

2. Medically Assisted Nutrition and Hydration

The Procedure

Medically assisted nutrition and hydration (MANH) is sometimes referred to as “artificial nutrition and hydration” or as “assisted nutrition and hydration” or as “tube feeding.” Basically, it involves using a tube to deliver nutritional substances and water to a person instead of the person taking in food and water by mouth.

Medically assisted nutrition and hydration can take various forms:

- *Peripheral intravenous feeding* consists in a needle inserted into a vein in the arm.
- A *nasogastric (NG) tube* is a thin plastic tube inserted through the nose into the stomach or into the first portion of the duodenum (small intestine).
- A *gastrostomy tube* is inserted directly into the stomach, either surgically or through an incision made with the assistance of an endoscope (*percutaneous endoscopic gastrostomy (PEG) tube*).
- A *jejunostomy tube* is placed in the small intestine.
- *Central intravenous feeding*, also known as *total parental feeding* or as *hyperalimentation*, is the insertion of a catheter into a central vein near the heart. (1)

Medically assisted nutrition and hydration may be used on a short-term basis following an accident or following surgery when the patient temporarily cannot eat. (2) Such short-term uses of medically assisted nutrition and hydration to help a patient through a temporary health crisis are not controversial.

Medically assisted nutrition and hydration can also be used for longer periods of time in circumstances in which the patient cannot get adequate nutrition and hydration by mouth. For example, a patient may be unable to swallow or have difficulty swallowing because of a head injury, ALS, a stroke, or Parkinson’s disease. Or a patient may have a blocked gastrointestinal tract due to cancer, or may lack enzymes necessary to absorb nutrients in the intestines. Or again, a patient may have a normal mouth, stomach, and intestinal tract but be adverse to or uninterested in eating. (3) It is when medically assisted nutrition and hydration is or may be used for a prolonged period of time that difficult decisions can be faced about initiating, continuing, or discontinuing its use.

Moral Principles to Guide Decision Making

The *Ethical and Religious Directives for Catholic Health Care Services* from the United States Conference of Catholic Bishops give us moral principles for making decisions about using or forgoing medically assisted nutrition and hydration:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration becomes morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort. (4)

This directive gives the following guidance:

- In principle, there is an obligation to provide medically assisted nutrition and hydration to patients in need of it. This is because providing someone with nutrition and hydration, even by medically assisted means, is considered part of the normal care due to the sick person. (5)
- However, there are cases in which it is morally permissible to forgo (withhold or withdraw) medically assisted nutrition and hydration.
- It is morally permissible to forgo medically assisted nutrition and hydration when the procedure cannot reasonably be expected to prolong the patient’s life.
- It is also morally permissible to forgo medically assisted nutrition and hydration when the procedure itself would be excessively burdensome for the patient or would cause significant physical discomfort for the patient.
- When a patient’s death is imminent, this is a case (although not the only case) when the use of medically assisted nutrition and hydration is not obligatory.

The Church’s general principles for using or forgoing medical treatments are presented in the *Ethical and Religious Directives for Catholic Health Care Services*, directives number 56 and 57 (see section II.1 Life-Sustaining Treatments). These are followed by a separate directive, number 58, on medically assisted nutrition and hydration (quoted above). The existence of a separate directive indicates that the procedure of medically assisted nutrition and hydration is placed in a special category. In fact, the directive on medically assisted nutrition and hydration is more restrictive than the general principles for using or forgoing medical treatments in several respects.

- Directive 58 states that there is, in principle, an obligation to provide medically assisted nutrition and hydration to patients who cannot take food orally. In the case of life-sustaining treatments such as antibiotics, resuscitation, kidney dialysis, chemotherapy, and the like, directives 56 and 57 make no claim of an “obligation in principle” to provide such treatments.

- Directive 57 speaks of “no reasonable hope of benefit” generically as a condition for forgoing a medical treatment. (6) In directive 58, the lack of benefit of medically assisted nutrition and hydration is limited to consideration of the benefit of prolonging life. (Cf. section II.1 Life-Sustaining Treatments for a broader interpretation of treatment “benefit.”)
- In directive 58, the example given of a “burden” (or of “significant physical discomfort”) is something “resulting from complications in the use of the means employed.” In other words, “burdens” to be considered are limited to those resulting from the procedure itself. (Cf. section II.1 Life-Sustaining Treatments for a broader interpretation of “burdens.”)
- Directives 56 and 57 include the condition of imposing “excessive expense on the family or the community” in evaluating medical treatment. (7) There is no mention of this consideration in directive 58 on medically assisted nutrition and hydration.

Benefits and Burdens of Medically Assisted Nutrition and Hydration

Medically assisted nutrition and hydration can benefit patients in a variety of ways. It may help to stabilize a patient’s physical status following severe trauma. (8) It may allow a restful healing time for a diseased or damaged gastrointestinal tract, or serve as a means to provide nutrition and hydration during a restoration period following surgery. (9) It can help patients suffering a bout of severe nausea and vomiting or patients who have diarrhea causing serious dehydration. (10) Very importantly, it offers the fundamental benefit of “prolonging life in patients who are unable to take adequate nutrition by mouth.” (11) For example, a patient who has a blockage of his/her mouth or esophagus due to cancer can have a feeding tube placed below the blockage in order to be able to receive nutrition and fluids. (12)

The benefits that medically assisted nutrition and hydration can have in sustaining life, and even in improving the quality of life, is illustrated by the story of one ALS (Lou Gehrig’s disease) patient:

My wife has been displaying symptoms of ALS for 2-3 years, but we just got the diagnosis in January. She has severe bulbar symptoms, making chewing virtually impossible. In November, it was suggested that she might want to look into having a feeding tube installed. By this time she had lost over 20 lbs. because she couldn’t eat enough. We were doing Ensure drinks and pudding; she would start trying to eat first thing in the morning and then eat (at a very slow rate) virtually all day long. By Christmas time she was down to less than 80 lbs. and we couldn’t wait until the scheduled date for the feeding tube. She ended up in the ICU for 2 weeks because of her inability to intake enough nutrition.

We have had the PEG (feeding tube) for 4 months now... Her quality of life has been so much improved by the PEG. Most likely she would have passed away months ago without it. Does it interfere with things? No, not really. She is hooked up to the feeding pump at night and gets 1200 – 1500 calories that way. When she

isn't hooked to the pump, the tube is out of sight and out of mind. It gives us a way to administer medications without needing to swallow. She is still mobile so it is important to her that the tube not tie her down to a bed, and it doesn't.

The PEG...allows her to do things besides spend entire days trying to get enough nutrition to stay live. (13)

On the other hand, there are cases in which a feeding tube will not be successful in prolonging someone's life. A patient may be suffering from such severe heart, kidney, or liver failure that his or her body cannot process, metabolize, or excrete the nutrients or fluids supplied through the feeding device. (14) Or again, a feeding tube may not work because the tube itself has developed complications such as infection or bleeding, or because it has become entangled in the bowels so that the bowel tissue dies and can no longer absorb nutrients. (15) In such cases, medically assisted nutrition and hydration is a futile procedure in a very basic physiological sense. Since it will not work to prolong the person's life, it is morally permissible to withhold or withdraw it.

As well as benefits, medically assisted nutrition and hydration may also carry burdens of physical risks and complications. These have been enumerated for the various types of medically assisted nutrition and hydration by Cheryl Arenella, M.D., M.P.H., who has extensive experience in the field of hospice and palliative care:

- *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.
- *TPN (total parental nutrition)* 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 a NG tube is in place. If a person is confused, s/he may need restraints to keep him or 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... .
- 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 previously described can occur. (16)

Fr. Tad Pacholczyk of the National Catholic Bioethics Center describes a case in which medically assisted nutrition and hydration has become “excessively burdensome” for the patient and morally may be withdrawn:

...if someone is very sick and dying, perhaps with partial bowel obstruction, the feeding tube may cause them to vomit repeatedly, with the attendant risk of inhaling their own vomit, raising the specter of lung infections and respiratory complications. The feeding tube under these conditions may become disproportionate and unduly burdensome, and therefore non-obligatory. (17)

Importantly, whether medically assisted nutrition and hydration should be used or may be forgone must always be determined on a case by case basis, for each patient in view of his/her particular health condition, in consultation with the patient’s health care providers.

If the potential benefits and burdens of medically assisted nutrition and hydration are unclear in the case of a particular patient, a *time-limited trial* may be used. In other words, medically assisted nutrition and hydration would be initiated for a defined period of time, after which its effects would be evaluated. If the procedure is prolonging the patient’s life without any excessive burden, then the medically assisted nutrition and hydration should be continued. On the other hand, if the procedure is really not working to prolong the patient’s life or if it is accompanied by excessive burdens, then the medically assisted nutrition and hydration may be stopped.

If medically assisted nutrition and hydration is initiated, its use should be monitored on a continuing basis because its effects on a patient may change as the patient’s disease progresses. If a point is reached at which the procedure is really not working to provide nourishment to the patient or if serious burdens have become attached to it, medically assisted nutrition and hydration may be stopped. In initiating medically assisted nutrition and hydration, patients may need to be reassured that they will not be locked into this treatment no matter what.

Persons with Advanced Dementia

When persons are in the advanced stages of dementia, feeding and eating difficulties leading to weight loss are common. (18) Such an individual may even exhibit behaviors resistant to eating, such as turning his/her head away while being fed, refusing to open his/her mouth, clamping teeth, spitting out food, leaving his/her mouth open allowing food to fall out, or refusing to swallow. (19) In such cases, the first course of action is to undertake a medical evaluation of the patient and attempt various interventions to encourage the person to eat. (20) However, if such interventions fail to improve the person’s oral intake, the issue of initiating medically assisted nutrition and hydration may well arise. (21)

When dealing with patients with advanced dementia, there is no evidence to suggest a difference in longevity between persons who have medically assisted nutrition and hydration and persons provided with assistance in regular oral feeding. (22) Further, medically assisted nutrition and hydration has not been shown to prevent aspiration, heal pressure wounds, or improve nutritional status in persons with advanced dementia. It does not have these benefits for persons with advanced dementia. Moreover, medically assisted nutrition and hydration may be accompanied by substantial burdens including recurrent and new onset aspiration, tube-associated and aspiration-related infection, increased oral secretions that are difficult to manage, discomfort, tube malfunction, and pressure wounds. Persons suffering from advanced dementia may need to be restrained to prevent them from pulling out the feeding tube. In fact, studies have shown that long-term care residents with advanced dementia and a feeding tube frequently need to be taken to a hospital emergency room to address tube-related complications. (23) *According to Catholic teaching, there is no moral obligation to provide medically assisted nutrition and hydration if it will not work to prolong the patient's life or if it would be excessively burdensome for the patient.*

It is noteworthy that the Alzheimer's Association has taken the position that it is permissible to withhold medically assisted nutrition and hydration when the person with Alzheimer's disease or dementia is in the end stages of the disease. (24) The American Geriatrics Society has also concluded that the benefits versus the burdens of tube feeding do not support its use in older adults with advanced dementia. (25)

Even when a feeding tube is not used for a person experiencing advanced dementia, that person should still be fed by hand as s/he is able to take food. (26) An approach of "comfort feeding only" may be recommended. (27) The person will be carefully hand fed so long as s/he is not showing signs of distress such as choking or coughing. If the oral feeding does cause distress, it is stopped. (28) When a person can no longer tolerate oral feeding, caregivers provide an alternative means of positive human interaction such as speaking to the person and therapeutic touch. (29)

Persons Whose Death is Imminent

The *Ethical and Religious Directives for Catholic Health Care Services* notes that, "as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort." (30)

Some may worry that not providing food and water by medical means to persons who are dying will cause them to suffer. This fear is not warranted. For one thing, sensations of hunger and thirst can be relieved without using medically assisted nutrition and hydration. For example, ice chips or glycerin swabbing of the mouth can be used to relieve the thirst of dehydrated patients. (31) Further, studies involving medically assisted nutrition and hydration for patients with varying degrees of consciousness have indicated that withdrawal of the feeding device does not cause suffering associated with hunger and dehydration. (32) In fact, there is evidence that patients who are allowed to die without assisted nutrition and hydration may die more comfortably than patients who receive conventional amounts of intravenous hydration. (33)

Dehydration can reduce swelling and increase comfort in a patient suffering from edema (swelling of the body caused by excess body fluids) or ascites (fluid in the abdominal cavity). Cough and congestion may be lessened because secretions in the lungs are diminished. A dehydrated person has less urine output so that problems with incontinence are lessened. Since there is less fluid in the gastrointestinal tract with dehydration, a patient may experience a decrease in nausea, vomiting, bloating, and regurgitation. Indeed, dehydration leads to death in ways that produce a sedative effect on the brain just before death, thus decreasing the need for pain medication. (34)

Some may also be concerned about not providing medically assisted nutrition and hydration to a dying person who is still awake and mentally alert and talking with them. This may seem like deliberately “starving” the person. However, the patient’s state of consciousness --- whether the patient is awake and aware or has reduced unconsciousness or is unconscious --- does not make a difference in itself. In any case in which a person’s death is imminent, what is important is that medically assisted nutrition and hydration may well be burdensome and is not likely to prolong the person’s life or provide comfort to him or her.

Persons in a Vegetative State

Consciousness has two components: wakefulness and awareness. (35) Among the various disorders of consciousness, the most commonly known is *coma*. In this condition a person’s eyes remain closed and the person appears to be asleep but cannot be aroused. (36) Someone in a coma lacks both wakefulness and awareness. (37) On the other hand, a person in a *vegetative state* (VS) is awake but unaware. Persons in a vegetative state exhibit sleep-wake cycles but show no awareness of self or their environment when awake. (38) The vegetative state has also been called *unresponsive wakefulness syndrome* (UWS) (39).

After the vegetative state has continued for at least one month, the patient is said to be in a *persistent vegetative state*. (40) A patient in a persistent vegetative state is said to enter a *permanent vegetative state* when the diagnosis is that the condition is irreversible and the chance that the person will regain consciousness is very small. (41) Some use the term “persistent vegetative state” less precisely as an umbrella term to include both the persistent and permanent vegetative states.

Some have taken the position that, once the vegetative state is diagnosed as being permanent, this is sufficient reason to withdraw the medically assisted nutrition and hydration that is keeping the person alive. (42) As indicated by the *Ethical and Religious Directives for Catholic Health Care Services*, the Catholic Church does not concur in this judgment. Rather, the Church affirms that the obligation in principle to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally, “extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care.” (43) As St. John Paul II has pointed out, continuing the minimal care of food and water in such a case is part of our respect for the dignity of the human person: “I feel the duty to reaffirm strongly that

the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. ...Even our brothers and sisters who find themselves in the clinical condition of a 'vegetative state' retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help. ... The evaluation of probabilities, founded on waning hopes for recovery...cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration." (44)

However, it would be morally permissible to forgo medically assisted nutrition and hydration for a patient in a persistent/permanent vegetative state if the procedure itself has become ineffective in prolonging the patient's life (for example, the tube itself has developed complications such as infection or bleeding) or if the procedure has become excessively burdensome for the patient (for example, causing severe diarrhea or aspiration pneumonia).

Forgoing Nutrition and Hydration and Euthanasia

Some may be concerned that not providing medically assisted nutrition and hydration to persons who cannot take adequate food by mouth is "starving the person to death" and represents an act of euthanasia.

The Church defines euthanasia as "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." (45) The *intent* behind withholding or withdrawing medically assisted nutrition and hydration is critical. If someone's intent is to use the withholding or withdrawing of medically assisted nutrition and hydration as the means to bring about the patient's death, then this is a case of euthanasia and is not morally permissible. (46) On the other hand, if the purpose is to relieve the patient of a procedure that really does not serve to prolong the patient's life or is excessively burdensome for the patient, this is different than a decision to kill a patient and is morally permissible.

VSED stands for "Voluntarily Stopping Eating and Drinking." It refers to "a decisionally-capable adult who has the physical ability to eat and drink but consciously refuses food and fluids in order to advance the time of their death." (47) Simply stated, a patient consciously makes a decision to stop eating and drinking as the way to cause his/her death. VSED is an act of euthanasia, and as such is not morally permissible.

Some dying patients may naturally "lose interest in eating and drinking as appetite and sensations associated with hunger and thirst fade." (48) For them, "eating, or the sensation of consuming more than a small amount of food or liquid, is unappealing or physically uncomfortable." (49) They will "refuse offers of food or will push food trays away." (50) Such natural cessation of eating and drinking as part of the dying process must be carefully distinguished from VSED.

There are individuals with serious cognitive impairments (dementia) who can swallow but who need assistance with oral feedings, that is, who need hand feedings. (51) The issue has arisen of stopping the hand feeding in order to end the person's life in a highly debilitated state. (52) By

intention, this constitutes an act of euthanasia and is not morally permissible. Again, this practice must be distinguished from the previously discussed cases in which a patient with advanced dementia cannot tolerate oral feeding (see section Persons with Advanced Dementia).

Advance Care Planning

For information on how to complete a Durable Power of Attorney for Health Care form or an IPOST form in accord with Church teaching on medically assisted nutrition and hydration, see section II.4 Advance Care Planning. For an advisory on a conflict between the standard language of Iowa's living will and Church teaching on medically assisted nutrition and hydration, see section II.4 Advance Care Planning.

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NOTES

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