U.S. DEPARTMENT
OF HEALTH AND
HUMAN SERVICES

NIH National Institute
on Aging

Advance Care Planning

Tips *from the National Institute on Aging*

Advance care planning is not just about old age. At any age, a medical crisis could leave you too ill to make your own healthcare decisions. Even if you are not sick now, planning for health care in the future is an important step toward making sure you get the medical care you would want, if you are unable to speak for yourself and doctors and family members are making the decisions for you.

Many Americans face questions about medical treatment but may not be capable of making those decisions, for example, in an emergency or at the end of life. This tip sheet will explain the types of decisions that may need to be made in such cases and questions you can think about now so you're prepared later. It can help you think about who you would want to make decisions for you if you can't make them yourself. It will also discuss ways you can share your wishes with others. Knowing who you want to make decisions on your behalf and how you would decide might take some of the burden off family and friends.

What Is Advance Care Planning?

Advance care planning involves learning about the types of decisions that might need to be made, considering those decisions ahead of time, and then letting others know—both your family and your healthcare providers—about your preferences. These preferences are often put into an *advance directive*, a legal document that goes into effect only if you are incapacitated and unable to speak for yourself. This could be the result of disease or severe injury—no matter how old you are. It helps others know what type of medical care you want.

An advance directive also allows you to express your values and desires related to end-of-life care. You might think of it as a living document—one that you can adjust as your situation changes because of new information or a change in your health.

Research shows that advance directives can make a difference, and that people who document their preferences in this way are more likely to get the care they prefer at the end of life than people who do not.

Decisions That Could Come Up

Sometimes decisions must be made about the use of emergency treatments to keep you alive. Doctors can use several artificial or mechanical ways to try to do this. Decisions that might come up at this time relate to:

- CPR (cardiopulmonary resuscitation)
- Ventilator use
- Artificial nutrition (tube feeding) and artificial hydration (IV, or intravenous, fluids)
- Comfort care

CPR. Cardiopulmonary resuscitation might restore your heartbeat if your heart stops or is in a life-threatening abnormal rhythm. It involves repeatedly pushing on the chest with force, while putting air into the lungs. This force has to be quite strong, and sometimes ribs are broken or a lung collapses. 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 after CPR. Often, CPR does not succeed in older adults who have multiple chronic illnesses or who are already frail.

Ventilator use. Ventilators are machines that help you breathe. A tube connected to the ventilator is put through the throat into the trachea (windpipe) so the machine can force air into the lungs. Putting the tube down the throat is called intubation. Because the tube is uncomfortable, medicines are often used to keep you sedated while on a ventilator. If you are expected to remain on a ventilator for a long time, a doctor may perform a tracheotomy or "trach" (rhymes with "make"). During this bedside surgery, the tube is inserted directly into the trachea through a hole in the neck. For long-term help with breathing, a trach is more comfortable, and sedation is not needed. People using such a breathing tube are not able to speak without special help because exhaled air does not go past their vocal cords.

Artificial nutrition and hydration. If you are not able to eat, you may be fed through a feeding tube that is threaded through the nose down to your stomach. If tube feeding is still needed for an extended period, a feeding tube may be surgically inserted directly into your stomach. Hand feeding (sometimes called assisted oral feeding) is an alternative to tube feeding. This approach may have fewer risks, especially for people with dementia.

If you are not able to drink, you may be provided with IV fluids. These are delivered through a thin plastic tube inserted into a vein.

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. Artificial nutrition and hydration may also be harmful if the dying body cannot use the nutrition properly.

Comfort care. Comfort care is anything that can be done to soothe you and relieve suffering while staying in line with your wishes. Comfort care includes managing shortness of breath; limiting medical testing; providing spiritual and emotional counseling; and giving medication for pain, anxiety, nausea, or constipation.

Getting Started

Start by thinking about what kind of treatment you do or do not want in a medical emergency. It might help to talk with your doctor about how your current health conditions might influence your health in the future. For example, what decisions would you or your family face if your high blood pressure leads to a stroke? You can ask your doctor to help you understand and think through your choices before you put them in writing. Medicare or private health insurance may cover advance care planning discussions with your doctor.

If you don't have any medical issues now, your family medical history might be a clue to help you think about the future. Talk with your doctor about decisions that might come up if you develop health problems similar to those of other family members.

In considering treatment decisions, your personal values are key. Is your main desire to have the most days of life? Or, would your focus be on quality of life, as you see it?

What Is Palliative Care? What Is Hospice Care?

Palliative 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 older person having a lot of general discomfort and disability with serious illness.

Hospice care is comfort care and support that is provided after attempts to cure or treat an illness have stopped. It may be offered in the home, a hospice facility, a skilled nursing facility, or a hospital. A team of healthcare providers works together to provide the care and support. 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 keep you comfortable. If you are receiving hospice care, you can choose to move back to curative care if you decide to pursue treatments to cure your illness.

For more information, see the NIA booklet *End of Life: Helping with Comfort and Care*.

What if an illness leaves you paralyzed or in a permanent coma and you need to be on a ventilator? Would you want that?

What makes life meaningful to you? If your heart stops or you have trouble breathing, would you want to undergo life-saving measures if it meant that, in the future, you could be well enough to spend time with your family? Would you be content if the emergency left you simply able to spend your days listening to books on tape or gazing out the window?

But, there are many other scenarios. Here are a few. What would you decide?

- If a stroke leaves you unable to move and then your heart stops, would you want CPR? What if you were also mentally impaired by a stroke—does your decision change?
- 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 more drowsy and lethargic?
- What if you are permanently unconscious and then develop pneumonia? Would you want antibiotics and to be placed on a ventilator?

For some people, staying alive as long as medically possible, or long enough to see an important event like a grandchild's wedding, is the most important thing. An advance directive can help to make that possible. Others have a clear idea about when they would no longer want to prolong their life. An advance directive can help with that, too.

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 an incurable condition as opposed to being generally healthy. An advance directive allows you to provide instructions for these types of situations and then to change the instructions as you get older or if your viewpoint changes.

Making Your Wishes Known

There are two main elements in an advance directive—a living will and a durable power of attorney for health care. There are also other documents that can supplement your advance directive. You can choose which documents to create, depending on how you want decisions to be made.

Living will. A living will is a written document that helps you tell doctors how you want to be treated if you are dying or permanently unconscious and cannot make your own decisions about emergency treatment. In a living will, you can say which of the procedures described above you would want, which ones you wouldn't want, and under which conditions each of your choices applies.

Durable power of attorney for health care. A durable power of attorney for health care is a legal document naming a healthcare proxy, someone to make medical decisions for you at times when you are unable to do so. Your proxy, also known as a representative, surrogate, or agent, should be familiar with your values and wishes. This means that he or she will be able to decide as you would when treatment decisions need to be made. A proxy can be chosen in addition to or instead of a living will. Having a healthcare proxy helps you plan for situations that cannot be foreseen, like a serious auto accident.

Some people are reluctant to put specific health decisions in writing. For them, naming a healthcare proxy might be a good approach, especially if there is someone they feel comfortable talking with about their values and preferences. A named proxy can evaluate each situation or treatment option independently.

Other advance care planning documents. You might also want to prepare documents to express your wishes about a single medical issue or something not already covered in your advance directive. A living will usually covers only the specific life-sustaining treatments discussed earlier. You might want to give your healthcare proxy specific instructions about other issues, such as blood transfusion or kidney dialysis. This is especially important if your doctor suggests that, given your health condition, such treatments might be needed in the future.

Medical issues that might arise at the end of life include DNR orders, organ and tissue donation, and POLST or MOLST forms.

A *DNR (do not resuscitate) order* tells medical staff in a hospital or nursing facility that you do not want them to try to return your heart to a normal rhythm if it stops or is beating unsustainably using CPR or other life-support measures. Sometimes this document is referred to as a DNAR (do not attempt resuscitation) or an AND (allow natural death) order. Even though a living will might say 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 bed might avoid confusion in an emergency situation. Without a DNR order, medical staff will make every effort to restore your breathing and the normal rhythm of your heart.

A similar document, called a *DNI (do not intubate) order*, tells medical staff in a hospital or nursing facility that you do not want to be put on a breathing machine.

A *non-hospital DNR* order will alert emergency medical personnel to your wishes regarding measures to restore your heartbeat or breathing if you are not in the hospital.

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. Some states allow you to add this decision to your driver's license. Some people also include organ donation in their advance care planning documents.

At the time of death, family members may be asked about organ donation. If those close to you, especially your proxy, know how you feel about organ donation, they will be ready to respond. There is no cost to the donor's family for this gift of life. If the person has requested a DNR order but wants to donate organs, he or she might have to indicate that the desire to donate supersedes the DNR. That is because it might be necessary to use machines to keep the heart beating until the medical staff is ready to remove the donated organs. See *For More Information* for resources about organ and tissue donation.

POLST and MOLST forms provide guidance about your medical care preferences in the form of a doctor's orders. Typically, you create a POLST (Physician Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) when you are near the end of life or critically ill and know the specific decisions that might need to be made on your behalf. These forms serve as a medical order in addition to your advance directive. They make it possible for you to provide guidance that healthcare professionals can act on immediately in an emergency.

A number of states use POLST and MOLST forms, which are filled out by your doctor or sometimes by a nurse practitioner or physician's assistant. The doctor fills out a POLST or MOLST after discussing your wishes with you and your family. Once signed by your doctor, this form has the same authority as any other medical order. Check with your state department of health to find out if these forms are available where you live.

What About 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. But, you might have an ICD (implantable cardioverter-defibrillator) placed under your skin to shock your heart back into regular beatings 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 directive what you want done if the doctor suggests it is time to turn it off.

Selecting Your Healthcare Proxy

If you decide to choose 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. It is especially important to have a detailed living will if you choose not to name a proxy.

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

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

Making It Official

Once you have talked with your doctor and have an idea of the types of decisions that could come up in the future and whom you would like as a proxy, if you want one at all, the next step is to fill out the legal forms detailing your wishes. A lawyer can help but is not required. If you decide to use a lawyer, don't depend on him or her to help you understand different medical treatments. Start the planning process by talking with your doctor.

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 agency phone number by calling the Eldercare Locator toll-free at 1-800-677-1116 or going online at *www.eldercare.gov*.

Some states require your advance directive to be witnessed; a few require your signature to be notarized. A notary is a person licensed by the state to witness signatures. You might find a notary at your bank, post office, or local library, or call your insurance agent. Some notaries charge a fee.

Some states have registries that can store your advance directive for quick access by healthcare providers, your proxy, and anyone else to whom you have given permission. Private firms also will store your advance directive. There may be a fee for storing your form in a registry. If you store your advance directive in a registry and later make changes, you must replace the original with the updated version in the registry.

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 an advance directive using forms for each state—and keeping a copy in each place, too.

After You Set Up Your Advance Directive

Give copies of your advance directive to your healthcare proxy and alternate proxy. Give your doctor a copy for your medical records. Tell close family members and friends where you keep a copy. If you have to go to the hospital, give staff there a copy to include in your records. Because you might change your advance directive in the future, it's a good idea to keep track of who receives a copy.

Talking About Your Wishes

It can be helpful to have conversations with the people close 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 directive.

It's especially helpful to talk about your thoughts, beliefs, and values with your healthcare proxy. This will help prepare him or her to make medical decisions that best reflect your values.

After you have completed your advance directive, talk about your decisions with your healthcare proxy, loved ones, and your doctor to explain what you have decided. This way, they are not surprised by your wishes if there is an emergency.

Another way to convey your wishes is to make a video of yourself talking about them. This lets you express your wishes in your own words. Videos do not replace an advance directive, but they can be helpful for your healthcare proxy and your loved ones.

Review your advance care planning decisions from time to time—for example, every 10 years, if not more often. You might want to revise your preferences for care if your situation or your health changes. Or, you might want to make adjustments if you receive a serious diagnosis; if you get married, separated, or divorced; if your spouse dies; or if something happens to your proxy or alternate. If your preferences change, you will want to make sure your doctor, proxy, and family know about them.

Be Prepared

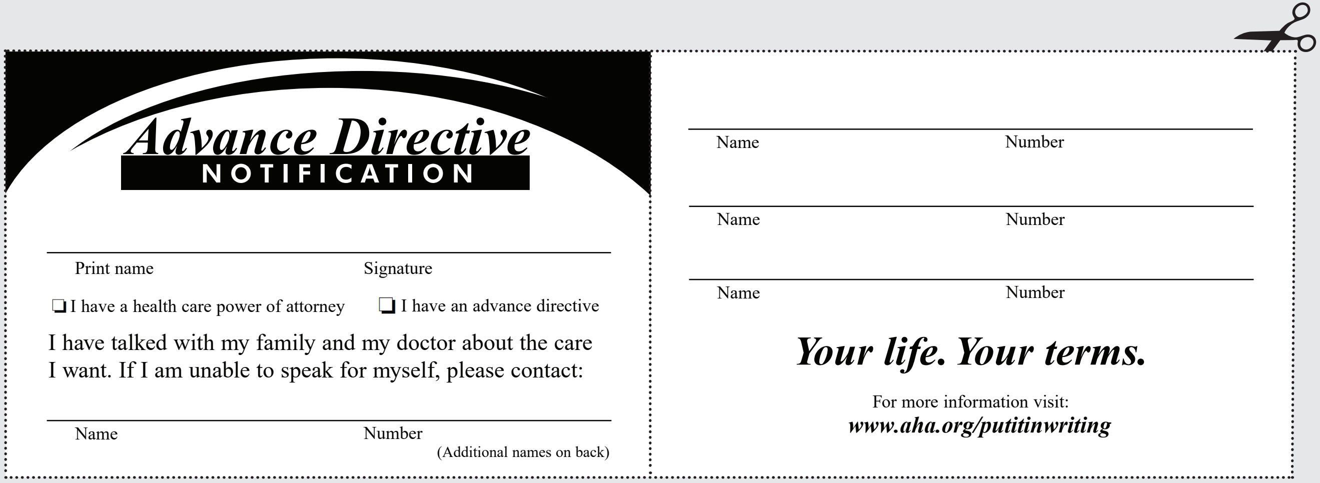
What happens if you have no advance directive or have made no plans and you become unable to speak for yourself? In such cases, the state where you live will assign someone to make medical decisions on your behalf. This will probably be your spouse, your parents if they are available, or your children if they are adults. If you have no family members, the state will choose someone to represent your best interests.

Always remember: an advance directive is only used if you are in danger of dying and need certain emergency or special measures to keep you alive, *but you are not able to make those decisions on your own*. An advance directive allows you to make your wishes about medical treatment known.

It is difficult to predict the future with certainty. You may never face a medical situation where you are unable to speak for yourself and make your wishes known. But having an advance directive may give you and those close to you some peace of mind.

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 a wallet card offered by the American Hospital Association. You might want to make a copy or cut this one out to fill out and carry with you. It can also be found online at *www.aha.org/2017-12-11-put-it-writing*.



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

Aging with Dignity
1-850-681-2010
fivewishes@agingwithdignity.org
www.agingwithdignity.org

American Bar Association
1-800-285-2221 (toll-free)
aging@americanbar.org
www.americanbar.org

CaringInfo
National Hospice and Palliative Care Organization
1-800-658-8898 (toll-free)
caringinfo@nhpco.org
www.caringinfo.org

Center for Practical Bioethics
1-800-344-3829 (toll-free)
center@centerforbioethics.org
www.practicalbioethics.org

Donate Life America
1-804-377-3580
donatelifeamerica@donatelife.net
www.donatelife.net

The Living Bank
1-800-528-2971 (toll-free)
info@livingbank.org
www.livingbank.org

National Academy of Elder Law Attorneys
1-703-942-5711
naela@naela.org
www.naela.org

National POLST Paradigm
1-202-780-8352
info@polst.org
www.polst.org

OrganDonor.gov
Health Resources & Services Administration
www.organdonor.gov

Put It In Writing
American Hospital Association
1-800-424-4301 (toll-free)
www.aha.org/contactAHA
www.putitinwriting.org

For more information about health and aging, contact:
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