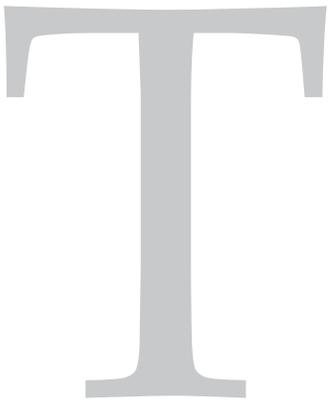


A
Matter
of
Life
and
Death

By William Richardson



Terri Schiavo is gone, but the issues raised by her life and death are not. In fact, many of those very issues have been lurking in the shadows of our consciousness since the invention of the first ventilator. Only occasionally have news stories forced us to venture warily into those shadows for answers to the usually avoided questions about end-of-life care. When, with the aid of the media, cases leap from the hospital room to our living rooms, we reluctantly start to talk about our preferences.

In 1975, Karen Quinlan, then 21, drank three gin and tonics at a party and suddenly fell unconscious and quit breathing. By the time paramedics were able to restore her breathing, her brain had been irreparably damaged. She lapsed into a persistent vegetative state (PVS) from which she would never emerge. Apparently the gin and tonics caused a tragic reaction with her stringent diet and the tranquilizer Valium. When at length her prognosis by several physicians became certain, her devout Catholic parents, after a period of great anguish, decided to unplug her ventilator. The hospital refused their request and a lengthy and rancorous court battle ensued that drew international attention. In time the parents won the case and the ventilator was unplugged. However, contrary to all predictions, she stabilized and began to breathe on her own—though no cognition returned. Apparently her brain stem had healed just enough to keep her autonomic reflexes, eye movement, breathing, and heart rate functioning. Thanks to artificial nutrition and hydration, she was kept alive in a persistent vegeta-

tive state for 10 years in a long-term-care facility before she died of pneumonia. It was a landmark case—no U.S. court had ever granted such a right.

On an icy night in 1983, 26-year-old Nancy Cruzan crashed her car and her head injury was so severe that, like Karen Quinlan, she lapsed into a persistent vegetative state. In Karen Quinlan's case, parents sought to unplug a ventilator. In Nancy Cruzan's case, her parents sought to remove a feeding tube. It turned out to be another lengthy, noisy battle in the courts, with the parents eventually, in 1990, winning the right to remove the feeding tube. Cruzan died a little over a week later.

The recent Terri Schiavo case began where the Cruzan case began—the difference being that Schiavo's "family" was bitterly divided. Before we dismiss any of these cases as quite removed from "where I live," we should keep in mind that at any one time, there are, in America, roughly 10,000 patients in a persistent vegetative state, and many are not old. As these recent cases make very clear, we should guard against the notion that "end of life" issues have to do only with the "elderly." Furthermore, the public overwhelmingly feels that a patient's freedom to choose death rather than linger in PVS should be honored. Regardless of how any of us would like to be treated if we were in such a condition, there are lessons to be learned from these now well-known cases.

First of all, we must come to grips with the issue of patient and personal autonomy. Given the many advances of medical technology, we are faced with heavy choices that only a few years ago were not options. Then, it was easy to say that everything about our lives and deaths was in God's hands because few alternatives were available to us. Now, with sophisticated meds and machines, we can decide on numerous interventions to prolong life, or hasten death. Of course there are those who feel that exercising such awesome power over our lives and deaths—but particularly our deaths—encroaches on territory that belongs only to God; that our cavalier uses of "autonomy" are fooling around with the mystique of life and death and that area should ever and always be left with Him.

But the whole realm of medical science and the healing professions impinges directly on that philosophy. If a medical intervention such as a mechanical ventilator dramatically “saves” a life, is there a God factor there at all? Or do we invoke the God factor only when we decide to unplug the machine?

For example, as the recent Terri Schiavo case heated up in the media, I saw no reasoned sidebar article that attempted to seriously address the issue of when to insert a feeding tube. All the inflamed verbiage focused on the withdrawal of the tube. As that

debate raged, my 88-year-old father-in-law with Parkinson’s disease quit eating and drinking. After carefully and prayerfully considering his prognosis, family members decided not to insert either a feeding tube or an IV. He was not technically in a coma or PVS, though lucidity had gone and he had quit communicating. Hospice was carefully monitoring his pain indicators—he did not appear to be in pain. Had we inserted an IV and a feeding tube, we might well have prolonged—what? His life or his death?

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Making Your Wishes Known

So, how does one go about creating unmistakable and unambiguous instructions for uncertain circumstances? And, how can one ensure that those instructions will be followed? It may not be comforting, but the first thing to accept is that perfect answers do not exist. There are guidelines, however, that can help:

1 Think carefully, and take counsel, before you decide on your instructions. These issues will affect your family and friends, so be sensitive to their concerns. A good resource for walking you through the process and all the various issues is a document called “Five Wishes.” You can find this document either by calling around to local hospitals, hospices and churches, or by going to www.agingwithdignity.org/5wishes.html.

2 Make it legal. The requirements vary from state to state and country to country. Do some research to find out what is necessary in the state where you live. You may or may not need a lawyer (in addition to peculiarities unique to your state or country, a lawyer generally is desirable if you have significant assets or if your family structure or relationships are complicated.) If you live in Michigan, you can go to www.andrews.edu/alumni/focus/dpoa and print a copy of the Durable Power of Attorney for Health Care document that was provided to Andrews University employees (this document is “legal” in Michigan).

3 Put it in writing. There is no “magic” in written words, over verbal words, but written words often can provide better “evidence” of your inten-

tions. According to Terry Schiavo’s husband, Ms. Schiavo did express her wishes to him and he was following her wishes; but some members of Ms. Schiavo’s family did not believe him. Had there been a written expression of her wishes, an entire area of dispute could have been prevented.

4 Have it witnessed and/or notarized. Specifically what is required likely depends on the laws of your state or country, but you certainly want to have disinterested witnesses who can attest to your wishes/signature.

5 Pray. It is last here, but it is not last or least in the process. Perhaps on our knees we will find the peace that passes understanding.

Disclaimer: The information contained in this sidebar is designed to be helpful, but it is not to be considered legal advice. If you need legal advice, you should seek the services of an attorney in your state and/or country.

But since we did neither, did our decision sentence him to an agonizing death by starvation, or did it simply ratify the decision of his body as it began the inevitable process of shutting down?

To a very large degree we were acting as stewards of life and of death—an awesome responsibility that we thinking humans must now exercise in ways previously impossible and unimagined. Ventilators are wonderful life-saving and life-prolonging machines that God has enabled us to create. They save life and we are grateful. But He has also given us rational minds with which we can and must, on occasion, decide whether or not to make use of life-prolonging, death-postponing technologies. The much-vaunted Hippocratic Oath, “First, do no harm,” is so abbreviated that it often begs for considerable interpretation. One thing seems certain: to “do no harm” is not tantamount to always doing everything conceivable to postpone death and/or prolong a semblance of life. And so, willing or not, we may find ourselves thrust into the role of stewards, not only of life, but of death as well.

But that autonomy, that freedom of the individual to make life and death decisions for him/herself, is fraught with often agonizing complications. For example, at what age does autonomy begin? When does a parent relinquish control over the decision-making for the child? And at the end of life, if a patient is both terminal and competent (can think lucidly), does society have a right to remove his/her autonomy and say that they must be restrained by law from voluntary, self-imposed euthanasia, regardless of the person’s religious or philosophical view of God and human life? (Such laws against suicide have existed, but it has always been difficult to figure out how to enforce them.) And of course, the next level of difficulty then is when such a patient needs help to carry out his/her own wishes and doesn’t live in Oregon, where it is not illegal for a physician to write a lethal prescription.

Whatever one’s personal view of life and death and human freedom to choose, the importance of crystal-clear communication can hardly be overstated. Every day in hospitals around the world, ventilators are quietly unplugged, feeding tubes are clamped and patients quietly die, as a result of an intentional decision—a decision

sometimes made by the patient when competent, but sometimes made by an agreeing family after close consultation with the medical caregivers.

And that is where such decisions should be made—between the patient, the family and the medical caregivers—often referred to as the sacred triangle. When we resort to the courts, the web becomes tangled indeed.

State laws governing end-of-life decisions are a crazy-

quilt of contradictions with some states never allowing removal of a feeding tube without a specific advanced directive signed by the patient, to others that require a legal guardian to make all decisions for an incapacitated spouse. Needless to say, such weighty decisions are best communicated by a written and witnessed document like a living will or a durable power

of attorney for health care. Even in states like Michigan where living wills are not given legal standing, a written statement of wishes by the patient is usually viewed with much sympathy by the courts.

Consequently, when family members gather in greater numbers around the Thanksgiving table, it just might not be totally macabre to have an informal discussion about what “end of life” treatment should look like. Better yet, after the pumpkin pie, pass around some paper and have each one write a description of a “good death” and sign it. The benefits later could be enormous.

Bill Richardson is Dean of the College of Arts and Sciences but tries to stay in touch with aspects of *Ethics*, one of his former teaching areas. In keeping with these interests, he chairs a monthly ethics committee at a large long-term care facility in South Bend and serves on the Lakeland Regional Ethics Committee.

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