

## THE CASE OF TERRI SCHIAVO: ETHICS AT THE END OF LIFE

ARTHUR L. CAPLAN, JAMES J. MCCARTNEY & DOMINIC A. SISTI, EDS.  
(Prometheus Books, Amherst, New York, 2006), 377 pages, \$21.00.

*Reviewed by Julius Grossenbacher, J.D., San Antonio, Texas.\**

### INTRODUCTION

Just when you thought it was safe to go back in the water,<sup>1</sup> the monster that surfaced during the Terri Schiavo case again has been found lurking below, alive and hungry. And you are about to go for a swim!

Due in part to the media attention drawn to the 2005 case of Ms. Schiavo, public and political debate over end-of-life care, euthanasia, and suicide appear to be more prevalent and heated today. Just as it was planning to jump off a bridge, the robot in a General Motors Super Bowl commercial was rescued by the American Foundation for Suicide Prevention,<sup>2</sup> and other commercials with suicide themes also were pulled or modified after protests by advocacy groups.<sup>3</sup> On February 3, 2007, Catholic Pro-Life Day in Italy, Pope Benedict XVI spoke out against “assisting the suffering to die with euthanasia” and urged followers to support the family “through pastoral *and political* initiatives.”<sup>4</sup> Bobby Schindler, brother of Terri Schiavo, now makes public speaking appearances advocating the same position as the Pope,<sup>5</sup> while Michael Schiavo, the husband of Terri Schiavo, campaigns against those

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<sup>1</sup> Tagline from the trailer to the movie *Jaws II*. See [http://en.wikipedia.org/wiki/Jaws\\_2](http://en.wikipedia.org/wiki/Jaws_2) (visited May 7, 2007).

<sup>2</sup> *Suicide-Prevention Group Wants GM Ad Pulled*, available at <http://www.msnbc.msn.com/id/17050378/> (visited May 7, 2007).

<sup>3</sup> *Anti-Suicide Groups Get Volkswagen to Pull Ad*, available at <http://www.msnbc.msn.com/id/17173371/> (visited May 7, 2007).

<sup>4</sup> Cindy Wooten, *Pope Calls Life “Mysterious Gift” to Be Defended Until Natural Death*, available at <http://www.catholicnews.com/data/stories/cns/0700687.htm> (visited May 7, 2007) (emphasis added).

<sup>5</sup> Stephen Beale, *Schiavo’s Brother Brings “Life Support” Fight to NH*, UNION LEADER (Manchester, NH), Jan. 19, 2007, at A7.

attempting to use the case as part of a political movement supporting the prolongation of life under virtually all circumstances.<sup>6</sup>

A patient's right to die is a controversial issue that touches upon medicine, law, and ethics, as well as religion, politics, common sense, and extremism. There appear to be few areas of agreement in sight.

*The Case of Terri Schiavo: Ethics at the End-of-Life* explores how these myriad forces collided in the debate surrounding the death of Terri Schiavo. The history of the case is well known—surrounded by a circus-like atmosphere during the final weeks of her life, Terri Schiavo had her feeding tube repeatedly removed and reinserted by court orders. After the feeding tube was disconnected for the third time [p. 288],\*\* Ms. Schiavo was allowed to die slowly, but painlessly, of dehydration. [p. 312] This comprehensive book details the medical aspects, the religious controversies, the political interventions by the legislative and executive branches of the state government of Florida and the federal government, the media involvement, and the internecine conflict of Terri Schiavo's family. [pp. 19-22]

Beneath the case's tawdry histrionics—one commentator called it “the longest public execution in American history”<sup>7</sup>—there are underlying issues of life and death that merit serious discussion. The editors of this book, Arthur Caplan, James McCartney, and Dominic Sisti,<sup>8</sup> have assembled an anthology of statements, court orders, and thoughtful articles analyzing the many sides of the moral, legal, and medical arguments involved in end-of-life decisions. Although most readers will start with a basic knowledge of this case, and there is some unavoidable repetition of basic issues in the text, the editors have taken care to avoid bias or prejudice in their compilation of articles from disparate sources, and the book is a significant contribution to the substantial literature on end-of-life care. Of particular note are the included commentaries, which frame a mosaic that presents the entire picture of the case.

The *Schiavo* case is summarized in a foreword by Jay Wolfson, Dr.P.H., J.D., the special guardian *ad litem* appointed to assist the court's deliberations and report to Governor Jeb Bush of Florida. Wolfson notes that Terri Schiavo “may have had the most public death of any private person in history.” Indeed, her dying was front-page news for months. [p. 13] Wolfson ends his commentary with a lessons-learned conclusion and rightly notes that in this

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<sup>6</sup> Anthony Man, *Michael Schiavo Takes on Politicians*, SUN-SENTINEL (Ft. Lauderdale, FL), Sept. 2, 2006, at 1A.

\*\* Editor's Note: The numbers in brackets in the text refer to pages in the reviewed work.

<sup>7</sup> Nat Hentoff, *Terri Schiavo: Judicial Murder*, available at [http://www.villagevoice.com/news/0513\\_hentoff.62489.6.html](http://www.villagevoice.com/news/0513_hentoff.62489.6.html) (visited May 7, 2007).

<sup>8</sup> Arthur Caplan, one of America's most recognized bioethicists, directs the Center for Bioethics at the University of Pennsylvania and chairs the Department of Medical Ethics at Penn's School of Medicine. James McCartney and Dominic Sisti are Associates at the Center.

book the editors have “assembled vital documents that define, in the broadest sense, the vicissitudes of Ms. Schiavo’s case.” [p. 16]

The body of the book is divided into five topical parts, with two appendices. An introduction in the first part recounts the story and identifies the central actors and issues. Excerpts from *The Preservation of Life*, by Charles J. McFadden, a respected teacher and medical ethics author, are included to show the moral and legal status of futile care law that existed as of 1975. At that time, those who would act to remove life support were beset with concerns that they might face criminal charges of homicide. Death at the time was described as the “cessation of heartbeat and respiration.” The state interest in such matters also concerned itself with the abuses that might result from a “pull the plug” mentality. Consistent with similar calls at the time, the McFadden article advocated a change in the definition of death to include cessation of brain wave functions. [p. 26]

*The Percutaneous Endoscopic Gastrostomy Tube, Medical and Ethical Issues in Placement*, by Floyd Angus, M.D. and Robert Burakoff, M.D., describes the medical aspects of using the PEG tube (the feeding tube used to deliver nutrition and hydration to Schiavo) and the medical-ethical issues associated with decisions to remove such tubes. This article states that “the role of healthcare professionals in the decision making process is poorly defined,” and suggests that one criterion in the process should be “to demonstrate that our interventions truly benefit the patient.” [p. 29] The quality-of-life criterion is strong among health care professionals; but it is not the primary focus of the law, which basically allows the patient or a surrogate to make final decisions regarding health care. [p. 20] Herein lies the potential conflict between patients’ directives and the wishes of their families, on the one hand, and the professional sensibilities and judgments of health care providers, on the other.

One of the central issues of the case, discussed in Part One of the book and a primary focus of many in Congress, is the debate over Ms. Schiavo’s state of consciousness: if Terri Schiavo was in a permanent vegetative state (PVS), there was no conscious person living in her body. The American Academy of Neurology’s definition of PVS states that “persistent vegetative state patients do not have the capacity to experience pain or suffering,” as pain and suffering are attributes of consciousness requiring cerebral cortical functioning. [p. 168] The article *Permanent Vegetative State*, by Dr. Ronald Cranford [p. 68], discusses the history of the PVS diagnosis, beginning in 1972 when Dr. Fred Plum and Brian Jennet originally described and named the syndrome. A lesser condition, “minimally conscious state,” further fueled the controversy. This condition, in the minds of the pro-life advocates, would have made a significant difference in deciding Terri Schiavo’s fate. This position was supported by Dr. William Polk Cheshire, Jr., who questioned the diagnosis of PVS by other physicians and suggested that Ms. Schiavo was probably in a minimally conscious state and not in PVS. [p. 165]

Suffice it to say that the further development of medical diagnosis techniques would have a significant impact on how the law is applied. The moral argument, however, is working against both the law, which is rather well settled, and medical science, which is still developing new techniques.

Part One also includes the majority opinion of the seminal 1990 United States Supreme Court right-to-die case, *Cruzan v. Director, Missouri Department of Health*.<sup>9</sup> *Cruzan*, like the *Schiavo* case, arose out of a request to remove the feeding tube from a young woman (Nancy Cruzan) who had suffered a severe brain injury. In deciding the case, the Supreme Court affirmed the right of competent individuals to refuse nutrition and hydration, and also affirmed the right of states to require a higher standard of proof—“clear and convincing evidence”—that the now decisionally incapable patient would not have wished to continue to live in his or her existing state. Nancy’s parents (who brought the case on behalf of their daughter) lost their case in the Supreme Court because, while they could assert their daughter’s right to have her feeding tube removed, they failed to meet the state of Missouri’s requisite burden of proof. The case was later resolved in a Missouri court decision. After additional evidence of Ms. Cruzan’s desire not to live in such a state became available, a court determined there was sufficient evidence of Ms. Cruzan’s end-of-life care desires, and the feeding tube was removed.

More significant in a practical sense, perhaps, than the majority opinion in the *Cruzan* case was the concurring opinion of Justice Sandra Day O’Connor, which was not included in the book.<sup>10</sup> She recommended the use of proxies in such cases, lending very visible support to the already growing practice of using a “durable” medical power of attorney.<sup>11</sup> Congress passed the Patient Self-Determination Act in 1990,<sup>12</sup> requiring all Medicare- and Medicaid-funded hospitals and care facilities to make available advance directives to patients and residents. This legislation has helped, but not everyone signs a directive or appoints a proxy.

## THE FLORIDA CONTROVERSIES AND THE FEDERAL ISSUES

Parts Two and Three of the book discuss the litigation involving Michael Schiavo, husband and guardian of Terri Schiavo, who sought to remove her feeding tube, and Terri’s parents, the Schindlers, who wanted to continue artificial nutrition and hydration. The Florida courts ordered the feeding

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<sup>9</sup> *Cruzan v. Director, Missouri Dep’t of Health*, 497 U.S. 261 (1990).

<sup>10</sup> *Id.* at 287 (O’Connor, J., concurring).

<sup>11</sup> A “durable” power of attorney is one written to survive the principal’s loss of competency. Under traditional notions of agency law, an agent has no greater power than the principal who delegates power to the agent. A durable power measures the delegation from the date of the grant, when the principal was competent, regardless of a subsequent change in the principal’s capacity.

<sup>12</sup> 42 U.S.C. § 1395cc(a).

tube removed. Ultimately, the federal effort to pass special laws to give the Schindlers access to the federal courts to retry the case and temporarily halt removal of the feeding tube while the case was pursued failed. [pp. 71-103]

### Catholic Controversies

The so-called “Christian Right” was the moving force behind the political aspects of the *Schiavo* case. Although this group is not predominately Catholic (despite a commonality of many positions, such as right-to-life tenets), there was a particularly Catholic aspect to the religious and moral considerations in the *Schiavo* case. [p. 177] The Schindlers, Terri Schiavo’s parents and siblings, are practicing Catholics and claimed that Terri actively professed her Catholic faith. Governor Jeb Bush also is Catholic. Part Four of the book, titled “Catholic Controversies,” addresses the Catholic moral position on end-of-life care, which, according to the editorial comments, is not as clear as the Schindler family and Governor Bush would have one believe. [p. 177]

Catholic moral theologians have argued that providing artificially delivered nutrition and hydration to persons in a persistent vegetative state is often disproportionate because it prevents lethal pathology (the inability to swallow) from achieving its end (natural death), and, therefore, is ethically optional. Others argue that withholding or withdrawing it is the moral equivalent of euthanasia by omission because the motive is to cause death. [p. 177]

The euthanasia issue seems less a case of fine distinctions, which make withholding or withdrawing artificially delivered nutrition and hydration morally permissible under some circumstances, than the unexpressed “slippery slope” principle that it invokes. The book does not discuss the terms “slippery slope,”<sup>13</sup> or “judicious neglect” (a term used by Dr. Julius Korein in his testimony in *Cruzan*). Both of these terms add a dimension to the attitudes of the moralists, on the one hand, and the medical practitioners, on the other.

The Catholic hierarchy is, by its very nature, paternalistic, with the Pope not only its head but armed with the Church’s highest form of paternalism, “infallibility.” One of the sustaining characteristics of the Catholic Church and one of the key areas of division in the Christian faith, infallibility supplies certainty in matters of faith and morals and is universally accepted by the Catholic faithful. In his book *Faith and Politics*, John Danforth, former United States Senator and an ordained Episcopal minister, devotes his longest chapter to the subject (“A Quest for Certainty”).<sup>14</sup>

Although the Pope speaks *ex cathedra* (as the infallible voice of the Catholic Church) only on rare occasions, and solely on matters of faith and morals, he utilizes other pronouncements, called “allocutions,” that are compelling, especially within Catholic agencies, such as educational institutions,

<sup>13</sup> See Eugene Volokh, *The Mechanisms of the Slippery Slope*, 116 HARV. L. REV. 1026 (2003).

<sup>14</sup> JOHN DANFORTH, *FAITH AND POLITICS* 32-53 (2006).

scientific organizations, advocacy groups, hospitals, and care facilities. An allocution is a statement by the Pope that is hortatory in nature. It is an entreaty for action or acceptance. Coming from the Pope, an allocution carries a lot of weight; although not an infallible statement as such, it is worthy of consideration, even if it is not entirely correct. In terms of Catholic theological thought, the subject remains debatable, as compared to *ex cathedra* proclamations for which debate is closed—*de gustibus non est disputandum*.<sup>15</sup>

Catholic thought on medical treatment has long been established; tradition, as well as prior Papal pronouncements, has held that one is morally obligated to use ordinary means to sustain life but is not obliged to make use of extraordinary means. [p. 198] However, when it comes to categorizing artificial nutrition and hydration as one or the other, statements from various Catholic authorities included in the book demonstrate that consensus is lacking. [pp. 191-92, 209]

James McCartney's article, *Reverence for Human Life*, eloquently sets out the Christian tradition on death and dying. [p. 220] In analyzing the ethical positions, he refers to an allocution by Pope Pius XII in 1957 in which the concept of burdensomeness was injected into the equation. McCartney calls it a "burden/benefit calculus." [p. 226] By coining his own term and equating it to the secular "best interest" principle, he further complicates an issue that has been more of a moral dilemma than a certain moral imperative.<sup>16</sup>

In *Implications of the Papal Allocution on Feeding Tubes*, Thomas A. Shannon and James J. Walter take issue with the position taken by Pope John Paul II on the matter of life-sustaining treatments for those in a vegetative state. They contend the Papal allocution is a "significant departure from the Roman Catholic bioethical tradition with respect to both the method and the basis upon which such decisions are made." [p. 231] They further observe that the Papal statement was "startling to many" because it "came out of the blue." [p. 237] The authors seem to answer their own question when they refer to the Catholic right-to-life debate and the political and religious power of the movement "clearly manifest in the Terri Schiavo case." [p. 238]

To the Pope's credit, his reasoning is consistent, despite the apparent change in the Catholic tradition. Pulling the plug is a form of euthanasia. Motive is too light an argument to ameliorate the term. It is merely a distinction without a difference. Remove the feeding tube and the patient dies. It is that simple.

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<sup>15</sup> "There is no disputing about taste." NEW DICTIONARY OF CULTURAL LITERACY (E.D. Hirsch, Jr. et al., eds., 3d ed. 2002), available at <http://www.bartleby.com/59/3/de gustibusno.html> (visited May 31, 2007).

<sup>16</sup> For a discussion of how the "benefit-burden" calculus relates to the distinction between ordinary and extraordinary care, see the opinion of the New Jersey Supreme Court in *Matter of Conroy*, 406 A.2d 1209 (1985).

In his article, *On the Death of Terri Schiavo*, Edward J. Furton makes the best moral argument, describing the death of Terri Schiavo as euthanasia by omission; but he is less convincing when he merges the moral issue with medical and scientific facts. He compares Terri Schiavo to the lowly snail, insisting that the nearly brainless snail feels pain if stuck by a pin because it “writhes.” Then he asks, with vacuous logic: “Did her slow process of dehydration, over a period of thirteen days, cause her any pain? A ‘no’ answer is hard to square with the facts.” [p. 250-51] He begs the question when he asks: How can we prove that someone is unaware? For Terri Schiavo, whose cerebral cortex had largely been replaced by cerebrospinal fluid, it is hard to imagine any cognitive sensations. A pin prick would have caused only a reflex action, a characteristic of PVS.

### The Aftermath

Part Five considers the possible consequences of the *Schiavo* case in terms of the strict position now taken by the Pope and those who agree with that stance. The political agenda of the Christian Right has had a major setback, but that may embolden their cause rather than weaken it. Legislatures in several states are largely conservative (strongly committed on right-to-life issues), and it is there that “futile care” laws are enacted. The editors conclude that the judicial process, and prevailing consensus, seem to have weathered the storm. [p. 255]

As for Catholic agencies, what will be their position in light of the Pope’s allocution about sustaining life in the PVS situation? Should patients enter these facilities under a shadow of doubt as to whether their express directives might not be followed in an end-of-life situation? Will physicians and caregivers comply with or simply ignore the trend of American society, which is reversing its stance of a generation ago (when the pull-the-plug mentality was popular) in favor of a more stringent view that life persists to the last breath even when only artificially supported?

Personal experiences of many families indicate that the reverse may be true, because they have criticized the heavy-handed attitude of some health care providers who are, in their observations, too quick to pull the plug. In Texas, George W. Bush, while he was Governor, signed a bill that gave a family only 10 days to remove the patient to another facility to continue futile care if the hospital decided it was time to discontinue further treatment, including nutrition and hydration. Beyond that limit, a court order would be required, thus possibly precipitating another *Schiavo* case or, in its absence, the death of the patient.<sup>17</sup>

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<sup>17</sup> TEX. HEALTH & SAFETY CODE tit. 2, §§ 166.052(a)(3) & (a)(5) (statements explaining patient’s right to transfer).

Disability groups have been ambivalent about the *Schiavo* case. They did not speak out, according to the article by Mary Johnson, at least not sufficiently to indicate a position relating the Schiavo situation to disabled people generally. [p. 373] She reports that Not Dead Yet, an advocacy group for the disabled, has proposed a moratorium on removal of food and water from people in a PVS until they have undergone newer diagnostic MRI procedures.

The book ends with helpful sections that fill in some of the gaps. One is the text of the autopsy of Terri Schiavo, which indicated the diagnosis of PVS was correct. [p. 399] There also is a time line of the case with other related events. [p. 454] Finally, there is a list of the people who played a part in the *Schiavo* case (and their credentials), including contributors to the book. [p. 488]

## CONCLUSION

This book is one that all health care professionals should read; and every physician who touches patients and every attorney who has people for clients should have a copy conspicuously displayed. The cover alone says enough to get the attention of anyone who is seriously ill or expects some day to be ill for the final time: there is a picture of Terri Schiavo getting a hug from a loving caretaker and showing in her expression what appears to be a genuine acceptance of love and compassion. But Terri Schiavo could probably best be described as a living corpse.

The solution to the problem need not be a continued moral dilemma or a separate standard for health care professionals. It should not be a financial convenience for hospitals and insurance companies or the continued anguish of families praying that God will take care of the problem. People should speak to their families about their wishes for end-of-life care, execute health care advance directives, and also use a medical power of attorney to appoint a proxy or proxies who can make the tough decisions regarding end-of-life health care in a way that best comports with the patient's belief system.

Directives to physicians should specifically mention withdrawal of food and water in appropriate circumstances—not only in terminally ill situations, but in cases of persistent vegetative state and even “minimally conscious state,” where there is no reasonable prospect of the patient's recovering consciousness.

At best, the art of dying is not yet perfected in our society. Perhaps a solution is a redefinition of the physical conditions that define death and a reevaluation of the slippery slope principle in forming some moral precepts. The American people seem to be watching their step and can maneuver a slippery slope when they see one. They may sometimes be slow, but they are sure, as the November 2006 congressional elections proved. Attempts by moralists to redefine artificial hydration and nutrition as ordinary care is a trump that would close debate and force the issue to support biological life in

all cases. But if the American public ultimately agrees with Senator Danforth and “reject[s] the notion that religion should present a series of wedge issues useful at election time for energizing a political base” [p. 316], then they may be able to turn that notion into a slippery slope down which may slide the credibility of its proponents.

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