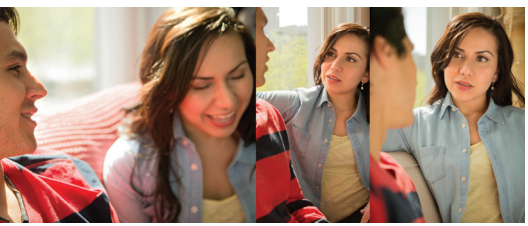
How to Choose a Health Care Proxy

&

How to Be a Health Care Proxy



Institute *for* Healthcare Improvement

the conversation project

CREATED BY THE CONVERSATION PROJECT AND THE INSTITUTE FOR HEALTHCARE IMPROVEMENT

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.

We developed the **Conversation Starter Kit** as a useful tool to help people have conversations with their family members and loved ones about their wishes.

In addition to having the conversation, it's important to choose a **health care proxy** — the person who will make decisions about your medical care if you become unable to make them for yourself. (This person is also called a **health care agent** or **Power of Attorney for Health Care.**)

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How to Choose a Health Care Proxy

Who would you want to make medical decisions for you if you were unable to make them for yourself?

A **health care proxy** (also called a **health care agent** or **Power of Attorney for Health Care**) is the person you choose to make health care decisions for you if you're too sick to make them for yourself. Your proxy can talk with your doctors, consult your medical records, and make decisions about tests, procedures, and other treatment.

We cannot overstate the importance of choosing a proxy. Too many people — including half of all the people over 65 who are admitted to a hospital — are unable to make decisions for themselves.*

*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.

Make sure you have chosen someone you trust to speak for you in case you are unable to speak for yourself!

USEFUL DEFINITIONS

It can be hard to keep track of the various names that are used — both for the **PERSON** you choose and the **DOCUMENT** you fill out. Here's the gist:

Names for the PERSON you choose:

- **Health care proxy**: The person you choose to make decisions about your medical care if you become unable to make them for yourself (*My brother is my health care proxy.*)
- **Health care agent**: Same as above (*My brother is my health care agent.*)
- **Power of Attorney for Health Care:** Same as above (*My brother is my Power of Attorney for Health Care.*)

Names for the DOCUMENT you fill out:

- **Health care proxy**: Can ALSO refer to the legal document in which you designate the person to make medical decisions for you (*I filled out my health care proxy.*)
- **Advance directive**: A general term for any written health care instruction specifying your wishes or naming a proxy (*I filled out my advance directive.*)

To keep it simple, we're using **"proxy"** for both the **PERSON** and the **DOCUMENT.**

Step 1

WHEN is the right time to choose your proxy?

As we say in The Conversation Project,
"It's always too soon, until it's too late."

Up until age 18, parents automatically serve as their children's proxy. After 18, no one can access your medical record or make decisions for you unless they have written permission. **So everyone age 18 or older should complete a health care proxy form — even if they're perfectly healthy. If you're over 18 and haven't yet chosen a proxy, the time is now!**

EARLY

When you come of age — at age 18 or 21

OFTEN

It's good to review your choice of proxy at the start of each decade — when you turn 20, 30, 40, 50, 60, 70…

AT A MAJOR LIFE EVENT

- When you go to college
- When you get married or divorced
- When you have children
- When you become eligible for Medicare
- When you are going on a major trip
- When you are newly diagnosed with a serious illness

Health care proxy forms

- Each state has its own health care proxy forms, which are available for free. For more information: ***www.caringinfo.org***
- You do not need a lawyer to fill out your health care proxy form. Some states require having two witnesses sign, saying that they have seen you sign the form. (Your proxy cannot sign as a witness.)

Step 2

WHO should you choose to be your health care proxy?

Remember: **Your proxy is the person who will speak for you if you're unable to speak for yourself.**

Being a proxy is not for everyone. Your proxy may have to make tough, quick decisions on your behalf — including decisions about treatments, procedures, even life support. Here are some questions to help you think about who you would like to be your proxy:

? Will the person make decisions that are in line with your wishes?

- Will the person be okay making decisions on your behalf **even if their own wishes are different from yours?**
- Will the person have a hard time making decisions on your behalf **because their emotional connection to you would get in the way?**

CHOOSING THE RIGHT PERSON

A young woman in St. Louis originally wanted her mother to be her proxy. But then she realized it might be too painful for her mother to be in that position. So she chose a friend instead.

? Will the person be comfortable speaking up on your behalf?

- Will the person stand up for you?
- Will the person be okay with asking questions of doctors and other busy providers?
- Will the person ask for clarification if they do not understand a situation or an answer?

? Will the person be good at making decisions in changing circumstances?

Your proxy might have to make fairly quick decisions along the way — things like *"Your mother has pneumonia. Do you want us to start antibiotics?"* or *"Your brother is no longer able to take food by mouth. Do you want us to insert a feeding tube?"* Your proxy doesn't need to be a medical expert, but he/she should be someone who can apply your general values to specific circumstances and make decisions that are consistent with your expressed wishes.

NOTE: We don't want to make being a proxy sound too hard. (Nobody finds it easy to interrupt a busy doctor and ask him/her to "say that again, slowly"!) At the same time, it's important to consider who has the qualities you need when the time comes.

? WHO might be a good choice to be your proxy?

- ☐ Mother/Father
- ☐ Spouse/Partner
- ☐ Son/Daughter
- ☐ Sister/Brother
- ☐ Friend
- ☐ Other

Frequently Asked Questions

What if I want to choose more than one person to be my proxy?

It's generally advisable not to name two people to serve as co-proxies — because if they disagree, the situation can become complicated. The rules for this vary from state to state: some states allow you to name co-proxies, and some states limit you to one at a time.

In all states, you can name an alternate proxy if your primary proxy is unable to serve. It's a good idea to name an alternate proxy.

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

Sometimes people feel obligated to choose their spouse, or their adult child — even when they don't think that person is the best choice to follow their wishes. **It's okay** if you want to choose someone who's not a family member — even if your family pushes back at first.

NOTE: Be sure you tell your family beforehand who your proxy is. You can say, ***"I chose [my friend] because she'll be able to speak for me without the emotional conflict my family members may face."*** Even if it creates tension, it is better for them to find out who your proxy is before a medical crisis.

TELLING THE FAMILY AHEAD OF TIME

A woman in Florida was the proxy for her husband. But his adult children from a previous marriage didn't know he had selected his current wife as his decision maker. If he had told them about this ahead of time, it would have allowed them to get used to the idea before a health crisis came up.

What if I don't want my spouse/partner to be my proxy?

Sometimes it is difficult for a partner or spouse to be a proxy. For example, they may find it too difficult to agree to ending treatment for their loved one, even when you have made your wishes very clear. In this case, it might be wiser to choose someone else.

A GOLDILOCKS STORY

A woman who lives in Hawaii wanted to choose a proxy. She started by asking her husband. His answer, "I could never unhook you from anything. I will hold your hand for 20 years even if you're not responsive." (Too hot.)

Next, the woman asked her son. His answer, "I got it, Mom. I know you don't want any extreme measures to save your life. I'll never let anyone hook you up." (Too cold.)

Finally, she asked her daughter. The daughter answered, "I hear what's important to you. And I know it depends on your prognosis and your chances for recovery." (Just right.)

? Are there any rules about who CANNOT legally be my proxy?

Yes. Here are a few simple restrictions on who you can choose to be your proxy:

- You may not choose someone under age 18 (in Alabama and Nebraska, under 19).
- If you're a patient in a health care facility, you may not choose an employee of that facility (unless the person is a relative).
- You may not choose a member of your current health care team (your doctor, nurse, etc.).
- Again, be sure to check your state's rules.

What if I want to change my proxy?

? Sometimes people change their mind about who they want to be their proxy. Maybe the person they chose moved away, or the relationship changed — or for any reason, the person no longer feels like the right one for the job.

It's okay to change your proxy. If you do, be sure to fill out a new proxy form and tell your family and your health care team about the change.

You can just say, ***"I've been thinking it over, and I wanted you to know that I've decided to change my proxy. Thank you so much, but I won't need you to take on this responsibility for me."***

? What if I don't have someone I would like to be my proxy?

Someone may not come to mind immediately. Remember that your proxy doesn't have to be a family member. It could be a friend, a more distant relative, or someone at your place of worship.

Even if you don't appoint a person to be your health care proxy (your agent), it's a good idea to complete the proxy form (the advance directive), listing medical treatments that you would or would not want if you became terminally ill and unable to make your own decisions.

TWO PEOPLE CHOOSE ONE ANOTHER

Two women attended a Conversation Starter Kit workshop at their church, at the end of which participants were encouraged to choose a health care agent/ proxy. One of the women, age 32, had multiple health issues and knew she needed to have a health care proxy. But she was single, had no children, and was estranged from her family of origin. She felt she had no one to ask to be her agent. The other, age 54, was a healthy single woman with two brothers she felt she couldn't rely on to be her health care proxy and had put off choosing one for years. The women often sat next to one another during Sunday service. One day, their pastor asked them if they might consider being health care agents for one another. They turned to each other and nodded.

? Is a health care proxy the same as an advance directive?

"Advance directive" is a general term for any written health care instruction specifying your wishes or naming a proxy. It encompasses both health care proxy forms and living wills. It states which medical treatments you want or don't want if you are no longer able to make decisions on your own (for example, if you're in a coma).

Step 3

HOW should you prepare your proxy?

First of all, ask if the person can take on this role.

Start by asking the person if they are comfortable being your proxy, and then sit back and listen to their answer. Do your best to answer any questions they might have. And make it very clear that it's okay for them to say no.

You might start by saying, ***"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'm unable to make them for myself. I'll tell you more about what my values and goals are so you won't have to guess. What do you think — is this something you would be comfortable taking on?"***

Make sure your proxy understands his or her responsibilities.

Your health care proxy has the legal power — and responsibility — to make medical decisions for you if you're unable to make them for yourself. Your proxy can talk with your doctors, consult your medical records, and make decisions about tests, procedures, and other treatment. Your proxy is entitled to full access to your medical information under federal privacy laws (commonly known as HIPAA).

Tell your proxy you will share what matters to you, so that they'll have a solid foundation for making decisions. And you'll make sure everyone in the family knows whom you've picked as your proxy and that you have discussed your wishes with them.

Make sure your proxy understands your wishes and choices.

It's important that your proxy really understands your wishes and choices regarding end-of-life care. Having these conversations before a crisis, when there's time to talk things through, will give your proxy a strong foundation for making decisions when the time comes.

Set aside time to go through the **Conversation Starter Kit** together, talking over your answers to the questions in the Kit and your preferences on the "Where I Stand" scales. (It's a good idea to write down your responses to the Conversation Starter Kit, so that it serves as a reference and a reminder for your proxy.) Additionally, you could then review your state's advance directive form to talk about some specific medical scenarios and your preferences (like resuscitation, feeding tube, etc.).

Make sure your proxy has all the necessary information:

- Give your proxy a copy of your health care proxy form and any other advance directive documents you have filled out.
- Make sure your proxy knows the names and contact information for your primary care provider and any other providers.
- Make sure your primary care provider knows the name and contact information for your proxy.

What is the most important thing you want your proxy to keep in mind?

After you talk through the **Conversation Starter Kit** with your proxy, and talk through some medical decisions that might come up and how you feel about them, it might be helpful to summarize it all: "What matters most to me is _____." (For example, ***being able to recognize my children; being in the hospital with excellent nursing care; being able to say goodbye to the ones I love.***)

How to Be a Health Care Proxy

Remember:

Being a good proxy means speaking for the person when they're unable to speak for themselves.

Being a proxy is not about what YOU want; it is about what the person you're speaking for wants. In any situation where you have to act as a proxy, ask yourself, ***"If he/she were able to speak and to make a decision right now, what would he/she say?"***

A SISTER TO HER BROTHER

"This was Mom's choice. Now we have to be her voice."

Being a good proxy is about doing your best.

Being a good proxy isn't about being perfect — it is about doing the best you can. Sometimes it's not possible to follow the person's wishes: maybe they said they want to be home, but it is not physically, financially, or safely possible to keep them there. In that case, just do the best you can. "The best you can do is the best you can do."

A LETTER FROM A MOTHER TO HER FAMILY

"If you are faced with a decision that you're not ready for, it's okay. I'll try to let you know what I would want for various circumstances, but if you come to something we haven't anticipated, it's okay. And if you come to a decision point and what you decide results in my death, it's okay. I will die because of my illness or my body failing or whatever. You do not need to feel responsible."

What if someone asks you to be their proxy, but you are not comfortable saying yes?

It's okay to decline the invitation. For whatever reason, you might not feel you can take it on. Maybe you just are not comfortable with the person's preferences. Or maybe you feel like you could not bring yourself to make a decision that might shorten their life. Or maybe you are just too overwhelmed to take on the responsibility.

If you are not comfortable saying yes, the best thing you can do is lovingly say no. Be honest. Say ***"Thank you for asking me — I am honored. I just do not think I can do a good job being your proxy."***

What if it is not possible to follow a person's wishes?

One of the hardest situations is when a loved one has clearly stated a wish, but it isn't a feasible option — medically, financially, or because of limited family support. Perhaps the most common example of this is when a loved one has expressed a clear wish to die at home, but it's not a feasible option.

There are no easy answers. But one thing you **can** do is find out what matters most to the person about "home" — and then do your best to come as close as possible. That might mean bringing in family pictures. Or a favorite piece of clothing or a favorite blanket. Or playing favorite music. Or having a visit from the family dog or cat. Or a taste of favorite food.

For more guidance on how to be a good proxy, see Making Medical Decisions for Someone Else: A How-To Guide — at *www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Proxyguide.html*

A checklist for being a good proxy:

☐ Make sure you understand your legal responsibilities as a proxy.

As a health care proxy, you have the legal power — and responsibility — to make medical decisions for the person if they are no longer able to make decisions for themself. As a proxy, you will talk with your person's doctors, consult their medical records, and make decisions about tests, procedures, and other treatment. The proxy is entitled to full access to medical information under federal privacy laws (commonly known as HIPAA).

☐ Make sure you understand your person's wishes and choices.

It is important that you really understand your person's wishes and choices regarding end-of-life care. It's a good idea to go through the **Conversation Starter Kit** with your person, talking over their answers to the questions in the Kit and their preferences on the "Where I Stand" scales. And it is a good idea to talk over the person's advance directive.

Having these conversations before a medical crisis, when there is time to talk things through, will give you a strong foundation for making decisions when the time comes.

☐ Be comfortable speaking up.

Even if your person's doctor or nurse is in a hurry, it's okay to ask questions. You could say:

- ***"I'd like to speak with you about my mother's wishes."***
- ***"I don't understand what you just said."***
- ***"I have some questions I'd like to ask you. When would be a good time for you?"***

You might want to write down your questions beforehand, just to make sure you don't forget anything.

In all these cases, the "North Star" for any decision is always the same:

What would your person (your mother, your husband, your best friend) want?

Cut out card, fold, and laminate for safe keeping.

NOTICE TO HEALTH CARE PROVIDER

I have a health care proxy.

The original signed document is located at

_____

My Health Care Proxy

Name _____

Address _____

City, State, Zip _____

Phone _____

the conversation project
www.theconversationproject.org

Signature _____

Phone _____

City, State, Zip _____

Address _____

Name _____

INFORMATION ABOUT ME

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www.theconversationproject.org

E-MAIL US

conversationproject@ihi.org

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