

DOVER POST

Health

What if I can't decide for myself?

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What you need to know about making

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Lifestyles editor

With the story of Terri Schiavo topping front pages and heading up broadcasts for the last couple of weeks, the rights of those medically unable to speak for themselves and the debate over who determines their fate have become the stuff of dinner table conversation.

In the midst of exhaustive coverage, the case has raised a topic that needs to be discussed at everyone's family dinner table: the matter of advance directives, more popularly called living wills.

"What we don't want to see is conflict as with the Schiavo case," said Tim Hoyle, the state's long term care ombudsman with the Division of Services for Aging and Adults with Physical Disabilities, whose office serves as impartial witness to about 150 advance directives a year made in the state's long-term care facilities.

"We encourage anybody in a long term care facility — or outside one — to make an advance directive. It lets everybody know what your intentions are. If there was an advance directive [in the Schiavo case], everyone would understand what Miss Schiavo wanted. Because she didn't have that in black and white, there is controversy," Hoyle said.

To help people avoid that situation, we asked Hoyle, along with two Dover attorneys whose offices handle advance directives as part of estate planning services — Glenn Hitchens of Morris, James, Hitchens & Williams, and Edward McNamara of Barros, McNamara, Malkiewicz & Taylor — for an overview of how advance directives are made and some of the options to consider.

What is a 'living will' and how binding is it?

"The term 'living will' is a misnomer. It's not about living at all. It's



about dying,” Hitchens said.

“The document is designed to be followed during one’s lifetime.”

In short, a living will, or advance directive, is a signed and witnessed legal document stating a person’s specific wishes regarding medical treatment should he or she be medically certified incapable of voicing his or her own decisions.

In Delaware, the advance directive is a simple form developed by the Delaware Bar Association which combines the naming of a person to serve as your medical power of attorney — a good idea, since it allows your representative to review your medical records and confer freely with your doctors about your care — with a statement of what medical techniques you do and do not want used in the event you cannot speak for yourself, Hoyle said.

A patient who remains competent and capable of voicing his or her own opinions is not bound by what is stated in his or her advance directive and may change it at any time, Hoyle said.

“An advance directive is a pretty solid document that’s going to protect you and protect your rights,” he continued, although the document can be challenged in court. “But it really is a blanket of protection. Most people back off when they see an advance directive. They understand it’s something they respect.”

Who should have an advance directive

McNamara is direct: without exception. “Everybody should have one,” he said.

The reason is just as simple: nobody likes to think about death — or worse, about being in a situation where someone must decide life-and-death matters for them, but anyone can be in an accident or suffer some other health cataclysm that will take the decisions out of their hands.

“A lot of younger people are not thinking about wills. That’s just not on their radar screen,” Hoyle said. “If you don’t want to make one, make sure your family understands your wishes,” he continued, adding you also must understand they are not legally bound to honor them.

“Let your family know and let them know in writing, so you don’t have courts making those decisions, because that’s not who should be making those kinds of decisions,” Hitchens said, noting that a person in a coma or other permanently uncommunicative state with no written wishes is a sure-fire recipe for family conflict as in the Schiavo case.

“This is a simple thing you can do to protect your rights, and I think it’s something we have an obligation to do to take the stress off our families,” Hoyle added.

Delaware law is similar to most states in terms of what happens in cases where a patient has been medically certified incapable of making his or her own decisions and has no advance directive: the surviving spouse is first in line legally to determine the patient’s care, Hoyle said.

If there is no spouse, adult children, parents and adult brothers or sisters are next, in that order — and the wishes of the person named by law are the ones that count, as in the Schiavo case.

How do I create an advance directive?

Creating an advance directive is simple, and can be done with or without an attorney. In making one, Hoyle, Hitchens and McNamara encourage people to first sit down and talk about their feelings and wishes with their families.

“Tell the kids how you feel about it. If you don’t, they might [try to] obstruct your wishes,” McNamara said, though having a document in place — and accessible when needed — gives a patient strong legal standing for his or her wishes being followed.

The next step is to visit your attorney or get a copy of Delaware’s advance directive for health care, fill it out and have it properly signed and witnessed.

To make it legal, the form must be made by a competent adult and signed by two witnesses age 18 or older who must not be: related to you by blood, marriage or adoption; directly responsible for your health care; an owner, operator or employee of a residential long-term health care institution in which you reside; or entitled to any portion of your estate. Witnesses also may not have a claim to any portion of your estate.

What’s on the form?

First, the form asks you to designate a person and two alternates who will hold medical power of attorney for you in the event you are unable to make your own decisions. Medical power of attorney is often given to a spouse, son or daughter or other close relative, Hoyle said.

Next, it lays down specific instructions for what you want done or not done if you are in a terminal condition or are permanently unconscious, which must be certified in writing by your attending

physician and one other physician.

In Delaware, terminal is defined as a illness or condition for which there is no reasonable hope of recovery and which will result in death regardless of the use or discontinuance of life-sustaining procedures; permanent unconsciousness (also known as persistent vegetative state or PVS) is defined as the total and irreversible loss of consciousness and capacity of interaction with your environment for at least four weeks.

Under each set of circumstances, the form asks if you want nutrition and hydration through a conduit (generally an IV or feeding tube), cardiopulmonary resuscitation (CPR) or mechanical respiration used to prolong your life. It also asks about the use of pain medications and other medical instructions, as well as the details of whether or not you want to be an organ donor.

At issue in the Schiavo case is the matter of nutrition and hydration. “Some say no. Some say give me water. Some say, yeah, I want both of them,” McNamara said. “Some say, ‘If I’m dying let me go.’”

Similarly, Hitchens said, some people don’t want CPR used; others specify it can be used only once. Pain relief is a given, he added, unless the patient specifically says no.

The form does not cover some specifics people may want to include, such as surgery, transplants, dialysis, specific uses of a respirator or ventilator and use of medications other than those for pain, such as antibiotics. Use of heroic measures — defined by Hitchens as measures greater than required or called for under the circumstances — also may be addressed.

“[The form] is sufficient in most cases, but it doesn’t cover all the details,” McNamara said.

What should I do with my advance directive?

Give a copy to your family physician and close family members who need to know about it. Also keep one in a safe but accessible place — not a safety deposit box or other storage space that may be inaccessible without you when the document is needed.

Some people put a copy of their living will in the glove box of the car with their insurance card, McNamara said.

Pressure to “pull the plug?”

“An advance directive doesn’t come into play until after the dust has

settled,” Hitchens said. “It’s not an emergency room or an EMT situation at all.”

For an advance directive to take effect, a patient must be certified in writing by two doctors to be either terminal or permanently unconscious for at least four weeks, and incapable of voicing his or her own decisions, Hoyle said.

“Some people ask, ‘How do I know a doctor will adhere to my advance directive?’ They won’t if nothing is in writing,” Hitchens added.

Where can I get a copy of form?

Call the office of the long-term care ombudsman in the Division of Services for Aging and Adults with Physical Disabilities at 800-233-9074 or visit www.dsaapd.com.

Other useful organizations include: The National Hospice & Palliative Care Organization at www.nhpco.org, and Virginia-based Caring Connections at 800-658-8898, www.caringinfo.org.



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