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Advance Directives

An advance health care directive is a legal document that tells your health care provider and loved ones your wishes about your health care. Here is general information about different advance health care directives, such as durable power of attorney for health care/medical power of attorney, living wills, POLST forms, Do Not Resuscitate orders, and other agreements like these.

- What Is an Advance Directive?
- Types of Advance Directives
- Frequently Asked Questions About Advance Directives
- Making Decisions for Your Advance Directive

What Is an Advance Directive?

An advance directive is a legal document that explains how you want medical decisions about you to be made if you cannot make the decisions yourself. An advance directive is used to guide your health care team and loved ones when they need to make these decisions or to decide who will make decisions for you when you can't. These medical decisions might include special actions or emergency care from your health care team. An advance directive can help you think ahead of time about what kind of care you want.

Advance directives only apply to health care decisions and do not affect financial or money matters. The laws around advance directives are different from state to state. Talk to your health care provider (or your lawyer) about filling out your advance directive

when you are still healthy, in case you become too ill or are unable to make medical decisions for yourself in the future.

The Patient Self-Determination Act

The 1990 Patient Self-Determination Act (PSDA) encourages everyone to decide ahead of time about the types and extent of medical care they want to accept or refuse if they become unable to make those decisions due to illness.

The PSDA requires hospitals, skilled nursing facilities, home health agencies, hospice programs, and Health Maintenance Organizations (HMOs):

- To give patients information on their state laws about their rights to make decisions about their care.
- To find out if patients have an advance directive.
- To recognize the advance directive and honor the patient's wishes.
- To never discriminate against patients based on whether they have filled out an advance directive or not.

Health care facilities can't require patients to have advance directives: It is the patient's choice.

Hyperlinks

- 1. www.agingwithdignity.org/
- 2. www.americanbar.org/groups/law_aging/resources/health_care_decision_making/
- 3. www.caringinfo.org/planning/advance-directives/what-is-an-advance-directive/
- 4. www.compassionandchoices.org/

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Additional resources

Along with the American Cancer Society, other sources of information and support include:

Aging with Dignity Toll-free number: 1-888-5WISHES (1-888-594-7437) Website: www.agingwithdignity.org¹

On this website, you can learn about and buy the Five Wishes advance directive and planning guide, which is available in 26 languages and in Braille.

American Bar Association – Consumer's Tool Kit for Health Care Advance Planning

Website: https://www.americanbar.org/groups/law_aging/resources/health_care_decisio n making/²

Free online tool kit includes worksheets, tips, guides, and resources to help you think and talk about your values, priorities, the meaning of your life, and your quality of life to help you put together the best advance directive for you

Caring Connections, from the National Hospice and Palliative Care Organization (NHPCO) Toll-free number: 1-800-658-8898 (answers as "End-of-Life Consumer

Helpline") Website: What are Advance Directives? | CaringInfo³

Website lists each state's' requirements for advance directives and has free downloads of "State-Specific Advance Directives" with forms and instructions for each state. It also has tips on selecting your health care agent, and preparing and storing your advance directive.

Compassion and Choices Toll-free number: 1-800-247-7421

Website: www.compassionandchoices.org4

Offers worksheets, forms, and help in completing advance directives, and in talking to families, friends, and health care providers about your health care wishes.

*Inclusion on this list does not imply endorsement by the American Cancer Society.

Last Revised: May 10, 2019

Types of Advance Directives

The most common types of advance directives are the **living will** and the **durable power of attorney for health care** (sometimes known as the **medical power of attorney**).

There are many advance directive formats. Some follow forms outlined in state laws, others are created by lawyers or even the patients themselves. State laws and courts decide whether these documents are valid. All states and the District of Columbia have laws about advance directives. Be sure to know specific requirements of writing legal advance directives in your state.

- The living will
- Durable power of attorney for health care/Medical power of attorney

- POLST (Physician Orders for Life-Sustaining Treatment)
- Do not resuscitate (DNR) orders
- Organ and tissue donation

Before you create an advance directive, you will want to talk with your health care provider, your loved ones, and at least one person that you may want to choose as your proxy or agent (substitute decision-maker). Tell them about your situation, wishes, and fears, because they are the ones who will help put your wishes into effect if you are unable to do so.

You can usually get advance directive forms from <u>your state bar association</u>¹, or from <u>Caring Con</u>²<u>nection</u>³ (part of the National Hospice and Palliative Care Organization). Additionally, when you are ready to fill out your advance directive, your health care team might be able to help.

The living will

The living will is a legal document used to state certain future health care decisions only when a person becomes unable to make the decisions and choices on their own. The living will is only used at the end of life if a person is terminally ill (can't be cured) or permanently unconscious. The living will describes the type of medical treatment the person would want or not want to receive in these situations. It can describe under what conditions an attempt to prolong life should be started or stopped. This applies to treatments including, but not limited to dialysis, tube feedings, or actual life support (such as the use of breathing machines).

Before your health care team uses your living will to guide medical decisions, 2 physicians must confirm that you are unable to make your own medical decisions and you are in a medical condition that is specified by your state law as terminal illness or permanent unconsciousness.

There are many things to think about when writing a living will. These include:

- If you want the use of equipment such as dialysis machines (kidney machines) or ventilators (breathing machines) to help keep you alive.
- Do not resuscitate orders (instructions **not** to use CPR if breathing or heartbeat stops).
- If you want fluid or liquid (usually by IV) and/or food (tube feeding into your stomach) if you couldn't eat or drink.
- If you want treatment for pain, nausea, or other symptoms, even if you can't make

other decisions (this may be called **comfort care** or **palliative care**).

• If you want to donate your organs or other body tissues after death.

It is important to know that choosing not to have aggressive medical treatment is different from refusing all medical care. A person can still get treatments such as antibiotics, food, pain medicines, or other treatments. It is just that the goal of treatment becomes comfort rather than cure.

You may end or take back a living will at any time.

Living will laws vary from state to state. Be sure to know your specific state laws. If you spend most of your time in more than one state, be sure to speak to your health care provider and review each of the states' laws. Also, check your state so you know if you have to renew your living will, and if so, how often you have to do it.

Durable power of attorney for health care/Medical power of attorney

A durable power of attorney for health care, also known as a medical power of attorney, is a legal document in which you name a person to be a **proxy** (agent) to make all your health care decisions if you become unable to do so. Before a medical power of attorney can be used to guide medical decisions, a person's physician must certify that the person is unable to make their own medical decisions.

If you become unable to make your own health care decisions, your proxy or agent can speak with your health care team and other caregivers on your behalf and make decisions according to the wishes or directions you gave earlier. If your wishes in a certain situation are not known, your proxy or agent will make a decision based on what they think you would want. If you regain the ability to make your own medical decisions, your proxy (agent) can't continue to make medical decisions on your behalf.

The person you name as a proxy or agent should be someone who knows you well and someone you trust to carry out your wishes. Your proxy or agent should understand how you would make decisions if you were able, and should be comfortable asking questions and advocating to your health care team on your behalf. Be sure to discuss your wishes in detail with that person. You may also choose to name a back-up person in case your first choice becomes unable or unwilling to act on your behalf.

Durable power of attorney laws vary from state to state. Talk to your health care team and check your state laws.

POLST (Physician Orders for Life-Sustaining Treatment)

A POLST form also helps describe your wishes for health care, but it is not an advance directive. A POLST form has a set of specific medical orders that a seriously ill person can fill in and ask their health care provider to sign. A POLST form addresses your wishes in an emergency, such as whether to use CPR (cardiopulmonary resuscitation) in an emergency, or whether to go to a hospital in an emergency and be put on a breathing machine if necessary, or stay where you are and be made comfortable.

A POLST form has to be signed by a qualified member of your health care team, such as your doctor. Emergency personnel, like paramedics and EMTs (Emergency Medical Technicians) **can't** use an advance directive, but they **can** use a POLST form. Without a POLST form, emergency personnel are **required** to provide every possible treatment to help keep you alive.

POLST forms are only available in some states. You can find out if your state is included and learn more at http://www.polst.org. If you would like to have a POLST form, talk to your health care team about your wishes.

Do not resuscitate (DNR) orders

Resuscitation means medical staff will try to re-start your heart and breathing using methods such as CPR (cardiopulmonary resuscitation) and AED (automated external defibrillator). In some cases, they may also use life-sustaining devices such as breathing machines. (See What is a life-sustaining medical treatment? in Frequently Asked Questions About Advanced Directives.

In the hospital

A Do Not Resuscitate or DNR order means that if you stop breathing or your heart stops, nothing will be done to try to keep you alive. If you are in the hospital, you can ask your doctor to add a DNR order to your medical record. You would only ask for this if you don't want the hospital staff to try to revive you if your heart or breathing stopped. Some hospitals require a new DNR order each time you are admitted, so you might need to ask every time you go into the hospital. But remember that this DNR order is only good while you are in the hospital. Outside the hospital, it's a little different.

Outside the hospital

Ask your health care provider how you can get a wallet card, bracelet, or other DNR documents to keep when you are at home or not in the hospitals. Some states have

standard DNR forms that are meant to be used outside the hospital. The non-hospital DNR is intended for Emergency Medical Service (EMS) teams. Unless you have a valid and visible DNR order, the EMS teams who answer 911 calls are **required** to try to revive and prolong life in every way they can. A non-hospital DNR must be signed by both the patient and the health care provider. Talk to your health care team if you would like a DNR order to keep with you.

Organ and tissue donation

Organ and tissue donation can be included in your advance directive. Many states also provide organ donor cards or add notations to your driver's license.

Hyperlinks

- 1. www.americanbar.org/groups/law_aging/resources/health_care_decision_making/
- 2. www.caringinfo.org/planning/advance-directives/what-is-an-advance-directive/
- 3. www.caringinfo.org/planning/advance-directives/what-is-an-advance-directive/
- 4. www.polst.org

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Last Revised: May 13, 2019

Frequently Asked Questions About Advance Directives

- What are end-of-life decisions?
- What is a terminal condition?
- What is life-sustaining treatment?
- When should I make an advance directive?
- How will my doctor know that I have an advance directive?
- Does the doctor have to follow my advance directive?
- Will my advance directive be used if I am taken to the emergency room?
- What happens if I don't have an advance directive?
- Do I need a lawyer to write my advance directive?
- Can I have an advance directive in more than one state?
- Does having an advance directive affect the quality of the health care I receive?
- Can I have both a living will and a durable power of attorney for health care?
- Can I change my mind about my advance directive instructions?
- Is my advance directive valid if I'm at home?

What are end-of-life decisions?

End-of-life decisions are those you can make now about how you wish to be cared for and treated when you are dying. End-of-life decisions can include whether to accept or refuse treatments that might prolong your life. An advance directive is one way to let others know about your decisions based on your values and priorities. It's important that those close to you fully understand what you want at this time, so it is as easy as possible for them to carry out your wishes. You can read more in End of Life Care1.

What is a terminal condition?

A terminal condition or illness is one that is life-limiting. In the near future it is expected the illness will result in permanent unconsciousness from which the person is unlikely to recover or death. Examples of terminal conditions may include but are not limited to advanced cancers², multiple organ failure, or some massive heart attacks and strokes. Definitions of terminal illness can be different from state to state.

What is life-sustaining treatment?

In most cases, life-sustaining medical treatment is any medical intervention, medication, or anything mechanical or artificial that sustains, restores that would prolong the dying process for a terminally ill patient. These may include but are not limited to:

- CPR (cardiopulmonary resuscitation) including use of an AED (automated external defibrillator)
- Breathing machines
- Medications such as antibiotics
- Nutrition and hydration (food and liquids) given through feeding tubes or IVs

Comfort measures, which are medicines or procedures used to provide comfort or ease pain, are not usually considered life-sustaining. In some states, tube feedings and IV fluids are considered comfort measures. States have different definitions, so be sure you **know what your state says**.

When should I make an advance directive?

The best time to make an advance directive is before you need one. In other words, before you become too sick to make your own decisions about what medical care you want to get or refuse. See Making Decisions for Your Advance Directive.

How will my doctor know that I have an advance directive?

If you have any type of advance directive, let your health care team know and make sure they have it in their records. You may also tell people close to you that you have it and where it's kept. Give copies of your advance directive to your proxy or agent, family members, and friends who would be contacted if you become seriously ill.

Does the doctor have to follow my advance directive?

Even though advance directives are legally recognized documents, there are times that a health care provider may reject a medical decision made by you or your health care proxy based on your advance directive. For example:

- When the decision goes against the individual health care provider's conscience.
- When the decision is against the health care institution's policy.

If the decision violates accepted health care standards.

In such cases, the health care provider or facility must tell you right away. Your health care provider or institution may help you be transferred to another facility that will honor your decisions.

To avoid these situations, it may be beneficial for you to discuss your wishes and values with your health care provider ahead of time and document them. This will help make sure your health care team is clear about what you want and is willing to support your wishes. This will also help make sure that your wishes are within the institution's health care standards.

Will my advance directive be used if I am taken to the emergency room?

Your advance directive is valid in an emergency room only if the health care providers there know about it. In serious emergency situations, it may not be possible for health care workers to know that you have an advance directive before emergency medical care is given. If you have specific wishes that you would like to be carried out in case you have an emergency, you may talk to your health care team about filling out a physician orders for life sustaining treatment (POLST) form .

What happens if I don't have an advance directive?

If you don't have an advance directive and become unable to make medical decisions by yourself, you could be given medical care that you would not have wanted. If there's no advance directive, the doctor may ask your family about your treatment.

Some states have passed family agency acts that choose which family members (listed in order of priority) may act on behalf of a patient if you don't have an advance directive. But some states do not have laws that require health care providers to check with family members. Family members (especially those who aren't close to you) might not know what you would want. Family members might also disagree on certain aspects of your care, which may cause delays or lead to you not getting the care you might have wanted. Sometimes, the courts can appoint a surrogate or proxy. This is someone a judge chooses to make decisions for you if you become unable to make decisions for yourself.

Do I need a lawyer to write my advance directive?

A lawyer can be helpful, but most people don't need one to write an advance directive. Some states have forms you must use, and all states have certain requirements. Talk to your health care team, as they may be able to help you write your advance directive. Sample forms and directives that meet your state's requirements may also be available.

Can I have an advance directive in more than one state?

Most states have their own rules about what's recognized as a valid advance directive. Some states recognize an out-of-state directive if it meets the legal requirements of the state in which you want to use it. If you want to use an advance directive in a state other than that in which you signed it, or if you want to have an advance directive in more than one state, it's a good idea to check with a lawyer in order to avoid any problems.

Does having an advance directive affect the quality of the health care I receive?

No, having or not having an advance directive will not affect the quality of health care you receive while you can make your own medical decisions. Your health care team will only use you r advance directive to guide medical decisions when you are unable to make decisions for yourself. For a living will to be used, two physicians must confirm that you are unable to make medical decisions for yourself. They must also confirm that you are in a medical condition defined by your state law as a **terminal illness** or **permanent unconsciousness**.

Can I have both a living will and a durable power of attorney for health care?

Yes, you can have both a living will and a durable power of attorney for health care at the same time. A durable power of attorney is used when you are unable to make your health care decisions. In this case, the person you selected to be your health care agent (proxy) will make all of your health care decisions after your physician certifies that you can't make your own medical decisions. A living will is only use d after two physicians confirm that you are unable to make medical decisions for yourself, and that you are in a medical condition defined by your states law as terminal illness or permanent unconsciousness. If you have both these documents, it is important to make sure they don't conflict with each other so that there will be no confusion about your wishes if you can't speak for yourself.

Can I change my mind about my advance directive instructions?

Yes, you can change your mind at any time about what's written in your advance directive. You can also revoke it (take it back) at any time. It is recommended that you review your advance directive every so often to make sure your wishes are still the same. For example, if you have a major health change, a major family change like a divorce, if something happens to your health care proxy (agent) or they become unwilling to be your proxy, or if an existing health condition or illness gets worse. If you change or cancel your advance directive, be sure to let your health care team, loved ones, and your health care proxy (agent) know and also replace any advance directive copies you may have given them with the new one. This will help to ensure that there is no confusion if you are unable to make your own decisions.

Is my advance directive valid if I'm at home?

It may be difficult to honor an advance directive in the event of an emergency while at home. EMS (Emergency Medical Service) teams are required to try to revive and prolong life in every way they can. Some states allow EMS teams to not resuscitate patients who may have valid DNR or POLST forms at home. If DNR or POLST forms are honored in your state, speak with your health care provider about getting these forms filled and signed to reflect your wishes in case of an emergency at home. Your health care provider may also be able to help you get a wallet card, bracelet, or other DNR documents to keep when you are at home or not in the hospital .

Hyperlinks

- 1. www.cancer.org/cancer/end-of-life-care.html
- 2. www.cancer.org/cancer/managing-cancer/advanced-cancer.html

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Last Revised: May 13, 2019

Making Decisions for Your Advance Directive

Thinking about your health care wishes and making an advance directive can be done by anyone at any age. Throughhonest talks with your loved ones, you can explain what's important to you and what kind of treatments you do and do not want. These talks can save your loved ones from guilt, uncertainty, or conflict if decisions about your health need to be made and you are unable to make them. Your loved ones can help make sure that your wishes are followed, but first they must know and understand what you want.

Some important steps and things to consider might include:

- Learn more about different advance directives such as a living will, durable power
 of attorney for health care, and/or other advance health care instructions.
 Understand the meaning of each and the differences.
- Discuss your decisions and wishes with your spouse or partner, family members, close friends, your health care provider, and/or your attorney. Telling those close to you about your end-of-life decisions will help ensure that your wishes are carried out.

- Decide who you want as your health care proxy or agent (decision-maker in case you are unable to make your own decisions). This is an important decision to make. Carefully choose someone you believe will be able to carry out your wishes even if it may mean ending life-sustaining treatments. Talk with the person to be sure they're OK with doing this for you and that they understand your wishes. You may also choose to name a back-up person in case your first choice becomes unable or unwilling to act on your behalf.
- If you have a health care proxy or agent (durable power of attorney for health care), give them a copy of your advance directive to keep in a safe place where it can be found quickly if needed. You may also give copies to loved ones who are likely to be nearby. Be sure your loved ones know who your health care proxy or agent is.
- If you want a living will, or if you're writing detailed instructions, be specific about such things as CPR (cardiopulmonary resuscitation), breathing machines (ventilators or respirators), medicines to make your heart work, kidney dialysis, artificial feeding (tube or intravenous), and certain surgical procedures.
- Remember, before your health care team uses your living will to guide medical
 decisions or your health care proxy can make medical decisions on your behalf, two
 physicians must confirm that you are unable to make your own medical decisions.
- If you need help writing an advance directive, ask your health care team if they
 might be able to help. You might also consider contacting an attorney or a
 mediator. But, most people don't need an attorney to write an advance directive.
- Do not lock your advance directive in a safe-deposit box, home safe, or filing cabinet that only you can open. Let your loved ones know where your original copies are.
- Be sure your health care team has your advance directive in their records. You may also keep copies of your advance directive in easy-to-find places so that someone else can find it if you are in the hospital and need it. You might also give a copy to your attorney and be sure your family knows exactly who has it.
- You can also store your advance directive on the <u>U.S. Living Will Registry</u>¹ (now known as the Advance Care Plan Registry) and access it at any time.
- Every once in a while, remind your health care proxy about your advance directive and their important responsibility. If your wishes change, be sure to talk this over with your proxy, your loved ones, and your health care team and update your advance directive.

Hyperlinks

1. www.usacpr.net

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Last Revised: May 13, 2019

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