

# *Reflections on Artificial Nutrition and Hydration*

Canadian Catholic Bioethics Institute

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## **Context of the “Reflections”**

Sometimes, as a result of injury or illness, the elderly lose their ability to swallow and so are unable to receive adequate nourishment orally. When they are in this situation, or when discussing advance directives for health care, the elderly, their families, and other care providers need to address the issue of artificial nutrition and hydration (ANH). Decisions about ANH call for good clinical judgment as well as good moral judgment. Such decisions may be difficult to arrive at in a context of uncertainty about present or future factors, or when there is a conflict in the ends being sought, or when the patient has a diminished capacity to make decisions with respect to his or her care.

The Canadian Catholic Bioethics Institute in Toronto hosted a colloquium from June 14-17, 2004, to identify and discuss some issues relating to ANH for the frail elderly and the dying. The aim was to be of service to those who are grappling with decisions or policies about ANH. An important context for this colloquium was the speech made by Pope John Paul II to participants in an international congress on “Life-Sustaining Treatments and the Vegetative State” in Rome on March 20, 2004. In his speech, the pope presented some general moral considerations and addressed a particular medical condition called persistent “vegetative” state (PVS), or post-coma unresponsiveness (PCU). The participants in the Toronto colloquium discussed the significance and implications of the papal speech for intervening in medical conditions affecting the elderly in which ANH is most commonly used. Such conditions include stroke, Alzheimer’s disease, Parkinson’s disease, and cancers of the head and neck.

## **The Process of Generating the “Reflections”**

The Toronto colloquium followed the general structure of the international colloquium of representatives from Catholic bioethics institutes held last year in Toronto, which resulted in a consensus statement on globalization and end-of-life care.<sup>1</sup> Participants were selected to represent a range of academic backgrounds, experiences, and views relevant to the topic of ANH. The thirty participants in this colloquium on ANH came variously from Canada, the United States, and Australia, and their collective expertise covered the fields of neurology, geriatrics, family medicine, philosophy,

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<sup>1</sup> International Colloquium of Catholic Bioethics Institutes, “Globalization and the Culture of Life Consensus Statement,” *The National Catholic Bioethics Quarterly* 4.1 (Spring 2004): 151-58.

theology, pastoral care, clinical ethics, and law. A few participants were commissioned to write papers that identified key issues and controversies in the literature, reviewed alternative stances, and highlighted some focal questions for discussion. These papers by Joseph Boyle, William Sullivan, Kevin O'Rourke, O.P., and Nicholas Tonti-Filippini were circulated to the other participants prior to the colloquium.<sup>2</sup> The colloquium itself took the form of intensive small-group discussions, followed, in plenary sessions, by a presentation and discussion of highlights from each group. The small-group discussions focused on a number of real-life clinical cases involving ANH in various medical conditions.

A document written by Barry Brown assembled the most important points raised in these plenary sessions, and brought to light areas of agreement and disagreement. This document was presented on the last day of the colloquium for discussion in small groups and at the plenary session. One representative from each group then worked as part of a team to edit the document, and this version was sent to the participants after the colloquium for a final round of feedback. The process resulted in a statement entitled "Reflections on Artificial Nutrition and Hydration." According to many participants, the most important aspects of this process were the emphasis placed on the daily celebration of the Eucharist and prayer, and the atmosphere of collegiality and mutual respect that allowed for frank discussions.

### **Overview and Highlights**

The "Reflections" do not prescribe what people ought to conclude in every situation where a decision about ANH for an elderly patient needs to be made. Rather, the statement draws attention to some moral principles, as well as an approach to making decisions about life-sustaining treatments in the Catholic moral tradition which were affirmed in "Life-Sustaining Treatments".

The pope, in his speech, asserted that ANH "should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality."<sup>3</sup> Paragraph 5 of the "Reflections" offers some points of interpretation of this quotation on which all the participants at the Toronto meeting agreed. Crucial to this interpretation were the words "in principle." Participants took these words to mean that there might be exceptions to the obligation to provide artificial nutrition and hydration when the method of delivery of ANH is "in itself in conflict with other grave responsibilities, or overly burdensome, costly or otherwise complicated" ("Reflections," paragraph 5).

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<sup>2</sup> Joseph Boyle, "Towards Ethical Guidelines for the Use of Artificial Nutrition and Hydration"; William Sullivan, "The Role of Artificial Nutrition and Hydration in the Care of the Frail Elderly: Empirical Issues and Disputed Questions"; Kevin O'Rourke, O.P., "Some Ethical Considerations Concerning Ordinary and Extraordinary Means to Prolong Life"; Nicholas Tonti-Filippini, "Advance Directives and Substitute Decision-Making in Relation to Providing Food and Water," <http://www.utoronto.ca/stmikes/bioethics>.

<sup>3</sup> John Paul II, Address of John Paul II to the Participants in the International Congress on "Life-Sustaining Treatments and the Vegetative State: Scientific Advances And Ethical Dilemmas", n. 4, original emphasis, [http://www.vatican.va/holy\\_father/john\\_paul\\_ii/speeches/2004/march/documents/hf\\_jp-ii\\_spe\\_20040320\\_congress-fiamc\\_en.html](http://www.vatican.va/holy_father/john_paul_ii/speeches/2004/march/documents/hf_jp-ii_spe_20040320_congress-fiamc_en.html).

The “Reflections” affirm that every human being has intrinsic value and personal dignity, and also that death is a part of the human condition (paragraph 2). Decisions about ANH, therefore, cannot be based on the judgment that persons with a severe cognitive and/or physical disability have less value and dignity than other persons. On the other hand, human life need not always be sustained for as long as possible. This is the basis for the ordinary/ extraordinary distinction in Catholic moral reasoning.

A very basic guideline for making decisions about life-sustaining treatments, including ANH, is stated in the “Reflections”: “Treatments cannot be classified ahead of time as ordinary or extraordinary,” i.e., as morally obligatory or optional. A careful assessment must be made of the benefits and burdens of particular treatments (paragraph 7). In this assessment, a patient’s responsibilities in the context of limited financial resources may be a morally relevant consideration (paragraph 9). Another important point is that the ordinary/extraordinary distinction applies to treatments in any stage of an illness, not simply to the time of imminent death (paragraph 8). In some cases, therefore, the withholding or withdrawing of ANH is not an act of euthanasia as defined in the strict sense in *Evangelium vitae*, n. 65 (paragraph 6).

The rest of the “Reflections” deals with two main topics: particular and contingent clinical considerations that may be morally relevant in assessing the benefits and burdens of ANH in medical conditions other than PVS or post-coma unresponsiveness (paragraphs 13-16), and advance directives regarding ANH (paragraphs 17-26). These important topics of concern in the care of the elderly were not addressed specifically in the papal speech.

The “Reflections” point out that the clinical features of medical conditions like stroke, Alzheimer’s disease, Parkinson’s disease, and cancers of the head and neck differ in important ways from PVS or post-coma unresponsiveness. In each medical condition, various appropriate methods of delivering ANH should be considered in light of the best available evidence concerning their efficacy for attaining desired benefits (paragraph 14). Similarly, in each medical condition, evidence regarding possible risks and burdens that are associated with those methods of ANH must be considered (paragraph 15). The “Reflections” note that the patient and/or family have the main responsibility to make the decision in each case, after considering this evidence in light of personal circumstances. Health care professionals are entitled to give a medical opinion (paragraph 16).

On the topic of advance directives regarding ANH, the “Reflections” acknowledge that there may be cultural and jurisdictional variations in practice (paragraphs 21 and 26). The “Reflections” propose that appointing a representative who knows well the patient’s wishes and values is preferable to issuing “instructional directives” about specific types of treatment and care (paragraph 22). The rights and responsibilities of such representatives must be acknowledged (paragraphs 23 and 24). Finally, a patient who formulates advance directives, the representative of the patient who is authorized to make decisions, and health care professionals and institutions that

implement these decisions, should always respect the patient's inherent value and dignity (paragraphs 18, 19, 20, and 25).

### **Significance of the “Reflections”**

The “Reflections” do not purport to offer a definitive interpretation of the papal speech of March 20, 2004. The participants in the Toronto colloquium propose that what the pope declared about ANH is not a departure from what is in the Catholic moral tradition concerning the value and dignity of the human person, and the moral difference between forgoing extraordinary treatments and euthanasia. The “Reflections” emphasize that understanding and accepting these general moral principles entails that patients, their family, and health care professionals have a responsibility to assess carefully the benefits and burdens of treatment options, including various methods of delivering ANH, in light of the patient's duties. They are also encouraged, whenever possible, to think and talk about end-of-life care. These tasks remain the same with respect to any medical condition and for any patient. Participants in the Toronto colloquium found that discussing particular cases was helpful in two ways: First, participants became aware of contingent factors in each case that were relevant to assessing benefits and burdens. Second, some disagreements that arose when participants were considering concepts and principles abstractly turned out not to be morally significant in concrete cases. An examination of particular cases, therefore, can be a useful starting point for thinking through moral issues. There is a need for carefully-considered case study commentaries in the bioethics literature.

Not all the signatories of the “Reflections” agreed with every point in the statement. Two topics elaborated in the footnotes of the statement call for further reflection and discussion by Catholic bioethicists. The first issue is whether it is a moral requirement for patients to make decisions about health care in accordance with some rational life plan. Fundamental questions here are whether feelings have some role in moral judgments, and if so, how these judgments are to be assessed by others. The second issue has to do with how to understand a treatment's burdens. Some confine burdens to those of the treatment modality itself, such as pain, suffering, or cost. Others also consider the burdens of the underlying illness. One key question here is what respecting the dignity of persons who are living with a cognitive and/or physical disability entails.

The “Reflections” are the result of an international collaboration. We wish to thank the board and supporters of the Canadian Catholic Bioethics Institute, participants in the Toronto colloquium, and those who helped to prepare and edit this document. Colloquia such as the ones held in Toronto in 2003 and 2004 affirm the fruitfulness of discussions and collaborations among Catholic bioethicists. There is need for similar opportunities for Catholic bioethicists to exchange ideas and to work together in their own countries and internationally. One recent initiative to promote such ongoing collaboration among Catholic bioethicists around the world is being supported under the aegis of various national associations and sponsored by the Sovereign Military Order of

Malta.<sup>4</sup> It is hoped that an international colloquium that is being planned for June 2005 in Melbourne, Australia, will take up some of the challenging residual questions discussed above.

## REFLECTIONS ON ARTIFICIAL NUTRITION AND HYDRATION

### Introduction

1. The Canadian Catholic Bioethics Institute sponsored a meeting in Toronto, June 14-17, 2004. The purpose of this meeting was to discuss the speech made by Pope John Paul II on March 20, 2004 to participants in the International Congress on 'Life-Sustaining Treatments and the Vegetative State' and to assist health care professionals, patients, their families, and the community in making decisions about artificial nutrition and hydration (ANH) for elderly patients who have medical conditions other than a "vegetative state". Participants at the Toronto meeting, who work in various fields related to bioethics and had different starting points and perspectives, agreed that the following reflections summarize generally the outcome of their discussions. Those participants who consented to be listed at the end of these reflections do so in their own name and not on behalf of their institutions. Although all the signatories agreed to the three points of interpretation of the papal speech in paragraph 5, they do not necessarily concur with everything in the reflections.

### Presuppositions

2. In keeping with the Catholic moral tradition:
  - Life is a gift from God for which we have stewardship. Illness, suffering, and death are part of the human condition.
  - Humans are relational beings who summon a response from others. All human beings, regardless of their state of health or function, are persons endowed with a spiritual soul and created in the image of God. As such, they possess an intrinsic dignity and value, and have moral status. It follows from this understanding that patients in the state known as "persistent vegetative state" (PVS) are persons. It also follows that, even when patients with advanced dementia, such as Alzheimer's disease, have personalities that are diminished, they remain persons throughout the course of their disease leading to death. Individuals with a developmental or physical disability, even in extreme degrees, also are persons with the same dignity and rights as other persons.

### **"Vegetative State" (Post-Coma Unresponsiveness)**

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<sup>4</sup> International Association of Catholic Bioethicists, <http://www.iacbweb.org>.

3. The term “vegetative state” was developed in reference to certain functions of the autonomic or “vegetative” nervous system. These functions, such as the regulation of breathing and the heart rate, are retained despite a patient’s unawareness of self and environment. Patients in a “vegetative state” have sleep-wake cycles in which they periodically open their eyes, but they show no evidence of response to the environment, purposeful responses to stimuli, and language comprehension or expression. Unfortunately some have misunderstood and misused the term “vegetative state” to suggest that persons in this state are less than fully human. To avoid this, it is preferable to designate the condition as a state of “post-coma unresponsiveness”.
4. If post-coma unresponsiveness lasts longer than six months following a brain injury from lack of oxygen, or twelve months following a traumatic brain injury, it is conventionally considered to be “permanent”. This means that the statistical probability of any recovery is minimal but not unprecedented.

#### The Papal Speech

5. In the responses to the papal speech of March 20, 2004, there has been uncertainty and speculation in regard to the statement that ANH “should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, insofar as and until it is seen to have attained its proper finality.”<sup>5</sup> The meeting reached the following interpretation of this sentence in the papal speech:
  - The papal speech needs to be understood in the context of the Catholic tradition. The words “in principle”(n.4) do not mean “absolute” in the sense of “exceptionless” but allow consideration of other duties that might apply.
  - Persons in a state of lost cognitive and affective capacity retain a spiritual soul; their life has intrinsic value and personal dignity, and they must be treated with the full respect and care owed to a human being.
  - For unresponsive patients to whom ANH can be delivered without being in itself in conflict with other grave responsibilities, or overly burdensome, costly or otherwise complicated, ANH should be considered ordinary and proportionate, and as such, morally obligatory.

### Is Withdrawing ANH from Post-Coma Unresponsive Patients an Act of Euthanasia?

6. *Evangelium vitae* states that:

*Euthanasia in the strict sense* is understood to be an action or omission which of itself and by intention causes death, with the purpose of eliminating all

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<sup>5</sup> John Paul II, “Life-Sustaining Treatments,” n. 4, original emphasis.

suffering. ‘Euthanasia’s terms of reference, therefore, are to be found in the intention of the will and in the methods used.’

Euthanasia must be distinguished from the decision to forego so-called “aggressive medical treatment,” in other words, medical procedures which no longer correspond to the real situation of the patient, either because they are by now disproportionate to any expected results or because they impose an excessive burden on the patient and his family.<sup>6</sup>

7. Treatments cannot be classified ahead of time as ordinary or extraordinary. Reference must be made to the wishes<sup>7</sup> and values of the patient, his or her condition, and the availability of health care in the given context. Ordinary measures, in the traditional moral sense, do not involve excessive pain, expense, or other burdens.<sup>8</sup> Extraordinary treatments are those that do involve excessive pain, expense, or other burdens. The requirement to undertake an assessment of the benefits and burdens is captured in the alternative designation: proportionate or disproportionate. Some treatments may involve burdens that are disproportionate to the benefits; therefore, such treatments are not morally obligatory.
8. The ordinary/extraordinary distinction applies to any stage of illness, not simply to imminent death. However, this distinction may be particularly significant when death is imminent, and the person does not respond positively to treatment. In such circumstances, medical responses other than comfort care and pain control are more likely to be deemed extraordinary and thus optional.

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<sup>6</sup> John Paul II, *Evangelium vitae* (March 25, 1995; Boston: Pauline Books and Media), n.65; internal quotation from Congregation for the Doctrine of the Faith, “Declaration on Euthanasia,” (*Iura et Bona*; May 5, 1980, [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19800505\\_euthanasia\\_en.html](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19800505_euthanasia_en.html)), II.

<sup>7</sup> Some participants thought that ‘wishes’ in this sentence should be replaced by ‘life plan’ or some similar term to indicate that such moral decisions ought not be based on whim, but on considerations such as spiritual ends and family obligations.

<sup>8</sup> There is considerable controversy over what constitutes burden. Some confine burden to those of the treatment modality itself, such as pain, suffering, or cost. Others contend that burden will also encompass the conditions of living after the treatment, including being in a state of diminished or minimal consciousness, totally dependent on others, incontinent, paralyzed, etc. Some would argue that these conditions are relevant even if the patient is incapable of experiencing them, as in post-coma unconsciousness. A distinction can be made between ontological dignity, which all persons, regardless of their level of functioning, have, and existential or ‘attributed’ dignity, which depends on the circumstances or conditions of living. For some, a diminished existential dignity is an insufficient reason for refusing treatment by advance directive. For others, it is a decisive factor in their reasons for not wanting to live in this state. No consensus was reached on this issue.

9. While recognizing that it is impossible to place monetary value on human life, the cost of treatment can be a morally relevant factor in health care decisions, especially if patients or their families have to bear the entire economic burden.
10. The increasing technological prolongation of life with its high costs should not eclipse basic human care. This is a matter of fundamental distributive justice.
11. While some treatments may be withheld or withdrawn, care should always be provided, and patients should never be abandoned.
12. Helping patients and their families to make responsible decisions is important. Health care professionals and institutions may be confronted by patients who, with suicidal wishes, refuse ordinary life-sustaining care. Such patients must be treated with concern for their dignity and well-being. Health care professionals should do their best to protect the life and health of the patient while recognizing that there may be legal and professional limits to their ability to intervene.

#### Methods of ANH

13. The most commonly used methods of ANH include the following: (a) enteral nutrition and hydration through, for example, a nasogastric (NG) tube that is inserted into a nostril, down the throat and into the stomach, or a percutaneous endoscopic gastrostomy (PEG) tube that is inserted through the abdominal wall and placed in the stomach with the guidance of an endoscope that is temporarily inserted through the mouth into the stomach; (b) parenteral techniques which include short-term intravenous (IV) feeding by direct infusion into a peripheral vein such as the arm or leg, and longer-term total parenteral nutrition (TPN), in which complete nutrition and water are delivered directly into a large central vein (such as the subclavian). When a condition warrants temporary nutritional support, very small NG tubes that are more easily and safely inserted than a PEG tube can be used.

#### Benefits and Risks of ANH

14. While raising many principles of universal applicability, the recent papal speech particularly addressed ANH for people in a state of post-coma unresponsiveness. However, in applying these principles to medical conditions from which the frail elderly are far more likely to suffer, such as Alzheimer's disease, Parkinson's disease, cancer and stroke, it is important to note that these conditions differ in important ways from post-coma unresponsiveness. The benefits of ANH may include improved nutritional status, the prolongation of life, the symbolic value of giving food and drink, relief of symptoms of hunger when these are experienced, preventing aspiration pneumonia, reducing the risk of pressure sores or infections due to poor nutritional status and immobility, improving function, providing

comfort, and maintaining human community. Even in those who have a terminal illness, including patients with advanced dementia, some of these benefits may be attainable.

15. The risks or burdens of ANH include, for NG tubes, irritation and discomfort, and the need for restraint when the patient is confused and repeatedly pulls the tube out. PEGs carry risks of complications, such as death, infection, perforation of the bowel, temporary diarrhea and cramping, temporary nausea and vomiting, and blockage of or leaking from the tube. Paradoxically, some patients for whom PEGs are initiated, in the hope of reducing their risk of aspiration, may still remain at significant risk of aspiration with the feeding tube. This risk is greater when nutrition is supplied to the stomach rather than the small bowel, given in bolus or single and discrete doses, and the patient is lying down when being fed rather than having his or her head elevated. There may be a need for temporary restraints in some confused patients to prevent the tube from being pulled out. Some restraints may constitute an assault on human dignity and autonomy in persons. Restraints can also lead to complications, such as pressure sores.

### **Is ANH Successful in Patients with Advanced Dementia?**

16. Randomized controlled trials are the gold standard in research. There appear to be no randomized controlled trials comparing the efficacy of ANH with oral feeding in patients with advanced dementia. However, there is some evidence from less rigorously controlled studies that ANH in these patients does not secure any of the benefits listed above. As it would be difficult ethically to conduct randomized controlled trials with patients suffering from advanced dementia, non-randomized studies and case studies may be the only evidence that we can base clinical practice on. Others may find these conclusions debatable. In this situation, the health care professional and the patient's family will have to consider the evidence as best they can. The health care professional is entitled to give an opinion as to the most beneficial and least burdensome type of ANH and course of action.

### **Advance Directives**

17. Advance directives, whether in the form of a written living will (instructional directive) or a durable power of attorney for health care (proxy directive) or both together, are legitimate instruments by which patients may indicate their wishes to accept or refuse a procedure when they are no longer capable of making the decision. Acceptable purposes include:
  - To lighten the burden of a patient's family in making the decision;
  - To ensure that future treatment is morally acceptable and consistent with respect for human life and dignity, and the patient's values and culture;
  - To take into consideration responsible stewardship of society's health resources;
  - To prevent inappropriate or disproportionate treatment.
18. An advance instructional directive must reflect the duty to respect human life and

dignity, and to continue ordinary/proportionate measures.

19. An advance directive must not require another to cooperate in a plan of care that is morally unacceptable to that other person.
20. A Catholic health care professional or institution should not cooperate in implementing a suicidal directive.
21. The requirement of an advance directive by a nursing home or long-term care facility as a condition of admission may be unacceptably coercive. In many cultures, advance directives are not valued, and end-of-life decisions for incompetent patients may be left to family members.
22. For a patient, appointing someone to represent him or her is preferable to issuing an instructional directive, but the representative must be well-instructed in the patient's wishes and values.
23. A person who is a representative of a patient has the same rights and responsibilities as the patient to respect and protect the patient's life and dignity and to authorize care.
24. A health care professional or other caregiver must respect the rights and responsibilities of the representative of an incompetent patient and discuss with the representative the care that is appropriate.
25. A health care professional or other caregiver must seek review of the representation in the event that the representative fails to act in the best interests of the patient, and the patient is endangered.
26. Health care professionals and families need to be aware of jurisdictional differences, in custom and law, relevant to advance directives.

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