

The Ethics of End-of-Life Care:

Lessons to be Learned from the Schiavo Case

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Recently, five Creighton faculty members convened to discuss the case of Terri Schiavo. Or rather, to discuss what we may learn from that tragic case. For there is little point in commenting yet again on the particulars of this case. Too many people have already done so, some qualified, many not so qualified, and most without firsthand information about her case. It is time that we allow Terri to rest in peace and her family to mourn the loss.

There is much we can learn. Although the Schiavo case was unusually complicated in that many vexing ethical issues converged in that one case, each of those ethical issues occurs elsewhere with considerable frequency. Thousands of patients, families and caregivers throughout the U.S. are dealing with similar issues right now or will be soon.

Consider, first of all, Schiavo's medical condition: PVS or "persistent vegetative state." As Richard O'Brien, M.D., a colleague of mine in Creighton's Center for Health Policy and Ethics, points out, "This is truly a devastating diagnosis. PVS essentially means that the patient's cortex (or higher brain) has been destroyed, hence the synonym 'cortical death.' The patient is not dead because her brain stem is still intact. It keeps the 'vegetative' functions of the body operating, such as breathing, heart rhythm, digestion and the wake-sleep cycle. The patient even responds reflexively to stimuli, such as following objects moved in front of her eyes. But the part of the brain that enables higher functions, such as thinking and emotion, has been damaged beyond repair. Awakening from PVS after three months is exceedingly rare and after 24 months essentially nonexistent." (An autopsy on Schiavo found that she had massive and irreversible brain damage, and that her brain was about half of its expected size. "No amount of therapy or treatment," the autopsy report states, "would have regenerated the massive loss of neurons.")

Is a patient in a PVS terminally ill? Is she actually dying? As long as life-sustaining technologies such as artificial nutrition and, in some cases, ventilatory support are applied, death is not imminent. But neither is there a real



Photo by Andrew Mankovich

Welie ... the key question to ask is not, "Shall we stop treatment?" But rather, "Should we begin or continue it?"

chance of recovery. The patient continues to breathe and metabolize, but she will never again be able to pursue life's ends. Medical technologies have allowed us to maintain physical existence and stretch out the dying phase over many years.

That brings us to the second issue: What is the proper role of medical treatment and technology in the dying phase of life? In the latter half of the 20th century, at the very time that we had finally obtained the biomedical science and technology to cure most patients or at least help them survive life-threatening illness and traumas, something strange happened. Patients began to refuse those life-sustaining interventions. Initially, this was shocking news to many physicians. But we came to realize that life-sustaining medical treatments are a mixed blessing. There can come a point when the burdens of such treatments outweigh the benefits. Instead of healing the patient, they harm her. The tricky question in all of this is: "When exactly does this happen? When does medical treatment become harmful to patients?" There is no simple answer, and there is

unlikely ever to be one. For as new treatments and technologies are invented, the same question will recur.

But the ethical literature provides some helpful conceptual tools. One dates back to ancient medical ethics, another to Catholic health care ethics. Ancient physicians were already aware of the fact that medical interventions may be harmful. They admonished their colleagues first and foremost to do no harm, to abstain when benefits are unclear, and not to treat when the patient is overmastered by disease. Today, we would say that treatment must be "medically indicated" before it is commenced or continued. In other words, physicians need scientific and clinical evidence that a particular intervention is likely to benefit the patient before they can recommend it to the patient. For example, if an infection is caused by a virus rather than a bacterium, penicillin will not work. Penicillin is not indicated, and hence should not be started. Likewise, if the reasons that originally motivated treatment no longer apply, the treatment should be discontinued. If

chemotherapy turns out not to shrink the tumor, it would be wrong for a physician to continue that intervention. Even if the patient were to insist on it, physicians may never do things to patients they cannot justify on sound scientific grounds.

One of the problems in cases such as the Schiavo case is that we ask the wrong question. Imagine you visit your doctor's office because of a persistent cough. The physician examines you and then tells you: "I am going to do lung surgery." This is certainly not what you expected her to say. So you respond: "Surgery? Why surgery?" But now the physician appears perplexed and answers: "Why not? Why should I not do surgery?" So you say, "I don't know; I am not a doctor." To which she replies: "Well if there is no reason to forgo surgery, we may as well begin." This would be a strange and perplexing conversation indeed. For you rightfully expected the physician to explain why and how lung surgery will help. Whenever physicians want to initiate treatment, they must have good reasons

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to do so. Without such a "medical indication" physicians should not treat.

So the key question to be asked is not: "Shall we stop treatment?" The key question is: "Shall we begin it?" Or if it has already begun: "Shall we continue it?" The burden of proof is always on the person who wants to begin or continue medical treatment; that person must justify the treatment. This rule applies to all medical interventions, including life-sustaining interventions. A physician may propose dialysis only if she has good reason to believe that dialysis will be an effective remedy. A physician should only resuscitate a patient whose heart has stopped beating if she has good reason to believe that CPR (cardio-pulmonary resuscitation) will benefit the patient. It may come as a shock to avid *ER* fans, but in many cases CPR is not an effective and beneficial intervention. The success statistics for the hospitalized patient whose heart stops beating and is then resuscitated are actually rather poor.

Some may wonder whether this is really an important issue. Why does it matter which question is asked? By asking the

wrong question, we become hostages of medical treatments and technologies. We begin to think that it is normal and natural for people to be hooked up to machines and to undergo multiple diagnostic and therapeutic interventions. Do we really want physicians to do anything and everything they can possibly do to us unless and until somebody can prove that they should stop? There is wisdom in the old medical-ethical rule: *In dubio abstinere*, when in doubt, abstain.

The second ethical tool comes to us from Catholic medical ethics, the so-called “ordinary vs. extraordinary” distinction. John Carlson, Ph.D., professor and chair of the Department of Philosophy at Creighton, explains that “Catholic moral doctrine has

always underscored the sanctity of human life, indeed of all of human life, including frail, sick and disabled persons. Each of us is individually responsible to be a good steward of our own life, and as a community we are charged to respect and protect the lives of our fellow men. However, the Church also acknowledges that good stewardship does not require that we use every possible medical treatment and technology to extend life. The Vatican Declaration on Euthanasia from 1980 underscores that we are morally required to use all ‘ordinary’ means but may forgo ‘extraordinary’ means.”

It should be emphasized that the word “ordinary” does not at all mean “common,” “routine” or “normal.” Rather, what is ordinary or

extraordinary treatment must always be determined in reference to the individual patient while considering his or her unique situation. For example, antibiotics may be perfectly ordinary for most patients, but maybe not for Mr. Jones, who is 96 years old and suffering from advanced dementia, kidney failure and an unhealed broken hip. Artificial nutrition may be perfectly ordinary for a patient who underwent abdominal surgery and whose intestines need a break from digesting food. On the other hand, it may not be ordinary for a patient who is dying.

“In fact, it may become too burdensome physically for a dying patient,” cautions Amy Haddad, Ph.D., professor and director of the Center for

A Legal Look at End-of-Life Issues

How can you prepare for the end of life?

Julia Belian, JD, assistant professor of law, encourages people to write down their wishes regarding end-of-life medical care, including any specific instructions to caregivers, as well as who should enforce those instructions.

In all 50 states, such documents — also called advance directives — are legally binding. These directives only take effect when you cannot express your wishes yourself anymore (e.g., because you are in a coma). Belian offers these tips:



Photo by Andrew Marinovich

Belian ... advance directives are legally binding in all 50 states.

- ✓ Be as precise as possible; try to avoid vague language that caregivers and family members will have difficulty interpreting.
- ✓ Know your options under the law. Most of us forget we live in a federalist system with 50 sovereign states, and each has the potential to handle things somewhat differently, including advance directives. However, in all states, such directives can take one of three forms:
 1. A specific description of your wishes for end-of-life care. This document is generally called a “living will,” but is known by different legal names in different states. Most of these state laws do not protect your written wishes about medical care in general, but only what medical care you are willing to accept when you are nearing death.
 2. A document in which you grant some other person the authority to make health care decisions on your behalf. These “power of attorney for health care” documents cover all situations (including end-of-life care situations) in which you cannot

- decide for yourself and need somebody else to make health care decisions for you.
- 3. It is also possible to issue both, or a combination of the former two documents. For example, you can grant a family member the power of attorney to make decisions on your behalf, but also specify what kinds of medical care you would (not) want to undergo.
- ✓ Share your directives. Provide copies to all health-care providers who might need them, to all persons named as decision-makers, and to all other family members or close friends who should know about their existence. Advance directives that are safely stored away are simply useless.

Although most state laws do not require that an advance directive be written by a lawyer, Belian says working with a lawyer is probably the most reliable way to make sure that your document will be legally effective. Second choice is to complete a form familiar to your doctor or health care system. Most hospitals have forms. Belian least favors documents provided by web-based companies.

Health Policy and Ethics. “Dying patients rarely feel hunger or thirst like healthy people. They don’t suffer discomfort as a result of dehydration. Rather, forcing food and fluids into dying patients may make them feel very uncomfortable once their organ systems are shutting down. Of course, this does not mean that if a competent dying patient asked for water or food, we would refuse his request. The intent here should be to alleviate the patient’s discomfort.”

How case-specific the ordinary-extraordinary distinction really is becomes clear from an example provided by Julia Fleming, Ph.D., associate professor of theology.




“The distinction actually predates modern medical technologies, for it was articulated in the 16th century. A 17th century Jesuit theologian provided this example of a potentially life-saving treatment that a patient could choose to forgo. Suppose that, for the sake of her good name, a virgin felt it necessary never to submit to a medical examination conducted by a man. Even if she were suffering from a life-threatening illness, such a medical examination would be unduly burdensome, and hence, not required, for that woman.”

We should not mistake the ordinary-extraordinary distinction for the modern right to refuse treatment. The 17th century physician in the previous example was not morally obligated to forgo treatment because the woman exercised her right to refuse even beneficial medical treatment. Rather, the treatment itself was no longer in her best interests because its benefits were outweighed by its burdens.

Unfortunately, modern medical ethics frequently makes this mistake. When the question arises whether antibiotics, ventilation or artificial nutrition is still indicated and ordinary, we are tempted to turn to the patient or his family members and say, “Well, you decide.” The same happened in the Schiavo case. Instead of focusing on the question whether the various medical interventions were benefiting Schiavo, the courts zoomed-in on the question, “Was there any evidence that she would

High-Profile ‘Right to Die’ Court Battles

Several court battles have shaped living will legislation since Karen Ann Quinlan’s parents fought the first right-to-die case in 1976. Three high-profile cases in which families fought court battles to take loved ones off life support and the legislative results that followed:

YEAR	RULING	RESULT
 Quinlan	1976 New Jersey Supreme Court ruled Karen Ann Quinlan’s parents had the right to remove her from life support. She had been in a coma for six years.	Many states passed laws recognizing living wills as legal documents.
 Cruzan	1990 Nancy Cruzan of Missouri was fed through a tube for seven years until the Supreme Court ruled in 1990 that it could be removed.	Congress passed law requiring hospitals to tell patients about state laws on living wills.
 Schiavo	2004 Florida Supreme Court struck down a law that reconnected the feeding tube of Terri Schiavo in a battle between her husband and parents.	Variety of actions in state legislatures are trying to beef up living will laws.
	2005 Supreme Court refused to step in to keep Schiavo hooked to a feeding tube.	

Source: AP Worldwide

have consented to or rather refused these interventions?” That is an important question, but it should be asked only *after* it has been decided that the interventions will benefit the patient.

Most assuredly, in order to determine what will benefit the patient, we have to consider the individual patient herself. That is exactly what the “ordinary-extraordinary” distinction requires. And nobody is a better source of information than the patient herself. So we need to engage the patient in the discussion. But the core questions are not: “Do you want treatment X — yes or no?” and “Is the patient competent to make such a decision? If not, who is legally authorized to consent to treatment?” Rather, the core questions are: “Who is this patient? How is her life broken and can we heal it? What are the patient’s expectations and goals, and can medical treatment realistically help her reach those? Does the patient have the physical and psychological resources to

bear the burdens of the treatment?”

Another frequent mistake results from medicine’s super-specialization. Such specialization, of course, has evident value but also carries risks. By focusing on one organ or organ part, and on one intervention at a time, we often lose sight of the whole picture. We forget that the patient is really undergoing all of these interventions at the same time. Consider again the example of a patient in PVS. The debates in Schiavo’s case focused on the artificial nutrition only, as if this was the only treatment she was undergoing.

But as Creighton’s Haddad reminds us, “These patients are not mobile but lie in bed all day. For example, they can quickly develop very persistent pressure ulcers that require extensive nursing care. Muscles contract and become atrophic, necessitating intensive physical therapy. And all of this is complicated by the fact that the patient cannot herself cooperate in any way in her own healing process.

Decision-Making and Families

Health professionals often reach a decision about the appropriateness of withdrawing useless or overly burdensome treatment before family members do, according to professor Amy Haddad, Ph.D., BSN'75, director of Creighton's Center for Health Policy and Ethics.

"The trajectory of illness or injury is not obvious to family members, and so it takes more time for them to appreciate that a treatment is futile or provides no benefit or that the benefits are outweighed by burdens to the patient," Haddad said.

She added that explanations about the course of the patient's pathology should be in terms that the family can understand and delivered in an unhurried, compassionate manner.

"There should be time for questions and repetition," Haddad said.

"Decisions to withhold or withdraw treatment are not routine for families, even if they may be for health professionals. Every consideration should be given to help mitigate the anguish families go through when deciding for a loved one who can no longer actively participate in decision-making."



Photo by Andrew Marinovich

Haddad ... health care professionals need to better explain to family members the stages of a loved one's disease and care options available.

We really need to make a continuous effort to focus on the patient as a whole person as opposed to a collection of organs, a patient with her own life story, a patient in context."

And here we find the third cause that rendered the Schiavo case so vexing: Nutrition and hydration are very context-specific terms.

"From a biomedical perspective, there really is no difference between artificial ventilation and artificial nutrition," O'Brien explains. "Both mechanically transport molecules into the body that are needed for our body to keep functioning. In the case of ventilation, it's oxygen; in the case of nutrition, it's proteins, carbohydrates and the like. Once inside, the body (respectively the lungs and the digestive tract) absorbs and processes those molecules. And yet, most people have far fewer ethical qualms about removal of a ventilator (as opposed to artificial nutrition)."

Why is this? The difference lies in the fact that food and drink — but not air — have very important social connotations. For example, when we share a meal with a patient or bring her a cup of freshly brewed coffee, we do so not only because we are trying to keep that person alive. Rather, the meal is a nonverbal way of communicating, a special way of being together, of expressing care and love. Yet it is precisely this value-added meaning that is lost when we switch to artificial nutrition and hydration. Some ethicists believe that this loss is not decisive, concluding that artificial nutrition is ethically analogous to regular feeding. Others think the loss is decisive, concluding that artificial nutrition is analogous to artificial ventilation instead. This issue is not likely to be settled soon.

In the meantime, we will all continue to grow old, fall ill and ultimately die.

"From a Christian perspective, death is inevitable, but it is not the end," Fleming reminds patients, family members and health care professionals. "Death is indeed an evil to be struggled against, but death is not the ultimate evil."

Indeed, letting go is not euthanasia. Euthanasia (and likewise physician-assisted suicide) requires that we want

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the other person to die, and we direct our actions toward that person's death. If a patient begs his physician to help him die, and the physician next injects a very large and lethal overdose of pain killers, there are only two possible conclusions: Either the physician is incompetent and does not know how to treat pain, or she committed euthanasia. On the other hand, if family members and caregivers jointly come to the conclusion that available medical treatments cannot heal our 96-year-old Mr. Jones; that these treatments add to, instead of relieve, the burden for the patient; that the various monitors and machines are now infringing on, instead of supporting, the patient's intrinsic and inviolable dignity; in short, when they find that it is time to let go, their discontinuing these medical interventions is not euthanasia.

There is a time to act vigorously to protect and extend human life, all human life. And there is a time to let go. ©

A Natural Means of Preserving Life?

By John W. Carlson, Ph.D.

Professor of Philosophy

Few issues have roiled the waters of Catholic biomedical ethics like the debate over medically delivered nutrition and hydration for patients in persistent vegetative (and similar) states. This issue has produced opposing positions among academics, medical professionals, and even bishops. It involves questions about both the interpretation of Church teachings and the application of these teachings to difficult cases. Classical starting points for the debate include a 1957 allocution by Pope Pius XII on “ordinary” vs. “extraordinary” means of maintaining life, and the Congregation for the Doctrine of the Faith’s 1980 document, *Iura et Bona*, on euthanasia and related matters. Pope John Paul II made several contributions to the discussion, the most famous coming in a 2004 address to a Vatican conference on this very issue.

Briefly, the Church’s pertinent moral teachings can be summarized as follows. Euthanasia, defined in *Iura et Bona* as “an act or omission that of its nature or by intention causes death” (i.e., the death of a patient), is never to be morally approved. However, some cases in which a patient is allowed to die can be seen, not as euthanasia by omission, but rather as justifiable decisions to discontinue — or not to begin — modes of treatment that constitute “extraordinary means.” The term “extraordinary” is defined by contrast with

“ordinary,” the latter applying to means of preserving life that satisfy two criteria: First, they offer a reasonable hope of benefit to the patient (considered as a whole individual). Second, they involve no excessive or disproportionate burden, in particular to the patient.

Interpretive controversy arises about the fuller articulation of “benefit” and about how it is to be determined whether a treatment’s burden is truly disproportionate. In the present type of case, a special question arises: whether continued biological life with no realistic possibility of cognitive awareness is to be regarded as a benefit, or a sufficient benefit, to fall under the standard teaching. But it also has been asked whether some medically delivered forms of sustenance are, so to speak, ordinary by their very nature, and thus, when medically necessary for continued life, always to be used.

In his 2004 address, John Paul II surprised many by seeming to side with those who answer the last question in the affirmative: “The administration of food and water, even when provided by artificial means, always represents a *natural means* of preserving life.” Moreover, its use “should be considered, in principle, *ordinary* and *proportionate*, and as such morally obligatory. ...” (Emphasis in original.)

Some commentators — e.g., Vatican Bishop Elio Sgreccia, and the Boston-

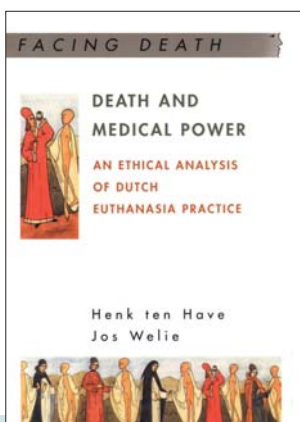


Photo by Andrew Marnkovich

Carlson ... the Church recognizes that in some cases a patient should be allowed to die.

based National Catholic Bioethics Center — regard the issue as now definitively resolved: If nutrients and fluids can be assimilated by the body, their provision is absolutely required. Other trusted commentators — e.g., Kevin O’Rourke, O.P., now of the medical center at Loyola of Chicago, and John Paris, S.J., a bioethicist at Boston College — disagree. My own view is that John Paul’s remarks are best read in the context of his call for building a “culture of life.” The phrase “in principle” in the previous quote indicates that the pope was not propounding a moral absolute; rather, he was pleading with societies to make it economically and psychologically feasible for patients and families to choose life even in *extremis*.

About the author: Carlson’s academic specialties are biomedical ethics and public policy and thought of Pope John Paul II.



About the author: Welie, a native of the Netherlands who joined Creighton in 1997, has studied the ethics of end-of-life care for many years. His most recent book is titled Death and Medical Power: An Ethical Analysis of Dutch Euthanasia Practice (Open University Press 2005). This volume is co-authored with Henk ten Have, M.D., Ph.D., a former senior visiting fellow at Creighton’s Center for Health Policy and Ethics and current director of the Division of Ethics of Science and Technology at the United Nations Educational Scientific and

Cultural Organization (UNESCO). Later this year, the second edition of Welie’s Educational Guide on End-of-Life Care Law and Public Policy in Nebraska will be published by the Nebraska Coalition for Compassionate Care. Readers interested in the “ordinary-extraordinary” distinction may want to obtain a copy of the autumn issue of The National Catholic Bioethics Quarterly, which will be devoted to this very topic and contain an article by Welie.