

Companioning People with Dementia

by Rita Hansen, John R. Mabry, and Robert B. Williams

“**G**ood Morning, I’m Arthur James. Wasn’t the service enjoyable? I like coming to Holy Trinity.” For the umpteenth time Arthur James introduces himself to other faithful worshipers at the service as though they had never before met. They all know Arthur, who is a spry, cheery, and pleasant 80-year-old who accompanies his wife, Alice, to church every week. During the worship service, Arthur knows exactly what to do. He sings, recites prayers and psalms, stands, processes, kneels to reverently receive communion, and is able to return unassisted to his place in the pew. From the view of any observer, Arthur’s behavior during the service is really no different than anyone else’s. It is Arthur’s recurring introductions of himself and his need to be reacquainted with those who are with him every week that reveals something of the problems that he and his wife are coping with.

Occasionally, Arthur and Alice attend social activities at Holy Trinity. At a recent ham and bean supper, Arthur was unable to recognize Pastor Green, who was dressed in a flannel shirt and jeans. This was surprising because Arthur had always addressed Pastor Green quite enthusiastically when greeting him after services. Arthur was not able to recognize him because he was “out of uniform.” Alice told us that Arthur does not recognize himself in recent photos. He can point himself out in photos taken when he was an adolescent and a young adult, but not beyond those years. Arthur has

occasions when he doesn’t even recognize Alice in photos, except in those taken when she’s wearing her nurse’s uniform.

Arthur is totally dependent on Alice for everything. He is unable to write, drive, shop, plan, or carry out even simple household chores, adequately maintain his personal hygiene, select clothing appropriate for the occasion or season, find the bathroom, or recognize the voices of relatives or friends on the phone. He depends upon assistance and cues from others for normal life experiences he knew and lived before being afflicted with a loss of his “everyday memory.” This loss has been noted by Arthur’s physician as a likely symptom of dementia.

The Burdens of Dementia

Those afflicted with dementia have problems applying their thinking to ordinary tasks such as dressing, personal hygiene, or remembering words or names. Over time, a person’s ability to live a self-directed life is progressively reduced by problems with thinking and remembering. Such problems are symptoms of dementia, seen in persons with Alzheimer’s disease; Lewy body disease; vascular dementia and dementia due to other medical conditions such as HIV; head trauma; Parkinson’s disease; Huntington’s disease; Pick’s disease; or Creutzfeldt-Jacob disease. Symptoms of dementia are due to actual physical changes occurring in one or more parts of the brain. With the exception of Creutzfeldt-Jacob, most people afflicted with dementia experience a slow decline

in thinking and remembering.¹

Prior traits and behavior become exaggerated in people with Alzheimer's. No one really knows when Alzheimer's begins, and the symptoms or signs are different for every person. A positive diagnosis can only be made in autopsy. The key is to observe a progression of change in behavior, cognition, and emotion.

Because of their uneven decline in thinking and remembering, persons with dementia often surprise family, pastors, and other caregivers by their responses. Arthur is a good example because he can participate fully in worship services but is limited in activities of daily living. Further, pastoral care personnel have observed responses that we have been taught are beyond the capabilities of a person with Alzheimer's. We do not really know enough about these people in general and we must tailor our pastoral or spiritual offerings for individuals.

Early Stages:

Recognizing Dementia in Directees

When Pamela showed up for her regular spiritual direction session, she was upset and shaken. "Let's take a minute of silence to center ourselves," suggested Leslie, her spiritual director. When she was calmer, Pamela explained that she seemed to be forgetting things more and more, and she was starting to panic. "I went to the supermarket because Jane and the kids were coming for supper. But when I got there, I forgot what I had come for, and for a few minutes, I couldn't figure out where I was. I was so scared I was shaking." Leslie was tempted to say, "I forget what I went to the store for all the time!" But Pamela was crying now, and she realized this was more serious than simple forgetfulness.

Memory loss in elderly people is normal, and does not necessarily denote the onset of dementia. Pamela's experience may have been a simple case of age-associated memory impairment, but the red flag had been waved. Leslie made a mental note of the experience and between sessions educated herself on the signs of dementia. When Pamela's experiences persisted, Leslie strongly recommended a medical consultation. Pamela was in strong denial for a while, but when another "episode" occurred while she was driving, she finally went to her doctor.

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1 | No cognitive decline. No subjective complaints of memory deficit. No memory deficit evident on clinical interview.

2 | Very mild cognitive decline (Age Associated Memory Impairment). Subjective complaints of memory deficit, most frequently in the following areas: (a) forgetting where one has placed familiar objects; (b) forgetting names one formerly knew well. No objective evidence of memory deficit on clinical interview. No objective deficits in employment or social situations. Appropriate concern with respect to symptomatology.

3 | Mild cognitive decline (Mild Cognitive Impairment). Earliest clear-cut deficits. Manifestations in more than one of the following areas: (a) patient may have gotten lost when traveling to an unfamiliar location; (b) co-workers become aware of patient's relatively poor performance; (c) word- and name-finding deficit becomes evident to intimates; (d) patient may read a passage or a book and retain relatively little material; (e) patient may demonstrate decreased facility in remembering names upon introduction to new people; (f) patient may have lost or misplaced an object of value; (g) concentration deficit may be evident on clinical testing. Objective evidence of memory deficit obtained only with an intensive interview. Decreased performance in demanding employment and social settings. Denial begins to become manifest in patient. Mild to moderate anxiety accompanies symptoms.

4 | Moderate cognitive decline (Mild Dementia). Clear-cut deficit on careful clinical interview. Deficit manifest in following areas: (a) decreased knowledge of current and recent events; (b) may exhibit some deficit in memory of one's personal history; (c) concentration deficit elicited on serial subtractions; (d)

The Global Deterioration Scale for Assessment of Primary Degenerative Dementia

decreased ability to travel, handle finances, etc. Frequently no deficit in following areas: (a) orientation to time and place; (b) recognition of familiar persons and faces; (c) ability to travel to familiar locations. Inability to perform complex tasks. Denial is dominant defense mechanism. Flattening of affect and withdrawal from challenging situations frequently occur.

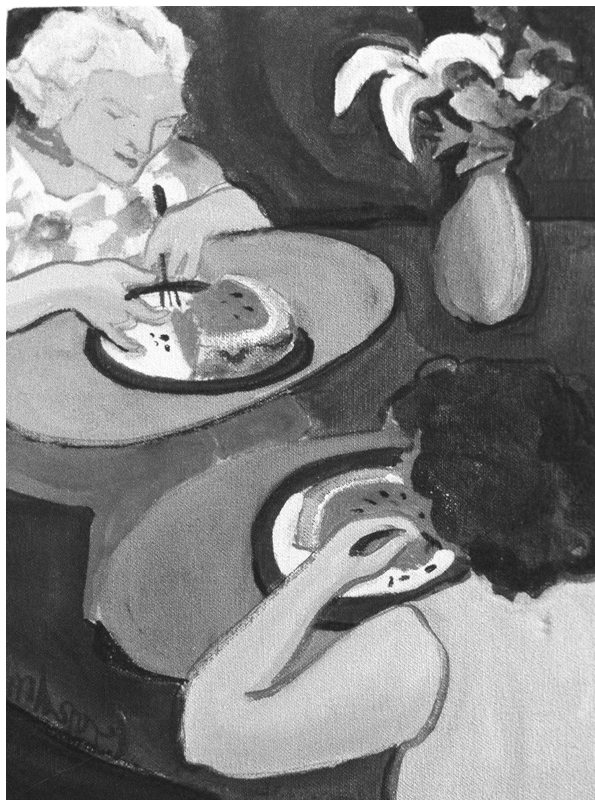
5 | Moderately severe cognitive decline (Moderate Dementia). Patient can no longer survive without some assistance. Patient is unable during interview to recall a major relevant aspect of his or her current life, e.g., an address or telephone number of many years, the names of close family members (such as grandchildren), the name of the high school or college from which they graduated. Frequently some disorientation to time (date, day of week, season, etc.) or to place. An educated person may have difficulty counting back from 40 by 4s or from 20 by 2s. Persons at this stage retain knowledge of many major facts regarding themselves and others. They invariably know their own names and generally know their spouses' and children's names. They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.

6 | Severe cognitive decline (Moderately Severe Dementia). May occasionally forget the name of the spouse upon whom they are entirely dependent for survival. Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is very sketchy. Generally unaware of their surroundings, the year, the season, etc. May have difficulty counting from 10, both backward and, sometimes, forward. Will require some assistance with activities of daily living, e.g., may become incontinent, will require

travel assistance but occasionally will be able to travel to familiar locations. Diurnal rhythm frequently disturbed. Almost always recall their own name. Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment. Personality and emotional changes occur. These are quite variable and include: (a) delusional behavior, e.g., patients may accuse their spouse of being an impostor, may talk to imaginary figures in the environment, or to their own reflection in the mirror; (b) obsessive symptoms, e.g., person may continually repeat simple cleaning activities; (c) anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur; (d) cognitive abulia, i.e., loss of willpower because an individual cannot carry a thought long enough to determine a purposeful course of action.

7 | Very severe cognitive decline (Severe Dementia). All verbal abilities are lost over the course of this stage. Frequently there is no speech at all—only unintelligible utterances and rare emergence of seemingly forgotten words and phrases. Incontinent of urine, requires assistance toileting and feeding. Basic psychomotor skills, e.g., ability to walk, are lost with the progression of this stage. The brain appears to no longer be able to tell the body what to do. Generalized rigidity and developmental neurologic reflexes are frequently present.

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In this case, Leslie's attention paid off. A spiritual director must become attuned to signs of even slight behavior change in older persons being companioned. The disease usually progresses in a linear fashion, and moves through seven stages (see pages 46–47 for the standard reference for dementia, the Global Deterioration Scale).

Initially, there are no symptoms (Stage 1). A person does not notice as the disease begins its work. The impairment is no greater than occasional memory loss experienced by most people.

Gradually, a person will experience a very mild decline (Stage 2). A directee may complain about not being able to remember names of people they *know* they ought to know. They may misplace objects more and more frequently. This stage may be accompanied by frustration and self-recrimination for being “so forgetful.” The directee will still be functional at work, and will continue to be articulate in direction at this stage. Such complaints should prompt a director to pay attention, but will not necessarily indicate that medical attention is necessary.

Eventually, however, the disease will manifest itself clearly (Stages 3 and 4). A directee may get lost when traveling to an unfamiliar location, his or her work performance will begin to suffer, and family members will notice the person's increasing difficulty with names and proper articulation. A directee may also be frustrated with how little he or she retains when reading, or have difficulty concentrating. A directee may also be feeling shame because he or she has lost an item of great value. He or she may begin to experience increasing levels of anxiety, and not a little bit of denial.

At this point a responsible director should recommend that his or her directee seek medical attention to discover the cause of their symptoms and to receive adequate medical care. The director should also turn attention to proper spiritual care for someone with progressive dementia, as spiritual direction in a typical setting and fashion may become increasingly difficult.

Spiritual Care as Condition Progresses

Each year the Gerontological Society of America brings out research about how religious or spiritual support positively mediates attitudes, coping, health, anxiety level, and life satisfaction in older people. There is, how-

ever, a lack of inquiry relating to religious and spiritual lives of elders who have serious cognitive impairment. According to Sandy Burgener, Rosemary Shimer, and Linda Murrell, "One explanation for the lack of attention to spiritual needs in demented elders may be an assumption on the part of the religious community caregivers and family members that spiritual support and practices may no longer be relevant or important for an elder with dementia" (*Journal of Gerontological Nursing* 19.4, 1992, p. 17).

This assumption, of course, is not correct. As spiritual directors, we see in our daily experience that there is no part of life in which the Spirit is not at work. To assume that people with dementia do not have spiritual lives or that spiritual care is no longer relevant for such people is the 21-century equivalent of such 19-century assertions as "animals are machines that do not feel pain," or "slaves are not human beings." These kinds of denials are ways that society has avoided collective responsibility, and there are many who would avoid the responsibility of treating people with dementia as real people. In certain circumstances, it may be tempting to any of us to want to avoid such responsibilities. But as spiritual directors, it is our responsibility to meet people where they are, to bear witness to the movement of the divine in a person's life, regardless of their societal, ethical, or medical state.

When one becomes aware that a directee's condition is progressing, there are several ways that a spiritual director can be of assistance. In the early phase of dementia, it is helpful to assess how you should proceed with direction and include the directee in this assessment. Sometimes, it's helpful to share what caregivers have learned about persons with Alzheimer's.

A director should also be prepared to assist the directee who is newly diagnosed with Alzheimer's disease with coping and grieving. Alzheimer's disease is a catastrophic chronic illness similar to cancer or stroke that carries with it a stigma, and imposes the loss of one's role, which can result in a devastating identity crisis. Eventually the condition will require extraordinary adaptations by the person and loved ones (Cotrell & Schulz). The impact of being told that one has Alzheimer's is well demonstrated in David Snowdon's *Aging with Grace*. He relates the story of a nun who was

misdiagnosed as having Alzheimer's. Her greatest worry was that she would forget Jesus but became consoled by the thought that he would not forget her. All during the time that others around her believed that she had Alzheimer's, they would check on her to be sure that she was not forgetting to turn off any equipment she used. There are many effective and important things one can do in companioning someone as their condition progresses:

Provide a Safe Container for Feelings. Articulating feelings is difficult for the directee with dementia. This will also touch the feelings of the spiritual director. Feeling useless, low, angry, surprised, and taken unaware may be part of a long list of negative feelings that a person with dementia can display. Inhibitions are let loose and he or she may say or do what could be inappropriate in a "normal" spiritual direction session. Directors can minister to directees with dementia by being present and listening as they describe their frustration and fears. The direction session may be the only safe space a directee has to process his or her feelings about what is happening, since family members may also be in denial, or may not want to talk about it.

Provide Comfort and Reassurance. Most people who suffer dementia are quite aware of what is happening to them, and fear and anxiety are quite common. People with dementia experience gradual loss of their internal landmarks, so anything that lessens the anxiety and distress caused by confusion and disorientation is a desirable goal for any caregiver. As every spiritual director knows, religious ritual and devotional activity goes very deep. Attention given to this aspect of life may provide a mental "anchor" for people with dementia that can significantly increase their quality of life. A director may want to incorporate a ritual into the sessions that can be done outside the session too, which may help the directee access the peace and comfort that the direction session affords between sessions as well. Simply reading aloud familiar scriptures such as the 23rd Psalm, the Lord's Prayer, or reciting the rosary can bring comfort and grounding to a directee even in the midst of a very frustrating and frightening day.

A spiritual director may find it helpful to identify a souvenir or symbol (Bible, cross, rosary, icon, picture, prayer, hymn, etc.) from the past that the directee with

dementia has used continuously. The symbol or souvenir can serve as a cue for the directee as to your continuing role. Directors can encourage directees to incorporate simple rituals into direction sessions and daily life, even if such rituals have not been particularly attractive to them in their earlier life.

Directees may feel very alone. It is important to remind the directee that, like Daniel's fourth man in the fire, God is present in all the pain and confusion, and is going through it all *with* them. The director is also with them, and should remind them that he or she is not going to go away. Bringing to mind others that are committed to the directee will encourage relaxation and trust that he or she will be cared for and loved even when their condition worsens.

Determining One's Own Commitment. Directors at this stage should also ask themselves some very important questions: What is my commitment to my directees? Will I continue to accompany them even after they have gone into assisted living? Even after they can no longer pay for service? How much time can I commit to spending with my client as his or her disease progresses? Do I have sufficient emotional and spiritual support to continue companionship with this person? Getting clear on these questions for oneself while one's client is still aware and articulate will help when comforting the directee, as one will know exactly what one can promise, and one's directee will not fear abandonment.

The most important thing at this stage is to provide directees with safe space to grieve the stage of life that they are passing out of, and to comfort them as they attempt to navigate the scary new world which is emerging. If there are hurts that are unhealed, apologies unsaid, or confessions unmade, directors can suggest that now is the time to make such connections, while they can still do so with care and attention.

Spiritual Care in Later Stages

Spiritual direction is ordinarily thought of as a quiet, uninterrupted hour. Since people with Alzheimer's have a very short attention span (or they may be focused on memories of a past reality), a standard one-on-one direction hour is usually impossible. Spiritual care in later stages of dementia is usually provided not by spiritual directors, or even by pastors or priests, but from people who are ostensibly performing other tasks, especially

once a person has been admitted to a care facility.

As a nurse, I (Rita) found plenty of opportunities to minister to patients in the course of performing other duties. Directors who continue to companion former clients will find that there will be much opportunity to extend their attention to other residents while they are there. Even the average visitor to an Alzheimer's unit has ample opportunity to minister to many patients when going to see their own family members.

Ministry does not require a large amount of time to make a difference in a person's life. For instance, as a chaplain, I (John) regularly spent five to ten minutes with each patient as I made my rounds in the unit. More time might tax a person's ability to pay attention or focus. As conversation with people with dementia becomes more difficult, the simple ministry of presence becomes more and more important.

When spending time with people in later stages, there are many things one can do to help them.

Treat people with respect. The greatest loss a person with dementia experiences is not the loss of memory (which is to be expected) but the loss of dignity. Family members can slide into behavior which infantilizes the dementia sufferer, robbing them of their pride of place within a family, and their sense of self-worth. Long-buried resentments may surface in children now forced into caregiving roles, and opportunities to "get even" for long-past events may unconsciously be at play. Loving families will want to be watchful of such dynamics, and spiritual directors can act as advocates for their clients even in an institutional environment.

As spiritual caregivers, we must also be careful to avoid the arrogance that suggests that God is no longer working in people with dementia—what do we know about Spirit's intimacy with other people—*any* other people? The only appropriate assumption for a spiritual director is that Mystery is always unfolding in a person's life, and that Spirit is indeed at work in the inner world of people with dementia, however unfamiliar or peculiar such processes may seem to us.

Facilitate Reconnection with Memories. Responding to people with Alzheimer's or dementia from the perspective of their memories comforts and sustains them. Caregivers who can uncover past memories will discover that this can alleviate anxiety and help those they care for find a place of peace. Nursing home staff have found they are

able to stimulate memories via the paraphernalia of former occupations, reminiscence groups, music, religious services, and orientation to self when consistently addressed with their own names.²

I (Rita) knew Margaret only a month before she died at age seventy-six from asthma, which she had all her life. She was gentle and very friendly. Her rosary was always in her hand. The Blessed Mother was on her bedstand, the Sacred Heart and St. Joseph on the wall.

One night Margaret had an asthma attack, and the medication needed time to take effect. To distract her, I started to ask questions about another time in her life. "Where did you grow up?" At first she resisted and couldn't remember. After gentle coaxing, she smiled to recall, "Brooklyn!" I said, "I know where Brooklyn is." (Repeating a word is always good.) "Where did you go to high school?" Margaret concentrated for a time. I was called out of the room and a nursing assistant sat with her for ten minutes. When I returned, she smiled but couldn't remember "the long name of the high school with all different kinds of sisters . . . but my breathing is much better now. I feel comfortable." "How about Bishop McDonnell?" I asked. As she burst into an even bigger smile, Margaret added, "Oh, how could I forget the name of that place?"

Margaret and I graduated from the same high school, ten years apart. She shared stories, memories, prayer, and music. We sang together "Memorial, Memorial," our school song. Margaret went to her eternal reward thinking about being greeted by many old friends, religious sisters, and Bishop McDonnell himself. She had a great imagination about the party planned for her in heaven.

People are still people, even with Alzheimer's. We meet them where they are. We give them what they need, when they need it, and how they need. In Margaret's case, songs and gentle promptings of her

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memory brought great comfort and increased the quality of her spiritual life.

Role-playing and Confession.

As Alzheimer's progresses, sufferers go more and more into early childhood regression, and may become confused and irritated. Repetitive behaviors can also be troubling. Sufferers may mistake visitors for long-dead family members, and

relive important or mundane moments from their past. If you are present for such scenes, do not tell them

you are not who they think you are. They will benefit from thinking you are someone else, and it is usually better to play along. Caregivers may discover much about the spiritual state of a person with dementia by careful observation of the daily scenes acted out over and over again.

Sometimes scenes that dementia sufferers live out over and over are not pleasant ones. Their sins come back to haunt them, and they are forced to endure a living hell of moments of great shame replayed. While serving as chaplain, I (John) ministered to one person who insisted on confessing the same sin each time I saw him. Of course, he did not remember that he had confessed and received absolution for his transgression many times over. No matter. Hearing his confession and granting him absolution brought comfort each time.

Continue to be a Comforting Presence. Whatever decreases confusion and anxiety and brings comfort is of primary importance. Hearing one's name called often gives hope. A person's name may be her only connection to self and world. Hope will lapse quickly in a person who doesn't hear her name, and it is very important to keep it refreshed. Without hope, flattened affect and withdrawal are likely to take over.

Sense of humor. Patience and common sense are necessary for the spiritual director working with victims of dementia. Take care of your own needs for rest, food, and recreation, and keep a good sense of humor. It is

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okay to laugh and often it can defuse a tense situation. While Chaplaining at an Alzheimer's unit in Pleasant Hill, CA, USA, I (John) ministered regularly to an elderly Irish woman named Mae. She suffered with Alzheimer's and frequently thought I was her son. One day when her daughter and son-in-law were present, she repeatedly asked me to help her with something. Her hands were waving in the air, and it was clear that whatever device she was manipulating existed only in her memories. She was frustrated that I was simply standing there and not assisting her. "Can't you see I can't make this work, Jerry? Help me!" She scolded me. I was taken aback, because I didn't know what she was trying to do nor how to help her. Finally, she dropped her hands in exasperation, and sighed, "Ah, Jerry, you're not worth a damn, anyway." I might've taken offense, but her timing was so comic that the daughter, her husband, and I all burst out laughing. Mae joined in our mirth, though she did look a little bewildered. Whatever frustration or anger she was feeling dissipated quickly into giggles, and she marched off like a soldier to pronounce judgment on something else. Her daughter rolled her eyes and gave me a pat on the shoulder. "That's my mom," she smiled.

Ministering to the Families of People with Dementia

Ministering to the person with Alzheimer's means being present to the family as well. Mary had become extremely sweet and docile. The expression on her once lively Italian face was flat. She was a brittle diabetic recovering from pneumonia. She did not remember being hospitalized two weeks earlier. Her nursing home room was switched because Medicare ran out. Mary's 56-year-old daughter had taken an unpaid leave of absence from her job in New York because of all her mother's problems. The daughter didn't understand "how a good God could do this." She told me (Rita) she was "going to sue." She collected herself in the silent moments that followed. Mary told her daughter to "go see the priest." The woman didn't sue, after all, but the threat was a clear indication of the daughter's great distress and sense of divine abandonment.

Spiritual direction in such a situation may mean discerning God at work under all the dust of family conflict and conversation. This can be very delicately uncovered. Paul and Nelly were members of an Oakland, CA, USA parish for many years. Paul had a terrible temper, often fueled by drinking bouts. Nelly habitually ran interference for Paul, but when she contracted Alzheimer's disease, her ability to do this effectively diminished quickly. Eventually she moved into a nursing facility and Paul was, for the first time in many years, truly responsible for his own anger. When Paul's pastor, David, tried to companion him through this he was repeatedly rebuffed, even to the point of verbal abuse. Finally, Paul told Pastor David to simply stop visiting. We are not always able to achieve a good outcome, yet God was using the difficult situation of Nelly's disease to call Paul to wholeness.

Caregivers can provide not only presence, but education as well by recommending books that will help family members understand what is happening to their loved ones. In spite of its formidable title, one of the best is *The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer's Disease, Related Dementing Illnesses, and Memory Loss in Later Life*, by Nancy L. Mace and Peter V. Rabins (Baltimore, MD, USA: John Hopkins University Press, 1999)—widely considered the bible of Alzheimer's caregiving.

The Person with Alzheimer's and Liturgy

While assessing a group of residents diagnosed with probable Alzheimer's dementia at a nursing care facility, I (Robert) learned about their positive responses at weekly ecumenical worship services. These residents were ages 63 to 89 years and very limited in their abilities to think or remember. Responses observed during liturgy included recitation of prayers, singing, receiving communion, weeping, and composure or quietness. These responses are noteworthy because some of these residents were unable to feed themselves, recognize family members, or respond to questions about who or where they were.

In spite of a decline in ability to think and remember, something triggered these people's memories and enabled them to respond to the liturgy as if unimpaired. This places some responsibility on us as caregivers to give attention to liturgy, and points to a need to work at thinking about how people with memory loss remember the world.³

When I (John) was serving as chaplain in an Alzheimer's Unit, I would offer a weekly communion service. Participation varied widely from person to person, according to stage of dementia. At the end of the service, I went around to distribute communion and gave a host to all who would receive it. One woman was, to the casual observer, completely oblivious to all that was going on around her. She stared blankly into space, and her mouth gaped perpetually. I knelt by her, held her hand, and asked, "Do you want to receive communion?" She did not respond, yet I felt a response. Acting on intuition, I placed the host into her mouth. Just then a single tear rolled down her cheek. All appearances to the contrary, there was "someone home," and that one was still touched and fed by the Body of Christ.

What do elderly Catholics and other liturgical Christians with severe cognitive impairment "know" as it relates to whether they are able to meaningfully receive communion? In *Guidelines for the Celebration of the Sacraments with Persons with Disabilities* (Washington, DC, 1995), the National Conference of Roman Catholic Bishops encourages clergy to consult with individuals knowledgeable about disabilities in deciding such questions. There is no reference to empirical studies relating to these issues. The most helpful approach is to use the same cri-

teria applied to ordinary persons to those with Alzheimer's dementia.

Worship and liturgy engage us from the beginning to the very end of our lives. In *Liturgy, Worship and Prayer* (Birmingham, UK: Maryvale Institute, 1999, p. 17), Michael Mulvihill notes that "[i]t is the Liturgy that is the first school of prayer, and it is by participating in its celebrations regularly and frequently that we grow in communion with God." This may explain how a lifelong history of attendance and participation in liturgy results in memories that allow persons with limited ability to think and remember to respond so well and meaningfully to worship when it is presented to them.

Selecting "old favorite" hymns is just one of many things that can be done to enhance the worship experience for persons with Alzheimer's. You might even go to hymns and music popular at the time when these people were young to reinforce meaningfulness of liturgy and worship and increase the likelihood of response. Singing hymns such as "The Old Rugged Cross" or "Onward Christian Soldiers" with its sacrificial and militaristic theologies might make contemporary clergy cringe, but they are balm for the soul indeed for those who grew up with such hymns, and caregivers should remember that they are there to serve the needs of their people. Personal theological preferences need to be set aside in favor of what is going to provide the most effective comfort.

Repetition helps people connect and respond to liturgy. When I (John) led music with my guitar, we sang the same songs every week. No one ever complained, and the singing was often robust, as even moderately impaired people were able to participate.

With the growing need for ministry in this area, we authors wonder why there aren't worship kits for this audience, with examples of prayers, hymns, sermon topics, versions of scripture, and descriptions of favored clerical dress? The Social Welfare Committee of the Bishop's Conference of England and Wales notes: "Many of those with dementia are helped by stirring their long-term memories of the Church with the use of familiar hymns, sights, and smells."⁴ Come to think of it, maybe the kits should include pictures, incense, lace, recorded organ and choral music, and various vintage objects; anything that will help people with dementia to reconnect with worship experiences in their past.

To implement a meaningful program of spiritual care for persons diagnosed with dementia, knowing their religious history and practices (such as church attendance, preferred prayers, religious readings, and meaningful objects) is a good place to start.⁵ This information can be obtained from family members or close friends. In some facilities, social workers include this as an essential part of patients' social history.

A Growing Need

All of these concerns take on special significance in the light of the prevalence of dementia among persons over 65. Estimates (1989, 1992) of the incidence of dementia among persons over 65 range from 6.5% to 10.3%.⁶ In this regard, the proportion of the US population over 65 years of age has gone from 4% (1 of every 25 individuals) in 1900, to 12.5% (1 of every 12 individuals) in 1990.⁷ A leading geriatric specialist noted that "more than half of the people who have lived past the age of 65 since the beginning of recorded history are alive today."⁸ By 2030, it is expected that 1 of every 4 persons (25% of the U.S. population) will be over 65!⁹

Where are we likely to find older persons with dementia who can benefit from pastoral and spiritual care? Our first thoughts are of parish congregations, assisted living communities, nursing homes, or even homeless shelters. British researcher P. G. Coleman recently made the observation that we must consider "the pastoral care needs of the relatively large number of the present older British population who do not actively belong to faith communities and yet continue to maintain a measure of spiritual belief."¹⁰ If estimates of the prevalence of dementia among persons over 65 noted above are correct, we can assume that many more people will be afflicted with dementia in the near future. Pastoral and spiritual caregivers across all denominations will find themselves working with individuals experiencing decline in their thinking and remembering, perhaps even including the caregivers themselves. ■

Notes

1. Cf. American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. (Washington, D. C.: Author, 1994): 139–143; American Psychiatric Association, *Practice Guideline for the Treatment of Patients with Alzheimer's Disease and Other Dementias of Late Life*. (Washington, DC: Author, 1997).

2. Richard B. Ferrell and Robert B. Williams, "Exploring the Loss and Preservation of Abilities Among Persons Diagnosed With Probable Dementia," *Program and Abstract Book of the International Psychogeriatric Association European Regional Meeting, Geneva, Switzerland*, 1–4 April (2003): 74 (abstract).

3. For more on this, see Victoria Cotrell and Richard Schulz, "The Perspective of the Patient with Alzheimer's Disease: A Neglected Dimension of Dementia Research," *The Gerontologist* 33 (1993): 205–211.

4. Social Welfare Committee of the Bishops' Conference of England and Wales, "Spiritual Needs of People With Dementia" [Press Release October, 1999], Retrieved 1 February 2000 from www.tasc.ac.uk/cc/cn/00/000306c.htm

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