



Department of Nursing and Patient Care Services  
Advance Care Planning Program

# Advance Care Planning (ACP) A Comprehensive Guide



2024 Version

This guide is to help you start your own advance care planning. It includes insights, step-by-step instructions, and tips to help you create a plan that aligns with your values, goals, and beliefs. We encourage you to use the space provided to write down your thoughts and share them with your agents, loved ones, and providers.

**It is never too early to plan for the future!**

At NYU Langone Health, we are committed to delivering quality person-centered care. This includes providing patients and families with opportunities to engage in meaningful conversations about their health. This way they can let us know the type of health care they would want in case an unexpected event or illness left them unable to communicate. Participating in these conversations and documenting their outcomes is a process. This process is known as advance care planning (ACP).

Life can be unpredictable, so ACP is important for everyone. This is regardless of age or current health condition. It is why we designed this guide to help you start your own ACP. It includes insights and step-by-step instructions. It also has tips to help you create a plan that aligns with your values, goals, and beliefs.

**Where should I begin?**

**Take it step by step**

Advance care planning is a process. There is no need to do it all at once. Take the time you need to think, talk, and figure out what works best for you.

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# Step 1

## Consider your wishes for future care

### **This involves thinking about:**

- What an acceptable quality of life means to you
- Understanding your health status
- What potential complications may come up for you

### **Reflect on the questions and statements below as you consider your wishes:**

- What gives my life purpose and meaning?
- What aspects of my physical and mental health are most important to me?
- Do I have any religious, spiritual, cultural or traditional beliefs that impact the type of health care I receive?
- When I think about the future, I want to avoid \_\_\_\_\_.
- What does a quality of life that is not acceptable look like to me?
- I would want to be kept alive as long as I am able to \_\_\_\_\_.
- Under what conditions would I decide to change my treatment goals from prolonging my life to a focus on my comfort?

### **You should also consider talking to your provider about the following:**

- Your current health status.
- Any potential complications from your condition that could come up
- What kinds of decisions you or your family might have to make in the future

### **Reflecting on your values and beliefs:**

When your health care agent (refer to page 3 for definition) and loved ones know what matters most to you, they can be comfortable making health care decisions for you. These decisions can reflect who you are and what you care about. Answering the following questions can help you and your loved ones better understand what is important to you:

What experience have you had with serious illness? Can you think of a family member or friend who became seriously ill or was injured (for example, in a car accident)? What did you learn from that experience?

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What does living well mean to you? If you were having a good day, what would happen on that day? Who would you talk to? What would you do?

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What cultural, religious, spiritual, or personal beliefs (if any) do you have that might help you choose the care you want? Or not want?

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**Think about a situation like this:**

A sudden event (such as a car accident, illness or complication from an existing medical condition) leaves you not able to communicate. You are getting all the care needed to keep you alive. The doctors believe there is little chance you will ever recover the ability to know who you are or who you are with. Would you want to **continue** medical treatment to keep you alive? Or, would you want to **stop** medical treatment to keep you alive?

In either case, you will be kept comfortable.

Please write down any additional instructions for your health care agent and care team:

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## Step 2

### Select a health care agent

A health care agent is an adult you appoint to make decisions for you in case you become unable to do so for yourself. **A good health care agent is someone:**

- You trust and who knows you well
- Is comfortable making decisions in a crisis
- Will make decisions on your behalf, even if they do not agree with them
- Can be easily reached by phone
- Agrees to take on this role

#### **Reflect on the questions and statements below as you consider your wishes:**

- Do I know someone who could fulfill this role?
- Am I ready to ask them to take on this role?

#### **You should also consider the following:**

- Many people choose 2 agents: a primary and an alternate
- This person does not need to live near you

#### ***An important note:***

If you lose capacity to make your own medical decisions and do not have an advance directive, a surrogate decision maker will be chosen for you based on the surrogate list outlined in the Family Health Care Decisions Act, if one is available. Without the presence of a court-appointed guardian, the surrogate list is as follows:

- Spouse (if not legally separated) or domestic partner
- Adult Child
- Parent
- Adult Sibling
- Close Friend

## Step 3

### Document your wishes for future care

#### Advance care planning documents come in 2 categories:

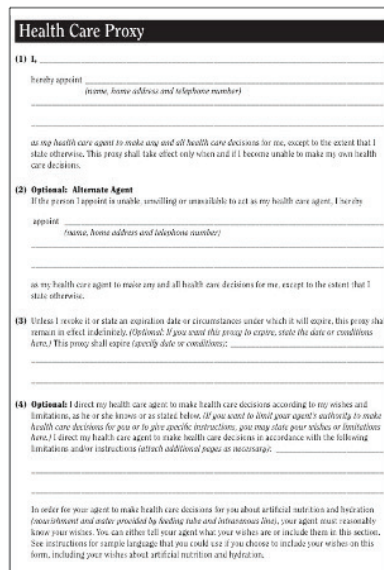
- Advance directives- these express your medical wishes if you become unable to communicate them on your own
- Medical orders- these are signed by your provider and address a limited number of critical medical decisions

Review the descriptions below to see what documents are right for you.

## Advance Directives

### Health Care Proxy Form

The New York State health care proxy form allows you to appoint 1 or 2 health care agents. This person/these persons will make medical decisions for you if you become unable to do so. Your health care agent should be 18 years or older. The form can be witnessed by any adult other than the appointed health care agent(s).



**Health Care Proxy**

(1) I, \_\_\_\_\_  
hereby appoint \_\_\_\_\_  
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect only when and if I become unable to make my own health care decisions.

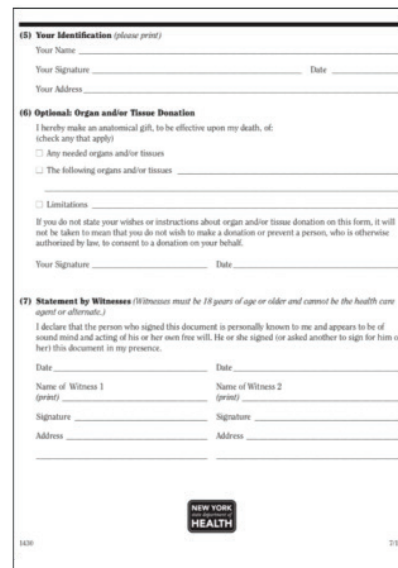
(2) **Optional: Alternate Agent**  
If the person I appoint is unable, unwilling or unavailable to act as my health care agent, I hereby appoint \_\_\_\_\_  
(name, home address and telephone number)

as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise.

(3) Unless I revoke it or state an expiration date or circumstances under which it will expire, this proxy shall remain in effect indefinitely. (Optional: If you want this proxy to expire, state the date or conditions here.) This proxy shall expire (specify date or conditions): \_\_\_\_\_

(4) **Optional:** I direct my health care agent to make health care decisions according to my wishes and limitations, as he or she knows or as stated below. If you want to limit your agent's authority to make health care decisions for you or to give specific instructions, you may state your wishes or limitations here. I direct my health care agent to make health care decisions in accordance with the following limitations and/or instructions (attach additional paper as necessary): \_\_\_\_\_

In order for your agent to make health care decisions for you about artificial nutrition and hydration (or both) and state provided by *Swallow Study and Intubation Study*, your agent must: reasonably know your wishes. You can either tell your agent what your wishes are or include them in this section. See instructions for sample language that you could use if you choose to include your wishes on this form, including your wishes about artificial nutrition and hydration.



(5) **Your Identification** (please print)  
Your Name \_\_\_\_\_  
Your Signature \_\_\_\_\_ Date \_\_\_\_\_  
Your Address \_\_\_\_\_

(6) **Optional: Organ and/or Tissue Donation**  
I hereby make an anatomical gift, to be effective upon my death, of:  
(check any that apply)  
 Any needed organs and/or tissues  
 The following organs and/or tissues: \_\_\_\_\_  
 Limitations: \_\_\_\_\_  
If you do not state your wishes or instructions about organ and/or tissue donation on this form, it will not be taken to mean that you do not wish to make a donation or present a person, who is otherwise authorized by law, to consent to a donation on your behalf.  
Your Signature \_\_\_\_\_ Date \_\_\_\_\_

(7) **Statement by Witnesses** (Witnesses must be 18 years of age or older and cannot be the health care agent or alternate.)  
I declare that the person who signed this document is personally known to me and appears to be of sound mind and acting of his or her own free will. He or she signed (or asked another to sign for him or her) this document in my presence.  
Date \_\_\_\_\_ Date \_\_\_\_\_  
Name of Witness 1 (print) \_\_\_\_\_ Name of Witness 2 (print) \_\_\_\_\_  
Signature \_\_\_\_\_ Signature \_\_\_\_\_  
Address \_\_\_\_\_ Address \_\_\_\_\_

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### Living Will

A living will is a written statement of your medical wishes. It is to be followed if you lose the ability to make your own decisions in the future. There is no standard living will form in New York State. However, the state recognizes any living will that provides clear and convincing evidence of your wishes.

## Medical Orders

### **MOLST Form**

In New York State, the preferred medical order form is the Medical Orders for Life-Sustaining Treatment (MOLST) form. This medical order form must be signed by a doctor or nurse practitioner (NP). These forms are honored by all New York State health care professionals, including emergency medical service technicians (EMTs) in any setting.

The MOLST form addresses wishes for life-sustaining treatment. The form is not for everyone. It is designed for people who reside in a long-term care facility or receive long-term care services at home. It is also designed for those who might die within the next year.

If you think a MOLST form might be right for you, speak to your doctor or nurse practitioner.

## Step 4

### Share your wishes for future care

Discussions about future care wishes with loved ones can be difficult. However, it is important to share your wishes with those closest to you.

#### **Below are some tips to help you do this:**

- Talk with your appointed health care agents about how you would want them to make decisions for you if you become unable.
- Have conversations with any other friends or family who you feel should know your wishes.
- Share your decisions with your providers.
- Give copies of your advance directives and medical order forms to your health care agents and providers. You should also give copies to any other friends or family you feel should have them.

#### **Next Steps**

- Talk with your health care agent(s).
- Meet with an Advance Care Planning facilitator.
- Complete a health care proxy form.
- Give copies of your health care proxy form to your health care agent(s) and health care professionals.
- Talk to the rest of your family and loved ones. Tell them who your health care agent(s) is/are and what your wishes are.
- If you have a serious illness, talk with your doctor about completing a MOLST.
- Keep a copy of your Advance Directive, and MOLST (if you have one) handy for others to easily find.
- Take a copy of your Advance Directive and/or MOLST with you if you go to a hospital or nursing home. Also ask for these to be put in your medical record.
- Review your health care proxy form, and MOLST (if you have one) from time to time.

Questions? Contact the NYU Langone Health Advance Care Planning Program at [advancecareplanning@nyulangone.org](mailto:advancecareplanning@nyulangone.org) or **212-263-0416**.



# Advance Care Planning, Advance Directives and Medical Orders

## Common Questions

Participating in advance care planning can bring up many questions. See below for answers to common questions.

### **Does my health care agent need to live near me?**

No. However, they should be easy to reach by phone.

### **What responsibilities does my health care agent have?**

Your agent will speak on your behalf if you become unable to do so. They are tasked with making the medical decisions you would make for yourself if you could.

### **Who can witness a health care proxy?**

Anyone over the age of 18, other than your appointed agents.

### **I'm healthy. Do I need an advance directive?**

Absolutely. Advance directives are important for all adults. They document our health care preferences in case of an unexpected illness or sudden event that leaves us unable to make our own decisions.

### **Do I need a lawyer and notary to complete my advance directives?**

No. In New York State, the forms must be signed by the patient and have two witnesses over the age of 18 who are not the appointed agents. A notary is not needed.

### **Can I document my wishes for organ donation?**

Yes. In New York any person 18 or older capable of making decisions may donate any or all parts of their body after death. They can donate to any hospital, surgeon, doctor, accredited medical school, storage facility, specific person or organization that assists with organ and tissue donation.

You can indicate your wish to be an organ donor in the following ways:

- State this on a health care proxy form
- State this on a living will
- Enroll in the New York State Organ and Tissue Donor Registry
- Enroll at the New York State Department of Motor Vehicles
- Enroll at the Board of Elections
- You will be automatically enrolled if you check the organ donor box on your driver's license. You will also be automatically enrolled if you check the organ donor box on a non-driver identification card application or renewal form.

**What if I am not a New York State resident?**

Each state has its own laws when it comes to requirements for valid advance directives. States may honor each other's documents but this is not a guarantee. It is recommended that you complete directives in your home and work state. You may also want to complete directives in any state where you spend much time.

**If my health care agent knows my wishes, do I really need a MOLST form too?**

If you have a wish to limit life-sustaining treatment, then yes. Any limitations to treatment (for example, DNR) should be documented on a MOLST form. This is to ensure your wishes are honored outside of the hospital.

**What should I do with my advance directives once they are completed?**

It is vital to have your advance directive available in case of an emergency. For this reason, the following people and places should have a copy:

- Each of your appointed health care agent(s)
- Your providers
- Hospital(s) most likely to treat you
- A safe and handy place in your home where those closest to you can locate it

**Do advance directives expire?**

While advance directives do not expire (unless you designated an expiration date specifically), it is recommended that you review them whenever one of the 5 Ds happen:

- Death of a loved one
- Divorce or separation
- Decade or other milestone birthday
- Diagnosis of a significant illness or injury
- Decline in your health status

**Can I cancel a health care proxy form?**

You can change or cancel your advance directives at any time.

**Can I appoint someone to be responsible for the disposition of my remains?**

Yes. You can appoint an agent by completing the

[Appointment of Agent to Control Disposition of Remains form.](#)

### **What is CPR?**

CPR is Cardiopulmonary Resuscitation. It is used if your heart or breathing stops. CPR may include one or all of the following:

- Chest compressions
- Defibrillation
- Intubation
- Medications to restart your heart

### **What is DNR?**

DNR stands for **Do Not Resuscitate**. A DNR order is placed when a person decides that they would not want an attempt at resuscitation if their heart or breathing stops.

### **Why might someone choose to be DNR?**

These are personal decisions. Some people feel that the likelihood of returning to an acceptable quality of life after receiving CPR is too low for it to be worth it for them. This is an important topic to discuss with your provider.

### **What is intubation?**

Intubation is a procedure that can be used for patients in respiratory distress and is also part of CPR. A flexible plastic tube is put through your mouth and into your airway. The tube keeps the airway open so air can get to the lungs. The tube is connected to a ventilator.

### **How do I cancel a DNR?**

You can cancel a DNR order at any time in any way that makes your wish known. It is recommended to speak to your provider to do so.

### **What is Palliative Care?**

Palliative Care is specialized care for people with serious illness. It is an approach where different disciplines focus on pain and symptom management. The goal is to maximize quality of life.

### **What is hospice care?**

Hospice care may be right for patients who are expected to live 6 months or less. It provides care focused on comfort and managing any type of distress. This includes easing pain and other physical symptoms and emotional or existential distress. Hospice care can be provided in different settings:

- at home
- in nursing homes
- in assisted living facilities
- in hospice centers



**Content adapted from Your Conversation Starter Guide**

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