Advance Health Care Directives and Living Wills

Making the Best End-of-Life Choices for You and Your Family

Although death is an inevitable part of life, many of us are reluctant to face the fact that we’re not going to live forever and plan for our end-of-life care. Thinking about your end-of-life choices today can improve your quality of life in the future and ease the burden on your family. Discussing your wishes with loved ones and preparing an advance health care directive offers the best assurance that decisions regarding your future medical care will reflect your own values and desires.

What is an advance health care directive (AHCD)?

An advance health care directive or AHCD (otherwise known as a living will, personal directive, or medical directive) is a document that instructs others about your medical care should you be unable to make decisions on your own. It only becomes effective under the circumstances delineated in the document, and allows you to do either or both of the following:

**Appoint a health care agent.** The advance directive allows you to appoint a health care agent (also known as “Durable Power of Attorney for Health Care,” “Health Care Proxy,” or “attorney-in-fact”), who will have the legal authority to make health care decisions for you if you are no longer able to speak for yourself. This is typically a spouse, but can be another family member, close friend, or anyone else you feel will ensure that your wishes and
expectations are met. The individual named will have authority to make decisions regarding artificial nutrition and hydration and any other measures that prolong life—or not.

**Prepare instructions for health care.** The advance directive allows you to make specific written instructions for your future health care in the event of any situation in which you can no longer speak for yourself. It outlines your wishes about life-sustaining medical treatment if you are terminally ill or permanently unconscious, for example.

The advance health care directive provides a clear statement of wishes about your choice to prolong your life or to withhold or withdraw treatment. You can also choose to request relief from pain even if doing so hastens death. A standard advance directive form provides room to state additional wishes and directions, and allows you to leave instructions about organ donations and disposition of remains (burial or cremation).

**Myths about advance health care directives**

**Myth:** You must have an advance health care directive to stop treatment near the end of life.

**Fact:** Treatment can be stopped without an advance directive if everyone involved agrees. However, without some kind of advance directive, decisions may be more difficult and disputes more likely.

**Myth:** An advance directive means “Do not treat.”

**Fact:** An advance directive can express both the treatment that you do want—and that which you don’t want. Even if you do NOT want treatment to cure you, you should always be kept reasonably pain free and comfortable.

**Myth:** If I name a health care proxy, I give up the right to make my own decisions.

**Fact:** Naming a health care proxy or agent does not take away any of your authority. You always have the right, while you are still competent, to override the decision of your proxy or revoke the directive.

**Myth:** I should wait until I am sure about what I want before signing an advance directive.

**Fact:** Most of us have some ambivalence about what we would want because treatment near the end of life can be complicated. Advance health care directives can always be changed if/when your wishes or circumstances change.

**Myth:** Advance directives are only for old people.

**Fact:** Younger adults actually have more at stake, because, if stricken by serious disease or accident, medical technology may keep them alive but comatose or insentient for decades. Every person aged 18 or over should prepare a directive.

**Why is an advance directive important?**

While most people would prefer to die in their own homes, the norm is still for terminally-ill patients to die in the hospital, often receiving ineffective treatments that they may not really want. Friends and family members often become embroiled in bitter arguments about the best way to care for the patient and consequently miss sharing the final stage of life with their loved one. And the opinions and wishes of the dying person are lost in all the chaos.

It’s almost impossible to know what a dying person’s wishes truly are unless they’ve been discussed ahead of time. Planning ahead with an advance directive can give your principal caregiver, family members, and other loved ones peace of mind when it comes to making decisions about your future health care. It lets everyone know what is important to you, and what is not. Talking about death with those close to you is not about being ghoulish or giving up on life, but a way to ensure greater quality of life, even when faced with a life-limiting illness or tragic accident. When your loved ones are clear about your preferences for treatment, they’re free to devote their energy to care and compassion.
End-of-life issues in an advance directive

Specific issues related to the end of your life can include:

1. Which person will make health care decisions for you if you are unable to make your own?
2. What medical treatments and care are acceptable to you? Are there some that you fear or don’t wish to have?
3. Do you want to be resuscitated if you stop breathing and/or your heart stops?
4. Do you want to be hospitalized or stay at home, or somewhere else, if you are seriously or terminally ill?
5. In countries such as the United States, how will your care be paid for? Will your insurance cover it? Some treatments and caregiving or nursing homes can be costly and leave your loved ones with a financial burden at a time when they’re already grieving your loss of health.
6. What actually happens when you die? Will your loved ones be prepared for the decisions they may have to make on your behalf?

Creating an advance health care directive

Advance health care directives and living wills are not complicated, but the content can be complex and should be thought through very carefully. It can be short, simple statements about what you want done or not done if you can’t speak for yourself. It’s important to discuss your wishes with family members, legal, health or other appropriate professionals when preparing such a document. It is particularly important to talk about your wishes with everyone who might be involved in your care. In times of stress, others may confuse their own wishes with yours.

In the U.S., most state governments have designed forms for people to complete on their own by filling in the blanks. While these are not usually mandatory, most states do require witnessing or other specific signing formalities. Anything you write by yourself or with a computer software package should follow your state laws. So, it’s essential for you to know what the specific laws are in your state or country. While you are not required to seek legal advice to prepare an advance health care directive in the U.S., it may be a good idea to do so to ensure that the actual instructions for your wishes are stated clearly and accurately.

Speak with your physician

It is important that you discuss your health care desires with your physician. They are likely to be the one caring for you when your instructions become relevant and are much more
likely to honor requests that have been communicated directly. Your physician can:

- Help you phrase your requests in a way that makes sense to medical professionals and can answer any questions you may have.
- Point out any inconsistent features of your requests. Sometimes refusing one kind of treatment contradicts your desire to receive another kind of treatment. Your physician can smooth out some of these “rough edges” and help make a consistent and coherent directive.
- Tell you if there are aspects of your requests that he or she cannot honor because of personal, moral, or professional constraints.

**Speak with your family**

Despite your best efforts to plan for all eventualities in a health care declaration, actual events may not “fit” your directives. It is therefore important that you discuss your desires with family and friends.

- Your family can often help clarify your directives on the basis of recollections of specific discussions under specific circumstances.
- If you have discussed your wishes with a number of people, it is more likely that those wishes will be honored.
- Discussions with family members can help avoid unpleasant scenes and confrontations when you are incapacitated. While family members may have little legal authority to make decisions for incapacitated patients, they often feel they have moral authority. They may be confused by statements not previously shared with them, and may even try to contest your wishes legally if they feel your choices are not in your “best interest.”

**Talking to your loved ones about end-of-life choices**

To ensure that your future care wishes are understood and respected by all those who are important to you, it’s imperative that you sit down and talk to your family and loved ones about your end-of-life choices. For many of us, the prospect of such a conversation can seem like a daunting task. You or your loved ones may be uncomfortable talking about serious illness or death, or it may seem “too soon” to have a conversation about end-of-life preparations. However, it’s better to have the conversation when you and your loved ones are in a calm and relaxed state, rather than in the midst of a medical emergency when everyone’s stressed and it’s difficult to think clearly.

While you may think that your loved ones already know what you want, the truth is there is often a startling difference between what people say they want and what their family
members *think* they want. The only way to be certain that your loved ones understand your wishes is to sit down and have the conversation.

**Choose a time and place where you and your loved ones feel comfortable** and at ease, such as after a family dinner, on a walk, or sitting outside in the sun.

**Not everything has to be discussed at once.** The conversation can be spread out over different times.

**Be patient with your loved ones.** Fear and denial are common. Some people need longer to become comfortable talking about dying, others may have different feelings about what end-of-life plans should involve.

**Don’t feel like you can never change your mind.** Your opinions and wishes can change over time and Advance Health Care Directives can be revised.

### How to get started

You can get started by sending your loved ones a copy of this article with a note saying, “I’d like to talk about this.”

Other ways you could break the ice:

- Remember how someone in the family died—was it a “good” death or a “hard” death? How do you want yours to be different? “I was thinking about what happened to (Uncle Joe), and it made me realize…”
- “Even though I’m okay right now, I’m worried that (I’ll get sick), and I want to be prepared.”
- “I need to think about the future. Will you help me?”
- “I just answered some questions about how I want the end of my life to be. I want you to see my answers. And I’m wondering what your answers would be.”

Source: theconversationproject.org

### What to do once your advance health care directive is complete

Once you have completed your advance directive, it may be necessary to have it notarized depending on who witnesses your signature—follow the instructions on the document in accordance with your state laws. Providing many trusted individuals with copies of your advance directive will insure that your health care wishes are met in the event that you
cannot express your wishes for yourself.

Keep the original copy of the advance directive yourself in a place that can easily be found, and give copies to:

- Your chosen health care proxy (with directions on where to find the original)
- Family members or other loved ones
- Your primary care physician, hospital, or health care institution. Ask that a copy is placed in your medical record and make sure your doctor will support your wishes.
- Anyone named in the directive

A copy can also be sent to your attorney or kept in a safety deposit box or anywhere else you may keep copies of a will or other important papers. Be sure that you have discussed the directive with the person you designate as your health care agent and that they both understand your wishes and the responsibilities involved and will agree to honor those wishes.

**What happens if I change my mind?**

It’s best to think of Advance Health Care Directives as a work in progress. Circumstances can change, as can your values and opinions about how you would best like your future health care needs to be met. Directives can be revoked or replaced at any time as long as you are capable of making your own decisions. It is recommended that you review your documents every few years or after important life changes and revise your directives to ensure that they continue to accurately reflect your situation and wishes.

**When to reassess your advance directive**

Re-examine your health care wishes every few years or whenever any of the “Five D’s” occur:

1. **Decade** - when you start each new decade of your life.
2. **Death** - whenever you experience the death of a loved one.
3. **Divorce** - when you experience a divorce or other major family change.
4. **Diagnosis** - when you are diagnosed with a serious health condition.
5. **Decline** - when you experience a significant decline or deterioration of an existing health condition, especially when it diminishes your ability to live independently.

Choices about end of life are important for all adults—not just for the older population. Not only does an advance health care directive let your voice be heard about what you want, but it also relieves others of making these decisions for you.
Changing your advance directive

If your current advance health care directive no longer reflects your wishes for end-of-life care, refer to your state’s (or country’s) laws for the correct way to cancel or amend the directive. Once you have revised the directive, it is important to discuss the changes with your physician and family members, and notify everyone who has copies of your old directive.

Other resources

- **Myths and Facts About Health Care Advance Directives** (PDF) - Common myths about advance directives and the facts that dispel them. (American Bar Association Commission on Law and Aging)

- **Tool Kit for Health Care Advance Planning** – Self-help worksheets, suggestions, and resources. (American Bar Association Commission on Law and Aging)

- **Making End-of-Life Decisions: What Are Your Important Papers** – The documents you should have when faced with end-of-life decision-making. (Family Caregiver Alliance)

- **Caring Connections** – State-by-state advance directive forms for use in the U.S. (NHPCO)

Authors: Lawrence Robinson, Monika White, Ph.D., and Jeanne Segal, Ph.D. Last updated: March 2019

Reviewed by: Lisa C. Alexander, attorney, certified by the State Bar of California as a legal specialist in Estate Planning, Trust and Probate Law. She is a partner of the law firm of Jakle & Alexander, LLP.