Communication Strategies to Promote Spiritual Well-being among People with Dementia*

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Declining communication skills in dementia threaten a person's sense of self. Building on enduring capabilities, pastoral visitors can significantly enhance spiritual well-being through the use of individualized, person-centered strategies. This article outlines the primary spiritual needs of older adults with dementia and some general strategies to improve communication based on enduring abilities. Detailed examples illustrate how these personhood-centered strategies can meet spiritual needs by connecting with individuals with dementia through life stories and through helping them to participate in religious life.

Garden Blossoms

I was lost in the
Garden of my mind,
A tangled confusion;
My thoughts flitted with no aim.
What was I just remembering?
Where was home?
Where were the others?

She tends the garden of my mind,
Widens the crooked pathways,
Darts to the very best flowers,
Creates stepping stones from one to the other,
Writes snapshots for me to hold.

She shines the sun of her listening upon me, and
My spirit blossoms.

—E. B. RYAN

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Interpersonal connections are especially important to older adults with dementia for maintaining their spirituality. Spiritual well-being arises from relationships with the self, others, God, and nature.[1] However, cognitive losses can mean that relationships with God, self, and the environment may primarily be experienced only through meaningful relationships with others.

Dementia as a Threat to Personhood and Communication

Dementia refers to a progressive and irreversible deterioration of the cognitive-functional capacities of the brain of older adults. Increasing confusion, memory loss, and communication difficulties are hallmarks of this condition caused by such progressive neurological disorders as Alzheimer's Disease. The prevalence of dementia in the population over age 65 has been estimated to be approximately 8 percent.[2] Alzheimer's Disease (AD) is the most prevalent condition associated with dementia, making up 55-65% of its incidence. These figures clearly have significance for communities who offer spiritual support to aging individuals.

The literature typically describes Alzheimer's Disease and related dementias as occurring in three stages: mild, moderate, and severe. Over a period of fifteen to twenty years, the person with dementia loses first the complex, abstract executive functions of the cerebral cortex, followed by changes in motor functioning that results in the loss of the ability to walk, eat, and swallow. In addition, the person with AD experiences profound changes in memory, so that once familiar faces become unrecognizable, and the purpose and application of specific objects are forgotten.

Table 1 outlines the memory and communication skills that are seriously affected by Alzheimer's Disease and related dementias.[3,4,5,6] As well, the table identifies skills within these domains which are maintained until very late in the disease. In particular, recent memory and new learning are seriously impaired by the progress of the disease, yet long term memories are preserved. The individual experiences significant losses in linguistic expression and comprehension, while maintaining abilities for expressing and understanding emotions nonverbally.

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[1]J. W. Ellor, "Spiritual Well-Being Defined," in J. Ellor, S. McFadden, & S. Sapp (Eds.), *Aging and Spirituality: The First Decade* (San Francisco, CA: American Society on Aging, 1999), pp. 40-43.
[2]Canadian Study of Health and Aging Working Group, "Canadian Study of Health and Aging: Study Methods and Prevalence of Dementia," *Canadian Medical Association Journal*, 1994, Vol. 150, pp. 899-913.
[3]R. Lubinski (Ed.), *Dementia and Communication* (San Diego, CA: Singular Publishing, 1995).
[4]J. B. Orange and E. B. Ryan, "Alzheimer's Disease and other Dementias: Implications for Physician Communication," in R. D. Adelman and M. G. Greene (Eds.), *Communication Between Older Patients and Their Physicians* (Clinics in Geriatric Medicine) (London: W.B. Saunders Co., 2000), pp. 153-175.
[5]D. N. Ripich, "Language and Communication in Dementia," in D. N. Ripich (Ed.), *Handbook of Geriatric Communication Disorders* (Austin, TX: Pro-Ed., 1991), pp. 255-284.
[6]M. J. Santo-Pietro and E. Ostuni, *Successful Communication with Persons with Alzheimer's Disease, 2nd Edition—An In-service Manual* (St. Louis, MO.: Butterworth-Heinemann, 2003).

TABLE 1.
Memory and Communication in Dementia

Abilities Best Preserved
Life-time memories
Nonverbal comprehension and expression of emotions
Speech pronunciation
Grammar
Abilities Deteriorating Progressively
Short-term and recent memory
Ability to learn new information
Intentional access to life memories
Word knowledge
Pragmatics (contextually appropriate language)

It is useful to describe the stages in terms of Alzheimer's Disease since it is the most prevalent and since many of the symptoms are common to other dementias. In each of the three stages of AD progression, changes impact significantly on the ability to communicate and interact with other people. The communication changes unique to each stage of the disease require specific adaptation so that individuals can participate in activities that are spiritual in nature. During the mild stage, individuals exhibit word-finding difficulty, use semantically empty words (*i.e.*, thing, stuff), and may have difficulty following complex or abstract language. However, most are able to get by adequately in social situations. By the moderate stage their awareness of their difficulties may have diminished and the word-finding problems and empty utterances become more severe. Increased difficulty in understanding conversations may lead to less initiation of conversation, and withdrawal from social situations. Despite these difficulties, individuals retain their ability to understand emotional meaning. People in late stage AD may become very disoriented to time and place and may be unaware of what is expected of them during conversations. Their inability to understand word meanings or form new memories causes partial or complete withdrawal from social interaction.[7,8]

Knowledge of the different stages can be a useful reference but it is important to remember that each person affected by dementia experiences it differently. Furthermore, symptoms may originate from, or be exacerbated by, a social environment that does not encourage or recognize remaining capabilities. For example, an individual in early stage dementia may seem increasingly withdrawn or uninterested in social interaction. While this behavior may be a sign of a worsening condition, it could be indicative of depression associated with being aware of cognitive losses.[9] Unwarranted assumptions about decline into the moderate stage could lead to further, unnecessary withdrawal.

The cognitive declines of dementia can have the effect of assaulting one's personhood as many of the cherished activities and meaningful conversations that previously confirmed the older person's sense of self no

[7]Ripich, *op. cit.*
[8]Santo-Pietro and Ostuni, *op. cit.*
[9]Lubinski, *op. cit.*

longer take place. Indeed, as an individual progresses through the stages of dementia, daily activities and interactions may become increasingly centered around the many "custodial" tasks that caregivers must perform in order to meet their physical needs. Norberg[10] states that the gradual loss of communication ability associated with dementia results in suffering as a feeling of being disconnected, disintegrated and not at home. Norberg suggests that communication with people with severe dementia is essential for both connectedness and integrity, and that it should be based on a consoling communion with caregivers.

While individuals with dementia clearly have increased physical needs over a normally aging adult, the mere presence of these needs negatively alters the way they are perceived and treated by others in their social environment. Norberg[11] states that certain behaviors typical of dementia have become stigmatized to the extent that they are seen only as problems, rather than attempts at maintaining interpersonal connectedness. Similarly, Kitwood and Bredin[12] describe this process as the problematizing of the dementia sufferer; "they" are labeled as "deficient" and categorized separately from "us," the normal, "undamaged" individuals.

The Communication Predicament Model of Aging[13] provides a useful framework for understanding how this labeling process is detrimental to the personhood of individuals with dementia. The model posits that a label such as "demented" and/or behaviors characteristic of dementia, trigger stereotyped expectations of incompetence from people in the social environment. Based on these lowered expectations, people modify their behavior toward the individual (*e.g.*, reduce conversation with them), resulting in constrained opportunities for the older person to reveal their "self." In terms of Learned Helplessness Theory, over time the dementia sufferer learns to stop responding if they feel their efforts are futile. The individual may still be capable of responding but gives up due to social and physical cues in the environment that tell them they are inadequate. It is critical to distinguish between innate helplessness, an individual's actual reduction in abilities due to dementia, and imposed helplessness, diminished performance due to a poor social environment.[14,15] Thus, dementia is associated with an excess disability caused by the inappropriate reactions of others.[16,17,18,19] For example, religious communities such as congregations

[10]A. Norberg, "Communication in the Care of People with Severe Dementia," in M. L. Hummert and J. F. Nussbaum (Eds.), *Aging, Health and Communication: Linking Research and Practice for Successful Aging* (Mahwah, NJ: Erlbaum, 2001), pp. 157-175.

[11]*Ibid.*

[12]T. Kitwood and K. Bredin, "Towards a Theory of Dementia Care: Personhood and Well-being," *Ageing and Society*, 1992, Vol. 12, pp. 268-287.

[13]E. B. Ryan, H. Giles, G. Bartolucci, & K. Henwood, "Psycholinguistic and Social Psychological Components of Communication by and with the Elderly," *Language and Communication*, 1986, Vol. 6, No. 1, pp. 1-24.

[14]Lubinski, *op. cit.*

[15]C. McWilliam, J. Brown, J. Carmichael, & J. Lehman, "A New perspective on Threatened Autonomy in Elderly Persons: The Disempowering Process," *Social Sciences & Medicine*, 1994, Vol. 38, pp. 327-338.

[16]P. Dawson, D. L. Wells, & K. Kline, *Enhancing the Abilities of Persons with Alzheimer's and Related Dementias: A Nursing Perspective* (New York, NY: Springer, 1993).

[17]T. Kitwood, *Dementia Reconsidered: The Person Comes First* (Philadelphia, PA: Open University Press, 1997).

[18]Kitwood and Bredin, *op. cit.*

[19]S. Sabat and R. Harre, "The Construction and Deconstruction of Self in Alzheimer's Disease," *Ageing and Society*, 1992, Vol. 12, pp. 443-461.

engaged in worship may assume that someone with dementia is receiving no benefit from attending a religious service because of a recent diagnosis, or behaviors such as dozing, wandering, or agitation. The perceptions of the congregation may be internalized by the family caregiver who then decides that the person is no longer capable of religious participation. This decision would further reduce the older person's opportunities for social interaction and regular stimulation, causing an overall decline in their responses.

It is clear that assuming that individuals with dementia are totally incapable will make it very difficult for caregivers to affirm the personhood of cognitively impaired older adults. Alternatively, a perspective that focuses on remaining competence builds a personhood-enhancing social environment.

Fostering Spiritual Well-Being in People with Dementia

Due to cognitive changes individuals with dementia become especially dependent on social partners to maintain their spirituality.[20,21] Harrison[22] argues that the personhood of individuals with dementia can be revealed by taking a life narrative approach, considering each individual's unique past roles, relationships, and experiences. Thus, a personhood-centered caregiver will devise strategies that help the older person maintain meaningful social interactions and emphasize their individuality. Such an interpersonal approach will move the caregiver- recipient dyad past the stigmatizing label of dementia to enable spiritual well-being.

The Communication Enhancement Model[23] illustrates how recognizing individuality can foster spiritual well-being. According to the model, a positive feedback loop ensues once the characteristics unique to each individual are acknowledged by caregivers. Based on individual cues, caregivers may modify their behavior in order to meet the specific needs of the older adult. Moreover, the increased awareness of the "individual" leads caregivers to respect and promote the older adult's remaining competencies (*e.g.*, singing of hymns embedded in long term memory). The model also highlights the role of the environment in facilitating or hindering an older adult's conversation and participation. For example, agitated or aggressive behaviors associated with dementia can be reduced by removing triggers in the environment (*e.g.*, turning off the television). An important intervention study has demonstrated that teaching nursing home staff to provide explicit social reinforcement for residents' independent behaviors can break the negative feedback cycle creating dependence and lead to a return of independence.[24] Older adults whose "person" has been recognized feel empowered and are better able to exhibit their communication abilities, further fueling others' perceptions of them as competent.

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[20]Kitwood and Bredin, *op. cit.*

[21]D. B. McCurdy, "Personhood, Spirituality, and Hope in the Care of Human Beings with Dementia," *The Journal of Clinical Ethics,* 1998, Vol. 9, pp. 81-91.

[22]C. Harrison, "Personhood, Dementia and the Integrity of a Life," *Canadian Journal on Aging,* 1993, Vol. 12, pp. 428-440.

[23]E. B. Ryan, S. Meredith, M. J. MacLean, & J. B. Orange, "Changing the Way We Talk with Elders: Promoting Health Using the Communication Enhancement Model," *International Journal of Aging and Human Development,* 1995, Vol. 41, pp. 9-107.

[24]M. Bates, E. Neumann, & S. Zank, "Maintenance and Rehabilitation of Independence in Old Age: An Intervention Program for Staff," *Psychology and Aging,* 1994, Vol. 9, pp. 179-188.

Attesting to the remaining competencies of individuals with dementia leads to the search for creative ways to foster their spiritual well-being. Table 2 presents spiritual needs of persons with dementia.[25,26,27] Although the list is based on universal human longings. some needs become stronger as personhood is threatened (such as affirmation of self worth and a sense of hope) while others are more difficult to address because of the disease's impact on communication and thinking (such as feeling connected, validation of feelings, and remembering experiences of beauty).

TABLE 2
Spiritual Needs of People with Dementia

Self	God	Community	Nature/Environment
Being known as a person	Assurance of God's love	Feeling connected	Experiencing beauty and wonder
Feeling competent	Support for prayer and worship	Able to share	Remembering such experiences
Being useful and successful	Opportunity to express and share grief	Feeling loved	Belonging to God's creation
A sense of hope	Dealing with hope/ fears about death	Offering love	
Acknowledgment of life story	Participating in rituals and religious services	Sense of belonging	
Validation of feelings		Communication with others	
Affirmation of worth		Giving to others	

Useful Personhood-Affirming Strategies

In this section, we present a variety of approaches for communicating with a person suffering from dementia so as to enable their spirit. Our focus is upon specific communication strategies, connecting with life stories, and facilitating religious participation.

Communication

As one attempts to communicate with a confused individual, it is important to maintain the focus upon the person within despite their diminished access to memory, ability to express intended meanings, and ability to follow a conversation.[28,29,30,31,32,33,34,35,36] Some key strategies are outlined in Table 3.

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[25]E. Cole, "Still a Person," in J. Ellor, S. McFadden, & S. Sapp (Eds.), *Aging and Spirituality: The First Decade* (San Francisco, CA: American Society on Aging, 1999), pp. 101-106.
[26]R. Davis, *My Journey into Alzheimer's Disease* (Wheaton, IL: Tyndale House Publishers, 1989).
[27]Ellor, *op. cit.*
[28]M. Goldsmith, *Hearing the Voice of People with Dementia: Opportunities and Obstacles* (London: Jessica Kingsley Publishers, 1996).
[29]Kitwood, *op. cit.*
[30]M. Bourgeois, "Where is My Wife and When am I Going Home? The Challenge of Communicating with Persons with Dementia," *Alzheimer Care Quarterly,* 2002, Vol. 3, pp. 132- 144.
[31]S. Hoffman and C. Platt, *Comforting the Confused: Strategies for Managing Dementia* (New York, NY: Springer, 1990).
[32]M. Kaplan and S. B. Hoffman (Eds.), *Behaviors in Dementia: Best Practices for Successful Management* (Baltimore, MD: Health Professions Press, 1998).
[33]P. MCCallion, R. W. Toseland, D. Lacey, & S. Banks, "Educating Nursing Assistant to Communicate more Effectively with Nursing Home Residents with Dementia," *The Gerontologist,* 1999, Vol. 39, pp. 546-558.
[34]M. T. Rau, *Coping with Communication Challenges in Alzheimer's Disease* (San Diego, CA: Singular Publishing, 1993).
[35]Santo-Pietro and Ostuni, *op. cit.*
[36]L. Souren and E. Franssen, *Broken Connections: Alzheimer's Disease, Part II—Practical Guidelines for Caring for the Alzheimer Patient* (Berwyn, PA: Swets & Zeitlinger, 1993).

TABLE 3
Strategies for Communicating with a Person with Dementia

Type	Strategy
Environment	Choose a private, quiet, well-lit location Minimize distractions
Nonverbal	Approach within the person's visual field Use calm tone of voice Maintain eye contact Use reassuring facial expressions, touch, gestures, and body postures Take time for a conversation, with long pauses as necessary Listen for the person's perspective and the feelings being expressed
Verbal	Use simpler, but adult grammar Avoid technical and jargon terms Communicate one idea at a time Ask questions with two alternatives from which to choose Beware of fatigue reducing communication performance
Interpersonal	Recognize individual as a person Validate the person's emotions and reassure Negotiate by taking into account preferences, needs, and anxieties Collaborate by working together and by responding to an expressed desire or need Facilitate accomplishments, by providing the missing steps between intention and completion

Adapted from Kitwood, 1997; Lubinski, 1995; Orange & Ryan, 2000

Communication begins with optimizing the environment by choosing a quiet, private location with good lighting and a minimum of distractions. Given the maintenance of nonverbal comprehension and expression in dementia, it is useful to focus on the underlying message by attending carefully to nonverbal cues, especially tone of voice, eye contact, timing, facial expressions, gestures, body postures, and touch. For example, pausing between utterances can enhance comprehension, and waiting a long time for responses can make the difference between a monologue and a conversation. A calming tone of voice and a smile can do much more to reassure an agitated person than any choice of words. Other strategies include active listening/watching, getting the person's attention before beginning a conversation, providing information one item at a time, and asking questions with two alternatives from which to choose.

From an interpersonal point of view, Kitwood's[37] personhood-oriented strategies consist of the following: recognizing an individual's identity, negotiating preferences and activities, collaborating jointly on specific tasks, validating emotions without agreeing to a disoriented sense of reali-

[37]Kitwood, *op. cit.*

ty, and facilitating intended actions to compensate for the disease-based loss of ability to follow through on one's own. By enabling the person with dementia to be successful in this way, a spiritual advisor or other caregiver can help reduce symptoms such as withdrawal, agitation, and aggression. These strategies can empower the person with dementia to exhibit remaining strengths, to achieve some of their goals within the conversation, and also to participate more fully in daily life.

Connecting Through Life Stories

Work with storytelling has identified numerous advantages of encouraging reminiscence and sharing of stories[38,39,40,41,42,43,44] These activities can be especially beneficial with persons with dementia given the greater retention of memories for long ago as compared to the present and the increased opportunity for a satisfying communication encounter when the topic is early life. Conversational remembering can be rewarding in that the older person enjoys the storytelling activity and the opportunity to contribute to conversation, and the life story content can remind the person of past achievements and joys. The conversational partner can develop a bond with the individual and then identify new ways to affirm personhood in future conversations. Recording life stories as a legacy for family can allow for a gift of immeasurable meaning when the teller is progressively losing connections with these memories. Recorded stories can also assist formal caregivers to understand the personal identity of the client and then to connect more effectively.

Remembering Boxes. We have begun working in the community and in long term care with individualized Remembering Boxes which can stimulate conversations about lifetime memories despite cognitive impairment. More than a decade of research by Michele Bourgeois and her colleagues has demonstrated the effectiveness of memory aids to enhance communication of staff members with nursing home residents with cognitive impairment.[45,46] Remembering Boxes include writings (*e.g.*, letters, stories, poems), pictures, and meaningful objects from a person's life. Collecting materials to create a Remembering Box in the early stages of dementia can

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[38]P. G. Clark, "Communication Between Provider and Patient: Values, Biography, and Empowerment in Clinical Practice," *Aging and Society*, 1996, Vol. 16, pp. 747-774.

[39]K. W. Hepburn, W.Caron, M. Luptak, S. Ostwald, L. Grant, & J. M. Keenan, "The Family Stories Workshop: Stories for Those Who Cannot Remember," *The Gerontologist*, 1997, Vol. 37, pp. 827-832.

[40]W. L. Randall and G. M. Kenyon, *Ordinary Wisdom: Biographical Aging and the Journey of Life* (Westport, CT: Praeger Publishers, 2000).

[41]E. B. Ryan, K. Pearce, A. P.Anas, & J. E. Norris, "Writing a Connection: Intergenerational Communication Through Stories," in M. W. Pratt and B. E. Fiese (Eds.), *Family Stories and the Lifecourse: Across Time and Generations* (Mahwah, NJ: Erlbaum, 2004), pp. 375-398.

[42]B. Rybarczyk and A. Bellg, *Listening to Life Stories* (New York, NY: Springer Publishing Co., 1997).

[43]H. Thorsheim and B. Roberts, *I Remember When: Activity Ideas to Help People Reminisce* (Forest Knolls, CA: Elder Books, 2000).

[44]P. M. Usita, I. E. Hyman, Jr., & K. C. Herman, "Narrative Intentions: Listening to Life Stories in Alzheimer's Disease," *Journal of Aging Studies*, 1998, Vol. 12, pp. 185-197.

[45]M. S. Bourgeois, "Enhancing Conversation Skills in Patients with Alzheimer's Disease Using a Prosthetic Memory Aid," *Journal of Applied Behavioral Analysis*, 1990, Vol. 23, pp. 29-42.

[46]L. D. Burgio, R. Allen-Burge, D. L. Roth, M. S. Bourgeois, K. Dijkstrad, J. Gerstle, E. Jackson, & L. Bankester, "Come Talk With Me: Improving Communication Between Nursing Assistants and Nursing Home Residents During Care Routines," *The Gerontologist*, 2001, Vol. 41, pp. 449-460.

be a rewarding activity for both the person with dementia and the family members who collaborate. This activity generates opportunities for meaningful life-review with loved ones. The making of a Remembering Box during the early stages of dementia allows the individual to make their own choices and to contribute stories that may not be spontaneously retrieved later on in the disease. The box then becomes an invaluable communication resource in the later stages as communication skills are lost and if the older adult is moved to a nursing home. In later stages of dementia, the preparation of a Remembering Box can be done by family members or close friends with consultation as feasible with the individuals themselves. The meaningful writings and items act as external memory aids eliciting rich stories and thereby generating satisfying conversations. Working with Remembering Boxes readily encourages the use of Kitwood's interpersonal strategies (as outlined in Table 3): recognizing the value of the individual's life memories, negotiating which items to discuss, validating the emotions arising from re-experiencing a life event, collaborating in the reconstruction of a story, and facilitating the recording of a newly elicited story about old times.

In long term care we have also been working with Remembering Boxes as a concrete tool for staff to engage in frequent, often short, but meaningful conversations despite a person's cognitive impairment.[47] The materials in the Remembering Box as well as the ongoing conversations increase the caregivers' knowledge of and comfort with the individual, thereby activating the positive feedback loop of communication outlined by the Communication Enhancement Model.[48]

The objects and stories that were collected from family members for the Remembering Boxes have offered interesting information about the residents to staff and visitors. Staff have found that using the Remembering Box during conversations increased the likelihood of the older person elaborating on topics in response to questions. Residents who had typically exhibited withdrawn, dependent behavior during conversations took some control of interactions with the aid of their Remembering Boxes. The meaningful items in the box have also been used by staff to calm an agitated resident, or to spark conversations in the night when particular residents were unable to sleep.

Thus, the information contained in the box broadens the repertoires of questions that can be asked by caregivers, eliciting richer responses from the person with dementia. Meaning-rich responses deepen conversations, further augmenting caregivers' knowledge, and they leave the older person feeling increasingly competent, valued, and connected to life.

Lucy Tailor's Story. Biographical stories can be an important resource for providing care in a long term facility. As outlined above, enabling the resident to share life stories and experiences in the form of a biography is one way to assist the resident and caregiver to establish a relationship of meaning and purpose, making the resident's capacity clearer to the caregiver. An example is the case of Lucy Tailor, pseudonym for a resident of Shalom Village Nursing Home, a Hebrew Home for the Aged in Hamilton,

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[47]C. Hagens, A. Beaman, & E. B. Ryan, "Reminiscing, Poetry Writing, and Remembering Boxes: Personhood-centered Communication with Cognitively Impaired Older Adults," *Activities, Adaptation, and Aging*, 2003, Vol. 27, No. 3/4, pp. 97-112.

[48]Ryan, *et al.*, *op. cit.*

Ontario that is affiliated with McMaster University as a teaching nursing home. Mrs. Tailor's dementia experience was fraught with fear and anxiety. She sought comfort through an active search for her mother, someone with whom she had had a close and deeply satisfying relationship as a young child. Mrs. Tailor would often become inconsolable while searching for her "Mother." The staff recognized that the search for "Mother" was symbolic, and that while the search would never result in "Mother" in the material sense, a biography might recapture the "essence" of "Mother." Staff members at Shalom began recording a biographical account of Mrs. Tailor's mother as a result of conversations with her during calmer moments. She described her mother's physical characteristics (beautiful, thick, curly, raven-black hair), her dreams and inspirations (coming to Canada from Hungary as an immigrant), her worries (being separated from her husband when he immigrated to Canada to prepare the way for the family, and caring for the needs of four children), her feelings for her mother (she was my "dear heart"), her mother's pet name (Charnala), and how others saw her (a wise, respected woman whose advice was sought by others in the village).

The fragments of Mrs. Tailor's mother's biography were pieced together like a beautiful quilt.[49,50,51] The biography was read to her during those moments when she was inconsolable and seeking out "Mother" in an agitated fashion. The story was available to all members of the clinical team caring for her, and was used frequently with success. She would usually become immediately engaged by the story, and add new "threads" to it. She was often given a printed copy of the story to carry with her.

This intervention was very helpful in affirming something that had deep and profound meaning. Her mother was given back to her symbolically through the reading of the story, and this gave her great spiritual comfort. It also assisted the staff members caring for Mrs. Tailor to stop feeling helpless in the face of her agitation. Reading of the biography was a simple, accessible and effective way for the staff to connect with her, and feel that they had contributed to her positive memories and her self-affirming life story.

It is important that staff be given concrete, practical and creative tools with which to respond to the resident in spiritual distress. The biographical activity described above can be initiated and implemented by anyone, including family members, and disseminated for use by all members of a clinical team. In addition, pastoral care workers who are visiting with congregants either in their own homes or in a nursing home facility could use a biographical story to offer comfort and to reconnect people to significant stories that represent their life journey.

Helping Persons with Dementia to Participate in Religious Life

Pastoral care for persons with dementia involves making an interpersonal spiritual connection through an emotional and symbolic plane.

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[49]J. Jones, "A Life-cycle Approach to Ministry with the Aging," *The Journal of Pastoral Care*, 1999, Vol. 53, pp. 323-331.

[50]L. Moore and B. Davis, "Quilting Narratives: Using Repetition Techniques to Help Elderly Communicators," *Geriatric Nursing*, 2002, Vol. 23, pp. 262-266.

[51]D. Shenk, B. Davis, J. R. Peacock, & L. Moore, "Narratives and Self-identity in Later Life: Two Rural American Women," *Journal of Aging Studies*, 2002, Vol. 16, pp. 401-413.

O'Connor[52] suggests that the spiritual care for the person with dementia can help facilitate a balance between the elements of Erikson's developmental stage of integrity *versus* despair.[53] The pastoral worker enters the resident's world, working in the here and now to mirror affective behavior, thereby creating a bond. The focus of pastoral care becomes presence and being, rather than progress and doing. The reciprocity of the relationship between pastoral care worker and resident is the key to promoting an interpersonal competence and mastery that promotes spiritual well-being.

Participation in religious life can involve a number of activities. Helping the person with dementia to join in on familiar chants, prayers and songs can facilitate an experience of the feeling-oriented aspects of spirituality and worship. Richards and Seicol[54] suggest that pastoral caregivers can assist the person with dementia to maintain a spiritual connection to God through memories, life stories and sharing in music, prayers. sacraments, symbols and rituals that are familiar. Clayton[55] suggests using the metaphorical strength of familiar parables and psalms to assist persons with dementia to discover the meaning behind life events, or to take comfort in particular words and rhythms. Davis,[56] in his autobiographical work that describes his personal experience of living with Alzheimer Disease, outlines some of the simple, yet profound ways in which congregants and family members helped to ease his wounded spirit. For example, hearing psalms such as *Isaiah* 43:2, "When you pass through the waters, I will be with you, and when you pass through the rivers, they will not sweep over you," gave him great comfort.

The abilities of even the most severely affected individuals to experience God must not be under-estimated. For example, persons disoriented with respect to person, place, and time have frequently been observed participating positively in the singing of hymns, parts of well- known prayers, or ritual gestures during religious services as well as having an uncanny sense of when it is the Lord's Day. The work of McFadden and Hanusa[57] suggests that spirituality and meaning in the nursing home is co-created through the dynamic reciprocal relationship between the staff and residents. They recommend that nursing assistants be taught to interpret their everyday duties as the means through which residents find meaning in day-to-day life events and connect to what is holy. The interpersonal relationship between the staff and the resident contributes to everyday spirituality in the nursing home. Everett,[58] a chaplain in a long term care facility in Alberta, suggests that even the most severely affected individuals can experience God's pres-

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[52]T. O'Connor, "Ministry Without a Future: A Pastoral Care Approach to Patients with Senile Dementia," *The Journal of Pastoral Care*, 1992, Vol. 46, No. 1, pp. 5-12.

[53]E. H. Erikson, J. M. Erikson, & H. Q. Kivnick, *Vital Involvement in Old Age* (New York, NY: W. W. Norton, 1989).

[54]M. Richards and S.Seicol, "The Challenge of Maintaining Spiritual Connectedness with Persons Institutionalized with Dementia," *Journal of Religious Gerontology*, 1991, Vol. 7, No. 3, pp. 27-40.

[55]J. Clayton, "Let There be Life: An Approach to Worship with Alzheimer's Patients andTheir Families," *The Journal of Pastoral Care*, 1991, Vol. 45, pp. 177-178.

[56]David, *op. cit.*

[57]F. McFadden and S. Hanusa, "Nourishing the Spirit in Long Term Care: Perspectives of Residents and Nursing Assistants on Sources of Meaning in Residents' Lives," *Journal of Religious Gerontology*, 1998, Vol. 10, No. 4, pp. 9-26.

[58]D. Everett, *Forget Me Not: The Spiritual Care of People with Alzheimer's Disease* (Edmonton: Inkwell Press, 1996).

ence through sensory experiences of life that are richly symbolic; the aroma of freshly baked bread, the smell of the earth on a crisp autumn day or the caress of a warm summer breeze not only stimulate the senses, but celebrate and honor the relationship with God and the universe. The pastoral visitor should recognize that spiritual ministry includes taking the person afflicted with dementia to the neighborhood park or the courtyard of the nursing home. Sitting quietly while the person enjoys this experience constitutes a ministry of presence.

It is also important that pastoral care workers look for and recognize the many opportunities available for persons with dementia to experience self-worth, purpose, and hope. Creativity and flexibility can assist the pastoral care workers in fulfilling the needs of the spirit. Shalom Village has undertaken to adapt religious services and all aspects of spiritual life to accommodate those who are cognitively impaired. During Sabbath, memorial services, and high holidays such as Passover, the religious leaders move throughout the congregants, helping them participate in chants and sing familiar religious text. The written materials read during services have been simplified. Those leading the services are careful to read slowly, using gestures, vocal pitches and rhythmic speech patterns that bring meaning and comfort to those with dementia. Should a congregant begin to chant out of context, the religious leaders will follow, leading others in the congregation to honor the individual's contribution to communal worship. Congregants are not prevented from leaving the service if it is clear they need to wander or have momentarily lost interest. They will continue to be welcomed each time they enter the place of worship, which might happen frequently during each service. In other words, behaviors that might be viewed as unacceptable are understood and accommodated.

At Shalom Village, family members and volunteers from a variety of congregations in the community assist with the services as well. The high number of spiritual facilitators ensures that nursing home residents will have their needs met quickly, for example, help turning pages in religious texts or simply offering fellowship or reassurance during the service. It also enables those persons with dementia to participate actively in parts of the religious service where they typically would not be engaged. For example, pastoral care workers and volunteers have assisted persons with dementia to stand at the front of the congregation in a place of honor as religious script is read, representing their participation "by proxy." Spiritual life can be enhanced when the pace and focus of the religious service is adapted to encourage participation by all members of the congregation, including those who are cognitively impaired.

Conclusion

Building upon and facilitating the use of enduring abilities among individuals with dementia can help them meet a variety of spiritual needs. Spirituality is based on a relationship of honorable reciprocity between the person with dementia and caregivers.[59] Pastoral care workers, community religious leaders, family, volunteers and professional care providers all have a role to play in enhancing spiritual well-being in persons with dementia. Participation in activities ranging from the religious to the most ordinary

[59]McCurdy, *op. cit.*

daily care tasks engage the person with dementia, maintaining a spiritual connection to what is "holy."

Learning to affirm the personhood of individuals with dementia can enable caregivers to help individuals to reconnect with their sense of self, others, environment, and their God. Moreover, pastoral care workers and other caregivers can also benefit spiritually from establishing a relationship deeper than words and often focused on the present moment. Educational programs that enhance nurturing skills in professional care givers of people with dementia can decrease their own stress and increase overall well-being.[60,61]

Caregivers can foster spiritual well-being by helping the person with dementia exercise every opportunity to engage in activities that have symbolic meaning, thereby making them feel valued and cherished. It is true that sharing a hug or a smile, swaying to the beat of music, savoring a meal, are simple interactions. However, they are also deeply profound ways whereby caregivers can ensure that persons with dementia continue to feel accompanied on their journey through life, while refreshing their own spirit. To paraphrase the introductory poem,

> You shine the sun of your listening upon me, and
> Our spirits blossom.

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[60]V. Bell and D. Troxel, *The Best Friends Approach to Alzheimer's Care* (Baltimore, MD: Health Professions Press, 1997).

[61]Kaplan and Hoffman, *op. cit.*