



## Advance Health Care Planning: Making Your Wishes Known





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# Why Health Care Planning Is Important

Sarah was 58 years old when she had a large stroke. Suddenly, she could not speak or move half of her body. She was rushed to the hospital in an ambulance.

When her family got to the hospital's intensive care unit, they found Sarah attached to a large breathing machine. She could not talk. She did not recognize her family. The physicians and nurses asked her husband and children whether Sarah had ever told them about her medical care wishes. Sarah's family had never thought to talk about this.

What would happen if you had a serious accident or illness that left you unable to make decisions or speak for yourself? Your family or other decision maker and your health care providers may not know what kind of medical care you want. An advance health care directive is a powerful tool you can use to make your wishes known.

You do not have to make an advance health care directive. You get medical care even if you do not have this kind of directive.

However, an advance health care directive speaks for you when you cannot speak for yourself. In your directive, you can:

- Name someone to make medical decisions for you when you cannot or choose not to do so.
- Make known the medical treatments you do and do not want to have.
- Do both of these things.

Advance health care directives are not just for older adults. Events you do not expect can happen at any age. It is important for all adults to have an advance health care directive.

This booklet can help you prepare an advance health care directive. Filling out the actual form is important. **However, your most important task is to work through the material in this booklet and talk about it with those close to you.** After you read this booklet, talk with your health care provider if you have questions or want more information.

***Note:** This booklet does not talk about mental health advance directives. Talk with your health care provider if you want to prepare that kind of directive.*





# What You Can Do



## Work through the advance health care planning process

Advance health care planning is a process with a number of steps. Writing an advance health care directive is just one step. This booklet guides you and those close to you through the planning process. Check off each step when you finish it.

- ☐ Learn why advance health care directives are important.
- ☐ Think about who you want to make health care decisions for you.
- ☐ Think about your values and health care goals.
- ☐ Think about what medical treatments you do and do not want.
- ☐ Share your values, goals and choices with those close to you and with your health care agent and health care providers.
- ☐ Write your advance health care directive. Follow your state's signature and witnessing laws.
- ☐ Review your advance health care directive often.



## Move past barriers

It is easy to put off advance health care planning. Most people find it hard to think about the end of life or the chance of a serious illness or injury. Maybe you have had some of these thoughts:

- **I'm healthy so I don't need an advance health care directive.** The best time to think about your health care goals and values is when you are healthy and can make your own decisions. You probably have thought ahead and made choices about other parts of your life. For example, you may have done retirement, education or estate planning. You have made choices about your job and your home. It is just as important to plan for your future health care needs.
- **I'm too young for an advance health care directive.** Life can change in an instant. Anyone can have a serious injury from a car accident, sports injury or fall. Even young adults may face a serious medical condition where they cannot choose their treatment.
- **Those close to me know what I would choose.** This may be true if you have talked with them about your health care goals and wishes. Otherwise, do not think your family members and friends know what you do and do not want. Without a clear statement from you, those close to you must make their best guess about your medical care choices during a very stressful time.
- **My doctor knows what's best for me.** There may be more than one way to treat an injury or illness. In that case, your health care providers cannot make the choice for you. While an advance directive is not the same as a medical order, it gives your providers insight into your goals and wishes.
- **I do not know what I would want.** Use the tools in this booklet to identify your goals and values and find out what is important to you. You also may want to talk with your health care provider about your current health and advance health care planning.
- **It's too hard to prepare an advance health care directive.** Most states have fairly simple rules about how to make this kind of document valid.



# Advance Health Care Directives

In all states, you have the right to accept or refuse some or all medical care. If you cannot think or speak for yourself, someone close to you, such as a spouse, an adult relative or a good friend, will be asked to help make health care decisions for you.

You also have the right to say in writing what kind of medical care you want and who can make decisions for you. You can do this with an advance health care directive. It is used only if you cannot make decisions or speak for yourself or if you choose not to take part in your health care decisions.

## Advance health care planning

Advance health care planning is more than simply filling out a form. It is a process in which you think about your values and health care goals. You decide what kind of medical care you want based on your goals and values. It is best to work through the process with the people you trust, such as your family, friends and health care providers.

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

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

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



## Reasons for an advance health care directive

**An advance health care directive is a gift** to your family and friends. If you do not have one and cannot say what you want done, your health care providers will turn to those close to you for guidance. Being asked to make medical decisions for someone else can cause a lot of stress. Studies have shown that most family members do not know what kind of care their loved ones would want at the end of life.

**An advance directive can lessen the stress** your family may feel about making decisions for you. It limits confusion. It frees those close to you from trying to guess what you would want and helps them agree on your care.

**An advance health care directive contains useful information** about what you value and what is important to you. It states your plan for medical choices if you cannot choose for yourself in the future. This can help guide your health care providers when they make treatment recommendations for you.

**It can be especially important to name a health care agent.** If you have not named a health care agent and those close to you cannot agree about your treatments, a court may need to appoint someone to make medical choices for you. This person is called a guardian.

If this happens, you have no control over who the court appoints. And you cannot be sure the medical decisions are what you would want. In addition, court proceedings can be costly. You can help to prevent this by naming a health care agent in your advance directive. This person becomes the first person the court would appoint.

Even if those close to you agree about the kind of care you want, they might not be available when a health care decision must be made for you. If that happens, your health care providers can use your advance directive to guide their actions.

However, an advance directive cannot serve as a command. Your health care providers will try to follow your wishes, but an advance directive is not a medical order.



# Choosing Your Health Care Agent

An advance health care directive cannot cover every possible event. If you are not able to make or state your own decisions, your health care providers will talk with those close to you. However, sometimes those may not be the people you would have chosen to make decisions for you. Therefore, it is important to think about naming a health care agent.

Choosing someone to act as your health care agent can be the most important part of your planning. Your agent makes medical decisions for you when you cannot or choose not to do so. Your agent uses what you say in your advance health care directive as a guide. In situations that your directive does not cover, your agent can decide what should be done.

Your agent does not have to be a family member. Do not pick someone out of feelings of guilt or duty. You may want your health care agent to be different from the person you choose to handle your finances. It may help if the person lives nearby, but he or she does not have to. You also may want to name an alternate agent in case your primary agent is not willing or able to act or cannot be reached.

Your agent must be at least 18 years old. Usually, you cannot name your health care provider as your agent.

## **Before you name a health care agent in your advance health care directive, talk with him or her:**

- Talk about what is important to you. Use the worksheets in this booklet to guide your conversations.
- Show your advance health care directive to your agent. Talk about your health care choices. Talk about any limits you placed on what your agent can decide.
- Make sure your agent will honor your choices even in hard or stressful situations.
- Make sure your agent will act based on what you want, even if others close to you want something else.





## How to choose your health care agent

Use the following chart to think about who you would trust to make medical decisions for you. At the top of each column, write the names of people you might ask to be your agent. Check the boxes under each person's name if a statement is true about him or her.

<b>Who I may ask to be my agent.</b>			
<b>This person:</b>	(name)	(name)	(name)
Is over age 18.			
Knows me well.			
Is easy to talk to about my health care goals.			
Understands and will honor my wishes.			
Will speak up for what I want rather than what other people want.			
Can make hard decisions.			
Is willing to be my agent.			
Is readily available in person or by phone.			



# Stating Your Values and Health Care Goals

Before you start to write an advance health care directive, take time to think about your values and health care goals. **This is a key step.** Your experiences, values and beliefs about life and death affect your treatment choices. Knowing what is important to you can help you and others decide what kind of medical care you would want in a serious or life-threatening situation.

What is most important to you? What makes your life worth living? Examples might include your family and friends, hobbies, faith tradition, and the ability to live on your own.

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

Consider your feelings and beliefs about quality of life. For example, imagine you have a serious illness or injury that is not likely to get better. Are there certain symptoms or situations that seem worse to you than dying? If so, your health care providers and others who care for you need to know this.





The following worksheet can help you state what is important to you. Take your time and think carefully about each section. You do not have to finish the whole worksheet at one time.

After you fill out the worksheet, share it with those close to you and with your health care agent and health care providers. **If you want this information to be part of your advance directive, you must include it in your directive.**

Your opinions and choices may change over time. Be sure to review and update this worksheet often.

### ***My Values and Health Care Goals worksheet***

I want my health care agent, health care providers and those close to me to know these things about me. I want them to use this information to help them decide about my health care.

#### **What is most important to me**

These things give me joy and purpose. They make my life worth living:

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I have these concerns or fears about medical treatment:

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## My feelings and thoughts about quality of life

**Instructions:** Put a check next to each statement if you agree. Cross out the statement if you do not agree.

I feel my life would **no longer be worth living** if I have a serious illness or injury that cannot be cured and will be in the following situation(s) for the rest of my life:

- ☐ I cannot think clearly or make my own decisions.
  - ☐ I cannot understand what others say or interact with others in a meaningful way.
  - ☐ I cannot recognize my family and friends.
  - ☐ I cannot feed, bathe or take care of myself.
  - ☐ I cannot walk.
  - ☐ I cannot control my bladder or bowels.
  - ☐ I have severe pain almost all the time and need medicine that makes me think less clearly, and there is little chance that this will improve.
  - ☐ I have other severe symptoms almost all the time, for example, nausea or trouble breathing, and there is little chance that this will improve.
  - ☐ I must use machines to stay alive and there is little chance that this will improve.
  - ☐ I need to live in a nursing home or assisted-care facility.
  - ☐ I can no longer do these activities: \_\_\_\_\_
- 

**OR**

- ☐ I feel my life is always worth living no matter what I can or cannot do or how sick I may be.

# Making Your Treatment Choices

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Many medical treatments may be offered to help save or prolong your life if you are in critical condition. Examples include breathing machines, feeding or fluids through tubes, and attempts to restart your heart. Other examples include surgery, kidney dialysis, devices to help your heart work, medicine to fight infections, and blood transfusions.

Most medical treatments can be tried for a while and then stopped if they do not help. Your health care providers will try to lessen your pain and keep you comfortable in all situations.

Talk with your primary health care provider. He or she can help answer questions about specific treatments including the risks, benefits and other possible treatment options. Your provider can identify other issues to think about and clarify things that are unclear.

Also talk with your family members and health care agent about the kind of treatments you do and do not want.

## **Common life-support treatment choices**

Certain treatments and procedures often are used at the end of life or for serious conditions such as a coma from which you probably will not recover. The following chart talks about some of these treatments. Ask your health care provider to tell you more about these and other life-support measures.

Treatment or procedure	Why it's done	How it's done	How it may affect you
<b>Cardiopulmonary resuscitation, or CPR</b>	Tries to restart a normal heartbeat if your heart stops beating or beats very irregularly and your breathing stops.	<ul style="list-style-type: none"> <li>• Health care providers press very hard on your chest many times and try to blow air into your lungs.</li> <li>• They may place a tube in your throat to get air to your lungs.</li> <li>• Sometimes they give an electric shock to your heart.</li> </ul>	<ul style="list-style-type: none"> <li>• After CPR, you may need to be on a breathing machine.</li> <li>• The success of CPR depends on factors such as your age, medical condition and how long your heart was not beating before CPR began.</li> <li>• Can cause injuries such as bruises or broken ribs.</li> </ul>
<b>Breathing machine, or ventilator</b>	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"> <li>• A tube is placed through your mouth, nose or an incision at the base of your neck.</li> <li>• The tube goes down your windpipe and into your lungs.</li> <li>• The tube connects to a machine called a ventilator or respirator.</li> </ul>	<ul style="list-style-type: none"> <li>• You may not be able to talk while you are on a breathing machine.</li> <li>• You may need a breathing machine for a short time or long term.</li> </ul>

Treatment or procedure	Why it's done	How it's done	How it may affect you
<b>Tube feeding</b>	Gives you fluids and nutrients in liquid form when you cannot chew or swallow.	<ul style="list-style-type: none"> <li>• A tube is placed through your nose, mouth or abdominal wall and into your stomach.</li> </ul>	<ul style="list-style-type: none"> <li>• You may need tube feeding for a short time or long term.</li> <li>• You cannot taste the liquid nutrients.</li> </ul>
<b>Kidney dialysis</b>	Takes out waste and extra fluid from your blood if your kidneys stop working.	<ul style="list-style-type: none"> <li>• A tube is placed into a vein.</li> <li>• The tube connects to a machine that removes waste and extra fluid from your blood and then returns the blood to your body.</li> </ul>	<ul style="list-style-type: none"> <li>• You may need to have dialysis several times a week.</li> <li>• Each session may take a few hours.</li> <li>• You may need dialysis for a short time or long term.</li> </ul>

Think about whether you would want any of these treatments. If so, when and for how long would you want to have them? Some people want to have all efforts to prolong life made on their behalf in any situation. Others want treatment only if a cure is possible. Some people weigh how much longer a treatment may help them live against the quality of life they may have during that time. Others do not want certain treatments even if they are very ill.



## Other choices you can make

### *Do not resuscitate (DNR) order*

If your heart stops, you may not want to have health care providers try to restart it. In order for this to happen, a physician must issue an order called a “Do not resuscitate” order, a “DNR” order or a “no code.” The purpose of a DNR order is to allow a natural death if your heart stops.

Your health care provider can put a DNR order in your medical chart if you ask for it. You or a person allowed to make decisions for you must give consent for a DNR order. This means that unless you or the person who can make decisions for you states something else, your health care team will try to restart your heart with CPR.

**An advance health care directive is not the same as a DNR order.** You do not have to ask for a DNR order in your advance directive. And you don’t need an advance directive to have a DNR order.

### *Donating your organs or body*

Your advance directive can say whether you want to give your organs, eyes and tissues for transplant. It also can say whether you want to donate your body for scientific study. If you wish to donate your body, contact the medical institution or school that you want to have your body. Ask about costs and what steps to follow.

### *Autopsy*

An autopsy examines a body after death. Sometimes it is done because of how a death happens, such as when a medical examiner investigates a death. However, 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 it in your advance directive. Or you may sign an autopsy consent form.



Use the following worksheet to state what is important to you. Take your time and think carefully about each section.

Remember, this is *your* plan — there are no right or wrong choices.

After you fill out the worksheet, talk about it with those close to you and with your health care agent and health care providers. **If you want this information to be part of your advance health care directive, you must include it in your actual advance directive form.**

Your opinions and choices may change over time. Be sure to review and update this worksheet often.

### ***My Treatment Choices worksheet***

The following is what I want and do not want for my health care if I am not able to decide or speak for myself.

#### **My treatment preferences**

If possible, I would like my primary health care provider to be:

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Whenever possible, I would like to receive health care at:

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Many medical treatments may be used to try to improve my medical condition or to prolong my life. Examples include a breathing machine, artificial feeding or fluids through tubes, attempts to start a stopped heart, surgeries, kidney dialysis, antibiotics and blood transfusions. Most medical treatments can be tried for a period of time and then stopped if they do not help.

**When I am not able to decide or speak for myself, I have the following preferences about my health care.**

**Instructions:** Put your initials next to the choice you prefer for each situation below. Cross out the choices you do not want.

***Treatments to prolong my life***

If I reach a point where it is reasonably certain that I will not recover the ability to think clearly and interact with others in a meaningful way:

\_\_\_\_\_ I want all possible efforts to prolong life made on my behalf, even if it means I may remain on life-sustaining equipment such as a breathing machine or kidney dialysis for the rest of my life.

**OR**

\_\_\_\_\_ I want my health care providers to try treatments to prolong my life for a period of time. However, I want to stop these treatments if they do not help or if they cause me pain and suffering.

**OR**

\_\_\_\_\_ I want to stop or withhold all treatments to prolong my life.

In all situations, I want to receive treatment and care to keep me comfortable.

***Cardiopulmonary resuscitation (CPR)***

If my heart or breathing stops:

\_\_\_\_\_ I want CPR in all cases.

**OR**

\_\_\_\_\_ I want CPR unless my health care providers determine that I have any of the following:

- An injury or illness that cannot be cured and I am dying.
- No reasonable chance of surviving if my heart or breathing stops.
- Little chance of surviving long term if my heart or breathing stops and it would be hard and painful for me to recover from CPR.

**OR**

\_\_\_\_\_ I do not want CPR but instead want to die a natural death.

### ***Pain relief***

I understand that my health care providers will try to keep me comfortable in all situations. They will try to lessen my pain. If I am in pain, I would also like these things for comfort and support:

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If pain relief could shorten my life or change how alert I am, I would want:

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### **My wishes and thoughts about death**

#### *How and where I would like to die*

If I am nearing my death, I would like these things for support and comfort:

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If I am dying, I would like to be: (*check one*)

☐ at home

☐ in a hospital

☐ not sure

#### ***Religion or spirituality***

I am of the \_\_\_\_\_ faith or think of myself as \_\_\_\_\_.

I am a member of the \_\_\_\_\_ church, synagogue or faith community. Please try to let them know of my death.

I want my health care providers to know these things about my religion or spirituality:

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## *My other wishes*

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### **After I die**

#### *Donating my organs, tissues or body*

**Instructions:** Check the box next to your choice or leave the boxes blank if you prefer.

- ☐ I **do** want to donate my eyes, organs and tissues, if possible.  
       \_\_\_\_\_ I have indicated this choice on my driver's license or state-issued identification card.  
       \_\_\_\_\_ I am registered on my state's online donor registry.
- ☐ I **do not** want to donate my eyes, organs and tissues.
- ☐ I want to donate **only** my \_\_\_\_\_.
- ☐ I **do** want to donate my body for scientific research. I have made arrangements for this with the following institution: \_\_\_\_\_
- 
- ☐ I **do not** want to donate my body for scientific research.

#### *My other requests*

Use this space to write other requests you may have such as autopsy, cremation or burial:

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# Sharing Your Wishes and Choices

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Injury, illness and death are not easy to talk about. But you should share your views 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 health care with those close to you, such as your spouse, adult children, other family members, close friends or members of your faith community. Share your fears and concerns about different medical treatments. Talk about whether you want cost to affect decisions about your health care.

Talk about the reasons for your values, beliefs and goals. Explain your feelings about medical care and the reasons for your choices. Offer to answer questions they may have about your choices. Your thoughts may differ from theirs.

Also talk with your health care providers and your health care agent if you name one. The more they know about you, the better able they will be to carry out your wishes.

If you plan to name a health care agent, be sure those close to you know who that person is. This helps to limit conflict and confusion in the future.

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

- Meet as a group. Then everyone hears the same messages about your values and treatment choices.
- If that is not possible or 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 each person may make different choices about medical care.
- Let them share their feelings, fears and choices.
- Ask them to try to understand your beliefs and wishes.

Also be sure to talk with your health care agent and your health care providers about what's important to you. They need to know your wishes before you become seriously ill.

# Putting Your Wishes in Writing

Each state has its own laws about advance health care directives. Common rules you must follow to make your directive legally binding include the following:

- Your advance health care directive must be in writing, state your name and be dated.
- It must name a health care agent, give instructions about your health care choices or do both.
- You or someone with the power to sign for you must sign the directive at a time when you can understand and state your health care wishes.
- You must follow your state's signature and witnessing laws. For example, you may need to sign in front of two witnesses or a notary public.

You can find forms that meet the rules of different states from many websites, such as a state health department or aging agency. You may want to have your health care team, religious or spiritual advisor or other qualified advisor help you prepare your advance directive. But you do not have to.

Keep your advance health care directive in a safe place where it can be found easily. **Do not** put it in a safety deposit box or in a home safe that only you can open. Give copies of your signed form to those close to you.

Also give copies to your health care agent, your primary health care provider and other providers you see regularly. Ask your health care provider to add this document to your medical record.



# Reviewing Your Advance Health Care Directive

Changes in your health, family situation or views on life may cause you to change your mind about some of your choices. Your health care agent's situation may change too.

Look over your advance health care directive every few years. Review it at the time of major life events, such as marriage, the birth of a child or the death of someone close to you. Decide whether you want to change any of your earlier choices.



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

- Fill out and sign a new advance health care directive form at a time when you are able to understand and state your health care wishes.
- Talk about your changes with those close to you and with your health care agent and your health care team.
- Give these people copies of your new form. Ask them to destroy the older one.
- Ask to have your new advance health care directive made a part of your medical record in place of your older one.

You may cancel your advance health care directive at any time. There are many ways to do this such as writing on it or tearing it up. If you cancel your directive, write or tell your health care provider and health care agent, and ask to have your directive taken out of your medical record.



## A Final Word

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Please take time to think about what you have read in this booklet. Talk about your situation, your choices and your wishes with your primary health care provider, health care agent, family and friends.

Try to be as specific as possible when you write your advance health care directive. Once you create your directive, it should become part of your medical record. Be sure to tell those close to you that you have prepared such a document.

### For more information

If you have questions about this information, call the appropriate Mayo Clinic number and ask for your health care provider.

**Phoenix and Scottsdale, Ariz.**

480-301-8000

**Jacksonville, Fla.**

904-953-2000

**Rochester, Minn.**

507-284-2511

Other numbers you may call

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