

Advance care planning

Think about the healthcare treatment you want—ahead of time



You can't always predict when you'll get sick or hurt. That's why it's important to make choices about your care ahead of time. Adults are never too young or too old for advance care planning.

This guide can help you talk with your family and close friends about your wishes for medical care and treatment. It may also help you discuss those plans with family members who may need an advance care plan.

Keep your values and treatment goals in mind. Think about how medical treatments could affect your quality of life. Decide how you feel about medical interventions that may prolong your life, such as tube feeding and ventilators. Update the plan every few years.

Talk with your family and close friends about your advance care plan. This allows them to advocate for you—especially when you can't make decisions or speak for yourself. Also be sure to share the plan with your personal doctor and on admission to a hospital.

This guide includes some advice from Consumer Reports and Choosing Wisely about a few treatments you might want to consider as you create your advance care plan. You can find more resources at [ConsumerHealthChoices.org/planning](https://www.ConsumerHealthChoices.org/planning).



Talking about advance care planning

It's not always easy to talk about planning for future medical needs. But whether you are making plans for yourself or encouraging someone else to do so, those conversations are important.

Once you start talking, don't feel that you need to get everything done at once. Even after you or someone close to you has made your wishes and values known, those preferences may change over time.

But once you've started, it will be easier to talk about changes or related issues in the future. It will also be easier to tell other family members, close friends, and doctors. They need to be informed so they understand your wishes.

As part of the conversation, make sure you put all of your decisions into a document called an advance directive. This is a way to make your wishes known if you are unable to speak for yourself or want someone else to speak for you. An advance directive tells your doctor what kind of care you want and who you have appointed to make decisions for you if needed. Adults are never too young or too old to have an advance directive. You can download forms at coalitionccc.org/ACPresources.

Key steps in the advance care planning process

- Choose your "healthcare surrogate"—the person or people you choose to speak for you if you are unable to speak for yourself.
- Have a conversation with your healthcare surrogates about your preferences in case of serious illness.
- Document your preferences and name your surrogates in an advance directive and have the form witnessed.
- Share copies of your advance directive with your surrogates, your doctor, and your family—and ask your doctor to place a copy of your advance directive in your electronic medical record
- Update your advance directive during major changes in your life, such as marriage, divorce, or a significant change in health status.

Treatment decisions to consider in advance

Here is some advice from *Choosing Wisely* to consider in advance, so you can be clear about what you want—and what you don't want.

Treatment for heart disease with an ICD

An implantable cardioverter defibrillator (ICD) is a small device that is placed in your chest. If your heart beats too fast, it sends a powerful shock to your heart to help it beat normally again. For many people with heart disease, this device can be a lifesaver. But if you are near death, those shocks can make things worse. An ICD won't help if you're dying from heart failure. The shocks can be very scary and painful. Think twice before getting an ICD if you are likely to live less than one year.

Cancer treatments

Talk with your doctor about how much your cancer has grown and how far it has spread. Use shared decision-making to make the best medical choices for yourself (see box). If you have tried several different treatments, and your cancer has grown or spread, talk to your doctor about whether you should consider stopping treatment. More treatment is not likely to help you live longer. In fact, it could cause bad side effects and reduce the quality of the time you have left. Ask your doctor about the risks and benefits of more treatment. If it isn't likely to help, ask about hospice care (see back cover).

Shared decision-making

Any time you have a serious diagnosis, partner with your doctor to choose the best treatment option for you including the option of no treatment.

- Ask about the risks of each treatment option, including side effects.
- Ask about the benefits of each treatment, such as how likely it is to cure your condition.
- Tell your doctor about your values and what quality of life you want.
- Work with your doctor to make choices about treatment.

Treatments for dementia

- **Drugs for thinking and memory problems:** Drugs such as donepezil (Aricept and generic) and memantine (Namenda and generic) may keep your memory and thinking from getting worse. But most people don't see much improvement, if any, and the drugs may cause side effects. Don't take these drugs for more than 12 weeks unless there are clear signs that they are working.



- **Drugs for behavior problems:** Antipsychotic drugs such as aripiprazole (Abilify and generic), olanzapine (Zyprexa and generic), and quetiapine (Seroquel and generic) may decrease behavior problems. But more often than not they don't work. Plus, they can cause bad side effects, or even make things worse. Take these drugs only if you are a danger to yourself or others. Your doctor should first look for the cause of your behavior problems and think about other treatments, such as antidepressants.

Advice from Consumer Reports

Palliative care and hospice care

Know the difference—especially during advance care planning.

What is palliative care?



Palliative care gives you and your caregivers extra support during a serious illness, including physical, emotional, and spiritual care and support. You keep getting treatment to cure your illness. Meanwhile, a team of specialists helps ease your pain and other symptoms, such as feeling tired, anxious, sick to your stomach, and

depressed. The team can also help you make tough choices about your care. The sooner palliative care starts, the better it works. You can even ask for a palliative care consult in the emergency department, so it can begin as soon as possible. Research shows that palliative care may help you live longer, and it can last for as long as you need it. It can help people of all ages, including children.

What is hospice care?

Hospice care is a type of palliative care for people who are near the end of their lives. It starts when you and your family decide it's time to stop getting treatment to cure your disease. This may be because the treatment is not working, or because the treatment hurts too much. Getting hospice care doesn't mean you are giving up. It just means you want to be as comfortable as you can be.



To learn more about making an advance care plan, visit the Coalition for Compassionate Care of California at coalitionccc.org/ACPresources.



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