

# Making Decisions for Someone with Dementia



## **Does someone you know have Alzheimer's disease or dementia?**

Will you help make medical, financial, or care decisions for this person? This guide can help you prepare for the changes that come with dementia.

Dementia gets worse over time. Eventually, you will need to make, or help make, decisions for the person with dementia.

For this guide, let's call the person with dementia Mary.

## How does dementia affect decision making?

Dementia affects more than just memory. It also affects the ability to understand things and communicate with others.



Things to consider:

- **The person with dementia may be able to make some decisions and not others.** For example, Mary might not be able to understand her financial investments, but she may be able to decide what to buy at the grocery store. Or, she might not understand the care options her doctor tells her about, but she may be able to decide who she wants to make medical decisions for her.
- **The ability to make decisions can change depending on the circumstances.** Some days or certain times of the day may be better than others. For example, Mary may become more confused and stressed in the evening. Hunger, noise, and other distractions can make it harder for her to make decisions. Choosing a good time to talk can help.
- **Including Mary in decisions, even as the dementia progresses, helps her maintain her dignity.**

## Why is planning for the future important?

Learning about Mary's wishes now will make it easier to honor those preferences later.

As soon as possible after a diagnosis, start talking with Mary about what is important to her, the medical and personal care she does and doesn't want, and her finances.

Encourage her to create legal documents:

- **A financial power of attorney, also known as a durable power of attorney.** This is a legal document in which Mary names another person, called an **agent**, to take care of her money and property for her when she is not able. Some decisions about her money and property cannot be made, even by a spouse, without a power of attorney. In some cases, if Mary doesn't appoint someone to make these decisions, the courts may appoint someone for her.
- **A health care power of attorney.** This is a legal document in which Mary names an **agent** to make health and personal care decisions for her when she is not able. Without a health care power of attorney, most states allow the next of kin to make medical and personal care decisions.

Mary can name the same person or different people to make her money and health care decisions. The financial and health care powers of attorney must be completed while Mary can still understand what she is signing. Work with an attorney who knows about elder law to make sure the documents meet her needs and the legal requirements in the state where she lives.

## 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.

## What can I do as Mary's ability to make decisions declines?

Over time, it will become harder for Mary 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 major, such as where to live.

What you can do:

- Support Mary to make her own decisions as much as possible. It's OK if you don't agree as long as her decision doesn't hurt herself or someone else.
- Use simple words and keep conversations short. If it's a bad day, try again later.
- If you're not sure whether Mary is able to make a particular decision, ask a professional, such as a psychologist, social worker, or neurologist. They can help determine whether she needs support and whether her agent needs to take over certain decisions.

## What should I do when making decisions about Mary's health and care?

**Do your best to honor Mary's wishes, and continue to ask Mary for her input as much as possible.**



You will need to communicate clearly with Mary's care team.

- Know what the health care power of attorney document says and keep a copy of the document on hand. Provide a copy to Mary's doctors to be included in her medical records.
- When a decision needs to be made, get the medical facts first. Ask the doctor(s) to explain the benefits and risks of different options, including how they affect Mary's quality of life. You may also decide to talk to another doctor for a second opinion.
- Share with the doctor what you know about Mary's values and wishes. Remember, it is your job to help her get the care that she would want and avoid the treatments she wouldn't want. Continue to ask Mary for her input as much as possible.
- Medical decisions can be complicated. Sometimes the right decision is not clear, even with the best advance planning and communication. Do your best to honor Mary's wishes.

## What should I do when making decisions about Mary's money and property?

**You need to fully understand her finances to manage them responsibly.**



There are several steps you can take to make good decisions for Mary.

- If Mary has signed a financial power of attorney, know what it says and provide banks or other financial institutions with a copy. If your authority is questioned, you may need to talk to higher-level staff in the financial institution or consult an attorney.
- Gather information about Mary's banking accounts, insurance policies, retirement and veterans benefits, Social Security payments, investments, real estate, credit cards and other debts, and any will or trust documents. You need to fully understand her finances to manage them responsibly.
- Make sure that all of Mary's bills and taxes are paid on time. Set up direct deposit and automatic bill payments when possible.
- Keep complete records of all financial transactions.
- Always act in Mary's best interest. Do not make decisions that may help you or someone else but may hurt Mary.
- Always keep her money separate from yours.
- Watch out for signs of exploitation and scams—for example, Mary's money or property disappears, or Mary starts buying services she doesn't need or making unusual gifts to other people.

## How do I work with other family members?

Dealing with a serious illness such as dementia can create stress in families.



Family members may not be able to acknowledge the realities of the illness or may have different ideas about what is best for Mary.

Tips for working with other family members:

- If Mary approves, you should share information about her with other family members. This may include sending e-mail updates after medical appointments or detailed records of how money has been spent. Keeping people informed can avoid misunderstandings and disagreements. There are many free websites that families can use to share medical and care information.
- Unless there is an emergency, give others time to think about information before making a decision.
- If you have a disagreement about what to do that you cannot resolve, get help from a social worker, geriatric care manager, therapist, or mediator.
- It is not always possible for everyone to agree. Decisions ultimately rest with the person Mary names as an agent, or, if she did not name an agent for medical decisions, with her closest family member.

## How do I make the most of limited time with doctors?

- Be prepared with a list of questions and concerns.
- Ask the most important questions first.
- Ask follow-up questions if you don't understand.
- Take notes, and request copies of after-visit summaries when possible.
- Bring someone with you to help listen and take notes.

## Where can I get more information?

- The American Bar Association Commission on Law and Aging [www.americanbar.org/aging](http://www.americanbar.org/aging) provides **Making Medical Decisions for Someone Else: A How-To Guide**
- The Consumer Financial Protection Bureau [www.consumerfinance.gov](http://www.consumerfinance.gov) (1-855-411-2372) offers **guides for managing someone else's money**

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