

Advance Directives

A guide for patients and their loved ones



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Introduction

Thinking about things like sickness and death is not easy for anyone. Yet, each of us may be faced with choices concerning life and death at some time in our lives. How comfortable we are with these choices affects our lives and the lives of those we love.

This booklet has been prepared to help you and your loved ones feel better about making these hard choices. It will answer questions you may be asking yourself.

Today, medical advances have made it possible for many diseases to be treated successfully, adding to life expectancy and quality of life. However, life-saving advances sometimes create situations in which you or someone you love is kept alive but is unable to communicate what their choice would have been about the treatment being given. Often, doctors and loved ones are asked to make difficult treatment decisions. In some cases, the courts have been called on to make life or death decisions.

This booklet contains information about decisions you can make before a medical crisis occurs. With this information, you can choose to prepare a legal document to guide loved ones, your doctor, and other healthcare providers in caring for you. Making these decisions in advance helps your loved ones, and spares them the burden of making decisions for you in a medical crisis.

What is the Patient Self-Determination Act?

The Patient Self-Determination Act, which went into effect in December 1991, gives adults with the capability to make medical decisions for themselves, **the right to make decisions today about healthcare treatment they would want to receive in the future** if they could not communicate what they want at that time.

This law requires that hospitals, nursing homes and other health agencies give all patients information about their right to have a legal document called an advance directive. New regulations for dialysis units require that patients be informed about advance directives and the right to refuse treatment.





What is an advance directive?

An advance directive is a **legal document that informs doctors and healthcare providers of medical decisions you have made** for future crisis care if you cannot communicate these decisions for yourself. If you have an advance directive in your medical record, your doctor and other healthcare providers can take care of you according to your wishes as stated in the advance directive.

Are there different kinds of advance directives?

There are **two basic kinds** of advance directives. A **living will**, the most common type of advance directive, tells your doctor or healthcare provider in writing what type of medical care you want or

do not want if you should become unable to make these decisions for yourself. Another type of advance directive is called a **durable power of attorney for healthcare decisions** or a **healthcare proxy**. This document allows you to name someone, such as a family member or close friend, to act on your behalf to make medical decisions for you if you are unable to make these decisions for yourself. The person who acts on your behalf is called your surrogate. It is important to ask this person if they are willing to act as your “agent” and to talk about which treatments you would and would not want as well as your short- and long-term goals and values. Your state’s laws typically allow you to have both a living will and a durable power of attorney or to combine them in a single form. You may want to speak to a lawyer or contact your state or local bar association about your state’s laws concerning advance directives. You may also want to speak to a social worker at your dialysis unit.

Why is an advance directive important to me?

An advance directive is important for two reasons. First, it lets you make your own decisions about your future healthcare, even if you are not able to make decisions, such as whether to continue or stop certain treatments, at the time these decisions are needed. Second, it **tells your doctor and loved ones which treatments you want and do not want** if you are not able to communicate your wishes. Knowing your wishes helps your doctor and loved ones feel more comfortable making healthcare decisions for you.

What types of decisions can I make?

With an advance directive, you may be able to:

- **accept all treatments** recommended by a healthcare provider
- **accept some treatments** and refuse others
- **refuse all recommended treatments**

Some states may limit your ability to delegate the authority to refuse one or more types of treatment to someone else, for example, providing artificial nutrition or water. Some states may require that treatment be continued once it is accepted by your surrogate. It is important to speak with a lawyer or a social worker at your hospital or dialysis unit, or get a copy of your state's advance directive forms. (See "Where can I get advance directives forms?" on page 12.)



Which treatments can I include in my advance directive?

You can choose to receive pain medicine for comfort, even if you refuse other treatments. You may be able to accept or refuse additional treatments, such as:

- **Cardiopulmonary resuscitation (CPR)** to attempt to revive a heart that has stopped beating. (CPR includes heart massage, drugs, electric shocks, and artificial breathing machines.)
- **Tube feedings**, including giving food, water or both through a tube into a vein or the stomach.
- **Artificial respiration**, which is a machine (ventilator or respirator) that breathes for a person through a tube in the throat.
- **Antibiotics** to fight infection.
- **Dialysis**, either hemodialysis or peritoneal for kidney failure.
- **Surgery** such as heart bypass, gall bladder removal, etc.
- **Blood transfusions** or blood products, including specifying whether you would want blood only from your family members or friends.

Can an advance directive state the conditions under which dialysis could be stopped or continued?

Yes. An advance directive enables you to tell your doctor and loved ones your feelings and wishes for continued treatment if and when you are no longer able to make this decision for yourself. You may tell your surrogate to stop dialysis if you:

- Develop severe brain damage (caused by stroke, Alzheimer’s disease, etc.) and that you do not know or understand what is happening around you
- Cannot move independently (due to a stroke, paralysis, etc)
- Need to totally depend on others

You may also state that you want to continue dialysis until:

- you die from another cause
- your doctor advises your surrogate that continued treatment is not medically reasonable

Am I required by law to have an advance directive?

No. The federal law and various state laws and regulations permit patients to sign advance directives but do not require you to sign them. A dialysis unit or hospital cannot require you to sign an advance directive.



Do I need to see a lawyer to make an advance directive?

You do not need to see a lawyer to make an advance directive. Usually, a social worker at your dialysis unit or hospital can help you. To find out more about the laws in your state, you may want to speak to a lawyer, a social worker at your treatment center or senior citizen center, or contact your state or local bar association. Also, see the resources listed starting on page 23.

Where can I get advance directives forms?

You can get copies of forms from your **state or local bar association**, most **senior citizen centers**, and those **healthcare providers** who are required to give information. You can also get your state forms on the Internet from state health department websites or from the National Hospice and Palliative Care Organization (call or write for forms at the address or phone number listed on page 23).

You can list the treatments you would or would not want without using a form, but a court or medical provider may not accept it. It is best to complete an advance directive on a state-approved form.



Do advance directives forms have to be witnessed?

Advance directives must comply with your state's laws and regulations. **State laws may require that these forms be witnessed** or notarized. Banks and many other businesses have notaries who will notarize these forms. In some states, doctors and other healthcare providers are not permitted to witness advance directives.

Should I speak to my doctor before making an advance directive?

Yes. Your doctor can help explain treatment options to help you fill out the form. Also, you can let your doctor know what you would want under an advance directive and find out whether he or she would object to carrying one out. If so, you may want to find a doctor who will agree to treat you the way you want.

How will people know if I have an advance directive?

The only way your loved ones, friends, doctor or other healthcare providers will know that you have an advance directive is if you **tell them**. You may also want to give them a copy of your advance directive. The advance directive **can be made a part of your medical record**. Give a copy to your doctor and ask the hospital where you are treated to put a copy in your medical record. Some people **carry a card** stating that they have an advance directive.

Do organized religions object to the use of advance directives?

Most religions endorse the use of advance directives. The answer to this question is between you, your family, and your religious adviser, and should be discussed with them.

What if I change my mind?

As long as you are able to understand what you are doing, you can change an advance directive or cancel it at any time. If you decide to change your advance directive, you need to **tell everyone you have given copies to and give them the new one**. If you decide to cancel it, you need to get back all of the copies and destroy them.

Could my family, a partner, or friend just decide for me without an advance directive?

Hospitals and other healthcare providers usually will not let an unmarried partner or friend decide, unless that person is named in an advance directive. Some states permit the family to make a decision for the patient, even without a written advance directive. However, some states may limit the decisions families are allowed to make, even if the family knows the patient would not want the treatments. If there is a disagreement between family members or the partner, friend, or family, the patient's wishes may be difficult to determine without a written advance directive.



Without an advance directive, your family may have to go to court to have treatment stopped. In some states, this is not an option.

When does an advance directive go into effect?

State laws control when an advance directive goes into effect. Usually, your advance directive **goes into effect only if and when you are not able to make and communicate your own healthcare decisions.**



Will having an advance directive affect the quality of care I receive?

No. You will receive the same care and no one can discriminate against you, whether you have an advance directive or not.

Does having an advance directive affect my life or health insurance?

No. An advance directive does not affect life or health insurance.

Can I make a provision for donating organs or tissues in my advance directive?

Yes. You can donate organs or tissues by stating your wishes in an advance directive. However, it is important to tell your loved ones about your wishes concerning organ donation so they will carry them out. You may also want to speak to your lawyer about having a special provision in your living will stating that ventilators may be used to the extent needed to preserve your organs until the donation can be made. If your state allows you to designate your organ donation wishes in your driver's license, you should do so to ensure that your wishes are respected.

Where can I get more information?

Talk to members of your **healthcare team** or any **healthcare provider**. Healthcare professionals are obliged to give you information about advance directives. Talk with your **lawyer**, your **local bar association**, or the **Legal Aid Society** in your community or your senior citizen center. Also, see the list of resources starting on page 22.

Topics to discuss with your loved ones

Dealing with life and death issues can be difficult for many people. Yet, it is important that you decide how you feel about these things and what you would want if you should ever become unable to make your own decisions or communicate them to others.

Talking over the following questions with a loved one may help.

- What is the poorest quality of life that would be acceptable for you?
- Under what circumstances, if any, would you want to stop dialysis?
- How do you feel about death and dying?
- How important is it to you being independent and making your own decisions?
- Do you have any health problems now? How would you describe them?
- Would your religious beliefs affect how you feel about life-sustaining treatments?
- If you were terminally ill with no hope of recovery, would you want any of the following life-sustaining treatments to continue?:
 - » comfort care (use of medicine to lessen pain)
 - » cardiopulmonary resuscitation (CPR)
 - » tube feeding of food, water, or both
 - » mechanical or artificial respiration using a machine that breathes for you

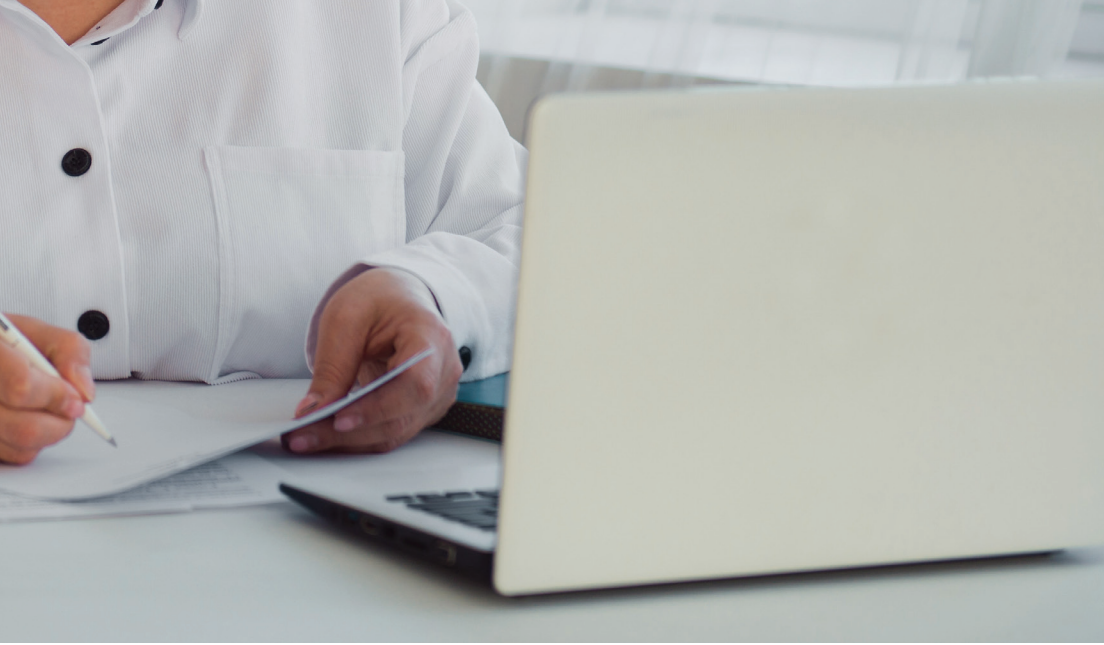
- » antibiotics to fight infection
- » dialysis
- » surgery
- » blood transfusions or blood products
- If you had severe and permanent brain damage, would you want any of the above life-sustaining treatments to continue? If so, which ones?
- If you were in a permanent coma, would you want any of these life-sustaining treatments to continue? If so, which ones?
- Do you think your family and friends would support you in your decisions about future medical care?
- Who would you want to state your decisions for you if you were unable to express them yourself? Would this person be agreeable to doing this?
- Would you want to donate any organs or tissue (heart, kidneys, liver, eyes, bone) to someone else at the time of your death? Specify which organs or tissues, if any, you would want to donate.
- Have you ever had to make a healthcare decision for someone? What was that like and were you prepared for it? What do you wish you had known at the time?



A checklist of things to consider

To be prepared for a possible medical crisis, you may want to make sure the following items are in order:

- Your will.
- Signed advance directive (living will, durable healthcare power of attorney, or healthcare proxy) complying with your state law.
- A durable power of attorney, complying with your state law, naming someone to act on your behalf on all matters other than medical (legal, financial, banking, and business matters). Your power of attorney must be “durable” to stay in effect, even if you become unable to make your own decisions or if you die.
- An inventory, including location of your bank, brokerage and other financial accounts, stock and bond holdings, real estate and business records, medical and other insurance policies, pension plans, and other legal papers.



- ❑ Names, addresses, and telephone numbers of your attorney, accountant, family members, and other loved ones, friends, and business associates who should be notified of your death or who may have information that will be helpful in dealing with estate affairs.
- ❑ A statement about your preference for funeral/ memorial services, burial or cremation instructions, and decisions about organ and tissue donation.
- ❑ Written, videotaped, or audiotaped message to family members and other loved ones, business associates, and friends.

Where can I get more information?

There are two ways to learn about the many free English and Spanish resources available to you:

- Call the NKF Cares Patient Information Help Line toll-free at **855.NKF.CARES** (855.653.2273) or email **nkfcare@kidney.org**
- Go to **[kidney.org](https://www.kidney.org)**



Other Resources

National Hospice and Palliative Care Organization (NHPCO)

1731 King Street
Alexandria, VA 22314
703.837.1500
nhpco.org

Caring Connections

A program of the NHPCO providing resources and information about end-of-life issues.
caringinfo.org

American Bar Association Commission on Law and Aging

For state-specific advance directives forms.
1050 Connecticut Avenue NW Suite 400
Washington, DC 20036
202.662.1000
service@americanbar.org
americanbar.org/aging

United Network for Organ Sharing (UNOS)

To learn more about deceased donation.
800.292.9548
unos.org



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Fueled by passion and urgency, the National Kidney Foundation (NKF) is a lifeline for all people affected by kidney disease. As pioneers of scientific research and innovation, we focus on the whole patient through the lens of kidney health. Relentless in our work, we enhance lives through action, education, and accelerating change.

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