

### Terri Schiavo's Gift

On December 22, 1990, I sat with the family of Nancy Cruzan around her hospital bed in southwest Missouri, eight days after the doctor had removed Nancy's feeding tube. Two years later I did the same with Christine Busalacchi's dad in a hospital in St. Louis. In front of both hospitals, protestors held aloft signs proclaiming "Murder!" as satellite television trucks captured the scene. Some of the same protestors are now gathering in Florida, where Terri Schiavo's fate is being decided.

The Cruzan and Busalacchi families "won" the right to remove the feeding tubes from their unconscious daughters after years of litigation against the state of Missouri. No Cruzan or Busalacchi felt like they'd won anything. And, however the current legal battle in Florida comes out, it seems unlikely that any of the battling family members will feel any triumph. These families lost when fate disrupted the normal order of life and sent young women into the medical-technological limbo of permanent unconsciousness.

Most of us don't like to think or talk about these heart-breaking stories. But if we can stop for just a minute and consider what we might learn from Terri Schiavo, perhaps some good can come from this latest tragedy.

Dying has grown complicated in this country. Go back thirty-three years and we wouldn't be talking about Terri Schiavo being in a persistent vegetative state because that diagnosis didn't exist until 1972. Today, most deaths occur in institutions and as a result of a decision about medicine or technology. The idea of letting nature take its course has fallen by the medical-technology wayside. Each day, about 460 people die in Florida, many by someone's decision – respirators removed, dialysis stopped, feeding tubes clamped, antibiotics refused. Tomorrow, families of all stripes will gather again in rooms across Florida and face hard decisions about someone they love.

Thankfully, disputes like the Schiavo case are rare. Far more common is the problem of families simply muddling through because they've never talked about dying.

My neighbor's father had Alzheimer's. Though he knew his father had a certain path downhill, they never talked, and then it was too late. The image stayed with him. Years later, he told me about how his family stood around the nursing home with blank looks on their faces when confronted with each new question: How aggressively do you want to treat pneumonia? Do you think your father would want a feeding tube? And on and on.

My own solution may not be the gold standard, but I've thought about a lot about the intersection of law and medical technology, and have taken these three steps. First, I filled out a legal document, a one-page power of attorney for healthcare. This document states that my wife (or the listed alternates) will make medical decisions for me if I cannot. Second, I've armed my wife to act as my advocate when the time comes. We

talked about Nancy Cruzan, and Alzheimer's, and more recently about the movie *Million Dollar Baby*. She knows that I believe that the purpose of medical technology is to serve as a bridge to recovery so that I can live life. When it cannot, I want it stopped.

Third, I've talked with my siblings, my mom, and others who might be in that room when decisions are made about me. Health care workers who deal with the dying can all tell a story about the somewhat-estranged adult child who flies in to "save" mom. Dysfunctional families do not turn into the Cleavers when standing around the hospital bed of an unconscious family member. To avoid conflict later, talk now.

The fractured legal journey of the Schiavo case shows us that the black and white of the law has a surprisingly limited ability to solve the emotionally gray questions of human dying. But what if in a happier time, just once while standing over a backyard grill, Terri and Michael Schiavo and Terri's parents, Bob and Mary Schindler, had talked about Nancy Cruzan? For five minutes? For two minutes? Would Terri Schiavo have spared her husband and her parents the unbearable dispute and grief they've had to endure? Don't we owe that five minutes to the people we love?

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