



So Many Questions for Guidance at the End

Ira R. Byock, M.D. March 27, 2005

The question of whether to remove Terri Schiavo's feeding tube is grabbing daily headlines, but half a world away an even more significant story on care at the end of life is unfolding.

As Pope John Paul II lives out his days increasingly ill but still mentally alert, his suffering is at once personal and public. Although he could sequester himself and preserve his privacy, this pope has chosen to fulfill as many of his public duties as possible. As many spiritual leaders have done through the ages, he is offering his illness and suffering for others to observe.

Since 1992, Parkinson's disease has progressively undermined the pope's health. He cannot walk and has difficulty speaking. At this stage it is likely that swallowing problems cause him to aspirate food or saliva. Recent respiratory problems required a tracheostomy.

But while he sees it as part of his calling to share his suffering, the pope's formal pronouncements on dying have left important questions unanswered. Last spring he departed from previous church policy by declaring that removing a feeding tube from someone in a persistent vegetative state, such as Terri Schiavo, was tantamount to euthanasia.

Unfortunately, he didn't elaborate on what are morally acceptable ways for a permanently unconscious or profoundly demented person to die. For instance, when an individual develops pneumonia from aspirating tube formula, must he always receive antibiotics? If the pneumonia worsens, must he be connected to a ventilator? If so, for how long? If he starts bleeding from an ulcer, are transfusions morally required? Is surgery?

These are not abstract dilemmas for the thousands of families who have loved ones in hospitals and nursing homes and are forced to make these heart-wrenching decisions.

This week I met a patient who is dying in the intensive care unit of the hospital where I am a palliative care physician. She is alert, comfortable and her mind is intact, but because her bone marrow has been replaced by cancer, she requires powerful intravenous antibiotics, antifungal medications and frequent transfusions. A hemofiltration machine continually cleans her blood, and a nutrient solution drips through a tube in her abdomen into her

stomach. As with the pope, a tracheostomy tube protects her airway.

Her husband told me, "It wasn't supposed to be this way." When I asked him how they had envisioned her last days, he said, "We never talked about it."

Now they are confronting the stark reality that everyone dies of something, and every decision to treat a potentially lethal problem means the person will succumb to something else. Through lip-reading and longhand they are discussing what would be the best way for her to die. Hard as this is, they are fortunate to have the conversation at all. So many families, as in the Schiavo case, are forced to make these decisions without the benefit of knowing for certain what treatments their loved ones would want and which they would refuse. Without serious forethought and preparation, it is easy for a person's death to become medicalized.

The large majority of people polled say they would like to spend their last days at home. Yet nearly 60 percent of U.S. deaths occur in hospitals and approximately 20 percent in ICUs. In recent years the idea of community-based projects has caught on as a way for people to take back control of the end of life.

In reading groups, symposia and discussions held in congregations, senior centers, libraries and schools, people have begun to explore what a fitting end to life would be.

One of the first places to do this was Missoula, Montana, where I have been involved since 1996 with the Life's End Institute, which is examining how people can live more communally or find community values with regard to illness, family caregiving, dying and grief. Doctors, nurses, clergy, teachers, attorneys and people from every walk of life have participated in research, task forces and meetings.

We have developed a simple form that enables people to say what they would and would not want in terms of treatment and personal care and have stored these in an electronic repository. Had Terri Schiavo been living in such a community when she had her heart attack in 1990, her own wishes might well be clear.

But whether we are deciding for ourselves or for someone else, sound guidance from the pope would be welcome. One can only speculate when in the course of his inevitable decline he will decide to stop medical treatments and allow death to come. The manner of his dying, and the statements he makes about it, will either inform or further complicate our ongoing exploration of how we should care for one another as we die.

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