

# Supporting Someone Living with Dementia in Making Decisions

If you care for someone with Alzheimer's disease or other dementia, you can provide support as they:

- Plan for their future health care and financial needs.
- Talk to providers.
- Communicate their wishes.
- Make difficult decisions.

This guide can help you plan for the changes that come with dementia and learn how to provide support with decision making.

## How does dementia affect decision making?

Dementia affects more than just memory. It also affects the ability to understand things and communicate with others. Even with these changes, there are many ways the person living with dementia can stay involved in decisions about their own life. You can support them in doing this. For this guide, let's call this person Louis.

### Things to consider:



- By including Louis in decisions, even as his thinking changes, you can help him meet his needs in the way that he wants.
- Louis may need help with some tasks or decisions and not others. For example, he may be able to decide what he wants to buy at the grocery store, but he may need help paying his bills. He may not understand a complex medical decision, but may be able to say who he trusts to help him make the decision.
- Louis' ability to make decisions can change depending on the situation. Some days or certain times of the day may be better than others. For example, it may be easier for him to have conversations early in the day. Hunger, noise, and other distractions can make it harder for him to think and make decisions. Choosing a good time to talk can help.

## Why is planning important?

It's never too soon to start talking with Louis about what's important to him, including the medical and personal care he does and doesn't want and how he wants to manage his money. Learning about his wishes now will make it easier to carry them out later.

### Encourage him to create legal documents:



- Louis can choose someone to help him with his money and property. Usually, this is a family member or close friend. Some decisions can't be made, even by a spouse, without the right legal paperwork. A **financial power of attorney**, also known as a durable power of attorney, is a legal document that names a person to help with decisions. This person is called an **agent**. If Louis doesn't legally name someone who can make these decisions, the courts may choose someone for him.
- Louis can also choose someone who can help with health care decisions. Again, this is usually a family member or close friend. A **health care power of attorney** is a legal document that names an **agent**—a person who can make health care decisions for him if he isn't able. Without a health care power of attorney, most states allow the next of kin to make medical and personal care decisions.
- Louis can name the same person or different people to make his money and health care decisions. If he hasn't already created powers of attorney, Louis should do this soon after memory problems start. Most states provide standard power of attorney forms; see the **Resources** section below. Or work with an attorney who knows about elder law.

## What can I do as Louis needs more support?

Over time, it may become harder for Louis to manage daily life and decisions. There will be many situations where you will need to help. Some decisions will be small, such as what to eat for dinner. Others may be big, such as where to live.

### What you can do:



- Support Louis in making his own decisions as much as possible. It's OK if you don't agree, as long as his decision doesn't hurt himself or someone else.
- Use simple words and keep conversations short. Talk with him as an adult. If it's a bad day, try again later.
- If you're not sure whether Louis is able to make a decision, ask a professional, such as a psychologist, social worker, or neurologist. They can help you know if he needs support and if his agent needs to make some decisions for him.

## How can I help Louis with health care and care decisions?



- Talk with Louis about what's important to him. See resources below that can help you understand Louis' values and wishes.
- Help him make and go to health care appointments.
- Know what the health care power of attorney document says, and keep a copy of the document on hand. Give a copy to Louis's doctors to put in his medical records.
- When a decision needs to be made, ask the doctor(s) to explain the benefits and risks of different options to both of you, including how they may change Louis's quality of life. You and Louis may also decide to talk to another doctor for a second opinion.
- Help Louis share his wishes with the doctor. Remember, your role is to help him get the care that he would want and avoid the care that he wouldn't want.
- Medical decisions can be complicated. Sometimes the right decision is not clear, even with good planning and communication. Do your best to support Louis in expressing his wishes to the care team.

## How can I help Louis with managing his money and property?



- Talk with Louis about what's important to him and how he wants to manage his money. Maybe he wants to continue giving money to certain charities or doesn't like to pay interest on credit cards. It's important to understand his values.
- Help Louis organize important documents like bank statements, insurance policies, retirement and veterans' benefits, Social Security payments, investments, real estate, credit cards and other debts, and any will or trust documents. You will need to understand his finances to help him manage them well.
- If Louis has signed a financial power of attorney, know what it says and provide banks or other financial institutions with a copy.
- Help Louis pay his bills and taxes on time. Set up direct deposit and automatic bill payments when possible.
- Always keep his money separate from yours.
- Keep complete records of all financial activity.
- Always do what is best for Louis. Do not make decisions that may help you or someone else but may hurt Louis.
- Watch out for signs of financial abuse and scams—for example, if Louis's money or property disappears, or if he starts buying things he doesn't need or making unusual gifts.

## How can I work with other family members?

Dealing with a serious illness such as dementia can create stress in families. Family members may not understand dementia or may have different ideas about what is best for Louis.

### Tips for working with other family members:



- Offer to be with Louis and support him if he wants to share his wishes with other family members.
- If it's OK with Louis, you should share information about him with other family members. This may include email updates after medical appointments or records of how money has been spent. Keeping people informed can avoid misunderstandings and disagreements.
- Unless there is an emergency, give other family members time to think about the information and share their thoughts before making decisions.
- It's not always possible for everyone to agree. The person Louis chooses as his agent will make the final decision, or if he did not name an agent, his closest family

### Additional Resources:

- **Support someone in making decisions:**
  - The Conversation Project—[Guide for Caregivers of People with Alzheimer's/Other Dementias](#)
  - The American Bar Association (ABA) Commission on Law and Aging—[Making Medical Decisions for Someone Else: A How-To Guide](#)
  - The Consumer Financial Protection Bureau—[Managing Someone Else's Money](#)
- **Create a health care power of attorney:**
  - The ABA—[Giving Someone A Power of Attorney for Your Healthcare](#) (includes a health care power of attorney form that works for most states)
  - AARP—[Find Advance Directives Forms by State](#)
- **Find an elder law attorney:**
  - The National Academy of Elder Law Attorneys—[Find a Lawyer](#)
  - The American Bar Association—[Bar Directories and Lawyer Finders](#) by state
  - [The National Elder Care Locator](#) (800-677-1116)

The National Alzheimer's and Dementia Resource Center (NADRC) developed this resource at the request of the Administration for Community Living (ACL). This resource is intended to support the work of ACL's grantees and others who deliver programs to support people living with Alzheimer's disease and related dementias and their caregivers. The NADRC's full array of dementia related materials and resources can be found at <https://nadrc.acl.gov/>.