

# Artificial Nutrition and Hydration in Advanced Alzheimer's Disease: Quality in End of Life Care

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## Brief Description:

The single most pressing issue in Alzheimer Disease ethics is the use of artificial nutrition and hydration. For those who have lost the capacity to swallow, artificial feeding via a gastrostomy tube has become a very common approach for sustaining life. This widespread practice of tube feeding needs to be carefully reconsidered and for the severely demented patient the practice needs to be evaluated on clinical grounds.

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*This submission was selected as part of a national challenge issued to leaders in all communities seeking new "best practices" and "best possibilities" for the future of nutrition and aging.*

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The increasing incidence of Alzheimer's disease (AD) has created an enormous challenge for individuals, families and health care providers. AD is a progressive degenerative disease characterized by decline in memory and function that is sustained over months to years. As the disease advances, caregivers become increasingly involved with basic functional tasks, including bathing, dressing, grooming and feeding. Nursing home placement most often occurs only after families have exhausted their financial, emotional and physical resources in caring for their family member at home.

Patients with advanced dementia are among the most challenging patients to care for because they are often become bedridden and dependent in all activities of daily living. Difficulty with eating is especially prominent and distresses family members and health care professionals. The use of artificial nutrition in patients in the later stages of dementia remains a controversial and an emotional issue. This topic has become increasingly important because the prevalence of dementia continues to rise as the population ages. This is also being identified as a global problem, with the population demographics internationally now aging as well.

Food is sustenance and is also a potent symbol of love and caring, deeply rooted in all cultures. Not surprising therefore, when an elderly nursing home patient loses the ability to eat, the family can become extremely distressed. Seeking to affirm their

devotion in traditional ways that is by providing nutrition, they can often arrive at the decision to begin artificial tube feeding.

Family members and physicians are often attracted to the perceived benefits of providing artificial nutrition and hydration to patients with severe dementia. Tube feeding continues to sometimes be presented as nearly risk free and beneficial treatment for these patients that can no longer eat.

The elderly person begins to have difficulty swallowing. Maybe is hospitalized for aspiration pneumonia. A Barium Swallow is ordered, the results then lead to the person becoming NPO. And now what?

### **To Feed or Not to Feed?**

Family surrogates are often made to feel that they have no choice in the matter and that a feeding tube is the only intervention available to sustain life. Families would have less difficulty in this decision if instead of talking about artificial nutrition, or to “feed or not to feed” the medical intervention was explained as – post surgical mechanically forced chemical supplementation via a gastrostomy tube!

**Allow a Natural Death** – could these three words change the way we provide End of Life Care? If additional time was given to communicating treatment goals for medical interventions would less invasive procedures be selected by older adults and their families?

I believe that is exactly the case. The progression of Alzheimer's Disease is a predictable course. It can be planned for and patient centered. Advance Care planning is possible and the Advance Medical Directive can be explicit regarding artificial nutrition and hydration.

Early identification of potential feeding difficulties enables the older person and their family to make end of life decisions in regard to artificial nutrition and hydration before the crisis. It should never become a question that a family member needs to answer: do you want to withhold a life sustaining treatment or intervention? Or worse, what is still heard “without the feeding tube, your mother will starve to death.” What a huge burden for that family member. To be presented that life is in their hands, vs. placing the medical problem exactly where it belongs – on the deteriorating condition of the parent.

Unfortunately, many doctors continue to fail to acknowledge the final stages of Alzheimer's disease and other forms of dementia as a terminal illness, and therefore subject patients to “curative interventions” when providing palliative care would be more appropriate.

For patients at end of life care, providing artificial nutrition and hydration may prolong the dying process, without contributing to patient comfort.