INTRODUCTION

In the early months of 2005, Theresa Marie Schindler Schiavo, known as "Terri," captured the national public spotlight—but she did not know it. Nor, at age forty-one, had she known anything of her previous fifteen birthdays. She was in what doctors call a persistent or permanent vegetative state. When patients are in a vegetative state, doctors believe they cannot experience life in any way—that they are completely unconscious. When the condition is properly diagnosed as permanent, there is no evidence that the patient can ever regain any consciousness; after fifteen years, the chance of recovery, even slight recovery, is most accurately described as zero.

While Terri's husband and her parents were initially in agreement about her care, through the years they became sharply and bitterly divided. In 1998, eight years after the collapse that caused Terri to enter a vegetative state, her husband, Michael Schiavo, began a long court battle to remove her feeding tube. Without it, Terri would certainly die. Yet Michael insisted that this—death rather than life in a permanent vegetative state—was what Terri would want.

Her parents, Robert and Mary Schindler, disagreed. In court, they argued that Terri would not have wanted the feeding tube removed. When that argument failed, they challenged the diagnosis that she was in a permanent vegetative state. Then they argued, as you are allowed to do in court, "in the alternative." That is, even if Terri *was* in a permanent vegetative state and *at one time* would have wanted to have the feeding tube removed, as a Catholic, she would have changed her mind when Pope John Paul II spoke on the general issue in 2004. These are some of the main arguments that the Schindlers made, but there were many others. Over seven years, the Schindlers exhausted every avenue of relief in the courts. Many of their methods were unconventional, and some were even of questionable propriety. But while their activities in court granted them some delay in the re-

moval of Terri's feeding tube—which over the seven-year battle was twice removed only to be reinserted—the courts gave them no ultimate relief. Circuit court judge George Greer in the initial hearing of 2000 agreed with Michael Schiavo that Terri would want the feeding tube removed, and neither that court nor any other would upset that ruling.

Beginning in 2003, the Schindlers turned to the legislative and executive branches of government. They also garnered substantial media attention and the support of various religious and disability rights groups. The tactic here was somewhat different. While the Schindlers continued to disagree with Michael about what Terri wanted and her medical condition, a new focus became whether it was *morally right* to cause someone's certain death by failing to provide the basic necessities of food and water.

In Florida, these efforts paid off. In October 2003, the Schindlers received a reprieve through special legislation under which the Florida governor, Jeb Bush, ordered the reinsertion of Terri's feeding tube after it had been removed. When that law was declared unconstitutional the following year by the Florida Supreme Court, the Schindlers and their supporters sought federal action. Appealing to President George W. Bush and the federal legislature, they were successful in achieving extraordinary legislation to force federal court review of the case. But the federal courts did not go along, refusing to revisit the issue of Terri's condition or her wishes. All legal means to block the removal of Terri's feeding tube had now been exhausted.

Terri died on March 31, 2005, thirteen days after her feeding tube was removed. Throughout these days, cable news programs provided continual updates of Terri's condition and the activities of protesters outside the hospice where she lived. They supplied endless commentary and debate among clergy, politicians, and medical and legal experts. And they reported how even in Terri's last days, her husband and parents publicly fought—over visitation rights, cremation versus burial, and the location of Terri's remains.

Choosing Sides

The story of Terri Schiavo is not a simple one. Yet during the controversy surrounding the removal of her feeding tube, people of all kinds—politicians, religious leaders, physicians, bioethicists, legal experts—made emphatic statements about the facts and offered even more certain opinions about what should be done. Some who protested the removal of Terri's feeding tube insisted, contrary to the opinions of medical experts who had examined her, that she was not in a permanent vegetative state but in a newly recognized condition called a "minimally conscious state." In fact, Senator (and doctor) Bill Frist, then Senate majority leader, was willing to state his medical opinion on this issue after viewing a few minutes of videotape of Terri. Similarly, others declared that removal of her feeding tube would amount to "starvation" and that starving someone to death was morally wrong. Many argued that when a person like Terri has not placed her wishes in writing, feeding tubes should never be removed. In the words of conservative bioethics commentator Wesley Smith, "casual conversations"—statements like "I wouldn't want to live like that," which a person might utter after seeing a relative in the hospital—should not be the basis of a "death order."[1] On the personal front, Michael Schiavo, Terri's husband, was openly accused of being a liar and a cheat. These were the perspectives shared by the parents of Terri Schiavo and their supporters—politicians seeking conservative support, many newscasters, right-to-life groups, and some disability rights groups.

Those who supported the removal of Terri's feeding tube spoke just as certainly in their views. According to this group, the removal of feeding tubes in situations like Terri's is not cruel starvation but a constitutional right. Feeding tubes, they insisted, are just like ventilators—advanced, intrusive medical treatment that people have an absolute right to refuse. So anxious were some of them to point up that Terri's case was beyond hope that they dismissed the very idea that a "minimally conscious state" might exist for any patient, characterizing this new category of patient condition as a political rather than a scientific discovery. But most important to commentators who

supported removal of the feeding tube was the fact that Terri didn't want to live this way: a court had clearly determined what her wishes were after a full and impartial hearing and according to proper legal standards—and not just one court but many (Internet blogs put the number at twenty) accepted that conclusion. In the end, according to this view, Terri's right to refuse medical treatment was supreme and was dutifully honored by a beleaguered husband and a courageous judge.

Those who study and comment on law tended to fall into the latter camp. Part of their support for the courts' decisions to allow the removal of Terri's feeding tube came from support more generally for the rule of law. Following the rule of law means that rather than throwing such decisions to the political winds, existing legal precedents and statutes are allowed to govern, and recognized, fair, and open processes to determine their application are followed. The Schiavo case erupted at a time when the judiciary was already under attack by conservative politicians and commentators who accused judges of using their positions on the bench to impose their liberal beliefs upon the American public. When the courts permitted the removal of Terri's feeding tube, critics rallied around the case with even greater charges of "judicial activism." The criticisms carried the threat of action. During this time, a number of legislative proposals were introduced at both the state and federal levels to restrict or otherwise affect judges' decision-making powers.

This context helped shape the response of legal academics to the Schiavo controversy, which tended, during its pendency, to be driven by concern for the independence of the judiciary and continued respect for the rule of law. A nearly singular response issued: the courts had followed the law, and the law was good. This support for the judiciary might have appeared weakened by admitting to any uncertainties or concerns about the law generally or its application in Terri's case.

And so it appeared, from the politician to the protester and from the clergy member to the legal academic, that there were only two sides to the Schiavo case. And in a way, there were. Either the feed-

ing tube would be removed and Terri would die, or the feeding tube would stay in place and Terri would live. But the issues involved in this case were more complex and more subtle than either side would admit, and each side made some compelling points.

This is not a "red state/blue state," conservative/liberal, Republican/Democrat issue. It is not as simple as pro-life versus pro–personal liberty. It's not a matter of choosing sides and you're done, although that's how the politics appeared to play out and the media chose to spin it.

What we lost in the Schiavo case is an appreciation for the uncertainties and doubts that these kinds of cases necessarily entail, and acceptance of the fact that despite such uncertainty and doubt decisions must be made. By failing to appreciate these complexities, we have not advanced our understanding of how best to handle end-of-life decisions. The Schiavo case brought only polarized—and ultimately false—clarity: one clear vision for conservatives and another clear vision for liberals.

Inspired by the case, conservatives have been seeking revision of state laws to make sure the "next Terri Schiavo" does not die. They are also seeking to change public attitudes about feeding tubes in general—to get more people to view them as morally necessary, for themselves and for their family members. The upshot, if they are successful, is less freedom in the future to decide what we would like done for ourselves and our loved ones. And this "we" includes "them," the conservatives themselves, although it's not clear that they appreciate this. They want to insist that we can all protect our individual freedoms by providing written instructions ahead of time in a "living will," but the evidence so far about living wills shows that they cannot by themselves guarantee that we will get what we want (and not get what we don't want) in terms of life support.[2]

Liberals, in the face of this threat to individual choice, risk digging in their heels and hanging on to existing laws without reflecting on their possible weaknesses. Many legal commentators and medical ethicists during and immediately after the Schiavo case, and still today, insist that there was nothing new about the case. The law and

ethics in this area, they repeatedly stated, have been long settled. Often they referred to the earlier famous cases of Karen Ann Quinlan in 1976, a young woman in a permanent vegetative state whose parents sought and won removal of her ventilator, and Nancy Cruzan in 1990, also in a permanent vegetative state whose parents sought and won removal of her feeding tube. Those cases created new law and ushered in new medical practices. But not Schiavo—that episode, according to these commentators, was essentially legally and ethically insignificant, merely a political circus stirred up by rabid conservatives.

Framing the Questions

But the case of Terri Schiavo is increasingly significant, both from a legal and an ethical perspective. As will be explained more fully in the coming chapters, there are weaknesses in existing law and many issues that are left to be decided. Perhaps to the liberal's surprise, our current legal system actually gives insufficient respect to a person's wishes in certain circumstances. Many states require that individuals' wishes be proved by such a high standard of evidence before life support can be removed that patients are more likely to have their wishes ignored rather than honored when they are in a permanent vegetative state.

Moreover, many legal and ethical issues are not or should not be considered settled, a point made clear when the Schiavo case is studied in its multifaceted dimensions. When a large number of Americans, a vocal media presence, and a majority of two legislative bodies are saying, "Wait a minute—" because they are uncertain or confused or unhappy about how end-of-life decisions are being made, then it is not enough to say, "We [meaning the legal and medical establishments] settled that issue years ago." As law and ethics scholar Rebecca Dresser has written, "[P]erhaps the public response was not so surprising. Over the past three decades, clinicians and legal authorities have constructed a basic approach to treatment decisions for incapacitated patients, but as the passions this latest case

unleashed suggest, this approach is both unfinished and vulnerable to challenge."[3]

While liberals are not antifamily any more than they embrace a "culture of death," as they are sometimes charged, during the Schiavo case they rarely were willing to engage in a careful discussion about how certain we should be of a patient's wishes before removing life support, or about the role of the family, or about the appropriateness of making quality-of-life decisions and the need to protect vulnerable individuals.

It might appear that we are at a crossroads in end-of-life law. Will we follow a path toward more restrictions on the removal of life support in the name of valuing all life, especially vulnerable life? Or will we strengthen a commitment to personal choice and expand what is commonly referred to as a "right to die"—to include physician aid in hastening death, for example?

More likely, we will choose neither but continue an uneasy balancing act between the two. When what is at stake is described in such polar and oversimplified terms (for which constitutional interpretation is partly to blame), the lines to be drawn will never be satisfactory.

But it may be possible to frame these issues in a way other than a preference of life over choice, or choice over life, or some uneasy balance or trade-off between the two. In this book, I suggest such a reframing of the issues—one that places primary importance on respect and care for the patient and the patient's family. Preservation of the patient's life and deference to the patient's choice will still be important, but building on a foundation of respect and care enriches our understanding of what is at stake in these matters. We have to think about "respect" more broadly than simply as respect for patient self-determination or choice; we must also include respect for the individual human life—are we making decisions to benefit this person, or others? Is the patient's privacy being protected? Similarly, we have to think about "care" in terms other than simple labels, such as the labeling of nutrition and hydration as "basic care," a term that

gained a certain traction during the Schiavo dispute. Sometimes, as we'll see, feeding tubes can actually cause a patient more pain and suffering with little or no benefit—and then it doesn't look like "care" at all.

"Respect" and "care" change the focus from what people have a right to—a right to live? A right to die?—to how we must act responsibly in our regard and treatment of them. Rights still matter, but as we'll see, legal rights tend, often for good reason, to be rather thin and often incomplete and inadequate, although they are important and at times determinative and completely necessary.

End-of-life law and ethics are due for a reexamination. The Schiavo case makes that abundantly clear. More was lost, after all, in the political and cultural battle surrounding the case than an appreciation for complexity and the necessity of making decisions in conditions of uncertainty: Terri Schiavo herself was lost. She became a pawn in the pursuit of larger agendas—agendas involving traditional and religious values, or the protection of people with disabilities, or libertarian notions of freedom of choice, or sometimes, even worse, individual politicians seeking a spotlight.

It is true that the political exploitation of the Schiavo case—in the federal Congress, at least—appeared to backfire. When a memo identifying the Schiavo case as one from which Republicans could benefit politically was traced to Senator Mel Martinez's office, he incurred swift and universal public condemnation. His general counsel, who admitted authorship of the memo, immediately resigned. Bill Frist has since publicly acknowledged that he made a mistake in pushing through special legislation authorizing federal court review of the case; some political commentators claim that Frist's involvement in the dispute—in particular, his "diagnosis" of Terri—severely diminished his chances of a 2008 presidential bid.

Polls have consistently shown that the American public thought the U.S. Congress had no business getting involved in the controversy. According to one CBS News poll conducted in March 2005 (during the flurry of federal activity to "save" Terri), 82 percent of

those surveyed believed that Congress and the president should stay out of the Schiavo dispute. Another CBS News poll showed that 74 percent of respondents thought the federal legislation was passed to advance a political agenda.[4] Candidates for the 2008 presidential election avoided taking firm positions on the extraordinary actions taken by Congress and the president in 2005 although repeatedly pressed to do so early in their campaigns.

This apparent calming of the waters should not be interpreted as a sign that the fundamental issues of the case are settled. While political motivation to become entangled in such individual matters may have waned, we as a society must still grapple with how best to approach—legally and ethically and practically—the sorts of questions raised by Terri's case. They are not going to go away.

A Strategy from Here

This book has several aims. The first is to provide an explanation of what happened and why in the battle over the removal of Terri Schiavo's feeding tube. To some extent, the facts are disputed. For example, was Terri in a permanent vegetative state or not? Could she be fed by spoon or straw? And if so, what then? At times, in the telling of the story of Terri Schiavo, I will have to choose which version of the facts is most credible, but I will explain why I believe those facts to be more credible than the alternative story. At other times, while I will acknowledge there to be a dispute about the facts, I will argue that which version of the facts one chooses to believe is not crucial to how one should assess the decisions made in the Schiavo case. While the facts have been set out in numerous books, articles, and television programs, the telling of them has more often than not been marred by hasty research, polemical characterizations, and crucial legal inaccuracies.

A second aim of the book is to see what we can learn from the Schiavo controversy in the larger context of the law, ethics, and culture of end-of-life decision making. In particular, the Schiavo case raised these questions:

—*How much do we know about the permanent vegetative state, and how strong was the evidence that Terri Schiavo had no hope of ever recovering consciousness?* Because of recent reports about new scientific evidence regarding the vegetative state and other disorders of consciousness, the subject of Terri's condition is given a separate chapter immediately following this introduction, before the book delves into the facts about Terri's medical treatment and life support (chapter 2) and the law as it relates to the permanent vegetative state (chapter 3).

—*In order to withdraw life support, how much and what kinds of evidence must be brought forward regarding the wishes of a formerly competent patient? Should we insist on a living will before we allow life support to be withdrawn?* Chapters 4 and 5 explain how our current legal standards of evidence in this area hinder us in making accurate legal decisions for the permanently vegetative patient and, more particularly, why we should not expect living wills to solve this problem.

—*How do we determine who should speak for the incapacitated patient in making decisions to refuse treatment, and how do we protect patients from surrogates making decisions in their own rather than the patient's interests?* In chapter 6, I'll discuss both the weaknesses and strengths of relying on surrogate decision making and how we might better take into account the full spectrum of the interests of everyone—especially those of the patient.

—*Should the quality of life of the patient factor into decisions to allow the removal of life support? Should the condition of the patient serve as a limit on when life support can be removed—for example, would it/should it have made a difference if Terri Schiavo were minimally conscious, or merely profoundly disabled?* Chapter 7 argues that we can better respect and care for both the profoundly disabled and those in a permanently vegetative state if we appreciate their differences. Considerations of quality of life cannot always be avoided.

—*Are feeding tubes different from other forms of life support, because feeding represents a basic form of care?* Chapter 8 challenges the idea that

tube-feeding and even hand-feeding always represent a form of care and finds that too often we think about care from the perspective of the caregiver rather than of the cared-for.

— *Does the law give enough protection to human life? Should our right to life be protected as much as our right to die? Should it be protected even more?* In chapter 9, I argue that a narrow "rights" approach too often fails to capture what is at stake in these cases. Our laws and practices do need changing—but more deeply, and foundationally, than a simple rights approach can capture. In chapter 10, I'll describe an alternative approach that emphasizes respect and care and explore how this new approach might be applied to different types of patient conditions, including the terminally ill, profoundly disabled and never competent, minimally conscious, and permanently vegetative.

My position on Terri's case should be made clear at the outset. I think she should have been allowed to die. In fact, I think she should have been allowed to die years before the final removal of her feeding tube and without an extended court battle over her wishes. Not only do I think her feeding tube should have been removed, but I think that even if she could have been forced to reflexively swallow food, she should not have been fed by hand, either.

In the past, I have taken strong positions in favor of disability rights and against a right to physician aid in hastening death (sometimes referred to as physician-assisted suicide). How can I now argue for allowing Terri Schiavo to die? Isn't starvation or, more accurately, dehydration a cruel way to end a life? Doesn't our failure to nourish mean that we are not properly caring for a patient?

No, to both questions. With respect to Terri, she could not experience dehydration, just as she could not experience anything. Properly respecting and caring for her as a patient meant caring for her body by keeping it clean and neat, protecting her privacy, respecting her wishes if they could be discerned, and, most important, treating her as a person rather than as an object. These do not, though, lead to

an assumption that she should have been maintained in a state of biological life so long after the person who really was Terri Schiavo had been gone.

Do I come to the conclusion that Terri should have been allowed to die because the evidence was so overwhelming about what her wishes were? No. In fact, I think we don't really know what Terri would have wanted. Some evidence exists about what she wanted, but when we review the testimony at trial (chapter 4), we'll find it's not nearly as clear as we might like to think it was.

Instead, I come to this conclusion because people in a permanent vegetative state have no present interest in continuing to live. They can experience nothing in this world, or even in the most inner world of their minds, and they never will. That means that if their lives are continued indefinitely, it is done so only for other people, not for them. They become an instrument, a mere object, for others to do with what they like. The exception would be if a person had made known his or her wish to continue to live in that condition. This was not the case with Terri Schiavo, which is not surprising, considering that studies show that the great majority of Americans would not want their own lives continued in a permanent vegetative state.

Some argue that if we remove feeding tubes from people like Terri, it would be easier to remove feeding tubes and other life support from people who might still have some consciousness or who might wake up from a coma. They fear we would be starting down a slippery slope where we might eventually wind up removing tubes from people who are profoundly disabled but not in a permanent vegetative state. This is apparently what concerned a number of disability rights groups, who vigorously joined the Schindlers' fight to prevent removal of Terri's feeding tube.

I would like to make clear my support for the protection of people with disabilities and for the provision of the utmost respect and care for such individuals, especially the profoundly disabled. Over the years, I have found myself in alignment with disability advocates on many issues. For example, I have written elsewhere of our shared concern that calls to respect "dignity" in dying may signify an in-

tolerance for certain conditions (and the people who live with them) that might seem undignified—conditions such as dependence on others for bodily care or incontinence.

But I part company with them on the Schiavo case. Here, I think their "slippery slope" concerns were misplaced and some of their tactics were worse—that even they were exploitative of Terri. People in a permanent vegetative state can be distinguished from people with profound disabilities—that distinction is consciousness, or the potential for consciousness. By adopting at times in the Schiavo controversy a clearly distorted view of the facts (for example, in a joint statement they suggested that Michael Schiavo improperly denied rehabilitation for Terri and made up evidence of her wish to die after winning a malpractice lawsuit),[5] disability rights groups have hurt their credibility. Of more concern, by failing to distinguish people in a permanent vegetative state from people who are profoundly disabled, I think they have done a disservice to the latter, who are conscious and therefore have present needs and desires that we should work diligently to meet.

It is for these reasons, all of which will be explored more fully in this book, that I have argued elsewhere for a presumption in favor of discontinuing the tube-feeding of people in a permanent vegetative state.[6] Currently, the law favors continued feeding. I have argued that for people in this unique state, where biological life continues without the capacity for any consciousness, the law should be changed, and that to do so would actually show more—rather than less—respect for them as people.

I know that many will remain unconvinced by this argument, but it is not crucial to agree with me on this point to find value in the discussion that follows, because *no matter what our positions*, we need to reevaluate the moral, legal, and policy reasoning we bring to this debate. In particular, we need to discard the notion that there will be simple solutions to these problems—like recent simplistic appeals to the living will. Further, we need to resist a tendency to rely on stock phrases, like "sanctity of life" or "freedom of choice" or "basic care," that have become slogans in this area. And we must reject the

current framing of end-of-life issues as being singularly or even primarily about an individual's rights. In early cases, it was the right to self-determination that gained recognition; during the Schiavo dispute, we heard rhetoric insisting on a right to life. Asking only what a person's rights are will not answer most of the important, practical questions about what should be done in a particular case. Asking about Terri's rights did not really answer what should be done in her case. And that may be why her case is unsettling. Upon close examination—like the examination you will find in this book—we see that we need to keep searching for better understanding of our responsibilities to one another in these contexts, not simply for more expressions of our rights.