Tube feeding, Catholic teaching, and dementia

If someone with dementia is no longer able to feed themselves, does Catholic teaching oblige us to insert a feeding tube or PEG and to feed them through it?

The Catholic approach to this question depends on our distinction between the ordinary and extraordinary means of preserving life. We have a moral responsibility to use the ordinary means of preserving our life. However, we may legitimately refuse extraordinary means. Reflecting this distinction, the *Code of Ethical Standards* states that "treatments may legitimately be forgone (withheld or withdrawn) if they are therapeutically futile, overly burdensome to the patient or not reasonably available without disproportionate hardship to the patient, carers or others."[1]

The official teaching of the Church has applied this distinction to the question of tube feeding for someone in a state of post-coma unresponsiveness (PCU). (This used to be called the vegetative state.) Such a person has suffered serious brain damage, perhaps through a car accident. After some time in a coma, they have regular sleep-wake cycles. However, they do not seem to be aware of, or in any conscious way responsive to, the world around them. They are profoundly disabled human beings.

For such a person, the Church teaches that tube feeding "should be considered in principle ordinary and proportionate, and as such morally obligatory" unless it imposes excessive burdens or will not sustain life. However, if it does impose excessive burdens or does not sustain life, the Church teaches that tube feeding for such a person may be refused, withheld or withdrawn.[2]

The official teaching of the Church has not explicitly addressed the question of tube feeding for someone with dementia. Further, we should note that PCU and dementia are very different conditions. With proper care, someone with PCU can live for many years. (For example, Queensland Christian Brother Dan Courtney, who died recently, lived for more than 10 years in PCU.[3]) By contrast, dementia is a terminal condition. Caused by progressive degeneration of the brain, dementia inevitably leads to death. Nothing we can do – not even tube feeding – alters this grim reality.

When someone with dementia is no longer able to feed themselves, the alternatives are hand feeding (i.e. being fed by another person) or inserting a feeding tube. Furthermore, the medical evidence is that for these patients tube feeding "is not likely to prevent or relieve aspiration pneumonia, increase patients' nutritional status (including prolonging life), or reduce feelings of hunger and thirst better than hand feeding."[4] It also deprives them of the human companionship and gustatory enjoyment of hand feeding. And it may impose significant burdens if a person with dementia must be physically restrained to stop them trying to pull out their feeding tube.

There may be some, fairly rare cases in which a feeding tube might be appropriate for someone with dementia.[5] For this reason, decisions about tube feeding for a person with dementia should be made in a Catholic facility on a case-by-case basis. It is wrong to think that Catholic teaching obliges us to insert and use a feeding tube in every case. In many cases, a Catholic facility and the family of a person with advanced dementia, having carefully reviewed his or her condition and circumstances, may reasonably conclude that tube feeding is not appropriate.

The National Palliative Care Program's *Guidelines for a Palliative Approach in Residential Aged Care* contains much valuable advice about good nutritional care in an aged care facility. Good care "includes early recognition of weight loss and identification and management of likely causes (e.g. adverse medication effects, poor oral health or depression)." And "giving residents oral foods and fluid, even in small amounts, is preferable to using more invasive enteral (e.g. nasogastric or PEG) feeding methods." Most importantly, the *Guidelines* provide a Tube Feeding Decision Aid which may be used with residents and their families to help them decide whether or not to pursue tube feeding.[6]

In many cases, the use of this Aid will help persons with dementia and their families to recognise that for them tube feeding would be futile or burdensome or even both, and therefore that it is for them an extraordinary means of preserving life which may legitimately be refused, withheld or withdrawn.

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[1] *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia* II.5.9.
[2] John Paul II, *Address to Participants in the International Congress on 'Life-Sustaining Treatments and Vegetative State: Scientific Advances and Ethical Dilemmas,'* #4; cf Congregation for the Doctrine of the Faith, *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration*; Bishops Committee for Health, Bishops Committee for Doctrine and Morals, and Catholic Health Australia*, Briefing Note on the Obligation to Provide Nutrition and Hydration*. For a fuller discussion of this teaching, see my "Catholic Teaching about Tube Feeding," *Chisholm Health Ethics Bulletin* 16, no. 2 (Summer 2010): 8-12; online at http://www.mercy.com.au/About_Us/Research/Bulletins/
[3] Tim Scott CFC, "Beloved Br Dan Courtney leaves a lasting legacy," *The Catholic Leader* 12 August 2012, p. 27.
[4] Alan Sanders, "The Clinical Reality of Artificial Nutrition and Hydration for Patients at the End of Life," *National Catholic Bioethics Quarterly* 9, no. 2 (Summer 2009): 293-304 at 302-303.This is a systematic review of more than 80 peer-reviewed studies about dementia and tube feeding. Another systematic review which reaches the same conclusions is Johanna Valiquette, "PEG tubes in end-stage dementia," in *Incapacity and Care: Controversies in Healthcare and Research*, ed. Helen Watt (Oxford: Linacre Centre, 2009), 106-121. The same conclusions are reached by the Australian and New Zealand Society for Geriatric Medicine in their Position Statement No. 6 *Under-Nutrition and the Older Person* and their Position Statement no. 12 *Dysphagia and Aspiration in Older People*.
[5] One example is offered in John S. Howland, "A Defense of Assisted Nutrition and Hydration in Patients with Dementia," *National Catholic Bioethics Quarterly* 9, no. 4 (Winter 2009): 697-710.
[6] National Palliative Care Program, "6.4 Nutrition and Hydration," *Guidelines for a Palliative Care Approach in Residential Aged Care* Enhanced Version May 2006, 87-96.