

Tools for Protecting Your Health Care Wishes

In health care settings, the right documents will help make sure your wishes are respected. Health care providers are required to respect these documents, including those presented by same-sex couples. This change in policy came about in the aftermath of a tragedy, when Janice Langbehn's partner of 15 years, Lisa Pond, collapsed with a brain aneurysm. Even though Janice faxed their health care proxy documents to the hospital, the staff denied Janice and the couple's three children access to Lisa, who ultimately died alone. While Lambda Legal's lawsuit on the family's behalf was unsuccessful, the hospital ultimately changed its visitation policies as a result of the related advocacy campaign. After calling Janice to thank her for her bravery, President Obama directed the Department of Health and Human Services to promulgate policies requiring hospitals across the country to respect visitation and health care decision-making documents without regard for the sexual orientation or gender identity of patients and their loved ones.

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. Consider what you would want to happen in the event of a medical emergency. Who would you want to be by your side? What kinds of medical care or life-sustaining procedures would you want?
2. 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. This should be someone you trust who is willing to take on the job. Be sure to talk to this individual to make her or him aware of what you are asking.
3. For legal help, consult Lambda Legal's Help Desk at 866-542-8336 www.lambdalegal.org/help or the other resources in the insert "Tools for Selecting an Attorney."

DESIGNATING AN AGENT TO MAKE MEDICAL DECISIONS

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 of your choice to be legally empowered to make those decisions. If you do not take steps to designate the person you want to make these decisions, you run the risk of health care providers turning to blood relatives, who may be recognized as legal next-of-kin, to make these complicated and personal medical decisions for you.

How it works: You create one or more legal documents, which may be called a **health care proxy** (see “Terms to Remember” on page 5 of this insert for all terms in **bold**), 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), which mandates that protected health information be kept confidential. Note that you might need a separate HIPAA release in addition to a **health care proxy**. Not only do some health care settings require them; a HIPAA release may provide for more than one person, or a “class” of people, to access your information.

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 to carry each other's documents. You also can carry your documents in



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.

digital form on your mobile phone or other handheld device or on a memory stick, or you can register for a paid service that makes your documents available online from anywhere in the world. 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 documents.

- 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 waterproof 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 you become incapacitated and your needs—such as the

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

need to make financial decisions on your behalf—go beyond those usually covered by a medical power of attorney or other documents that grant limited authority. See insert "Tools for Protecting Your Assets in Life." A court should look to such a designation if it is asked to appoint a guardian with authority to make the full range of decisions for you, though practice will vary from state to state.

- If you are transgender, you may want to add an instruction that your gender identity be respected, to further empower your proxy to advocate on your behalf, though health care providers that receive any federal funding (which is almost all of them) are already required not to discriminate on the basis of gender identity under the Affordable Care Act.

LIVING WILL

TAKE THE POWER! Creating a **living will** ensures that your wishes about life-sustaining procedures will be honored, 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



When Cindy Meneghin, a plaintiff in one of Lambda Legal's marriage equality cases, was rushed to the emergency room with meningitis, hospital staff at first ignored her partner of 30 years, Maureen Kilian. Terrified of losing consciousness without Maureen 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.

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 interventions 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

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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:

- 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.

VISITATION DIRECTIVE

TAKE THE POWER! Create a document that directs health care providers to allow your loved ones to visit you in the hospital or in a long-term care facility.

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. A **visitation directive** is the clearest way to ensure that the person you want by your side can be there. Federal law requires hospitals

and long-term care facilities to respect a patient's desires regarding who may visit and may not deny or limit visitation based on sexual orientation or gender identity. Having your intentions regarding visitation in writing makes it much harder for hospital or facility staff to avoid those obligations. Though they should also recognize any legal relationship you have with your same-sex partner or your designation of your partner as your agent in a health care proxy as evidence of your consent to visitation, having a visitation directive reduces the potential for discrimination.

How it works: A visitation directive designating who can visit you in health care settings 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, state law may allow your health care agent to visit you regardless of whether you have decision-making capacity. Such a law would confirm the use of a health care proxy document 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:

- Federal regulations state explicitly that hospitals and long-term care facilities must recognize a patient's right to designate a same-sex spouse or partner, another family member, or a friend for visitation. In your directive, it may be helpful to include a reference to these regulations, which can be found at [http://www.](http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/surveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-11-36-Part-I.pdf)

[cms.gov/Medicare/Provider-Enrollment-and-Certification/surveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-11-36-Part-I.pdf](http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/surveyCertificationGenInfo/Downloads/Survey-and-Cert-Letter-11-36-Part-I.pdf), as a reminder to facility staff of their obligation to treat you appropriately. This can be especially important when you travel outside your home state.

- Depending on how you feel about your legal relatives, you also may want to consider naming individuals who 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.

IN RE GUARDIANSHIP OF KOWALSKI

Sharon Kowalski and Karen Thompson were together for four years when a drunk driver struck Kowalski and her niece, paralyzing Kowalski and killing her niece. Kowalski's parents learned of their daughter's relationship with Thompson only after the accident and refused to acknowledge Thompson as Kowalski's partner. Kowalski's father assumed guardianship of her, despite her requests to be placed in Thompson's care. Kowalski's father then moved her to a nursing home 200 miles away from Thompson, who was denied visitation rights. Thompson began the lengthy legal battle to bring her partner home. Lambda Legal filed supporting legal arguments on her behalf. Finally, eight years after the accident, Kowalski returned home with Thompson.



Power Tool Tip: Thompson's legal vulnerability was a wakeup call for many in the LGBT community. Thompson's battle was the first of its kind in the courts—and drove home the importance of same-sex couples drawing up basic legal documents, such as a medical power of attorney and appointment of a guardian, for protection in times of crisis. It also underscores why we must win equal access to marriage and all of family law, so the same recognition and default legal protections are available to all devoted couples.

TERMS TO REMEMBER

Agent: A person appointed to make medical decisions on someone else's behalf, through a health care proxy, durable power of attorney for health care or medical power of attorney.

Designation of pre-need guardian: A legal document naming someone to be a "guardian" or "conservator" for someone else who becomes incapacitated and whose needs go beyond those usually covered by a medical power of attorney or a durable power of attorney—such as to take care of financial or health matters that are expected to be long-term. This document can also specify your choice in the event a court is asked to appoint a guardian with authority to make the full range of decisions for you.

Health care proxy (also known as durable power of attorney for health care or medical power of attorney): A legal document which empowers a person of your choice to make medical decisions on your behalf if you're hospitalized or otherwise unable to make these decisions yourself.

Living will (also known as advance directive): A legal document which specifies a person's wishes about life-sustaining procedures, and which provides loved ones with the information they need to advocate for that person's wishes.

Principal: The person who appoints another person (see Agent) to make medical decisions on his or her behalf should the principal become incapacitated. The principal specifies their agent through a health care proxy, durable power of attorney for health care or medical power of attorney.

Visitation directive: A legal document that directs health care providers to allow your loved ones to visit you in the hospital or in a long-term care setting. Can be part of another document, like a health care proxy or living will, or it can be a stand-alone document, depending partly on the state you live in.

WHAT DO I DO IF MY DOCUMENTS ARE IGNORED?

Dealing with the discrimination of others means having to be your own advocate. Here are some tips if your relationship or your documents are not respected:

- Ask to speak to a supervisor. Take your request up the chain of the hospital or facility's administration, including to their lawyers. Pursue any internal grievance systems.
- Directives may be enforceable in court, where a judge may be able to order the health care provider to follow the directives or the decisions of the designated agent.
- If a health care provider refuses to follow a patient's desires regarding visitation or designation of an agent, you may also be able to file a complaint with your state's agency that oversees compliance with federal requirements (<http://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/SurveyCertificationGenInfo/Downloads/Complaintcontacts.pdf>).
- If you feel you have been discriminated against because of your race, color, national origin, disability, age, sex (including gender identity and sex stereotyping) or religion by a health care provider, you can file a complaint with the Office of Civil Rights of the U.S. Department of Health and Human Services (<http://www.hhs.gov/ocr/civilrights/complaints/index.html>).
- Be aware that under some circumstances, health care institutions and providers may be able to refuse to follow directives regarding particular *types* of care for reasons of conscience, but there are no conscience exceptions to recognizing a *person* who has been designated as an agent for health care decisions.
- Call Lambda Legal's Help Desk at 866-542-8336 or visit www.lambdalegal.org/help.