

All About Aging

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Taking a Clearer Look at Alzheimer's and Dementia

I want to bring awareness to Alzheimer's disease and dementia and highlight these health problems and some issues faced by family members of those with advanced dementia.

Dementia is the loss of one or more cognitive abilities, such as memory, language and judgment, which affect activities of daily life.

Alzheimer's disease is the most common and well-known type of dementia. Today, more than five million people have Alzheimer's disease and that figure is expected to increase to a staggering 13 million by 2050.

Dementia becomes more common as we age. One in nine people age 65-74 has Alzheimer's disease, which increases to one in three people at age 85 or older. For individuals with dementia, symptoms gradually worsen over time. In the early stages, typically years one to three from symptom onset, individuals may have short-term memory problems and difficulty with complex tasks, such as driving, paying bills and managing medications. In the middle stages, typically two to eight years, individuals develop worsening cognitive abilities and may need supervision and help with

basic tasks such as bathing, dressing and toileting. In its late stages, usually years six to 12, individuals have long-term memory problems. They are unable to recognize loved ones and need complete assistance in their daily lives.

Advanced dementia should be thought of as a terminal condition. In 2009, a landmark study published in the New England Journal of Medicine looked at nursing home residents over an 18-month period. More than 50 percent died by the end of the study and nearly all of them from dementia, as opposed to other health issues such as heart attack or stroke.

Individuals with advanced dementia lose the desire and the ability to eat. In that same study, over 85 percent of nursing home residents with advanced dementia had an "eating problem," such as difficulty with chewing and swallowing, decreased food intake or refusal to eat and drink. Earlier this year, the American Geriatrics Society published a position statement saying tube feeding to provide nutrition is not recommended in advanced dementia. Studies have shown no benefit to the patient or improvement in overall mortality. Additionally, tube feeding is associated with pain, diarrhea, agitation, physical and chemical restraints,

immobility and decreased socialization. Hand feeding, in which loved ones and caregivers feed individuals with dementia by hand, is an alternative to tube feeding. Hand feeding eliminates the side effects seen with tube feeding and allows for comfort and socialization.

Decisions about tube feeding in advanced dementia should follow the patient's wishes. In advanced dementia, an individual is unable to communicate his or her wishes, which means that healthcare providers and loved ones need to follow what they believe the individual would have wanted based on verbal statements or written documents, including an Advance Health Care Directive. The latter is a legal document in which medical wishes are made known and a surrogate decision maker is identified to help communicate those preferences.

Although talking about tube feeding in advanced dementia before the fact can be uncomfortable for some people, preparation helps guide family and friends to make difficult medical decisions and ensures individuals with advanced dementia get their preferred care when they can no longer speak for themselves.

The UCLA Alzheimer's and Dementia Care Program helps patients and families better deal with the complex medical, behavioral and social issues that arise with these diseases. For more information, visit its website: dementia.uclahealth.org/.



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