Will More Patients Sign Advance Directives Post-Schiavo?*

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The national debate about Terri Schiavo’s wishes that raged in 2004 and early 2005 in the media, various state and federal courts, the Florida legislature and the U.S. Congress would most likely never have occurred had Ms. Schiavo executed appropriate advance directives. Her failure to have these documents in place was not unusual, however. Surveys indicate that, while many individuals believe in the value of advance directives (or living wills), the majority of Americans have not actually signed a living will or other advance directive,¹ leaving health care providers to determine a patient’s wishes only from discussion with family members.

In Ms. Schiavo’s case, the central issue was deciding whether Ms. Schiavo wished to be kept alive by artificial nutrition and hydration. The legal issues posed by this aspect of the Schiavo case are not particularly novel. Several court cases have upheld a patient’s refusal to consent to allegedly necessary life-saving treatment. However, when a person lacks capacity to consent to (or refuse) medical treatment, most states have statutes appointing a hierarchical list of relatives as decision-makers for the patient.² Although spouses are usually first in any hierarchy, their decisions may be challenged by relatives lower in the hierarchy (such as parents of a patient). In all cases, the law does not seek to make the “best decision” for the patient who lacks capacity, but rather seeks to determine what the incompetent person would decide if he or she were competent.

An individual who wishes to express his or her own wishes can do so by executing a so-called “advance directive” or “living will.” The rise in popularity of these documents can be traced to a U.S. Supreme Court case decided in 1990.³ The Cruzan case addressed the evidentiary standard required to prove a patient’s wishes expressed while the patient was competent. Nancy Beth Cruzan was injured in an automobile accident on January 11,

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¹ Estimates of the number of Americans who have signed advance directives vary widely. One article cited surveys by the American Association of Retired Persons and the National Council on Aging that indicate 70 to 80 percent of those groups’ members “favor” having living wills. The article also says that 80 percent of Death with Dignity National Center’s members have some form of advance directives. See Michael Gougis, Living Will Lets Cancer Patient Avoid Agony, LOS ANGELES DAILY NEWS, Nov. 2, 2003, available at http://www.dwd.org/fss/news/ladn.11.01.03.asp. In 2005, Kathy Brandt, vice president for the National Hospice and Palliative Care Organization, said that between 25 and 40 percent of Americans have a living will. See Robin Rupli, Living Wills: Everyone Ought to Have One (Mar. 2005), available at http://www.voa.org/english/AmericanLife/2005-03-24-voa73.cfm. Other estimates have been much lower. For example, one study of terminally ill patients found that less than 15 percent had executed any form of advance directive while another study of the population at large found that less than 10 percent had executed a living will. See T Gallanis, Write and Wrong: Rethinking the Way Health Care Decisions are Communicated, 31 Conn. L. Rev. 1015, 1026 (1998).


She was found in a ditch without detectable respiratory or cardiac function, but the paramedics were able to restore her breathing and heartbeat and transported her to a hospital. Her neurosurgeon diagnosed a cerebral contusion complicated by lack of oxygen (anoxia). She progressed to an unconscious state and a gastrostomy feeding and hydration tube was implanted. She remained for eight years in a persistent vegetative state with motor reflexes but almost no cognitive function. However, because she was not otherwise terminally ill, experts predicted that she could live another 30 years.

Ms. Cruzan’s parents obtained a court order to have nutrition and hydration withdrawn, but the Missouri Supreme Court reversed the lower court, holding that there was no “clear and convincing” evidence that Ms. Cruzan would have wanted life-sustaining treatment withdrawn. On appeal, the U.S. Supreme Court affirmed the Missouri Supreme Court and held that the U.S. Constitution does not forbid the “clear and convincing” evidence standard required under Missouri law.

As a result of the Cruzan case, mechanisms for documenting choices about terminating life-sustaining treatment became popular. Numerous states enacted statutes that provided for advance medical directives, including living wills and durable powers of attorney for health care. The U.S. Congress responded by passing The Patient Self-Determination Act of 1990, which requires hospitals to furnish information to patients regarding advance medical directives, institutional protocols, and current state laws. Hospitals must specifically provide information describing a patient’s right to refuse medical treatment in accordance with state law and, after providing the required information, must document whether the patient has executed an advance directive.

All 50 states currently have some form of a living will statute, which allows competent individuals to exercise their right to refuse health care even if they subsequently become incompetent. Most, if not all, states also have statutes that provide for execution of a durable power of attorney for health care as an alternative to, or in addition to, a living will. With a durable power of attorney for health care, an individual may appoint an agent or “proxy” to make decisions about medical treatment on his or her behalf. Even if an individual has a living will, appointing a proxy may be advisable because a living will may not anticipate every possible medical decision required. Most states have standardized forms for living wills and durable powers of attorney. Individuals may complete and sign the forms on their own, or may seek counsel from an attorney or health care provider.

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4 Id. at 2845.
5 Id.
6 Id.
7 Id. at note 1.
8 Id.
9 Id. at 2846.
10 Id. at 2854.
13 Id.
The public bioethics debate surrounding the Schiavo case may create more interest in advance directives, but barriers remain. Few of us are comfortable with contemplating our eventual death, and fewer still are comfortable discussing the issue with others. Physicians can and should play a unique role in such discussions. As an attorney, I would much prefer discussing advance directives with a physician than an attorney. State statutes often distinguish between “irreversible” and “terminal” conditions in their advance directives’ statutes. For example, a typical form requires individuals to state separately whether they wish to have life-sustaining treatments withdrawn (or continued) depending on whether their condition is “irreversible” or “terminal.” These distinctions may be confusing to many patients, and physicians can help patients understand the choices they are making. Many statutes also distinguish artificial nutrition and hydration from other forms of life-sustaining medical treatment, requiring similarly difficult choices for individuals executing advance directives. Patients need to understand that they may easily revoke advance directives at any time as long as they are able to speak for themselves. On a practical level, a physician can easily initiate a discussion of advance directives during a routine office visit simply by asking a patient whether he or she has a living will. If the patient has executed any advance directives, copies need to be included in the patient’s medical record. If not, the physician’s question may provoke discussion of the issue.

*A version of this article was originally published in the May 2005 edition of Internal Medicine World Report and is reprinted with permission.

15 Id.
16 Id.