal of Qualitative Methods*, 2(1), 1–22.
- Htay, U. H. (2010). We learn to enter her world. In L. Whitman (Ed.), *Telling tales about dementia: Experiences of caring* (pp. 58–64). London: Jessica Kingsley.
- Jackson, D. (2010). The most difficult decision of my life. In L. Whitman (Ed.), *Telling tales about dementia: Experiences of caring* (pp. 52–57). London: Jessica Kingsley.

- James, O. (2009). *Contented dementia* (2nd ed.). London: Vermilion.
- Jeffery, S. (2010). A very important moustache. In L. Whitman (Ed.), *Telling tales about dementia: Experiences of caring* (pp. 117–121). London: Jessica Kingsley.
- Jones, S. H. (2005). Autoethnography: Making the personal political. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (3rd ed.; pp. 763–792). Thousand Oaks, CA: Sage Publications.
- Kapleau, P. (1998). *The Zen of living and dying: A practical and spiritual guide*. Boston: Shambhala.
- Kumar, S. M. (2005). *Grieving mindfully*. Oakland, CA: New Harbinger Publications.
- Lindgren, C. L., Connelly, C. T., & Gaspar, H. L. (1999). Grief in spouse and children caregivers of dementia patients. *Western Journal of Nursing Research*, 21, 521–537.
- Macaskie, J. (2010, May). *Dreaming the research process*. Paper presented at the British Association for Counselling and Psychotherapy, London.
- Mackenzie, C. S., Wiprzycka, U. J., Hasher, L., & Goldstein, D. (2007). Does expressive writing reduce stress for family caregivers of older adults? *The Gerontologist*, 47(3), 296–306.
- Mackenzie, C. S., Wiprzycka, U. J., Hasher, L., & Goldstein, D. (2008). Seeing the glass half full: Optimistic expressive writing improves mental health among chronically stressed caregivers. *British Journal of Health Psychology*, 13(1), 73–76.
- Magai, C., & Cohen, C. I. (1998). Attachment style and emotion regulation in dementia patients and their relation to caregiver burden. *Journal of Gerontology: Psychological Sciences*, 53(3), 147–154.
- Mahy, M. (2002). *Memory* (2nd ed.). London: Collins Flamingo.
- Mataira, P. (2003, June). *Māori evaluation research, theory, and practice: Lessons for native Hawaiian evaluation studies*. Paper presented at the Evaluation Hui, Kamehameha, Hawaii.
- McLeod, J. (2003). *Doing counselling research* (2nd ed.). London: Sage.
- Medford, K. (2006). Caught with a fake ID: Ethical questions about slippage in autoethnography. *Qualitative Inquiry*, 12(5), 853–864.
- Nation, I. (2007). Alzheimer's, artichokes, and forgiveness. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 87–89). New York: LaChance Publishing.
- Neimeyer, R. A. (1998). *Lessons of loss: A guide to coping*. New York: McGraw-Hill.
- New Zealand Association of Counsellors. (2002). *Code of ethics: A framework for ethical practice*. Hamilton, NZ: Author.
- Newman, R. (2010). Surely the world has changed. In L. Whitman (Ed.), *Telling tales about dementia: Experiences of caring* (pp. 145–151). London: Jessica Kingsley.
- Nicholson, K. (2009). Carers' narratives: Finding dementia with Lewy bodies experiences. *Australasian Journal on Ageing*, 28(4), 177–181.
- O'Dell, C. (2007). Mothering mother. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 3–6). New York: LaChance Publishing.

- Peller, J., & Walter, J. (1993). Celebrating the living: A solution-focused approach to the normal grieving process. *Family Therapy Case Studies*, 7(2), 3–7.
- Pennebaker, J. W. (1993). Putting stress into words: Health, linguistic and therapeutic implications. *Behaviour Research and Therapy*, 31(6), 539–548.
- Penwarden, S. (2009). Visionary words. *New Zealand Journal of Counselling*, 29(2), 1–11.
- Perkins, D. C. (2004). *The New Zealand dementia guide*. Auckland, NZ: Random House.
- Richardson, L. (2000a). Evaluating ethnography. *Qualitative Inquiry*, 6(2), 253–255.
- Richardson, L. (2000b). A method of inquiry. In N. K. Denzin & Y. S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed.; pp. 923–948). Thousand Oaks, CA: Sage.
- Rom, R. (2007). Another dementia. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 231–234). New York: LaChance Publishing.
- Roos, S. (2002). *Chronic sorrow: A living loss*. New York: Brunner-Routledge.
- Sanders, S., Ott, C. H., Kelber, S. T., & Noonan, P. (2008). The experience of high levels of grief in caregivers of persons with Alzheimer's disease and related dementia. *Death Studies*, 32, 495–523.
- Shenk, D. (2003). *The forgetting: Alzheimer's: A portrait of an epidemic* (2nd ed.). London: Flamingo.
- Shenk, D. (2007). Foreword. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage comfort and strength* (pp. ix–x). New York: LaChance Publishing.
- Silverberg, E. (2007). Introducing the 3-A grief intervention model for dementia caregivers: Acknowledge, assess, and assist. *Omega*, 54(3), 215–235.
- Sörensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist*, 42(3), 356–372.
- Steele, H., Phibbs, E., & Woods, R. T. (2004). Coherence of mind in daughter caregivers of mothers with dementia: Links with their mothers' joy and relatedness on reunion in a strange situation. *Attachment and Human Development*, 6(4), 439–450.
- Sweeting, H. N. (1991). *Caring for a relative with dementia: Anticipatory grief and social death*. Unpublished doctoral thesis, University of Glasgow, Glasgow.
- Terry, P. (2010). Dementia: A “death of the mind.” *Therapy Today*, 21(8), 20–24.
- The Healing Project (Ed.). (2007). *Voices of Alzheimer's: The healing companion: Stories for courage comfort and strength*. New York: LaChance Publishing.
- Valenzuela, D. M. J. (2009). *It's never too late to change your mind: The latest medical thinking on what you can do to avoid dementia*. Sydney: ABC Books.
- Van Dyck, B. (2007). Losing my father. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 91–96). New York: LaChance Publishing.
- Waelde, L. C., Thompson, L., & Gallagher-Thompson, D. (2004). A pilot study of a yoga and

- meditation intervention for dementia caregiver stress. *Journal of Clinical Psychology*, 60(6), 677–687.
- Wall, S. (2008). Easier said than done: Writing an autoethnography. *International Journal of Qualitative Methods*, 7(1), 38–53.
- Weingarten, K. (2010). Hope in a time of global despair. *New Zealand Journal of Counselling*, 30(1), 1–14.
- Whitman, L. (Ed.). (2010). *Telling tales about dementia: Experiences of caring*. London: Jessica Kingsley.
- Williams, K. (2007). The stolen goodbye. In The Healing Project (Ed.), *Voices of Alzheimer's: The healing companion: Stories for courage, comfort and strength* (pp. 13–15). New York: LaChance Publishing.
- “Winners of research funding”. (2010). *Therapy Today*, 21(8), 43.
- Wright, J. K. (2009). Autoethnography and therapy writing on the move. *Qualitative Inquiry*, 15(4), 623–640.

### **Appendix 1: Resources for Caregivers**

#### **[www.alzheimers.org.nz](http://www.alzheimers.org.nz)**

This website includes almost all the information needed about services available for AD sufferers and caregivers in Aotearoa New Zealand. It provides links to a large number of health and social services organisations that are very important for caregivers, as well as links to a number of overseas government websites that provide comprehensive psychoeducational material. Contact details for local support groups in Aotearoa New Zealand are also listed.

#### **[www.tepou.co.nz](http://www.tepou.co.nz)**

This website is relevant to counsellors and caregivers in Aotearoa. It has downloads available of publications by Te Pou, Mental Health Programmes Limited. The one entitled “Talking Therapies for Older Adults” offers clear guidelines for working therapeutically with the elderly and those with dementia. A list of contacts for appropriate support services and numerous relevant publications is provided.

#### **[www.specal.co.uk](http://www.specal.co.uk)**

Although this website provides information for British caregivers, it is worth downloading a copy of the “Important Information Sheet,” which gives excellent guidelines for caregivers conversing with a person with dementia. Counsellors could read this sheet if they are unfamiliar with this area as it provides extremely practical advice for communicating well with people with dementia. (This website has evolved out of the book *Contented Dementia* listed below.)

[www.theforgetting.com](http://www.theforgetting.com)

This website provides a gateway to an online family caregiver support group, which may appeal to some caregivers, especially those who are unable or reluctant to attend local support groups. Caregivers can register free of charge and read and post comments. The discussions cover a range of issues of real relevance to caregivers, and the “Alzheimer’s List,” as it is termed, provides access to a supportive community of people.

*Contented Dementia*, by Oliver James, published by Vermilion, 2009

This book is an invaluable guide for anyone caring for a family member with dementia. It explains an alternative method, invented by Penelope Garner, to help caregivers communicate easily with their family member with AD. Garner uses a very clever analogy of a photograph album to explain the workings of the brain and memory, and the changes that occur for someone with dementia. Through using this analogy, she suggests practical ways to diminish distress for people with dementia. I constantly keep her analogy and methods in mind when communicating with my mother. I highly recommend this book as an indispensable addition to counsellors’ libraries.

*The New Zealand Dementia Guide*, by Chris Perkins, published by Random House, 2004

This comprehensive guide was written by a New Zealand doctor who initially worked as a general practitioner before specialising in geriatric psychiatry. It provides both an immensely practical and a very sensitive guide for dementia caregivers. Perkins covers a wide number of pertinent issues ranging from spiritual matters, to legal guidelines about Enduring Power of Attorney, to ways to stop someone with dementia from driving. The book includes an extensive glossary of medical terms, useful contacts for caregivers, and guidance as to financial assistance available.

*It’s Never Too Late to Change Your Mind*, by Dr Michael J. Valenzuela, published by ABC Books, 2009

This book presents the latest medical thinking about the possibility of preventing dementia. Valenzuela explains what is known about protective links, and makes clear health and life-style recommendations. This is an inspirational, hopeful book, written by a medical doctor who is able to convey complex concepts in a way that is readily accessible to lay people. He combines his medical knowledge with compassion and optimism, and I believe this book provides a wonderful resource for caregivers concerned about genetic links as well as for those who want to inform themselves about current medical thinking.