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## Nutrition and Hydration: Moral and Pastoral Reflections

### A Statement of the NCCB Committee for Pro-Life Activities

April 1992

#### Introduction

Modern medical technology seems to confront us with many questions not faced even a decade ago. Corresponding changes in medical practice have benefited many but have also prompted fears by some that they will be aggressively treated against their will or denied the kind of care that is their due as human persons with inherent dignity. Current debates about life-sustaining treatment suggest that our society's moral reflection is having difficulty keeping pace with its technological progress.

A religious view of life has an important contribution to make to these modern debates. Our Catholic tradition has developed a rich body of thought on these questions, which affirms a duty to preserve human life but recognizes limits to that duty.

Our first goal in making this statement is to reaffirm some basic principles of our moral tradition, to assist Catholics and others in making treatment decisions in accord with respect for God's gift of life.

These principles do not provide clear and final answers to all moral questions that arise as individuals make difficult decisions. Catholic theologians may differ on how best to apply moral principles to some questions not explicitly resolved by the Church's teaching authority. Likewise, we understand that those who must make serious health care decisions for themselves or for others face a complexity of issues, circumstances, thoughts, and emotions in each unique case.

This is the case with some questions involving the medically assisted provision of nutrition and hydration to helpless patients—those who are seriously ill, disabled, or persistently unconscious. These questions have been made more urgent by widely publicized court cases and the public debate to which they have given rise.

Our second purpose in issuing this statement, then, is to provide some clarification of the moral issues involved in decisions about medically assisted nutrition and hydration. We are fully aware that such guidance is not necessarily final, because there are many unresolved medical and ethical questions related to these issues, and the continuing development of medical technology will necessitate ongoing reflection. But these decisions already confront patients, families, and health care personnel every day. They arise whenever competent patients make decisions about medically assisted nutrition and hydration for their own present situation, when they consider signing an advance directive such as a "living will" or health care proxy document, and when families or other proxy decision makers make decisions about those entrusted to their care. We offer guidance to those who, facing these issues, might be confused by opinions that at times threaten to deny the inherent dignity of human life. We therefore address our reflections first to those who share our Judeo-Christian traditions, and second to others concerned about the dignity and value of human life who seek guidance in making their own moral decisions.

#### Moral Principles

The Judeo-Christian moral tradition celebrates life as the gift of a loving God, and respects the life of each human being because each is made in the image and likeness of God. As Christians we also believe we are redeemed by Christ and called to share eternal life with him. From these roots the Catholic tradition has developed a distinctive approach to fostering and sustaining human life. Our Church views life as a sacred trust, a gift over which we are given stewardship and not absolute dominion. The Church thus opposes all direct attacks on innocent life. As conscientious stewards we have a duty to preserve life, while recognizing certain limits to that duty:

1. Because human life is the foundation for all other human goods, it has a special value and significance. Life is "the first right of the human person" and "the condition of all the others."<sup>(1)</sup>
2. All crimes against life, including "euthanasia or willful suicide," must be opposed.<sup>(2)</sup> Euthanasia is "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." Its terms of reference are to be found "in the intention of the will and in the methods used."<sup>(3)</sup> Thus defined, euthanasia is an attack on life which no one has a right to make or request, and which no government or other human authority can legitimately recommend or permit. Although individual guilt may be reduced or absent because of suffering or emotional factors that cloud the conscience, this does not change the objective wrongfulness of the act. It should also be recognized that an apparent plea for death may really be a plea for help and love.
3. Suffering is a fact of human life, and has special significance for the Christian as an opportunity to share in Christ's redemptive suffering. Nevertheless there is nothing wrong in trying to relieve someone's suffering; in fact, it is a positive good to do so, as long as one does not intentionally cause death or interfere with other moral and religious duties.<sup>(4)</sup>
4. Everyone has the duty to care for his or her own life and health and to seek necessary medical care from others, but this does not mean that all possible remedies must be used in all circumstances. One is not obliged to use either "extraordinary" means or "disproportionate" means of preserving life—that is, means which are understood as offering no reasonable hope of benefit or as involving excessive burdens. Decisions regarding such means are complex and should ordinarily be made by the patient in consultation with his or her family, chaplain or pastor, and physician when that is possible.<sup>(5)</sup>
5. In the final stage of dying one is not obliged to prolong the life of a patient by every possible means: "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 normal care due to the sick person in similar cases is not interrupted."<sup>(6)</sup>
6. While affirming life as a gift of God, the Church recognizes that death is unavoidable and that it can open the door to eternal life. Thus,

"without in any way hastening the hour of death," the dying person should accept its reality and prepare for it emotionally and spiritually.(7)

7. Decisions regarding human life must respect the demands of justice, viewing each human being as our neighbor and avoiding all discrimination based on age or dependency.(8) A human being has "a unique dignity and an independent value, from the moment of conception and in every stage of development, whatever his or her physical condition." In particular, "the disabled person (whether the disability be the result of a congenital handicap, chronic illness or accident, or from mental or physical deficiency, and whatever the severity of the disability) is a fully human subject, with the corresponding innate, sacred and inviolable rights." First among these is "the fundamental and inalienable right to life."(9)

8. The dignity and value of the human person, which lie at the foundation of the Church's teaching on the right to life, also provide a basis for any just social order. Not only to become more Christian, but to become more truly human, society should protect the right to life through its laws and other policies.(10)

While these principles grow out of a specific religious tradition, they appeal to a common respect for the dignity of the human person. We commend them to all people of goodwill.

#### Questions About Medically Assisted Nutrition and Hydration

In what follows we apply these well-established moral principles to the difficult issue of providing medically assisted nutrition and hydration to persons who are seriously ill, disabled, or persistently unconscious. We recognize the complexity involved in applying these principles to individual cases and acknowledge that, at this time and on this particular issue, our applications do not have the same authority as the principles themselves.

#### 1. Is the withholding or withdrawing of medically assisted nutrition and hydration always a direct killing?

In answering this question one should avoid two extremes.

First, it is wrong to say that this could not be a matter of killing simply because it involves an omission rather than a positive action. In fact a deliberate omission may be an effective and certain way to kill, especially to kill someone weakened by illness. Catholic teaching condemns as euthanasia "an action or an omission which of itself or by intention causes death, in order that all suffering may in this way be eliminated." Thus "euthanasia includes not only active mercy killing but also the omission of treatment when the purpose of the omission is to kill the patient."(11)

Second, we should not assume that *all* or *most* decisions to withhold or withdraw medically assisted nutrition and hydration are attempts to cause death. To be sure, any patient will die if all nutrition and hydration are withheld.(12) But sometimes other causes are at work—for example, the patient may be imminently dying, whether feeding takes place or not, from an already existing terminal condition. At other times, although the shortening of the patient's life is one foreseeable result of an omission, the *real purpose* of the omission was to relieve the patient of a particular procedure that was of limited usefulness to the patient or unreasonably burdensome for the patient and the patient's family or caregivers. This kind of decision should not be equated with a decision to kill or with suicide.

The harsh reality is that some who propose withdrawal of nutrition and hydration from certain patients do directly *intend* to bring about a patient's death, and would even prefer a change in the law to allow for what they see as more "quick and painless" means to cause death.(13) In other words, nutrition and hydration (whether orally administered or medically assisted) are sometimes withdrawn not because a patient is dying, but precisely because a patient is not dying (or not dying quickly) and someone believes it would be better if he or she did, generally because the patient is perceived as having an unacceptably low "quality of life" or as imposing burdens on others.(14)

When deciding whether to withhold or withdraw medically assisted nutrition and hydration, or other forms of life support, we are called by our moral tradition to ask ourselves: What will my decision do for this patient? And what am I trying to achieve by doing it? We must be sure that it is not our intent to cause the patient's death—either for its own sake or as a means to achieving some other goal such as the relief of suffering.

#### 2. Is medically assisted nutrition and hydration a form of "treatment" or "care"?

Catholic teaching provides that a person in the final stages of dying need not accept "forms of treatment that would only secure a precarious and burdensome prolongation of life," but should still receive "the normal care due to the sick person in similar cases."(15) All patients deserve to receive normal care out of respect for their inherent dignity as persons. As Pope John Paul II has said, a decision to forgo "purely experimental or ineffective interventions" does not "dispense from the valid therapeutic task of sustaining life or from assistance with the normal means of sustaining life. Science, even when it is unable to heal, can and should care for and assist the sick."(16) But the teaching of the Church has not resolved the question whether medically assisted nutrition and hydration should always be seen as a form of normal care.(17)

Almost everyone agrees that oral feeding, when it can be accepted and assimilated by a patient, is a form of care owed to all helpless people. Christians should be especially sensitive to this obligation, because giving food and drink to those in need is an important expression of Christian love and concern (Mt. 10:42 and 25:35; Mk. 9:41). But our obligations become less clear when adequate nutrition and hydration require the skills of trained medical personnel and the use of technologies that may be perceived as very burdensome—that is, as intrusive, painful, or repugnant. Such factors vary from one type of feeding procedure to another, and from one patient to another, making it difficult to classify all feeding procedures as either "care" or "treatment."

Perhaps this dilemma should be viewed in a broader context. Even medical "treatments" are morally obligatory when they are "ordinary" means—that is, if they provide a reasonable hope of benefit and do not involve excessive burdens. Therefore, we believe people should make decisions in light of a simple and fundamental insight: *Out of respect for the dignity of the human person, we are obliged to preserve our own lives, and help others preserve theirs, by the use of means that have a reasonable hope of sustaining life without imposing unreasonable burdens on those we seek to help, that is, on the patient and his or her family and community.*

We must therefore address the question of benefits and burdens next, recognizing that a full moral analysis is only possible when one knows the effects of a given procedure on a particular patient.

#### 3. What are the benefits of medically assisted nutrition and hydration?

According to international codes of medical ethics, a physician will see a medical procedure as appropriate "if in his or her judgment it offers hope of saving life, reestablishing health or alleviating suffering."(18)

Nutrition and hydration, whether provided in the usual way or with medical assistance, do not by themselves remedy pathological conditions, except those caused by dietary deficiencies. But patients benefit from them in several ways. First, for all patients who can assimilate them, suitable food and fluids sustain life, and providing them normally expresses loving concern and solidarity with the helpless. Second, for patients being treated with the hope of a cure, appropriate food and fluids are an important element of sound health care. Third, even for patients who are imminently dying and incurable, food and fluids can prevent the suffering that may arise from dehydration, hunger, and thirst.

The benefit of sustaining and fostering life is fundamental, because life is our first gift from a loving God and the condition for receiving his other gifts. But sometimes even food and fluids are no longer effective in providing this benefit, because a patient has entered the final stage of a terminal condition. At such times we should make the dying person as comfortable as possible and provide nursing care and proper hygiene as well as companionship and appropriate spiritual aid. Such a person may lose all desire for food and drink and even be unable to ingest them. Initiating medically assisted feeding or intravenous fluids in this case may increase the patient's discomfort while providing no real benefit; ice chips or sips of water may instead be appropriate to provide comfort and counteract the adverse effects of dehydration.(19) Even in the case of the imminently dying patient, of course, any action or omission that of itself or by intention causes death is to be absolutely rejected.

As Christians who trust in the promise of eternal life, we recognize that death does not have the final word. Accordingly, we need not always prevent death until the last possible moment; but we should never intentionally cause death or abandon the dying person as though he or she were unworthy of care and respect.

#### 4. What are the burdens of medically assisted nutrition and hydration?

Our tradition does not demand heroic measures in fulfilling the obligation to sustain life. A person may legitimately refuse even procedures that effectively prolong life, if he or she believes they would impose excessively grave burdens on himself or herself, or on his or her family and community. Catholic theologians have traditionally viewed medical treatment as excessively burdensome if it is "too painful, too damaging to the patient's bodily self and functioning, too psychologically repugnant to the patient, too restrictive to the patient's liberty and preferred activities, too suppressive of the patient's mental life, or too expensive."<sup>(20)</sup>

Because assessment of these burdens necessarily involves some subjective judgments, a conscious and competent patient is generally the best judge of whether a particular burden or risk is too grave to be tolerated in his or her own case. But because of the serious consequences of withdrawing all nutrition and hydration, patients and those helping them make decisions should assess such burdens or risks with special care.

Here we offer some brief reflections and cautions regarding the kinds of burdens sometimes associated with medically assisted nutrition and hydration.

*Physical risks and burdens.* The risks and objective complications of medically assisted nutrition and hydration will depend on the procedure used and the condition of the patient. In a given case a feeding procedure may become harmful or even life-threatening. (These medical data are discussed at length in an appendix to this paper.)

If the risks and burdens of a particular feeding procedure are deemed serious enough to warrant withdrawing it, we should not automatically deprive the patient of all nutrition and hydration but should ask whether another procedure is feasible that would be less burdensome. We say this because some helpless patients, including some in a "persistent vegetative state," receive tube feedings not because they cannot swallow food at all but because the tube feeding is less costly and difficult for health care personnel.<sup>(21)</sup>

Moreover, because burdens are assessed in relation to benefits, we should ask whether the risks and discomfort of a feeding procedure are really excessive as compared with the adverse effects of dehydration or malnutrition.

*Psychological burdens on the patient.* Many people see feeding tubes as frightening or even as bodily violations. Assessments of such burdens are necessarily subjective; they should not be dismissed on that account, but we offer some practical cautions to help prevent abuse.

First, in keeping with our moral teaching against the intentional causing of death by omission, one should distinguish between repugnance to a particular procedure and repugnance to life itself. The latter may occur when a patient views a life of helplessness and dependency on others as itself a heavy burden, leading him or her to wish or even to pray for death. Especially in our achievement-oriented society, the burden of living in such a condition may seem to outweigh any possible benefit of medical treatment and even lead a person to despair. But we should not assume that the burdens in such a case always outweigh the benefits; for the sufferer, given good counseling and spiritual support, may be brought again to appreciate the precious gift of life.

Second, our tradition recognizes that when treatment decisions are made, "account will have to be taken of the *reasonable* wishes of the patient and the patient's family, as also of the advice of the doctors who are specially competent in the matter."<sup>(22)</sup> The word "reasonable" is important here. Good health care providers will try to help patients assess psychological burdens with full information and without undue fear of unfamiliar procedures.<sup>(23)</sup> A well-trained and compassionate hospital chaplain can provide valuable personal and spiritual support to patients and families facing these difficult situations.

Third, we should not assume that a feeding procedure is inherently repugnant to all patients without specific evidence. In contrast to Americans' general distaste for the idea of being supported by "tubes and machines," some studies indicate surprisingly favorable views of medically assisted nutrition and hydration among patients and families with actual experience of such procedures.<sup>(24)</sup>

*Economic and other burdens on caregivers.* While some balk at the idea, in principle cost can be a valid factor in decisions about life support. For example, money spent on expensive treatment for one family member may be money otherwise needed for food, housing, and other necessities for the rest of the family. Here, also, we offer some cautions.

First, particularly when a form of treatment "carries a risk or is burdensome" on other grounds, a critically ill person may have a legitimate and altruistic desire "not to impose excessive expense on the family or the community."<sup>(25)</sup> Even for altruistic reasons a patient should not directly intend his or her own death by malnutrition or dehydration, but may accept an earlier death as a consequence of his or her refusal of an unreasonably expensive treatment. Decisions by *others* to deny an incompetent patient medically assisted nutrition and hydration for reasons of cost raise additional concerns about justice to the individual patient, who could wrongly be deprived of life itself to serve the less fundamental needs of others.

Second, we do not think individual decisions about medically assisted nutrition and hydration should be determined by macro-economic concerns such as national budget priorities and the high cost of health care. These social problems are serious, but it is by no means established that they require depriving chronically ill and helpless patients of effective and easily tolerated measures that they need to survive.<sup>(26)</sup>

Third, tube feeding alone is generally not very expensive and may cost no more than oral feeding.<sup>(27)</sup> What is seen by many as a grave financial and emotional burden on caregivers is the total long-term care of severely debilitated patients, who may survive for many years with no life support except medically assisted nutrition and hydration and nursing care.

The difficulties families may face in this regard, and their need for improved financial and other assistance from the rest of society, should not be underestimated. While caring for a helpless loved one can provide many intangible benefits to family members and bring them closer together, the responsibilities of care can also strain even close and loving family relationships; complex medical decisions must be made under emotionally difficult circumstances not easily appreciated by those who have never faced such situations.

Even here, however, we must try to think through carefully what we intend by withdrawing medically assisted nutrition and hydration. Are we deliberately trying to make sure that the patient dies, in order to relieve caregivers of the financial and emotional burdens that will fall upon them if the patient survives? Are we really implementing a decision to withdraw all other forms of care, precisely because the patient offers so little response to the efforts of caregivers? Decisions like these seem to reach beyond the weighing of burdens and benefits of medically assisted nutrition and hydration as such.

In the context of official church teaching, it is not yet clear to what extent we may assess the burden of a patient's total care rather than the burden of a particular treatment when we seek to refuse "burdensome" life support. On a practical level, those seeking to make good decisions might assure themselves of their own intentions by asking: Does my decision aim at relieving the patient of a particularly grave burden imposed by medically assisted nutrition and hydration? Or does it aim to avoid the total burden of caring for the patient? If so, does it achieve this aim by deliberately bringing about his or her death?

Rather than leaving families to confront such dilemmas alone, society and government should improve their assistance to families whose financial and emotional resources are strained by long-term care of loved ones.<sup>(28)</sup>

#### 5. What role should "quality of life" play in our decisions?

Financial and emotional burdens are willingly endured by most families to raise their children or to care for mentally aware but weak and elderly family members. It is sometimes argued that we need not endure comparable burdens to feed and care for persons with severe mental and physical disabilities, because their low "quality of life" makes it unnecessary or pointless to preserve their lives.(29)

But this argument—even when it seems motivated by a humanitarian concern to reduce suffering and hardship—ignores the equal dignity and sanctity of all human life. Its key assumption—that people with disabilities necessarily enjoy life less than others or lack the potential to lead meaningful lives—is also mistaken.(30) Where suffering does exist, society's response should not be to neglect or eliminate the lives of people with disabilities, but to help correct their inadequate living conditions.(31) Very often the worst threat to a good "quality of life" for these people is not the disability itself, but the prejudicial attitudes of others—attitudes based on the idea that a life with serious disabilities is not worth living.(32)

This being said, our moral tradition allows for three ways in which the "quality of life" of a seriously ill patient is relevant to treatment decisions.

1. Consistent with respect for the inherent sanctity of life, we should relieve needless suffering and support morally acceptable ways of improving each patient's quality of life.(33)
2. One may legitimately refuse a treatment because it would itself create an impairment imposing *new* serious burdens or risks on the patient. This decision to avoid the new burdens or risks created by a treatment is not the same as directly intending to end life in order to avoid the burden of living in a disabled state.(34)
3. Sometimes a disabling condition may directly influence the benefits and burdens of a specific treatment for a particular patient. For example, a confused or demented patient may find medically assisted nutrition and hydration more frightening and burdensome than other patients do because he or she cannot understand what it is. The patient may even repeatedly pull out feeding tubes, requiring burdensome physical restraints if this form of feeding is to be continued. In such cases, ways of alleviating such special burdens should be explored before concluding that they justify withholding all food and fluids needed to sustain life.

These humane considerations are quite different from a "quality of life" ethic that would judge individuals with disabilities or limited potential as not worthy of care or respect. It is one thing to withhold a procedure because it would impose new disabilities on a patient, and quite another thing to say that patients who already have such disabilities should not have their lives preserved. A means considered ordinary or proportionate for other patients should not be considered extraordinary or disproportionate for severely impaired patients solely because of a judgment that their lives are not worth living.

In short, while considerations regarding a person's quality of life have some validity in weighing the burdens and benefits of medical treatment, at the present time in our society judgments about the quality of life are sometimes used to promote euthanasia. The Church must emphasize the sanctity of life of each person as a fundamental principle in all moral decision making.

#### **6. Do persistently unconscious patients represent a special case?**

Even Catholics who accept the same basic moral principles may strongly disagree on how to apply them to patients who appear to be persistently unconscious—that is, those who are in a permanent coma or a "persistent vegetative state" (PVS).(35) Some moral questions in this area have not been explicitly resolved by the Church's teaching authority.

On some points there is wide agreement among Catholic theologians.

1. An unconscious patient must be treated as a living human person with inherent dignity and value. Direct killing of such a patient is as morally reprehensible as the direct killing of anyone else. Even the medical terminology used to describe these patients as "vegetative" unfortunately tends to obscure this vitally important point, inviting speculation that a patient in this state is a "vegetable" or a subhuman animal.(36)
2. The area of legitimate controversy does not concern patients with conditions like mental retardation, senility, dementia, or even temporary unconsciousness. Where serious disagreement begins is with the patient who has been diagnosed as completely and permanently unconscious after careful testing over a period of weeks or months.

Some moral theologians argue that a particular form of care or treatment is morally obligatory only when its benefits outweigh its burdens to a patient or the care providers. In weighing burdens, they say, the total burden of a procedure and the consequent requirements of care must be taken into account. If no benefit can be demonstrated, the procedure, whatever its burdens, cannot be obligatory. These moralists also hold that the chief criterion to determine the benefit of a procedure cannot be merely that it prolongs physical life, since physical life is not an absolute good but is relative to the spiritual good of the person. They assert that the spiritual good of the person is union with God, which can be advanced only by human acts, i.e., conscious, free acts. Since the best current medical opinion holds that persons in the persistent vegetative state (PVS) are incapable now or in the future of conscious, free human acts, these moralists conclude that, when careful diagnosis verifies this condition, it is not obligatory to prolong life by such interventions as a respirator, antibiotics, or medically assisted hydration and nutrition. To decide to omit non-obligatory care, therefore, is not to intend the patient's death, but only to avoid the burden of the procedure. Hence, though foreseen, the patient's death is to be attributed to the patient's pathological condition and not to the omission of care. Therefore, these theologians conclude, while it is always wrong directly to intend or cause the death of such patients, the natural dying process which would have occurred without these interventions may be permitted to proceed.

While this rationale is convincing to some, it is not theologically conclusive and we are not persuaded by it. In fact, other theologians argue cogently that theological inquiry could lead one to a more carefully limited conclusion.

These moral theologians argue that while particular treatments can be judged useless or burdensome, it is morally questionable and would create a dangerous precedent to imply that any human life is not a positive good or "benefit." They emphasize that while life is not the highest good, it is always and everywhere a basic good of the human person and not merely a means to other goods. They further assert that if the "burden" one is trying to relieve by discontinuing medically assisted nutrition and hydration is the burden of remaining alive in the allegedly undignified condition of PVS, such a decision is unacceptable, because one's intent is only achieved by deliberately ensuring the patient's death from malnutrition or dehydration. Finally, these moralists suggest that PVS is best seen as an extreme form of mental and physical disability—one whose causes, nature, and prognosis are as yet imperfectly understood—and not as a terminal illness or fatal pathology from which patients should generally be allowed to die. Because the patient's life can often be sustained indefinitely by medically assisted nutrition and hydration that is not unreasonably risky or burdensome for that patient, they say, we are not dealing here with a case where "inevitable death is imminent in spite of the means used."(37) Rather, because the patient will die in a few days if medically assisted nutrition and hydration are discontinued,(38) but can often live a long time if they are provided, the inherent dignity and worth of the human person obligates us to provide this patient with care and support.

Further complicating this debate is a disagreement over what responsible Catholics should do in the absence of a final resolution of this question. Some point to our moral tradition of probabilism, which would allow individuals to follow the appropriate moral analysis that they find persuasive. Others point to the principle that in cases where one might risk unjustly depriving someone of life, we should take the safer course.

In the face of the uncertainties and unresolved medical and theological issues, it is important to defend and preserve important values. On the one hand, there is a concern that patients and families should not be subjected to unnecessary burdens, ineffective treatments, and indignities when death is approaching. On the other hand, it is important to ensure that the inherent dignity of human persons, even those who are persistently unconscious, is respected, and that no one is deprived of nutrition and hydration with the intent of bringing on his or her death.

It is not easy to arrive at a single answer to some of the real and personal dilemmas involved in this issue. In study, prayer, and compassion, we continue to reflect on this issue and hope to discover additional information that will lead to its ultimate resolution.

In the meantime, at a practical level, we are concerned that withdrawal of all life support, including nutrition and hydration, not be viewed as appropriate or automatically indicated for the entire class of PVS patients simply because of a judgment that they are beyond the reach of medical treatment that would restore consciousness. We note the current absence of conclusive scientific data on the causes and implications of different degrees of brain damage, on the PVS patient's ability to experience pain, and on the reliability of prognoses for many such patients.(39) We do know that many of these patients have a good prognosis for long-term survival when given medically assisted nutrition and hydration, and a certain prognosis for death otherwise—and we know that many in our society view such an early death as a positive good for a patient in this condition. Therefore we are gravely concerned about current attitudes and policy trends in our society that would too easily dismiss patients without apparent mental faculties as non-persons or as undeserving of human care and concern. In this climate, even legitimate moral arguments intended to have a careful and limited application can easily be misinterpreted, broadened, and abused by others to erode respect for the lives of some of our society's most helpless members.

In light of these concerns, it is our considered judgment that while legitimate Catholic moral debate continues, decisions about these patients should be guided by a presumption in favor of medically assisted nutrition and hydration. A decision to discontinue such measures should be made in light of a careful assessment of the burdens and benefits of nutrition and hydration for the individual patient and his or her family and community. Such measures must not be withdrawn in order to cause death, but they may be withdrawn if they offer no reasonable hope of sustaining life or pose excessive risks or burdens. We also believe that social and health care policies should be carefully framed so that these patients are not routinely classified as "terminal" or as prime candidates for the discontinuance of even minimal means of life support.

#### **7. Who should make decisions about medically assisted nutrition and hydration?**

"Who decides?" In our society many believe this is the most important or even the only important question regarding this issue, and many understand it in terms of who has *legal* status to decide. Our Catholic tradition is more concerned with the principles for good *moral* decision making, which apply to everyone involved in a decision. Some general observations are appropriate here.

A competent patient is the primary decision maker about his or her own health care and is in the best situation to judge how the benefits and burdens of a particular procedure will be experienced. Ideally the patient will act with the advice of loved ones, of health care personnel who have expert knowledge of medical aspects of the case, and of pastoral counselors who can help explore the moral issues and spiritual values involved. A patient may wish to make known his or her general wishes about life support in advance; such expressions cannot have the weight of a fully informed decision made in the actual circumstances of an illness, but can help guide others in the event of a later state of incompetency.(40) Morally even the patient making decisions for himself or herself is bound by norms that prohibit the directly intended causing of death through action or omission and by the distinction between ordinary and extraordinary means.

When a patient is not competent to make his or her own decisions, a proxy decision maker who shares the patient's moral convictions, such as a family member or guardian, may be designated to represent the patient's interests and interpret his or her wishes. Here, too, moral limits remain relevant—that is, morally the proxy may not deliberately cause a patient's death or refuse what is clearly ordinary means, even if he or she believes the patient would have made such a decision.

Health care personnel should generally follow the reasonable wishes of patient or family, but must also consult their own consciences when participating in these decisions. A physician or nurse told to participate in a course of action that he or she views as clearly immoral has a right and responsibility either to refuse to participate in this course of action or to withdraw from the case, and he or she should be given the opportunity to express the reasons for such refusal in the appropriate forum. Social and legal policies must protect such rights of conscience.

Finally, because these are matters of life and death for human persons, society as a whole has a legitimate interest in responsible decision making.(41)

#### **Conclusion**

In this document we reaffirm moral principles that provide a basis for responsible discussion of the morality of life support. We also offer tentative guidance on how to apply these principles to the difficult issue of medically assisted nutrition and hydration.

We reject any omission of nutrition and hydration intended to cause a patient's death. We hold for a presumption in favor of providing medically assisted nutrition and hydration to patients who need it, which presumption would yield in cases where such procedures have no medically reasonable hope of sustaining life or pose excessive risks or burdens. Recognizing that judgments about the benefits and burdens of medically assisted nutrition and hydration in individual cases have a subjective element and are generally best made by the patient directly involved, we also affirm a legitimate role for families' love and guidance, health care professionals' ethical concerns, and society's interest in preserving life and protecting the helpless. In rejecting broadly permissive policies on withdrawal of nutrition and hydration from vulnerable patients, we must also help ensure that the burdens of caring for the helpless are more equitably shared throughout our society.

We recognize that this document is our first word, not our last word, on some of the complex questions involved in this subject. We urge Catholics and others concerned about the dignity of the human person to study these reflections and participate in the continuing public discussion of how best to address the needs of the helpless in our society.

#### **Appendix: Technical Aspects of Medically Assisted Nutrition and Hydration**

Procedures for providing nourishment and fluids to patients who cannot swallow food orally are either "parenteral" (bypassing the digestive tract) or "enteral" (using the digestive tract).

Parenteral or intravenous feeding is generally considered "more hazardous and more expensive" than enteral feeding.(42) It can be subdivided into peripheral intravenous feeding (using a needle inserted into a peripheral vein) and central intravenous feeding, also known as total parenteral feeding or hyperalimentation (using a larger needle inserted into a central vein near the heart). Peripheral intravenous lines can provide fluids and electrolytes as well as some nutrients; they can maintain fluid balance and prevent dehydration, but cannot provide adequate nutrition in the long-term.(43) Total parenteral feeding can provide a more adequate nutritional balance, but poses significant risks to the patient and may involve costs an order of magnitude higher than other methods of tube feeding. It is no longer considered experimental and has become "a mainstay for helping critically ill patients to survive acute illnesses where the prognosis had previously been nearly hopeless," but its feasibility for lifelong maintenance of patients without a functioning gastrointestinal tract has been questioned.(44)

Because of the limited usefulness of peripheral intravenous feeding and the special burdens of total parenteral feeding—and because few patients so completely lack a digestive system that they must depend on these measures for their sole source of nutrition—enteral tube feeding is the focus of the current debate over medically assisted nutrition and hydration. Such methods are used when a patient has a functioning digestive system but is unable or unwilling to ingest food orally and/or to swallow. The most common routes for enteral tube feeding are nasogastric (introducing a thin plastic tube through the nasal cavity to reach into the stomach), gastrostomy (surgical insertion of a tube through the abdominal wall into the stomach), and jejunostomy (surgical insertion of a tube through the abdominal wall into the small intestine).(45) These methods are the primary focus of this document.

Each method of enteral tube feeding has potential side effects. For example, nasogastric tubes must be inserted and monitored carefully so that they will not introduce food or fluids into the lungs. They may also irritate sensitive tissues and create discomfort; confused or angry patients may sometimes try to remove them; and efforts to restrain a patient to prevent this can impose additional discomfort and other burdens. On the positive side, insertion of these tubes requires no surgery and only a modicum of training.(46)

Gastrostomy and jejunostomy tubes are better tolerated by many patients in need of long-term feeding. Their most serious physical burdens arise from the fact that their insertion requires surgery using local or general anesthesia, which involves some risk of infection and other

complications. Once the surgical procedure is completed, these tubes can often be maintained without serious pain or medical complications, and confused patients do not often attempt to remove them.(47)

#### Notes

1. Congregation for the Doctrine of the Faith, *Declaration on Procured Abortion* (Washington, D.C.: United States Catholic Conference, 1974), no. 11.
2. Second Vatican Council, *Pastoral Constitution on the Church in the Modern World (Gaudium et Spes)*, no. 27. Suicide must be distinguished from "that sacrifice of one's life whereby for a higher cause, such as God's glory, the salvation of souls or the service of one's brethren, a person offers his or her own life or puts it in danger," Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (Washington, D.C.: United States Catholic Conference, 1980), part 1.
3. Declaration on Euthanasia, part 2.
4. See *Declaration on Euthanasia*, part 3; United States Catholic Conference, *Ethical and Religious Directives for Catholic Health Facilities* (Washington, D.C.: United States Catholic Conference, 1971), directive 29.
5. *Declaration on Euthanasia*, part 4.
6. Ibid.
7. Ibid., Conclusion.
8. *Gaudium et Spes*, no. 27; *Declaration on Procured Abortion*, no. 12.
9. Vatican Statement on the International Year of Disabled Persons (March 4, 1981), section 1, no. 1, and section 2, no. 1 in *Origins* 10:47 (May 7, 1981): 747-748.
10. Declaration on Euthanasia, Introduction; Declaration on Procured Abortion, nos. 10-11, 21; Congregation for the Doctrine of the Faith, *Instruction on Respect for Human Life in Its Origin* (Boston: St. Paul Editions, 1987), part 3.
11. Archbishop John Roach, "Life-Support Removal: No Easy Answers," *Catholic Bulletin* (March 7, 1991): 1 (citing Biomedical Ethics Commission of the Archdiocese of St. Paul-Minneapolis).
12. "If all fluids and nutrition are withdrawn from any patient, regardless of the condition, he or she will die—inevitably and invariably. Death may come in a few days or take up to two weeks. Rarely in medicine is an earlier death for the patient so certain," Ronald E. Cranford, M.D., "Patients with Permanent Loss of Consciousness," in *By No Extraordinary Means*, ed. Joanne Lynn (Bloomington, Ind.: Indiana University Press, 1986), 191.
13. See the arguments made by a judge in the Elizabeth Bouvia case and by the attorneys in the Hector Rodas case, among others. See *Bouvia v. Superior Court*, 225 Cal. Rptr. 297, 307-308 (1986) (Compton, J., concurring); *Complaint for the Declaratory Relief in Rodas Case, Issues in Law and Medicine* 2 (1987): 499-501, quoted verbatim from *Rodas v. Erkenbrack*, no. 87 ev. 142 (Mesa County, Colo., filed Jan. 30, 1987).
14. As one medical ethicist observes, interest in a broadly permissive policy for removing nutrition and hydration has grown "because a denial of nutrition may in a long run become the only effective way to make certain that a large number of biologically tenacious patients actually die." Daniel Callahan, "On Feeding the Dying," *Hastings Center Report* 13 (October 1983): 22.
15. Alfred O'Rahilly, *Moral Principles* (Cork, Ireland: Cork University Press, 1948), no. 5.
16. Address to a Human Pre-Leukemia Conference, November 15, 1985: *Acta Apostolicae Sedis* 78 (1986): 361. Also see his October 21, 1985 address to a study group of the Pontifical Academy of Sciences: "Even when the sick are incurable, they are never untreatable; whatever their condition, appropriate care should be provided for them," *Acta Apostolicae Sedis* 78 (1986): 314; *Origins* 15:25 (December 5, 1985): 416.
17. Some groups advising the Holy See have ventured opinions on this point, but these do not have the force of official church teaching. For example, in 1985 a study group of the Pontifical Academy of Sciences concluded: "If a patient is in a permanent, irreversible coma, as far as can be foreseen, treatment is not required, but all care should be lavished on him, including feeding," Pontifical Academy of Sciences, "The Artificial Prolongation of Life," *Origins* 15:25 (December 5, 1985): 415. Since comatose patients cannot generally take food orally, the statement evidently refers to medically assisted feeding. Similar statements are found in Pontifical Council Cor Unum, *Question of Ethics Regarding the Fatally Ill and the Dying (Vatican City: Vatican Press, 1981)*, 9; "Ne Eutanasia Ne Accanimento Terapeutico," *La Civiltà Cattolica* 3280 (February 21, 1987): 324.
18. World Medical Association, *Declaration of Helsinki* (1975), II.1.
19. See Joyce V. Zerwekh, "The Dehydration Question," *Nursing* (January 1983): 47-51.
20. See William E. May et al., "Feeding and Hydrating the Permanently Unconscious and Other Vulnerable Persons," *Issues in Law and Medicine* 3 (Winter 1987): 208.
21. Ronald E. Cranford, "The Persistent Vegetative State: The Medical Reality (Getting the Facts Straight)," *Hastings Center Report* 18 (February/March 1988): 31.
22. *Declaration on Euthanasia*, part 4 (emphasis added).
23. Current ethical guidelines for nurses, while generally defending patient autonomy, reflect this concern: "Obligations to prevent harm and bring benefit . . . require that nurses seek to understand the patient's reasons for refusal. . . . Nurses should make every effort to correct inaccurate views, to modify superficially held beliefs and overly dramatic gestures, and to restore hope where there is reason to hope," American Nurses' Association Committee on Ethics, "Guidelines on Withdrawing or Withholding Food and Fluids," *BioLaw* 2 (October 1988): U1124-1125.
24. In one such study, "70 percent of patients and families were 100 percent willing to undergo intensive care again to achieve even one month of survival"; "age, severity of critical illness, length of stay, and charges for intensive care did not influence willingness to undergo intensive care," Danis et al., "Patients' and Families' Preferences for Medical Intensive Care," *Journal of the American Medical Association* 260 (August 12, 1988): 797. In another study, out of thirty-three people who had close relatives in a "persistent vegetative state," twenty-nine agreed with the initial decision to initiate tube feeding and twenty-five strongly agreed that such feeding should be continued, although none of those surveyed had made the decision to initiate it. See Tresch et al., "Patients in a Persistent Vegetative State: Attitudes and Reactions of Family Members," *Journal of the American Geriatrics Society* 39 (January 1991): 17-21.
25. *Declaration on Euthanasia*, part 4.

26. "In striving to contain medical care costs, it is important to avoid discriminating against the critically ill and dying, to shun invidious comparisons of the economic value of various individuals to society, and to refuse to abandon patients and hasten death to save money," Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying* (Briar Cliff Manor, N.Y.: Hastings Center, 1987), 120.
27. A possible exception is total parenteral feeding, which requires carefully prepared sterile formulas and more intensive daily monitoring. Ironically, some current health care policies may exert economic pressure in favor of TPN because it is easier to obtain third-party reimbursement. Families may pay more for other forms of feeding because some insurance companies do not see them as "medical treatment." See U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, OTA-BA-306 (Washington, D.C.: Government Printing Office, July 1987), 286.
28. "One can never claim that one wishes to bring comfort to a family by suppressing one of its members. The respect, the dedication, the time and the means required for the care of handicapped persons, even of those whose mental faculties are gravely affected, is the price that a society should generously pay in order to remain truly human," *Vatican Statement*, section II, no. 1 in *Origins*, p. 748 (see no. 9 above). The Holy See acknowledges that society as a whole should willingly assume these burdens, not leave them on the shoulders of individuals and families.
29. For example, see P. Singer, "Sanctity of Life or Quality of Life?" *Pediatrics* 72 (July 1983): 128-129. On the use and misuse of the term "quality of life," see Cardinal John O'Connor, "Who Will Care for the AIDS Victims?" *Origins* 19:33 (January 18, 1990): 544-548. Some Catholic theologians agree that a low "quality of life" justifies withdrawal of medically assisted feeding only from patients diagnosed as permanently unconscious. This argument is discussed separately in section 6 below.
30. See David Milne, "Urges MDs to Get Birth Defects Patient's Own Story," *Medical Tribune* (December 12, 1979): 6.
31. United States Catholic Conference, *Pastoral Statement of the U.S. Catholic Bishops on Persons with Disabilities* (Washington, D.C.: United States Catholic Conference, 1978).
32. Some patients with disabilities ask for death because all their efforts to build a life of self-respect are thwarted; a "right to die" is the first right for which they receive enthusiastic support from the able-bodied. See Paul K. Longmore, "Elizabeth Bouvia, Assisted Suicide and Social Prejudice," *Issues in Law and Medicine* 3 (Fall 1987): 141-168.
33. "Quality of life must be sought, in so far as it is possible, by proportionate and appropriate treatment, but it presupposes life and the right to life for everyone, without discrimination and abandonment," John Paul II, Address of April 14, 1988 to the Eleventh European Congress of Perinatal Medicine, *Acta Apostolicae Sedis* 80 (1988): 1426; *The Pope Speaks* 33 (1988): 264-265.
34. See Archbishop Roger Mahony, "Two Statements on the Bouvia Case," *Linacre Quarterly* 55 (February 1988): 85-87.
35. Coma and persistent vegetative state are not the same. Coma, strictly speaking, is generally not a long-term condition, for within a few weeks a comatose patient usually dies, recovers, or reaches the plateau of a persistent vegetative state. "Coma implies the absence of both arousal and content. In terms of observable behavior, the comatose patient appears to be asleep, but unlike the sleeping patient, he cannot be aroused from this state. . . . The patient in the vegetative state appears awake but shows no evidence of content, either confused or appropriate. He often has sleep-wake cycles but cannot demonstrate an awareness either of himself or his environment," Levy, "The Comatose Patient," in *The Clinical Neurosciences*, ed. R. Rosenberg (New York: Churchill Livingstone, 1983), 1:956.
36. While his pejorative connotation was surely not intended by those coining the phrase, we invite the medical profession to consider a less discriminatory term for this diagnostic state.
37. O'Rahilly, no. 5.
38. Because patients need nutritional support to live during the weeks or months of observation required for responsible assessment of PVS, the cases discussed here involve decisions about discontinuing such support rather than initiating it.
39. One recent scientific study of recovery rates followed up 84 patients with a firm diagnosis of PVS. Of these patients, "41 percent became conscious by six months, 52 percent regained consciousness by one year, and 58 percent recovered consciousness within the three-year follow-up interval." The study was unable to identify "predictors of recovery from the vegetative state," that is, there is no established test by which physicians can tell in advance which PVS patients will ultimately wake up. The data "do not exclude the possibility of vegetative patients regaining consciousness after the second year," though this "must be regarded as a rare event," H. S. Levin, C. Saydjari, et al., "Vegetative State After Closed-Head Injury: A Traumatic Coma Data Bank Report," *Archives of Neurology* 48 (June 1991): 580-585.
40. Some Catholic moralists, using the concept of a "virtual intention," note that a person may give spiritual significance to his or her later suffering during incompetency by deciding in advance to join these sufferings with those of Christ for the redemption of others.
41. See NCCB Committee for Pro-Life Activities, "Guidelines for Legislation on Life-Sustaining Treatment" (November 10, 1984), *Origins* 14:32 (January 24, 1985): 526-528; "Statement on the Uniform Rights of the Terminally Ill Act" (June 1986), *Origins* 16:12 (September 4, 1986): 222-224; United States Catholic Conference, Brief as *Amicus Curiae* in Support of Petitioners, "*Cruzan v. Director of Missouri Department of Health v. McCaense*," U.S. Supreme Court, No. 88-1503, *Origins* 19:21 (October 26, 1989): 345-351.
42. David Major, M.D., "The Medical Procedures for Providing Food and Water: Indications and Effects," in *By No Extraordinary Means*, ed. Joanne Lynn (Bloomington, Ind.: Indiana University Press, 1986), 27.
43. Peripheral veins (e.g., those found in an arm or leg) will eventually collapse after a period of intravenous feeding and will collapse much faster if complex nutrients such as proteins are included in the formula. See U.S. Congress, Office of Technology Assessment, *Life-Sustaining Technologies and the Elderly*, OTA-BA-306 (Washington, D.C.: U.S. Government Printing Office, July 1987), 283-284.
44. Major, 22, 24-25. Also see OTA, 284-286.
45. See Major, 22, 25-26.
46. Major, 22; OTA, 282-283; Ross Laboratories, *Tube Feedings: Clinical Applications* (1982), 28-30.
47. Major, 22; OTA, 282. Many ethicists observe that there is no morally significant difference in principle between withdrawing a life-sustaining procedure and failing to initiate it. However, surgically implanting a feeding tube and maintaining it once implanted may involve a different proportion of benefit to burden, because the transient risks of the initial surgical procedure will not continue or recur during routine maintenance of the tube.

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