

Legal and Financial Planning for People Living With Dementia

FACT SHEET

Learn About

- Why It's Important To Plan Ahead
- How To Plan Ahead
- Where To Get Help
- Advice and Things To Consider
- Finding More Resources



Many people are unprepared to deal with the legal and financial consequences of a serious illness such as Alzheimer's disease or a related dementia. Legal and medical experts encourage people recently diagnosed with a serious illness — particularly one that is expected to cause declining mental and physical health — to examine and update their financial and health care arrangements as soon as possible. Basic legal and financial documents, such as a will, a living trust, and advance directives, are available to ensure that the person's late-stage or end-of-life health care and financial decisions are carried out.

A complication of diseases such as Alzheimer's and related dementias is that the person may lack or gradually lose the

ability to think clearly. This change affects his or her ability to make decisions and participate in legal and financial planning.

People with early-stage Alzheimer's or a related dementia can often understand many aspects and consequences of legal decision-making. However, legal and medical experts say that many forms of planning can help the person and his or her family address current issues and plan for next steps, even if the person is diagnosed with later-stage dementia.

There are good reasons to retain a lawyer when preparing advance planning documents. For example, a lawyer can help interpret different state laws and suggest ways to ensure that the person's and family's wishes are carried out.

It's important to understand that laws vary by state, and changes in a person's situation — for example, a divorce, relocation, or death in the family — can influence how documents are prepared and maintained. **Life changes may also mean a document needs to be revised to remain valid.**

Legal, Financial, and Health Care Planning Documents

Families beginning the legal planning process should discuss their approach, what they want to happen, and which legal documents they'll need. Depending on the family situation and the applicable state laws, a lawyer may introduce a variety of documents to assist in this process, including documents that communicate:

- Health care wishes of someone who can no longer make health care decisions.
- Financial management and estate plan wishes of someone who can no longer make financial decisions.

Advance Health Care Directives for People With Dementia

Advance directives for health care are documents that communicate a person's health care wishes.

Advance directives go into effect after the person no longer can make decisions on their own. In most cases, these documents must be prepared while the person is legally able to execute them. Health care directives may include the following:

A **durable power of attorney for health care** designates a person, sometimes called an agent or proxy, to make health care decisions when the person with dementia can no longer do so.

A **living will** records a person's wishes for medical treatment near the end of life or if the person is permanently unconscious and cannot make decisions about emergency treatment.

A **do not resuscitate order**, or DNR, instructs health care professionals not to perform cardiopulmonary resuscitation (CPR) if a person's heart stops or if he or she stops breathing. A DNR order is signed by a doctor and put in a person's medical chart.

In addition to these, there may be other documents for specific health care procedures including organ and tissue donation, dialysis, brain donation, and blood transfusions.

Tip: Get Permission for Caregiver Communication in Advance

Get permission in advance from the person with dementia to have his or her doctor and lawyer talk with a caregiver as needed. Advance permission can also be provided to others, such as Medicare or a credit card company, bank, or financial advisor. This can help with questions about care, a bill, or a health insurance claim. Without consent, the caregiver may not be able to get needed information.

Advance Directives for Financial and Estate Management

Advance directives for financial and estate management must be created while the person with Alzheimer's or a related dementia has "legal capacity" to make decisions on their own, meaning they can still understand the decisions and what they might mean. These directives may include the following:

A **durable power of attorney for finances** names someone to make financial decisions when the person with Alzheimer's or a related dementia no longer can. It can help avoid court actions that may take away control of financial affairs.

A **will** indicates how a person's assets and estate will be distributed upon their death. It also can specify:

- Arrangements for care of minors or pets
- Gifts
- Trusts to manage the estate
- Funeral and/or burial arrangements

Medical and legal experts say that the person newly diagnosed with Alzheimer's or a related dementia and his or her family should create or update a will as soon as possible after diagnosis.

A **living trust** addresses the management of money and property while a person is still living. The trust provides instructions about the person's estate and appoints someone, called the trustee, to hold titles to property and money on the person's behalf. Using the instructions in the living trust, the trustee can pay bills or make other financial and property decisions when the person with dementia can no longer manage his or her affairs.

A living trust can:

- Cover a wide range of property (including cars, homes, jewelry, bonds, cash, etc.)
- Provide a detailed plan for property transfer or sale
- Avoid the expense and delay of probate (in which the courts establish the validity of a will)
- State how property and funds should be distributed when the last beneficiary dies

Where Can I Get Help With Legal and Financial Planning?

Health care providers cannot act as legal or financial advisers, but they can encourage planning discussions between patients and their families. Doctors can also guide patients, families, the care team, attorneys, and judges regarding the patient's ability to make decisions. Discussing advance care planning decisions with a doctor is free through Medicare during the annual wellness visit. Private health insurance may also cover these discussions.

An **elder law attorney** helps older adults and their families interpret state laws, plan how wishes will be carried out, understand financial options, and learn how to preserve financial assets.

It's a good idea to ask about a lawyer's fees before making an appointment. The National Academy of Elder Law Attorneys and the American Bar Association can help families find qualified attorneys. Also, a local bar association can help identify free legal aid options. See the resources at the end of this fact sheet for more information.

Geriatric care managers are trained social workers or nurses who can help people with dementia and their families.

Advance Planning Advice for People With Dementia

Start discussions early. The rate of decline differs for each person with dementia, and his or her ability to be involved in planning will decline over time. People in the early stages of the disease may be able to understand the issues, but they may also be defensive, frustrated, and/or emotionally unable to deal with difficult questions. The person may even be in denial or not ready to face their diagnosis. This is normal. Be patient and seek outside help from a lawyer or geriatric care manager if needed. Remember that not all people

are diagnosed at an early stage. Decision-making may already be difficult by the time the person with dementia is diagnosed.

Gather important papers. When an emergency arises or when the person with dementia can no longer manage their own affairs, family members or a proxy will need access to important papers, such as a living will or financial documents. To make sure the wishes of the person with dementia are followed, put important papers in a secure place and provide copies to family members or another trusted person. A lawyer can keep a set of the papers as well.

Money Matters: How to Help A Person With Dementia

Problems managing money may be one of the first noticeable signs of dementia. To provide support, while also respecting the person's independence, a family member or trusted friend can help:

- **Watch for signs of money problems** — Trouble paying for a purchase or a pile of unopened bills may indicate money issues. Start a conversation about available services to help older adults with their expenses. Giving the person small amounts of cash to have on hand and limiting credit cards may help manage spending.
- **Set up automated bill payments** — Arrange for utilities, mortgage, rent, or other expenses to be paid through automatic deductions from a bank account. This will make sure that bills are paid correctly and on time.
- **Protect against scams or fraud** — To lower the risk of telemarketing schemes, help place the person's phone number on the National Do Not Call Registry. Consider registering the person for fraud alerts through their bank, credit card company, a national credit bureau, or other credit monitoring service. Learn more about common scams and frauds at www.usa.gov/common-scams-frauds.

As the disease progresses, a family member or trustee can take additional steps to:

- **Establish consent to manage finances** — To prevent serious problems, consider being named as a legal proxy to access and manage the person's financial affairs.
- **Plan for in-home and long-term care costs** — Consider options for a personal care assistant or home health care aide and their costs, including possible Medicare or Medicaid support. If the person needs more care, consider assisted living communities and nursing homes.

Review plans over time. Changes in personal situations — such as a divorce, relocation, or death in the family — and in state laws can affect how legal documents are prepared and maintained. Review plans regularly and update documents as needed.

Reduce anxiety about funeral and burial arrangements. Advance planning for the funeral and burial can provide a sense of peace and reduce anxiety for the person with dementia as well as his or her family.

Legal and Financial Planning Resources for Low-Income Families

Families who cannot afford a lawyer can still plan for the future. 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.

Overview of Medical Documents

Medical Document	How It Is Used
Durable Power of Attorney for Health Care	Gives a designated person the authority to make health care decisions on behalf of the person with dementia
Living Will	Describes and instructs how and when the person wants different types of end-of-life health care
Do Not Resuscitate Order	Instructs health care professionals not to perform CPR in case of stopped heart or stopped breathing

Overview of Legal and Financial Documents

Legal/Financial Document	How It Is Used
Durable Power of Attorney for Finances	Gives a designated person the authority to make legal and financial decisions on behalf of the person with Alzheimer's or a related dementia
Will	Indicates how a person's assets and estate will be distributed among beneficiaries after his or her death
Living Trust	Gives a designated person (trustee) the authority to hold and distribute property and money for the person with Alzheimer's or a related dementia

For More Information About Advance Care Planning for a Person With Dementia

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

800-438-4380 (toll-free)

adear@nia.nih.gov

www.nia.nih.gov/alzheimers

The National Institute on Aging's ADEAR Center offers information and publications for families, caregivers, and health professionals on Alzheimer's disease and related dementias, including information on caregiving, clinical trials, and research. Staff members answer inquiries by phone, email, and in writing and make referrals to local and national resources. Visit the ADEAR website to learn more about Alzheimer's and related dementias, find clinical trials, and sign up for email updates.

AARP

888-687-2277 (toll-free)

877-434-7598 (TTY/toll-free)

member@aarp.org

www.aarp.org/home-family/caregiving/

Centers for Medicare and Medicaid Services

Fraud Prevention Toolkit

www.cms.gov/Outreach-and-Education/Outreach/Partnerships/FraudPreventionToolkit

Consumer Financial Protection Bureau

Office for Older Americans

855-411-2372 (toll-free)

olderamericans@cfpb.gov

www.consumerfinance.gov/olderamericans

U.S. Department of Justice

202-514-2000

800-877-8339 (TTY/toll-free)

elder.justice@usdoj.gov

www.justice.gov/elderjustice

www.justice.gov/elderjustice/roadmap

Eldercare Locator

800-677-1116 (toll-free)

eldercarelocator@n4a.org

<https://eldercare.acl.gov>

Financial Literacy and Education Commission

U.S. Department of the Treasury

www.mymoney.gov

800-FED-INFO

National Academy of Elder Law Attorneys

703-942-5711

naela@naela.org | www.naela.org

National Elder Law Foundation

520-881-1076

info@nelf.org | www.nelf.org

CaringInfo

National Hospice and Palliative Care Organization

800-658-8898 (toll-free)

caringinfo@nhpco.org | www.caringinfo.org

OrganDonor.gov

Health Resources & Services Administration

www.organdonor.gov

For information on health and aging, including resources on caregiving and Alzheimer's disease, contact:

National Institute on Aging Information Center

800-222-2225 (toll-free)

800-222-4225 (TTY/toll-free)

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

Visit www.nia.nih.gov/health to find more health and aging information from NIA and subscribe to email alerts. Visit <https://order.nia.nih.gov> to order free print publications.



National Institute
on Aging

NIH Publication No. 20-AG-6422 | October 2020