

Remembering Terri Schiavo

Bill Colby

March 31 will mark the third [3/31/08] anniversary of Terri Schiavo's death. I believe we would best honor Terri Schiavo by collectively setting aside time on the anniversary to talk with one another about this question: "What would you want if you found yourself in Terri Schiavo's shoes?"

On one level that question is impossible for most of us to answer. In the fall of 1987 I first met Nancy Cruzan. At that point Nancy had been in a persistent vegetative state, or PVS, for over four years, the result of an early morning car accident that left her face down in a deserted farm field, not breathing, for possibly as long as thirty minutes.

PVS is a horrific brain injury, first defined in the medical literature in 1972. The PVS patient's eyes are open and moving, but the patient is nonetheless permanently unconscious. The condition is caused when some part of the brain stem, where our basic reflexes are housed, survives an accident, but the upper, thinking part of the brain does not. The upper part of the brain is far more fragile than the stem, and suffers permanent damage after only four to six minutes without oxygen. With the invention of CPR, portable defibrillators, training of EMTs and other developments, by 1972 doctors had begun to see more and more accident victims, like Nancy, brought back from the brink of death, but not all the way back.

But whether in 1972, or today, most of us have little ability to understand that a person with her eyes open can be unconscious. The very idea runs counter to our basic intuition. Millions in 2005 viewed the video footage of Terri Schiavo appearing to smile at her mother. Not surprisingly, Americans had varied and visceral reactions to that video. In part, that's the Brave New World into which medical technology has dropped us.

I've watched the video, read the court records, and reviewed the CT scans and autopsy report, which provide compelling evidence of the tragic, complete destruction of Terri Schiavo's thinking brain. I believe the conclusion of the court system that Terri Schiavo was permanently unconscious without hope for recovery. Remembering back to that day twenty years ago when I first walked into Nancy Cruzan's hospital room, I likewise understand people who don't share that conclusion.

In a fundamental way, it doesn't matter how exactly we understand Terri Schiavo's or Nancy Cruzan's brain injuries as long as we share their stories and learn from that discussion. *That* is what our society should consider doing each March 31. I've traveled and talked with people across this country about the right to die in America. My sense is that while any particular family, or doctor/patient, discussion may be hard to get started, people everywhere want to have this talk. And once it's started, the conversation tends to take off on its own, one story leading to the next.

My own solution may not be the gold standard, but I have talked and written about these issues for many years. So when people ask me at events what I myself have done to prepare, I outline these three steps.

First, I've filled out a one-page legal document which says that my wife (or the listed alternates) will make medical decisions for me if I cannot. It's called a durable power of attorney for healthcare. Anyone can get a free copy that's appropriate for their state, by calling 1 800 658 8898, or at www.CaringInfo.org, and click on "Advance Care Planning."

Second, I've armed my wife to act as an advocate when decision time comes. We've talked about Terri Schiavo, my grandmother's Alzheimer's disease, and other stories. My wife knows that I believe the goal of medical treatment is to serve as a bridge to recovery so that I can live life. If the treatment cannot, I want it stopped.

Third, I've talked with my siblings, doctor, and others who will likely be in the room when decisions are made about me. Health care workers who deal with the seriously ill all can tell a story about the adult child who flies in to "save" mom. To avoid that family conflict later, talk now.

Of course, there's no need to wait until March 31. If you've made it to the end of this op ed, you're likely going to be the instigator in your own family. So why not right now? Go to the web site and print out the free document. Sit down with the person who you want as your decision-maker. Invite other family members to join you. Then start with this question: "What would you want if you found yourself in Terri Schiavo's shoes?"

Bill Colby is a former Senior Fellow of the National Hospice and Palliative Care Organization and author of *Unplugged: Reclaiming Our Right to Die in America*. For more information and free planning documents, go to www.CaringInfo.org or call 1-800-658-8898.