

Father Tom Knoblach, Ph.D.

Consultant for Healthcare Ethics, Diocese of Saint Cloud

Introductory Comments

The provision of nutrition and hydration through the use of various medical interventions – often referred to imprecisely as “tube feeding” – remains one of the most complex and controversial issues in contemporary bioethics. Media attention, even nationally, has focused on a number of high-profile cases since the 1980s, involving persons receiving medically-assisted nutrition and hydration (MANH): Claire Conroy, Paul Brophy, Nancy Cruzan, Christine Busalacchi, Jamie Butcher, Hugh Finn, and Terri Schiavo are just a few of the familiar names. In addition, many other persons are also recipients of MANH; their cases, though not covered by the media, often share the same complex moral issues of how best to care for those who cannot take food or water on their own in a normal manner. Controversy often arises with patients who are diagnosed in a “persistent vegetative state” (PVS), in which brain stem functions like temperature regulation, wake/sleep cycles, and other autonomic nervous system functions continue, but all detectible activity of the neocortex has ceased, with no expected prospects for recovery.

The Current Teaching

Directive 58 of the U.S. Bishops’ ***Ethical and Religious Directives for Catholic Health Care Services*** (ERD) succinctly summarized Catholic teaching on this complex question:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

As a preamble to a fuller discussion of the history of this teaching, contrast this detailed discussion with the previous version of Directive 58, which had correctly but more implicitly stated:

There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.

In order to interpret and apply Directive 58 in accord with Catholic teaching, it will be helpful to understand the context of this evolution in the statements cited above.

A Complex Question

There is a great deal of complexity to the question of MANH behind the headlines, even apart from the ethical controversies. Nutrition and hydration can be provided by a variety of medical means, with varying degrees of risk and side effects. A nasogastric (NG) tube is inserted through the nose and into the stomach, and is better suited to short-term MANH. A percutaneous endogastric tube (PEG tube) passes through an incision in the abdominal wall and into the stomach. A jejunostomy tube also passes through the abdomen into a portion of the small intestine. In addition to tubes that enter the digestive system, MANH can also be provided directly into the bloodstream through total parenteral nutrition (TPN).

Further, MANH can be used to address a range of medical situations. Sometimes MANH is a short-term, bridge technology until the person can resume regular eating and drinking. At other times, it is required indefinitely to sustain life. Some persons need MANH because there is no other way to receive needed nutrients and fluids for medical reasons; some receive MANH because of shortages of staff to do oral feeding.

And, the condition and prognosis of persons receiving MANH can vary greatly. Important ethical differences exist between patients who depend solely on MANH for continued survival but are otherwise not in a terminal condition, and patients who are receiving MANH but for whom death is imminent for some other reason.

Thus, as with any other determination about medical interventions, an informed decision about the use of MANH must take into account all the relevant factors: the person's diagnosis, prognosis, and current condition with any complicating factors regarding the use of MANH; what are the treatment goals of the person and of the medical staff caring for that person; what means of MANH is envisioned, and for how long; the relative benefits to be realized and burdens to be endured by the person with the means in question; and what are the side-effects, risks, costs, and alternatives to using MANH in this situation. There is no single, simple answer to the question of the feeding tube.

A Long Debate

The ethical debate over MANH has a long history, which will not be reviewed here. Over forty courts in the U.S. have addressed this issue in the past several decades, and an almost universal legal consensus exists that MANH are medical treatments that may be withheld or withdrawn following the same decision-making process as would be used for any medical procedure. These court decisions have relied heavily upon the legal principle of individual autonomy in making health care decisions.

Since many of these cases have involved persons who lacked decision-making capacity, the courts have spurred development of advance directives and the value of ethics consultation. Their decisions have extended the notion of individual autonomy through such concepts as the ***“subjective standard”***

(relying upon any prior explicit oral or written statements made by the person to guide current treatment decisions);

“substituted judgments”

(attempting to discern what the person would have wanted based on knowledge of his or her personal value system and other statements of preference); and the

“best interests”

standard (in the absence of knowledge about the person's preferences regarding treatment decisions, the attempt is made to discern what would be in the person's best interests in light of what is known of his or her life plan, the standards of medical practice, the person's diagnosis and prognosis, and the overall context of the situation).

Within the medical field, less consensus exists. Surveys suggest that responding clinicians are divided roughly down the middle: about half think that MANH is more like basic care and therefore must be considered by different standards, while about half support considering MANH by the same decision-making standards as with any other medical intervention. Yet even these latter clinicians generally think that withholding or withdrawing MANH is appropriate only when 1) it is truly medically futile; that is, unlikely to provide effective nutritional support or to

prevent dehydration; or 2) when the patient would experience no real benefit beyond maintaining biological life; or 3) when the burdens for the patient outweigh the benefits expected from using MANH.

While these conditions are fairly easy to state in concise terms, assessing each of them is accompanied with imprecision, subjective judgments, and various subjective interpretations of what is meant by futility, benefit, and burden. Individuals may agree with these general principles but reach very different conclusions about particular cases. This is not surprising; a mathematical degree of certitude is not to be expected in ethical decisions. As the great Greek philosopher Aristotle wrote over 2300 years ago: “It is wisdom to expect no more certainty than the subject matter allows.” When controversial, life-and-death questions arise, our often-unexamined presumptions must be made explicit. It is important to remember that people of good faith may disagree with the interpretation and application of ethical principles. In the face of this imprecision, we must also consider the degree to which important values – like life itself – may be put at risk.

Within the Catholic Tradition

Given the above considerations, it is not surprising that within the Catholic tradition, a number of theologians and ethicists, along with various groups of bishops in the United States and elsewhere, have come to different conclusions in studying this issue, and divergent viewpoints remain. Central questions continue to revolve around whether MANH is a medical intervention that can be withheld or withdrawn even if death is not imminent, or if it always constitutes basic and ordinary care; the difficulty in diagnosing PVS with certitude; how to make determinations about the quality of life of persons in PVS; how to assess the benefits and burdens associated with the use of MANH; and confusion about the various methods and uses of MANH.

Key documents for understanding the Church’s current teaching on MANH are the following: the Congregation of the Doctrine of the Faith (CDF), *Declaration on Euthanasia (Jura et bona)* (May 5, 1980); U.S. Bishops’ Committee on Pro-Life Activities, *Moral and Pastoral Reflections on Artificial Nutrition and Hydration* (April 2, 1992); U.S. Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, fourth edition (2001), directive 58; and John Paul II’s *allocutio* on March 20, 2004 to the International Congress on “Life-Sustaining Treatments and the Vegetative State: Scientific Progress and Ethical Dilemmas.” Following the 2004 allocutio, the Terri Schiavo case focused worldwide attention on the question, and the CDR issued a Response to two questions on MANH from the U.S. Bishops. In light of this Response, Directive 58 was revised in 2009. Highlights of the history of this complex development of teaching follow.

1) The Declaration on Euthanasia

The CDF's 1980 *Declaration on Euthanasia (Jura et Bona)* stated the Church's continuous teaching that the direct and intentional killing of an innocent human being is wrong, even if done with a subjectively good intention to alleviate suffering. It also noted the increasing complexity of making decisions about the use of medical technology to sustain life, and emphasized the general principles that ordinary (or "proportionate") means are always to be used to sustain life, and that extraordinary (or "disproportionate") means may be used to sustain life although no one is morally required to use them. Even when the decision is made not to pursue extraordinary means, the normal care given to any sick person must be continued.

Jura et Bona

did not address the specific question of MANH. (For more information on these questions, see ***A Brief Ethical Primer on Medical Decisions Regarding Life-Sustaining Treatments in the Catholic Tradition.***)

2) The Moral and Pastoral Reflections on Artificial Nutrition and Hydration

The *Moral and Pastoral Reflections on Artificial Nutrition and Hydration* from the U.S. Bishops' Committee on Pro-Life Activities is an important piece in the developing history of teaching in this issue, but it does not carry the Magisterial weight of the other documents cited. It was a work prepared by the Committee but not brought to a vote or approved by the full body of bishops. The research and reasoning regarding this question provide useful background, but it is perhaps most significant for its influence on the wording of Directive 58 of the *Ethical and Religious Directives for Catholic Healthcare Services* (ERD).

3) The Ethical and Religious Directives (4th Edition, 2001)

The ERDs are approved by the whole body of U.S. bishops and are periodically revised to stay current with developments in medical technology and moral theology. The latest version is the Fifth Edition, approved in 2009. Although the whole document was reviewed, the only change was Directive 58 Fourth Edition, approved in 2001.

Directives 56 and 57 restate the teaching of *Jura et Bona*:

Dir. 56. A person has a moral obligation to use ordinary or proportionate means of preserving his or her life. Proportionate means are those that in the judgment of the patient offer a reasonable hope of benefit and do not entail an excessive burden or impose excessive expense on the family or the community.

Dir. 57. A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope or benefit or entail an excessive burden, or impose excessive expense on the family or the community.

These are general principles, subject to interpretation and application in specific cases, as noted. In cases where the patient is not capable of rendering a competent judgment, a surrogate decision-maker steps in to assist with the moral discernment about life-sustaining means. This is discussed in directive 25:

Dir. 25. Each person may identify in advance a representative to make health care decisions as his or her surrogate in the event that the person loses the capacity to make health care decisions. Decisions by the designated surrogate should be faithful to Catholic moral principles and to the person's intentions and values, or if the person's intentions are unknown, to the person's best interests. In the event that an advance directive is not executed, those who are in a position to know best the patient's wishes – usually family members and loved ones – should participate in the treatment decisions for the person who has lost the capacity to make health care decisions.

Because of the complexity and controversy that continue to surround MANH, these general principles were applied to this specific technology in the earlier versions of directive 58, following the lead of the 1992 *Moral and Pastoral Reflections on Artificial Nutrition and Hydration*:

Dir. 58. There should be a presumption in favor of providing nutrition and hydration to all patients, including patients who require medically assisted nutrition and hydration, as long as this is of sufficient benefit to outweigh the burdens involved to the patient.

Note that directive 58 speaks of a *presumption in favor* of MANH, but does not mandate its use in every case. The basic criterion for deciding whether this presumption in favor of MANH is verified in the specific case is that the benefits expected outweigh the burdens on the patient. Again, these general principles do not settle the complex question of the nature and assessment of these “benefits and burdens.” This leaves both room and need for interpretation. It was arguably to advance this interpretation of understanding the benefits and burdens of MANH in the persistent vegetative state, and to correct some misinterpretations that have developed within healthcare in the past fifteen to twenty years, that prompted Pope John Paul to address these questions in his *allocutio* of March 20, 2004.

The Papal Allocutio of March 20, 2004

The March 2004 papal *allocutio* is the latest and most authoritative statement of the Catholic position on MANH, although it only applies the earlier teaching on MANH to the specific and vexing question of MANH in PVS. This primer therefore discusses the *allocutio* with regard to MANH in PVS, and speculates on the possible implications of this papal teaching.

*It is essential to note that current papal teaching addresses in detail only the specific question of medically-assisted nutrition and hydration for persons presumed to be in the persistent vegetative state. While this is a crucial question, it is not the only situation in which MANH is employed. **Therefore, the views expressed in this Primer regarding the use of MANH in other situations do not represent definitive Church teaching as of this writing, but are strictly the interpretation of this author. As such teaching develops, this Primer will be adapted to reflect such developments***

The full text of this *allocutio* is found appended to this Primer. The following discussion summarizes the *allocutio* and discusses in more detail the particular texts that address MANH itself.

Pope John Paul delivered an allocution to the participants in the International Congress on “Life-Sustaining Treatments and the Vegetative State: Scientific Progress and Ethical Dilemmas,” held in Rome from March 17-20. This Congress was organized and promoted by the International Federation of Catholic Medical Associations (FIAMC), and by the Pontifical Academy for Life.

In the allocution, the Pope makes several key points important for understanding his remarks on MANH. First, he acknowledges the great and important contributions of scientists and researchers who dedicate themselves to investigate the “vegetative state.” He encourages their efforts to find better ways to diagnose it accurately, to predict its course, and to provide therapies and rehabilitation for persons in this condition to the extent possible. He notes the difficulties in correctly diagnosing the vegetative state, referring to studies that have shown up to 43% of patients misdiagnosed and to cases of recovery after a period of time and sometimes with persevering rehabilitative efforts. Currently, medical science simply cannot predict with accuracy which persons will recover consciousness and which will not, and why their cases diverge. At the same time, he accepts that some persons will indeed not recover and will remain in lifelong dependence on others.

The Pope goes on to comment that the term “permanent vegetative state” (PVS) [sometimes also known as persistent vegetative state] has been coined to indicate that recovery of consciousness is highly unlikely for those who have been in this state for over a year. (Medically, the type of brain injury influences this time period: for injuries caused by anoxia [lack of oxygen], unresponsiveness lasting longer than six months is considered “permanent;” while for traumatic brain injuries like blows and falls, a period of one year is allotted before the term “permanent” is assigned. The Pope’s comment covers both). He notes that PVS does not refer to a different diagnosis or separate condition, but simply reflects a *“conventional predictive judgment related to the fact that the recovery of the patient, statistically speaking, is always more difficult the longer the condition of the vegetative state is prolonged in time.”*

Next, the Pope notes that the term “vegetative state,” although it is in common usage, is unfortunate if it reflects a judgment of lower value or lesser dignity for PVS patients

. He says:

“I feel the need to reaffirm with vigor that the intrinsic worth and the personal dignity of every human being do not change, whatever might be the concrete circumstances of his life. A man, even if gravely ill or impeded in the exercise of his higher functions, is and will always be a man, never becoming a ‘vegetable’ ... Even our brothers and sisters who find themselves in the clinical condition of the “vegetative state” retain completely their human dignity. The loving attention of God the Father continues to rest on them, recognizing them as His children in

particular need of help.”

Due to the negative connotations of the term “vegetative state,” some have proposed new terminology, such as “post-coma unresponsiveness.”

Thus, PVS patients retain their complete human dignity. Their very dependence creates moral duties on the part of medical professionals, society, and the Church. Whether they will recover or die, they retain the right to basic health care

. He notes in particular their right to nutrition, hydration, hygiene, a comfortable environment, and the prevention of complications they might face due to being confined to bed. They also have the right to efforts at rehabilitation and to clinical monitoring of signs of eventual recovery. Thus, even though they may not recover awareness and meaningful interaction with others or their environment, PVS patients retain their moral claim, as persons, on the care and expertise of medical professionals and society.

Then, the Pope addresses the specific question of MANH in PVS:

In particular, I wish to underscore that the administration of water and food, even when given through artificial means, always represents a natural means of the conservation of life, not a medical act. Its use therefore will be considered, in principle, ordinary and proportionate, and as such morally obligatory, in the measure in which and to the extent that it is shown to achieve its proper end, which in this case consists of procuring the nutrition of the patient and the alleviation of suffering.

Several key points are made here. First, he addresses an ongoing debate about how to categorize MANH. Some have argued that assisted feeding in any way is a “medical act” (even when a patient is assisted by another to eat orally, without the complexities of feeding tubes). Pope John Paul asserts that this is a false interpretation, and that such assistance – no matter how delivered – is essentially a natural means to conserve life. He is arguably concerned to preserve the centrality of the person receiving care: the fact that one is being fed, bathed, housed, or clothed in a medical facility does not change the very nature of those acts of ordinary human life in “medical acts.” Taking an aspirin in a hospital bed, in a nursing home, or in one’s own kitchen, is in itself the same act. It does not become subject to radically different ethical standards by the “accident of place” (philosophically speaking).

Second, since providing nutrition and hydration is a natural means, it is *in principle ordinary and*

proportionate . “In principle” here means considering MANH in and of itself, apart from any extenuating circumstances that may be involved in the particular case. This can be interpreted as equivalent to Directive 58 of the ERD: that the presumption is in favor of its use. In other words, it is presumed that MANH will be used, and credible and sufficiently weighty evidence must be produced to show why it should not be used in a particular instance. This evidence must be based in medical reasons for the patient (as opposed to demographic, economic, or social reasons surrounding the patient), and must demonstrate that using MANH is “disproportionate” – in other words, that the burdens on the patient are out of proportion to the benefits the patient will receive from using MANH. This can be contrasted with what is arguably the prevailing presumption (legally and medically) that MANH will not be used in PVS, requiring instead that credible and sufficiently weighty evidence must be produced to show why it should be used. In either case, the evidence to be considered, based in the assessment of benefits and burdens, is the same. But the attitude and presumptions with which that evidence is evaluated is very different. Arguably, then, the Pope is attempting to counter the developing presumption that MANH in PVS is extraordinary in principle (that is, considered in and of itself) and requires strong evidence in order to use it. Instead, he is teaching that in principle, MANH is ordinary, that the presumption is in favor of its use, and that strong, medically-based evidence must be presented why it ought not be used in a specific case.

As a presumptively ordinary and proportionate means to conserve life, MANH for PVS patients is morally obligatory. This simply applies the teaching of *Jura et Bona* to the question. The next clause is crucial: “*in the measure in which and to the extent that it is shown to achieve its proper end, which in this case consists of procuring the nutrition of the patient and the alleviation of suffering.*” The Pope’s words do not require the use of MANH in every case: the moral obligation is conditioned by the medical efficacy of the means used to achieve its proper end: to nourish the patient and alleviate suffering. When it is medically demonstrable that these ends are not being achieved, the moral obligation to use MANH ceases. Thus Pope John Paul is not reversing the moral tradition on the use of life-sustaining means by requiring that a particular intervention (MANH) must be used in every case. He is simply specifying that the withholding or withdrawing of this particular intervention requires a founded medical reason not to provide the minimal and ordinary care of providing nutrition and hydration to the PVS patient.

It is also important that the Pope specifies the medical goals of MANH: the patient receives necessary nutrition and his or her suffering is alleviated. Eventual recovery of consciousness or the ability to interact meaningfully with others is not among the medical goals that must be attainable before the use of MANH is justified.

The Pope goes even further to specify that not only is the interruption of MANH in PVS unjustified when these means are achieving their own proper end, but that such an interruption constitutes euthanasia by omission when it is deliberately and intentionally done. In other words, when MANH is withheld or withdrawn precisely in order to bring about death (prompted by whatever subjective motivation), it is euthanasia and thus never morally justified.

Pope John Paul anticipates several objections to this treatment of MANH in PVS. He acknowledges the lack of certitude that can accompany judgments about matters such as the quality of life of the PVS patient, his or her suffering, and potential benefits enjoyed by the patient. Both the experience of benefits and burdens is conditioned by being in a persistent vegetative state, and by the very fact that such patients may not be conscious of benefits, neither are they conscious of burdens. Precisely because of this lack of certitude, the Pope appeals to the long moral tradition of erring on the side of preserving life when in doubt: *“even simple doubt of being in the presence of a living person already imposes the obligation of full respect and of abstaining from any action directed at anticipating his death.”*

Discussions of “quality of life” were developed in the course of wrestling with questions about the use of life-sustaining technology. This concept is acceptable in itself when it attempts to integrate the experience of benefits and burdens into the whole of the person’s life and its ultimate purpose, as *Jura et Bona* argued. However, “quality of life” judgments can sometimes be used to assert that the very lives of some persons are of lesser value or “quality” and that therefore less demanding moral standards can be employed in assessing interventions for those persons.

Pope John Paul notes that in practice, “quality of life” judgments are often motivated by psychological, social, and economic pressures. In other words, the meaning of “quality of life” is shifted subtly away from considering the subjective experience of benefits and burdens in the individual patient’s own life. Instead, “quality of life” can come to mean how persons around the patient assess benefits and burdens – either projecting their own interpretations of the experience of the patient’s benefits and burdens upon him or her, or effectively substituting considerations of

their own benefits and burdens in caring for the patient for his or her own benefits and burdens in receiving care. The focus is taken off the patient's quality of life in itself and placed upon the impact of the patient's life on others. While this is an important aspect to consider, since we are relational beings, the Pope insists that these relational, psychological, social, or economic factors cannot prevail over the right of the individual patient, even if severely debilitated, to ordinary care, including MANH when it is medically effective and therefore proportionate. The quality of life of an individual is something intrinsic and discovered by observation, not a measure of the individual's value as something extrinsic and either attributed or withheld by others.

As a final aspect of the consideration of the quality of life of the patient in PVS, he notes we cannot exclude the possibility that the person will experience suffering when MANH is withheld. As he writes: "modern techniques of clinical neurophysiology and of cerebral diagnosis through imaging in fact seem to indicate that elementary forms of communication and of analysis of stimuli perdure in these patients." Here again, in the face of doubt, we must do our best to err on the side of the avoidance of suffering, seeking clinical evidence rather than presumptions that the patient in PVS does not suffer.

Finally, the Pope concludes his *allocutio* by acknowledging the real sufferings and burdens experienced by families and other concerned persons when a loved one is afflicted with PVS. He asserts that it is not sufficient merely to teach that MANH may not be withdrawn based on false quality of life judgments; we must also promote those positive actions that will counteract pressures to resort to such judgments at all. First, he encourages concrete forms of support for families who have had a member afflicted with this "terrible condition": "they may not be left alone with their heavy human, psychological, and economic burden." Even when the financial cost of caring for PVS patients may not be particularly high, society has the responsibility to assist with this care, not only in terms of monetary help, but also the creation of organized networks for rehabilitation efforts, economic support to the family when the patient is returned home after rehabilitation efforts, and "the creation of structures of help in cases in which there may not be a family able to cope or to offer periods of respite to families at risk of psychological or moral weariness." Above all, these forms of support must not only provide the material necessities of care, but psychological support, spiritual counsel, pastoral care, and solidarity so that medical professionals and volunteers helping with care may be "understood by families as their allies in their struggles" and may help to "alleviate the isolation of the family and to help them to feel a precious part of society, and not abandoned from its network."

The 2007 "Response" by the Congregation of the Doctrine of the Faith

On August 1, 2007, the Congregation for the Doctrine of the Faith issued responses to two questions regarding artificial nutrition and hydration (ANH) for patients in a "vegetative state." These questions were submitted to the CDF by Bishop William Skylstad on behalf of the United

States Conference of Catholic Bishops. The full text is relatively brief:

Undoubtedly, the controversy surrounding the case of Terri Schiavo was an immediate impetus for presenting these questions to Rome, especially in light of the diverse interpretations given to Pope John Paul II's allocution on ANH in March, 2004, discussed above.

Legally, courts at all levels (in the U.S. and abroad) have almost always ruled that ANH is a form of medical treatment that, like any other, may be forgone or withdrawn if it is judged medically futile, is contrary to the patient's wishes, or is considered excessively burdensome. Vast amounts of literature have debated these points: what do we mean by "futility?" What if a patient's wishes are contrary to the emerging standard of medical practice, or to those of the family or medical team? What happens if the patient is unresponsive or psychologically impaired? How do we assess "benefit" and "burden" correctly, particularly for patients who will not regain full consciousness?

The questions submitted by the USCCB, then, were specifically related to the question of providing nutrition and hydration, even by artificial means, for patients in a "vegetative" state – that is, a state of minimal consciousness with internal regulation of temperature and respiration, sleep-wake cycles, and other basic life functions, but no discernible awareness of one's environment or purposeful activity. Such a state can be temporary or more enduring.

In response, the CDF simply restated the teaching of Pope John Paul's allocution:

The administration of food and water, even by artificial means, is in principle an ordinary and proportionate means of preserving life. It is therefore obligatory to the extent which, and for as long as, it is shown to accomplish its proper finality, which is the hydration and nourishment of

the patient. In this way suffering and death by starvation and dehydration are prevented.

The assumption here – and the accompanying CDF Commentary addresses this more fully – is that removing ANH would be the actual cause of death. The term “in principle” here means “in itself, all other things being equal,” thus prescinding from other medical conditions or terminal illnesses that the patient may have, which may alter this obligation.

Even if the vegetative state is judged permanent – that is, it is judged with moral certitude that the patient will never recover consciousness – this obligation continues; the mere conviction that the patient will not recover consciousness is not sufficient alone to justify withholding ANH if there are no other complications.

However, the obligation does not hold “in very remote places or in situations of extreme poverty” when it is physically impossible to provide ANH. Further, the CDF notes in its own *Commentary on the Response* :

... the possibility is not absolutely excluded that, in some rare cases, ANH 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.

In such cases, the obligation ceases.

These latter points were included to make clear that it is not intrinsically wrong to withhold or withdraw ANH, either; that is, it need not always be employed regardless of circumstances. The CDF is striving to engage the complexity of this question, which does not admit of a simple “yes or no” answer. Rather, prudential judgments regarding moral certitude are required, but beginning with the presumption in favor of ANH, even in a permanent vegetative state. “Presumption in favor of” ANH means that, in principle, ANH is ordinary care, and that strong, medically-based evidence must be presented why it ought

not

be used in a specific case. Such evidence does exist in some cases; but there must be serious, objective, and patient-centered reasons not to employ ANH.

Note again that these responses by the CDF relate specifically to the question of ANH for patients in a vegetative state – which is, thankfully, relatively rare. While the moral principles used in the Responses and Commentary definitely help to guide discussion about ANH in other circumstances (for instance, in dementia, trauma, or terminal illness), these documents do not authoritatively address these issues.

The 2009 Revision of Directive 58

Although this history is admittedly long and complicated, it is necessary to have some idea of the evolution of thinking to understand and correctly apply the revised Directive 58, cited above and repeated here for convenience:

In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the “persistent vegetative state”) who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be “excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.” For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort.

As noted above, the ERD are revised occasionally as health care evolves and Church teaching responds to changed circumstances. Although the whole text of the ERDs was reviewed, the only change made to the fifth edition in 2009 was this updating of Directive 58. Since much of the text of the Directive is taken from the CDF *Response*, it is clear that the changes to this wording is intended to incorporate this Magisterial teaching into the ERDs. It is therefore appropriate to interpret the newer Directive 58 in terms of the discussion in the previous section of this Primer.

Possible Implications for MANH in Other Conditions

Again, it is important to keep Pope John Paul II's remarks in the 2004 allocution in their proper and intended context: he was speaking specifically about the provision of MANH to patients judged to be in the persistent vegetative state. Extrapolating his teaching to the use of MANH in other medical conditions must be done carefully, with respect and docility for the Pope's actual teaching and the broader Catholic moral tradition of which it is an integral part. This impression is confirmed in both the 2007 Response and the 2009 ERDs: although there was clear opportunity to expand the application of the teaching to other conditions, this expansion was not made explicit.

That being said, it is the opinion of the author of this Primer that it is important to avoid two extremes: first, that this more recent teaching since 2004 is immediately and directly applicable to all patients receiving MANH, and second, that the teaching has no relevance for discerning the use of MANH for patients not in a persistent vegetative state. I believe that both of these extremes are false. The first is false because both Pope John Paul II and the CDF addressed very specific and limited questions, and did not explicitly comment on the use of MANH in general. To generalize these remarks and apply them authoritatively to questions not addressed does not respect the integrity of the actual teaching. On the other hand, both the Pope and the CDF refer to the broader ethical tradition of the Church on limits to the use of medical technology and it is equally an error to ignore this broader context.

Much of the quandary about how this more recent teaching applies to other uses of MANH can be resolved if it is read in light of that larger tradition. It is my opinion that the Pope, the CDF, and the U.S. bishops did not intend to introduce any new teaching or to single out MANH as an exception to the traditional discernment of ordinary and extraordinary means. Rather, I suggest this teaching corrects some prevalent misinterpretations of that traditional discernment, and underscore some of its key points.

Arguably, these key points include:

- 1) the inviolable dignity of the human person, regardless of his or her state of development or decline
- 2) the right of each person to receive ordinary means to preserve life and alleviate discomfort

3) the necessity that judgments that using a medical technology is futile or excessively burdensome be based on the actual medical condition and status of the patient, and not on external and potentially arbitrary evaluations of that person's "quality of life" or abstract discussions about a particular technology or intervention out of the context of that patient's situation

4) assuring that even if a means is determined to be extraordinary or disproportionate, and is thus withheld, the person must still be the object of care, comfort, and love

5) that the value of the person's life does not depend on some functional criteria or capacities, but simply on his or her being made in the image of God, redeemed by Christ, and called to eternal life

6) that even a radically poor prognosis does not justify intentional actions to end the person's life.

When making discernments about the use of MANH, whether the patient is in a PVS or not, it is important to recall that current teaching holds that there is a presumption in favor of its use. That is, all things being equal, even if the patient will not recover consciousness or normal health, the use of MANH to preserve life is presumed to be the appropriate course, and the evidence for and against its use in a particular case is to be weighed beginning with that presumption. As a presumption, however, it does not imply an exceptionless requirement to use MANH.

Several factors must be weighed in the discernment about a specific case. When applying the teaching to conditions the frail elderly are far more likely to suffer (such as Alzheimer's disease, Parkinson's disease, cancer, or stroke), both the benefits and burdens must be weighed. In such cases, the possible benefits include: improved nutritional status; the prolongation of life; the symbolic value of giving food and drink; relief of hunger and/or thirst when they are experienced by the patient; helping to preclude aspiration pneumonia from improper oral feeding; reducing the risk of pressure sores and infection due to poor nutrition and immobility; improving patient function; and providing comfort. The possible risks and burdens of MANH include: for nasogastric tubes: irritation and discomfort; the need for restraints if the tube is pulled out repeatedly by the patient; and for PEG tubes: infections; bowel perforation; diarrhea and cramping; nausea and vomiting; blockage; leaking from the tube; aspiration if improper

methods of feeding are used. With any form of MANH, if the body can no longer assimilate what is provided by the tubes, and death is imminent, providing MANH can actually serve to increase the patient's discomfort.

It is crucial to note that there is no clear consensus on how to assess and weigh some of these benefits and risks, and no decisive evidence on its advantages or disadvantages for many patients as a class (for instance, those with dementia). The use of MANH remains a controversial and complex question. However, it is my opinion that the broader Catholic tradition on discerning whether a given medical intervention is an ordinary/proportionate or extraordinary/disproportionate means can be reliably applied to MANH as well. I believe the CDF's own Commentary on its 2007 Response confirms this interpretation. We remain obliged to respect life as a gift from God that is to be preserved when reasonably possible, but one that can be surrendered back to Him in good conscience when the benefits of its preservation by medical means are outweighed by the burdens connected with those means.

Appendix: The Text of the Papal Allocutio of March 20, 2004

[N.B.: the allocutio was originally written in Italian. This translation is by the author. The Italian text and the Vatican translation into English can be found at www.vatican.va]

This morning, the Holy Father John Paul II received in audience the participants in the (March 17-20, 2004, at the Augustinianum), organized and promoted by the International Federation of Catholic Medical Associations (FIAMC), and by the Pontifical Academy for Life.

We report the following discourse that the Pope gave to those present in the course of the meeting:

Discourse of the Holy Father

Esteemed Ladies and Gentlemen!

1) Most cordial greetings to all of you who are participating in the International Congress on “Life-Sustaining Treatments and the Vegetative State: Scientific Progress and Ethical Dilemmas.” I wish to offer a particular greeting to Monsignor Elio Sgreccia, vice-president of the Pontifical Academy for Life, and to Professor Gian Luigi Gigli, President of the International Federation of Catholic Medical Associations and generous champion of the fundamental value of life, who acted as an eloquent spokesman of our common feelings.

This important Congress, organized jointly by the Pontifical Academy for Life and by the International Federation of Catholic Medical Associations, is confronting a theme of great relevance: the clinical condition called the “vegetative state.” The complex scientific, ethical, social, and pastoral implications of such a condition necessitate a profound reflection and a fruitful interdisciplinary dialogue, as shown in the substantial program of your work.

2) With living esteem and sincere hope, the Church encourages the efforts of the men of science who daily, and often with great sacrifices, dedicate their labors to study and research for the improvement of diagnostic, therapeutic, prognostic, and rehabilitative possibilities regarding these patients who are totally entrusted to those who care for and assist them. The person in the vegetative state, in fact, gives no evident sign of consciousness of self or of awareness of the environment, and seems incapable of interacting with others or of reacting to stimuli.

Scholars advise that is necessary first of all to persevere toward a correct diagnosis, which normally requires a long and attentive observation in specialized institutions, taking into account the high number of diagnostic errors reported in the literature. Not a few of these persons, with appropriate care and with programs aimed at rehabilitation, are able eventually to emerge from coma. Many others, on the contrary, unfortunately remain prisoners of their state even through a long period of time, without the need for technological support.

In particular, to indicate the condition of those whose “vegetative state” is prolonged for more than a year, the term “permanent vegetative state” has been coined. In reality, such a definition does not refer to a different diagnosis, but only to a conventional predictive judgment related to the fact that the recovery of the patient, statistically speaking, is always more difficult the longer the condition of the vegetative state is prolonged in time.

Nevertheless, it should not be forgotten or undervalued that there are well documented cases of

at least partial recovery, even after many years, which affirm that medical science, even today, is not yet able to predict with confidence which patients in this condition will be able to recover and which will not.

3. The deficiency of a patient in similar clinical conditions is not sufficient to put into doubt the persistence of the same “human quality,” so that the adjective “vegetative” (the use of which is now common) symbolically descriptive of a clinical state, might or must be referred instead to the sick person in such a way that degrades the fact of his worth and personal dignity. In this sense, one notices how terms, even confined to the clinical setting, may certainly not be the most appropriate in referring to human subjects.

Against similar tendencies of thought, I feel the need to reaffirm with vigor that the intrinsic worth and the personal dignity of every human being do not change, whatever might be the concrete circumstances of his life. A man, even if gravely ill or impeded in the exercise of his higher functions, is and will always be a man, never becoming a “vegetable” or an “animal.”

Even our brothers and sisters who find themselves in the clinical condition of the “vegetative state” retain completely their human dignity. The loving attention of God the Father continues to rest on them, recognizing them as His children in particular need of help.

4. Toward such persons, doctors and healthcare workers, society, and the Church have moral duties from which they may not exempt themselves without failing in their responsibilities whether of professional requirements or of human and Christian solidarity.

Those afflicted in the vegetative state, awaiting either recovery or their natural end, have therefore the right to basic health care (nutrition, hydration, hygiene, a comfortable environment, etc.), and to the prevention of complications joined to being bedridden. They also have the right to interventions aimed at rehabilitation and to the monitoring of clinical signs of eventual recovery.

In particular, I wish to underscore that the administration of water and food, even when given through artificial means, always represents a natural means of the conservation of life, not a medical act. Its use therefore will be considered, in principle, ordinary and proportionate, and as such morally obligatory, in the measure in which and to the extent that it is shown to achieve its

proper end, which in this case consists of procuring the nutrition of the patient and the alleviation of suffering.

The obligation not to omit “the normal care given to the sick in similar cases” (Congregation for the Doctrine of the Faith, *Iura et bona*, part IV) includes, in fact, also the need for feeding and hydration (cfr. Pontifical Council “Cor Unum,” *Dans le cadre*, 2.4.4; Pontifical Council for the Pastoral Care of Healthcare Workers, *Carta degli Operatori Sanitari*, n. 120). The evaluation of probabilities, founded upon small hopes for recovery when the vegetative state has persisted for over a year, cannot ethically justify the abandonment or interruption of the minimal care of the patient, including feeding and hydration. Death through hunger or thirst, in fact, is the only possible result following their suspension. In this sense, it becomes, if effected consciously and deliberately, truly and properly euthanasia by omission.

On this topic, I recall what I wrote in the encyclical *Evangelium vitae*, clarifying that “by *euthanasia in the true and proper sense* one intends an action or an omission that of its own nature and intention procures death, such that all suffering may be eliminated”; such an action always represents a grave violation of the Law of God, since the deliberate killing of a human person is morally unacceptable” (n. 65).

Moreover, one notes the moral principle according to which even simple doubt of being in the presence of a living person already imposes the obligation of full respect and of abstaining from any action directed at anticipating his death.

5. Considerations surrounding “quality of life,” often dictated in reality by psychological, social, and economic pressures, cannot prevail over these points of reference.

Above all, no evaluation of expenses may prevail over the value of the fundamental good that one seeks to protect: human life. Moreover, to admit that one may judge the life of man on the basis of an external recognition of its quality is equivalent to recognizing that to any subject may externally be attributed increasing or decreasing levels of quality of life, and therefore of human dignity, introducing a discriminatory and eugenic principle into social relations.

Besides, according to many reports from reliable studies, it is not possible to exclude *a priori* that removing feeding and hydration may cause great sufferings for the sick person, even if we can only see reactions at the level of the autonomous nervous system or of gestures. Modern techniques of clinical neurophysiology and of cerebral diagnosis through imaging in fact seem to indicate that elementary forms of communication and of analysis of stimuli perdure in these patients.

6. Nevertheless, it is not enough to reaffirm the general principle according to which the value of the life of a person cannot be subject to a judgment of quality expressed by other persons; it is necessary to promote positive actions to counteract the pressures for the suspension of hydration and nutrition as means to bring about the end of the lives of these patients.

Required first of all is to sustain the families that have had this terrible clinical condition befall their loved ones. They may not be left alone with their heavy human, psychological, and economic burden. Although the assistance to these patients may not be particularly costly in general, society must devote sufficient resources to the care of this type of fragility, through realizing opportune concrete initiatives such as, for example, the creation of a united network for recuperation, with specific programs of assistance and rehabilitation; economic sustenance and assistance to the family in the home when the patient is transferred to the home at the end of the program of intensive rehabilitation; the creation of structures of help in cases in which there may not be a family able to cope or to offer periods of respite to families at risk of psychological or moral weariness.

Appropriate assistance to these patients and their families must, above all, provide presence and evidence of doctors and other healthcare workers, who should be understood by families as their allies in their struggles; also the participation of volunteers represents a fundamental support to alleviate the isolation of the family and to help them to feel a precious part of society, and not abandoned from its network.

In these situations, then, spiritual counsel and pastoral help are of particular importance, as a help to discover the deeper significance of an apparently hopeless condition.

7. Esteemed ladies and gentlemen, in conclusion I exhort you, as persons of science, responsible for the dignity of the medical profession, to safeguard jealously the principle according to which the true duty of medicine is “to cure if possible, always to care.”

To confirm and to support this authentic humanitarian mission of yours to comfort and assist our suffering brethren, I remind you of the words of Jesus: “In truth I say to you: every time you did this for one of these least of my brothers, you did it to me” (Matt. 25:40).

In this light, I invoke upon you the help of Him Whom a suggestive patristic formula calls “Christ the Physician” and, in committing your work to the protection of Mary, the Consoler of the afflicted and the comfort of the dying, I impart to all with affection a special Apostolic Blessing.