How to Be a Health Care Agent

This information explains what you need to do as a health care agent. It contains information about how to talk with your loved one about the care they would want if they’re not able to speak for themselves.

A health care agent (also called a proxy or representative) is a person who makes healthcare decisions for someone if they can’t make them for themselves. Choosing a health care agent is an important part of advance care planning. Advance care planning is the process of thinking about important health decisions when you’re healthy and don’t need to make these decisions right away.

It can be hard to be a health care agent. As a health care agent, you take on the responsibility of carrying out your loved one’s wishes when they become very sick or as they near the end of their life. This information will help you think about what you and your loved one need to talk about to help you make decisions as their health care agent.

Being a Health Care Agent

As a health care agent, you will be in charge of making healthcare decisions for your loved one if they aren’t able to make them for themselves. You may need to make the following types of decisions:

- Choices about medical care, including medical treatment, tests, or surgery.
- Where your loved one will receive medical treatment, 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.
- The right to apply for Medicare, Medicaid, or other programs or insurance benefits for your loved one.

Your role as a health care agent starts when your loved one is no longer able to make health care decisions on their own. Their doctor will decide when this happens and will let you know when you need to begin your role as a health care agent.

Understanding Your Role

As a health care agent, you will talk to your loved one’s doctor, review their medical records, and make decisions about their treatment, tests, and surgeries. You will have full access to their medical information. You will only be involved in medical decisions. As the health care agent, you will not have legal authority to make decisions about the person’s finances or anything else.

Remember, being a health care agent isn’t 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 would’ve
wanted for them. When you have to make a decision, ask yourself “If they were able to speak right now, what would they say?” It’s also important to talk about their wishes and choices with your loved one before the situation arises when they can no longer speak for themselves. Having these conversations while you can will help you make healthcare decisions for them when you need to. For more information about how you can prepare for your role as a health care agent, read the “Talk About Their Beliefs and Goals” section of this resource.

There may be times when following your loved one’s wishes isn’t possible. There may be physical, medical, financial, or safety reasons you can’t choose what they wanted. For example, they may say they want to die in their home, but it may not be possible to move them from their hospital bed when the time comes. It isn’t easy to go against your loved one’s wishes, especially when they can’t speak up for themselves. When this happens, do the best you can. You can bring things from their home, such as blankets, photos, or a pet, to make the environment close to what your loved one wants.

**How to Say No**

If you’re not comfortable taking on the role of health care agent, it’s okay to say so. You may not agree with your loved one’s wishes, or you may not be comfortable with making someone’s end of life decisions. No matter what your reasoning is, it’s okay to be honest. You can say, “Thank you for asking me. I’m honored, but I don’t think I can do a good job being your health care agent.” This way, your loved one can think about who else they would like to have as their health care agent.

**Communicate with Your Loved One’s Family**

As someone’s health care agent, you have the right to make decisions on your own. However, you may want to talk with the person’s family while you’re making decisions. Open communication allows everyone to know what’s going on and feel like they are a part of the process. This can also give you a support system at a difficult and emotional time.

**Understanding Advance Directives**

Advance directives are written instructions on how someone wants medical decisions to be made if they’re not able to communicate or make the decisions themselves. The 2 most common types of advance directives are a health care proxy and a living will.

A **Health Care Proxy** form is a legal document that identifies the person who will make medical decisions on someone’s behalf if they’re unable to make them for themselves.

A **living will** is a document that states the person’s wishes about their medical care. Their healthcare providers will look at their living will for guidance if they’re unable to communicate for themselves. In the document, they specify which treatments they do or don’t want to receive if they’re in this situation.

You should prepare for your role as a health care agent by reviewing the information in the next section with your loved one. It’s important to review this from time to time because their thoughts may change.

**Talk About Their Beliefs and Goals**

Talk with your loved one about what they would want and discuss why they feel that way. This will help you understand their wishes.
Talking about your loved one’s beliefs and goals can be hard. To help you start, here are some examples of questions you can ask them. Remember, advance care planning is a process, not something that gets done all at once. Ask your loved one the following:

- Are there certain situations in which you would not want a lot of medical treatment?

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- How much are you willing to go through to extend your life?

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Palliative care (also called supportive care) focuses on the relief of pain and other symptoms, both physical and emotional. It can be provided at any point during an illness, even while receiving treatment for a specific disease. Palliative care is not the same as hospice care, which is explained below.

- What are your feelings about palliative care?

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Palliative care and hospice care are not the same. Hospice care starts when a person has 6 months or less to live. The goal of hospice care is to provide comfort and support while stopping any treatments that try to cure a disease. Hospice care can take place at home or in a healthcare facility. Ask your loved one the following:

- Would you be interested in hospice care at the end of your life?

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

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

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- How important is it for you to be able to take care of yourself at the end of your life?

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It may be helpful to talk with your loved one about specific treatments that they may or may not want to receive and the circumstances when they would or wouldn’t want to receive them.
Here are some examples of conversations you can have with your loved one:

Cardiopulmonary resuscitation (CPR) can be done if your heart stops beating. To try to restart your heart, you may get forceful pressure on your chest (compressions) and electric shocks (defibrillation). To give you air, you may get mouth to mouth breathing, have a breathing tube put in your airway (intubation), have a machine breathe for you (mechanical ventilation), or all 3. Think about questions and thoughts you may have about whether you would want CPR and in what situations.

If you stop breathing while your heart is still beating, you may get mouth to mouth breathing, have a breathing tube put in your airway (intubation), have a machine breathe for you (mechanical ventilation), or all 3. Think about questions and thoughts you may have about whether you would want to be placed on a breathing machine and in what situations.

Artificial hydration and nutrition adds to or replaces normal eating and drinking. A feeding tube to give you food and liquids can be placed either directly into your stomach or intestine, or through your nose and into your stomach. You can also receive nutrition through a vein. Artificial hydration and nutrition can be used if you’re unable to eat or drink enough while you’re getting treatment that might help you recover. It can also be used to keep your body alive if you are unconscious and there is very little chance you will become conscious again. Think about questions and thoughts you may have about whether you would want to receive artificial hydration or nutrition, and in what situations.

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 completing a Health Care Proxy form. Forms are available from their healthcare provider at Memorial Sloan Kettering (MSK), a Patient Representative, or on the websites listed at the end of this resource.

In New York, a Health Care Proxy form becomes valid once it’s signed and dated in front of 2 witnesses. Anyone who is 18 years of age or older can be a witness, but a health care agent can’t be a witness. Witnesses will also need to sign the form. You don’t need a lawyer or a notary to complete this form.

With advance care planning, you will be better able to carry out the wishes of your loved one if they’re not able to speak for themselves. Agreeing to be a health care agent is just the beginning. Once you’ve started, it will be easier to talk about changes or other things that come up in the future. Their wishes may change over time, so it’s a good idea to talk about their plan every time their treatment goals change.
Additional Resources

If you have any questions about advance care planning, speak with your healthcare team. You can also speak with a staff member from our Patient Representatives office by calling 212-639-7202.

CaringInfo
www.caringinfo.org
Provides many resources for advance care planning, including Health Care Proxy forms from any state.

State of New Jersey Department of Health Website.
www.state.nj.us/health/advancedirective/ad/what-is/
Information about advance care planning in general and specific to New Jersey.

New York State Department of Health
www.health.ny.gov/professionals/patients/health_care_proxy/
Information about advance care planning and NY Health Care Proxy forms in many languages.

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