

This column explores an applied description from the field of a program or design that has been very successful. If you know of someone whose expertise and experience has been shared, please contact the editor at PO Box 39, #2107 Highway #215, Walton, Nova Scotia, Canada B0R 2R0; e-mail: csifton@ns.sympatico.ca.

About Me

Knowing the Person With Advanced Dementia

Ruth spends most of her day dozing in her wheelchair by the nurse's station. Around 3:00 PM, she awakens and begins calling out for help. Frequent attempts are made by the staff to respond to Ruth's ever growing calls of distress. By 11:00 PM, the staff members have grown weary of Ruth and put her to bed despite continued shouts. "That's just the way she is," responds a very fatigued evening nurse.

Robert sits in his Gerichair staring at a blank wall. He appears to be reaching out for something that is not there. His chatter is filled with nonsense and repetitive vocalizations. His physical needs are met on demand, and the staff generally interacts with him only when care is delivered.

Clare stares blankly into space, while caring but the busy staff comes bustling by her wheelchair offering "Good Morning" along the way. Clare's daughter visits her frequently, sitting silently by her wheelchair. Her attempts for connection by talking with Clare about recent events are seemingly futile. Finally, she leaves, feeling sad and longing for the mother she no longer knows.

ADVANCED DEMENTIA THREATENS PERSONHOOD

Ruth, Robert, and Clare are among the 1 million Americans whose minds are ravaged by the advanced stages of Alzheimer's disease. The disease has run its course, leaving

their memory, thinking, communication skills, and functional abilities severely impaired. As health professionals focus on the cognitive and functional deficits, these 3 individuals fall prey to labels such as "severely demented," "total care," "total feeder". If challenging behaviors exist, further labels may include, "screamer," "combative," "resistive to care," "biter," and more.

Families watch the slow and progressive decline over an average of 8 to 10 years and experience their own grief.¹ Each incremental change in memory, thinking, and function takes them further away from the person they once knew, and leads to comments such as "she is no longer my mother," "this is not the man I married," or "I am now the parent, not the child." Many articles and books about Alzheimer's disease perpetuate the notion that the person with dementia experiences 2 deaths: death of the mind followed by death of the body.

Hopeless and meaningless are words often used to describe this final phase of dementia, suggesting that the person is wholly lost to the disease and is only an empty shell² or a forgotten soul.³ Thus, advanced dementia can severely compromise the individual's personhood. When

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professional and family caregivers focus on the effects of the disease rather than the person, persons with dementia are at risk for losing not only self but also respect and dignity.

RETHINKING PERSONHOOD IN ADVANCED DEMENTIA

Kitwood⁴ posits that each person has unique value and therefore, we each have a duty to treat one another with dignity and respect. His theories on personhood remind us that persons with dementia are capable of communicating their desires and feelings. They also desire and are capable of meaningful engagement with others. Post believes that “deep into the progression of dementia, continuity with the past usually exists amidst discontinuities.”^{5(p10)} We are the sum of our memories, therefore, everything we perceive and every moment we make is shaped by them.⁶ Kovach⁷ directs us to give serious consideration to 3 essential needs that require balance and fulfillment in order to maintain personhood in advanced dementia. We must satisfy the primary, inner, and social selves. The *primary self* represents the person’s basic needs such as hunger, thirst, and pain. The *inner self* is less easily defined and is generally considered within the context of the social self. Together, they encompass the meaning of a person’s private and shared life experiences.

Persons with advanced dementia continue to communicate in an ever-changing and decreasing fashion despite limited speech, masked faces, and behavioral expressions. A greater emphasis is needed to “know” the person with dementia—especially those with advanced dementia. However, “knowing” the person requires vigilance on part of the family and professional caregivers alike. It necessitates looking beyond the losses of memory, function, and cognition and focusing on the unique spirit contained within. To achieve this end, family and professional caregivers need to (re)create the memories for persons with advanced dementia who can no longer communicate them to us. Not only will the person’s primary, inner, and social needs be satisfied but also dignity and respect can be maintained until the very end.

ABOUT ME

Hospice of the Valley is a large nonprofit hospice in Phoenix, Ariz. The Dementia Program was established in 2003 to enhance dignity, comfort, and quality of life in persons with advanced dementia. Although it may be difficult

to predict death during the final 1 to 3 years of life with advanced dementia, it is quite possible to provide comfortable, respectful, and dignified care. The person’s life story or abbreviated biography serves as an important tool to better know the person with dementia by preserving and reconstructing his or her story.⁸ This promotes individualized care, and new or continued opportunities for connection.

The “About Me” form (Fig 1) was created to help hospice staff and other professional caregivers become more familiar with the person, including preferences, rituals, and past interests. It reminds family and professional caregivers to focus on the person and not the disease. The form is completed by family members and then posted at the person’s bedside in order for all caregivers to *know* more about the person receiving care. Since the form does not contain any sensitive medical or social information, the Health Insurance Portability and Accountability Act of 1996 (HIPAA) does not prevent posting of this information.

Families may need assistance in completing the *About Me* form, as they may not know or have not considered past interests, preferences, or rituals over the years. However, the hospice social worker and/or chaplain can assist the family with life review activities in order to obtain food, music, activity, and spiritual preferences. The hospice nurse can ask the family about established routines including eating to bathing and other personal care activities. Massage or other forms of touch preferences, along with favorite smells, can also be integrated into daily care that is facilitated by the hospice certified nursing assistants. Each can be very helpful in creating meaningful moments in daily activities. Our experience shows that continuity in past simple pleasures can be maintained when emphasis is placed on those same comfort strategies used by the person throughout life. Information from the form can also be used successfully to distract the person, especially during personal care activities, which may cause resistance to care. Comforting distracters such as favorite foods, music, and prayers may be validating and reassuring to persons who are too confused to understand the intent of caregiving activities.

The unique individual is honored and respected when caregivers address each human need incorporating the *About Me* form. Hospice staff and other caregivers learn to anticipate and gratify the “primary self” necessities by joining the person on his or her journey, and appreciating the person’s continuously changing level of cognition and need for assistance. *About Me* encourages a change in perspective—caregivers are able to engage in positive affirmation of the personhood of each individual with advanced dementia. Table 1 provides an outline for the implementation of *About Me*.



About Me[®]

This information will allow us to personalize this individual's care and honor who they are and what brings them joy. Please do not answer any questions that you feel would violate this person's privacy.

My name is: _____ I prefer to be called: _____

I was born in (city and state): _____

Important people in my life are (include relationship): _____

I like to be remembered for: _____

I like to reminisce about: _____

My work in life includes: _____

My interests, hobbies and talents: _____

Things that bring me peace or solace (prayers, readings, rituals, music, nature): _____

Favorite movies, TV shows, and videos: _____

Music, song or sound preferences: _____

Massage or other forms of touch preferences (neck, hands, feet): _____

Favorite foods and beverages: _____

I like the smell of: _____

My sleeping habits are (waking, napping, things that help me sleep): _____

Things I dislike include (food, situations): _____

Other things I would like you to know about me (routines, quiet time, bath or shower): _____

HOSPICE *of the* VALLEY

Figure 1. The *About Me* form.

ABOUT ME IN PRACTICE

Ruth was admitted to Hospice of the Valley and the staff learned much more about Ruth from her family. Her story created a different image than that of a woman crying out in distress each day. Ruth's favorite songs were used by the hospice certified nursing assistant while personal care and baths were provided. Her once "resistive behaviors" during

bath time were replaced with sing-alongs and giggling. Pain was determined to be a primary unmet need that resulted in yelling after prolonged sitting in her wheelchair. Her medications were adjusted so that the sedating medications were not given during the day and routine pain medication was added. The staff learned that she was always fearful at night and that listening to her favorite music was a comfort. In addition, Ruth was able to tell the staff

Table 1.

Steps to Implementation of <i>About Me</i>
1. Create a life history/abbreviated biography form and make it readily available.
2. Inservice all staff members about the purpose and use of the <i>About Me</i> form, ensuring that each discipline knows how to use the information to personalize their care and interactions.
3. Designate a member of the healthcare team (usually the social worker) to meet with the family and explain the purpose of the <i>About Me</i> form.
4. Have the family complete the form and assist them as needed. In case of no family, utilize friends and other proxies that are available.
5. Take time to present the person's life story during a team meeting. Add any other pertinent information about the person's life story or preferences from other team members.
6. Make a copy of the form readily available so that all team members know the person for whom they are caring.
7. Identify and facilitate obtaining any additional comfort items that are needed. Such items may include scented lotions, favorite foods, blankets, familiar music, etc.
8. Ask permission to post the person's story on the wall in his or her room so that all other professional caregivers have the opportunity to know the person. (Many professionals will need to be educated that this information does not violate HIPAA*.)
9. Continue to add any additional pleasurable activities and remove negative stimuli that are identified.

*HIPAA indicates Health Insurance Portability and Accountability Act of 1996.

that what brought her the most comfort during the night was when her mother would "tuck me in and give me a kiss on the cheek." This information was communicated to the night shift. Her nighttime care now includes putting her favorite music on at bedtime and tucking her in and giving her a kiss on the cheek. Ruth is now much improved with all the staff seeing the real Ruth.

Robert's *About Me* reflects a man who completed a Doctorate degree in Divinity and grew one of the largest churches in the local area. Besides being very involved in his faith community, he was a much loved husband and father. His favorite Bible verses and hymns were determined by the hospice chaplain and communicated with all staff members. Cards with Robert's favorite Bible verses and prayers were made available for all staff members to utilize

to enhance daily care. When the staff began to sing with Robert, his repetitive vocalizations transformed into clear and harmonized singing. The staff was amazed and delighted, and they now utilize every opportunity to connect him with his Creator, thereby honoring his inner and spiritual selves.

Clare's daughter was grieving the loss of the relationship she once shared with her mother. *About Me* was a useful means to assist her daughter with discussing her own issues of grief and loss with the hospice social worker. She put together a Memory Book showing pictures of Clare's parents, siblings, and her younger years. Pictures of Clare with her 3 children and 7 grandchildren were also chronicled. Clare's daughter had forgotten many of her mother's individual preferences, but given the time and encouragement to remember, she assisted in identifying past preferences of many sensory pleasures. The hospice nurse taught Clare's daughter how to use the Memory Book to share fun stories with her mother. She learned to bring Clare's favorite chocolate candy and to give her mother a gentle hand massage. Rather than feeling frustrated and sad, the daughter's visits proved to be more meaningful for both. Clare appears to be more present, as she now responds with direct and brightened eye contact, an occasional smile, and reciprocates hand squeezes with her daughter. Her daughter now states, "I feel like I have a part of my mom back with me."

If personhood is embedded in the individual's life-history and engagement with others, as well as in his or her bodily form, then it makes sense still to talk with the person even in severe dementia. We have the potential to enhance the personhood of people with even severe dementia.^{9(p90)}

About Me provides a useful and practical method to help family and professional caregivers better know and connect to the person with advanced dementia.

A FINAL TRIBUTE: ABOUT JOAN (BY CAROL O. LONG, PhD, RN)

My 80-year-old mother lived alone for 8 years after my father died. She enjoyed her independence, group trips to the theatre, lunch out with the neighborhood ladies, all types of music, and her toy poodle "Max." She did well until dementia began to rob her of her memory and intellect. Driving became dangerous and she was forgetting to eat. My brothers and I made the difficult decision to move her to an assisted living facility for persons with dementia. Like others who make the transition to these settings, she

seemed lost in the day-to-day routine, aware of what was happening, but unable to escape. She was adjusting to the newness of her new home. Just weeks after the move, her wobbly legs gave way and her tiny, fragile, osteoporotic body could not withstand the fall. She sustained a life-changing impact—a hip fracture. Suddenly life turned upside down. It was hard to imagine that she would become yet another grim statistic in the 47% to 71% mortality rate that is common 6 months after a fall.

We never thought that a hip replacement and the hope of a full recovery would soon shift to palliative care. Her hospital recovery was scarred with restraints, delirium, pain, and suffering. She was just not getting better. We were devastated as she deteriorated right before our eyes. Her transfer to hospice was obvious. She would either revel in her recovery or journey to a better life, free from dementia and pain. The latter would occur. Soon after her admission to the Dobson House at Hospice of the Valley, we knew she was home. *About Me* was really *About Joan*. It was our chance to tell her caregivers who my mother was: her life story. The entire hospice and dementia team would come to know Joan a little bit better and understand more how much we cherished her. Her life, her journey, her personhood came alive. With photographs, music, and her faithful dog at her side, we reminisced and shared it all with the hospice team, reliving the good and bad times, and yes, the unforgotten moments. What dementia stripped away of my mother's memory did not obliterate ours or the chance to tell her story. A raised eyebrow, a faint smile, a quick squeeze of the hand told us that we were still making connections.

Four days later, our mother slept and never awoke, leaving this world and us. Her relief from suffering was profound. Her wrinkles, weathered by age and pain, magically

disappeared. The suffering ended. She entered eternal peace. There were no regrets. We had the final chance to say our good-byes. There is no dementia in the spiritual afterlife. In the end, it was all about Joan.

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