

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. ©