Memo to CHAS Institutional Members
Re: Papal Instruction on the Use of Nutrition & Hydration Tubes
For Patients in a Permanent Vegetative State
From: Mark Miller, Ethicist

On March 20, 2004 Pope John Paul II spoke on the issue of using nutrition/hydration tubes for persons in a permanent vegetative state. His statement was the first official (i.e., from Rome) commentary specifically on this issue. As a presentation at an international ethics conference, his statement is not seen as a definitive pronouncement. Rather it has, to quote canon lawyer Fr. Frank Morrissey, the authority of leading an ongoing ecclesial discussion on this topic. And, at the present time, there is significant discussion taking place within the Catholic community about the meaning and application of the Pope's statement.

For members of CHAS, I would like to give my understanding of both what the Pope said and what the Pope did not say. Then I will suggest how this teaching may be implemented in our facilities.

It is important to note that Pope is focusing his attention narrowly on the issue of "persons in a persistent vegetative state," rather than providing any general direction for persons at the end of life, even if in a comatose state. **The persistent/permanent vegetative state (PVS) occurs when all of the brain has died, irreversibly, except the brain stem**, which keeps the body functioning (heart beat, temperature control, respiration, etc.). PVS involves a total lack of consciousness and, as far as we can tell, no sensation or pain, despite sleep/wake cycles, and occasional reflex responses like twitches. "Persistent" means that the diagnosis is not definite; the state is vegetative but nobody knows if it is irreversible (i.e., it may be some form of coma). Modern diagnostic tests can generally confirm this state relatively quickly, but in some cases it may take 9 to 12 months to confirm the diagnosis. The person is then said to be in a **permanent vegetative state**, which is irreversible, meaning that there is no chance of regaining awareness. At this point, says the Pope, other persons cannot make the decision to withdraw the nutrition/hydration tube because the only purpose would be to let the person die which is to intend the death of the patient.

It is also important to understand that a permanent vegetative state is only one form of a coma. People may recover from various kinds of comas; they cannot regain awareness if in a true permanent vegetative state. Hence the importance of a correct diagnosis.

To say that the Pope's statement refers rather narrowly to persons in a permanent vegetative state, in my opinion, means that he is not making a sweeping generalization about the use of feeding tubes at the end of life. The Pope does not speak to the situation where a patient could weigh the benefits and burdens of this treatment for him/herself under these circumstances and, for example, conclude that

the burdens outweigh any possible benefit. Following traditional Catholic principles concerning care, a patient could ethically refuse the treatment, just as the patient could refuse, as too burdensome, a ventilator or surgery or chemotherapy, any of which may be life-extending or life-saving. For many people such interventions are nothing more than prolonging the dying process. Of course, when one is no longer conscious and never will be again, then the decision would have to have been made previously in an advance health care directive or provided through wishes previously communicated to loved ones.

The Pope was also not speaking about the many other circumstances where a feeding tube may or may not be beneficial. Treatment choices near the end of life are made by persons suffering from end-stage lung disease, renal failure, a stroke, ALS, MS, cancer, etc. Good palliative care respects patient wishes about end-of-life treatment and strives to ensure that the patient is neither under-treated nor over-treated. Every person has the right to make his or her own decision about feeding tubes for themselves, and I am suggesting that this includes the case of a permanent vegetative state (again, using prior wishes). **What the Pope explicitly condemns is the making of this decision for another person without their known wishes.**

Two troubling aspects of the Pope's statement can and will be taken out of context and may be interpreted much more broadly than I think they should be. First, he speaks about "death by starvation." This language is not common in the care of the dying. Our understanding is that when patients are dying, the body shuts down in such a way that the provision of nourishment and even water may do more harm than good. Patients lose their appetites and feeding them may create problems with bloat, indigestion, reflux, diarrhea, etc. Too much water, through a tube or an IV, may increase congestive heart failure, damage kidneys, etc. Good palliative care aims neither at over-treating patients nor under-treating them. Hence, comfort care, in accord with patient wishes, becomes the foundation of proper care at the end of life. And when people are ready to die, there is no moral demand to drag out the dying process simply because we can keep persons alive with various medical interventions.

Second, the Pope states that "…the administration of water and food, even when provided by artificial means, always represents a natural means of preserving life, not a medical act." I am not at all sure what is meant by this statement because the use of a feeding/hydration tube in any patient care is certainly a medical act. However, perhaps the Pope is stressing that when a feeding tube is appropriately used, then it is an ordinary, natural form of care—which really adds little to the ethical issue of the proper use of these devices.

Health care providers need to understand that some Catholics will interpret this statement to mean that feeding tubes are ordinary care and therefore must be used when people cannot feed themselves. And we need to respect their decisions made in good conscience. But for anyone working in palliative care, this conclusion is not an absolute, requiring the use of feeding/hydration tubes, because all treatments have to

be for the good of the patient in accord with the patient's own weighing of benefits and burdens. Again, at times feeding tubes and hydration lines can cause more harm than good. And, at other times, the patient refuses them as too burdensome or simply prolonging the dying process.

Whether a patient (or family) chooses a feeding tube or not, our commitment is to care for those entrusted to us. Catholics (and others) may come to health care facilities (especially Catholic ones) and speak of not 'starving a loved one to death' or of 'having to accept the feeding tube as ordinary care.' Our response needs to be a respectful one that points out that patients die from complex problems and feeding tubes may or may not be appropriate care. We are obliged to inform them that any treatment that is too burdensome under the appropriate circumstances can be refused—and it is the patient who weighs the benefits and burdens of each treatment, even if through an instructed proxy.

Thus, the guidelines provided for Catholic health care facilities in the *Health Ethics Guide* continue to hold for assisting patients, residents and family to make these decisions. The only change is really a clarification that feeding tubes must be used in the particular case of the person in a permanent vegetative state who has never expressed any wishes about treatment. **We cannot assume that they would not want treatment and so we respectfully continue to care for them.**

What the Pope is adamant about in his teaching is that as long as human beings are alive—and he notes that the language around 'vegetative states' can be very misleading about the reality of a person being present—they deserve proper care. A person in a permanent vegetative state is alive and must be cared for, whether a feeding tube is used or refused. Good palliative care is appropriate for either situation.

I note in conclusion that the above reflections might make us doubly aware of encouraging people in our care to write advance health care directives, to appoint proxies, and especially to talk with loved ones about possible treatment decisions at the end of life or when they no longer have the capacity to make decisions. Most people (which does not mean 'everybody') that I talk to would not want to be kept alive in a permanent vegetative state or when suffering from severe, irreversible dementia. Not using or removing a feeding tube may be much less burdensome to some people than carrying on.

Even when they have stopped eating, people in palliative care generally do not starve to death. They are dying and we are caring for them. We respect their wishes to accept death as it comes and to accept or refuse particular treatments in accord with their own judgements about the benefits and burdens. In all situations, we must provide good palliative care.

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