



Advance Care Planning

A Conversation Guide



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INTRODUCTION

It is not uncommon to hear stories about families feeling deeply conflicted or even being torn apart over decisions for their loved ones at the end of life. Many people assume their loved ones know what they would want. However, research suggests that this is not always true. When participants in a research study were asked to predict which end-of-life decisions their loved one would make, they guessed nearly one in three decisions incorrectly.

One Family's Story

After a severe heart attack, Roger was on life support and his likelihood of recovery was uncertain. The medical team asked his wife, Donna, and two adult sons, Anton and Mike, if they wanted to continue life support. They had never discussed with Roger what he would want in a situation like this. Without knowing his wishes, they debated and agonized for days. Donna and Anton were still hopeful something could change. Mike, however, was certain that his father would never want to spend his life like this. Mike could not bear to see him in the hospital. Eventually, the doctors announced that Roger was unlikely to recover, and the family made the difficult decision to withdraw life support. Even after the funeral, Donna and Anton questioned if there was something more they could have done to help Roger recover, while Mike wondered if they should have withdrawn life support sooner.

People are more likely to get the care they want if they discuss or document their wishes. Although it can be tough, having these conversations and a plan can help reduce the burden on your loved ones later, help them feel less guilt and depression, and grieve more easily. Sharing your wishes in advance and identifying a health care proxy can make life a little easier on your family and save them from wondering if they made the right decisions for you.

This book from the National Institute on Aging (NIA), part of the National Institutes of Health, will help you learn about advance care planning and how to establish your advance directives. It provides worksheets, conversation guides, and other tools to help you prepare and plan. The terms in bold can also be found in the **Words To Know** section.



CHAPTER 1

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 is the most important part of advance care planning.

People of all ages can benefit from **advance care planning** because a serious illness or severe injury can strike at any time. As we get older, it's also common to need more help making decisions about health care. One study found that half of all adults age 65 or older who are admitted to a hospital had someone else involved in making their medical decisions. Having your documents in place and discussing your values with loved ones can help them make decisions that align with your preferences.

Advance Care Planning for People With Dementia

Many people do not realize that Alzheimer's disease and related dementias are terminal conditions and ultimately result in death. People in the later stages of dementia often lose their ability to do the simplest tasks. Dementia can also progress unpredictably. Some people may lose their ability to make decisions earlier than anticipated. Understanding how dementia progresses may help you and your family prepare for future care decisions.

If you have dementia, advance care planning can give you a sense of control over an uncertain future and you can participate directly in decision-making about your future care. If you are a loved one of someone in the later stages of dementia, discussing advance care planning decisions with the person's family, health care provider, or another trusted friend may help you plan and feel more supported when deciding the types of care and treatments the person would want.

What Are Advance Directives?

To make your wishes official, you can develop **advance directives**. Advance directives are legal documents that provide instructions for medical care and only go into effect if you cannot communicate your own wishes due to disease or severe injury. 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.

The two most common advance directives are:

- A **living will** is a document that helps you tell doctors how you want to be treated if you cannot make your own decisions about emergency treatment.

In a living will, you can say which common medical treatments or care you would want, which ones you would want to avoid, and under which conditions each of your choices would apply.

- A **durable power of attorney for health care** is a legal document that names your health care proxy, a person who can make health care decisions for you if you are 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 situations that cannot be foreseen, such as a serious auto accident or stroke.

Think of your advance directives as living documents that you review at least once each year and update if a major life event occurs such as retirement, moving out of state, or a significant change in your health.

Some people are reluctant to put specific health decisions in writing and it can be difficult to anticipate future treatment decisions. For these reasons, naming a **health care proxy** is often a good approach, especially if there is someone you feel comfortable talking with about your values and preferences. A proxy can evaluate each situation or treatment option independently and use their knowledge of what's most important to you to make decisions with your health care providers.



What's Standing in My Way?



Explore some common concerns about advance directives and how you can create a plan that works for you.

“I don’t need to do it right now.” *Aya, age 45, Madison, Wisconsin*

Even if you are perfectly healthy, you can experience unanticipated events, such as a car accident, that could leave you unable to speak for yourself. Putting a plan in place now helps ensure that you’re not making decisions during a medical emergency. Planning ahead also enables you to choose who will make decisions on your behalf if you are not able to communicate them yourself. As your life changes, you can update your advance directives to ensure they reflect your wishes.



“I don’t want to sign my life away.” *Harold, age 64, Hattiesburg, Mississippi*

Advance directives and living wills only go into effect if you become unable to communicate your wishes due to a serious illness or injury. You also have the power to change your plans at any time.



“I don’t want to talk about death or dying with my family. It’s too difficult.” *Xavier, age 63, Modesto, California*

It’s true that advance care planning conversations may be difficult. Yet, many people find that these conversations create a sense of empowerment, help them learn more about themselves and their life situation, and bring them closer to their family members. You do not need to discuss specific treatments or care decisions right away. Instead, talk about your general preferences and who you trust to make medical decisions for you. You can also try other ways to share your wishes, such as writing a letter, reviewing this conversation guide together, or watching a video on this topic.

What Happens if I Do Not Have an Advance Directive?

If you do not have an advance directive and you are unable to make decisions on your own, the state laws where you live will determine who may make medical decisions on your behalf. This is typically 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 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.

It is impossible to predict the future. You may never face a medical situation in which you are unable to communicate your wishes. Still, having an advance directive can provide you and those close to you with some peace of mind. Remember that an advance directive is only used if you are unable to make decisions on your own.

Will an Advance Directive Guarantee My Wishes Are Followed?

An advance directive is legally recognized but not legally binding. This means that your health care provider and proxy will do their best to respect your advance directive, but there may be circumstances in which they cannot follow your wishes exactly. For example, you may be in a complex medical situation where it is unclear what exactly you would want. This is a key reason why having conversations about advance care planning is so important. Open, honest discussion can help your loved ones understand your values and preferences and better navigate unanticipated issues.

In some emergency situations, it may not be possible for the health care team to know your wishes before delivering care. For example, if you have a sudden heart

attack and need an ambulance, it's unlikely that first responders will be able to locate your advance directive or health care proxy before providing emergency care. For these types of situations, you can talk to your doctor about establishing out-of-hospital **Do-Not-Resuscitate (DNR) orders**, portable medical orders called **Physician Orders for Life-Sustaining Treatment (POLST)**, or similarly named orders. These orders can help make your treatment wishes clear to health professionals during a medical emergency. In contrast, an advance directive often helps guide treatment after a medical emergency. Learn more about these orders in Chapter 3.

Finally, there is the possibility that a health care provider refuses to follow your advance directive. This might happen if the decision goes against:

- The health care provider's conscience
- The health care institution's policy
- Accepted health care standards

In these situations, the health care provider must inform your health care proxy immediately and consider transferring your care to another provider.





CHAPTER 2

How Do I Prepare a Living Will?

Creating your **living will** or **durable power of attorney** for health care can help you reflect and make decisions about what matters most at the end of life. 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 experience an important family event, is the most important goal. Advance directives can help 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.

One Family's Story

Nothing was more important to Rosa than her family. When she was diagnosed with cancer, she told her doctor and her family that she wanted to do whatever it took to be able to see her granddaughter's college graduation, even if treatments would make her very sick. She decided on an aggressive treatment that required frequent stays in the hospital. After attending the graduation, she asked to stop treatment so she could spend more time at home and her final days surrounded by family.

Everyone approaches advance care planning differently. Be flexible and take it one step at a time. For example, try simply talking with your loved ones about what you appreciate and enjoy most about life. Your values, treatment preferences, and even the people you involve in your plan may change over time. The most important part is to start the conversation.

Use the worksheet *Think About What Matters Most When Making Medical Decisions* on page 55 to help you or a loved one get started.

Talk With Your Doctor

Talking with a doctor about advance care planning is covered by Medicare as part of your annual wellness visit. Medicare may also cover this service as part of your medical treatment. If you have private health insurance, check with your insurance provider.

It can help to talk with one or more health care providers 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. You can ask a doctor to help you understand

and think through your choices before you put them in writing. Use the *Health Care Providers to Involve in Advance Care Planning* worksheet on page 59 to keep track of all your providers.

Some people may find it difficult to ask their doctor directly about their current prognosis or end-of-life care. Preparing for your appointment can help. If it makes you more comfortable, ask your health care proxy to come to your appointment with you. In some cases, you could even have your proxy speak directly with your doctor. Use the *Tips for Talking With Your Doctor About Advance Care Planning* worksheet on page 61 to help organize your questions when you visit your health care provider.



Common Care and Treatment Decisions in a Living Will

A living will is a written document that helps inform doctors on 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. This is different from a **will**, which provides legal guidance about a person's estate — their property and financial assets — as well as care for child or adult dependents, gifts, and end-of-life arrangements, such as a funeral or memorial service and burial or cremation.

Through a living will, you can share your preferences about the use of emergency treatments to keep you alive. You should also talk with your health care proxy about your choices. Decisions that might come up at this time relate to:

- **CPR.** This procedure tries to 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 among older adults who have chronic medical conditions or are hospitalized with a serious illness.
- **Ventilators.** If you are not 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 are 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. Some people have an implantable cardioverter-defibrillator (ICD) that will shock the heart back into regular beats if the rhythm becomes irregular. If you decline other life-sustaining measures, the ICD may be turned off. You should state in your advance directives what you want done if a doctor suggests it is time to turn it off.
- **Artificial nutrition and hydration.** If you are not 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 are recovering from an illness. However, studies have shown that artificial nutrition toward the end of life does not 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 is 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, disability, or stress due to 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 is 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 are not the same thing, but both have the same goal: to give you the highest quality of life possible. If you are 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.

Use the *Care and Treatment Decisions: What Would You Choose?* worksheet on page 57 to help think through care and treatment decisions commonly included in a living will.

Other Treatment and Care Decisions and Forms

You might 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 around options such as organ and **brain donation**.

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 with a doctor about establishing the following orders:

- **Do not resuscitate (DNR) order:** A DNR becomes part of your medical chart to inform medical staff in a hospital or nursing facility that you do not want CPR

or other life-support measures to be attempted if your heartbeat and breathing stop. Sometimes this document is referred to as a Do Not Attempt Resuscitation (DNAR) order or an Allow Natural Death (AND) order. Even though a living will might state that CPR is not wanted, it is 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 attempt every effort to restore your breathing and the normal rhythm of your heart.

- **Do not intubate (DNI) order:** A similar document, a DNI informs medical staff in a hospital or nursing facility that you do not want to be 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 are not in a 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 are 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 (POST). Check with your state 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 is



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, 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. 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.

A photograph of two men sitting on a couch in a living room. The man on the left is older, with grey hair, wearing a blue and white checkered shirt. The man on the right is younger, with dark curly hair and a beard, wearing a brown sweater. He has his hand on the older man's shoulder. The background shows a window with curtains and a white wall.

CHAPTER 3

How Do I Choose My Health Care Proxy?

You can choose a person to make medical decisions for you if you are unable to communicate them yourself due to a serious illness or injury.

This person is called a health care proxy. Some important things to know:

- Your proxy will work with your health care team to ensure your care and treatment preferences are followed.
- It's okay to change your health care proxy. Fill out a new proxy form and let your family and health care team know about the change.
- You may name an **alternate proxy** if your proxy is unavailable.

You can choose a proxy in addition to or instead of having a living will.

Having a health care proxy can help you plan for unexpected situations.

What Can a Health Care Proxy Do?

Your proxy can only make decisions for you if you are too sick to make them yourself. You can specify how much say your proxy has over your medical care, including whether he or she can 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 health care proxy some flexibility to ensure they can give you the best care possible.



Although it can vary by state, common responsibilities of a health care proxy include:

- Deciding the types of medical care, procedures, treatments, or services you receive
- Identifying your health care providers and where you will receive care
- Overseeing information about your physical or mental health and your personal affairs, including medical and hospital records
- Making decisions about autopsy, tissue, and organ donation, and what happens to your body after death
- Becoming your guardian if one is needed

Choosing a Health Care Proxy

Here are some people you might consider:

- Parent
- Spouse or partner
- Adult child or grandchild
- Sibling
- Other relative, such as a cousin or niece
- Friend
- Trusted neighbor
- Lawyer

You might also pick an alternate proxy, a backup if your primary proxy is unavailable for any reason.

Who Can Be a Health Care Proxy?

In most states, your health care proxy must be age 18 or older. In Alabama and Nebraska, however, a proxy must be age 19 or older. In all cases, a proxy must be of sound mind. Think carefully about the person you choose to be your health care proxy. The worksheet, *Who Should I Choose as My Health Care Proxy?* on page 67, includes questions that can help you pick a proxy.

While state requirements vary greatly, the American Bar Association generally recommends **not** choosing:

- Your health care provider or their spouse, employee, or spouse of an employee
- The owner or operator of your health or residential care facility or someone working for a government agency financially responsible for your care
- A professional evaluating your ability to make decisions
- Your court-appointed guardian or conservator
- Someone who serves as a health care proxy for 10 or more other people

Be sure to check your state's rules to find out if there are any other limitations on who can be your proxy.

How To Ask Someone To Be Your Health Care Proxy

Once you've identified someone you would like to serve as your proxy, ask them if they are willing to take on the responsibility. You may want to talk to more than one person about your wishes before deciding who is the right proxy for you. After you have chosen someone, share your decision with your loved ones. Use these tips to help prepare for and start the conversation:

- **It's okay to feel uncomfortable or emotional.** Although it may push you out of your comfort zone, having this conversation will help you and your loved ones in the future. You may also find that you feel closer to the person after discussing these important decisions with them.
- **Decide on a conversation starter that works for you.** If it makes you feel more comfortable, you might start by writing a letter, watching a video about advance care planning with the person, or making a video of yourself talking about your wishes.
- **Understand that the person may say no.** Serving as someone's proxy is a big responsibility. Some people may say no because they feel they cannot honor your wishes or that it would be too stressful to make medical decisions on your behalf. Some people may need time to think about it. That's okay. The important thing is to ask, listen, answer their questions, and let them decide.



Bring this guide and any advance care planning documents with you. Use them as resources to explain what it means to be a proxy and share what matters most to you. Here are some things you might say:

- “This isn’t easy to talk about, but I’d like you to make my medical decisions if I’m too sick to speak for myself. I’d like to tell you more about what that means. Is that okay?”
- “I’d like you to be my health care proxy. That means you would make medical decisions for me if I couldn’t make them for myself. Is this something you would be comfortable doing?”

Tell them what it means to be a proxy. For example, you might say: “As my proxy, if I am unable to speak for myself, you will be the one to make medical decisions for me. This might include talking to my doctors, making decisions about my care, and communicating to my loved ones — even if they don’t agree with certain decisions.” Consider sharing **Chapter 6: Advance Care Planning for Caregivers and Family Members** with the person you choose. The chapter covers what it means to be someone’s health care proxy and offers tips to help them in their role.





Make sure your proxy has the right information:

- After they agree to be your proxy, give them a copy of the signed durable power of attorney for health care form, your living will, and any other documents you think they may need.
- Make sure your proxy knows the names and contact information for your health care providers.
- Ensure your health care provider knows the name and contact information for your proxy.

Finally, keep the conversation going over time. As your care preferences and decisions change, keep your proxy informed. Plan to talk to your proxy at least once each year about your wishes. If you choose to change your proxy, be sure to notify the person and your health care providers.

A photograph of two women walking outdoors in a park-like setting. The woman on the left is older with short, wavy brown hair, wearing a light grey button-down shirt. The woman on the right is younger with dark hair pulled back, wearing a white long-sleeved top. They are both looking off to the right with pleasant expressions. The background is filled with green trees and bushes.

CHAPTER 4

How To Make Your Advance Directives Official

To make your decisions about care and treatment official, you can complete a living will. Similarly, once you decide on your health care proxy, you can make it official by completing a durable power of attorney for health care. The living will and durable power of attorney for health care forms are commonly part of the advance directive forms available for free in most states.

Some people might not feel comfortable putting their wishes in writing. If completing these legal documents is not the right choice for you, that's okay. The most important part of advance care planning is to have conversations with your loved ones about what matters to you.

Where To Find Advance Directive Forms

You can establish your advance directive for little or no cost. Many states have their own forms that you can access and complete for free. Here are some ways you might find free advance directive forms in your state:

- Contact your State Attorney General’s Office.
- Reach out to your local Area Agency on Aging or the Eldercare Locator. Call the Eldercare Locator **800-677-1116** or visit <https://eldercare.acl.gov>.
- Download your state’s form online from one of these national organizations: AARP, American Bar Association, or National Hospice and Palliative Care Organization.
- If you are a veteran, contact your local Veteran’s Affairs (VA) office. The VA offers an advance directive specifically for veterans.

Some people spend a lot of time in more than one state due to, for example, visiting children and grandchildren. If that’s your situation, consider preparing advance directives using the form for each state, and keep a copy in each place, too.

There are websites that enable you to create, download, and print your forms, but some websites may charge fees. Before you pay, remember there are several ways to get your forms for free. Some free online resources include:

- **PREPARE for Your Care** (<https://prepareforyourcare.org>), an interactive online program that was funded in part by NIA. It is available in English and Spanish.
- **The Conversation Project** (<https://theconversationproject.org>), a series of online conversation guides and advance care documents available in English, Spanish, and Chinese. The Conversation Project is a public engagement initiative led by the Institute for Healthcare Improvement.

If you use forms from a website, check to make sure they are legally recognized in your state. You should also make sure the website is secure and will protect your personal information. Read the website’s privacy policy and check that the website link begins with “https” (make sure it has an “s”) and that it has a small lock icon next to its web address.

Where Can I Find Help With Advance Care Planning?

A lawyer can help but is not required to create your advance care plan. However, if you have a lawyer, you should give them a copy of your advance directive. If you need help with planning, contact your local Area Agency on Aging. Call **800-677-1116** or search the Eldercare Locator at <https://eldercare.acl.gov> to find your agency. Other possible sources of legal assistance and referral include state legal aid offices, state bar associations, local nonprofit agencies, foundations, and social service agencies. If you need advance care planning information in other languages, visit <https://medlineplus.gov/languages/advancedirectives.html>.

Complete Your Advance Directive

To make your plan official, most states require your advance directive to be witnessed. This means that there are people who watch you sign the form. Often, a state requires two adult witnesses, and some states have additional requirements. For example, in some places, family members may not serve as witnesses.

Other states require that your signature be notarized. A **notary** is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, local library, or at an insurance agency. Some notaries charge a fee. Your form will likely include directions on whether a witness or notary is needed. Check with your state if you are unsure.

Where To Keep Your Advance Directives

Make copies of your advance directive forms and store them in a safe place. If you created forms online, download and print copies and share the password with your proxy.

Give copies of your advance directive to:

- Your health care proxy and alternate proxy
- Your health care providers

Other important people in your life might need to know about your plans, too. For example, you might share your wishes with close family members, trusted friends, or your lawyer.

Because you might change your advance directive in the future, it's a good idea to keep track of who receives a copy. It can also be helpful to bring a copy with you if you go to the hospital. Tear out the **Advance Directive Wallet Card** found on page 46 and keep it with you.

Some states have registries that can store your advance directive for quick access by health care providers and your proxy. Private firms may also store your advance directive, but they may charge a fee. You may also be able to store copies using other tools, such as a secure smartphone app.

If you update your forms, file and keep your previous versions. Note the date the older copy was replaced by a new one. If you use a registry, make sure the latest version is on record.

Maintaining Your Advance Directive and Preparing for Future Decisions

Review your advance directive regularly and update documents as needed. Changes in your life such as a divorce, death of a loved one, change in employment (including retirement), moving, or new state laws, may all affect your decisions. You should also update your documents if there are any changes to your health, such as a disease diagnosis. Everyone should update their plans at least once each year. Consider choosing a date every year — like New Year's Day — to revisit your advance directive.



CHAPTER 5

Advance Care Planning for Caregivers and Family Members

As a family member or caregiver, knowing what matters most to your loved one can help you honor their wishes and give you peace of mind if they become too sick to make decisions. Starting the conversation about advance care planning can help you understand their preferences and more easily navigate future medical decisions.

One Family's Story

Navina started noticing that her mother, Padma, had a mild tremor in her hand and difficulty getting out of her chair sometimes. At first, they viewed it as a normal part of aging, but eventually Padma was diagnosed with Parkinson's disease. The diagnosis hit Padma hard. She prided herself on being independent and the kind of person who cared for everyone else. The idea of not being able to take care of her loved ones, let alone herself, was overwhelming. Navina tried to talk to her mother about preparing for future health care decisions, but it took a few times for Padma to feel ready for a conversation. After talking about her wishes, Padma felt like she had more control over an uncertain future. She understood this was a meaningful way she could help her family when tough decisions arose down the road. Navina was always grateful for these conversations with her mother. Knowing her mother's wishes helped the entire family feel more confident, supported, and prepared for the decisions they faced.

If your loved one is growing older or was recently diagnosed with a serious condition, it is a good idea to ask if they have an advance directive. You might ask: "Do you have an advance directive or have you done any advance care planning?" Since there are multiple terms used, you may ask about other things such as a living will or health care proxy. If they do have an advance directive, ask them to share their plan with you and whether it needs to be updated.

Unfortunately, only one in three people in the United States has a plan in place. If your loved one does not have a plan, there are steps you can take to better understand their wishes and help them create one. Consider working through this book together.

How To Support Advance Care Planning

Talk to the person about their wishes. It's especially important to start the conversation early if the person has been diagnosed with a disease that affects their cognitive health, such as Alzheimer's or another dementia. Here are some ways you might start the conversation:

- “I love you and wouldn't want to do anything you didn't agree with. It would make me feel better, though, if I knew what was important to you. Will you tell me what matters most to you if you were ever too sick to speak for yourself?”
- After a movie or news story that touches on end-of-life issues: “What would you want us to do if you were in this situation?”
- Remind them of an experience with someone at the end of life: “Remember when Grandma died?” Ask how they felt about it and what they would want for themselves.

Some other tips:

- **Start simple.** Sometimes, talking about specific medical treatments or decisions can be scary and overwhelming. Instead, try asking about any concerns they may have and if there is someone they trust to make decisions for them.
- **Share what's important to you.** Sharing what matters most to you can help start the conversation. It can also help your loved one feel more comfortable discussing their preferences.
- **Remind them why it's important.** Talk about the benefits of having these conversations and why it can help to make an advance care plan. By sharing their wishes, they are more likely to get the care they want. It can also help reduce the burden on loved ones and help them feel less guilt, depression, and anxiety while grieving. You can find examples and information about the many benefits of talking about advance care planning in Chapter 1.

- **Try to be understanding.** After a recent diagnosis or health change, it can be overwhelming and difficult to discuss future health care needs. Some people may be in denial about the seriousness of their condition. Listen and reassure them. The person may react negatively and not want to talk about it. That's okay. You can ask if there is someone else they would feel comfortable talking with, such as a family member, doctor, or someone in their spiritual community. You can also encourage the person to think about it and plan to discuss it another time.
- **Keep the conversation going.** Listen carefully to what the person says and encourage them to continue sharing. You can also let them know you would like to keep the conversation going. You might say: "I'd like to keep talking about this and learning more about what matters most to you."

If the person is open to creating an advance directive, give them a copy of this book to help them start the process. You can also print and provide copies of the advance directive forms for their state. While an advance directive can be helpful, it's possible your loved one may not want one. Still, talking to them about what matters most if they become seriously ill can help you prepare for future decisions, whether or not you end up with official documents.

Advance Care Planning When the Person Is Not Able To Make Decisions

It can feel overwhelming to make medical decisions for someone else. For example, a complication of diseases such as Alzheimer's is that the person loses the ability to think clearly. This change affects the ability to participate meaningfully in decision-making, so early planning becomes even more important.

Thinking about advance care planning decisions can still be helpful if your loved one has lost the ability to make decisions.

If the person is no longer able to speak for themselves, you can:

- Talk to family members, friends, or close loved ones who know the person well.
- Think about how the person lived their life. What values and wishes did they express in the past? What did they find most meaningful in life?
- Talk with the doctor about what to expect as the disease progresses and the types of decisions you may need to make.

If a person is in the later stages of dementia, they may still have moments of clarity. You can use one of these moments to try and talk about their wishes. Remember that too much information can be overwhelming. Keep it as simple as possible and try to focus on one question at a time.

Talking about these decisions with close loved ones and the person's health care provider can help you prepare and feel more supported when decisions arise.

What Does a Health Care Proxy Need To Do?

If someone has asked you to be their health care proxy, it means that person is trusting you to make medical decisions on their behalf if they become seriously ill and cannot communicate their wishes.

As the person's proxy, you will be responsible for talking with their doctors and making decisions about tests, procedures, and treatments. Some common responsibilities of a proxy include:

- Deciding the types of care and treatments the person may or may not receive
- Determining where the person receives care, for example the hospital or a nursing home, and their health care providers
- Asking doctors questions and advocating for the person
- Communicating to other loved ones about medical decisions

Talk to the person about what matters to them and ask for a copy of their living will to learn about the kinds of medical treatments and care they prefer. Understand that the person may decide they only want you to make certain decisions as their proxy. This should be outlined clearly in the durable power of attorney for health care, a legal document that names the proxy. They may also choose to name an alternate proxy, someone who will



take on your duties when you are unavailable for any reason. In addition, they may decide to name someone else as their health care proxy at any time.

Is Being a Health Care Proxy Right for You?

You must first agree to be someone's health care proxy. There may be reasons you choose not to be one. Ask yourself:

- **Can I honor this person's wishes and values about life, health, health care, and dying?** Sometimes this can be challenging if your values are not the same. For example, if they would want to stop all treatment, but you don't agree with that approach. It's important to be honest with yourself and the person about whether you can honor their wishes.
- **Are you comfortable speaking up on the person's behalf?** Will you be comfortable asking health care providers questions and making medical decisions? It's okay if you don't know a lot about health care, but it's important that you are willing to ask questions so you can stand up for the person.

- **Are you comfortable dealing with conflict?** Sometimes a proxy may need to uphold the person’s wishes even if other family members, friends, or loved ones don’t agree. Would you be able to say no and stand up for the person’s wishes? It’s okay to say no if you are not comfortable with the responsibility. You might say, “Thank you for asking me, but I don’t feel I’m the right person to take on this role.”

Tips for Being a Health Care Proxy

If you have agreed to be someone’s health care proxy, here are a few tips:

- Talk to the person about their values. Learn what matters most to them when it comes to life, health care, and dying.
- Learn about their current and future health concerns. If they already have a living will, walk through it together and ask questions. The more you understand their wishes, the more prepared you will be to make decisions for them when the time comes.
- Ask for a copy of their advance directive, which should include a living will and durable power of attorney for health care forms.
- Keep a copy of their health care providers’ contact information.
- Ask about other considerations. For example, is there anyone other than the medical team that you should talk with when making decisions? Are there spiritual, cultural, or religious traditions the person wants you to consider?
- Have conversations each year and as major life changes happen, such as a divorce, death, or change in their health.

Even when you have a person’s decisions in writing and have talked about their wishes, you may still face difficult choices. For example, maybe there is a situation you didn’t consider. Try to put yourself in the place of the person who is dying and choose as they would. Some experts believe that decisions should be made like this as much as possible.

There is no such thing as a perfect proxy. When making decisions, always come back to the question: “If they could decide, what would they choose right now?” You may also find it’s not possible to follow the person’s wishes exactly. Maybe the person said they never wanted to be in a nursing home, but for financial, medical, or other reasons you must make that decision. In a situation like this, you might be able to reflect on your discussions and still try and honor their wishes to the extent possible. For example, you can help to make the nursing home feel more like home with music, family photos, a bird feeder outside the window, or a favorite chair. Ultimately, being a good proxy means making the best decision that you can at the time and doing your best to honor the person’s wishes.

Advocating for Your Loved One’s Care

When a person becomes too sick to make decisions for themselves, family members and caregivers may need to navigate the health care system and advocate for the person’s care — especially if a proxy was not named. In some cases, it may not be possible to get the exact care the person would have wanted. This could happen because of an emergency, or the health care team may not have the person’s advance directive. Or it could happen because your loved one’s medical situation has changed in a new or unexpected way. By preparing in advance, you can be a better advocate for your loved one’s care.

Here are a few tips to help you advocate for someone’s care:

- **Ask questions.** If you are unclear about something you are told, don’t be afraid to ask the doctor or nurse to repeat it or to say it another way.
- **Make the person’s wishes clear.** Share copies of the person’s advance directive and the proxy’s contact information with the health care team, nursing home staff, or others caring for the person. If the person is still living at home, you can put a colorful envelope near their bed or on the fridge for emergency responders.

- **Write down contact information.** Ask for a specific person on the medical team that you can contact for questions or if the person needs something.
- **Try to choose one person to make health care choices.** Choosing one person to be the main point of contact for the medical team can help everyone stay more organized, coordinate upcoming appointments, and manage medications or changing medical needs.
- **Keep family members looped in.** Even with one person named as the decision-maker, it is a good idea to have family agreement about the care plan, if possible. If you can't agree on a care plan, you might consider working with a mediator, a person trained to bring people with different opinions to a common decision.
- **Try to decide on an end-of-life approach.** When it becomes clear the person is nearing the end of life, the family should try to discuss the desired end-of-life care approach with the health care team. This might include hospice care. Discussing the options and making decisions as early as possible can help with planning.
- **Remind the health care team who the person is.** Remind them that the person is not just a patient. Tell them about the person. Share what they were like, discuss the things they enjoyed most, and post pictures in their room.



What Questions Should I Ask Before Making Medical Decisions?

Before making a decision as a health care proxy, you need as much information as possible. You might ask the doctor:

- What might we expect in the next few hours, days, or weeks if we continue the current course of treatment?
- Why is this new test being suggested?
- Will the results of the test change the current treatment plan?
- Will a new treatment help my loved one recover?
- How would the new treatment change their quality of life?
- Will a change in treatment help provide more quality time with family and friends?
- How long will this treatment take to make a difference?
- If we choose to try this treatment, can we stop it at any time? For any reason?
- What are the side effects of the approach you are suggesting?
- If we try this new treatment and it doesn't work, what then?
- If we don't try this treatment, what will happen?
- Is the improvement we saw today an overall positive sign or just something temporary?

It is a good idea to have someone with you when discussing these issues with medical staff. Having someone you trust there to take notes or remember details can be very helpful.

Where Can Caregivers and Family Members Find Resources and Support?

Being a caregiver is a labor of love, but it can also be stressful. Remember to take care of yourself. It's important to ask for help when you need it. You may ask for assistance from family members or a close friend. There may also be people in your community who can help you navigate the health care system and advocate for your loved one's care. You might:

- **Ask if the hospital has a patient advocate or care navigator.** These members of the health care team help coordinate a patient's care. This can include anything from coordinating appointments, arranging transportation, providing emotional support, or securing language translation services. The person might be a social worker, nurse, or chaplain. Organizations in your community may also offer care navigators. For example, some local offices of the American Cancer Society provide patient navigator services at hospitals across the country.



- **Consider working with a geriatric care manager.** A geriatric care manager is usually a trained nurse or social worker who is used to working with older adults and their families. They can help you identify needs, make short- and long-term plans, coordinate medical services, choose care personnel, and more. They can be especially helpful when family members live far apart.

You can also find local, state, and national organizations and services that help provide support for patients and caregivers. For example, they may offer support groups, patient and caregiver education, transportation services, and other resources.

- **Alzheimer’s Disease Research Centers (ADRCs):** NIA supports ADRCs at major medical institutions across the United States. For people and families affected by Alzheimer’s and related dementias, ADRCs offer help obtaining diagnosis and medical management, Alzheimer’s and related dementias information and resources, opportunities to participate in clinical trials, and support groups and other special programs for families.
- **Eldercare Locator:** The Eldercare Locator can help you find services in your community. Call **800-677-1116** or visit <https://eldercare.acl.gov>.
- **Respite care services:** Respite care provides short-term relief for primary caregivers at home, in a health care facility, or at an adult day center. It can be arranged for just an afternoon or for several days or weeks. Most insurance plans do not cover these costs. You must pay all costs not covered by insurance or other funding sources. Medicare and Medicaid may offer some assistance paying for respite care in certain situations.

At some point, support from family, friends, and local programs may not be enough. People who require help full-time might need to be moved to a residential facility that provides many or all of the long-term care services they need. Learn more about these types of services at www.nia.nih.gov/ltc.



CHAPTER 6

Plan for Other Decisions

You might also want to prepare for other possible decisions as you age. This may include considerations around long-term care and future health care, making estate and financial plans, planning for a funeral or memorial service, and deciding on a burial or cremation. In this section, you can learn more about each of these decisions.

How To Plan for Long-term Care

Long-term care involves a variety of services designed to meet a person's health or personal-care needs. These services help people live as independently and safely as possible when they can no longer perform everyday activities on their own. Long-term care can be provided within the home or at an outside facility. At some point, a person with a disease such as dementia may require around-the-clock care or they may exhibit behaviors, such as aggression and wandering, that make it no longer safe to stay at home. People who require help full-time can move to an assisted living, nursing home, or residential facility that provides many or all of the long-term care services they need.

When planning for long-term care, it may be helpful to think about:

- Where you will live as you age and how your home can best support your needs and safety
- What services are available in the community and how much they will cost
- How far in advance you need to plan so that you can make important decisions while you are still able

Many types of long-term care are not covered by Medicare, so planning for how to pay for long-term care is also important. You can learn more about long-term care options at www.nia.nih.gov/ltc.

How To Establish a Will and Create a Financial Plan for Your Estate

In addition to advance directives for health care, you can establish advance directives for financial matters. These forms, which help document and communicate your financial wishes, must be created while you can still make decisions.

Three common documents are included in a financial directive:

- A **will** specifies how your estate — your property, money, and other assets — will be distributed and managed when you die. A will can also address care for children under age 18, adult dependents, pets, as well as gifts and end-of-life arrangements, such as a funeral or memorial service and burial or cremation. If you do not have a will, your estate will be distributed according to the laws in your state.
- A **durable power of attorney for finances** names someone who will make financial decisions for you when you are unable.
- A **living trust** names and instructs a person, called the trustee, to hold and distribute property and funds on your behalf when you are no longer able to manage your affairs.

Lawyers can help prepare these documents with you. A listing of lawyers in your area can be found on the internet, at your local library, through a local bar association, or by contacting the National Academy of Elder Law Attorneys at www.naela.org.

How To Pay for Future Health Care

As part of your financial planning, it's important to think about how to pay for future health care, particularly long-term care. Long-term care can be expensive, and it's hard to predict how much care you may need and for how long. How people pay for long-term care depends on their financial situation and the kinds of services they require. Most rely on a variety of payment sources. This might include:

- Personal funds
- State and federal government health care programs such as Medicare or Medicaid
- Private financing options, for example, long-term care insurance or life insurance.
- Employer-provided long-term care insurance.

Learn more about options and resources available to help pay for future health care by visiting www.nia.nih.gov/health/paying-care.

How To Make Funeral or Memorial and Burial or Cremation Arrangements in Advance

It's possible to plan ahead and make funeral or memorial service and burial or cremation arrangements for yourself. Similar to advance care planning, making your decisions known in advance can help your loved ones during a stressful time and ensure your wishes are understood and respected. You can plan:

- **What kind of funeral or memorial service you would like and where it will be held.** For example, some people hold both a visitation, an informal opportunity to gather in honor of the person; and a funeral, a ceremony to honor the deceased. A funeral may include the burial. Others may choose to be cremated after death and have a memorial service.
- **What you would like to happen to your body.** For example, whether you want your body to be buried or cremated. You can decide on a conventional burial, green burial, or if you choose cremation, you can state whether you want your body's ashes kept by loved ones or scattered in a favorite place.
- **Other details that are important to you.** For example, you might want to specify certain religious, spiritual, or cultural traditions that you would like to have during your visitation or funeral, or memorial service.

You can make arrangements directly with a funeral home or crematory. Here are a few tips for planning:

- **Shop around.** Compare prices and options at at least two funeral homes or crematories and ask for a price list. Federal law requires these businesses provide you with written price lists for products and services. Every funeral and crematory may price things differently. Find one that is willing to work with you, understands your needs, and respects your budget.

- **You can make arrangements in advance, but you do not have to pay in advance.** Prices may change over time. Before putting any money down, get information from the Federal Trade Commission on which questions you should ask first at www.consumer.ftc.gov/funeral.
- **Review and revise your funeral and burial or cremation plans every few years.** What you want may change as you grow older. Revisiting your plans can help make sure they reflect what you want.
- **Put your preferences in writing and give copies to your loved ones and, if you have one, your lawyer.** The funeral home or crematory may also keep a copy of your wishes on file. Your will may not be found or read until after the funeral or cremation, so it is important to share information on your preferred end-of-life arrangements in advance.

In most states, a funeral home does not have to handle a loved one's body after death if there is no embalming or cremation. Families can take care of transportation, preparation of the body, filling out the necessary paperwork, working with a cemetery for the burial, and all other needed arrangements. You can learn more about the options in your state from the National Home Funeral Alliance at www.homefuneralalliance.org.



Summary

Advance care planning should be an ongoing conversation. Be sure to update your plan and continue talking with your loved ones about your wishes at least once each year and when major life events happen. Come back to this book to help guide those conversations.

Remember:

- The most important part of advance care planning is to have conversations with your loved ones about what matters most to you.
- Having a plan in place can help you get the care you want and reduce burden on your loved ones when making decisions during a stressful time.
- Everyone approaches advance care planning differently. Be flexible, decide what works best for you, and take it one step at a time.

Ready to get started?

Here are common steps that you can use to begin advance care planning:

1. Think about what makes life meaningful to you and consider someone you would trust to make medical decisions for you.
2. Talk about making an advance directive with your doctor.
3. Choose a health care proxy and talk about your wishes with your loved ones.
4. Make it official: Complete your living will and durable power of attorney for health care forms.
5. Share your forms with your doctor and loved ones. Keep copies in a safe place and tell people you trust where they can be found.
6. Keep the conversation going. Continue to talk about your wishes and update your forms at least once each year or after major life changes.

Advance Directive Wallet Card

You might want to make a card to carry in your wallet indicating that you have an advance directive and where it is kept. Here is an example of the wallet card offered by the American Hospital Association. You might consider copying this, filling it out, and carrying it with you. A PDF can be found at www.aha.org/putitinwriting.

Advance Directive NOTIFICATION	
Print name	Signature
<input type="checkbox"/> I have a health care power of attorney	<input type="checkbox"/> 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
<i>(Additional names on back)</i>	
Name	Number
Name	Number
<i>Your life. Your terms.</i>	
For more information visit: www.aha.org/putitinwriting	

Where Can I Get More Information?

Contact the following organizations to learn more about advance care planning.

Federal Government Resources

National Institute on Aging (NIA) Information Center

800-222-2225 or 800-222-4225 (TTY)

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

The NIA Information Center offers information and publications on health and aging for families, caregivers, and health professionals.

Alzheimer's and related Dementias Education and Referral (ADEAR) Center

800-438-4380

adear@nia.nih.gov | www.alzheimers.gov

The NIA ADEAR Center offers information on diagnosis, treatment, patient care, caregiver needs, long-term care, and research related to Alzheimer's and related dementias. Staff can refer you to local and national resources.

Administration for Community Living (ACL)

800-677-1116

eldercarelocator@n4a.org | <https://eldercare.acl.gov>

ACL offers offers resources on advance care planning as well as the Eldercare Locator. Contact the Eldercare Locator to find information about community resources, such as home care, adult day care, and nursing homes in your area.

Centers for Disease Control and Prevention (CDC)

800-232-4636

cdcinfo@cdc.gov | www.cdc.gov

CDC offers information on advance care planning for older adults and their families at www.cdc.gov/aging/advancecareplanning. The CDC also has a course on advance care planning for public health and aging services professionals at www.cdc.gov/aging/advancecareplanning/care-planning-course.html.

Medicare.gov

800-633-4227

www.medicare.gov | www.cms.gov

The Centers for Medicare & Medicaid Services (CMS) runs the Medicare program. Medicare is the federal health insurance program for people age 65 and older. Medicare covers advance care planning as part of your yearly wellness visit with your doctor. Learn more about what is covered at www.medicare.gov/coverage/advance-care-planning.

Organdonor.gov

www.organdonor.gov

The Health Resources & Services Administration (HRSA) oversees organdonor.gov. The website provides information on organ and tissue donation, including how to register to be an organ donor, statistics, and stories.

U.S. Department of Veterans Affairs (VA)

800-698-2411

www.va.gov

The VA provides health care benefits and services for veterans and their family members. If you are a veteran, the VA offers advance care planning information at www.va.gov/geriatrics/pages/advance_care_planning_topics.asp and advance directive forms at www.va.gov/geriatrics/pages/advance_care_planning_advance_directives.asp.

Nonprofit and Other Organization Resources

AARP

888-687-2277

www.aarp.org

AARP offers health and lifestyle information as well as resources for people age 50 and older. Find and print advance directive forms for your state at www.aarp.org/caregiving/financial-legal/free-printable-advance-directives.

American Bar Association (ABA)

800-285-2221

www.americanbar.org

The ABA provides legal information and resources to professionals and the public. Search its website for state advance directive forms as well as guides to help you prepare your advance care plan at www.americanbar.org/groups/law_aging/resources/health_care_decision_making/Stateforms/.

American Hospital Association (AHA)

800-424-4301

www.aha.org

AHA's *Put It in Writing* program includes key resources to enhance education and awareness around advance care planning. Materials include a writing brochure, wallet ID card (see page 46), and other resources.

Center for Practical Bioethics

816-221-1100

www.practicalbioethics.org

The Center for Practical Bioethics offers several resources to support advance care planning materials for different settings, including the community, workplace, faith communities, long-term care, and more.

The Conversation Project

866-787-0831

<https://theconversationproject.org>

Led by the Institute for Healthcare Improvement, the Conversation Project aims to help everyone talk about their wishes for care through the end of life, so those wishes can be understood and respected. They offer free conversation guides on advance care planning that you can download or print at home. The guides are available in English, Spanish, and Chinese.

National Hospice and Palliative Care Organization (NHPCO)

703-837-1500

www.nhpco.org

NHPCO offers advance care directive forms for each state and information on how to prepare and store your advance directive at www.nhpco.org/advancedirective. CaringInfo, a program of the NHPCO, offers guides, resources, and tools to help families and caregivers prepare and plan for care for a serious illness, find a care provider, and talk with their doctor at www.caringinfo.org.

National POLST

202-780-8352

www.polst.org

National POLST is a nonprofit organization that organizes the effort to standardize the process, form, and education around portable medical orders. Its website includes advance directive and POLST forms and resources.

PREPARE for Your Care

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

Funded in part by NIA, PREPARE for Your Care is an interactive online program that can help you fill out an advance directive and express your wishes in writing. This tool is available in English and Spanish. You can also download and print copies of your forms.

Words To Know

Advance care planning

Learning about the types of medical decisions you might need to make, considering those decisions ahead of time, and then letting others know about your preferences.

Advance directive

Instructions for your medical care that only go into effect if you cannot communicate. An advance directive usually includes instructions for your wishes (living will) and names a person to make decisions about your medical care (durable power of attorney for health care).

Alternate proxy

A second person you name who can make medical decisions for you if your health care proxy is not available. May also be referred to as backup agent.

Artificial nutrition and hydration

Fluids delivered into a vein or through a tube into the stomach.

Brain donation

Donating the brain from a person who has died to help advance scientific research. Both healthy brains and brains affected by diseases such as Alzheimer's are needed for research.

Comfort care

Medication or other care that helps soothe and relieve suffering when care for the condition is no longer likely to help.

CPR

Repeatedly pushing on the chest with force to restore blood flow 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.

Do not intubate (DNI) order

An order in your medical chart that lets health care staff know that you do not want to be put on a ventilator.

Do not resuscitate (DNR) order

An order in your medical chart that tells health care staff not to perform CPR or other life-support procedures if your heart or breathing stops. Other terms that may be used include do not attempt resuscitation (DNAR) and allow natural death to occur (AND).

Durable power of attorney for health care

A legal document used to name someone who can make health care decisions for you if you are unable to communicate (health care proxy), name an alternate proxy, and provide special instructions or limits for your health care proxy.

Health care proxy (or proxy)

A person who can make medical decisions for you if you are unable to communicate. Other terms may also be used, such as health care agent, surrogate, representative, or power of attorney for health care.

Living will

A legal document outlining what you want to happen if you are too sick to make your own medical decisions.

Notary

A notary is a person licensed by the state to witness signatures. You may need a notary to make your advance directive official.

Organ and tissue donation

Donating organs or tissue from a person who has died to people who need them.

Pacemakers and implantable cardioverter-defibrillators (ICDs)

Medical devices that help the heart beat regularly. ICDs shock the heart, which can be uncomfortable. If you have one of these medical devices, you may make the decision to turn it off at the end of life if comfort care is chosen.

Physician Orders for Life-Sustaining Treatment (POLST)

Forms that let your health care team know your preferences for medical care when you are near the end of life or critically ill. This may also be called portable medical orders, Medical Orders for Life-Sustaining Treatment (MOLST), or Physician Orders for Scope of Treatment (POST).

Ventilator

Ventilators are machines that help you breathe. A tube connected to the ventilator is put into the trachea so the machine can force air into the lungs.

Will

A legal document outlining how a person's estate — their property, money, and other financial assets — will be distributed and managed when they die. It may also address care for a child or adult dependent, gifts, and end-of-life arrangements, such as the funeral and burial or cremation.

Think About What Matters Most When Making Medical Decisions

What matters most to you and makes your life meaningful may affect the kind of medical care you would want. For some people, staying alive as long as medically possible, or long enough to see an important event like a grandchild's birth, is the most important thing. Advance care planning can help make that possible. The questions below can help you think through what you might want. You can pick and choose which ones you want to respond to or discuss with your loved ones.

Would you rather live as long as possible or focus on quality of life?

For example, is it more important to live longer or would you rather focus on being able to function physically or mentally even if you may not live as long? Is there a point in life where you would not want to keep living?

If you are seriously ill or nearing the end of life, how much medical treatment would you feel was right for you?

For example, would you want to try every available treatment even if it's uncomfortable or painful, or would you want to avoid treatments that may impact your quality of life?

Who do you trust to make decisions about your care?

For example, would you like to leave decisions up to your health care provider or a member of your family or community?

What worries you most about your future health care needs? The end of life?

For example, are you concerned about finances, feeling like a burden, mending broken relationships, staying home as long as possible?

What does a “good death” mean to you?

For example, would you like to die at home with family around you? Would you like to avoid pain? Are there other important things like having prayers read or certain music played?

Are there religious or spiritual beliefs that affect the types of care you want?

For example, is it important to have a religious leader involved in certain care decisions? What should loved ones know about the spiritual or religious part of your life?

Your decisions about how to handle any of these situations could be different at age 40 than at age 85. Or they could be different if you have a chronic condition compared to being generally healthy. An advance directive enables you to provide instructions for these types of situations. You can adjust the instructions as you get older or if your viewpoint changes.

Care and Treatment Decisions: What Would You Choose?

Sometimes thinking through different situations can help you make decisions about your care and treatment preferences. Consider the situations below and write down your thoughts or discuss them with a loved one. Remember: You may feel differently as time goes on.

If an illness leaves you paralyzed or in a permanent coma and you need to be on a ventilator, would you want that?

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?

If a stroke leaves you unable to move and then your heart stops, would you want to be given CPR? If the stroke also affected your thinking, does that change your decision?

What if you are in pain at the end of life? Do you want medication to treat the pain, even if it will make you drowsy and tired?

What if you are permanently unconscious and then develop pneumonia? Would you want antibiotics? To be placed on a ventilator?

If you were at the end of life and dying, would you prefer to spend your last days in a health care facility or would you prefer to spend your last days at home?

Health Care Providers To Involve in Advance Care Planning

What is the name of your health care provider?	
What is their phone number?	
What do you see them for? (Regular checkups and when you are sick, diabetes, dementia, heart disease, kidney disease, etc.)	
When is your next appointment?	
Have you shared your advance directive with this health care provider?	

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Tips for Talking With Your Doctor About Advance Care Planning

Talking with a doctor about advance care planning is covered by Medicare as part of your annual wellness visit. If you have private health insurance, check with your insurance provider. When you are ready to talk to your doctor, these tips and conversation starters can help you make the most out of your visit. You will also find examples of questions you might ask during your appointment. You may decide that not all the questions are important to you. Or you may not be ready to talk about all of these things right now. That's okay. The important thing is to start the conversation.

Before Your Visit

You can prepare for your visit by writing down some of your current health issues and your questions about future health care and end-of-life care. Remember, the goal is simply to start the conversation. You do not have to make specific decisions about your medical care until you feel ready.

How would you describe your current health? What illnesses or conditions do you have right now?

What concerns or questions do you have about your future health or health care?

What concerns or questions do you have about end-of-life care?

Circle the medical treatments you would like to discuss further with your health care provider.

CPR

Organ and tissue donation

Ventilator use

Brain donation

Artificial nutrition and hydration

Pacemakers and ICDs

Comfort care

Do not resuscitate orders

Physician Orders for Life-Sustaining Treatment (POLST), or other medical orders

Other Tips Before Your Visit

- **Decide if you would like someone to join you for your visit.** You can invite your health care proxy or someone else you trust to join you. You can even ask them to take notes. Your doctor may ask you to sign a release form before sharing information about your health with someone else.
- **Call or email in advance.** Let your doctor know that you would like to discuss advance care planning during your appointment.
- **Ask for an interpreter, if needed:** If you need an interpreter, email or call your doctor in advance to let them know.
- **Bring this booklet, worksheet, and any forms you've started or completed.** This can help guide your conversation and prioritize what you most want to discuss. If you've decided on your health care proxy, bring their contact information.

During Your Visit

Start the conversation. Here are some examples of ways to start the conversation during your appointment:

- “I want to talk about my goals for care and living with my serious illness.”
- “I want to have a conversation about my wishes for end-of-life care.”
- “I’ve been thinking a lot about my health. I’d like to talk more about what to expect in the years ahead and how I can prepare myself and my family for future medical decisions.”

Talk about your current health and share what matters to you. If you have a health condition, like diabetes or heart disease, talk with your doctor about your condition and how it might progress. If you don’t have any medical issues right now, talk with your doctor about decisions that might come up if you develop health problems that may run in your family. For example, you might ask:

How serious is this illness or condition?

How might this condition worsen other conditions I have?

What types of treatment or changes to my daily life should I expect in the coming weeks, months, or years?

What can I expect from this course of treatment? What are my other choices?

What can I expect if I decide to do nothing?

Will I be able to continue to live independently?

What types of treatment or care would you recommend if your own family member had this condition?

Share what's most important to you. You might have certain events you want to attend. Or you may have an idea of care you do or do not want based on your experiences with someone close to you. If you feel comfortable, you might choose to share what you wrote down in the *Think About What Matters Most When Making Medical Decisions* worksheet. Here are examples of things you might say:

- **Sharing what is important to you:** “What matters most to me is _____.”
- **Sharing an important event:** “My granddaughter is having her first child later this year and I’d really like to meet the baby. Can you help me understand what I might need to do to see that happen?”
- **Sharing a loved one’s experience:** “My mother-in-law was diagnosed with cancer and no one understood how quickly it would progress. I want you to be open with me and let me know your best estimate for how much time I have left.”

Make sure you have all the information you need. It's okay to ask your doctor questions even if it feels uncomfortable. You can also ask your doctor to write down what you've discussed or even document it in your medical record and share a copy so you can think about it further or share it with your loved ones. You can tell your doctor that you'd like to think about what you've discussed and ask to set up an appointment to have another conversation in a couple of weeks.

After Your Visit

Your wishes may change over time. Plan to talk to your doctor about your advance directive at least once each year and after major life changes such as a divorce, death, or a serious disease diagnosis. When you complete your advance directive forms, remember to give your health care provider a copy. You can bring them to the office, or you may be able to submit them via your electronic health record.

Who Should I Choose as My Health Care Proxy?

It's important to think carefully about the person you choose to be your health care proxy and ensure they will be able to honor your wishes. This worksheet can help you consider who may be a good fit. Write down each person's name and answer the questions below.

Name: _____

1. Am I comfortable talking with this person about my wishes and priorities for health care? Yes _____ No _____
2. Will this person honor my wishes, and do as I ask when the time comes? Yes _____ No _____
3. Do I trust this person with my life? Yes _____ No _____
4. Can this person handle conflicting opinions from my family, friends, and health care providers? Yes _____ No _____
5. Is this person comfortable asking questions of doctors, insurance companies, and other busy providers and will this person stand up for me? Yes _____ No _____
6. Does this person live near me or would they travel to be with me if needed? Yes _____ No _____

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