



# Advance Care Planning Guide

*Making Choices for Your Health Care*



AT THE FOREFRONT

**UChicago  
Medicine**

## This Book Belongs To

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**My Healthcare Team**

Some of the content in this guide was originally developed by the Advance Care Planning Committee at North Shore University Health System.

All information reviewed for  
Health Literacy and Plain Language by  
University of Chicago Medicine  
Urban Health Initiative Office of Diversity, Equity and Inclusion  
11-21-202r

# Advance Care Planning

Read this guide and follow the steps below to create your Advance Care Plan

		Page
What are Advance Directives		4
Information on Advance Care Planning		5-6
<b>Steps to Create Your Advance Care Plan</b>		
<b>Step 1</b>	<b>Choose the person to be your medical decision-maker.</b>	7
<b>Step 2</b>	<b>Assess Your Values.</b> Decide what values are most important in your life and can help guide future decisions.	8-9
<b>Step 3</b>	<b>Think about</b> how you would care for yourself in different possible conditions and prepare to talk about it with your medical decision-maker.	10-11
<b>Step 4</b>	<b>Have the conversation.</b> Talk with your medical decision-maker about your Advance Care Plan.	12
<b>Step 5</b>	<b>Fill out a Power of Attorney for Health Care form.</b> Use the Illinois form or one for your state. To get the free Illinois form, go to: <a href="https://dph.illinois.gov/sites/default/files/forms/powerofattorneyhealthcareform.pdf">https://dph.illinois.gov/sites/default/files/forms/powerofattorneyhealthcareform.pdf</a>	13
<b>Step 6</b>	<b>Share a copy of your signed Power of Attorney for Health Care form</b> with your medical decision-maker and your healthcare team.	13
<b>Step 7</b>	<b>Review your Advance Care Plan.</b> Review your plan every 10 years, with any change in your health, when there is a decline in your health, at the death of loved ones or if there is a divorce.	14
<b>More Information</b>		
Resources		15
Checklist		16

# What are Advance Directives

Advance Directives are written instructions about your health care if you are not able to make your own decisions. Advance directives are accepted by state law.

In this guide, we focus on the Healthcare Power of Attorney. There are other kinds of Advance Directives you can choose, such as a Living Will. It is your right to have an Advance Directive.

## Kinds of Advance Directives

**Do Not Resuscitate (DNR):** A medical order written by a doctor (with the permission of the patient). It tells health care providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating.

**Healthcare Power of Attorney (POA):** A legal document to allow another person to make medical decisions for you.

**Living Will Declaration:** Living Will is a document that explains whether or not you want to be kept on life support if you become terminally ill and will die soon without life support, or go into an ongoing vegetative state. A Living Will becomes effective only when you are not able on your own to share what you wanted.

**Practitioner Orders for Life-Sustaining Treatment (POLST):** A doctor's order that goes over a patient's plan for life-sustaining therapy at end of life. The order shows what kind of care a patient wants at the end of their life and a doctor's judgment based on medical evaluations.

## Common definitions used when talking about Advance Directives

**Cardiopulmonary Resuscitation (CPR):** An emergency procedure using both chest compressions and artificial breathing machines. This is done to manually keep the brain working until more can be done to restore heart and lung function.

**Long-Term Care (LTC) Insurance:** An insurance policy that helps cover the costs of that care when you have a chronic (long term) medical condition or a disability. Most policies will pay you back for care given in many places, such as: your home, a nursing home or an assisted living facility.

**Medical Decision Maker:** A person selected by the patient to make medical decisions for them, before they lose the ability to make decisions on their own.

# Advance Care Planning

**Advance care planning** is the process of taking time to decide and share what is important to you and what you want for your future medical care.

Advance care planning is important in case you are not able to make your own decisions because of an accident or illness.

Advance care planning is not a single decision made one time. It happens over your lifetime as goals and values change.



An **Advance Care Plan** is a written plan shared with those you trust and your medical team. It includes your personal values, life goals, and what you want for future medical care. An Advance Care Plan can be a gift you give your loved ones who may struggle to make choices about your care during a medical emergency.

## **Advance care planning includes these steps:**

1. Choose someone you trust to be your medical decision-maker
2. Go over what your values are
3. Think about what you want for your medical care in different situations
4. Talk with your medical decision maker
5. Complete the Illinois Power of Attorney Health Care form or one for your state
6. Share your plan with your healthcare team
7. Make sure to keep your Advance Care Plan up-to-date.

An Advance Care Plan is recommended for **adults at any age (greater than 18) and at any stage of illness or health**. No one knows the future, so it is best to be prepared. The easiest time to talk about your Advance Care Plan is before illness or injury, when you have time to talk about and reflect with those you trust.

# Advance Care Planning

**In Illinois, your medical decision-maker may also be called a healthcare agent.**

You can only have one healthcare agent at a time. However, it is recommended that you choose 2 people as back-up options.

Your second and third options are called your **successor agents** and are back-up to the person you chose as your first agent.



Only one successor agent at a time may act for you in case your first healthcare agent is not able to make decisions for you. Successor agents can only act in the order you list them.

**If there is no one you trust to be your agent it is very important to talk to your doctor and other healthcare team members about what you want.**

When you have difficult medical decisions, you may think about getting support from:

- Family or your family of choice
- Your spouse or life partner
- Friends
- Your religious community
- Different doctors

**Complete the steps on the following pages to help create your Advance Care Plan.**

Use this guide to help you:

- Choose a medical decision maker (healthcare agent)
- Think about what is important to you
- Share what you want
- Make your plan legal with a healthcare power of attorney form



# Step 1: Choose Your Medical Decision-Maker

**Choose the person to be your medical decision-maker (healthcare agent).** Think about how you would want your medical decision-maker to act on your behalf.

**We recommend you choose one person you trust who:**

- Will follow what you want
- Understands your values
- Can work well under pressure
- Can make difficult medical decisions
- Will make medical decisions based on what you wanted to be done



Choose someone who will not be too upset to carry out what you want if you are not able to make your own medical decisions.

Having one medical decision-maker does not mean that others cannot be involved.

**Here are examples of what your medical decision-maker can do on your behalf:**

- Talk with your healthcare team about your condition.
- See your medical records and approve who else can see them.
- Give permission for medical tests, medications, surgery, or other treatments.
- Choose where you get care and who your healthcare providers are.
- Decide to accept, withdraw, or decline treatments made to keep you alive if you are near death or not likely to recover. You may choose to include guidelines or restrictions to what your medical decision-maker can do during this time.
- Agree or decline to donate your organs or your whole body if you have not already made this decision yourself. This could include donation for transplant, research, and education.
- Decide what to do with your remains (your body) after you have died, if you have not already made plans.
- Talk with your other loved ones to help come to a decision. Your designated agent will have the final say.
- Your designated agent is not automatically responsible for your health care expenses.

**In Illinois, your legal medical decision-maker must be 18 years old or older.**

## Step 2: Assess Your Values

**Rate each item below** to help you decide what values are most important in guiding decisions for your future medical care.

<b>Medical Values</b>	<b>Not at all</b>	<b>A little</b>	<b>Some-what</b>	<b>Very</b>
Be mentally alert and recognize loved ones				
Take medication to lessen pain, even if there are some side effects				
Eat and enjoy food naturally, not by artificial or medical means				
Know all options with my condition				
Know what will happen to my body over time with my disease				
Try every medical treatment possible				
Be involved with research studies, even if just to help others				
Live every day possible, no matter the condition of my body				
Have a machine help me breathe if I cannot breathe on my own				
Have my organs or body donated				
<b>Personal Values</b>	<b>Not at all</b>	<b>A little</b>	<b>Some-what</b>	<b>Very</b>
Keep my dignity				
Not have to live in a nursing home				
Be able to reasonably perform my normal daily activities				
Share words of advice and guidance				

## Step 2: Continued

Rate each item on how important it is to you.

Personal Values	Not at all	A little	Some-what	Very
Have my family not argue				
Make sure my affairs are in order to lessen the effect on loved ones				
Talk openly about fears and anxieties (concerns)				
Ask for forgiveness				
Make sure I accomplish important life goals				
Include religious or spiritual traditions, beliefs and practices				
Get support from my religious or spiritual leader				
Values About Death	Not at all	A little	Some-what	Very
Have family with me and not die alone				
Be able to say goodbye to loved ones				
Die at home				
Die in the hospital				
Have a natural death, without tubes or machines				
What I want done with my remains				
If I want a memorial or funeral service				

## Step 3: Think About Different Situations

Think about the kind of medical care you would want if something happens to you such as an accident or a medical condition. These examples can help your medical decision-maker with difficult decisions. Remember, there are no right or wrong answers.

- Is there a physical condition that you would not want to have, especially if it was for an extended length of time? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_
- Can you think of any conditions or a disease in which you would not want aggressive medical care to keep you alive? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Sudden Accident

You are healthy and then you are in a major car accident. You have serious brain damage and are on medical equipment to keep your heart, lungs and other vital organs going. Your future is unknown.

#### Would you want to stay on life support?

- No**, I would not want to stay on life support
- Yes**, I would stay on life support

If yes, when would this not be okay for you? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

### Invasive Medical Procedures

You have heart disease and diabetes. Treating them to extend your life may involve invasive heart procedures that often involves surgery and long, complicated hospital stays.

#### Would you want to have invasive treatments?

- No**, I would let life take its course
- Yes**, I would pursue aggressive treatments

If yes, is there a limit of what treatment you want done? Is there something that would change your mind? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

## Step 3: Continued

### Tube Feeding

You have been diagnosed (told by a medical doctor) with a condition that can cause changes in your ability to manage daily tasks.

The disease will get worse and you cannot take care of yourself, speak or swallow. The only way to survive is to have a tube put into your stomach to give you liquid nutrition.

#### Would you want the tube placed?

- No**, I would not want the tube placed
- Yes**, I would want the tube placed

If yes, how long would you want to stay on artificial feeding? \_\_\_\_\_

\_\_\_\_\_

### Location of Care

You are diagnosed with cancer that has spread. Treatments temporarily stop its growth. At some point the treatments will stop working and the cancer will cause death.

#### When you are not able to get further cancer treatment, where would you want to get care?

- Home**, I would want to be cared for at home
- Hospital**, I would want to be cared for in the hospital
- Other**

If other, where would you want to get care? \_\_\_\_\_

\_\_\_\_\_

### Medical Procedures at the End of Life

You are very ill and not able to interact with loved ones. There is a very small chance of recovery that gets smaller with time.

#### How long would you want to try every medical means possible? (This includes procedures that could possibly be very painful)

- I would only try options if my chances of recovery are good
- I would want to try every option possible until I die

Other comments: \_\_\_\_\_

\_\_\_\_\_

## Step 4: Have the Conversation

**The time to share this information** is after you have spent time thinking about what your values are, what decisions you would make and how you would want your medical decision-maker to make decisions for you.



### To make sure your conversation goes smoothly:

- **Use this guidebook to help lead the conversation.** You may even choose to provide others with a copy of what you wrote down and let them think about your responses before you talk.
- Talk about this in a comfortable setting.
- Decide if you want to talk one-on-one with your medical decision maker or if others need to be included, to make sure everyone is on the same page.
- Tell your medical decision-maker why they were chosen for this important role.
- Tell them what you think your health condition is like now and what could possibly happen to you.
- Tell them what you value in life and what is most important to you.
- Tell them which possible situations you would not want to find yourself in.
- Give them information as to how you would make life or death decisions for yourself. For example:
  - ✓ Talk to friends, family, religious or spiritual leaders for advice
  - ✓ Follow what I want as strictly as possible
  - ✓ I trust you and know that you would make the right choice, no matter what.
  - ✓ Seek the advice of a trusted personal doctor to see what they feel would be in my best personal interest.
  - ✓ Consider cultural, religious, and spiritual values that are important to me.
  - ✓ Explore every possible treatment option, including seeking second opinions and experimental treatments there may be.

## Step 5: Complete a Healthcare Power of Attorney

### You must complete a Healthcare Power of Attorney form.

To legally choose a medical decision-maker, complete the **Illinois Power of Attorney for Health Care form**. To find it free online, go to:

<https://dph.illinois.gov/sites/default/files/forms/powerofattorneyhealthcareform.pdf>

You may also use another form as long as it meets the legal standards for the state you live in. Your legal Healthcare Power of Attorney from another state or country is valid and legal in the State of Illinois.

### You and a witness must sign the form.

You must have one person who is over 18 years of age sign the form as a witness.

#### The witness cannot be:

- Your medical decision-maker.
- Related to you by blood, marriage or adoption.
- A member of your current healthcare team.
- An owner or operator of the health care facility you are in.

In Illinois, you do not need to have the form notarized.

## Step 6: Share a copy with your Healthcare Team

After you complete your Power of Attorney for Health Care form, share it with your healthcare team. **Bring it with you to your next appointment at UChicago Medicine and other places where you get medical care.** Your healthcare team will add this to your medical record.

**Sharing this information with your healthcare team** allows them to know who your medical decision-maker is and helps make sure what your want is followed.

- Tell them who you have chosen as your medical decision-maker.
- Give them with a copy of your Power of Attorney for Health Care form.
- Tell them your values and what you want added to your medical record.

**Always keep this information in an easy-to-find location,  
in case of an emergency.**

## Step 7: Review and Update Your Plan

### What You Value May Change with Major Life Events

#### Review and update your Advance Care Plan

on a regular basis, or when there is a major event that happens in your life. For example:

- **Decade:** Every 10 years of your life
- **Dependents:** Changes or new dependents in your family. For example, a new child in your family
- **Divorce or Marriage:** A divorce or separation, a new marriage or union, and other changes in your relationship
- **Death:** A death of a loved one
- **Disease:** You are told you have a new disease
- **Decline:** When there is a change in your health



**Tell your medical decision-maker  
about any changes to your Advance Care Plan.**

### You Can Change Your Mind at Any Time

**If you change your mind** about your Medical Decision-Maker or anything else on your Power of Attorney for Health Care form:

1. Tell someone who is at least 18 years old.
2. Fill out a new Power of Attorney for Health Care form and sign with a witness.
3. Shred your old document and any copies.
4. Make sure everyone you gave the old form to has a copy of the new one including your healthcare team.



**Always make sure to put the date on your forms.**

## Resources

**Aging with Dignity** is a non-profit providing additional resources and advocacy tools for all seeking better end-of-life care and decision-making. Visit their website here: [www.agingwithdignity.org](http://www.agingwithdignity.org)

**CaringInfo** is a program of the National Hospice and Palliative Care Organization. They provide free resources to help people make decisions about end-of-life care and services before crisis. Visit their website here: [www.caringinfo.org](http://www.caringinfo.org)

**Death Over Dinner** is an uplifting interactive way for friends and families to talk about death. Visit their website here: [www.deathoverdinner.org](http://www.deathoverdinner.org)

**Go Wish Game by Coda Alliance** is a game you can play online to consider the importance of various choices. Playing this game with your relatives or close friends can help you learn how you can best comfort your loved ones when they need you the most. Use the free online version of the game here: [www.gowish.org/gowish/gowish.html](http://www.gowish.org/gowish/gowish.html)

**Illinois Power of Attorney for Health Care form** is available free online on this website. Get the form here: <https://dph.illinois.gov/sites/default/files/forms/powerofattorneyhealthcareform.pdf>

**Prepare for Your Care** is a free step-by-step tool developed by the University of California with video stories to help you with your advance care planning. Visit their website here: [www.prepareforyourcare.org](http://www.prepareforyourcare.org)

**UChicago Medicine Advance Care Planning Website**  
[www.uchicagomedicine.org/advancecareplanning](http://www.uchicagomedicine.org/advancecareplanning)

## My Advance Care Plan Checklist

- Choose my medical decision-maker.
- Fill out the form for Power of Attorney for Health Care or any other Advance Directive you choose.
- Decide what my values are in life and share them with my medical decision-maker.
- Tell others, including close relatives, of my values and decisions.
- Go over choices with my doctors and healthcare team.
- Provide my medical decision-maker, close relatives and healthcare team copies of any legal documents.
- Go over and update my Advance Care Plan every decade (10 years), new dependents, marriage or union, divorce or separation, new disease or change in my health, decline in my health, or death of a loved one.