

END-OF-LIFE DECISIONS WITH ALZHEIMER'S DISEASE

Ann S. Morrison, PhD, RN, CS,* and Constantine Lyketsos, MD, MHS†

ABSTRACT

Once patients with Alzheimer's disease (AD) reach the advanced stage of AD, death can be expected within 1 to 2 years. During these last months, critical decisions must be made by the caregiver and family regarding how the patient will die. It is an ongoing discussion that includes the patient, the identified proxy, and the health-care team. End-of-life palliative care is designed to relieve a patient's suffering and maximize quality of life as the patient approaches death; it is not curative care. Discussion regarding end-of-life palliative care should begin well before the end stage of the disease. The nurse works with the family as the patient progresses through the stages of AD, acting as a central information coordinator, problem solver, and care provider. Palliative care is multifaceted and deals with complex issues. This article discusses the concept of end-of-life palliative care, where it takes place, and how it is paid for. Legal aspects of end-of-life care, including ethical considerations, are also reviewed. A caregiver's experience of a loved one's death can be as varied as the caregivers themselves. Nurses have a central role to play in all of the medical and psychosocial needs of the

caregiver and family, through the disease and death and into bereavement. The more prepared the primary care nurse is to handle end-of-life issues, the better the chances of a dignified death for the patient, and as smooth a transition as possible for the family to life after the patient's death. (*Adv Stud Nurs*. 2005;3(10):355-362)

The Alzheimer's Association Ethics Advisory Panel defines the advanced stage of Alzheimer's disease (AD) as terminal when the patient loses the ability to recognize loved ones, communicate by speech, ambulate, or maintain bowel/bladder control.¹ Death can be expected within 1 to 2 years of this stage. Most patients with AD die of an infection (eg, pneumonia). During these last months, critical decisions must be made by the caregiver and family regarding how the patient will die. As Nuland describes in his book, *How We Die: Reflections on Life's Final Chapter*, the family of a patient with AD is caught in a "sea of conflicting emotions...the difficulty of deciding is compounded by living with what has been decided."²

PALLIATIVE OR HOSPICE CARE

Palliative care is designed to relieve a patient's suffering and maximize quality of life; it is not curative care. Discussion regarding end-of-life palliative care should begin well before the end stage of the disease. Palliative care can be administered in a hospital, long-term care facility, the patient's home, or in a hospice.

*Clinical Nurse Specialist Coordinator, Department of Psychiatry, Alzheimer's Disease Research Center, The Johns Hopkins Hospital, Baltimore, Maryland.

†Professor of Psychiatry and Behavioral Sciences, Codirector, Division of Geriatric Psychiatry and Neuropsychiatry, The Johns Hopkins Hospital, Baltimore, Maryland.

Address correspondence to: Ann S. Morrison, PhD, RN, CS, Clinical Nurse Specialist Coordinator, Department of Psychiatry, Alzheimer's Disease Research Center, The Johns Hopkins Hospital, 550 Broadway Avenue, Baltimore, MD 21205. E-mail: amorris7@jhmi.edu.

Hospice care includes comprehensive palliative care plus support services, including bereavement counseling for family members. The hospice team includes professionals from many disciplines, including nurses, physicians, social workers, physical and occupational therapists, nutritionists, home aid workers, pastoral counselors, and trained volunteers.³ They perform a wide range of activities, including medical support, emotional support, art/touch/music therapy, pet care, and shopping, and for the family grief/spiritual counseling, follow-up contact, and bereavement counseling. Hospice workers also have expertise in managing many of the problems and issues that develop in patients with AD (eg, incontinence, safety, restlessness, sleep, and skin/mouth hygiene).³

The concept of hospice care was originally developed for patients with cancer, but it is now used for many long-term illnesses (eg, AIDS, amyotrophic lateral sclerosis, and heart disease), including AD. Hospice care is usually applied to patients who are projected to have 6 months of life remaining. This 6-month cutoff was based on patients with cancer, whose prognosis was more reliably predicted. With AD, progression in the latter stages of the illness is less predictable. The National Hospice Association guidelines for predicting 6-month mortality in patients with dementia are shown in Tables 1 and 2.^{4,5}

Hospice care offers many benefits to patients, notably avoiding the significant burdens of aggressive treatment (especially to a patient who is not oriented to his or her surroundings and is unable to understand the intentions of the care provider) and possible limited attention given to pain control, which is not uncommon in a hospital setting.¹ However, its use by patients with dementia remains limited. Less than 1% to 2% of patients in hospice have a primary diagnosis of dementia.^{4,6} The average length of stay in hospice for all types of patients is only 51 days. Thus, hospice care should be taken advantage of earlier.³ There are several reasons why patients do not enter hospice earlier. Clearly, and especially with AD, survival times are difficult to predict. Also, families may be reluctant to move a patient to hospice care, perhaps feeling that they are giving up on the patient.

Hospice care for eligible patients is covered by Medicaid or Medicare, and often by private insurance. Medicare covers hospice if the patient has Medicare Part A and the patient's physician and hospice medical director certify that the patient is terminally ill and has

a life expectancy of 6 months or less. Once hospice care begins, the patient waives the right for Medicare to pay for any services that treat the terminal illness, although other nonrelated medical services are covered. Medicare-covered hospice care can take place in the patient's home, in a hospice facility, or in a hospital or nursing facility (in a nursing facility, room and board is not covered by Medicare). Costs do not include deductibles, and there are only limited co-payments for hospice services. Maximum drug costs are \$5. Respite care is covered with a 5% co-payment per day.⁷

Shega et al describe a program that aims to incorporate palliative care into primary care geriatric practice—Palliative Excellence in Alzheimer Care Efforts (PEACE).⁸ This program, which is a disease management model for dementia, is coordinated through the primary care geriatric practice of the University of Chicago. It focuses on advance care planning, symptom management, education on the disease process, caregiver support, optimal use of community resources, and improved coordination of care. It also aims to ensure that all patients and families are offered

Table 1. Guidelines for Determining Mortality in the Next 6 Months of Patients with Dementia

- I. Functional Assessment Staging
 - A. The patient should be at or beyond stage 7 of the functional assessment staging scale (Table 2)
 - B. The patient should show all of the following characteristics
 1. Unable to ambulate without assistance
 2. Unable to dress without assistance
 3. Unable to bathe
 4. Urinary and fecal incontinence
 5. Unable to speak or communicate meaningfully
- II. Presence of Medical Complications
 - A. Presence of comorbid condition of sufficient severity to warrant treatment whether or not treatment was given
 - B. Comorbid conditions commonly associated with dementia
 1. Aspiration pneumonia
 2. Pyelonephritis or upper urinary tract infection
 3. Septicemia
 4. Decubitus ulcers, multiple, stage 3–4
 5. Fever recurrent after antibiotics
 - C. Difficulty swallowing food or refusal to eat
 1. Patients who are tube fed must have documented impaired nutritional status

Source: National Hospice Association. Reprinted with permission from Rabins et al. *Practical Dementia Care*. New York, NY: Oxford University Press; 1999.⁴

hospice care. Indeed, hospice referral was offered to 66% of the patients seen in that program; 50% had enrolled in hospice at the time of death. Roughly 66% of the deaths occurred at home. During the program, patients and caregivers were interviewed every 6 months for 2 years, and a postdeath interview was conducted with caregivers. The information from these interviews was reviewed by the nurse coordinator, who then applied it to patient care and provided feedback to families and physicians. The nurse coordinator also

made appropriate social work referrals, performed educational interventions, provided behavior management suggestions, and fostered continuous quality improvement. The interviews of patients and caregivers were performed separately, each lasting 15 to 30 minutes. Importantly, the program was designed to fit within a busy primary care practice setting. Some of the barriers encountered in this study involved scheduling logistics, such as difficulty for the family and patient to stay at the clinic for the clinic visit and inter-

Table 2. Functional Assessment Staging Scale

Stage	Characteristics	Clinical Diagnosis
1	No objective or subjective functional decrement	Normal adult
2	Subjective deficit in recalling names or other word finding and/or subjective deficit in recalling location of objects and/or subjectively decreased ability to recall appointments. No objectively manifest functional deficits	Normal aged adult
3	Deficits noted in demanding occupational and social settings (eg, individual may begin to forget important appointments for the first time; work productivity may decline); problems may be noted in traveling to unfamiliar locations	Compatible with incipient AD
4	Deficits in performance of complex tasks of daily living (eg, paying bills and/or balancing checkbook; decreased capacity in planning and/or preparing an elaborate meal; decreased capacity in marketing, such as in the correct purchase of grocery items)	Mild AD
5	Deficient performance in choosing proper attire, and assistance is required for independent community functioning—the spouse or other caregiver frequently must help the individual choose the appropriate clothing for the occasion or season; some patients may also begin to forget to bathe regularly and automobile driving ability becomes compromised	Moderate AD
6a	Requires actual physical assistance in putting on clothing properly—the caregiver must provide increasing assistance with the actual mechanics of helping the individual clothe himself properly	Moderately severe AD
6b	Requires assistance bathing properly—the patient's ability to adjust bathwater temperature diminishes; the patient may have difficulty entering and leaving the bath; there may be problems with washing properly and completely drying oneself	Moderately severe AD
6c	Requires assistance with mechanics of toileting—patients at this stage may forget to flush the toilet and may begin to wipe themselves improperly or less fastidiously when toileting	Moderately severe AD
6d	Urinary incontinence	Moderately severe AD
6e	Fecal incontinence	Moderately severe AD
7a	Speech limited to approximately 6 words in the course of an average day (short phrases or words, such as "Yes," "No," "OK," "Please," "Get away," "Get out of here," "I like you," and "Please don't hurt me")	Severe AD
7b	Intelligible vocabulary limited to generally a single word in the course of an average day ("Yes," "No," and "OK")	Severe AD
7c	Ambulatory ability lost	Severe AD
7d	Ability to sit up lost	Severe AD
7e	Ability to smile lost (but other facial movements and sometimes grimacing are observed)	Severe AD
7f	Ability to hold head up lost	Severe AD

AD = Alzheimer's disease.

Adapted with permission from Rabins et al⁴; Reisberg.⁵

view, poor access to a telephone or changed telephone numbers, limited caregiver availability, caregiver stress (as a reason to defer interview or withdraw from program), and patients becoming frustrated, agitated, or fatigued while in the waiting room. Modifications to the program to include home visits, flexible scheduling, and phone interviews have helped to overcome these barriers. Although a cost analysis has not yet been performed, the investigators indicated that the implementation costs were not large and are expected to be offset by decreased hospitalizations and decreased use of certain technologies (eg, feeding tubes) with palliative care.⁸

The PEACE program is just one example of how palliative care can be successfully integrated into primary care, and how the nurse serves as the pivotal player in providing holistic, well-rounded care for patients with dementia. Head also reviews the broad and critical role of nurses in palliative care.⁹

LEGAL ASPECTS OF END-OF-LIFE CARE

One of the most difficult decisions the family of a patient with AD will need to make regards the competency and decision-making capacity of their loved one. Preparations for this decision should be made with the patient well in advance of when these discussions must take place. Competency refers to the ability of a person to make decisions and is legally established when a person reaches the age of 18 years. Competency and incompetency are legal concepts.⁴ Incompetency can only be determined by a judge who must find that a person lacks the ability to make responsible decisions. By contrast, capacity, incapacity, and partial capacity are clinical concepts. Capacity refers to the abilities a person needs to make decisions, and includes the ability to communicate, the ability to understand what is being communicated, and the ability to make decisions. Incapacity involves an impairment in 1 of these 3 criteria, along with a diagnosable condition that causes the impairment. Partial capacity describes a person who is capable of making some decisions but not others.⁴ Note that capacity can change over time (as with delirium). Rabins et al suggest 6 elements that should be considered when evaluating capacity in patients with dementia, as outlined in Table 3.⁴ Clinicians can use these criteria to help determine capacity in their patient with AD. However, others

have proposed that just 4 or 5 criteria are necessary, thus some clinical decision making is necessary.¹⁰

Once the patient is deemed incapable of making decisions, their care is turned over to a medical proxy. This person should be identified long before questions of competency and capacity arise. In fact, there are several legal documents that should be obtained soon after AD is diagnosed. Power of attorney refers to the delegation to another person the ability to sign papers and carry out other legal processes. Power of attorney can be removed or discontinued at any time. Durable power of attorney is power of attorney that remains active after the person becomes incompetent, thus durable power of attorney is preferred for patients with dementia. Also, this transfer of power begins only at the time that incompetency develops. It is often recommended that a person have a separate power of attorney for health and financial issues.

Many people talk about a living will, which states a person's wishes should he or she become terminally ill. However, living wills are less useful for patients with AD. Many of the very difficult decisions surrounding AD care occur well before the patient is deemed to be terminally ill (ie, requiring feeding tubes and/or ventilators) but long after they are capable of making decisions. Also, it is very difficult to predict what will happen during the course of AD and to include all possible contingencies in a living will. Also, incapacitated patients with AD lose the ability to change their mind about their living will, a common occurrence with patients with cancer. By contrast, a different kind of advance directive, which is recognized in all states, allows the patient to designate someone to make their health decisions for them should

Table 3. Six Elements to Deciding Capacity in Patients with Dementia

Can the dementia patient:

1. Identify the issue at hand?
2. State the major options to address the issue?
3. Know the most likely outcome(s) of each option?
4. State a choice from among the options?
5. Provide a reason that justifies the choice?
6. Show consistency over time?

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they become incapacitated.⁴ Importantly, regulations regarding the withdrawal of artificial nutrition and hydration vary from state.¹¹ Unfortunately, most patients with AD do not have these legal documents (power of attorney, advance directives, or living wills), which can complicate ethical considerations later in the disease. The National Academy of Elder Law Attorneys (www.naela.com) provides information on attorneys who specialize in legal service to seniors.

ETHICAL CONSIDERATIONS

As with any terminal illness, ethical considerations in AD are inevitable. In general, the patient's wishes should always be the highest priority, when possible. However, ethical discussions can be frustrating because they rarely lead to a single "right" answer. And, if there is disagreement amongst family members, decision making can be fraught with even greater emotional gravity. If the patient cannot express his or her wishes and no durable power of attorney or advance directive is available, the clinician should decide on someone (most likely from the immediate family) who will know the patient's lifelong values to act as a surrogate (or proxy). A family member is usually most likely to know what the patient would have wanted, unless there is reason to suspect the family member does not have the patient's best interest in mind. However, rarely does a family member put his or her needs first, and a legal solution (eg, court-appointed guardianship) should be considered when this occurs.⁴ In this monograph, Carol Fedor, ND, has described a consensus-building approach originally published by Karlawish et al for providing palliative care (which was ultimately endorsed by the American College of Physicians and American Society of Internal Medicine).¹² Karlawish et al also offer suggestions on what to do if no consensus emerges (Table 4).¹²

The decision to place or to remove a feeding tube can be a difficult and highly emotional issue. As patients approach death, they begin to lose weight. Depression as a cause of refusing to eat should always be ruled out. Discussion regarding the placement of a nasogastric or gastrostomy tube should be started as soon as weight loss is noted, not when it becomes life threatening. Some maintain that not placing a feeding tube is unethical, whereas others point out that feeding tube placement can do more harm than good. For example, feeding tubes increase the physical risk of

aspiration of food into the lungs. From the patients' perspective, if they are relying on tube feeding as their sole source of nutrition, the tube deprives them of the dignity and sensation of "natural" eating and a chance to interact with the caregiver. Although these may seem to be minor advantages of eating, to a sensory-deprived and deteriorating patient, the sensation of food and the bonding with the caregiver are highly valued aspects of quality of life. While it is not possible to say definitively that a patient does not suffer when starved to death, the evidence suggests that pain is unlikely.¹³ Also, there is no evidence to suggest that dehydration is painful, and it may help to alleviate some discomforts, such as reducing incontinence, and decreasing the risk of choking or vomiting.^{4,13} Also, evidence indicates that as the body shuts down during the dying process, its need for food and water diminish.^{14,15}

Regarding pain and anxiety, opioid analgesics should be used to relieve suffering from pain and lorazepam can be used to reduce fear or anxiety.⁴ The Alzheimer's Association Ethics Advisory Panel indicates that, at the end of life, medical problems that require hospitalization, cardiopulmonary resuscitation, dialysis, tube feeding, and all invasive technologies should be avoided. Also, antibiotics do not prolong survival and are not recommended.¹

Table 4. What to Do If No Consensus Emerges Regarding Care for the Incapacitated Patient with AD

- Postpone the decision making and recommend that the participants take time to think about and discuss key issues
- Understand and separate from each person's perspective the goals of medical care and the treatment choices to achieve these goals
- Invent new solutions (eg, a time-limited trial rather than an all-or-nothing solution)
- Avoid power struggles or personalizing the conflict
- Call in a third party (eg, trusted clergy, ethic consult, or palliative care consult)
- Don't violate the fundamental values of the patient, family, or physician

AD = Alzheimer's disease.
Reprinted with permission from Karlawish et al. *Ann Intern Med.* 1999;130:835-840.¹²

Clearly there is no single right answer for these types of ethical considerations. The nurse should encourage discussion, provide information and emotional support, raise questions, and allow time for a decision to be reached amongst the family members and especially the proxy. The family should also be reminded that any of these acts are not a permanent medical treatment; they can always be reversed or removed.⁴ Furthermore, all palliative care discussions may need to be repeated several times because they are so emotionally difficult.

THE CAREGIVER'S EXPERIENCE AT END OF LIFE/DEATH

A caregiver's experience of their loved one's death is in some ways as unique as the caregiver. Anger, frustration, guilt, bitterness, exhaustion, stress, sadness, and relief are some of the many emotions that accompany the passing of a patient with AD. Many investigators have tried to describe categorically the caregiver's experience at the patient's death, only to discover conflicting results. Some caregivers may experience a sense of relief due to the end of their loved one's suffering, the end of their caregiver burden, or the end of the image of their loved one as a shell of their former person.¹⁶ Indeed, during AD progression, each decrement in functionality is viewed as a "little death," with the patient sometimes described as "the walking dead."¹⁵ Some have called this the "social death," the loss of the persona, the patient as he or she was known to others.^{17,18} Some caregivers have described the progression of AD as a funeral that never ends, remarking about the patient, "I said good-bye to her years ago."

Conversely, many family members may be surprised at their sense of loss with the patient's passing, even after a chronic battle with AD. Although they are intellectually prepared for the death, they may not be emotionally prepared, particularly if the strain of caregiving before death has prohibited an exploration of the relationship to the patient and a chance to say good-bye. As a result, the caregiver or family member may be embarrassed at "losing it" when they had so much preparation time for the death. Family members should be advised that "intellectually understanding" death and saying good-bye to a loved one are 2 separate components of grief.

It does appear that the caregiver's experiences immediately preceding the patient's death are the

defining influences on the caregiver's response to the death, particularly if the caregiver strain is especially high.^{16,19} Aneshensel et al showed that the course of depressive symptoms after bereavement depends, at least in part, on the immediate predeath caregiving experiences (eg, exposure to stressors and access to resources), in addition to education level and income.¹⁹ As described by Nuland, "A life that has been well lived is forever seen through the filter of the last few years."²

The healthcare team may want to meet with the family several months after the patient's death to remember the patient when they were well and as a chance for the healthcare team to provide praise for all of the family's caregiving efforts. These interactions can help to start ending the mourning, thus the family members can move on in their lives.

THE NURSE'S ROLE IN END-OF-LIFE DECISION MAKING

The caregiver and family struggle with many priorities during the course of AD, all of which intensify as the patient approaches the end of life. These include the more concrete issues (Table 5) of understanding the illness and medications, communicating with the healthcare team, providing hands-on care, handling legal and financial matters, and knowing what to expect at the time of death and making decisions based on that knowledge.

Table 5. Alzheimer's Disease Caregiver Priorities

Medical

- Understanding illness
- Giving medications
- Communicating with healthcare team
- Giving hands-on care
- Handling legal and financial matters
- Knowing what to expect at time of death
- Making decisions at end of life

Psychosocial

- Adapting to a changing role
- Developing skills to care for self
- Spiritual/religious matters
- Finding meaning and purpose
- Feeling closure

However, caregivers also carry several psychosocial needs that often are not priorities (Table 5), but which ultimately contribute significantly to caregiver strain. These needs include adapting to a changing role. For adult children of patients with AD, the child now becomes the parent; for a traditionally dependent spouse of a patient with AD, deference turns to leadership; for a marriage based on partnership, the relationship now becomes more one-sided. Caregivers must also develop skills to care for themselves, including maintaining their social network, handling the loss of employment or change of job, and maintaining a sense of balance, which includes socialization, getting out of the house, regular exercise, proper nutrition, and preventive healthcare. Caregivers may struggle with maintaining balance because of guilt for leaving the patient, but they need to be reminded that they will have nothing to give if they do not replenish themselves. Many caregivers also struggle with spiritual/religious matters, perhaps rediscovering religion when faced with the crisis of a terminal illness or questioning the role religion has played in their life. Similarly, caregivers look for meaning among the myriad signs of deterioration and death in their loved one. Nurses have a key role to play in meeting all of these needs.

Several resources are available to help caregivers reshape the caregiving experience to find the positive aspects. Most notably, Bell and Troxel's *A Dignified Life: The Best Friends Approach to Alzheimer's Care* and Koenig-Coste's *Learning to Speak Alzheimer's: A Groundbreaking Approach for Everyone Dealing with the Disease* describe ways to reframe the relationship between caregiver and care recipient, thus helping to find meaning and purpose in the caregiver's struggles.^{20,21} For example, caregiving can help forge the commitment made between caregiver and care recipient as husband and wife. It allows the caregiver to fulfill the vow of "for better or for worse, in sickness and in health." For the spouse or adult child, the act of caregiving can help bring the family or the specific relationship with the patient closer together and offer a sense of closure with no regrets. Some caregivers have expressed gratitude for being able to provide care to their loved one. For the caregiver as a person, the forced change in schedule (and possibly direction in life) offers a chance to pause and re-evaluate personal goals and direction. Many caregivers find new careers that they would not have imagined had they not been

forced to step off the path they were following. Other caregivers have noted a renewed awareness of the importance of family and renewed appreciation of living life now and enjoying the simple pleasures of life. Most caregivers also say they feel like they have become a better person. As nurses embark on the long-term care of a patient with dementia and build a relationship with the caregiver, it is worthwhile to consider the caregiver experience and to think about how the nurse can counsel the caregiver through this ultimately life-changing chapter.

CONCLUSIONS

At the patient's end of life, the family of a patient with AD has traveled a long and harrowing journey, only to be faced with some of the most difficult decisions they may ever have to make. Therefore, preparation for this stage of the disease needs to begin well before the end stage of the disease. It is an ongoing discussion that includes the patient, the identified proxy, and the healthcare team. The nurse stands in the middle of this effort as a central information coordinator, problem solver, and care provider. Palliative care is multifaceted and deals with complex issues. The more prepared the primary care nurse is for handling end-of-life issues, the better the chances of a dignified death for the patient, and a smooth transition for the family to life after the patient's death.

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