

# Preparing for End of Life



**Home and Hospice Services**

# Preparing for End of Life

Dying, like being born, is one of life's major transitions. Thinking about one's own death, or the death of a loved one, is difficult and can feel overwhelming. Many people put off talking about or planning for death, yet death comes to all of us. Thinking ahead and creating a plan to address end-of-life needs and the needs of survivors is very important.

## WHY PREPARING FOR END OF LIFE MATTERS

- Coping with the death of a loved one is difficult. Planning ahead can ease some of the suffering and stress loved ones experience at the time of death.
- Knowing loved ones are prepared, that a plan is in place and that your affairs are in order can be a comfort to you as well as others in your final days.

## WHAT CAN HELP

- Developing a plan if you have not already done so (There is no time like the present, when you still have the energy and presence of mind to direct family and caregivers about what matters to you, to begin end-of-life planning.)
- Completing advanced healthcare directives and specifying your wishes for end-of-life care
- Organizing important legal papers and completing a legal will regarding your estate
- Creating a list of bank accounts, insurance policies and investments (Include online accounts, passwords, access codes, account numbers, etc., and share this list with key family members.)
- Talking openly with loved ones about funeral arrangements, finances, final wishes and preferences for end-of-life care



Call our 24 hour number **(847) 475-3002** with questions or concerns so we can provide timely care.

- Considering your personal belongings and special items, and creating a list designating who you want certain items to go to; sharing this list with multiple family members to ensure that all interested parties are aware of your wishes
- Creating a meaningful record of your life, or letters, videos or taped messages to share with loved ones
- Seeking spiritual or religious counsel if desired
- Using the social work and spiritual/pastoral care support available through hospice

## **WHAT TO REPORT TO YOUR HOSPICE CARE TEAM**

- Questions about the dying process and what to expect in the final weeks, days and hours
- Concerns about finances, benefits and resources you may be entitled to
- Questions about medical bills, complex paperwork, health and life insurance policies
- Issues of loss and grief; feeling alone, overwhelmed, anxious, stressed-out or unable to cope

## **WHAT YOUR HOSPICE CARE TEAM WILL DO**

- Listen carefully and help address concerns
- Ask questions and evaluate needs
- Communicate your concerns to your doctor and to others on your hospice care team
- Provide training, support, referrals and resources for end-of-life care planning, counseling and other needs
- Offer help and assistance with making arrangements if needed or requested

*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



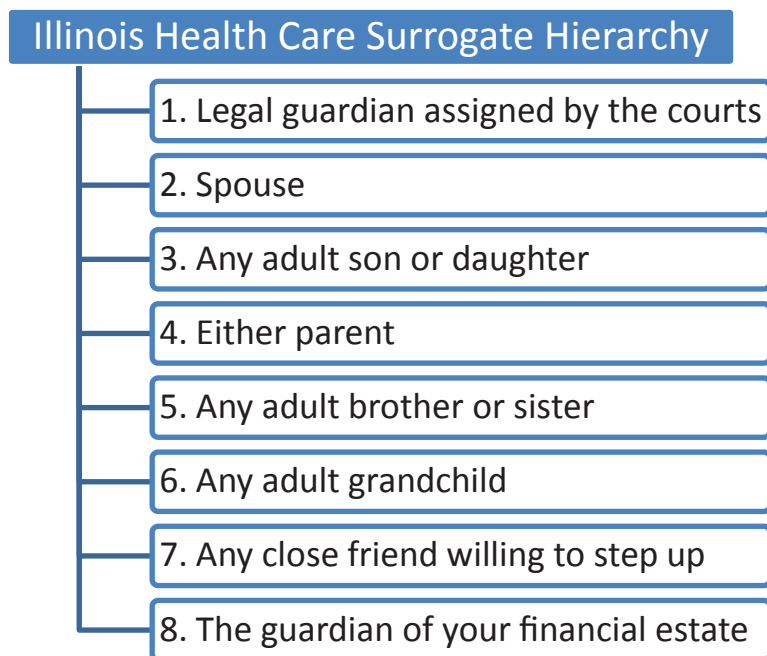
Your medical decision-maker may be placed in high-pressure situations, which can cause a great deal of emotional distress. We recommend that you select **one** person who:

- 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 |   |   | Very Important |   |
|---|---------------|---|---|----------------|---|
|   | 1             | 2 | 3 | 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 |   |   | Very Important |   |
|--------------------------------------|---------------|---|---|----------------|---|
|                                      | 1             | 2 | 3 | 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><b>Imagine that...</b></i>  | <i><b>Select one option for each scenario</b></i>  | <i><b>Comments</b></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><b>Imagine that...</b></i>   | <i><b>Select one option for each scenario</b></i>   | <i><b>Comments</b></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.**



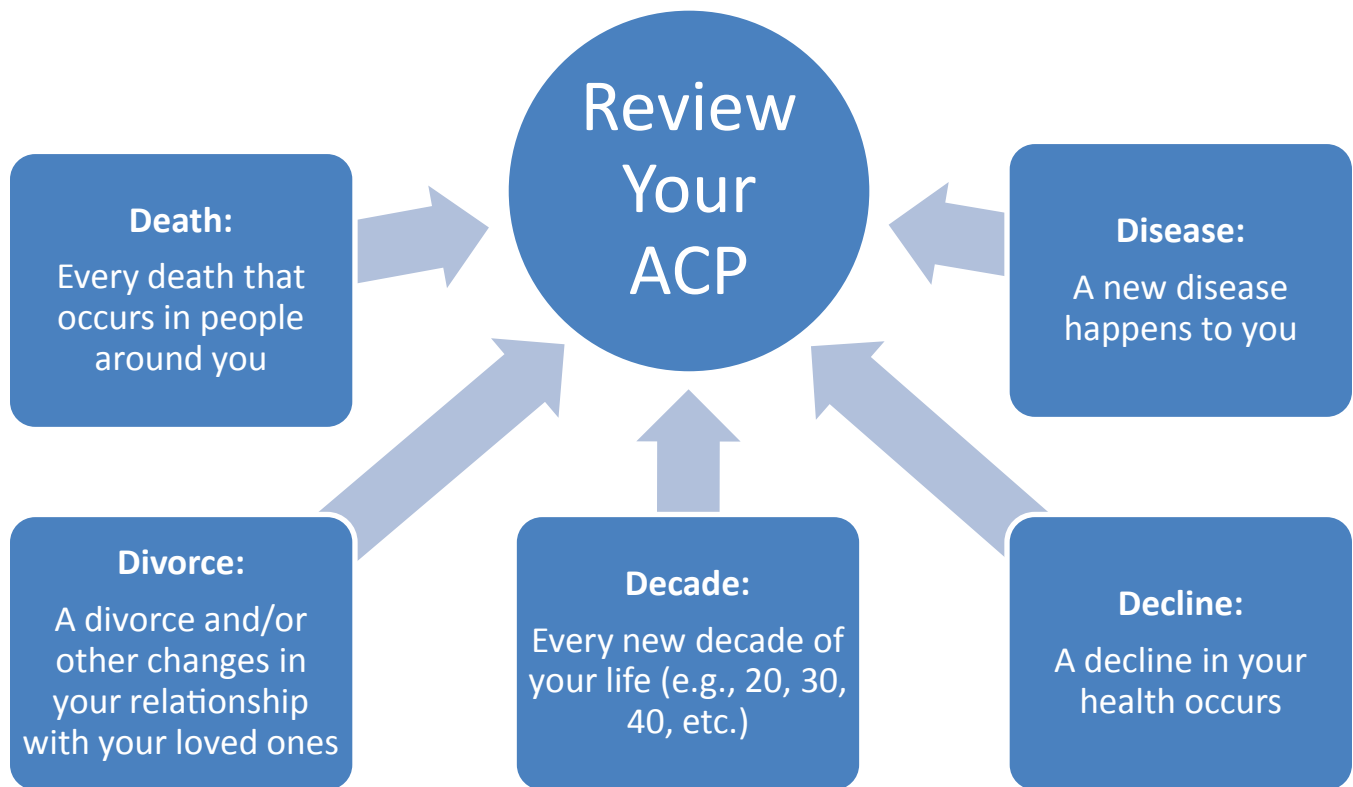
After you complete the form, bring it with you on your next appointment. Sharing this information with your healthcare team allows them to know who your medical decision-maker is and helps ensure that your wishes are granted.

- 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)

# Power of Attorney for Health Care

The attached form meets the requirements under the Illinois Power of Attorney for Health Care Act

## **NOTICE TO THE INDIVIDUAL SIGNING THIS HEALTH CARE POWER OF ATTORNEY (HPOA) FORM**

No one can predict when a serious illness or accident might occur. If something happened to you and you were not able to communicate your wishes, you may need someone else to speak or make health care decisions for you. If you plan now, you can increase the chances that the medical treatment you get will be the treatment you want.

You can choose someone you trust to make health care decisions for you if you are unable or do not want to make them yourself. The person you choose is called your “Health Care Agent.” It is important that you identify your Health Care Agent and record your health care preferences in writing based on your personal values and wishes by completing this form or another power of attorney form that complies with the Illinois legal requirements.

## **WHAT ARE THE THINGS I WANT MY HEALTH CARE AGENT TO KNOW?**

It is important to talk to the person you want to be your Health Care Agent about such things that are most important to you in your life:

- How important is it for you to avoid pain and suffering?
- If you had to choose, is it more important to you to live a quality life as long as possible, and avoid prolonged suffering, additional procedures, or disability, or live as long as possible even if it means losing quality of life?
- Would you rather be at home or in the hospital for the last days or weeks of your life?
- Do you have religious, spiritual or cultural beliefs you want your Health Care Agent to consider when fulfilling your care and end-of-life wishes?

## **WHOM SHOULD I CHOOSE TO BE MY HEALTH CARE AGENT?**

Choose a family member or friend who:

- Is at least 18 years old
- Knows you well
- Can be there for you when you need them
- You trust to do what is best for you and is willing to carry out your wishes even if they personally may not agree with your wishes
- Will tell your health care providers about the decisions you made on this form
- If your first choice is unable to serve this role, you may list a second or third alternate agent

The Health Care Agent you choose cannot be your physician, nurse, or other health care provider who works at your hospital or clinic unless that person is a family member who is not providing your treatment.

## WHAT WILL HAPPEN IF I DO NOT CHOOSE A HEALTH CARE AGENT?

If you are too sick to make your own decisions, your physicians will ask your relatives or close friends to make decisions for you. In Illinois, the law directs the order in which these individuals will be asked. In that law, the individual is called a “surrogate.” (In Illinois, a partner is not considered close family unless you are legally married or have a civil union.)

There are reasons why relying on a surrogate may pose a problem. For example, a person who agrees to be your surrogate may not be who you want to make health care decisions for you. Also, family members and friends may disagree with one another about the best health care decisions for you or what you would have wanted. Further, the person who agrees to be your surrogate may not be able to make all needed decisions. If this occurs, a court may appoint someone, possibly someone whom you do not know, to make health care decisions for you.

**If you do not want someone whom you have not chosen to make health care decisions for you, then you must write the name of your Health Care Agent on the form.**

## WHAT DO I DO WITH THIS FORM ONCE I COMPLETE IT?

- Sign the form in front of a witness.  
(See the form for a list of who can and cannot witness it)
- Ask the witness to sign it, too
- You do not need to have the form notarized
- Give a copy of the signed form to your Health Care Agent and each of your Alternate Health Care Agents
- Share the form with those who care for you including: physicians, nurses, social workers, family and friends

## WHAT IF I CHANGE MY MIND?

You may change your mind at any time. If you do, tell someone who is at least 18 years old you have changed your mind and/or destroy your Power of Attorney for Health Care and any copies. If you wish, fill out a new form and date and sign it with a witness. Then, make sure people destroy the old form and replace it with the revised version.

*Note that you are not required to use this form. Other health care power of attorney forms may be used in Illinois. If you have questions about the use of any form, you may want to consult your physician, other health care provider, and/or an attorney.*

## Power of Attorney For Health Care

This form meets the requirements under the Illinois Power of Attorney For Health Care Act

**Completing this Power of Attorney Form revokes all previous Powers of Attorney for Health Care.  
Both you and a witness must sign this form before it is valid.**

### 1. My Information

My Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_  
Print First and Last Name MM/DD/YYYY

My Address: \_\_\_\_\_  
Street Address, City, State, Zip Code

### 2. Health Care Agent Information

**I want the following person to be my health care agent or primary power of attorney for healthcare:**

(I understand that I may not choose my doctor or health care provider or health care professional administering healthcare to me to be my agent.)

Agent name: \_\_\_\_\_ Agent's phone # \_\_\_\_\_

Agent's address: \_\_\_\_\_

### 3. Powers of My Health Care Agent

**My agent may make decisions for me, include:**

- Deciding whether to accept, withdraw or decline treatment for any physical or mental condition of mind, including life-and-death decisions.
- Agreeing to admit me to or discharge me from any hospital, home, or other institution.
- Having the same access to my medical and mental health records as I have, and sharing my records with my agent as needed, including accessing my records after I die.
- Carrying out the plans I have already made, or, if I have not done so, making decisions about my body/remains, including organ, tissue or body donation, autopsy, cremation, or burial.

### 4. Start of Agency

**I want my agent to make health care decisions for me (initial one option below):**

\_\_\_\_\_ Only when I cannot make them for myself. The physicians caring for me will decide when I lack this ability.  
(If neither option is selected, *this option will be implemented.*)

\_\_\_\_\_ Starting now, and continuing after I am no longer able to make them for myself. While I am still able to make my own decisions, I can do so if I so elect.

### 5. Alternate Health Care Agent(s)

If the Health Care Agent I named above is unable or does not wish to make decisions, then I name the person(s) below, in the order listed, to be my Health Care Agent. Only one person at a time can serve as my Health Care Agent.

Alternate  
Agent #1: \_\_\_\_\_  
Print First and Last Name Street Address, City, State, Zip Code Area Code and Number

Alternate  
Agent #2: \_\_\_\_\_  
Print First and Last Name Street Address, City, State, Zip Code Area Code and Number

## Power of Attorney For Health Care

This form meets the requirements under the Illinois Power of Attorney For Health Care Act

### 6. Life Sustaining Treatment

The subject of life-sustaining treatment is of particular importance. Life-sustaining treatments may include CPR (chest compressions), breathing machines, tube feedings or fluids through a tube, blood transfusions or dialysis. Your agent will weigh the burdens versus benefits of proposed treatments in making decisions on your behalf. In making decisions concerning life-sustaining treatment, your agent is instructed to consider the relief of suffering, the quality as well as the possible extension of your life, and your previously expressed wishes. Making a selection of one of the statements in the next section can serve as a guide for your agent when making decisions for you. Ask your physician or health care provider if you have any questions about the statements.

INITIAL ONLY ONE STATEMENT BELOW THAT BEST EXPRESSES YOUR WISHES (optional):

\_\_\_ The quality of my life is more important than the length of my life. If I am unconscious and my attending physician believes, in accordance with reasonable medical standards, that I will not wake up or recover my ability to think, communicate with my family and friends, and experience my surroundings, I do not want treatments to prolong my life or delay my death, but I do want treatment or care to make me comfortable and to relieve me of pain.

\_\_\_ Staying alive is more important to me, no matter how sick I am, how much I am suffering, the cost of the procedures, or how unlikely my chances for recovery. I want my life to be prolonged to the greatest extent possible in accordance with reasonable medical standards.

### 7. Specific Limitations on My Agent's Decision-Making Authority:

**OPTIONAL:** The above grant of power is intended to be as broad as possible so that your agent will have the authority to make any decision you could make to obtain or terminate any type of health care. If you wish to limit the scope of your agent's powers or prescribe special rules or limit the power to authorize autopsy or dispose of remains, you specifically may include any limitations on the following lines. (You may add another page if more space is needed).

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### 8. Your Signature

My Signature or Mark: \_\_\_\_\_ Today's Date: \_\_\_\_\_  
MM/DD/YYYY

### 9. Witness Signature

Have your witness agree to what is written below, and then complete the lines below:

- I am at least 18 years old.
- I saw this document being signed by the principal or the principal told me that it is his/her signature or mark.
- I am not the principal, agent, one of the successor agent(s) named in this document, or a relative of one of those individuals by blood, marriage or adoption. I am not the principal's doctor, mental health service provider, advanced practice nurse, physician assistant, dentist, podiatric physician, optometrist, or a relative of one of those individuals by blood, marriage or adoption.
- I am not an owner or operator (or the relative of an owner/operator) of the health care facility where the signer is a patient or resident. This prohibition does not apply to employees of the facility including social workers, chaplains, nurses, and other employees who are not owners of the facility.

\_\_\_\_\_  
Witness name (print)

\_\_\_\_\_  
Witness signature

\_\_\_\_\_  
Witness address

\_\_\_\_\_  
Today's date



# Questions for Your Social Worker

Your hospice social worker is a great resource to help you and your loved ones navigate your way through this difficult time. Many of your common questions and concerns are addressed here. Use them as a springboard for conversations with your hospice social worker.

## HOW ARE WE GOING TO MANAGE?

While every patient and his or her support system is unique, there are a number of patterns we see when hospice care is elected and the end of life is anticipated. In spite of the shock and sadness at the thought of losing life or the life of a loved one, family and caregivers might also feel relief—relief that the suffering is winding down, relief that the burdens of caregiving are time-limited, and relief that there will be far fewer medical appointments and treatments. Responses like these are perfectly normal. Your hospice social worker and the entire hospice team is available to support everyone affected by this experience.

Keep in mind that just as you may be short on sleep, do not have time to yourself, or are dealing with untold stress and grief, those closest to you are struggling as well. Everyone needs a little “extra”—extra compassion, extra TLC, extra freedom to process grief and loss, and the space to bear it all with extra grace. Quirks become annoyances, and what was in the past “just Sally” becomes a source of consternation. Just when everyone needs a little more, there is simply no one with anything extra to give. Your hospice social worker will help you work out the adjustment issues you are facing as an individual and as a group of family and friends. It is important to be honest about what is happening so that we can work with you and help bring some stability back into your situation. A calmer support system allows each family member and friend to focus on being their best for the patient and for each other, which in turn opens space to create special memories and momentary blessings during a very difficult time.

## ARE THERE BENEFITS FOR WHICH I AM ELIGIBLE?

Your hospice social worker is a good go-to person for some very practical questions that often come up when a person elects to live the last season of his or her life in the care of a hospice program.

Every state and local community has a myriad of resources that might be helpful during this time. Libraries have home delivery and pickup services for books, music and movies. Grocery stores, Meals on Wheels and other social service agencies can help a patient get the nutrition he or she needs. There are handicapped parking placards available for those still able to leave their home. There are airlines that collect mileage rewards for donations to terminally ill patients, special discounts on Lifeline systems and ramps to make living at home safer. Whatever your unique circumstance, your hospice social worker will do everything possible to make this season in your life comfortable and to help meet not only your medical needs, but your very real psychosocial needs.

## HOW WILL I SORT OUT FINANCIAL RESOURCE INFORMATION?

While your hospice social worker is not a financial expert, there are many documents that he or she will be willing to sort through with you. Long-term care insurance policies, public aid applications and human resource documents are among the items a social worker might help you navigate. There are also certain state and local entitlement programs for which some low-income patients might qualify.

## WHAT DISCOMFORT DOES A SOCIAL WORKER MONITOR?

Your NorthShore Hospice social worker is specifically trained and certified in hospice and palliative care work. While our expertise should in no way be considered a substitute for your nurse's care, your hospice social worker will be monitoring aspects of your medical condition at every visit. Your potential pain, shortness of breath and anxiety levels will be discussed and noted. Any changes in your sleeping, eating, memory or troubling sensation will be of interest to the social worker who may determine

that your nurse be notified of new, worsening or otherwise troubling symptoms. Of course, it is hoped that if a patient, family member or caregiver notices anything unusual, NorthShore will be called regardless of the time of day at **(847) 475-3002** so that your needs are addressed as quickly as possible.

## **DO I NEED SHORT-TERM THERAPY?**

You don't need anyone to tell you that this experience is extraordinarily stressful. You may feel flooded with new and unwelcomed realities. Your hospice social worker is available to stand in the chaos and help you sort through it. Your hospice social worker will listen, answer your questions and help you find ways to cope.

On the really bad days, your hospice social worker will be available to help steady and reassure you by normalizing your experience and providing a much-needed perspective. You will not be alone. If your struggles are more complicated issues, your social worker can teach you and your loved ones various coping strategies. These include, but are not limited to, deep breathing, meditation and new self-care strategies. Your social worker can also serve as a referral source to counselors in your area. Both your social worker and the hospice grief counselor are available to support you through this time of transition. If you find yourself stuck, just call us and we will make sure you get the support you need.

## **WHAT IF I JUST WANT SOMEONE TO TALK WITH?**

Some days when your hospice social worker visits, you will be doing well and enjoying your day. Knowing that life is limited makes many patients and their families eager to retell old stories. Life review is a very important part of the hospice experience. For all the things that are difficult and not what you would have chosen in this experience, this time also provides everyone with an opportunity to remember, share and record your personal history. Talk to your social worker about our Life Stories and Lessons program if you are interested in leaving a recorded message for future generations. Social workers—as well as chaplains, volunteers and your nurse—love hearing about how you met your spouse, what you did for a living and what you enjoy doing in your free time.

## **WHAT IF MY LIVING ARRANGEMENTS DO NOT WORK OUT?**

Especially if you have been living independently before your admission to NorthShore Hospice or if you live with someone with health issues and physical limitations, changes in your condition may require some additional support. This does not mean that hospice care requires a particular household arrangement or that one will be dictated to you. Your hospice social worker, in conversation with your nurse, will assist you in transitioning to and from various care settings. If you have been living independently, there may come a time when you will need to hire a caregiver for some portion of the day or full time, 24/7. These services are usually paid privately by the patient and family, but there are some options for low-income households. Your social worker has a list of agencies with which we have worked in the past and whose caregivers are bonded and insured.

If your pain and other symptoms cannot be managed at home, your hospice team, in consultation with your physicians, may recommend that you be admitted temporarily to the NorthShore Palliative Care Unit located at Evanston Hospital to stabilize your condition. Although the Palliative Care Unit is typically not designed for long-term hospitalization, each case is assessed individually. A five-day respite stay in a skilled nursing facility may be another option. Respite care allows you to be professionally cared for while your regular caregivers attend to their own needs. Caregivers may need to attend an out-of-town wedding or simply feel overwhelmed by the responsibility of keeping you comfortable. Placement in a long-term skilled nursing facility may be necessary if a home environment becomes unsafe. Situations like these are determined in consultation with your hospice team and are executed by your hospice social worker. The costs are paid by patients or their families. The only exception is that public aid does cover the costs in a few designated skilled nursing facilities for those who qualify for that benefit, and the five-day respite stay is covered fully by the hospice benefit.

## HOW WILL I GET TO MEDICAL APPOINTMENTS OR GET ERRANDS RUN?

For many hospice patients and their families, a network of friends, co-workers, neighbors, faith community members or the extended family rallies to help with whatever needs arise. When such a network is not available, NorthShore Hospice has a group of dedicated volunteers who can provide patients with companionship or simply provide a compassionate presence for a few hours when loved ones are unable to be present. Some patients have volunteers drive them or their loved ones to necessary appointments or even for a treat like a lunch out. Volunteers also do light household tasks like meal preparation and laundry. If you have a unique need, let us know and we will attempt to match you with a hospice-trained volunteer in our program.

## WHAT IF THINGS GET OUT OF CONTROL?

Self-care is an important part of maintaining the role of a caregiver. If you are not getting enough sleep or are eating poorly and denying yourself little pleasures like an occasional lunch with a friend, you will compromise the care we are able to provide. Because your hospice team will be with you so routinely, it is unusual for tensions and anxieties to spin totally out of control. But if that does happen, your team will come around you and make whatever adjustments in the treatment plan are appropriate.

Thankfully, it is very rare, but there are times when either hired caregivers or family do not follow the hospice team's plan of care, neglect the personal care and needs of a patient, and/or leave the patient unattended for inappropriately long periods of time. Cases of abuse and neglect will be reported to the appropriate authorities.

## WHAT ABOUT ADVANCED DIRECTIVES AND MAKING A WILL?

As the term suggests, advanced directives are documents prepared in advance of their need to be used. They include the group of documents needed in order for you to be assured that your desires for end-of-life decisions around both your healthcare

and your property will be carried out by those who are charged with that responsibility. In many cases family and friends do indeed "know what you want," but it is important to reinforce these wishes in a legal document. Here are two main documents that you should prepare with or without the help of your hospice social worker:

### 1. Healthcare Power of Attorney

### 2. Legal Will for Property

1. The healthcare power of attorney (HCPOA) is a person you designate to make medical decisions for you in the event that you are not able to make these decisions for yourself. The person you choose should not only be informed of your medical care preferences, but also be capable of making these difficult decisions on your behalf, especially when confronted by other family members with conflicting points of view. For example, if your first-born child would want "everything" done to keep you alive and you prefer only comfort care, another person might be better able to act in your stead. Of more pragmatic help is the general decision to have "everything" done to prolong life, comfort measures only, or "everything" done under certain circumstances like no more than two weeks or if recovery is expected by two physicians familiar with the case.

Along with choosing the healthcare power of attorney, some people like to get very specific about other important preferences, like what sort of music they would like played at their bedside or how caregivers are to attend to hair and makeup. These are obviously intensely personal and virtually limitless in their options.

Your hospice medical team will also ask you about your willingness to sign a Do Not Resuscitate (DNR) form. This is an election not to have CPR or intubation or other invasive attempts to revive you should your heart or lungs stop functioning. Technically, this is a medical order since it must be signed not only by the patient or his or her selected surrogate decision-maker, but also by a physician to be valid. It is included here simply because most hospice patients are ready to forgo aggressive curative treatments in favor of palliative or comfort care and want a DNR on file to make this clear.

2. Your hospice social worker is not directly involved in the preparation of a legal will for property since this is outside their scope of practice. You will generally need to consult with an attorney to accomplish this task. Wills vary in complexity. Forms are available online to help in the preparation of simple wills. At the very least, you should consider naming an executor for your estate to handle the paperwork after your death. There should also be a plan in place for the custodial care of any minor children. Currently, NorthShore Hospice has social workers who are *notary publics* and can authenticate and verify signatures of legal documents that are prepared during your illness.

## WHEN IS IT APPROPRIATE TO START PLANNING A FUNERAL OR MEMORIAL SERVICE?

Timing regarding planning a funeral or memorial service is sometimes dictated by culture or religion but is basically a matter of personal preference. You should not be surprised if some family members may not agree on this matter or have varying abilities to tolerate discussions around end-of-life issues. Minimally, within the first week of admission to hospice you will want to select a funeral home or cremation service. This allows everyone involved to feel a sense of direction when death occurs. It also gives your hospice team the information they need to assist you at this most stressful time. Your hospice social worker and chaplain maintain a full listing of area funeral homes and cremation services. They are also experienced at helping you tailor planning to reflect the family budget. Today, the cost of services ranges from \$1,000 for direct cremation to tens of thousands of dollars for more elaborate services.

## WHAT CAN SOCIAL WORKERS DO IF FAMILY AND CLOSE FRIENDS ARE FAR AWAY?

If you or someone close to you needs to make or change travel plans because of a terminal illness, the hospice social worker can usually either secure reduced fares or have change fees waived by writing a letter on official letterhead. These identify those

who are traveling and verify the patient to be in the NorthShore Hospice program. These letters are addressed to the relevant airline or other transportation office.

In the event of an emergency and you need to contact someone deployed in the U.S. military service, the Red Cross is the agency to contact. Military case workers are available 24/7 and can be reached for reporting and communication services at **(214) 678-4800**. Your social worker will be happy to help out with this after you provide as much information as you have available about the military personnel.

In the event that family and/or friends are in foreign countries or if a hospice patient is to be buried abroad, you will likely benefit from help working through some potentially complicated systems.

If you would like relatives who live outside of the country to be able to gather in the U.S., they will need passports and/or visas. Details of what this entails varies from country to country, so details and potential expediting processes will need to be ascertained through the appropriate consulate or embassy. If your loved ones will be traveling abroad for burial, funeral homes know the procedures and requirements and can give you price ranges. Please note that this can be very expensive unless the body is cremated and it is only the remains that are taken for burial. Also, note that everyone traveling will need a passport. These may take weeks to procure, so be proactive.

While the aforementioned questions are common, you will possibly have many more. In addition to your social worker, the entire NorthShore Hospice interdisciplinary team remains attentive to support you and your loved ones through this difficult time. In many ways your social worker acts as a vital bridge to connect you to other support services. Take advantage of this resource. As questions arise, please feel free to contact your social worker for direction and support.

# Important Papers

An important gift to leave your family is an organized state of affairs. This sheet is provided to identify the locations of important papers. The items listed on this page should not be considered comprehensive, but merely a starting point for organizing your personal documents.

## AUTOMOTIVE

Title

---

Loan

---

## FINANCIAL

Bank accounts

---

Brokerage accounts

---

Checking/savings accounts

---

Credit cards

---

List of investments

---

Outstanding loans

---

Pension

---

Retirement benefits

---

Safe deposit box key and list of its contents

---

Stocks and bonds

---

Tax returns

---

Trust agreements

---

Utilities

---

## FUNERAL INSTRUCTIONS

Burial ☐ Cremation ☐

Cemetery name

---

Location

---

Have plots been purchased?

No ☐ Yes ☐ # \_\_\_\_\_

Funeral home prearrangements made?

No ☐ Yes ☐

Location

---

## GOVERNMENT BENEFITS

Social Security

---

Military record

---

Military benefits

---

Discharge papers

---

## INSURANCE POLICIES

Life

---



Health

Long-term care

Auto

Residential

**LEGAL**

Will

Trust

Powers of Attorney

Divorce/separation papers

Guardianship of minor children

**PERSONAL**

Birth/marriage certificates

Citizenship papers

Adoption papers

Children's documentation

Passport

Home safe combination

Residence

Mortgage/title/lease agreements

Other personal property (e.g., boat, 2nd home, etc.)

**ACCOUNT INFORMATION**

Do not forget to include an accurate list of account names and passwords on all accounts, including email, websites and online accounts.

**OTHER IMPORTANT CONTACT INFORMATION**

Attorney

Personal banker

Accountant

Insurance agent

Broker

**OTHER DOCUMENTS NOT LISTED HERE**

# Funeral Planner

This worksheet is provided to you and your family as an outline to discuss any wishes you may have regarding a funeral or memorial service. Make use of additional sheets as needed.

## FUNERAL HOME

Name:

---

Location:

---

Phone:

---

Type of casket or urn:

---

Clothing or items included with body:

---

Disposition of remains:

Burial ☐    Cremation ☐

Disposition of ashes or cemetery information:

Location/plot # \_\_\_\_\_

Marker

---

Shiva/visitation/wake service

---

---

Donations to charities (in lieu of flowers):

---

---

Meal/hospitality:

---

---

---

---

## FUNERAL OR MEMORIAL SERVICE

Location:

---

Officiant/minister:

---

Eulogy/remembrances:

---

---

Readings:

---

---

Pallbearers:

---

---

Flowers (if applicable):

---

---

Music (if applicable):

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---

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---

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---

---

# Obituary Information

Full legal name \_\_\_\_\_

Legal address \_\_\_\_\_

\_\_\_\_\_

Citizenship \_\_\_\_\_

Date/place of birth \_\_\_\_\_

(Maiden name) \_\_\_\_\_

Parents' names \_\_\_\_\_

Mother's maiden name \_\_\_\_\_

Spouse \_\_\_\_\_

Wedding date and location \_\_\_\_\_

Preceded in death by children's names, their spouse's name and city of residence

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Grandchildren's names \_\_\_\_\_

\_\_\_\_\_

Education \_\_\_\_\_

\_\_\_\_\_

Employment \_\_\_\_\_

\_\_\_\_\_

Organizations/memberships \_\_\_\_\_

\_\_\_\_\_

Faith community affiliation \_\_\_\_\_

Military service \_\_\_\_\_

Character description and other noteworthy information \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_