

A Primer for Understanding the CDF's *Responses* Regarding AANH for the PVS Patient

EDITOR'S NOTE

The recent statement from the Vatican's Congregation for the Doctrine of the Faith (issued Sept. 14, 2007), concerning artificially administered nutrition and hydration to patients in a persistent vegetative state, has generated a lot of discussion within Catholic health care, resulting in a range of perspectives and interpretations. The following is one organization's attempt to help others in Catholic health care understand this potentially confusing development.

On Sept. 4, 2007, the Congregation for the Doctrine of the Faith of the Roman Catholic Church issued *Responses* and a *Commentary* to two questions posed in 2005 by the bishops of the United States regarding artificially administered nutrition and hydration for patients in a persistent vegetative state. Since then, many people have raised concerns about its significance for us in Catholic health care. As a way to begin to address these concerns for Providence Health & Services, The Providence Center for Health Care Ethics in the Oregon Region has prepared this primer in a Q&A format. We hope it will be helpful to you in understanding and discussing the documents, as well as be of use to gain insight into what, if any, practical implications they have for you, your facility or department as we carry on the tradition of excellence in health care.

Is this new document related to the *allocation* of Pope John Paul II on this topic in March of 2004?

Yes. As a direct result of that allocation, the United States bishops sent two questions in July of 2005 to the Congregation for the Doctrine of the Faith (CDF), the Vatican congregation that deals with these types of issues. The bishops wanted to know first if it is always morally required to provide artificially administered nutrition and hydration (AANH) to a patient in a persistent vegetative state (PVS) as long as the patient's body can assimilate the nutrition or hydration, unless doing so causes significant physical discomfort. Second, they wanted to know if having "moral certainty" that a patient in PVS will never regain

consciousness is a sufficient reason to forgo continued AANH.

And the answer?

To the first question, the response is yes. AANH is, "in principle, an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent to which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and the nourishment of the patient." In the *Commentary* that accompanied this statement, the CDF clarified that significant physical discomfort may be one of those rare or exceptional instances in which there would be no obligation to provide AANH. In response to the second question, the CDF said that even with "moral certainty" that the patient will not regain consciousness, the moral obligation to offer AANH, remains. The "persistence" or "permanence" of the vegetative state does not change the ethical obligations.

Does this statement apply only to patients in PVS, and only to whether they should always receive AANH?

Yes, both questions and responses refer explicitly to patients in a PVS, and only to whether they should be offered AANH. The *Commentary* is quite succinct: "the provision of water and food, even by artificial means, is in principle an ordinary and proportionate means of preserving life for patients in a *vegetative state*" [emphasis added.]

One aspect of the Catholic moral and legal tradition is that laws and norms should be interpreted narrowly without undermining their purpose. Put differently, an official text says only what it says—no more and no less. Suggesting that these *Responses* apply, say, only to whether or not Terri Schiavo should have had her AANH removed, because the initial allocation was given during the controversy surrounding her death, would be too narrow an interpretation. On the other hand, saying it applies to all patients who cannot take food or water by mouth would be too broad.

The 2004 allocution, the U.S. bishops' questions, and the CDF's *Responses* speak only to patients who are in PVS, and only to the issue of nutrition and hydration. It does not speak to the issue of patients who, for example, cannot safely swallow due to end-stage progressive dementia, nor does it say anything about how to care for PVS patients who develop pneumonia, renal failure or other life-threatening pathologies.

Is the CDF saying something new then?

Yes, and no. There has been some debate both within and outside Catholic ethical and medical circles over the years as to whether patients in PVS are a special case when it comes to AANH. Some have held that PVS is a neurological state that cannot be medically managed in such a way as to allow the person to actively live out his or her life. From this perspective, the person in PVS is not unlike the patient with end-stage renal disease dependent on dialysis—both can be seen as chronic states not able to be sufficiently medically managed for the patient's benefit. As such, the same moral norms would apply—either can be forgone when there is no benefit for the patient. Others have held that the PVS patient is not “end-stage,” is not suffering from a progressive disease, and is neither terminally ill nor imminently dying. In this case, AANH is considered basic care that should always be offered.

What is “new,” if you want to call it that, is that it has now been clarified that the official position of the ordinary magisterium, the teaching office of the church, is that AANH for the patient who is in a PVS is to be understood as basic care. It is, in principle, morally obligatory for those patients. The *Commentary* does cite other church documents that speak about AANH, but none of these carries the authority or clarity of these texts.

What does it mean to say AANH is “in principle” obligatory?

The expression “in principle” (*in linea principii*) means more than “as a general rule,” as the common English expression might suggest. That makes it sound “optional.” The expression “in principle” is similar to the notion of a *prima facie* obligation: it refers to a duty or obligation that ought to always be fulfilled if it can be fulfilled. In this sense, the obligation to provide AANH for these patients is

not optional. As explained in the *Commentary* however, it is not always possible to fulfill this obligation. The text does not exclude the possibility of circumstances in which it is impossible to fulfill this obligation, or impossible to do so without causing harm, even if this is a rare and exceptional case.

When is it not an obligation?

The *Commentary* acknowledges the reality that in remote and poor nations, fulfilling this obligation will be impossible. They further mention the possibility that discomfort related to the provision of AANH may make it imprudent to fulfill this obligation.

Although neither the *Responses* nor the *Commentary* address the issue explicitly in light of the specific questions being asked, it would also be true that there is no obligation to provide AANH to the PVS patient who develops some other life-threatening pathology or co-morbidity that makes end-of-life care appropriate. Clearly, in the case of a patient dying for example of renal failure, AANH cannot achieve what the first response states is its purpose for the PVS patient: providing nourishment and hydration to sustain life. When AANH cannot sustain the life of the patient who is PVS due to some other underlying life-threatening pathology, it can be forgone as part of palliative or end-of-life care for the patient.¹

Is this statement different from Directive 58 from the Ethical and Religious Directives for Catholic Health Care Services?

Yes. Directive 58 speaks of a presumption in favor of providing AANH in all instances, but does not speak of a positive moral obligation to provide AANH in any specific case. The CDF statement makes clear that the standard that may be applied in making AANH decisions for the person with end-stage dementia is not the same standard as shall be used in making AANH decisions for the person in a PVS.

What is the authority of the CDF's Responses, and how does it compare to the authority of the ERDs that we already follow?

The *ERDs* are a pastoral statement from the United States bishops. They are intended, as stated in the Introduction, to offer guidance on ethical issues related to health care. Because it is a pastoral document, each bishop may, within

certain limits, interpret and implement some of the directives in ways he feels is most pastorally appropriate for his diocese. For example, some bishops already understood Directive 58 to apply differently to PVS patients than to non-PVS patients, and some others began to do so after Pope John Paul II's allocution in 2004. Other bishops continued to address the issue of AANH for PVS patients in the same way as other patients.

These *Responses*, published by the CDF and approved by Pope Benedict XVI, are classified as a "doctrinal document." This means that the text is intended to remove uncertainty regarding the question of AANH for patients in PVS in order to prevent moral error from happening in their care. *Origins*, a Catholic News Service documentary service that is sponsored by the United States bishops, refers to the text as "reaffirming the *church's teaching* that it is morally obligatory to provide nutrition and hydration in such [PVS] cases" [emphasis added]. The text is not irreformable, and is able to be amended at some later time. Nevertheless, it is to be considered as authoritative and carries the expectation that appropriate attention will be given to it. With respect to patients in PVS then, the *Responses* are different from the pastoral Directive 58. Without in any way diminishing the guidance in Directive 58 for all other patients, there is now understood to be an in principle obligation to provide AANH to PVS patients.

It is also interesting to note that the *Responses* and *Commentary*, written in Latin, were published not only in English, but also in French, German, Italian, Polish, Portuguese and Spanish. The CDF clearly understands this issue to be one of universal significance.

Why is withdrawing AANH seen as morally different from removing a ventilator or stopping dialysis?

As seen from the point of view of the CDF statement, interventions like mechanical ventilation or dialysis are interventions that replace or supplement an involuntary biological process stimulated by the activity of the brain stem. For example, people do not decide to breathe or cleanse their blood of impurities—these happen as an involuntary biological process. Interventions to address these situations are seen as medical care because they are initiated to address the pathology that undermines this involuntary process.

Eating and drinking, on the other hand, are voluntary human acts made possible by the upper cortical part of the brain—people can decide whether, how much, when and what to eat or drink. Digestion is an involuntary biological process, but eating and drinking are voluntary human acts. Interventions to replace or supplement the loss of the ability to engage in voluntary human acts do not address the underlying pathology *per se*, but only the inability to initiate a voluntary human act. They are therefore seen as "basic care." In the *Commentary* and in other writings surrounding the debate, this distinction between the loss of involuntary biological processes and the loss of the ability to perform a voluntary human act is viewed as morally decisive.

With patients in PVS, the involuntary biological process of assimilating nourishment remains intact because the brain stem is intact. The voluntary human action of eating is impossible because the upper cortical part of the brain is catastrophically and irretrievably damaged. Specifically, the loss of the ability to engage in the voluntary human act of eating and drinking, while at the same time retaining the involuntary biological digestive process, creates a situation in which it is in principle morally obligatory to provide the nourishment to the patient who cannot take it voluntarily.

This understanding as to why AANH is in principle obligatory for PVS patients also makes clear that these *Responses* do not apply to non-PVS patients, such as the patient in a terminal coma due to a series of strokes or the patient with severe dementia.

The Responses mention that "significant discomfort" may allow for forgoing AANH. Can he or she feel significant physical discomfort, and how are we to understand "significant"?

The importance of the issue of pain or discomfort is acknowledged by both the first question posed by the bishops, and the *Commentary*. Clinically, it is a matter of debate.

A survey of physicians from the American Academy of Neurology and the American Medical Directors Association showed that 30 percent believed PVS patients could experience pain.² The 1994 consensus statement of the Multi-Society Task Force was not so definite.³ In the face of a doubt of fact about the experience of pain, some may hold

that it is morally prudent to act on the presumption that the patient does experience pain or discomfort. There may be a sense of urgency with this question due to the fact that patients in PVS seem neurologically incapable of demonstrating to us they are in pain, and hence we may cause pain with no way of knowing it.

Adding to the moral imperative to be alert to issues of pain are studies that show that somatosensory stimulation of PVS patients, at intensities that elicit pain in non-PVS patients, results in an increase of neuronal activity in the primary somatosensory cortex.⁴ Even if we are uncertain whether the PVS patient *subjectively* experiences pain or discomfort, the fact that neuronal activity experienced as pain in non-PVS patients is observable in PVS patients should cause us to take very seriously the moral imperative to be attentive to the possibility of pain or discomfort in the PVS patient. Painful stimuli may impact PVS patients negatively in the same *objective* way as non-PVS patients even if we cannot say with certainty that the PVS patient experiences pain *subjectively*.

Regardless of whether PVS patients can feel pain *subjectively*, we remain ethically obligated by traditional Catholic ethical principles to avoid causing *objectively* painful or discomforting stimuli. Care for PVS patients should take seriously the statement in the *Commentary* that “the possibility is not absolutely excluded that, in some rare cases, artificial nourishment and hydration may be excessively burdensome for the patient or may cause significant physical discomfort, for example resulting from complications in the use of the means employed.”

Therefore, if AANH is associated with the *objective* discomfort that a reasonable person would describe as unacceptable *subjective* discomfort, the withdrawal of AANH would appear to be permissible.

What are some examples of objective discomfort?

Development of a reflux that causes irritation of the esophagus, or puts the PVS patient at risk for aspiration and repeated pneumonias might be an example of objective discomfort. If the patient develops diarrhea that cannot be easily managed, that too might constitute unacceptable discomfort. Patients in PVS are also prone to urinary tract infections, which can be a source of significant flank pain.

If these infections are chronic and difficult to manage, one might argue that patient is at risk for significant discomfort.

Because PVS patients have sleep and wake cycles and display non-purposeful movement, it is also conceivable that the feeding tube could be dislodged from time to time. This could happen even with careful bathing or physical therapy. Dislodgment of the tube might require repeated procedures to replace it, and these procedures might be a source of objective discomfort that a reasonable person would not find acceptable. This is recognized in the *Commentary* where we read that examples of physical discomfort may result “from complications in the use of the means employed.”

Family members can best inform us as to whether any objective discomfort that might be present is or would be considered by the patient as “significant,” since they would know best the patient’s ability to tolerate discomfort. There can be no moral obligation to subject a patient to objective discomfort that would be judged as subjectively intolerable.

If AANH is basic care and not a medical intervention, does it matter if the family says the patient would not want it, or the patient has an advance directive that states they would not want it?

This question will be a difficult one for Catholic health care facilities. Patients can legally refuse both medical and basic care, and Catholic health care cannot legally or ethically require patients to accept what they do not want.

It should also be said that, while providing nutrition and hydration may be considered basic care, it cannot be overlooked that clinical expertise is needed as part of the provision of that basic care. Therefore, even if AANH is not a clinical intervention in the same way that a ventilator is a clinical intervention, AANH is not basic care in the same way that maintaining good hygiene is basic care. This raises questions: Even if AANH *per se* is in principle morally obligatory, does this mean that medical interventions necessary to provide that basic care are also in principle obligatory? Can patients through an advanced directive or their surrogate refuse the clinical interventions needed to allow that basic care to be administered even in a Catholic health care setting? Seemingly, a refusal of consent to replace a dislodged tube or to flush a plugged tube would constitute a

legal prohibition to touch the patient and should be respected. Is it permissible to allow the situation to unfold, or should the patient be transferred? What if there are no facilities available for discharge for the removal of the tube? These are questions with which all Catholic health care providers will have to struggle.

Is it material cooperation in or toleration of euthanasia for a Catholic facility to comply with a refusal by a surrogate to allow us to replace a nutrition or hydration source?

No. The principle of material cooperation addresses the question of whether or not a person can perform some act that will in some way assist another person in the performance of a wrong act. In the case of a surrogate refusing to allow AANH to continue, we would not be performing any action. Instead, there would be an omission on our part if we complied with that refusal. The ethical principle that deals with omissions is toleration of wrong-doing.

But, the principle of toleration asks the question of whether there is an obligation to prevent some wrong from happening when it is possible to prevent that wrong. If a surrogate makes the legally informed decision to forgo flushing or replacing a clogged or dislodged tube, or withdraws consent to replacing the nutritional or hydration source, we are legally prohibited from overriding that decision. It is not toleration in the moral sense because we are legally powerless to do anything about it.

Should Catholic health care refuse to admit PVS patients whose surrogate will not agree to continue AANH after admission?

This is also a hard question, and will need to be sorted out over time in particular situations. It is hard to maintain, for example, that family members should have to choose between excellent care in a Catholic facility and less optimal care in another facility. It may also be the case that families have few if any other options than the Catholic facility, either due to insurance or the lack of other options.

Not allowing certain actions as a condition for admission, such as prohibiting physician aid in dying in a facility, can and should be done in the Catholic setting. However, requiring indefinite consent to even basic care as a condition for admission is not as simple. Certainly upon admission families need to understand our moral stance. Still, in most cases, we are limited in what we can do on this issue because our actions depend on the consent of another, and it will not always be possible, feasible or pastorally desirable to transfer the patient to another facility.

It is important that the communities served by Catholic health care understand that the wishes of patients, their health care representatives or surrogate will ultimately be respected as provided by law. If we cannot withdraw AANH for a PVS patient in our care as requested, we will work with the family, health care representative or surrogate to see if the patient can be transferred to a facility where this can be done, and that we will effect this transfer with as little disruption to the patient and his or her loved ones as is humanly possible.

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NOTES

1. This is an important point. Although Terri Schiavo lived 15 years, studies show that mortality rates for patients in PVS are 70 percent at three years and 84 percent at five years due to medical complications. See, The Multi-Society Task Force on PVS, "Medical Aspect of the Persistent Vegetative State—A Correction." *The New England Journal of Medicine* 333 (1995) 130-a.
2. Kirk Payne, MD; Robert M. Taylor, MD; Carol Stocking, PhD; and Greg A. Sachs, MD, "Physicians' Attitudes about the Care of Patients in the Persistent Vegetative State: A National Survey." *Annals of Internal Medicine* 125 (1996): 104-110.
3. The Multi-Society Task Force on PVS, "Medical Aspect of the Persistent Vegetative State - First of Two Parts." *NEJM* 330 (1994) 1499-1508. See also "Medical Aspects of the Persistent Vegetative State - Second of Two Parts." *NEJM* 330 (1994) 1572-1579.
4. S. Laureys, et al., "Cortical processing of noxious somatosensory stimuli in the persistent vegetative state." *Neuroimage* 2002 Oct; 17(2):732-41.