

## Feeding Issues in Advanced Dementia

### COMMON QUESTIONS

- When an individual with Alzheimer's disease reaches the advanced stages of the disease and is no longer able to eat, is it ethically or medically necessary to insert a feeding tube for artificial nutrition and hydration?
- Can a decision to withhold or withdraw artificial nutrition and hydration be made by someone other than the individual with Alzheimer's disease?
- What are the arguments in favor of careful hand feeding?

### BACKGROUND INFORMATION

Individuals with advanced Alzheimer's and other dementias commonly develop difficulty with eating and drinking, even with assistance, in the final stages of the disease process. This is different than nutritional issues that arise in earlier stages due to decline in memory and executive function. Early in the course of Alzheimer's disease, individuals may over- or under-eat due to their forgetfulness and begin to require mealtime supervision. As Alzheimer's progresses, neurologic control over the oral and swallowing phases of eating and drinking is gradually lost, and individuals with the disease will be at high risk of nutritional decline and aspiration pneumonia. This irreversible stage is the expected course of Alzheimer's disease.

In 1981, the percutaneous endoscopic gastrostomy tube (PEG) procedure was developed as a way to deliver nutrition and hydration to someone who cannot swallow safely. In this procedure, a feeding tube passes through the skin of the abdomen and directly into the stomach. This technology was rapidly applied to persons with advanced Alzheimer's disease. Over subsequent decades, researchers have published the results of studies to determine if tube feeding delivers benefits over the traditional approach of careful hand feeding — where the caregiver offers food and fluids to the degree they can be comfortably handled by the person with dementia — in regard to preventing aspiration pneumonia, prolonging survival, preventing pressure ulcers, improving functional status or increasing patient comfort. These studies have shown that in comparison with careful hand feeding, tube feeding by PEG or nasogastric tube offers no advantages and incurs a number of disadvantages.

Research on tube feeding shows that it does not usually improve nutritional status, nor does it prevent or lower the incidence of aspiration pneumonia. There is no evidence to suggest that tube feeding reduces the likelihood of pressure sores. Contrary to common belief, there is no average difference in longevity between individuals with advanced Alzheimer's disease who are tube fed and those provided with careful hand feeding. Furthermore, tube feeding has been associated with increased use of physical restraints to prevent individuals from pulling the tubes out of their noses or abdomens. Finally, tube feeding denies the person the gratification of tasting preferred foods and the emotional and relational benefits of interacting with a caregiver through careful hand feeding.

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Decisions regarding tube feeding can be extremely difficult for caregivers and/or surrogates. It is critical that health care staff assist the caregivers in the decision-making process and offer alternatives to tube feeding that demonstrate care and compassion to the person with advanced dementia.

### **ASSOCIATION POSITION**

The Association asserts that research evidence supports no medical benefit from feeding tubes in advance dementia and that feeding tubes may actually cause harm in the advanced stages of Alzheimer's. Additionally, it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the individual with Alzheimer's or dementia is in the end stages of the disease and is no longer able to receive food or water by mouth. The Association emphasizes that careful hand feeding offers the highest quality of care and should be offered to all individuals with advanced Alzheimer's disease who can competently and comfortably handle oral feeding. Concerted efforts are called for to educate and support professional and family caregivers in techniques of careful hand feeding.

Moreover, the Association recommends that evidence on the risks and benefits of tube feeding versus careful hand feeding be provided to individuals with Alzheimer's disease and their caregivers so they can make an informed decision. Individuals with Alzheimer's disease should discuss this and other end-of-life decisions with their care partners, including their physician, early in the course of the disease.

The Association emphasizes the need for planning by the individual with Alzheimer's disease while still competent and endorses the use of advance directives: legal documents specifying an individual's wishes for future care decisions. The Association also asserts that in the absence of such directives, a surrogate (usually a trusted family member) may make decisions consistent with the person's expressed wishes or best interests and consistent with state law. The Association encourages surrogates to discuss the risks and benefits of all feeding alternatives with the medical care team to arrive at a choice that ensures the highest quality of care and is consistent with the person's values.

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### **Feeding Issues in Advanced Dementia Bibliography**

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