

Living Wills and Health Proxies

Steps to take for people living with a neurologic disease and their caregivers.

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Use the term “living will” these days and people usually recall the case of Terri Schiavo, a young woman whose husband battled her parents for almost seven years to terminate her life support. One of the delicate issues in the case, which ended in 2005, involved who should make decisions for Schiavo in the absence of a living will.

Underneath the sensationalistic media sound bites, the Schiavo case taught us that everyone of legal age should clarify their health care wishes—including those that affect the end of life—and specify who has the power to make medical decisions in case they cannot.

A living will should plan for life, not just death. This is especially true for people living with neurologic conditions. If you are hospitalized and cannot make your own medical decisions for a period of time, a clear statement of your health care wishes will be vital. For example, you might want experimental treatments, but no one will know that for sure unless you say so in a living will. Or, you might want a close friend who is more sensitive to your health challenges than a family member to make medical decisions for you. In that case, you must name the person as your health care agent in a document called a health care proxy.

MANY DOCUMENTS IMPACT HEALTH CARE

A living will is only one of several essential legal documents that everyone should sign. While it's preferable to have an attorney specializing in estate planning prepare these documents, financial realities may make that impractical. Thankfully, a number of websites provide free sample forms. An example is laweasy.com; you can find other sites by Googling the name of the document you're looking for along with the word “form.” Also, many websites and software programs, such as nolo.com, provide free information and low-cost forms you can create. In addition, your hospital may provide free health-related documents such as living wills and health care proxies. Finally, many religious



PART II
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articles on financial and
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organizations provide free living wills and health care proxies that conform to the tenants of a particular faith on their websites.

Not all Internet or free forms are created equal, and whatever source you use—attorney, website, or otherwise—you must carefully read the form and be sure it is tailored to address your personal circumstances. Some of the points you want to address are discussed in this article. These key documents include:

Living Will: The most obvious document is the living will, which is a statement of your health care wishes. Most living wills provide simplistic, generic statements about not wanting “heroic measures” taken in case of terminal illness. This isn't enough: A living will should address the type of care you want in detail, such as the magnitude of pain relief. What about experimental medical treatments? Some people with neurologic diseases are willing to take the risk of an experimental therapy if it has the potential of providing relief or slowing down the disease. You should enlist the help of your neurologist in making such decisions and then make your wishes clear in the living will.

However, while a living will should be comprehensive, it should also provide your health care agent—the person authorized to make medical decisions for you if you cannot—with general guidelines for making decisions. This is important because you can never anticipate every situation that might arise, and you don't want to prevent the agent from making reasonable decisions in areas you have not addressed. For example, some people include a statement such as this: “My health care agent is authorized to permit experimental medical treatments if any of my physicians indicate that it has potential to help me, regardless of the risks involved.”

Health Care Proxy: In my opinion, the most important legal document addressing health care is a health care proxy, also referred to as medical power of attorney. This document authorizes a

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person, called the health care agent, to make medical decisions for you if you cannot—including the measures that should or should not be taken to prolong or terminate life support. You might want to appoint someone who is capable of negotiating and coordinating medical services. A health care proxy adds flexibility to the medical decision-

making process, since not even the most comprehensive living will can anticipate every situation that might arise.

HIPAA Release: The Health Insurance Portability and Accountability Act of 1996 (HIPAA) was created to protect private health information. But the law can also make it difficult for someone to access your health records even if that is desired. As a result, many people sign a HIPAA release, which gives a trusted family member or friend—called a HIPAA representative—access to their medical records. Why might you sign a HIPAA release? Because not every medical situation requires giving decision-making authority to a health care agent under your health care proxy. Let's say you're in the hospital for elective surgery, requiring a week of recuperation. You often experience severe migraines that can last for days. It might be helpful for a close friend to assist you in monitoring your medical records if decisions have to be made before or after your surgery and a severe migraine makes it difficult for you to absorb the details. This can be done under a HIPAA release without your ceding control to a health care agent under your health care proxy.

My father's HIPAA release saved his life. My wife, who is a physician, used the release to view his patient chart while he was in a community hospital. As a result,

we moved my father to a major medical center, where he had an emergency procedure the next morning.

Financial Power of Attorney: This document appoints a person—called the financial agent—to handle legal, tax, and financial matters if you cannot. You might want to name someone with financial

know-how to be your financial agent. Let's say your son the CPA would make a great financial agent while your daughter the social worker would be the best choice as your health care agent. It can be crucial to clarify in your financial power of attorney that your financial agent must pay for the medical care that your health care agent opts for. You want to avoid a situation in which the financial agent dictates medical decisions by controlling the purse strings. In addition, because your financial agent must pay medical bills, he or she must have access to limited medical data in order to verify that the bills are correct, which requires a HIPAA release.

All of these documents need to be coordinated to avoid conflicts in carrying out your wishes. Signing a legal document and then filing it away is a mistake; you should review these documents at least every three years in light of your current health status

and the other documents you have signed. If you have a major health change, you may need to review the documents well before three years. Even the most astute lawyer will not be able to help you communicate important medical decisions without guidance from you about your health status. The guidance you give should be based on discussions you have with your neurologist and other medical providers.

GUARDIANSHIP

Many neurologic conditions are progressive in nature; some will trigger cognitive problems. One way to protect yourself is to specify a guardianship in your health care proxy. Guardianship refers to a court proceeding in which the court designates a person to be responsible for your personal and financial matters. In some cases, a separate guardian is appointed for personal matters (guardian of the person) and a different guardian for your financial matters (guardian of the property).

You can minimize the cost and intrusiveness of a court proceeding if you specify in your health care proxy that the person you have named as your health care agent should also become the guardian of your person should such an appointment become necessary. A health care agent has only the powers given under your medical power of attorney. A guardian, in contrast, is appointed by a court and can be given much broader powers.

RESOURCES ON LIVING WILLS

- ▶ **Mayo Foundation for Medical Education and Research:** bit.ly/MrzCHV
- ▶ **Medline Plus (also in Spanish):** 1.usa.gov/NumSCw, 1.usa.gov/Q2JgVu, 1.usa.gov/NCh230
- ▶ **National Cancer Institute of the National Institutes of Health (also available in Spanish):** 1.usa.gov/gEAOHA
- ▶ **National Institute on Aging:** 1.usa.gov/MmxPVq

Sample language to discuss with your attorney:

“To the extent that I am permitted by law to do so, I hereby nominate my financial agent, **FINANCIAL AGENT NAME**, to serve as the guardian of my property; and my health care agent, **HEALTH CARE AGENT NAME**, to serve as the guardian of my person, or in any similar representative capacity, and if I am not permitted by law to so nominate, then I request that any court that may be involved in the appointment of a guardian, special medical guardian, conservator, or similar representative for me give the greatest weight to this request.”

RELIGIOUS CONSIDERATIONS

In my opinion, there has been more strife and heartache over the failure of legal documents to deal with religious concerns than perhaps any other matter. Never assume that anyone will know your religious preferences. State them clearly. For example, some people living with a neurologic condition feel strongly about donating central nervous system tissue for research purposes; however, donations of tissue for research conflicts with the precepts of many religious faiths. Discuss your wishes with trusted religious advisers, decide what you want, and then document it in your living will. If some of your family or loved ones have different belief systems than you, consider also specifying what religious customs or rules you do not want to adhere to. Finally, be certain that whomever you wish to name as your health care proxy will not be precluded by his or her own faith from carrying out your wishes.

When properly prepared and coordinated—and with consideration for the neurologic condition you or a loved one faces—living wills and these other legal documents can provide peace of mind, assure your wishes are carried out, and minimize the emotional difficulties that so often accompany medical decision making. 

TAILORING LEGAL DOCUMENTS FOR NEUROLOGIC CONDITIONS

Whatever health challenges you might face, communicate your current status and likely future prognosis to your attorney, if you have one, so that he or she can tailor your document to reflect any special considerations. The following examples illustrate how living wills and related documents can address your neurologic challenges. Discuss with your health care team what tailoring might be appropriate for your documents:

▶ A diagnosis of Alzheimer’s disease (AD) can only be confirmed with certainty through a brain autopsy, so you might wish to mandate in your living will that a brain autopsy be performed following your death. This is not something necessarily covered by insurance, and there is usually a charge for it. Patients and families should understand that it will happen simply because they want it to. You might also wish to have your brain donated to promote research into finding a cure for AD. Arrangements should be made for this in advance.

If you want these steps taken knowing they violate the precepts of your religion, address that explicitly in your living will. Sample Provision: “I am a member of the _____ faith, and with the exception of the following, state that I want all customs and observances of my faith adhered to. The only exception to the forgoing is that I expressly wish to have my brain donated to further research in Alzheimer’s disease following my death, recognizing that such donation is contrary to my expressed religious affiliation and faith. I request that my agent and all medical personnel be as respectful as feasible to the precepts of my faith in carrying out this donation.”

▶ Some of the symptoms of Parkinson’s disease—including motor symptoms such as tremor or slowness of movement—may make it difficult for you to handle routine medical matters like completing insurance forms, signing releases and so forth. To prevent problems, you might prepare a stand-alone HIPAA release authorizing your HIPAA representative to receive medical information even though you continue to retain the right to make all medical decisions.

▶ Depression and apathy are symptoms of a number of neurologic conditions, including Parkinson’s disease, epilepsy, multiple sclerosis (MS), and stroke. It might be advisable to sign a HIPAA release and encourage your HIPAA representative—who is often also the health care agent—to stay informed of your routine health care visits. While most people think of health care decision-making in terms of dramatic end-of-life decisions, if your neurologic condition makes it difficult for you to follow up on routine care, informing your HIPAA representative on a regular basis and encouraging him or her to intervene if you don’t follow up can be an important component of your care. Giving someone that you trust a HIPAA release will authorize your physicians to communicate with that person as well as with you about missed appointments, the need to renew prescriptions, and other matters you might not have the focus or memory to address.

▶ Many neurologic conditions, including peripheral neuropathy, MS, trigeminal neuralgia, shingles, cause chronic pain. If the pain is severe, the provisions in your living will should be modified to assure that they reflect your wishes.