Has your doctor told you that you have Alzheimer’s disease or dementia?

Dementia can make it harder to understand things and communicate with others. When your doctor tells you that you have dementia, it is important to plan where you want to live, what care you want, and how you want your money taken care of.

Why should I plan?

Planning early lets you

✔ Decide who will make health care choices for you when you cannot make your own choices.

✔ Tell the people close to you what kind of health care you do and don’t want.
When should I plan?

Dementia gets worse over time.

Plan for how your health care will be managed as soon as possible. Even in the early stages of dementia, you may find it difficult to understand some things or make certain decisions.

How can I plan for managing my health care decisions?

You can make things easier for yourself and others by taking three steps.

Step 1. Choose someone to make health care decisions for you when you no longer can.

Ask someone you trust to become your agent. An agent will have the right to make health care decisions for you if you cannot. Usually an agent is a family member or close friend.

Your agent should be someone

• You can talk to about serious illness.

• Willing and able to learn about your health care options and talk to your doctors.

• Willing and able to make decisions according to what you want and what is important to you.
To name an agent, you sign a document called a **health care power of attorney**, also known as appointment of a health care surrogate or proxy. You must sign the document while you can still understand what it says.

When you are no longer able to make health care decisions, your agent will

- Talk to your doctors about your medical care.
- Agree to or refuse treatments based on what you would want, or, if that is not possible, what is best for you.
- Make decisions about medical tests, surgery, and treatments such as feeding tubes.
- Make decisions about where you will get care, such as home care or hospice.

If you do not sign a power of attorney, most states will give your next of kin the right to make health care decisions for you when you cannot. The types of decisions this person can make are different in each state.
Step 2. Think about what kind of care you want, and talk to those who will make choices for you.

Talk with your agent, your family, and your doctor about these things. This might be hard.

Websites listed at the end of this guide can help with the conversation.
Step 3. **Let others know what your wishes are and write them down.**

You can do this in several ways:

- Include your wishes and instructions in your health care power of attorney.

- Make a **living will**, a document that describes your wishes and instructions. This is the best option if you don’t have someone you trust to be your health care agent.

- Use one of the conversation tools listed on page 7 to record your wishes. (See “Where can I get more information?”)

- Be sure to talk to your doctor about what you want, and give your doctor a copy of your health care power of attorney.

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**Where can I find a lawyer who can help me?**

- Lawyers who specialize in helping older adults are called elder law attorneys.

- American Bar Association [www.findlegalhelp.org](http://www.findlegalhelp.org)

- National Elder Care Locator [www.eldercare.gov](http://www.eldercare.gov) (1-800-677-1116)

- National Academy of Elder Law Attorneys, Inc. [www.naela.org](http://www.naela.org)

Laws are different in each state. If you move, talk to an elder law attorney in your new state about updating your directives.
Terms to know

**Advance directives**: Any legal document that says how you want medical decisions made for you if you are unable to speak for yourself. Advance directives can include a health care power of attorney and living will.

**Health care power of attorney**: A document that gives someone the power to make health care decisions for you when you are not able to make them for yourself.

**Living will**: A document that spells out the medical treatments you want and don’t want if you are not able to make decisions for yourself.

**Do not resuscitate (DNR) orders**: Medical orders that tell health care providers not to perform CPR while you are in the hospital. A DNR needs to be signed by a doctor and put in your medical chart. It does not stop care to keep you comfortable.

**Out-of-hospital DNR orders**: Medical orders that tell emergency responders and other health care providers not to perform CPR outside of the hospital. You should put this document in your home where it is easy to see, such as on the refrigerator or inside the front door. Most states also provide a special DNR bracelet.

**Physician’s Orders for Life-Sustaining Treatment (POLST)**: If you are very sick, you and your doctor can complete a POLST form, which is placed in your chart to give health care workers medical orders for the treatments you want or don’t want in an emergency. It is used for people who have a serious illness or who are near the end of life. The form stays with you whether you are in the hospital, in a nursing home, or at home. You or your agent should ask your doctor to update these orders when your health changes. Different states have different names for this form.

**Organ donation**: Make sure that your agent and others close to you know whether you want to be an organ and tissue donor.
Where can I get more information?

Having the conversation and writing your wishes down

– The Conversation Project
  www.theconversationproject.org (1-617-301-4800)
– Five Wishes www.agingwithdignity.org
– PREPARE www.prepareforyourcare.org

Advance directives and making medical decisions

The American Bar Association Commission on Law and Aging
www.americanbar.org/aging

– Toolkit for Health Care Advance Planning
– Making Medical Decisions for Someone Else: A How-To Guide
– Myths and Facts about Health Care Advance Directives

Organ and tissue donation

www.OrganDonor.gov provides information and links to state registries

POLST

The National POLST Paradigm www.polst.org provides information on POLST and other advance care planning resources

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