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Planning After a Dementia Diagnosis



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Tips for Planning

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If you or a loved one has been diagnosed with Alzheimer's disease or a related dementia, it may be difficult to think beyond the day to day. However, taking steps now can help prepare for a smoother tomorrow.

Over time, the symptoms of Alzheimer's and related dementias will make it difficult to think clearly. Planning as early as possible enables you to make decisions and communicate those decisions to the right people.

Below are important legal documents to consider, and resources and tips that can help with planning ahead for health care, financial, long-term care, and end-of-life decisions.

Health Care Planning

Advance directives are legal documents that outline your preferences and apply only if you are unable to make decisions. For health care planning, they communicate a person's wishes ahead of time. Doctors and other providers follow these directives for your medical treatment. There are two main documents that are part of an advance directive:

- A **living will** lets doctors know how you want to be treated if you are dying or permanently unconscious and

cannot make your own decisions about emergency treatment.

- A **durable power of attorney for health care** names someone as a “proxy” to make medical decisions for you when you are not able.

If advance directives are not in place and a patient can no longer speak for him or herself, someone else will need to make medical decisions on their behalf. Talk to your family, friends, and health care providers about what types of care you would want. It can also be helpful to talk with your doctor about common problems associated with your condition.

For example, in the later stages of Alzheimer’s disease, people may have trouble swallowing, which can bring food or liquid into the lungs and cause pneumonia. Doctors may recommend a feeding tube connected from the nose to the stomach for nutrition, a ventilator to help with breathing, and antibiotics to fight the lung infection to help with recovery. However, some people may want to focus on comfort rather than recovery if the illness occurs near the end of life.

Medical decisions to consider when planning ahead include:

- A **do not intubate (DNI) order**, which lets medical staff in a hospital or nursing facility know that you do not want to be put on a breathing machine.
- A **do not resuscitate (DNR) order**, which tells health care professionals not to perform CPR (cardiopulmonary

resuscitation) or other life-support procedures in case the heart or breathing stops.

- Other types of **medical orders**, which inform health care professionals about your preferences for life-sustaining and life-supporting treatment measures during a medical emergency. These have various names but are commonly called POLST (Physician Orders for Life-Sustaining Treatment) or MOLST (Medical Orders for Life-Sustaining Treatment) forms.
- **Organ and tissue donation**, which allows healthy organs or other body parts from a person who has died to be transplanted into people who need them.
- **Brain donation** for scientific research, which helps researchers better understand how Alzheimer's and related dementias affect the brain and how they might be better treated and prevented.

Watch this video that describes four advance directives important to have as you age.

What Are Advance Directives?



Financial Planning

Advance directives for financial planning are documents that communicate the financial wishes of a person. These must be created while the person still has the legal capacity to make decisions. Three common documents are included in a financial directive:

- A **will** specifies how a person's estate — property, money, and other financial assets — will be distributed and managed when they die. It may also address care for minors, gifts, and end-of-life arrangements, such as funeral and burial.
- A **durable power of attorney for finances** names someone who will make financial decisions for you when you are not able.
- A **living trust** names and instructs someone, 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 and your family members. 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](#).

Help With Legal Needs

Families who cannot afford a lawyer can still prepare documents and express their wishes in advance.

Samples of basic health planning documents are available online. Area Agency on Aging officials may provide legal advice or help. Other possible sources of legal assistance and referrals include state legal aid offices, state bar associations, local nonprofit agencies, foundations, and social service agencies.

Visit the National Hospice and Palliative Care Organization for [free sample documents](#).

For help with legal advice, contact the [Eldercare Locator](#).

Long-Term Care Planning

As symptoms progress, long-term care may be needed.

People diagnosed with Alzheimer's or a related dementia and their family members should begin planning for the possibility of long-term care as soon as possible. Geriatric care managers, often nurses or social workers, can work with you to create a long-term care plan.

Long-term care can be provided within the home or at an outside facility. At some point, a person with dementia may require around-the-clock care or 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 the person will live as they age and how their place of residence can best support their 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 the person can make important decisions while they are still capable

End-of-Life Planning

Currently, there is no cure for Alzheimer's and related dementias. Some treatments may help manage symptoms for a period of time. However, a person's condition will gradually

decline and result in death. That's why planning and making decisions for your health care early on is important. When planning end-of-life care, quality of life should be considered alongside care that may extend life.

If you did not choose a health care proxy or your advance directives are not clear, someone else may need to make decisions for you at the end of life. These situations can be difficult and emotional. For caregivers in the role of making those decisions, it may be helpful to imagine what the person would want and try to choose accordingly.

Tips for Planning

There are tips and checklists that can help you get started on what to do after an Alzheimer's or related dementia diagnosis. In preparation for the future, you can:

- Start discussions early with your family members.
- Put important papers in one place and make sure a trusted person knows where.
- Update documents as situations change.
- Make copies of health care directives to be placed in all medical files.
- Give the doctor or lawyer advance permission to talk directly with a caregiver if needed.

Planning now will help you and your loved ones later when symptoms of Alzheimer's or a related dementia worsen.

Find Care and Local Services

What types of help are available and where can you find help for Alzheimer's and related dementias?

Learn about finding local services.

Sign up for weekly tips from Alzheimers.gov

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Find More Resources on Planning

Explore the resources on this website and linked below to find more information from federal government agencies.

National Institute on Aging (NIA), National Institutes of Health

Advance Care Planning Health Topic From NIA

Learn about financial and health care planning, including advance directives. Also available in Spanish.

National Institute on Aging (NIA), National Institutes of Health

Alzheimer's Caregiving: Finding Long-Term Care

Find out about different types of long-term care facilities and what questions to ask. Also available in Spanish.

Administration for Community Living (ACL)

Eldercare Locator

Use this free public service by searching online or calling toll-free to get connected to services in your community.

Administration for Community Living (ACL)

Planning for Dementia

Read about long-term care, medical and legal documents, and specific challenges.

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[Can I Prevent Dementia?](#)

Questions? Contact the ADEAR Center

The Alzheimer's & related Dementias Education & Referral (ADEAR) Center is a service of the National Institute on Aging at the National Institutes of Health. Call [800-438-4380](tel:800-438-4380) or email adear@nia.nih.gov to talk with an information specialist.

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