

## **USING NARRATIVE ARTS TO FOSTER PERSONHOOD IN DEMENTIA**

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### **[A] Introduction**

The cognitive losses in dementia and the excess disability associated with the label of dementia threaten personal identity and sense of self (Fontana and Smith 1989). Opportunities for communication are especially constrained for individuals with dementia who reside in assisted living or long-term care facilities (MacDonald, 2006). The construction, telling or writing, and sharing of stories serve to promote connections between the person living with dementia and others, thereby fostering personhood.

This paper will explain the use of narrative arts in the promotion of personhood in dementia care. It addresses the use of narrative arts such as storytelling, life writing, memory boxes, and collaborative poetry, and provides case examples. The clinical implications of narrative arts for the care of persons with dementia as well as staff development needs are also discussed. We begin with a description of the Canadian context for research concerning older adults with dementia.

### **[A] Aging, dementia, and caregiving in Canada**

Canada's population of older people is growing, increasing from 11% of the total population in 1987 to 13% in 2007. By 2056, it is anticipated that the number of people over the age of 65 years will further increase to 27% of the total population. It is forecasted that the population segment that will experience the most growth will be older people over the age of 80 years. This group is predicted to increase from 3% of the total population in 2007 to 10% by 2056 (Statistics Canada 2008). Given that age is considered to be the number one risk factor for Alzheimer's disease and related dementias (ADRD), the aging of Canada's population will have direct consequences on the number of people living with these illnesses. The incidence of ADRD in Canada was 103,700 new cases per year by 2008. The prevalence of ADRD in Canada was 480,600 people (1.5% of the total population) in 2008. This is expected to rise to 1,125,184 or 2.8% of Canada's total population by 2038 (ASC 2010).

The economic costs associated with ADRD are considerable. It is estimated that the cumulative incidence of dementia will be more than 5.5 million people by 2038, with an associated economic cost of C\$872 billion. While individuals with dementia in the early to moderate stages of the illness will most likely be cared for at home, most persons in the later stages of the illness will require some type of facility-based care. In 2008, 45% of Canadians with dementia over the age of 65 years were being cared for in long-term care homes. It is anticipated that the demand for long-term care beds will increase but there will most likely be a shortfall (ASC 2010).

Clearly, the burden associated with care requirements that are and will be needed for older people with ADRD, demands attention to the development and testing of creative, useful interventions. Narrative arts offer important approaches to enhance the care for such individuals, particularly those in mid to late stages of the disease process who are living in facility-based care.

### **[A] Personhood in dementia care**

Within the bio-medical paradigm, personhood is frequently presented as dependent on cognition. Until recent times, the predominant health care discourse focused on understanding the deterioration or ‘de-selfing’ of the person with dementia (Fontana and Smith 1989). This negative discourse was challenged by Kitwood (1990, 1993, 1997), who argued that – instead of focusing on intellect, cognitive capacity, and autonomy – personhood should be based on feelings and the ability to live in relationships. He conceptualized personhood as a status that is granted upon one person by others within the context of their social interactions. Personhood is recognized and validated through the relationship-centered aspects of conversation and communication through engagement, insightful listening, acknowledgement of emotions, sharing ideas, reflection, and demonstrating acceptance. Kitwood believed that personhood can be maintained for individuals living with dementia by enabling choice, the use of remaining abilities, and expression of feelings.

Sabat and Harre (1992) have also argued that the excess disability created by others around dementia threatens the self as much as the disease itself. Through detailed presentation of personhood-oriented conversations, Sabat (2001) has shown that people with moderate to severe dementia can connect with a conversational partner and overcome the loss of self-worth associated with their typical treatment. Furthermore, he has shown how inappropriate behaviors, usually taken as symptoms of pathology, are often strategies for coping with boredom, frustration, and isolation (see also Hughes et al. 2006). Through the work of Kitwood, Sabat, and others, an emergent key theme is that efforts to find the person behind the dementia repay the caregiver with reciprocity, creativity, and humor.

Placement in long-term care homes can have a negative impact on both the person with dementia and their family caregivers. Emotional distress and depression are common during the post-institutionalization transition period (Paun and Farran 2006). According to Brooker (2007), formal caregivers can promote person-centered care of persons with dementia by regularly asking clients and families for their preferences, consent, opinions, and thinking about decisions from the resident’s point of view, as well as being attentive to and recognizing physical needs, and analyzing challenging behavior to understand underlying reasons for it. Developing these habits can prevent formal caregivers from attaching stereotypical meanings to behavior by bringing the person’s unique personhood into clear view.

Creating a supportive social environment is also a means of getting to know residents’ personal characteristics. Brooker (2007) encourages the inclusion of residents with dementia in conversation, that is, treating them with respect, warmth and acceptance, taking their fears seriously, helping them be active in their care, and keeping them in contact with the community. Attentiveness to social needs and encouraging involvement in these ways can help to continuously remind staff of residents’ personal identities. While Brooker’s recommendations are reasonable, it is important for professional caregivers to identify specific interventions that

help build and maintain a rich social environment by taking the residents' personal identities into full account. Narrative art forms create ideal contexts within which person-centered conversations can take place.

### **[A] Narrative arts in dementia care**

Older adults with dementia usually experience an impoverished social environment unless conscious, deliberate opportunities to engage in meaningful conversation are provided (Hopper et al. 2007). Older adults with cognitive impairment experience decline in various aspects of language function, including narrative discourse. Narrative discourse involves the oral representation of a significant, meaningful event or series of events in a person's life. Narrative discourse capacity is impaired in ADRD as a result of reduced access to vocabulary and to poorer topic management skills (Davis 2005). However, persons with ADRD can often produce socially ritualized aspects of conversation, particularly when facilitated by other people who are familiar with the individual's typical communicative strategies such as pitch, rate, intensity, movements, facial expression, and gestures (Moss et al. 2002). It is increasingly apparent that arts-based therapies such as visual art, music, drama, poetry, horticulture, dance and storytelling can be important vehicles for patients to express their thoughts, emotions and ideas in symbolic fashion. It is the process of creation, not the product that remains the focus of such intervention (Lamb 2009).

In particular, the sharing of stories is a medium through which people who are ill can transcend their experience of illness so that their humanness is affirmed (Cangelosi and Sorrell 2008; Frank 1995; Mitty 2010; Scott and DeBrew 2009). In the case of an older person with advanced dementia, the storyteller is often a family member or formal caregiver, who, by telling the story, bears witness to the survival of the person's fundamental spirit. By preserving and re-telling the older person's favorite stories, the caregiver serves a moral imperative that builds and maintains personal identity through becoming a comforting companion (Mitty 2010). Persons in various stages of dementia can succeed in telling episodes from their lives or in writing life stories within a facilitating environment. The goal of narrative arts in dementia care is to provide just the right assistance so that the person can express their message – the voice is their own. The narrative arts we address here include storytelling, facilitated writing, and narrative thematic conversation.

### **[A] Storytelling to connect**

Storytelling reconstructs personal identity through active exchange with the listener. Thus, the story serves as a medium to sustain the self while at the same time communicating information about the self with others. The storyteller can choose to select life events that will be shared, and some details may become embellished or be eliminated over time. The telling and retelling of the story will continue to change and shape personal identity as the plot ebbs and flows (Holstein and Gubrium 2000). Stories inform us who we were, who we are now, and who we could be if all things were possible. Stories also help all people, including those living with dementia, to make sense of what has happened, what is presently happening, and what they fear might happen to them in an unknown future (Somers 1994). Past, present and future become linked and

understood through the chronology of events presented in life stories. Personal identity is reinforced as the story of the self changes (Rasmussen 1995). By telling and retelling personal stories, older adults engage others in conversation that reinforces and shapes their identity and their position within the internal and external world.

Through a series of case studies, we have come to understand how conversation based on narrative art forms between persons with dementia and their formal caregivers can lead to the building and remodeling of a personal story to fit shifting circumstances. We have discovered how building the story together, then telling, writing and retelling the story leads to conversation and relationship, and how relationship and story lead to a sense of belonging and reclaimed identity. While the stories are important in themselves, they also have direct application to clinical situations, thus enhancing professional caregiving.

### **[B] Life story dictation**

Personal storytelling can be used by caregivers to help the person reconnect with life moments and family members of great importance (Ryan, Schindel Martin and Beamer 2005). As one example, life story dictation was used by LSM in clinical practice to address an older client's repetitive yearning for her long-dead mother – creating, telling and re-reading the story of her mother acknowledged and satisfied the deep need underneath this seemingly impossible request.

### **[C] Case example**

Mrs. Hazel Broadfoote (pseudonym) was a 98-year-old resident of a long-term care facility situated in Central Ontario. Mrs. B grew up on a rural dairy farm that had been owned by her family for many generations. The family were United Empire Loyalists who originally came to Canada from rural Pennsylvania just prior to the revolutionary war in the United States. Mrs. B married at the age of 16 to a second cousin who took over her parents' farm. Together they raised five children. Despite hard times during the depression, Mrs. B was proud that they always served nutritious food at the table, and were able to provide free lodging to the school teacher who taught at the local one-room school house. Mr. and Mrs. B retired in 1968 and moved to town where they became actively involved in church life. Mr. B died in 1982, and Mrs. B continued to live in their home until her daughters noticed that she was beginning to have trouble cooking and preparing food. She lost approximately 30 pounds over the space of 3 months. She was admitted to a long-term care facility after a fire broke out in the kitchen. Mrs. B's daughters all live nearby and take turns visiting her. Mrs. B frequently interprets her surroundings as the bus station. She frequently asks passersby for a 'nickel' for the bus so she can get to the farmer's market to help her mother. In fact, her major preoccupation most days is to roam the hallways and dining room of the long-term care home looking for her mother. She talks of needing to get the cows in for milking, or hoping her mother isn't angry because she thinks the cows have been forgotten in the pasture. Sometimes she becomes agitated because she needs to leave to get the cows in before her mother returns from market.

The health care team worked directly with Mrs. B to record many details with respect to her mother, family, and farm life. These details have been written into the form of a story in which Mrs. B is cast as the main 'character' as a young child. Copies of the story were recorded

in large print text and when Mrs. B became agitated, the formal caregivers would engage her in the following conversation:

**[Conversation btw. MRS. B and TEAM MEMBER here]**

Mrs. B would listen to these stories and provide additional details such as ‘There was an iron gate that led to the front garden. Mother wouldn’t let us swing on the gate. We always did anyway. One day I fell off the gate and mother said that was why I have flat feet.’ The additional details were added to the story over time so that it included moments of significance from life events and thus had more meaning for Mrs. B. Layering in additional details as she told more stories, allowed us to give back information that led her to feel deeply ‘understood.’ While this process was not always helpful, for example, if Mrs. B was physically ill, the storytelling approach was very effective for the majority of episodes. Indeed, Mrs. B’s response to the storytelling was used as a clinical predictor of the etiology of her agitation. If she did not respond positively to the story, it was hypothesized that her agitation might be the result of a medical problem, such as a urinary tract infection; therefore, treatment needs could be identified.

Life storytelling is a tool through which professional and family caregivers can help the older person with dementia make sense of the present moment. Without the story, reassurance will not be as meaningful or effective. The story grounds reassurance in the context of familiar, concrete life events through things only a real friend would know about and share back and forth on a regular basis. This helps staff to have very specific life events to retell to the resident, thus avoiding general platitudes such as ‘don’t worry, you’re okay’ that only serve to patronize and frustrate the individual. In this case example, life storytelling brought Mrs. Broadfoote’s mother ‘back to her’, not in person but, rather more importantly, in essence.

**[B] Conversational remembering boxes**

The Conversational Remembering Box represents another strategy we have developed to engage persons with dementia and promote personhood-preserving strategies in conversation and storytelling (Hagens et al. 2003). At the early stage of dementia, individuals can be encouraged to prepare their own Remembering Box which they can use when conversation becomes difficult. At the moderate or late/moderate stages of dementia, family and staff can initiate the preparation of a Remembering Box, with pictures, objects, audio/video tapes, and writings. The box itself can be meaningful, such as a nostalgic hat box from the 1940s or a man’s longtime fishing tackle box. Remembering Boxes have included personal and family photos, pictures and information related to homes and travels (saved or from the Internet), religious items, medals or award certificates, hobby materials such as fabric for a quilter, favorite music and movies, grandchildren’s letters or drawings, and ancient or recent letters.

In our experience, written (or taped) records of individuals telling their stories in their own words is very important for the Remembering Box. Individuals able to read aloud often begin adding to their stories when reading their own words (the use of larger fonts can often help). Those unable to read are often induced to continue their story by hearing their own favorite expressions, their own way of telling that story (see also Davis and Smith, this volume). The Remembering Box is intended to grow and change over time as new items are brought for inclusion. Most importantly, a journal is included in the box so that visitors/staff can write down

new stories and additional details offered by the individual. The best of these are later typed for inclusion in the Box.

The Remembering Box can be used by family or staff to engage the individual in conversation. Again, the critical element here is that the memory boxes are much more than the opportunity to present familiar objects. Rather, it is a process whereby elements of the self are introduced to reinforce personhood. This resource helps family members move away from short-term memory questions which are so problematic for the person with dementia and move them toward conversational topics where the person with dementia can often participate 'richly' and become 'more like themselves'. Staff responses in Hagens et al. (2003) showed that long-term care residents wanted visitors in the room to look into the box (even if not remembering why) and that they were sometimes able to take control of the conversation as they remembered. This resource can be especially useful when long-term care staff have just a few minutes to talk or when the resident is agitated in the middle of the night. Finally, creating a Remembering Box is an excellent activity for family to carry out with loved ones moving into long-term care.

Basting in her (2009) book on dementia demonstrates the deep desire of both individuals with dementia and their families to connect in the present and for the purposes of creating a legacy: the Remembering Box, especially the written stories in the person's own words, connect in the present and also serve as a valuable legacy for family. Furthermore, Basting (2007) reports that individuals with dementia and their families have been eager to participate in the StoryCorps Memory Loss Initiative. In this initiative, a family member or friend is guided in deep listening and the asking of appropriate questions to elicit stories from the person with dementia in an audio recording booth. The recorded stories, Basting showed, become a magnificent mutual family accomplishment as well as a valued contribution to a legacy. Such audio (or video) recordings would fit very well in the person's Remembering Box.

### **[C] Case example**

Mrs. Verna Stemple was a 79-year-old resident in a long-term care facility who made her living in Paris as a seamstress. She worked for a couture fashion house for many years. She came to Canada just before WWII broke out in Europe. She was called upon by many famous people in the Toronto arts community to design and sew replica ball gowns and dresses for parties during the 1950s and 1960s. For example, they would bring her photos of Jacqueline Kennedy published in *Look* magazine and ask her to design something similar to wear during the holiday season. Mrs. S enjoyed some degree of celebrity during this time. After admission to the long-term care facility she became quite certain that no-one knew who she was, not as the mother of her children, and wife of her husband, but as the very famous seamstress who enjoyed considerable success. Her family brought in her seamstress measuring tape, her thimbles, her patterns, sketches, and photos, and all were placed in a Remembering Box. Both professional staff and family members used the items from the box regularly. Mrs. S was particularly fond of looking at the photograph of her youngest daughter in the wedding gown that Mrs. S had designed and sewed for her. Although she did not recognize her daughter in person, she absolutely knew who the person in the picture was, and this photo in the Remembering Box served as the bridge through which mother and daughter could connect in the past/present moment.

## **[A] Facilitated writing**

Many older adults enjoy putting stories from their lives into written form – through personal journals or letters initially and, for some, then sharing written stories more widely with family or a writing group or through publication of memoirs and autobiographies (Ray 2000). As presented in Ryan (2006), individuals experiencing chronic illness or acquired disability, including dementia, have been drawn to write as a means to reflect systematically on their experiences and threatened sense of self. Finding one’s voice through personal writing fosters self-expression, creativity, emotional outlet, problem solving, perspective taking, and memory. For persons whose condition, like dementia, is associated with communication and memory problems, writing one’s story offers some specific benefits over telling one’s story orally. These specific benefits include: greater control over time, topic and environment; flexible pace; reliance on others or on technology not visible in the product; less reliance on good memory; no need for hearing or monitoring nonverbal cues (Ryan, Spykerman and Anas 2005; Ryan 2006). Moreover, the ideal reader understands perfectly so there is no need to have a specific interested and empathetic listener immediately at hand.

## **[B] Memoir writing**

Some individuals with diagnoses of probable Alzheimer’s disease have published their memoirs in book or essay form. Basting’s (2003) analysis of books by three authors offered numerous insights into dementia, especially about the continuing sense of self. Ryan and colleagues (2009) extended this work by analyzing the published dementia memoirs of nine writers, using the authors’ own words to show how these individuals, after being diagnosed with Alzheimer’s or related neurological disorders, had reclaimed their identity through their writing roles as creators, chroniclers, teachers, advocates, and social contributors.

Dementia memoirs articulately and compellingly counter the stereotypes of persons with dementia as no longer capable of new learning and as without insight into their losses and strengths. These autobiographical writings each put a distinctive face on dementia and draw attention to the accomplishments possible after such a diagnosis. The metaphoric language characteristic of dementia, as Killick and Allan have shown (2001), emerges especially positively as authors reach for words to describe what is happening to them. The following are a few examples of particularly telling metaphorical language, collected from various memoirs.

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

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)

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)

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)

Authors describe counter-stereotypical experiences such as learning to use the computer after diagnosis as a way to cope with deteriorating handwriting and as a means of staying in touch with people when going out has become difficult. Under favorable writing conditions, they can recount daily experiences of figuring out how to get something done when they cannot rely on their memory and give reasonable explanations for their otherwise weird behavior. For example, Henderson in his *Alzheimer's journal* (1998) explains (to his daughter) that he froze on the stairs the day before because his vision was so distorted he could not tell whether the stairs went up or down at a time when his ability to talk had also fled.

Authors with dementia write about how they manage to write a book, giving worthy insights on adaptation to cognitive difficulties and wise use of technical and family help. Most poignantly, they write about how the behavior of others constrains their opportunities to participate in life and realize their potential.

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 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)

Watch my face for hints that I do not understand. Sometimes I don't speak, but my nonverbals shout [...] It is not so much what people say; it is how they say it. It is their body language. (Taylor 2007: 153, 189)

For these authors, writing first for themselves and then for publication has been the way out of the narrow confines of otherwise low expectations for persons with dementia. They experience a rich sense of contribution as they share, teach, and advocate:

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 [...] 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: viii, 118).

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)

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 [...] 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)

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)

The authority of writers with dementia cannot be denied. These voices offer words to other persons with dementia who no longer have the words and can also inspire them to try writing. Beyond the early stages, writing is most likely if care partners are available to facilitate the process with highly visible markers, computers with large simple fonts, dictation opportunities, and timely encouragement to write when they are particularly lucid. This type of assistance, as well as help in editing, is frequently mentioned by the writers of the published memoirs. For reasons mentioned earlier, persons with dementia can often express themselves better in writing or in dictation than in conversation. Thus, writing provides opportunity for self-mastery, an element essential for the strengthening of personhood.

### **[B] Facilitated poetry**

Hagens and colleagues (2003, 2006) describe the process of facilitating poetry with small groups of residents with varying levels of cognitive impairment. A facilitator records all the phrases of participants, rereading them throughout the group session, and rearranging them into poetry for the group's response. The process extends the traditional group reminiscence by paying more attention to the specific words of each individual (recording them on an easel for all the group to see and hear), by repeatedly bringing the group back to the theme for the day so that a product can be achieved, by using the participants' own words to nudge them to contribute further, and by creating a product to share outside the group over time.

The creation of poetry also takes advantage of the metaphoric language of dementia (Killick and Allan 2001; Killick 2003). Moreover, the gaps and topic jumps of Alzheimer's discourse can energize a poem, whereas it is often frustrating and confusing in oral or written storytelling. Moreover, a poem with tangentially related phrases from different individuals can work, whereas a joint story would require much more facilitation by the leader.

The group poem presented here – 'On Seeing Red' – includes many shifts of subtopic, but all relate to the color theme. Although some of the phrases are generic, some are very specific. Often family members can read the large print framed poem in a resident's room and recognize their loved one's contribution. For example, one husband was astounded and touched to learn that his wife (who had not communicated orally with him for some time) actually remembered his giving her roses at Christmas (only in the early years before life got so busy). Sharing the poems with family and with staff is key, so that each understands that the person remains.

---- Poem 'On Seeing Red' here ----

These reminisce and write activities can be used with one person at a time – for example, to create a life story in the person’s own words so that staff can more readily relate personally. The second poem presented here – ‘Shani’s Brushing’ – was facilitated by a researcher working with a cognitively intact resident, called Thelma T., and a resident with dementia, called Lily P., who had been a poet. The three met over approximately 20 sessions, with Lily not recognizing Thelma’s face or name. Near the end, they learned that Lily did remember Thelma as the lady with the cat.

Most of the poems facilitated with persons with dementia emphasize long-term memory – either semantic memory, verbal expressions, or long ago episodes. This poem demonstrates that a person with moderate dementia, who has great difficulty with conversation and current memory, can be very sensitive to the present and to relationships.

---- Poem ‘Shani’s Brushing’ here ----

Creating personal poetry with a facilitator and sharing the poems with a group as well as family and staff provides the opportunity for aspects of the vulnerable ‘self’ in dementia to be expressed, acknowledged, and celebrated. The written words create contexts for ongoing conversations, in which understanding becomes possible at a feeling, imagery level less linked to the losses of dementia than typical conversation.

### **[A] Narrative thematic conversation**

For professional caregivers and families of people with dementia it is often difficult to identify and implement strategies that promote and sustain personhood. Storytelling, life writing and remembering boxes are all such strategies. Narrative Thematic Conversation (Schindel Martin, 2007, 2011), an innovative form of narrative arts, is another strategy that can help develop connectedness between the person with dementia and both professional and family caregivers. The construction of the narrative can take the form of a poem, a story or a visual art piece. The process involves deep listening and recognition of the person. The art products both connect in the moment and provide a narrative record for the resident. The narrative record can then be used as a medium to strengthen the quality of the continuous relationship between the person with dementia and both families and formal caregivers. It is important to recognize that narrative arts cannot be useful in dementia care if they are only displayed as static images. The poem, picture or story cannot simply be framed and mounted as an object. Rather, the art form becomes a tool that is used to guide conversation so that interactions occurring in the present moment are grounded in tangible meanings from the past.

A case study will be used to illustrate how one example of the narrative arts, a collage, can be utilized as a continuous link between professional care staff, family members and the person with dementia.

### **[C] Case example**

Mr. Jimmy Jacobs (pseudonym) was a 83-year-old resident of a long-term care facility situated in a metropolitan area of Central Ontario. Mr. J was born in rural Nova Scotia, a maritime

province in Canada. He had begun his working life as a member of the rural constabulary force, but experienced a difficult case involving the investigation of the abuse and subsequent murder of an infant during his rookie year. The case traumatized him to the degree that he suffered symptoms of what we would now diagnose as significant post-traumatic stress disorder (PTSD). Immediately after this traumatic event, Mr. J moved west to Ontario where he worked hard as the sole proprietor of a small, independent used car dealership. He married and divorced three times, twice to his first wife, all within the space of 10 years. He had no long-term relationship after his third divorce. He had one daughter, from whom he was estranged for the better part of 30 years. He spent a lot of his personal time perfecting his considerable skills as a guitarist. He joined a band as the lead guitarist in a small country band that enjoyed some success on the local bar circuit. His support network consisted solely of his band mates. Just prior to admission in the long-term care facility he experienced a one-sided stroke. Consequently, he has no voluntary movement in the left side of his body. His left shoulder was subluxed, and thus would cause him considerable pain and discomfort, particularly during any personal care such as bathing. His agitation was such that during any attempts at personal care he would shout loud profanities at his caregivers. He would also engage in the same behavior with his daughter, with whom he had re-established a tentative relationship just prior to his stroke.

The care plan for Mr. J was well developed, ensuring pain control for his subluxed shoulder and the neuropathic pain he was experiencing in the left side of his body subsequent to the stroke. It became apparent to the health care team, however, that something at the core of Mr. J's experience was not being acknowledged or 'cared for' to the degree that was necessary to establish a therapeutic relationship. Despite good pain control, his agitated behavior continued. The health care team met and decided that it seemed necessary to acknowledge Mr. J as a person in very concrete ways before and during personal care. He seemed to interpret any attempts at personal care as attempts to objectify him. The health care team interviewed some of the members of his band who were continuing to visit him. Based on the personal history and clinical information, we then developed a long list of his personality characteristics, his stories, his hobbies, his life choices that might help us 'give back' to him who he saw himself to be. The health care team also interviewed his daughter to determine her memories of Mr. J as a father during his early adult life. These details were then translated to props, pictures, and typed phrases in large print. The members of the health care team who worked with Mr. J to provide direct care such as bathing, then approached Mr. J and invited him to work with them to develop a collage that represented important aspects of his life. Mr. J was immediately intrigued, and became very engaged in developing the collage. While his left-sided paralysis prevented him from manipulating many of the objects that would comprise the collage, he was instrumental in choosing the pictures and their placement in the collage.

The creation of the collage became a top-priority event for Mr. J that he always looked forward to. Rather than shouting at his care providers, he began to speak to them differently, talking about the progress of the collage and additional items that might be added to it. The focus of conversation during bathing became the collage, not uttering threats to the nurses. In this way, the co-creation of this art piece became the medium through which the person with dementia and his formal caregivers could connect and become true partners in care. Mr. J's daughter also became involved in the development of the collage, answering her father's questions about items, and offering her opinions. The collage became the focus of their tentative relationship, and helped to dissolve the tension between them. The collage included pictures of musical instruments, photographs of Mr. J with his band mates, pictures of his used car lot, and his other

interests such as visiting Canada's lighthouses, fishing and collecting model automobiles and trains. When the collage was completed, it was presented at a team conference that included Mr. J and his daughter. A photograph of Mr. J holding the collage with two of the team members who helped him construct it was printed in the long-term care facility's newsletter. The picture was added to the bottom of the collage. Mr. J, his daughter and the health care team agreed that the collage should be framed and displayed at his bedside. The health care team noticed that if they used the collage to initiate any conversations with Mr. J, his displays of anger and agitation were diminished, and for the most part could be averted. In some instances, when Mr. J was having severe pain associated with his stroke-affected left side, the collage would not be effective in reducing agitation. As with the case of Mrs. B, described above, Mr. J's response to the collage was used as a clinical indicator of pain control. Overall, the collage became a focal point that symbolized important events and feelings held by Mr. J about his journey through life. For the health care team the collage also represented the development of a high-quality interpersonal relationship with a client they might otherwise have only seen as challenging. By the time of Mr. J's death, the health care team had developed a deep affection for Mr. J and the collage was presented to his daughter during a memorial service.

Narrative thematic conversation can take many forms. But, as the case study of Mr. J demonstrates, what is important is that the health care team identify ways that the key elements of the constructed story can be displayed and accessed at a moment's notice for use by both formal care providers and families.

## **[A] Discussion and recommendations for practitioners**

The communication enhancement model (Ryan et al. 1995) highlights the importance of strategies for caregiving staff to personalize care, so that both recipient and giver of care are empowered. Research that captures the voices of people living with dementia does not show the stereotypical 'loss of self' but rather ongoing and creative efforts to cope with dementia as a manageable disability (Beard et al. 2009; Snyder 2000). The application of narrative arts in conversation and through writing confirms the identity and personhood of people living with dementia, creates connection, and fosters hope.

One of the critical practice implications of narrative art forms and their role in maintaining communication between persons with dementia and their caregivers is educational programs. It is important that all members of the health care team who work with older adults, whether this be professional staff of day programs or long-term care homes, be trained in the use of art forms to promote meaningful conversation. In addition, it is crucial for family caregivers to be educated by resource and support agencies to use narrative art forms to communicate (Charters and Murray 2006). Such programs could include students of professional programs learning ways to express their own knowledge and experience with dementia using art forms. Projects could include building a professional coat of arms and writing a reflective paper that explains the significance of such for professional practice behaviors. In addition, professional caregivers could be assigned a specific older adult to work with, and design an art piece that would represent the voice of that person and the students' intuitive sense of what their behavior represents. Journaling, poetry, photo-voice as well as creative writing could also be included as a learning tool for professional caregivers. Without policy changes, however, uptake of such interventions is unlikely. Thus, it is vital that health care regulations are extended to identify and

support the use of art forms as a practical way to engage the person with dementia in meaningful interactions.

In addition, it is important for professional caregivers to interact with each other so that narrative arts are used by all members of the health care team. It is critical that leisure and recreation therapists are not seen as the only members of the team to take responsibility for designing person-centered art forms that give voice to the personhood of the individual. Because of staffing and human resource restrictions, the very culture of long-term care is set up so that leisure activities are rushed and often a source of stress for both families and residents alike. Thus, all team members can contribute to narrative art forms that are meaningful, yet highly individualized. It is critically important that narrative art forms be understood as very distinct from 'art classes' in which persons with dementia may be invited to attend. Goyder (2009) explains that, traditionally, older adults with cognitive impairments who live in long-term care facilities only reluctantly engage in set leisure programs because they are coerced and grouped. This is because activities are not designed as an opportunity to 'find the self'. Rather, they are time-fillers that have no direct bearing on what happens to the older adult at any other time of the day. The products coming out of a program such as this are rarely shared with health care team members, although they might be hung on the wall or seen in an art exhibition. Thus it is important that long-term care funding include the possibility of hiring art therapists who can work not only with older adults with dementia and their family, but also work with staff to enhance their skills repertoire in the area of narrative arts. Our vision is that a truly useful enterprise would see all members of the health care team capable of facilitating the development of narrative art forms that would then serve as a consistent basis for care interventions. The art forms are living documents representative of the person's desires, hopes, dreams and past lives, and directly guide and inform the development of caregiving plans as illustrated in the case of Mr. J described above.

Research has shown that there are benefits that result from narrative art forms that extend far beyond the context of professional caregiving and care interactions. McFadden and McFadden (2011, in press) argue that learning to 'walk with people down the road of dementia' can reduce our own fear of aging, death and loss of memory. They add that persons with dementia can flourish in communities of friendship where all persons – regardless of cognitive status – are valued. Such communities can offer support and connection to all. An insightful formal caregiver who uses narrative art forms to guide practice is essential to the therapeutic relationship. It is our position that, without creative art forms to mediate it, conversations between professional caregivers and persons with dementia become stilted, arcane and formulaic. Conversations that use art forms as a bridge for connection become more meaningful because they are grounded in what matters to the individual with cognitive impairments, persons who would otherwise be shut off from a deeper experience of the world.

## References

- ASC (Alzheimer Society of Canada). 2010. *Rising tide: The impact of dementia on Canadian society*. [http://www.alzheimer.ca/english/rising\\_tide/rising\\_tide.htm](http://www.alzheimer.ca/english/rising_tide/rising_tide.htm) (accessed 14 April 2010).
- Basting, A. D. 2003. Looking back from loss: Views of the self in Alzheimer's disease. *Journal of Aging Studies* 17. 87–99.
- Basting, A. D. 2007. NPR's StoryCorps initiative helps preserve fading memories. *Aging Today* 28(4). 14–15.
- Basting, A. D. 2009. *Forget memory: Creating better lives for people with dementia*. Baltimore MD: Johns Hopkins University Press.
- Beard, R. L., J. Knauss & D. Moyer. 2009. Managing disability and enjoying life: How we reframe dementia through personal narratives. *Journal of Aging Studies* 23. 227–235.
- Brooker, D. 2007. *Person-centred dementia care: Making services better*. Philadelphia, PA: Jessica Kingsley Publishers.
- Bryden, C. 2005. *Dancing with dementia: My story of living positively with dementia*. Vancouver: University of British Columbia Press.
- Charters, J. & S. Murray. 2006. Design and evaluation of a leisure education program for caregivers of institutionalized care recipients. *Topics in Geriatric Rehabilitation* 22(4). 334–347.
- Cangelosi, P. & J. Sorrell. 2008. Storytelling as an educational strategy for older adults with chronic illness. *Journal of Psychosocial Nursing* 46(7). 19–22.
- Davis, B. H. (ed.). 2005. *Alzheimer talk, text and context: Enhancing communication*. New York: Palgrave Macmillan.
- Davis, Robert. 1989. *My journey into Alzheimer's disease*. Wheaton, IL: Tyndale House Publishers.
- DeBaggio, Thomas. 2003. *When it gets dark: An enlightened reflection on life with Alzheimer's*. New York: Free Press.
- Fontana, A. & R. Smith. 1989. Alzheimer's disease victims: The unbecoming of self and the normalization of competence. *Sociological Perspectives* 32. 35–46.
- Frank, A. 1995. *The wounded storyteller: Body, illness and ethics*. Chicago: University of Chicago Press.
- Goyder, J. 2009. Alzheimer's disease, personhood, and intervention: A perspective. *Alzheimer's Care Today* 10(4). 183–188.
- Hagens, C., A. Beaman & E. B. Ryan. 2003. Reminiscing, poetry writing, and remembering boxes: Personhood-centered communication with cognitively impaired older adults. *Activities, Adaptation, and Aging* 27(3/4). 97–112.
- Hagens, C., A. Cosentino & E. B. Ryan. 2006. *You grow out of winter: Poetry in long term care* (Writing Down Our Years Series, No. 6). Hamilton, Canada: McMaster Centre for Gerontological Studies.
- Henderson, Cary Smith. 1998. *Partial view: An Alzheimer's journal*. Dallas: Southern Methodist University Press.
- Holstein, J. & J. Gubrium. 2000. *The self we live by: Narrative identity in a postmodern world*. Oxford: Oxford University Press.

- Hopper, T., S. Cleary, N. Baumack & A. Fragomeni. 2007. Table fellowship: Mealtimes as a context for conversation with individuals who have dementia. *Alzheimer's Care Quarterly* 8(1). 34–42.
- Hughes, J., S. Louw & S. Sabat (eds.). 2006. *Dementia – mind, meaning and the person*. New York: Oxford University Press.
- Killick, J. 2003. Memorializing dementia. *Alzheimer's Care Quarterly* 4. 18–25.
- Killick, J. & K. Allan. 2001. *Communication and the care of people with dementia*. Buckingham, England: Open University.
- Kitwood, T. 1990. The dialectic of dementia: with particular reference to Alzheimer's disease. *Ageing and Society* 10. 177–196.
- Kitwood, T. 1993. Person and process in dementia. *International Journal of Geriatric Psychiatry* 8(7). 541–545.
- Kitwood, T. 1997. *Dementia reconsidered: The person comes first*. Philadelphia: Open University Press.
- Lamb, J. 2009. Creating change: Using the arts to help stop the stigma of mental illness and foster social integration. *Journal of Holistic Nursing* 27(1). 57–65.
- MacDonald, K. 2006. Family and staff perceptions of the impact of the long-term care environment on leisure. *Topics in Geriatric Rehabilitation* 22(4). 294–308.
- McFadden, S. H. & J. T. McFadden. 2011, in press. *Ageing together: Dementia, friendship, and flourishing communities*. Baltimore MD: Johns Hopkins University Press.
- McGowin, D. F. 1993. *Living in the labyrinth: A personal journey through the maze of Alzheimer's*. New York: Delacorte Press.
- Mitty, E. 2010. Storytelling. *Geriatric Nursing* 31. 58–62.
- Moss, S., E. Polignano, C. White, M. Minichiello & T. Sunderland. 2002. Reminiscence group activities and discourse interaction with Alzheimer's disease. *Journal of Gerontological Nursing* 28(8). 36–44.
- Paun, O. & C. Farran. 2006. Nursing home placement of persons with Alzheimer's disease. *Alzheimer's Care Quarterly* 7(2). 104–114.
- Rasmussen, D. 1995. Rethinking subjectivity: Narrative identity and the self. *Philosophy and Social Criticism* 21(5/6). 159–172.
- Ray, R. E. 2000. *Beyond nostalgia: Aging and life story writing*. Charlottesville: University Press of Virginia.
- Ryan, E. B. 2006. Finding a new voice: Writing through health adversity. *Journal of Language and Social Psychology* 25. 423–436.
- Ryan, E. B., K. A. Bannister & A. P. Anas. 2009. The dementia narrative: Writing to reclaim social identity. *Journal of Aging Studies* 23. 145–157.
- Ryan, E. B., S. D. Meredith, M. J. MacLean & J. B. Orange. 1995. Changing the way we talk with elders: Promoting health using the Communication Enhancement Model. *International Journal of Aging and Human Development* 41(2). 87–105.
- Ryan, E. B., L. Schindel Martin & A. Beaman. 2005. Communication strategies to promote spiritual well-being among people with dementia. *Journal of Pastoral Care and Counseling* 59. 43–55.
- Ryan, E. B., H. Spykerman & A. Anas. 2005. Writers with dementia: The interplay among reading, writing, and personhood. In B. H. Davis (ed.), *Alzheimer talk, text and context: Identifying communication enhancements*, 190–198. New York: Palgrave Macmillan.

- Sabat, S. 2001. *The experience of Alzheimer's disease: Life through a tangled veil*. Oxford: Blackwell Publishers.
- Sabat, S. & R. Harre. 1992. The construction and deconstruction of self in Alzheimer's disease. *Ageing and Society* 12. 443–461.
- Schindel Martin, L. (2007). *Thematic Narrative Conversation*. Paper presented at Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT). Toronto, Ontario, June 2007. chindel Martin, L. (2011, forthcoming). Narrative thematic dictation: An interpersonal bridging strategy useful in dementia.
- Scott, K. & J. K. DeBrew. 2009. Helping older adults find meaning and purpose through storytelling. *Journal of Gerontological Nursing* 35(12). 38–43.
- Snyder, L. 2000. *Speaking our minds: Personal reflections from individuals with Alzheimer's*. San Francisco: W. H. Freeman & Co.
- Somers, M. 1994. The narrative constitution of identity: a relational and network approach. *Theory and Society* 23. 605–649.
- Statistics Canada (2008). *Canada year book*, chapter 28: 'Seniors', 365–374. Cat.:11-402-X. <http://www.statcan.gc.ca/pub/11-402-x/2008000/pdf/seniors-aines-eng.pdf> (accessed 14 April 2010).
- Taylor, R. 2007. *Alzheimer's from the inside out*. Baltimore, MD: Health Professions Press.



MRS. B: 'Have you got a nickel for the bus? I have to take the milk to market. My mother is expecting me. Has she been asking for me?'

TEAM MEMBER: 'Hello Mrs. B. Thank you for stopping by. You are very thoughtful to be asking about your mother.'

MRS. B: 'Yes, my mother relies on me.'

TEAM MEMBER: 'Yes, you are very reliable. I haven't met your mother, but you've told me many stories about her.'

MRS. B: 'Yes, my mother is a very good woman. She is always there to help others, and I want to help her too.'

TEAM MEMBER: 'Yes, you've told me that your mother was an excellent cook, and a very important member of the church you attended when you were a little girl. The church was on Concession 17. Your farm was on Concession 19, just off the Arkell Road.'

MRS. B: 'Why yes, have you visited us there?'

TEAM MEMBER: 'No, I haven't, but I feel like I have. You've told me a lot about it.' The team member then reaches for the story, copies of which are always kept at the team station, and begins to read excerpts from the written stories by starting with, 'In fact, here are some stories you've told me of the farm that you grew up on...'

**On Seeing Red**

Red  
Wash it separately.  
They called me carrots...  
I always wished  
my hair was a different colour.  
Kids made fun of us...about 1914 it was...  
used to make me  
all knuckles and teeth.  
Made me see red!  
I gave her the hardest kiss she ever had.  
The colouring does everything.  
Makes you smile a smile,  
makes you feel good.

Red roses remind me  
of someone I love.  
Flowers remind me of death and sickness.  
When you feel it, you feel it,  
when someone you love passes away.  
My husband  
always gave me  
red roses at Christmas.  
I think  
we did everything  
together.  
Always had flowers in the house.  
I like  
every red I see.

(quoted in Hagens et al. 2006: 109)

**Shani's Brushing**

I can't get over that cat helping her do the job.

Now look, he's licking the hand that fixed him.

Look at him,  
he's behaving so beautifully.  
He's a darling.

He loves that doesn't he?  
She loves it too,  
but the cat loves it more.  
He could get lost,  
and wouldn't know where to come back to.  
But then again,  
he has no reason to leave.

We're talking about a white cat today.  
His name is Shani.

(excerpt, quoted in Hagens et al. 2006: 137)