
End-of-Life Care

COMMON QUESTIONS

- What is ethically appropriate care at the end of life for individuals with Alzheimer's disease?
- What do research findings tell us about hospitalization of people with advanced dementia?

BACKGROUND INFORMATION

Alzheimer's disease is fatal, and individuals 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.

A number of studies have concluded that hospitalization for individuals with advanced dementia is often more harmful than helpful given the lack of improved outcomes when comparing interventions typically used on people without dementia. There can be significant burdens upon a person with dementia, such as:

- Heightened agitation and frequency of delirium.
- Limited attention to pain control in hospital settings.
- Utilization of harmful physical and pharmacologic restraints.
- Higher complication rates.

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 individual 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. People 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.

Research supports that the highest quality of end-of-life care for individuals with advanced dementia is provided through a palliative or comfort-oriented approach. The Association

supports decisions to forgo hospitalization and invasive treatments, including cardiopulmonary resuscitation, dialysis, artificial nutrition and hydration, in favor of palliative and comfort care in the person's residence (home or care 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 invasive treatments will assist families in making compassionate choices.

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