

Assisted Oral Feeding and Tube Feeding

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 assisted oral feeding?

BACKGROUND INFORMATION

Persons with advanced Alzheimer's disease who survive to the point of being unable to swallow, even with assistance, or who have lost all interest in eating and drinking, are in the final phase of the disease process. This irreversible stage is the expected course of Alzheimer's disease. An increased amount of sleep naturally limits their intake of food or water. Some dehydration may occur, and dry mucous membranes can be cared for with artificial saliva and ice chips.

In the absence of nutrition and hydration, the body draws on endorphin, a morphine-like substance in the body that blunts nerve endings. An emerging consensus indicates that this form of natural dying is not painful. These effects can be supplemented with the use of morphine to assure comfort with many of these symptoms of dying.

The practice of long-term tube feeding in persons with advanced dementia has its roots in nursing home regulation that required facilities to provide adequate hydration and nutrition to all residents even though they were close to death. The trend to use feeding tubes accelerated in the mid-1980s after the development of a technique called percutaneous endoscopic gastrostomy (PEG). In this procedure, a feeding tube passes through the skin of the abdomen and directly into the stomach. Before the introduction of PEG tube feeding, such persons were cared for through assisted oral feeding and nasogastric tube feeding. (Assisted oral feeding is the provision of food or water by a caregiver, and it is used when the person with Alzheimer's disease can no longer feed him or herself. It allows for the person with end-stage dementia to take in food or water as desired and provides human touch and contact.)

In comparison with assisted oral feeding, long-term tube feeding 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 skin breakdown or the likelihood of pressure sores. Contrary to common belief, there is no average difference in longevity between persons with advanced Alzheimer's disease who are tube fed and those provided with assistance in oral feeding. Furthermore, tube feeding has been associated with increased diarrhea and related discomfort. It can also result in greatly increased use of physical restraints to prevent individuals from pulling the tubes out of their 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 assisted oral feeding.

The decision to tube feed is 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 to demonstrate care and compassion to the person with advanced dementia.

ASSOCIATION POSITION

The Association asserts that it is ethically permissible to withhold nutrition and hydration artificially administered by vein or gastric tube when the person with Alzheimer's disease 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 assisted oral feeding should be available to all persons with advanced Alzheimer's disease. Neglect in this area should not be tolerated, and concerted efforts are called for to educate and support professional and family caregivers in techniques of assisted oral feeding.

Moreover, the Association recommends that evidence on the risks and benefits of tube feeding and assisted oral feeding be provided to individuals with Alzheimer's disease and their care partners/families so they can make an informed decision. Persons 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 is consistent with the person's values.

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Assisted Oral Feeding & Tube Feeding Bibliography

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