

Artificially Administered Nutrition and Hydration in Advanced Dementia

Should the Option Even Be Offered?

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Artificially administered nutrition and hydration (ANH) is the provision of food and fluid to a patient in a manner that does not require swallowing. It most commonly refers to enteral feeding via a tube placed through the nose (nasogastric tube, NGT) or by endoscopic surgical procedure through the abdominal wall into the stomach (percutaneous endoscopic gastrostomy, PEG). Total parenteral nutrition (TPN), which bypasses the gastrointestinal tract and employs special techniques including central venous catheterization, can provide all or most nutritional needs on a temporary or long-term basis, albeit at far greater expense and with a higher complication rate. In the broadest sense of the term, ANH would also include ordinary intravenous or subcutaneous hydration, although proteins and other essential nutrients cannot be delivered that way. For the purposes of this paper, ANH will refer to the most common usage of the term: enteral tube feeding via NGT or PEG.

In the following discussion, I will compare the appropriateness of offering ANH as a treatment option in two conditions: advanced dementia and the persistent vegetative state (PVS). In PVS, I believe that ANH should be offered as a treatment option because it can prolong life, even though there may be good reasons for rejecting this option. In advanced dementia, I will argue that ANH should not even be offered because it does not prolong life, does not provide palliative benefit, and carries substantial burdens.

The presumption in favor of ANH

When a patient has inadequate oral intake, ANH is employed as a standard treatment. Some observers even consider ANH to be part of basic care like keeping a patient clean, warm, and pain free, and believe it should never be withheld, even at the request of a qualified surrogate. According to the U.S. Conference of Catholic Bishops: "there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally." That obligation applies beyond vegetative states to include patients with advanced dementia [2]. New York State's health care proxy law creates a special category for ANH: a surrogate named in a proxy document is, by default, empowered to make all health care decisions for an

incapacitated patient *except* for decisions regarding ANH; the latter requires specific knowledge by the surrogate of the patient's preferences [15].

Underlying the presumption in favor of ANH are three assumptions: that it is indeed a life prolonging treatment, that it is well tolerated, and that it has an acceptably low complication rate. In some settings, there is good evidence that ANH (usually via PEG) fulfills these assumptions. One example is amyotrophic lateral sclerosis (ALS, "Lou Gehrig's disease"), a neuromuscular condition where the swallowing mechanism becomes impaired with usually intact cognitive functioning. In ALS, ANH clearly prolongs life, decreases aspiration, and prevents hunger, thirst, and dryness [19]. Another example, extensively covered in the lay press, is the persistent vegetative state. PVS is a chronic condition, most commonly following severe brain trauma or cerebral anoxia from cardiac arrest, in which the patient may appear alert but has no evidence of awareness of self or surroundings. PVS patients can be quite stable when maintained by ANH. Karen Ann Quinlan survived for 10 years with ANH until her death from pneumonia. Nancy Cruzan and Terry Schiavo lived for 7 and 15 years, respectively, and died only after ANH was withdrawn [8].

Withdrawal of ANH in persistent vegetative states

Despite the presumption in favor of ANH in PVS, there is no consensus that it should be used. When the prognosis is clear that there will be no recovery of consciousness, most people, including those residing in nursing homes, would prefer *not* to be maintained alive indefinitely by artificial means [30]. Implicit in that preference is a benefit/burden analysis. The benefits of ANH are arguably small for the patient who is permanently unaware. The burdens *on the patient* are also small, since the patient does not experience pain, discomfort, or awareness of his existence. However, the burdens (emotional and financial) on the patient's loved ones may be great, and are not justified by the "benefit" of mere prolongation of insapient life.

The decision to discontinue ANH in PVS is appropriately made by a qualified surrogate. Surrogate decision-making should be based on the patient's actual wishes if known, or an estimate of what those wishes would have been based on knowledge of the patient's values and beliefs (substituted judgment), or in the patient's best interest (which may be unclear in the setting of permanent unconsciousness), or based on a benefit/burden analysis as described above, which has also been called a "reasonable person" standard [4]. Surrogates may assume they have the right to make the decision to withdraw ANH. However, those rights can be infringed when evidence of the patient's wishes regarding ANH is lacking. There is also legitimate worry that Catholic health care institutions will be pressured to comply with the Conference of Catholic Bishops and not allow ANH withdrawal, even *with* an advance directive.

In PVS with no chance of recovery, I personally do not believe that the benefits of ANH justify the burdens. However, because ANH is sometimes perceived as basic nurturing (i.e., not a form of medical treatment), and because insapient life prolongation is

perceived by some people as a benefit, I would not advocate withdrawal without seeking permission of available surrogates. The benefit/burden analysis that drives a decision to withdraw ANH will vary among individuals, families, and religious and ethnic groups. Some Orthodox Jews, for example, may value life prolongation so highly that large burdens can be justified.

In circumstances when prognosis in PVS is uncertain, decision making for ANH becomes even more problematic. Rarely, PVS patients can recover consciousness or even degrees of independent functioning. Recovery is more likely when the incident event is brain trauma (vs. cerebral anoxia and ischemia from cardiac arrest or stroke), when there has been a relatively short interval since the incident event (less than 1 year for brain trauma or 3 months for anoxia), and when the patient shows some awareness of his or her surroundings (i.e., the minimally conscious state). Advanced imaging techniques, such as functional MRI, might also provide prognostic information. Surrogates should be clearly informed of the possibility of recovery when it exists, as that would increase the potential benefit side of a benefit/burden analysis.

Advanced progressive dementia is different from persistent vegetative state

Advanced or end-stage progressive dementia is another condition in which ANH is sometimes administered, and its use in dementia will be the focus of the remainder of this review. Alzheimer disease is the most common dementing condition. Alzheimer begins as a mostly amnesic (memory deficit) disorder, followed by executive dysfunction and language impairment, and finally motor impairment. Progression is slow over several years. Eventually, however, the patient becomes bed-bound and poorly responsive. Other dementing illnesses such as vascular and Parkinson dementia typically progress more rapidly and have earlier motor features, but the end stage is similar to Alzheimer disease. Common to all of these conditions is a progressive mental and motor decline leading ultimately to a state in which oral intake becomes inadequate to maintain normal nutrition, body weight, and fluid balance. In a prospective study of advanced dementia in nursing home patients, 86% developed an eating problem [27]. Oral feedings become inadequate because the patient refuses to cooperate, or cannot manage the food bolus within the mouth, or aspirates when swallowing is attempted [9]. That is when feeding tubes and ANH are considered.

Although end-stage dementia can look similar to a post-anoxic or post-traumatic PVS, the onset, progression, and prognosis are markedly different. PVS can be quite stable, and there is sometimes the question of reversibility. In a dementia such as Alzheimer, progression is slow but relentless, and there is no question of reversibility. Demented patients who become bed-bound with diminished responsiveness can be said to have a terminal illness with short life expectancy [27].

Does ANH provide clinical benefit in advanced dementia?

ANH is a medical intervention. It is not the natural way people eat and drink, any more than a ventilator is the natural way people breathe. It requires threading a tube into the stomach, either via the nose or by a surgical procedure through the abdominal wall. In either case, tube insertion requires clinical expertise. It is associated with side-effects and complications, some of which could become serious problems and shorten life [7][36]. The life-prolonging properties of ANH that have been shown in PVS should not automatically be assumed to exist in advanced dementia. Whether or not ANH prolongs life, reduces morbidity, or provides palliative benefit would have to be established by clinical investigation. As with any medical intervention, the burden of proof is on showing that ANH is effective, not on proving beyond a doubt that it is ineffective.

Ideally, the benefit of any medical intervention, be it a drug, device, or procedure, should be established by randomized controlled trial (RCT) with appropriate blinding of patients and investigators to minimize sources of bias. This ideal is met for newly introduced pharmaceuticals, but RCTs are less often available for devices and procedures. There have been no published RCTs for ANH in advanced dementia [37].

The absence of controlled studies of ANH in dementia has not prevented its extensive use in that setting. In 1995, gastrostomy tubes were inserted in 121,000 elderly patients in the United States [14]; approximately 30 percent of these patients had dementia [34]. In a 2003 survey, over one third of severely cognitively impaired patients in US nursing homes had feeding tubes [22].

ANH has a high mortality rate, especially in advanced dementia. PEG insertion itself can cause serious complications including fatalities [7]. Sanders et al. [36] studied 361 consecutive patients requiring PEG feeding. For all patients the mortality was 28% by 30 days, reflecting the underlying disease mix (e.g., severe stroke, oropharyngeal and esophageal cancer, as well as dementia). The demented patients however, had the highest mortality: 54% dead at 1 month, and 90% at 1 year. In the series reported by Kuo et al. [17], the median survival for demented patients after feeding tube insertion was 56 days.

Finucane et al. [9] exhaustively reviewed all published studies over a 34-year period (1966 through 1999) that compared advanced dementia patients who received ANH with those who did not. There was no reported evidence of benefit of ANH for any clinically important outcomes including survival, aspiration pneumonia, infections, pressure sores, improved functioning, or palliation. A 2009 Cochrane review came to the same conclusion [35].

Several of these studies deserve special mention. A study of admissions to a single acute care hospital of severely demented patients found a 50% 6-month mortality rate which did not differ between the 2/3 of patients who received (or already had) a feeding tube vs the 1/3 of patients who did not have a tube placed [21]. A VA study showed no difference in survival of demented patients who received PEG vs patients for whom PEG was recommended but the surrogates declined [29].

Mitchell et al. [25] compared outcomes in 1386 institutionalized demented patients for those receiving vs not receiving ANH. Even after adjusting for multiple risk factors that could decrease survival in the ANH group, there was no survival benefit demonstrable for ANH. Nor did ANH improve complication rates. Aspiration pneumonia was more common in ANH patients, and pressure sore formation was not decreased. In a data set of 5266 nursing home residents (not all demented) studied by the same group, tube fed residents had a higher mortality rate than those who were not tube fed, even after adjusting for confounding covariates [26].

In a controlled study involving severely demented patients in a nursing home, aspiration pneumonia occurred more often in ANH patients (48% vs 17%, $P < 0.01$), as did decubitus ulcer formation (21% vs 14%, NS) and use of restraints (71% vs 56%, NS) [32]. Jejunostomy has not been found not superior to gastrostomy in reducing aspiration pneumonia [7]. Although better nutrition could theoretically reduce the risk of decubitus ulcers or pressure sores, no studies have found ANH to provide that benefit [7][16]. It is plausible that ANH could even increase the risk of pressure sores, by necessitating restraints to prevent tube dislodgement [9].

In addition to increasing the complications of immobility, ANH can cause diarrhea, vomiting, and electrolyte disturbances [28]. Tube dislodgement, blockage, and leakage are not uncommon (4%-11%) [3] and can precipitate hospitalization.

There is no evidence that tube-fed demented patients respond better, perform on tasks better, or are made more comfortable in any way by the tube feeding [9]. Patients with advanced dementia and inadequate oral intake can appear to be rejecting food by closing the mouth, spitting out food, or not swallowing. Such patients are not verbal and it is impossible to tell if on some level they are hungry. However, there is no increase in the appearance of discomfort when ANH is stopped [31]. Although discomfort due to poor oral intake cannot be easily assessed in dementia, it has been looked at in other settings. For example, patients with advanced cancer who are refusing food do not report hunger or thirst [20]. The oral dryness caused by inadequate hydration can be relieved with ice chips and oral swabbing. Dehydration could even be beneficial to the patient by decreasing episodes of urinary incontinence.

There is also no perceived benefit to ANH by family members; in fact, available data suggests the opposite. Healthcare proxy satisfaction with nursing home care of demented patients is strongly negatively correlated with tube feeding [6].

In summary, ANH in advanced dementia has not been shown to be of benefit (other than for preventing weight loss [32]), and it has substantial complications. The studies of ANH cited here were not randomized, and therefore could have bias. It is likely that conditions causing the perceived need for ANH, even when controlled for, also increased the risk of adverse events, and therefore affected the results. However, the

burden of proof on a proposed medical intervention is showing that it is beneficial, or at least likely to be so. That proof is sorely lacking for this commonly performed procedure.

What accounts for ANH use in advanced dementia?

Despite the lack of evidence for ANH benefit, over one third of severely cognitively impaired patients in US nursing homes have feeding tubes [22]. It is worth exploring why this apparently ineffective treatment is used at all, and what factors lead to variation in its use.

Personal preference is clearly *not* the reason. Surveys have shown an overwhelming opposition to the use of ANH in advanced dementia. For example, in a study of 84 cognitively normal American men and women over 65 years, only 4% said they would desire tube feeding if they could not communicate and care for themselves [13]. Another study found that only 11% of adults would want tube feeding if they were to develop Alzheimer disease [5].

Financial incentives for nursing homes favor ANH. The actual cost to the nursing home of patient care is higher in patients who are hand fed compared to those who are tube fed, principally because the former takes far more staff time [24]. Reimbursement to the nursing home, however, is higher for tube fed patients [10][24]. Regulatory oversight may also perversely favor ANH, as citations have been issued for weight loss in patients who have foregone tube feedings [4][10].

There is a 10-fold variation among nursing homes in the rates of ANH usage in demented patients [39]. Some of this is accounted for by individual patient characteristics and variation in patient mix. For example, there are far higher rates of ANH in nonwhite patients [21], and in patients without DNR orders or other advance directives [22]. However, characteristics of the nursing homes themselves may be responsible for much of the variation. For-profit facilities and larger facilities are independent risk factors for increased ANH use [22]. Less measurable, qualitative differences among nursing homes should not be ignored. In an ethnographic study of 2 nursing homes with highly disparate dementia ANH rates (42% vs 11%), the low ANH facility was characterized by a homelike environment, staff trained in hand feeding, and a palliative care focus, while the high ANH facility was characterized by an institutional environment, inadequate and impersonal staff, and a focus on regulatory compliance [18].

Variation among hospitals in ANH use is also noteworthy. In nursing home patients, most feeding tubes are inserted during acute care hospitalizations. The rate of feeding tube insertion for hospitalized nursing home patients with advanced dementia ranges from 0 to 39 per 100 hospitalizations. For-profit ownership of the hospital, larger hospital size, and greater use of ICU beds during the last 6 months of life all correlate with higher rates of tube insertion [41].

Gillick [12] cites the "symbolic value of nutrition" leading to family requests for tube feeding. Religiosity among surrogate offspring correlated with requests for aggressive treatment in advanced dementia, including tube feedings [38].

However, the single greatest factor accounting for ANH use appears to be surrogate education and understanding, or rather the lack thereof. Patients whose surrogates understood the poor prognosis and clinical complications expected in advanced dementia had an 8-fold lower risk of burdensome interventions such as feeding tube insertion than when the surrogates did not have this understanding [27]. Advance directives, obtained while the patient still has capacity for medical decision-making, can be invaluable in avoiding ANH and other inappropriate interventions.

If ANH neither prolongs life nor provides palliation, should it even be offered?

Patient autonomy is supported by the process of informed consent. The clinician discloses information about a proposed diagnostic or therapeutic intervention, the purpose of the intervention, the expected benefits and burdens, the consequences of nontreatment, and alternatives to the proposed intervention. Guidance is given in making choices among the reasonable alternatives. Interventions that have no clinical indication and which can provide no real benefit ("false choices") should not be presented as reasonable alternatives.

Is ANH in advanced dementia a false choice? Available evidence is that it does not prolong life, and neither does it provide any benefit in the form of palliation. On the contrary, it is often uncomfortable and is associated with a high rate of complications, including serious and fatal complications. Based on all of the above, I do not believe ANH should be recommended as an option for patients with advanced dementia. The next question: should it even be mentioned in discussion?

I see three problems with failing to even mention ANH as a part of an end-of-life discussion in advanced dementia. First, it has not been definitively proven (by randomized controlled trial) that life is not prolonged by ANH. Even if such proof were available, it is possible that subsets of patients could have their lives prolonged. Reasonable decision-makers might wish to be informed of these uncertainties. Second, there are people who remain convinced that nutritional support, regardless how delivered, is not a medical treatment, but rather a necessary component of basic care. Such a belief, however misguided, should not be ignored, especially if that belief was deeply held by the patient while he had capacity. Finally, it remains common clinical practice – albeit an inappropriate one – to recommend ANH in advanced dementia, and if the physician providing primary care does not raise this issue, it is likely that someone else will.

How should the issue be raised? In my opinion, ANH should not be offered as if it were an indicated treatment. Instead, the surrogate should be told that, eventually, patients with progressive dementia may stop taking food and fluids in amounts adequate to

maintain body weight and hydration. Malnutrition is a normal process that precedes death and should not be confused with starvation. Tube feedings, to the best of good (but not perfect) evidence, do not prolong life in this setting, nor is it evident that the patient finds the lack of nutrients and fluid to be uncomfortable. On the contrary, insertion and maintenance of a feeding tube can cause substantial discomfort, and it increases the risk of aspiration and gastrointestinal disturbances. Tube feeding does not duplicate the pleasurable sensations of eating, the taste of food in the mouth, or the human contact of hand feeding.

After explaining these facts, the treating physician should then make the recommendation to *not* insert a feeding tube, to continue oral feedings by hand as tolerated, and to administer mouth care, ice chips, and small amounts of oral fluids to avoid drying of the oral mucosa. Asking the surrogate to sign a "refusal of treatment" form for ANH is, of course, highly inappropriate. If the surrogate still wants a feeding tube to be placed, that preference should be explored to see why such a burdensome and non-beneficial treatment is being chosen.

Is the discussion different when a PEG has already been placed and ANH is being given? A fundamental ethical principle is that withdrawing treatment is equivalent to withholding it [33], but withdrawing can be emotionally more difficult. If ANH is being administered and there are no evident complications, there may be no urgent reason to stop it. Surrogates should still be told, however, that ANH is neither life-prolonging nor of palliative value and that there is no requirement that it be continued, especially if the tube becomes dislodged or other complications develop.

One last caveat: there are occasions in dementia when there is a superimposed acute process that may be reversible and affects oral intake. Case-by-case decision-making is appropriate in this setting. However, a decision to start ANH should be time-limited. If the diagnosis is incorrect and the process turns out not to be reversible, there should be a plan, agreed to in advance by surrogates and clinical staff, to terminate ANH [11].

Alternatives to ANH

If nutrition and hydration is not given artificially, it has to be given the old-fashioned way: through the mouth, and propelled down the esophagus by swallowing. At the end stage of dementia, the patient requires considerable assistance to eat. Hand-feeding may require 45 to 90 minutes per day per patient [23], and nursing home staffing schedules should accommodate this need. Food should be given with sufficient liquid to minimize dehydration, but with no specific caloric goals. Different foods should be tried and consistencies altered to optimize intake.

There are ways of improving nutrition other than ANH in nursing home patients. Tranquilizing medications can be decreased or withdrawn, staff time dedicated to oral feeding can be increased, staff can be trained in oral feeding techniques, and foods can be adjusted to meet patient preferences. An 8-week multiple intervention trial in nursing

home patients (not all demented) for whom ANH was considered resulted in a 4.5 kg weight gain without the need to resort to feeding tubes [1].

Ways to decrease ANH use

Casarett et al. [4] make five recommendations for decreasing ANH use in advanced dementia. First, there needs to be more discussion among clinicians, patients, and families regarding medical and ethical issues involving ANH. Better reimbursement for end-of-life discussions (and, I would add, less talk about "death panels") would help this process. Second, decision-makers need to be identified before decisions have to be made, and if possible the patient's opinions should be ascertained before the capacity to express opinions is lost. Third, perverse pressures on nursing homes should be removed (e.g., citations for weight loss in patients who have foregone ANH, or reimbursement that is greater for tube feeding than for hand feeding). Fourth, state laws should be rewritten that currently require a higher level of evidence (of an incapacitated patient's preferences) for ANH decisions vs other health care decisions. Finally, because feeding tube insertion often follows a patient transfer from one facility to another [40], patient transfer should be accompanied by improved information transfer.

Conclusion

Artificially administered nutrition and hydration (ANH, "tube feeding") in advanced dementia has not been shown to be beneficial either in prolonging life or in any form of palliation, and current best evidence is that it may be harmful. Therefore, it should not be recommended or offered as an option, except possibly when there is clear evidence of an acute reversible process, and even then it should be withdrawn if the diagnosis of reversibility proves to be incorrect. Discussion of ANH in advanced dementia should be accompanied by a strong recommendation that it should not be performed.

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