

Assisted Oral Feeding and Tube Feeding

COMMON QUESTIONS

- When an individual with Alzheimer's reaches the advanced stages of the disease, 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?
- 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 process of dying. Their increasing sleep naturally limits intake of food or water. They will usually die comfortably in several days or a week. Some dehydration may occur, and dry mucous membranes can be cared for with artificial saliva and ice chips.

The physiological responses and probable physical reactions to the cessation of nutrition and hydration have been described in medical literature. 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 comfortable. This effect can be supplemented with the use of morphine to provide absolute comfort.

The practice of long-term tube feeding in persons with advanced dementia began only in the mid-1980s after the development of a technique called percutaneous endoscopic gastrostomy (PEG). With 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. In comparison with assisted oral feeding, however, long-term tube feeding has no advantages and a number of disadvantages.

ASSOCIATION POSITIONS

The Alzheimer's Association has addressed the issue of end-of-life nutrition and hydration in several documents. The 1994 statement *Guidelines for the Treatment of Patients with Advanced Dementia* includes the following position:

Severely and irreversibly demented patients need only care given to make them comfortable. If such a patient is unable to receive food and water by mouth, it is ethically permissible to choose to withhold nutrition and hydration artificially administered by vein or gastric tube. Spoon feeding should be continued if needed for comfort.

In the 1997 publication *Ethical Considerations: Issues in Death and Dying*, the Association affirmed the need for planning by the individual with Alzheimer's while still competent and endorsed the use of advance directives, legal documents specifying an individual's wishes for future care decisions. The Association also asserted that in the absence of such directives, a surrogate (usually a trusted family member) may make decisions consistent with the patient's expressed

wishes or best interests. This statement refers not just to an absolute right to avoid mechanical ventilators, dialysis, and cardiopulmonary resuscitation, but also to tube feeding and antibiotics. In all these categories, surrogate choice to refuse or withdraw treatments should be honored.

In 2000, the Ethics Advisory Panel moved to a firm recommendation of assisted oral feeding coupled with hospice care when needed as the compassionate alternative to tube feeding. This recommendation emerged primarily from two major studies. Muriel R. Gillick, MD, published "Rethinking the Role of Tube Feeding in Patients with Advanced Dementia" in the January 20, 2000, issue of the *New England Journal of Medicine*; Thomas E. Finucane, MD, was the lead author of "Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence" in the October 13, 1999, issue of the *Journal of the American Medical Association*.

In both articles, the authors point out that PEG tube-feeding is associated with increased diarrhea and related discomfort. PEG tube-feeding also results in greatly increased use of physical restraints to prevent patients from pulling the tubes out of their abdomens. Paradoxically, this is occurring at a time when most long-term care facilities recognize the benefits of minimal or no restraint policies.

Moreover, nutritional status does not usually improve with the use of tube feeding, nor does such use prevent or lower the incidence of aspiration pneumonia. There is no evidence to suggest that tube feeding reduces skin breakdown and the likelihood of pressure sores. Contrary to myth, there is no average difference in longevity between persons with advanced Alzheimer's who are tube fed and those provided with assistance in oral feeding as needed.

Other studies support the Association's position to withhold or withdraw the use of feeding tubes. A research group led by Dwenda K. Gjerdingen, MD, published a survey on this topic in the September/October 1999 issue of *Archives of Family Medicine*. The researchers found that the use of PEG tube-feeding is contrary to the preferences of an overwhelming number of elderly persons. More than 95 percent of cognitively intact respondents, 65 years and older, indicated that should they ever have severe dementia, they would not want cardiopulmonary resuscitation, use of a respirator, or tube feeding. Susan L. Mitchell, MD, and her colleagues published a related study in the April 2000 issue of the *Journal of the American Geriatrics Society*. The researchers found that most family surrogates who consent to tube feeding for a loved one with advanced Alzheimer's come to regret the decision.

The Ethics Advisory Panel has also noted that the person receiving long-term tube feeding is denied the gratification of tasting preferred foods. The person with advanced dementia has suffered many losses that severely diminish the quality of life, including the capacity to communicate by speech, to recognize loved ones, to control bowel and bladder, and to enjoy continuity with the past. In such circumstances, small gratifications are all that remain. Tube feeding denies the sensory benefits of assisted oral feeding, as well as the emotional and relational benefits of interacting with a good caregiver who assists in an emotionally affirming manner.

The Association emphasizes that assisted oral feeding should be available to all persons with advanced Alzheimer's as needed. 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.