
From Quinlan to Cruzan to Schiavo: What Have We Learned?

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Well, what an interesting time for us to gather and consider questions of death and dying in modern culture, with the tragic story of Terri Schiavo still fresh in the minds of most Americans.¹ I plan to talk about the *Schiavo* case, of course.² I also want to spend some time telling you the story of Nancy Cruzan to lay the foundation for our discussion of *Schiavo*.³ And I will do my best to leave time at the end for all of us to discuss these important societal questions.

Before I start on *Cruzan* though, I've found as a lay person, being a lawyer and not a doctor, that it helps me understand the issues raised in these cases by trying to frame them in some kind of historical context. There are various ways we might accomplish that task, but let's do it with a couple of quiz questions. Twice I've taught a class at the University of Kansas School of Law called Law & Bioethics. So, let's begin tonight with the exam I gave recently to the law students in Law & Bioethics. This is a twenty-minute essay question, last question on the exam. I know you didn't read the textbook and that you didn't attend class where we discussed this issue, but that actually puts you in

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1. See *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1289, 1303 (11th Cir. 2005) (denying motion for temporary restraining order that would have permitted reinsertion of a feeding tube into Terry Schiavo); see also Kathy Cerminara & Kenneth Goodman, Key Events in the Case of Theresa Marie Schiavo, <http://www.miami.edu/ethics2/schiavo/timeline.htm> (2005) (delineating a chronological timeline of significant events in Terry Schiavo's case and death on March 31, 2005).

2. *Schiavo*, 403 F.3d at 1291.

3. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 265-70 (1990).

the same boat with at least three students who took the exam, so you can't get out of the exercise with that excuse. So here's the question.

A well-known local rabbi is driving down the New Jersey turnpike and has a horrible car accident. EMTs arrive, resuscitate the rabbi, and then rush him to the hospital. But it's not just any hospital. This hospital is a new joint venture between the states of Pennsylvania and New Jersey, and it was built straddling the state line between the two states. As fate would have it, the bed that they took the rabbi to that night in the ER is in fact straddling the state line between the two states. The medical team does everything they can to bring about recovery for the rabbi, without success. The attending physician does the various clinical tests, like testing the corneal reflex, to see if there's any brain activity. There's not. Two separate EEGs, or electroencephalograms, are performed, and the result is a flat line – no electrical activity in his brain whatsoever. But, the rabbi's heart and his lungs continue to function with all of the support that we can bring to bear in the modern day emergency room. Dejected, the doctor walks out of the ER, just as the rabbi's brother rushes into the waiting room, sees the doctor, and says, "oh my God, doctor, my brother, is he dead?"

What do you think? You've got twenty minutes. It's an upper level law school exam question, so of course the answer's going to be, "it depends." In Pennsylvania, the rabbi is most certainly dead. He meets the Pennsylvania definition of brain death.⁴ In New Jersey, he may or may not be dead, depending on what the attending physician knows about the tenets of the rabbi's faith, and depending on what's written in his medical chart about his beliefs.⁵ The point for us tonight is not to study how one state defines death differently than another, but isn't it amazing that this could be a serious question on a law school exam? For most of recorded time, when we were dead, we were dead. Our heart, lungs, brain, all stopped at roughly the same time. Technology has changed that equation forever.

All right, second quiz question, and as I look out on the audience I see we have a good mix to ask this one. How many of you used to

4. Pennsylvania law provides that "[o]nly an individual who has sustained either: (1) irreversible cessation of circulatory and respiratory functions; or (2) irreversible cessation of all functions of the entire brain, including the brain stem is dead." PA. STAT. ANN. § 10203 (West 2003).

5. See N.J. STAT. ANN. § 26:6A-5 (West 2005) (forbidding declaration of death based on neurological criteria when the physician "has reason to believe . . . that such a declaration would violate the personal religious beliefs of the individual"). Absent such knowledge of the patient's intent, New Jersey allows a person "whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain" to be declared dead. N.J. STAT. ANN. § 26:6A-3 (West 2005).

watch Dr. Kildare? Several of the less-seasoned audience members are shaking their heads quizzically. Dr. Kildare was on television in the 1960s. He was the kind of doctor we all want—his success rate was amazing. But, every now and then, when he ran into a particularly hard case, he would turn to a nurse and say, “Go get the Bird.” Anybody know what he was talking about? That’s right, a Bird ventilator—one of the early versions of a mechanical ventilator, invented by a doctor from California named Forrest Bird.⁶ They looked like green workers’ lunch boxes, made of glass, perched on a gray metal stand.

In Kansas City in the late ‘60s, at Bethany Medical Center in Kansas City, Kansas, a large, city teaching hospital, there was a Bird ventilator in use that did not have an automatic switch. Student doctors or nurses would sit with the patient and the machine in three-hour shifts, and every five to six seconds, flip a switch, shoot a blast of air into the body, and turn it off. How often do you think the questions about the appropriateness of prolonged use of medical technology came up in that facility then? They didn’t. You either breathed on your own after a few days, or you died. It wasn’t long ago in our culture that we wanted every bit of medicine and technology that the medical world could bring to bear on serious illness, because compared to today, it just wasn’t much.

Fast forward to an article that appeared recently in the journal *Nature* about a doctor in New York City doing gallbladder surgery.⁷ The reason it was in the journal was because the doctor was not standing over his patient plying his scalpel, but instead was in a capsule of sorts, manipulating robot arms, doing the new robotic surgery. And his patient was not right outside his capsule. She was overseas in France. The signals went under the ocean on transatlantic cable. They called it the Lindbergh operation, named after the first transatlantic plane flight by Charles Lindbergh.

I’m forty-nine now, God willing thirty years from now I’ll be seventy-nine. If our society has moved from the Bird respirator to the Lindbergh operation in roughly thirty years, what kind of choices am I going to have when I’m seventy-nine? What kind of choices are there going to be for my parents’ generation just five years from now? I don’t even think our science fiction writers can tell us. But our society will be talking about this intersection of medicine and technology and

6. See Forrest Bird - Wikipedia, http://en.wikipedia.org/wiki/Forrest_Bird (last visited Oct. 14, 2005) (detailing the history and function of the Bird Ventilator).

7. Jacques Marescaux et al., *Transatlantic Robot-Assisted Telesurgery*, 413 *NATURE* 379, 379–80 (2001), available at <http://www.nature.com/nature/journal/v413/n6854/index.html>.

humanity and the law all the time. And when the law gets involved, at the base of that discussion will be the case and the story of Nancy Cruzan. So, let me spend a few minutes telling you the story of that family.

The Cruzan case starts like a lot of stories for a lot of families. One of Joe Cruzan's phrases in life was that "life can turn on a dime."⁸ A car tire goes off the road just a bit, and everything that he knew as normal was changed forever. In Nancy's case, she was in a single car accident in rural southwestern Missouri after midnight. We don't know what caused the accident. We do know from the police and ambulance reports that alcohol and drugs were not involved. Whether she fell asleep, or an animal crossed her path, we don't know. We do know the path of her car from those reports.

The car crossed the center line, went off the side of the road, down an embankment, hit several small saplings, hit a rural mailbox, went back up the culvert on the side of the road, smashed a fence on the other side, and flipped on its top. Nancy was thrown thirty-five feet beyond where the car stopped. From the point where she left the road to the point where the car stopped was almost the length of two football fields. So, we know that she was going very fast.

A neighbor some ways down the road heard this commotion, came running out, took in the scene, ran back, yelled and woke his stepfather. His stepfather came running out, took in the scene, he ran back, yelled to his wife to call the highway patrol. She did, and sometime later an ambulance, highway patrol car and fire truck arrived. The paramedics started CPR and Nancy was resuscitated.⁹

As we reconstructed what happened that night, and this was years later, as part of getting ready for the first trial in Cruzan, I concluded that it could have been as long as thirty minutes that Nancy Cruzan was without oxygen before she was revived that night.¹⁰ At the very least, it was in the high teens. Every part of her brain that made her uniquely Nancy Cruzan was simply gone by the time the EMTs arrived. The shrinkage of the brain tissue did not happen that night, of course, but the damage had been done.

The paramedics could not know that as they rushed to a dark farm field in the middle of the night, trying to save lives. And in the same way, Nancy Cruzan's family knew none of that as they got the phone call from the state trooper in the middle of the night—the call that

8. WILLIAM H. COLBY, LONG GOODBYE: THE DEATHS OF NANCY CRUZAN 7-9 (2002).

9. *Id.* at 9.

10. *Id.* at 124.

changed everything in their lives—and rushed to the ER. Their education about anoxia, or lack of oxygen, and the damage that begins to happen to the brain after just four to six minutes without oxygen came over time. And if you asked them, as I did, “can you pinpoint a time when you lost hope, when you started to believe that your daughter was not going to come back, not going to recover consciousness?” They really couldn’t. Their lives simply began to change, as a lot of families’ lives change. Hobbies fell away. Friends fell away. And visiting and trying to bring Nancy back simply became what they did.

But, they remember starting—years after the accident—to talk as a family, hesitantly, tentatively at first, about what their options were, and what Nancy would want. And they realized as they talked that they were basically down to two choices only, both of them bad. The accident had taken away all good choices.

Nancy, very predictably with that amount of time without oxygen, had moved from a full coma for the first few weeks into an open-eyed kind of unconsciousness that the doctors called a vegetative state.¹¹ Her eyes opening had been a period of brief hope for the family, but doctors told them that the open eyes did not mean Nancy had regained consciousness. True enough, try as they might, they could not get Nancy to respond to them in any way. After some period of time in this open-eyed state, the entries in the medical records started to appear as “persistent vegetative state” or “permanent vegetative state.”¹²

The brain stem, that part of our brain where our basic reflexes—breathing, sleeping, waking—are controlled, can go much longer without oxygen and survive than the upper, “thinking” part of the brain. So, Nancy’s eyes would open. They would move around the room much as we’ve seen with the video of Terri Schiavo on television. At times they would appear to stop and fix on an object, and then they would move again. She would grimace. She would smile from time to time. She would groan. She would react with a reflexive startle to noises in the room. Her body was almost completely frozen with contractures. Her nails bent in to the point that they would cut into her wrist and her parents would wedge her fingers back and put a pillow in to stop that from happening.

11. *Id.* at 17–20, 25–28.

12. See AMERICAN ACADEMY OF NEUROLOGY, PRACTICE PARAMETERS: ASSESSMENT AND MANAGEMENT OF PATIENTS IN THE PERSISTENT VEGETATIVE STATE 1–7 (1995), http://www.aan.com/professionals/practice/pdfs/pdf_1995_thru_1998/1995.45.1015.pdf (providing methodology for diagnosis and treatment of patients in a Persistent Vegetative State).

Nancy's family saw no conscious interaction from Nancy whatsoever, no matter what they tried to stimulate a response—playing music, talking with her, holding her. Doctors told the Cruzans that Nancy had no consciousness, and that she would never regain consciousness, and that she could live thirty years in that condition with good nursing care and with the feeding tube in place—the same tube they had agreed to, twenty-four days after the accident, when hope for recovery remained. That was one choice.

The second was to seek removal of that tube and have that hand in the death of their child. The accident had taken away all good choices. As they talked about these limited choices, it grew clear to the Cruzans fairly quickly that if Nancy could speak with them, she would say given those bad choices, I want the tube out. And that's what they decided they wanted for her as well.

They first approached the director of the state hospital where Nancy lived. He sent that question up the line to our Department of Health in Missouri.¹³ The answer came back that the hospital could not take that step without a court order. The director suggested moving Nancy to a private facility. But the family thought the state hospital was her home, she'd been there for years, and they didn't want to move her.

They next talked to the probate judge who was involved in Nancy's case. As legal guardians, the Cruzans had to report each year to the judge on Nancy's medical condition and her financial condition. Joe Cruzan met with the judge and told him that the family wanted to take Nancy home and remove her feeding tube there. The probate judge said, "I can't let you do that and if I find out you've taken that step without a court order, I'll intervene to stop you."

So they made the decision to go to court. They were not a family of means. They began scouting around for lawyers to take on the case as a public service, or a pro bono case. They talked to groups all over the country, including the ACLU in Kansas City. One of the senior lawyers of a large law firm that I had just joined, Shook, Hardy & Bacon, was active in the ACLU. He agreed to take the case and for our firm, and in a cautionary tale I always give the new lawyers, he called me and said, "Do you want to do this new case? It's no big deal, probably a half-day trial in probate court, but the issues look interesting." I was doing a lot of pro bono work; I thought then and believe today that pro bono work is an important part of a lawyer's social obligation, and I said, "sure."

13. COLBY, *supra* note 8, at 45–50.

And I've never been able to confirm this, but I believe they had a high-level partnership meeting at the time, and discussed taking Mr. Bacon or Mr. Hardy off of the high-paying corporate work providing for the livelihoods of hundreds of people at the firm, or assigning the case to me, a fairly new lawyer without much to do yet. In that balancing the firm decided that I had just the skill set needed to help the Cruzans on this free case. So off we went.

We had a three-day trial in southern Missouri with the Attorney General of the state and the general counsel of the Department of Health on the other side, which we won. They appealed directly to the Missouri Supreme Court, where we lost in a 4-3 decision.¹⁴ We decided to petition the U.S. Supreme Court to hear an appeal, not necessarily hopeful that they would. As some of you may know, the Supreme Court hears very few of the appeals that are filed there—in almost all cases, the Court decides not to hear the appeal, and the lower court decision stands. And they had turned down, in the past, from New Jersey the Karen Ann Quinlan case, as well as at least two other state right-to-die cases.¹⁵

So, I wasn't hopeful that the Court would take *Cruzan*, but of course, it did.¹⁶ And, from that day, this salt of the earth, God-fearing, blue-collar, southern Missouri family found themselves moving very uneasily right into the middle of a national debate about what was "right" for their daughter and sister.

At all appellate court levels, but particularly at the U.S. Supreme Court, groups with an interest in a case can file briefs with the Court. They're called *amicus*, or friends of the court briefs.¹⁷ Typically, those briefs tell the Court, "here's who we are, here's how many people are in our organization, here's our expertise in the area that you're considering, and here's how we recommend you decide the case before you." In *Cruzan*, there were almost twice as many *amicus* briefs filed

14. *Cruzan v. Harmon*, 760 S.W.2d 408, 427 (Mo. 1988), *aff'd sub nom. Cruzan v. Director, Mo. Dep't of Health*, 497 U.S. 261 (1990). The opinion of the trial court is not published separately, but Judge Higgins of the Missouri Supreme Court reprints the trial opinion in its entirety in his dissent. *Id.* at 430–34.

15. *In re Quinlan*, 355 A.2d 647 (N.J.), *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976); *In re Jobes*, 531 A.2d 1360 (N.J.), *stay denied sub nom. Lincoln Park Nursing & Convalescent Home v. Kahn*, 483 U.S. 1036 (1987); *In re Prange*, 527 N.E.2d 303 (Ill.), *cert. denied sub nom. Murphy v. Benson*, 488 U.S. 892 (1988).

16. *Cruzan v. Dir., Mo. Dep't of Health*, 492 U.S. 917 (1989) (granting certiorari).

17. *Amicus curiae* is defined as "[a] person who is not a party to a lawsuit but who petitions the court or is requested by the court to file a brief in the action because that person has a strong interest in the subject matter." BLACK'S LAW DICTIONARY 93 (8th ed. 2004).

as had been filed in *Roe v. Wade*, the abortion case.¹⁸ Many, many groups supported the family: the American Medical Association, American Nursing Association, American Hospital Association, many ethics groups, many national religious groups. And almost exactly the same number of groups filed on the other side: national medical, ethical, religious groups.¹⁹ The State of Missouri was obviously actively opposing the family. Our governor at the time in Missouri was John Ashcroft, whose pro-life position was well-known.²⁰ And the federal government made the decision to become involved at the Supreme Court level and they actually split the thirty minutes that each side is given at the Supreme Court podium with the State of Missouri. The federal government was represented at the podium by former federal judge Kenneth Starr.²¹

So, there were important, powerful forces in our society on both sides of this case, with this family from southern Missouri caught in the middle of the dispute. I'll talk in a few minutes in more detail about the ruling of the Court. But as part of their decision, they gave us an avenue to have a second trial back in Missouri based on new witnesses who had come forward as a result of all of the publicity in the case. We had that trial the following fall, and this time the case was not appealed.

Within minutes of receiving the final trial court ruling, Nancy Cruzan's feeding tube was removed, the gastrostomy hole in her stomach was taped over with white athletic tape, and Nancy was moved to the hospice wing of the state hospital. Over the course of the next several days, we saw protestors from around the country descend on rural, rolling, southwestern Missouri. Satellite television trucks arrived out front. On day four, the protestors sought to gain access to the hospice through two different avenues. Several were arrested and the facility was locked down. Near the end, on many days, there were as many as thirty-two police officers in this small hospital, between the families and the protestors.²² So, a story that started out ordinary

18. *Roe v. Wade*, 410 U.S. 113, 113 (1973) (amicus briefs were filed by the American College of Obstetricians and Gynecologists, Planned Parenthood, the National Legal Program on Health Problems of the Poor, and the Attorney Generals of five states, amongst others).

19. *Cruzan*, 497 U.S. at 261. Groups filing amicus briefs in opposition to the Cruzan family included the Association of American Physicians and Surgeons, the Knights of Columbus, the Association for Retarded Citizens of the United States, the American Academy of Medical Ethics, and the United States Catholic Conference. *Id.*

20. Gov. Ashcroft would later become the Attorney General of the United States under President George W. Bush.

21. Ken Starr later gained national prominence as the Special Prosecutor in the impeachment proceedings of President Bill Clinton.

22. Six emergency appeals were filed and dismissed during this time. *Mahoney v. Mo.*

enough in the beginning—a car wreck, like some car wreck that will happen tonight for some tragic family—by the end was not ordinary at all; it was really unique in our culture in many ways.

When people hear that as the lawyer for the family, I've written a book about that experience, a question I often get is, "Is it a law book? Is it a book for lawyers?"²³ Given the course I've just described, you'll understand there is some law in the book. But it's not very much, because I don't think the Cruzans' story, or Terri Schiavo's story for that matter, is to any great extent about the law. Though the stories played out in the court system, they are really about how decisions are made in a democratic society on our hardest questions, when people of good will and strong belief on both sides of those questions differ, and at times differ vehemently, about how the question should be resolved. And the heart of the Cruzans' story is about what happens to the human beings who are caught in the middle of that democratic decision making process. The Cruzans' story, for me, is the story of Joe Cruzan.

I have four children. As a father, I can't imagine getting the phone call in the night from the state trooper. But to then layer on top of that call, years of your child not emerging from unconsciousness, facing and making the unbelievably horrific decision, even though you think it's right, to remove a feeding tube, and then having to fight a highly public, highly contentious three-year legal battle to implement that decision. And then when you ultimately win, what you "win" is ten days of watching your child die. It's just hard to know the toll that would take on another human being. But for Joe, in the end, it was the ultimate toll.

If you will indulge me in the telling of the family story, I'd like to read two short passages from the book about their experience. I think hearing about the people helps tell the true story of the law cases. I'll just forewarn you, the two parts I'm going to read are hard parts of a very tragic story. But then, when we finish that, we'll come back out of the valley. Joe Cruzan always said that ultimately their story was one of hope for the rest of us. So, we've got to go through that part, but then we'll come back out and talk about what we can learn from this experience.

Rehab. Center, No. 903085WM (9th Cir. filed Dec. 22, denied Dec. 24, 1990); *Mahoney v. Mo. Rehab. Center*, No. 90-5055-CV-SW-1 (W.D. Mo. filed Dec. 20, dismissed Dec. 21, 1990); *State ex rel. Williams v. Bagby*, No. 73324 (Mo. filed Dec. 19, dismissed Dec. 20, 1990); *State ex rel. Tebbets v. Tell*, No. 17306-2 (Mo. Ct. App. filed Dec. 18, dismissed Dec. 18, 1990); *State ex rel. Williams v. Bagby*, No. 17312-1 (Mo. Ct. App. filed Dec. 19, dismissed Dec. 20, 1990). Yvette Williams also filed a lawsuit in Cole County Circuit Court which Judge Byron Kinder dismissed in open court on December 22, 1990.

23. WILLIAM H. COLBY, *LONG GOODBYE: THE DEATHS OF NANCY CRUZAN* (2002).

The first passage I'm going to read is from the start of the book. Chapter One of the book starts with Nancy's accident in 1983 and moves forward in a fairly direct line to the Supreme Court in 1990. But prior to Chapter One, there's this half-page inset, from a much more recent time, which sets the tragic tone of Joe's sad story ahead.

Cartersville, Missouri: August 17, 1996, 3 a.m.

The heat in the southwestern corner of Missouri, near Oklahoma, seldom relents in August, even in the middle of the night. On August 17, 1996, likely just before three in the morning, 62-year-old Joe Cruzan rose from the twin bed he slept in alone, wedged against the wall in a tiny, narrow bedroom he'd made for himself in the back corner of his house.

He looked like the empty shell of the sheet-metal worker he'd once been—his square shoulders now stooped as if the muscles were missing, and his skin just hung on his collarbones. Black circles ringed his bloodshot eyes, and the thick, gray calluses that used to be on each hand were gone, replaced by soft pink buttons, smaller than a dime. By the summer of 1996, on the rare occasion when Joe Cruzan ventured out of his house and ran into someone he knew, that person would need to look twice to make sure it was really Joe.

Once out of his bed, Joe made his way to the kitchen, and in an unsteady hand, he began this note to his wife:

Joyce,

1. I love you. 2. I love Chris & Donna and especilly Angie & Miranda. 3. Call police before going on carport.

Joe finished his numbered instructions and left the note on the kitchen table in a conspicuous spot. Then he headed out the side door of his house into the humid August night.²⁴

One of the emotions that it was very important to me to try to capture in telling Joe Cruzan's story was his growing frustration with the world around him the deeper he made his way into the legal system. We went from a trial to the Missouri Supreme Court, U.S. Supreme Court, second trial, and seven emergency appeals in just over three years. In the lawyer's world, that was a sprint, and much had to fall into place for all of that law that happened in that short amount of time. In Joe's world, it took forever. And the rhythms that we get used to as lawyers, of having action and then waiting for results, layered on top of his other stresses, just worked on him in fundamental ways. I'd get a call from the Attorney General saying, "I'm too busy, I can't get the brief done, I need thirty more days." Then I'd have to call Joe and tell him that it would be another thirty days before we heard what the Attorney General

24. COLBY, *supra* note 8, at xiii.

had to say. By the spring of 1990, as we waited for the decision from the U.S. Supreme Court, he was getting near the end of his energy and his patience. Throughout most of that June, shortly after nine in the morning, I'd have to call Joe and tell him, "no decision today," until June 25, when we finally got word from the Court.

The decision was 5-4, and of the nine justices, five wrote his or her own opinion as to what the law was.²⁵ For the amicus groups on either side, there was cause to declare victory, which many did. The Court did say, for the first time, that all of us, conscious, competent adults, have a federal constitutional right to make decisions about our own medical treatment.²⁶ It had never said that directly before. Five of the nine justices also concluded that a feeding tube is medical treatment, like a respirator, or dialysis.²⁷ It's a technology that's taken the place of a natural function that's been lost, typically intended to serve as a bridge to recovery of that function.

But, the Court also said that nothing in the Constitution of the United States requires a state, in this case Missouri, to defer to the parents of an adult—Nancy Cruzan was twenty-five at the time of her accident—to make medical decisions for that adult.²⁸ If Missouri chooses to insist on only evidence of Nancy's own wishes before treatment is stopped, it can make that policy. The Court did not say that such a standard was a good policy; it simply said that the Missouri standard did not violate the Constitution. And it left it up to each state to figure out its own rules.²⁹

So, from my point of view, there wasn't much winning in that decision or that day at all, and that call to Joe Cruzan was a very hard telephone call that morning. But, as I said, the Court did give us a path to have a second trial, which we did. Again, we won, and this time, the decision was not appealed. Nancy's feeding tube was removed, and then we had that somewhat circus-like scene at the state hospital at the end with the protestors and the police and the television trucks. The focus of the Cruzan family throughout the case, but most especially at

25. *Cruzan v. Dir., Mo. Dep't of Health*, 497 U.S. 261, 263–64 (1990). Justice Rehnquist wrote the majority opinion, Justices O'Connor and Scalia filed concurrences, and Justices Stevens and Brennan filed dissents. *Id.*

26. *Id.* at 277.

27. *See id.* at 288 (O'Connor, J., concurring) ("Artificial feeding cannot readily be distinguished from other forms of medical treatment."); *id.* at 309 (Brennan, J., dissenting) ("Neither artificial nutrition nor any other form of medical treatment available today can cure or in any way ameliorate her condition."); *id.* at 334 (Stevens, J., dissenting) (referring to the feeding tube as medical treatment).

28. *Id.* at 286–87.

29. *See id.* (holding that "the State may choose to defer only to [the wishes of the patient], rather than confide the decision to close family members.").

the end, they tried to keep where they thought it belonged, which was on Nancy, and their family.

The last passage from the book that I'd like to read is from near that time. This takes place on Christmas day of 1990:

By late afternoon, the nurse who came on after Angela could not detect Nancy's blood pressure. Her breathing had become slightly more rapid, and she was less reactive to stimuli. At 5:05 P.M., Dr. Davis downgraded Nancy's condition from serious to critical, yet her appearance remained peaceful. The trembling of the day before had stopped, and by now even her neck had grown less rigid. The family sat around Nancy's bed talking holding her hands, and praying.

. . . .

When the new nurse arrived at midnight, Joyce [that's Nancy's mother] asked that she not turn Nancy or try to take her blood pressure – Joyce didn't want Nancy to be disturbed any further. Joe kept falling asleep in a chair, and Joyce made him go across the hallway to rest in a bed. She told him they would come get him if anything changed.

Chris [that's Nancy's sister] was lying on the floor on a camping mat that [Uncle] George had brought [from Colorado], dozing on and off. George sat in a chair, doing the same. Joyce stayed-awake. Around one in the morning, Nancy's breathing grew more labored. At about 1:15 A.M., she spit up about a tablespoon of dark, foul-smelling liquid. Joyce cleaned it away and called out to Uncle George, "George, go get Joe." Joe walked back into the room with his uncle, startled out of an uneasy sleep, Joe's hair going in several directions.

George left to go get coffee to leave the Cruzans alone. The three of them stood around Nancy's bed. Nancy's breathing grew weaker. For the next hour and a half, they held her hands, kissed her, and told her they loved her. Joe put his forehead on Nancy's and whispered, "Everything will be okay."

Around 2:30 A.M., Nancy's breathing grew even more labored – a book one nurse had given Joe called it "fish-out-of-water" breathing. Joe cradled Nancy's head in his arms; Joyce stood right next to him, holding Nancy's hand; Chris stood across the bed, rubbing her other hand.

At 2:47 A.M., Nancy's breathing stopped. Joe reached his hand to Nancy's face and pulled her eyelids closed. Uncle George looked back into the room and saw the end had come. He walked down to the nursing station and said, "I think it's over."

Fifteen minutes later, Joe reached me in Florida. "Bill?"

"Hi Joe," I said, not fully roused from a sound sleep.

"It's over," he said. His voice was clear and steady.

“Thank God,” I said. He told me about the last few hours. “What are you going to do now?” I asked.

He paused for a time, the question harder than it sounded. “I guess we’ll all go home,” he said.”³⁰

Now, if we just stopped there, you would have heard a tragic story like a lot of tragic stories, Joe Cruzan’s “life turning on a dime.” *Cruzan*, of course, ultimately meant much more than that to the rest of us. In the wake of the case, many states, including Missouri, passed laws seeking to address the issues *Cruzan* raised.³¹ The federal government, led by then Senator John Danforth from Missouri, passed the Patient Self Determination Act,³² which provides that when any of us enter a hospital, we’re told about living wills and other kinds of advance care planning.

But, I think that, more importantly than new laws, for the extended period of time that Nancy Cruzan’s story was on the front pages of the nation, that news caused families to stop for a minute and talk about something we don’t readily or easily discuss. And, today, I think we are seeing this kind of talk happening on a level that few who work in the field of death and dying would have ever anticipated. I may be Pollyanna from Kansas, but I believe that Terri Schiavo has changed and will continue for a long time to change how we die in this country. The level of attention the case received was far more than even *Cruzan*, to the point that Terri Schiavo is now part of our culture. Millions of families are having talks that start, “if I’m ever like Terri Schiavo I want. . . .” That talk is the great gift from these sad families to the rest of us and the great silver lining from these incredible tragedies.

The cases of course were different in some fundamental ways. In *Cruzan*, a united family aligned against the government. In *Schiavo*, a

30. COLBY, *supra* note 8, at 388–89.

31. Missouri law states that

[a]ny competent person may execute a declaration directing the withholding or withdrawal of death-prolonging procedures. The declaration made pursuant to sections 459.010 to 459.055 shall be:

- (1) In writing;
- (2) Signed by the person making the declaration, or by another person in the declarant’s presence and by the declarant’s expressed direction;
- (3) Dated; and
- (4) If not wholly in the declarant’s handwriting, signed in the presence of two or more witnesses at least eighteen years of age neither of whom shall be the person who signed the declaration on behalf of and at the direction of the person making the declaration.

MO. REV. STAT. § 459.015 (2000).

32. Patient Self-Determination Act of 1990, Pub. L. 101-508, Title IV, §§ 4206, 4571, 104 Stat. 1388–115, 1388–204 (codified as amended in scattered sections of 42 U.S.C.).

family was torn apart by lack of understanding and lack of agreement about what should happen with their daughter and wife. But both cases are the same in this respect—they cause the rest of us to talk.

So, let's talk for a second about "the talk." The talk is not dark, not sinister, not macabre, not something to be avoided. And if you have the talk at a time when the people you care about are relatively healthy, it's actually not even that hard to get started. I've got a twelve year old son, and I recently had the "other talk" with him. I can promise you this talk is easier to get started than that one.

Let's start with a primer on the documents. There are two basic kinds of documents. The first that grew up in the law is the one that most people have heard about, called the living will.³³ One lawyer in Chicago, in the late 1960s, seeing technology beginning to develop, started thinking, "You know, I can do a will to dispose of my property, there ought to be a way if I don't want medical treatment that I can write it down." He came up with the idea of the living will, and the idea soon spread.³⁴

Much more recent in the law are documents that are called by different names in different states—power of attorney for healthcare, durable power of attorney for healthcare, healthcare agent document, healthcare proxy document, advance directive document.³⁵ But they're all basically the same legal document—a piece of paper that states, "if I can't speak for myself, here's who speaks for me. Here's the first alternate. Here's the second alternate." That's it really, two kinds of legal documents.

I know from having talked about this subject for a while that if I let this issue go to the question and answer session, there's a decent chance someone would stand up and say: "I've got my Illinois living will, but I'm driving to Indiana to see my daughter this weekend. I'm taking my Illinois living will with me. Will my Illinois living will work in Indiana?" I always give the (I hope) humorous, but nonetheless I believe exactly accurate answer: "There's a pretty good chance that

33. A "living will" is defined as "[a]n instrument, signed with the formalities statutorily required for a will, by which a person directs that his or her life not be artificially prolonged by extraordinary measures when there is no reasonable expectation of recovery from extreme physical or mental disability." BLACK'S LAW DICTIONARY 953 (8th ed. 2004).

34. Luis Kutner, a famous Chicago civil rights lawyer, was the first to come up with the idea of a living will. See Luis Kutner, *Due Process of Euthanasia: The Living Will, A Proposal*, 44 IND. L.J. 539, 550–54 (1969) (suggesting the use of living wills as a method for individuals to predetermine the extent of their consent for medical treatment, for use in the event they lack capacity at the time treatment is rendered).

35. A "power of attorney" is defined as "[a]n instrument granting someone authority to act as agent or attorney-in-fact for the grantor." BLACK'S LAW DICTIONARY 1209 (8th ed. 2004).

your Illinois living will won't work that well in Illinois, so I wouldn't worry too much about whether it's going to work in Indiana or not."

Of course, many times the documents work fine, but study after study in the end-of-life world has shown that living wills and durable powers of attorney for healthcare far too often don't work.³⁶ There are all kinds of reasons why, and you likely will come up after, and add some to my list. For example, there's only one copy of the document, it's in the safe deposit box at the bank, and the only person with access to that safe deposit box is in the emergency room, in a coma. Or the document is too generic, and the doctor says, "it's of no use, it doesn't tell me anything."

Or the document may be very clear, naming as the decision maker the adult child who's been caring for mom for ten years. But a second adult son who moved away five years ago, and didn't get along with the family that well before he left, is now flying in and is going to "save" mom from the sibling who's been caring for her, and the doctor. Healthcare workers faced with a piece of paper versus a living, breathing relative who's in their face will often be reluctant to try to overrule that family member using a piece of paper. The default is to leave the treatment in place.

Without question, the documents can help. In the best case, a living will or power of attorney can comfort a family to know they are following a loved one's wishes. But the coaching point here is clear; to help the people you love, and leave behind, you must take the next step, and do the work now to talk with your family about your wishes. And not just the person you've given the power to, but everyone who will be in the room, especially the son who left, and is hardest to talk to. The conversation is critical.

People are often surprised by the limited reach of the law in the area of making medical decisions at the end of life. The black and white of the law, a written document, is just not very good at sorting through the gray and emotion of our dying. The *Schiavo* case is an example of this point. The law in Florida is pretty clear about what should happen in a case like Terri Schiavo's. Florida has what some people call a hierarchy law.³⁷ That law specifies for an incapacitated person that if you do not

36. See e.g., The SUPPORT Principal Investigators, American Medical Association, *A Controlled Trial to Improve Care for Seriously Ill Hospitalized Patients* 274 (20) JOURNAL OF THE AMERICAN MEDICAL ASSOCIATION 1591, 1591-98 (1995) (documenting a study aimed at improving end-of-life decision-making and finding there is often poor communication between physicians and patients).

37. FLA. STAT. ANN. § 765.401 (West 2005) (defining the hierarchy of decision making for an incapacitated patient).

fill out a living will or healthcare proxy, then state law determines the order, or hierarchy, of who makes decisions for a person who has lost capacity to decide.³⁸ For a married person the first decision maker is the spouse; if the spouse is not available, then adult children; if there are no adult children, then the parents of an adult. And the list goes on. And basically the person making decisions must pick from among acceptable medical alternatives.

In the *Schiavo* case, Michael Schiavo made the decision to remove a feeding tube from a woman who had been in a vegetative state after suffering an anoxic cardiac arrest.³⁹ She'd been in that state for many, many years. This decision is within the guidelines of every major medical and ethical group in the country. Patients simply do not regain consciousness after a prolonged period of the vegetative state when the cause was anoxia. Those brain cells are dead. So Michael Schiavo's decision was within the medical and religious guidelines that govern this kind of decision making.

But it didn't matter, because he had had a fight with her parents many years before about money, they stopped speaking to one another and the parents went to court to challenge his motivation as Terri Schiavo's guardian. They had a trial. The tube was clamped until a second judge order it unclamped. That order went up through the Florida appellate courts and a second trial was ordered. The trial court ruled in the husband's favor a second time, the case went back up through the Florida appellate courts, and with appeals exhausted, the tube was removed and artificial nutrition and hydration stopped for the second time. At this point the Florida legislature got involved and passed a special law, "Terri's Law", directing the tube to be put back in a second time, which it was.⁴⁰

They spent over a year litigating the question of whether or not it was constitutional for the governor and the state legislature to become involved. The Florida Supreme Court finally concluded that that intervention was not constitutional.⁴¹ And then, of course, the dispute moved to a whole new level when the federal Congress became involved over Easter weekend of 2005, and the President of the United States flew back early from vacation to sign a bill in the middle of the

38. *Id.*

39. *Schindler v. Schiavo*, 780 So.2d 176, 177-78 (Fla. Dist. Ct. App. 2001).

40. Terri's Law, 2003 Fla. Laws 418 (authorizing the Governor of Florida to issue a "one-time stay to prevent withholding of nutrition & hydration under certain circumstances").

41. *Bush v. Schiavo*, 885 So. 2d 321, 337 (Fla. 2004), available at <http://www.floridasupremecourt.org/decisions/2004/ops/sc04-925.pdf>.

night, involving one woman, and a probate court dispute in Florida.⁴² Unprecedented in our history.

No doubt many of you watched the news coverage of the *Schiavo* case and had some reaction about which side was “right.” To me that question is far less important than the real lesson of *Schiavo*, showing the country the limited ability of the black-and-white of the law to solve disputes in the gray, emotional area of human decisions that must be made at the end of life. Often people speak of “letting nature take its course.” *Schiavo* helped people consider how that idea simply no longer works in the world of modern medical technology. Most deaths in our country, and there are roughly seven thousand each day, occur as a result of some sort of decision about medical treatment—respirators turned off, medicines not started, dialysis stopped, feeding tubes clamped. And even when everyone in a family is in agreement about the proper decision, and the family gets along well, and the medical team agrees that the decision made is the right one—even then, making a decision to stop medical treatment for someone you love is profoundly emotional and difficult. When a family is in dispute, such decision making is infinitely more difficult.

Now, if you all are here on this beautiful spring evening, listening to a lawyer talking about death and dying, you’re probably going to be the instigators either with your family or your patients or your clients—or whoever it might be—just as I was in my own family. I don’t show up each Thanksgiving and say, “Mom, I’m home, let’s update our death and dying talk.” But, I did show up once, with the forms, and we talked. I think I have a decent sense of what my mother’s views and values are, I’ve got the document that names me as her decision maker if she cannot speak for herself, and everybody who will be in the room when decisions will be made, was either there for this conversation or knows about it. I hope and believe that when I am faced with making a decision for my mother, as I likely will be, that my siblings and I will work together, and we will have some comfort in knowing that we are deciding as she would want us to decide. Giving that comfort to your family is a gift.

Terri Schiavo and her family have given the rest of us a gift, too, and an unprecedented opportunity. We now have an opening to start this

42. Relief of the Parents of Theresa Marie Schiavo, Pub. L. No. 109-3, 119 Stat. 15 (2005), available at <http://www.thomas.loc.gov> (“Grants jurisdiction to the U.S. District Court for the Middle District of Florida to hear, determine, and render judgment on a suit or claim by or on behalf of Theresa Marie Schiavo (Ms. Schiavo) for the alleged violation of any right of hers under the U.S. Constitution or laws relating to the withholding or withdrawal of food, fluids, or medical treatment necessary to sustain her life.”).

discussion with people that is fresh in people's minds: "If you were in Terri Schiavo's shoes what would you want?" Many news people asked me the same question: "If Terri Schiavo had had a living will, that would have solved this case, right?" They are surprised each time when I tell them that likely that paper would not have solved anything at all. The Florida hierarchy law couldn't resolve or solve their family discord—I believe that they would have still had the family dispute, because Terri Schiavo never talked with her parents about her wishes.

But consider one side of that sad case that never received much media attention. There was a time, before her cardiac arrest, when Terri and Michael Schiavo and Bob and Mary Schindler lived together, took vacations together, had meals together. What if just once she had talked with her parents and husband together for two minutes, for a minute, about Nancy Cruzan? Would she have saved these people she cared about all of this incredible strife that we saw played out on the public stage? We don't know. But I think there are families now who are being saved from that kind of family debate and dispute by Terri Schiavo, because they're talking. That talk is a gift.

Before we begin questions, let me just close with the last line of the review of the Cruzan story that was done in one of the American Bar Association magazines. Because of all that's been written about what they went through, this quote captures how the Cruzans would like their own story remembered, and it's this: "[I]n the end, [*Long Goodbye*] leaves the reader with hope and a belief that this trail, cleared once, has been made forever more welcoming for the rest of us who are all traveling their way."⁴³

43. Charles P. Sabatino, *Books Worth Reading*, BAR ASSOCIATION IN FOCUS ON AGING AND THE LAW, Spring 2003, at 7.