

compassion & choices

Compassion In Dying • End-of-Life Choices

Advance Directive

Planning for Important Healthcare Decisions



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Congratulations on taking the first step in protecting your right to freedom and choice at the end of life. These documents will help ensure that you continue to make your own health care decisions. They offer not only personal autonomy – they also give you and your loved ones peace of mind, knowing that your wishes are firm and clear.

We'll be here when you need us! Providing advance directive documents is just one of the many services we offer. Compassion & Choices members receive, free of charge, counseling and guidance on how to complete and how to use advance directives. Those who join at the Benefactor level or above can receive a wallet-sized CD of their advance directives, which they can carry with them at all times. Emergency personnel will find this CD tucked in with your health insurance card and it will speak for you when you cannot speak for yourself. Please contact us to learn more about this service!

Your dues and donations to Compassion & Choices assure the continuation of our programs and services. Our Client Support Program is unsurpassed in offering comprehensive service and support for individuals and families as they contemplate life's end. Our education program provides literature and speakers in communities across the nation. And our advocacy team defends your right to a peaceful death on legal and legislative fronts.

Join today to enlist Compassion & Choices as your lifelong advocate! Count on us to help you protect yourself from government intrusion into health care, and to protect your family from disputes over your end-of-life care. Through our national team of volunteers and top-notch legal talent, we stand ready to deliver advocacy services by telephone, at the bedside, and even in the courtroom, if necessary.

Please join us in our effort to ensure care, choice, dignity and control at life's end!

□ Individual (\$45) □ Individual Life (\$450)	□ Couple/Dual (\$60) □ Couple/Dual Life (\$600)	☐ Benefactor (\$100)
	w, but please accept my enclosed dona 50 □\$ (make your check pay	
Credit card number:		Expiration:
□ Visa □ Ma	astercard	
☐ I cannot contribute rigl	nt now, but please keep me on your ma	iling list.
Name:		



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HOW TO USE THESE MATERIALS

- 1. Check to be sure that you have the materials for your state. You should complete a form for the state in which you expect to receive healthcare.
- 2. These materials include:
 - Instructions for preparing your advance directive
 - Your state-specific advance directive forms.
- 3. Read the instructions in their entirety. They give you specific information about the requirements in your state.
- 4. You may want to photocopy these forms before you start so you will have a clean copy if you need to start over.
- 5. Talk with your family, friends, and physicians about your decision to complete an advance directive. Be sure the person you appoint to make decisions on your behalf understands your wishes.

If you have questions or need guidance in preparing your advance directive or about what you should do with it after you have completed it, you may call our toll free number (800) 247-7421 and a staff member will be glad to assist you.

www.compassionandchoices.org

Introduction to your Pennsylvania Advance Directive for Health Care

Every adult needs an advance directive for health care. Regardless of age, regardless of health, none of us knows when a future event might leave us unable to speak for ourselves. If you were not able to make or communicate decisions about your medical treatment, a written record of your health care wishes would prove invaluable.

What is an Advance Directive for Health Care?

Advance directive is a generic term used for documents that traditionally include a living will and the appointment of a health care agent. These documents allow you to provide instructions relating to your future health care, such as when you wish to receive medical treatment or when you wish to stop or refuse life-sustaining medical treatments.

The living will portion of an advance directive is a place for you to specify what kinds of treatment and care you would or would not want if you were unable to speak for yourself. The living will is also known as the Pennsylvania Declaration. The second part, often referred to as the durable power of attorney for health care, allows you to appoint someone to act on your behalf in matters concerning your health care when you are unable to speak for yourself due to illness or incapacitation. Please note that the person you appoint to speak on your behalf may be called your health care agent, proxy, surrogate, or representative.

Why is it useful?

Whereas traditional living wills are limited to cases of terminal illness, health care advance directives are not. Rather, they help you to maintain control over health care decisions that are important to you when you are unable to make or communicate decisions due to temporary or permanent injury or illness. An advance directive for health care allows you to express your wishes about any aspect of your health care, including decisions about life-sustaining treatment. It also allows you to choose a person to speak on your behalf and communicate your decisions when you are not able to do so. Appointing an agent and making sure your agent is aware of and understands your wishes is one of the most important things you can do. If the time comes for a decision to be made, your agent can participate in relevant discussions, weighing the pros and cons of treatment decisions based upon your wishes. Your agent can make health care decisions on your behalf whenever you cannot do so for yourself, even if your decision-making capacity is only temporarily affected. If you choose not to appoint an agent, many health care providers and institutions will make decisions for you. As they tend to err on the side of prolonging life, their decisions may not be based on your wishes. In some cases, if you do not have an advance directive, a court may have to appoint a guardian. Another important consideration is your family. Advance directives help relieve the stress and duress associated with having to make important health care decisions on behalf of someone you care about. By making your wishes known in advance, you help your family and friends, who may otherwise struggle to decide on their own, know what you would want done.

Are Advance Directives for Health Care legally valid in every state?

Yes, advance directives are legally valid in every state. Each state and the District of Columbia have laws that permit individuals to sign documents stating their wishes about health care decisions when they cannot speak for themselves. The specifics of these laws vary, but the basic principle of listening to the patient's wishes is the same everywhere. The law gives great weight to any form of written directive. If the courts become involved, they usually try to follow the patient's stated values and preferences, especially if they are in written form. An advance directive for health care may be the most convincing evidence of your wishes you can create. It is important to note that while it is legal to have an advance directive in every state, no current law requires that they be strictly honored by health care professionals.

What does an Advance Directive for Health Care say?

There are two parts to this advance directive for health care. The first, and most important, portion allows you to appoint someone (your agent) to make health care decisions on your behalf, should you be unable to decide for yourself. You can define the degree of authority (how much or how little) you want your agent to have. Also, you can name those you wish to be your alternate agents, should your primary agent be unwilling or unable to act on your behalf. Additionally, you can state individuals you do not want to make decisions for you.

If there is no one whom you trust to serve as your agent, then you should not name an agent. The second part of the advance directive can be used as a guideline for your heath care providers. If this is your case, contact Compassion & Choices at 800-247-7421 for help with finding an agent.

In the second part of the advance directive, you specify your health care treatment wishes. Remember, you can include treatments and procedures you *do or do not* want. You can also include statements regarding organ and tissue donation. The instructions you provide in this portion of the form provides evidence of your wishes. Your agent and anyone providing you with medical care should follow them. Although you are not required to complete either or both parts of an advance directive, Compassion & Choices encourages you to do both.

How do I make an Advance Directive for Health Care?

The procedure for creating an advance directive for health care varies, depending on where you live. Most states have laws that provide specific forms and signing procedures. Most states also have witnessing requirements and restrictions on who you can appoint as your agent (such as prohibiting your physician from being your appointed agent). Make sure to follow these rules closely. Most states require two witnesses and many either require or allow a notarized signature. Some even have special witnessing requirements if you reside in a care facility (nursing home, assisted living facility, etc.). Even if witnesses are not required, we encourage you to consider using them anyway. Doing so reinforces the deliberate nature of your act and may help increase the likelihood that health care providers in other states will honor the document. If you use the attached form, you should be able to meet most states' advance directive requirements.

In Pennsylvania, the law requires that you sign your advance directive in the presence of two witnesses who are at least 18 years old. These witnesses must also sign your advance directive. This is done to show that they know you and believe you to be of sound mind. At this time, you are not required to have your advance directive notarized.

If I change my mind, can I change or cancel my Advance Directive for Health Care?

Yes, you can change or cancel your advance directive at any time. You can do this by notifying your agent and/or health care provider in writing of your decision to do so. It is best to destroy all copies of your old advance directive and create a new one. Make sure to provide copies of your new form to the appropriate individuals. Compassion & Choices recommends that you review your advance directive every year and re-sign and date it to indicate that this document continues to reflect your wishes.

Before you begin: What do I need to consider before completing my Advance Directive for Health Care?

What are my goals for medical treatment?

When thinking about goals of medical treatment, it is important to consider two main conditions, an extended period of disability and terminal illness. While it is impossible to anticipate all of the different situations that could arise, you can make your wishes known by clearly stating your treatment goals. Consider what you want medical treatments to accomplish. Do you want treatments to prolong your life, regardless of it's quality? Or would you prefer to stop (or not start) life-sustaining treatments if your consciousness and ability to communicate could not be restored? By stating your medical treatment goals, you help your family and health care provider make decisions on your behalf. If a particular treatment would help achieve one of your goals, it would be provided. But if it would not help achieve a treatment goal, it would not be provided.

In creating your treatment goals, it is helpful to consider how you feel about a particular treatment after you decide what your wishes are. For example, if you do not want to be kept alive on a ventilator (a machine that helps you breathe), why don't you want this? Do you not like that it inhibits your mobility or independence? Or is there another factor? Would it make any difference if you needed a ventilator for only a few days as opposed to many months? Answers to these types of questions reflect what you value and will shape your medical treatment goals. To help you in determining these goals, you may wish to complete the Values Statement found on the following two pages and consider the following questions:

How do you feel about your current health?

How important is independence and self-sufficiency?

How to you envision handling disability, illness, dying, and death?

How might your personal relationships affect medical decision-making near the end of life? Is there anyone you do not want involved in your health care decisions (e.g., specific family members, friends, or professionals)?

What role should physicians and other health care providers play in your medical decision-making processes? Is there a particular doctor you want to help your family make decisions about your care?

If you become seriously ill or disabled, what type of living environment is important to you?

Are there any financial aspects you wish to be considered during any decision-making process?

What are your general thoughts on life and its end – hopes, fears, joys, sorrows?

Are there basic functions you believe you must have in order to feel that you would want to continue to live? Do you feel you must be able to recognize loved ones and respond to others?

Do your spiritual or religious beliefs affect your attitudes about a terminal illness, treatment decisions, or death and dying? Do you believe life-sustaining treatments should never be withheld or withdrawn? Or do you believe that when there is no hope of recovery, death should be allowed?

Are there specific life-sustaining treatments you would want to have if you were diagnosed with a terminal condition? If you could not eat or drink, would you want a feeding tube?

Values Statement to accompany Advance Directive:

When I am dying, the following are important to me family, friends, or pets present, special objects I wan	
I do not want the following around me when I am dy not want to be, etc.):	
In the case of a terminal illness, permanent coma, or Alzheimer's disease), I feel that life-sustaining treatr	
I would like the following financial aspects to be cormade (such as expenses not to exceed health insuran	
Additional thoughts on death and dying (place of deacremation, funeral, memorial service, etc.):	
Not everyone that participates in my end-of-life heal that are involved in my decision-making processes. held by me and represent what I feel is important as decisions I want made on my behalf if and when I are	However, the above values are thoughtfully I near my death. They reflect the choices and
Signature	Date

	1 = Not Important 5 = Very Important				
I want to know the truth about my condition.	1	2	3	4	5
I want to take part in decision-making involving my health care.	1	2	3	4	5
I want my health care agent to participate in my health care decision-making if I am unable to decide for myself.	1	2	3	4	5
Letting nature "take its course".	1	2	3	4	5
Maintaining my quality of life.	1	2	3	4	5
Maintaining my dignity.	1	2	3	4	5
Maintaining my privacy.	1	2	3	4	5
Living as long as possible, regardless of quality of life.	1	2	3	4	5
Having physical mobility.	1	2	3	4	5
Having good eyesight.	1	2	3	4	5
Having good hearing.	1	2	3	4	5
Having reasonable mental capacity.	1	2	3	4	5
Being able to speak.	1	2	3	4	5
Being able to communicate with others nonverbally – writing, touch, blinking, etc.	1	2	3	4	5
Having independence and control in my life.	1	2	3	4	5
Avoiding being a burden on others.	1	2	3	4	5
Being comfortable and pain-free, even if it may hasten my death.	1	2	3	4	5
Leaving good memories for friends and family.	1	2	3	4	5
Leaving assets for family, friends, charities, etc.	1	2	3	4	5
Dying in a short while, as opposed to a lingering process.	1	2	3	4	5
Financial aspects.	1	2	3	4	5

Other thoughts and feelings regarding medical tre	atments:
Signature	Date

Who should be my agent?

One of the most important things you can do is to appoint an agent to speak for you if and when you are ever unable to do so for yourself. An agent has great power over your health care and should be carefully chosen. In normal circumstances, no one will be monitoring your agent and their decisions

To help avoid disagreements, we recommend selecting one primary agent and at least one alternate agent. Your alternate agent would speak on your behalf if your primary agent were unwilling or unable to speak for you. Your agent must agree to serve this role. It might be important to mention that your health care agent bears no financial burden or liability if they agree.

Before deciding on an agent (and alternatives), ask yourself: "Are they assertive? Will they be able to make difficult and possibly emotional decisions? Do they live nearby? Are they comfortable talking about death? Will they respect my values and wishes?" Then, talk to them. Share your wishes and make sure they clearly understand what is important to you. Confirm their willingness to speak on your behalf.

If you can not think of anyone you trust to serve as your agent, do not appoint anyone. Make sure to complete the living will portion of the advance directive to express your wishes. This will act as a guideline for your treating physicians. If this is your situation, contact Compassion & Choices at 800-247-7421 for help in locating an agent.

Can I include personal instructions? If so, how specific should I be?

If you have any preferences or specific wishes, it is important to put them down on paper and to discuss them with your agent and health care providers. Since it would be nearly impossible to predict every situation you may face, note those that are important to you. Consider ventilator support, artificial nutrition and hydration, kidney dialysis, and the use of antibiotics. You may feel differently about enduring a treatment for a few weeks as opposed to several months or years; it is important to note such things. Use statements such as, "If I am terminally ill and nearing the end of my life, I do not want to be put on a ventilator if doing so would only prolong my life," instead of, "I never want to be put on a ventilator." The purpose of an advance directive is to provide guidance. Express your beliefs and be as specific as you are comfortable being.

How can I make sure health care providers will follow my advance directive?

Currently, there are no state laws that oblige medical personnel to honor your advance directive. Some health care providers have values and opinions that do not agree with the wishes you have expressed. Because of this, they may not want to follow the directions you provide in your advance directive. Most state laws allow doctors to refuse to honor your advance directive on conscience grounds. However, they must help you find another physician willing to honor your wishes. While this is rare, it is important to be aware of its potential.

To help avoid this situation, talk to your health care providers ahead of time. Make sure they

understand your wishes and are familiar with your advance directive documents. And make sure they are willing to honor them. If they object, work out the issues or find another health care provider.

Once your advance directive is completed and signed, provide your agent, all health care providers, close friends and relatives, and anyone else who may be involved with your care with a copy.

What happens if I do not have an Advance Directive for Health Care?

If you do not have a health care advance directive and you are unable to make health care decisions for yourself, some state laws allow surrogates, default decision-makers, to make treatment decisions on your behalf. Typically, surrogates are family members (by order of kinship). Some states authorize close friends to make medical decisions for you, but usually only in rare instances when family are not available.

Even without such statutes, many physicians and health care facilities routinely consult family, as long as close family members are available and do not disagree. Be aware that problems can arise if family members do not know what a patient would want in a given situation. There is also the potential for disagreement regarding the best course of action to take. Disagreement can easily undermine family consent. If this is the case, a physician or other specialist who does not know you well may become your decision-maker. In rare instances, a court may become involved in order to resolve disagreements. In these situations, decisions regarding your health care may not reflect your wishes. And decisions may be made by individuals you would not want doing so. If left without guidance, your family and friends may suffer needless agony in making life and death decisions on your behalf. We recommend appointing a health care agent and making your wishes known by completing an advance directive.

Who can help me create my Advance Directive for Health Care?

You do not need a lawyer to create your health care advance directive. A lawyer may be helpful if your family situation is complex or if you expect problems to arise. Compassion & Choices recommends you start by talking to someone you trust, who knows you well, and who you feel can help you to state your values and wishes.

Your primary health care providers are important participants to include in the creation of your advance directive. Based on your medical history and your current health, discuss the types of medical problems you may face. Your provider can help you to better understand potential treatment options. Make sure your provider clearly understands your treatment wishes and goals.

Compassion & Choices provides up-to-date state-specific information about advance directives. Take the time to consider what is important to you and seek advice so that your advance directive reflects your beliefs. If you would like help completing your advance directive for health care, contact Compassion & Choices at 800-247-7421.

After you have completed your forms:

What do I do once I have completed my Advance Directive for Health Care?

Once you have completed your advance directive, review it with your agent and any alternate agents you may have appointed. We recommend doing this to make sure those that may have to act on your behalf clearly understand what your wishes are. Completing the advance directive form is not enough. Conversations with agents, family, and health care providers are critical.

Next, you want to make photocopies of your original signed documents. Provide copies to your agent, alternate agent, close family and friends, health care providers, clergy, and anyone else you feel may become involved in your health care or would like to share it with. When distributing these copies, make sure to review your wishes and expectations with them.

While you can keep a copy of your advance directive in a safe deposit box, the original should not be stored there. Rather, keep your documents in an accessible place and let others know where they are, in case they are ever needed.

And remember, you can change or revoke your advance directive at any time.

Other important information:

It is important to note that your advance directive may not be honored in the event of an emergency, such as when someone calls 911. Emergency medical personnel are legally obligated to treat you and require a separate order that states not to do so. These orders are commonly called "out-of-hospital do-not-resuscitate orders (DNR)," "out-of-hospital DNRs," and "non-hospital DNRs." In addition to these forms, some states allow Physician Order for Life-Sustaining Treatment (POLST) forms. In these forms, a physician is able to turn your wishes into specific written medical orders that reflect your medical situation. This is a form signed by your physician and is usually provided to those with a terminal prognosis or illness. Currently not all states have laws authorizing non-hospital DNRs and POLSTs. If you would like further information on this, call Compassion & Choices at 800-247-7421.



Pennsylvania Declaration

I,			
	In addition, if I am in the condition described above, I feel especially strongly about the following forms of treatment:		
	I()do()do not want cardiac resuscitation.		
	I()do()do not want mechanical respiration.		
	I()do()do not want tube feeding or any other artificial or invasive form of nutrition (food) or hydration (water).		
	I()do()do not want blood or blood products.		
	I () do () do not want any form of surgery or invasive diagnostic tests.		
	I()do()do not want kidney dialysis.		
	I () do () do not want antibiotics.		
	I realize that if I do not specifically indicate my preference regarding any of the forms of treatment listed above, I may receive that form of treatment.		
	Other instructions:		

(Continued)



Pennsylvania Declaration : Page 2 of 2

Surrogate decisionmaking:
I () do () do not want to designate another person as my surrogate to make medical treatment decisions for me if I should be incompetent and in a terminal condition or in a state of permanent unconsciousness.
Name:
Address:
Phone:
Name and address of substitute surrogate (if surrogate designated above is unable to serve):
Name:
Address:
Phone:
I made this declaration on the day of (day) (month, year)
Declarant's signature:
Declarant's address:
The declarant, or the person on behalf of and at the direction of the declarant, knowingly and voluntarily signed this writing by signature or mark in my presence.
Witness's signature:
Witness's address:
Witness's signature:
Witness's address:



The Dementia Provision

Most Advance Directives become operative only when a person is unable to make health care decisions and is either "permanently unconscious" or "terminally ill." There is usually no provision that applies to the situation in which a person suffers from severe dementia but is neither unconscious nor dying.

The following language can be added to any Advance Directive or Living Will. There it will serve to advise physicians and family of the wishes of a patient with Alzheimer's Disease or other forms of dementia. You may simply sign and date this form and include it with the form *My Particular Wishes* in your Advance Directive.

If I am unconscious and it is unlikely that I will ever become conscious again, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled *My Particular Wishes* to be followed.

If I remain conscious but have a progressive illness that will be fatal and the illness is in an advanced stage, and I am consistently and permanently unable to communicate, swallow food and water safely, care for myself and recognize my family and other people, and it is very unlikely that my condition will substantially improve, I would like my wishes regarding specific life-sustaining treatments, as indicated on the attached document entitled *My Particular Wishes* to be followed.

If I am unable to feed myself while in this condition

I <u>do</u> / <u>do not</u> (circle one) want to be fed.

I hereby incorporate this provision into my durable power of attorney for health care, liv-
ing will and any other previously executed advance directive for health care decisions.

Signature	Date



My Particular Wishes

My Particular Wishes for Therapies that Could Sustain Life

In addition to the information on other Advance Directive forms I have completed, I wish to make my instructions known with respect to specific therapies that could save or prolong my life.

This form is meant to inform my physician, nurse or other care provider of my consent or refusal of certain specific therapies. It is also meant to guide my family or any other person I name to make health care decisions for me if I cannot make these decisions myself.

I understand it is impossible to know what a person would want in a particular circumstance, unless that person has previously stated his or her wishes. I hope this document helps those who must make difficult decisions to proceed with comfort and confidence. By following these instructions they know they are acting in my best interests and are consenting or refusing certain therapies just as I would if I could hear, understand and speak.

Decisions While I am Capable

So long as I am able to understand my condition, the nature of any proposed therapy and the consequences of accepting or refusing the therapy, I want to make these decisions myself. I will consult my doctor, family and those close to me, spiritual advisors and others as I choose. But the final decision is mine. If I am unable to make decisions only because I am being kept sedated, I would like the sedation lifted so I can rationally consider my situation and decide to accept or refuse a particular therapy.

Comfort Care

I want any and all therapies to maintain my comfort and dignity. If following my instructions in this document causes uncomfortable symptoms such as pain or breathlessness, I want those symptoms relieved. I desire vigorous treatment of my discomfort, even if the treatment unintentionally causes or hastens my death.

(Continued)



My Particular Wishes

Decisions for Specific Therapies

If my mental or physical state has deteriorated, the prognosis is grave and there is little chance that I will ever regain mental or physical function, I would like the following:

	Yes	Trial period*	No
1. Antibiotics, if I develop a life-threatening infection of any kind.			
2. Dialysis, if my kidneys cease to function, either temporarily or permently.	a-		
3. Artificial ventilation, if I stop breathing.			
4. Electroshock, if my heart stops beating.			
5. Heart regulating drugs including electrolyte replacement, if my heartbe becomes irregular.	at		
6. Cortisone or other steroid therapy, if tissue swelling threatens vital center in my brain.	ers		
7. Stimulants, diuretics or any other treatment for heart failure, if the streng and function of my heart is impaired.	ıth		
8. Blood, plasma or replacement fluids, if I bleed or lose fluid circulation my body.	ng		
* This means doctors may see if the therapy quickly reverses my of I want it discontinued.	onditi	on. If it does	not,
Signature Date			