



Advance Care Planning Guidebook

Establishing Your Preferences for Healthcare



Making future healthcare plans helps ensure that you get the care that you want, even when others are making medical decisions for you.

This guidebook is an important personal planning tool developed for you by NorthShore University HealthSystem.

Helpful Definitions

Advance Care Plan (ACP)—A document that provides direction to healthcare professionals when a person is not in a position to make and/or communicate their own healthcare choices.

Cardiopulmonary Resuscitation (CPR)—An emergency procedure that combines chest compressions often with artificial breathing machines in an effort to manually preserve intact brain function until further measures are taken to restore heart and/or lung function.

Do Not Resuscitate (DNR)—A Do Not Resuscitate order, or DNR order, is a medical order written by a doctor. It instructs health care providers not to do cardiopulmonary resuscitation (CPR) if a patient's breathing stops or if the patient's heart stops beating.

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 shortly without life support, or fall into a persistent vegetative state. A Living Will becomes effective only when you cannot communicate your desires on your own.

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

Medical Decision Maker—If a patient is unable to make decisions for themselves about medical care, a person selected by the patient, prior to loss of capacity to decide, will make decisions for them.

Power of Attorney (POA)—A legal document you use to allow another person to act for you.

Practitioner Orders for Life-Sustaining Treatment—The Practitioner Orders for Life-sustaining Treatment (POLST) is a practitioner's order that outlines a plan for life-sustaining therapies at end of life reflecting both a patient's preferences concerning care at life's end and a practitioner's judgment based on medical evaluations.

What is Advance Care Planning?

What if your health was affected in a devastating way?

- What are the important things in your life that you value?
- How would you want to be treated to make sure your dignity is preserved?
- What medical treatment would you desire to achieve your values and dignity?

These are questions most of us will have to face at one time or another in our life and we will most likely think deeply about them. Unfortunately, there are some conditions that will not allow us to actively participate in these decisions at the time needed.

Now, imagine that someone has to make medical decisions for you because you are unable to do so for yourself, even temporarily.

Step 1: Do I Need an Advance Care Plan (ACP)?

The goal of the ACP is to have your wishes known and honored by someone you trust, who:

- Is ready and willing to become your advocate and medical decision-maker if you cannot make your own decisions
- Is informed about what you value in life and in health
- Can honor your wishes working with your healthcare team

This guidebook will help you:

- Select a medical decision-maker
- Assess what is important to you and not so important to you
- Communicate your wants and wishes
- Ensure this plan is followed by your healthcare team



Because accidents and changes in medical conditions can happen unexpectedly, it is important for anyone over the age of 18 to have an Advance Care Plan.

You may want to preview the webpage at northshore.org/acp prior to completing this guidebook to get an overview of what Advance Care Planning is.

Step 2: Select the Right Person

Who do you trust to make medical decisions for you if you cannot?

Your medical decision-maker may be placed in high-pressure situations, which can cause a great deal of emotional distress. NorthShore recommends that you select one person who:

- Can honor your wishes
- Has similar values to you (in terms of what makes life worth living)
- Can think like you
- Can weigh difficult medical decisions
- Can work well under pressure
- Will accept the responsibility to make medical decisions with your best interest in mind

Power of Attorney for Healthcare

Once you have made a choice of who you would trust to make your healthcare decisions for you if you could not, it is highly recommended that you complete a Power of Attorney for Healthcare.

This can be downloaded free from northshore.org/acp or a copy can be provided by your healthcare team.

Some important details about this:

- It requires someone to co-sign this form witnessing that it is you signing it. The witness cannot be a family member or your healthcare provider. No lawyer or notary is needed.
- Selecting one medical decision-maker does not mean that others will not have an opinion, but can help minimize arguments and tension.
- It is advisable to have a second or third back-up decision-maker in case your first choice is not available.
- Remember, the more you communicate your wishes to all your loved ones, the easier it will be for your medical decision-maker to address challenging decisions without family tension.
- Bring copies of this document to all your healthcare providers.

If you do not select a medical decision-maker for yourself, the State of Illinois will choose one for you based on the following order:

1. The patient's legally appointed "guardian of the person;"
2. The patient's spouse;
3. Any adult son or daughter of the patient;
4. Either parent of the patient;
5. Any adult brother or sister of the patient;
6. Any grandchild of the patient;
7. A close friend of the patient;
8. The patient's legally appointed "guardian of the estate."

At a minimum, completing this document will give you an Advance Care Plan.

However, NorthShore recommends that you complete the steps in this Guidebook to:

- Help with conversations we encourage you to have with your loved ones.
- Empower loved ones to make similar choices to what you would make.

If done right, this is a gift you are giving to your family.

Everyone is unique in how they view life and what is most important to them. The following tables will help you determine which values are most important in your life and can help guide future decisions. Rate each item on its importance to you.

Step 3: Assess Your Values

Medical Values

| I want to... | Not Important —————> Very Important | | | | |
|---|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 |
| Be mentally alert and recognize loved ones | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Reduce my pain with medication, even if there are some side effects | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Eat and enjoy food naturally, not by artificial or medical means | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Know all options with my disease, illness, or condition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Know what will happen to my body over time with my disease, illness, or condition | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Try every medical treatment possible | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Be involved with research studies, even if just to help others | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Live every day possible, no matter the condition of my body | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have mechanical assistance to help me breathe if I cannot breathe on my own | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Be resuscitated if my heart stops (i.e., CPR) | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have my organs donated | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Step 3: Assess Your Values >>continued

Personal Values

| I want to... | Not Important —————→ Very Important | | | | |
|---|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 |
| Maintain my dignity | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Be able to reasonably perform my normal daily activities | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Pass on words of advice and guidance | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have my family not argue | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Make sure my affairs are in order to minimize the effect on loved ones | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Talk openly about fears/anxieties | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Ask for forgiveness | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Include consideration of religious/spiritual traditions, beliefs, and practices | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Make sure I accomplish important life goals | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Receive support from my religious or spiritual leaders | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

| I do not want to... | Not Important —————→ Very Important | | | | |
|--|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 |
| To live in a nursing home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have treatment or care that could lead to financial stress for my family | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Values About End of Life

| I want to... | Not Important —————> Very Important | | | | |
|---|-------------------------------------|--------------------------|--------------------------|--------------------------|--------------------------|
| | 1 | 2 | 3 | 4 | 5 |
| Have family with me/not die alone | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Be able to say goodbye to loved ones | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Die at home | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Die in the hospital | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Have a natural death, focused on comfort care, not hooked to tubes or machines | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Not have cardiopulmonary resuscitation (CPR) performed on me if my breathing stops or my heart stops beating | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Additional Values

I want...

Step 4: Various Health Scenerios

Now, think about how you would care for yourself in various situations. While some scenarios might be difficult to think about, we encourage you to select answers and write comments that might help your medical decision-maker with difficult decisions.

Please ask your healthcare team for help if you would like to talk about other potential scenarios that could be possible with your present health.

Imagine that...

Select one option for each senerio

You are healthy when you have a major car accident. You have significant brain damage and are on life support and medical equipment to keep your heart, lungs and other vital organs going. The doctors say you will likely not recover but they can't be certain so early after your injury.

☐ Yes

☐ No

Comments:

Do you stay on life support? How long?

You've had two heart attacks. You have a third, massive heart attack. It leaves you unconscious. If you survive, your quality of life will be greatly lessened. While unconscious, your heart stops. The doctors must try to restart your heart with CPR to keep you alive.

☐ Yes

☐ No

Comments:

Do you want doctors to do everything to keep you alive or do you let nature take its course?

You have an incurable lung disease and have been in and out of the hospital several times with shortness of breath. One day, you are admitted to the Intensive Care Unit and placed on a ventilator to breathe and survive.

☐ Yes

☐ No

Comments:

Do you stay on the ventilation? And for how long?

Imagine that...

Select one option for each senerio

You have been diagnosed with irreversible dementia. The disease progresses so much that you cannot take care of yourself or recognize your loved ones. You get another acute medical condition (like pneumonia).

☐ Yes

☐ No

Comments:

Do you seek aggressive medical care in the hospital?

You are diagnosed with cancer that has spread. Treatments temporarily stop its growth, but at some point they will stop working. The cancer will cause death.

☐ Home

☐ Hospital

Comments:

When you are too weak to walk, where do you want to receive care: at home or in the hospital?

You are very ill and unable to interact with loved ones. There is a very small chance of recovery, which decreases with time.

How long are you willing to try every medical means possible, including procedures that could potentially be very painful?

Comments:

Step 5: Other Considerations

There may be additional considerations which may help your medical decision-maker with important decisions.

Please write your answers to the following questions.

Is there a physical condition that you could not tolerate, especially if it was for an extended length of time?

Can you think of any conditions or disease states in which you would not want aggressive medical care to keep you alive? Which scenarios would you prefer to die naturally, comfortably and possibly at home?

After you die, do you want a funeral or a memorial service? Do you prefer to be buried, cremated or to have your body donated to science? Are you an organ donor?

Step 6: Advise Your Medical Decision-Maker

Now that you have assessed your values and considered various situations, think about how you would want your medical decision-maker to make these decisions.

In the table below, select the items that you would like your medical decision-maker to consider and write any additional comments for clarification.

| When making medical decisions on my behalf... | Comments <i>(Add additional comments below, if needed)</i> |
|--|--|
| <input type="checkbox"/> Try to follow my wishes as strictly as possible | |
| <input type="checkbox"/> I trust you and know that you would make the right choice, no matter what | |
| <input type="checkbox"/> Seek the advice of a trusted personal physician to see what he or she feels would be in my best personal interest | |
| <input type="checkbox"/> Please explore every possible treatment option, including seeking second opinions and experimental treatments that might be available | |
| <input type="checkbox"/> Ask _____ for advice (e.g., specific friends, family, or religious/spiritual leaders) | |
| <input type="checkbox"/> Consider cultural or religious or spiritual values that are important to me | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |
| | |

Step 7: Have the Conversation

After you have determined what your values are, what decisions you would make and how you would want your medical decision-maker to make decisions for you, it is time to communicate this information.

To ensure that your conversation goes smoothly:

- Have the conversation in a comfortable setting
- Determine if you would like your conversation one-on-one with your medical decision-maker or with others, to ensure everyone is on the same page
- Tell your medical decision-maker why they were selected for this important role
- Use this guidebook to help lead the conversation — you may even choose to provide others with a copy of what you wrote in advance and let them think about your responses before you talk
- Tell them what you think your health condition is like at present and what could possibly happen to you
- Tell them what you value in life and what is most important to you
- Tell them which scenarios you would not want to find yourself in
- Provide them with useful hints as to how you would make life or death decisions for yourself

- Give important loved ones a copy of any legal documents, so they have them readily available when needed.

Examples include:

- Power of Attorney forms
- Living Wills
- Practitioner Orders for Life-sustaining Treatment (POLST) forms
- Long-term Care Insurance Policies



Step 8: Ensure Your ACP is Followed

This guidebook is not a legal document. To legally select a medical decision-maker, you must fill out an Illinois Power of Attorney for Healthcare form.

After you complete the form, bring it to your next appointment. Sharing this information with your healthcare team allows them to know who your medical decision-maker is and helps ensure that your wishes are granted.

- Inform them who you have selected as your medical decision-maker.
- Provide them with a copy of your Illinois Power of Attorney for Healthcare form.

- A special visit to discuss your Advance Care Plan can be made as part of an Annual Wellness Visit and is paid for by most insurances. At this visit, you can inform them of your values and wishes to add to your medical record. You can bring in a copy of this Guidebook to help with this conversation.
- If you are worried about aggressive life support, you may want to talk to your physician about complementary forms like the POLST form, focusing on things like CPR or other life support measures at the end of life.

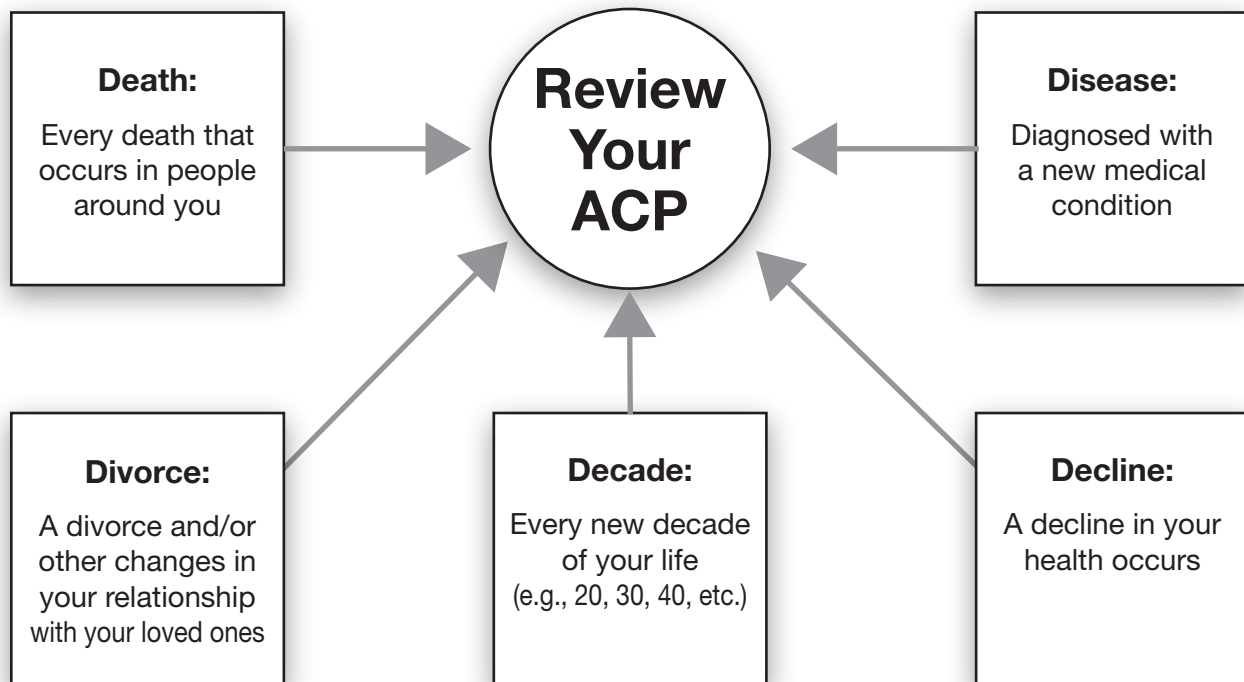
Bring these documents with you for all hospital visits or if you see a new doctor.

Always keep them in an easy-to-find location, in case of an emergency. Ambulance personnel tend to look for these on refrigerators.

Step 9: Review Often

Because what you value in life may change with major life events, you can change your ACP at any time.

At a minimum, NorthShore recommends that you review and update your Advance Care Plan on a regular basis, or when any of the 5 D's occur in your life: Death, Divorce, Decade, Decline or Disease.



Be sure to communicate any adjustments to your appointed medical decision-maker to everyone involved.

If you decide to change who your medical decision-maker is:

- Update your Illinois Power of Attorney for Healthcare form
- Communicate the change with your healthcare team

Advance Care Planning Helps Loved Ones

Sharing your ACP with loved ones or someone you trust can be considered a gift that can help them make very difficult medical decisions at very stressful times.

Use the following checklist to help create your ACP.

My ACP Checklist

- ☐ Select my medical decision-maker
- ☐ Fill out the Illinois Power of Attorney for Healthcare form (available for free online)
- ☐ Determine what my values are in life and communicate it with my selected medical decision-maker
- ☐ Inform others of my values and decisions, including close relatives
- ☐ Review choices with my physicians, and complete other forms (e.g., POLST)
- ☐ Provide my medical decision-maker, close relatives and healthcare team copies of any legal documents
- ☐ Review my ACP with every decade, new disease, decline in health, death of loved ones or divorce



Additional Resources

Visit northshore.org/acp to view additional information and videos related to Advance Care Planning and how it has impacted patients and their families at NorthShore University HealthSystem.

Additional online resources include:

- Prepare for your care
- National Hospice and Palliative Care Organization > Advance Care Planning
- National Institute on Aging > Advance Care Planning
- The Go Wish Game