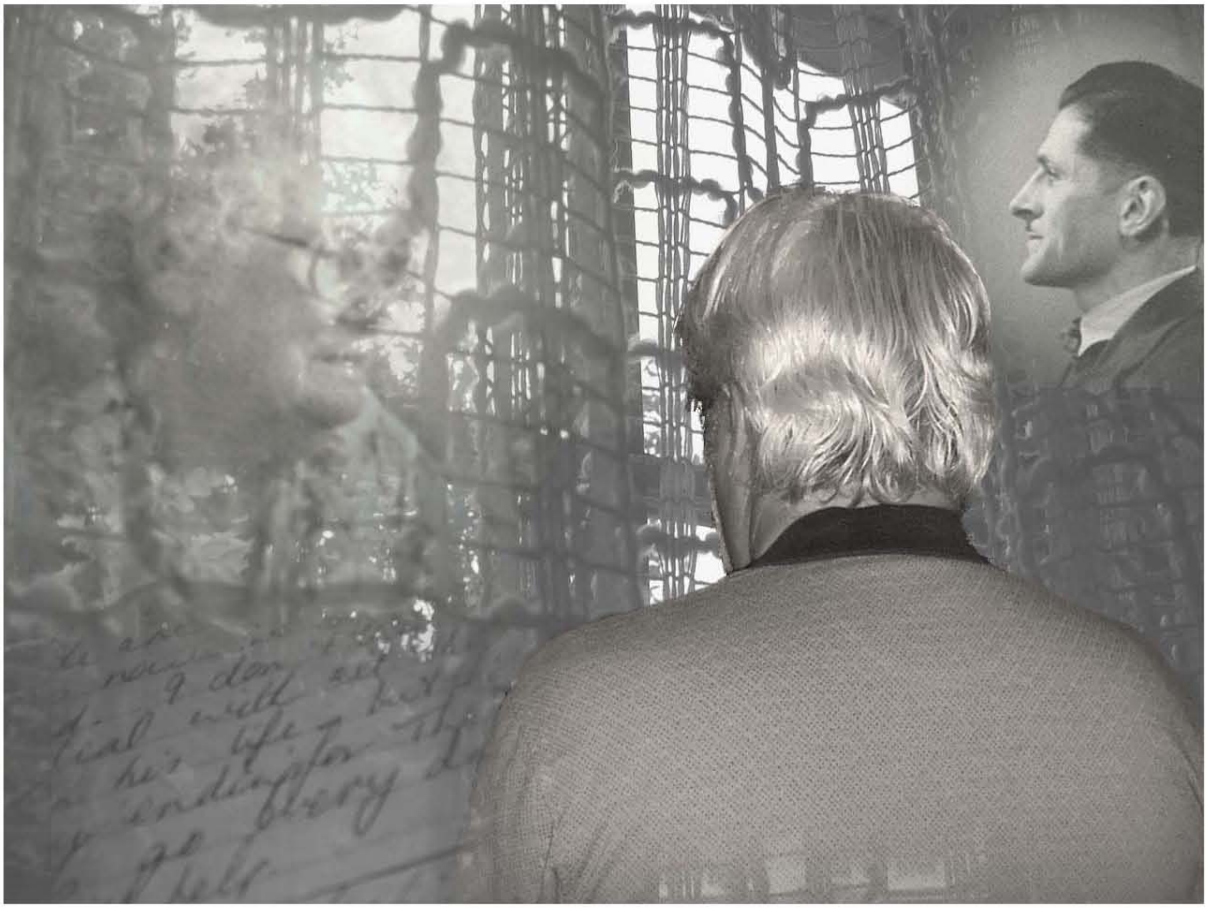
LOOKING THROUGH MY GRANDMOTHER'S LACE CURTAINS:

WRITING TO RECLAIM IDENTITY IN DEMENTIA



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ELLEN B. RYAN,
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AND ANN P. ANAS

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EXPLANATION OF TITLE

Right now, I feel as if I am sitting in my grandmother's living room, looking at the world through her lace curtains. From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world. There are large knots in the curtains and I cannot see through them. There is a web of lace connecting the knots to each other, around which I can sometimes see. However, this entire filter keeps shifting unpredictably in the wind.

Taylor 2007: 16

* * *

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* * *

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FOREWORD

Lisa Snyder

On a Wednesday morning, ten individuals with dementia settle into the weekly ritual of finding a seat within the circle of chairs that form the sanctity of their support group. For an hour and a half, they share their thoughts and feelings about living with memory loss, and they unfold to one another the rich contours and patterns of their lives. They have the experience of dementia in common, but in this group, it does not wholly define them. Rather, dementia sits in the context of their personal and social identities. Through their interest in one another as whole human beings, they affirm and value each other's selfhood and build a community of caring and camaraderie.

Bill's profession was writing. As a journalist and editor, he reported on international events and explored salient topics; as a poet and beloved husband, he has written countless poems for his wife on the occasions of her birthday, their wedding anniversary, and other milestone events. As a man with dementia he suffers from profound aphasia such that words escape him now – fluttering out of his reach before he can grasp them long enough to utter them. Writing is a chore. Alzheimer's disease has robbed him of his memory for spelling, and typing is nearly impossible as he struggles to find the keys that he once pressed effortlessly.

In Bill's increasingly disorienting mind, his poetry lives on. Deprived of his verbal and written language abilities early on in the course of dementia, he composes in thoughts that often now remain private. He is very attentive in the support group, engaged by his friends, their comments, their concerns. He nods, laughs, and at times, tears well in his eyes; he feels deeply and fully. He can no longer verbally contribute a great deal to the group, but at the end of each meeting, he selects one of his poems from the bound collection of his works. He gives it to me to read as a closing ritual. Bill is our poet; his social identity is preserved by a group of people who will not allow dementia to take it away from him.

One week Bill comes to the support group anxious and animated. His one-word sentence speaks the depth of his painful predicament. Anniversary. It is their wedding anniversary, and it is apparent that he is frantic to maintain the tradition of writing his wife a poem, but he no longer can manage the functional tasks required to put pen to paper or type his prose. He produces from his pocket and places on the table, a small game comprising over one hundred words, individually printed on small magnetic squares. Largely through mime, he gathers his friends around the table. He begins to point to words he wants to use to compose a poem. Through his expressions of disapproval or pleasure, the group deciphers his desired message, transcribes it onto a blackboard for his review and gestured editing, and his selected words gradually take the shape of a poem.

My love
You are gorgeous.
There is so much beauty in my life with you.
I have visions of
flowers
forests
earth
petals
gardens
trees
and the sun.
I treasure you.
I feel so much pleasure in my life with you.

Bill's infectious and grateful smile is radiant and a few days later, he presents his anniversary poem to his wife.

Writing is connection and creative expression as well as an avenue for affirming and maintaining selfhood, value, and meaning in the face of a disease that threatens the cornerstones of one's personal and social core. In their work, ***Writing to Reclaim Identity in Dementia***, authors Ryan, Bannister, and Anas elegantly explore quotes from persons with dementia that lead us to a greater discovery of the way in which the act of writing not only forms bridges between persons with dementia and others, but maintains the bridges to their own sense of self. Drawing on the work of Social Constructionists, they explore threats to selfhood imposed by dementia. Threads of loss weave through the quotes as writers with dementia illuminate their subjective experience of devaluation and isolation. In contrast, the act of writing or narrating one's story into text can be empowering for the writer and informative for the reader. Maintaining and expressing selfhood becomes a collaborative process whereby the writer and the reader co-construct a continuity of selfhood that endures through the transformative process of dementia.

Some years after that day in the support group Bill's advanced symptoms require a move into a long-term care home. Now, completely unable to communicate verbally, he seeks ways to communicate who he is to staff. In the years prior to his advanced aphasia, I interviewed Bill about his life and experience of Alzheimer's. His transcribed words ultimately became a chapter in the book *Speaking Our Minds*. Bill carries the book with him to his new residence. He opens it to his chapter and presents it to staff to read. Pointing to the text, he emphatically states a singular word, "me!" that implores staff to learn about, and help to maintain, the construction of his threatened selfhood.

Surely just as Bill found continued affirmation through the written narrative of his thoughts, so can we work to ensure that the voices of so many persons with dementia are documented in texts that build the bridges to our shared humanity. We connect, we interrelate, we belong when we are afforded the opportunity to communicate – to define and express our selfhood while being acknowledged and understood by another. Kudos to Ellen Ryan, Karen Bannister, and Ann Anas for their excellent work in illuminating the power of written narrative in the expression and construction of selfhood and for providing tools for facilitating the writing process with persons with dementia. There are many more promising writers with messages waiting to be read.

Biography

Lisa Snyder, MSW, LCSW is a clinical social worker at the Shiley-Marcos Alzheimer's Disease Research Center at the University of California, San Diego, where she has counselled persons with dementia and their families since 1987. She is author of the book *Speaking Our Minds – Personal Reflections from Individuals with Alzheimer's* and editor of the international quarterly newsletter *Perspectives – A Newsletter for Individuals with Alzheimer's or a Related Disorder.* Her ongoing work is supported by a grant through the National Institute on Aging (AGO5131).

* * *

SUMMARY

The social needs of individuals with dementia are often not addressed. Impoverished social interactions can place the person at risk of being negatively positioned by others and without means to assert their unique identity. In seeking strategies to help these individuals reclaim their social and personal identity, we have turned to an analysis of published memoirs by writers with dementia. Selected quotations show that through writing it is possible for an individual with dementia to engage with others in a dialogue that creates meaning and forms identity. Writing renews an individual's status as a contributing social partner, provides new and positive roles, and introduces empowerment and control. The memoirs demonstrate that dementia can be a time of growth and that authors with dementia construct and project positive new identities, which are full expressions of personhood.

INTRODUCTION

"Who will I be when I die?" asks Christine Bryden (1998) in her book about living with dementia (progressive cognitive deterioration due to Alzheimer's and other related neurological diseases). With this question, she names one of our greatest fears – losing our sense of self.

Individuals with dementia typically experience deficits in memory, language, and other abilities. These deficits impair social functioning: conversations with others can be laborious, the paternalistic behaviors of others can be stifling, and awareness of declining ability can be distressing. It is common for individuals with dementia to withdraw from social activity.

Social isolation has negative consequences for the expression and exploration of identity. Diagnosis can mean diminished power in relationships, fewer social roles, and fewer satisfying social interactions. These consequences bring difficult issues that must be resolved for continued emotional well-being. However, social isolation provides little opportunity to assert and explore one's social identity.

Researchers have begun to look at the social needs of individuals with dementia. Intervention strategies designed to affirm personhood often focus on engaging the person in oral storytelling. One possible disadvantage of this strategy is that the social dialogue, as well as the time at which it occurs, is most often directed by the conversation partner (as interviewer) and not explicitly by the individual with dementia. Thoughts and feelings come in response to questions, and only if the individual is able to access the right words at the moment of interaction.

In previous articles we have suggested that writing is a means of communication that provides many benefits to people with acquired disability: an increased level of control and empowerment, as well as more time and greater flexibility for constructing thoughts (Ryan 2006; Ryan, Spykerman, and Anas 2005c).

In this book, we expand upon these benefits and focus on the role of writing in reclaiming social identity. In writing about their experiences, thoughts and feelings, individuals with dementia engage in a social dialogue with others that affirms their past, present and future identities as unique, intriguing and contributing persons. Writing enables an individual with dementia to explore and express a renewed social identity that is built upon positive traits, roles and personal control.

We examine the concept of social identity, the social condition of individuals with dementia and the particular ways writing can assist in reclaiming social identity. For this purpose, we have selected quotations from thirteen published memoirs by nine individuals with dementia. These works are listed in chronological order in the Appendix and marked with an asterisk in the reference section. We have analyzed these texts for thoughts explicitly relevant to identity and/or the process of writing.

* * *

IDENTITY ACROSS THE LIFESPAN: PERSONAL AND SOCIAL

Throughout an extensive history of multidisciplinary exploration, several key concepts about the construct ‘identity’ have emerged. Identity encompasses the set of beliefs an individual holds about him or herself (Brehm, Kassin, and Fein 2002). It is intuitively and popularly thought to have elements of both stasis and fluidity, and consequently to be plural. The core, or stable sense of self, has been described as an unconscious experience of who one is, which is formed and shaped through early interactions with parents and others of significance, or present at birth (Whitbourne 2001). Many theorists refer to this core and stable sense of identity as the ‘personal’ self (Gergen 1971; Hogg and Abrams 1988; Sabat and Harré 1992).

The ‘personal self’ is thought to be accompanied by a set of fluid selves (or personae), which collectively comprise an individual’s social identity. Manifested in relations with others, social identity is derived from the circumstances, environment and society in which one lives. For example, roles, attributes and personal beliefs about one’s appearance can shift through the life course and can depend on career, family, social status and cultural beliefs, among other things. Social identity is “the individual’s knowledge that he belongs to certain social groups together with some emotional significance to him of the group membership” (Hogg and Abrams 1998: 7). Social and personal identity are not necessarily distinct entities, but can be considered opposite ends of a continuum, with each influenced by the other and by outside forces (Basting 2003b).

According to Social Constructionism, a social theory of identity, an individual communicates various personae to others; and each must be accepted socially before it can come to exist (Sabat and Harré 1992). Thus, we are not solely who we think we are, but also who others believe us to be; we come to learn about ourselves through the reactions of others

(Gergen 1971). Consequently, we are all in danger of being socially positioned in unfavorable ways; that is, to having our desired projected selves rejected and other undesirable selves thrust upon us. This marks the process of marginalization and is of key importance to Positioning Theory, an offshoot of Social Constructionism that explores the ways in which "psychological phenomena are produced in discourse" (Harré and van Langenhove 1999: 4).

According to Positioning Theory, social identity is created through discourse with others; "identity is not an essence but a social manifestation that is created and re-created through language acts, social patterns and human relationships" (Ray 2000: 21). It is very much a cultural construct (Basting 2003b).

Our identity is "a map with moveable boundaries that we negotiate with others" (Shadden 2005: 215). Consequently, social interaction is necessary in the ongoing construction of self. Identity theorists suggest we need to continually update our social identities in the face of changing circumstances; this is integral to life course development. According to Erik Erikson (1950; 1998), an individual faces an identity challenge or crisis at each stage of the life course. Proper resolution of the identity crisis is necessary for emotional growth and continued well-being. If identity is seen as a continuum, social interaction is as important for the maintenance of personal identity as it is for social identity.

Erikson's theory of life course development consists of eight stages – from infancy to late adulthood, with a ninth stage added and published posthumously. For example, middle adulthood is characterized by generativity versus stagnation. In this stage, the primary objectives are to guide others and to contribute to society. This gives way to ego integrity versus despair in late adulthood, where the primary motivation is examination and acceptance of the life as it was lived (Erikson 1950; Erikson and Erikson 1998). The ninth phase was added to account for particular challenges facing those in the eighth and ninth decades of life. This latest stage is primarily occupied with finding existential peace and achieving spiritual resolution (Erikson and Erikson 1998).

Across the lifespan, adaptation involves recycling through earlier stages when serious life changes occur, such as the onset of cognitive impairment.

Susan Krauss Whitbourne (2001) has proposed a dynamic theory for how this process of identity change occurs. Identity Process theory is based on the Piagetian concepts of assimilation and accommodation. When individuals confront a new event, they first try to assimilate it into their sense of self. If their sense of self is in conjunction with this new event, assimilation is successful and the identity in its current form remains. However, if the new event is significantly discordant with the existing identity, the identity shifts to accommodate the new information.

Changes in physical appearance and cognitive functioning can trigger the accommodation and assimilation process in adulthood. The Multiple Threshold Model proposes that individuals pass through various stages or thresholds in adulthood when different parts of the body are perceived as 'old' (Whitbourne 2001). For example, the greying of hair presents a threshold, easily crossed by some but very difficult for others. As individuals cross a threshold, they are reminded of their aging; the process of accommodation and assimilation is triggered in order to adjust identity accordingly. Social interaction with others is integral to the process of adapting social identity; validation from others is necessary for the enactment of new personae.

Diagnosis in older age of a life-changing chronic progressive illness like dementia is a powerful trigger for the process of assimilation and accommodation. It is a time of 'biographical disruption' when "normal social structures and roles of reciprocity and support are disrupted" (Hunt 2000: 88). Coping with a diagnosis involves learning to live within the boundaries of declining abilities, to take on new roles (such as that of patient) and to respond to new and negative perceptions held by others. For a terminal illness, like progressive neurological impairment, it also means confronting death. Specifically, individuals with dementia face loss of status as a competent social partner, loss of social and familial roles, declining abilities, and changing mood. As a consequence, individuals with dementia can come to live in social isolation, at continual risk of being positioned by others in an unfavorable light. It is a time of ‘biographical disruption’ when “normal social structures and roles of reciprocity and support are disrupted” (Hunt 2000: 88).

◆

METHODOLOGICAL APPROACH

Memoirs written by individuals with dementia tell us about the personal experience of living with progressive neurological impairment. These personal narratives are told with a distinct confidence that challenges popularly held beliefs about lack of insight.

In a 2003 study, Anne Davis Basting examined three books written by individuals with dementia (Davis 1989; Henderson 1998; McGowin 1993). Her work, similar to ours, examined views of the self within narratives of Alzheimer's and raised questions regarding the impact of a diminished memory on identity. Basting concluded that selfhood is more than memory; rather self is "forged on a continuum of memory and creativity that exists in a social context" (Basting 2003b: 97). Expanding upon Basting's point, we examine the social context of individuals living with dementia and, more specifically, resultant changes and challenges in social identity.

This study is driven by the question of how writing has served authors with dementia. We have analyzed each of thirteen memoirs, extracting quotations relevant to changing social identity and/or the process of writing, with our emphasis not on the words chosen but the observations behind them. The publications represent the full known chronological range of writings by individuals with dementia from 1993 to 2007. These texts were written by nine individuals, with two books each by two authors (Bryden and DeBaggio) and three articles by a single author (Truscott). The three texts analyzed by Basting are included here.

We acknowledge that memoir writers are exceptional individuals, but their insights document the diversity of the lived experience of dementia and ways in which people can reclaim identity as a complete person despite distressing symptoms. We also acknowledge that the memoirs raise questions of authorship. Many of the writers examined here did have help from others in completing the book and the narrative itself is usually ‘cleansed’ of the disease (sentence, word and thought structure remains essentially coherent) (Basting 2003b). We contend that issues of authorship are less important when examining this work for the thoughts inherent to it than when examining it for form or literary style. Writing, because it embraces the editor, is an exceptional medium for communicating thoughts.

For each text, one author of this essay selected a lengthy set of relevant quotations after which a second reader read the text for additional quotations representing new thoughts. The final selection of quotations was based on agreement among the three authors. In addition to quotations in the text, the richness of the memoirs is displayed through a series of tables covering the main themes.

* * *

THE CHANGING SELF

> *I want to shout. I want to raise some hell. I want to be somebody I'm not* (Henderson 1998: 17).
>
> *I am an empty vessel into which I throw a hand and a half of pills twice a day, and I desperately want the pills to reconstruct me* (Taylor 2007: 75).

Loss of Status as a Competent Social Partner

Dementia usually attacks the memory centre of the brain initially and then moves across other areas responsible for language, vision, movement and judgment (Snyder 2000; Whitbourne 2001). These impairments can manifest themselves in losses in recent memory, periods of mental confusion, reduced ability to assess risk, hallucinations, depression and insomnia – among other symptoms. Language deficiencies make oral communication challenging, word-finding and memory difficulties disrupt fluent speech and decrease one's confidence in conversation. Impaired vision, judgment and emotional disturbance similarly restrict one's power and ability in social interactions.

We live in a society that places great value on cognitive ability and the able-bodied, such that individuals with disability are often cast into the darkness of stereotypes and lowered expectations (Post 2000; Snyder 2000).

Able-bodied people tend to view individuals with disability as a source of shame, guilt and fear, to be approached with apprehension, benevolence, condescension, and/or curiosity (Fox and Giles 1996; Gallois 2004; Killick and Allen 2001; McBryde Johnson 2005; McColgan, Valentine and Downs 2000; Ryan, Bajorek, Beaman and Anas 2005a). It would appear that negative stereotypes lead people to become apprehensive and unsure in the presence of 'different or diseased people', and to alter their style of communication; disease labels carry perceptions of incompetence (Shadden

2005). See Table 1 for an extensive list of quotations from the dementia writers concerning identity problems.

> *Another really crazy thing about Alzheimer's, nobody really wants to talk to you any longer. They're maybe afraid of us* (Henderson 1998: 18).
>
> *Some friends and family seem to fear coming close to us to touch our true spirits. Perhaps they are uncomfortable, because they know instinctively that we are now different and they believe that their relationship with us has changed* (Truscott 2004b: 276).
>
> *I have become keenly aware of a patterned response from some individuals as soon as they find out I have Alzheimer's disease. They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility* (Taylor 2007: 152).

In particular, popular constructions of 'dementia sufferer' engage perceptions of incompetence. Common stereotypes include 'loss of self' – which suggests the individual is a vacant vessel and no longer 'a person' of coherence; and 'holy innocent' – which suggests the individual is like a child in need of continual care (Cohen-Mansfield, Parpura-Gill and Golander 2006; McColgan et al. 2000). It is also believed that due to memory impairments an individual's sense of self cannot continue to be entirely intact (Basting 2003b). These perceptions then create impoverished social interactions.

> *Isolation is a real problem for us. Many of us feel that some people even think dementia is contagious! We don't see many friends any more. It seems as if people treat us differently now, because they know we have dementia, and they don't know what to do. Maybe they are worried about us saying something odd or doing something*

> *bizarre? Often we feel like we are being watched in case we do the wrong thing* (Bryden 2005: 121).
>
> *I am becoming more and more withdrawn. It is so much easier to stay in the safety of my home, where Stella treats me with love and respect, than to expose myself to people who don't understand* (Rose 1996: 32).

Kitwood (1990; 1997) described the treatment of individuals with dementia as malignant psychology, the tendency of caregivers to treat individuals with dementia in ways that diminish their skills and capacities as human beings, thereby creating excess social disability (a position of disempowerment within social frameworks, which for individuals with dementia often means isolation) (Kitwood 1990; 1997; Kitwood and Bredin 1992). According to Kitwood (1990; 1997), examples of malignant psychology include treachery, disempowerment, infantilization, intimidation, labeling and stigmatization. Attempts to assert oneself positively, such as in projecting a persona marked by confidence, are likely to be misunderstood and rejected. The ability of persons with Alzheimer's disease to position themselves as possessing valued social identities is compromised by the malignant positioning of others – they often mainly receive support for diminished personae like 'patient' and 'dysfunctional person' (Sabat, Napolitano, and Fath 2004).

Furthermore, impoverished social interactions reduce one's access to opportunities for self-assertion in communication with another person. Caregiver-patient conversations may become reduced to addressing the tasks of caregiving – such as "here is your lunch" and "today we are going to the doctor." Without constructive interaction, individuals are not only stalled in the process of expressing a social identity and counteracting those personae thrust upon them, but also in working through the meaning of the changes. For example, losses of social and familial roles, as a consequence of the disease, require emotional resolution and understanding. As has been suggested by Social

Constructionism and Positioning Theory, people usually rely on positive dialogue with others to find this kind of resolution or meaning.

Loss of Social and Familial Roles

Our society has a way of defining people according to the roles that they play in life (Hunt 2000). Like stereotypes, roles serve the function of organizing and providing information from which to begin interactions (Bruce 2004). Diagnosis immediately imposes the role of 'patient' and with this come the connotations of 'incompetence,' 'disability,' 'need of care,' 'helpless' and so forth. For diagnosed individuals, these labels may be in sharp discord with how they see themselves, making social interactions stagnant and frustrating.

> *Thou, yours truly, has started to become an It. Of necessity, my caregivers would argue, but nonetheless an It. The same words are used to represent me – Richard, Dad, Grandpa, my husband – but what follows does not refer to who I think and feel I am. My behavior is treated as something apart from me. 'It's not him, it's the disease.' Unfortunately, I am both, and to the extent the disease has altered my behavior and thinking, it has altered who I am* (Taylor 2007: 150-151).

Dementia also affects an individual's ability to function within a working environment where losses in memory, communication and cognitive ability can often be detected in job performance. Needing to give up one's career – the hallmark of who we are in many respects – can represent a terrifying trauma that elicits feelings of grief. The individual may suffer lowered self-esteem and depression, made worse by a dramatic change in daily routine that brings an excess of rumination time.

> *It's depressing to think you might not be able to work again; that your days as a productive member of society might be over* (Lee 2003: 37).

> *I told no one else that I had stopped working. I felt guilty that I could not function and was ashamed of my loss of capacities* (McGowin 1993: 68).
>
> *Sometimes I feel very uneasy about the whole thing, that I should be out making money or I should help people more. I just feel so darn useless at times. I just feel a sense of shame, in a way, for being so unable to do things, and so dense* (Henderson 1998: 18).

The usefulness of the self is very much equated with a role within society (Basting 2003b).

Individuals with dementia may also lose their status within the family structure, as they come to be represented not as caretaker or parent but as care-receiver. The impact of dementia on marriage is an area with little research. Within the romantic or marital relationship both people must recognize the changing dynamic of the relationship; equality shifts when one person occupies the role of caregiver and directs daily activity (see Wright, 1993). This can be troubling for both parties.

> *Having always been the outspoken extroverted pivotal center of both my family and group of friends, I was now reluctantly in the non-contributing purgatory of the early diagnosed* (McGowin 1993: 67).
>
> *During this illness our roles have changed. Suddenly she is not only the wife I have loved, but now she is also my caregiver. She has to guide me through daily living, as I have become a care-receiver* (Davis 1989: 22).

Loss of roles within the family unit also means that important chores, such as cleaning the house or managing the cheque book, are no longer placed in the hands of the individual. This decreasing control over daily activities can reinforce caregiver expectations in ways described by Kitwood's concept of malignant psychology. That is, declining abilities beget treatment by caregivers that involves domination of daily routine; this leaves individuals with few opportunities for self-assertion. Because we all tend to fall to the level of expectations of others, individuals with dementia may live up (down) to the standards set for them, perpetuating a cycle of lived-expectation characteristic of excess social disability (Kitwood 1990; Kitwood and Bredin 1992; Orange, Ryan, Meredith, and MacLean 1995; Ryan, Byrne, Spykerman, and Orange 2005b).

Feelings in Social Situations

Until recently, little research addressed how declines in memory, language, and cognition affect social interactions and how mood in dementia is affected by the quality of social interactions. Kitwood, Sabat and Killick have been examining the social lives of individuals with dementia in an effort to emphasize personhood and call attention to possible misunderstanding when it comes to interacting with dementia sufferers. Their analyses begin to tease apart biological symptoms and social consequences; this feat is necessary but challenging as the etiology of dementia is not fully understood (Lyman 1998).

From our review of dementia memoirs, we have identified several social consequences of symptoms. First, language and memory impairments create feelings of embarrassment, which in turn perpetuates withdrawal from social activities.

> *When I was first diagnosed with dementia, the thing that caused me the greatest shame and what really drove me into hiding was my problems with language* (Lee 2003: 31-32).

> *I had become increasingly selective in my acquaintances… I had become particularly selective in making new friends, due to my fear of my memory and directional problems being discovered* (McGowin 1993: 48).

Secondly, individuals with dementia can find social situations overwhelming; the dementia memoirs cite difficulty concentrating in noisy and chaotic environments.

> *Multiple simultaneous conversations make it incredibly confusing for me to try to focus on my own little conversation or activity* (Truscott 2003: 16).
>
> *Unhappiness shows itself often, especially when there is a group in the house. Amid chatter, I am silent. I sit with my elbows on my knees and stare straight ahead. My mind is nearly empty in these moments* (DeBaggio 2003: 201).

Individuals with dementia can also withdraw from social activities for fear of being seen as a burden to others or as failures, when their disabilities come to show themselves. The dementia narratives reveal to us that the authors are keenly aware of the reactions of others and of how much they must depend on loved ones; their reflections suggest this is a source of sadness and frustration.

> *Apprehension and fear of failure are major roadblocks for people with early stage dementias* (Truscott 2004a: 93).
>
> *What would become of me should my condition deteriorate? Would I be cared for; treated with kindness and concern? Or would I be an unwelcome and resented burden, a source of contention* (McGowin 1993: 105).
>
> *Alzheimer's creates private family pain, the kind hidden and denied. It is so corrosive it can leave scars on the soul and disrupt relationships … I worry I might hurt my wife and son and engender frustration in their lives* (DeBaggio 2002: 108).
>
> *I feel loved, ignored, needed and like a dying albatross that is chained around each of the people who cares about me* (Taylor 2007: 128).

An awareness of declining abilities, the negative perceptions of others and the disease itself can produce feelings of despair and depression. As well, individuals must come to terms with their mortality, and this is likely to bring great sadness. Depression is very common amongst individuals with dementia, and may be a direct symptom of the disease (Whitbourne 2001). Negative ruminations can occupy depressed individuals' minds and make it difficult for them to see beyond their own emotional state. Depression very often results in withdrawal, which may then serve to reinforce negative feelings; positive experiences are reduced. Depression can also exacerbate the symptoms of dementia. Moreover, social withdrawal itself can lead to depression.

> *I could not pray as I wanted because my emotions were dead and cut off* (Davis 1989: 53).
>
> *I was on a downward spiral of hopelessness and despair, as a result of which I was withdrawing into dysfunction* (Bryden 2005: 17).
>
> *I felt depressed and defeated. I tried to pick myself up for visits to the doctor, but otherwise I just stayed in the house and didn't do anything. I became a recluse* (Lee 2003: 19).
>
> *I believe individuals who are confronted by the advancing stages of the disease withdraw prematurely because it is easier, it is safer, and they do not know what else to do* (Taylor 2007: 70).

In summary, we have outlined four different ways that disease symptoms lead to social withdrawal amongst individuals with dementia: declining language and memory abilities can cause embarrassment; attention difficulties can cause feelings of being overwhelmed; needing help can feel like being a burden; and lowered mood can alter thinking and suppress a motivation to interact with the world. With a broader set of texts, the themes of loss addressed by Basting (2003b) have been elaborated.

When combined with the negative positioning by others, the social condition of people with dementia can be bleak with little opportunity for constructive, meaningful interaction. If, as Erikson and other identity theorists suggest, we need to integrate new experiences and circumstances (such as diagnosis) into our sense of self to achieve continued emotional well-being; and if, as Positioning Theory and Social Constructionism suggest, we need to search for this meaning and resolution in our social interactions with others, we can speculate that the experience of individuals with dementia is one characterized by thwarted identity construction. Erikson would suggest this experience produces a state of anxiety and frustration (Erikson 1950; Erikson and Erikson 1998). Perhaps some of the behaviours of individuals with dementia, including apathy, restlessness and paranoia, are a result of this anxiety and frustration and not necessarily of the disease itself.

We would argue that writing can be a powerful tool in counteracting the social effects associated with dementia by enabling individuals to claim and revise their identity.

* * *

RECLAIMING AND EXPRESSING SOCIAL IDENTITY THROUGH WRITING

I wrote to clarify for myself what was going on with me and in me (Taylor 2007: 4).

I am working today, tapping at this keyboard with little time left, in an attempt to understand who I was and what is left (DeBaggio 2003: 204).

In this section we wish to map how individuals can use writing to reclaim their social identity, where social identity involves the projection and acceptance by others of various social personae. The first step in identity development after acquiring a disability, such as dementia, is negotiating new social personae, and the second step is projecting these new personae to others. In writing, these processes are intimately linked: simultaneously writing can be "an agent of self-discovery and self-creation" (Harter, Japp, and Beck 2005: 7).

Finding Social Identity

Writing provides an opportunity to engage in meaning-making dialogue with others, an activity that facilitates the integration of diagnosis and altered abilities into a new sense of self. By deconstructing the self and building it back up through the process of writing, an individual is able to achieve new clarity, empowerment and roles.

Writing Brings Clarity

A breadth of literature addresses reminiscence and storytelling as a powerful tool of self-discovery, healing, and reconciliation (see also Ryan 2006; Ryan et al. 2005c). A point of agreement is that storytelling brings form, structure and clarity to otherwise disparate thoughts and feelings (Kenyon 1996). Storytelling, or narrative, enables the integration of multiple events into a coherent account. This process both demands and creates clarity (Frank 1995; Gubrium and Holstein 1998).

Furthermore, storytelling is a natural human activity (Randall 1999). According to Hardy (1968), "we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, gossip, learn, hate, and love by narrative" (as cited in Randall 1999: 11). Indeed, Erikson (1950; 1998) suggests in his psychosocial model of life stage development that individuals nearing the late stages of their life engage in a process of life review that very often takes the form of telling stories to loved ones. It would seem natural that we turn to storytelling when we need to find clarity.

In comparison to oral storytelling, writing provides many particular benefits to individuals with language and other cognitive impairments (Ryan et al. 2005c). Briefly, writing, as an avenue of self-expression, allows for time in constructing each response and can be done at an individual's leisure or discretion (at times when it is best for them) and can transcend language difficulties (such as word-finding problems typical of dementia) (Ryan et al. 2005c). Writing is more forgiving than speech; it does not demand perfect grammar and implicitly it invites metaphor and creative language use. Moreover, the assistance of technology and other people does not obstruct the flow of communication as in speech.

According to Smyth and Pennebaker (1999), writing about emotional experiences has great therapeutic value (see also Ryan 2006). By transforming emotion and images into words, a person can reorganize the way a traumatic event is remembered, contemplated and even forgotten. Writing enables an individual to find positive meaning and an emotional outlet; it enables the adjustment of goals and activities and allows an individual to see oneself in a greater context. This can lead to lessons learned and the attainment of new ways to think of oneself as much more than one's impaired brain or diminished social roles. An individual can also find perspective through humour in writing (e.g., "When I hurt, I yell, which is what I've been doing for several years now, and it's food for thought, at least, an Alzheimer's picnic [Henderson 1998: 3]").

The act of writing, often spared better than speech, can foster remembering, mirror the ups and downs of life with the disease, and evoke insights about coping.

> *The words in my brain are silent, and the flood of sentences begins only when my pen unleashes a flood of writing memory* (DeBaggio 2002: 199).
>
> *Watching my spelling, especially when it goes out of control, is a way I keep tabs on Ol' Alzheimer's ... I use it as a fingerprint of what is happening in my brain* (DeBaggio 2002: 125).
>
> *In the other, slower world where I write on paper or directly on the computer, vocabulary is more fluid and I often surprise myself when the perfect word finds its way into the sentence without effort. This has puzzled me from the first sentence I wrote for this book. It is only now, eight months later, I begin to see more clearly how necessary it is to slow the pace to achieve a former normality* (DeBaggio 2002: 180).

Individuals with illness or disability have a unique need to find expression in writing; they may feel that their voice has been taken from them by the expectations of others and by their medical diagnosis (Frank 1995). Writing can be a means to reclaim their voice, to put a face on a disease, to advocate for social change and to educate others (Ryan 2006). By constructing illness narratives, patients can actively re-make an identity; they are choosing to find opportunity in the "social space of indeterminacy and ambiguity" created by illness (Hunt 2000: 91). Thus, writing is also a way to explore new social personae.

Writing facilitates exploration of new social personae by enabling a critical examination of self and environment, which leads to new insight. For example, through writing an individual is able to encounter difficult emotions in a safe and positive way. DeBaggio grapples with the complex dichotomy of peace and suffering, which dementia presents to him:

> *What I have been unable to tell Joyce clearly is that I don't want to wander outside my deteriorating brain. With the onset of Alzheimer's, I saw new revelations and visited places I had never been. They have turned out to be as useful, frightening, pleasant and beautiful as anything I could have wished* (2003: 205).

Reflecting on complex thoughts and ideas with the help of the written word creates insight. The dementia writers seem to arrive at a new kind of spiritual awareness. Li and Orleans (2002) suggest that people with dementia inhabit new spaces of being and that it is us who must see their changes as journeys and not deteriorations.

Writing about one's life places diagnosis within a greater context (Birren and Hedlund 1987). When seen as another event in a person's life, the negative meaning of diagnosis may be diminished and can be seen positively as an event that enabled an individual to impart wisdom to others and to experience life from a new perspective.

> *As I read over this book … I realize how far I have come psychologically, if not intellectually. Living in the Labyrinth was written in a state of grief such as I'd never experienced, and it jumps out at me as I read back over the pages* (McGowin 1993: 125).

> *I have a life that can be either frustrating and frightening or peaceful and submissive. The choice is mine. I choose to take things moment-by-moment, thankful for everything that I have, instead of raging wildly at the things that I have lost* (Davis 1989: 57).

> *It is now 2004, and I am still here, and it has been quite a journey of understanding, of seeing more clearly who I am now, who I am becoming, and who I will be when I die* (Bryden 2005: 10).

Writing Through Metaphor to Elaborate Insights

Difficult feelings can also be confronted through the use of metaphor. Creative language can enable individuals to better understand their feelings. The metaphor is used to create the image for the reader; but in deconstructing the image into words, the writer moves toward greater clarity. The dementia narratives demonstrate ample use of metaphor by some of the authors. See Table 2 for numerous illustrations of the use of metaphor to elaborate insights.

> *In the swings of my emotion, from sunlight into ever blackening moonlight …* (Davis 1989: 22).

There is great variability among the authors in the use of metaphor (note that no distinction is made here between simile and metaphor). Bryden (1998, 2005) and Taylor (2007) use metaphor very effectively to make their points largely from an educational and advocacy viewpoint.

> *The unreliability of my memory is as if the printer ink is running low and it sometimes works and sometimes doesn't* (Bryden 2005: 106).
>
> *Each person with dementia is a gift, and has a great deal of wisdom about life. It is those around us who need to unwrap this beautiful package* (Bryden 2005: 170).
>
> *I feel as if I am sitting in my grandmother's living room, looking at the world through her lace curtains. From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world* (Taylor 2007: 16).
>
> *All who are ingredients in the pressure cooker of Alzheimer's should write and share their thoughts and writings with others* (Taylor 2007: 186).

DeBaggio (2002, 2003) is a gardener and creative writer who describes the landscape of his life experiences specifically through images.

> *Alzheimer's provided me an opportunity to give up dirt and search the rocky hillside of memory for places where freshets remained to tell me who I was and where I have been* (DeBaggio 2003: 74).
>
> *I will float on a tranquil sea of memory one moment and be swept away the next by boisterous waves that leave me confused and uncertain* (DeBaggio 2002: 42).
>
> *Now, weakened by Alzheimer's, memories leak through holes in my brain, giving me one last glimpse of who I was and where I went, a last picture show* (DeBaggio 2003: 35).
>
> *The interiors and exteriors of the world flash before me but I cannot find ways to open them* (DeBaggio 2003: 191).

Killick and Allan (2001) demonstrate that the language of dementia is much more understandable when viewed in terms of metaphor. The writers here use metaphor within an explicit narrative, which makes the meanings clear. Those working with people with dementia might well benefit from practice in reading such metaphorical texts to raise awareness and develop specific image-based comprehension skills.

Writing Provides Empowerment

Through the act of writing an individual is positioned as 'writer,' 'storyteller' and 'teacher.' These new roles provide feelings of accomplishment and purpose that can be empowering and effective in elevating self-esteem (Birren and Hedlund 1987).

Individuals are able to embody the personae of these roles and, in the process, re-establish themselves as satisfying social partners and contributing members of society. Writing, especially about one's past, can also be effective in reminding an individual of his or her spirit, his or her likes-dislikes, beliefs, motivations and inner feelings. This can serve to re-affirm the existing personality, which may have been lost in feelings of lowered self-worth.

Empowerment is also derived from the control that writing provides. That is, an individual is able to control the words on the page and to direct themselves (and often their caregiver) in an activity. According to Sabat (2001), individuals with dementia are not given many opportunities to direct activities.

Writing helps an individual with dementia come to negotiate new social personae. The next step in the process of social identity development is the simultaneous projection of these personae and its acceptance by others.

Finding and Projecting Social Identity Through Writing for Publication

Writing helps an individual not only to find clarity and empowerment, but also to project a renewed sense of self to loved ones and the greater community. Through private journaling or by writing for an audience (and eventual publication as in the authors here), individuals with dementia can express themselves, projecting new roles – expert, chronicler, teacher, advocate and organizer, and wisdom figure.

In this section we describe the authors one by one and address their unique reasons for publishing. In the subsequent section, we speak to the different roles these experts take on within their writings.

Robert Davis [1989] is a pastor and dynamic preacher who once led one of the largest churches in Miami. Diagnosed with Alzheimer's, Davis has relied on his memory of the scriptures and a closeness with God, as well as the support of his parishioners and family, in confronting and understanding his experience with the disease. *My Journey into Alzheimer's*

Disease originated in a series of sermons: “As I lay in the hospital, I resolved that I would ask my church officers for the opportunity to preach a series of five farewell sermons. I felt compelled to preach them regardless of my then stuttering speech and impaired vision (59).” The text is rich with a sense of meditation and looking forward: “why has God left me this little window of ability? As I pondered this, I thought that perhaps it happened so that I can be the voice for the voiceless people who suffer from this devastating disease (21).” The book was written with the assistance of his wife Betty, and this assistance increased as the project moved along. Davis talks about the book in terms of his changing abilities: “At my own speed and in keeping with my individual body rhythms, I can still act with the skills and knowledge I have acquired over the years. This book is an example of this. It was dictated at all hours of the day and night, whenever I had a clear enough mind to string thoughts together (86).”

◆

Diana Friel McGowin [1993] of Florida was not a writer by profession but had always hoped to be one by interest; instead she held a successful career as a legal secretary and was mother to three children. *Living in the Labyrinth* is a very personal account of McGowin’s life with Alzheimer’s, beginning with diagnosis. Through therapy, McGowin was encouraged to keep a journal of her personal reflections; these journal entries became the book. Her husband Jack provided support: “With my husband’s dogged skills at the word processor, I’ve continued to keep a journal. It is written with an eye towards coping, and when I reread it I am reminded that, even with Alzheimer’s, life can be fun … (125).” McGowin cites a desire to reach out to others as a motivation in writing the book: “I don’t feel courageous. I feel I’m a pebble in a rapid brook. I hope this little pebble can send out ripples upon ripples, in an ever widening circle, until the ripples eventually lap up on a shore where someone like me is stranded and feeling alone (118).” For McGowin, writing became a way to reach out to others and to extract good, positive experiences from the disease: “I hope that it [the book] offers comfort to patients and their families and demonstrates that dignity is imperative for the survival of the self (viii).”

* * *

Larry Rose [1996] was a successful engineer when he was diagnosed with early-onset Alzheimer’s. With the help of his wife, Stella, Rose came to terms with not only the new boundaries of his changing abilities but also feelings of depression and isolation: “Slowly and painfully, I was becoming aware of the darkness of my mind. I realized that my mental abilities were fading and that I must work to overcome my fear of this loss (12).” Writing the book, *Show Me the Way to Go Home*, gave Rose an opportunity to reach out to others and find new understanding for himself: “I try to channel my anger in practical ways. The best way for me to do this is to write down my thoughts (52).” According to Rose, “if the words that I write don’t make any sense, I mow the grass … (52).” Through writing, and through meeting another author Diana Friel McGowin, Rose has moved past feelings of isolation: “I don’t feel alone anymore, and the emptiness in the pit of my stomach is gone (103).”

* * *

Cary Smith Henderson [1998] was a history professor in Virginia. He spoke his thoughts and stories entirely into a tape recorder, with the understanding that his daughter Jackie would then make selections for the book, such as “It’s somebody’s version of hell and I guess I’ll someday have to write a book about that, which is exactly what I am trying to do (4).” His commitment to helping others afflicted with the disease “understand the world they are now forced to live in” (4) comes through clearly. “We can to some degree, I hope, encourage people who have Alzheimer’s to not be ashamed and not be any more, you might say mind-paralyzed, than they are (57).” Henderson’s book is the only one of the memoirs not put into a narrative format. As discussed by

Basting (2003b), his memoir selections also are the most reflective of the memory and language symptoms of dementia.

* * *

Christine [Boden] Bryden [1998, 2005] was a top civil servant in the Australian government and single mother of three children when diagnosed with dementia. The purpose of her first book, *Who Will I Be When I Die*, (written with the encouragement and feedback of her spiritual advisor) was "to try to write down my experiences, not just about me and my girls, but also to explain Alzheimer's in a way that lots of people might be able to understand this physical disease, which whittles away at the brain until eventually life ceases (1998: 137)." She ends her book: "I have shared with you some of my experiences of an incurable terminal illness, and the spiritual journey I have made (1998: 140)." "Writing this book about my experiences is yet another triumph of faith over medical expectations – the specialist's advice to write quickly was way back in early 1996. I'm still writing, and planning to write more things for my daughters (1998: 110)." Her second book, *Dancing with Dementia*, (written seven years later, after marrying Paul) emerged from the notes for the many speeches she has made advocating on behalf of persons with dementia. The opportunities to speak and advocate had been opened up by the visibility of being a published author with dementia and led to the founding of the Dementia Advocacy and Support Network International (DASNI). The more recent book shifts from the fear of ceasing to be alive, with which the first began, to an acceptance of life: "I reflect on a journey of living positively with dementia, and of discovering a journey into the centre of self. I speak to professional care-givers, families, medical professionals, and others, telling them what we feel like, what we need, and trying to give hope and understanding in the face of this mystery illness that robs us of who we think we are (2005: 10)."

* * *

Thomas DeBaggio [2002, 2003], lives in Virginia with his wife Joyce, and has been a commercial herb-grower and journalist. After being diagnosed with Alzheimer's, DeBaggio wrote his first book *Losing My Mind*, which he followed a year late with a second book *When it Gets Dark*. DeBaggio writes with poetic vibrancy and incorporates detailed observations of nature, employing metaphors to draw parallels between the natural world he understands and the disease he can't quite grasp. Both books are a vivid recounting of his own feelings into an inquiry of how the self can survive beyond memory and face death. His intention in writing his first book, and in nationally broadcast periodic radio interviews, was "to break through the sense of shame and silence Alzheimer's has engendered. I want people with the disease to come forward, unafraid of exposing their illness, and tell the world what it is like (2002: 141)." The purpose of his second book was "to open my inner life and at the same time reflect on everyday simple things, as death's shadow falls across my dwindling days (2003: 5)." For him writing is what he needs to do: "When I am writing, I am someone else looking at me and the world … Writing is a truly liberating experience for me and I do not want to give it up (2002: 97)."

* * *

Jeanne Lee [2003] lives in Hawaii with her partner Vern and is mother to five children and grandmother to eleven grandchildren. She has enjoyed many professions in her life, including hairdresser, printing broker, pilot and graphic artist. After receiving a diagnosis of Alzheimer's, Lee decided to record her thoughts and feelings for the benefit of others. This became her book, *Just Love Me*. She acknowledges the assistance of an editor who "performed the monumental task of converting my mumblejumble, night-typing, seven years of journals, and tape-recordings to paper in a manner that is readable (ix)." In the process of writing the book, Lee realized that "if my desire is strong enough and I just keep chugging along, and don't let the slips and falls stop me, I will eventually succeed (72)." Feeling alone was a key motivation for Lee in writing the book "as a means of sharing what I have learned with others; to help open things up for all of us, and if not for us, then for those that will follow (43)." Her book "deals with some serious and possibly depressing issues and experiences, but it's also about learning to enjoy life to the fullest extent possible (xviii)."

◆

Marilyn Truscott [2003, 2004a, b] lives in Ontario and is an active volunteer with the Alzheimer Society and with DASNI. She is a former scientist and environmental consultant, who is married with two grown children. She has published three articles in the *Alzheimer's Care Quarterly*, all of which were examined in this survey. Her articles come, in part, from the preparation she does for her speeches. For her the process is slow: "I have to do the writing very slowly, in brief spurts of activity – of perhaps an hour each day – with laborious reviewing, editing, and re-editing … (2003: 12)." Truscott is assisted in this process by her family and friends, who "listen to me and review my ideas. These people are enabling me to do these activities by supporting my efforts in critical ways (2003: 12)." Truscott also makes use of email and poetry in communicating and forming ideas. She uses her writing to advocate for change: "Accept us as we are. We are still the same person inside, but now with new and changing challenges (2004b: 277)."

◆

Richard Taylor [2007] is a retired psychologist and university professor, living with his wife Linda in Texas. Like Truscott, Taylor has written several articles for *Alzheimer's Care Quarterly*. These articles led to the collection of essays published as the book, *Alzheimer's From the Inside Out* in 2007. This book contains, in vivid prose, the many thoughts Taylor has about the experience of Alzheimer's, including his advice to caregivers: "I do not want to become an advice columnist on caregiving. I do want caregivers to read my writings and figure out for themselves how this information and these insights can help them understand, appreciate, and honor their loved ones (4)." Taylor outlines for the reader a regular routine of writing that he indicates provides a means of therapy for him: "writing became my 'therapy without a co-pay.' It was a way for me to attempt to figure things out for myself, or at least think about them and recall what I had concluded (201)." Taylor believes that writing has provided him with a means to achieve greater clarity: "Now, 'where was the moment of clarity' you may still be asking yourself. It came after I wrote this! (206)"

Experts on the Lived Experience of Dementia

Writing renews an individual's status as a contributing social partner and imparts new roles and meaning, which can bring feelings of empowerment and control. Thus, social personae characterized by competence and authority can be projected. Here we discuss how this projection can take place through writing with reduced fear of social rejection.

Writing is distinct from oral communication in that it is permanent. Even if never read by another person, permanence imbues the thoughts and ideas with an existence. In absence of an interlocutor, the page becomes a person, and a non-judgmental one who facilitates the telling of the whole idea, no matter how long it takes. This acceptance is implicit. For example, if someone writes that they are a firefighter, somewhere – even in a fictional world – that social identity exists for them (and continues to exist). Writing does not rely on truth, as conversation does; we as a society accept fiction. We also recognize, through the conventions of storytelling that there is a break or distance between writer and protagonist, even if the protagonist is explicitly stated as writer (Linde 1993). This means that a writer can say things as protagonist and have these accepted, without dependence on a lived reality.

Most writing is, however, read by others and is, therefore, situated within a framework of shared meaning. All stories are created in a context (Miller 1994) and are culturally mediated: genre, language, form and concept are all pre-existing institutions upon which an individual grafts a story (Ray 2000). These institutions are shared by writer and reader without any explicit teaching and, as such, they enable a dialogue between two people. The reader 'speaks' through the interpretation of the story; their own personhood affects how they internalize the story and this will come to change the meaning (Harré and van Langenhove 1999). The reader is not able to impose his or her thoughts explicitly on the writer; this dialogue is free at one end (the writer's) to come to its full expression without rejection. Where the writing is one's life story, it facilitates the strengthening of a relationship and, in its permanency, will create a bond that transcends the barrier of death.

As well, because a piece of writing exists immediately within the larger context of a world of pre-supposed meaning, the story carries an added importance. It takes on a life and admits a writer into a community; his or her story joins other stories in making up genres, cultural and family histories (Schuster 1998). This helps strengthen a sense of belonging and contribution. Writing allows the individual with dementia to re-engage with society in new or re-claimed roles – all of which provide new purpose, meaning and self-worth to an individual's life.

Chronicler

> *When I die nothing will be left except someone else's memory of me. Only these words of mine will remain to shred my life into moments I now quickly forget* (DeBaggio 2003: 19).

It is a natural desire to want to be remembered and loved after one's natural life has ceased. For many individuals facing life altering circumstances and a fatal disease, the need to leave a legacy behind is particularly strong. Writing is a permanent art that enables an individual's memory to live on in a real form. The essence of the individuals' personality and the idiosyncrasies of their lives come through in the words they choose and the stories they write, making it an important medium for sharing.

For the authors, this need to leave something behind relates also to wanting to educate others about Alzheimer's through chronicling the effects of the disease:

> *While I am still able to communicate, I want to share this incredible journey into Alzheimer's disease* (Davis 1989: 20).
>
> *This book is a chronicle of my battle with Alzheimer's. It is a plain-language, 'as it happened,' chronicle which I pray will assist others like me who are dealing with this perplexing problem, and their families* (McGowin 1993: viii).
>
> *It is an interesting adventure, this Alzheimer's, because no one can predict what functions I will lose or when. And because of my scientific training, I feel I have a unique opportunity to live my own experiment -- and to record what is happening to me in the hope it may give some insight into this 'brain-rot', as I have called it in some of my darker moments* (Bryden 1998: 87).
>
> *I want to write the truest sentences I can in the hope my words give others the sense of struggle and joy I feel* (DeBaggio 2002: 29).

It is also possible, through writing to remind others of an individual's continued wellness and sense of competence in some domains. Through writing, the authors are announcing their continuing presence:

> *And although there are many days when I am painfully aware that less of me exists than the day before, for now, I can say, I am still here! Diane McGowin exists! Perhaps someday, someone will be glad I did* (McGowin 1993: 116).
>
> *One great source of comfort for me, though, was that a month or so before he died, my father had read the draft of this book, and had 'heard' me speak out about the really important things in life, and also how much better I was feeling. He was keen to speak to me, too, after reading it* (Bryden 1998: 120).

Teacher

Through writing the individual is reaching out to others as a teacher to a student. These bicultural teachers are using their own experiences with dementia for the greater purpose of impacting the knowledge and perceptions of others. Some of the authors explicitly address the desire to educate others. For example, Diana McGowin (1993) states of her book "I hope that it offers comfort to patients and their families and demonstrates that dignity is imperative for the survival of the self (vxiii)." However, all authors are projecting the role of teacher, simply by sharing their experiences; each book provides insight into the experience of dementia that benefits medical practitioners, family members and other individuals with dementia. See Table 3 for quotations exhibiting the teachings directed toward caregivers.

> *Alzheimer's is a bit of a taboo subject -- or a bit of a joke. Families of sufferers are often ashamed of their very odd, 'batty' relative, and can't understand why they can't stop this silly behaviour. I am hoping to break that taboo -- of being ashamed of a disease* (Bryden 1998: xi).
>
> *As survivors of the journey with dementia, we can share with you the insider's knowledge that we have* (Bryden 2005: 171).

> *I've accepted that I'll never be the way I once was, but I'm still a person. I just want people to understand that it's not easy, but life goes on. If I ever lose my sense of humor, that's when I really have a problem* (Lee 2003: 35).
>
> *Watch my face for hints that I do not understand. Sometimes I don't speak, but my nonverbals shout* (Taylor 2007: 153).
>
> *What a sense of accomplishment, and reinforcement of self-worth it is, to make something, paint something, and finish something, in spite of cognitive problems* (Truscott 2004a: 94).
>
> *How you relate to us has a big impact on the course of the disease. You can restore our personhood, and give us a sense of being needed and valued. There is a Zulu saying that is very true, 'A person is a person through others'* (Bryden 2005: 127).

Table 4 presents quotations of insights and advice for others with dementia – in many ways the key recipients of their writings.

> *It is by 'focusing,' or channeling our energies into one tight circumference of attention, that we patients are able to 'pass,' or perform satisfactorily. We still have much to contribute, but must be granted our individual requirements for successfully contributing* (McGowin 1993: 137).
>
> *I would love to see some people with Alzheimer's not trying to stay in the shadows all the time but to say, damn it, we're people too. And we want to be talked to and respected as if we were honest to God real people* (Henderson 1998: 7).

> *I have suggested to many people that they try a handheld recording device, speak into it whenever ideas or messages strike them, and then have someone else type it out for them* (Truscott 2003: 15).
>
> *I crave someone to talk to that has it too; someone to compare stories with; someone to cry with; someone to laugh with; someone who really knows what it's like from the inside* (Lee 2003: 44).

Advocate and Organizer

The dementia memoirs allow the authors to advocate for change in the treatment of individuals with dementia. The authors explicitly counsel others on how to interact with people with dementia, such as when Truscott (2004b) says "We are still the same person inside, but now with new and changing challenges. If we act differently, please focus on blaming the disease and not blaming us. Continue to love us and respect us and show others that this is the model to which they should aspire (277)." As well, they become a positive example of dementia 'sufferer,' thereby shattering stereotypes of incompetence.

For example, both Bryden and Lee confront situations where, as competent writers and speakers, they need to prove themselves as individuals with dementia, as though the two identities cannot co-exist. Bryden (2005) tells us, "I had also managed to insert my latest scan on one of the slides, to 'prove' my credibility as a person with dementia (69)." Lee (2003) notes one doctor's inability to accept that an individual with dementia could write an email, suggesting that he firmly disbelieved the individual's diagnosis. The authors are able to perform functions that many people, even those with direct and daily contact with individuals with dementia, feel are not possible. Moreover, the authors are declaring: many people believe we cannot do this but we can and it is the way that others approach us that needs to change. This is perhaps the most pervasive message apparent in these books; it comes out simply by their existence on a library shelf.

> *This attitude bothers all of us who receive an Alzheimer's diagnosis. By struggling to maintain a plateau through mental stimulation exercises (this manuscript was one), we are upsetting the medical applecart. If we succeed, our very success confuses the heck out of the medical professionals who would be much more comfortable if we resigned ourselves to rapid deterioration, relinquished our tenuous hold on cognitive ability, and sank to the state of the severely devastated. Then, we realize, we would fit the 'mold.' Then we would not confuse the 'unaffected experts' by proclaiming ourselves affected experts* (McGowin 1993: 123).

Many of the authors explored here are also active participants in Alzheimer's organizations: as organizers and pioneers for early-stage support groups (locally and online through DASNI), new websites and chat rooms, and as public speakers (Bryden, DeBaggio, Lee, McGowin, Taylor, and Truscott). In this role of organizer, their writing can fuel and flow from their speeches and organization activities.

> *I know there will always be periods when my lack of worth gnaws at me, obstinately. However, I must hang in and hang tough. My first efforts to find a publisher for this manuscript were met with the response that "Alzheimer's disease is a topic of too limited interest." Too limited interest? With millions affected? With such a high profile, today? Too limited interest. Always a person of passion, I do not intend to take this disorder with cold stoicism* (McGowin 1993: 113).

> *Due to both the acceptance of my book and the wide gamut of media attention it has received, patients have the privilege of communicating for the first time with others like themselves* (McGowin 1993: 138).

> *Why be ashamed of the physical breakdown of brain cells any more than the physical breakdown of other parts of our body? We are not mad, but sick, so please treat us with dignity, do not make fun of us, and do not be ashamed* (Bryden 1998: xi).
>
> *All of us travelling this journey have a right to be heard, to be listened to, and to be regarded with respect. There is no time to lose to hear our voice as we struggle to communicate* (Bryden 2005: 44).
>
> *We seek recognition and inclusion alongside our care-partners, as companions on a journey of care* (Bryden 2005: 65).
>
> *We had been emailing each other, developing this proposal for Alzheimer's Disease International (ADI), responding to its annual report of that year, which stated that: 'all the ordinary pleasures of life ... are no longer possible' for the person with dementia, and 'The mind is absent and the body is left as an empty shell.'* (Bryden 2005: 62).
>
> We [founders of DASNI] *felt like we had been the first runners in a relay race. We knew we could only run the first stretch, because each of us had progressive illnesses that would take our ability away bit by bit, so that we would no longer have as much energy to try to change attitudes* (Bryden 2005: 71).
>
> *Why not see us as a source of answers to our problems, rather than as a source of problems to which our caregivers need answers. We, too, want to be proactive when dealing with our symptoms, not just reactive to our problems!* (Taylor 2007: 68)

In summary, writing enables the individual with dementia to engage in positive social interaction with others, which facilitates the development of a social identity. Writing can be done at any time and in any time frame. It hides one's disability, and enables thoughts to become fully expressed without interruption and the fear of immediate rejection. This means that personae can emerge and be presented without reliance on others to overtly accept them.

The writers we have quoted in this article are exemplary human beings who have written powerful reflections of their experiences. They have successfully come to resolve issues of social identity construction and taken on new and important roles. These individuals are growing positively with dementia; they are achieving new insight and awareness and passing this wisdom on to others. They have joined a discourse community of readers and other writers and in so doing are breaking down stereotypes of 'dementia sufferer.'

Wisdom Figure: Beyond Loss of Some Brain Cells

Our final selection of quotations demonstrates how the writers with dementia have disentangled intelligence from everyday memory to give us important wisdom statements based on the authority of lived experience. We see within the wisdom statements that individuals with dementia who write about their experience have done more than reclaim their voice and reach out to others through words – they have found in the process of writing new knowledge about themselves and about the world, as Lee states near the end of her book.

> … *life as I know it is over, and what that life-changing circumstance has caused me to recognize is that I have two choices. The same two, I now realize, that I've always had; I can grow or shrivel; I can be happy or unhappy; I can dwell in the light or in the darkness; I can live in love or in fear* (Lee 2003: 71).

Through diagnosis and the chosen and positive way of coping, the authors have used writing to arrive at new found enlightenment. They have become figures of wisdom, who demonstrate the desire and ability to pass this wisdom along to others. As is seemingly inherent of wisdom figures, these authors embody a sense of hope that is itself contrary to cultural expectations of disease (O'Brien 2005). Hope can be defined as a way of looking "positively towards a desired but uncertain future where something that may once have been considered impossible now becomes possible (O'Brien 2005: 11)."

The following quotations demonstrate how the authors have arrived at a sense of hope and acceptance. Growth has taken place within each author during the course of their illness, an idea in stark contrast to the popular notion that dementia is a state of perpetual decline.

> *I never really knew how many people are in this special fellowship [people with dementia] because I only looked into the lives of the heroic from my wholeness* (Davis 1989: 58).
>
> *This knowledge enables me to savor life more openly and ravenously. I appreciate all good things more, whether they be trusted friends, cherished memories, nature's beauty or physical pleasures* (McGowin 1993: 87).
>
> *There have been many changes in my life since the onset of Alzheimer's, some for which I am not at all ungrateful. I have more compassion for people, birds, deer, and the like. I have fallen more and more in love with Stella* (Rose, 1996: 126).
>
> *There are things I wish I could do, but on the other side, there are still things that I can do and I plan to hold on to them as long as I possibly can. Laughing is absolutely wonderful. A sense of humor is probably the most important valuable thing you can have when you have Alzheimer's* (Henderson 1998: 14).

After years of thriving on intellectual challenges, of learning new things, of achieving change, of looking down on those at work who were not as quick in their brain gymnastics, now I have been humbled, and realise just how valueless intellect really is (Bryden 1998: 137).

I have begun to adjust my life so each day has a structure to it, and a purpose: to enjoy every minute I can and to focus on the work I love with herb plants, and with words (DeBaggio 2002: 29).

As I grow older with Alzheimer's, I become more open (DeBaggio 2003: 168).

I am daily in a state of adjustment, trying to reconcile the old me with the new me, and accept that being slow, doing less, experiencing less, achieving less, is all right (Truscott 2003: 12-13).

I choose a new identity as a survivor. I want to learn to dance with dementia. I want to live positively each day, in a vital relationship of trust with my care-partners alongside me. By rejecting the lie of dementia, and focusing on my spirit rather than my mind, I can be free of fear of loss of self, and in so doing can also help you to lose your fear that you are losing me (Bryden 2005: 170).

I appreciate and sometimes immerse myself in the process rather than only or mostly on the outcome. I like doing things. I like and appreciate the doing. Doing is how I know I am alive, and how I appreciate being alive (Taylor 2007: 105).

* * *

CONCLUSION

Individuals with dementia face many challenges to their sense of identity. In particular, their social identity is in danger, as the quality of their social interactions decline. We suggest writing as a way to reclaim opportunities for social identity exploration and projection. Writing is a meaning-making experience that provides for empowerment and control; it is patient, unbiased and implicitly accepting. The page, as the perfect conversation partner, enables communication.

Most importantly, writing provides the opportunity for an individual to grow positively with dementia. This analysis offers a balance to the generalizations made on the basis of scientific study of groups of people. Too often, those diagnosed with dementia are assumed to be on a path of all-encompassing decline. It is common to assume an individual with dementia decays quickly into a state of inevitable absence. We have shown, by highlighting selections from published dementia memoirs, that growth and learning can still occur. Writing provides a medium that supports this growth. We have emphasized the social needs of individuals with dementia and the dependency on interaction with others for the re-expression of social identity. Social interaction, however, is also important in the expression and maintenance of personal identity: an individual's core sense of self may be threatened by the responses of others or even fractured by the effects of impaired memory and communication skills (Basting 2003b). These authors have demonstrated the perseverance of the personal self – the wit, wisdom and drive with which they write is what makes them unique, not their disease. The authors have used writing to achieve and communicate a sense of a whole self (Basting 2003b).

The authors profiled here are undoubtedly exceptional people, able to write their story for the public and receive the privilege of publication. Yet, writing about one's life is not exclusive to the well-educated or experienced. Even amongst these authors, there is diversity: some had welcomed writing into their life prior to diagnosis (DeBaggio) and held positions of prominence like scientist, professor, and pastor (Truscott, Taylor, Henderson, Davis). Others had not previously written for others and held positions requiring more moderate levels of education, like hairdresser (Lee) and legal secretary (McGowin).

Rather, the homogeneity amongst this group refers to the level of emotional support and concrete assistance from other people in producing a book. All of the authors had support and assistance of caregivers (usually spouses); helpers were involved in the story project in various ways, sometimes as transcribers, sometimes as interpreters and editors and always as motivators. This emotional support was likely instrumental in allowing these individuals to realize their story. The authors also cite the use of technology, including computers (word-processors, voice recognition software) and tape recorders.

While most people will not publish their work, writing is an activity that can be accomplished by all in the early stages of dementia. It is the level of outside assistance required that may differ for each person. Some people may need to have others write their words for them and re-construct ideas to achieve clarity. The attractive aspect of writing is that it hides this process, ensuring that for even the most ill the final product is a complete thought ready for consumption. While the authors cited here were in an early to moderate stage of dementia, group poetry writing in long-term care facilities suggests that individuals in late-stage dementia can participate in facilitated writing exercises (see Hagens, Beaman and Ryan 2003).

This essay is situated within a framework of previous research and existent theories that suggest the importance of affirming personhood among individuals with dementia (Basting 2003b; Killick and Allan 2001; Kitwood 1997; Sabat and Harré 1992). Writing supports personhood-centred approaches; it can not only empower individuals with dementia but also provide information to caregivers and medical practitioners. Information about a person's history and personality, including fears, interests and desires, can help in the creation of treatment programs that address individual needs. Research has begun to show that these kinds of treatment programs produce many positive results (Cohen-Mansfield et al. 2006; Kitwood, 1997). These approaches can truly enrich the lives of individuals living with dementia. As more and more people are diagnosed with dementia, we must continue to seek how best we can help one another.

To conclude we suggest ways, supported by the dementia memoirs, whereby one could bring writing into the life of another person. Whether through life story, poetry, fiction or journal writing, one can engage individuals with dementia in telling their story (see Basting 2003a; Killick and Allan 2001; Snyder 2000; Thorsheim & Roberts 2000).

A story project is an opportunity to record family history, but also an exercise in affirming an individual's identity. One may begin by encouraging a loved one to record thoughts and ideas in a personal journal, either in written or oral form (as in recording thoughts with a tape recorder). By introducing the story project in this way, one encourages the incorporation of personal reflection and thoughts in the recall of stories.

Individuals with dementia work best in well-lit, uncluttered and noise-controlled environments (Santo Pietro and Ostuni 2003; Truscott 2004a). Technology can provide great assistance as handwriting declines. Many of the writers cited here made use of tape recorders (Bryden 2005; Henderson 1998; Lee 2003) and computers (Bryden 2005; Davis 1989; DeBaggio 2002; 2003; Taylor 2007; Truscott 2003).

An encouraging environment is important; it is useful to tell family and friends about the writer's story project and encourage these individuals to participate by sparking story ideas or sharing their own memories. Story ideas can come from a number of sources: engaging in pleasurable activities (Thorsheim and Roberts 2000; Truscott 2004a), creating a memory book or box of treasured items (Hagens et al. 2003; Truscott 2004a), or just talking. Story ideas can be sparked by using active listening techniques with open posture, sitting close and maintaining eye contact (Killick and Allan 2001; Ryan et al. 2005b), asking questions and paraphrasing important information (Snyder, 2000; Thorsheim and Roberts 2000), making use of open-ended questions (Ryan et al. 2005b; Truscott 2004a), reading an individual's story aloud and probing for more details (Hagens, Cosentino, and Ryan 2006). It is especially important to provide the individuals with the opportunity to direct the conversation and the duration of the activity; this includes understanding that some days and hours in the day are better than others and enabling them to set their own limits (Davis 1989; DeBaggio 2003). Regardless of the extent of support provided, the facilitator's goal is to empower the person with dementia to tell his or her own story in his or her own words and for these words to be recorded.

In this overview, we have examined the social condition of individuals with dementia and suggested that it is one often marked by impoverished social interaction, malignant psychology and excess social disability. Consequently, individuals with dementia are provided with few opportunities to assert themselves and to (re)negotiate their social identity in the face of great transformation. We have demonstrated here through the memoirs of individuals with dementia that writing can be a powerful tool for identity negotiation and expression for persons with dementia. By enabling an individual to write about thoughts, feelings and life experiences, we can assist that person in achieving the growth necessary to live positively with progressive neurological impairment.

* * *

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TABLE 1

IDENTITY PROBLEMS IN DEMENTIA

[* indicates quotations given within the text]

*During this illness our roles have changed. Suddenly she is not only the wife I have loved, but now she is also my caregiver. She has to guide me through daily living, as I have become a care-receiver (Davis 1989: 22).

Even if I had every bit of my mind capacity, I still could not have dealt with this inescapable darkness (Davis 1989: 49).

*I could not pray as I wanted because my emotions were dead and cut off (Davis 1989: 53).

In my rational moments I am still me (Davis 1989: 86).

The loss of self, which I was experiencing, the helplessness to control this insidious thief who was little by little taking away my most valued possession, my mind, had made me especially wary of the rest of my possessions in an unreasonable way (Davis 1989: 91).

*I had become increasingly selective in my acquaintances … I had become particularly selective in making new friends, due to my fear of my memory and directional problems being discovered (McGowin 1993: 48).

To raise my spirits and self-esteem, I had plastic surgery to rejuvenate my eyelids. I was now desperately clinging to the belief that if I looked younger outside my inside might be fooled (McGowin 1993: 65).

*Having always been the outspoken extroverted pivotal center of both my family and group of friends, I was now reluctantly in the non-contributing purgatory of the early diagnosed (McGowin 1993: 67).

*I told no one else that I had stopped working. I felt guilty that I could not function and was ashamed of my loss of capacities (McGowin 1993: 68).

One day I stood in front of the enormous mirrored closet doors … I studied my reflection closely … No one could tell just by looking at me that I wasn't perfect any more (McGowin 1993: 74).

I feared the possibility of someday losing control over my own home, my own meals, my own family, and my own automobile. In short, I feared losing my last shred of dignity and control over myself. My diagnosis exposed me to the elements (McGowin 1993: 82).

I had also associated all of the dementias, not just Alzheimer's, with the elderly, and that made it harder to accept my lot. I was not elderly. I was not totally incognizant, incontinent or incompetent (McGowin 1993: 89).

Sometimes my attempts to rekindle old relationships were pitiful and self-demeaning. I was desperate. These individuals knew the old Diane Friel, and through them I could lift the veil of time and view her, myself, once again (McGowin 1993: 111).

*Slowly and painfully, I was becoming aware of the darkness in my mind (Rose 1996: 12).

My son and daughter had known from the beginning, but they took the attitude that if they just ignored it and didn't talk about it, it would go away, like the flu (Rose 1996: 27).

Maybe it's cancer, and if I do not get it treated, I could die as 'me', not some very altered person who is totally confused and not connecting with life around her! (Bryden 1998: 47)

Slowly there might be less and less of 'the old me', as my brain slowly erodes away (Bryden 1998: 48).

Friends and relatives lose you by minute amounts each day, each week, each month, each year. So perhaps they will get used to this slowly evolving new person, until they have forgotten what you were really like before your brain started disappearing (Bryden 1998: 48).

I'm like a slow motion version of my old self - not physically, but mentally (Bryden 1998: 49).

*I want to shout. I want to raise some hell. I want to be somebody I'm not (Henderson 1998: 17).

Alzheimer's is a lot of stress, mainly because you know what you have been earlier and you know very well you're not that good now and it's real hard to reconcile (Henderson 1998: 74).

I will never see myself or the world the same way ... It is as if I received a death sentence and I have to begin a circumscribed life in a prison of fear. I see myself differently, almost as if a death ray penetrated me. l look in a mirror and discover I am crying (DeBaggio 2002: 26).

I can't explain why I didn't ask for help. Perhaps I was embarrassed at my sudden disability to solve minor problems. It was the first time I felt old, decrepit, and utterly useless (DeBaggio 2002: 116).

I am losing familiarity with myself (DeBaggio 2002: 172).

The reservoir of memory soon disappears and even the sound of breathing becomes unfamiliar (DeBaggio 2003: 17).

I looked at my left hand, as if for the first time. In the light I did not recognize the owner of these digits (DeBaggio 2003: 71).

When you can't remember yesterday, memory is your only link to who you are. What happens when memory is gone? Alzheimer's finishes you off (DeBaggio 2003: 190).

You may find this strange, but I consider my Alzheimer's diagnosis to be the best news I'd heard in my life ... I wasn't crazy. I wasn't stupid. I could quit trying so hard to cover up my forgetfulness (Lee 2003: 23).

*When I was first diagnosed with dementia, the thing that caused me the greatest shame and what really drove me into hiding was my problems with language (Lee 2003: 31-32).

Almost worse than having Alzheimer's is to have to always be convincing others that you have it ... The other thing is when people do believe, and then are overprotective and try to help too much. I'm tossed between feeling really grateful and kind of staying off on my own, just so I can be myself (Lee 2003: 33).

*It's depressing to think you might not be able to work again; that your days as a productive member of society might be over (Lee 2003: 37).

I'm so afraid to become a burden (Lee 2003: 73).

As I was losing my old identity I struggled with being depressed about it. This was indeed the "Twilight Zone"! ... I wonder if some of the depression and emotional fragility that we experience is due to the fight to reconcile the old and new self, when the fears and grief briefly overwhelm the inner positive spirit (Truscott 2003: 12-13).

But sometimes perhaps we 'look so well' and even 'seem so well,' that our care giver temporarily suspends the knowledge that we have dementia and expects us to perform once again like our old selves (Truscott 2004b: 277).

*It is now 2004, and I am still here, and it has been quite a journey of understanding, of seeing more clearly who I am now, who I am becoming, and who I will be when I die (Bryden 2005: 10).

Our main fear is the 'loss of self' associated with dementia. We face an identity crisis. We all believe the toxic lie of dementia that the mind is absent and the body is an empty shell. Our sense of self is shattered with this new label of dementia (Bryden 2005: 156).

I have always thought of it as a disease in three acts. The first act is the semiprivate act. The script is mostly within my own head. Only those around me really know I am not myself' but I am, in effect, acting the part of my old, pre-Alzheimer's self (Taylor 2007: 21).

I simply can't imagine who I will be or how I will think once the semi-transparent veil of Alzheimer's turns into the opaque curtain of Alzheimer's (Taylor 2007: 24).

I am starting to fear the coming of the end of me. Not the death of me, but the end of me as I know myself and as others have known me (Taylor 2007: 69).

*I am an empty vessel into which I throw a hand and a half of pills twice a day, and I desperately want the pills to reconstruct me (Taylor 2007: 75).

There are times when even I find it hard to find the Thou that I was before Alzheimer's (Taylor 2007: 153).

◆

TABLE 2

DEMENTIA EXPERIENCE THROUGH METAPHOR

My mind has become a sieve that can only catch and hold certain random things (Davis 1989: 21).

*In the swings of my emotion, from sunlight into ever blackening moonlight (Davis 1989: 22).

It is an old military maxim that the best generals win because they choose their battlefields carefully. The same thing is true with the early Alzheimer's patient (Davis 1989: 89).

These thoughts must be put on paper now. Tomorrow they may be gone as fleeting as the bloom of night jasmine beside my door (McGowin 1993: viii).

It was as though I was standing at one end of a telescope and my family at the other, each peering intently into the instrument, each with a quite opposite perspective ... From the opposite end of the telescope, my family focused not on what was now missing, but on what remained (McGowin 1993: 97-98).

I do not feel courageous. I feel I'm a pebble in a rapid brook. I hope this little pebble can send out ripples upon ripples, in an ever widening circle, until the ripples eventually lap up on a shore where someone like me is stranded and feeling alone (McGowin 1993: 118).

It was unsettling and unnerving, and for a time, I felt the uncertainty of a person experiencing a hurricane or a tornado for the first time; the terrifying sensation that comes on realizing that what should be firm and solid is no longer so, and cannot be relied upon (Rose 1996: 4).

Yes, it's a bit like the wheels of the roller-coaster cart, keeping us clinging onto the rails somehow (Bryden 1998: 11).

As I unfold before God, as this disease unwraps me, opens up the treasures of what lies within my multifold personality, I can feel safe as each layer is gently opened out. The fullness of who I once was will be seen in the simplicity of who I am within, surrounded by layer upon layer of memories (Bryden 1998: 49).

My sieve brain leaks too much! (Bryden 1998: 65)

It is like someone saying 'You will like my new compact discs. Here, I'll put three or four of them on at once so you can enjoy them' (Bryden 1998: 68).

The jumble of words inside my 'treacle brain' feels as if shelves of neatly ordered words in my head, all filed appropriately according to subject and so on, have been swept to the floor and are lying there in muddled heaps for me to sort through and try to find the one that belongs to what I am trying to say (Bryden 1998: 76).

If you were to ask me what are the most important things to help me now, in this stage of the disease, I'd say tacrine and brain gym. They keep me functioning, and keep challenging my brain to function, hopefully delaying my deterioration – and keeping me clinging to that precipice by my fingernails! (Bryden 1998: 84)

The disease works slowly, destroying the mind, stealing life in a tedious silent dance of death (DeBaggio 2002: 5).

The inspiration for this book appeared a few days after I was diagnosed with Alzheimer's. It was to be a word picture of the outside and inside, present and past, of a man's naked struggle with the unknown on his way to trembling silence and unexplainable torment without the torturer (DeBaggio 2002: 7).

It is a snapshot of a room that mirrors my brain, a jumble of words awaiting order with nowhere to go. Meaning is lost in a hurried moment, a word lost in confusion is never recovered. So it is that Alzheimer's begins its conquest (DeBaggio 2002: 15).

Now writing is like walking through a dark room. Sometimes I have to get down on my knees and crawl to find a path through the silent jungle where words are not easily picked and meaning is untrustworthy (DeBaggio 2002: 17).

Words slice through my mind so fast I cannot catch them and marry them to the eternity of the page (DeBaggio 2002: 27).

*Without memory you lose the idea of who you are. I am struggling more than ever to find answers to questions of identity ... At some time in the near future, I will begin to slip out of time, casually, in small increments. I will float on a tranquil sea of memory one moment and be swept away the next by boisterous waves that leave me confused and uncertain (DeBaggio 2002: 42).

My conversation with the world, in person or through this computer, has become something like a game show or a Scrabble contest (DeBaggio 2002: 73).

I concluded my brain was under siege from Alzheimer's at a quick march (DeBaggio 2002: 175).

*The words in my brain are silent, and the flood of sentences begins only when my pen unleashes a flood of writing memory (DeBaggio 2002: 199).

This is not a book crafted with care and threaded with hope. It is a book of anger and tears, expressed in a cage of waiting death ruled by Alzheimer's, a disease without survivors (DeBaggio 2003: 5).

In the end, this book is about becoming silent, while all around cars honk impatiently (DeBaggio 2003: 5).

My world today has all the strangeness of the flowing images of an underwater world (DeBaggio 2003: 7).

*When I die nothing will be left except someone else's memory of me. Only these words of mine will remain to shred my life into moments I now quickly forget (DeBaggio 2003: 19).

*Now, weakened by Alzheimer's, memories leak through holes in my brain, giving me one last glimpse of who I was and where I went, a last picture show (DeBaggio 2003: 35).

I sit at my worktable and rub my hand over the hard brown wood. I try to squeeze words onto the clean white paper. I cannot spill the words hiding in my brain (DeBaggio 2003: 47).

*Alzheimer's provided me an opportunity to give up dirt and search the rocky hillsides of memory for places where freshets remained to tell me who I was and where I have been. All around me I am greeted by my past, familiar places of memories from baby days to dying days, almost all in the same little community (DeBaggio 2003: 74).

The longer I carry Alzheimer's, the more I find myself seeking memories, even little shards to lick. It is a vain attempt to remember who I was and who was scattered around me (DeBaggio 2003: 183).

*The interiors and exteriors of the world flash before me but I cannot find ways to open them (DeBaggio 2003: 191).

*I am working today, tapping at this keyboard with little time left, in an attempt to understand who I was and what is left. I have little chance at knocking this computer many more days. I am up against the wall with little time before I hang up my passport and shiver into the last time of my life (DeBaggio 2003: 204).

My long-term memory is left battered; trying to find moments of the past is like fishing with a dull, rusting hook without bait (DeBaggio 2003: 205).

I used to be a race horse and master juggler, rushing from one activity to the next, and keeping many balls in the air at the same time (Truscott 2003: 11).

We feel as if we are hanging onto a high cliff, above a lurking black hole (Bryden 2005: 98).

Life has become a fragmented kaleidoscope of problems as we juggle an enormous pile of difficult tasks (Bryden 2005: 98).

*The unreliability of my memory is as if the printer ink is running low and it sometimes works and sometimes doesn't (Bryden 2005: 106).

It's as if I have lost all but one remaining key to the filing cabinet of my memories (Bryden 2005: 108).

All this effort at the computer, to try to keep reading, to keep active in my thinking -- it's a bit like I'm a 'brain athlete' from doing all those exercises ... Maybe it's a bit like being a wheelchair athlete, in that I feel as if I have a very muscled 115-year-old brain (Bryden 2005: 138).

*Right now, I feel as if I am sitting in my grandmother's living room, looking at the world through her lace curtains. From time to time, a gentle wind blows the curtains and changes the patterns through which I see the world. There are large knots in the curtains and I cannot see through them. There is a web of lace connecting the knots to each other, around which I can sometimes see. However, this entire filter keeps shifting unpredictably in the wind (Taylor 2007: 16).

I race up and down the corridors of my mind, frantically seeking to make sense of what's going on around me (Taylor 2007: 35).

Trying to figure out Alzheimer's when you have Alzheimer's is like trying to figure out how to build the space shuttle from a set of plans written in 10 different languages which were dropped on the way over and just randomly reassembled (Taylor 2007: 54).

I was afraid of Act Two because I heard I would be required to drift in and out, back and forth, from my old self to my new self. Playing two characters both at the same time; I wasn't looking forward to being someone with two identities (Taylor 2007: 57).

Fear, the fears generated by Alzheimer's disease, behaves much like magma. It spends most of the time unseen, under the crust. Some fear runs deep into our inner being. When it bursts, it burns all in its path. It quickly hardens, with a crust that cannot be penetrated easily. When someone or something manages to break the crust, more fear rushes out to burn all in its path and then to crust over again (Taylor 2007: 59).

When I first stumbled across Dr. Alzheimer in my brain, he was an occasional nuisance. He would empty a room full of memories here and there, and cause a couple of doors to stick, but I devised strategies to get around his tricks (Taylor 2007: 65).

My two largest and most active tumors … are my growing sense of loss of independence and my growing dependence on others (Taylor 2007: 92).

I have no idea who I will be when I am wheeled out for the final act on the Alzheimer's stage. But, I do know … I will still be me … perhaps a me different from what I have ever been before (Taylor 2007: 118).

When we both started this journey down Alzheimer’s Boulevard, we both believed and agreed that we were on this journey together, hand in hand, as husband or wife, or daughter and father, etc. I have learned that although we believe we are on the same road, we are, in fact, confined to our own lanes. We can’t cross over the double yellow line. It’s not against the law; it’s physically and mentally impossible. We can see each other, speak with each other, and even hold each other. Yet, we each have our own pot holes, our own detours, and our own road and life hazards that we must traverse by ourselves and within ourselves (Taylor 2007: 147-148).

As the weave of the lace curtain becomes thicker, as the wind blows away even the most recent memories, people do not have time to explain to me time and again the things that I don’t understand (Taylor 2007: 148).

Real or imagined personality changes, thinking patterns, and fears growing out of Alzheimer’s diagnosis have shuffled our own cards, and our couple’s cards, and our family’s deck (Taylor 2007: 164).

* * *

TABLE 3

DEMENTIA INSIGHTS FOR CAREGIVERS

People need to be better educated about Alzheimer's. Most people really want to know; there are just no teachers (Rose 1996: 32).

If only there was a way to tell them, without being arrogant, "Don't patronize me; I am not an idiot, although I now do some stupid things" (Rose 1996: 32).

*Alzheimer's is a bit of a taboo subject – or a bit of a joke. Families of sufferers are often ashamed of their very odd, 'batty' relative, and can't understand why they can't stop this silly behaviour. I am hoping to break that taboo – of being ashamed of a disease (Bryden 1998: xi).

Unfortunately I have a disease of the brain, so you just can't see the diseased bit of me. My outer shell is fine, it's just my mental powerhouse that is on the blink! What's wrong with me is inside my head (Bryden 1998: 46-47).

Conversations, chats, children playing, background music – all these are very hard for us to deal with because our brains work so much harder to sort out the competing sounds and sights in our surroundings so as to make sense of them (Bryden 1998: 52).

It is far easier to say your beloved family member has cancer, than to say he or she has dementia if they are no longer 'normal', no longer as easily acceptable in social settings (Bryden 1998: 53).

No one knows quite how to treat someone with dementia. Is it because we don't look sick? Is it because we seem to behave as if we have a mental illness? Should you talk to us as if we are 'normal'? Should you try to ignore us (not too obviously, of course)? Should you talk to our 'carer' ? (Bryden 1998: 53)

We need all the help and support we can get. Don’t hide us away – involve us, let us still experience the joy of living, with the help of your memory, your abilities, and your patience (Bryden 1998: 53).

Perhaps we need to rethink our approach to this terminal illness, and not only continue to give plenty of support to the carers (who need compassion, counselling and lots of practical help), but also support the sufferers (who will lose their capacity to think, to function, to be themselves). They, too, need help to overcome the shame of the disease, to alleviate some of its effects with modern drugs, and to understand more about what is happening to them (Bryden 1998: 53).

I am adept at ‘cover-up’ strategies. I laugh and joke; I speak slowly so as to make sure I don’t say silly words; I avoid questions; I try to cover up when my sentences aren’t going the way I intended. I try so very hard for the short time I am with you that you would hardly know I was ill (Bryden 1998: 58).

Even a quiet shopping trip can be very stressful if to go with someone, and am expected to hold a conversation as well as cope with the shopping decisions, and the sights and sounds around me (Bryden 1998: 68).

The reason for the blank stare of many Alzheimer’s patients may well be that they have been exposed to too much stimulus so there would be little point, and indeed it may be quite counterproductive, to try to ‘jolly them out of it’ by more stimulus, whether visual or sound (Bryden 1998: 71-72).

I can understand how Alzheimer’s patients might become quite violent when hurried or harried along by well-meaning carers, because they have pent-up frustration inside at simply being unable to get the words out – ‘I don’t want to do this!’ and to tell you why not (Bryden 1998: 74).

*One great source of comfort for me, though, was that a month or so before he died, my father had read the draft of this book, and had 'heard' me speak out about the really important things in life, and also how much better I was feeling. He was keen to speak to me, too, after reading it (Bryden 1998: 120).

I think for a lot of us the feeling of being cheated, or the feeling of being belittled and somehow made jokes of, I think that's one thing that is among the worst things about Alzheimer's (Henderson 1998: 37).

If we're not allowed or encouraged to tell the truth about ourselves, then we surely will be isolated on private, individual, lonely islands (Truscott 2004b: 276).

*Some friends and family seem to fear coming close to us to touch our true spirits. Perhaps they are uncomfortable, because they know instinctively that we are now different and they believe that their relationship with us has changed (Truscott 2004b: 276).

*Accept us as we are. We are still the same person inside, but now with new and changing challenges (Truscott 2004b: 277).

Continue to love us and respect us and show others that this is the model to which they should aspire. Do not speak for us unless we give you permission to do so; please reinforce that others give us the same respect. Help us to maintain our sense of identity and our self-respect. Do not smother us, but enable us to continue to be independent persons to the best of our ability and our choice (Truscott 2004b: 277).

*I reflect on a journey of living positively with dementia, and of discovering a journey into the centre of self. I speak to professional care-givers, families, medical professionals, and others, telling them what we feel like, what we need, and trying to give hope and understanding in the face of this mystery illness that robs us of who we think we are (Bryden 2005: 10).

*All of us travelling this journey have a right to be heard, to be listened to, and to be regarded with respect. There is no time to lose to hear our voice as we struggle to communicate (Bryden 2005: 44).

Maybe many of us would survive better and longer if we did not have to battle against the stereotype of dementia. Maybe many of us find it easier to give up and act like you expect us to, not speaking much or really 'being there' (Bryden 2005: 50).

*We seek recognition and inclusion alongside our care-partners, as companions on a journey of care (Bryden 2005: 65).

But this fact that we live in the present, with a depth of spirit and some tangled emotions, rather than cognition, means you can connect with us at a deep level through touch, eye contact, smiles (Bryden 2005: 99).

*Isolation is a real problem for us. Many of us feel that some people even think dementia is contagious! We don't see many friends any more. It seems as if people treat us differently now, because they know we have dementia, and they don't know what to do. Maybe they are worried about us saying something odd or doing something bizarre? Often we feel like we are being watched in case we do the wrong thing (Bryden 2005: 121).

It is very hard for us to be who we once were, so let us be who we are now – and realise the effort we are making to function (Bryden 2005: 127).

*How you relate to us has a big impact on the course of the disease. You can restore our personhood, and give us a sense of being needed and valued. There is a Zulu saying that is very true, 'A person is a person through others' (Bryden 2005: 127).

At the beginning, information is important and empowering. Tell us about the diagnosis, about how little is known, and how individual each one of us is. Refer us to the local Alzheimer's association for information and support about dementia (Bryden 2005: 129).

Make sure we don't give up, but don't overtax us. We will get easily exhausted, and need simple tasks that make us feel good about ourselves. Give us time and space to try to keep doing as much as we can. Don't take over unless you really have to. Let us make mistakes or fail, but don't let us feel a failure. Encourage us and make us feel worthwhile, still useful and valued (Bryden 2005: 135).

As we become more emotional and less cognitive, it's the way you talk to us, not what you say, that we will remember. We know the feeling, but don't know the plot. Your smile, your laugh and your touch are what we will connect with (Bryden 2005: 138).

*Each person with dementia is a gift, and has a great deal of wisdom about life. It is those around us who need to unwrap this beautiful package (Bryden 2005: 170).

What happens when you tell people you have Alzheimer's disease? My experience has been that the announcement is initially met with silence. People then express their sorrow, mention something about an article they read about new advances in the fight against the disease, and then change the subject (Taylor 2007: 51).

*Why not see us as a source of answers to our problems, rather than as a source of problems to which our caregivers need answers. We, too, want to be proactive when dealing with our symptoms, not just reactive to our problems! (Taylor 2007: 68)

As Alzheimer's progresses, human beings don't become aliens. They are still human beings, just repackaged in a way that is unique (Taylor 2007: 70).

I am on a mission to provide firsthand feedback about how I feel and what I think to those who treat me and those who take care of me. It helps me to continue to feel good about myself (Taylor 2007: 112).

I want my caregivers to better appreciate the differences concerning how I think and what I think about. For instance, if I call you 'Mom' or 'Dad', I am probably not confusing you with my mom or dad; I know they are dead. I may be thinking about the feelings and behaviors associated with my mom and dad (Taylor 2007: 135).

My brain is not the opposite of yours – rational versus irrational. We are, each of us, captives of our own paradigms, our own minds, our own memories, our own hardware. From your perspective, I have faulty hardware. From my perspective, you have faulty hardware (Taylor 2007: 137).

They [caregivers] spend even more time sharing practical suggestions on how to prevent me from hurting myself and others. I wish they would spend twice as much time on practical suggestions to enable me to continue doing what I want to do without hurting myself or others (Taylor 2007: 137).

We should listen to each other as we speak today. Take what we say, as best we can, at face value. Look for meaning based on who we honestly believe the other person is today, not yesterday or pre-diagnosis (Taylor 2007: 144).

I do know that I continue to need to be recognized as a Thou, to have my personhood recognized. Please understand, I am still here (Taylor 2007: 149).

*Thou, yours truly, has started to become an It. Of necessity, my caregivers would argue, but nonetheless an It. The same words are used to represent me – Richard, Dad, Grandpa, my husband – but what follows does not refer to who I think and feel I am. My behavior is treated as something apart from me. 'It's not him, it's the disease.' Unfortunately, I am both, and to the extent the disease has altered my behavior and thinking, it has altered who I am (Taylor 2007: 150-151).

*Watch my face for hints that I do not understand. Sometimes I don't speak, but my nonverbals shout (Taylor 2007: 153).

Present circumstances require us to talk more, not less. Even though it is no guarantee of success, if we do not try we are guaranteed, at best, limited success and, at worst, hurt feelings, which can lead to failure (Taylor 2007: 168).

It is not so much *what* people say; it is how they say it. It is their body language (Taylor 2007: 189).

I am not a child. Even if sometimes I act like one, check me out – I AM NOT A CHILD! (Taylor 2007: 190)

"Will you please work with me to find ways to enable me to do more, rather than disable me to do less?" plead I (Taylor 2007: 212).

* * *

TABLE 4

INSIGHTS FOR PERSONS WITH DEMENTIA

I am learning to take strength and comfort whenever and wherever it comes to me (Davis 1989: 57).

*I have a life that can be either frustrating and frightening or peaceful and submissive. The choice is mine. I choose to take things moment by moment, thankful for everything that I have, instead of raging wildly at the things that I have lost (Davis 1989: 57).

I must learn new ways to get things programmed into my brain, and I must find new ways to get my communication out to others. I must adapt to these handicaps for as long as I still have enough undamaged brain to do it (Davis 1989: 96).

I am still human. I laugh at the ridiculous disease that steals the most obvious things from my thoughts and leaves me sprouting some of the most obscure, irrelevant information when the right button is pushed. I want to participate in life to my utmost limit (Davis 1989: 100).

There is still a part of that vital person living inside that sometimes helpless-looking body, a person who deserves to be treated with dignity (Davis 1989: 101-102).

If I see someone approaching me, I try to ask the first question. It will be a timely question but one that makes little difference what the answer is ... sometimes this will buy me enough time to bring to mind some personal info so that I can ask about their work or family (Davis 1989: 103).

*I hope that it [the book] offers comfort to patients and their families and demonstrates that dignity is imperative for the survival of the self (McGowin 1993: viii).

I wished I could unload this burden, reveal my thoughts to someone, state my innermost fears and anxieties and receive kind support and understanding (McGowin 1993: 53).

Sharing perspectives, fears, empathy, moral support, even a few healing laughs is invaluable. Other people, those not in the labyrinth with us, may not understand our plight. Because we 'look okay,' others are surprised when we become lost in familiar surroundings. Because we 'look okay,' people raise an eyebrow when we cannot recall our children's ages, or perhaps their names. Because we 'look okay,' clerks become annoyed as we fumble, trying to count out the money for a purchase (McGowin 1993: 115).

*And although there are many days when I am painfully aware that less of me exists than the day before, for now, I can say, I am still here (McGowin 1993: 116).

*With my husband's dogged skills at the word processor, I've continued to keep a journal. It is written with an eye towards coping, and when I reread it I am reminded that, even with Alzheimer's, life can be fun (McGowin 1993: 125).

*It is by 'focusing,' or channeling our energies into one tight circumference of attention, that we patients are able to 'pass,' or perform satisfactorily. We still have much to contribute, but must be granted our individual requirements for successfully contributing (McGowin 1993: 137).

*Diana encouraged me to write, and to keep pressing myself to the limit (Rose 1996: 103).

I would love to see some people with Alzheimer's not trying to stay in the shadows all the time but to say, damn it, we're people too. And we want to be talked to and respected as if we were honest to God real people (Henderson 1998: 7).

*There are things I wish I could do, but on the other side, there are still things that I can do and I plan to hold on to them as long as I possibly can. Laughing is absolutely wonderful. A sense of humor is probably the most important valuable thing you can have when you have Alzheimer's (Henderson 1998: 14).

I think one of the worst things about Alzheimer's is you're so alone with it. Nobody around you really knows what's going on. And half the time, most of the time, we don't know what's going on ourselves. I would like some exchange of views, exchange of experience, and I think for me at least, this is a very important part of life (Henderson 1998: 55).

To some degree, we can be just like any other people, although we do forget more and we lose more. We really do want to be like human beings (Henderson 1998: 56).

*We can to some degree, I hope, encourage people who have Alzheimer's to not be ashamed and not be any more, you might say mind-paralyzed, than they are (Henderson 1998: 57).

Sometimes we miss being important – miss being needed (Henderson 1998: 74).

With more information, I hope some people may get diagnosed earlier, and that they and their families can be helped to understand and cope with this disease that robs you of much of what makes you who you are (Bryden 1998: ix).

*Why be ashamed of the physical breakdown of brain cells any more than the physical breakdown of other parts of our body? We are not mad, but sick, so please treat us with dignity, do not make fun of us, and do not be ashamed (Bryden 1998: xi).

Having a disease which slowly takes away your mind bit by bit makes you realize how important it is to hang onto those few freedoms you already have for as long as possible (such as driving, or operating your finances), because the world out there is only too willing to take those freedoms away from you (Bryden 1998: 87-88).

I want to carry on drinking in the beauty of this world, feel the love of my family and friends, and even if I might not remember these experiences for very long, I still want to have them. Surely remembering an experience doesn't constitute the sole enjoyment of that moment! (Bryden 1998: 145)

*I have begun to adjust my life so each day has a structure to it, and a purpose: to enjoy every minute I can and to focus on the work I love with herb plants, and with words (DeBaggio 2002: 29).

*Alzheimer's creates private family pain, the kind hidden and denied. It is so corrosive it can leave scars on the soul and disrupt relationships ... I worry I might hurt my wife and son and engender frustration in their lives (DeBaggio 2002: 108).

*... to break through the sense of shame and silence Alzheimer's has engendered. I want people with the disease to come forward, unafraid of exposing their illness, and tell the world what it is like (DeBaggio 2002: 141).

*In the other, slower world where I write on paper or directly on the computer, vocabulary is more fluid and I often surprise myself when the perfect word finds its way into the sentence without effort. This has puzzled me from the first sentence I wrote for this book. It is only now, eight months later, I begin to see more clearly how necessary it is to slow the pace to achieve a former normality (DeBaggio 2002: 180).

My cats, Sabina and Una, by their presence alone, help me remember who I am when I can't (DeBaggio 2002: 185).

With Joyce's arms around me for comfort, I began mumbling, "I am home. I am home." I needed assurance I was no longer in the terrible dream in a broken world out of order, licked by chaos (DeBaggio 2002: 190).

My exchange with the world brings to life the dead places in me (DeBaggio 2003: 190).

*I've accepted that I'll never be the way I once was, but I'm still a person. I just want people to understand that it's not easy, but life goes on. If I ever lose my sense of humor, that's when I really have a problem (Lee 2003: 35).

Having regressed in life from management positions to caregiving to housekeeping gets me down sometimes ... The most important thing to me is that my work is appreciated, and I am constantly being reminded that it is appreciated. In many ways, my present jobs are more rewarding than those former management positions, because I know that I'm doing the very best work that I can, and I'm not sure that was always the case earlier in my life (Lee 2003: 41-42).

*I crave someone to talk to that has it too; someone to compare stories with; someone to cry with; someone to laugh with; someone who really knows what it's like from the inside (Lee 2003: 44).

No wonder we hide. We are in a world alone, where lots of people try, but no one really understands, because we have no voice (Lee 2003: 45).

We, who have the disease, need to be able to grab onto the little pieces that are still there and make them wonderful (Lee 2003: 46).

*I am daily in a state of adjustment, trying to reconcile the old me with the new me, and accept that being slow, doing less, experiencing less, achieving less, is all right (Truscott 2003: 12-13).

I have, like many people in the early stages of Alzheimer's disease, strong insight into my situation (Truscott 2003: 13).

I have started to communicate with the outside world by email … Like many other people with early stage dementia, I have a network of friends in that world wide community, and I keep in touch with a regular exchange of chatter, humor, coping hints, and encouragement (Truscott 2003: 15).

*What a sense of accomplishment, and reinforcement of self-worth it is, to make something, paint something, and finish something, in spite of cognitive problems (Truscott 2004a: 94).

I make poems as I feel moved and I am collecting them in a personal book that I will someday share with my children (Truscott 2004a: 96).

They can use tape recorders and speak their stories and have someone else type them out later (Truscott 2004a: 97).

If we're not allowed or encouraged to tell the truth about ourselves, then we surely will be isolated on private, individual, lonely islands (Truscott 2004b: 276).

The publication of my book catapulted me reluctantly into the public eye in mid 1998, as someone with dementia who could still speak, and who was also prepared to talk openly about this disease … I had 'come out', disclosing my disease, rather like those with AIDS must feel, brave enough to admit to a disease that people dread. Dementia was a shameful disease, to be feared or denied, not one to be acknowledged and battled with (Bryden 2005: 39-40).

A few days later, a beautiful sunny, warm May morning, I received the galley proofs of my first book. They looked great! Maybe they would act as a 'prop' for talking to someone at the Association, maybe they would prove I was someone with dementia, give me the necessary credentials somehow? (Bryden 2005: 41)

Such charts and graphs and stages [of dementia] deny me my individuality, stripping me of any credibility at still being able to speak after years of living the journey of dementia (Bryden 2005: 49).

There is such a terrible stigma attached to this disease that no one wants to talk about it or admit to a diagnosis, even seek one. So we struggle to remain 'normal' and pretend we are feeling fine. But we are not – it feels very different now to how we once felt. We know what it felt like to be normal, and that is not what it feels like now (Bryden 2005: 97).

We need to focus on enhancing our remaining abilities and compensating for any losses, and maybe even working towards a new perspective of daring to try to recover skills, develop new talents, and create a new future invested with meaning and hope (Bryden 2005: 134).

If we do believe the lie of dementia, that we can't learn new things, remember anything reliably, or find our way around, we are blindfolded to our own potential. We withdraw into helplessness and let our families take over (Bryden 2005: 143).

*I choose a new identity as a survivor. I want to learn to dance with dementia. I want to live positively each day, in a vital relationship of trust with my care-partners alongside me. By rejecting the lie of dementia, and focusing on my spirit rather than my mind, I can be free of fear of loss of self, and in so doing can also help you to lose your fear that you are losing me (Bryden 2005: 170).

I would encourage people with a disease that alters their thinking to write; not just a journal of what happened today or a dozen to-do lists for tomorrow. Think about yourself, your caregivers, your relationships, your present, and your future – and write (Taylor 2007: xviii).

I believe our fears, and specifically my fears – fear of losing control, fear of what will happen tomorrow, fear of who I will become, fear of the unknown, and the list goes on – are as much or more of a problem for me in my day-to-day living than is the disease itself (Taylor 2007: 60).

I live with the disease, but the disease lives in my mind, not in me. I can observe it. I can speak about it, think about it and worry about it (Taylor 2007: 89).

*I appreciate and sometimes immerse myself in the process rather than only or mostly on the outcome. I like doing things. I like and appreciate the doing. Doing is how I know I am alive, and how I appreciate being alive (Taylor 2007: 105).

The locus of my attention is definitely shifting from my head to my heart. I feel and think about feelings more that I think about thinking (Taylor 2007: 128).

I developed some pretty slick strategies to hide my scrambled and fading cognitive functions. I would control conversations, change subjects, use words few understand (and, thus, were hesitant to question) and on and on (Taylor 2007: 138).

If I must lose control of my cognitive processes, knowing what is happening is the next best thing (Taylor 2007: 135).

*I have become keenly aware of a patterned response from some individuals as soon as they find out I have Alzheimer's disease. They switch their eye contact and attention to whomever I am with. It is as if knowledge of the disease immediately cloaks me in invisibility (Taylor 2007: 152).

Actually, what I need is to feel that I am still taking care of something. Something that returns love, that gives itself away without expecting anything back, that wants to please me … all the time! Something that never, ever judges me but just accepts me for who and what I am at that particular moment. Something that is not hung-up about who I was, or who I am, or who I will be (Taylor 2007: 179).

*All who are ingredients in the pressure cooker of Alzheimer's should write and share their thoughts and writings with others (Taylor 2007: 186).

I am talking about the way we speak and write about our experiences to each other, and frequently to ourselves, through journals and, now, blogs. Once the disease is conquered, and it will be at some future point in time, readers and writers will lose forever the sense of what it was like to live with the disease of probably the first 50 or so years of the 21st century (Taylor 2007: 186).

Pick up your pens, or sit down at your word processors. Think, feel, and write! You are writing the poetry of Alzheimer's disease (Taylor 2007: 187).

◆

APPENDIX:

CHRONOLOGY OF DEMENTIA MEMOIRS

1989 Davis, Robert. *My Journey into Alzheimer's Disease.* Wheaton, Il: Tyndale House Publishers.

1993 McGowin, Diana. F. *Living in the Labyrinth: A Personal Journey Through the Maze of Alzheimer's.* New York: Delacorte Press.

1996 Rose, Larry. *Show Me the Way to Go Home*. Forest Knolls, CA: Elder Books.

1998 Bryden, Christine. *Who Will I Be When I Die?* East Melbourne, Australia: Harper Collins [original edition Christine Boden].

1998 Henderson, Cary Smith. *Partial View: An Alzheimer's Journal.* Dallas: Southern Methodist University Press. (Selections made for book from tape recorder transcripts by Nancy Henderson).

2002 DeBaggio, Thomas. *Losing My Mind: An Intimate Look at Life with Alzheimer's.* New York: Free Press.

2003 DeBaggio, Thomas. *When It Gets Dark: An Enlightened Reflection on Life with Alzheimer's.* New York: Free Press.

2003 Lee, Jeanne. *Just Love Me: My Life Turned Upside Down by Alzheimer's*. West Lafayette IN: Purdue University Press.

2003 Truscott, Marilyn. "Life in the Slow Lane." *Alzheimer's Care Quarterly 4*(1): 11-17.

2004a Truscott, Marilyn. "Adapting Leisure and Creative Activities for People with Early Stage Dementias." *Alzheimer's Care Quarterly 5*(2): 92-102.

2004b. Truscott, Marilyn. "Looks Can Be Deceiving - Dementia, The Invisible Disease." *Alzheimer's Care Quarterly 5*(4): 274-277.

2005 Bryden, Christine. *Dancing with Dementia: My Story of Living Positively with Dementia*. London: Jessica Kingsley Publishers.

2007 Taylor, Richard. *Alzheimer's from the Inside Out.* Baltimore: Health Professions Press.

ABOUT THE AUTHORS

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WRITING DOWN OUR YEARS SERIES

FROM
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