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## The dementia narrative: Writing to reclaim social identity

Ellen Bouchard Ryan\*, Karen A. Bannister, Ann P. Anas

McMaster University, Canada

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## ABSTRACT

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 the 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.

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"Who will I be when I die?" asks Christine Boden (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, & Anas, 2005c).

In this article, 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. This helps individuals to move beyond 'suffering' to truly 'surviving.'

We examine the concept of social identity, the social condition of individuals with dementia, and the particular

\* Corresponding author. McMaster Centre for Gerontological Studies, KTH-226, McMaster University, Hamilton ON CANADA L8S 4M4. Tel.: +1 905 648 0437; fax: +1 905 525 9148.

E-mail address: [ryaneb@mcmaster.ca](mailto:ryaneb@mcmaster.ca) (E.B. Ryan).

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 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, & 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 & Abrams, 1988; Sabat & 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 & Abrams, 1988: 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 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 & 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 & 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), 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 proposes that individuals move through eight stages – from infancy to late adulthood; a ninth stage was added, but published post-humously (Erikson & Erikson, 1998). 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 & Erikson, 1998). The ninth stage was added to account for the 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 & 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 a different part of the body feels old (Whitbourne, 2001). For example, the graying 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. In Whitbourne's theory, as in Erikson, there is room for human variability; as with all models, they do not assume universal truth. The models do, however, contribute to an understanding of how individuals might confront major life changes.

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 contributing 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.

### 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 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 article 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.

### 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 center 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 impair 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 & Giles, 1997; Gallois, 2004; Killick & Allan, 2001; McBryde Johnson, 2005; McColgan, Valentine & Downs, 2000; Ryan, Bajorek, Beaman & 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).

*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 & 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 (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 & 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 with 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 in the construction of personae like 'patient' and 'dysfunctional' (Sabat, Napolitano, & 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 be easily 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).*

*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 checkbook, 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 & Bredin, 1992; Orange, Ryan, Meredith, & MacLean, 1995; Ryan, Byrne, Spykerman, & 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).*

*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 and reduce positive experiences. 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 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 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 & Erikson, 1998). Perhaps some of the behaviors 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, & Beck, 2005: 7).

### Finding social identity

Writing provides an opportunity to engage in meaning-making dialogue with others, an activity which 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 powerful tools 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 & Holstein, 1998).

Furthermore, storytelling is a natural human activity (Randall, 1999). According to Hardy (1968, as cited in Randall, 1999: 11): “we dream in narrative, daydream in narrative, remember, anticipate, hope, despair, believe, doubt, plan, revise, criticize, construct, gossip, learn, hate, and love by narrative.” Indeed, Erikson (1950) 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. An individual can also find perspective through humor 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 & 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).*

*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*

Complex ideas 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 benefits from greater clarity. The dementia narratives demonstrate ample use of metaphor by some of the authors.

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. Moreover, Basting (2003a) draws attention to the creative potential of individuals even in the moderate to advanced stages of dementia. 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 & 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 in chronological order 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 changed 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 the mother of 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)."

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 center 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 later 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 cannot 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 the mother of 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 mumble jumble, night-typing, seven years of journals, and tape-recordings to paper in a manner that is readable (2003: 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 has been an active volunteer with the Alzheimer Society of Canada 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.

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 & 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 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 impose 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 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' personalities 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 to remind others of an individual's continued wellness and sense of competence. 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).*

#### 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, 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." (viii). 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.

*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).*

The authors offer 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.

*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.

*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).*

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

*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 author(ity) 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 newfound 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 declines. We suggest that writing is 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 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 the 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 had 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 & Ryan, 2003). Writing is an activity that can be performed by all, regardless of education, income or cultural background. It is most likely accomplished, however, where social support systems exist – whether family- or community-driven.

This article 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 & Allan, 2001; Kitwood, 1997; Sabat & Harré, 1992). Writing supports personhood-centered 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.

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<sup>1</sup> [Dementia memoirs are identified by an asterisk.]