



Your Guide to Choosing a Health Care Proxy

How to choose an advocate who could speak for you — and help you have a say in your health care.



the **conversation** project

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National Brain Tumor Society

A Proxy: Your Health Care Advocate

We can't plan for everything. But we can talk about what is most important — in our life, and in our health care — with those who matter most.

Talking with the important people in our life can bring us closer together. It also helps us create the foundation of a care plan that's right for us — a plan that will be available when the need arises.

The Conversation Project wants to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. An important step in that conversation is to choose a health care proxy (also known as a health care agent, power of attorney for health care, or surrogate decision-maker). That's the one person who speaks on your behalf if you can't make your own health care decisions. If you were unable to speak due to an accident or illness, your proxy would advocate for you. That's why it's really important to plan now, since we can't predict the future.

We created this guide to help you choose a health care proxy. Read our [Conversation Starter Guide](#) for guidance on starting and continuing conversations about your care through the end of life.

This document does not seek to provide legal advice.



We'll help you choose a proxy step by step.

You can take your time! It's all about what works best for you.

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If you are completing this document on a computer, first save it to your desktop with a name you can easily find again. Then open your saved document and type in your answers. (Otherwise, what you type will not be saved.)

Completing it on your computer will create a digital document that you can easily share with others.

STEP 1

Learn About Choosing a Proxy

Getting the kind of health care that works for you – now and through the end of life – means talking about what matters to you with the people who matter most. It also means choosing the one person you'd want to speak for you, and advocate for the care that's right for you, if you're unable to speak for yourself. That person is a health care proxy.



What does it mean?

Your proxy can talk with your doctors, nurses, and other members of your care team, and read your medical records. They would use what they know about the health care you want to make decisions about tests, procedures, and treatments if you became too sick to make those decisions yourself.

There are three steps in naming a health care proxy:

1. Picking a person
2. Having a conversation with that person
3. Adding that person's information to your official documents

It's important to know that although your proxy's decisions on your behalf could have some financial impact, the proxy does not make financial decisions for you – they only speak for you about health care decisions.

A health care proxy may also be called: health care agent, power of attorney for health care, or surrogate decision-maker.

The legal document that allows a proxy to speak for someone else may be called a health care proxy form or an advance directive. The advance directive document includes both a health care proxy form and a living will, where specific medical treatments a person would or would not want can be listed.

➤ Why do you need one?

We can't predict the future, or what it might mean for our health and our ability to receive the health care that's right for us. The COVID-19 pandemic and unexpected accidents have shown us that even healthy people can suddenly need someone else to speak for them and help make health care decisions. And as we get older, we're less likely to be able to make decisions for ourselves: half of all people over 65 admitted to a hospital need help from someone else.*

"It always seems too soon, until it's too late."

➤ When do you need one?

Everyone over age 18 needs a proxy. Up until then, a parent or legal guardian is automatically considered a child's proxy. But after age 18 that is no longer the case. In fact, in most places, if you are over 18 and have not filled out a proxy, the legal system will choose one for you.

That's why it's so important to choose a proxy for yourself, as soon as you can. It's also a good idea to review your proxy choice:

- At the start of each decade of your life: when you turn 20, 30, 40, 50, etc.
- Around a major life event, like going to college; getting married, divorced, or widowed; or the birth or adoption of a child
- If you are planning to go on a major trip
- If you are diagnosed with a serious illness

* Torke AM, Sachs GA, Helft PR, et al. Scope and outcomes of surrogate decision making among hospitalized older adults. *JAMA Intern Med.* 2014;174(3):370-377.



STEP 2

Think About It

Now that we've explained why it's so important to have a proxy, let's help you think about how to choose a proxy.

First, there are some things you need to know about the best people to choose as your proxy. You may be considering a spouse/partner; family member like an adult child, sibling, cousin, niece or nephew; friend; neighbor; or community member.

Here are some things to think about as you make your choice:

- It's best to choose just one person as your proxy.
 - Different states and countries have different rules — some only allow you to name one proxy, while others let you name more than one.
 - In general, since different proxies could disagree about a situation, it's best to keep things simple with one proxy.
 - It's a good idea to name an alternate proxy in case your main proxy is unavailable for some reason.

- There are some laws that could affect your choice.

The rules can vary between states and countries, so it's best to check your local laws. In the United States, here are examples of how some states decide who you can choose to be your proxy:

- Your proxy must be over 18. In Alabama and Nebraska, your proxy must be over 19.
- Patients who live or stay in a health care facility, such as a long-term care facility, can't choose an employee of that facility (unless the person is a relative).
- You can't choose a member of your current health care team (your doctor, nurse, etc.) as your proxy.

- If you aren't sure who to choose as your proxy, it's still a good idea to fill out an advance directive.

- Even if you don't name a specific person when you fill out your advance directive, you can still have a say in your care by listing medical treatments that you would or would not want if you became seriously ill or unable to make your own decisions.
- You can then choose a proxy later. For some people, it's not possible to choose a family member — and you don't have to. For example, it could be a friend, a more distant relative, or someone at your place of worship.
- If you don't name your proxy and you are married, in most states your spouse may automatically become your legal proxy. If you think your spouse might find it too difficult to make decisions such as starting or ending treatments if you were seriously ill, it's probably a good idea to choose someone else as your proxy.

STEP 3

Pick Your Person

Now that you know more about what's involved in choosing a proxy, it's good to think about the best qualities of a proxy as you make your decision. Your proxy is the person who will make medical decisions for you if you can't speak for yourself. They may have to make tough, quick decisions on your behalf — including decisions about treatments, procedures, or even life support. Some people are more comfortable with that than others.

Here are some things to help you think about who you will ask to be your proxy:

- Will the person make decisions that follow your wishes?
 - Your proxy may need to make certain decisions on your behalf — even if their own wishes are different from yours. This may be emotionally difficult for some people.

- Will the person be comfortable making quick decisions in a changing situation?
 - Your proxy doesn't need to be a medical expert, but they may need to make quick decisions as information becomes available about your care, such as whether to give you antibiotics for an infection or insert a feeding tube if you can't eat.
 - That's why your proxy should be someone who could understand your values and wishes in any situation. That way, they can make decisions more easily about the kind of care that's right for you. Will the person be comfortable speaking up on your behalf?
 - Your proxy may need to ask doctors and other members of your care team questions to make sure they understand the situation.
 - Your proxy may need to advocate strongly on your behalf to get you the care that's right for you — not only with your health care team, but with others in your life who may not agree with the proxy's decision for you.

➤ What if I don't want to pick a family member?

- That is OK! Sometimes a spouse, adult child, sibling, or other family member may not be the best choice to follow your wishes.
- Your proxy doesn't need to be someone local; the person you choose can act as your proxy and make choices for you over the phone.
- If you do choose someone who's not a family member, certain members of your family may have questions. It's a good idea to let family know who your proxy is, and why you made that decision, before a medical problem happens.
- You can say something like, "I want you to be able to focus fully on our time together, rather than on health care decisions that may cause you stress."

➤ Here are some people you can consider.

- Parent
- Spouse/partner
- Adult child (at least 18 years old)
- Sibling
- Cousin
- Friend
- Trusted neighbor
- Member of a faith community

Who is the one person you would want to choose?

Who is your alternate choice, as your backup proxy?

STEP 4

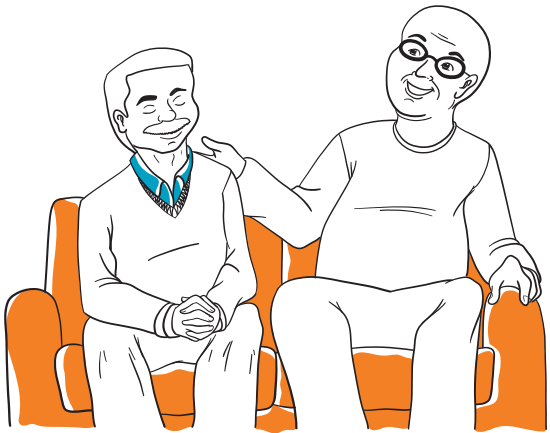
Talk About It

Once you've chosen a proxy, it's time to talk about it with the person you chose. Here are some tips to help you have that conversation.

- ▶ Start by asking if the person is comfortable taking on this role.
 - You can say, "I'd like you to be my health care proxy. That means you would be the person who would make medical decisions for me if I can't make them for myself. I would share what matters to me in my care, so you wouldn't have to guess. Is this something you would be comfortable doing?"
 - Ask, then sit back and listen to their answer. Do your best to answer any questions they might have. And tell them it's OK if they need to say no.
- ▶ Talk about what it means to be a proxy.
 - They would have the legal power and responsibility to make medical decisions for you if you're unable to make them for yourself.
 - They can talk with your doctors, read your medical records, and make decisions about tests, procedures, and other treatment.
 - In the United States, they are entitled to full access to your medical information under federal privacy laws (known as HIPAA).
 - They will need to ask questions and get information to make decisions for you, and at times may need to advocate for you.
 - You can give the person our [Guide to Being a Health Care Proxy](#) for more information about what it means.

➤ Make sure your proxy understands what matters to you.

- It's really important to talk to your proxy about what matters to you — about the kind of health care you'd want now and through the end of life.
- When these conversations happen before a health challenge or crisis, it will be easier for your proxy to make decisions for you if it becomes necessary.
- Our [Conversation Starter Guide](#) is a good place to start. You can work through that guide yourself first, then talk over your answers to the questions with your proxy so that you can have a detailed conversation about what matters to you.
- You can also use your own state's or country's proxy/advance directive form to talk about more specific medical scenarios and what would be right for you.
- If you are diagnosed with a serious illness, you could ask your proxy to join an upcoming doctor's appointment in person or by phone, so they understand your diagnosis, treatment, and decisions.



STEP 5

Write It Down and Share It

Now, it's a good idea to record your conversation with an important legal document to be sure your choices are followed. This is called an advance directive. It has two parts.

1. Your Health Care Proxy

This is the part of the advance directive where you name the person you have chosen to make health care decisions on your behalf, if needed, as well as an alternate if your first choice is unavailable. Be sure to have a conversation — and keep talking — with these people to be sure they understand what matters to you.

2. Your Living Will

This is the part of the advance directive where you describe your preferences and wishes for your health care if you cannot speak for yourself. These are many of the same things that you have thought about and discussed throughout this guide.

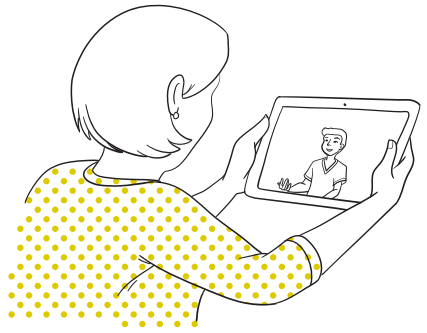
▶ You can fill out your advance directive yourself!

Here's how to get one in the US.

- Every state and most countries have their own advance directive forms. In the United States, the NHPCO (National Hospice and Palliative Care Organization) can help you find the right forms in your state (nhpco.org/advancedirective).
- Most states need two witnesses to sign your proxy, saying that they have seen you sign the form. In most states and countries, your proxy cannot sign as a witness. In many states, you may have your advance directive notarized instead of signing before two witnesses. Some states require a notary and two witnesses. Check the above site for more information about your own state.

- ▶ Once you complete your advance directive, make sure your proxy has all the information they need, so they are prepared to speak for you if needed.
 - Give your proxy a copy of the health care proxy form and any other advance directive documents you completed.
 - Give your proxy a list of names and contact information for your primary care doctor and any other important members of your health care team.
 - Give your proxy's name and contact information to your primary care doctor and any other important members of your health care team.

- ▶ Tell other important people in your life who you've selected as your proxy.
 - It's important to share your advance directive with more than your proxy alone, and provide copies to anyone who may need them.
 - For example, if you pick an adult child to be your proxy and you have other children, they should all be aware of what matters to you in your health care and know who you have chosen as your proxy.
 - Talk to anyone who may have a say in your care through the end of life. Talk to those you don't want to have a say, too – and let them know who will be speaking for you instead.
 - Talk to anyone who can help you have a say in your care through the end of life and provide copies of your advance directive to anyone who may need them.
 - If you want tips on talking about what matters to you with your health care team, visit our [Guide for Talking with a Health Care Team](#).



STEP 6

Keep Thinking and Talking

Sometimes, situations or relationships change, and you may choose to change your proxy. It's OK to change your proxy. In fact, it's a good idea to think regularly about whether your proxy is still the right person.

- ▶ If you do want to make a change
 - Fill out a new form and tell the people close to you, along with your health care team, about the change.
 - File and keep your previous advance directive form, noting the date when it was replaced by the new one.
 - Let your previous proxy know you've decided to make a change. You can say, "I've been thinking about it, and I've decided to change my proxy. Thank you for agreeing to do this for me, but I won't need you to take on this responsibility anymore."
- ▶ No matter who your proxy is, keep talking.
 - It's important to keep the conversation with your proxy going.
 - From time to time, think about the questions in our [Conversation Starter Guide](#), and tell your proxy if anything changes about the health care that works for you – now and through the end of your life.
 - As stated above, it's good to have a new conversation around certain events, such as the arrival of a baby, the start or end of a marriage, or a new decade of life.

Stories About Picking a Proxy

Here are some real-world examples of how a proxy can be chosen and named.

> Siblings and Partners

When Andre set out to choose his proxy, he thought about choosing his sister. They were extremely close. He realized, however, that if something unexpected were to happen to him she would be devastated, and he didn't want to put her in that position. He'd want her nearby for comfort.

Andre decided to pick his partner Dylan, who would be equally upset, but was more comfortable talking to doctors and making decisions like this. At first, he felt guilty, but then realized he'd be putting his sister in a potentially difficult position if he'd chosen her.

> The Just-Right Answer

Joy, a married mother of grown children, needed to choose her proxy. She talked to her husband first. He told her, "I could never unhook you from anything. I will hold your hand for 20 years even if you're too sick to respond."

Joy then went to her son. He said, "Got it, Mom — I know you don't want any extreme measures to save your life. I'll never let anyone hook you up."

Finally, Joy went to her daughter, who said, "I hear what's important to you, and I know any choice I would make should depend on your prognosis and chances for recovery."

After hearing that her daughter had really listened to her, while her husband and son weren't able to put aside their own thoughts and feelings in decision-making, Joy chose her daughter as her proxy.

> Chosen in Good Faith

Sofia, age 59, and Alex, age 42, attended a Conversation Starter Workshop at their church. Sofia had health issues and knew she needed a proxy – but was single, with no kids, and estranged from her family. Alex was a healthy single person with two brothers – neither of whom she'd be comfortable asking to be her proxy.

At the end of the workshop, the speaker encouraged attendees to choose a proxy. He added that if people didn't have an obvious choice in their lives, they might find someone in the group capable of serving. Sofia and Alex had sat next to each other many times in church, so they turned to each other and started talking. After meeting for coffee several times and talking about what matters to them and what's important in a proxy, they felt comfortable choosing each other.

Choosing a proxy and sharing what matters to you is an important step to getting the health care that's right for you. For more help having the conversation, visit our [Conversation Starter Guide](#).

This document has been modified by the following organization: