



Advance Care Planning

This information describes how you can protect your right to make your own decisions about your healthcare. It contains information about:

- How to talk with your loved ones about the care you would want if you're not able to speak for yourself.
- How to choose someone to make healthcare decisions for you if you can't.
- How to document your choices in a way that is recognized by the law.

This process is called advance care planning. Advance care planning allows you to think about important health issues when you're healthy and don't need to make these decisions right away. Planning your care when you aren't under too much emotional stress will help you get the care you would want if you're not able to make decisions on your own. Planning in advance helps put your loved ones at ease because they don't have to guess what you would want and worry whether they've made the right decision.

It can be hard to think about what kind of care you would want if you become very sick or as you near the end of your life. We've designed this information to help you think about what you would want and talk to your loved ones about it. As you follow along with this guide, you may want to use the spaces provided to write in notes and questions.

Choose Your Health Care Agent

Your health care agent (also called a proxy or representative) is someone you choose to make healthcare decisions for you if you can't make them for yourself. If you can communicate and are able to understand your treatment options, you will work with your healthcare team to make your own decisions about your treatment. Your health care agent is involved in medical decisions only and does not have legal authority to make decisions about your finances or anything else.

Choose someone who can legally serve as your health care agent. A friend, family member, or anyone you trust can be your health care agent, as long as the person is at least age 18 and isn't a member of your healthcare team. Also, it's important you choose someone who:

- Is willing to talk with you about your wishes regarding medical care.
- You trust to follow through with your choices.
- Understands your religious and ethical beliefs.
- Will be available in the future.
- Understands the role of a health care agent and is willing to serve as one.
- Is able to communicate well with others.
- Can make difficult decisions.

Many people choose their spouse, partner, or other family member. However, not everyone will feel comfortable being a health care agent. No matter who you choose, it's important to talk openly and honestly with the person before making a decision. *How to Be a Health Care Agent* is a resource that can help your health care agent understand their role and what to expect. They can search for it on our website at www.mskcc.org/pe.

You can choose more than 1 health care agent. For example, you might have a primary health care agent and a secondary health care agent. That way, if your primary health care agent is not available in an emergency, your doctor will call the second person.

When you have someone in mind, review the information in the next section with them. It's important to review this from time to time because your thoughts may change.

Talk About Your Beliefs and Goals

Talk with your health care agent about what you would want, and discuss why you feel that way. This will help them understand your wishes. You don't have to spell out specific medical treatments that you want or don't want. It's also helpful to talk with your healthcare providers, other friends and family, and other people you trust, such as a spiritual advisor or lawyer.

Talking about your beliefs and goals can be hard. To help you start, we've given examples of some questions to ask yourself. Remember, advance care planning is a process, not something that gets done all at once.

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

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

Palliative 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 at the same time as other treatments. Palliative care is not the same as hospice care, which is explained below.

What are your feelings about palliative care?

Understanding Advance Directives

Advance directives are written instructions on how you want medical decisions to be made if you are unable to communicate or make the decisions yourself. 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 you want to make medical decisions on your behalf if you're unable to make them for yourself.

A **living will** is a document that states your wishes about your medical care. Your healthcare providers will look at your living will for guidance if you are unable to communicate for yourself. In the document, you specify which treatments you do or don't want to receive if you are in this situation.

Palliative care and hospice 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. Would you be interested in 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 concerns or fears about the end of your life?

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

It may be helpful to talk with your health care agent about specific treatments that you may or may not want to receive and the circumstances when you would or would not want to receive them. Here are some examples:

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. Write your questions and thoughts 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. Write your questions and thoughts 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. Write your questions and thoughts about whether you would want to receive artificial hydration or nutrition, and in what situations.

Other Notes: _____

Document Your Choices

Once you have someone who has agreed to be your health care agent, you'll need to put it in writing. You can do this by completing a Health Care Proxy form. Forms are available from your healthcare provider at 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 you sign and date it in front of 2 witnesses. Anyone who is 18 years of age or older can be your witness, but your health care agent cannot be your witness. Your witness will also need to sign the form. You do not need a lawyer or a notary to complete this form.

Give a copy of your completed Health Care Proxy form to all of your healthcare providers, your health care agent, and your lawyer, if you have one. You should also keep a copy for yourself. Tell your other loved ones who your health care agent is and ask them to be supportive of that person.

With advance care planning, your loved ones will be better able to carry out your wishes if you're not able to speak for yourself. Choosing and documenting your 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. Your wishes may change over time, so it's a good idea to talk about your plan every time your 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. What is Advance Directive?

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.

Use this space to write down questions for your healthcare provider. _____

