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Kenneth W. Goodman

The Case of Terri Schiavo

Ethics, Politics, and Death in the 21st Century

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Ethics, Politics, and Death in the
21st Century

Edited by

Kenneth W. Goodman

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PREFACE ❖

The case of Theresa Schiavo is a watershed in bioethics, U.S. politics, jurisprudence, and health policy. It became clear early on that not only was the case extraordinary, but it had a rare power: a power to anger, to confound, to ennoble.

In assembling the team of contributors to this volume, the goal was to identify leading authorities in the various disciplines that bore on the case. As it developed, several of them were directly involved in the case. They are frank, and their arguments are as forceful as any in contemporary bioethics. There are disagreements herein, and the project is richer for it. Even those not directly involved in the case lived it, and throughout the book one should get the sense of passionate argument tempered by scholarly expertise. The “bioethics community” itself receives reasoned lumps. While books by other key players—husband, parents, lawyers—have appeared, it is necessary to produce a volume to inform and stimulate students as well as professors, patients and clinicians, voters and representatives.

The result, one hopes, is a collection that provides an exciting and comprehensive overview and analysis of key aspects of the case.

The case was exciting. It also became clear early on that it was hard to follow. Schiavo I, Schiavo II ... Schiavo *n*, with a tangle of suits and appeals and rulings: a mire without precedent. To try to keep it all straight, we began listing and annotating events in a Web-based timeline. Key rulings could then be accompanied by copies of the associated bills, reports, and court opinions. We added a bibliography, a list of links, etc. It was, in many respects, precisely what the World Wide Web

is most useful for. The Timeline¹ would have been an uninterpreted flood of dates if not for the legal expertise and supererogatory efforts of Prof. Kathy Cerminara of Nova Southeastern University's Shepard Broad Law Center. Her expertise, shaped by work on the standard reference *The Right to Die*,² has also been invaluable at several points in the preparation of this volume. It has been a delightful surprise that the Timeline has itself come to be recognized as a reputable, if not authoritative, resource on the case.

Readers will use the Timeline most profitably by consulting it in conjunction with the chapters here. In cases where it seems particularly apt, notes to the chapters include reminders of documents' availability on the Web.

This book owes much to many. My dear Jacqueline Schneider, an elder law attorney, spent countless hours assisting with the volume's preparation and editing, evincing grace and patience, the latter of which was sorely tried on several occasions. University of Miami Ethics Programs Administrator Gary Dunbar has done superheroic work, as usual, in helping to pull the many pieces together.

Author Ron Cranford, a major figure in bioethics for a quarter-century, died during the preparation of this volume.³ The chapter here is his last scholarly effort. Special thanks are due to Kristin Cranford, his daughter, Candy Cranford, his wife, and Joanne Roberts, a close friend and scholarly collaborator, for quiet and dignified efforts to polish his manuscript and make it ready for publication during a very difficult time. A statement prepared by family members noted that "Dr. Cranford will long be recognized as a forerunner in advocating that individuals establish health care directives, the right of the patient to make informed health decisions and the right of family members to carry out the expressed wishes of the patient. Those rights he so passionately advocated for others, he demonstrated in his own life and his passing."

Thanks are due the Florida Bioethics Network and its board and members for providing a nonpartisan platform for airing a variety of ideas, some of them controversial. (Several passages of my chapter here first appeared in *Florida Bioethics*, the FBN's newsletter.) Colleagues from universities across Florida were in regular touch during the most heated seasons of the case, and the result is a collegial network dedicated to improving ethics education. FBN Board Member Robin N. Fiore, a contributor to this volume, has been a wise and generous collaborator, and

her patient insights and editing advice have improved the volume in ways too numerous to count.

We are indebted to Peter Ohlin at Oxford University Press for his insight and encouragement. Anita Cava and Jacqueline Goodman helped keep the coast clear when necessary. Allison Goodman continued to ask superb questions and learned how to juggle many complex ideas, and balls, during the preparation of this book.

University of Miami students of philosophy, medicine, religious studies, law, and other disciplines have for years constituted precious audiences for testing both arguments and intuitions as the case unfolded, and since. They were a constant reminder of the primacy of education in politics, policy, and ethics.

Kenneth W. Goodman
Miami
January 2009

NOTES

1. Cerminara, K.L., and Goodman, K.W. Key events in the case of Theresa Marie Schiavo. Available at http://www.miami.edu/ethics/schiavo/schiavo_timeline.html.
2. Meisel, A., and Cerminara, K.L. *The Right to Die: The Law of End-of-Life Decisionmaking*. New York: Aspen, 3rd ed., 2004.
3. Pearce, J. Ronald E. Cranford, 65, an expert on coma, is dead. *The New York Times*, June 3, 2006, p. A14.

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Jon B. Eisenberg, J.D., was one of the attorneys on Michael Schiavo's side in the Terri Schiavo case and represented a nationwide group of bioethicists as *amici curiae* in the case. He has litigated in appellate courts on a variety of civil rights and business issues, including free speech, the right to die, reproductive choice, mediation, ethics, and corporate fraud. He is with the law firm of Eisenberg & Hancock LLP and teaches appellate procedure at University of California Hastings Law School in San Francisco.

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Daniel N. Robinson, Ph.D., is a member of the Oxford University Philosophy faculty and is Distinguished Professor, Emeritus, Georgetown University, on whose faculty he served for 30 years. Author and editor of more than 40 volumes, Professor Robinson's scholarship covers an unusually wide range of disciplines, including the brain sciences, philosophy and history of science, moral philosophy, philosophy of law, philosophy of mind, and intellectual history. In 2001 he received the Lifetime Achievement Award from the Division of the History of Psychology of the American Psychological Association and, in the same year, the Distinguished Contribution Award from the APA's Division of Theoretical and Philosophical Psychology. He has served as consultant to a number of governmental and private organizations, including the National Science Foundation, the National Institutes of Health, and the Department of Health and Human Services. Columbia University Press published his *Consciousness and Mental Life* in 2008.

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1 ■

Terri Schiavo and the Culture Wars: Ethics vs. Politics

Kenneth W. Goodman

■ From Family Tragedy to Political Drama

It is the most extraordinary end-of-life case, ever.

By the time Terri Schiavo died on March 31, 2005, at Hospice of the Florida Suncoast in Clearwater, the nation—indeed the world—had eavesdropped on a family conflict with no equal, had witnessed unprecedented legislative machinations in the state capital and in Washington, and had seen dozens of courts hear and rule on scores of motions and pleadings that addressed cornerstone issues in end-of-life care: What are the powers of guardians and other surrogates? How much evidence is needed before their requests or refusals are honored? What is the role of government in bedside medical decisions? How should “disability” be defined? Are artificial nutrition and hydration like or unlike other forms of treatment?

Then, when politics intervened in the kind of case familiar to many hospital ethics committees, the Terri Schiavo story turned from tragedy to farce. At one point, the Congress of the United States of America subpoenaed the permanently unconscious Ms. Schiavo to appear and testify. It was a riot of kooky views and political vehemence.

The brightest light in the ultra-heated debate was that ordinary people talked about it with their family and friends. They talked about life, cognition, and death. They talked about what they value in being alive. They talked about advance-care planning, including living wills. In survey after survey, ordinary people said they would not want to live like Terri Schiavo.

And who would? That some *said* they would seemed to make sense only as an act of keeping faith with Culture War comrades. As Terri Schiavo became a heroine of rightist resurgence in post-New Deal America, it became disloyal to suggest that you didn't desire a life of permanent unconsciousness. The dominant value here was that of "vitalism," a view that holds that all human life (even humans who have no mental life, no cognition or consciousness) was to be prolonged *come what may*. Until the Schiavo case, vitalism was a remnant of ancient or animist faiths. Ultimately, the Schiavo case came to serve as a vehicle for resurgent proselytizing on issues ranging from embryonic stem cell research to abortion.

Ms. Schiavo was in a permanent vegetative state (PVS).¹ That diagnosis was never in doubt among credible medical sources. People in a PVS cannot see, hear, feel. They cannot think.² They do not experience or interact purposefully with their environment. In Ms. Schiavo's case, brain scans showed a cerebral cortex filled with spinal fluid. Highly edited videos of her moving and appearing to follow a balloon with her eyes were, to neurologists, clearly bogus. Indeed, neurologists generally looked on with either slack-jawed wonder or incandescent fury at the attempt to deceive the courts and to manipulate the court of public opinion with videos made by those who wanted to prolong her life support. (See the late Ron Cranford's contribution to this volume.) That the videos were indeed deceptive was made bold face when Ms. Schiavo's autopsy results incontrovertibly documented that she suffered from what is called "cortical blindness"—the part of the brain that controls vision had been destroyed. She could not track the movement of a balloon, or anything else, because she could not see the balloon, or anything else. The role and effect of those video images is discussed by several authors in this volume.

Ms. Schiavo was being kept alive by a percutaneous endoscopic gastrostomy (PEG) tube, which delivered a nutrient solution directly to her stomach. During the court battles the tube was removed three times, and reinserted twice.

The dispute between husband Michael Schiavo and parents Robert and Mary Schindler was an awful demonstration of what can go wrong when stakes are high and disputes are hot. The Schindlers, by most accounts sincere and caring, became allied with a variety of partisans who saw in the case a chance to make political hay over everything from "judicial activism" to abortion to creationism to same-sex marriage to

stem cell research to end-of-life care itself; some of the “Save Terri” shibboleths and agit-prop went so far as to suggest that hospice care was active euthanasia in disguise. That, too, is false, but America’s Culture Wars too often are about seeking power rather than insight.

Perversely, the case started to unravel a longstanding trans-political and interfaith accord, especially in Florida: Conservatives and liberals had once agreed that there was something wrong when tubes could be stuck—or kept—in people without their consent or that of their next of kin.³ Moreover, a huge investment in bipartisan, interfaith understanding was being squandered. The Robert Wood Johnson Foundation had just recently concluded a program to support end-of-life education. Some \$150 million had been spent over the previous 15 years, in part with the intention of educating policymakers and legislators. The work of dozens of “Community–State Partnerships” (including one in Florida that included support for the program I direct) was unraveling.

The judge at the center of the case, Pinellas-Pasco County Circuit Court Judge George Greer, consistently ruled in favor of Michael Schiavo, who argued that withdrawal of the PEG tube was what Ms. Schiavo would have wanted. The Schindlers disagreed. Greer endured death threats, relied on bodyguards, and was eventually asked to leave his church.

Michael Schiavo, who later established a political action committee, was similarly reviled by partisans, many of whom alleged, without evidence, that he (a) abused Ms. Schiavo and caused her 1990 collapse, (b) worsened her condition by intentionally waiting to summon help after that collapse, and/or (c) abused her after she was in a PVS. Indeed, in 2005, two-and-a-half months after her death, Florida Governor Jeb Bush asked a state prosecutor to investigate the circumstances of the 1990 cardiac arrest, especially the amount of time that elapsed between Ms. Schiavo’s collapse and Mr. Schiavo calling 911. The prosecutors found no evidence of wrongdoing.

None of that dissuaded Mark Fuhrman, the former Los Angeles police detective famous for being the first to arrive at the O.J. Simpson crime scene and finding the bloody glove. Fuhrman, who once admitted to torturing gang members, was seen in a video shown to the Simpson jury in which he repeatedly uttered a racial slur. He later apologized and denied being a racist. His was the first book on the Schiavo case.⁴ The book begins, according to the *St. Petersburg Times*, “with a short introduction, explaining that he watched the Schiavo saga from afar

and decided to write the book several days after her death. He said he received a telephone call from Sean Hannity, the conservative Fox News talk show host, who asked him to look into the case. Hannity had grown close to Schiavo's parents, Bob and Mary Schindler, while covering the story in Florida. . . . Fuhrman said he wanted to answer several key questions: How did Schiavo collapse? Had she been abused or murdered?"⁵

Since then, several books have been published about the case, almost all of them similarly partisan.⁶ The debate across all media was too often about spectacle, too little about illumination.

In a thoroughlygoing sad case, perhaps the saddest aspect was the invocation of disability rights. Those on the political right, traditionally loath to endorse, or at least pay for, reasonable accommodations for people with disabilities, somehow reckoned that Ms. Schiavo was disabled. This produced one of the more paradoxical alliances in American politics: disability rights activists—at the vanguard of one of the most important civil rights movement in a generation—arm-in-arm with far-right-wing politicians, who in some jurisdictions will not build a wheelchair ramp without a court order.⁷

Make no mistake: there was a credible conservative stance on the Schiavo case (and it is expressed superbly by Prof. Daniel Robinson in this volume).⁸ The problem was that there was no room for it at the time, given the vehemence and volume of the "Save Terri" machine. The Schiavo case was, for operators of that machine, never about the traditional conservative values of limited government, self-determination, and personal responsibility. It was in part about newly empowered, pre-Obama-era rightists who wanted to revile those they opposed on judicial activism, creationism, and stem cells, issues on which most Americans hold ordinary, that is, not peculiar, views. It was also about a deep and apparently sincere belief that something awful happened when PEG tubes were removed from patients in permanent vegetative states—a belief that no amount of medical evidence could shake.

The Schiavo case will last much longer than Terri Schiavo and, indeed, was an issue through the 2008 U.S. presidential campaign. The politicians who decided there was something in it for them also began to do what legislators are best and worst at: They introduced legislation. In Florida and several other states, laws have been proposed that would invalidate living wills and surrogate refusals of treatment unless such refusals were made explicitly and included the precise future context under which it would be permissible to withdraw or withhold

treatment—a burden that as a practical matter would be impossible to meet. PEG tubes are often singled out: The idea is that a surgically implanted tube to deliver a nutrient solution is somehow different than dialysis or ventilator support or antibiotics. Mind you, those advocating “life in any form” tend, at least in Florida, to be unwilling to pay any of the associated costs. As she lay dying, the same Florida Legislature that passed “Terri’s Law” to keep her PEG tube from being removed cut the Medicaid budget that pays for the nutrient solution used with PEG tubes to keep patients alive.

While many see Ms. Schiavo’s legacy as a greater awareness of living wills, that will be too optimistic if the nation’s legislatures succeed in invalidating advance directives and thereby undermine several decades of ecumenical agreement on death and dying. If that happens, it will not be because free people have finally declared solidarity with the vulnerable, affirmed their commitment to life, or taken a stand against over-hasty withholding or withdrawal of life-sustaining treatment. It will be because a narrow band of political outliers framed the debate in such a way as to frighten ordinary people and make them uncertain about what they rightly and sincerely valued.

❖ Right-to-Life and Right-to-Die

This section addresses several core issues in more detail—namely, why the case took its extraordinary course, the controversy over disability, and the role of language in framing debates.

There is something striking about the frequency with which the State of Florida has acquired a significant role in Big Stories (or at least Big Cases). Think Cuban exiles, the missile crisis, and the brink of war (and perhaps the assassination of John F. Kennedy); Watergate and its burglars; the explosion of the Space Shuttle Challenger; Elian; the 2000 presidential election. If state flags were fashioned from grim whimsy, Florida’s would be revised to resemble a hanging chad, with a picture of Elian Gonzalez on one side and Terri Schiavo on the other, flapping in a hurricane’s gales.

It is not clear whether there really is something about *Florida* that engenders such. Perhaps it is the state’s status as a cultural frontier in an era when all geographic frontiers have been used up. Or in the case of protracted legal proceedings it might be coincidence, the tip of a national iceberg shaped by litigation such that there is always one more

lawsuit, one more court, one more expert, one more zealot with a filing fee. Then, every once in a while, a case gets so wedged in the courts that it cannot be pried loose. It could happen anywhere.

Some 6,500 people die every day in the United States,⁹ and precious few warrant more than a paid death announcement or an agate couplet in the daily paper. End-of-life disputes are common enough, but most of them are resolved by rapprochement, truce, or death. Those cases in which combatants at the death-bedside enjoy no accord, and in which death is reluctant, usually find it is some machine that makes it so. The machines—customarily ventilators, dialysis units, PEG tubes—supplant a vital function and become *sine qua nons* for life itself. They are good machines, generally speaking.

Indeed, why would one ever disdain such a device?

The “right-to-die” movement, along with hospice, are creatures of the realization that such medical machines are not always tools with which brave people combat death, infrequently ways to help stick one’s thumb in the Grim Reaper’s eye, rarely means by which one doesn’t go gentle into . . . that is, while medical machines can prolong life in extraordinary ways, the lives they prolong are too often dark and bleak and silent, and not particularly valued by anyone without a political train to catch. If one would be dead but for the machine, the machine is a kind of blessing—unless one is not aware enough to know or realize it, and never will. Some clergy have been teaching us this for years, insisting that there is no duty to prolong a life “when the body has become prison to the soul.”

Throughout the Schiavo case, those who sought to maintain her on the PEG tube tacitly conceded as much. They did so by denying the accuracy of the PVS diagnosis, and insisting that Ms. Schiavo interacted purposefully with the environment, communicated with loved ones and, generally, had a mental life not significantly different than that of others.¹⁰ This was false, but it was argued with such vehemence that it was clearly a recognition of the fact that if the diagnosis were accurate, then there was little point in postponing the inevitable. That is, if Ms. Schiavo were really in a PVS, then the right thing to do would align with the wishes and desires of any ordinary, reasonable person—and she would be allowed to die.

It would in some respects have been far more interesting if the Schiavo case were a public debate over the deep and interesting questions:

- What is the moral value of the life of a human body that has no human consciousness?
- What are our duties to such a life?
- Can a person while competent make a plausible demand to be maintained indefinitely in a PVS should one occur in the future?
- Beside her PVS, Ms. Schiavo was diagnosed with no malady that would have caused her death. Does *that* make the withdrawal of hydration and nutrition treatment a kind of suicide?

To be sure, those who sought to keep Ms. Schiavo alive were keen to prevail in the courts, and so thoughtful and reasoned end-of-life debate was not a goal. When the diagnosis was bleak, they condemned the physicians. When the family fractured, they assailed the husband. When the rulings went against them, they decried the judges.

❖ Personhood and Process

Many wondered why anti-abortion activists—and the Schiavo case attracted the most extreme and zealous exemplars—would care so much about a non-fetus. What on earth did Terri Schiavo have to do with abortion? The answer can take several paths, but the one with the greatest traction is that, like a fetus, a person in a PVS has no awareness, no cognition, no intentions. As Robin N. Fiore observes in her contribution to this volume, “Theresa Schiavo is recast as a fully accessible fetus: she exhibits arousal without awareness, movement without intention . . .” To be sure, a fetus is in many respects better off than Ms. Schiavo because after a point it does experience sensation. Ms. Schiavo experienced nothing. Further, absent forces to the contrary, a fetus will in the normal course of things become a person; Ms. Schiavo had no such hope. Still, the explanation might go, if Ms. Schiavo and others like her can be taken off life support, then a block has been pulled from the wheels of an engine that will then roll over all life, willy-nilly.

The necessary and sufficient conditions for *personhood* have been a source of great and illuminating debate since antiquity, and that which distinguishes a person from a non-person is and has been a central theme in philosophy. From Boethius (a person is “an individual substance of a rational nature”) through Plato, Aristotle and Aquinas, and, in the modern era, from Descartes to Locke to Kant (who likewise

emphasized rationality), the analyses of “person” and “personhood” have orbited around reason, rationality, and cognition.¹¹

Here, philosophers and ordinary folk reach the same or similar conclusions.¹² If to be a person is to be able to communicate, remember, plan, interact, and reason, and if this is what makes life precious and special, then the permanent absence of an ability to communicate, remember, plan, interact, and reason means that whatever is left has fewer entitlements and protections than those who enjoy full personhood.

This is emphatically not to say that the permanently unconscious have no entitlements and should not be protected. They should be treated in a dignified manner. They should not be abused. They should be accorded some measure of respect. But none of these entitlements includes or entails perpetual medical maintenance. Indeed, if reasonable people generally do not value permanent unconsciousness, one could make the case that perpetual medical maintenance is a moral disservice, the imposition of a device or gadget of the sort dreaded by all those ordinary people who are not ideologues, who don’t know much about bioethics and its arguments but who are nonetheless quite clear that they do not want to live or die “on tubes.” They believe that such tubes are in fact an affront to dignity, a form of abuse, a diminution of respect. It becomes creepy and perverse to argue that in the absence of an explicit refusal of such indignity, the silence somehow begs for medical intervention. Worse, to suggest that failure to provide the intervention is a form of discrimination or—listen to this—*murder* is to stand in opposition to ordinary moral intuitions, interfaith accord, and social, political, and legal agreement. Alas, that is the unhappy position taken by the zealots who started the Culture Wars. It seemed to be about power and social control, not values or ethics.

The third question asked above—Can a person while competent make a plausible demand to be maintained indefinitely in a PVS should one occur in the future?—is a source of some anxiety. This is because we attach such importance to high-stakes expressions of anticipated future desires. A last will and testament allows me to influence the behavior of others after I am dead; indeed, the law in most cases *requires* the terms of a will be met. If I ask you to bury me on a hill, drink my favorite brandy, or give my fortune to my daughter, then you must do so, *ceteris paribus*. Living wills and other advance directives are additional means to have an influence or to command compliance after the point at which the signer or utterer has lost the ability to interact purposefully with the world. So it has come to be uncontroversial in many contexts to assert

that living wills are just as good for requesting future treatment as for denying it. This is a mistake.

One of the most important and paradoxically overlooked distinctions in contemporary bioethics is that between refusals and requests. There is overwhelming and correct agreement that a competent, informed adult who is acting voluntarily can refuse any treatment, service, or intervention she wishes: From breakfast to brain surgery, “no” means “no,” even for life-prolonging treatment. This is essential if the concept of informed or valid consent is to be anything but a hollow risk-management stratagem. Morality¹³ requires we ask for consent in medicine because we rightly reckon that free agents can and ought to control access to their bodies. But the concept is eviscerated if a competent, free adult cannot also refuse treatment.¹⁴ So, valid refusals are primary and fundamental protections against unwanted medical and other touching.

Requests on the other hand need to be reasonable. One cannot request anything and expect that doing so compels compliance in the same way as a valid refusal. A patient cannot request to be a human subject in a clinical trial, cannot request a dose of morphine for recreational purposes or an antibiotic for a viral infection, cannot request a brain transplant—and expect that the request places any kind of duty on a physician or nurse. So, what kind of reasons might be available to support a request for perpetual medical maintenance in the event of a PVS? There are at least three.

One might suggest that permanent unconsciousness is itself of value. This, as above, is difficult to understand, or believe. What we value about life is consciousness, communication, *interaction*—not simply that we are not dead. One might insist (by slogan rather than argument) that “all human life has value” or “is precious.” In such a case, there is really nothing to respond, exactly because it is a slogan. All extraterrestrial life and sea life and bunny life has value, too, depending on how and how precisely we are prepared to define “value.” Indeed, we could even accept the sentiment of the slogan but suggest its meager force is worthy of consideration only in cases in which the process of terminating treatment is hasty—obviously not an issue in the Schiavo case. Moreover, such a request attempts to impose extraordinary duties on others. Modern medicine brings us to the point where we can in fact prolong the existence of permanently unconscious humans for quite some time. If requests to do so were in fact reasonable, we should then have to contemplate—and prepare to support financially—the indefinite

maintenance of potentially hundreds of thousands of people. This does not look or feel like “respect for the value of life.” This looks and feels more like a deliberate attempt to mock it, or to attempt a demonstration of the superiority of our machines over nature’s (or God’s) processes.

Second, a request for perennial PVS maintenance might also invoke the possibility of future discoveries. That is, a person might express while competent or via a living will a desire to remain on life support (for a while? as long as possible? indefinitely? forever?) in case of a future diagnosis of a PVS because there might be a future treatment that could reverse the diagnosis. Such fantasies are common enough in medicine, and they are usually expressed by the medically desperate or by those prepared to spend hundreds of thousands of dollars to have their heads frozen (large deposit required) by cryonics companies with the expectation they will later be “revivified” and (thereby?) achieve immortality. In fact, though, medical science does not progress in any sort of way that should provide succor. It is slow and accretive. Those both enthralled and encouraged by “gee whiz” news media accounts might thus be deluded into thinking that some breakthrough or other is around the corner for *any* malady. As an argument, therefore, the hope for a future discovery proves too much. It entails—against all evidence—that one ought always to take seriously that if there were just another day of life, then everything would change. As arguments go, it is more to be pitied than scorned.¹⁵

Another possible reason to request perpetual maintenance is that it might bring comfort or pleasure or even joy to family and friends. Indeed, at a number of points during the case, right-to-life partisans suggested that Mr. Schiavo should relinquish his guardianship authority and duties to the Schindlers, who clearly were prepared to do whatever was necessary to keep Ms. Schiavo alive. The problem with this kind of argument is that it suggests that it is morally permissible to do extraordinary things without consent to a patient for the sake of other people. But we do not permit, for instance, even the harvesting of organs from cadavers for the sake of others without permission in advance from the source of the organs. The idea that it might be acceptable to insert or maintain a tube in someone for the emotional comfort of others, no matter how deep their love, is a bold-face violation of the moral rule that one should not *use* other people. This is Ethics 101, and it is attributed to Immanuel Kant, who held, rightly, that one ought always to treat others as ends in themselves and never as means to an end.¹⁶ This view is quite close to that espoused by many social and political conservatives who

want to reject Utilitarian requirements to do the greatest good for the greatest number.¹⁷

The last of the four questions we are considering here—Does the withdrawal of artificial hydration and nutrition in the absence of any other malady constitute a kind of suicide?—is one that arises even in non-PVS cases. The standard view on this issue is that withholding or withdrawing life-sustaining treatment constitutes a getting-out-of-the-way of the dying process. A patient with end-stage kidney disease who forgoes dialysis dies because of the kidney disease; a heart attack patient who refuses cardiopulmonary resuscitation dies because of heart disease; a pneumonia patient who insists that ventilator support be removed dies of pneumonia. But withdrawing Ms. Schiavo's PEG tube allowed no independent fatal process to overwhelm her. The argument may be put this way:¹⁸

1. If a patient has no underlying malady that would lead to death, and
2. Withdrawing or withholding medical hydration and nutrition will lead to death, then
3. Withholding or withdrawal in such cases must involve the *intent* to cause death (perhaps a good death); therefore,
4. A capacitated person's successful intent to bring about one's own death is suicide, and a surrogate's successful intent to bring about another person's death is assisted suicide.

But this illicitly overlooks other reasonable and plausible intentions. For instance, PEG tube refusal in the absence of a distinct fatal malady might be motivated by any of a number of rational desires or intentions. That is, by refusing a PEG tube, one might one might intend primarily to:

1. Refuse an invasive procedure, or
2. Avoid running any of the risks of tube placement or maintenance, or
3. Make a political point, or
4. Exercise personal liberty, or
5. Express and act upon an unwillingness to forgo *eating*, or
6. Express and act upon the view that PEG tubes reduce dignity . . . and so on.

Now, none of these intentions involves intending to die (or bring about death), even though it is known that dying will follow from any of them being acted on. This is not intending to die, any more than a parent, say,

intends to die by interposing himself between a child and a deadly force; or a soldier *intends* to die by doing something brave and foreseeably fatal. The intention of these acts is not to *cause* one's own or another's death, even as the act is a sufficient condition for the death.

It might be objected that some of the reasons here exaggerate the burdens of PEG insertion and maintenance and under-emphasize the concomitant burdens on family members and society.¹⁹ But the point here is that this larger debate was not engaged, perhaps partly out of shyness by those who knew morality either permitted or required removal of Ms. Schiavo's PEG tube and were reluctant to argue that even the intent to cause one's or another's death *in such circumstances* is itself not blameworthy. To do so would have been to risk allowing "save Terri" advocates to exult—with the cameras rolling—that the case was really about assisted suicide after all. They would have been mistaken, but that would not be discovered in public in the absence of reasoned debate, or in the presence of political and religious advocacy.

What should be clear is that the overarching *ethical* issues raised by the Schiavo case had been resolved well before the case made the evening news, especially that:

- People and their surrogates have the right to refuse medical treatment.
- What we value about life is not merely the absence of death.
- Irrational desires do not impose bona fide duties on health professionals.

So how, in the face of broad agreement, did the Schiavo disagreement come to take its extraordinary and ugly course?

❖ Money, Politics, and Zealotry

By most accounts, Bob and Mary Schindler, Ms. Schiavo's parents, were dedicated and compassionate. It is an awful thing to lose a child, and they fought vigorously. Michael Schiavo and the Schindlers got along well from 1990, when Ms. Schiavo collapsed during heart failure, apparently as a result of an eating disorder, to 1993, when a malpractice jury awarded \$300,000 to Mr. Schiavo and about \$700,000 to Ms. Schiavo. The relationship deteriorated, and in 1993 the Schindlers attempted to have Mr. Schiavo removed as guardian. From 1994 to 1998, they disagreed

over the level of Ms. Schiavo's care. In 1998, Mr. Schiavo petitioned the court to authorize the removal of Ms. Schiavo's PEG tube; the Schindlers opposed him, saying that she would want to remain alive. The trial began in January 2000, with Pinellas-Pasco County Circuit Court Judge Greer presiding.

During the trial, the Schindlers were adamant—passionate—in expressing the view that there were no circumstances under which they would ever agree to withdrawing the PEG tube or, indeed, any other form of treatment. University of South Florida professor Jay Wolfson, appointed as guardian *ad litem* in October 2003, observed this in his report to Governor Bush:

Testimony provided by members of the Schindler family included very personal statements about their desire and intention to ensure that Theresa remain alive. Throughout the course of the litigation, deposition and trial testimony by members of the Schindler family voiced the disturbing belief that they would keep Theresa alive at any and all costs. Nearly gruesome examples were given, eliciting agreement by family members that in the event Theresa should contract diabetes and subsequent gangrene in each of her limbs, they would agree to amputate each limb, and would then, were she to be diagnosed with heart disease, perform open heart surgery. There was additional, difficult testimony that appeared to establish that despite the sad and undesirable condition of Theresa, the parents still derived joy from having her alive, even if Theresa might not be at all aware of her environment given the persistent vegetative state. Within the testimony, as part of the hypotheticals presented, Schindler family members stated that even if Theresa had told them of her intention to have artificial nutrition withdrawn, they would not do it. Throughout this painful and difficult trial, the family acknowledged that Theresa was in a diagnosed persistent vegetative state.²⁰

Such impassioned parental advocacy was neither new nor a surprise. Family members of loved ones in permanent vegetative states often both believe they are somehow communicating with them and reckon that anything less than never-say-die advocacy constitutes failure or abandonment, or both. The Schindlers' perseverance in the courts was noted by various news media, which were in turn noticed by what Jon Eisenberg calls "the right-wing think-tank machinery":

I heeded the advice given by Mark "Deep Throat" Felt to *Washington Post* reporters Bob Woodward and Carl Bernstein during the Watergate scandal: "Follow the money." I began to study the right-wing think-tank machinery and trace its funding of advocates for Bob and Mary Schindler and Governor Jeb Bush. I was increasingly amazed as I learned that nearly everyone on the Schindler-Bush team was somehow connected—mostly