

# Alzheimer Disease

## "It's Okay, Mama, If You Want to Go, It's Okay"

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### THE PATIENT'S STORY

Mrs R, an 80-year-old African American woman with a long history of diabetes, had Alzheimer disease (AD) for 9 years before her death. She was a junior college graduate who had worked in state government and later, according to her daughter, was the first African American manager in a major department store. At age 71 years, she was diagnosed as having AD. Within a year she required full-time supervision. One of her 2 daughters, Ms P, moved into her home. Mrs R joined a PACE program (Program for All-inclusive Care of the Elderly) and traveled daily by van to a dementia day-care program. She also received home care so her daughter could continue to work.

During the next few years she became incontinent of urine and exhibited some behavioral symptoms associated with AD, including agitation and wandering. By the sixth year after her diagnosis, she was wheelchair dependent. Around this time, the family discussed prognosis and plans with her physician and agreed that they did not want resuscitation or life-sustaining treatment. They were undecided about tube feeding. Soon after this, Mrs R was hospitalized when her leg became severely infected after a wheelchair injury. She was discharged to a skilled nursing facility, where her intake was poor despite nutritional supplements and feeding assistance at meals. She also refused or was unable to take oral medications.

While Ms P was on a short vacation, her mother became comatose in the skilled nursing facility and was hospitalized for a diabetic hyperosmolar coma. After recovery, she often refused to eat. A feeding gastrostomy tube was placed, and she returned to the skilled nursing facility. She had no complications from the feeding tube, apart from an initial undesirable weight gain, but her mental function continued to deteriorate, and she became increasingly less verbally responsive. She developed such severe flexion contractures of both her arms and legs that it was difficult to position her in a chair, which left her almost entirely bedbound. A new physician described her as being vegetative, with no purposeful responses of any kind. Her daughters continued to visit her regularly and were very attentive to her care.

Three years after placement of the feeding tube, her daughters expressed dismay at her condition but felt unable to dis-

About 4 million people in the United States have Alzheimer disease (AD) and the number of incident cases is expected to more than double from 377 000 in 1995 to 959 000 in 2050. Patients, their families, and health care professionals struggle with a relentless and irreversible neurological syndrome that can last from 2 to 20 years. Alzheimer disease causes both cognitive and functional impairments that predispose the patient to behavioral symptoms, destroy intellectual capacity and personality, erase the ability to communicate one's wishes for care, and lead to life-threatening consequences. At the close of life, family members and clinicians face decisions regarding degrees of intensive medical care to be provided for treatment of the late-stage consequences of AD, including withdrawal of invasive interventions, initiation of hospice, and treatment of a range of progressive medical conditions. Physicians can assist patients with AD and their loved ones through the terminal phases of the illness by preparing them for the relentless progression of the disease and by supporting them through the intellectual and emotional conflicts accompanying the end of life.

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continue the tube feedings. After further discussion with the physician, Mrs R's daughters placed her in a hospice program. Her feeding tube was removed, and she died comfortably, an hour after her daughters' last visit, when they had given her "permission" to do so: "It's okay, Mama, if you want to go, it's okay. We're doing fine, we love you, you can go."

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## PERSPECTIVES

Shortly after Mrs R's death, in May 2001, a *Perspectives* editor separately interviewed Mrs R's daughter (Ms P), and her PACE physician, Dr C.

Ms P: *About 8 years ago my mother was showing signs of dementia. She was in the house by herself and she was forgetting things like the utility bill or her telephone bill. She wasn't keeping the house tidy, as she would in the past. She wasn't bathing and she would put on the same clothes all the time . . . she had had tons of clothes and would take pride in wearing her outfits and keeping herself together. We didn't pick it up right off, I guess because we would always see her. Other people picked up [on it], but they didn't say anything until we took her to have an assessment done. They said that she was suffering from Alzheimer's. Her short-term memory was gone, pretty much, or it was going.*

Alzheimer disease affects about 4 million people in the United States.<sup>1</sup> The number of incident cases is expected to double from 377 000 in 1995 to 959 000 in 2050.<sup>2</sup> Alzheimer disease is a long-term, relentlessly progressive, life-limiting, and ultimately terminal illness in which the afflicted person may live for 2 to 20 years after diagnosis.<sup>3,4</sup> It is difficult to estimate when AD patients will need nursing home-type care or will die. A longitudinal study of 236 patients with AD found the need for nursing home placement was predicted by younger age at AD onset, lower cognitive test scores, shorter estimated disease duration, and presence of extrapyramidal signs or psychotic symptoms at the initial visit.<sup>5</sup> Mortality risk was increased by extrapyramidal signs, lower cognitive test scores, shorter AD duration, and male sex.<sup>5</sup> The most frequent immediate cause of death is a life-threatening infection such as pneumonia, usually related to risk factors of eating difficulties, immobility, and incontinence caused by functional impairment and behavioral symptoms of late stage AD.<sup>6</sup>

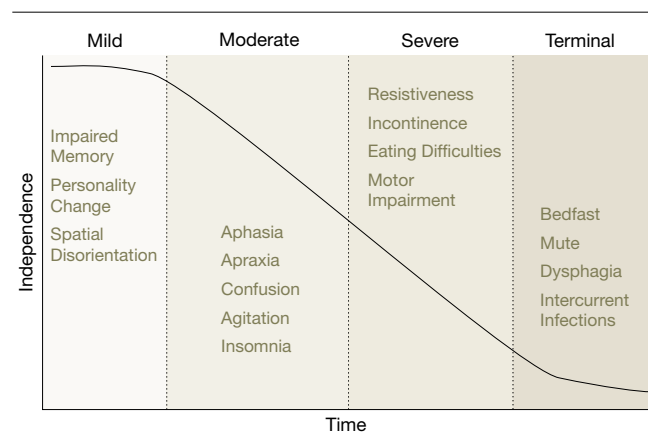
Among the many issues the primary care provider must address with the patient and family are the diagnosis<sup>7</sup> and progressive nature of AD.<sup>8</sup> Potentially life-saving safety issues such as not driving<sup>9</sup> have to be addressed early in the course of AD. Although not an immediate safety concern, clinicians should initiate discussions about selecting a health care proxy and informing the proxy about future treatment preferences, since only in the early stage do patients have the capacity for making complex decisions.<sup>10</sup>

### Preparing for Lack of Decision-Making Capacity

Ms P: *Well, we hadn't discussed that [care she wanted for herself if her health deteriorated and quality of life diminished] with my mother. We just didn't have that conversation. We hadn't discussed that and we really didn't discuss her quality of life, where we'd want it to end if it got to that point. Which I really regret 'cause . . . if we would have talked about it, my mother and I, it probably wouldn't have lasted this long for all of us.*

Clinicians should use the time soon after diagnosis to learn the patient's wishes for future treatment modalities and willingness to discuss these issues and make these choices. With-

**Figure.** Progressive Decline Observed in Alzheimer Disease



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out having ongoing discussions, future care may be provided based on caregivers' views<sup>11</sup> instead of patients' expressed preferences or wishes derived from known values. Educated decision making should be established and maintained throughout the progressive course, with the roles changing from the early stage when patients can represent themselves to later stages when the proxy presents the patient's wishes.<sup>12</sup>

Mrs R's family regretted they had not talked about these issues with their mother.

Many families are unfamiliar with the dying process of a person with terminal AD and are thrust into the role of proxy decision maker. Families need support from their professional caregivers as they make and live through some of the most difficult decisions of their lives—selecting life-prolonging treatments that may also increase discomfort, or choosing care that would provide comfort but may be seen as hastening death.<sup>13,14</sup>

### Preparing for Progressive Decline

The progression of AD can be characterized by 4 phases<sup>15</sup> forming a sigmoidal curve.<sup>16</sup> We<sup>17</sup> have presented a simplified depiction of AD progression (FIGURE) divided into 4 stages defined by the Clinical Dementia Rating Scale<sup>18</sup> that has been expanded further by Dooneief et al.<sup>19</sup> For simplicity, severe and profoundly demented stages were combined. Health teaching should target the patient's current problems and those likely to occur soon and for which caregivers should be prepared.

### Community Care

More than 70% of Americans with AD live at home<sup>4</sup> receiving community-based care. Counseling and support programs for spouse caregivers can delay nursing home placement for elders with AD.<sup>20</sup> An intervention of 6 sessions of family counseling, including joining a support group, and hav-

### **Box. Issues to Consider When Selecting a Nursing Home**

#### **Safe Physical Environment**

- Is the unit locked?
- Are there protected inside and outdoor wandering paths?
- How is elopement prevented?
- How are falls prevented?
- Are physical or chemical restraints ever used?
- What types of assistive devices are used?

#### **Dementia Health**

- How often does a physician or nurse practitioner routinely visit each resident?
- What memory-enhancing medications are typically used?
- What cognitively enhancing activities are used?

#### **Overall Health**

- What is the range of drugs and treatment for other medical conditions that are available without being transferred?
- How are chronic preexisting and other new problems assessed and managed?
- What are the procedures if acute care is needed?
- Where is terminal care provided?
- Is hospice available on the unit?

#### **Knowledgeable and Available Staff**

- What kinds of staff training programs are there?
- How often are they provided?
- What percentage of staff attend?
- What percentage of nursing assistants are certified?
- What percentage of nursing assistants are certified in dementia care?
- What special consultants are available?
- How many hours of direct nursing care does each resident receive each 24-hour segment?
- How many full-time equivalent registered nurses are there per resident?

#### **Quality-of-Life Issues**

- What programs are there to maintain physical functioning (toileting, feeding assistance, ambulation)?
- What is the pain management program?
- How much time in each 24-hour period do residents spend outside their bedrooms?
- What are the ongoing activities and daily events?

#### **Support Services**

- What types of family support groups are there and how frequently do they meet?
- What family education programs are provided?

#### **Interdisciplinary Team Approach**

- How are individual resident care plans developed, evaluated, revised, and shared with the family?
- How frequently does the team evaluate each resident's careplan?
- Is there a system to include family input?

ing access to counselors resulted in almost 1 additional year in the community before nursing home placement.<sup>21</sup> When frail older patients cared for by physicians in their homes selected their preference for a specific place of death, plans were successful in 91%<sup>22</sup>; however, we could identify no similar studies for patients with AD. Providing physician care at home may improve end-of-life care for older persons.<sup>22,23</sup>

#### **The Move to a Nursing Home**

Ms P: *It was getting to be too much: rushing home, even though we had care, considering . . . her diabetes, her high blood pressure, her walking out. So we made the decision [that she would be placed in a nursing home].*

There often comes a time when the family has to relinquish home care because of inability to manage problematic patient behaviors<sup>24</sup> or because they lack the resources to provide 24-hour a day care<sup>25</sup> and must seek institutionalized care. Smith et al<sup>26</sup> found that during 3600 person-years of surveillance, 203 (40%) of 512 AD patients were placed in nursing homes.<sup>26</sup> In a study of 5788 community-residing elders with AD and their caregivers, Yaffe and colleagues<sup>27</sup> found that both patient and caregiver characteristics independently predicted nursing home placement. Patient predictors included living alone, being white, having cognitive and functional impairment, and having behavioral problems. Caregiver predictors included older age and higher caregiver burden.<sup>27</sup>

Caregiving costs are enormous. Family caregiving can distress and disable caregivers causing intense physical, emotional, and financial burden, yet families provide unpaid care for AD valued at \$65 billion per year<sup>28</sup> of the at least \$100 billion spent by all sectors of US society.<sup>4</sup> Annual per patient costs of informal care are estimated to range from \$10 400 to \$34 517.<sup>29</sup> Medicare expenses for persons with AD are 70% higher than for other beneficiaries.<sup>30</sup> Because nursing home admissions for persons with AD are almost twice as long as for the average beneficiary, when Medicaid pays for long-term care, the cost is about \$7700 more for persons with AD.<sup>31</sup>

Deciding to place a patient in a nursing home carries dual concerns of finding an appropriate facility and managing the guilt of giving up primary caregiver responsibilities.<sup>32</sup> The family selects the nursing home. The physician can help the family in this process by providing a list of questions to ask when visiting potential nursing homes, such as those listed in the BOX, which are suggested by our clinical experience.

After transferring the patient, family caregivers should have emotional support to help them cope with their own sense of "failing" the patient. Physicians and other health care professionals should be willing to help family members deal with their guilt, depression, and grief.<sup>33</sup> At this juncture, symptoms of grieving seem to cycle around 2 losses: admitting a loved one to long-term care and needing to make an advance care plan for the end of life.<sup>33,34</sup> The physician can help provide reassurance: "You have done such a fine job of caregiving. Look at the nursing home staff. It takes a team of

nurses working 3 shifts a day, 7 days a week to do what you have been doing.” The physician should also reiterate that no matter how fine the nursing home care is, the disease will progress relentlessly, the patient’s condition will continue to worsen,<sup>8</sup> and the patient will ultimately die either from a consequence of AD or from another illness.

### Nutrition and Hydration

**DR C:** *Right after she got into the nursing home they noted she had a lot of difficulty eating. She would push food away or refuse to swallow it. At that time the family discussed goals of care with the physician: a do not resuscitate order, do not intubate, no CPR [cardiopulmonary resuscitation]—comfort type of care—but they were undecided about a feeding tube. Not long after that, as the daughter arrived home from a vacation, her mother was admitted to the hospital in a comatose state (hyperosmolar coma). When she regained alertness, the feeding problems persisted. A gastrostomy took place during the hospitalization. Then she went back to the nursing home with the gastrostomy [and] initially had a weight gain that was undesirable.*

**MS P:** *We talked to the doctors and they said, “We can’t feed her, she’s resistant, and not only that her swallowing mechanisms are off.” That’s when we decided to use the feeder, the tube.*

**Use of a Feeding Tube.** An important goal of care for AD patients is to provide adequate nutrition by promoting eating and preventing food refusal. Those caring for the patient must have time for, and the system must support, the individual needs of patients who initially refuse food.<sup>35</sup> It takes time to sit and make eye contact, chat, and make eating a pleasurable experience, yet it is one of the most important components of nursing home care.<sup>36</sup> Patients use many behaviors to refuse food. In a study of eating difficulties of patients with severe AD, 36 (51%) of 71 residents refused food.<sup>37</sup> During attempts at feeding, 89% of these turned their heads away when food was offered; 78% kept their mouths shut; 72% pushed the spoon or hand away; and 39% spit out food. However, all these patients were eventually successfully fed by hand, and their mortality rate was not different from patients who did not refuse food.<sup>37</sup> Unfortunately, feeding tubes are often inserted in acute care settings if a patient has even mild eating difficulties.

Food refusal may be an unrecognized symptom of depression, which may be precipitated by admission to a nursing home.<sup>38</sup> Patients who refuse food often respond well to antidepressant therapy, even those with advanced dementia.<sup>39</sup>

Tube feeding might have been indicated shortly after Mrs R’s diabetic coma, when her consciousness was impaired, but later her eating ability should have been reevaluated. Because there was no discussion between the physician and the family, the default decision was made to maintain permanent tube feeding. Although such discussions are not easy, it is incumbent on the physician to initiate the dialogue and involve the interdisciplinary team. The videotape *Alzheimer’s Disease: The Family Conference* illustrates how this may

be accomplished (see Other Resources at <http://www.jama.com>). Natural feeding should be resumed as soon as the medical crisis passes.

Even patients with a progressive dementia can revert to natural feeding after tube feeding.<sup>40</sup> An interdisciplinary team, including a nurse, dietitian, and physician should develop an individualized plan based on the patient’s target body weight and functional eating abilities.<sup>41</sup> Natural feeding can begin while the tube is in place, facilitating both types of feeding until the patient’s eating is re-established. Then the tube may be removed. A program of functional feeding using the patient’s remaining skills combined with skillful hand feeding should be initiated.<sup>42</sup> The caregiver may place his/her hand over the patient’s hand, place a small amount of sweetened food, such as applesauce, on the tip of a large spoon, move it to the patient’s mouth, and place the tip between the patient’s lips to stimulate eating.<sup>35</sup>

Permanent tube feeding is not recommended for persons with advanced dementia,<sup>40</sup> even those who choke on food and liquids.<sup>37,42</sup> In advanced AD, tube feeding does not prevent aspiration, improve functioning or quality of life, increase comfort, or promote weight gain.<sup>43</sup> Meier et al<sup>44</sup> found hospitalized AD patients had a 50% chance of dying in 6 months, with or without a feeding tube. Although use of a feeding tube may have advantages for others to save staff time or decrease fear of regulatory complaints for undernutrition, it also has many disadvantages for the patient, including decreased pleasure from eating, less human contact, and, frequently, the need to use restraints to prevent the patient from removing the tube.<sup>35</sup>

**Removing Feeding Tubes.** **MS P:** *The last year, it started being painful for me to go and visit. At Easter, when we went out we started crying and said, “We can’t do this anymore, not for us, or for her.” So we made the decision to remove the tube.*

**DR C:** *They had actually gone to visit the [city’s nursing home hospice] on their own . . . [and] they spoke with the hospice director. He was very compelling about cessation of tube feeding. He said years ago we didn’t have feeding tubes and the natural way [to feed dying] people was [to give] sips of soup, and then just mouth care, and not have feeding tubes. After talking with him about simply discontinuing the feeding tube they felt comfortable and were fortunately able to get her into that setting.*

After 4 years of tube feeding, it may have been considered natural for Mrs R to continue receiving food by a tube. However, one of several widely held misconceptions about feeding, is that it is “ordinary care like spoon feeding.” Except for providing a means to administer calories and fluids, tube feeding is not like natural eating or drinking.<sup>45</sup> Tube feeding rates vary widely by state,<sup>46</sup> suggesting that variables other than patient needs are the primary determinants. Despite the data, physicians, nursing care staff, and family members must deal with decisions to withdraw therapy that is still considered life-sustaining, and ultimately allow the person to die of natural causes.

Many health care professionals lack knowledge about artificial nutrition and hydration at the end of life and may convey inaccurate or misleading information to patients and their families.<sup>47</sup> Family members may fear that the patient will starve to death if she/he stops being fed, but patients who are cognitively intact and dying report that they often do not feel thirsty or hungry. In a study of 32 mentally aware patients with terminal illness, monitored on a comfort care unit until death,<sup>48</sup> 20 never experienced hunger and 11 experienced hunger only initially. Twenty patients never experienced thirst or only initially. Body functions are shutting down during the dying process and food and liquids are no longer necessary.<sup>49</sup> In fact, decreased hydration is beneficial during the dying process because dehydration decreases the sensation of pain and prevents edema and excessive respiratory secretions. Dehydration also decreases the incidence of vomiting and diarrhea. The only consequence of dehydration that may lead to discomfort for dying patients is dryness of the mouth, lips or eyes, which can be prevented or alleviated by moisturizing spray, swabs, ice chips, or lubricating eye drops.<sup>49</sup>

### The Family's Emotional and Intellectual Conflict During Disease Progression

MS P: *Two years ago, it got to the point where she would be lying there. They would move her from side to side and get her in the reclining wheelchair. She was getting bedsores. I had problems with [the nursing home staff], insofar as making sure they moved her, making sure they got her up, making sure they did her hygiene. It was almost like she was just a vegetable. Every now and then she would mumble something but it wasn't recognizable. We all had our feelings, I thought, "Oh God, you know, maybe I wish she would just go, I wish God would just take her." And then I would think, "Oh but that's a horrible thought." But I was being honest with myself. I didn't share it with my sister, and I'm sure she was thinking the same thing. At night I would wait for the phone, it was always in the back of my mind, maybe she had a heart attack, or maybe she's just gone to sleep and didn't wake up. That didn't happen.*

The feelings expressed by Mrs R's daughters are common. Mrs R went from being wheelchair mobile, to a reclining wheelchair, to being bedbound with pressure ulcers. These decrements can be viewed as a series of crises, each one representing a "little death." Analysis of data from support groups revealed that loved ones are described as "the walking dead" early in the course of the disease because, at best, only remnants remain of the unique persons they once were.<sup>50</sup>

Families grieve over decrements in functional ability, inability to interact in a meaningful way, and the loss of the very personhood of the patient. It is important to be aware of the multidimensional aspects of grieving, its extended duration, and potential sequelae of unresolved grieving—depression, illness, lack of self-care, and social isolation.<sup>51</sup> As Brown et al<sup>52(p39)</sup> noted,

An important aspect of family support is acknowledgment that the wish for the victim's death may be the ultimate expression of love as well as a wish for relief from the pain of observing its process. Families must be helped to anticipate death and learn to live with the mixture of joy and rage at the prolongation of the dying process. Grief and mourning seem never ending.

As the disease progresses, there is a period of accelerated mourning<sup>52</sup> and a definite need for bereavement services,<sup>53</sup> but regrettably, very few nursing homes use the services of bereavement counselors.<sup>54</sup>

### MANAGEMENT OF LATE-STAGE PROBLEMS

Treatment of medical problems and other co-morbid conditions should weigh possible benefits against the burdens imposed by treatment. Treatment burdens are increased because the patient does not understand the rationale for medical interventions and may actively oppose them. Treatment benefits are decreased in dementia because of decreased treatment effectiveness and reduced life expectancy.<sup>55</sup> Another factor to consider is the inability of patients to report adverse effects of treatment. Therefore, long-term illnesses, such as hypertension and diabetes, should be treated conservatively with the goals of reducing short-term complications of the disease and preventing consequences of over-treatment, such as dizziness resulting in falls and hypoglycemic episodes.

Treatment of cognitive impairment is an unrealistic goal in severe dementia. Cholinesterase inhibitors such as donepezil<sup>56</sup> may produce modest improvements in patients with mild or moderate AD, characterized as a Mini-Mental State Examination score<sup>57</sup> between 10 and 24.<sup>58</sup> There is no evidence that cholinesterase inhibitors would be effective in patients with severe AD. Similarly, treatment with vitamin E delayed loss of function but not death in patients with moderate AD.<sup>59</sup> Estrogen replacement therapy does not appear to slow the progression of AD or improve global, cognitive, or functional outcomes in women with mild to moderate AD.<sup>60</sup> Since estrogen also does not appear to reduce coronary heart disease events,<sup>61</sup> there is no evidence to support estrogen treatment of women with AD.

### Treating Infections

Infections are a common consequence of advanced dementia because of changes in immune function, incontinence, decreased mobility, and aspiration.<sup>6</sup> Oral antibiotic treatment of infections in AD is preferred over parenteral antibiotics because oral antibiotics are at least equally effective<sup>62,63</sup> and do not require restraints to prevent removal of an intravenous catheter. Intramuscular administration of cephalosporins offers a reasonable alternative in patients with poor oral intake.<sup>64</sup> Hospitalization for pneumonia not only does not improve the outcome in nursing home patients but actually results in more frequent death and functional deterioration.<sup>65</sup>

The effectiveness of antibiotic treatment is diminished in the terminal stage of AD when infections become recurrent.

Antibiotic treatment did not extend survival in cognitively impaired patients who were unable to ambulate and who were mute.<sup>66</sup> Similarly, Luchins et al<sup>67</sup> found no significant difference in survival rates between patients with advanced dementia who were treated with antibiotics and those who were not. Pneumonia is the most common cause of death in persons with dementia,<sup>68</sup> reflecting the limited effectiveness of antibiotic therapy in this patient population. Antibiotics are not necessary to maintain comfort of the patient during an infectious episode because comfort can be maintained by administration of analgesics and antipyretics,<sup>69</sup> and antibiotic administration does not affect AD progression.<sup>70</sup>

### Treating Other Chronic Conditions

For patients with advanced dementia and other long-term conditions, physicians should take a conservative treatment approach that prevents or alleviates uncomfortable symptoms. The goal for AD patients nearing the end of their lives should be symptom rather than disease management. Inadequate pain management is a problem in end-of-life care in general<sup>71</sup> and in nursing homes in particular.<sup>72,73</sup> It is a serious problem for persons with AD because they cannot report symptoms<sup>74-76</sup> and may exhibit atypical pain symptoms such as changes in behavior.<sup>77</sup> Pain assessment in cognitively impaired elders may include observation of facial expression, vocalization, body movements, and changes in interpersonal interactions, activity patterns, and mental status.<sup>78</sup> Successful management of both pain and behavioral symptoms is critical for patients with advanced AD.

Elders with AD are often excluded from pain studies.<sup>79</sup> However, using a protocol to assess discomfort has been shown to increase use of scheduled analgesics and nonpharmacologic comfort interventions.<sup>79</sup> In a follow-up study, when an analgesic was administered, 84% showed improved symptoms.<sup>80</sup> Because of atypical expression of pain symptoms by elders with advanced AD, Kovach<sup>81</sup> suggests liberal use of acetaminophen as an early approach to managing behavioral problems by treating potentially unrecognized pain.

Undertreated or untreated behavioral symptoms of dementia can cause the patient needless discomfort and are as important to relieve as pain in cancer.<sup>82</sup> The physician should consider the context of the symptom and suggest treatment targeting the origin whenever possible.<sup>83</sup> Nonpharmacologic strategies generally should be tried and evaluated before medications. If medications are used, they are used for the sole purpose of providing comfort to the patient, which follows the geriatric principle of "start low and go slow."

### Engaging Hospice

MS P: *Dr C immediately mentioned hospice care provided at the convalescent home. We were against [having it there]. Then there was a long waiting period, maybe 2 weeks, because Dr C was trying to locate a hospice. The hospice programs that she had initially contacted weren't able to take my mother because she had an open foot sore.*

DR C: *After offering hospice, I found it extraordinarily difficult to achieve. We considered several options, including the option of taking her home, which initially one of the sisters liked. And then she got some advice that this would be really too stressful for her. There are 3 resident hospices in the city, 1 associated with the city health services and 2 freestanding ones. But the stumbling block for [admitting her to 1 of the hospices] turned out to be the skin breakdown. They have a community care license and cannot have more than a stage-2 skin lesion in the facility. The other freestanding hospice would not consider her because she was not interactive and they wanted the patient to be able to participate in the community. The third option was the city's nursing home hospice.*

Despite long-standing recommendations,<sup>84</sup> the number of patients with advanced dementia enrolled in hospice programs is small. A survey of hospice programs showed that fewer than 1% of hospice patients had a primary diagnosis of dementia and 7% had dementia as a secondary diagnosis in addition to cancer.<sup>85</sup> A study of 45 AD caregivers found that while 84% knew of hospice, only 11% had considered hospice as an option for their care recipient.<sup>86</sup> In addition to the barriers identified by Dr C, it is difficult to predict whether a patient with AD will die within 6 months. Although it is relatively easy to predict which patients will not die within 6 months because their dementia is not advanced, for the remaining patients the probability of dying is still only about 50%.<sup>87</sup>

The National Hospice Organization published guidelines for inclusion of demented individuals in hospice programs.<sup>88</sup> However, these guidelines are not based on actual data, some of the criteria are vague, and they are better at predicting who will not die within 6 months than those who will die. Additionally, almost half of the patients could not be rated by these criteria because their disease symptoms did not proceed in the expected order.<sup>67</sup> Predicting 6-month survival is difficult because the death of AD patients is often caused by infections<sup>6</sup> and other unpredictable complications. However, once enrolled in a Medicare-certified hospice program, the patient may remain beyond 6 months as long as continued decline is documented. The physician also needs to help the family understand the unpredictability of death.

Effective and reliable end-of-life care for persons with AD and other conditions with a slowly dwindling course to death requires compassionate and skillful clinicians and changes in the organization and financing of care to match these trajectories.<sup>89</sup> Instead of linking reimbursable health care services to limited prognosis, severity of illness and the expectation of declining status should trigger the initiation of tailored services.<sup>90</sup>

### CONCLUSION

Although caring for patients with AD can be challenging and involves many difficult decisions, good endings are possible. By encouraging patient discussions regarding care preferences early in the course of the disease and educating fam-

ily and caregivers about what to expect and how to deal with each stage of the disease, physicians can ease the transition for patients and families. Patients with advanced dementia should receive end-of-life care focused on maximizing the patient's comfort rather than prolonging life.

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**Other Resources:** For a list of relevant materials and Web sites, see the JAMA Web site at <http://www.ama-assn.org/issues/v288n1/abs/jel20001>.

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## Other Resources

### **American Academy of Hospice Physicians**

<http://www.aahpm.org>

Provides selected articles from the Academy's quarterly newsletter, position statements, and press releases.

### **Alzheimer's Association**

<http://www.alz.org>

Has a wealth of information including help for persons with Alzheimer disease, their family caregivers and friends, physicians and health care professionals, and the research community. From this site, families may reach their local chapter and learn their services, eg, how to enroll in a support group, learn about nursing homes and other long-term care options available in their community.

### **National Institute on Aging**

<http://www.alzheimers.org>

Supports the Alzheimer's Disease Education & Referral Center (ADEAR), which provides information about Alzheimer disease including fact sheets, research and technical reports, quarterly newsletter as well as links to research updates, and Alzheimer disease centers.

### **American Hospice Foundation**

<http://www.americanhospice.org>

Provides articles, publications, and related links to online resources for hospice care and advocacy.

### **Facts on Dying Web page**

<http://www.chcr.brown.edu/dying/factsondying.htm>

Describes the dying experience in the United States, answers fundamental questions about care of the dying, and illustrates state variation in feeding tube use displayed on a map of the United States. Links are provided to instruments for measuring end-of-life care with a resource guide for using toolkit instruments, a slide presentation of a conceptual model of patient-focused family-centered medical care and links to other sites, eg, the End of Life Physician Education Resource Center.

### **End of Life Physician Education Resource Center**

<http://www.eperc.mcw.edu>

Provides online peer-reviewed information about instructional and evaluation materials (eg, lectures, small-group exercises, slide sets, videotapes, self-study guides, assessment tools) focused on end-of-life issues.

### **Medicare**

<http://www.medicare.gov>

Provides information on nursing homes, including "guide to choosing a nursing home" (64 pages), nursing home check list (4 pages), and information on comparing nursing homes.

### **National Hospice and Palliative Care Organization**

<http://www.nhpco.org>

Offers grief and bereavement guides and addresses hospice provider concerns.

### **National Public Radio**

<http://www.npr.org/programs/death>

Provides information on exploring death in the United States with transcripts, resources, bibliography, readings, and opportunity to tell one's story and receive feedback.

### **California HealthCare Foundation**

<http://www.calnhs.org>

Offers detailed information on each of California's nursing homes and quality factors to consider when selecting a nursing home.

### **Patient Safety Center of Inquiry**

<http://www.qualityscholar.com/ahead.htm>

Shares documents and presentations made during 3 learning sessions for 20 interdisciplinary teams who participated in a Department of Veterans Affairs quality improvement program to provide better care for veterans with progressive dementia who are cared for at home. Advances in Home Based Primary Care for End of Life in Advancing Dementia (AHEAD).

### **Videotape Resources**

#### ***Alzheimer's Disease: The Family Conference***

This videotape shows an interdisciplinary team meeting with the family caregiver who will make a decision for the type of care (degree of comfort or palliative and aggressive medical care) to be provided for the hospitalized veteran with late-stage dementia. This videotape was made at the Bedford, Va, GRECC and each VA medical center was provided with a copy, which may be accessed through the interlibrary loan system.

#### ***Alzheimer's Disease: Natural Feeding Techniques***

This 14-minute videotape also made at the Bedford GRECC, illustrates feeding techniques and is available for purchase from Terra Nova Films, Inc; 9848 S Winchester Ave, Chicago, IL 60643-1704; (773) 881-8491, e-mail: [tnf@terranova.org](mailto:tnf@terranova.org).