

Living Wills and Beyond: Planning for Possible Future Incapacity

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Summary

If you become incapacitated, whether temporarily or long-term, you should still be able to have things done the way you want them. You should be able to have extraordinary steps taken to keep you alive if you want, or to avoid them if you don't. Someone you care about and trust should be able to make medical decisions for you, and take care of your financial needs, if you are unable to. But these things are unlikely to happen as you would wish, unless you take some simple steps to prepare ahead.

Three documents for three related purposes

You don't necessarily need separate documents to handle the basics, but there are three different functions to be performed:

- A *living will* (or advance directive) describes what kind of medical care you want under various circumstances, and what you don't want, if you become incapable of expressing this for yourself. It particularly deals with use of life support, but may also consider other concerns and treatments. Without a living will, doctors will follow hospital or state guidelines, and neither your own nor your family's wishes will necessarily determine what happens. A living will is important, because it helps give the doctors guidance. If you or someone close to you is terminally ill, you might consider a variation on living wills called a POLST (Physician Orders for Life-Sustaining Treatment), if such are accepted in your state.
- A *health care proxy* (medical power of attorney) lets you name someone whose judgment you trust to make medical decisions on your behalf, if you can't. What if you are incapacitated in a manner that is not precisely anticipated by your living will? What if you need a risky surgery or medication, but are not conscious at the time the decision needs to be made? If you are not married, there may be uncertainty about who makes such decisions. Even if you are married, your spouse may not be in the best position to decide or your health care proxy can specify someone else, or at least name an alternate in case your spouse is unavailable or otherwise unable to help.
- A *durable power of attorney* gives someone else the ability to handle your finances for you, if you are not able to: to use your funds to pay your bills, to buy or sell assets, to make charitable or other gifts you intend, and so on. Without such a document, your finances are likely to be tied up in paperwork and perhaps legal proceedings, if you become incapacitated, and your wishes may not be realized. A court may appoint a guardian for you, but it may not be the person you would want, and that person may not follow or may not even know what your wishes are. Meanwhile, while you are still healthy and capable, the durable power of attorney does *not* allow anyone else to mess with your finances.

Not difficult, not expensive

You can do all this cheaply, and with fairly little trouble, if your needs are straightforward. Appropriate forms can be found at a legal stationery store, or for free on the internet (see the web site list at the end of this paper). You generally don't need a lawyer or notary to make it official — just a couple of friends or family members to witness the signing. In addition, standardized documents may be more readily understood and accepted by medical and financial officials.

Still, you should consider consulting a lawyer.

An attorney specializing in elder law can help you think through the issues that pertain to your particular needs. If your family or financial situation is complex, you may need a customized document. In fact, you may need something altogether different: perhaps a living trust, or some other arrangement. Only a specialist can determine that for you.

Thinking it through

Your first step is to spend some time pondering what you really want.

Are there circumstances under which you would not want to be kept alive, or would you always prefer to be kept going, no matter what? Do you want to be an organ donor? Do you have specific instructions for funeral or burial? What would your family members want? Who would be the best person to make medical decisions for you, if you couldn't? Would the same person be the best at making financial decisions, or should that be someone else? If the person you prefer couldn't do it for some reason, who would be your second choice? If you were no longer capable of handling your own finances, what would you want to happen with your money? Beyond the obvious, are there people or institutions that you would want to make sure were taken care of on your behalf, or special instructions you would want your financial representative to know about?

Some of these decisions are literally life-and-death, some potentially could be, and some are not. Some have religious or philosophical overtones. But all of them are important, and they deserve serious consideration. You should discuss some of them with people you care about or whose judgment you respect, as well as relevant professionals (your lawyer, your doctor, your clergyman, your financial advisor).

If you already have a serious or terminal illness, give special consideration to the various paths the condition might take, and what treatments could be applied. If you don't know, do some research, and ask your medical caregivers about it. Ask about risks, recovery rates, side effects, rehabilitation, costs. Then decide which treatments you would be willing to have performed, and which you would not.

In particular, the person or persons you name to make medical or financial decisions for you need to be in on the discussion. Specialists in this field talk about these relationships being more of a "covenant" than a "contract." It's about someone being able to represent you because they understand you and know what's important to you, not just about executing some words written on paper. Make sure they know what your wishes really are, and what *you* mean when you talk about "extraordinary measures" or "quality of life," and that they are really willing to take on what could be a very serious responsibility.

Things to watch out for

In general:

- Applicable laws vary by state. If you use standardized forms, make sure you have ones that apply to your state of residence. Don't copy them from a friend or relative who lives somewhere else.
- Documents need to be reviewed every few years, at least. Your circumstances may change, your wishes may change, the medical or legal or financial environment may change, and the people you nominate to make decisions for you may themselves become unavailable or inappropriate, while others may arise as better candidates. If you want to make changes, complete an entirely new document from scratch, and destroy all copies of the old one.

In regard to living wills:

- Try not to be too specific, or too vague. If your directions are highly specific about what conditions you are concerned about, it is less likely that if a need arises it will actually fit your description. But if your directions are too vague, doctors might feel that you have not considered situations as serious as the one you perhaps could find yourself in. Following standardized language is usually the best choice, unless you already suffer from a serious illness or have other special circumstances to deal with.

In regard to health care proxies:

- The federal Health Insurance Portability and Accountability Act may be construed by some medical officials as preventing them from sharing your medical information with the person you have nominated to make decisions for you. This can be avoided by proper language in the health care proxy. If you have an existing document that does not contain such language, it is time to sign a new one, or sign a HIPAA release form specifically permitting disclosures to your medical representative (and any back-ups).
- You should have only one person responsible for making decisions, and another named only if the first is unable or unwilling to serve. Team decision-making can lead to impasses at a critical time.
- The health care proxy should allow your representative to move you to another hospital, even in another state, if your wishes cannot be fulfilled wherever you happen to be. You can't assume that you will be treated by your own physician or at your favorite hospital (especially if you travel occasionally, but even if you don't).

In regard to durable powers of attorney:

- Not all financial institutions will readily accept your document. In order to avoid delays, check with them ahead of time. Some might require that their own forms be used, and some might require that these be updated fairly often.
- Standardized forms usually will not provide gift-giving powers. If you want such provisions, you may need an attorney's help in adding them.

- The IRS has its own power-of-attorney form (IRS Form 2848). You generally do not have to worry about this ahead of time, though. A durable power of attorney will usually qualify your financial designee to apply for the IRS version.
- Some types of authority cannot be legally designated, such as the power to amend a will.
- You are giving considerable power to the person you choose to act for you. Discuss with your lawyer how to restrict and review what can be done — for example, by requiring a written summary of actions to be provided to a third party, by notifying others about this document, by assigning two or three people to work together, or by limiting the powers.

Other steps you should consider

- It is often a good idea to own a bank account jointly with another member of your family. This will enable that person to get at funds immediately, if you are unable to, and without any possible delays or hassles over powers of attorney. Of course, the joint account holder must be someone very trustworthy, since he or she could get your money even while you are healthy. Another drawback: the other account owner will automatically own the account when you die, even if your will says otherwise. So if you use this kind of arrangement, it is best to keep a fairly modest account balance — enough to take care of any likely short-term needs, but not more than that.
- Consider having payments from Social Security, pensions, annuities, and investment income directly deposited to your bank account, if you are not doing so already, so funds will get deposited even if you are unable to endorse them.
- If you have not fully consulted with others in forming your plans, then do let your family members (and doctors) know about your documents after the fact. There should not be any confusion or squabbling about what to do or who gets to make decisions, if the need arises. This is especially important if you expect that someone may have religious or other objections to your plans.

For more information:

- For general information:
 - To help find an attorney specifically qualified in this area, check out the National Academy of Elder Law Attorneys web site:
[http://www.naela.org/Public/About/For More Information/Find an Elder Lawyer/Public/About NAELA/Public or Consumer/Find an Elder Lawyer/Find an Elder Lawyer.aspx](http://www.naela.org/Public/About/For_More_Information/Find_an_Elder_Lawyer/Public/About_NAELA/Public_or_Consumer/Find_an_Elder_Lawyer/Find_an_Elder_Lawyer.aspx)
 - AARP's legal services network is accessible at:
<https://www.aarplsn.com/lsn/home.do>
 - National Hospice and Palliative Care Organization, Caring Connections:
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3278>

- For help in having the family conversations that are necessary before legal documents are ready to be signed, check out The Conversation Project website at <http://theconversationproject.org/>.
- Standard forms and documents: Living wills / advance directives / health care proxies / medical powers of attorney (note: most state forms now include living wills and health care proxies in the same document):
 - U.S. living will directory: <http://liv-will1.uslivingwillregistry.com/forms.html>
 - CompassionAndChoices.org: <https://community.compassionandchoices.org/sslpage.aspx?pid=484&nccsm=15&nccscid=14&nccsct=Advance+Directives>
 - Aging With Dignity's "Five Wishes" document (usable in most states): <http://agingwithdignity.org/5wishes.html>
 - Google: "health care proxy" combined with your state name to find information and sample documents for your own state.
 - For information about POLST programs: <http://www.ohsu.edu/polst/>
 - HIPAA release forms: <http://www.caring.com/forms/hipaa-release-form/free-hipaa-release-form.pdf>
- Standard forms and documents: Durable powers of attorney
 - A basic form from ExpertLaw.com: http://www.expertlaw.com/library/estate_planning/durable_power_of_attorney.html
 - Another from Free-Legal-Document.com: <http://www.free-legal-document.com/free-durable-power-of-attorney.html>
 - Best bet: Google "durable power of attorney" combined with your state name to find information and sample documents specific for your own state.