

## Artificial Nutrition and Hydration at the End of Life: Beneficial or Harmful?

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There are few treatment decisions more difficult for families and loved ones to make than those surrounding the use of artificial nutrition and hydration in the seriously or terminally ill person:

“Should nutrition be given intravenously if my wife’s gut isn’t working right?”

“Should intravenous fluids be given to my father when he stops drinking and becomes dehydrated?”

“Should a feeding tube be placed if my mother can’t swallow without choking?”

Family members agonize over these questions, especially if they are not given clear explanations about the effectiveness or lack of effectiveness of various available treatments, and what kind of burdens, side effects and complications each treatment can place on the patient *and* the caregivers. Myths and misconceptions abound.

This article will define and describe in a straightforward manner what each treatment is, when each treatment might be useful, when each treatment is not likely to be useful, and the known burdens, side effects and complications of each treatment.

But first, let us dispel the myth that artificial nutrition and hydration is not really a medical treatment at all but rather basic care, like giving a meal to someone.

Like many medical interventions, all forms of artificial nutrition and hydration:

- Require the patient to undergo uncomfortable, and at times painful, procedures for the treatment to be started;
- Have known side effects and potential complications, including serious infections, fluid overload, nausea/vomiting and diarrhea, electrolyte and mineral imbalances, and even death;
- Have indications (use of the treatment for patients with similar conditions has been usually more beneficial than harmful);
- Have contraindications (use of the treatment for patients with similar conditions has been usually more harmful than beneficial);
- Hold very little similarity to a person sitting with family and socializing while enjoying a tasty meal.

### **What is meant by “artificial nutrition and hydration”?**

Artificial nutrition and/or hydration is a treatment intervention that delivers fluids and/or nutrition by means other than a person taking something in his/her mouth and swallowing it.

There are several different types of artificial nutrition and hydration, broadly divided into two major categories:

- **Enteral:** Nutrition and/or fluids are delivered through a tube placed in the gastrointestinal tract. The tube may be passed through the nose and throat into the esophagus and ultimately into the stomach (nasogastric tube) or small intestine, or the tube may be surgically placed directly into the stomach (gastrostomy tube) or intestine (jejunostomy tube) through the wall of the abdomen.

- **Parenteral:** Nutrition and/or fluids are delivered via a catheter (very small tube) placed in a vein of the body. The catheter may be placed in a “peripheral vein” (usually in the lower part of the arm), or a “central vein” (one of the body’s larger veins, closer to the heart).

### **What is being given to a person who receives “artificial nutrition and hydration?”**

The nutrients and/or fluids being given varies greatly according to the type of artificial nutrition and hydration and the needs of each patient:

- Enteral feeding tubes may deliver water, other liquids, special liquid diets, or even pureed foods.
- Parenteral nutrition can be either partial (having some of the nutrients needed by the body) or total (having all of the basic nutrients, in very simple form, needed by the body to produce energy and maintain weight).
- Parenteral fluids (intravenous fluids) are usually a salt and sugar water solution, with other substances like minerals added occasionally.

Initially, these treatments were intended to be used temporarily, for short periods of time, until a person with a reversible problem regained the ability to eat and drink normally. Their use has become both more widespread and applied for longer periods.

Recently the scientific community has taken a closer look at the use of artificial nutrition and hydration to see if there is good evidence that these treatments are useful. There have been some surprising findings! Myths that have been held about the usefulness of artificial nutrition and hydration are being challenged, particularly as they have been used for persons who have incurable disease, in persons who have neurologic or brain disorders, and in the frail elderly person.

#### ***Let’s take a look at some of these myths:***

**Myth:** A person who gets aspiration pneumonia (pneumonia which develops because contents of the mouth are seeping down the trachea into the lungs) because of difficulty with swallowing and choking needs to have a gastrostomy tube placed to prevent recurrence of the aspiration pneumonia.

**Fact:** There is no good evidence that demonstrates that gastrostomy tubes, or tubes into the small intestine, prevent aspiration pneumonia in a person who has difficulty swallowing. In fact, there is good evidence in persons with advanced Alzheimer’s disease that gastrostomy tubes actually cause more harm than if no tube had been placed. Other evidence shows that tube feeding may actually increase episodes of aspiration pneumonia. Careful feeding by hand is a better alternative.

**Myth:** Artificial nutrition speeds wound healing in a person who is unable to eat normally.

**Fact:** There are no good studies demonstrating that artificial nutrition and hydration speeds wound healing. In fact, if a person is incontinent (unable to control urination and/or defecation) they may suffer from increased skin breakdown due to constant moisture and the irritation of urine and/or feces on the skin.

**Myth:** Persons with cancer cachexia (a condition where the person keeps losing weight and does not eat well) should receive total parenteral nutrition (TPN) to maintain weight and strength.

**Fact:** Medical science has been unable to show any benefit from TPN use in patients with cancer cachexia: It does not keep a person from losing weight, does not improve a person's nutrition, and does not help the person gain strength and energy. Some studies even show shortened survival in persons with cancer cachexia who are treated with TPN.

**Myth:** A dying person who has become dehydrated due to lack of fluids experiences extreme thirst, pain and distress.

**Fact:** Dehydration in a seriously ill person with a terminal condition, and in the frail elderly, is not painful. In fact, frail elderly persons have a blunted sense of thirst, which allows them to slip rather easily into a dehydrated state. This is generally characterized by increased sleepiness and less mental alertness without other signs of distress. In the dying patient, studies have shown that the majority never experience thirst, or only initially, and the thirst that occurs is easily alleviated by small amounts of fluids or ice chips given by mouth, and by lubricating the lips.

**Myth:** A person with advanced disease or a terminal illness who stops eating will "starve to death" painfully.

**Fact:** When a person with advanced disease or a terminal illness stops eating, usually it is because his/her disease has progressed to the point where the person is no longer able to process food and fluids as does a healthy person. Forcing this person to eat, or starting artificial nutrition and hydration does not help the person to live longer, feel better, feel stronger, or be able to do more. In fact, such a person given artificial nutrition and/or hydration will often feel bloated, nauseated, and/or develop diarrhea. Studies have shown that the majority of dying patients never experience hunger, and in those who do, small amounts of food and fluids, offered whenever the person wants, relieves the hunger.

### **What is known about the side effects and complications of artificial nutrition and hydration?**

Complications and side effects vary by the type of artificial nutrition and hydration used:

- TPN and central catheters can cause infection at the site of the catheter and in the catheter itself as well as sepsis (a generalized life-threatening infection). Pneumothorax (collapse of the lung) can occur at the time of inserting the catheter. Thrombosis (clots in the vein) can occur, causing local swelling. Sometimes these clots can travel to other parts of the body such as the brain or lung and can be life-threatening. Cardiac arrhythmias (irregularities of the heart beat) as well as electrolyte disturbances such as low sodium, low potassium or low blood sugar can occur. These are all potentially life-threatening.
- A nasogastric tube can cause choking and extreme discomfort at placement and afterwards. At the time of insertion, it can be misplaced in the trachea and cause pneumonia. The tube can cause erosions and abrasions, even perforations (holes) in the nasal passages, esophagus and stomach, and can cause acute and chronic bleeding. Aspiration pneumonia is a risk whenever an NG tube is in place. If a person is confused, he/she may need restraints to keep him/her from pulling the tube out. This can cause a whole host of problems, including psychic distress and increased agitation and anxiety, skin breakdown due to immobility, pneumonia due to immobility, and injury from restraints, to name a few.

- A gastrostomy tube requires anesthesia during placement and has risks associated with the use of anesthesia. There is also a risk of infection of the abdominal wall and peritonitis (life threatening infection of the abdominal cavity). Gastrointestinal bleeding, blockage of the bowel or perforation of the bowel may occur. Diarrhea from the feeding formula is fairly common. Aspiration pneumonia is also common. If the person requires restraints to keep from pulling the tube out, the same complications listed above can occur.
- Intravenous fluids require IV tubing, with associated pain on insertion. Localized infection or cellulitis (a more serious infection of the skin that can spread) can occur. Thrombophlebitis (clotting in the vein) can occur and cause swelling and discomfort. Fluid overload is possible, causing swelling of the legs, arms and body. Electrolyte imbalances such as low sodium or low potassium are common.

### **Are there any beneficial effects of dehydration?**

Dehydration can actually have several potential benefits for a person who is at the end stages of his/her life:

- Secretions in the lungs are diminished, so cough and congestion are less, and procedure.
- Dehydration can lead to a melting away of the swelling and increased comfort in a person who has edema (swelling of the body caused by excess body fluids) or ascites (fluid in the abdominal cavity).
- With dehydration, there is less fluid in the gastrointestinal tract, which may decrease nausea, vomiting, bloating and regurgitation.
- A dehydrated person has less urine output, thus less need to go to the bathroom for extremely weak and frail patients and less skin irritation when the bedbound person develops incontinence. There is also less need to place a foley catheter in such a person. Foley catheters are irritating, can cause extremely painful bladder spasms, and are known to increase the risk of serious infections of the urinary tract and body.

### **Are there any situations in the seriously ill where artificial nutrition and hydration are helpful?**

There are situations where artificial nutrition and hydration, in a specific person and in specific situations, are likely to be more beneficial than harmful:

- A person who has a mechanical blockage of his/her mouth, esophagus, or stomach, but is otherwise functioning fairly well, especially if this person is experiencing hunger, is likely to benefit if a tube is placed below the blockage in order to be able to receive nutrition and fluids. This is the case in many persons who suffer from head and neck or esophageal cancer, especially in the earlier stages of the cancer.
- In some cases, when a blocked bowel develops, such as in spread of ovarian cancer, but the person is otherwise fairly functional, TPN has been helpful in allowing that person to live and function longer than without the treatment.
- A person who has a temporary bout of severe nausea and vomiting or has diarrhea causing serious dehydration can often benefit from a short course of intravenous fluids to rest the bowel.

- Evidence is conflicting in some persons with cachexia due to HIV disease. Some persons appear to benefit from artificial nutrition and hydration, especially those who have no active infection at the time of receiving it.

From time immemorial, human beings have expressed their love for one another through the act of feeding and sharing meals. Much of the anguish over decisions to start, withhold, or discontinue artificial nutrition and hydration stems from a mistaken feeling that the act of administering artificial nutrition and hydration is equivalent to the nurturing acts of feeding our babies or serving a meal to our family.

Artificial nutrition and hydration is a medical treatment, with intended beneficial effects but many side effects and complications attached to its use. Decisions about its use need to be based on a dispassionate look at what, if any, benefits will occur, what side effects and burdens are likely to occur, and what the individuals' and families' goals are for the treatment.

When artificial nutrition and hydration is more likely to be burdensome than helpful, it should be avoided or discontinued. Nurturing can be expressed in more helpful ways, such as gentle presence, touch, talking with the person (regardless of his/her ability to respond), keeping the person's lips and mouth moist, gently massaging the skin using lubricants, praying with the person, or playing favorite music selections. These alternative ways of nurturing can be very powerful and moving for both the person with the life-threatening illness and his/her loved one.

*About the author: Dr. Cheryl Arenella does health care consulting for programs focused on improving end-of-life care. She has over 20 years of experience in the field of Hospice and Palliative Medicine. She is a former trustee of the American Board of Hospice and Palliative Medicine and served for many years as a Medical Director for a large Medicare certified hospice, where she provided medical oversight, direct patient care and administrative program support.*