



How to Be a Health Care Agent

This information explains health care agents and advance care planning. It will help you understand and carry out your loved one's wishes if they cannot speak for themselves.

The topics we discuss include:

- What is a health care agent?
- What does a health care agent do?
- How can you become a health care agent?
- How can a health care agent help your loved one?
- What is advance care planning?
- How can you talk with your loved one about advance care planning?

The job and responsibility of being a health care agent can be hard to think about. It can also be hard to talk about with your loved one. This resource can help you with this.

What Is a Health Care Agent

A health care agent is a person who makes healthcare decisions (choices) for someone. They will make these decisions if someone is not able to make healthcare decisions for themselves.

A health care agent is also called a:

- Proxy
- Surrogate
- Representative

A health care agent can be a:

- Friend
- Family member

- Partner
- Anyone your loved one trusts

The person who is a health care agent must be at least 18 years old. They cannot be a member of your loved one's care team.

Choosing a health care agent is an important part of advance care planning. Advance care planning is the process of thinking about important health issues that may come up in the future. Talking with your loved one about these issues helps them make clear decisions now, while they are still able to. This way, you and your loved one will not have to worry about making decisions at a time of crisis.

Being a Health Care Agent

As a health care agent, you will be in charge of making healthcare decisions for your loved one. You may need to make these types of decisions:

- Choices about medical care, including treatments, tests, and surgeries.
- Where your loved one will get medical care, such as a hospital, nursing home, or hospice facility.
- Choices about life support and end-of-life care.
- Whether to take legal action to defend your loved one's rights and wishes.
- Whether to apply for Medicare, Medicaid, or other programs or insurance benefits.

Your role as a health care agent starts when your loved one can no longer make decisions for themselves. Their healthcare providers will decide when this happens. They will tell you when you must start your role as a health care agent.

Understanding your role

As a health care agent, you will:

- Talk with your loved one's healthcare providers.
- Review their medical records.
- Make decisions about their treatments, tests, and surgeries.

You will have full access to your loved one's medical information. You will only be able to make decisions about their medical care. You will not have legal authority (power) to make decisions about their finances (money) or anything else.

Remember, being a health care agent is not about what you want for your loved one. It's about what your loved one wants for themselves. Sometimes, their wishes may go against what you want for them.

When you make a decision, ask yourself: "If they could talk right now, what would they say?"

It's also important to talk with your loved one about their wishes before they become very sick. Have these conversations with them while they are still healthy and can speak for themselves. It will help you know what healthcare decisions to make for them when the time comes.

For more information, read the "Talk About Their Choices and Goals" section of this resource.

There may be times when following your loved one's wishes is not possible. There may be physical, medical, financial, or safety reasons why you cannot choose what they wanted. It's not easy to go against their wishes, especially when they cannot speak for themselves. Do the best you can.

For example, they may say they want to die in their home. But when the time comes, it's not possible to move them from their hospital bed. Instead, you can bring personal items from their home, such as blankets and photos.

What Is an Advance Directive?

Advance directives are legal documents. They have written instructions about someone's decisions for their medical care. Healthcare providers will look at advance directive documents for guidance. They will do this if your loved one is not able to communicate or make decisions for themselves.

The 2 most common types of advance directives are a health care proxy and a living will. Each state has its own laws for advance directives. However, most states accept a health care proxy, a living will, or both.

What is the difference between a health care proxy and a living will?

A **Health Care Proxy** form is a legal document that names someone's health care agent. Your loved one can name more than 1 health care agent on the form. They can name a primary (first choice) and secondary (second choice) health care agent. If the primary agent is not available in an emergency, healthcare providers can contact the second person.

A **living will** is a legal document that states someone's wishes for their medical care. It will go into effect if your loved one can no longer make decisions for themselves. In the living will, they can name the medical treatments they want or do not want. They can also describe the situations when they would want these treatments, and when they would not want them.

Depending on the location, you may be able to bring a pet. This can help make their setting as close to home as possible.

How to say no

If you're not comfortable taking on the role of a health care agent, it's OK to say so. You may not agree with your loved one's wishes. You may not be comfortable with making end-of-life decisions for them. No matter what your reason is, it's OK to be honest.

You can say: "Thank you for asking me. I'm honored, but I do not think I can do a good job being your health care agent." This way, your loved one can think about who else they may want as their health care agent.

Communicating with your loved one's family

As a health care agent, you have the right to make decisions by yourself. But you may want to talk with your loved one's family while you're making decisions. Talking openly lets everyone know what's going on. It also lets them feel like they are a part of the process. This can also give you a support system during an emotional time.

Review the information in the next section with your loved one. It will help you get ready for your role as a health care agent. It's important to review this from time to time because their thoughts and choices may change.

Talk About Their Choices and Goals

Talk with your loved one about the care they want, and why. This will help you understand their wishes and make sure they are followed.

Talking about your loved one's choices and goals can be hard. To help you start, here are some questions you can ask them now. They also serve as examples of conversations you can have with your loved one. It's important to talk about their choices and goals now, while they are still able to speak for themselves.

Remember, advance care planning is a process. It's not something that gets done all at once. It's important to review their choices from time to time and change them when you need to.

Here are examples of questions you can ask your loved one:

Tell me about situations that would make you want to limit medical treatments.

How much are you willing to go through so you can live longer?

Palliative care

Palliative care is also called supportive care. It helps to ease pain and other symptoms of illness. It's an approach to care that focuses on you as a whole person, not just your illness. It includes physical, emotional, and spiritual care for you and your loved ones.

You can get palliative care at any point during an illness, even while you're still getting treatment. Palliative care does not need to be end-of-life care. It's not the same as hospice care.

Here's an example of a question you can ask your loved one:

What are your feelings about palliative care?

Hospice care

While palliative care can start at any point of an illness, hospice care starts after you stop getting treatment. It starts when you have 6 months or less to live. It provides end-of-life comfort and support to you and your loved ones when treatment is not working or wanted anymore. You can often get hospice care in your home. It can also be given in nursing homes, assisted living facilities, and hospice centers.

Here are examples of questions you can ask your loved one:

Do you want to get hospice care at the end of your life?

What are some things that would make the end of your life most peaceful?

What are your biggest worries or fears about the end of your life?

Treatments to keep someone alive

Sometimes healthcare providers try to keep someone alive with medical devices, such as ventilators and feeding tubes. These devices are used in life-saving treatments that we describe below. Talk with your loved one about which treatments they may want.

- Ask them about situations when they would want these treatments.
- Ask them about specific treatments they would not want.

Here are examples of these types of treatments.

Cardiopulmonary resuscitation (CPR)

Cardiopulmonary resuscitation (KAR-dee-oh-PUL-muh-NAYR-ee ree-SUH-sih-TAY-shun) or CPR, can be given when a heart stops beating. To try to restart your heart, healthcare providers do chest compressions while putting air into your lungs. They push down hard and fast on your chest to keep blood flowing throughout your body. They may also use a defibrillator (dee-FIH-brih-LAY-ter). This is a machine that sends electric shocks to your heart.

Here are examples of questions you can ask your loved one:

What are your feelings about having CPR?

In what situations do you want CPR?

In what situations do you not want CPR?

If you stop breathing while your heart is still beating, healthcare providers will try to put air into your lungs. They may do 1 or all 3 of these treatments:

- **Mouth-to-mouth resuscitation.** This is when they blow air into your mouth to send oxygen to your lungs.
- **Intubation (IN-too-BAY-shun).** This is when they place a breathing tube in your airway.
- **Mechanical ventilation (VEN-tih-LAY-shun).** This is when they place you on a breathing machine called a ventilator (VEN-tih-LAY-ter).

Ventilators are machines that help you breathe. A breathing tube connected to the ventilator is placed down your throat and into your trachea (windpipe). This helps the ventilator put air into your lungs. The process of placing the breathing tube down your throat is called intubation. Because the breathing tube can be uncomfortable, you will be sedated (sleepy) while on the ventilator.

Here are examples of questions you can ask your loved one:

What are your feelings about being placed on a ventilator?

In what situations do you want to be placed on a ventilator?

In what situations do you not want to be placed on a ventilator?

Do not resuscitate (DNR) order

Some people do not want to get medical treatment if their heart stops beating. They would rather have a natural death. They can put this decision in writing by setting up a do not resuscitate (DNR) order.

A DNR order is also called a do not attempt resuscitation (DNAR) order or an allow natural death (AND) order.

A DNR order is a legal order that you can set up while you're still well. It tells healthcare providers that you do not want CPR if you stop breathing or your heart stops beating.

Even if your living will says you do not want CPR, it's helpful to also have a DNR order.

Here are examples of questions you can ask your loved one:

What are your feelings about having a DNR order?

In what situations do you want a DNR order?

In what situations do you not want a DNR order?

Artificial hydration and nutrition

Artificial hydration and nutrition is treatment that gives you liquids and food. There are times when you are unable to drink or eat by mouth. This treatment replaces the way you normally eat and drink. It adds to it if you sometimes can eat or drink.

You may be fed through a feeding tube that puts liquids and food into your body. The tube is placed into your nose, down your throat, and into your stomach. Some people may need to have a feeding tube for a long period of time. If this is the case, you will have surgery to place it directly into your stomach or intestine.

You may also get an IV (a small, thin, flexible tube) that puts nutrition directly into your vein.

Artificial hydration and nutrition can be used if you're not able to eat or drink enough during treatment. It can also be used to keep your body alive if you're unconscious (for example, in a coma).

Here are examples of questions you can ask your loved one:

What are your feelings about artificial hydration and nutrition?

In what situations do you want to get artificial hydration and nutrition?

In what situations do you not want to get artificial hydration and nutrition?

Other notes:

Document Their Choices

Once you agree to be someone's health care agent, your loved one will need to put it in writing. They can do this by filling out a Health Care Proxy form. They can get the form from their healthcare provider or a Patient Representative at MSK. They can also get the form from the websites listed at the end of this resource.

In New York State, a Health Care Proxy form becomes legal once your loved one signs and dates it. They must sign and date the form in front of 2 witnesses. Anyone who is age 18 or older can be a witness, except the health care agent. Your loved one's witnesses will also need to sign and date the form. Your loved one does not need a lawyer or a notary to fill out the form.

Advance care planning protects your loved one's right to make their own healthcare decisions. It lets you carry out their wishes if they are not able to speak for themselves. Choosing a health care agent and documenting their choices is just the beginning for your loved one. Once they've started the process, it will be easier to talk about changes that may come up in the future. Make sure to talk about and review your loved one's plan every time their treatment goals change.

Contact Information

If you have questions about advance care planning, talk with your loved one's care team. You can also talk with a staff member from our Patient Representatives Department by calling 212-639-7202.

Resources

CaringInfo

www.caringinfo.org

This organization has many resources for advance care planning, including a Health Care Proxy form from every state.

State of New Jersey Department of Health

www.state.nj.us/health/advancedirective/ad/what-is

This website has general information about advance care planning and information specific to New Jersey.

New York State Department of Health

www.health.ny.gov/professionals/patients/health_care_proxy

This website has general information about advance care planning and information specific to New York. It offers the New York Health Care Proxy form in different languages (English, Spanish, Russian, Chinese, Korean, and Haitian Creole).

Make sure you have all the information you need

- A copy of your loved one's completed Health Care Proxy form and any other advance directive documents they filled out.
- The names and contact information of their healthcare providers.
- Make sure their providers have your name and contact information.

