

A Case Studies Approach to Assisted Nutrition and Hydration

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Assisted nutrition and hydration (ANH) techniques are used frequently for a variety of illnesses, and are often lifesaving. Recently, however, ethical questions have arisen over when ANH should be withdrawn or withheld. The case of Terri Schiavo, which was widely reported in the media, highlights this point. Reportedly suffering from a persistent vegetative state, Mrs. Schiavo had her feeding tube removed by court order, and died of dehydration thirteen days later. In this paper, I discuss the medical indications for ANH (sometimes referred to as *artificial* nutrition and hydration), the different techniques available to provide ANH, and the medical complications that can occur with use. Ethical considerations that arise with the use of ANH are then discussed, and specific patient cases are examined to highlight the practical application of the medical and ethical principles involved in ANH.

Medical Aspects of Assisted Nutrition and Hydration

A certain minimal amount of caloric-energy-containing food, essential nutrients, and water are necessary to maintain life. Caloric requirements are increased above this baseline amount in patients suffering from burns, wounds, infections, and similar conditions.¹ Patients who are unable to ingest enough food and liquids to meet their needs or who suffer from certain conditions—impaired cognition, neurological conditions affecting the swallowing mechanism, mechanical obstructions or lack of motility of the

¹ R. Y. Haddad, D. R. Thomas, “Enteral Nutrition and Enteral Tube Feeding: Review of the Evidence,” *Clinics in Geriatric Medicine* 18.4 (November 2002): 867–881.

gastrointestinal system, or inability to absorb ingested nutrients—are candidates for ANH. With ANH, the patient is given additional caloric and nutritionally rich food and water, either by administering intravenous fluids (parenteral nutrition and hydration) or by directly placing the food and liquids in the stomach or small intestines, bypassing the normal swallowing mechanism (enteral nutrition and hydration).

In parenteral nutrition and hydration, food and water are provided by intravenous fluids, bypassing the gastrointestinal tract. In my experience this is the most commonly employed means for providing short-term ANH in medical settings. Intravenous fluid is infused either into small veins in the arms or legs (peripheral circulation) or into the larger veins in the neck or shoulder area (central circulation). Glucose, amino acids, and lipids can be added to meet caloric requirements. Intravenous ANH is very useful, and is commonly applied for short-term indications, as in post-surgical patients or patients with altered cognition that is expected to clear rapidly with medical treatment. Long-term parenteral ANH has also been lifesaving for patients who could not be nourished by gastrointestinal routes because of various medical conditions, including malabsorption syndromes, in which nutrients cannot be absorbed across the intestinal mucosa; “short gut syndrome,” which hinders digestion and absorption and may occur after resection of the intestines; enteric fistulas, through which intestinal fluid leaks into another organ or to the skin; and congenital anomalies of the gastrointestinal tract.²

Peripheral intravenous nutrition can be uncomfortable, however, during both the initial intravenous (IV) placement and certain types of fluid administration. Risks of peripheral IV placement and use include infection, bleeding complications, thrombosis (blood clot formation), and sclerosis (destructive scarring) of the vein. Access to a particular peripheral vein can be maintained for only a few days at most before the vein becomes nonfunctional due to infiltration, infection, or thrombosis. Placing a catheter into the larger, central veins is technically more difficult; potential complications include pneumothorax (collapse of the lung), arterial and venous bleeding, thrombosis, and infection. A central intravenous catheter, however, allows for more calories to be provided to the patient, is more comfortable for the patient after it has been placed, and is less likely to cause vein sclerosis from the nutrition or medications. Central venous catheters can also be maintained for a longer period, but not as long as tubes placed directly into the gastrointestinal system.

Intravenous ANH can cause liver dysfunction and various metabolic disturbances, especially with long-term use.³ Other potential drawbacks of parenteral ANH include the skill required to mix the nutrition solutions; the requisite close monitoring of blood glucose, renal (kidney), electrolyte, and nutritional parameters; and the expense of the nutritional products. With long-term parenteral nutrition, there is also a loss of structural and functional integrity of the gastrointestinal system, which may increase the risk of infection.⁴ Therefore, the parenteral approach to ANH is not the

²B. T. Burton, W. R. Foster, *Human Nutrition: A Textbook of Nutrition in Health and Disease*, 4th ed. (New York: McGraw-Hill, 1988), 486.

³*Ibid.*, 487.

⁴P. L. Marino, *The ICU Book* (Philadelphia: Lea & Febiger, 1991), 555.

best choice for patients with a functioning gastrointestinal system who require long-term nutrition and hydration.

Enteral nutrition, in which the nutritive products are delivered directly into the gastrointestinal tract, is the preferred means of providing nutritional support long term. The advantages of enteral nutrition compared with parenteral nutrition include maintenance of intestinal integrity; a more physiologic absorption of calories, with lower risks of high glucose or sugar levels and other metabolic derangements; the lower cost of preparing, delivering, and monitoring the nutrition and hydration; and a lower risk of infection.

For the patient who is unable to take in enough calories by the normal swallowing mechanism, enteral nutrition can be provided by a variety of means. The simplest approach is to place a thin tube through the nose into the stomach (nasogastric tube) or into the first part of the small intestines, the duodenum (nasoduodenal tube). These tubes can be easily inserted at the bedside, but the nasoduodenal tube often requires the use of x-rays during placement. Nasogastric and nasoduodenal tubes can be used to meet the full requirements for nutrition and hydration. They are typically used short term (typically for less than two weeks) because of the discomfort the tubes may cause to the nose and throat. These tubes also frequently become clogged and require changing because of their thin caliber. They are also associated with an increased risk of sinus infections.

A surgically inserted gastric (stomach) or jejunal (second part of the small intestine) tube is the most useful device for meeting long-term nutritional needs in a patient with an intact gastrointestinal system. Gastrostomy tubes (feeding tubes in the stomach) can be inserted using normal surgical techniques, but they are usually placed using an endoscope (a flexible fiber-optic scope) and mild sedation. These tubes are known as percutaneous endoscopic gastrostomy (PEG) tubes. Jejunal tubes are usually inserted in the operating room but can be placed by means of an extension tube through a PEG tube. Risks of placing enteral feeding tubes include complications from anesthesia, infection, bleeding, holes or tears of the intestine, pneumothorax (collapse of the lung), and death.⁵ The overall complication rate for the placement of PEG tubes is approximately 4 percent.⁶

Ethical Considerations in Assisted Nutrition and Hydration

Ethical considerations are critical in deciding on the initiation and withdrawal of ANH. In traditional Catholic medical ethics, a distinction is made between ordinary and extraordinary care. This distinction was first made by the Dominican theologian Domingo Banez in 1595, and has been further elaborated by many other thinkers

⁵ Haddad and Thomas, "Enteral Nutrition," 867–881.

⁶ C. Loser, S. Wolters, U. R. Folsch, "Enteral Long-Term Nutrition via Percutaneous Endoscopic Gastrostomy (PEG) in 210 Patients: A Four-Year Prospective Study," *Digestive Diseases and Science* 43.11 (November 1998): 2549–2557; and L. Rabeneck, "Long-Term Outcomes of Patients Receiving Percutaneous Endoscopic Gastrostomy Tubes," *Journal of General Internal Medicine* 11.5 (May 1996): 287–293.

throughout the ensuing centuries.⁷ In moral theology, medical care or treatment is felt to be an ordinary means if it is beneficial, useful, and not unreasonably burdensome (physically or psychologically) to the patient. Ordinary means may also be determined with some consideration of reasonable cost.⁸ Pope Pius XII summarized this teaching in an address to Catholic physicians and anesthesiologists in 1957:

Normally one is held to use only ordinary means—according to the circumstances of persons, places, times and culture—that is to say, means that do not involve any grave burden for oneself or another. A stricter obligation would be too burdensome for most people and would render the attainment of the higher, more important good too difficult. Life, health, all temporal activities are in fact subordinated to spiritual ends. On the other hand, one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as one does not fail in some more serious duty.⁹

In some Catholic ethical documents, the terms “proportionate” and “disproportionate” are sometimes used instead of “ordinary” and “extraordinary” in reference to means of care, to help distinguish whether a treatment is ethically obligatory or optional.¹⁰ The *Declaration on Euthanasia*, from the Congregation for the Doctrine of the Faith, gives excellent guidelines on how to approach ethical decisions using these principles:

In the past, moralists replied that one is never obliged to use “extraordinary” means. This reply, which as a principle still holds good, is perhaps less clear today, by reason of the imprecision of the term and the rapid progress made in the treatment of sickness. Thus some people prefer to speak of “proportionate” and “disproportionate” means. In any case, it will be possible to make a correct judgment as to the means by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources.¹¹

The *Declaration* also clarifies the meaning of “extraordinary” and “disproportionate”:

Everyone has the duty to care for his or her own life and health and to seek necessary medical care from others, but this does not mean that all possible remedies must be used in all circumstances. One is not obliged to use either “extraordinary” means or “disproportionate” means of preserving life—that is, means which are understood as offering no reasonable hope of benefit or as involving excessive burdens. Decisions regarding such means are complex

⁷R. E. Smith, “Ordinary and Extraordinary Means,” *Ethics & Medics* 20.4 (April 1995): 1–2.

⁸Ibid.

⁹Pius XII, “The Prolongation of Life” (November 24, 1957), quoted in K. D. O’Rourke and P. Boyle, *Medical Ethics: Sources of Catholic Teachings* (St. Louis, MO: Catholic Health Association, 1989), 207.

¹⁰Smith, “Ordinary and Extraordinary Means,” 1–2.

¹¹Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), part IV (Washington, D.C.: U.S. Catholic Conference, 1980), 8–9.

and should ordinarily be made by the patient in consultation with his or her family, chaplain or pastor, and physician when that is possible.¹²

Finally, the *Declaration* describes the proper attitude to medical treatment in terminal illness:

When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.¹³

This last quotation brings up a major ethical debate regarding ANH: is ANH a medical treatment or is it a part of normal care? This is an important issue, since it is generally agreed that normal care must be provided for every patient, regardless of his or her condition, level of consciousness, or quality of life. Medical treatments, on the other hand, may be forgone if they impose excessive burdens without securing proportionate benefits.¹⁴

In her textbook *Issues in Medical Ethics*, Eileen Flynn evaluates this issue. She asserts that enteral ANH should be considered a medical treatment and not normal care, because skilled medical professionals are required to insert feeding tubes and design feeding formulas; because enteral feeding is, for the patient, a passive experience devoid of the normal enjoyment of meals; and because medical complications can occur with the placement and use of enteral tubes.¹⁵ The American College of Physicians states that, “artificial administration of nutrition and fluids is a medical intervention subject to the same principle of decision making as other treatments.”¹⁶ This is also the consensus of opinion in U.S. courts, which view ANH as a medical treatment with burdens as well as benefits—a treatment that, as such, may be withdrawn.¹⁷

Eugene Diamond, M.D., has come to a different conclusion:

It is probably more valid to view self feeding, assisted feeding, nasogastric tube feeding, hyperalimentation, and gastrostomy feedings as strategies for providing basic support for persons capable of varying degrees of cooperation. (The decision to use one or the other may be related as much to staff convenience as patient competence. It may be a lot quicker to feed by tube

¹² Ibid., quoted in U.S. Conference of Catholic Bishops, *Nutrition and Hydration: Moral and Pastoral Reflections* (1990), n. 4 under “Moral Principles,” <http://www.usccb.org/prolife/issues/euthanas/nutmoral.htm>.

¹³ CDF, *Declaration on Euthanasia*, 10.

¹⁴ T. J. O'Donnell, *Medicine and Christian Morality*, 2nd rev. ed. (New York: Alba House, 1991), 70–73.

¹⁵ E. P. Flynn, *Issues in Medical Ethics* (Kansas City, MO: Sheed & Ward, 1997), 137–139.

¹⁶ American College of Physicians, *Ethics Manual*, 5th ed. (Philadelphia: ACP, 2005), 28.

¹⁷ A. R. Derse, “Limitation of Treatment at the End-of-Life: Withholding and Withdrawal,” *Clinics in Geriatric Medicine* 21.1 (February 2005): 223–238.

rather than teaspoon.) ... If anything, the burden of providing nutrition is reduced by the advancement of technology (such as the technology of introducing flexible gastrostomy tubes by way of endoscopy).¹⁸

Monsignor Kevin McMahon concurs:

When we feed those who cannot feed themselves—the infant, those who suffer from paralysis, or the persistently unconscious—we do more than sustain their lives. We demonstrate our love and concern for them as fellow human beings and, from a specifically Christian perspective, as brothers and sisters in the Lord. By feeding those who cannot feed themselves, we maintain communion with them, and give powerful witness to our reverence for life, even a life as impaired as that of the [patient in a persistent vegetative state]. Is ANH therapy or is it care? I think it is most assuredly care.¹⁹

In the *Charter for Health Care Workers*, the Pontifical Council for Pastoral Assistance states that “the administration of food and liquids, even artificially, is part of the normal treatment always due to the patient when this is not burdensome for him: their undue suspension could be real and properly so-called euthanasia.”²⁰

In their publication *Nutrition and Hydration: Moral and Pastoral Reflections*, the Committee for Pro-Life Activities of the National Conference of Catholic Bishops proposes a very pragmatic approach to the question of whether ANH is a medical treatment or an element of usual care:

Perhaps this dilemma should be viewed in a broader context. Even medical “treatments” are morally obligatory when they are “ordinary” means—that is, if they provide a reasonable hope of benefit and do not involve excessive burdens. Therefore, we believe people should make decisions in light of a simple and fundamental insight: *Out of respect for the dignity of the human person, we are obliged to preserve our own lives, and help others preserve theirs, by the use of means that have a reasonable hope of sustaining life without imposing unreasonable burdens on those we seek to help, that is, on the patient and his or her family and community.*²¹

Pope John Paul II also addressed the issue of whether ANH is a medical treatment or normal care during a speech to the Pontifical Academy for Life and the International Federation of Catholic Medical Associations regarding the clinical condition of the persistent vegetative state:

¹⁸ E. F. Diamond, *A Catholic Guide to Medical Ethics: Catholic Principles in Clinical Practice* (Palos Park, IL: Linacre Institute, 2001), 104.

¹⁹ K. T. McMahon, “Nutrition and Hydration: Should They be Considered Medical Therapy?” *Linacre Quarterly* 72.3 (August 2005): 229–239.

²⁰ Pontifical Council for Pastoral Assistance, *The Charter for Health Care Workers* (Boston: St. Paul Books & Media, n.d.), 105.

²¹ National Conference of Catholic Bishops, Committee for Pro-Life Activities, *Nutrition and Hydration: Moral and Pastoral Reflections* (Washington, D.C.: U.S. Conference of Catholic Bishops, 1992), 3, original emphasis, <http://www.usccb.org/prolife/issues/euthanas/nutqa.htm>.

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.²²

In this statement, Pope John Paul II seems to be stating that ANH should be considered an ordinary or proportionate means of care due to all patients unless the normal benefits of nutrition, even if it is to simply sustain a life which has been significantly impaired by disease or injury, can not be actualized.²³

The *Ethical and Religious Directives for Catholic Health Care Services* summarizes some conclusions from this ethical discussion in directives 56 through 60:

A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community. (n. 56)

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community. (n. 57)

There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient. (n. 58)

The free and informed judgment made by a competent adult patient concerning the use or withdrawal of life-sustaining procedures should always be respected and normally complied with, unless it is contrary to Catholic moral teaching. (n. 59)

Euthanasia is an action or omission that of itself or by intention causes death in order to alleviate suffering. Catholic health care institutions may never condone or participate in euthanasia or assisted suicide in any way. Dying patients who request euthanasia should receive loving care, psychological and spiritual support, and appropriate remedies for pain and other symptoms so that they can live with dignity until the time of natural death. (n. 60)²⁴

These statements are in close agreement with the teachings on euthanasia found in the *Catechism of the Catholic Church*:

²² John Paul II, "Address to the Participants in the International Congress on 'Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas'" (March 20, 2004), Vatican edition, n. 4, original emphasis.

²³ P. J. Cataldo, "Pope John Paul II on Nutrition and Hydration: A Change of Catholic Teaching?" *National Catholic Bioethics Quarterly* 4.3 (Autumn 2004): 513–536.

²⁴ U.S. Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 4th ed. (Washington, D.C.: USCCB, 2001), 31–32.

Discontinuing medical procedures that are burdensome, dangerous, extraordinary, or disproportionate to the expected outcome can be legitimate; it is the refusal of "over-zealous" treatment. Here one does not will to cause death; one's inability to impede it is merely accepted. The decisions should be made by the patient if he is competent and able or, if not, by those legally entitled to act for the patient, whose reasonable will and legitimate interests must always be respected. (n. 2278)

Even if death is thought imminent, the ordinary care owed to a sick person cannot be legitimately interrupted. The use of painkillers to alleviate the sufferings of the dying, even at the risk of shortening their days, can be morally in conformity with human dignity if death is not willed as either an end or a means, but foreseen and tolerated as inevitable. Palliative care is a special form of disinterested charity. As such it should be encouraged. (n. 2279)²⁵

When these principles are applied to ANH for an individual patient, both the medical and ethical issues must be examined. In certain cases, such as when a patient who has recently undergone intestinal surgery is awaiting the return of bowel function and is unable to eat, there is little debate that intravenous ANH must be given for the couple of days or weeks to sustain life until normal oral intake can resume. The questions become more difficult in patients who have a terminal malignancy, who are suffering from advanced dementia, or who have suffered a severe neurological injury and are now in a persistent vegetative state.

A good way to illustrate the medical and ethical issues involving ANH is to examine them in individual cases. I will discuss the decisions to use or not use ANH in five patients for whom I have cared recently. In regard to the use of ANH for patients in a persistent vegetative state, I would refer to the excellent discussion contained in *Nutrition and Hydration: Moral and Pastoral Reflections*, from the NCCB Committee for Pro-Life Activities,²⁶ and the papal address on food and water,²⁷ which both state that ANH should be considered ordinary or proportionate care and should not be withheld from patients in a persistent vegetative state.

Cases

Case 1

J.N. was a 62-year-old man who was referred to me by his oncologist for a cough and a fever. He had recently been diagnosed with posterior pharyngeal cancer, a cancer involving tissue in the back of his throat. The cancer was also present in the multiple lymph nodes in his neck. He began a combination of chemotherapy and radiation therapy to treat the cancer with the intent of shrinking and possibly curing the cancer. Shortly after beginning the chemotherapy and radiation treatments, he reported marked discomfort in the throat when swallowing food or liquids. He also experienced frequent coughing episodes with meals.

²⁵ *Catechism of the Catholic Church*, 2nd ed., trans. U.S. Conference of Catholic Bishops (Vatican City: Libreria Editrice Vaticana, 1997).

²⁶ NCCB, *Nutrition and Hydration*, 3.

²⁷ John Paul II, "Life-Sustaining Treatments and Vegetative State," n. 4.

J.N. was a tall, thin man with frequent labored breathing. On examination, he had a fever of 101°F. A large quantity of oral secretions were present in his mouth, with some drooling. His throat was red and swollen. His lung sounds suggested that he had a pneumonia, which was confirmed by a chest x-ray. Laboratory results showed mild kidney dysfunction that was probably due to dehydration.

I admitted J.N. to our local hospital and started him on intravenous antibiotics to treat the pneumonia, and intravenous fluids to treat the dehydration and kidney dysfunction. His otorhinolaryngologist (ear, nose, and throat doctor) felt that his posterior pharynx was swollen and red because of the recent radiation therapy. J.N. was started on topical medications to his throat and was given analgesic medications. A speech therapist performed a test of his swallowing function at my request, which showed that orally ingested food and liquids were frequently aspirated into his lungs. At this point, a discussion was held with J.N. and his wife regarding treatment options for providing nutrition and hydration.

The medical facts, as far as we could ascertain, were that J.N. had had a potentially fatal cancer of the pharynx. He had an excellent chance for complete remission and long-term survival, however, and a chance that the cancer had been cured with the chemotherapy and radiation treatments. He was unlikely to support his life on the number of calories he was currently able to consume orally, however, and continued oral ingestion of food and liquids put him at high risk for recurrent pneumonia. He was felt to have an excellent chance of recovering normal swallowing function over the next one or two months as he healed from the radiation treatments and began speech therapy training.

On the basis of these medical assumptions, ANH seemed to be a proportionate or ordinary means of care. It would have the benefit of maintaining his life by providing the required amount of nutrition and hydration, would prevent the discomfort of hunger and thirst, and would potentially prevent morbidity and mortality from pneumonia. The best medical option for providing the ANH was felt to be a PEG tube. The burdens of this therapy would be the discomfort and potential surgical complications associated with placement of the tube, potential problems with infection and bleeding, and the need for replacements due to malfunction with continuing use. The psychological burdens of the change in body image and the inability to enjoy the flavor sensations and companionship of meals were also noted. Financial concerns were minimal, because of the coverage provided by his medical insurance.

J.N. and his wife agreed to the PEG tube placement, which was performed successfully. At home, after discharge from the hospital but with the PEG tube still in place, J.N. supplemented the parenteral ANH with self-feeding of enteral food products, and the tubes were kept free of obstruction by water flushes. The swelling and tenderness in his throat gradually improved. He continued with speech therapy sessions and was able to regain a good control of his swallowing function over the next six weeks. He began taking food and water orally again while the PEG tube was in place, to provide additional caloric supplementation. Eventually, he was able to meet all his caloric requirements by regular eating, and the PEG tube was removed.

In this case, the ANH was medically and ethically indicated as proportionate and ordinary care. I think that few people would have recommended withholding ANH in these circumstances.

Case 2

S.C. was a 34-year-old man whom I had been treating for the last nine years for HIV/AIDS. He initially presented to the hospital in 1996 with *Pneumocystis carinii* pneumonia, an opportunistic infection, and was diagnosed with AIDS, which had severely impaired his ability to fight infection. The pneumonia was treated successfully, and S.C. was started on an antiviral regimen to treat the AIDS. He initially did well, and some reconstitution of his immune system occurred. Unfortunately, he later began missing follow-up appointments, and he eventually stopped taking all his medications.

S.C. returned to my office approximately nine months ago with a cough and a fever. He was found to have a mass in his chest and a pneumonia. He was referred to a tertiary care hospital and the services of an infectious disease specialist. Biopsies revealed a cryptococcal infection, for which he received treatment. His antiretroviral medications (for AIDS) were restarted. Despite poor immune system function, he initially did well. Then he again stopped taking his medications routinely.

When S.C. saw me back in the office a month ago, he complained of increased clumsiness of his hands and confusion. An MRI scan of the brain revealed progressive multifocal leukoencephalopathy (PML), a viral infection of the brain. He was referred to an infectious disease specialist, and confirmatory tests were obtained.

The only treatment available for PML is to try to restore the native immune system so that it can fight the infection. Repeated testing of the patient's HIV viral DNA was performed, and his medications to treat the AIDS virus were maximized. Despite these measures, S.C. continued to decline in his function, with worsening of his thinking, speech, and movements. S.C. was discharged from the tertiary care hospital to his own home with visiting nurses. Two days after he returned home, I received a call from his mother, who said he was having marked difficulty taking his pills, eating, and drinking.

At his home, I found him lying in bed in no pain. He had a low-grade fever, borderline low blood pressure, and elevated heart rate. His speech was slurred, and he had trouble handling his secretions. He was able to walk only with significant assistance. He was still able to speak to me, was able to answer my questions appropriately, and seemed capable of making decisions. S.C., his mother, and I then discussed his future medical care, including the possibility of ANH.

Our medical assumptions were that S.C. had two potentially lethal viral infections (AIDS and PML). We had no treatment for the PML, which was causing his current decline in neurological function, except to treat his AIDS in the hope that this would allow his own immune system to fight the virus causing the PML. Despite aggressive treatment of the HIV virus for the past few weeks, however, S.C.'s condition had steadily worsened. The opinion of his infectious disease physician was that there was, at best, a 5 percent chance that continued treatment of the HIV virus would succeed in preventing S.C.'s death from PML. This specialist felt that S.C. would most likely die from the PML within the next two or three weeks. With his

current swallowing difficulties, he was unable to take pills. He was also unable to eat or drink enough to sustain his life.

The ethical analysis of this case is complicated by the difficulties inherent in the probabilistic nature of medicine. If we examine the expected, or most probable, clinical course in this case, the use of ANH could be considered an extraordinary or disproportionate treatment. ANH would not be likely to provide the usual benefit of extending life, since S.C.'s viral infections would, in all probability, be fatal before dehydration or malnutrition caused any organ system dysfunction. Withholding ANH would not, therefore, have the effect of euthanasia. The burdens of administering ANH would include the discomfort of placing IV lines and enteral feeding devices, and the potential for increased complication rates with these devices because of S.C.'s compromised immune system and debilitated state. I informed S.C. that continued aggressive treatment of his AIDS would require at least a nasogastric tube to administer his medications. Such treatment of his AIDS would be very unlikely to be successful, but would not be completely hopeless.

I offered S.C. entry into the hospice program with continued oral consumption of food and liquids for as long as he was conscious, and analgesics if he developed any signs or symptoms of pain. I also offered him the option of continued aggressive care, even though the odds of its success were very low.

After this discussion, S.C. decided he wanted to pursue treatments directed toward recovery, despite the poor odds. He said he would not want to be placed on a mechanical ventilator or have cardiopulmonary resuscitation in the event of cardiopulmonary arrest, but he would like to have a PEG tube to provide him with his medications and food and water. He said he did not want to have a nasogastric tube for any significant length of time, because of previous experiences with it.

S.C. was admitted to the hospital. Intravenous fluids were given, and a temporary nasogastric tube was placed to administer the antiretroviral medications, food, and water. A PEG tube was then placed by a gastroenterologist. S.C.'s recovery from this surgery was complicated by a post-operative pneumonia and a delay in the resumption of gastrointestinal motility. His neurological condition continued to decline.

S.C. was discharged to a nursing home for continuing care after the one-week hospitalization. At the nursing home, he tolerated the enteral feeds and pills satisfactorily, but his neurological condition steadily deteriorated, and he eventually became comatose. After being in the nursing home approximately ten days, S.C. developed apneic respirations and died.

This case shows some important points about the ethical use of ANH in actual cases. I believe S.C.'s poor prognosis fulfilled the criteria for a terminal condition as found in the *Declaration on Euthanasia*, which I repeat here:

When inevitable death is imminent in spite of the means used, it is permitted in conscience to take the decision to refuse forms of treatment that would only secure a precarious and burdensome prolongation of life, so long as the normal care due to the sick person in similar cases is not interrupted.²⁸

²⁸ CDF, *Declaration on Euthanasia*, 10.

Directive 57 also addresses this point:

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community.²⁹

Normal care could have included providing food and drink for as long as S.C. was able to consume them and ice chips to keep his mouth moist when his consciousness declined further. ANH could have ethically been withheld.

This case also points out that the use of "extraordinary" or "disproportionate" care can be a valid choice for a patient, too, as indicated by Pope Pius XII: "one is not forbidden to take more than the strictly necessary steps to preserve life and health, as long as one does not fail in some more serious duty."³⁰

Case 3

S.R. was an 83-year-old woman who passed out at home and was taken by ambulance to an emergency department, where I was asked to see her. She had deep frequent breaths, did not speak, and was unable to follow any commands. In response to noxious stimuli, she was able to withdraw her extremities on the left side only. A CT scan of her brain revealed a large left-sided hemorrhage within the brain, with bleeding into the brain and swelling of the surrounding tissue. The neurologist felt that her prognosis was extremely poor, with death likely in the next twenty-four to forty-eight hours with or without surgical intervention. Given the poor prognosis, her husband, who was also her agent with durable power of attorney for health care, requested that only comfort measures be used to treat her condition.

S.R. was admitted to the hospital and given oxygen, normal saline intravenous fluids, and intravenous morphine to keep her free of pain, as best judged by maintaining her respiratory rate under thirty breaths per minute. No parenteral nutrition or enteral feeds were given. The patient died within twenty-four hours after admission.

This brief case emphasizes that nutritional support is not ethically obligatory if it would offer the patient no benefit, such as relieving suffering or extending life.

Case 4

M.B. was a thin, 24-year-old man who was born with severe cerebral palsy and mental retardation, whom I saw in my office because of continued weight loss. He had had tendon release surgeries as a child to relieve contractions in his legs, and had been living in a group home for the severely disabled since childhood.

M.B. had been hospitalized with a severe pneumonia one year prior to this visit, and had required supplemental oxygen since that time. Although he received nutritional supplements, he had lost weight over the past year, going from his baseline weight of 120 lbs. to his current weight of 95 lbs. He had frequent coughing during the day, which seemed worse when he was spoon-fed.

²⁹ USCCB, *Ethical and Religious Directives*, n. 11.

³⁰ Pius XII, "Prolongation of Life," in O'Rourke and Boyle, *Medical Ethics*, 207.

On this visit, M.B. was nonverbal and unable to follow any commands. His vital signs were normal, but his respiratory rate was raised, and he appeared anxious when examined. Loud upper respiratory sounds were heard on examination. Because of the tendon-release surgeries, M.B. had limited movement of his upper extremities and no movement of his lower extremities. An evaluation for causes of his weight loss revealed difficulty with his swallowing mechanism. A swallowing test performed by a speech therapist showed frequent aspiration of food at all the consistencies offered.

M.B.'s father, who was his agent with durable power of attorney for health care, was contacted, and we discussed the possibility of ANH for M.B. The medical indications for ANH, which were explained to his father, included M.B.'s inability to consume enough calories to maintain his weight, his gradually worsening weakness, which was probably related to malnutrition, and the risk of further pneumonias due to food aspiration. M.B.'s father was advised that enteral feeding should allow M.B. to gain strength and regain some weight. Aspiration pneumonia, which is caused by food or liquids entering the airway, might or might not be reduced. (There are few data showing a reduction in aspiration pneumonia in patients given PEG tube feedings.) The burdens of ANH would include possible surgical and post-surgical complications and the added expense. I felt that placing a PEG tube and initiating ANH would be an "ordinary" or "proportionate" means of providing adequate nutrition for the patient.

M.B.'s father agreed to placement of a PEG tube, which was performed by a gastroenterologist. Post-procedure complications included a pneumonia and a longer-than-expected delay in the return of normal bowel function. M.B. was placed on enteral feeds and has done well since then, with some increase in strength and a gradual weight gain, so that his weight is now close to his prior baseline.

Some might argue that for a patient who has limited cognitive abilities, is unable to communicate effectively with the outside world, is bed bound, and is nearly quadriplegic, the placement of an enteral feeding tube would be just another burden in his life. They might say that nature should be allowed to take its course. William May offers a contrary opinion, with which I agree:

We can say that the two principal criteria for determining whether to withhold or withdraw a treatment because it is "extraordinary/disproportionate" are *burdensomeness* and *uselessness*. The former is the major criterion, insofar as the relative uselessness of many treatments is contingent upon the burdens they impose when compared with the benefits they bring. But what is most important is that these criteria draw attention to the *burdensomeness* and/or *uselessness* of the means used to preserve life. They do not lead one to conclude that treatments are to be withheld or withdrawn because of a judgment that the patient's *life* is either burdensome or useless—and this, as we have seen, is the judgment reached in the "ethics of euthanasia." Judgments of the burdensomeness and/or uselessness of treatments are compatible with a respect and love for the dignity of human life, which is *always* a precious good, a gift from God, no matter how heavily burdened it may be.³¹

³¹ W. E. May, *Catholic Bioethics and the Gift of Human Life* (Huntington, IN: Our Sunday Visitor Books, 2000), 262.

Case 5

P.S. was a frail, thin 92-year-old woman who suffered from advanced Alzheimer-type dementia. She was first diagnosed with dementia six years ago. She was initially able to live alone at home. Then, three years ago, when she was no longer able to care for herself safely because of her cognitive impairments, she began living with her son and daughter-in-law. Two years ago, because of her wandering behaviors and incontinence, her family could no longer care for her, and she was placed in a skilled nursing facility. She had been on medication to slow the progression of her disease for the past six years.

For the past year, she had not been able to recognize her family. For the past six months, she had had more difficulty speaking in comprehensible sentences. She was hostile and combative when being helped to bathe or dress and during examinations. She had been eating poorly over the past year, and had gradually been losing weight. She was given high-caloric supplements, and foods of different consistencies had been tried with limited success. Despite frequent turning and the use of pressure-relieving mattresses, she had developed pressure ulcers on her skin that were not healing.

P.S. was uncooperative when I examined her. She repeatedly said, "Leave me alone!" and tried to hit me. She was oriented to her first name only. Her vital signs were normal. She had a shallow 1-cm. skin ulceration on her right hip, but no evidence of infection. She had an intact gag reflex, which indicated a low risk for food or liquids going down the trachea rather than the esophagus. With assistance, she could walk only a few steps. She denied any hunger or thirst.

Unfortunately, P.S. was suffering from severe Alzheimer-type dementia. Weight loss commonly begins prior to the diagnosis of dementia and is progressive throughout the illness.³² As the disease progresses, patients' desire for food frequently decreases, and they develop chewing and swallowing difficulties, weight loss, and aspiration pneumonias.³³ With the decrease in caloric and protein intake and mobility problems, skin pressure ulcerations are more likely to occur and become difficult to treat.³⁴ In patients with advanced dementia, nutritional support through oral supplements has been associated with some reduction in infections and mortality.³⁵

Many questions remain unanswered. It is unclear whether ANH is useful in preventing or treating skin ulcers, preventing aspiration pneumonias, decreasing suf-

³² R. Stewart et al. "A 32-Year Prospective Study of Change in Body Weight and Incident Dementia: The Honolulu-Asia Aging Study," *Archives of Neurology* 62.1 (January 2005): 55–60.

³³ T. E. Finucane, C. Christmas, and K. Travis, "Tube Feeding in Patients with Advanced Dementia: A Review of the Evidence," *JAMA* 282.14 (October 13, 1999): 1365–1370.

³⁴ Ibid. See also R. A. Breslow et al. "The Importance of Dietary Protein in Healing Pressure Ulcers," *Journal of the American Geriatrics Society* 41.4 (April 1993): 357–362.

³⁵ P. Gil Gregorio, S. P. Ramirez Diaz, and J. M. Ribera Casado for the DEMENU group, "Dementia and Nutrition: Intervention Study in Institutionalized Patients with Alzheimer Disease," *Journal of Nutrition, Health, and Aging* 7.5 (2003): 304–308.

fering from hunger or thirst, or prolonging life in patients with dementia. These are my findings on review of the literature:

- *Skin ulcerations.* On review of the evidence in 2003, using the Cochrane Database, only four randomized controlled trials were found that evaluated the effectiveness of enteral feedings in the prevention of pressure ulcers.³⁶ The largest study found that nutritional supplements reduced the number of new pressure ulcers. The three smaller studies lacked the power to form conclusions. In terms of healing existing pressure ulcers, one study evaluated the value of zinc supplementation, two evaluated vitamin C supplementation, and one evaluated protein supplementation. No randomized controlled studies compared the use of ANH with its non-use in the healing of pressure ulcers.³⁷ The study evaluating dietary protein intake did, however, find that increased intake correlated with a decrease in ulcer size.³⁸ Further studies would clearly be useful to clarify the potential benefits of ANH for the prevention and healing of pressure ulcers.
- *Aspiration pneumonia.* I could find no randomized controlled studies evaluating the effectiveness of enteral feedings in preventing aspiration pneumonia. There also have been no good trials comparing aspiration rates with jejunal and PEG tube feedings.³⁹ In a chart review of 109 nursing home patients who had gastrostomy tubes, 22.9 percent of the patients aspirated.⁴⁰ It is uncertain, however, what percentage of patients without gastrostomy tubes would have aspirated without gastrostomy tubes during spoon feedings. A recent literature review found studies reporting that 40 percent of deaths associated with tube feedings result directly from aspiration pneumonia, and that aspiration of gastric contents occurs as a late complication in 15 percent of patients.⁴¹ These studies were not limited to patients with dementia, however, and the aspiration rates and mortality without the tube feedings are again unknown.
- *Survival.* No randomized controlled studies have evaluated any potential survival advantage provided by the use of ANH in patients with dementia. One study looked at the natural history of seventy-one patients with Alzheimer-type dementia who were institutionalized.⁴² The patients were divided into

³⁶ G. Langer et al., "Nutritional Interventions for Preventing and Treating Pressure Ulcers," *Cochrane Database of Systematic Reviews* 4 (2003): CD003216.

³⁷ Ibid.

³⁸ Breslow et al., "Importance of Dietary Protein."

³⁹ B. A. Lazarus, J. B. Murphy, L. Culpepper, "Aspiration Associated with Long-term Gastric versus Jejunal Feeding: A Critical Analysis of the Literature," *Archives of Physical Medicine and Rehabilitation* 71.1 (January 1990): 46–53.

⁴⁰ Cogen R. "Aspiration Pneumonia in Nursing Home Patients Fed via Gastrostomy Tubes," *American Journal of Gastroenterology* 84.12 (December 1989): 1509–1512.

⁴¹ Haddad and Thomas, "Enteral Nutrition," 867–881.

⁴² L. Volicer et al., "Eating Difficulties in Patients with Probable Dementia of the Alzheimer Type," *Journal of Geriatric Psychology and Neurology* 2.4 (October–December 1989): 188–195.

four groups on the basis of their difficulty with eating. Patients in group 1 were able to feed themselves independently. Patients in group 2 had to be fed but had no other eating problems. Patients in group 3 refused food, although they were able to swallow it. Patients in group 4 choked on liquid or solid food, or both, and some also refused food. The study found that the two-year mortality rate was similar in all four groups. It also found a similar mortality rate in patients whose body weight was 20 percent below the median weight for their age and in patients whose weight was higher.

In a retrospective study,⁴³ charts were reviewed for forty-one patients with dementia referred for PEG tube placement. PEG tubes were placed in twenty-three patients, but surrogates for the other eighteen refused tube placement. The median survival was fifty-nine days for the patients who received the PEG tube feedings and sixty days for the patients who did not.

In another study,⁴⁴ which had some significant flaws, the mortality rate was evaluated in ninety-nine patients with advanced dementia who were admitted to a hospital. A feeding tube was placed in 62 percent of the patients during their hospitalization, 17 percent already had a feeding tube at the time of hospital admission, and 31 percent left the hospital without a feeding tube. The study made no attempt to match patients on the basis of the presence or severity of an eating dysfunction, so the patients who received the enteral feeding tubes may have had more difficulty with eating than the patients who did not receive tubes. The overall survival was 195 days for patients who received new feeding tubes during the hospitalization, compared with 189 days in the patients who either already had a feeding tube or never had a feeding tube placed during the hospitalization.

A third study⁴⁵ evaluated the mortality rate of nursing home patients who had swallowing disorders and developed eating problems that made them totally dependent on the staff for feeding. The researchers compared the one-year survival rates of patients who received tube feeding and those who did not. (These patients did not necessarily suffer from dementia. Also, this was just a retrospective analysis, and the group of patients who received tube feedings may have differed from the group that did not.) The data did show a survival advantage in the group that received the tube feedings. The tube-fed group had a one-year survival rate of 50 percent, compared with 39 percent in the group that did not receive tube feedings.

⁴³ L. M. Murphy, T. O. Lipman, "Percutaneous Endoscopic Gastrostomy Does Not Prolong Survival in Patients with Dementia," *Archives of Internal Medicine* 163.11 (June 9, 2003): 1351–1353.

⁴⁴ D. E. Meier et al., "High Short-Term Mortality in Hospitalized Patients with Advanced Dementia: Lack of Benefit of Tube Feeding," *Archives of Internal Medicine* 161.4 (February 26, 2001): 594–599.

⁴⁵ M. A. Rudberg et al., "Effectiveness of Feeding Tubes in Nursing Home Residents with Swallowing Disorders," *Journal of Parenteral and Enteral Nutrition* 24.2 (March–April 2000): 97–102.

- *Patient comfort.* The question of whether ANH provides comfort to patients with advanced dementia has been difficult to assess because of the poor communication skills of these patients. Inferences have been made from the cancer literature, in which it was found that hunger and thirst in patients dying from cancer was minimal and could be relieved by small amounts of food and fluids or by ice chips and lip lubrication.⁴⁶ It has been unclear whether patients with advanced dementia would have similarly decreased hunger and thirst in the terminal stages of the disease.

A recent study tried to assess discomfort in nursing home patients with severe dementia in whom ANH was not used.⁴⁷ The Dutch researchers tried to compare this group of patients with patients who were given ANH, but there were too few patients in the ANH group to make a valid comparison. The researchers evaluated discomfort by monitoring the patients for the following factors: noisy breathing, negative vocalizations, sad facial expressions, frightened expressions, frowns, tense body language, fidgeting, content facial expressions, and relaxed body language. They found the initial average level of discomfort to be lower than that reported in prior studies of patients with dementia and pneumonia or patients with dementia in traditional long-term care settings in the United States. The initial average level of discomfort was higher than that reported in patients with dementia in specialized dementia case facilities. The average level of discomfort decreased over the next five days without ANH. After day 5, the discomfort level increased, but the average level never reached the baseline discomfort level. Researcher-observed dehydration was weakly associated with a higher level of discomfort on multivariate analysis. Fifty-nine percent of patients died in the first week of the study, and 77 percent had died by the fourteenth day of the study. The researchers concluded that patients who had advanced dementia and were deprived of ANH did not suffer high levels of discomfort. The authors did note “substantial individual differences” between patients.

Given this degree of medical uncertainty of the benefits and burdens of ANH in patients with dementia, it is not surprising that the Catholic medical ethics community is also divided on the utility of ANH in these patients. Dr. Gregory Burke evaluated the medical literature, which lacks convincing evidence that ANH provides any substantive benefit to patients suffering from advanced dementia. He found that ANH can be considered extraordinary or disproportionate care in these patients, stating that “in light of [the] data, it seems a morally sound course to forgo tube feeding in patients with advanced dementia and substitute the admittedly more labor-intensive but loving alter-

⁴⁶ R. M. McCann, W. J. Hall, and A. Groth-Juncker, “Comfort Care for Terminally Ill Patients: The Appropriate Use of Nutrition and Hydration,” *JAMA* 272.16 (October 26, 1994): 1263–1266.

⁴⁷ H. R. Pasman et al., “Discomfort in Nursing Home Patients with Severe Dementia in Whom Artificial Nutrition and Hydration is Forgone,” *Archives of Internal Medicine* 165.15 (August 8, 2005): 1729–1735.

native of hand and spoon feeding.”⁴⁸ Dr. Chris Kahlenborn disagrees with Dr. Burke’s assessment, finding tube feeding in advanced dementia to be a part of ordinary care and thus obligatory.⁴⁹ Dr. Eugene Diamond states that patients with irreversible dementia should not have their nutritional support withheld.⁵⁰

I believe that in patients with advanced dementia, nutrition and hydration should be given by mouth for as long as the patient is able to consume it this way. Nutritional support in the form of high-caloric supplements should be given between and during meals, if needed, to provide as much protein and caloric intake as possible. If the patient has symptoms of hunger or thirst that cannot be alleviated by the oral route, if the patient cannot effectively swallow, or if the patient’s condition worsens to the point that death becomes likely from the effects of starvation or dehydration, then ANH should be recommended as ordinary care to prolong life and prevent potential suffering. This approach to patients with dementia may change in the future, as more information is developed in the medical literature.

In the case of P.S., I reviewed the data in the medical literature with her son, who was her agent with durable power of attorney. We decided to continue high-caloric and protein supplements and not to insert a PEG tube. P.S. consumed small amounts of food and liquid and drank some of her high-caloric supplements. She continued to deny thirst or discomfort, except for pain in her knees (due to arthritis) when she walked. She became weaker and eventually bed-bound. She gradually became more confused and less communicative. The family again stated that they did not want a feeding tube placed. P.S. died about a month after this second decision not to insert a feeding tube. No autopsy was performed. The cause of death was felt to be general organ system dysfunction due at least in part to malnutrition and dehydration.

Conclusion

I hope these cases have been helpful in showing the utility, limitations, and ethical issues involved in the use of ANH in clinical practice. With further advances in medicine, the medical and ethical considerations will need to be reexamined as we promote a culture that strives to reach the ideal stated in Isaiah: “No longer shall there be in it an infant who lives but a few days, or an old man who does not round out his full lifetime.”⁵¹

⁴⁸ G. Burke, “Tube Feeding and Advanced Dementia: Why Hand Feeding is Preferable,” *Ethics & Medics* 26.3 (March 2001): 1–2.

⁴⁹ C. Kahlenborn, “A Necessary Tension and Tube Feeding: Revisiting ANH for Demented Patients,” *Ethics & Medics* 26.8 (August 2001): 1–2.

⁵⁰ Diamond, *Catholic Guide to Medical Ethics*, 104.

⁵¹ Isaiah 65:20.