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THE RULE IN TERRI'S CASE: AN ESSAY ON THE PUBLIC DEATH OF THERESA MARIE SCHIAVO

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The Rule in Terri's Case speaks as much to the substance of the law as it does to the political climate that surrounds it—and does so more expressly, indeed, more openly and notoriously than is often the case in United States jurisprudence.

The undercurrent of profound enmity that existed between the husband of a severely brain damaged woman and her parents and siblings combined with political and spiritual timeliness to create a perfect storm for the most volatile and litigated end-of-life case in United States history. Make no mistake about it: the Theresa Marie Schiavo case was about right-to-life and abortion as much as it was about privacy, autonomy, death with dignity, and the rights of family members.

Here is the cheat sheet formula for the Rule in Terri's Case:

Given:

1. An assiduously crafted, bipartisan guardianship law containing legal and medical metrics of incompetence with express references to end-of-life, terminal or persistent vegetative states; and
2. Statutory and case law establishing decisions a guardian can make regarding continuation or termination of a ward's artificial life support; and

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3. Legal standards requiring clear and convincing evidence to support withdrawal of artificial life support;

Then:

It shall require fifteen years, the passage of a state law in special session, the personal intervention of a state's governor, the passage of a federal law in special session, the personal intervention of the President of the United States, and the activation of all levels of state and federal judicial review including multiple reviews by state and federal supreme courts, before the law and the medical and scientific evidence permit the intentions of an incapacitated person, expressed by the spouse/guardian, based on clear, convincing, and competent evidence, to result in the withdrawal of artificial nutrition and hydration leading to death—death that results from dehydration and possibly starvation, as well as the shutting down of vital organs, but death, nonetheless.

A vital part of the October 2003 Florida special session statute known as “Terri’s Law”¹ was a provision requiring the appointment of a special guardian ad litem who was charged with reporting to the Governor and the courts as to the feasibility of conducting additional tests on the severely brain damaged, singular target of the state law. The guardian ad litem was also charged with providing a comprehensive summary of the legal and medical history of the then fourteen-year-old case.

At the end of October 2003, I was appointed to serve as Ms. Schiavo’s special guardian ad litem. I was afforded thirty days to conduct a comprehensive review of what turned out to be some 30,000 pages of legal and medical documents, including sealed records. I consulted with the family members and attorneys, and I met with my ward, Ms. Schiavo. Of those thirty days, I spent twenty with Ms. Schiavo for time periods ranging from one to four hours, sometimes more than once a day. I visited her alone, in the company of her parents, Robert and Mary Schindler, and with her husband, Michael Schiavo. I consulted dozens of clinical special-

1. 2003 Fla. Laws ch. 418.

ists in various neuroscience and medical fields, attorneys, ethicists, and leaders of multiple religious persuasions. The Governor and his legal staff provided strong support for the conduct of a scientifically and medically sound assessment of the facts within the construct of Florida law.

The now well-worn public story of Terri Schiavo had become a statutory matter, and the Governor acted upon the law's special authority to replace the nutrition and hydration tube that had been removed following a court order. Over the course of the previous decade, the courts had consistently concluded that Mr. Schiavo was the bona fide legal guardian, not subject to replacement for cause, and that he was acting upon his wife's expressed intentions not to be kept alive by artificial means.

The vicissitudes include the fact that Ms. Schiavo's husband, Michael, was named, unopposed by her parents, as her legal guardian shortly after her collapse in the early morning hours of February 25, 1990. Ms. Schiavo's heart stopped beating (cardiac arrest), she experienced about twelve minutes of oxygen deprivation to her brain (anoxia) prior to the arrival of the emergency medical team, was resuscitated, had a hole cut in her throat for a respirator (tracheotomy), fell into a coma, and emerged a month later into a persistent vegetative state (PVS). For nearly four years thereafter, Mr. Schiavo and his in-laws, principally Ms. Schiavo's mother, Mary, diligently tended to the woman they both loved. Ms. Schiavo was given extensive physical and occupational therapy and was even taken to California to have electrodes implanted in her brain to stimulate some activity. But the medical experts all agreed that her brain damage was profound and irreversible and that she was neither aware of nor able to interact with her environment. The diagnosis of PVS, while not embraced by the family, was not patently denied.

Theories about the cause of her collapse include the possibility that she suffered from an eating disorder called bulimia, which may have led to a potassium imbalance that caused her heart to stop. She had weighed 250 pounds as a teenager, only to make a decision at eighteen to lose weight. By the time of her collapse at age twenty-six, Ms. Schiavo had worked her way down to a remarkable 110 pounds, and the couple had been trying for a year-and-a-half to have children with the assistance of a fertility physician.

A medical malpractice lawsuit was initiated, alleging that, if Ms. Schiavo's fertility physician had performed a more thorough history and physical examination, he might have had insight into her possible eating disorder. It was not a shoe-in case, but after three-and-a-half years, Ms. Schiavo won a judgment consisting of an award of \$300,000 for loss of consortium to her husband and \$700,000 that was placed in a court-managed trust account for her maintenance. There was no medical hope of rehabilitation.

Shortly after the judgment, what had been a very close relationship between Mr. Schiavo and his wife's family degenerated mightily. The feud devolved into a challenge to Mr. Schiavo's right to serve as his wife's guardian. Years later, after Mr. Schiavo had dated (with the encouragement of his in-laws), there were arguments that he could no longer represent the interests of his wife. The courts determined, multiple times, that there was no evidence to serve as a legal basis for removing Mr. Schiavo as his wife's guardian.

Many people of faith consistently argued that it was a mockery of justice and morality to permit a married man who was cohabitating with another woman, and who had children with that other woman, to be permitted to represent the totality of life interests of his incapacitated wife. This became a powerful challenge to the nature and scope of law as against the beliefs of the petitioners. It remains a centerpiece of arguments against Mr. Schiavo's interests.

The fact that each day in the United States, hundreds of people of every age, race, and socioeconomic status are removed from various forms of artificial life support is of no solace to people who have an absolute belief in the sanctity of life. An Orthodox Jewish Rabbi standing outside of the Florida Capitol the day before Ms. Schiavo died told me that the scintilla of life provides hope for all life and must be respected and ensured. David Gibbs, the attorney for the Schindler family, consistently referenced a slippery slope: at what point does a disability become a death sentence? These are not coy questions, but fundamental and important ethical, moral, and spiritual matters. And who among us would claim that there is no morality in the law?

Each time I visited Ms. Schiavo, I sought to disprove the diagnosis of PVS; I sought to elicit some evidence of a response, rather than a reflex. The snippets of video that dominated televi-

sion and newspapers were rare, indeed, uncommon instances captured within more than three hours of home video. Ms. Schiavo would make the same movements and sounds randomly when nobody was in the room. I held her hands, stroked her hair, held her head in my hands, played music for her, spoke to her, cajoled her—indeed begged her to respond. But her behavior was consistent with all of the scientific and medical literature defining PVS. As much as I hoped and wanted to find evidence contrary to the medical and scientific literature as it related to Ms. Schiavo, I could not.

Some physicians, including at least one board-certified neurologist who did examine her, claimed that Ms. Schiavo was not a victim of PVS. Some argued that she was capable of being rehabilitated, perhaps with exotic therapies. The legal and scientific dilemma was that none of these individuals were able to produce any medical evidence or case studies in support of their medical and clinical claims. As passionate and caring as some of these physicians were, and, as often as judges in the case asked them to produce substantiating evidence, they could not. In that regard, the medical experts who testified on behalf of the Schindler family (one a board-certified neurologist, the other a bariatric physician) failed to produce competent, clear, and convincing evidence in support of their contentions. The court, then, found this to be the case, and in retrospect, the record continues to substantiate that finding.

Following Ms. Schiavo's death, her husband wisely agreed to have an autopsy performed—something he was not obliged to do. The results were remarkable, scientifically. The damage to Ms. Schiavo's brain was far more extensive than even the experts had earlier deduced. The medical examiner, an exceptionally competent, highly conservative physician, stated unequivocally that her condition was irreversible—there was no hope, no possibility of recovery—and that she was blind as well. Contrary to aggressive allegations by third parties, there was no evidence of any abuse or foul play.

But the factor of hope cannot be ignored in the Schiavo matter. Her parents—kind, decent and loving people—watched as their daughter lay helpless and deteriorating—consistently being told there was no hope. No parent takes easily to the prospect of being predeceased by a child. And the parents were joined, albeit

late in the day, by powerful political forces, including national right-to-life groups, disability advocates, conservative Christian organizations, Governor Jeb Bush, and leaders of the state and national Republican Party. Pope John Paul II even spoke to this case in what has been a confusing, non-encyclical admonishment against the removal of feeding tubes. It is worth noting that on the day Ms. Schiavo's feeding tube was removed for the last time, Pope John Paul II had one inserted.

The law—that is, statutes and cases—provided a consistent, albeit painful domain for the resolution of Ms. Schiavo's exceptionally personal family matter. She was a very private, shy woman who would have been loath to serve as a flashpoint between her husband and her parents. She would have been aghast had she known that images of her partially clad, manifestly disabled body had been transmitted and published on television screens, tabloids, and magazines across the world. Everybody knew about Ms. Schiavo—but very few people knew who she was.

Judge George Greer's management of the case, when viewed objectively, was consistent, thorough, and judicious. He afforded the benefit of the doubt over and over again to the petitioners seeking to keep Ms. Schiavo's feeding tube in place. I was often amazed at the frequency with which the same motion would reappear without any substantive changes, after having been denied. The elements of law applied to this case required meticulous attention to the specifications of the Florida guardianship statutes and the established case law. There was nothing radical or unique about Florida law in this regard. It is important, however, to note that had Ms. Schiavo resided in Missouri or New York State, for example, the fact that she did not have a written, executed living will or healthcare surrogate would have precluded her guardian husband from exercising any form of substituted judgment.² It is also worthy of note that, had Ms. Schiavo resided

2. See Mo. Rev. Stat § 459.025 (2005) (stating that a patient's declaration is only given effect if his or her condition is terminal and he or she is incapable of making treatment decisions); Mo. Rev. Stat. § 459.055 (2005) (granting each person a right to refuse medical treatment subject to the State's interest, but creating no presumption on behalf of a person who has not executed a declaration); N.Y. Pub. Health Law § 2989 (McKinney 2005) (indicating that a failure to provide specific healthcare instructions will not create a presumption regarding a person's wishes about healthcare); *Cruzan v. Dir., Mo. Dept. of Health*, 497 U.S. 261, 286–288 (1990) (upholding Missouri's decision to refuse to accept the substi-

in Texas, a decision about the termination of artificial life support could have been made by the hospital or by the State, over the objections of her family.³

In my role as special guardian ad litem, my only power was to require access to all data and to my ward. The scope of my charge was limited to questions about her capacity to swallow and the history of the case. The effort was guided by principles of good science, good medicine, and good law. Within that construct, it became clear that the parties to the dispute, the Schindlers and Mr. Schiavo, were intransigent in their positions. But it was also clear that they were both seeking some closure—some hope of concluding the matter in the best interests of Ms. Schiavo. During those brief but intense thirty days, the parties came to a tacit agreement about how they might proceed toward a common goal of Ms. Schiavo's best interests.

We discussed and drafted an agreement that would have provided for a neutral third party, accepted by both sides, to be afforded the authority to conduct tests, outside of the sunshine and the press. The third party would assemble a team of neuroscientists who had previously not been involved in the case, and would direct them regarding the conduct of neurological and swallowing tests using the most current, medically recognized standards. The hook, however, was that the parties would have to agree in advance as to how the test results would be used. To wit: if there was a scintilla of evidence that Ms. Schiavo had reactive and interactive conscious capacity, as opposed to reflexive actions, Mr. Schiavo would agree to abdicate his guardianship to the Schindlers. If, however, no such capacity was discovered—then the Schindlers would agree to allow Mr. Schiavo to have the feeding tube removed and she would die.

tuted judgment of close family members when there is no clear and convincing evidence of the patient's wishes).

3. See Tex. Health & Safety Code Ann. § 166.039 (2005) (permitting the attending physician and the patient's legal guardian or an agent under a medical power of attorney to make a treatment decision, including the decision to withhold or withdraw life-sustaining treatment, when the patient issued no directive and is incompetent); Tex. Health & Safety Code Ann. § 166.046 (2005) (allowing an ethics or medical committee to review a physician's refusal to honor a healthcare or treatment decision made on behalf of the patient, and requiring the physician to make a reasonable effort to transfer a patient if the physician, the patient, or the person responsible for the healthcare decisions does not agree with the decision reached during the review process).

My final report was due to the Governor's office and the courts on Monday morning, December 1, 2003. I had been frantically drafting the agreement and speaking with attorneys for all of the parties (including the Governor's office). At 11:50 p.m. on the evening of November 30—the end of the eleventh hour—the agreement collapsed. Mr. Felos, attorney for Mr. Schiavo, called and said that he could not proceed. His argument was that he was in the midst of a challenge to the constitutionality of the law that had permitted the Governor to replace Ms. Schiavo's feeding tube—and that same law had appointed me. Were he to acquiesce to any proposal made by and through a process he claimed to be unconstitutional, he could be lending credence to the law that was the subject of his challenge. He was correct.

More than a year later, during the early months of 2005, a most exceptional display of legal, political, and media energy was manifest around Ms. Schiavo. But all the king's horses and all the king's men could not change the law, the medicine, or the science that drove the final removal of Ms. Schiavo's feeding tube.

Terri Schiavo died one of the most public deaths in history, thirteen days after her feeding tube was removed. Her parents agonized as the fifteen-year tragic saga of their daughter's life ended. Her autopsy revealed that she suffered from profound and irreversible brain damage and that there was no evidence of any trauma or foul play. She was cremated and her ashes interred in Clearwater, Florida. Within a day, there were renewed allegations about the circumstances surrounding the initial collapse of Ms. Schiavo.

Sometimes good law is not enough, good medicine is not enough, and all too often, good intentions do not suffice. Sometimes, the answer is in the process, not the presumed outcome. We must be left with hope that the right thing will be done well.⁴

Perhaps Ms. Schiavo has, as National Public Radio commentator Daniel Schorr suggested, unconsciously helped to kindle a

4. Jay Wolfson, *A Report to Governor Jeb Bush in the Matter of Theresa Marie Schiavo 1* (Dec. 1, 2003) (available at http://www.myflorida.com/myflorida/governorsoffice/review_year/docs/wolfson.pdf).

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timely national discussion about death and dying, end-of-life decisions, and the allocation of scarce healthcare resources.⁵ If not, then we face the horrific prospect of reapplying the Rule in Terri's Case, and that would be a profound disservice to Ms. Schiavo's memory.

5. Daniel Schorr, *News Analysis: Schiavo Case Tied to Politics and Morality*, All Things Considered (NPR Mar. 21, 2005) (radio broadcast).