

Florida Bioethics

July 2005

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Email: ethics@miami.edu

NOW WHAT?

Schiavo's Life, Death Spur Global Debate; Fallout from Florida Case May Alter Laws

KENNETH W. GOODMAN

Director, Florida Bioethics Network

It is the most extraordinary end-of-life case, ever. By the time Terri Schiavo died on March 31 at Hospice of the Florida Suncoast in Clearwater, the nation – indeed the world – had eavesdropped on a fam-

ily conflict with no equal, witnessed unprecedented legislative machinations in Tallahassee and Washington, saw dozens of courts rule on scores of motions and pleadings that addressed cornerstone issues in end-of-life care: What are the powers of guardians and

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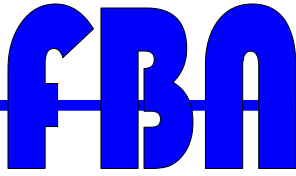
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Online Resource Developed

MIAAMI — With the goal of producing a comprehensive and unbiased resource on the Terri Schiavo case, two Florida universities have developed a Website that features a timeline, bibliography, list of religion-based resources, collection of links and a selection of streaming video presentations.

The resource, by the University of Miami Bioethics Program and the Shepard Broad Law Center at Nova Southeastern University, is said to be "intended for use by students, health care professionals and policy makers." The site's timeline, which includes links to key legal and other documents, has emerged as a trusted national resource.

The url: <http://www.ethics.miami.edu>. Comments, corrections and suggestions should be emailed to ethics@miami.edu.



Florida Bioethics Network

The Florida Bioethics Network is a program of

- Program in Bioethics, Law, and Medical Professionalism, University of Florida College of Medicine
- Bioethics Program, University of Miami
- Division of Medical Ethics and Humanities, University of South Florida School of Medicine
- Nova Southeastern University
- Florida State University College of Medicine

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Florida Bioethics

Articles in *Florida Bioethics* reflect the opinions of their authors and not necessarily those of their employers, the FBN or any other entity. Contributions are welcome.

Florida Ethics Calendar

Please e-mail submissions to ethics@miami.edu.

August 22-25, 2005, Orlando — The Florida Council on Aging's annual conference will celebrate the organization's 50th anniversary. Program includes an **FBN-sponsored** workshop, "Ethics and Aging: Priorities for the 21st Century." Information: www.FCOA.org.

September 15-16, 2005, Miami and Tampa — The Florida Bar Real Property, Probate and Trust Law section will sponsor "Powers of Attorney, Living Wills and More." Information: www.flabarrptl.org/cle.cfm

September 16, 2005, Panama City — The 10th Annual Community Bioethics Consortium presents "Death & Dying in the Age of Aquarius." **Co-sponsored by the Florida Bioethics Network.** *FBN members can attend for free.* Information: (850) 747-7133 or michelle.hampton@hcahealthcare.com.

September 16-17, 2005, Naples — The Florida Bar Elder Law Section's annual retreat will address issues in guardianship and ethics and Medicaid planning, among others. Information: www.eldersection.org/index.asp

October 24-27, 2005, St. Pete Beach — The University of South Florida Department of Mental Health Law and Policy will sponsor "Ethics In Research: An Intensive Training Course Focusing On Behavioral Health Sciences." Information: www.fmhi.usf.edu/mhlp/Training/ethics/ethics.html

February 17, 2006, Fort Lauderdale — The South Florida Environmental Ethics Consortium (SFEEC) will sponsor its Fifth Annual Environmental Ethics Conference. Information: www.ethics.miami.edu

March 2-5, 2006, Jacksonville — The national Association for Practical and Professional Ethics will hold its 15th Annual Meeting in Florida. Information: www.indiana.edu/~appe/

April 7, 2006, Miami Beach — The FBN's annual **spring meeting** will feature programs on social work ethics, ethics committees and other topics. Information: www.ethics.miami.edu.

ETHICS BRIEFS

From various news reports

Judge Permits Parental Notification Law

TALLAHASSEE — A federal judge has refused to block enforcement of a new Florida law requiring doctors to tell parents before an abortion on a minor. The measure requires that doctors notify parents by phone, in person or by certified mail before an abortion. A suit challenging the law is still pending.

State Ends Battle over Teen's Abortion

WEST PALM BEACH — A 13-year-old foster child had an abortion after Governor Jeb Bush announced in May the state would no longer fight a court ruling permitting the procedure. The Department of Children and Families twice appealed and thus forestalled the abortion. DCF officials had contended that state law forbade giving consent for abortion

Rush Limbaugh Loses Privacy Ruling

TALLAHASSEE — The Florida Supreme Court has rejected conservative radio host Rush Limbaugh's request to strike down a lower court decision that the state could seize his medical records. Limbaugh is being investigated for illegally obtaining painkiller prescriptions by "doctor shopping." While he had publicly admitted having been addicted to painkillers, he has also denied legal wrongdoing.

Patient Dies after Living Will Battle

ORLANDO — Hanford L. Pinette, the man whose living will said he wanted to "die naturally" but whose wife wanted to override the advance directive, died after an Orange County court said the living will "must be respected." The end-of-life dispute became public after an Orlando hospital went to court to seek permission to honor the advance directive.

FAU Creates Ethics Position

BOCA RATON — Florida Atlantic University's Dorothy F. Schmidt College of Arts and Letters has named Associate Professor of Philosophy Robin N. Fiore to the new position of Special Assistant to the Dean for Ethics Initiatives. Fiore, an FBN Board of Advisors member, has also been appointed Adelaide R. Snyder Professor of Ethics.

Armstrong Bracelets Raise Concern

Florida's BayCare Health System hospitals might tape over or remove yellow LiveStrong bracelets, sold by the Lance Armstrong Foundation to raise funds for cancer research. The bracelets are the same color as the system's "do not resuscitate" bands. A new policy is intended to prevent confusion.

State Guardianship Group Creates Ethics Committee

JACQUELINE SCHNEIDER

MIAMI — In an ongoing effort to raise standards and promote the protection, dignity and value of incapacitated persons, the Florida State Guardianship Association (FSGA) has established an ethics committee.

The committee, which began meeting in November 2004, has identified a number of key issues. These include a need for guardians and licensed clinical social workers (LCSW) to work together in light of the 2003 amendment to section 765.401 of Florida Statutes. That amendment added LCSWs to the list of those who may be appointed health care proxy for an incapacitated or developmentally disabled patient.

LCSWs can therefore be appointed to make difficult health care decisions that require the proxy to consider the patient's overall health, lifestyle, values and cultural and religious beliefs. Among the greatest challenges faced by social workers is maintaining consistency in the long-term health care and financial decisions of an incapacitated or developmentally disabled patient. Accordingly, there are circumstances in which it might be necessary to pursue a guardianship proceeding with appointment of a guardian to serve as proxy.

Another issue identified by the committee is the need to explore and expand mediation as an alternative to litigation in contested guardianship proceedings. The idea is to encourage and assist rival siblings, for example, to work together for the benefit of a ward by making them aware of the financial and emotional impact a contested proceeding entails, to allow them to express their positions or otherwise "vent," and to attempt to work through various issues with them.

Other issues and projects include:

- Development of an ethics curriculum for guardians.
- Review of various codes of ethics for guardians.
- Making recommendations about conflicts of interest faced by guardians and others when they are paid by institutions which also house their wards.

FBN Director Kenneth W. Goodman, who also heads the University of Miami Bioethics Program, has been appointed to chair the committee. Those interested in learning more about the committee and its work should email him at kgoodman@miami.edu.

Jacqueline Schneider practices elder law with the firm of Jerome Ira Solkoff, P.A., in Deerfield Beach, is an adjunct professor at St. Thomas University's School of Law and is a member of the FSGA Ethics Committee.

Radio Frequency Identification and Privacy

NANCY RUBIN

Florida Atlantic University

The Food and Drug Administration (FDA) recently decided to allow RFID chips to be implanted in humans as a way to access medical records instantly. This decision increases the need to safeguard personal information. In a world that is increasingly made up of sophisticated wireless and satellite networks, privacy implications arise when data about people is being read or accessed without their knowledge or permission. Barry Steinhardt, director of the American Civil Liberties Union's technology and liberty program stated, "Our privacy is on life support, and we need to take some heroic measures to save it."

Radio-frequency identification (RFID) chips have been around for more than 50 years but in the last 10 years they have become smaller in size and less expensive. RFID chips can be as small as the size of a grain of rice, and are currently being used by pet owners to keep track of their animals, by manufacturers to track goods to their destination, and in security badges for access to buildings and locked rooms. In Florida and elsewhere, radio-frequency identification chips are being used for automated toll collection, animal tracking tags and wireless cards controlling access to buildings. They are also replacing bar codes as a way of managing inventory.

High-tech tagging is moving from the grocery store to the school yard. An elementary school in Japan is testing RFID tags for school children as a way to log the time they enter and leave the school property. Parents will receive notification by email that their child has arrived or left. In Houston, Texas, a school district is

using identification badges for their 28,000 students containing computer chips that are read when the students get on and off school buses. The information will be sent to the police and school administrators.

American passports will soon be embedded with RFID chips. The State Department hopes that RFID chips will make passports more secure and harder to forge. Diplomats and employees of the State Department will receive the new passports first and everyone else will start getting the new passports in the spring. Other countries will begin embedding tags in their passports because of the requirements by the United States government that some countries add biometric identification in order for their citizens to visit without a visa. All new U.S. passports issued by the end of 2005 are expected to have a chip containing the owner's name, birth date, issuing office and a 'biometric identifier' – a photo of the owner's face. Privacy advocates are concerned that anyone with the right reader will be able to read a person's biographical information and photo from several feet away.

The American Civil Liberties Union (ACLU) recently raised concerns about the lack of encryption required for personal data stored on passports. "The ability to read remotely, or 'skim,' personal data raises the possibility that passport holders would be vulnerable to identity theft" (Kanellos 2004). Documents obtained by the ACLU under the Freedom of Information Act showed that information technology experts in Canada, the Netherlands, Germany and Britain all expressed concern about the international standard set for the electronic passports because of inadequate protections for privacy and security.

Implantable chips will provide medical information that can be accessed by health-care

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RFID: New Challenges in Privacy and Technology

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providers over the Internet. The company that is producing the implantable chips, Applied Digital Solutions, is touting the potential life-saving benefits by providing access to medical records even if a patient is unconscious. Embedding RFID chips in the human body remained largely theoretical until the Sept. 11, 2001, terror attacks when a technology executive saw firefighters writing their badge numbers on their arms so that they could be identified in case they became disfigured or trapped (Kanellos 2004). In Mexico, government officials had chips implanted in their arms to provide them with access to secure areas. Chips are being embedded in hospital patients and are even being used by European night club patrons as identification and to pay for drinks.

The MIT AutoID Center, which coordinated the development of RFID with a partnership of 100 multinational corporations and major universities, envisions a “global infrastructure – a layer on top of the Internet – that will make it possible for computers to identify any object anywhere in the world instantly” (Givens 2003). Databases will contain information about products (unique product codes), “but also personally identifying information connecting us with the RFID-coded items we buy or otherwise obtain. It is this association of personal identity with the object’s unique identity that will enable profiling and location tracking” (Givens 2003).

How do we support technological advances while at the same time ensuring that privacy is protected? Traditional ways of understanding and protecting privacy do not take into account emerging technologies and the unique challenges that digital information presents. Senator Patrick Leahy of Vermont recently called on Congress to open a dialogue that would make sure “innovation is encouraged while the public’s privacy rights are protected” (Bacheldor 2004). Speaking at a conference at Georgetown University’s Law School in March of this year, Leahy

pointed out that while it may be efficient for manufacturers and retailers to use RFID chips to manage their inventories, consumers need to know how to deactivate them, what information is being collected, and how that information will be used.

In today’s networked world, governments and corporations are increasingly relying on commercially accessible databases and data-mining technology. Customers should know how data collected about them will be used and whether or not it will be sold or traded to third parties. Given the fact that RFID chips are now being implanted in humans with medical records and other sensitive personal information, the time has come to formally address this issue in the public eye. Public discussion should not be the last step in the process, one often used to tell the consumer or the public the way things are going to be not to find out how the public would *like* things to be. Consumer and privacy rights groups are concerned that RFID technology will pose significant challenges to consumer privacy, unless some action is taken now. Privacy-protection must be built into the technology and its applications and must not be seen as an add-on luxury.

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The Schiavo Case

Terri Schiavo Died 15 Years Ago

LOFTY L. BASTA

Project GRACE

CLEARWATER — Justice Louis Brandeis had it right when he said in 1928, “the greatest dangers to liberty lurk in insidious encroachment by men of zeal, well meaning but without understanding.” Terri Schiavo’s heart stopped on February 25, 1990; 15 years ago. Her brain suffered irreversible massive hypoxic damage. As a person, she has been dead since this. Terri’s case had six components: the power of words, medical facts as well as legal, legislative, familial and Living Will components.

The Power of Words

Just 40 years ago, people in our society commonly died of old age, advanced cancer or heart failure. In these illnesses, individuals stopped eating and drinking before they said their final good-bye. No one was accused of starving these individuals to death. Starvation connotes suffering. Since the dawn of history, emperors had their captives confess by denying them food and water. Television images of people dying of hunger and thirst are all too powerful. But did Terri suffer when artificial nutrition or hydration was stopped? The answer is no.

The use of words like “starving to death,” “hunger” and “thirst” ignores the facts that unaware victims and those who have no desire for food or water will never suffer, and that dying is a natural event that is commonly achieved by voluntarily ceasing to eat or drink.

The Medical Facts

According to two papers published in 1994 by the American Academy of Neurology on permanent vegetative state in the *New England Journal of Medicine*, recovery for victims like Terri is unlikely after three months. It never occurs after six months of the cardiac arrest.

Terri had no high brain left, according to repeated CT scans of the brain (later confirmed by autopsy findings). She was void of all potential content of awareness. She did not see, hear or smell. She did not have any memory, emotions or dreams, nor could she analyze or execute. She was incapable of knowing who she was or where she was. Her brain could never recover. During her involuntary eye or face movement, there was no electric brain activity. Terri would never be able to swallow on her own.

Lofty Basta, M.D., F.A.C.C., is Founder and Past President of Project GRACE (Guidelines for Resuscitation And Care at End-of-Life), a Clinical Professor of Medicine at University of South Florida and author of Life and Death On Your Own Terms (Prometheus).

In a review of people who were in permanent vegetative states, the famed English neurologists, Drs. Kenneth R. Mitchell, Ian H. Kerridge and J. Lovat from the University of Newcastle, England, asked the following question in 1993 in the *Journal of Clinical Ethics*:

“Why do we persist in the relentless pursuit of artificial nourishment and other treatments to maintain unconscious existence? Will they be treated because of our ethical commitment to their humanity, or because of an ethical paralysis in the face of biotechnical progress?”

Indeed, this statement should not be construed as putting a lesser human value on a person who has lost what constituted his or her personhood. Simply, it underscores that once the ingredients of reason, passions, and desires defining a person are permanently and irretrievably lost, there is no ethical imperative to sustain such an existence.

Legal Facts

Once permanent vegetative state has been established as the diagnosis, the court may apply any of the following standards:

- Clear and convincing evidence in writing that the victim would not want to exist in that state year after year. In Florida and California, as in some other states, an oral statement is sufficient.
- In the absence of a living will, a patient-chosen surrogate or court-appointed guardian who can speak for the incompetent victim is allowed to decide for the incompetent victim. The spouse is considered by the courts to be the patient’s surrogate and is placed before other relatives. He/she should know and act in the patient’s best interests.

In 1990, the U.S. Supreme Court ruled that artificial nutrition through a stomach tube is *no different* from other intrusive medical treatments. After all, the stomach tube was inserted without Ms. Schiavo’s consent in hopes that she would recover consciousness. She did not recover any high brain function. Removal of the stomach tube simply allowed nature to take its course.

Many courts have heard this case. They ruled in favor of removing the stomach tube, since it did not achieve its desired effect.

In Britain, the House of Lords heard the case of Tony Bland (judgment by the Judicial Council of the House of Lords on February 4, 1993). Mr. Bland was in a permanent vegetative state for three years following an accident that resulted in him being asphyxiated against the fence in a Liverpool, England soccer game. Prolonged deprivation of oxy-

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gen caused the cerebral cortex to become a watery mass (exactly like Terri Schiavo). Although that judgment deserves to be read in its entirety, I am quoting only the words of Lord Browne-Wilkinson:

“ . . . there comes a stage where the responsible doctor comes to the reasonable conclusion . . . that further continuance of an intrusive life support system is not in the best interests of the patient, he can no longer lawfully continue that life support system: to do so would constitute the crime of battery and the tort of trespass to the person . . . ”

In England, as with many Western countries, permanent vegetative state means death of the person. Anthony Bland was considered to be dead as a person and was allowed to die naturally.

The Legislators

Any member of the uninformed public could be made to believe that Ms. Schiavo interacted with her mother and father. Heavily edited websites and videotapes suggested that Ms. Schiavo responded. The court reviewed the four hours of unedited videotape and all the medical evidence cited above and arrived at the conclusion that Ms. Schiavo is unaware; she reacts unconsciously to noise or bright light and never repeats her response twice in a row. Unconscious eye roving and facial grimacing are part of permanent vegetative state. In my view, the legislators' action was well-intentioned even though the Florida legislators themselves were uninformed.

The Family

We can not legislate love, compassion or understanding. My heart goes out to Michael Schiavo (Terri's husband) and the Schindlers (Terri's parents). We should not have compounded their pain by giving them unfulfillable hopes and unrealistic expectations. I wish the Schindlers had been in accord with allowing Ms. Schiavo to meet her maker naturally. Let us now celebrate February 25th as Terri's Day, instead of persisting in beliefs that are both unrealistic and irrational.

Proper Advance Medical Planning

All individuals, 18 years and older, need to document their choices for medical treatment near the end of life. People frequently refer to living wills to identify their wishes; however, living wills fall far short of their intended purpose. Why? Living wills are usually written by lawyers and are written in language used by the courts and by legis-

Patients understand suffering, awareness, daily activities such as bodily hygiene, movement, combing one's hair, feeding and dressing, as well as eligibility for hospice care. The Project GRACE Advance Care Plan document bridges this gap by translating the complex medical interventions into simple daily functions that patients understand and identify with.

lators, but they are not specific enough. They use words such as “terminal,” “irreversible,” “heroic” and “artificial.” Is a stomach tube heroic? Is a pneumonia complicating advanced dementia treatable? Pneumonia is reversible while dementia is irreversible. Experience indicates that primary care physicians err on the side of caution while the surrogates' view is not always that of the patient.

On the other hand, an advance care plan document is a *medical* document that is scenario specific and will provide a clear direction for physicians, family members and health care surrogates to honor treatment choices not only regarding underlying illnesses, but also potentially reversible *complications* of a terminal illness. The document should be legally and ethically valid. We need to bridge the gap between patient and doctor. Doctors understand medical science and technology. Patients understand suffering, awareness, daily activities such as bodily hygiene, movement, combing one's hair, feeding and dressing, as well as eligibility for hospice care. The Project GRACE Advance Care Plan document bridges this gap by translating the complex medical interventions into simple daily functions that patients understand and identify with.

Project GRACE (Guidelines for Resuscitation And Care at End-of-Life) is a not-for-profit patient advocacy organization. It distributes its advance medical care plan document for free. The document has been endorsed by the Florida Medical Association, puts the patient (not the doctor, lawyer or appointed surrogate) in control of medical treatment decisions, is simple to understand and covers almost all underlying diseases and complications. The document gives each patient a chance to answer “yes” or “no” to every treatment option, is legally binding in most states (including Florida), and can (and should) be an integral part of the patient's medical record.

For more information or to obtain a free Advance Care Plan from Project GRACE, call 1-877-99-GRACE or visit our website at www.projectgrace.org.

The Schiavo Case

A View from the Battleground — Or Lessons for Physicians from *Schiavo*

KATHY L. CERMINARA

Nova Southeastern University

FORT LAUDERDALE — Theresa Marie Schiavo's death on March 31, 2005, brought to an end years of litigation and weeks of incessant television coverage, political wrangling and demonstrations. People across the nation, not to mention Ms. Schiavo's poor family, could turn back to everyday life and put that intense end-of-life drama behind them. In addition to shining a spotlight on the law of end-of-life decision-making in Florida and raising unprecedented constitutional questions, *Schiavo* contained some lessons for health care professionals. At least two come to mind in the immediate aftermath of the case: (1) the lesson of increasing communication, and (2) the lesson of seeking ethics consults.

Lesson Number One: Talk!

The first important lesson that health care professionals should take from *Schiavo* is one of communication. Ms. Schiavo did not have a written advance directive. While this is not unusual,¹ especially among younger patients, it leaves loving family members and courts to make decisions based on testimony regarding their understandings of what the patient would want offered by persons who are interested in the outcome. As flawed as they are, advance directives at a minimum provide better evidence than this of an incompetent patient's wishes. Living wills or similar instruction directives give some idea of the types of treatments a patient would or would not desire, and proxy directives (such as health care surrogate designations or durable powers of attorney for health care decisions) identify for others the person(s) the patient trusts to make medical decisions. In addition, when used as a basis for exploring the patient's values and attitudes, written advance directives and conversations about them can give physicians, other care team members, family members and courts a good picture of what a patient would decide, even if the written words are not clear.

Kathy L. Cerminara is Professor at the Shepard Broad Law Center at Nova Southeastern University in Fort Lauderdale and co-author of The Right to Die (Aspen).

During the *Schiavo* media fervor, pundits urged that the dispute could have been avoided had Ms. Schiavo had an advance directive. That is unlikely for two reasons. First, advance directives are regularly challenged, so the mere presence of one does not resolve all issues. Second, the parties arguing about Ms. Schiavo's care had well-entrenched, fundamentally divergent views of the propriety of withholding or withdrawal of life-sustaining treatment in general, not simply in Ms. Schiavo's case. An advance directive nonetheless might have helped.

Those watching *Schiavo* unfold could be certain about one thing even if they could not be certain of Ms. Schiavo's wishes: They could be certain that Ms. Schiavo would not have wanted to see her parents, her siblings and her husband fighting so vehemently for such a long period of time. At a minimum, a patient can take steps to minimize that possibility by executing an advance directive and then discussing the contents of that advance directive with his or her family, friends and health care professionals. Health care professionals should invite and engage in conversations with patients about advance directives to a much greater extent than they currently do, in an effort to help the patient do this.

Legal and regulatory authority already encourages such discussions. The patient self-determination provisions incorporated into the federal Omnibus Reconciliation Act of 1990² require as a condition of Medicare or Medicaid participation that patients be asked whether they have advance directives and be provided with information about the state law governing their end-of-life decision-making choices. The American Medical Association Council on Ethical and Judicial Affairs has opined that physicians have an obligation to discuss advance directives with their patients.³ Yet the federal statutory requirement has been accomplished primarily through quick inquiry upon initial admission to or contact with a facility about whether a patient has an advance directive, and distribution of material about the applicable state law if the answer is negative. Little professional caregiver-patient discussion typically occurs, which may explain the results of many studies indicating that patients' advance directives are not followed.⁴

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View from the Battleground: Lessons for Physicians

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Certainly, many barriers stand in the way of health care professionals' engaging in such discussion. Today's medical system does not permit much conversation at all,⁵ let alone conversation about a matter that many people wish to avoid. It may be difficult to justify spending time engaging in such conversations, especially since the execution of a written advance directive still may not head off intractable disputes among family members who hold strong and truly divergent views. Yet the patient's execution of a written advance directive should not be the only goal of such conversations; the wishes orally expressed during such conversations can be valuable evidence. Even in the absence of a written advance directive, the members of Ms. Schiavo's care team could have added valuable information to the debate over her wishes if they had engaged her in conversations about advance directives prior to her cardiac arrest and subsequently reported what they had discussed.

Lesson Number Two: Seek Help!

Another lesson to be gleaned from *Schiavo* relates to the way that health care professionals and facilities deal with families who disagree about an incompetent patient's end-of-life care. Health care professionals dealing with family disputes should not forget the availability of institutional alternative dispute resolution mechanisms such as ethics committees. They should turn to such committees for assistance before family members' opposing positions become so entrenched that mutual understanding and agreement become impossible.

Nearly every health care facility has some mechanism for reviewing and resolving ethical issues. The Joint Commission on Accreditation of Healthcare Organizations (JCAHO) requires that accredited facilities have in place some process for addressing ethical issues in providing patient care.⁶ In some states, such as New Jersey, physicians and others encountering end-of-life decision-making issues must seek review from the ethics committee at the hospital in question; in other states, courts have recommended the establishment and use of ethics committees as a method of reviewing difficult end-of-life decisions.⁷ Taking matters a step beyond review, and explicitly focusing on dispute resolution, Montefiore Medical Center in New York has garnered much attention for its bioethics mediation program.⁸

One of the mysteries of *Schiavo* is the fact that there

is no mention of ethics committee involvement or review in all of the writing about the case. Even the comprehensive report of the final guardian ad litem reviewing the case mentions no ethics committee review. The startling lack of ethics committee involvement may help explain why the parties' positions remained so entrenched and why the parties seemed to have wildly varying views about the truth of Ms. Schiavo's condition. Review by ethics committees can not only ensure appropriate decision-making, but can also assist in mediating between family members (or others) who question the propriety of diagnoses or other determinations.⁹ Health care professionals foreseeing disputes over such matters should seek ethics consults so that disputes may be resolved as soon as possible, thus potentially avoiding – or at least taking all steps possible to avoid – a *Schiavo* situation.

References

1. See Angela Fagerlin & Carl E. Schneider, *Enough: The Failure of the Living Will*, 34 *Hastings Center Report* 30 (March-April 2004). The facts of Ms. Schiavo's case and links to the text of all major court opinions, many pleadings, related state and federal bills and laws, as well as much other material, are available online. See Kathy L. Cerminara & Kenneth W. Goodman, *Key Events in the Case of Theresa Marie Schiavo*, available at http://www.miami.edu/ethics/schiavo_project.htm.
2. 42 U.S.C. " 1395cc(f) & 1396a (2004).
3. American Medical Association Council on Ethical and Judicial Affairs, *Optimal Use of Orders Not to Intervene and Advance Directives*, 4 *Psychol., Pub. Pol'y & L.* 668 (1998).
4. See, e.g., M.D. Goodman, M. Tarnoff & G.J. Slotman, *Effect of Advance Directives on the Management of Elderly Critically Ill Patients*, 26 *Critical Care Med.* 701 (1998).
5. Kathy L. Cerminara, *Eliciting Patient Preferences in Today's Health Care System*, 4 *Psychol., Pub. Pol'y & L.* 688 (1998).
6. Joint Comm'n on Accreditation of Healthcare Organizations, 1998 Hospital Accreditation Standards (Standard RI.1).
7. See Alan Meisel & Kathy L. Cerminara, *The Right to Die: The Law of End-of-Life Decisionmaking* ' 3.25 (3d ed. Aspen 2004) (with annual supplementation).
8. John Schwartz, *For the End of Life, Hospital Pairs Ethics and Medicine*, *New York Times*, July 4, 2005.
9. American Medical Association Council on Ethical and Judicial Affairs, *Code of Medical Ethics: Current Opinions With Annotations* ' 8.081, at 211 (2002).

The Schiavo Case

Now What? Discord, Politics Reshaping Legislation

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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 hydration and hydration like or unlike all other forms of treatment?

Then, when politics and religion intervened in what once was the kind of case familiar to many ethics committees, the Terri Schiavo story turned from tragedy to farce. At one point, Congress even subpoenaed the permanently unconscious Ms. Schiavo to appear and testify.

The brightest light in the ultra-heated debate was that ordinary people talked about it to 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 a number of surveys, ordinary people said they would not want to live like Terri Schiavo.

Life in a PVS

Ms. Schiavo was in a persistent vegetative state (PVS). That diagnosis was never in doubt among credible medical sources. People in a PVS cannot see, hear, feel. They cannot think. They do not interact purposefully with their environment. In Ms. Schiavo’s case, brain scans showed a cerebral cortex filled with spinal fluid. 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 as the videos were used by those who wanted to prolong her life. The videos were a kind of lie, made bold face when Ms. Schiavo’s autopsy results showed that she suffered from what is called “cortical blindness” – the part of the brain that controls vision had been destroyed.

She 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 all ac-

counts sincere and caring, became allied with a variety of right-wing outsiders who saw in the case a chance to make hay over everything from “judicial activism” to abortion to end-of-life care itself; some of the “Save Terri” agit-prop went so far as to suggest that hospice was actually active euthanasia in disguise. Perversely, the case started to unravel a longstanding trans-political 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.

Courts and Families

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. Greer endured death threats, relied on bodyguards and was eventually asked to leave his church. The Florida Bar has since awarded him the President’s Award of Merit.

Michael Schiavo was similarly reviled by partisans, many of whom alleged, variously, 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 persistent vegetative state. Indeed, 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 prosecutor found no evidence of wrongdoing. Mr. Schiavo has since been honored by the Florida State Guardianship Association.

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 boasted about 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. Fuhrman, now an author, wrote, *Silent Witness, The Untold Story of Terri Schiavo's Death*.

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Schiavo Book Club

Released in June, 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?”

The Schindlers, too, are working on a book. So is the author of this article.

In a thoroughgoingly sad case, perhaps the saddest aspect is the invocation of disability rights. Some partisans who are traditionally loathe 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 stranger alliances in American politics: Right-wing politicians embracing disability rights activists.

The Schiavo case will last much longer than Terri Schiavo. 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 were proposed that would invalidate living wills and surrogate refusals of treatment unless such refusals were precise and explicit. PEG tubes (too many of us called them “feeding tubes,” making it sound as if removing one were like snatching a spoon out of your mouth) 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 at all costs” are actually unprepared to *pay* any of the costs.

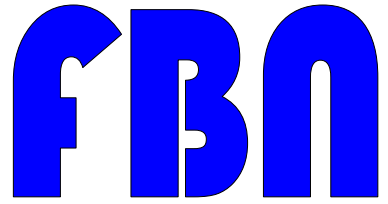
Were such bills to be approved, they would undermine hospice, force unwanted treatment on those who “don’t want to live or die on tubes” and, generally, set aside a quarter-century of bipartisan progress on end-of-life care.

While many see Ms. Schiavo’s legacy as a greater awareness of living wills, that will be too optimistic if these legislatures succeed in invalidating advance directives which don’t toe the vitalist party line. If that happens, it will not be because free people have finally

declared solidarity with the vulnerable, or affirmed their commitment to life. It will be because a narrow band of political outliers framed the debate in such a way as to frighten you and make you uncertain about what you value.

If we are truly concerned about her legacy, then surely Terri Schiavo deserves better than that.

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