

Tips for Advance Care Planning

TIP SHEET



Advance care planning is important for adults at any age. During an emergency or at the end of life, you or your loved ones may not be capable of making decisions about medical care. This tip sheet covers common care and treatment decisions, deciding on your health care proxy, and how to make your care decisions official. Preparing for your care is one way you can make it easier on your loved ones in the future.

What Is Advance Care Planning?

Advance care planning involves sharing and discussing potential decisions about medical care if you become seriously ill or unable to communicate your wishes.

Having meaningful conversations with your loved ones about your preferences is the most important part of advance care planning.

Your requests can also be included in **advance directives**, which are legal documents that provide instructions for medical care and only go into effect when you can no longer clearly communicate due to disease or severe injury. No matter how old you are, advance directives let others know what type of medical care you want.

The two most common advance directives are the living will and the durable power of attorney for health care. You can choose which documents to create, depending on your wishes.

Living will. A living will is a document that helps you tell doctors how you want to be treated if you can't make your own decisions about emergency treatment. You can state which common medical treatments or care you would want, which ones you would want to avoid, and under which conditions each of your choices applies.

Durable power of attorney for health care. A durable power of attorney for health care is a legal document that names your health care proxy, someone who can make health care decisions if you're unable to communicate these yourself. Your proxy (also known as a representative, surrogate, or agent) should be familiar with your values and wishes. A proxy can be chosen in addition to or instead of a living will. Having a health care proxy helps you plan for unexpected situations, such as a serious auto accident or stroke.

Think of your advance directives as living documents that you review at least once a year and update if a major life event occurs, such as retirement, moving out of state, or a change in your health. Some people are reluctant to put specific health decisions in writing. For these individuals,



naming a health care proxy may be a good approach, especially if there is someone they feel comfortable talking with about their values and preferences. A proxy can evaluate each situation or treatment option independently.

Research shows that advance directives can make a positive difference, and that people who document their preferences are more likely to get the medical and comfort care they prefer at the end of life.

Getting Started

The process of creating your advance directives can help you reflect and make decisions about what matters most to you at the end of life. It can also spark important conversations with your loved ones and provide you with a greater sense of comfort and peace of mind.

Many people begin the process by thinking about their values and wishes. For example, if your heart stops or you have trouble breathing, would you want to undergo lifesaving measures if it meant that, in the future, you could be well enough to spend time with your family? For some people, staying alive as long as medically possible, or long enough to see an important event such as a grandchild's college graduation, is the most important thing. Advance directives can help to make that possible. Other individuals have a clear idea about when they would no longer want to prolong their life. Advance directives can help with that, too.

Your decisions about how to handle medical decisions and care may be different at age 40 than at age 85. You can update your advance directives as you get older or if your viewpoints change.

Consider Common Treatment and Care Decisions

Think about the kinds of treatment you do or don't want in a medical emergency. It can help to talk with your doctor about your current health and the kinds of decisions that are likely to come up. For example, you might ask about the decisions you or your family may face if your high blood pressure leads to a stroke. Your doctor can help you understand and think through choices before you put them in writing. Medicare or private health insurance may cover some advance care planning discussions with a health care professional.

In your living will, you can provide instructions about the use of emergency treatments to keep you alive. You should also talk about these decisions with your health care proxy. Decisions that might come up at this time relate to:

CPR. Cardiopulmonary resuscitation (CPR) might restore your heartbeat if your heart stops or is in a life-threatening abnormal rhythm. It involves repeatedly pushing on the chest with force, while putting air into the lungs. This force can sometimes break a person's ribs. Electric shocks, known as defibrillation, and medicines might also be used as part of the process. The heart of a young, otherwise healthy person might resume beating normally, but CPR is less likely to work in older adults who have chronic medical conditions.

Ventilators. If you aren't able to breathe adequately, you may need a ventilator, a machine that uses a tube in the throat to force air into the lungs to help you breathe. Inserting the tube down the throat is called intubation. Intubation can be very uncomfortable, so medicine is often used

to keep the person sedated. If you're expected to remain on a ventilator for a long time, a doctor may insert the tube directly into your trachea (a part of the throat) through a hole in the neck. This is called a tracheotomy. For long-term help with breathing, this procedure makes it more comfortable. People who have had a tracheotomy need additional help to speak.

Pacemakers and ICDs. Some people have pacemakers to help their hearts beat regularly. If you have one and are near death, it may not necessarily keep you alive. You might have an implantable cardioverter-defibrillator (ICD) placed under your skin to shock your heart back into regular beats if the rhythm becomes irregular. If you decline other life-sustaining measures, the ICD may be turned off. You need to state in your advance directives what you want done if the doctor suggests it is time to turn it off.

Artificial nutrition and hydration. If you aren't able to eat or drink, fluids and nutrients may be delivered into a vein through an IV, or through a feeding tube. A feeding tube that is needed for a short time goes through the nose and esophagus into the stomach. If a feeding tube is needed for an extended period, it may be surgically inserted directly into the stomach through the skin of the abdomen. Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

Artificial nutrition and hydration can be helpful if you're recovering from an illness. However, studies have shown that artificial nutrition toward the end of life doesn't meaningfully prolong life.

You can also consider the types of care you might want as you age. Learning about these options can help you plan ahead.

Types of care may include:

Palliative care. This type of care treats the symptoms of a serious illness, such as pain and discomfort. It's offered alongside medical treatment for the illness itself; for example, chemotherapy for cancer or dialysis for kidney failure. In addition to helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any person having a lot of general discomfort and disability because of a serious illness.

Hospice care. This refers to care and support that's provided by your health care team after attempts to cure an illness have stopped. It may be offered in the home, a hospice facility, a skilled nursing facility, or a hospital. The goal is to ensure the best

quality of life in a patient's final days, weeks, or months. After death, the hospice team continues to offer support to the family.

Hospice and palliative care aren't the same things, but both have the same goal: to keep you comfortable. If you're receiving hospice care, you can choose to move back to curative care if you decide to pursue treatments to cure your illness.

Read more about end-of-life care at www.nia.nih.gov/health/end-of-life.

Consider Choosing a Health Care Proxy

Use the advance directive called the durable power of attorney for health care to name your health care proxy. This person can make decisions if you are unable to make decisions for yourself. If you decide to name a proxy, think about people you know who share your views and values about life and

Talking About Your Wishes

It's important to have conversations with the people who matter most to you about how you want to be cared for in a medical emergency or at the end of life. These talks can help you think through the wishes you want to put in your advance directives.

Talking about your thoughts, beliefs, and values with your health care proxy will be especially helpful. This conversation will help prepare them to make medical decisions that best reflect your values.

After you have completed your advance directives, talk about your decisions with your health care proxy and other loved ones, and your doctor, to explain what you have decided. That way, they won't be surprised by your wishes if there is an emergency.

Another way to convey your wishes is to make a video of yourself talking about them in your own words. Videos don't replace advance directives, but they can be helpful for your health care proxy and other loved ones.

medical decisions. Your proxy might be a family member, a friend, your lawyer, or someone in your social or spiritual community. It's a good idea to also name an alternate proxy. If you choose not to name a proxy, it's especially important to have a detailed living will.

You can decide how much authority your proxy has over your medical care — whether they make a wide range of decisions or only a few specific ones. Try not to include guidelines that make it impossible for the proxy to fulfill their duties. For example, it's probably not unusual for someone to say in conversation, "I don't want to go to a nursing home," but think carefully about whether you want a restriction like that in your advance directives. Sometimes, for financial or medical reasons, that may be the best choice for you.

Of course, check with those you choose as your health care proxy and alternate proxy before you name them officially. Make sure they are comfortable with this responsibility.

Other Planning Documents

You might also want to prepare documents to express your wishes about a single medical issue or something not already covered in your advance directives. A living will usually covers the life-sustaining treatments discussed earlier. It may also include other care and treatment decisions as well as preferences about matters such as organ and tissue donation and brain donation. You can give your health care proxy instructions about these issues, too.

In some emergency situations, it may not be possible for the health care team to know your wishes before delivering care. To help ensure your wishes are known, you can

talk to your doctor about establishing the following forms:

Do not resuscitate (DNR) order. A DNR becomes part of your medical chart to tell medical staff in a hospital or nursing facility that you don't want CPR or other life-support measures to restore your heartbeat and breathing. Sometimes this document is referred to as a Do Not Attempt Resuscitation order or an Allow Natural Death order. Even though a living will might say CPR isn't wanted, it's helpful to have a DNR order as part of your medical file if you go to a hospital. Posting a DNR next to your hospital bed might avoid confusion in an emergency. Without a DNR order, medical staff will make every effort to restore your breathing and the normal rhythm of your heart.

Do not intubate (DNI) order. A similar document, a DNI tells medical staff in a hospital or nursing facility that you don't want to be put on a ventilator.

Out-of-hospital DNR order. An out-of-hospital DNR alerts emergency medical personnel to your wishes regarding measures to restore your heartbeat or breathing if you aren't in the hospital.

Physician orders for life-sustaining treatment (POLST) and medical orders for life-sustaining treatment (MOLST) forms. These forms provide guidance about your medical care that health care professionals can act on immediately in an emergency. They serve as a medical order in addition to your advance directives. Typically, you create a POLST or MOLST when you're near the end of life or critically ill and know the specific decisions that might need to be made on your behalf. These forms may also be called portable medical orders or physician orders for scope of treatment (POST). Check with your state's department of health to find out if these forms are available where you live.

You may also want to document your wishes about organ and tissue donation, and brain donation.

Organ and tissue donation allows organs or body parts from a generally healthy person who has died to be transplanted into people who need them. Commonly, the heart, lungs, pancreas, kidneys, corneas, liver, and skin are donated. There's no age limit for organ and tissue donation. You can carry a donation card in your wallet, and some states allow you to add this decision to your driver's license. You may also include organ donation in your advance care planning documents. Tell your family and proxy about your wishes and include a statement about organ donation in your living will.

Brain donation helps researchers study brain disorders, such as Alzheimer's disease and related dementias, that affect millions of people. While many people think that signing up to be an organ donor includes donating their brain, the purpose and the process of brain donation are different. Rather than helping to keep others alive, brain donation helps advance scientific research. Similar to organ and tissue donation, you should state your wishes about brain donation in your living will.

Visit www.nia.nih.gov/organdonation and www.nia.nih.gov/braindonation to learn more.

Making It Official

Once you are ready to make your plans official, the next step is to fill out the legal forms detailing your wishes. A lawyer can help but isn't required.

Many states have their own advance directives forms. Your local Area Agency on Aging can help you locate the right

forms. You can find your area's agency phone number by calling the Eldercare Locator at 800-677-1116 or visiting <https://eldercare.acl.gov>.

Some states require your advance directives to be witnessed, your signature to be notarized, or both. A notary is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, local library, shipping store, or insurance agency. Some notaries charge a fee.

Check to see if your state has a registry that can store your advance directives for quick access by health care providers, your proxy, and anyone else to whom you have given permission. Private firms also will store your advance directives. There may be a fee for storing your form in a registry. If you store your advance directives in a registry and later make changes, you must replace the original with the updated version.

Some people spend a lot of time in more than one state, for example, visiting children and grandchildren. If that's your situation, consider preparing advance directives using forms for each state, and keeping a copy in each location, too.

After You Set Up Your Advance Directives

Provide copies of your advance directives to your health care proxy and alternate proxy. Give your doctor a copy for your medical records. Tell close family members and friends where you keep a copy. If your advance directives are only available electronically, be sure to share the access information (such as a password) with your proxy. If you receive care at a hospital, provide a copy to include in your records. Because you might change your advance directives in the future, it's a good idea to keep track of who has a copy.

Review your advance care directives regularly and make any needed updates. For example, you might want to make adjustments after certain life changes such as moving, a marriage or divorce, or a new health condition. If your preferences change, you will want to make sure your doctor, proxy, and family know about them. Consider choosing a date every year — such as New Year’s Day — to revisit your advance directives.

Be Prepared

What happens if you have no advance directives and you become unable to communicate your wishes? In such cases, the state where you live will assign someone to make medical decisions on your behalf. This will probably be your

spouse, your parents if they are available, or your children if they are adults. If you have no family members, the state will choose someone to represent your best interests.

Remember: Advance directives are only used if you are not able to make care and treatment decisions on your own. Advance directives allow you to make your wishes about medical treatment known.

It’s difficult to predict the future with certainty. You may never face a medical situation in which you’re unable to make your wishes known. But having advance directives may give you and those closest to you some peace of mind.

Read more about advance care planning at www.nia.nih.gov/advance-care-planning.

Advance Directive Wallet Card

You might want to make a card to carry in your wallet indicating that you have advance directives and where it’s kept. Here’s an example of a wallet card offered by the American Hospital Association. You might want to make a copy or cut this one out to fill out and carry with you. It can also be found online at www.aha.org/putitinwriting.

Advance Directive
NOTIFICATION

Print name _____ Signature _____

I have a health care power of attorney I have an advance directive

I have talked with my family and my doctor about the care I want. If I am unable to speak for myself, please contact:

Name _____ Number _____
(Additional names on back)

Name _____ Number _____

Name _____ Number _____

Your life. Your terms.

For more information visit:
www.aha.org/putitinwriting

For More Information

National Institute on Aging Information Center

800-222-2225
800-222-4225 (TTY)
niaic@nia.nih.gov
www.nia.nih.gov/health

Aging with Dignity

850-681-2010
fivewishes@agingwithdignity.org
www.agingwithdignity.org

American Bar Association

800-285-2221
aging@americanbar.org
www.americanbar.org/aging

Brain Donor Project

513-393-7878
<https://braindonorproject.org>

CaringInfo

National Hospice and Palliative Care Organization

800-658-8898
caringinfo@nhpco.org
www.caringinfo.org

Center for Practical Bioethics

800-344-3829
center@practicalbioethics.org
www.practicalbioethics.org/programs/advance-care-planning

The Conversation Project

866-787-0831
conversationproject@IHI.org
<https://theconversationproject.org>

Donate Life America

804-377-3580
www.donatelife.net

Eldercare Locator

800-677-1116
eldercarelocator@n4a.org
<https://eldercare.acl.gov>

The Living Bank

800-528-2971
info@livingbank.org
www.livingbank.org

National Academy of Elder Law Attorneys

703-942-5711
naela@naela.org
www.naela.org

National POLST

202-780-8352
info@polst.org
www.polst.org

Organdonor.gov

Health Resources & Services Administration
donation@hrsa.gov
www.organdonor.gov

PREPARE for Your Care

info@prepareforyourcare.org
<https://prepareforyourcare.org>

Put It In Writing

American Hospital Association
800-424-4301
www.aha.org/contactaha
www.aha.org/putitinwriting

