

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



# Advance Care Planning Guidebook

*Establishing Your Preferences for Healthcare*

**An important personal planning tool developed for you by**



# Advance Care Planning

When life presents you with tough medical decisions, you may consider gathering many opinions from:

- Family and friends
- Your religious community
- Multiple physicians
- Internet



Imagine that someone has to make these decisions *for you* because you are unable to do so for yourself.

The goal of an Advance Care Plan (ACP) is to have someone that you trust:

- Who is *ready and willing* to become your advocate and medical decision-maker if you cannot make your own decisions
- Who is *informed* about what you value in life and in health
- Who 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
- Communicate your wants and wishes
- Make your plan legal and at no cost

## Creating an ACP



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 do *not* need a lawyer to create an ACP.

If you need assistance with this guidebook, please ask for help from your healthcare team.

My healthcare team: \_\_\_\_\_

Contact information: \_\_\_\_\_

## Step 1: Select the Right Person



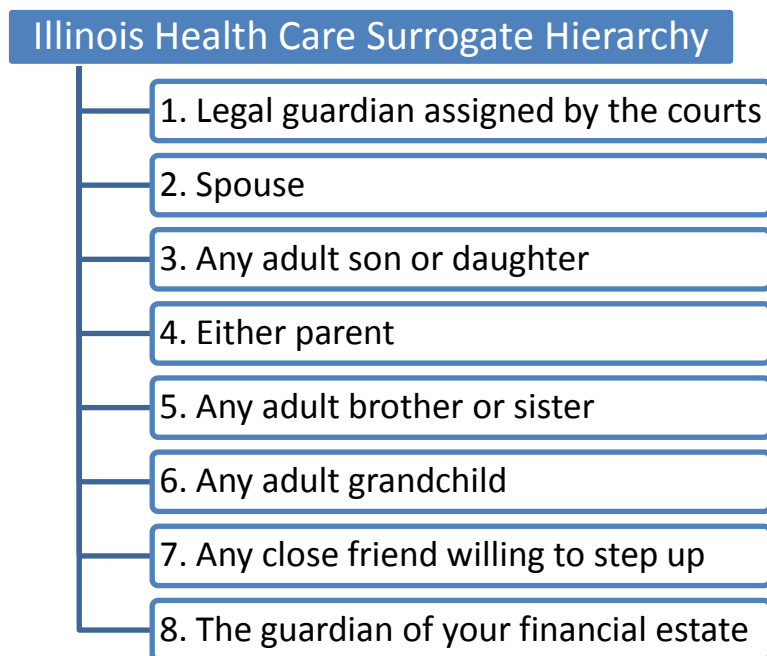
Your medical decision-maker may be placed in high-pressure situations, which can cause a great deal of emotional distress. We recommend that you select **one** person who:

- 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

Remember, selecting one medical decision-maker does not mean that others will not have an opinion, but can help minimize arguments and tension.

# Illinois Health Care Surrogate Hierarchy

If you do not have an ACP, the state of Illinois decides who will be your medical decision-maker. The Illinois Health Care Surrogate Act gives medical decision-making authority in the following order:



Remember, the more you communicate your wishes, the easier it will be for your medical decision-maker to address challenging decisions. Complete the following steps to help create your ACP. At a minimum, please inform your healthcare team of your selected medical decision-maker.



## Step 2: Assess Your Values

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.

### Medical Values

<i>I want to...</i>	Not Important			Very Important	
	1	2	3	4	5
Be mentally alert and recognize loved ones					
Reduce my pain with medication, 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					
Have tried 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 mechanical assistance to help me breathe if I cannot breathe on my own					
Have my organs donated					

## Personal Values

<i>I want to...</i>	Not Important			Very Important	
	1	2	3	4	5
Maintain my dignity					
Not have to live in a nursing home					
Be able to reasonably perform my normal daily activities					
Pass on words of advice and guidance					
Have my family not argue					
Make sure my affairs are in order to minimize the effect on loved ones					
Talk openly about fears/anxieties					
Ask for forgiveness					
Leave my life in God's hands, not medical treatments with extreme measures					
Include consideration of religious traditions, beliefs and practices					
Make sure I accomplish important life goals					
Receive support from my pastor, rabbi or clergy					

## Values About Death

<i>I want to...</i>	Not Important		3	Very Important	
	1	2		4	5
Have family with me/not die alone					
Be able to say goodbye to loved ones					
Die at home					
Die in the hospital					
Have a natural death, not hooked to tubes or machines					

## Additional Values

<i>I want to...</i>	Not Important		3	Very Important	
	1	2		4	5
<i>Insert additional values here</i>					





## Step 3: Consider Various Scenarios

Now, think about how you would care for yourself in various situations. While some scenarios might be difficult to think about, you are encouraged to select answers and write comments about how you would like to be cared for. These scenarios can help your medical decision-maker with difficult decisions.

Remember, there are no right or wrong answers.

Please ask for help from your healthcare team if you need assistance.

<i>Imagine that...</i>	<i>Select one option for each scenario</i>	<i>Comments</i>
<p>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. Your future is uncertain.</p> <p>Do you stay on life support?</p>	<p><input type="checkbox"/> Yes, I would stay on life support</p> <p><input type="checkbox"/> No, I would not want to stay on life support</p> <p><input type="checkbox"/> Other</p>	
<p>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.</p> <p>Do you have doctors do everything to keep you alive or do you let nature take its course?</p>	<p><input type="checkbox"/> Do everything to keep me alive</p> <p><input type="checkbox"/> Let nature take its course</p> <p><input type="checkbox"/> Other</p>	
<p>You are significantly overweight with heart disease and diabetes. Treating them to prolong life could potentially involve invasive heart procedures and long, complicated hospital stays.</p> <p>Would you want to pursue aggressive treatments or do you let life happens as it occurs?</p>	<p><input type="checkbox"/> I would pursue aggressive treatments</p> <p><input type="checkbox"/> I would let life take its course</p> <p><input type="checkbox"/> Other</p>	

<i>Imagine that...</i>	<i>Select one option for each scenario</i>	<i>Comments</i>
<p>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. Would you stay on the ventilator?</p>	<p><input type="checkbox"/> Yes, I would want to remain on the ventilator</p> <p><input type="checkbox"/> No, I would not want to remain on the ventilator</p> <p><input type="checkbox"/> Other</p>	
<p>You have been diagnosed with irreversible dementia. The disease progresses so much that you cannot take care of yourself, speak or swallow. The only way to survive is to have a tube inserted into your stomach to give you liquid nutrition. Would you want the tube placed?</p>	<p><input type="checkbox"/> Yes, I would want the tube placed</p> <p><input type="checkbox"/> No, I would not want the tubes placed</p> <p><input type="checkbox"/> Other</p>	
<p>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. When you are too weak to walk, where would you want to receive care: at home or in the hospital?</p>	<p><input type="checkbox"/> I would want to be cared for at home</p> <p><input type="checkbox"/> I would want to be cared for in the hospital</p> <p><input type="checkbox"/> Other</p>	
<p>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?</p>	<p><input type="checkbox"/> I would want to try every option possible until I die</p> <p><input type="checkbox"/> I would only try options if my chances of recovery are good</p> <p><input type="checkbox"/> Other</p>	

## Step 4: Communicate Additional Considerations

There are 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?

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

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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?

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## Step 5: Determine How You Want Your Medical Decision-Maker to Take Action

Now that you have assessed your values and considered various situations, think about how you would want your medical decision-maker to act on your behalf.

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

<i>When making medical decisions on my behalf...</i>	<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"/> Talk to friends, family and religious leaders for advice	
<input type="checkbox"/> Consider cultural and/or religious values that are important to me	

**Printed Name:** \_\_\_\_\_

**Signature:** \_\_\_\_\_ **Date:** \_\_\_\_\_

## Step 6: 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 down 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



## Next Steps

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:

[www.learningtechnologyteam.com/AdvanceCarePlanning/2015-NorthShore-HPOA-Form.pdf](http://www.learningtechnologyteam.com/AdvanceCarePlanning/2015-NorthShore-HPOA-Form.pdf). It is a free document, is available online or from your healthcare team and requires one witness's signature. **The witness cannot be your medical decision-maker.**



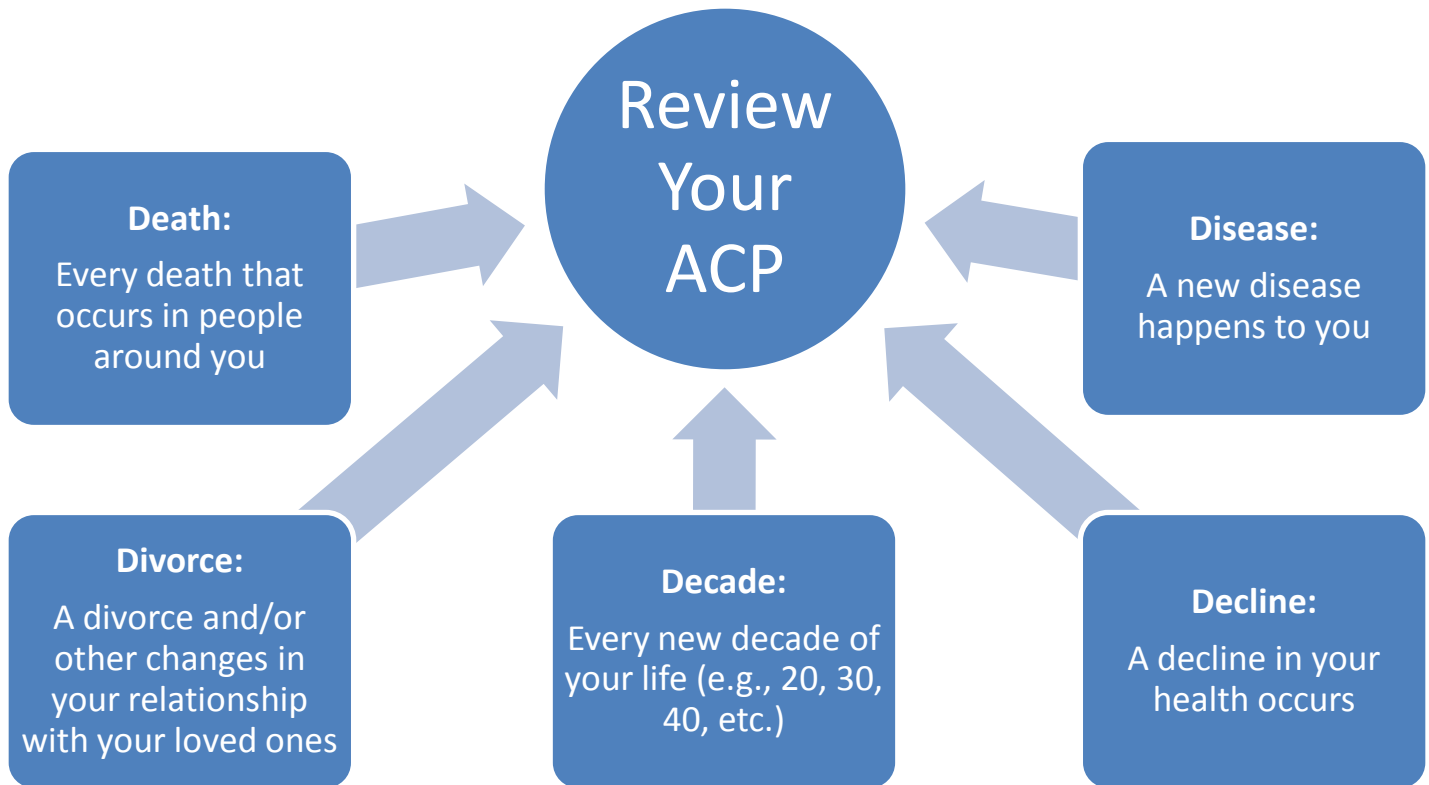
After you complete the form, bring it with you on your next appointment. Sharing this information with your healthcare team allows them to know who your medical decision-maker is and helps ensure that your wishes are granted.

- 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
- Inform them of your values and wishes to add to your medical record

Bring these documents with you for all hospital visits and if you see a new doctor. Always keep them in an easy-to-find location, in case of an emergency.

# Review Often

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

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 Your 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 checklist below to help create your ACP.

## MY ACP Checklist

- Select my medical decision-maker
- If my selected medical decision-maker is not on the top of the Illinois Health Care Surrogate list, fill out the [Illinois Power of Attorney for Healthcare form](#) (available for free online)
- Determine what I value and communicate it with my selected medical decision-maker
- Inform others of my decision, including close relatives
- Inform my healthcare team of my decision
- 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](http://northshore.org/acp) to view additional information and a video about how Advance Care Planning impacted patients and their families at NorthShore University HealthSystem.

Additional resources include:

- [www.learningtechnologyteam.com/AdvanceCarePlanning/2015-NorthShore-HPOA-Form.pdf](http://www.learningtechnologyteam.com/AdvanceCarePlanning/2015-NorthShore-HPOA-Form.pdf)
- [www.prepareforyourcare.org/](http://www.prepareforyourcare.org/)
- [www.caringinfo.org/i4a/pages/index.cfm?pageid=3277](http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3277)
- [www.agingwithdignity.org/catalog/product\\_info.php?products\\_id=28](http://www.agingwithdignity.org/catalog/product_info.php?products_id=28)
- [well.blogs.nytimes.com/2009/03/20/planning-for-death-when-youre-healthy/](http://well.blogs.nytimes.com/2009/03/20/planning-for-death-when-youre-healthy/)
- [www.gowish.org/staticpages/index.php/thegame](http://www.gowish.org/staticpages/index.php/thegame)