

Care Planning Guide Making Choices about Your End of Life Care





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Table of Contents

Steps to Create Your Advance Care Plan		Page
Step 1	Choose the right person to be your medical decision-maker.	6
Step 2	Assess Your Values. Decide what values are most important in your life and can help guide future decisions.	6-8
Step 3	Think about how you would care for yourself in different possible situations.	9-12
Step 4	Communicate other considerations.	13
Step 5	Have the conversation. Talk with your medical decision-maker about your Advance Care Plan.	14
Step 6	Fill out the Illinois Power of Attorney for Health Care form (free online).	15
Step 7	Review your Advance Care Plan. Review your plan every 10 years, with any new disease, when there is a decline in health, at the death of loved ones or if there is a divorce.	16
Additional Resources		17
Form	S	
Power of Attorney for Health Care form		17-22
Living Will information and form		23-26

My Contact Information

Name:		
Address:		
City:	State:	Zip code:
Phone:		
e-mail:		
My H	ealthcare Team	



Advance Care Planning

An accident or a change in your medical condition can happen suddenly without warning. If you are over the age of 18 it is important to have an Advance Care Plan.

An Advance Care Plan is a written document that shares what you would and would not want done if you are ever hurt in an accident or become so sick that you are not able to make medical decisions about your care.

Making future healthcare plans helps make sure you get the care you want, even when someone has to make medical decisions for you because you are not able to do so for yourself.

You do not need a lawyer to make an Advance Care Plan. If you need help with this guidebook, ask your healthcare team.

If you do not have an Advance Care Plan, the state of Illinois decides who will be your medical decision-maker.

A Medical Decision-maker is a person you choose to make medical decisions for you when your doctor believes that you cannot make your own healthcare decisions, or if you do not want to make your own decisions.











Page 2 of 27 v.12.05.2017

Advance Care Planning

The Illinois Health Care Surrogate Act gives medical decision-making authority in the following order:

- **1.** Legal guardian assigned by the courts
- 2. Spouse
- **3.**Same sex domestic partner
- 4. Any adult son or daughter
- 5. Any parent

In Illinois, your medical decision-maker is called your "healthcare agent".

If the person who is your first choice to be your agent is not able to carry out this role, then the second agent you chose will make the decisions; if your second agent is not available, then the third agent you chose will make the decisions.

The second and third agents are called your successor agents and are back-up agents to the person you choose as your first agent. Successor agents may act only one at a time and 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 providers.

Talk about what you want and do not want, in case you are ever so sick that you cannot express your own wishes. Make a written guide and ask your doctor or other healthcare provider to write it down in your chart.

You can also make what is called a "living will". A living will says what your wishes are if you have been diagnosed with a terminal condition. There is a copy of a living will attached to this guidebook.



- 6. Any adult brother or sister
- 7. Any adult grandchild
- 8. Any close friend willing to step up
- **9.** The guardian of your financial estate





Advance Care Planning

Making future healthcare plans helps makes sure you get the care you want, even when someone has to make medical decisions for you because you are not able to do so for yourself.

Share your Advance Care Plan with loved ones or someone you trust. This can be a gift to help them make very difficult medical decisions at stressful times.

The more you share your wishes with others, the easier it will be for your medical decision-maker to deal with challenging decisions. Make sure that you at least tell your healthcare team who you want as your medical decision-maker.

When you have difficult medical decisions, you may consider getting many opinions from:

- Family and friends
- Your religious community
- Different doctors
- Internet

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

- Who is ready and willing to be 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:

- Choose a medical decision-maker
- Think about and decide what is important to you
- Communicate your wants and wishes
- Make your plan legal and at no cost



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



Page 4 of 27 v.12.05.2017



Step 1: Choose Your Medical Decision-Maker

Choose the right person to be your medical decision-maker. Think about how you would want your medical decisionmaker to act on your behalf.

Your medical decision-maker may be put in a difficult situation and feel a lot of pressure. This can cause a lot of emotional distress.



Choose someone who would not be too

upset to carry out your wishes if you became very sick. Having one medical decision-maker does not mean that others will not have an opinion but it can lessen arguments and stress.

We recommend you choose one person who:

- Can honor your wishes
- Has the same values of you (in terms of what makes life worth living)
- Can think like you
- Can think about the differences between difficult medical decisions
- Can work well under pressure
- Will be responsible to make medical decisions with your best interest in mind

Step 2: Assess Your Values

Everyone is different in how they view life and what is most important to them. Use the following tables to help you decide what values are most important in your life and can help guide future decisions. Rate each item on its importance to you using a scale of 1 to 3.

- 1 means that this is something that is **very important** to you
- 2 means that this is something you want
- **3** means that this is **not important** to you



Page 5 of 27 v.12.05.2017

Step 2: Assess Your Values Rate each item on its importance to you using a scale of 1 to 3. 1- means that this is something that is **very important** to you 2- means that this is something you want - means that this is **not important** to you **Medical Values** 1, 2 or 3 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 help me breathe if I cannot breathe on my own Have my organs donated 1, 2 or 3 **Personal Values** 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 religious or spiritual leader



Page 6 of 27 v.12.05.2017

Step 2: Assess Your Values			
Rate each item on its importance to you using a scale of 1 to 3. 1 - means that this is something that is very important to you			
2 - means that this is something you want			
3 - means that this is not important to you			
Values About Death	1,	2 o	r 3
Have family with me and not die alone	1	2	3
Be able to say goodbye to loved ones	1	2	3
Die at home	1	2	3
Die in the hospital	1	2	3
Have a natural death, not hooked to tubes or machines	1	2	3
Other Values (Write in other values)	1,	2 o	r 3
	1	2	3
	1	2	3
	1	2	3
	1	2	3
	1	2	3
	1	2	3
	1	2	3
	1	2	3
	1	2	3



Page 7 of 27 v.12.05.2017

Step 3: Think about Different Situations

Think about how you would care for yourself in different possible situations.

Some situations may be difficult to think about, but you should choose answers and write comments about how you would like to be cared for.

These situations can help your medical decision-maker with difficult decisions.



Remember, there are no right or wrong answers. Talk to your healthcare team if you need help.

Possible Situation 1

You are healthy and then 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 unknown.

Do you stay on life support?

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

Comments:



Page 8 of 27 v.12.05.2017

Step 3: Continued

Possible Situation 2

You have 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.

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

- O Do everything to keep me alive
- O Let nature take its course
- O Other

Comments:

Possible Situation 3

You are very overweight with heart disease and diabetes. Treating them to extend your life could involve invasive heart procedures and long, complicated hospital stays.

Would you want to pursue aggressive treatments or do you let life happens as it occurs?

- O I would pursue aggressive treatments
- O I would let life take its course
- O Other

Comments:



Page 9 of 27 v.12.05.2017

Step 3: Continued

Possible Situation 4

You have a lung disease that cannot be cured. You 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?

- O Yes, I would want to stay on the ventilator
- O No, I would not want to stay on the ventilator
- O Other

Comments:

Possible Situation 5

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?

- O Yes, I would want the tube placed
- O No, I would not want the tube placed
- O Other

Comments:



Page 10 of 27 v.12.05.2017

Step 3: Continued

Possible Situation 6

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 get care: at home or in the hospital?

- O I would want to be cared for at home
- O I would want to be cared for in the hospital
- O Other

Comments:

Possible Situation 7

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?

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

Comments:



Page 11 of 27 v.12.05.2017

Step 4: Communicate Other Considerations

There are other things you should think about, that 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 stages in a disease when you would not want aggressive medical care to keep you alive?

In what possible situations would you want 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?



Page 12 of 27 v.12.05.2017

Step 5: 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 make sure 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 make sure everyone is on the same page.
- Tell your medical decisionmaker why they were chosen 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 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 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 ready when needed.



Page 13 of 27 v.12.05.2017

Step 6: Complete the Power of Attorney for Health Care

This Guidebook is Not a Legal Document.

To legally choose a medical decision-maker, you must fill out an Illinois Power of Attorney for Health Care form. This form is a free document. You can get it online or from your healthcare team.

You can also use the Power of Attorney for Health Care that is attached to this guidebook.



For the online form go to: <u>https://www.illinois.gov/aging/ProtectionAdvocacy/</u> <u>Documents/POA_HealthCare.pdf</u>

You must have one person as a witness who also signs the document. The witness cannot be your medical decision-maker. There is no need to have the form notarized.

If you do not want to use the Illinois power of attorney you can write down your wishes and make your own form. Choose an agent who is over 18 years of age and not prohibited from serving as your agent. Write down what medical decisions the agent can and cannot make for you.

Share Information with Your Healthcare Team

After you complete the information in this guidebook and have completed the Illinois Power of Attorney for Health Care, bring them 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 make sure that your wishes are granted.

• Tell them who you have chosen as your medical decision-maker



- Provide them with a copy of your Illinois Power of Attorney for Health Care 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.



Page 14 of 27 v.12.05.2017

Step 7: Review and Update Your Plan

What You Value May Change with Major Life Events

You should review and update your Advance Care Plan on a regular basis, or when there is a **Death, Divorce, Decade, Decline or Disease** that happens in your life.

- **Death:** Every death that occurs in people around you
- **Divorce:** A divorce and/or other changes in your relationship with your loved ones
- Decade: Every 10 years of your life
- **Decline**: A decline in your health occurs



• Disease: A new disease happens to you

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

You Can Change Your Mind at Any Time.

If you change your mind, tell someone who is at least 18 years old and then destroy your document and any copies.

You can also fill out a new form. Make sure everyone you gave the old form to has a copy of the new one including your healthcare agents and your doctors.



If You Change Your Medical Decision-Maker:

- Update your Illinois Power of Attorney for Health Care form
- Tell your healthcare team about the change



Page 15 of 27 v.12.05.2017

Resources

Prepare for Your Care www.prepareforyourcare.org

National Hospice and Palliative Care Organization www.caringinfo.org

Aging With Dignity www.agingwithdignity.org

New York Times Well Blog well.blogs.nytimes.com/2009/03/20/planning-for-death-when-you'rehealthy

Go Wish Game by Coda Alliance www.gowish.org/staticpages/index.php/thegame

Illinois Power of Attorney for Health Care form (free online) https://www.illinois.gov/aging/ProtectionAdvocacy/Documents/POA_Hea lthCare.pdf



Page 16 of 27 v.12.05.2017

My Advance Care Plan



Page 17 of 27 v.12.05.2017

My Power of	Attorney for Health Care
This power of attorn	ey revokes all previous Powers of
Attorney for Health	Care.
My Information	
Name:	
Address:	
City:	
State:	Zip Code:
Phone:	
Email:	
My Healthcare Agent	
	on to be my healthcare agent. If a guardian is ate the agent acting under this power of attorney as
Name:	
Address:	
City:	
State:	Zip Code:
Phone:	
Email:	
Successor Healthcare	Agents
decisions for me, then I re	not able or does not want to make healthcare equest the persons I name below to be my successor one person at a time can serve as my agent.
Successor Healthcare	Agent 1
Name:	
Address:	
City:	
State:	Zip Code:
Phone:	
Email:	

Power of Attorney for Health Care - Page 1 of 6



Page 18 of 27 v.12.05.2017

My Power of Attorney for Health Care

Successor Healthca	re Agent 2
Name:	
Address:	
City:	
State:	Zip Code:
Phone:	
Email:	
Healthcare decision	s my agent can make for me
My agent can make	healthcare decisions for me, including:
•	t, withdraw or decline treatment for any physical or of mine, including life-and-death decisions.
	me to or discharge me from any hospital, home, or ncluding a mental health facility.
• •	access to my medical and mental health records, and others as needed, including after I die.
making decisions a	lans I have already made, or, if I have not done so, about my body or remains, including organ, tissue or ion, autopsy, cremation, and burial.
agent will have the authority	er is intended to be as broad as possible so that my prity to make any decision I could make to obtain or ealth care, including withdrawal of nutrition and sustaining measures.

Power of Attorney for Health Care - Page 2 of 6



Page 19 of 27 v.12.05.2017

My Power of Attorney for Health Care
Healthcare decisions my agent can make for me
I authorize my agent to (check only one box):
To make decisions for me only when I cannot make them for myself. The doctors taking care of me will determine when I lack this ability.
(If no box is checked, then the box above shall be implemented.)
 To make decisions for me only when I cannot make them for myself. The doctors taking care of me will determine when I lack this ability. Starting now, for the purpose of helping me with my healthcare plans and decisions, my agent shall have complete access to my medical and mental health records, the authority to share them with others as needed, and the complete ability to communicate with my personal doctors and other healthcare providers, including the ability to require an opinion of my doctor to whether I lack the ability to make decisions for myself. To make decisions for me 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 still do so if I want to.
Healthcare decisions my agent can make for me
Check only one statement below that best expresses your wishes.
☐ The quality of my life is more important than the length of my life. If I am unconscious and my attending doctor 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 are. I want my life to be prolonged to the greatest extent possible according to reasonable medical standards.



Page 20 of 27 v.12.05.2017

My Power of Attorney for Health Care

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 give special rules or limit the power to authorize autopsy or dispose of remains, you may do so in this space.

Limits to Decisions My Agent Can Make for Me

Power of Attorney for Health Care - Page 4 of 6



Page 21 of 27 v.12.05.2017

My Power of Attorney for Health

In the table below, check the items that you would want your medical decision- maker to follow. You can add other comments for clarification.

Wh	en Making Medical Decisions for Me: (check all that apply)
	Talk to friends, family and religious leaders for advice.
	Follow my wishes 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 and religious values that are important to me.
	Please explore every possible treatment option, including seeking second opinions and experimental treatments that might be available.

Power of Attorney for Health Care - Page 5 of 6



Page 22 of 27 v.12.05.2017

My Power of Attorney for Health Care

Patient (Principal) Signature

My Signature

Date

Witness Signature

witness Signature
Have your witness agree to what is written below, and then complete the signature portion:
I am at least 18 years old. (check one of the boxes below)
I saw the patient (principal) sign this document
The patient (principal) told me that the signature or mark on the principal signature line is his or hers.
I am not the agent or a successor agent named in this document. I am not related to the principal, the agent, or the successor agents by blood, marriage, or adoption. I am not the principal's doctor, advanced practice nurse, dentist, podiatric physician, optometrist, psychologist, or a relative of one of those individuals. I am not an owner or operator (or the relative of an owner or operator) of the healthcare facility where the principal is a patient or resident.
Witness Printed Name
Witness Address
Witness Signature
Today's Date:

Power of Attorney for Health Care - Page 6 of 6



Page 23 of 27 v.12.05.2017

Information About a Living Will

A Living Will is a document in which a person can declare their desire to have death-delaying procedures withheld or withdrawn if they have been diagnosed with a terminal condition by a doctor.

A Living Will makes sure that your rights will be respected if you are not able to actively participate in death-delaying decisions relating to your own health care due to a physical or mental condition.

A Living saves your family from the burden of having to make healthcare decisions about consenting to or refusing death-delaying procedures without knowing your wishes.

Anyone age 18 or older who is a resident of Illinois may make a Living Will at any time. The Living Will document must be signed by you and 2 witnesses.

You do not need a lawyer. Illinois law does not require that an attorney prepare a Living Will document. However, you may want to consult with an attorney for more advice in protecting your interests using advance directives.

The best time for you to make a Living Will is right now, long before you think anything could happen to you. This will make sure the doctor and your family know your wishes if you are ever in a situation where death-delaying procedures become necessary.

Under Illinois law, a properly signed and witnessed Living Will takes effect as soon as a person has been diagnosed with a terminal condition and their doctor verifies such information in writing as a part of the medical record.

If the doctor is not willing to go along with and does not agree with the instructions stated in a Living Will document, then the doctor must tell the patient of that fact.

If the patient is not able to turn over their care to another doctor, then the doctor must by law do 3 things.

- **1.** The doctor must tell any person authorized by the patient to make the arrangements for the patients care to be turned over to another doctor.
- **2.** The doctor must tell the patient's guardian so that they can make the arrangements for the patients care to be turned over to another doctor.



Page 24 of 27 v.12.05.2017

Information About a Living Will

A Living Will does not take effect if there is a person who is authorized to deal with death-delaying decisions on your behalf under a Durable Power of Attorney for Health Care.

You may revoke your Living Will by (1) burning, tearing, or otherwise destroying or defacing the document, (2) signing a written revocation, or (3) making an oral revocation in the presence of a witness 18 years of age or older who then puts the revocation in writing for you.

Most states will recognize a Living Will. However, some states require a document to be witnessed and notarized to be valid. After you make a Living Will, you should sign it in the presence of your witnesses and a notary public to avoid any possible problems.

A Living Will document that has been made according to the law of any other state will be recognized in the state of Illinois.

Other Things to Consider:

- You should talk to your doctor about your Living Will. Make sure that they will agree and go along with your instructions about withholding or withdrawing death-delaying procedures.
- You should give the original Living Will document (signed, witnessed, and notarized) to your doctor.
- You should give copies to your healthcare facility, hospital, lawyer, agent under a Durable Power of Attorney for Health Care, family, or other persons who you can rely on to act according to your interests and values.
- You may want to make a note about your Living Will on the back of your driver's license or add a notification card to your wallet.



Page 25 of 27 v.12.05.2017

Illinois Living Will Act Illinois Compiled Statutes, 755 ILCS 35/1 et seq.

	Declaration	I	
This declaration is made this	day of	(month)	(year).
I,		being of sou	nd mind,
willfully and voluntarily make kr not be artificially postponed.	nown my desires	s that my moment of de	ath shall
If at any time I should have an incurable and irreversible injury, disease, or illness judged to be a terminal condition by my attending physician who has personally examined me and has determined that my death is imminent except for death delaying procedures, I direct that such procedures which would only prolong the dying process be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication, sustenance, or the performance of any medical procedure deemed necessary by my attending physician to provide me with comfort care.		o has t except ess be ly the nedical	
In the absence of my ability to give directions regarding the use of such death delaying procedures, it is my intention that this declaration shall be honored by my family and physician as the final expression of my legal right to refuse medical or surgical treatment and accept the consequences from such refusal.			nored by Ise
Name:			
Signed:			
City:	County:	State:	

Living Will - Page 1 of 2



Page 26 of 27 v.12.05.2017

Illinois Living Will Act Illinois Compiled Statutes, 755 ILCS 35/1 et seq.

The declarant is personally known to me and I believe him or her to be of sound mind.

I saw the declarant sign the declaration in my presence (or the declarant acknowledged in my presence that he or she had signed the declaration) and I signed the declaration as a witness in the presence of the declarant.

I did not sign the declarant's signature above for or at the direction of the declarant.

At the date of this instrument, I am not entitled to any portion of the estate of the declarant according to the laws of intestate succession or, to the best of my knowledge and belief, under any will of declarant or other instrument taking effect at declarant's death, or directly financially responsible for declarant's medical care.

Witness 1 Name:
Signature:
Witness 2 Name:
Signature:
The Illinois Department on Aging does not discriminate in admission to programs or treatment of employment in programs or activities in compliance with appropriate State and Federal Statutes.
If you feel you have been discriminated against, you have a right to file a complaint with the Illinois Department on Aging.
For information, call the Senior Help Line at 1-800-252-8966, 1-888-206-1327 (TTY). <u>www.illinois.gov/aging</u>
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Page 27 of 27 v.12.05.2017

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