

The ethics of care for those with post-coma unresponsiveness and related conditions

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In *The Gospel of Life* (1995) Pope John Paul II wrote of the ‘intolerable’ neglect that some of the elderly, handicapped and dying experience even in affluent nations. He exhorts us “to preserve, or to re-establish where it has been lost, a sort of covenant between the generations”, a relationship of acceptance and solidarity, closeness and service. In his recent *Address to a Congress on Life-sustaining Treatments and the ‘Vegetative’ State* (20 March 2004) he drew out the implications of this covenant promise by considering how we should regard and care for the persistently unconscious—whether they are of an older generation than ourselves or not. His principles clearly have wider application than just the so-called ‘vegetative’ patient, to include other patients in comas, advanced dementia, late stages of cancers or other conditions. How are we to show love, care and respect for such people in the context of our Catholic health and aged care mission, and our range of opportunities and responsibilities?

There are I think four positions commonly adopted by ethicists, health professionals and others on the question of whether people who are at a very low ebb, especially those unlikely ever again to recover consciousness, should be fed with medical or nursing assistance.

The first position I will call the “Never Feed View”. It says, quite simply, don’t feed such people. If you have started feeding artificially in the hope of recovery of consciousness and – after a prudent period – you find the patient has not recovered, you should stop feeding them artificially. Otherwise you are simply drawing out their dying process or creating a rod for your back in terms of the care they will require in the future and a rod for the family’s back as they become increasingly exhausted by how long their loved one is taking to die. Life in that state is not worth living. There are no human, intellectual, spiritual acts. Whatever of the assisted feeding, the life itself is futile or burdensome both to the patient and to others around her.

On this view there is nothing wrong with allowing the natural dying process to proceed unimpeded in such cases; indeed it would be an offence to human dignity, even torture, to extend the life of such a person; the sooner they are with God the better. People should be encouraged to make

declarations early that if they were ever in the future to be in this situation they do not want to be fed; other people should be encouraged to respect such declarations or, in the absence of them, to assume they would have been made had the patient had the opportunity.

An opposite view—which I will call the “Always Feed View”—runs something like this: no human being is ever a vegetable or in a vegetative state; no human life is ever useless or worthless. Human dignity is inalienable: we cannot lose it or give it away, no matter how low an ebb we are at. This is the long Judeo-Christian tradition.

In the face of trends of thought demeaning the dignity of the person suffering ‘PVS’, I strongly reaffirm “that the intrinsic value and personal dignity of every human being do not change, no matter what their concrete circumstances”. Even if seriously ill or disabled “a person is and always will be a man, *not a ‘vegetable’* or an ‘animal’. Our brothers and sisters in the condition clinicians call 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.” (John Paul II, *Address on Life-Sustaining Treatment and the ‘Vegetative’ State* §3)

Furthermore, supporters of the Always Feed View argue, brain-injured people are entitled to appropriate health services and support, including palliative and nursing care, addressing their individual needs. Not to feed them would be discrimination on the basis of disability and eventually homicide by neglect of reasonable care.

Just because the chances of recovery are judged small and waning, when the ‘vegetative’ state lasts more than a year, does not justify withdrawing minimal care for the patient, including nutrition and hydration. Death by starvation or thirst is, in fact, the only possible outcome of such a withdrawal. If done knowingly and willingly, this ends up being *euthanasia by omission*. (John Paul II, *Address on Life-Sustaining Treatment and the ‘Vegetative’ State* §4)

On this view we should be especially vigilant not to abandon patients in the face of economic pressures to be rid of certain patients or to clear beds for others, of physical and emotional exhaustion of bystanders, and of an advancing culture of death sometimes found even in our own ranks. Any policy not to feed or not to feed artificially whole classes of patients or all those in certain institutions should be regarded with suspicion. Advanced directives encouraging such a course could very well be suicidal in their intent and should not be offered to people, let alone respected if they are given.

A third view, which might be called the “Seldom Feed View”, has much in common with the Never Feed View. It argues that while it is normally inappropriate to feed patients in PVS or like situations, there will be some exceptions, e.g. where the diagnosis or prognosis is still in some doubt, or where organs are marked for harvest, or where relatives are returning from overseas and would like the patient to be alive to say goodbye, or where the patient’s family have peculiar religious beliefs which require that everything possible be done. Some institutions and professionals might have a ‘No PEGs’ or ‘No tube feeding for PVS’ policy, others might not, and families should be free to choose. But overall health professionals should discourage assisted feeding unless there is a fair prospect of return to a reasonable quality of life.

A fourth view, which was taken by Pope John Paul in his address and which I will call the “Usually Feed View”, has much in common with the Always Feed View as it proposes a presumption in favour of feeding to which there will be some exceptions. Everyone is entitled at least to food, clothing, shelter, sanitation, company and prayer. So if they need artificial nutrition or hydration they should normally be given it.

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 want particularly to emphasize that 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 should be considered, in principle, *ordinary* and *proportionate*, and thus morally obligatory, insofar as and until it attains its proper goal of nourishing the patient and alleviating his suffering. (John Paul II, *Address on Life-Sustaining Treatment and the ‘Vegetative’ State* §4)

But as John Paul points out, this kind of care is (only) ‘in principle’ obligatory: if it can no longer achieve its proper goal it is no longer required. Thus assisted feeding and hydration will not be appropriate

- where the patient is imminently dying or already dead;
- where the delivery of such nutrition and hydration is futile: i.e. it is ineffective in feeding, hydrating or comforting the patient
- where the mode of delivery is too burdensome for the patient; or
- where the mode of delivery places an unreasonable burden upon others.

This means that sometimes it *will* be appropriate to withhold, reduce or withdraw assisted nutrition and hydration. But it also means that *prima facie* such care should be given to those with post-coma unresponsiveness. After all, despite some sloppy talk, they are not dead, not dying, not burdened by assisted feeding; it does work for them in the same way that it works for anyone else; and tube-feeding is usually relatively easily and inexpensively provided in this country. One way of examining our intentions here might be to ask: if PVS or demented or other patients could be adequately fed and hydrated by spoon or with a simple and cheap patch, would we? If our instinct is still ‘no’ then our reason for withholding tube feeding is not one of the ones traditionally recognised medicine and nursing.

In other places I have argued that to label post-coma unresponsive and like patients as ‘dying’ or as having a ‘lethal pathology’ and to call withholding food and water from them ‘allowing a natural dying process to proceed’ is often confused and inclines people to unethical behaviour. How can someone who, if fed, will live for weeks or years (as the doctors said ‘BWW’ would do in the Victorian case last year) be said to be dying? Is this simply a tag we apply to create a special class of patients who will, once so labelled, be denied even fairly basic care? After all, everyone suffers from the ‘life-threatening condition’ so-called that if we are denied nourishment and water, we will undergo a ‘natural dying process’; and some people are more dependent than others upon technology or other people’s energies for the satisfaction of such basic needs: babies, for instance, and the severely handicapped.

The conference which occasioned the recent papal speech demonstrated that the jury is out on just what, if anything, PVS is and how it is best diagnosed and treated, and just how much instinct and sensation survive even in those suffering very severe post-coma unresponsiveness. It seems that such categorisations are rough at best, describe a wide range of conditions, are sometimes though rarely recovered from (if the patients are not starved first), and involve *some* responsiveness to *some* stimuli. Just what might be experienced by the person is in doubt. But that such patients are often sedated or restrained suggests that they are far from ‘vegetative’ even from a purely biological point of view. And even if they cannot *experience* the agonies of death by starvation and thirst or react to them, it does not follow that it is morally permissible deliberately to induce that state or that they are no longer the proper subjects of human dignity and the proper objects of human care. Many an illness and many an injustice are suffered unawares but are no less serious for that; and many a person, indeed whole class of person, has

been deemed unworthy of care and respect in the past out of what we later came to realize was simple prejudice.

Underlying the Church's concerns here is the long philosophical and theological tradition that human life is of intrinsic value, a 'basic human good'. It is an idea presumed in, until recently, both law and healthcare practice. An increasingly popular alternative, however, is to say that people below a certain quality-of-life threshold do not command the same respect and care as those above it; in particular, their lives are not inviolable and they are not necessarily worthy of medical, nursing and other care. Post-coma unresponsive people need not be fed—whether by tube or otherwise—because they lack the capacity to achieve life's purpose, however this is characterised. Such a view is common amongst those who support the Never Feed and Seldom Feed approaches.

“Quality of life” considerations, often actually dictated by psychological, social and economic pressures, cannot take precedence over general principles. No evaluation of costs can outweigh the value of the fundamental good of human life. Moreover, to make decisions regarding a person's life on the basis of someone's external evaluation of its quality amounts to attributing more or less dignity to that particular person, thus introducing into social relations a discriminatory and eugenic principle. (John Paul II, *Address on Life-Sustaining Treatment and the 'Vegetative' State* §5)

The problems with this sort of thinking have been exposed many times before and I will not rehearse the arguments here. Suffice it to ask why we will not actively kill, or remove vital organs from, or experiment upon, or otherwise subject to indignity people who we think 'as good as dead'? Surely it is because they are not yet dead. Or to ask whether we regard it as irrational or cruel that a woman goes day by day to hold the hand and spoon soup into the mouth and pray with and for her long-demented husband? Such care will make sense to those who understand the preciousness of life and love, even for the profoundly handicapped, but may be mysterious to quality-of-life thinkers.

In the quality of life mind-set there is, as John Paul II observes, a tendency to value life 'only to the extent that it brings pleasure and well-being', to view all suffering as 'an unbearable setback, something from which one must be freed at all costs' and to view 'the growing number of elderly and disabled people as intolerable and too burdensome'—ideas all too familiar in the feeding debate. 'In this context,' the Pope notes, 'the temptation grows to take control of death and bring it about before its time, "gently" ending another's life.' Whether motivated a selfish refusal to be burdened with another person or by a nobler but misguided mercy, it

is ‘the height of arbitrariness and injustice’ to take it upon ourselves to judge ‘who ought to live and who ought to die’.

The Pope’s teaching on this matter in his recent *Allocution* should have surprised no-one. It was in keeping with the US Bishops’ Committee for Pro-Life Activities *Statement on Nutrition and Hydration* in 1992, the US *Ethical and Religious Directives for Catholic Health Care Services* in 1994, the Vatican *Charter for Health Professionals* in the same year and the Australian *Code of Ethical Standards for Catholic Health and Aged Care Services* in 2001 all supported what I have described as the Usually Feed View. Several bishops and Catholic organisations have taken a similar position, such as Archbishop Hart of Melbourne and Catholic Health Australia when they sought to speak for feeding BWV in the Federal Court last year.

We must promote positive action as a stand against pressures to withdraw hydration and nutrition and so put an end to patients’ lives. It is necessary, above all, to support the families of those suffering this terrible condition. They must not 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 this care. There must be appropriate, concrete initiatives such as: a network of ‘awakening centres’, with *specialized treatment and rehabilitation* programmes; *financial support and home assistance* for families; *facilities to accommodate* those who cannot be cared for at home; and *respite for families* at risk of psychological and moral burn-out... *Spiritual counselling and pastoral aid* are particularly important as they help the family find meaning in this apparently hopeless situation. (John Paul II, *Address on Life-Sustaining Treatment and the ‘Vegetative’* §6)

Rather than the positions of those who say ‘always feed’, ‘seldom feed’ or ‘never feed’, the Church proposes that feeding and hydrating, even by artificial means, is a kind of basic caring which should be given unless there are very strong reasons against it in a particular case. This means we should revisit any policies like “we don’t accept patients with PEGs” or “we don’t use artificial life-sustaining measures” and that we must resist recent proposals to offer patients advanced directives which exclude artificial feeding. We need to offer positive alternatives such as those listed here by the Pope. Some of our institutions should have a specialty in the care of patients suffering post-coma unresponsiveness as some would undoubtedly improve. But even when we cannot cure we can always care. The covenant between the generations demands that at least we try.