



Your Guide to Choosing a Healthcare Agent

How to choose an advocate who will speak for you when you are unable to speak for yourself.

Summit Care Partners
the **conversation** project

Healthcare Agent: Your 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.

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.

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). That's the one person who speaks on your behalf when you can't make your own healthcare decisions. When you were unable to speak due to an accident or illness, your agent 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 healthcare agent. Read our Conversation Starter Guide for guidance on starting and continuing conversations about your care through the end of life.



We'll help you choose an agent 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 an Agent

Getting the kind of healthcare 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, when you're unable to speak for yourself. That person is a healthcare agent.

What does it mean?

Your agent 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 when you become too sick to make those decisions yourself.

There are three steps in naming a healthcare agent:

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 agent'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 healthcare decisions.

A healthcare agent may also be called: healthcare proxy, power of attorney for healthcare, 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.

➤ 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 healthcare 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 healthcare 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 too early, until it's too late."

➤ When do you need one?

Everyone over age 18 needs an agent. Up until then, a parent or legal guardian is automatically considered a child's agent. 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 an agent, the legal system will choose one for you.

That's why it's so important to choose an agent for yourself, as soon as you can. It's also a good idea to review your agent 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 an agent, let's help you think about how to choose an agent.

First, there are some things you need to know about the best people to choose as your agent. 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 agent:
 - Different states and countries have different rules — some only allow you to name one agent, while others let you name more than one.
 - In general, since different agents could disagree about a situation, it's best to keep things simple with one primary agent.
 - It's a good idea to name a successor agent in case your primary agent 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 healthcare agent.

- Your agent must be over 18. In Alabama and Nebraska, your agent must be over 19.
- Patients who live or stay in a healthcare 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 healthcare team (your doctor, nurse, etc.) as your agent.

➤ If you aren't sure who to choose as your primary agent, 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 an agent 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 agent and you are married, in most states your spouse may automatically become your legal agent. 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 agent.

STEP 3

Pick Your Person

Now that you know more about what's involved in choosing an agent, it's good to think about the best qualities of an agent as you make your decision. Your agent is the person who will make medical decisions for you when you can't speak for yourself. *They may have to make quick, difficult 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 agent:

- Will the person make decisions that follow your wishes?
 - Your agent will 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 agent 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 agent 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 agent may need to ask doctors and other members of your care team questions to make sure they understand the situation.
 - Your agent will need to advocate strongly on your behalf to get you the care that's right for you — not only with your healthcare team, but with others in your life who may not agree with the agent's decision for you.

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

- That's okay! Sometimes a spouse, adult child, sibling, or other family member may not be the best choice to follow your wishes.
- Your agent doesn't *need* to be someone local; the person you choose can act as your agent and make choices for you over the phone if necessary.
- 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 agent 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 healthcare 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 agent?

STEP 4

Talk About It

Once you've chosen a primary healthcare agent, 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 healthcare agent. That means you would be the person who would make medical decisions for me when 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 an agent:
 - They would have the legal power and responsibility to make medical decisions for you when 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 Healthcare Agent](#) for more information about what it means.

➤ Make sure your agent understands what matters to you:

- It's really important to talk to your agent about what matters to you — about the kind of healthcare 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 healthcare agent to make decisions for you when 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 agent so that you can have a detailed conversation about what matters to you.
- You can also use your own state's or country's healthcare 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 agent to join an upcoming doctor's appointment in person or by phone, so they understand your diagnosis, treatment, and decisions.
- Using an advance care planning facilitator is a great opportunity to participate in a comprehensive, guided conversation, and be able to discuss any questions or concerns either of you might have. A facilitator also assists with completion of your advance directive documents.



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 Healthcare Agent (& Successor Agent)

This is the part of the advance directive where you name the person you have chosen to make healthcare decisions on your behalf, when 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 healthcare when 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 United States:

- Every state and most countries have their own advance directive forms. In the United States, CaringInfo (A Program of the National Alliance for Care at Home) can help you find the right forms in your state (caringinfo.org/planning/advance-directives/).
- An advance care planning facilitator will have your state's advance directive forms.
- Most states need two witnesses to sign your advance directive, saying that they have seen you sign the form. In most states and countries, your agent 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 or your advance care planning facilitator for more information about your own state.

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

- Tell other important people in your life who you've selected as your agent:
 - It's important to share your advance directive with more than your agent alone, and provide copies to anyone who may need them.
 - For example, if you pick an adult child to be your agent and you have other children, they should all be aware of what matters to you in your healthcare and know who you have chosen as your healthcare agent.
 - 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.



STEP 6

Keep Thinking and Talking

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

- If you do want to make a change:
 - Fill out a new form and tell the people close to you, along with your healthcare team, about the change.
 - File and keep your advance directive form, noting the date when it was created and make a note that it has replaced a previous version.
 - Let your previous healthcare agent know you've decided to make a change. You can say, "I've been thinking about it, and I've decided to change my primary agent. 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 agent is, keep talking:
 - It's important to keep the conversation with your chosen agent going.
 - From time to time, think about the questions in our Conversation Starter Guide, and tell your agent if anything changes about the healthcare 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 an Agent

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

> Siblings and Partners

When Andre set out to choose his agent, 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 healthcare agent. 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 primary healthcare agent.

> 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 healthcare agent — 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 primary agent.

At the end of the workshop, the speaker encouraged attendees to choose an agent. 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 healthcare agent, they felt comfortable choosing each other.

Choosing an agent and sharing what matters to you is an important step to getting the healthcare that's right for you. For more help having the conversation, visit our Conversation Starter Guide.

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