Is Assisted Nutrition and Hydration Always Mandated?

The Persistent Vegetative State Differs from Dementia and Frailty

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Abstract. There is controversy in the Catholic medical ethics community surrounding assisted nutrition and hydration (ANH). Recently, the *Ethical and Religious Directives for Catholic Health Care Services* were amended to make ANH "obligatory." The persistent vegetative state is cited specifically in the document, and the sentence following its mention states that ANH is "optional" when it cannot be expected to "prolong life" or when it would be "excessively burdensome." For patients suffering from other medical conditions, such as dementia and frailty, ANH may be excessively burdensome and may not prolong life. For these patients, ANH may be of no real benefit and may even have significant morbidity and mortality. Competent individuals with these conditions can ethically elect to forgo ANH. *National Catholic Bioethics Quarterly* 10.3 (Autumn 2010): 481–488.

In the fifth edition of the *Ethical and Religious Directives for Catholic Health Care Services*, the U.S. Conference of Catholic Bishops changed the moral weight of directive 58 from a "presumption" to an "obligation" to provide assisted nutrition and hydration (ANH) to patients in a persistent vegetative state (PVS).[1] Many have

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[1]U.S. Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. (Washington, DC: USCCB, 2009).

assumed that the obligation to provide ANH now applies to all patients with nutritional compromise. I will argue that there are exceptions.

This essay will (1) summarize the Church's teaching on ANH, (2) outline the medical conditions that may require ANH, (3) describe the limitations and side effects of ANH, and (4) describe the role of autonomy and possible exceptions to mandated ANH.

Church Teaching

Church teaching on ANH has evolved as medicinal and nutritional science and ANH delivery techniques have developed. The Church's position on ANH was clearly stated as early as the sixteenth century by Francisco de Vitoria: "If a sick man can take food or nourishment with some hope of life, he is held to take the food, as he would be held to give it to one who is sick."[2] The overriding principle has been that ordinary means of preserving life are required and extraordinary means are optional. This principle is outlined in the *Catechism of the Catholic Church* and in the *ERD*s.[3]

The development of doctrine regarding ANH is outlined in Table 1. Pope Pius XII, at a 1957 congress on anesthesiology, stated that ordinary care is required and extraordinary care is optional.[4] In 1980, the Congregation of the Doctrine of the Faith stated that "it is permitted … to refuse" extraordinary care.[5] In 1995, the Pontifical Council for Health Care Workers declared 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."[6]

In 2004, Pope John Paul II asserted that the administration of food and water, even by artificial means, is not a medical act and is mandatory.[7] This, in the minds of some, seemed to contradict the tradition described above. John Paul II was motivated by the relatively recent description of the PVS. This in turn resulted in a change in directive 58 from a "presumption" to an "obligation to provide patients with food and water."[8] Although the amended directive specifies the PVS, some have interpreted it

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[2]Francisco de Vitoria, "Reletio de Temperantia," n. 1, quoted in *Conserving Human Life*, by Daniel A. Cronin (Braintree, MA: Pope John XXIII Medical-Moral Research Center, 1989), 35.

[3]*Catechism of the Catholic Church*, 2nd ed., trans. U.S. Conference of Catholic Bishops (Vatican City: Libreria Editrice Vaticana, 1997), nn. 1782 and 2278; and USCCB, *Ethical and Religious Directives*, n. 56.

[4]Pius XII, "The Prolongation of Life," address to an International Congress of Anesthesiologists (November 24, 1957), in *The Pope Speaks* 4.4 (Spring 1958): 393–398.

[5]CDF, *Declaration on Euthanasia* (May 5, 1980), part IV.

[6]Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter for Health Care Workers* (Vatican City: Libreria Editrice Vaticana, 1995), n. 120.

[7]John Paul II, Address to the Participants in the International Congress on "Life-Sustaining Treatments and the Vegetative State: Scientific and Ethical Dilemmas" (March 20, 2004), n. 4.

[8]USCCB, *Ethical and Religious Directives*, n. 58.

Table 1. Church Statements on Assisted Nutrition and Hydration

Date	Source	Statement	PVS Mentioned?
1957	Speech of Pope Pius XII[1]	Only ordinary care is required.	No
1980	*Declaration on Euthanasia*[2]	Refusal of ANH is permitted.	No
1994	*Catechism of the Catholic Church*[3]	Decisions should be made freely, personally, and according to one's conscience. (n. 1782)	No
		It may be legitimate to discontinue procedures that are burdensome, dangerous, or extraordinary. (n. 2278)	No
1995	*Charter for Health Care Workers*[4]	Food and liquid are to be provided when "not burdensome."	No
2004	Speech of Pope John Paul II[5]	The administration of food and water is not a medical act.	Yes
2007	CDF response to questions of Bishop Skylstad of the USCCB[6]	Provision of food and water represents ordinary means and is not therapeutic treatment.	Yes
2009	Fifth edition of USCCB's *Ethical and Religious Directives*[7]	Presumption in favor of providing ANH changed to obligation to provide ANH.	Yes

ABBREVIATIONS: CDF, Congregation for the Doctrine of the Faith; ANH, assisted nutrition and hydration; USCCB, United States Conference of Catholic Bishops.

SOURCES: (1) Pius XII, "The Prolongation of Life," Address to an International Congress of Anesthesiologists (November 24, 1957), in *The Pope Speaks* 4.4 (Spring 1958): 396. (2) Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (May 5, 1980), part IV. (3) *Catechism of the Catholic Church,* trans. U.S. Conference of Catholic Bishops (Vatican City: Libreria Editrice Vaticana, 1994). (4) Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter for Health Care Workers* (Vatican City: Libreria Editrice Vaticana, 1995), n. 120. (5) John Paul II, Address to the Participants in the International Congress on "Life-Sustaining Treatments and the Vegetative State: Scientific and Ethical Dilemmas" (March 20, 2004), n. 4. (6) Congregation for the Doctrine of the Faith, Responses to Certain Questions of the USCCB concerning Artificial Nutrition and Hydration (August 1, 2007), reprinted in *Ethics & Medics* 32.11 (November 2007). (7) USCCB, *Ethical and Religious Directive for Catholic Health Care Services*, 5th ed. (Washington, DC: USCCB, 2009), n. 58.

as mandating ANH generally, including the use of percutaneous enteral gastrostomy (PEG) when that is the only effective means of delivery.

John Paul II's 2004 statement created controversy. In 2009, a Jesuit consortium criticized the Pope for contradicting the then-approved fourth edition of the *ERDs*.[9] The consortium alleged that the Pope diminished patient autonomy and required burdensome expenses. The consortium's position was in turn criticized by The National Catholic Bioethics Center and the Catholic Medical Association.[10]

While this controversy simmers, it may be opportune to highlight some distinctions. The first has to do with various medical syndromes—including the PVS, dementia, and frailty—which may be associated with nutritional deficiencies. The second has to do with patient autonomy.

Medical Conditions Potentially Requiring ANH

ANH may be required in several serious medical conditions, which are listed in Table 2. These do not include cases in which a brief period of ANH is required because a patient may take nothing by mouth, such as following abdominal surgery or during a gastrointestinal infection. The more common diseases that may require ANH are the dementias, especially Alzheimer's disease and atherosclerotic vascular compromise.

Dementia is defined as "a general loss of cognitive abilities including impairment of memory as well as one or more of the following: aphasia, apraxia, agnosia, or disturbed planning, organizing and abstract thinking abilities."[11] The most prevalent form of dementia is Alzheimer's disease, constituting over 70 percent of cases.[12] Alzheimer's is a degenerative disease of the nervous system characterized psychologically by the loss of critical memory and pathologically by the formation of amyloid plaques and intraneuronal neurofibrillary tangles.[13] Alzheimer's disease causes deterioration of mental function and physical performance. This deterioration tends to be an inexorable process that results in death. Alzheimer's disease can be slowed but not cured.

Dementia of the atherosclerotic type, often referred to as senility, is second in prevalence (10 to 20 percent).[14] Atherosclerotic dementia is an occlusion of the cerebral

[9] Consortium of Jesuit Bioethics Programs, "Undue Burden? The Vatican and Artificial Nutrition and Hydration," *Commonweal* 136.3 (February 13, 2009).

[10] Ethicists of the National Catholic Bioethics Center, "A Defense of the Vatican on ANH," *Ethics & Medics* 34.6 (June 2009): 1–3. Catholic Medical Association, "Response to the Consortium of Jesuit Bioethics Programs Statement 'Undue Burden?'" *Linacre Quarterly* 76.3 (August 2009): 296–303.

[11] *Dorland's Illustrated Medical Dictionary*, 30th ed. (Philadelphia: Saunders, 2003), s.v. "dementia."

[12] Lee Goldman and Dennis Ausiello, eds. *Cecil Medicine*, 23rd ed. (Philadelphia: Saunders, 2008), 2669.

[13] Ibid., 2670.

[14] Ibid., 2672.

Table 2. Medical Conditions That May Require Assisted Nutrition and Hydration

Dementia
Alzheimer's type dementia
Vascular dementia, principally atherosclerosis
Psychosis
Schizophrenia
Bipolar depressive psychosis
Coma
Trauma-induced coma (due to brain injury)
Drug-induced coma
Transient (alcoholic) coma
Persistent vegetative state
Short-bowel syndrome
Frailty

vasculature that also results in a deterioration of mental function. Alzheimer's disease is usually imperceptibly progressive, whereas vascular dementia is characterized by loss and then stabilization with subsequent rounds of deficit and repeat stabilization. Coma of the PVS variety is much less common. It is defined as an awake but unresponsive state.[15]

Frailty is defined as a syndrome of decreased reserve in multiple systems, which results from dysregulation that usually occurs with aging. This decline, often referred to as impaired homeostatic reserve, can be evident by as early as the third decade.[16] It consists of a "constellation of symptoms including weight loss, weakness, fatigue, inactivity and decreased food intake."[17] Frailty is not limited to what is called a "terminal" condition (limited to the final three or four weeks of life). The end of life is considered by some "to begin with the onset of advanced illness that is beyond cure, rather than limiting it to the time of imminent death."[18]

[15] Ibid., 2695.

[16] *Principles of Geriatric Medicine and Gerontology,* 5th ed., Linda Fried, Jeremy Walston, and Luigi Ferrucci, eds. (McGraw Hill Medical: New York, 2003), 1487–1502.

[17] Ibid., 1497; and Amy Markowitz and Steven Pantilat, "Palliative Care for Frail Older Adults: 'These Are Things I Can't Do Anymore That I Wish I Could,'" *Journal of the American Medical Association* 296.24 (December 27, 2006): 2967.

[18] Jean Kutner, "An 86-Year-Old Woman with Cardiac Cachexia Contemplating the End of Her Life," *Journal of the American Medical Association* 303.4 (January 27, 2010): 249–256.

Assisted Hydration and Nutrition

ANH can be delivered either parenterally (directly into the bloodstream, commonly by intravenous needle) or enterally (directly into the gastrointestinal tract, usually into the stomach or jejunum). Humans can survive seven to ten days without nourishment. Feedings must contain water, energy or glucose, fats, carbohydrates, protein, and nutrients. Short-term ANH (lasting days or weeks) can be effectively administered intravenously, possibly by a central line directly into the vena cava. Some patients may require ANH for months or years, such as those with short-bowel syndrome or those in a PVS. Long-term ANH usually requires enteral delivery and can be fraught with difficulties.

The two major objections to tube feeding are its reported adverse side effects and its questionable efficacy. More than forty separate complications of tube feeding have been described.[19] Side effects have to do with placement and maintenance. Placement should be exact.[20] Because of the possibilities of regurgitation, aspiration, and pneumonia, the proximal end of the feeding tube should ideally be in the jejunum. With pneumonia, the tube frequently migrates retrograde into the stomach. Placement often requires radiographic confirmation. In addition, feeding-tube management may not be routine care that can be given by a nurses' aid; it requires the supervision of a professional registered nurse or physician.

Second, and of more importance, is the question of the efficacy of tube feeding. Does it actually nourish patients? The answer could well be no. John Hoffer states that clinical experience suggests that "tube feeding severely demented patients fails to prevent death or improve quality of life."[21] Baldomero Álvarez-Fernández reports that tube feeding actually reduces patient survival.[22] The rationale for these statements is that advanced dementia and frailty, like advanced cancer, are associated with significant negative physiologic homeostasis, which is often irreversible in any event. John Howland has recently written a fine review of ANH.[23] He concludes that until well-controlled randomized trials are conducted we will not know whether "it is best to PEG or not to PEG."[24] Unfortunately, he does not discuss the role of the patient in this process, but *ERD* directives 57 and 59 do.

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[19]Ina Li, "Feeding Tubes in Patients with Severe Dementia," *American Family Physician* 65.8 (April 15, 2002): 1605–1610.

[20]Khursheed N. Jeejeebhoy, "Enteral and Parenteral Nutrition," in *ACP Medicine*, 2nd ed., ed. David Dale et al. (Hamilton, Ontario: B. C. Decker, 2005), 905–913.

[21]L. John Hoffer, "Tube Feeding in Advanced Dementia: The Metabolic Perspective," *British Medical Journal* 333.7580 (December 9, 2006): 1214–1218.

[22]Baldomero Álvarez-Fernández et al., "Survival of a Cohort of Elderly Patients with Advanced Dementia," *International Journal of Geriatric Psychiatry* 20.4 (April 2005): 365.

[23]John Howland, "A Defense of Assisted Nutrition and Hydration in Patients with Dementia," *National Catholic Bioethics Quarterly* 9.4 (Winter 2009): 697–711.

[24]William Plonk, "To PEG or Not to PEG," *Practical Gastroenterology* 29.7 (July 2005): 16–31.

Once started, the dying process can be inexorable. A patient with terminal cancer will not gain weight, ANH notwithstanding.[25] Some feel that ANH will only "feed the tumor" without benefiting the patient. Others claim that senility and frailty are part of the dying process. When this point is passed is difficult to determine. Is it humanly possible to reverse this natural process? Perhaps the patient instinctively knows more than the doctor.

But if tube feeding does not even slow the dying process, what value is it? Spoon feeding is time consuming and labor intensive. Is not part of the emotional value of tube feeding the fact that it allows us to feel that we are benefiting the patient (when we really may not be) and it is cost effective (if indeed it is)?

Can we slow the inexorable physiological process of aging? If we really want to maintain weight and muscle mass, why not aim to reverse menopause and andropause, which are normal aspects of aging? Why not also provide the elderly with estrogens, androgens, anabolic steroids, and perhaps even Viagra? Is the human condition of aging not rather to be accepted?

Autonomy

Another contentious issue of ANH is *who* decides what is "burdensome": the ethicist and the doctor, or the patient? Some state that the doctor, being more knowledgeable, is a better judge of what is ordinary and what is extraordinary care.[26] Others lean toward the patient as the decision maker.[27] Obviously, the critical issues are the interpretations of how life is "prolonged" and what is "burdensome." But it seems clear that the *ERDs* consider it an obligation that doctors, ethicists, and pastors should "comply with" as well as "respect" the judgments of a competent patient.[28]

The *ERDs* seem to have answered this question rather definitively. Directive 57 states that extraordinary means "are those that in the *patient's* judgment" do not offer a reasonable hope of benefit.[29] There is no mention of the patient's priest, ethicist, or doctor. Also, directive 59 states, "judgment made by a competent adult … should always be respected." In the case of a noncompetent patient, the legal surrogate, knowing the wishes of the person, would decide. Directives 57 and 59 bracket directive 58, which suggests that ANH is "obligatory." Directives 57 and 59 seem to suggest flexibility in the application of ANH in conditions other than the PVS.

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[25] Vincent T. DeVita, Theodore S. Lawrence, and Steven A. Rosenberg, eds., *Devita, Hellman and Rosenberg's Cancer: Principles and Practice of Oncology*, vol. 2, 8th ed. (Philadelphia: Lippincott, Williams, and Wilkins, 2008), 2794.

[26] George Isajiw, "To PEG or Not to PEG: A Case for Hospice Referral for Vitamin B12 Deficiency," *Linacre Quarterly* 76.2 (May 2009): 212–217.

[27] Thomas A. Shannon and James J. Walter, "Implications of the Papal Allocution on Feeding Tubes," *Hastings Center Report* 34.4 (July–August 2004): 18–20; and Daniel Sulmasy, "Are Feeding Tubes Morally Obligatory?" *St. Anthony Messenger*, January 2006, http://www.americancatholic.org/messenger/jan2006/feature1.asp.

[28] USCCB, *Ethical and Religious Directives*, n. 59.

[29] Ibid., emphasis added.

Each individual must use his or her conscience, hopefully properly informed, to make these difficult decisions. Whether ANH is always of medical, not to say social or psychological, benefit has not yet been definitively determined. The use of ANH is a complex issue that can be summed up by saying that some syndromes, such as the PVS, where nutrition can only be artificially delivered, require ANH. But in the majority of cases, the decision to accept or reject ANH can be made at the discretion of the patient (as in cases of frailty) or a designated surrogate (dementia) with the advice of the doctor. In the final analysis, the dignity of the human person, made in the image of God, must always be respected.