# Terri Schiavo

For several weeks this spring, the story of Terri Schiavo dominated the headlines. Finally, on April 4, 2005 she died.

Or, should we really say that on that date, Terri Schiavo was killed?

I think the first description fits, but there are people whom I respect who think the second fits better.

Let me say at the outset that I think that Michael Schiavo's decision to have his wife Terri's "tube feeding" withdrawn was morally permissible and that it was not wrong for the professionals caring for Terri to comply with that decision. At the same time care for people in conditions like Terri Schiavo's is a relatively new thing—made possible only since the invention of high-quality, long-lasting "tubes"—and the ethics of such care is still being debated. Christians and others of strong moral conviction may reasonably differ as to what is right and wrong in this area. Thoughtful, prayerful, respectful and congenial pursuit of wisdom is needed. I am far from certain that I have things fully worked out, and I am sure that I cannot explain myself fully in one short article. Nonetheless, what follows is an explanation of my thinking.

Terri had suffered cardiac arrest in 1990, when she was 26 years old. Her heart stopped and that meant that circulation of life-sustaining oxygen to all parts of her body,



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including her brain, stopped too. By the time her heart was started again, Terri had suffered catastrophic and medically irreversible brain damage.

Terri Schiavo was in a "persistent (or permanent) vegetative state." (This is the diagnosis that neurologists like Dr. Ronald Cranford, an leading expert in the condition, made after examining Terri in 2002. The courts accepted their judgment and I do too, even though others have disputed it.) What does "PVS" mean? It describes "the behaviour of people who have profound cortical brain damage. Although they display a sleep-awake pattern, they respond to stimuli only reflexly and with no evidence of cognitive function....Because the brain-stem is intact, there is spontaneous respiration and heartbeat. Thus there is no question of artificial ventilation being needed...However, there is no known intellectual activity, no rational response, no sentience, no cognitive function. The condition has been summed-up vividly as 'awake but not aware.'" So says Dr. Andrew Fergusson, a Christian physician who disagreed with the court-approved withdrawal of "tube-feeding" from Tony Bland, a British man whose condition was similar to Terri Schiavo's.

Because Terri lost consciousness in 1990 and never recovered it, it would have been cruel to try to feed her by mouth. Food in her mouth could well have been "aspirated," going into her lungs rather than her stomach. So, Terri was "tube-fed." In her case this meant that a small operation was done on her abdomen and a plastic tube was permanently implanted through which pureed food and fluid was delivered to her stomach. With a quality hospital bed and attentive care of her skin so that she didn't



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develop bedsores, Terri could have remained in much the same state that she was in in 1990 for many more years.

That brings us to the core ethical question: knowing that without nutrients and water human life is unsustainable, is it morally permissible for "tube feeding" to be discontinued on anyone who is in the kind of condition Terri Schiavo was in? If so, why? And if not, why not?

For some people the answer all hinges on the patient's "autonomous wishes." According to this way of thinking, if a person in full possession of their reasoning powers declares that they would not want to be "tube fed" if they were ever permanently unconscious, then it would be a violation of their moral and legal right if others were to impose tube feeding on them. That's why many people think Terri Schiavo's case would have been much less complicated if she had left a "living will" or "advance directive." Whether or not Terri actually expressed a firm view before her heart failed was debated in the courts. They determined that she did, and that she had made "reliable oral declarations" that she would not have wanted to be "tube fed" for fifteen years.

There is another group of people who also find the ethical issue quite straightforward, but their principles take them in a very different direction. According to them the question of what Terri wanted is morally secondary even if it is legally critical. For them the fundamental moral issue is that human life is "sacred," that it is given by God and may only be ended by God. The human responsibility is to protect, preserve and prolong life.



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While this is a principle embraced by some Christians, it is not only Christians who hold it. According to the great Canadian Orthodox Jewish bioethicist Benjamin Freedman, "In spite of scanty Biblical warrant [the chief scripture used by the rabbis was Deuteronomy 4:9], a clear norm was established in Judaism that persons are obliged to preserve and protect their lives, to seek to be healed, if necessary." Freedman quotes Dr. Steinberg's 1991 article to show how traditional Jewish ethics ranks the obligation to preserve life in relation to the principle of patient autonomy. "The central principle underlying the concept of informed consent is the value of autonomy. However, the power of this value is limited according to the view of *halakha*. In the *halakhic* understanding, there is a duty upon the physician to heal, and a duty upon the ill person to be healed, and therefore the entire value foundation underlying the principle of informed consent is almost totally nullified. … The ill person who refuses treatment in case of danger is coerced, and [his express refusal] is not accepted; all that is needed to save life is done, even against the ill person's will."

Now, my perspective differs from both of these. I grant that "autonomy" is a factor. It certainly matters what Terri Schiavo said (or would have said) about continuing to tube feed her. I also grant that the sanctity of human life is a factor. It matters to me that we treat embodied human life as a divine gift whose value is not determined by how intelligent or how healthy or how productive it is. I agree that human lives are not to be ended by us because we think them of insufficient quality.

At the same time, I do not believe that Christian ethics requires that we do everything possible to maintain and prolong human life. As great a gift as life is, it is permissible to set limits on the lengths to which we go to preserve it. It is permissible –



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indeed it is in some instances mandatory – to set other goods or other duties above the prolongation of life.

I think this is a critical point in Christian ethics. We know that Jesus did not make the prolongation of his life his highest goal. Though he could have called ten thousand angels, he did not. Many of the saints of the church have likewise made choices that risked their lives, and doubtless that meant they lived shorter lives than they could have if they'd made other choices.

Jesus healed many people during his earthly ministry, and thereby improved the length and quality of their lives. But he didn't heal them all, even though he could have. He told us, his followers, to do good to everyone, to love our neighbors (including neighbors who were enemies, strangers, or especially vulnerable), but he did not tell us that loving them would always equate with lengthening their days.

Christian ethics has always been strongly "pro-life" – death and disease are not part of God's original creative design – and so we find in Roman Catholic ethics, for instance, the statement that it is intrinsically wrong directly to intend the death of any innocent human being. But Christian ethics has also acknowledged that death may come in other ways than by direct intention, and it has long held that it is sometimes allowable for us to do things that mean a person dies otherwise than as a result of a direct intention that they die.

In medical ethics one of the standard questions is whether the treatment is in the patient's best interests or not. If a treatment is providing no benefit, or is harmful or



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burdensome to the patient, or is outweighed by greater goods with which it is interfering, that is a reason for forgoing the treatment. Even if by so doing, the patient's death ensues.

Just what constitutes a "benefit" or "burden" is a vexed question. So is knowing when other worthwhile ends or other duties outweigh the prolongation of life by medical means. These matters call for wise discernment. Difficult as they are, I think grappling with them is unavoidable if we are to understand the ethics of cases like Terri Schiavo's.

So we ask, by 2005 was "tube feeding" continuing to benefit Terri? Was it doing her any good? Or on the other hand, in the language of medicine, was it "futile treatment"?

When I looked at the video clips of Terri on the internet, I admit that it appeared like she was looking at her mother. It was eerie. I defer to the experts in neurology, however, and accept their word when they say that the best evidence they have is that such phenomena are attributable to the autonomic nervous system whose control centre is the brain stem, not the brain cortex (the physical infrastructure that supports bodily consciousness in human beings). Because of the destruction of her cortex, Terri was not aware of herself or her surroundings. She could not feel the warmth of her room or feel the nurses' touch when she was being washed. She could get no satisfaction from the food put into her stomach, and she could feel no thirst if her body was not "hydrated." She could not enjoy the table fellowship and hospitality that makes eating and drinking enjoyable for most of us. She could not be happy that people were continuing to care for her. And on the other side, she could not suffer either. In the days between the discontinuation of her "tube feeding" and April 4 when she died, she felt no pain.



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What fifteen years of "tube feeding" did was to keep Terri Schiavo alive. In that sense it was not futile. It worked. But did it benefit her? Did it do Terri any good? Was it in her best interests, all things considered? Or were there even weightier burdens on the other side?

What you say about this may depend on what you think about some other possibilities that could have happened to Terri Schiavo. Suppose Terri had developed a serious bacterial pneumonia (as could happen to people who are permanently bedridden and "tube-fed"). Would antibiotics have been necessary? They would likely have cured the pneumonia; and if not given, the pneumonia could have become fatal. In that sense antibiotics would not be futile. But if Terri's doctor recommended not treating the pneumonia, would the doctor be guilty of harming the patient (as would surely be the case if a doctor recommended not treating a similar pneumonia in you or me)? Or suppose that Terri developed breast cancer that had advanced by the time it was detected. If that happened to you or me, surgery or chemotherapy or radiation therapy would be the order of the day, since it would not be in our interests to let us die of a cancer for which there is a highly effective treatment. But would surgery on Terri be called for because it would be in her best interests just as it would be in ours?

My sense of it is that, all things considered, Terri would not really be benefited by antibiotics or cancer treatment. If she had died of complications of these diseases it would not have been gross negligence. How then, if ceasing tube feeding is different, is it different? I cannot see that it is.



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Which of us would say, "If I happen to suffer an accident like Terri Schiavo's and am rendered completely and irreversibly unaware of myself, my surroundings and any capacity for pain or pleasure, I would like to be tube-fed indefinitely"? I know I wouldn't say that. Not only do I find myself wondering "what would be the point of keeping me tube-fed?" but I find myself recoiling at the prospect of lying there year after year my muscles becoming more and more contracted. You might wonder why it would matter, since I would not be able to feel any pain and wouldn't be aware of my condition. To appreciate what I am getting at, suppose the nursing home, realizing that I couldn't feel anything and couldn't possibly object, were to strip me naked and leave me uncovered while they did my laundry. That would be horrible, wouldn't it? Even though I was incapable of feeling the shame at the time, such disrespectful treatment would be contrary to my interests and shouldn't be allowed by anyone who cared about me. I think the same could be said about causing me to linger year after year.

Another reason I wouldn't want to be maintained like this has to do with the costs that would be paid by others. We might like to think that costs should never be a consideration in determining the ethics of life-sustaining medical treatments but I think they are one legitimate consideration.

If Terri Schiavo had developed a breathing problem that meant that prolonging her life would require not only a feeding tube but a respirator too, I know that it would be highly unlikely that the medical specialists who control access to Intensive Care Units in Canada would even contemplate offering to take Terri in. Why? Because ICU equipment and staff are scarce and others who would "benefit" more than Terri would otherwise be



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denied access. It's a hard reality, but it is a reality. And I think it's ethically justifiable to factor it in.

How great were the costs borne by others (and I hope it's clear that I don't mean only monetary costs) by tube feeding Terri Schiavo for fifteen years? How much greater would they have been if the treatment she was receiving had been continued for another fifteen or twenty years? This is not something that can be reduced to a calculus. It inherently involves personal factors that means that one family might legitimately find the costs too onerous and another family decide it's a cost worth paying. In the public debate about Terri's treatment, a number of people were critical of her husband Michael's having "moved on" with his life. They thought he should be willing to pay a greater cost. I cannot judge him. I just know that I myself would not want to impose very much cost at all on my surviving family if somehow I were to suffer Terri's plight.

My greatest fear in saying that the medical interventions that had been forestalling Terri Schiavo's death could legitimately be discontinued out of consideration for her is that this will expose others who are disabled, poor, weak and already easily-overlooked to even greater vulnerability. Giving Terri Schiavo medical treatment may be of no benefit to her, but it could be of great benefit to many others. Christians need to decide not only on the basis of their own personal interests, but also bearing in mind the character of the community in which they live and die. My hope is that we don't really have to make it one or the other.

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