

6-STEPS Living Will

A Guide for creating a 3-part Living Will
that will help you get the type of
end-of-life care you need and want.

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*A few key concepts are repeated to verify consistency in your choices.
Also, examples of some concepts are offered to verify your understanding.*

Please use the Guide tab to help you complete your 6-Steps Living Will.

*You may also want the help of a facilitator as an aid to fully understand
the nature and implications of the decisions you are about to make.*

*Many healthcare organizations have dedicated professionals
who are skilled in assisting in the creation of Living Wills.*

Let's begin with answers to questions about the 6-Steps

What is advance care planning?

In 1990, the US government granted patients the right to create an advance directive to clearly state the kind of care they would like and to choose a healthcare representative or surrogate who will express their wishes if they are too sick to speak for themselves. Involving loved ones is a good way to discuss end-of-life care with healthcare providers.

Why should I even think about this now?

6-Steps is designed to help you choose the kind of treatment you want if an illness or accident makes you unable to express your preference. If you don't decide the type of treatment you want for yourself, the decision will be made for you. Without your written wishes, your doctor and/or your loved ones may choose measures that they believe you would want or what they would choose for themselves - even if these are not the decisions you would have made if you were able to speak for yourself. The best way for you to be sure your goals and treatment preferences are known is by completing a Living Will. You will be able to choose between three general types of treatment:

What 3 kinds of treatment will be available to me?

1. Full (Aggressive or Curative) Treatment
2. Limited Treatment
3. Comfort Care Only

1. Full (aggressive or curative) treatment includes the use of any drug, surgery, or other treatment that could prolong life, even when there is little chance of cure or remission. Comfort is usually taken into consideration, but many of the curative procedures have both benefits and unwanted effects as indicated in the table below. Full treatment often includes the following procedures.

Important benefits of treatment options	Some unwanted effects of treatment options
CPR (Cardiopulmonary resuscitation) uses chest compression to try to restore heartbeat and electric shock to try to restore heart rhythm. It works best with healthier patients.	CPR may break ribs in a way that can puncture lungs, and if the procedure is not done quickly enough, patients may suffer brain damage. In effect, CPR interferes with a natural death.
Drugs can help recovery from illness.	Drugs can have harmful or even life threatening effects and they may delay an otherwise desirable death.
Breathing tubes inserted through the nose, a mask, or into the trachea will help with lung problems or recovery from surgery.	Breathing tubes may painfully irritate the nose and mouth, often can complicate or prevent speaking and swallowing.
Tubes for fluid and nutrition inserted into the nose, a vein, or directly into the stomach can be helpful if the person is not extremely sick and if their use is time-limited.	Tubes for fluid and nutrition may cause painful swelling if they deliver more content than the body can use, may cause gagging if patients inhale the fluids into their lungs, may require hands and feet to be restrained so tubes are not pulled out, and the tubes may not be removable.
Surgery can remove obstructions and tumors or insert mechanical devices to extend life.	Surgery can cause wound infections and other serious problems from which very ill patients may not recover.



These measures may also cause nausea, pain, fatigue, or other forms of distress. In addition, some people lose the sense of dignity, autonomy, and identity. *Medical technology may externally extend life, but physical and mental conditions may worsen.* Although the standard treatment approach is to do everything possible to keep a person alive if you want full treatment, it is best to state your wishes in writing so you don't receive less care than you want. If you choose limited treatment or comfort care only instead of full treatment, these must be requested by your healthcare representative.

2. Limited treatment includes the use of drugs or other treatments to manage and control medical conditions and pain. Limited treatment might include very *short-term* use of surgically inserted tubes for food, water, and drainage of bodily wastes, possibly dialysis, and procedures to ease breathing including oxygen, oral suctioning, and breathing aides like small CPAP or Bi-PAP machines. Limited treatment usually does not involve surgery other than to combat pain or infection. It may involve CPR and/or heart shocks. It can be terminated if your condition gets worse. You can decide how long it continues.

3. Comfort care only includes the use of drugs only to treat pain, procedures to make patients comfortable such as positioning and wound care, and procedures to ease breathing including oxygen, oral suction, and manual methods to clear airways. Comfort measures do not include surgery, CPR, shocks or ventilators, surgically-inserted tubes for food and water, or other curative or life-support measures. Palliative care doctors, and others, who offer comfort care are specialists in helping patients be comfortable at the end-of-life. Comfort care often begins in the hospital and extends to hospices and patients' homes. It may also include psychological and/or spiritual counselling. Patients who receive comfort care only often live longer than those who receive full aggressive treatment because their bodies are spared the trauma resulting from many invasive curative treatments. Many regard the decision not to prolong their lives by artificial means as the decision to die naturally.

More information about these types of care is available at:
<http://www.caringinfo.org/i4a/pages/index.cfm?pageid=1>

What if I don't know what I want now or I change my mind later?

The only wrong decision is choosing not to express your wishes, as specifically as possible, in writing. Don't delay stating your wishes. If you have different ideas in the future, you can easily rewrite all or any part of this document.

Advance care planning documents have different names in various settings.

Here, "Living Will" has three components:

1. **A Personal Statement** in which you express your values and beliefs to fill any gaps in your Advance Directive.
2. **An Advance Directive** that describes the kind of care you want to receive if you have a terminal illness.
3. **A Durable Power of Attorney for Healthcare** through which you choose someone to speak for you if you are unable to speak for yourself.

After discussing your Living Will with you, your doctor may create a CMO (Conditional Medical Order), MOELI (Medical Orders for End-of-Life Intervention) or POLST (Physician Orders for Life-Sustaining Treatment) or documents with different names in some states. It enters your preferences for full, limited, or comfort only treatment into your medical record.



What are the 6 Steps I am being asked to take?

Step 1 **Think through your values about end-of-life care.** Your values provide the basis for the choices you are about to make in your Personal Statement and Advance Directive.

Why is this important? Clarifying your values now will make it easier for you to make critical decisions more quickly in the future.

Step 2 **Write a Personal Statement** that clarifies how you have lived your life and how you would like your life to end. Your statement will be most useful if it tells decision-makers who you are as a person so they view you as more than a patient with a severe illness. It is your story about yourself, and how you would like to be remembered.

Why is this important? The Advance Directive that you will complete next covers many conditions and options, but it cannot cover every possibility. This Personal Statement will fill in the inevitable gaps.

Step 3 **Create an Advance Directive** that tells your healthcare providers about the type of end-of-life care that you would like to receive. This is a clear and complete statement of your wishes.

Why is this important? Many people prepare statements that are not specific enough to guide the kind of care they want to receive. This step ensures that your Advance Directive includes the required details.

Step 4 **Create a Durable Power of Attorney for Healthcare** in which you name the person you choose to act for you if you cannot act for yourself, those with whom you would like your chosen healthcare representative (or "surrogate") to discuss decisions, and those you do not want to participate in decision-making. No advance plan can consider every possibility, so the person who acts for you may have to make some important decisions very fast. This step guides discussion of your wishes with your surrogate and encourages you to discuss them with all interested family members, and others who will be affected by your decision.

Why is this important? This is the person who will speak for you if you are unable to speak for yourself. This person will be able to help you get the type of care you want only if he or she fully understands your wishes.

Step 5 **Explain your wishes to your doctors** and determine their willingness to deliver the kind of care you request. **Also create a summary of your condition and treatment preferences** as a source of much needed information for doctors who may not know you and first responders can use in treating you.

Why is this important? Many health professionals are uncomfortable discussing dying and death with their patients. This step helps you raise the topic so you and your doctor can discuss it honestly and reach a common understanding. In addition, you may be seen by providers who have never had the opportunity to get to know you. This statement conveys information they need to treat you as a unique person with specific requests rather than an unknown patient with a health issue.

Step 6

Set up a plan to make sure that all the effort you put into a Living Will helps you get the kind of care you want. This will remind you to keep the requests in your Living Will current and to make it easily available when needed. It will also remind you to complete the tasks that are important to you at the end of your life.

Why is this important? Because many people hide their living wills and they cannot be found when needed in a crisis making their final days more stressful because they have not conveyed the messages they intended to deliver.

Step 1 Thinking about Your Values and Preferences

Expressing your values and preferences is an important first step toward you being able to make decisions with which you can be comfortable in the future. The following statements are designed to help you begin to think about your values and preferences for end-of-life care. Please add others that occur to you while considering the choices below.

For each pair of statements below, pick the one closest to your beliefs, even if both have some truth.

X	COLUMN A		X	COLUMN B
	I believe it is my religious and/or spiritual duty to do everything I can to stay alive as long as possible.	OR		My religious and/or spiritual beliefs do not require me to do everything I can to stay alive as long as possible.
	I believe in miracles and I hope that one can cure me if I am dying.	OR		I do not believe that a miracle will cure me if medical care fails.
	I believe my life has value and should be prolonged regardless of its quality.	OR		I do not want my life prolonged if: (Check all that apply) <input type="checkbox"/> I lose my identity, cannot think clearly, and cannot communicate with others. <input type="checkbox"/> I cannot control my bodily functions and must depend on machines or other people. <input type="checkbox"/> I have very severe pain that cannot be controlled and that prevents my enjoyment of life. Other: _____ _____ _____ _____
	I want to live as long as possible and do not care about the level of suffering and incapacity before my death.	OR		I prefer to die a little earlier if doing so allows me to die with dignity.
	I want all life-prolonging treatments, even if there is less than a 1% chance of success.	OR		I want only those treatments that have a good chance to restore my functioning.
	Economic cost and burden on others, should NOT be considered when planning my end-of-life care.	OR		Economic cost and burden on others, SHOULD be considered when planning my end-of-life care.
	I believe that doctors always know best and I should not question their advice.	OR		I will consider my doctors' advice when I make my own treatment decisions.
	It is too hard for me to decide now, so I will leave decisions to my family or others.	OR		I will make these decisions now so I will not burden my family with guessing what I want later.

What have you learned from your responses?

If you mostly checked the options in Column A, you prefer aggressive treatment and wish to leave your death in the control of a Higher Power, healthcare professionals, or loved ones.

If you mostly checked the options in Column B, you want to make your own end-of-life decisions and be open to the option of comfort care only. The examples below will help you reflect on the implications of the values that you have expressed.

The following illustrations are offered to help you clarify the three types of end-of-life care. You can keep these images in mind as you make your own decisions. Which type of treatment did each person receive:

1. **Alex** was unconscious as the result of a long illness. He was on a breathing machine, received food and water by tube, his bladder was being drained by a tube, and he was receiving medication to prevent certain illnesses. He died after living in this state for 14 weeks. No one could tell whether he was aware of his condition or if he experienced pain.
2. **Betty** became unconscious as a result of a long illness. Unlike Alex, her advance directive specified that she not be put on a breathing machine, not be given food or water by surgically-inserted tubes, and not be given CPR or any medications other than those to relieve pain. She died of pneumonia in 5 days.
3. **Carol** suffered from an advanced stage of cancer with many large tumors. She had her cancer treatment stopped. Although great efforts were made to manage her pain, the level of medication that would be needed to control it completely would make her almost unconscious. She was told that her condition could only get worse, never better. She chose to receive oxygen via nasal tube and to try food and fluid intake by a surgically inserted tube. She did not want CPR or medication because she hoped that her heart would stop or that she could die of pneumonia. She lived in this state for 7 weeks before dying.
4. **Dan's** health had been failing for several years, but he was too uncomfortable about dying to think about it, and too busy to create an advance directive or discuss his wishes with his family. He lost consciousness shortly after entering the hospital following a serious relapse. His wife believed that he would want to accept death and die peacefully, but two of their children believed that he would want to fight death as long as possible and that he wanted to try to benefit from every available procedure. While the family argument raged on, the hospital had no choice but to put him on a ventilator and other life support devices until he finally died 29 weeks later without regaining consciousness. Conflict over these issues drove a major wedge between Dan's wife and their children, lasting many years.

The table below helps you visualize the practical implications of your choices.

Procedures	Alex	Betty	Carol	Dan
Level of care	Full	Comfort Only	Limited	Full
Aggressive cure	Yes	No	No	Yes
CPR, etc.	Yes	No	No	Yes
Breathing and/or nutrition and hydration tubes	Yes	No	Yes	Yes
Antibiotics	Yes	No	No	Yes
Pain and comfort measures, including oral fluids and food	Yes	Yes	Yes	Yes

Step 2

Writing Your Values & Beliefs in a Personal Statement

People's deaths are as different and as unpredictable as their lives. Neither you nor your doctor can know in advance what you will face at the end of your life. By writing a Personal Statement you can let people know more about you as a person, including your core beliefs and values and how and where you would like to die, to the extent that you have a choice. Others can use your perspective in making choices for you in situations not covered by your Advance Directive. Your statement can be a few sentences or several pages.

Writing a personal statement can be a difficult task so we've included five examples that will give you some ideas to consider. Some people can write their own personal statement in a matter of minutes, while others write several drafts before they are satisfied. Feel free to use any of the words and phrases included in any of the sample statements. You might find it useful to reflect on these questions as you think about your statement.

- What are your core values and beliefs?
- What gives meaning to your life? What brings you joy?
- What is most important to you? How do you define "quality of life?"
- What special message or words would you like to communicate to your family members and friends?
- How would you like to be remembered? How can the way you die contribute to this memory?
- What do you wish to avoid in your own final days or weeks?
- Do you have any wishes regarding your remains, the way your life is celebrated, or your obituary?

Sample Personal Statements

Stephen: I have been a devout Catholic all my life. I have lived by the teachings of the Church to the best of my abilities and wish to die by its teachings as well. No matter how sick I may be, or how much pain I may endure, please sustain my life until I am revived by the miracle for which I hope you will pray.

Tanya: My core values are connections with those I love, intellectual growth, social responsibility, and autonomy. I do not want my life prolonged if I permanently lose the ability to interact meaningfully with my wife and children, to contribute to my community in some small way, and to lead a dignified and independent life. I do not want to preserve a body that my identity no longer inhabits.

Joe: Dear Loved Ones. You know how hard it is to get me to turn off Sports Center. I love being with you but if I can't pay attention to sports on TV, I certainly won't know who you are or what you're saying. So please use TV as a test and take me out of the game if I can't recognize the players and the plays.

Jenny: I value my family and friends and worked hard to lead a good and honest life. I want my kids and grandkids to be able to enjoy some of the money that I have saved. Therefore, I don't want a bunch of money spent on treatments that won't make me better but will just keep me alive either in pain or not knowing who I am or who I'm with. I want people to let me have a natural, tamper-free death.

May: I believe that only the Lord gives life and only the Lord should decide when and how my life ends. I believe that as He did with Job, the Lord may present my soul with challenges to demonstrate that I fully embrace and live within the Light of His Grace. That means that the Lord expects me to do what I can to maintain my health so I can do His work. However, I believe that when the Lord calls my soul home, I must heed His call. Therefore, I want to receive any treatment that will cure my illness, but I do not want to receive treatments that will at best only prolong my life. In Jesus' name, I hope that everyone will honor this prayer for mercy and free my soul to reach its higher place in heaven.

PERSONAL STATEMENT OF: _____

Since I cannot know how a terminal illness will develop, the requests I make now for end-of-life care cannot be specific to my condition if I am dying and cannot speak for myself. I am writing the following statement of my values and perspective to guide you as you make decisions about my end-of-life care consistent with my wishes to manage situations not addressed in my Advance Directive.

Your Signature: _____ Date: _____

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Step 3

Create an Advance Directive

By signing and having witnesses sign the document below, you will complete your Advance Directive.

ADVANCE DIRECTIVE TO PHYSICIANS

Declaration made this _____ day of _____ (month), 20 _____

I, (PRINT NAME) _____, having the capacity to make healthcare decisions, willfully and voluntarily make known my wishes for my end-of-life care.

1. I reserve the right to make decisions about the care I receive as long as I retain the capacity to do so.
2. As an overview of my beliefs, I choose either "2a" OR "2b" as my belief, (not both).
 - 2a. I believe that life is worth living regardless of its quality and I request that I be given all possible treatments to prolong my life, regardless of their expected effects and their physical, psychological, and/or economic impact.
_____ This is my belief (initial).
If 2(a) is your belief, draw an "X" over Item 3 and skip to Item 4.
 - 2b. If my condition reaches a point that I regard as worse than death, I want palliative care to manage my pain, make me as comfortable as possible, and allow me to preserve my dignity with no effort made to prolong my life.
_____ This is my belief (initial).
If 2(b) is your belief, draw an "X" over Item 2a and please continue to Item 3.

3. **Since I endorsed #2b**, I want it known that I consider any condition or combination of conditions checked below to be a state that I consider to be worse than death **if they cannot be controlled and have little to no chance of being reversed**. (Initial all that apply).
 - a. _____ I am unconscious with little to no chance of ever regaining consciousness, that is, if I am in a "permanent vegetative state."
 - b. _____ I have permanent uncontrollable pain that makes it difficult for me to pay attention to anything else.
 - c. _____ I cannot breathe unless I am on a ventilator.
 - d. _____ I cannot take in food or water other than by tube.
 - e. _____ I cannot remember who or where I am and cannot recognize my family or friends.
 - f. _____ I cannot control my destructive or anti-social behavior, putting myself or others at risk of serious injury.
 - g. _____ Other: _____

4. As a **general guide**, when I am suffering with a terminal illness that could end my life, I would like the following scope of treatment: (Initial ONE)
_____ **Full aggressive or curative treatment to externally prolong life**. This includes any treatment recommended by my doctors to manage my condition and control my pain and discomfort. This may include any drug, surgical procedure, life support measures such as CPR, shocks to restart my heart, food, and water by tube (e.g. PEG), mechanical ventilator to aid breathing, and body wastes drained by tube. I understand that I may be unable to live without mechanical support prior to death.
_____ **Limited use of invasive measures and avoidance of aggressive procedures**. This may include use of drugs and other methods to control my illness, infection and/or pain, IV fluids but not via PEG, body drains; breathing assistance via CPAP or BiPAP machine, minor surgery, and/or use of CPR or shocks only if my heart stopped due to a temporary reversible event. I understand this is likely to delay my dying and that I can decide how long I want to use limited treatment before switching to comfort care only.
_____ **Comfort care only, allowing natural death**. This includes the use of drugs only to treat pain and psychological discomfort, other procedures such as positioning and wound care, procedures to ease my breathing, including oxygen, oral suctioning, and manual methods to clear my airways, but NO surgery, CPR, shocks, ventilators, tubes for food or water, or other aggressive measures. I understand that because I am refusing aggressive procedures, I may die sooner.

5. Cardiopulmonary Resuscitation (CPR). Initial ONE:

- AACPR** Always DO attempt to resuscitate (CPR) any time my heart stops beating.
- DNAR-X** DO resuscitate only if my heart stopped or breathing due to a temporary reversible event, e.g. anaphylactic shock or medical error, etc.
- DNAR** DO NOT resuscitate or use defibrillator under any circumstance. Always allow natural death.

6. Added requests. If I am in a condition that I consider **worse than death**, I do/do not want the following procedures, with qualifications indicated:

Procedure		If yes, conditions including duration in days of any trials
a. Defibrillation (shocks to heart)	<input type="checkbox"/> Yes <input type="checkbox"/> No	
b. Mechanical respiration (ventilator)	<input type="checkbox"/> Yes <input type="checkbox"/> No	
c. Nutrition by surgically inserted tube	<input type="checkbox"/> Yes <input type="checkbox"/> No	
d. Fluids by surgically inserted tube	<input type="checkbox"/> Yes <input type="checkbox"/> No	
e. Kidney dialysis	<input type="checkbox"/> Yes <input type="checkbox"/> No	
f. Pacemaker or other mechanical device	<input type="checkbox"/> Yes <input type="checkbox"/> No	
g. If I already have a pacemaker or other inserted device, I would like it turned off.	<input type="checkbox"/> Yes <input type="checkbox"/> No	

- h. Transfer to hospital: Whenever suggested.
 Only for brief management of treatable problem.
 Only if essential to relieve pain/discomfort.

7. To clarify my wishes by examples, I would want the treatment indicated if I experience any of the conditions described below.

My Condition	The Level of Treatment I would Like
If I have lost consciousness with no hope of becoming conscious again, e.g. if I am in a "permanent vegetative state" and I have a terminal illness or injury that cannot be reversed and will get worse no matter what treatment I undergo, I wish to receive...:	CHOOSE ONE <input type="checkbox"/> Full Aggressive Treatment <input type="checkbox"/> Limited Treatment <input type="checkbox"/> Comfort Care Only
If I am conscious and I am experiencing permanent pain so intense that I can barely think of anything else, and I have a terminal illness that cannot be reversed and will get worse no matter what treatment I undergo, I wish to receive...:	CHOOSE ONE <input type="checkbox"/> Full Aggressive Treatment <input type="checkbox"/> Limited Treatment <input type="checkbox"/> Comfort Care Only
If I lose my identity because I cannot think or communicate clearly due to an incapacitating stroke, aneurysm, or some form of progressive permanent, and I have a terminal illness that cannot be reversed and will get worse no matter what treatment I undergo, I wish to receive...:	CHOOSE ONE <input type="checkbox"/> Full Aggressive Treatment <input type="checkbox"/> Limited Treatment <input type="checkbox"/> Comfort Care Only
If it is impossible for me to control my breathing, movement, or other bodily functions because I have an advanced stage of a severe irreversible progressive disease with symptoms such as those of ALS or "Locked in Syndrome" and my condition will get worse no matter what treatment I undergo, I wish to receive...:	CHOOSE ONE <input type="checkbox"/> Full Aggressive Treatment <input type="checkbox"/> Limited Treatment <input type="checkbox"/> Comfort Care Only

8. I have stated my requests as clearly as I can at this time. Realizing that I may not have anticipated all possible details about the illness and/or infirmity that I may suffer, I ask that my providers and Healthcare Representative base decisions about aspects of my care that are not covered in my Advance Directive on my values and beliefs as expressed in my attached Personal Statement dated _____ and after consulting with others named in my Durable Power of Attorney for Healthcare.

9. To the extent that it is possible, I prefer to die (Please indicate 1st, 2nd, and 3rd choice):

_____ At home, with-in home hospice care if necessary. _____ In a hospice. _____ In a nursing home or a hospital.

10. If it is permitted in the jurisdiction in which I am terminally ill, and if I request this service, and if I meet the requirements for the procedure, (Please initial ONE) _____ I DO _____ I DO NOT want to be considered for medical aid in dying (MAID).

11. Upon my death, regarding organ donation (Please initial ONE):

- _____ I wish to leave this decision to my Healthcare Representative.
- _____ I DO NOT want to donate any part of my body.
- _____ I DO want to donate all organs, tissues, or body parts that are useful.
- _____ I DO want to donate only the following organs, tissues or body parts:

If any part of my body is taken I agree that these donations can be used for (Initial all that apply):

_____ Transplants _____ Research _____ Education

12. I acknowledge that if it is legally required, my body will be subject to autopsy. If autopsy is not required but is desired by my heirs or providers (Please initial ONE):

_____ I DO or _____ I DO NOT authorize this procedure.

13. If my provider or the institution in which I am receiving care is either unwilling or unable to honor any of these requests, upon consultation with the Healthcare Representative named in my Durable Power of Attorney for Health dated _____, I want to be transferred to a provider and/or institution that will honor my wishes. I will construe failure to honor this request as denial of my right to receive the treatment I request.

14. I understand that State law requires that If I have been diagnosed as pregnant, and that diagnosis is known to my physician, this directive shall have no force or effect during the course of my pregnancy.

15. I understand that as long as I have the capacity to do so, I can add to, delete from, or otherwise change the wording of this Advance Directive and the related documents at any time, and that any changes will be legally valid if they are consistent with State and Federal law.

16. It is my wish that every part of this Advance Directive be fully implemented. If for any reason any part is held invalid, it is my wish that the remainder of this Advance Directive be implemented.

17. I hold blameless and ask my survivors to hold blameless any provider who honors my requests so long as that service meets the community standard of care for treatment of patients in my condition.

18. This Advance Directive supersedes all prior "Living Wills" or similar instruments that I may have signed, and I hereby revoke such prior instruments.

19. I will discuss these options with my MD or ARNP and request a Conditional Medical Order, MOELI, POST, or similar form.

_____ Signature _____ Print Name _____ Date _____

Step 4

Questions to Ask Your Healthcare Representative, Family, and Friends

Durable Power of Attorney for Healthcare (DPOA or DPOAH)

You can choose a healthcare representative to make decisions for you if you cannot make them yourself. Make this official by naming this person in a Durable Power of Attorney for Healthcare (DPOA or DPOAH). Your healthcare representative will present your Advanced Directive to the doctors, nurses, and others who provide your end-of-life care. He or she will act for you in circumstances not covered in your Advance Directive. Not just anyone will do this job well. The person you choose should:

1. Know your preferences very well;
2. Be able learn and understand your diagnosis, possible treatments, and the expected outcomes of each;
3. Be able to discuss the alternatives with your doctors and family;
4. Be able to stay calm yet assertive enough to make decisions in a crisis;
5. Be available when needed;
6. Be able to relate well to your family and significant others; and,
7. **Not** be your healthcare provider or an employee of a health or residential facility currently serving you.

Who Cannot Act for You

Most states list others whose opinions will be respected if your representative cannot act for you, for example, a) your spouse or domestic partner, b) your adult children, c) your parents and, d) your adult brothers and sisters. Because it is very important that they know your wishes, you should inform them about the kind of end-of-life care you want.

What to Give Your Representative

Give your representative copies of your Advance Directive, Personal Statement, Durable Power of Attorney for Healthcare, and your Conditional Medical Order, or similar form if one exists. Ask that they read each item and tell you what they think you want. Continue the discussion until they can accurately describe the care you want to receive. Also discuss your Living Will with your family.

Ask Your Representative

Ask which of the following scenarios the other person thinks comes closest to your wishes if you are suffering from a terminal illness with no chance of recovery.

1. I want full treatment under any circumstances in order to prolong my life, regardless of its impact on me or my loved ones.
2. I want limited care to prolong my life if it is likely to slow the rate of my decline, but only as long as it does not increase my pain or undermine my dignity.
3. If my condition reaches a point that I regard as worse than death, I want comfort care only with no effort made to interfere with my natural death.

To double-check their answers, ask each whether he or she thinks you would:

_____ Want to receive CPR and defibrillation (shocks)

_____ whenever my heart stops, OR

_____ my heart stops due to a temporary reversible event, OR

_____ never.

_____ Want to be kept alive by machine-aided breathing, fluids and food by tube, and/or other life-sustaining measures.

_____ Want to undergo surgery or similar procedures that my doctor says might help.

_____ Want to be given antibiotics to treat a potentially terminal illness like pneumonia.

_____ Want to be given drugs and/or other measures to control pain.

Prefer to die (check ONE):

_____ at home. _____ in hospice or nursing home. _____ in hospital.

Discuss the answers with your healthcare representative and all family members who may have decision-making influence. Ask if they promise to support your wishes. This commitment is important: If one voice strongly demands that "everything possible be done," the loudest voice is likely to prevail.

If your healthcare representative is unsure about what you would want. What do you advise (check ONE)?

_____ Ignore such doubts and act on my Living Will as written.

_____ Make the best decision he/she can on their own in the face of uncertainty.

_____ Discuss the situation with:

_____ my doctor(s) (Who? _____); and/or

_____ member(s) of my family (Who? _____); and/or

_____ my spiritual advisor(s) (Who? _____).

Give a copy of Step 5 to your healthcare representative and others who may help with decisions about your care.

DURABLE POWER OF ATTORNEY FOR HEALTHCARE

Declaration made this _____ day of _____ (month), 20 _____

I, _____ having the capacity to make healthcare decisions, willfully and voluntarily wish to identify the person and/or people I have chosen to represent me if I temporarily or permanently lose the capacity to make healthcare decisions for myself. If I regain that capacity, I wish to reassert my own right to make decisions pertaining to the treatment that I receive.

1a. I appoint as my **PRIMARY Healthcare Representative:**

Name: _____

Address: _____

Email: _____ Phone(s): _____

Relationship to me: _____

1b. If the above named individual is not available to act on my behalf, I appoint the following person as my **ALTERNATE Healthcare Representative:**

Name: _____

Address: _____

Email: _____ Phone(s): _____

Relationship to me: _____

1c. If neither of the above named individuals is available to represent me, I authorize my healthcare providers to contact, in order, the following substitute decision-makers as approved for this purpose by the jurisdiction in which I am receiving care, i.e. my spouse or domestic partner, my adult children, my parents; and/or my adult brothers and sisters.

Name	Relationship
1. _____	_____
2. _____	_____

1d. I do not want the following people to participate in planning my end-of-life care.

Name	Relationship
1. _____	_____
2. _____	_____

2. I grant my representative(s) complete authority to make decisions consistent with my stated wishes with regard to starting, refusing, stopping, and/or removing all forms of medical, mechanical, and surgical intervention. I herewith hold my representative(s) blameless for good faith efforts to honor my preferences.

3. If my healthcare representative is unsure about what to decide, I want him or her to please (*initial ONE*):

- _____ ignore such doubts and act on my Living Will as written OR
- _____ make the best decision he or she can in the face of uncertainty OR
- _____ discuss the situation with my doctor, family members, and/or spiritual advisors named below, then use his or her best judgment and after considering their opinions.

Doctor(s) Name: _____

Family Member(s) Name: _____

Spiritual Advisor Name: _____

4. I Do _____ Do Not _____ (*initial ONE*) want this decision-making authority to extend to decisions that are made after my death with regard to autopsy, organ donation, and the handling of my remains.

5. I instruct my healthcare providers to release to my representative(s) any information about my medical condition, possible treatments, and prognosis pursuant to the attached HIPAA authorization for release of information.

6. This agreement supersedes and replaces any and all formerly executed Durable Power of Attorney Healthcare documents.

Sign only in the presence of witnesses:

Signed this _____ day in the month of _____, 20 _____

Signature: _____ Print name: _____

Step 5

Make Yourself and Your Preferences Known

How to Have the Conversation

Questions to Ask Your Healthcare Provider

Your doctor and other healthcare providers cannot honor your requests for the kind of end-of-life care you want unless you tell them what you want. It is therefore important for you to bring copies of your Personal Statement, Advance Directive, and Durable Power of Attorney for Healthcare to the professionals who will provide your end-of-life care. This will give you a chance to have a very important conversation in which you make yourself and your preferences known.

You might begin the discussion by describing your ideas about how you would like to die and any religious or cultural beliefs that have shaped your point of view.

You can continue the discussion by asking your provider to state his or her understanding of what you want. Does he or she believe that you want?

____ Full treatment, regardless of your condition, to prolong your life as long as possible.

____ Limited treatment if it will slow the progress of your illness, shifting to comfort care if your illness continues to progress despite these efforts.

____ Comfort care only if you have a terminal illness and your condition is one that you consider to be worse than death, allowing natural death.

You could then ask whether your providers are willing to help you in the following ways.

- Discuss treatment alternatives with you, including comfort care only, to help you understand the benefits and harms of each treatment alternative.
- Assure you that the providers and settings in which they will care for you have policies that permit them to offer the kind of care you request, e.g. do they have the capacity to offer full treatment or the willingness to offer comfort care only.
- Assure you that if they or the setting in which they work have policies that might prevent them from honoring your requests, they will assist you in transferring to other providers and/or settings where your requests will be honored.
- Assure you that a CMO (Conditional Medical Order), MOELI (Medical Orders for End of Life Intervention) or a POLST (Physician's Orders for Life Sustaining Treatment) or similar form (e.g. MOLST) will be prepared for you and entered into your medical record.

If it is important to you to have all the facts so you can make wise decisions about your healthcare, ask your providers to assure you that they will tell you the facts about your condition and the likely benefits and costs of each available treatment alternative. You may also ask that your doctor refer you to sources and sites where you can get more information about your illness and possible treatment.

Create a Summary Form

1. Complete the following page to provide much of the information that your providers will need in helping you and your healthcare representative make end-of-life plans.

NOTE: Since many doctors believe that they must do "everything possible" in order to avoid being sued for malpractice, this form also asks you to sign a statement declaring that you will ask your significant others not sue your doctor for following your wishes. This is not absolute protection for your doctor, but it is a commitment of good faith on your part.

2. Practice having the recommended conversation with a friend or family member.
3. When the information is complete, schedule an appointment with your critical care provider(s) to deliver this Step 5 and your 3-part Living Will so you can have this very important conversation.
4. Consider asking your healthcare representative and a significant other to join at least one meeting with your doctor so they have a chance to get to know each other a little under calm conditions. This will make it easier for them to collaborate with each other more efficiently if/when they must share decisions about how to handle a crisis. Make many copies of the next page. Update this form any time your medication or treatment changes. Bring the updated copy each time you meet with a new critical care provider and give copies to your healthcare representative and others who will speak for you when you cannot speak for yourself.

Name: _____

5. I have the following metal devices or supports implanted in my body.

- a) _____ b) _____
- c) _____ d) _____

6. If this is an emergency contact, the provider who I see regularly now is:

- a) Name of Provider: _____
- b) Provider's contact information: _____
- c) Provider's organization: _____

7. My healthcare representative (surrogate or DPOA) is:

Name: _____ Phone: _____ E-mail: _____
Address: _____

8. If this person is unavailable, my backup healthcare representative is:

Name: _____ Phone: _____ E-mail: _____
Address: _____

9. I currently live with (*Initial ONE*): _____ my spouse _____ a domestic partner _____ or live alone

Name: _____ Phone: _____ E-mail: _____
Address: _____

I DO _____ DO NOT _____ (*Initial ONE*) grant this person access to my medical records and participation in discussion of my medical treatment.

10. I DO _____ DO NOT _____ (*Initial ONE*) have an advance directive and/or Conditional Medical Order, dated: _____

- a) Not an advance directive, In general, if I have a terminal condition, I am likely to prefer: (*Initial ONE*)
_____ Full treatment _____ Limited treatment _____ Comfort care only

11. I, and my significant others, will hold you blameless for meeting community standards for the level of care I requested in my advance care planning documents. (Initial if accepted, write "X" if not) _____

12. Additional important information about you that you would like your provider to know:

Your Signature: _____ Date: _____



Step 6

Living Will Checklist

You have made many very important decisions that will guide decisions about your end-of-life care. Remember that the decisions are not cast in stone; you can change them whenever you wish. But to make sure that all of the effort you have put into decision-making is not wasted, please follow the recommendations below to increase the chances that your wishes will be known and respected when they are needed. Other suggestions below are intended to help you have greater peace of mind.

What Should be Done	Date to Do	Date Finished
<p>Discuss your thoughts about your end-of-life care with:</p> <ul style="list-style-type: none"> a. Close family members and friends; b. A spiritual advisor (if you have one); c. Other professionals (e.g. counselors) or those who can offer informed second opinions. 		
<p>If you wish to donate any organs after your death, complete the necessary donor card. You can obtain information about organ donation from www.DonateLifeToday.com</p>		
<p>You have completed a Personal Statement describing the quality of life that makes your life worth living. Make an audio or video recording of your statement so loved ones and others can see you expressing your wishes.</p>		
<p>You have completed the Advance Directive and Durable Power of Attorney for Healthcare in this Guide. Other forms, suitable for all states, can be downloaded without charge from http://www.caringinfo.org/i4a/pages/index.cfm?pageid=3289 or http://www.compassionandchoices.org/what-we-do/advance-planning/</p>		
<p>Discuss your wishes with your doctor and ask whether a CMO, MOELI, POLST or other form should be created for you.</p> <p>If you are admitted to a healthcare facility, ask that any such orders be included in your medical record.</p> <p>If you are to be discharged, request the original copy of your CMO, MOELI, POLST (or similar form) and your Living Will to give to your next healthcare providers.</p>		
<p>Locate and destroy all earlier versions of these items.</p>		
<p>Discuss and provide copies of all three parts of your Living Will to your:</p> <ul style="list-style-type: none"> a. Critical care providers; b. Healthcare representative; c. Family members and friends who will potentially participate in decision-making. <p>Ask them to honor your preference unless you tell them you have created new documents.</p>		
<p>Locate and destroy all earlier versions of these items.</p>		



What Should be Done	Date to Do	Date Finished
<p>Schedule times to review all documents, ideally every 12 months as a minimum.</p> <p>This is particularly important if:</p> <ol style="list-style-type: none"> Your healthcare representative dies or you wish to change representatives; You divorce or marry; Your health status changes; or You move to another state or country. 		
<p>Because it is often difficult to have these important documents where and when you want them, it is very helpful to register your documents on-line so they will be instantly available.</p> <p>Ask your State Health Department if it has a registry for Living Wills. This service is offered by organizations such as the American Bar Association (http://www.americanbar.org/news/abanews/aba-news archives/2014/04/new_aba_mobile_app.html)</p> <p>It is also possible to order an inexpensive flash drive on which you can download all 3 components of your Living Will and even parts of any medical records in your possession.</p>		
<p>Complete a release of information form (e.g. HIPPA) and bring it to the providers and/or settings in which your end-of-life care will be delivered. This lists the people with whom your medical information can be shared.</p>		
<p>Prepare a Last Will and Testament and discuss it with the person you name as executor. Also inform that person where to find the documents and any necessary passwords or keys after you die.</p>		
<p>Ongoing: Say or do what is important before you die so you can leave the legacy through which you would like to be remembered. You can never really know which conversation will be the last one you will have with the people who are important to you. The Caring Conversations document, is an excellent guide for these discussions. It can be downloaded free of charge at https://www.practicalbioethics.org/featured-resources/caring-conversations/</p>		