Tips for Advance Care Planning

TIP SHEET

National Institute on Aging

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 struggle to make decisions about your medical care. Preparing for your care is one way you can make it easier on your loved ones in the future. This tip sheet covers common care and treatment decisions, deciding on your health care proxy, and how to make your care decisions official.

What Is Advance Care Planning?

Advance care planning involves discussing and preparing for future decisions about your 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 if you can no longer communicate your own wishes due to disease or severe injury. No matter how old you are, advance directives let others know what type of medical and comfort care you want.

The two most common advance directives are the living will and the durable power of attorney for health care. Additionally, there are advance directives for financial and estate management. You can choose which documents to create, depending on your needs and preferences.

Living will. This is a written document that helps inform doctors how you want to be treated if you are unable to make your own decisions about emergency care. It enables you to make clear which treatments you would or would not want, and under which conditions each of your choices applies.

Durable power of attorney for health care. This is a legal document that names your health care proxy, a person who can make health care decisions for you 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. You can choose a proxy in addition to or instead of having a living will. Having a proxy helps you plan for unexpected situations, such as a serious car accident or stroke. A proxy can evaluate each situation or treatment option independently and use their knowledge about what's important to you to make decisions with your health care providers.

Advance directives for financial and estate management. These legal documents outline how your property, money, and other assets are to be handled if you become unable to manage them yourself and when you die. Common documents include a will, a durable power of attorney for finances, and a living trust. Visit www.nia.nih.gov/important-documents-checklist to learn more.

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

Creating your advance directives can help you reflect on and make decisions about what matters most 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, 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 family event, is the most important goal. Advance directives can help to make that possible.

Other individuals have a clear idea about when they would no longer want to prolong their lives. Advance directives can help with that, too.

Advance Care Planning for People With Dementia

People in the later stages of dementia often lose their ability to do the simplest tasks, and some people may lose their ability to make decisions earlier than expected. Understanding what can happen with dementia may help you and your family prepare for future care decisions.

Advance care planning can give you a sense of control by helping to choose your future care. In the later stages of dementia, a health care proxy can discuss advance care planning decisions with your family, health care provider, or a trusted friend to help them plan and feel more supported when deciding on the types of care and treatments you would want.

Visit www.alzheimers.gov/life-with-dementia/planning-for-future to learn more.

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.

Choosing a Health Care Proxy

Use the durable power of attorney for health care to name your health care proxy. If you decide to name a proxy, think about people you know who share your views and values about life and 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 — a backup if your primary proxy is unavailable for any reason. If you choose not to name a proxy, it's especially important to have a detailed living will.

You can specify how much say your proxy has over your medical care — whether they make a wide range of decisions or only a few specific ones. You can also choose which decisions you'd prefer your doctor to make and outline other preferences, such as requiring your proxy to talk with certain family members before making a decision. However, it's important to give your proxy some flexibility to ensure they can help you get the most appropriate care. Make sure the people you choose as your proxies are comfortable with this responsibility before you name them officially.

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, share your decisions with your proxy, 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 preferences 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 proxy and loved ones.

Visit **www.nia.nih.gov/acp-worksheets** to find tools to help you discuss and prepare for the future.

Consider Common Treatment and Care Decisions

Think about the kinds of treatment you would or wouldn't want in a medical emergency. It can help to talk with a 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 might face if your high blood pressure led to a stroke. You can ask a doctor to help you understand and think through your 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. This procedure tries to restore your heartbeat and keep blood flow active if your heart stops or is in a life-threatening, abnormal rhythm. 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 or are hospitalized with a serious illness.

Ventilators. If you aren't able to breathe adequately, you may need a ventilator, a machine that uses a tube in the throat to push 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 windpipe (trachea) through a hole in the neck. This procedure is called a tracheotomy. For long-term help with breathing, this procedure makes using a ventilator 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 into the stomach 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) may be 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 at 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, such as 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. Palliative care can also provide support to caregivers and loved ones affected by the illness.

Hospice care. This refers to care and support that are provided by a 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 care and palliative care aren't the same thing, but they have the same goal: to give you the highest quality of life possible. If you're receiving hospice care, you can choose to move back to curative care if you decide to pursue treatments that could possibly cure your illness.

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

Other Treatment, Care Decisions, and Forms

You might also want to prepare documents to express your wishes about a single medical issue or something else not already covered in your advance directives.

A living will usually covers the life-sustaining treatments discussed earlier, but some may include other care and treatment decisions as well as preferences about options such as organ 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. For these types of situations, you can talk to your doctor about establishing the following orders in advance:

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 if your heartbeat and breathing stop. 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. Having a DNR posted 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.

Do not hospitalize (DNH) order. A DNH indicates to long-term care providers, such as nursing home staff, that you prefer not to be sent to a hospital for treatment at the end of life.

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 directive. Typically, you create a POLST or MOLST when you're near the end of life or critically ill and understand 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. 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. This 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 can be 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 indicate this decision on 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. This helps researchers study brain disorders, such as Alzheimer's and related dementias, which 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 from other organ and tissue donation. Rather than helping to keep others alive, brain donation helps advance scientific understanding. 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 advance care 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 directive 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.**

Most states require your advance directives to be witnessed, your signature to be notarized, or both. A notary is 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. Your form will likely include directions on whether a witness or notary is needed.

Your state may have a registry that can store your advance directives for quick access by health care providers and your health care proxy. Private firms can store your advance directives for a fee. You may also be able to store copies using other tools, such as a secure smartphone app.

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.

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 store these documents. 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. Changes in your life, such as a divorce, death of a loved one, change in employment (including retirement), moving, or new state laws, may affect your decisions. You should also update your documents if there are any changes to your health, such as a disease diagnosis. Consider choosing a date every year — such as New Year's Day — to revisit your advance directives.

Be Prepared

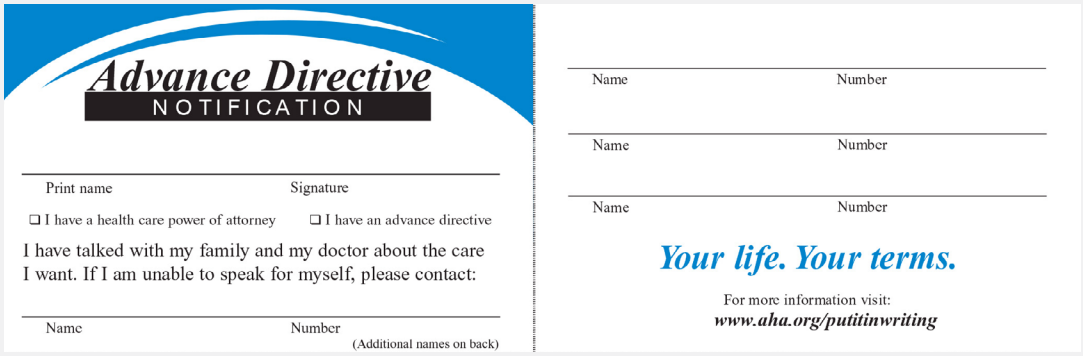
What happens if you have no advance directives and you become unable to communicate your wishes? In these cases, the state where you live will assign someone to make medical decisions on your behalf. This will probably be your spouse, your parents if they are available, or your children if they are adults. If you are unmarried and have not named your partner as your health care proxy, it's possible they would be excluded from decision-making. If you have no family members, some states allow a close friend who is familiar with your values to help. Or they may assign a physician to represent your best interests.

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

Some people choose to carry a card in their wallet indicating they have an advance directive and noting where it's kept. Below is an example from the American Hospital Association. You might want to make a copy or cut this one out to fill in and carry with you.



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

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
niaic@nia.nih.gov
www.nia.nih.gov/health

Eldercare Locator
800-677-1116
eldercarelocator@USAging.org
https://eldercare.acl.gov

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

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

The Conversation Project
866-787-0831
conversationproject@IHI.org
https://theconversationproject.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

American Hospital Association Put It In Writing
American Hospital Association
800-424-4301
www.aha.org/contactaha
www.aha.org/putitinwriting

National Institute on Aging

National Institutes of Health
NIH...Turning Discovery Into Health®

U.S. Department of Health and Human Services

NIH Publication No. 24-AG-8039 | April 2024