

Advance healthcare planning

Making your wishes known



What's Inside

The Importance of Advance Healthcare Planning	2
Advance Healthcare Directives	3
Advance healthcare planning Reasons for an advance healthcare directive	
Choosing Your Medical Treatment Decision-Maker	4
Defining Your Values and Goals of Care	6
Life Support or Life-Prolonging Treatment Choices	7
Common life-support treatment choices Autopsy and organ or body donation	
Helpful Tips To Start the Conversation	11
Putting Your Wishes in Writing	12
Reviewing Your Advance Healthcare Directive	13

To watch a video about advance care planning, open the camera on your smartphone or tablet. Aim it at the following QR code. Then tap the screen over the code. You are taken to a video.



You also may watch the video at this link:
<https://www.mayoclinic.org/pe?mc=MC2107-13>

Note: The video is in English.

The Importance of Advance Healthcare Planning

Life can change in an instant

At 58 years old, Sarah considered herself to be in good health. She was active and visited her doctor regularly. Then she had a massive stroke. Suddenly, she could not speak or move half her body. She was rushed to the hospital in an ambulance.

When Sarah's family got to the hospital's intensive care unit, they found her attached to a breathing machine. She could not talk. She did not recognize her family. Her healthcare team asked her husband and adult children whether Sarah had ever told them about her medical wishes. Sarah and her family had never talked about her or her family having a serious illness or accident.

Because Sarah and her family had never thought to talk about what to do if a sudden life-changing event occurred, Sarah's family did not know what her wishes would be.

Why should I complete an advance healthcare directive?

Imagine a time when you're not able to make your own medical decisions. What if you couldn't speak for yourself? Have you thought about sharing with loved ones what would be most important to you?

An advance healthcare directive states your wishes if you cannot speak for yourself. It is a powerful tool that ensures your wishes are known and respected.

When you cannot speak for yourself, an advance healthcare directive speaks for you. In your directive, you can:

- Name a person who knows you well to make medical decisions on your behalf.
- Make known the medical treatments and care you do and do not want.
- Share your hopes and concerns about medical care.
- Express your wishes on what you would like done upon your passing.

It is important for all adults, regardless of age, to consider an advance healthcare directive. This resource explains the advance healthcare planning process. It also guides you through important topics to discuss and options to consider.

Conversations about healthcare planning are the most important steps in creating an advance healthcare directive. Have open and honest conversations with those closest to you. Talk about the type of care you want should something unexpected happen.

If you have questions after you read this resource, talk with members of your healthcare team. They can help answer questions about healthcare planning and advance healthcare directives.

Note: This resource does not talk about mental health advance directives. Talk with a mental health professional to learn more about them.



Advance Healthcare Directives

In all states, you have the right to accept or refuse some or all medical care.

If you have not named in writing a specific person to make medical decisions on your behalf, someone close to you may be asked to help make them. This may be your spouse or significant other, an adult relative, or a good friend. The person called upon to make these decisions may vary from state to state.

You have the right to say in writing what kind of medical care you want. You can name who you want to make decisions for you. You do this by filling out an advance healthcare directive.

This document is a part of your medical record. **It is used when you cannot make decisions or speak for yourself.** It also may be used if you choose not to take part in your healthcare decisions.

Advance healthcare planning

Advance healthcare planning shares with others the kind of medical care you want based on your values and healthcare goals. Advance healthcare planning lets you start conversations early. You do this before an unexpected, life-changing event occurs. The directive ensures your wishes are followed within the law of the state where you receive care. It is best to work through the process with people you trust, such as your family, friends and healthcare team.

When you are ready to put your thoughts and choices in writing, the actual form you fill out is called an advance healthcare directive. This document is used only when you cannot speak or make decisions for yourself.

Your advance healthcare directive may do one or both of the following:

- State specific medical treatments you do and do not want. These kinds of instructions are sometimes called a living will.
- Name a person, called a healthcare agent or proxy, to make decisions for you when you cannot or choose not to do so. This is called a power of attorney for healthcare. Some states call this a “healthcare surrogate.”

Reasons for an advance healthcare directive

An advance healthcare directive can lessen your family’s stress about making decisions for you. It limits confusion and helps family members agree on decisions. It also frees those close to you from guessing what you may want or not want. And it helps your family agree on certain medical care decisions.

Choosing Your Medical Treatment Decision-Maker

Choosing someone to act as your medical treatment decision-maker can be the most important part of healthcare planning. This person:

- Has your authorization to speak with your healthcare professional and healthcare team about your care.
- Has access to your medical records.
- Makes medical treatment decisions for when you cannot do so or choose not to do so.

Your medical decision-maker should be chosen by you. Your medical treatment decision-maker must:

- Be your advocate.
- Be willing to fulfill this role. The person you appoint should not be surprised to be chosen.
- Be able to remain calm during a stressful time and help your loved ones understand your choices.
- Know what is important to you to help guide decisions. Your advance healthcare directive guides decision-making.
- In situations that your directive may not cover, your medical treatment decision-maker should be able to make choices that you would have wanted.

Your medical decision-maker is referred to in different ways. They include:

- Healthcare agent.
- Healthcare surrogate.
- Healthcare proxy.

This resource uses the terms “medical treatment decision-maker” and “healthcare agent.” They mean the same as healthcare surrogate and healthcare proxy.

Your medical treatment decision-maker makes decisions on your behalf when you are not able to understand, verbalize or make those decisions on your own.

An advance healthcare directive cannot cover every possible event. Other questions may arise for your healthcare team and more conversations may be needed.

Choosing the right person

Selecting a decision-maker is a serious matter. Select someone you trust to support your wishes and be your decision-maker. This person does not have to be a family member.

A medical treatment decision-maker must be at least 18 years old. Usually, you cannot name a member of your healthcare team as your agent.

Most states offer the option to choose a primary healthcare agent and 1 to 2 alternate agents. An alternate agent steps in when your primary healthcare agent is not able or not willing to fulfill the duty.



Defining Your Values and Healthcare Goals

Knowing what is important to you can help you and others decide what kind of medical care you want in a serious or life-threatening situation. Consider the following questions:

- What is most important to you?
- What makes your life worth living?

Examples of what is important to you may include your family and friends. Other examples may include hobbies, faith and traditions. It may include the ability to live on your own without the assistance of a person or treatment.

Reflect on life events, family and cultural traditions, and spiritual beliefs. Think about experiences you or those close to you have had when dealing with a serious illness or injury.

Consider your feelings and beliefs about quality of life. Imagine a serious illness or injury that will not get better and will affect your quality of life.

For example, imagine you are not able to speak or understand what happens around you. Do you want to remain alive as long as possible? If so, your healthcare team and others who care for you need to know this.



Life Support or Life-Prolonging Treatment Choices

If you are in critical condition, several medical treatments may help save or prolong your life. These treatments may include:

- A breathing machine, also called a ventilator.
- Artificial nutrition through a feeding tube. The use of a feeding tube may be for a short time or long term.
- Mechanical circulatory support. This device helps your heart function when it is not working as it should.
- Infection-fighting medicines, also called antibiotics.
- Blood transfusions.
- Kidney dialysis.
- Amputation of limbs. For example, hand, arm or leg.

Many medical treatments may be offered to help save or prolong your life if you are in critical condition. Most medical treatments can be tried for a while and then stopped if they do not help. Your treatment team tries to lessen your pain and keep you comfortable in all situations.

Your healthcare team also may have conversations with you or your family about what to do if you become sicker, if you stop breathing on your own, or if your heart stops.

Have open communication and conversations with your family and healthcare team about different medical situations. Your healthcare team can help answer questions about specific treatments, including risks, benefits and other possible treatment options.

Common life-support treatment choices

Treatment or procedure	Why it's done	How it's done	How it may affect you
Cardiopulmonary resuscitation, also called CPR	Tries to restart your heart if it stops beating or gives you breaths if you stop breathing	<ul style="list-style-type: none">• The healthcare team presses hard on your chest to restart your heart. Air is blown into your lungs.• You may have a tube put into your mouth and down your throat to get air into your lungs if you cannot breathe.• You may receive an electric shock from an automated external defibrillator to restart your heart or return it to a regular rhythm. This device also is called an AED.	<ul style="list-style-type: none">• After CPR, you may need to be on a breathing machine.• The success of CPR depends on factors such as your age, medical condition and how long your heart was not beating before CPR was started.

Treatment or procedure	Why it's done	How it's done	How it may affect you
Breathing machine, also called a ventilator	Gives oxygen to your lungs if you stop breathing or are too ill to breathe well on your own	<ul style="list-style-type: none"> • A breathing tube is placed through your mouth, nose or an incision at the base of your neck. • The tube goes down your windpipe and into your lungs. • The tube connects to a machine called a ventilator. 	<ul style="list-style-type: none"> • You are not able to talk while you are on a ventilator. • You may need to be on a ventilator for a short time or long term.
Tube feeding	Gives you fluids and nutrients in liquid form when you cannot chew or swallow	<ul style="list-style-type: none"> • A tube is placed through your nose, mouth or abdominal wall and into your stomach. 	<ul style="list-style-type: none"> • You may need tube feeding for a short time or long term. • You cannot taste the liquid nutrients. This does not affect your ability to talk but may be uncomfortable.
Kidney dialysis	A machine that removes waste and extra fluid from your blood if your kidneys stop working or are not working correctly	<ul style="list-style-type: none"> • A tube is placed into a vein. • The tube connects to a machine that removes waste and extra fluid from your blood and then returns the blood to your body. 	<ul style="list-style-type: none"> • You may need to have dialysis several times a week. • Each session may take a few hours. • You may need dialysis for a short time or long term.

Think about whether you may want any of these treatments. If so, when and for how long would you want to have them?

Some people prefer to have all possible efforts made to prolong their lives in any situation. Some may only want treatment if a cure is possible. Others may want to focus on quality of life and controlling symptoms of illness.



Autopsy and organ or body donation

Autopsy

An autopsy examines a body after death. Sometimes, it is done because of how a death happened or when a death occurred. But you may want an autopsy to find out a diagnosis or to help researchers learn more about a medical condition or disease. If so, you may ask for an autopsy in your advance healthcare directive. Other forms need to be completed to have this arranged.

Donating your organs or body

Your advance healthcare directive can say whether you want to donate your organs, eyes and tissue for transplant. It also can tell whether you want to donate your body for scientific study. This is for the education of medical professionals. It also helps medical scientists advance their knowledge of the human body.

If you wish to donate your body, contact the medical institution or school that you want to have your body.

Helpful Tips To Start The Conversation

Injury, illness and death are not easy to talk about. But you should share your thoughts and wishes with those who may help with your medical care. They will be better able to carry out your wishes if they know what's important to you.

Talk about your values and goals for medical care with those close to you. They may include your spouse or significant other, adult children, family members, close friends, or faith community members. Share your fears and concerns about different medical treatments. Talk about whether you want cost to affect decisions about your care.

Also, talk with your healthcare agent if you have named one. Be sure those close to you know who that person is. This helps limit conflict and confusion in the future. Finally, let your healthcare team know your wishes. Both your healthcare agent and team need to know what you wish before you become seriously ill or injured.

These tips may help you talk with those close to you:

- When you meet with close family members and friends, meet as a group. This lets everyone hear the same message about your values and treatment choices.
- If that is not possible or if you have concerns about a group meeting, talk with each person alone.
- Choose a quiet setting where you won't be interrupted.
- Recognize that each person may have different values and beliefs.
- Recognize that people close to you may make different choices about their own medical care.
- Let them share their feelings, fears, concerns and choices.
- Ask them to try to understand your beliefs and wishes.

There is a lot to share and discuss. Advance care planning is a process. You may need to meet more than once to ensure everyone understands your wishes. This allows your chosen decision-makers to prepare to take on the role as your advocate.



Putting Your Wishes in Writing

Every state has its own laws about advance healthcare directives. Check with the requirements in your state. Standard rules you must follow to make your directive legally binding include:

- Your advance healthcare directive must state your name and a date.
- Your directive must name a medical treatment decision-maker, serve as a guide about your medical choices, or do both.
- You must follow your state's signature and witnessing laws. For example, you may need to sign the document before two witnesses or a notary public.

You can find forms that meet the rules of different states from websites, such as your state health department or aging agency. If you wish, you may want your healthcare team, religious or spiritual adviser, or other qualified advisers to help you prepare your advance healthcare directive. This is not required.

Keep your advance healthcare directive in a safe place where it can be found easily. Do not put it in a safety deposit box or a home safe that only you can open. Ask your healthcare team to add this document to your medical record. Give copies of your signed form to those close to you and anyone named in the document.

Reviewing Your Advance Healthcare Directive

You can update your advance healthcare directive at any time. Changes in your health, family or experiences may change your views and earlier choices. Your decision-makers' situations also may change.

Follow the 5 D's

Review your advance healthcare directive when any of the following changes occur:

- **Divorce or major family change.**
- **New diagnosis.**
- **Decline or change in health.**
- **Death of a loved one or a medical treatment decision-maker.**
- **New decisions about earlier choices and changes over time.**

You may change your advance healthcare directive form at any time. Follow the same steps you used to create it the first time.

- Fill out and sign a new advance healthcare directive form at a time when you are capable of doing so.
- Talk about your changes with those close to you, your healthcare agent and your healthcare team.
- Share updated copies of your advance healthcare directive. Ask your decision-making partners to destroy the older form.
- Ask to make your new advance healthcare directive a part of your medical record in place of your older one.

You may cancel or revoke your advance healthcare directive at any time. You may write changes on it or tear it up. If you cancel your directive, tell your healthcare agent and your healthcare team. Ask to have your directive removed from your medical record.



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Barbara Woodward Lips

PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal patient of Mayo Clinic for more than 40 years. She was a self-made business leader who significantly expanded her family's activities in oil, gas and ranching, even as she assembled a museum-quality collection of antiques and fine art. She was best known by Mayo staff for her patient advocacy and support. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic.

Mrs. Lips had a profound appreciation for the care she received at Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo Clinic honors her generosity, her love of learning, her belief in patient empowerment, and her dedication to high-quality care.

This information is for your education only. It does not replace medical advice, diagnosis or treatment. New medical research or practices may change this information. If you have questions about a medical condition, talk with a member of your healthcare team.

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MC2107-14rev0625