



X-Plain

The Living Will

Reference Summary

Introduction

Advance directives are instructions you give your doctors telling them what kind of medical care you do or do not want if you become unable to make medical decisions for yourself.

In a living will, you specify the medical care you do or do not want to receive if you become unable to make decisions for yourself. Living wills usually apply to end-of-life situations.

This reference summary explains living wills. It is for informational purposes and does not replace the advice of your doctor or lawyer.

Advance Directives

Many terminally ill patients become unable to make decisions or let their doctors know their wishes, as the illness gets worse. Terminally ill means a medical condition that is incurable or irreversible and will most likely lead to death. Even if life-sustaining procedures are used, there is no reasonable expectation of recovery. If a patient cannot make decisions or communicate, and does not have an advance directive, doctors have no way of knowing whether or not the patient wants to be treated.

The best time to write a living will, stating which treatments are or are not wanted, is while a patient can still make decisions and communicate them.

Because it takes effect while you are still living, it is called a living will. It is different from the will you write to dispose of property, which takes effect only at death.



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Examples of medical situations where a person can no longer make decisions include:

- Being in a permanent coma also called a permanent vegetative state
- Losing the ability to think competently, such as after a massive stroke
- Losing the ability to think and communicate due to severe dementia

Living Will

A living will comes into effect while you are still alive but unable to make decisions. It specifies the medical care you do or do not want to receive if you become unable to make decisions for yourself.

A simple living will can include a statement such as,

“If I should have an incurable or irreversible condition that will cause my death within a relatively short time, or a state of permanent unconsciousness from which to a reasonable degree of certainty there can be no recovery, it is my desire that my life not be prolonged by the administration of life-sustaining procedures. If I am unable to participate in my health care decisions, I direct my attending physician to withhold or withdraw life-sustaining procedures that merely prolong the dying process and are not necessary for my comfort or freedom from pain.”

Life-sustaining care is the use of medical equipment to sustain life when the patient can no longer breathe, eat or clean the blood on his or her own. A mechanical ventilator, or respirator, can help the lungs breathe, a feeding tube or intravenous line helps food get to the body and a dialysis machine helps to clean the blood by performing the functions of the kidneys.

Many hospitals have a Do Not Resuscitate Order Form, also known as DNR Order or Allow Natural Death order. In it, a patient can request not to be resuscitated. Resuscitation refers to restarting the heart or lungs when they have stopped working. During a heart attack, the patient’s heart can be stimulated by cardiopulmonary resuscitation (CPR) or by a device that delivers an electric shock to stimulate the heart. In addition, a living will can include an order not to resuscitate.



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In addition to protecting the patient's rights to communicate his or her decisions in advance, a living will removes the burden of making difficult decisions from family and friends.

A living will can include a person's wishes regarding resuscitation, life-sustaining procedures, palliative care and aggressive treatments. However, a living will cannot cover all medical scenarios. Palliative care is medical care that aims at providing comfort rather than a cure. For instance, pain medications, antibiotics and radiation therapy can be given to improve the patient's quality of life rather than to cure a terminally ill cancer patient. Aggressive treatment refers to medical treatments that have high levels of risks and complications and that tend to be invasive, such as major surgeries. Experimental treatments and high-risk surgery are examples of aggressive treatment. This is why appointing someone to make medical decisions for you when you cannot make them for yourself is important.

Some treatments that are not available now may someday become available. The laws in your state may also change. Because of this you should include all of your wishes in your advance directives, even if the treatments or wishes are not available or legal currently.

Doctors who refuse to honor your advance directives are required in many states to make efforts to transfer you to another provider who would comply. Your doctors may not have an obligation to inform you ahead of time whether they would honor your wishes, so ask them! Hospitals and healthcare institutions, on the other hand, are supposed to inform you at the time of admission.

Most hospitals and healthcare facilities such as nursing homes and home healthcare agencies are required to observe the following patient's rights.

- Give you a written summary of your healthcare decision-making rights at the time of admission.
- Ask you if you have advance directives and document that fact in your medical record. However, it is up to you to give them a copy of your advance directives.



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- Never require that you have or not have advance directives, or discriminate against you based on whether you have them or not.
- Make the facility's policies available regarding recognizing advance directives.

Since some healthcare facilities and providers may not honor certain wishes in advance directives, it is very important for patients and health care staff to maintain good communication. You should discuss your wishes with your doctors, understand your treatment options and find out whether or not they can honor them.

Other Directives

The living will is one form of advance directives. However, there are other advance directives as well. The durable power of attorney for health care and your desires regarding organ donation after death are also advance directives.

A durable power of attorney for health care lets you name another person to make medical decisions for you if you become unable to make and express your own decisions. Power of attorney documents expire when the patient becomes incapacitated unless it is a durable power of attorney. The term "durable" indicates that the document is still valid even if the person appointing the agent becomes incapacitated. The agent you name acts as your appointed proxy but only for making decisions regarding the healthcare matters you specify AND when you cannot make the decisions yourself. The person appointed as agent in the durable power of attorney for health care is also referred to as health care proxy, health care surrogate or attorney-in-law.

Many states use ID cards and hospitals use forms to ask if you would like to donate your body organs after death. Answering "yes" or "no" to such questions is a form of advance directives. In general, people dying of a chronic illness can donate only corneas, skin and bone. People who die unexpectedly generally can donate more organs, such as kidneys, liver, heart and lungs.

Some hospitals have a special form called a "Do Not Resuscitate (DNR) order form". It is another kind of advance directive. A DNR is a request not to have cardiopulmonary resuscitation (CPR) if your heart or breathing stops. Unless given other instructions, hospital staff will try to help anyone whose heart has stopped or who has stopped breathing.

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You can also include in your advance directives your wishes regarding nursing homes, blood transfusions, autopsies, donating your body for medical research and any other issue of importance to you.

The living will, durable power of attorney for health care, DNR order, and organ donation are all forms of written advance directive. It is possible to combine forms into one legal document that lists a patient's wishes regarding medical treatment and appoints an agent. Such a legal document is usually called "Advance Health Care Directives".



Legal AD Forms

State laws govern advance directives documents. All 50 states and the District of Columbia have laws that permit individuals to sign documents stating their wishes about health care decisions when they cannot speak for themselves. The laws vary from state to state, but the basic idea of honoring a patient's wishes is the same across the United States.

You do not need a lawyer to write advance directives. Most states have laws that provide special forms. However, use a lawyer if you think your family situation is complex or if you expect problems to arise.

Since living wills apply mostly to end-of-life situations, they cannot be used in cases of temporary coma. For this reason, it is best to write both a living will and a power of attorney for health care. You can also combine the forms in one legal document called the Advance Health Care Directives. Many states have this comprehensive form.

Some states have forms for a living will AND a durable power of attorney for health care. Some recognize one form only, and other states combine the two forms into one. If your state form does not allow you to express all your wishes, you can attach an additional page to the form recognized by your state.



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To obtain advance directive forms that are specific to your state, ask for the forms at your hospital or health care facility. You can also check with your state's medical or legal association.

If you use a computer, your state forms may be available online. You can also buy computer software packages that provide the legal forms for your state.



The laws in your state specify who can and cannot be your health care agent. Make sure your health care agent meets the criteria. Most states prohibit your doctor and other healthcare professionals from being your agent, unless they are related to you.

Plan before you fill out your advance directives forms. The following tips are also discussed in the “Planning for AD” section.

1. Consider your values and specify your goals.
2. Understand your treatment options and outcomes.
3. Specify your wishes.

Specify how much authority you want your health care agent to have. It can be unlimited or can follow your wishes in the living will. If your state does not have a living will form, attach a statement to the durable power of attorney document stating the limitations or power of your agent, if have any. State laws may put restrictions on what an agent can order. For example, an agent cannot order an abortion.

When you are satisfied with your directives, the document should be notarized or signed according to your state's requirements. States usually require 2 witnesses. Some require or permit a notarized signature. It is very important that you follow your state requirements, which are explained on your state form.

After signing your advance directive, give copies to:

- your durable power of attorney for health care
- your family
- your doctor

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You may want to keep a small card in your wallet or purse indicating that you have advance directives.

You can review your advance directives at any time. Inform your doctor, attorney, healthcare agent and family of any changes. Changes must be made, signed and notarized according to the laws in your state. It may be as easy to write a new medical directive instead of changing the current one since the signing requirements are the same.

In most states, advance directives are in effect until you cancel them or change them. In some states, they expire and you have to renew them every few years. Check your state forms for instructions.



You can cancel your advance directives verbally or in writing. However, it is best to do it by writing a new directive. Remember to sign it according to your state rules, and then give it to your agent, doctors and anyone else who has a copy of the previous directive. Destroy your old copy and ask them to destroy their old copies.

Preparing for AD

Merely filling out an advance directive form will not help you if it does not reflect your wishes. To have the advance directive reflect what you want, you need to identify your values and goals and understand your treatment options and outcomes.

The type of medical care you want in a terminal illness depends on your beliefs and values. Beliefs and values may be based on religious, social, financial or other considerations. They also depend on your self-image regarding the need for independence, dignity and ability to communicate with others. You should consider your whole value system before deciding on a goal statement that will guide others if you cannot express yourself.

Your goal statement could be one of dozens of statements, such as:

- I want to receive all medical treatment possible, no matter what my condition is.
OR
- I would like treatment to stop if I am in a state of permanent unconsciousness.
OR

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- I do not want to prolong my life if I am in severe continuous pain that cannot be controlled.
OR
- I do not want to prolong my life if I cannot think, talk and respond to commands.

You need to understand the diagnosis, the treatment options and their outcomes to be able to state your wishes. Ask your doctor for information. Do you understand the difference between terminally ill and irreversible coma? Do you know what resuscitation, respirator, tube feeding and kidney dialysis mean?



If you are healthy now, it is difficult to know what disease or sudden injury you may have in the future and what the alternative treatments or likely outcomes might be. That is one of the reasons why appointing a healthcare agent is important.

Write instructions carefully so they do not restrict the authority of your agent in ways you did not intend. For instance, do not say, “I do not want a respirator” if you really mean “I do not want a respirator if I am permanently unconscious.” Some statements can limit your healthcare agent, so specify if they are guidelines to be followed or strict wishes. The more you trust your healthcare agent, the more you should set guidelines rather than strict wishes.

If you have a terminal illness, talk to your doctor about the treatment options and how they may affect your quality of life. Ask how they may affect your independence, pain level and mobility. Check about your pain medications and comfort care options.

Finally, decide what health care you would want in a life-threatening situation. Relate your treatment options to your values and check which options fit your stated goal best. You can be as specific as you want. For instance, you can say, “I do not want a respirator when terminally ill but I want nutrition, hydration, pain management and kidney dialysis.”

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Conclusion

A terminal illness or a sudden injury can leave you unable to convey your decisions regarding your medical care. Advance directives tell your doctor what kind of medical care you would like to receive if you become unable to make medical decisions.

The 2 main types of advance directives are the living will and the durable power of attorney for health care. In a living will, you state your wishes about life-sustaining medical treatments if you are terminally ill. In a durable power of attorney for health care, you appoint someone else to make medical treatment decisions for you if you cannot make them for yourself.

Laws about advance directives vary from state to state. You should use the forms for your state. Forms should be available in hospitals, healthcare facilities, and your state medical and legal associations. Consult an attorney if you think your family or medical situation is complex.

Advance directives are not only for the elderly. Incapacitating accidents can hit anyone at any age. The time to write your advance directive is when you can still communicate your desires. This way, you will ensure that your healthcare wishes will be followed, and may relieve your family members of the burden of making difficult health care decisions for you.



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