Memorial Sloan Kettering Cancer Center

PATIENT & CAREGIVER EDUCATION

Advance Care Planning for Cancer Patients and Their Loved Ones

This information describes how you can protect your right to make healthcare decisions (choices) with advance care planning. It has information about the process of advance care planning, including how to:

- Talk with your loved ones about the care you would want if you're not able to speak for yourself.
- Choose someone to make healthcare decisions for you if you're not able to make them for yourself.
- Document (put in writing) your choices in a way that's recognized by the law.

In this resource, "loved ones" refer to family members, close friends, and people you trust to help you make healthcare decisions.

What is advance care planning?

Advance care planning is the process of talking about and documenting your choices for future healthcare. The goal of advance care planning is to set up a plan to make sure you get the care you want in the future. This includes any treatment, service, or procedure to help find the cause of your medical problem and treat it.

What are the benefits of advance care planning?

There are many benefits of advance care planning. The main benefits are:

- It lets you and your loved ones talk about important cancer care issues that may come up in the future.
- It lets you make clear decisions ahead of time, while you're still healthy.

This way, you and your loved ones will not have to worry about making decisions at a time of crisis. For example, if you become seriously ill or are near the end of your life.

If you have a medical crisis, it could leave you too ill to make your own healthcare decisions. That's why planning ahead is important. It will help you get the care you want if you're not able to make decisions on your own. Planning ahead also helps to put your loved ones at ease. They will not have to guess what you would want or worry if they've made the right decision for you.

What is the advance care planning process?

The process of advance care planning can be hard to think about. It can also be hard to talk about with your loved ones. That's why we have created this resource to help guide you through the process. Reading this resource will help you know what to include in your advance care planning.

Understanding advance directives

Advance directives are legal documents that contain written instructions about your decisions for medical care. Your healthcare providers will look at your advance directive documents for guidance. They'll do this if you're not able to communicate or make decisions for yourself. The 2 most common types of advance directives are a health care proxy and a living will. Each state has its own laws related to advance directives. However, most states recognize a health care proxy, a living will, or both.

A **Health Care Proxy** form is a legal document that names your health care agent. Your health care agent is the person who will make medical decisions for you. They'll make these decisions if you're not able to make them for yourself. You can name more than 1 health care agent on the Health Care Proxy form. You can name a primary (first choice) health care agent and a secondary (second choice) health care agent. If your primary agent isn't available in an emergency, your healthcare providers can contact the second person.

A **living will** is a legal document that states your wishes for your medical care. It will go into effect if you become unable to make decisions for yourself. In the living will, you name the medical treatments that you want or don't want. You can also specify the situations in which you would or wouldn't want to get these treatments. Your healthcare providers will look at your living will for guidance if you're not able to make decisions for yourself.

Choose your health care agent

Your health care agent is someone you choose to make healthcare decisions for you. They'll make these decisions if you're not able to make them for yourself. A health care agent is also called a proxy, surrogate, or representative.

Your health care agent only makes decisions about your medical care when you're not able to do so yourself. You can decide how much authority (power) your health care agent has over your medical care.

For example, you can let them make many healthcare decisions for you or only a few specific ones. Your health care agent doesn't have legal authority to make decisions about your finances (money) or anything else.

Choosing a health care agent is an important decision that only you can make. No one can pick your health care agent for you. No one can choose themself to be your health care agent.

You can choose anyone to be your legal health care agent, except a member of your care team. A person who is on your care team can't be your health care agent. Make sure the person you choose is an adult (age 18 or older). They can be a friend, family member, partner, or anyone you trust to speak for you. It's important you choose someone who:

- Is willing to talk with you about your choices for your medical care, including treatments, tests, and surgeries.
- You trust to follow through with your choices.
- Understands your personal, religious, cultural, and ethical values and beliefs.
- Will be available to help in the future when you need them.
- Understands the role of a health care agent and is willing to be one.
- Can communicate well with others.
- Can make hard decisions.

Many people choose their spouse, partner, or other family member to be their health care agent. However, some people may not feel comfortable being a health care agent. That's why it's important to talk openly and honestly with the person before choosing them as your health care agent.

How to Be a Health Care Agent (www.msk.org/pe/health_care_agent) is a resource for your health care agent. It can help them understand their role and what to expect.

You can choose more than 1 health care agent. For example, you might have a primary (first choice) health care agent and a secondary (second choice) health care agent. If your primary agent isn't available in an emergency, your healthcare providers can contact the second person.

Think about the type of medical care you may want and who you want to be your health care agent. 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 and choices may change.

Talk about your choices and goals

Talk with your health care agent and healthcare providers about the care you would want and why. This will help them understand your choices and make sure they're followed. It's also helpful to talk with other people you trust, such as your friends, family, spiritual advisor, and lawyer, if you have one.

Talking about your choices and goals can be hard. To help you start, here are some examples of questions you can ask yourself now so you're prepared for later. Remember, advance care planning is a process. It's not something that gets done all at once. It's important to review your choices from time to time and change them when you need to.

Think about the following:

In what situations would I want to limit medical treatments?

_____

_____

_____

How much am I willing to go through so I can live longer?

_____

_____

_____

Palliative care

Palliative care (also called supportive care) helps to ease your pain and other symptoms of illness. It's a holistic 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 doesn't need to be end-of-life care and isn't the same as hospice care.

Think about the following:

What are my feelings about palliative care?

_____

_____

_____

Hospice care

While palliative care and hospice care both offer holistic approaches to care, they're not the same. Palliative care can start at any point of an illness. Hospice care starts after you stop getting treatment, 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 isn't 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.

Think about the following:

Do I want to get hospice care at the end of my life?

_____

_____

_____

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

_____

_____

_____

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

_____

_____

_____

Artificial and mechanical treatments

Sometimes healthcare providers use artificial or mechanical treatments to try to keep you alive. Talk with your health care agent about specific treatments you may want. Talk about the situations in which you would want to get these treatments. Do the same for specific treatments you wouldn't want. The following are some 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 to you if your heart stops beating. To try to restart your heart, healthcare providers do chest compressions while putting air into your lungs. They'll push down hard and fast on your chest to keep blood flowing throughout your body. They may also use a defibrillator (a machine that sends electric shocks to your heart).

Think about the following:

What are my feelings about CPR?

_____

_____

_____

In what situations would I want CPR?

_____

_____

_____

In what situations would I not want CPR?

_____

_____

_____

If you stop breathing while your heart is still beating, healthcare providers may do one or all of these to give you air:

- Mouth-to-mouth resuscitation (blow air into your mouth to send oxygen to your lungs)
- Intubation (place a breathing tube in your airway)
- Mechanical ventilation (place you on a ventilator, which is a machine that breathes for you)

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 bring 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'll be sedated (sleepy) while on the ventilator.

Think about the following:

What are my feelings about being placed on a breathing machine?

_____

_____

_____

In what situations would I want to be placed on a breathing machine?

_____

_____

_____

In what situations would I not want to be placed on a breathing machine?

_____

_____

_____

Do not resuscitate (DNR) order

Some people don't 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 can also be called a DNAR (do not attempt resuscitation) order or an AND (allow natural death) order.

A DNR order is a legal order that you can set up while you're still healthy. It tells healthcare providers that you don't want them to give you CPR if you stop breathing or your heart stops beating. Even though your living will may state that you don't want CPR, it's helpful to have a DNR order too.

Think about the following:

What are my feelings about a DNR?

_____

_____

_____

In what situations would I want a DNR?

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_____

_____

In what situations would I not want a DNR?

_____

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_____

Artificial hydration and nutrition

Artificial hydration and nutrition adds to or replaces the way you usually eat and drink. It's a treatment that gives you hydration (liquids) and nutrition (food) when you're not able to take them by mouth.

You may be fed through a feeding tube that puts food and liquids into your body. The tube can be placed through your nose and into your stomach. You may need to be fed through a feeding tube for a period of time. If that happens, you'll 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 while you're getting treatment. It can also be used to keep your body alive if you're unconscious (for example, if you're in a coma).

Think about the following:

What are my feelings about artificial hydration and nutrition?

_____

_____

_____

In what situations would I want to get artificial hydration and nutrition?

_____

_____

_____

In what situations would I not want to get artificial hydration and nutrition?

Other notes:

Document your choices

Once someone agrees to be your health care agent, you'll need to put it in writing. You can do this by filling out a Health Care Proxy form. You can get the form from your healthcare provider or a Patient Representative at Memorial Sloan Kettering (MSK). You 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 official once you sign and date it. You must sign and date the form in front of 2 witnesses.

Anyone who is age 18 or older can be your witness, except your health care agent. A person who is your health care agent can't be your witness. Your witnesses will also need to sign and date the form. You don't need a lawyer or a notary to fill out this form. A notary is a licensed person who witnesses the signing of important documents.

Once the form is signed, make copies of it and any other advance directive documents you filled out. Give a copy to all your healthcare providers, your health care agent, and your lawyer, if you have one. You should also keep a copy for yourself in a safe place. Because you may change your advance directive documents in the future, keep track of who you gave a copy to.

Make sure your loved ones and care team have all the information they need

- ☐ Tell your loved ones about your health care agent. Ask them to be supportive of that person.
- ☐ Tell your healthcare providers the name and contact information of your health care agent.
- ☐ Tell your health care agent the names and contact information of your healthcare providers.

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

Contact information

If you have questions about advance care planning, talk with your 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.nj.gov/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. You can get the New York Health Care Proxy form in different languages (English, Spanish, Russian, Chinese, Korean, and Haitian Creole).

Use this space to write down questions for your healthcare provider:

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