

End-of-Life Care

COMMON QUESTIONS

- What is ethically appropriate care at the end of life for individuals with Alzheimer's disease?
- Is palliative or "comfort" care ethical as a substitution for hospitalization for people in the end stages of Alzheimer's disease?

BACKGROUND INFORMATION

Alzheimer's disease is fatal, and persons in the advanced stages are considered terminally ill. The advanced stage is often characterized 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 individuals within a year or two, or even sooner, regardless of medical efforts.

Research indicates that when persons with Alzheimer's disease are hospitalized for pneumonia or hip fracture, half die within six months. Cognitively intact individuals receiving the same aggressive treatments are much less likely to die following hospitalization. In addition, pain was not well treated in the hospital setting.

A number of studies conclude that hospitalization is not recommended, given the life expectancy of persons with advanced dementia, the significant burdens of aggressive treatment and the limited attention given to pain control in hospital settings. Other research supports the findings that individuals whose surrogate decision-makers had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last three months of life.

ASSOCIATION POSITION

The person with Alzheimer's disease and his or her care partners have a choice about treatments at the end of life. Discussing options and making decisions about end-of-life care should happen early in the disease process. Persons with Alzheimer's disease should complete advance directives and/or talk with their care partners and physicians about their choices. Families should be aware that the laws regarding advance directives vary from state to state; therefore, it is important to update advance directives in the event of a move or if the person resides in more than one state.

Given the research on the efficacy of aggressive treatments and the burden experienced by the person in the advanced stage of Alzheimer's disease, the Association supports the elimination of hospitalization and aggressive treatments, including cardiopulmonary resuscitation, dialysis and all other invasive technologies, in favor of palliative and comfort care in the person's residence, whether in the person's home or in a nursing facility.

To assist individuals and families as they make decisions about end-of-life care, the Association recommends that physicians and other health care providers educate families regarding the choice of burdensome treatments in the advanced stages of dementia versus the choice to provide comfort through palliative and hospice services. The Association asserts that open and honest communication between health care providers and families as to the person's prognosis as well as the implications for aggressive treatments will assist families in making compassionate choices.

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