

# Ethics and Intellectual Disability

## Terri Schiavo and Disabled Persons

**O**n March 11, 2005, 41-year old Florida resident, Terri Schiavo, died after 15 years of what the courts determined was a permanent vegetative state. She died after nutrition and hydration supplied through a gastrostomy was discontinued based on the claim of her husband confirmed by many courts that there was clear and convincing evidence that her wishes expressed while she was mentally competent were not to have the feeding continued if she were ever in this condition. Her parents rejected the

findings of the court that she was in a permanent vegetative state and that her wishes were that she not be fed. Since her severe, indeed total, mental impairment played a key role in the controversy, many committed to the rights and welfare of the disabled have expressed great concern about the implications of her case for the disabled. In this issue of the *Newsletter on Ethics and Intellectual Disability*, four scholars provide perspectives on the importance of the case for those with severe mental disabilities.

### Not Yet Dead

**Steve Eidelman and  
Steve Drake**

By the time you read this, Terri Schiavo may already be dead. Her fate has been a topic of intense debate for months, and it's likely that her death will not end the dialogue. In fact, Terri Schiavo's death may propel end-of-life issues even further into public consciousness. If there is anything positive to emerge from her ordeal, perhaps it is that more Americans will consider having the difficult end-of-life conversation with all of their loved ones.

The case of Terri Schiavo raises a number of troubling questions for Americans, questions that reach far beyond Ms. Schiavo's family.

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### Terri Schiavo Was Not Disabled

**Ronald Cranford**

The case of Terri Schiavo in Florida has turned out to be the most extensively litigated, most widely debated, and most controversial legal and ethical case in the history of the American right to die cases; in some respects, even more so than the previous two most widely publicized cases of Karen Quinlan and Nancy Cruzan.

However, in one important respect, Terri's case was very similar to many of the previous landmark right to die cases of the past two decades – a patient in a permanent vegetative state where the central non-treatment issue was

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For people with disabilities and their families, the case represents a slippery slope and raises the possibility that the right to life of people with significant intellectual and or physical disabilities might one day be questioned. It was only 20 years ago that the starvation and dehydration of an infant with Down syndrome exposed this all-too-common practice in the United States. In that case, two judges sanctioned the death of the infant, an infant whose life could have been saved without heroics. Although few would agree with that ruling now, it was fiercely defended as a private matter between families and doctors back in the mid-1980s.

Today, there are thousands of people with various physical and cognitive disabilities who use feeding tubes as their normal means of getting food and water. For these people, a feeding tube is not life support or heroic intervention. It is a simple way of getting hydration and nourishment. When they are hospitalized for any reason – however minor – they risk having their normal means of eating and drinking be classified as “extraordinary treatment” or “life support.”

Of course, the Schiavo case is a complicated one. There are conflicting stories about what Terri Schiavo would have wanted. And few of us have enough experience with severe disability to make an informed choice in an advanced directive. Having a significant disability does not mean you are “pre-dead.” People with disabilities are within the precepts of the Americans with Dis-

abilities Act, that Disability is a natural part of the human experience. So is death. There is unreliability regarding the persistent vegetative state diagnosis. The question of just allocation of health care and long term support resources is often in the back of our minds, whether we talk about it or not. These are ample reasons why we must put aside the partisan posturing and have an open and inclusive discussion of the issues at hand.

One thought that troubles the disability community is that Terri Schiavo’s life, and death, may cause legal protections for people under guardianship to be dismantled, making it

**There must be a way to balance a person’s right to expressly refuse treatment against a person’s right not to be deprived of life without due process of law.**

easier for guardians to kill by withholding food and water. There must be a way to balance a person’s right to expressly refuse treatment against a person’s right not to be deprived of life without due process of law. That due process of law must understand the wishes and interests of people with disabilities, even if their lives are devalued by other people. Today, we fear it does not.

Terri Schiavo’s wishes were not documented, and her husband and family have many conflicting needs that may be clouding their memory or judgment. Advocates for the disabled

would be the last to deprive her of her right to self-determination regarding the end of her life, had her wishes only been documented in a living will with power of attorney. But they were not.

Given these ambiguities, the disability community feels that the courts should err on the side of sustaining her life, not allowing her to die. This is the position of 26 national disability groups, many of which represent people under guardianship, like Terri Schiavo.

The disability community has grappled with these issues in the past and has come to the conclusion that in such cases, it is best to assume that life is preferable over death. Is that not what the Schiavo case is all about? Laws governing surrogate decision-making vary among states and are often the result of well-funded advocacy from a narrow group of professionals. In most cases, disability organizations were not included in changes of statutes on the state level, and the drafters of those statutes did not take into account the views of those with disabilities. This case focuses our attention on the need for a “federal floor” to protect people under guardianship.

In situations in which a guardian is indicated – particularly a state-appointed guardian – the possibility for conflicts of interest is clear. Many families are left to deal with very serious disabilities with few or no supports. Research indicates that people with living wills and advance directives frequently change their minds when the time comes to implement those direc-

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tives. Once people experience severe disability, their horror of it might evaporate. We now know, too, that people who “cannot speak for themselves” are often able to use assistive technology that would allow them to communicate their wishes, hopes, fears and good-byes even if they can no longer speak. In today’s climate, it might be even more important to write down what you do want in terms of treatment or supportive care and assistance with communication, not just what you don’t want.

Our society must stop using the term “persistent vegetative state.” Too many people with significant disabilities have been called “vegetables,” and this must stop. It is beyond demeaning; it is dehumanizing. In fact, some of the people who use the term most freely are doctors, and what comes next is a discussion of the death or warehousing of the individual labeled that way.

When a person has serious disabilities, the debate should not be about whether or not they are going to “get better” some day. For millions of Americans, disability is a fact of life, every day of our lives. People with disabilities have wonderful lives. And some have lousy lives. In that way, they are just like other Americans. Just because a person has a significant disability does not mean that they do not love their life. It does not mean that they should be assumed to be better off dead.

It is time for a call to conscience to both the Right and the Left. Guardianship should not be a death ship. People like Terri Schiavo are persons under the law, and they deserve constitutional protection.

The disability community is grateful that so many in Congress supported Terri Schiavo’s right to live, even though we are concerned about the precedent they set. We would like to see them follow up with the same level of concern for making sure we can provide care and support for the millions of Americans with disabilities by supporting the Medicaid Community

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Attendant Services and Supports Act, which would allow people receiving Medicaid funding to have a life, not just stay to alive. We call on them to ensure continued appropriate funding of Medicaid and other programs that people need; and we look forward to the passage of the Family Opportunity Act, to allow families of children with significant disabilities to buy into Medicaid, to help their sons and daughters live at home in the community, not banished to a nursing home or institution.

Terri Schiavo’s case is every family’s nightmare. Disability doesn’t have to be a nightmare. Even if our nation disagrees on how we define compassion, we must certainly agree that all lives are equal under the law.

*This is an Op-Ed piece pending publication written by Steve Eidelman, Executive Director of The Arc and Steve Drake of Not Dead Yet.*

## Catholic Perspectives on Nutrition

**John Langan, S.J.**

What are we bound to do to preserve life in those who are suffering from grave illnesses or who have suffered devastating injuries? Human feeling and respect for human dignity require that we make strenuous efforts to help them. Common sense, medical experience and economic rationality suggest that these efforts will have to be limited. If care is to be limited, who is to decide where the limits are, and what is to be the basis for the decision? A key part of the Catholic response to these widely shared human dilemmas has been the distinction between ordinary and extraordinary means of preserving one’s life. Both for individuals who are able to make decisions for their own care and for surrogates and institutions who have to decide for others, the guiding norm has been that there is an obligation to take or to provide ordinary means for the maintenance of life and that there is not an obligation to employ extraordinary means. This, of course, cries out for interpretation and clarification...Just what counts as an ordinary means or extraordinary means? A medical procedure which puts this question in a direct and pressing form is artificial nutrition and hydration. On the one side, it seems to be perfectly ordinary to provide food and water to a sick patient. The denial of food and water seems to fall below the minimal standard of care which everyone should expect to receive. On

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## Catholic Perspectives on Nutrition

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the other side, the provision of food and water through a tube inserted in the body seems to be an extraordinary procedure which is used for patients whose bodies are no longer able to function in a normal way. It is associated in the minds of many with a mechanization of the body's functions and with the end of normal human life. Making the use of such procedures a matter of obligation seems to put an unnecessary and even futile burden on patients who are near death, even while it prolongs their survival. Not surprisingly, the existence of this polarity of interpretations led to divergent responses within the Catholic community, with bishops in different states coming out with contradictory views on whether there was or was not a moral obligation to provide nutrition and hydration.

John Paul II in an allocution in April 2004 came down on the affirmative side. He was focusing particularly on patients in a persistent vegetative state, and he was clearly urging caution in making and acting on judgments that

patients were beyond hope of recovery. His position should probably be seen as a valuable warning against the hasty removal of feeding tubes rather than as definitive teaching on a matter where both our knowledge and our ability to solve the problems of patients are likely to grow. It is worth remembering that as his own illness entered its last stage, John Paul II did not return to the hospital and received what was probably little more than palliative care. But his 2004 statement led many Catholic commentators and bishops to oppose the withdrawal of the feeding tube from Terri Schiavo. The results of the autopsy made it clear that the medical judgment that there was no point in further treatment was correct. What is not clear is how Benedict XVI will want to move the tradition forward.

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the withdrawal of artificial nutrition and hydration (ANH). Beginning with the case of Paul Brophy in Massachusetts in 1986, then Nancy Jobes in New Jersey, all the way to Nancy Cruzan to

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the US Supreme Court in 1990, over 10 landmark cases in various states have focused on the legal permissibility of withdrawing artificial feeding from a PVS patient. So Schiavo broke no new ground nor established any legal precedents not already well established in case and statutory law. The withdrawal of ANH from a PVS patient is well-established and settled law in many jurisdictions, including Florida with both case and statutory law for withdrawing this form of treatment from PVS patients.

The critical distinguishing feature of the Terri Schiavo dilemma which made this case so uniquely different from most of the others was the longstanding, acrimonious disagreement between Terri's parents and blood relatives, the Schindler family, and her husband, Michael Schiavo, over Terri's true neurological condition and the appropriate treatment or non-treatment based on this condition, and their interpretations of

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Terri's wishes. It should be noted that previous two major right to die cases in the US, Michael Martin in Michigan and Robert Wendland, both involved irreconcilable disputes between the families, more specifically in each case between the mother and the spouse. However, in Martin and Wendland, the patients were clearly conscious to some degree and thus in a minimally conscious state.

The other unique features of Schiavo were the battle of the videotapes, the extensive use of the internet by special interest groups and commentators, and eventually the unprecedented conflict between the proper roles of the executive and legislative branches of government and the judicial branches, both at the state and federal level.

In retrospect, however, throughout this seven year conflict over the removal of the feeding tube, from 1998 through 2005, there never was any doubt as to the neurological condition of Terri Schiavo, notwithstanding the feelings of the Schindler family and the videotapes apparently showing Terri interacting with her family. Of the eight board-certified neurologists who personally examined Terri, seven (four were consulting neurologists who cared for Terri from 1990 the time of the evidentiary hearing in October, 2002, and three neurologists who examined Terri and testified in court) said that Terri was in a permanent (persistent) vegetative state. The credentials and testimony of the other board-certified neurologist were thoroughly discredited by the trial court judge. In addition to the trial court judge, the three-person appeals court in Florida also

reviewed the opinions of the neurologists, the CT scans, and videotapes of the clinical examinations and strongly agreed with the conclusion of the trial court judge on Terri's neurological condition. It should be noted that the evidentiary hearing before the trial court judge, as mandated by the appeals court, was the longest, most extensive evidentiary hearing on a right to die case in the history of American law. Not only were there uncontroverted opinions from the neurologists at the evidentiary hearing, but the CT scans of Terri's brain showed extremely severe atrophy of the cerebral hemispheres (indicating irreversibility, and no chance whatsoever that Terri was a candidate for treatment or rehabilitation), and two EEGs which were flat (confirming that Terri was unconscious and thus in a vegetative state). The autopsy performed by the medical examiner of Pinellas County, the most complete and comprehensive autopsy and medical examiner's report in any right to die case in the US, showed unequivocal changes in the brain compatible with profound hypoxic-ischemic encephalopathy that correlated extremely well with the clinical diagnosis, and CT scans and EEGs. Terri's brain was so severely atrophied, it weighed only 615 grams, less than 50% of the weight of a normal brain and 25% less in weight than Karen Quinlan's brain. The autopsy findings were exactly what the neurologists had predicted Terri's brain would look like at autopsy, compatible with the clinical findings, the CT scans, and the EEGs and thoroughly undermined the testimony of those doctors who said Terri was conscious, and capable of improving or responding to treatment.

With respect to the concern of dis-

ability groups about this case, two major factors should be kept in mind. First, this case broke no new ground, nor set any precedent not already established previously in numerous right to die cases on neither the neurological condition of the patient nor the withdrawal of artificial nutrition and hydration. The opinions of the Florida judicial system were consistent with the consensus medical-legal-ethical standards of the last two decades—from the President's Commission on the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research of 1983, the Hastings Center report of 1986, the consensus statements of numerous national medical organizations, and the US Supreme Court decision in Cruzan in 1990.

Second, it is unfair to compare the permanent vegetative state to lesser degrees of neurological dysfunction, or disabilities, since the vegetative state is the most extreme neurological dysfunction possible, short of brain death.

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# Euthanasia and Disability: Comments on the Terry Schiavo Case

Hans S. Reinders

The decision to remove the feeding tube of Terri Schiavo and her subsequent death has stirred considerable debate in the US and abroad. For observers from abroad such as myself, the way Americans tend to cast hard cases in medical ethics is in terms of how they are — or ought to be — handled by the courts. It remains a significant difference between both continents that the intertwining of ethics and the law appears to be much stronger in the US than it is in Europe. Explanations of this observation, assuming there is some truth in it, must remain hypothetical. My own hypothesis would be that in the US “ethics” has come to be regarded as belonging to a particular group defined by — a mixture of — religious, cultural, or ethnic identity. More in particular in the US “bioethics” — probably even more than “medical ethics” — has come to be perceived as being deeply enmeshed in the culture wars that have been sweeping through the country in recent decades. On this hypothesis, the law suggests itself as the only viable alternative for the resolution of moral conflict.

From a theoretical perspective it would be interesting, in this respect, to revisit the various proposals for a philosophical grounding of the field, either defined as medical ethics or as bioethics, that have been published since the 1970s. If my observation regarding the public perception of “ethics” in America holds true, this suggests that these proposals have failed to be convincing insofar as the pacifying role and

consensus-building capacity that most of the authors attributed to it is in fact not functioning, which in turn accounts for the continuing prominence of moral arguments based on court decisions in American textbooks.

In the Schiavo case the failure of bioethics to provide moral guidance capable of transcending the boundaries of particular “moralities” is most conspicuous in the *Amicus Curiae Brief*

**If autonomous decision-making is the decisive issue in cases like this one, why do we need three instead of two bioethical models for decision-making?**

that a number of American colleagues submitted to the Supreme Court in the State of Florida on behalf of the plaintiff, Terri’s husband acting as her legal representative. Framing the issue exclusively as an issue of autonomous decision-making, without asking any further questions, these colleagues chose to represent only one perspective of the case. The fact that they claimed to present moral principles that “bioethics” has established, as if that were in any way a unified field with a body of authoritative knowledge, does not help to build the plausibility of their argument. Nor did the further fact that they identified themselves as being among the nation’s leading figures in bioethics help, because if there were a unified field called “bio-

ethics” with a well established body of knowledge from which such moral principles could be inferred, it would be irrelevant to know who represents it. As it stands, the self-congratulatory title of being leaders in the field only testifies to the implicit recognition of their partisan role in the conflict.

From the many questions to be raised I will raise only one, mainly for reasons of space, but also because of the other contributions to the present issue. Michael Schiavo decided to ask for an autopsy of his wife’s brain in order to find out which of the conflicting medical assessments of her condition was correct. It turned out that a large part of her brain was irreparably damaged such that the diagnosis PVS apparently had been the correct one. Question: does the condition of PVS warrant the decision of a life not worth living? I know, of course, that this question was circumvented by presenting Terri’s case as a case about autonomous decision-making regarding the right to refuse medical treatment. Presenting it as such made it necessary, first, to assume that using a feeding tube to feed someone amounts to a medical procedure. The assumption is discussed by Father Langan elsewhere in this issue, but my position is that it does not. Second, as a case of autonomous decision-making, it was necessary to rely on information by proxy about Terri’s will with regard to the question of discontinuing medical treatment in her condition.

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Appearance to the contrary, however, the Schiavo case does presuppose a judgment on whether Terri's life in a PVS was worth living. My argument for this claim concerns the basis of professional responsibility in medicine. In recent times it has been argued in the context of bioethics that in some cases death would be morally preferable to merely being alive. For someone who holds this view, there are clearly cases in which continuing to feed a patient by means of a feeding tube would not be considered to contribute to that patient's well-being. Presumably the case of Terri Schiavo would count as one of these cases.

What follows is that the concept of well-being and even the concept of health for that matter, has emerged as a contested concept. Public recognition of this fact has changed the moral nature of the professional relationship into a political one, because the question now is whose meaning is going to prevail in any given case. Contemporary bioethics has answered this question by establishing the rights of patients to refuse medical treatment. When a patient does not regard (the continuation) of a particular treatment to be contributing to her well-being as she regards it, she may refuse it. But this right is not absolute. The right to refuse medical treatment is limited by the condition that the patient is not acting against her own interest because of incompetence.

Competency, however, needs to be determined with regard to specific decisions. So, whether or not your right to refuse medical treatment will stand up

depends on what the doctor involved makes of your judgment in the decision at hand. In other words, doctors will only respect your right to refuse medical treatment in a given case when they think your decision does not harm your own interests, otherwise they will press for having you declared incompetent. What follows is that when doctors respect a patient's refusal as a matter of her right in a case where this will result

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in her death, this in fact presupposes that they tacitly accept her judgment. In this case, letting the patient die is not against her own interest.

Coming from a country that has some experience with these matters, I know for sure that in cases where patients declare they want to die, it still is the doctor's decision to accept their judgment as "reasonable." If a patient claims unbearable suffering and the doctor complies with the request for euthanasia, this necessarily implies that he has accepted her judgment. The reverse is also true, of course.

Even when we think that feeding a PVS patient with a tube is a medical procedure, then the underlying issue in Terri Schiavo's case is still not merely one of patient autonomy and the right to refuse the continuation of feeding her by tube, as the *Amicus Curiae Brief* of my

learned American colleagues suggests. The refusal must be assessed and the assessment must regard the judgment on which it is based. If it is accepted, it is accepted because the wish to be dead rather than to continue to live in a PVS is considered not to go against the patient's own interest.

Here is final proof for this claim from the *Brief* itself. If autonomous decision-making is the decisive issue in cases like this one, why do we need three instead of two bioethical models for decision-making? Only the models of *advanced directives* and *substituted judgment* regard the value of personal decision-making; the third one regards best interest, which implies that your proxy tells your doctor what she thinks about your condition because there is no way of knowing what you would have said about it.

"Bioethics" as represented by America's self-declared leading members of the field wants to be morally and legally justified in passing judgments on whether human life in Terri Schiavo's condition is worth living. I know a number of people living with a condition that in important respects is similar to hers, people with profound intellectual disabilities. I do not accept that it is in their best interest to die, so my understanding of bioethics must be different.

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