

On not being a vegetable

Of all the dilemmas classified under end-of-life issues, the most divisive even for Catholics has been the treatment of people diagnosed as being in a “vegetative state.”

The phrase has been used to describe patients who are not comatose (because they have sleep-wake cycles) but seem unaware of their environment, most often due to a head injury. They may live a long time in this state if provided nursing care and nourishment; but the reigning assumption has been that after a few weeks or months in this state, they will not get better either.

In 1983, ethicist Daniel Callahan said many of his colleagues were interested in withdrawing food and fluids from these helpless but medically stable patients because “a denial of nutrition may in the long run become the only effective way to make certain that a large number of biologically tenacious patients actually die.”

Those colleagues generally prevailed in secular medical ethics and the law. Court cases involving patients like Nancy Cruzan, Nancy Ellen Jobes and Terri Schiavo have established a broad right to discontinue feeding and let patients in a vegetative state die of dehydration.

Now enters the American Academy of Neurology with new guidelines on treatment of these patients, developed along with other experts and the National Institute on Disability, Independent Living and Rehabilitation Research. This group’s findings and recommendations are game-changing:

— A more descriptive term for “vegetative state” is “unresponsive wakefulness syndrome.” (This will be welcomed by families who don’t appreciate their ailing loved ones being compared to broccoli.)

— There is a significant chance for rehabilitation (sometimes allowing patients to return home and resume employment) even in patients who have been in this state for a year or more, so “continued use of the term ‘permanent vegetative state’ is not justified.” The term “chronic” should be used, as it does not imply irreversibility. Protocols are recommended for enhancing the prospects for recovery.

— Studies show that the likelihood of misdiagnosing the condition is about 40 percent. This includes cases where patients diagnosed as “vegetative” actually had locked-in syndrome, where they cannot respond but are fully aware (so presumably they can hear their doctors calling them vegetables).

— One study found that 32 percent of patients with severe traumatic brain injury died in the hospital — but 70 percent of the deaths were due to withdrawal of life support, and such withdrawal had more to do with the facility where care was provided than with the severity of the symptoms.

In short, our medical system has been giving up on far too many of these patients, prematurely ensuring their deaths based on faulty diagnoses and self-fulfilling hopeless predictions.

I have seen these conclusions before. In 2004, I attended a conference on the “vegetative state” co-sponsored by the Pontifical Academy for Life. There medical experts presented findings very similar to what the American Academy of Neurology now says (including the 40 percent misdiagnosis rate) — but at that time they were on the cutting edge of medicine, ignored or dismissed by many as being too optimistic.

At that conference, St. John Paul II gave an address affirming our moral obligation to provide basic care, generally including assisted feeding, to patients in this condition. He cited some of the experts’ findings, though he based his moral statement chiefly on the dignity of our fellow human beings that endures regardless of their condition.

Some say there is a divide between the church and science, including medical science. There was on this issue. The divide was about 14 years, with the medical establishment finally catching up with what the pope already knew.

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