





Your Guide to Being a Health Care Proxy

How to be an advocate for someone you care about, as their proxy — and help them have a say in their health care.



the conversation project

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National Brain Tumor Society

A Proxy: A 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.

Discussing what matters most can bring us closer to the people who matter most, and help them make sure they get the kind of health care that's right for them, now and through the end of life.

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). You may be reading this because someone has asked you to speak on their behalf, as their proxy, if they become unable to make their own health care decisions. It's an honor to be asked to fill this role for someone. It shows their trust in you to make important decisions for them, and it can deepen your relationship.

You may need to advocate for this person if they have a serious accident or illness and cannot speak for themselves. That's why it's really important to understand your role now, since we can't predict the future.

We created this guide to help you be the best possible health care proxy. It's a good idea to read this along with our <u>Conversation Starter Guide</u>. For more information, see our <u>Guide to Choosing a Health Care Proxy</u>.

We'll help you learn to be a proxy step by step.

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This document does not seek to provide legal advice.

STEP 1

Learn About It



First, let's review what it means to be someone's proxy.

As a proxy, you can talk with doctors, nurses, and other members of the care team, and read medical records to help make decisions for the person you're representing. By talking with this person now about the kind of health care that works for them, you can prepare to make decisions about tests, procedures, and treatments if they became too sick to make those decisions themselves.

It's important to know that although decisions you make on behalf of the person you are representing could have some financial impact, as a proxy, you do not make financial decisions. You only speak 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. STEP 2





Someone has asked you to be their health care proxy. It's an honor to be asked to take this step for someone. How can you be prepared to answer them and possibly act as their proxy?

Things to consider:

As you think about whether you'd be comfortable acting as a proxy, it's helpful to understand the role of a proxy.

There is no perfect proxy.

- As a proxy, you will only need to try your best. No one expects you to be perfect.
- A proxy bases decisions on what they know matters to the person they're representing.
- In any situation, your goal will be to give a voice to what you know about the person's values.
- You would need to speak for the person if they were unable to speak for themselves.
 - That means putting aside your own priorities and preferences and thinking about what the person you are speaking for would want.
 - You would need to be able to answer the question, "If they could speak and make their own decision, what would they say?"

As a proxy, you would have certain legal responsibilities.

- As a proxy, you would have the legal power to make medical decisions for the person if they can no longer make them for themselves.
 - In order to do that, you would have full access to the person's medical information under the health care privacy law known as HIPAA.
 - You would talk to the person's doctors and gather information on their condition so you could make an informed decision about tests, procedures, and other treatment for the person.
- Serving as a proxy does not make you responsible to pay for that person's care.

Preferences aren't always possible.

- Sometimes it's not possible physically, medically, or financially to follow every one of someone's health care preferences, and that's OK.
 - For example, someone might prefer to spend their last days at home, but their condition may make that impossible.
 - In that case, you would do your best to make a decision based on the information you have, and try to find other ways to meet the person's preferences based on what matters most to them. For example, if they have to enter a nursing facility to get medical support that is not available at home, you may be able to choose a facility that lets the person have a beloved pet with them.

It's OK to say no.

- Although it's an honor to be asked, there are many reasons that being a
 proxy may not be right for you. Maybe you're just not comfortable with the
 person's preferences, or making such a big decision for them. Or maybe
 it's just not something you can take on at this time.
 - In that case, it's best to be honest and kind.
 - Thank the person for asking you, tell them you are honored, and let them know why it won't work for you, if you feel comfortable sharing this information.

STEP 3



Talk About It

If you've said yes to being someone's proxy, you can feel proud of the role you will play in reassuring the person that someone will be there for them to make health care decisions now and through the end of life.

We will help you feel prepared. When you've agreed to be someone's proxy, it's important to understand your person's preferences. That way, if you need to represent them, you can help them get the kind of health care that works for them.

It's a good idea to set up a time right away to talk with this person about what matters to them and how you can best advocate for them. Allow for plenty of time to talk — it's important not to rush these conversations, and they can happen in multiple sittings.

Understand what matters.

- Our <u>Conversation Starter Guide</u> is a helpful resource for you to use in speaking with the person you've agreed to represent. It can help you understand what matters most to them in their life and in their care through the end of life.
- You can go through the guide with them and talk over their answers to questions that would help you make informed choices for them.
- It's also a good idea to talk to the person you will represent about their advance directive — specific instructions for their care preferences in certain situations.
- It's important to have these conversations before a medical crisis so you can be ready to make decisions for the person if the time comes.

- Here are some things you can say to start a conversation and get the information you need to fulfill your important role as a proxy. You can see our <u>Conversation Starter Guide</u> for more ideas.
 - Do you have any worries about your health?
 - What do you need to address to feel more prepared (examples: finances, property, legal documents, relationships, health care situations)?
 - Do you have any fears, concerns, or mistrust about where or how you receive health care?
 - Who do you want (or not want) to be involved in your health care?
 - When you look ahead to the future, are there important events or dates you hope you're there for?
 - Are there kinds of treatment you would want or not want (examples: resuscitation attempts, ventilation, feeding tube)?
 - If your health condition changed, when would it be OK with you to shift from trying to cure an illness to trying to enjoy the end of life as much as possible?

Speak up if you need to.

- If there's something you don't know about what matters to the person you will advocate for, have another conversation with them and ask questions.
- If the time comes when you need to speak for the person as their proxy, it is important to speak up with doctors, nurses, and other members of the care team. That way, you can make sure you understand the situation and can make the best possible decisions for the person.
- You can ask the care team to repeat information, explain things that aren't clear, and help you understand the details of a certain test or treatment. For example, you could say:
 - I'd like to speak to you about (person you represent)'s wishes.
 - I don't understand what you just said.
 - I have some questions I would like to ask you. When would be a good time for you?
- You may want to write down questions in advance, so you remember them.

Since your role as a proxy is so important and it can bring you closer to the person you represent, make sure to have all the information you need to answer the question, "What would they want?"

For more information on becoming a proxy from the American Bar Association, visit <u>Making Medical</u> <u>Decisions for Someone Else: A How-To Guide</u>.

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