Common Questions and Answers About Artificial Nutrition and Hydration

Artificial nutrition and hydration

There often comes a time when patients are so ill that they may only be kept alive by "artificial" means. Prior to about 1960, such patients died, but since then a number of life-sustaining technologies have been invented, providing patients, families and physicians with previously unavailable options. These technologies may at times be clearly beneficial and assist in restoring the patient to health. At other times the very same technology serves only to prolong dying and even increase the suffering of the patient. In such cases, physicians will often recommend that the measure be withheld and that the focus of treatment shift from cure to comfort.

Of all the life-sustaining technologies that may be withheld, one of the most difficult to make decisions about is artificial nutrition and hydration, or ANH, often referred to as "tube feeding." It is natural to associate the provision of food and water as an essential sign of our love and concern; thus it can be very difficult when families (or patients) hear a physician, nurse or therapist recommend that artificial nutrition and hydration be avoided. Decisions to either provide or withhold life-sustaining treatments should be based upon sound medical science, clinical judgment and ethical concerns, including patient and/or family values. The following information is provided to help you understand the medical science, including the benefits, burdens and risks involved with ANH, as well as to briefly share with you some of the ethical issues as we understand them.

What do we mean by artificial nutrition and hydration (ANH)?

ANH is the provision of nutrition and fluids by any method other than normal eating and drinking. ANH may be provided either directly into the veins or directly into the stomach or intestines when patients are unable to take in adequate nutrition and hydration by mouth due to underlying disease or injury. Artificially provided nutrition cannot be tasted or otherwise enjoyed in the way we enjoy foods that are swallowed. When ANH is provided directly into a large central vein, it is referred to as TPN (total parenteral nutrition). When ANH is provided directly into the gastrointestinal tract, it is commonly referred to as going through a "feeding tube," of which there are three basic types. The first is a NG or naso-gastric tube running from the nose into the stomach. Such a device may be used for short periods of time ranging from days to weeks. However, such tubes are often quite uncomfortable and if a longer duration of artificial nutrition is indicated, it is better given through a PEG or J-tube. These are tubes surgically inserted directly through the skin into the stomach (PEG) or intestines (J-tube).

Is artificial nutrition and hydration effective?

It depends upon the patient's overall condition and the reason(s) they are unable to swallow and/ or drink normally. ANH may be quite beneficial in the right circumstances. ANH is excellent for patients with a temporary inability to swallow or to use their gastrointestinal tract (stomach and intestines) due to otherwise reversible conditions. ANH may also benefit persons with certain types of chronic disabling conditions. For example, a patient who must have some sort of surgery may not be able to handle nutrition by mouth for days or even weeks while awaiting recovery from the surgery. A tube placed in the stomach or intestines through which liquid nutritional supplements may be provided may benefit these patients. If patients are unable to use the stomach and intestines (gastrointestinal tract), ANH provided by vein may be effective. For cases in which it is uncertain whether or not a patient has a reversible or non-terminal condition, ANH may prolong life and allow a more accurate assessment of the patient's chance of recovery. For patients with chronic disabilities who are unable to take in adequate nutrition by mouth and who can enjoy life, ANH is clearly a useful and life-sustaining treatment.

On the other hand, ANH alone does not cure or reverse any terminal or irreversible disease or injury. Multiple studies published in the medical literature have consistently failed to show meaningful clinical benefit from ANH in terminally ill patients, whether provided by vein or by feeding tube. For example, among cancer patients, 12 studies of TPN demonstrated no net survival benefit and some showed either decreased survival or increased rates of infection.[1,2] In addition, ANH does not cure or reverse any degenerative disease of the brain such as dementia (Alzheimer's disease), ALS (Lou Gehrig's disease), multiple sclerosis or Parkinson's. ANH does not cure stroke or any organ failure (heart, lung, liver, kidney, etc.). Not only will ANH not reverse terminal or irreversible conditions, ANH, whether provided by "feeding tube" or vein, is often associated with significant complications, including bleeding, infection, physical restraints like tying the patient down, and in some cases with a more rapid death.[3,4,5] Thus, in cases of otherwise irreversible or terminal illness, ANH is much more controversial and frequently is not recommended by the most knowledgeable physicians, nutritionists and speech therapists (specialists in swallowing disorders).

Is there a standard of care for the use of ANH in patients with irreversible or terminal illness?

As noted above, physicians, nutritionists and others have come to understand the lack of benefit and frequent harm caused by ANH in certain patients; however, practice patterns remain quite variable. For example, a nationwide study of nursing home patients with severe brain impairment such as dementia or stroke and an inability to swallow revealed that 18.1 percent of patients had a feeding tube in 1999 with a range of 3.8 percent in Nebraska to 44.8 percent in the District of Columbia. In Texas, 23.1 percent of such patients received a feed tube and 76.9 percent did not.[6] Despite the wide range of feeding tube use, there is no difference in overall mortality between different parts of the country. In other words, more than 10 times as many patients receive feeding tubes in the highest usage area compared to the lowest usage area, but there is no increased survival in the high-use areas. One of the conclusions by the authors of this study is that a more consistent standard of practice in this area should be developed. We are striving to provide such a consistent standard of practice across Baylor Scott & White.

My loved one does not have terminal cancer but instead has dementia (Alzheimer's) or some other brain injury leading to swallowing problems. Will ANH help?

Many patients with Alzheimer's disease and other forms of dementia lose interest in food and lose the ability to swallow. The largest review of the medical literature ever published on the subject of ANH and dementia covered 30 years of research. This landmark scientific review revealed that ANH has never been shown to increase patient survival when compared to hand feeding of demented patients. In addition, they found that ANH did not lower the risk of aspiration pneumonia. ANH could not be shown to promote healing of pressure ulcers (decubiti). Patients with ANH still experienced weight loss. No study could be found documenting increased patient comfort or functional status when given ANH.[7]

What if my loved one doesn't have dementia or cancer, but is just frail, elderly, has trouble swallowing and lives in a nursing home? Will placing a "feeding tube" help patients like this?

Even prior to the studies reported above, there was evidence that feeding tube placement in nursing home patients who could no longer eat independently did not prolong overall survival.[8] Furthermore, ANH does not enhance the strength or function of frail elders.[9,10] Not only has medical science failed to demonstrate a clear benefit for feeding tubes in these patients, such tubes may do more harm than good in many cases. A study of 5,266 nursing home residents with chewing and swallowing problems revealed that such patients who received feeding

tubes died at a significantly faster rate – 1.44 times that of those who were not given feeding tubes.[11]

Even if my loved one has dementia, cancer, or some other terminal or irreversible condition, doesn't nutrition and hydration make the patient feel better? Won't my loved one be hungry and thirsty? Will my loved one suffer if adequate nutrition and fluids are not provided?

ANH, whether by PEG or by vein, does not make patients with advanced life-limiting illness feel better. On the contrary, ANH and even simple intravenous hydration (sugar and salt water by vein) in dying patients has been clearly associated with increased nausea, vomiting, lung problems, bladder problems and swelling of the body, leading to the need for more intervention with catheters, other treatments and medications.[12] These patients are often tied down to keep them from pulling out the various tubes inserted in their bodies.[13,14]

It is important to note that most dying patients do not experience hunger or thirst, and when they do, they generally want to taste specific foods and have the dryness in their mouths relieved by oral liquids. Remember that artificially provided nutrition and/ or intravenous fluids cannot be tasted. In addition, they generally are not as effective in relieving either hunger or thirst in dying patients as small amounts of "comfort foods," sips of liquids, ice chips and good mouth care.[15,16]

On the other hand, avoiding artificial nutrition and hydration is clearly associated with comfort in many terminally ill patients, allowing such patients to become sleepy and die naturally in their sleep.[17] In the most comprehensive study dealing with this issue to date, nurses of terminally ill patients who had refused food and fluids were asked to rate the patient's comfort and peacefulness through the dying process. The rating scale ranged from 0 (a very bad death) to 9 (a very good death). The median score for these terminally ill patients who chose to "die naturally" without ANH or other life-sustaining technologies was 8.[18] Another study examined pain and other symptoms of patients with advanced dementia who did not receive ANH when they could no longer swallow effectively. These patients experienced declining discomfort and declining pain (increased comfort) until the moment of death, even without artificial nutrition and hydration. Furthermore, their discomfort without ANH was less than that of demented patients under routine care in the typical nursing home and less than that of demented patients with pneumonia (another common cause of death in the elderly demented patient).[19]

Patients with advanced life-limiting illness, although generally not hungry or thirsty, may still enjoy favorite foods or drinks. We believe that dietary restrictions should be removed from such patients and that "comfort foods and liquids" should be offered to such patients, even if the patient has difficulty swallowing. A comfort food is any food or liquid that the patient says they want, or if they are unable to speak, may be something that they always enjoyed at a healthier time in their life. Speech therapists that specialize in swallowing disorders may be able to teach patients and families techniques that allow at least some swallowing, making it possible for families to more easily maintain human contact and provide for some of the comfort needs of their dying loved ones. Even if this modified swallowing leads to some aspiration (food or liquids getting down into the lung), this is acceptable if the patient is on a comfort or palliative plan of care. Remember that placing "feeding tubes" does not prevent aspiration and can be associated with increased aspiration.[20,21]

Are you saying that ANH is never helpful for terminally or irreversibly ill patients?

No. Although the overwhelming scientific evidence clearly points against artificial nutrition and hydration for terminally or irreversibly ill patients, there are individual circumstances in which ANH may be appropriate. Consider for example a patient with

a severe brain injury that leaves the patient in a persistent vegetative state (please see Baylor Scott & White information materials on brain injuries). These patients are able to breath without the assistance of a breathing machine. They have sleep-wake cycles, but when awake, they show no awareness or response to the environment around them. They do not follow commands although they may have some reflex movements. ANH will not reverse such a severe brain injury, but it may clearly keep some individuals alive in this condition for prolonged periods of time, often many years, until the patient dies from some other cause, typically pneumonia or some other infection. Whether or not to provide ANH to such a patient who cannot perceive either pleasure or pain, who cannot perceive that they are alive, is a deeply personal decision. There are other times in which a trial of ANH may be warranted, either due to clinical uncertainty about the patient's underlying condition and prognosis, or as a trial in the treatment of a confusional state known as delirium.[22]

What are the ethical issues involved?

Deciding what is ethically right or wrong is a complicated process and individual beliefs certainly play a role in this process. We would like to share a few of our thoughts based upon years of study and reflection upon the ethical aspects of modern medicine. At Baylor Scott & White we pride ourselves on delivering modern, quality treatment while at the same time accepting the classic goals of medicine dating back over 2,500 years to the time of Hippocrates. Those goals in modern language are:

1. cure whenever possible,
2. relieve suffering always, and
3. never prolong the dying process.

In our attempts to cure patients and follow the other goals of medicine, we strive to follow sound medical science and clinical judgment based upon our experience. We acknowledge, as should patients and families, that scientifically based treatments intended to have only benefits are always accompanied by burdens and risks. We also recognize that even the best science is accompanied by uncertainty that varies with the unique clinical circumstances of each case. These unique circumstances are not only biological, but also psychological, social and even spiritual. Thus, we endorse "patient-centered decision making." Competent patients able to communicate their preferences may make their own treatment decisions, accepting or rejecting any offered therapy. However, when patients are no longer able to communicate, we believe that decisions should be made based upon what the patient would want if they could know all of the medical facts about their condition, and/ or what is in the best interest of the patient. In these circumstances in which patients are no longer able to directly make their wishes known, we turn to advance directives such as Living Wills. We also turn to families or others close to the patient, asking them to serve not so much as the final decision maker for the patient, but as a "messenger" for the patient.

We respect different cultural and religious traditions and acknowledge that persons of good will may disagree with each other about what is ethically right or wrong in any particular case. Individual religious leaders may express a variety of opinions and each patient or family may wish to consult their own religious adviser. In general, the major religious traditions consider life-sustaining treatments appropriate only when the benefits for the patient significantly outweigh the burdens on the patient. There is no state or federal law that prohibits the removal or withholding of ANH when medically appropriate. Under Texas law, ANH is considered no different from any other life-sustaining treatment.

Given the complexity of medical science, the uncertainty of clinical practice and the psychological, spiritual, cultural and legal aspects of ethical decisions, it can be difficult to decide what is right or wrong in a particular circumstance. At Baylor Scott & White, we have a skilled multidisciplinary ethics consultation process available to advise all parties and even help resolve ethical disagreements when they arise. We also provide Palliative Care services designed to assist the primary treatment team in meeting the comfort needs for patients who are in the "last chapter" of their life.

In closing, although modern science has created treatments unimaginable to the ancient healers,

their moral insights remain relevant today. The biblical wisdom that there is, "a time to be born and a time to die," remains true. When we can no longer meet the first goal of medicine by cure or temporary remission, or return the patient to a quality of life that the patient can enjoy, we believe the most appropriate goal of medicine becomes comfort, allowing the patient to pass away as peacefully as possible, surrounded by a caring family and community.

Prepared by the Office of Clinical Ethics and Palliative Care, Baylor Scott & White Health.

REFERENCES

[1] Winter, SM. Terminal Nutrition: Framing the debate for withdrawal of nutritional support in terminally ill patients. *American Journal of Medicine*. 2000; 109:723-726.

[2] Klein S. Clinical efficacy of nutritional support in patients with cancer. *Oncology.* 1993. 7(11, Suppl): 87-92.

[3] Finucane TE, Christmas 0, and Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA*. 1999; 282(14): 1365-1370, 1999.

[4] Mitchell SL, Kiely OK, Lipsitz LA. Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *J Gerontology.* 1998; 53(3): M207-213.

[5] Rabanceck L, McCullough LB, Wray NP. Ethically justified, clinically comprehensive guidelines for percutaneous endoscopic gastrostomy tube placement. *Lancet.* 1997; 349(9050): 496-498.

[6] Teno J, Mor V, et al. Use of feeding tubes in nursing home residents with severe cognitive impairment. *JAMA*. 2002; 287(24): 3211-3212.

[7] Finucane TE, Christmas D. and Travis K. Tube feeding in patients with advanced dementia: a review of the evidence. *JAMA.* 1999; 282(14): 1365-1370. 1999.

[8] Mitchell SL, Kiely OK, Lipsitz. SA. The risk factors and impact on survival of feeding tube placement in nursing home residents with severe brain impairment. *Archives of Internal Medicine.* 1997; 157:327-332.

[9] Fiatarone M, O'Neill E, Ryan N. et al. Exercise training and nutritional supplementation for physical frailty in very elderly people. *NEJM.* 1994; 330(25): 1769-1775.

[10] Kaw M. Sekas G. Long-term follow-up of consequences of percutaneous endoscopic gastrostomy (PEG) tubes in nursing home patients. *Digest Dis Sc*i. 1994; 39(4): 738-743.

[11] Mitchell SL. Kiely DK, Lipsitz LA. Does artificial enteral nutrition prolong the survival of institutionalized elders with chewing and swallowing problems? *J Gerontology*. 1998; 53(3): M207-213.

[12] Rouseau PC. How fluid deprivation affects the terminally ill. *RN*: 54 (1), 73-76.

[13] Evans LK, Strumpf NE. Tying down the elderly. A review of the literature on physical restraint. *Journal of the American Geriatric Society*. 1989; 37(1): 65-74.

[14] Sullivan-Marx EM, Strumpf NE, et al. Predictors of continued physical restraint use in nursing home residents following restraint reduction efforts. *Journal of the American Geriatrics Society*. 1999; 4'7(3):342-348.

[15] Ellershaw JE. Dehydration and the dying patient. *Journal of Pain and Symptom Management*. 1995;10(3): 192-197.

[16] Mcann RM, Hall WJ, Groth-Junker A. Comfort care for terminally ill patients: the appropriate use of nutrition and hydration. *JAMA.* 1994; 272(16): 1263-1266.

[17] Position of the American Dietetic Association: Issues in feeding the terminally ill adult. 1987. *American Dietetic Association Reports.* 87: 78-85.

[18] Ganzini L, Goy ER, Miller LL, et al. Nurses' experience with hospice patients who refuse food and fluids to hasten death. *NEJM*. 349:4. 359 - 365.

[19] Pasman HRW, Onwuteaka-Philipsen BD, Kriegsman OM, et al. Discomfort in nursing home patients with severe dementia in whom artificial nutrition and hydration is forgone. *Archives of Internal Medicine.* 2005. 165: 1729-1735.

[20] Kadakia SC, Sullivan HO, Starnes E. Percutaneous endoscopic gastrostomy or jejunostomy and the incidence of aspiration in 79 patients. *American Journal of Surgery.* 1992; 164(2): 114-118.

[21] Finucane TE, Bynum JP. Use of tube feeding to prevent aspiration pneumonia. *Lancet.* 1996. 348 (9039): 1421-1424.

[22] Fainsinger RL, Bruera E. When to treat dehydration in a terminally ill patient? *Support Care Cancer*. 1997. 5(3) 205-211.