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Post-coma unresponsiveness: NHMRC issues a clinical framework for diagnosis

Bernadette Tobin

Earlier this year, Australia's National Health and Medical Research Council issued an information paper setting out a clinical framework for the diagnosis of 'post-coma unresponsiveness'.¹ Post-coma unresponsiveness is the term coined by the Council to describe a clinical state that can follow a person's emergence from a coma: in such a state people still have normal cardiorespiratory function, their brain stems still work, but they apparently lack all purposeful responsiveness.²

Post-coma unresponsiveness is a manifestation of severe brain damage, one of a range of conditions of impaired responsiveness that includes coma, loss of brain function (so-called

'brain death'), 'locked-in syndrome, minimally responsive state and dementia, states which are often difficult to diagnose. Though estimates of the likelihood of post-coma unresponsiveness developing in patients who have been in a coma for a long time vary greatly, the condition has rarely been diagnosed in Australia, and very few specialists have experience of large numbers of cases. So the next question which arises is why did the NHMRC think it important enough to address in an 'information paper'?

The short answer is that the Council was asked to do so. Some years before, a man in his thirties had been admitted to a Sydney hospital in an unconscious state, having suffered a cardiac arrest after an overdose of heroin. After weeks of intensive life-sustaining treatment, he was said to be 'vegetative' (even though his sister found him responsive to her presence) and, on the basis of a neurological assessment, it was proposed that life-sustaining treatments should be withdrawn. The young man's sister sought a court order to prevent this happening. Subsequently the NSW Health Department asked the NHMRC to develop guidelines on the proper diagnosis of the so-called 'vegetative'

In this issue

The four articles in this issue are connected: they each address questions about the treatment and care of people in what used to be called a 'persistent vegetative state'.

The NHMRC urges health care practitioners to adopt the term 'postcoma unresponsiveness' as a more accurate and more humane description of this state, and to take proper care in diagnosing it.

The Pope restates traditional Catholic teaching about our responsibilities to people so diagnosed, with particular regard to questions about the administration of artificially-supplied nutrition and hydration.

The Canadian Catholic Bioethics Association follows both the NHMRC and the Pope in its expression of a series of conclusions on the care of patients so diagnosed which were reached at a recent meeting in Toronto.

And Dr Gerald Gleeson sets out some 'short cuts' in thinking about these questions which have recently caused intellectual confusions.

state. The NHMRC's information paper is thus concerned with the diagnosis of patients traditionally described as being in a 'persistent' (or 'permanent') vegetative state.

Given the familiarity of the term 'persistent vegetative state', it might be wondered why the NHMRC adopted a new name for the condition. The reason is simple: the Council wishes to discourage the use of terminology that may be misunderstood or that may be prejudicial to the care of patients with the condition. The terms 'persistent vegetative state', 'permanent vegetative state' and 'continuing vegetative state' are both pejorative and open to misunderstanding. In addition none of them is used in a consistent way in the medical, ethical or legal literature. The new term avoids the potentially pejorative term 'vegetative'. It avoids the time-based qualifiers: that is to say, it can be applied as soon as emergence from coma occurs and for as long as the patient remains unresponsive, and it avoids the false implication that once unresponsiveness has lasted for (say) a year it has become permanent.³

The steps set out in the framework for diagnosis are relatively straightforward.⁴ Given that people can slip in and out of coma for some time after having suffered brain injury (whether traumatic or non-traumatic), the framework should not be applied until approximately four weeks after the appearance of unresponsive wakefulness. Then, diagnosis can only be made after repeated clinical examination which obtains consistent results for the following range of questions and supplementary tests.

Answers to the following questions should be consistently 'yes':

- *Is the patient in good general health?
- *Are the conditions for testing optimal?
- *Are relatives or carers available to give extra clinical information?
- *Is there evidence of cycles of eye opening and closing (sleep-wake cycle)?
- *Is there preservation of respiration and circulation (brain stem function)?
- *Is the patient incontinent?

Answers to the following questions should be consistently 'no':

- *Are there signs of responsiveness to the environment?

*Are there purposeful responses to auditory, visual or tactile stimuli?

*Is there any evidence of language comprehension or expression?

What effect should the issuing of this clinical diagnostic framework have on the practice of medicine and health care generally? For one thing, doctors and allied health practitioners have now been asked not to use the disparaging term 'vegetative' about any of their patients. For another, doctors and others are been advised to be much more careful about making the diagnosis of post-coma unresponsiveness (vs) than some have been in the past: the document makes it very clear that the process of making this diagnosis is an iterative one that can only be made over time and under appropriate conditions. And for a third, health care practitioners should be less likely to allow their thinking about future treatment options to be infected by the idea that certain lives, or any lives in certain conditions, are not worth living. As the NHMRC say in this document: 'In all instances the question is never whether the patient's life is worthwhile, but whether a treatment is worthwhile.'⁵

Footnotes

1 Preparation of the clinical framework was undertaken by a Working Party, chaired by Dr Michael O'Callaghan who is Director of Child Development and Rehabilitation Services at the Mater Children's Hospital in Brisbane. Membership included a physician, a general practitioner, an intensivist, an expert in road accident trauma, a neuropsychologist, a representative of health 'consumers', a research scientist and myself.

2 A summary of the paper can be found at www.nhmrc.gov.au. Copies can be obtained from the NHMRC (phone: 1800 020 103).

3 Since 'vegetative state' is used widely in the international literature, the NHMRC recommends that we build 'vs' into the title: thus, post-coma unresponsiveness (vs). This will ensure that the Australian recommendations about the proper way to diagnose this condition will be picked up in international data bases. It is notable that the Canadian Catholic Bioethics Association which has already followed the Australian lead on the issue of nomenclature has already dropped the 'vs'!

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**ADDRESS OF JOHN PAUL II
TO THE PARTICIPANTS IN THE INTERNATIONAL
CONGRESS
ON "LIFE-SUSTAINING TREATMENTS AND
VEGETATIVE STATE:
SCIENTIFIC ADVANCES AND ETHICAL
DILEMMAS"**

Saturday, 20 March 2004

Distinguished Ladies and Gentlemen,

1. I cordially greet all of you who took part in the International Congress: *"Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas"*. I wish to extend a special greeting to Bishop Elio Sgreccia, Vice-President of the Pontifical Academy for Life, and to Prof. Gian Luigi Gigli, President of the International Federation of Catholic Medical Associations and selfless champion of the fundamental value of life, who has kindly expressed your shared feelings.

This important Congress, organized jointly by the Pontifical Academy for Life and the International Federation of Catholic Medical Associations, is dealing with a very significant issue: *the clinical condition called the "vegetative state"*. The complex scientific, ethical, social and pastoral implications of such a condition require in-depth reflections and a fruitful interdisciplinary dialogue, as evidenced by the intense and carefully structured programme of your work sessions.

2. With deep esteem and sincere hope, the Church encourages the efforts of men and women of science who, sometimes at great sacrifice, daily dedicate their task of study and research to the improvement of the diagnostic, therapeutic, prognostic and rehabilitative possibilities confronting those patients who rely completely on those who care for and assist them. The person in a vegetative state, in fact, shows no evident sign of self-awareness or of awareness of the environment, and seems unable to interact with others or to react to specific stimuli.

Scientists and researchers realize that one must, first of all, arrive at a correct diagnosis, which usually requires prolonged and careful observation in specialized centres, given also the high number of diagnostic errors reported in the literature. Moreover, not a few of these persons, with appropriate treatment and with specific rehabilitation programmes, have been able to emerge from a vegetative state. On the contrary, many others unfortunately remain prisoners of their condition even for long stretches of time and without needing technological support.

In particular, the term *permanent vegetative state* has been coined to indicate the condition of those patients whose "vegetative state" continues for over a year. Actually, there is no different diagnosis that corresponds to such a definition, but only a conventional prognostic judgment, relative to the fact that the recovery of patients, statistically speaking, is ever more difficult as the condition of vegetative state is prolonged in time.

However, we must neither forget nor underestimate that there are well-documented cases of at least partial recovery even after many years; we can thus state that medical science, up until now, is still unable to predict with certainty who among patients in this condition will recover and who will not.

3. Faced with patients in similar clinical conditions, there are some who cast doubt on the persistence of the "human quality" itself, almost as if the adjective "vegetative" (whose

use is now solidly established), which symbolically describes a clinical state, could or should be instead applied to the sick as such, actually demeaning their value and personal dignity. In this sense, it must be noted that this term, even when confined to the clinical context, is certainly not the most felicitous when applied to human beings.

In opposition to such trends of thought, I feel the duty to reaffirm strongly that the intrinsic value and personal dignity of every human being do not change, no matter what the concrete circumstances of his or her life. *A man, even if seriously ill or disabled in the exercise of his highest functions, is and always will be a man, and he will never become a "vegetable" or an "animal".*

Even our brothers and sisters who find themselves in the clinical condition of a "vegetative state" retain their human dignity in all its fullness. The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help.

4. Medical doctors and health-care personnel, society and the Church have moral duties toward these persons from which they cannot exempt themselves without lessening the demands both of professional ethics and human and Christian solidarity.

The sick person in a vegetative state, awaiting recovery or a natural end, still has the right to basic health care (nutrition, hydration, cleanliness, warmth, etc.), and to the prevention of complications related to his confinement to bed. He also has the right to appropriate rehabilitative care and to be monitored for clinical signs of eventual recovery.

I should like particularly to underline how the administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life, not a *medical act*. Its use, furthermore, 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, which in the present case consists in providing nourishment to the patient and alleviation of his suffering.

The obligation to provide the "normal care due to the sick in such cases" (Congregation

for the Doctrine of the Faith, *Iura et Bona*, p. IV) includes, in fact, the use of nutrition and hydration (cf. Pontifical Council "Cor Unum", *Dans le Cadre*, 2, 4, 4; Pontifical Council for Pastoral Assistance to Health Care Workers, *Charter of Health Care Workers*, n. 120). The evaluation of probabilities, founded on waning hopes for recovery when the vegetative state is prolonged beyond a year, cannot ethically justify the cessation or interruption of *minimal care* for the patient, including nutrition and hydration. Death by starvation or dehydration is, in fact, the only possible outcome as a result of their withdrawal. In this sense it ends up becoming, if done knowingly and willingly, true and proper euthanasia by omission.

In this regard, I recall what I wrote in the Encyclical *Evangelium Vitae*, making it clear that "by euthanasia in the true and proper sense must be understood an action or omission which by its very nature and intention brings about death, with the purpose of eliminating all pain"; such an act is always "a serious violation of the law of God, since it is the deliberate and morally unacceptable killing of a human person" (n. 65).

Besides, the moral principle is well known, according to which even the simple doubt of being in the presence of a living person already imposes the obligation of full respect and of abstaining from any act that aims at anticipating the person's death.

5. Considerations about the "quality of life", often actually dictated by psychological, social and economic pressures, cannot take precedence over general principles.

First of all, no evaluation of costs can outweigh the value of the fundamental good which we are trying to protect, that of human life. Moreover, to admit that decisions regarding man's life can be based on the external acknowledgment of its quality, is the same as acknowledging that increasing and decreasing levels of quality of life, and therefore of human dignity, can be attributed from an external perspective to any subject, thus introducing into social relations a discriminatory and eugenic principle.

Moreover, it is not possible to rule out *a priori* that the withdrawal of nutrition and hydration, as reported by authoritative

studies, is the source of considerable suffering for the sick person, even if we can see only the reactions at the level of the autonomic nervous system or of gestures. Modern clinical neurophysiology and neuro-imaging techniques, in fact, seem to point to the lasting quality in these patients of elementary forms of communication and analysis of stimuli.

6. However, it is not enough to reaffirm the general principle according to which the value of a man's life cannot be made subordinate to any judgment of its quality expressed by other men; it is necessary to promote the *taking of positive actions* as a stand against pressures to withdraw hydration and nutrition as a way to put an end to the lives of these patients.

It is necessary, above all, *to support those families* who have had one of their loved ones struck down by this terrible clinical condition. They cannot be left alone with their heavy human, psychological and financial burden. Although the care for these patients is not, in general, particularly costly, society must allot sufficient resources for the care of this sort of frailty, by way of bringing about appropriate, concrete initiatives such as, for example, the creation of a network of awakening centres with specialized treatment and rehabilitation programmes; financial support and home assistance for families when patients are moved back home at the end of intensive rehabilitation programmes; the establishment of facilities which can accommodate those cases in which there is no family able to deal with the problem or to provide "breaks" for those families who are at risk of psychological and moral burn-out.

Proper care for these patients and their families should, moreover, include the presence and the witness of a medical doctor and an entire team, who are asked to help the family understand that they are there as allies who are in this struggle with them. The participation of volunteers represents a basic support to enable the family to break out of its isolation and to help it to realize that it is a precious and not a forsaken part of the social fabric.

In these situations, then, spiritual counselling and pastoral aid are particularly important as help for recovering the deepest meaning of an apparently desperate condition.

7. Distinguished Ladies and Gentlemen, in conclusion I exhort you, as men and women of science responsible for the dignity of the medical profession, to guard jealously the principle according to which the true task of medicine is "to cure if possible, always to care".

As a pledge and support of this, your authentic humanitarian mission to give comfort and support to your suffering brothers and sisters, I remind you of the words of Jesus: "Amen, I say to you, whatever you did for one of these least brothers of mine, you did for me" (Mt 25: 40).

In this light, I invoke upon you the assistance of him, whom a meaningful saying of the Church Fathers describes as *Christus medicus*, and in entrusting your work to the protection of Mary, Consoler of the sick and Comforter of the dying, I lovingly bestow on all of you a special Apostolic Blessing.

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Reflections on Artificial Nutrition and Hydration

Colloquium of the Canadian Catholic Bioethics Institute

Introduction

1. The Canadian Catholic Bioethics Institute sponsored a colloquium in Toronto, June 14-17, 2004. The purpose of this colloquium was to discuss the speech made by Pope John Paul II on March 20, 2004 to participants in the International Congress on 'Life-Sustaining Treatment and 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 in the Toronto colloquium, 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 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)

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 6 months following a brain injury from lack of oxygen, or 12 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 have 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." The colloquium in Toronto 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. "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 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." (*Evangelium vitae*, n.65)

7. Treatments cannot be classified ahead of time as ordinary or extraordinary. Reference must be made to the wishes¹ 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.² 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/extrordinary 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.
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 addressed particularly 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 disease, Parkinson 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, blockage 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.

Footnotes:

1 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.

2 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, paralysed, 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.

Signatories

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July 22, 2004.	

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4 In the process of preparing this framework, the Working Party reviewed the literature on the subject. It found that studies of post-coma unresponsiveness (vs) are confounded by a range of factors: prospective cohorts of patients have not been studied in detail, there is incomplete follow-up, a high death rate, a heterogeneous patient group (caused by the variation in the terminology used to describe the condition), no diagnostic test, difficulties in distinguishing between the various manifestations of impaired consciousness, and a reported misdiagnosis in up to 40% of cases. In addition, since the condition is associated with a variety of pathological causes, it has not been practicable to establish clear, objective structure-function relationships. So the existing literature is therefore largely descriptive rather than investigative. In addition, most reported studies of series of patients who remain in a state of post-coma unresponsiveness are limited by methodological problems (including the heterogeneity of the cohort, inadequate description of process for follow-up, loss of subjects to longer term follow-up that is not adequately accounted for, inconsistent intervals between evaluations, and failure to make allowance for variation in patient management within a series).

5 There is much more in the information paper than the points made here. Chapters address the differential diagnosis, the clinical management during diagnosis, imaging and other tests, and prognosis and emergence.

Clinical - Ethical Judgements without “short cuts”

Gerald Gleeson

Catholic Institute & Plunkett Centre for Ethics

Pope John Paul II's address to the recent conference on life-sustaining treatments and the 'vegetative state' brings further clarification to a long running debate among Catholic ethicists about our obligations towards persistently unresponsive patients.¹ All participants in this debate agree that there is an obligation to take reasonable (or "ordinary") means of sustaining a person's life, unless and until doing so becomes "futile" or "unduly burdensome" (i.e. "extraordinary"). The debate has centred on the application of this principle to unresponsive patients.

With respect to the principle itself, one of the most impressive contributions at the conference was from Maurizio Calipari, a bioethicist with the Pontifical Academy for Life.² Reviewing the traditional teaching of the Church and of Catholic moralists, he argued that the tradition understands a treatment to be ordinary and obligatory unless there is reason in a particular case for it to be judged extraordinary (and so not obligatory). The terms "ordinary" and "extraordinary" have, of course, become ambiguous in recent years, since they are often taken to measure simply the "ordinariness" of a treatment in medical practice; thus treatments once extraordinary (in a numerical or financial sense) may now be quite ordinary, cost effective, and in common use. For purposes of ethical analysis alternative terms have been suggested, e.g. "proportionate" and "disproportionate".

Calipari proposes that these sets of terms be distinguished and applied to two distinct steps in a clinical-ethical analysis. The first issue concerns the appropriateness of a treatment *from the medical point of view*. A treatment is "proportionate" to the extent that it is suitable for achieving an appropriate medical goal in the circumstances. The second issue concerns the appropriateness of a treatment *for this particular patient*. At this point, the issue is

whether a proportionate treatment would be "ordinary" or "extraordinary": would it involve a certain "impossibility" for the patient, because it would impose an undue burden on the patient or on carers or health care resources?

Returning to the debate among Catholic ethicists, Calipari's analysis enables us to identify what I will call two "short cuts" in clinical-ethical reasoning that are commonly deployed in this debate. While accepting the obligation to use ordinary life-sustaining means, some Catholic ethicists have argued that persistently unresponsive patients (those said to be in a "vegetative state") constitute a special category of patients. Given their lack of responsiveness and the unlikelihood of any improvement, it has been argued that no legitimate medical benefit arises simply from keeping these patients alive. (A few ethicists have gone further and argued that to prolong the life of such patients is contrary to their dignity; they claim these patients are dying and should be allowed to die.) This approach involves the first "short cut" - namely, to suppose that the unresponsive state of itself alters the kind of obligation there is to preserve a person's life, or to suppose that the normal medical goal of sustaining life no longer holds for these patients.

Of course, if persistently unresponsive patients are to be kept alive, they need to be given food and water by other people, and typically, by tubes inserted through the nose or directly into the stomach. Where tubes are used, the patients are said to be receiving nutrition and hydration by "artificial means". Some Catholic ethicists have argued that the need to use tubes, given the medical expertise required to insert the tubes and supervise their use, shows that such feeding is "extraordinary", and is disproportionate to the proposed benefit. The Supreme Court in Victoria in 2003 adopted this view when it held that tube-feeding was indeed a "medical

treatment", and as such was optional, able to be withheld or withdrawn at the guardian's request. This approach involves a second "short cut" - namely, to suppose that because a procedure is, or involves, a medical treatment it is not an ordinary and so obligatory means of sustaining life.

The Pope's address can be summarised as rejecting both these "short cuts". First, the Pope says that persistently unresponsive patients are not a special class of persons for whom the normal medical goals and obligations do not apply. They are human persons, with the same rights as others, albeit they are severely disabled. Although they are unresponsive, these patients are not as such dying. Their situation is not like that of patients who are close to death (in a few days or hours), irrespective of what care or feeding is offered to them. So to say that unresponsive patients need not (or should not) be fed amounts to saying it would be better if they died. To stop feeding an unresponsive person for this reason would be equivalent to euthanasia.

Secondly, the Pope says that "artificial" feeding through tubes is not in itself an "extraordinary" means of sustaining life. On the contrary, feeding a person is a "natural" means of caring for him or her, and, in the context of modern medicine, the use of tubes can be a convenient and cost effective way of feeding a person. Tube feeding is "in principle, [an] *ordinary* and *proportionate*, and as such morally obligatory", way of caring for a patient.

If we avoid the two "short cuts" I have noted, and following Calipari's analysis, we see there are two sets of questions we need to ask about tube feeding: first, is it *proportionate* or effective? Is it keeping the person alive? If it is not, e.g. because the patient cannot absorb the nutrition, then it should be stopped. Secondly, is it *extraordinary* for this patient? Does it involve burdens to the patient which outweigh its benefits? If it does, e.g. because of infections and problems in maintaining the tube in place, then it may be stopped.

The key sentences in the pope's address are: "The administration of water and food, even when provided by artificial means, always represents a *natural means* of preserving life,

not a *medical act*. Its use, furthermore, should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory, to the extent in which and as long as it is seen to achieve its proper purpose which in the present case consists in providing nourishment to the patient and alleviation of his suffering."

An issue the Pope does not address specifically is whether, even if the act of feeding a patient is "ordinary" and "natural", the insertion of a feeding tube is in itself a "medical act". I think it is clear that the insertion and monitoring of a tube, and of the substances and quantities inserted, does involve medical and nursing expertise. To this extent, it is a medical procedure that needs to be judged by the usual clinical and ethical criteria. The degree of medical intervention that tube feeding requires in a particular case needs to be proportionate to the prospective benefit, and not unduly burdensome. In making this judgment, it is important to recall that keeping a patient alive, even an unresponsive patient, is always in principle a legitimate and obligatory medical goal.

Conclusion

I have said that the pope's address warns us against two "short cuts" in ethical reasoning. There should be a presumption, in principle, that all patients be given food and water (if necessary through tubes) unless and until this is disproportionate (not effective) and/or extraordinary (unduly burdensome). Each case must therefore be examined on its own merits - there should be no short cuts that save us from examining the facts in each case. In particular cases it may be apparent that tube feeding is not obligatory: e.g. in contexts such as the developing world where there is no medical expertise available to insert and monitor the tube; or where the tube is causing infection and other disproportionate side-effects, thereby adding to the patient's complications; or where the patient cannot absorb the food etc.

Footnotes

1 I use the term 'vegetative state' because that is the term used in the papal statement.

2 Calipari's paper is available in the special edition of *L'arco di Giano*, published for the conference by Istituto per l'Analisi dello Stato Sociale, (March, 2004), pp. 50-57.