



Get It in Writing!

Advance directives give you control over your health care.

BY LISA PHILLIPS

As Cathy Riechers prepared to start a new drug regimen to treat her multiple sclerosis (MS) five years ago, she knew it was time to finalize a living will—a written document stating her end-of-life health care wishes.

One of the rare possible side effects of natalizumab, her new MS medication, was progressive multifocal leukoencephalopathy (PML), which is a debilitating and potentially fatal brain infection. Riechers, 46, worried that if she were to become unable to express her health care wishes, some of her family members “might not have my best interests at heart,” she says. In other words, they might not be capable emotionally of letting her go.

Using forms available on the Internet for Wisconsin, her home state, Riechers made a living will. She also completed a document giving her husband durable power of attorney, meaning that he would make decisions about her care if she were to become incapacitated. “I was so concerned that my family would interfere that I actually had it notarized by four people, even though I was only required to have two,” she says.

WHAT'S THE FUSS ABOUT?

Advance health care directives hit the news this summer as part of the debate over health care reform. Reform critics attacked a provision in a pending U.S. House of Representatives health care measure to reimburse doctors for end-of-life care discussions with Medicare patients, with rumors that the measure would encourage elderly Americans to end their lives sooner.

Under the measure, end-of-life care discussions would be optional, and the provision does not specify how doctors should advise their patients.

Lost in the political fray is the importance of making your end-of-life health care choices, whatever they may be, known to your family members, doc-



tors, and other loved ones, says Michael A. Williams, M.D., the medical director of the Sandra and Malcolm Berman Brain & Spine Institute in Baltimore, MD, and the past-chair of the Ethics, Law and Humanities Committee of the American Academy of Neurology (AAN).

“A living will is a way for patients to say what they want done if they aren't able to speak for themselves,” he says. “The common perception is that a living will only states the measures you don't want. But a living will can capture whatever a patient wants. Some say they want all life-sustaining measures. Others say, if I reach a certain condition and the prognosis is poor, it's time to stop.”

While living wills, durable power of attorney, and other types of advance health care directives can benefit everyone, they're particularly important for people with degenerative neurological conditions, notes James Bernat, M.D., a professor of neurology and medicine at Dartmouth Medical School and the director of the program in medical ethics at Dartmouth-Hitchcock Medical Center.

“Someone with Alzheimer's disease in an early stage can execute an advance

directive in anticipation of the expected deterioration in his neurological condition,” he says. “Three years later, after he's demented, his doctors and the person he named as his durable power of attorney can follow his treatment wishes.”

An advance directive can lift a big weight off the shoulders of family members who may struggle to make the right end-of-life care choices for you, says Murray Sagsveen, general counsel for the AAN.

“The advance directive is designed for the author of the advanced directive and the author's family,” Sagsveen explains. “If a family has to decide without guidance whether to withdraw life support or withdraw nutrition or hydration, it may generate a huge amount of reluctance or family feuding. But if a family has an advanced directive or living will that provides guidance, it takes away pressure and possibility of infighting.”

Without an advance directive, family and loved ones may feel tremendous guilt about the choices they make for the patient, however well considered. “If they don't have the direction, their decision to limit or stop treatment can feel like they're giving up or stopping,” Dr.

Williams says. “Although such decisions are always difficult, they’re often easier if the family knows they’re choosing what the patient would want.”

KNOW THE JARGON AND THE LAW

As you begin to make choices about your end-of-life care, you’ll want to be familiar with several terms.

Advance directive is the general term for any document that gives directions about your health care when you can no longer express them yourself. Types of advance directives include a **living will**, which is a statement of your end-of-life preferences, and a **durable power of attorney for health care**, which authorizes the person of your choice to make decisions for you when a doctor determines you can’t make decisions for yourself. This person is also called a **health care agent** or **proxy**.

Federal law requires most hospitals, nursing homes, and home health agencies to provide information about advance directives during the admission process.

However, laws covering advance directives vary from state to state, and the array of advance directive forms online can be confusing. A good place to start is the National Hospice and Palliative Care Organization Web site’s list of advance directives by state: caringinfo.org/stateaddownload. (See box, “More Advance Directive Resources,” for

additional options. Also see Resource Central, page 37.)

Some states combine the health care proxy form and the living will into one document, while others keep them separate. Some living wills are in checklist form, asking you to indicate your preferences on the use of feeding tubes, resuscitation, organ donation, and other end-of-life issues. You can add any additional instructions or concerns at the end. Some states give you the option of adding end-of-life care instructions as part of a health care proxy form.

You generally don’t need a lawyer to file an advance directive, but you will likely need at least two witnesses to sign your forms. Your health care proxy and alternate, if you choose one, must agree to the role and sign the form.

It’s also important to distribute copies of your advance directive to your doctor, your attorney, and any other family members or close friends you choose. Keep a copy in your wallet or purse and in a safe place at home. Bring a copy if you are admitted to the hospital, even for minor surgery, or if you undergo outpatient surgery.

It is possible for you to change or cancel your advance directive at any time, as long as you are considered of sound

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mind—meaning are able to think rationally and express your wishes clearly. Changes must be implemented, signed, and notarized

according to your state laws, and don’t forget to inform your doctor and family members who know about your directives that you made changes.

Sagsveen, AAN general counsel, advises people to avoid choosing their parents as health care proxies. “Elderly parents have enough on their plate,” he says. “I urge horizontal proxies, such as spouses or siblings, or children as proxies, not parents.”

Choosing a health care proxy when completing an advance directive should take first priority, because living wills can be limited in practice, says Dr. Bernat. “You can’t fully anticipate everything that may happen to you and what you’d want done,” he says. “The major limitation of living wills is that they’re vague. That’s why it’s important to have a person you trust as your health care agent and talk to them about your general wishes. That way he or she can make the right decision—the one you want—when the time comes.”

Don’t assume that your closest family member—a spouse, for example—will automatically become your health care proxy if you do not designate one. In the well-known case of Terri Schiavo, her husband fought a seven-year legal battle with her parents to have her feeding tube disconnected while she was in a persistent vegetative state.

Riechers, for one, is relieved to have her wishes in writing as she copes with her MS and drug treatment. After making her husband durable power of attorney, she is confident her health care requests will be upheld. “I don’t want my husband to go through a fight with my mother,” she says. “I want him to be able to say, that’s it, she’s my wife, I make the decisions.” NN

More Advance Directive Resources

- ▶ AARP Advance Directive Information: aarp.org/research or 1-888-OUR-AARP
- ▶ The American Bar Association’s Tool Kit for Health Care Advance Planning: abanet.org/aging/toolkit/home.html
- ▶ Mayo Clinic Resources for Advance Directives: mayoclinic.com/health/living-wills/HA00014
- ▶ National Hospice and Palliative Care Organization’s List of Advance Directive Forms by State: caringinfo.org/stateaddownload
- ▶ U.S. Living Wills Registry: liv-will1.uslivingwillregistry.com/individuals.html or 1-800-LIV-WILL