

Your Rights in Healthcare: Decision Making Authority

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1 What is this topic about?

This topic is about what legal rights you have to make medical decisions. It covers healthcare-related legal documents, state laws about medical decision making, what to do if you disagree with a healthcare decision, and where you can go for help relating to medical decision making.

2 Consent and Self-advocacy in Healthcare

All people are worthy of inclusion and respect. Respectful healthcare does not make people feel bad, guilty, or inferior. It is important that you know your rights and how to advocate for them. There are some situations where your rights may be limited. For example, if you have a conservator or guardian, that person may make decisions about your medical care that you do not always agree with. Or if a professional is concerned that you might be suicidal or dangerous to others, he or she may have the right to take actions you don't agree with in order to ensure your safety. However, in most circumstances, you should not be forced into a healthcare situation without your permission. If you are uncomfortable with a healthcare provider, then you have the right to say "no" to their services and to seek healthcare from someone else. If a professional makes you feel uncomfortable, or does something you feel is

wrong, bring it up to him or her. Make it known that you are uncomfortable and that you would appreciate if they would respect your boundaries and concerns. Your healthcare provider should always be able to explain to you why they are doing something and how it relates to your healthcare. If your healthcare provider cannot respect your wishes, you do not have to continue seeing them and you can look for another provider if it's a bad fit. If you feel you have been treated wrongly by a healthcare provider, two places to try asking for help are:

- Contact your state's [Protection and Advocacy](#) (P&A) program
- Contact the healthcare provider's professional licensing board in your state; for example, search for terms like "osteopath licensing board Arizona" or "family practice licensing board Oregon".

3 What state laws exist about medical decision making?

The laws differ from state to state but most states assume adults can make medical decisions on their own. In some states, having a developmental disability may put into question someone's decision-making capacity. The American Bar Association has [a chart](#) describing each state's default medical decision making law. This chart lists the priority order of decision makers for each state. It also describes the procedure for determining the decision maker if there is a disagreement. The chart also describes the procedure for when there is a disagreement on who is the decision maker. (Note: this chart was last updated in 2009, so some information may be out of date.)

4 Can healthcare providers determine my ability to make a healthcare decision?

Healthcare providers often use an interview and their clinical judgment to determine if someone is able to make a particular healthcare decision for himself or herself. A person may have the ability to make a simple decision, but may not be able to make a more complex decision. Their ability to make a decision may also change at different times. For example, a person who is very ill may be confused one day, but may be thinking clearly another day. Healthcare providers cannot determine if someone needs a guardian. Decisions about guardianship have to be made in the legal system.

5 What happens if I'm unable to make medical decisions and I don't have a legal medical decision maker?

You can name the person you would like to have as a legal medical decision maker using an advance directive. This person would be able to make medical decisions for you if you became incapacitated (unable to make decisions for yourself). For example, they might make decisions if you were in a coma. If you don't have an advance directive and become incapacitated, hospitals follow state laws about who can make healthcare decisions for you. Many states rank possible decision makers (called surrogate decision makers) and mandate that hospitals follow this priority order. The ranking for each state is listed in this [American Bar Association chart](#) (Note: this chart was last updated in 2009, so some information may be out of date.)

5.1 What about domestic partners or close friends?

In most states, domestic partners or close friends are last on the list of potential proxies. In some states, domestic partners and close friends are not

on the list at all. Family members generally have higher priority than friends. If you want to allow your domestic partner or a close friend to make medical decisions for you when you can not make decisions for yourself, you need to name them on an advance directive.

5.2 What about emergency situations?

In emergencies, most states allow medical providers to act without the consent of the patient or surrogate decision maker.

6 What are advance directives and how do they relate to decision making?

Advance healthcare directives are legal documents. They have instructions telling healthcare providers what actions to take or not take when an individual is no longer able to make healthcare decisions for himself or herself. This is usually due to illness or incapacitation. The purpose of these documents is to make sure the patient's medical wishes will be followed even when he or she isn't able to communicate them.

Advance directives are also known as living wills, personal directives, or advance decisions.

The two most common types of advance directives for healthcare are living wills and durable power of attorney for healthcare (or healthcare proxy). Advance directives will only be used if you are unable to make medical decisions for yourself. An individual may have more than one kind of advance directive. You can create these documents with a lawyer. Information about how to get help seeing a lawyer is in the section "Where can I get legal help related to decision making?" Many doctors' offices and hospitals also have forms ready that you can fill out without a lawyer. You can ask your doctor or the clinic or hospital staff for help filling out advance directive forms.

6.1 Living Wills

Living wills outline what types of medical treatments should or shouldn't be performed. These may include (but are not limited to) drug administration, hydration, feeding, or resuscitation and life support decisions. A living will doesn't let you select someone to make decisions for you, only what kind of treatments to give you. For that you need to name someone as having durable power of attorney or guardianship.

6.2 Durable Power Of Attorney for Healthcare (also known as a healthcare proxy)

When you give someone written permission to represent you or act on your behalf in legal matters, it is called giving that person power of attorney. Durable power of attorney for healthcare lets you name someone to make healthcare decisions for you, if you were to become unable to make your own decisions. The person you name as a healthcare proxy can make any healthcare decision that you could make, but only if you were unable to make your own decisions.

6.3 What happens if I don't have an advance directive?

If you do not have an advance directive, hospitals follow state laws about who can make healthcare decisions for you. Many states rank potential decision makers in order of priority. States differ on who they will consider. For example, in most states, spouses and blood relatives rank first while a domestic partner or close friend may be last on the list of potential proxies. In some states, domestic partners and close friends are not on the list at all. The ranking for each state is listed in this [American Bar Association chart](#). (Note: this chart was last updated in 2009, so some information may be out of date.) If you want to be sure that the people you name can make medical decisions

for you if you become unable to make them for yourself, you need an advance directive.

7 What are Physician Orders for Life Sustaining Treatments (POLST)?

A Physician Orders for Life Sustaining Treatments (POLST) documents a patient's preferences for end-of-life treatments. POLST forms are often used when a person is chronically ill or near the end of life. POLST forms are physician orders that can tell other professionals what to do or not do in the case of an emergency. The POLST document can communicate to a first responder that the patient does not want cardiopulmonary resuscitation (CPR), or to be transported to the hospital if they had stopped breathing. If a POLST were not in place, the first responder would be obligated by law to do these things. POLST forms are not only used to limit treatment. They can also document life-sustaining treatments a person wants. POLST isn't available in every state but a growing number of states are adopting them. For information about POLST in your state, see polst.org POLST orders are also known as medical orders on life-sustaining treatment (MOLST), medical orders on scope of treatment (MOST), or physician's orders on scope of treatment (POST).

8 What is the Difference between Advanced Directives and Physician Orders for Life Sustaining Treatments (POLST)?

Advance directives indicate what a person would want IF they were to become too incapacitated to make their own decisions. They are filled out while the person can make his or her own decisions. They only come into use in the future when the person becomes incapacitated. POLST forms are active orders that are in place now. They can be filled out by the person themselves or by their power of attorney for healthcare. For example, someone may say on an

advance directive that if he were ever in a persistent vegetative state (“brain death”), he would not want to be kept alive on a breathing machine. But if that person is at home and suddenly stops breathing, paramedics can’t use the advance directive to decide whether or not to put him on a breathing machine. A person with a terminal cancer may not want paramedics to resuscitate him, even if he is not in a persistent vegetative state. That person may wish to fill out a POLST form indicating that he does not wish to have cardiopulmonary resuscitation (CPR) or be put on a breathing machine. Paramedics can see a POLST form, read the person’s wishes, and not start CPR.

9 What should I know about guardians or conservators?

9.1 What is a guardian or conservator?

A guardian or conservator is someone who can act as the legal authority for another person. A guardian is usually appointed by a court. Guardians are appointed for a number of reasons. If the ward is a minor without parents, guardians are assigned by the courts until the ward reaches the age of 18. Guardians can be appointed for adults as well. This is only done if the ward is incapacitated or someone has decided that their disability makes them unable to care for themselves. Because establishing a guardianship may remove considerable rights from an individual, it should only be considered after all other alternatives to guardianship have proven ineffective or are unavailable.

9.2 Is there a difference between a guardian and a conservator?

This depends greatly on what state you reside in. In some states there are few differences but in other states there are many differences. In some states one term or the other isn’t used at all. See your [state resources](#) for more information about guardianship in your state.

9.3 What role does guardianship play in healthcare?

Guardians or conservators are allowed to make healthcare decisions for another person. A guardian may be appointed by the courts if the patient's illness or disability makes him or her unable to make their own decisions.

9.4 What are alternatives to guardianship?

Because having a guardian or conservator takes away a great deal of power from the ward, people often seek alternatives to guardianship. Some alternatives to guardianship might be:

- Representatives or substitute payees
- Case/care management
- Durable powers of attorney for health care
- Living wills
- Financial powers of attorneys
- Personal advocates or supporters

9.5 How can I have guardianship or conservatorship removed?

Guardianship can be removed through a legal process at the court that made the determination.

10 What should I do if I disagree with a healthcare decision a guardian has made for me?

A guardian has a legal duty to act in the best interests of the ward, but there are times when the ward and guardian may disagree about medical treatment.

Disagreements about healthcare can be difficult because in most states the guardianship laws consider the ward unable to make informed healthcare decisions. If you disagree with your guardian about treatment, and the treatment could have a big impact on you, then the courts may need to get involved. The court usually acts as the final decision maker when the ward and guardian can't agree.

10.1 If I have a guardian, is my consent needed for medical care?

No. A guardian is authorized to consent on the ward's behalf. The guardian should take into account the ward's preferences for healthcare providers, treatments, and other healthcare services,. It is appropriate for a guardian to communicate with and seek the ward's involvement and agreement whenever possible. This is called getting the "assent" of the ward."

10.2 Are there any treatments that cannot be forced on me?

There are certain treatments that a guardian cannot force on a ward without a court's consent. For example, treatments that have substantial side effects such as psychotropic medications often require consent from a court. Another example would be major or experimental surgeries.

10.3 How do I petition the court about a medical disagreement?

A petition asking the court to review the guardianship can be filed with the court that issued the guardianship. The court may have a form that you can fill out. The petition can be filed by the you (the ward), your attorney, a family member, a friend, or a supporter. The petition should simply say why you are requesting a hearing. It is strongly recommended that you speak to a lawyer before submitting the form to make sure everything is in order. See

the section on "Where can I get legal help related to decision making?" for more information.

10.4 Are there other alternatives to court proceedings?

Full court proceedings can be costly. Many states have options such as ombudsman programs, or medical or legal advocates that help resolve the disagreement. See the section on "Where can I get legal help related to decision making?" for who to contact.

10.5 What if my guardian and my healthcare proxy don't agree?

When a ward has both a healthcare proxy from an advance directive and a guardian, there is sometimes confusion over who has the authority to make health care decisions on the ward's behalf. Unfortunately there is no easy answer here. It varies by state. See the section on "Where can I get legal help related to decision making?" for more information.

11 Where can I get legal help related to decision making?

The US [Administration on Intellectual and Developmental Disabilities](#) (AIDD) is a government agency that works to support programs that help people with intellectual and developmental disabilities fully participate and contribute to their communities. The AIDD is a good place to start if you are looking for help understanding legal decision making. The AIDD oversees the [State Protection and Advocacy Systems](#) (P&As). The P&As work at the state level to help individuals with intellectual and developmental disabilities advocate for themselves. The P&As are another good resource if you are looking for help. Because they work on the state and local level they are more likely to know of services local to you. Some of the services they provide include:

- Information and referral
- The protection and advocacy of legal and human rights.
- Investigation of into the violation of rights of individuals with developmental disabilities.
- Help to resolve complaints through mediation, alternative dispute resolution and litigation.

Some areas also have legal aid clinics that offer low-cost or free legal help. Law school clinics also sometimes offer free legal advice. There are also some organizations and individual lawyers that do pro bono work (work for free). You can contact your local university or search the Internet to look for these types of services. Note: This information is provided in hopes that it will be helpful. We cannot say whether or not these resources will be able to address your legal questions or issues. We cannot say whether or not you will be able to get the legal outcome you would like. We cannot say whether or not you will receive good legal advice from these sources.

12 Summary

In most situations, you have the right to have a say in your own medical decisions. The situations when you may not have a say are:

- If you become unable to make your own decisions due to illness or injury.
- If a healthcare provider is concerned that you may harm yourself or others.
- If you have a legal guardian or conservator.

If you become incapacitated and unable to make your own decisions due to illness or injury, each state has its own list of who gets to make decisions for you.

- If you would like someone you name to make decisions for you, you will need a legal document called a durable power of attorney for healthcare, which is a kind of advance directive.
- Other kinds of advance directives include living wills, which name the kinds of treatments you would or would not like done if you become incapacitated.
- You can create an advance directive with the help of a lawyer. Many healthcare offices and hospitals can also help you fill out advance directives.

Physician Orders for Life Sustaining Treatments (POLST) give directions to emergency personnel and other healthcare providers about what life-sustaining treatments you do or do not want. If you have a guardian or conservator, they are allowed to make healthcare decisions for you without your consent.

- A guardian may be appointed if you are incapacitated and do not have an advance directive.
- A guardian may be appointed if some process has determined you are unable to make medical decisions for yourself.
- If you have a guardian and disagree with medical decisions they are making for you, you may need the help of a lawyer.
- Some treatments may require a court approval before they can be given to you, even if the guardian wants them done.

The [State Protection and Advocacy Systems \(P&As\)](#) may be a good place to start if you want more information about how to get legal help or better understand laws about medical decision making.

13 Links

13.1 Advance Directives

- [Family Doctor.org](#)
- [The Patient's Rights Council](#)
- American Bar Association links to every state's [advance directive forms](#) (PDF)
- [Caring Connections](#) is an organization that helps individuals access information about advance care planning and care at the end of life. This site has helpful information on Advance Directives and access to Advance Directive forms for all 50 U.S. states.
- Many states have laws that allow Advanced Directives for mental health. The [National Alliance On Mental Illness](#) (NAMI) has information on Advance Directives relating to mental illness.

13.2 Physician Orders for Life Sustaining Treatments

- [www.polst.org](#) has nation-wide information about POLST.

13.3 Decision Making Laws and Priorities

- American Bar Association's [priorities-by-state table](#)
- Information about domestic partners and healthcare decision making from [Unmarried Equality](#)

13.4 State Protection and Advocacy Systems and Other Legal Help

- The US [Administration on Intellectual and Developmental Disabilities \(AIDD\)](#)
- The State [Protection and Advocacy Systems \(P&As\)](#)

13.5 Guardians / Conservators

- General [information about guardians / conservators](#).
- Table of guardian / conservator [laws by state](#)