

# Tools for Protecting Your Health Care Wishes

In health care settings like an emergency room, the right documents will help make sure your wishes are respected. If you're procrastinating about creating those documents, think about the experience of Cindy Meneghin, a Lambda Legal plaintiff in one of our marriage cases. When she was rushed to the emergency room with meningitis, hospital staff at first ignored her partner of 30 years. Terrified of losing consciousness without her partner in charge of medical decisions, Cindy yelled, "She's my partner!" several times. But that didn't work, so she screamed, "She has my power of attorney!" That worked like a charm.

*Please note: This document offers general information only and is not intended to provide guidance or legal advice regarding anyone's specific situation.*

## FIRST STEPS

1. Give some thought to who's the best person to understand what decisions you would make for your health care if you couldn't make them yourself.
2. Consult the following resources for legal help:
  - Lambda Legal's Help Desk, 866-542-8336 or send email by visiting [www.lambdalegal.org/help/online-form](http://www.lambdalegal.org/help/online-form) (for legal assistance on LGBT and HIV related issues or help identifying an LGBT/HIV friendly attorney in your area)
  - [www.lawhelp.org](http://www.lawhelp.org) (for help determining whether there is an affordable attorney or legal aid organization in your area)
  - [www.abanet.org/legalservices/findlegalhelp/home.cfm](http://www.abanet.org/legalservices/findlegalhelp/home.cfm) (to find attorneys in your area who may reduce charges)

## HEALTH CARE PROXY, OR DURABLE POWER OF ATTORNEY FOR HEALTH CARE

**Take the power!** Create a document to make sure that the right person makes medical decisions for you when you can't make them yourself, and that everyone knows your wishes about key health care decisions that could become necessary.

### Why do I need this power tool?

If you are in a serious accident or you become sick enough that you can no longer make medical decisions for yourself, you want the person you choose to be empowered to make those decisions. Otherwise the first relative who arrives at the scene might be called upon to make complicated and personal medical decisions for you. In one Lambda Legal case, Paula Long's same-sex partner was hospitalized unconscious with heart, lung and kidney failure, and staff refused to give Paula

information, instead telling her they needed contacts for blood relatives. Lambda Legal eventually put things right, but a health care proxy likely would have helped Paula avoid, or at least reduce, the emotional nightmare in the first place.

**How it works:** You create one or more legal documents, which may be called a health care proxy, a durable power of attorney for health care or a medical power of attorney, depending on what state you live in. You are the "principal," and the person you appoint to make medical decisions for you is the "agent." The document should say that medical personnel are authorized to release medical information to your agent under the federal Health Insurance Portability and Accountability Act (HIPAA). Here are a few tips for creating and using a health care proxy.

- The call your loved ones dread—you're critically hurt or ill—often comes while they're at work, school or otherwise away from home. Most people will rush to your side, not go home for your health care documents. Keep in mind that even if you carry your documents with you, if you are incapacitated you can't authorize access to any items you may have been carrying. Many same-sex couples use satchels created for passports and airline tickets



Janice Langbehn's partner of 15 years, Lisa Pond, collapsed with a brain aneurysm while the family was in Miami, Florida, for a cruise. Even after Janice had faxed their health care proxy documents to the hospital, the staff still denied Janice and the couple's three children access to Lisa's bedside, asserting that the family had no rights because they were "in an antigay city and state." Tragically, Lisa died alone. Lambda Legal sought redress for the Langbehn-Pond family; while the case was unsuccessful in court, the hospital ultimately changed its visitation policies as a result of the related advocacy campaign. And when President Obama called Janice from Air Force One to thank her for her bravery in taking a stand, she realized that her tragedy and courage had led to changes in national laws to ensure that hospitals across the country will be required to respect documents for hospital visitation and health care decision-making, without regard for sexual orientation and gender identity of the patient and their loved ones.

For all documents, sign multiple copies so you have extra originals in case health care staff says a copy is insufficient. Sign in blue ink to reduce the chances that health care staff will claim it's not an original.

to carry each other's documents. You also can carry your documents in digital form on your mobile phone or other hand-held device or on a memory stick. It can be helpful to have copies of any certificate of marriage or civil union, or domestic partnership registration, and papers evidencing your legal relationship to your children, as well as your health care proxy.

- To make it easy for your agent, family and friends to find your documents in a crisis, here's an old trick: put your important documents in a zipper bag in the freezer, and tell your loved ones that you're keeping them there—before an emergency strikes. The papers will be easier to locate in your freezer than in a desk drawer or filing cabinet.
- Talk to your attorney about whether you should supplement a health care proxy with a document (**designation of pre-need guardian**) naming the person you'd want to be a "guardian" or "conservator" for you if your needs go beyond those usually covered by a medical power of attorney or a durable power of attorney for financial matters and a court is asked to appoint a guardian with authority to make the full range of decisions for you.
- If you are transgender, you may need to add an instruction that your gender identity be respected, to further empower your proxy to advocate on your behalf.

## LIVING WILL

**Take the power!** Create a document to make sure that your wishes will be honored for life-sustaining procedures, and that your loved ones will have the information they need to advocate for your wishes.

### Why do I need this power tool?

You may feel strongly about whether or not you want resuscitation or insertion of a feeding tube if you are in a persistent vegetative state or likely to die soon. For good reason, in hospital settings it can be very hard to block or end procedures that keep a person alive. A living will gives guidance about your wishes on this very serious matter and is all the more important if your loved one's authority to carry out your wishes is more likely to be questioned, as often is the case for unmarried partners and friends with no legal relationship.

**How it works:** A living will is not a last will and testament. It is your wishes in writing for what should happen if you need certain medical intervention to stay alive. A living will tells medical professionals and your advocates whether you wish to receive specified life-sustaining treatment such as resuscitation, insertion of tubes for breathing or feeding, and medication to relieve pain. Because it is guidance given in advance, this document often is called an "advance directive." Many hospitals keep living will forms on hand and some states have an official form to make things easier. In some states, the living will is incorporated into a power of attorney or health care proxy. A couple of things to remember:



Though **Cindy Meneghin and Maureen Kilian** had been partners for 30 years, Cindy had to fight with hospital staff to allow Maureen to be by her side in an emergency. Fortunately, they had taken the power by preparing legal documents in advance to protect them in a hospital setting.

- Given the gravity of the decision to prolong or terminate life, health care providers are all the more cautious if your relatives object to the directions in your living will. Consider telling your wishes and your reasoning to anyone who might raise objections.
- Ask your attorney if your state has an official form for the living will, which may reduce the potential for doubts or objections.

## HOSPITAL VISITATION DIRECTIVE

**Take the power!** Create a document that directs health care providers to allow your loved ones to visit you in the hospital.

### Why do I need this power tool?

If you have a health care emergency, hospital staff may treat the people who have significant roles in your life like strangers. Staff at a Maryland hospital kept Lambda Legal plaintiff Bill Flanigan from seeing his dying partner for six hours, until his partner's mother arrived. Even if you are married to your same-sex partner, and even if your spouse/partner has the right under your health care proxy to make decisions about your medical care, she or he may still be barred at the door of your hospital room and/or denied information about you. And although you may have created a health care proxy appointing your loved one or best friend as your agent, medical staff often refuse to honor the role of a health care agent unless a patient is incapacitated. Yet you still may be conscious but too ill or distraught to advocate effectively for your needs.

**How it works:** A “directive” designating who can visit you in the hospital can be part of another document like a health care proxy or living will, or it can be a stand-alone document. The best choice depends partly on the state you live in. For example, a state law describing the role of a “health care agent” also can provide that the agent may visit the principal regardless of whether the principal has decision-making capacity at a particular time. Such a law would confirm the use of a health care proxy to cover visitation privileges, too. States use different approaches, however, so you need an attorney licensed to practice in your state to guide you. Here are a couple of tips:

- Hospitals prioritize “family” for visitation. The Joint Commission, which evaluates and accredits hospitals all over the United States, defines family as: “The person(s) who plays a significant role in the individual’s [patient’s] life. This may include a person(s) not legally related to the individual.” In your directive, it may be helpful to include a reference to the Joint Commission and

its definition of family because hospital staff will recognize the name of the commission and may treat you more appropriately. This can be especially important when you travel outside your home state. (If you do have trouble, call the Joint Commission’s complaint line at 1-800-994-6610, or email [complaints@jointcommission.org](mailto:complaints@jointcommission.org).)

- Depending on how you feel about your legal relatives, you also may want to consider naming individuals whom you do NOT want to visit you (if you wish to avoid naming one person in particular, you might refer generally to your relatives or subgroups of your relatives). Being explicit that you wish to exclude some people can reduce the stressful haggling your spouse/partner or close friends may have to do over dividing the time spent with you, and may signal to hospital staff in a helpful way what visitors you most welcome.