

End-of-Life Care

COMMON QUESTIONS

- What is ethically appropriate care at the end of life for individuals with Alzheimer's disease?
 - Can palliative or "comfort" care alleviate the need for hospitalization for people with Alzheimer's?
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BACKGROUND INFORMATION

The Alzheimer's Association Ethics Advisory Panel concluded at a meeting on June 19, 2000, that Alzheimer's disease in its advanced stage should be defined as a terminal disease. Advanced stage can roughly be delineated by such features as the inability to recognize loved ones, communicate by speech, ambulate, or maintain bowel or bladder control. When Alzheimer's disease progresses to this stage, weight loss and swallowing difficulties will inevitably emerge. Death can be expected for most patients within a year or two, or even sooner, regardless of medical efforts. One consequence of viewing the advanced stage of Alzheimer's as a terminal illness is that family members will better appreciate the importance of palliative care, or the use of pain medications, as an alternative to medical treatments intended to extend the dying process.

ASSOCIATION POSITIONS

To assist individuals and families as they make decisions about end-of-life care, professionals should inform them of studies that indicate the immense value of a comfort care approach that avoids hospitalization. These studies include "Survival in End-Stage Dementia Following

Acute Illness," a report by R. Sean Morrison, MD, and Albert L. Siu, MD, MSPH, published on July 5, 2000, in the *Journal of the American Medical Association*. The report indicated that when persons with Alzheimer's were hospitalized for pneumonia or hip fracture, half died within six months. Cognitively intact patients receiving the same aggressive treatments were much less likely to die. In addition, pain was not well treated in the hospital setting. A number of similar studies now conclude that hospitalization is not recommended, given the limited life expectancy of persons with advanced dementia, the significant burdens of aggressive treatment, and the limited attention given to pain control in hospital settings. The most compassionate decision for such persons is to eliminate hospitalization and concentrate on palliation and comfort care in the nursing home. If a person with advanced dementia is at home, family caregivers should usually call the local home hospice team in moments of crisis.

Therefore, the Ethics Advisory Panel has noted that all efforts at life extension in the advanced stage of Alzheimer's create burdens and avoidable suffering for patients who could otherwise live out the remainder of their lives in greater comfort and peace. Cardiopulmonary resuscitation, dialysis, tube feeding, and all other invasive technologies should be avoided. The use of antibiotics usually does not prolong survival, and comfort can be maintained without antibiotic use for patients experiencing infections.

Physicians and other health care professionals should recommend this less burdensome and,

therefore, more appropriate late-stage approach to family members and to persons with dementia who are competent, ideally soon after initial diagnosis. Early discussions of a peaceful dying should occur between persons with dementia and their families, guided by information from health care professionals on the relative benefits of a palliative care approach. After having these discussions, the individual diagnosed with Alzheimer's

should create advance directives, legal documents establishing his or her wishes for future decisions. One such document, a durable power of attorney for health care, grants a designated person the right to make medical decisions when the individual with Alzheimer's is no longer able to make such decisions. A living will allows the person with Alzheimer's to declare his or her preferences for end-of-life care.

To receive additional Association materials on this topic, log onto the Association's Web site (<http://www.alz.org>) or call (800) 272-3900.

