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## A Linacre Institute Paper

# Assisted Nutrition and Hydration in Persistent Vegetative State

by

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Human bodily life is a great personal good. It is a good of the person and not merely for the person. Such life is inherently good and not merely instrumental to other goods. This philosophical starting point is profoundly and emphatically nondualistic: human bodily life is neither a nonhuman nor a subhuman good, but a true human good of the person.<sup>1</sup> To say that a human person lacks value if incapable of cognitive and affective function is to reduce human personal life to a good not inherent but merely instrumental to other goals.<sup>2</sup>

A patient in a persistent vegetative state is alive. Such a patient is not dying unless from some underlying disease separate and distinct from the persistent vegetative state. The patient is not in a state of suspended animation from which all possibility of recovery is foreclosed. The persistent vegetative state should be distinguished from coma. Coma and vegetative state are states devoid of consciousness. In order to be conscious, the patient must be awake and aware. A patient in a coma is neither awake nor aware. A patient in a vegetative state is awake but not aware. Awareness requires wakefulness but wakefulness can be present without awareness. It is the wakefulness of the vegetative state that those at the bedside find so unnerving — both family and physician.

The Multi Society Task Force on the medical aspects of PVS specified a set of seven criteria for the diagnosis of the vegetative state:

- 1) No evidence of awareness of self or environment and an inability to interact with others.
- 2) No evidence of sustained, reproducible, purposeful or voluntary behavioral responses to visual, auditory, tactile or noxious stimuli.
- 3) No evidence of language comprehension or expression.
- 4) Intermittent wakefulness and sleep-wake cycles.
- 5) Sufficiently preserved hypothalamus and brain stem autonomic function to permit survival with medical and nursing care.
- 6) Bowel and bladder incontinence.
- 7) Variably preserved cranial nerve reflexes and spinal reflexes.

Criteria 1-3 are negative and 4-7 are positive. Furthermore, criteria 2 and 3 are subservient to criterion 1. If a patient lacks awareness of self, he will not respond to stimuli or language. The diagnosis therefore really comes down to one central criterion, i.e. no evidence of awareness of self or environment. If this continues for a month, the patient is said to be in a persistent vegetative state. After a year of persistence without improvement, the patient is said to be in a permanent vegetative state.

### **Reliability of Diagnosis an Issue**

How reliable, then, is the diagnosis of PVS? Two distinct possibilities qualify the reliability of the diagnosis. 1) The patient does exhibit evidence of awareness but the diagnostician has missed the relevant evidence and, 2) The patient does not exhibit any evidence of awareness but does, nevertheless, retain some measure of awareness. The evidence that some PVS patients may experience pain would imply that they are not devoid of awareness.

Evidence for lack of awareness may be established by 1) motor responses to stimuli, 2) cortical glucose consumption and 3) anatomical evidence of lesions so profound that awareness would not be retained. We should remember that when Karen Quinlan died, her autopsy showed that most of her cerebral mantle was intact.

It must be acknowledged that the cause of the vegetative state can relate to its prognosis. Non-traumatic injuries to the central nervous system have a worse prognosis than those that are traumatic. In any event, the use of the term "permanent" is really creating a false impression of certainty of irreversibility since the most we are entitled to say in any case is that recovery of consciousness is "unlikely." Even if PVS has been deemed permanent by Task Force standards it is not correct to say that recovery of consciousness is "impossible."

This is important because of studies that have been done which involve polls taken of normal persons thinking prospectively about the

possibility of life in a persistent vegetative state. These studies have posited the notion of life in PVS *without possibility of recovery*.<sup>4,5</sup> These studies would support the presumption that a majority (but not all) of people would choose prospectively to reject life-sustaining treatment if the presumption was that they would *never* recover consciousness. They would infer that such a life would be meaningless and burdensome to others. However, if we honestly focus on prognostic uncertainties (not to mention mistaken diagnosis), some patients might come to a different conclusion. Some might conclude that existence in a state of impaired consciousness would not be a fate worse than death. One wonders what polls would show if people were asked if they wanted to be starved to death. One philosopher<sup>6</sup> suggests that a version of Pascal's wager applies to PVS. Since there is a possibility however slight that a PVS patient might regain consciousness, Stone states, "You have everything to win and nothing to lose if you gamble on staying alive. You may wake up and, if you do not, unconscious life is no worse than being dead. This argument concludes that it is in your interest to stay alive, the more so the younger you are." Recent dramatic cases of unexpected awakening in patients who had been in persistent vegetative states for as long as 20-30 years lend credence to this wager.

More recent technologies such as cerebral glucose metabolism, positive emission tomography and cerebral blood flow studies and radioisotopic imaging have complicated rather than clarified prognosis and diagnosis of entities such as the minimally conscious state<sup>7</sup> and the locked-in syndrome.<sup>3</sup>

Decisions to withhold or withdraw life-sustaining treatments for patients who have become incompetent may arise in various contexts. If instructional advance directives are in place, decisions are based on these instructional stipulations. If proxy directives are in place, health care providers would ordinarily follow the stipulations of the proxy health care agent. If there are no directives, as is frequently the case, the treatment team must identify a surrogate decision maker, ordinarily a family member or close personal friend. The understanding is that the surrogate would apply the substituted judgment standard. If no reliable basis exists for a substituted judgment, the surrogate would retreat to a best interest standard. If at any point the attending physician feels that the decision is contrary to his ethical principles and/or violates the patient's best interests, he must be free to refuse to concur and participate in the carrying out of the decision.

In the real world, conflict situations arise among patients who are in a persistent vegetative state and are *not* dying. Virtually every litigated case in the United States involved a patient who was not dying and in whom the decision to withhold food and drink would be the proximate cause of death. In such instances, the continuation of feedings does not constitute extraordinary care. The use of nasogastric feedings is probably a century

old and gastrostomies have been employed for at least 50 years and have become less invasive as laparoscopic methods have been perfected. Therefore the allegations that decisions regarding such feedings are a result of advances in life saving technologies are moot. Such feedings are frequently described as "artificial" nutrition and hydration. This is a misnomer, however, since tube feedings contain water, calories, protein, carbohydrates, fat, vitamins, etc., none of which is artificial. The same material used for tube feeding is also employed for dietary supplements in conscious patients on special diets. The appropriate term is not "artificial" feedings but "assisted" feedings. That is, the delivery of natural hydration and nutrition through a conduit. Some theologians<sup>8</sup> state that assisted feedings are the treatment for the "fatal pathology" consisting in the inability to chew and swallow. The nerves and muscles of deglutition are intact in PVS, however, and when patients awake from PVS, they awaken with the ability to chew and swallow as long as they remain conscious. No human being has ever survived to adulthood without assisted feeding since we are all born dependent upon it through infancy. The placing of a nasogastric tube by a nurse or the insertion of a gastrostomy by a physician may be a medical procedure. Feeding the patient through these conduits, however, is not a medical procedure, since lay people at the bedside in the home can perform it. Feeding the unconscious patient is ordinary care. In the celebrated court cases in which the court orders discontinuation of ANH the gastrostomy is typically not removed but hydration and nutrition are withheld. The effect of the court order then is thus not to discontinue medical treatment but to forego ordinary care. Providing this care is an important symbol of our human relatedness and commitment. Denying such care poses a serious threat to the relationship between the doctor and the patient as well as the relationship between the health care facility and the patient. Permitting the withdrawal of nutrition and hydration undermines the psychological separation between killing and letting die. Whether a patient is in a vegetative state or not is a medical question. Whether a patient should live or die is not merely a medical question. It is a complex moral, legal, philosophical social question.

Caring for the unconscious patient is an opportunity for the physician to recover the understanding that there remains a residual human wholeness, however precarious that can be served even in the face of the incurable.

Dying of dehydration and starvation must be a singularly unpleasant way to die. We have much testimony to that effect from those who were shipwrecked or trapped in a storm and *almost* starved or died from thirst. Some advocates declare categorically that comatose people are unaware of such discomfort. And yet we know from studies that some comatose patients have changes in heart rate, respiratory rate and other physiological

changes when merely spoken to lovingly at the bedside. How can we be so confident that they escape the agonies of starvation? In all of these cases we have testimony from nurses and relatives that watching a patient die from starvation and dehydration is a terrible experience for spectators. How long will it be before someone suggests that the more humane thing to do would be to put an end to the misery with a bolus of KCl?

In all candor we act mostly out of ignorance. We consign patients to hopelessness without research and investigation. In Israel, combat soldiers in coma were placed in an upright position and their calorie intake doubled. Prognosis for recovery increased by 50%.

A mother of a patient comatose for 19 years sensed that he was depressed. When the doctor gave him an antidepressant, Paxil, he woke up. A dentist working on a patient who had been in PVS for 20 years gave him Valium to abolish his grimace; he woke up and went home on Valium. Such occurrences emphasize our primitive ignorance and our need to explore fully the chemical and physiological milieu of the brain in PVS. The unwillingness of Catholic physicians to give up on PVS patients has been called a "futile vitalism" or a "lack of belief in an afterlife." In reality, we are only extending the protection of the human family. We have attached value and sought protection for our sister the embryo and our brother the fetus. Now we reach out to the patient in a persistent vegetative state. It may well be that in recognizing his irreducible value made in the image and likeness of God we are giving ourselves the opportunity to study him and, as a human subject, to improve his quality of life and find a solution to his return to consciousness.

### **Relevant Church Teachings**

The definition of euthanasia from the Sacred Congregation for the Doctrine of the Faith is as follows: "By euthanasia is understood an action or omission which of itself or by intention causes death in order that all suffering may be in this way eliminated." Thus the terms of reference pertain both to the intention of the will and the method used or omitted.

The *Ethical and Religious Directives for Catholic Health Facilities*<sup>10</sup> states, "The failure to supply ordinary means of preserving life is equivalent to euthanasia. However neither the physician nor the patient is obligated to use extraordinary means."

The *Declaration on Euthanasia* further states, "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 care due to the sick person is not interrupted."<sup>9</sup>

Pope John Paul II, in addressing the Human Leukemia Conference on November 15, 1985, further clarifies this principle when he states, "It does not dispense from the valid therapeutic task of sustaining life nor from the normal means of vital support. Science, even when it is unable to heal, can and should care for and assist the sick."<sup>11</sup> He further concretizes the statement of principle in the pediatric context in his address to the 11th European Congress on Perinatal Medicine (April 14, 1988) when he states, "Not even the parents themselves in the throes of emotion may request euthanasia by means of suspension of treatment and nourishment" (This was in reference probably to the starvation of handicapped infants in the Baby Doe case).

No one is arguing to use all means, at all costs for all persons in all circumstances, particularly those who are imminently dying and unable to benefit from the treatment.

The question really relates to patients who are not dying. The shift in emphasis in the so-called "Right to Die" Movement in their propaganda and their litigation from *dying* patients to patients who are *not dying* is an ominous change indeed. The precise question is not whether to treat comatose non-dying patients but rather whether to conserve or sustain their lives. Since feeding is ordinary care, our choice is really between caring for such persons or abandoning them.

Supporting life, keeping a person alive, does benefit the person because it expresses a love of neighbor. It maintains human solidarity that affirms the dignity of both patient and caregiver. Human communion with and solidarity among persons is a robust bulwark against the euthanasia movements.

Between the first cry of a baby being born and the last breath of an old man dying in peace, so runs our course and to those who would introduce the curet at one end of life and the knockout drops at the other, we would proclaim our unyielding opposition.

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