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## Palliative Care for Patients with Alzheimer's Dementia: Advance Care Planning Across Transition Points

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Alzheimer's Dementia (AD) is the most prevalent progressive neurodegenerative disease. It begins with minute memory impairment and ultimately leads to the loss of all mental and physical function. A person with AD lives an average of eight years from diagnosis and could live as many as 20 years (Odle, 2003 ). By the year 2000, there were about 4.5 million in the U.S. population with A.D, with one in 10 persons over the age of 65, and nearly half of those over 85 having AD By 2050, the number is projected to increase to 13.2 million (Hebert *et al.*, 2003). Since there is no cure for AD, “persons with AD need interventions that are directed to relief of suffering, pain control, and comfort, often associated with ‘palliative’ rather than . . . curative measures.’ This chapter is intended to assist health care administrators, health care planners, and public policy professionals to make policy decisions that may improve quality of life for those afflicted with AD and that may minimize the burden of care on family and loved ones. The authors trace the illness through transition points and discuss advance care planning and palliative care- focusing on issues specific to patients with AD.

The natural history or progression of disease depends on the dementia type. The distinguishing characteristics of AD are the presence of two abnormalities in the brain; amyloid plaques and neurofibrillary tangles. Amyloid plaques, in the tissue between nerve cells. Are composed of the protein beta-amyloid with degenerating parts of neurons and other cells. Researchers do not know if amyloid plaques or neurofibrillary tangles are harmful, or consequences of the disease process that damages neurons and leads to symptoms of AD. A study by Marshall *et al.* (2006) revealed a correlation between decline in activities of daily living or ADL scores and higher plaque and neurofibrillary tangle counts suggesting a “greater overall pathologic burden”.

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About 60 to 80% of dementia patients have AD (Shadlen and Larson, 2004). Vascular dementia is the second most common cause of dementia, accounting for up to 20% of all dementias. Vascular dementia is caused by brain damage from cerebrovascular or cardiovascular disease. While AD progresses gradually over time, symptoms of vascular dementia often begin suddenly, frequently after a stroke, and typically progresses in a step-wise manner. This means that there is a decline in memory and function, which remains at a stable level until the next vascular insult when the next plateau in memory and function is reached. By contrast AD progresses gradually over time.

Other forms of dementia include Lewy body dementia (about 10%), dementia due to Parkinson's disease (about 5%), and the small remainder of patients have dementia resulting from alcohol abuse, medication side effects, depression and other central nervous system illnesses (Shadlen and Larosn, 2004; Rahkonen *et al.*, 2003).

Nevertheless, the ultimate deficits and co-morbidities of these dementing illnesses are the same and typically include paucity of speech, aphasia (difficulty speaking), an inability to recognize family members, impaired ambulation, urinary and fecal incontinence, anorexia, dysphasia (difficulty swallowing), weight loss, pressure sores, and pneumonia. Pneumonia is the most frequent immediate cause of death in AD (Molsa *et al.*, 1986; Volicer *et al.*, 2001).

Mild cognitive impairment is defined as cognitive decline greater than expected for an individual's age but that does not interfere notably with activities of daily life. While some individuals with mild cognitive impairment appear to remain stable over time, it is relevant that possibly more than half may progress to dementia within five years. The International Psychogeriatric Association Expert Conference to review available data on mild cognitive impairment was convened in Bethesda, Maryland, January 2005. According to the proceedings mild cognitive impairment portends a high risk of progression. Mild cognitive impairment may represent a prodromal stage of AD, and its identification could facilitate secondary prevention.

Although, this chapter focuses specifically on the issues that arise as AD progresses, the same management principles may be applied to patients with other types of dementia.

AD is a clinical diagnosis that is based upon criteria defined by the Diagnostic and Statistical Manual of Mental Disorders, 4<sup>th</sup> ed. (American Psychiatric Association, 1994). These criteria include impairments in short and long term memory that are severe enough to interfere with work or usual social activities.

Diagnosis is made by a physician experienced in the assessment of dementia who obtains information from a close family member or friend regarding the patient's ability to function. Mental status tests are also administered. These clinical assessment methods are time consuming, yet can provide predictive accuracy rates of 85% to 90% for AD (Morris, 2003).

The gradual decline in health for patients with AD varies from individual to individual, but typically the first evidence of decline is marked by impairment in executive function or the instrumental activities of daily living (IADLs) such as bill paying, shopping, and cooking. The individual may get lost while driving or taking the bus. Additionally, there may be new depression, changes in personality, and behavioral problems such as paranoia or agitation.

The individual may or may not be aware of his/her new deficits or psychiatric problems. Often family brings the person to the doctor for an evaluation because they notice some of these initial problems. It is important, in the early stage of AD, to educate family about the natural history of AD so that they know what to expect, and to permit planning for the future. This planning should include designation of a health care proxy, completion of a living will, and designation of a durable power of attorney to manage finances. It is also advised, that the patient and family meet with an elder lawyer or estate planner to try and protect spousal assets. Furthermore, it is helpful to the patient, family and medical science, to discuss with the patient early on in the disease, whether or not the patient wishes to donate his or her brain upon death to further medical research.

There is no cure for AD. However, data show that some agents (cholinesterase inhibitors) may slow AD progression, but provide at best only minimal improvement in memory (Cummings, 2004). Data also suggest that cholinesterase inhibitors may enable AD patients to have fewer behavioral changes, maintain their ability to care for themselves, be less burdensome to caregivers, and defer their placement in nursing homes (Cummings, 2004). Of note, these drugs are costly, particularly to patients whose insurance does not cover medications.

Aside from medication, even though evidence is limited in terms of impact on AD progression, individuals should be encouraged to continue to be both physically and mentally active. As for vascular dementia, it now appears that some forms of vascular dementia may be preventable with the control of vascular risk factors, in particular hypertension, high cholesterol levels, and diabetes.

There comes a point in the illness when the individual's functional losses make safety a particular concern. For instance, it may no longer be safe for her to drive because she gets lost and has poor judgment. Also, there may be concern that she no longer can live at home because she may leave the stove burner or iron on, or if there were a fire that she would not be able to get out of the building independently. Home assistance or an assisted living residence may be needed, and ultimately 24 hour home care or nursing home placement.

Unfortunately, Medicare insurance does not pay for home services for patients who need help with personal care needs, unless the patients predicted survival is less than six months and thus she would qualify for the Medicare hospice benefit. Of note, patients who are poor enough to qualify for Medicaid insurance can get a home health aide for help with personal care. Otherwise people must pay for this custodial care "out of pocket."

Families should be referred to their local Department for the Aging program social workers as well as social workers at the Alzheimer's Foundation who can direct families to services in their areas based on their needs. These services include Meals on Wheels, Senior Center Programs, and Day Programs for the elderly. Please refer to the chapter on case management and the elderly.

A major issue of concern for families and health care providers is the management of psychiatric problems associated with AD. These include delusions, hallucinations, depression, anxiety and agitation (Head, 2003).

Environmental, behavioral, and communication modification should always be the first recourse for paranoid, agitated or anxious patients. Families and/or staff caring for patients with these issues benefit from specialized training. But measures based on these strategies may not be sufficient to protect patients who are a danger to themselves or others. If this is the case then the use of medication is recommended.

Depression is very prevalent among patients with AD. This is particularly true early in the illness, but it may develop at any time. Antidepressant medications are warranted (Head, 2003).

The final stages of AD are marked by functional losses in self-care or Activities of Daily Living (ADLs). These include toileting, dressing, bathing, and self-feeding. These losses also frequently occur concurrently with a paucity of speech, aphasia (difficulty in speaking), an inability to recognize family members, impaired ambulation, urinary and fecal incontinence, anorexia, dysphasia (difficulty swallowing), weight loss, recurrent pneumonia, and often pressure sores (decubiti). As has been mentioned earlier, these symptoms are also common in other forms of dementia.

The functional status and behavior of the patient are major determinants of nursing home placement. As demonstrated by researchers Heyman *et al.* (1997) and Porsteinsson *et al.* (2001), patient variables include severity of cognitive impairment, inability to perform self-care tasks, incontinence, sleep/wake cycle disturbances, and behavioral changes.

With the progressive development of multiple impairments in AD patients, caring for a relative with AD takes a huge toll on the caregiver physically, emotionally, and financially. Thus, the capabilities and time commitments of caregivers also play an important role in whether or not individuals with dementia are placed in a nursing home and at what point in the disease placement occurs. Cohen *et al.* (1993) prospectively studied the factors determining the decision to institutionalize dementing individuals. Predictors of placement included younger caregivers, their need to work outside of the home, and caring for more than one person (Cohen *et al.*, 1993). One randomized, controlled trial showed that a structured, continuous, caregiver support program can delay nursing home placement (Mittelman *et al.*, 1996). A controlled study of respite services for caregivers of AD patients demonstrated that families with respite care maintained their relative significantly longer in the community (22 days) (Lawton *et al.*, 1989).

The patient's physician should also discuss "goals of care" with his family before the disease is in its advanced stages; before the onset of losses in ADLs. The "goals of care" for the patient in the advanced stages of AD should focus on comfort. In other words, so as not to burden the patient, medical testing and interventions should only occur if it is likely that the testing and interventions will result in improved quality of life. This philosophy should also guide the management of all problems that arise.

Consistent with the goal of comfort is the recommendation that a DNR (Do Not Resuscitate) order be issued. Appelbaum *et al.* (1990) reviewed outcomes of attempted cardiopulmonary resuscitation by pre-hospital ambulance crews where CPR was initiated in a nursing home, compared to attempted CPR in non-residents. Only 2% (2/117) of nursing home patients and 11% (61/580) nonresidents survived until discharge from the hospital. Of the two nursing home patients who survived, one spent 30 days in the hospital and died 8 months after returning to the nursing home demented, cachectic and with a large sacral pressure sore. The other patient spent 60 days in the hospital and died 14 days after returning to the nursing home. The researchers concluded that "the benefits of cardiopulmonary resuscitation initiated in nursing homes are extremely limited" (Appelbaum *et al.*, 1990).

One of the most challenging issues faced by the family and physician caring for a patient with advanced AD is that of anorexia and dysphasia. A commonly asked question asked, by families of physicians is "Are you going to let my mother starve to death?" This question has two aspects; 1) Does tube feeding the patient with AD prolong life via caloric support? 2) Does tube feeding the patient with AD enhance quality of life or reduce suffering? In regards to the former, non-randomized, retrospective studies have found no survival advantage for feeding tubes in patients with dementia (Finucane *et al.*, 1999). This may be contrasted with research that has found that the use of feeding tubes in patients with such reversible conditions as early stage head and neck cancer prolonged life.

It is important to note that most dying patients do *not* experience hunger or thirst. Although dry mouth is a common problem, it is usually multifactorial and not relieved by artificial hydration (Finucane *et al.*, 1999). Although the literature is limited to a few observational studies, there are no studies that demonstrate that the use of tube feeding improves the quality of life. It may make quality of life worse because of an increased need for physical restraints (some patients try to pull out the tube) pain, infections, "indignity" cost, and the denial of the pleasure of eating (Finucane *et al.*, 1999).

Another question related to tube feeding, in the setting of anorexia and dysphasia, is whether or not tube feeding is a means to prevent aspiration pneumonia. No study has demonstrated a reduction in the incidence of pneumonia through tube feeding. There are no published randomized control studies of this question. But we have had three retrospective studies comparing patients with and without tube feeding which showed that tube feeding did not reduce the incidence of pneumonia (Finucane and Bynum, 1996).

And there are many observational studies demonstrating a high rate of aspiration pneumonia in patients who are tube fed (Finucane *et al.*, 1999).

There are some measures that families and health care providers can take to try to decrease anorexia and improve calorie intake. A trial of megestrol acetate or the antidepressant medication mirtazapine may stimulate appetite (Morley, 2002). Families should also be encouraged to bring the person's favorite food to the nursing home or hospital. It is unfortunate that most nursing homes and hospitals do not serve "ethnic" foods. This problem of dietary preferences can contribute to low food intake. Other beneficial measures include ensuring that patients eat in a group setting, that staff spends enough time feeding those who need assistance, that there is a minimum of distraction that surroundings are pleasant, that family are present at meal times, that patients are fed as soon as they are seated, that their favorite music is played, and so forth. The provision of supplemental calorie drinks or puddings between meals is also recommended (Head, 2003).

The prediction of survival in end-stage dementia is challenging. In contrast to patients with terminal cancer, in which decline is typically a straight downward course, the disease trajectory for patients with end-stage dementia is marked by "ups and downs" (Lunney *et al.*, 2003). Researchers have, however, made some strides in prognostication in end-stage dementia. Early research by Volicer *et al.* (1993) demonstrated a relationship between severity of Alzheimer's dementia and development of fevers. Furthermore, their research revealed that older age at the time of occurrence of fever, an antibiotic free management strategy, and nursing home admission within 6 months, were associated with a higher 6-month mortality (Volicer *et al.*, 1993). More recent research by Morrison and Siu (2000) compared the survival of cognitively intact to cognitively impaired individuals aged 70 and older who were hospitalized for pneumonia or hip fracture. End-stage dementia patients who received usual care in a hospital setting for either pneumonia or hip fracture had a four fold increase in 6-month mortality compared to their cognitively intact counterparts (Morrison and Siu, 2000).

The National Hospice and Palliative Care Organization (NHPCO) is particularly concerned with the development of accurate prediction tools for survival of dementia patients since patients need to be given a prognosis of six months or less to qualify for the Medicare Hospice Benefit. The NHPCO Guidelines for Determining Prognosis in Dementia combine functional assessment staging and the presence of medical co-morbidities (Stuart *et al.*, 1998) (Table 9.2). The functional assessment staging instrument (FAST) has the user rate the patient's level of disability in order of increasing severity from 1 to 7F (Table 9.1) (Reisberg, 1988). Currently, the NHPCO recommends stage 7A as an enrollment cut-off point for hospice care. In addition, the patient needs to have medical complications related to dementia and be non-ambulatory. Of note, researchers evaluated the mean survival time once stage 7C is reached, which was the NHPCO's previous cut off, Luchins *et al.* demonstrated a mean survival time of 6.9 months and

TABLE 9.1. Functional assessment staging (FAST): check highest consecutive level of disability

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1. No difficulty either subjectively or objectively
  2. Complaints that locations of objects have been forgotten, subjective work difficulties
  3. Decreased job functioning evident to coworkers, difficulty in traveling to new locations, decreased organizational capacity\*
  4. Decreased ability to perform complex tasks (e.g., planning dinner for guests, handling personal finances such as forgetting to pay bills, difficulty marketing etc)
  5. Required assistance in choosing proper clothing to wear for the day, season, or occasion (e.g., patients may wear the same clothing repeatedly unless supervised)\*
  6. A) Improperly putting on clothes without assistance or cuing (e.g., may put street clothes on over night clothes, put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks\*
    - B) Unable to bathe properly (e.g., difficulty adjusting bath-water temperature) occasionally or more frequently over the past weeks\*
    - C) Inability to handle mechanics of toileting (e.g., forgets to flush toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past few weeks\*
    - D) Urinary incontinence (occasionally or more frequently over the past weeks)\*
    - E) Fecal incontinence (occasionally or more frequently over the past weeks)\*
  7. A) Ability to speak limited to approximately a half-dozen different intelligible words or fewer in the course of an average day or in the course of an intensive interview
    - B) Speech ability limited to the use of a single intelligible word in an average day or in the course of an intensive interview (e.g., the person may repeat the word over and over)
    - C) Loss of ambulatory ability (e.g., the individual cannot walk without personal assistance)
    - D) Inability to sit up without assistance (e.g., the individual will fall over if there are not lateral rests [arms] on the chair)
    - E) Loss of ability to smile
    - F) Loss of ability to hold up head independently
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\* Scored primarily on the basis of information obtained from a knowledgeable informant and/or category.

Source: Reisberg

Hanrahan *et al.* demonstrated a mean survival time of 4.1 months (Luchins *et al.*, 1997; Hanrahan *et al.*, 1999).

However, these NHPCO guidelines for prognostication are too limited for many patients. Luchins *et al.* and Hanrahan *et al.* determined that about 50 to 60% of patients do not decline in the step by step manner described in FAST (Luchins *et al.*, 1997; Hanrahan *et al.*, 1999). Researchers need to continue to develop prognostication guidelines to assist health care providers in enrolling patients in hospice. And other obstacles to the enrollment of advanced dementia patients in hospice also need exploration, as until recently only 1% of patients in hospice care have a diagnosis of dementia (Hanrahan Luchins, 1995).

Should patients in their final stages of AD be admitted to the hospital and/or given antibiotics when there is an acute illness or infection? These are important issues that doctors should discuss with families as part of “goals of care.” If it is decided that the “goals of care” should focus solely on comfort,



TABLE 9.2. National hospice and palliative care organization medical guidelines for determining prognosis in dementia

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I. Functional Assessment Staging (FAST)
A. May have a prognosis of up to 2 years. Survival time depends on variables such as the incidence of co-morbidities and the comprehensiveness of care.
B. Is at or beyond stage 7 of the FAST scale.
C. Displays <i>all</i> of the following characteristics:
1. Unable to ambulate without assistance
2. Unable to dress without assistance
3. Unable to bathe properly
4. Urinary and fecal incontinence
a. Occasionally or more frequently, over the past weeks
b. Reported by knowledgeable informant or caregiver
5. Unable to speak or communicate meaningfully
a. Ability to speak is limited to approximately a half dozen or fewer intelligible and different words, in the course of an average day or in the course of an intensive interview
II. Presence of medical complications
A. Has displayed co morbid conditions of sufficient severity to warrant medical treatment, documented within the past year.
B. Co morbid conditions 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, sufficiently severe that patient cannot maintain sufficient fluid and calorie intake to sustain life, with patient or surrogate refusing tube feeding or parenteral nutrition.
1. Patients who are receiving tube feedings must have documented impaired nutritional status as indicated by:
a. Unintentional, progressive weight loss of greater than 10% over the prior six months.
b. Serum albumin less than 2.5 mg/dl may be a helpful prognostic indicator, but should not be used by itself.

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Source: National Hospice and Palliative Care Organization.

then in the setting of most acute illnesses the person should be made comfortable at home or in the nursing home without admission to the hospital. This is because hospitalization for older patients, particularly those with cognitive impairment, can be hazardous. These hazards include delirium, pressure sores, functional decline, new incontinence, and nosocomial infections.

Once advanced dementia patients are admitted to the hospital they are often subjected to invasive and nonpalliative treatments (defined as treatments which were associated with risk and not provided to produce palliation) (Ahronheim *et al.*, 1996). In this retrospective chart review of 164 patients (80 with dementia and 84 with cancer), 47% received invasive non-palliative treatments. There were no statistical differences in the use of non-palliative treatments between patients with dementia and patients with metastatic cancer. Patients with dementia were more likely to have complex noninvasive



diagnostic tests. Eighty-eight percent received antibiotics, often empirically, but patients with dementia were more likely to receive antibiotics for an identifiable infection. (Morrison *et al.*, 1998). If the goal is to achieve comfort at the end of life, the authors note, “then one should consider that serious infection may produce sedation and coma, allowing the patient a peaceful death, whereas antibiotics can awaken the terminally ill patient and prolong the process of dying.”

A study of nursing home residents with pneumonia suggest that there may be less functional decline or death in the two months after the resolution of pneumonia in patients who are not transferred to the hospital (Fried *et al.*, 1997).

Lastly, it is important to discuss with the patient’s family where they believe the patient would want to die. Unfortunately, most Americans die in an austere hospital environment.

Another issue for individuals with advanced dementia and a public health concern is the use of antibiotics for acute illness. Data suggest that survival is enhanced for patients with end-stage dementia receiving antibiotics for a febrile episode is limited (Hanrahan and Luchins, 1995; Muder *et al.*, 1996; Volicer, 1993; Fabiszewski *et al.*, 1990). Additionally, negative consequences for individuals receiving antibiotics can include: the pain of intravenous line placement, infection and blood clots at intravenous line sites, clostridium difficile infection (*c. difficile* causing diarrhea or colitis, allergic reactions, increased use of invasive tests, and increased use of mechanical restraints to prevent the patient from removing the intravenous line.

Lastly, the excessive use of antibiotics can increase the number of resistant bacterial infections and may prolong life for only a very short period of time, but at great expense (Diekema *et al.*, 2004).

Thus, the decision to hospitalize or give a patient antibiotics should not be automatic or capricious. It is often time consuming, but nonetheless there needs to be frequent and open dialogue with families about the patient’s care plan.

The final palliative care element, and possibly the most important, for patients with dementia is the adequate management of pain. The prevalence of pain in several nursing home populations, in which the vast majority of patients are cognitively impaired, has been reported to be as high as 45% to 80% (Ferrell a,b, 1995). In the inpatient setting Morrison and Siu, 2000, compared pain and its treatment in advanced dementia and cognitively intact patients with hip fracture. Advanced dementia patients received one-third the amount of opioid analgesia as compared to cognitively intact subjects-40% of whom reported severe pain postoperatively. This suggested strongly that the majority of dementia patients were in severe pain postoperatively. Of note, only 24% of patients with end-stage dementia and hip fracture received a standing order for analgesics (Morrison and Siu, 2000). This is a serious issue for healthcare planners, administrators, and providers alike.

Barriers to adequate pain control in patients with dementia are multifold and include: limited ability to communicate, presence of multiple pain problems, increased sensitivity to drug side effects, and lack of physician

education in regard to pain management. The consequences of inadequate pain control include: sleep disturbances, behavioral problems, decreased socialization, depression, impaired ambulation, and increased health care use and costs (Ferrell, 1995; Parmelee *et al.*, 1991).

In studies until comparatively recently only 1% of patients receiving hospice services had dementia as the primary diagnosis whereas 80% of patients receiving hospice services had a diagnosis of cancer, reflecting the misconception that dementia is not a terminal illness. The PEACE program (Palliative Excellence in Alzheimer Care Efforts) was developed with the mission of moving palliative care “upstream”, that is to integrate palliative care into the primary care of patients with dementia. Data were collected on 150, predominately African-American patient caregiver dyads and initial feedback by patients and families indicated high rates of satisfaction with the quality of care, adequate pain control, and appropriate attention to prior stated wishes. Two-thirds of the deaths occurred at home, the desired site for most patients known to have a preference (Diwwan *et al.*, 2004).

Findings from the PEACE program reinforce the idea that effective palliative care for dementia patients must address the various sources and types of caregiver strain and stress, provide adequate support to caregivers for the management of problem behavior, and offer counseling to help them families cope with the emotional challenge presented by the progression of dementia (Dwain *et al.*, 2004).

## 1. Conclusion

We have explored the complex array of palliative care issues that arise for families and physicians as AD progresses in this chapter. The functional impairments, personality changes and behavioral disturbances associated with AD are extremely burdensome for caregivers physically, emotionally, and financially. The burden may be diminished and nursing home placement may be delayed with continuous support and respite programs.

It is of crucial importance that physicians discuss the goals of care with both caregivers and patients. Physicians should emphasize the appropriateness of a focus on comfort when the disease is in its advanced stages. We are suggesting that medical testing and interventions should only occur if it is likely that they will result in improved quality of life. Hospital admissions and antibiotic use should be minimized and a “Do Not Resuscitate” order is recommended. Families need to be alerted to the fact that feeding tubes do not prevent aspiration pneumonia and are likely to have a negative impact on quality of life.

While medical testing and interventions are of questionable usefulness, we cannot overemphasize the importance of pain medication. Additionally, patients with AD should be referred to hospice relatively early, and not just in the last few weeks of life. While optimal care for AD patients and their families is extremely time consuming, when the suffering of patients is

minimized their families and physicians are much more likely to be pleased with both treatments and outcomes.

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