End-of-Life Care Practice Recommendations for Assisted Living Residences and Nursing Homes Serving Individuals With Dementia

BY JANE TILLY, DRPH; PETER REED, PHD; ELIZABETH GOULD, MSW; AND ABEL FOK, BSC, LLB

The Alzheimer's Association Dementia Care Practice Recommendations for end of life are based on the latest evidence in research and the experience of care experts. To gain experiential evidence, the association engaged experts from its 79 chapters, representatives of more than 30 national associations, and other experts in a consensus-building process to translate the research into specific recommendations. The recommendations, summarized in this article, fall into 8 specific categories: (1) communication, (2) decision making, (3) care coordination with hospice services, (4) physical symptoms, (5) behavioral symptoms, (6) psychosocial and spiritual support, (7) staff training, and (8) bereavement. All recommendations are based on a person-centered approach to care, which tailors care to the abilities and changing needs of each resident and to his or her wishes regarding care at the end of life.

Key words: decision making, dementia, nursing homes, practice guidelines, terminal care

On receiving a diagnosis of dementia, many issues must be considered, including the resident's preferences regarding end-of-life care. Over time, the losses associated with dementia often result in a transition to a nursing home or an assisted living residence. Sometimes residents choose hospice services while in 1 of these residential settings. Available research indicates that about 67% of dementia-related deaths occur in nursing homes.[1] Assisted living residences also have a role in end-of-life care because many states allow hospices to serve people

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there. In assisted living, the residences and hospice services work together to serve the person dying with dementia.

The Alzheimer's Association Phase 3 Dementia Care Practice Recommendations on end-of-life care are based on the latest evidence in dementia care research and the experience of care experts. The association used 2 primary sources of research evidence—an association-sponsored literature review[2] and qualitative work that describes what practitioners, providers, professionals, and researchers believe constitutes high-quality end-of-life care for residents with dementia.[3]

To gain experiential evidence, the association engaged experts from its 79 chapters, representatives of more than 30 national associations, and other experts in a consensus-building process to translate the research into specific recommendations for dementia care in assisted living residences and nursing homes.[4] Underlying the end-of-life care practice recommendations is a person-centered approach to dementia care, which involves tailoring care to the abilities and changing needs of each resident.

The practice recommendations, which are designed to improve the dying experience for people with dementia who live in long-term care settings, are based on the following goals:

- to use a person-centered, culturally sensitive approach to providing care that meets a resident's changing needs and respects his or her preferences regarding end-of-life care;
- to minimize the resident's physical, emotional, and spiritual distress, while maximizing comfort and well-being in a manner consistent with an individual's preferences regarding end-of-life care;
- to ensure open and ongoing communication among the resident, proxy decision maker, family, and care team so that all parties have a clear and common understanding of what constitutes optimal end-of-life care for the individual resident; and
- to provide support to families, other residents, and staff when an individual is dying, and after death has occurred, to help them achieve meaningful closure after the person has died.

To implement these goals, the Alzheimer's Association has developed detailed practice recommendations that fall into several categories: (1) communication, (2) decision making, (3) care coordination with hospice services, (4) physical symptoms, (5) behavioral symptoms, (6) psychosocial and spiritual support, (7) staff training, and (8) bereavement. A full copy of the *Dementia Care Practice Recommendations for Assisted Living Residences and Nursing Homes Phase 3: End-of-Life Care* may be accessed from the Alzheimer's Association Web site (http://www.alz.org/national/documents/brochure_DCPRphases1n2.pdf).

COMMUNICATION

Close communication among the resident, proxy decision maker, family, and the broader care team is critical to ensuring the best possible end-of-life care and honoring the resident's preferences. While communicating, it is important for providers to consider difficulties and differences, including the cultural and linguistic background of a resident and family, and their ability to understand and express themselves. For example, residents with dementia may require additional time to understand and respond to questions and interpreters may be needed for non–English-speaking residents and their families.

Residents with advanced dementia frequently communicate nonverbally through their behaviors, including their reactions to care. Thus, effective communication at the end of life involves staff understanding a resident's behaviors and communicating via methods that the individual can understand, such as gentle touch, direct eye contact, smiles, and pleasant tone of voice. Even if there is little expectation that a resident will understand the words, it is best to tell residents what is happening before touching them.

Providers, persons with dementia, and their loved ones need a clear, common understanding of the resident's care preferences when the end of life approaches. This understanding can be reached when all parties are educated about the course of dementia and the benefits and burdens of different care options. Such education could address differences between palliative care and Medicare and Medicaid hospice benefits, assisted living and nursing home policies on transfer or discharge when a resident is dying, and availability of palliative and hospice care.

Effective communication is ongoing as dementia progresses so that everyone understands how a resident's functional and health status is changing and what these changes mean for the resident's ongoing care. This is particularly important before the resident shows symptoms associated with active dying so that the family knows what to expect. At this point, they will likely need more information and counseling. Hospice staff with expertise in dementia care can be helpful in educating and counseling the family about the dying process.

Regularly scheduled care planning meetings that involve the resident, proxy decision maker, family, and the broader care team facilitate communication about end-of-life care and help ensure that care is person-centered and adapted to the resident's changing condition. The care team is the group of people who work together to plan, determine, and implement a resident's care plan. This group may include the resident, family members, the person who is able to make care decisions on behalf of the resident (ie, proxy decision maker), professionals and staff involved in care, and those who provide spiritual support. When a resident receives hospice services, the hospice nurse or care coordinator is typically involved in care planning.

DECISION MAKING

Discussions about care and treatment decisions are of critical importance because of the progressive and inevitable decline associated with dementia, and the potential for moral dilemmas to surround end-of-life care. Peer-reviewed research has shown that many medical interventions either produce no benefit or have detrimental effects on people with advanced dementia.[2] In addition, effective treatment for conditions such as severe pain may be perceived as hastening death, although research shows otherwise.[5-7] Thus, it is important for residents, proxy decision makers, and families to understand the benefits and burdens of care and treatments so that they can make informed decisions. It is also important for the residence to have and apply policies and procedures regarding implementation of care and treatment decisions.

During the initial assessment and care planning process, it is important to discuss the resident's preferences regarding end-of-life decisions and any related doctor's orders such as "comfort care only," "do not resuscitate," "do not hospitalize," or "do not intubate." These orders are designed to prevent reviving, hospitalizing, or inserting a tube to help a resident breathe when he or she is dying.

When meeting with the resident, proxy decision maker, or family, the broader care team can discuss potential medical crises and treatment alternatives and make decisions about the best course of action on the basis of the resident's condition. Some of the alternatives to discuss include the following:

- cardiopulmonary resuscitation;
- invasive medical procedures and tests (eg, surgery, blood tests, dialysis);
- hospitalization;
- use of intensive care units and ventilators;
- artificial nutrition/hydration;
- use of antibiotics; and
- use of preventive health screenings, medications, and dietary restrictions.

If planning for end-of-life decisions does not take place upon admission, residence staff can discuss these decisions with the individual with dementia, proxy decision maker, and family as soon as possible after the individual's admission to allow everyone time to adjust to the resident's new living environment. This adjustment time also allows the resident, proxy decision maker, and family to begin building a relationship with the broader care team, which is conducive to an effective care planning process.

Discussions about end-of-life care are ongoing and always involve the resident, proxy decision maker, and family to the degree possible. As the resident's condition declines with the progression of dementia, care goals may change from curing coexisting conditions or preserving function to palliative care. It is important to reevaluate and, if necessary, revise the care goals and decisions in regularly scheduled care planning meetings on the basis of the resident's current status, desires regarding care, and family input. For example, a person with dementia who has been eating with cueing may progress to needing hand-over-hand assistance during meals. When the person's condition worsens and swallowing is affected, thickened liquids given with natural feeding techniques may be appropriate. When the person does not know what to do with food substances in his or her mouth or cannot swallow, a decision for comfort may be made to stop feeding the patient. Under these circumstances, attempting to put food into the person's mouth can cause choking and aspiration pneumonia.

No amount of advance planning can anticipate all the care decisions that must be made during the course of a resident's dementia. All 50 states and the District of Columbia permit the designation of proxy decision makers who can make the decisions because they believe the resident would have made them, or in the absence of such information, in the best interest of the resident. By having a properly designated proxy decision maker, complications that arise from disagreements among family members may more easily be resolved.

Ideally, the proxy decision maker is someone who knows the resident's values and preferences regarding care at the end of life and will take into account the individual's cultural and spiritual beliefs about end-of-life care. If the resident agrees, the proxy decision maker can be part of care discussions, even before assuming the decision-making role. This enables the proxy decision maker to become familiar with the resident's condition, preferences, and care. Also, the proxy decision maker could get information from the broader care team about the tradeoff between the goals of prolonging life or maximizing comfort after a medical crisis or a major change in the resident's condition.

Residents with advanced dementia who do not have family caregivers or others who can serve as decision makers may need assistance in identifying individuals to make decisions on their behalf. Some states have public guardianship programs for people who cannot manage their affairs and who have no family or proxy decision maker. These programs may enable guardians to make care decisions. Guardians are empowered only to the extent spelled out in the court's order of guardianship. Courts may also appoint private parties, such as attorneys, to serve as guardians.

To facilitate decision making, the residence can make sure it has signed copies of any advance directives. Advance directives are legal documents that enable people to plan for and communicate their wishes about end-of-life care when they are unable to do so. A living will states a person's wishes about use of life-sustaining medical treatments at the end of life. A durable power of attorney for healthcare allows people to appoint someone to make medical treatment decisions on their behalf. Both types of documents are critical to ensuring that a resident's wishes are respected. However, the durable power of attorney for healthcare is most flexible because the person with the power of attorney can make decisions about care that a living will may not address. In addition, the durable power of attorney helps ensure that the proxy decision maker is the person selected by the resident.

Residences can help prepare the resident, proxy decision maker, and family for end-of-life care discussions by providing them with materials, such as advance directives or workbooks, which help them work through decisions and care options.

CARE PROVISION, COORDINATION, AND COMMUNICATION WHEN RESIDENTS CHOOSE HOSPICE SERVICES

When residents choose hospice care, care coordination with the nursing home or assisted living residence is critical to high-quality end-of-life care. The goals of care coordination are to ensure that hospice and residence staff communicate with each other about the resident's life, current condition, and care issues; care plans for residents are integrated; and disruption of care routines is minimized.

ASSESSMENT AND CARE FOR PHYSICAL SYMPTOMS, INCLUDING PAIN

Good end-of-life care for people with dementia ensures that residents are treated for pain and other physical symptoms that may cause discomfort. Undertreatment for these symptoms can occur when residents have difficulty communicating their discomfort or because staff skills in recognizing discomfort vary. Regular assessment and monitoring of a resident's physical symptoms and pain are critical to enabling preemptive treatment. For example, maintaining good oral hygiene for residents can prevent a buildup of debris on dentures and conditions such as tooth decay and gum disease, which, in turn, can affect food and fluid intake and overall health. Because direct care workers may be the first to notice a resident's symptoms, they need training to help them recognize and report symptoms to their supervisors. Workers could use a checklist to observe a resident's comfort level at the end of life and such things as changes in behaviors or mental status.

Comfort care approaches to physical symptoms can be beneficial. For example, difficulty with swallowing can be addressed by hands-on assistance with eating, changing food texture, or increasing the thickness of liquids. Ensuring appropriate treatment of a resident's pain is critical. Sometimes just holding the resident's hand will provide some comfort when the source of distress is unknown.

Residents at the end of life often have a limited range of expression. Staff who are more familiar with residents may be able to better identify change in a resident's condition. Consistent staff assignment is one approach that may help staff become more familiar with residents and anticipate their needs. Regardless of the staffing structure, thorough and regular reporting of information about residents verbally and in the resident's chart will help ensure that the individual receives consistent care. Regular consultation with family can provide valuable information about how the resident typically communicates discomfort.

ASSESSMENT AND CARE FOR BEHAVIORAL SYMPTOMS

At the end of life, behavioral changes may indicate distress, so investigating the cause of any change is important. Direct care workers may be the first to notice a resident's behavioral and psychological symptoms. Therefore, it is important to consider training direct care workers to recognize and report the symptoms to their supervisors. For example, workers could use a checklist, including such items as changes in mood, attention span, and level of arousal. It is important to determine whether a particular resident's behavior is due to a known cause (eg, medication effect) or a change in health or emotional conditions (eg, dehydration, pain, or depression) that requires assessment and possible treatment.

Once the underlying cause for the behavior has been addressed, behavioral interventions should be pursued only if a particular behavioral symptom is found to be distressing for the resident involved or poses a risk or harm to the resident or others. For example, using a psychotropic medication to sedate a resident who has verbal outbursts without evidence that these outbursts are causing harm or distress to the resident is inappropriate. Instead, the care team needs to investigate the reasons behind the outbursts, perhaps untreated pain, and address these needs.

Once physical causes of behaviors of concern have been resolved, nonpharmacological approaches can be used to address unmet physical and psychological needs and eliminate or reduce environmental irritants. For example, a resident may be distressed if he or she is isolated. So, providing companionship could be very beneficial and accomplished through the use of residence staff, hospice staff, if the resident has chosen hospice, or volunteers. Altering the environment for comfort, such as providing a calm environment, soft music, and privacy, may help minimize a resident's restlessness at the end of life.

PSYCHOSOCIAL AND SPIRITUAL SUPPORT OF RESIDENTS AND THEIR FAMILIES

Although residences need to meet the daily physical needs of individuals with dementia, their psychosocial and spiritual needs at the end of life also require careful attention. In this context, spiritual support means care that helps residents and their families find meaning and comfort at the end of life and is consistent with their philosophical or religious values or outlook on life.

Residents with dementia are able to derive a sense of comfort from familiar and meaningful interactions. Members of the care team can enhance a resident's quality of life by assuming that the resident benefits from positive interactions, although he or she may be incapable of responding to them. Quality of life for residents with dementia depends in large part on the quality of the interaction and relationships they have with direct care staff.

Providing appropriate support to dying residents with severe dementia involves staff's, family's, and volunteers' learning and communicating as much as possible about the resident's life story, preferences, and abilities, and honoring the resident's needs, desires, and cultural backgrounds, for example, encouraging Spanish-speaking staff or volunteers to converse in that language with residents whose first language is Spanish. Playing violin music for a resident who played this instrument in an orchestra would provide comfort.

Some residents have no family members who can be with them as they are dying. In these instances, residence-based volunteer programs can help ensure that these individuals have companionship during this critical time. Residences also can help ensure that these individuals have access to hospice services, if they want them, and the services are available. In addition to their regular staff, hospices frequently offer volunteer support as part of their services.

Staff need to know as much as possible about whether an individual has cultural or religious values or a certain outlook toward the end of life. Staff can provide the best support when they know which practices are most significant to the individual resident. Family and friends, when they are available, are likely to have this information and need to be consulted about care plans that address spiritual support. Access to hospice and palliative care can be particularly helpful in providing expertise regarding the complicated psychosocial and spiritual support needs that residents and families may have.

For family members and their loved ones, grieving for a person with dementia may be a prolonged, ongoing experience marked by conflicting emotions. The debilitating nature of dementia causes grief at multiple stages, beginning with diagnosis. Grief may also be experienced when a resident is first placed in a nursing residence and then by the unavoidable decline and eventual death of the individual.

Proxy decision makers may experience guilt in planning and implementing the end-of-life care choices that they must make on behalf of their loved ones. The interdisciplinary care team plays an important role in providing access to psychosocial and spiritual support for the family throughout the grieving process. Some families may require referral to a professional, such as a trained grief counselor, or, if there is disagreement about care, someone skilled in conflict resolution.

Family members may desire psychosocial and spiritual support when a resident is actively dying. During this time, a staff member trained in providing support to families, such as a counselor, a social worker, a chaplain, or a nurse, can help educate and guide the family through the resident's dying process and ultimate death. For example, a knowledgeable nurse can inform family members and allay their fears about the signs of approaching death, such as changes in respiration and skin color. Providing information to families about the signs and symptoms of the dying will help them have a better understanding of what their loved ones are experiencing. The symptoms may include such things as a decreased need for food and drink because body functions are gradually slowing down, increased sleeping, and more difficulty in waking up, apnea, and fevers.

Family members are an important part of the care team and often derive satisfaction in knowing that they can still help with the care and comfort of their loved ones. To facilitate this, staff may provide suggestions for activities that the family members can engage in with the resident. For example, staff can teach the family how to regularly moisten the resident's mouth and how to massage the resident's hands and feet or encourage family members to play music that the resident enjoys or read aloud passages from the resident's favorite book.

Members of the care team can show support for the family while the resident dies. For example, it can be helpful to provide the family member with a pillow, blanket, and recliner if he or she plans to stay the night or access to a "comfort cart." Comfort carts can include snacks, sandwiches, beverages, inspirational passages and books, a listing of places of worship in the area, a CD player with comforting music, massage aides, and other items that can help family spend meaningful time with the resident. Another way of showing support for the family is to offer on-site access to a nondenominational chapel or a quiet setting for reflection and meditation. The quiet setting can also help other residents and staff as they deal with end-of-life issues.

Providers may also encourage the development of family support networks to connect those families that share the same experience in their role as caregivers and proxy decision makers. Family councils could play a role in this. In addition, staff can refer families to the Alzheimer's Association or other caregiver support groups in the community. The involvement of hospice services can provide additional, experienced staff members who are skilled at meeting the grief and bereavement needs of family members.

Sharing information with the family about what will happen immediately following death is important. For example, who will be called first, what will happen to the body, and how long (hours or days) the family has to take away the resident's belongings. This will enable the family to plan as needed for the time immediately following the resident's death.

STAFF TRAINING

Staff education and training is an essential part of the delivery of quality end-of-life care for individuals with dementia. Good preparation for the unique challenges of providing quality end-of-life care requires that staff have training in caring for people with dementia, which covers dementia, effective communication, the need to honor advance directives, symptom assessment and management, signs of impending death, and family and staff grieving, among other topics. For example, it is important for staff to know that in severe or late-stage dementia, individuals often lose the ability to carry out daily activities, swallow, and move. Sometimes these individuals lose the ability to speak. People with severe dementia often lose interest in eating and drinking and may lose weight.

New or part-time staff members can benefit greatly by learning from experienced staff members who are familiar with dementia care at the end of life. For example, a palliative care mentoring program, which pairs a new frontline or part-time staff member with an experienced staff member, can provide the opportunity for experienced staff members to share their knowledge, experience, and skill. In addition, residences who have contracts with hospices or palliative care services may request the hospice to provide palliative care training to staff.

ACKNOWLEDGEMENT OF DEATH AND BEREAVEMENT SERVICES

An essential part of quality end-of-life care is providing services and support to the family following the dignified death of a resident. Properly acknowledging a resident's death supports the care community because it grieves and celebrates the resident's life. For example, the residence could alert all staff members on duty that a resident has just died to ensure that staff members do not walk into the resident's room unaware. Many residences create a "memorial book" or "book of condolences" and place it in the lobby or foyer so that members of the community can pay tribute to the resident by writing words of encouragement for the family and signing their names. However, families should have an opportunity to decide whether this is something they want.

Assisted living residences and nursing homes, in coordination with hospice services, can recognize staff and family bereavement in a number of ways. Depending on the residence's and the individuals' preferences, there may be a reading of a prayer or a poem, or the group may join together in singing a familiar song as a way to honor the person's passing. Families could be sent a condolence card signed by the care team and a card on the first-year anniversary of the resident's death. It is important to note that bereavement services for families are available from hospices for a year after a resident's death.

Staff and residents need time to grieve and say goodbye to a resident they have cared for or lived with over the years. It would be helpful to inform workers who have an emotional attachment to their residents about imminent death and provide them with an opportunity to be present and supportive during the resident's final hours and to say farewell.

Jane Tilly, DrPH, is Director for Quality Care Advocacy for the National Office of the Alzheimer's Association, Washington, DC.

Peter Reed, PhD, is Senior Director of Programs for the National Office of the Alzheimer's Association, Chicago, Illinois.

Elizabeth Gould, MSW, is Associate Director for Clinical Care, Alzheimer's Association, Chicago, Illinois.

Abel Fok, BSc, LLB, is Candidate, Queen's University Faculty of Law, Kingston, Ontario, Canada.

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Address correspondence to: Jane Tilly, DrPH, Quality Care Advocacy, Alzheimer's Association,1319 F St. NW, Suite 500, Washington, DC 20004 (jane.tilly@alz.org).

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