



# Your Guide to Being a Healthcare Agent

How to advocate for someone you care about, as their agent - and help them remain in control of their healthcare.

*Summit Care Partners*  
the **conversation** project

# An Agent: A Healthcare Advocate

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

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

Summit Care Partners and The Conversation Project want 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 healthcare agent (also known as a healthcare proxy, power of attorney for healthcare, or surrogate decision-maker).

You may be reading this because someone has asked you to speak on their behalf, as their agent, when they become unable to make their own healthcare 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 will need to advocate for this person when they are in a serious accident or illness and cannot speak for themselves.

The healthcare agent makes medical treatment decisions for a person while that person is incapacitated, based on the person's preferences and instructions for care. All adults are encouraged to choose a healthcare agent before a medical crisis.

We created this guide to help you be the best possible healthcare agent. It's a good idea to read this along with our Conversation Starter Guide.

For more information, see our Guide to Choosing a Healthcare Agent.

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We'll help you learn to be an agent step by step.

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# Learn About It



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

The healthcare agent makes medical treatment decisions for a person while the person is incapacitated, based on the person's preferences and instructions for care. A meaningful conversation between that person and the healthcare agent, along with documenting those preferences in a living will, helps the healthcare agent know what to do when that person becomes unable to speak for themselves.

An agent only makes decisions when the person cannot communicate their own decisions and have been deemed incapacitated.

Every state has its own laws defining the assessment process regarding decisional capacity.

Every adult has the right to make their own decisions until it is determined that the person can no longer make their own decisions.

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

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

As an agent, you may need to need to suddenly make decisions about treatment options (such as hospitalization, IV fluids, and mechanical ventilation), and where the person might want to receive care, such as at home, in a hospital, or a care facility.

Additionally, you might need to make decisions about:

- Releasing medical records
- Choosing which healthcare professionals should provide care
- Other medical care and services, such as medicine, surgery, tests, etc.
- Visitation - who is and is not allowed to visit the person during this time

*It's important to know that although decisions you make on behalf of the person you are representing could have some financial impact, as an agent, you do not make financial decisions.*

***You only speak about healthcare decisions.***

You should be able to answer "**yes**" to the following questions:

- Am I willing to accept this role and all of its responsibilities?
- Am I willing to discuss what matters most to the individual?
- Can I follow the person's decisions and preferences even if I do not agree with them?
- Am I able to make these decisions in stressful, emotional situations?
- Am I comfortable advocating for this person's preferences and instructions during potentially complex conversations with medical professionals?

If you answered "**no**" to any of these questions, you should talk to the person who chose you about your concerns.

# Think About It



Being chosen as someone's healthcare agent means that this person trusts you to act on their behalf when they are incapacitated. How can you be prepared to answer them and possibly act as their agent?

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### Things to consider:

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

- There is no perfect agent:
  - As an agent, you will only need to try your best. No one expects you to be perfect.
  - An agent 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 when they are 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 an agent, you would have certain legal responsibilities:

As an agent, you would have the legal power to make medical decisions for the person when they are no longer able to make them.

- In order to do that, you would have full access to the person's medical information under the health care privacy laws 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 an agent does not make you responsible for paying 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 healthcare preferences, and that's okay.

- For example, someone might prefer to spend their last days at home, but their condition might 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 receive medical support that is not available at home, you may be able to choose a facility that allows the person to keep a beloved pet with them.

> It's okay to say no:

Although it's an honor to be asked, there are many reasons that being an agent 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.

# Talk About It



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

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

It's a good idea to set up a time to talk with this person right away about what matters most 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 sessions.

➤ Understand what matters:

An advance care planning facilitator is a great resource to help guide your conversation if you remain unsure of how to start or what questions you want to ask.

- You can go through our Conversation Starter Guide with them and discuss the answers to the questions to help you make informed choices for them.
- Utilizing an advance care planning facilitator allows you both to participate in a comprehensive, guided conversation while documenting preferences and instructions in a living will, and it is a great resource for answering questions and concerns that arise.
- It's important to have these conversations before a medical crisis - so you can be ready to make decisions for the person when 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 an agent. You can see our Conversation Starter Guide for more ideas.
  - What spiritual, religious, or cultural beliefs do you have that would impact your care, and which should I clearly understand?
  - What does “quality of life” mean to you? ’
  - Do you have any fears, concerns, or mistrust about where or how you receive healthcare?
  - Whom do you want (or not want) to be involved in your healthcare?
  - When you look ahead, are there important events or dates you hope to be there for?
  - Are there kinds of treatment you would want or not want? (examples: resuscitation attempts, ventilation, feeding tube)
  - When would you want doctors to stop treatments to keep you alive?

➤ 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.
- When the time comes for you to speak on behalf of the person as their agent, it is important to speak up with doctors, nurses, and other members of the care team. That way, you can ensure you understand the situation and make the best possible decisions for the person.
- You can ask the care team to repeat information, clarify anything that isn’t clear, and help you understand the details of a specific 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 an agent 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?”

Being a healthcare agent is a significant responsibility, and it is natural to feel some trepidation about taking on such a role.

It is also an opportunity to support and advocate for someone you care about during a difficult time in life.



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