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# Family Caregiver Resources

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## Living with early-stage dementia

There are many advantages to catching a dementia diagnosis early. In particular, it allows you to plan together about finances and health care while your loved one still has the ability to make decisions and express them readily. As scary as the diagnosis is, be careful that you don't jump to the worst-case scenario and begin treating him or her as incompetent. Most memory loss conditions "progress" slowly over time. Best to stay present and support what he or she *can* do, while remaining calmly watchful for signs that a change may be in order.

## Balancing safety and independence



Everyone with a memory loss condition deserves the opportunity to stay engaged in life for as long as possible. Early in the disease, your loved one will continue to do many things quite well.

Your challenge is to balance respect for your relative's independence with the need to ensure safety. All this while preserving a trusting relationship.

In the beginning, just keep an eye on things. Encourage engagement and support self-esteem. Over time, you may need to provide some assistance. Not to do things "for" him or her, but "with." As abilities decline, suggest alternative approaches. And when you notice risky and unwise decisions, transition into taking over. Respectfully.

**Finances.** Managing mail and doing calculations can become confusing early on. Watch for unopened bills, an unbalanced checkbook, utility shut-off notices, or difficulty calculating the tip at a restaurant. Offer to "make life easier" by putting bills on autopay. At tax time, suggest doing it together. Or that you take it on, as he or she has "done that chore long enough." Poor judgment may leave your relative open to scams. Look for odd purchases or erratic spending. Work with your loved one's financial advisors to talk about money management options. Eventually, if you have power of attorney, you may need to activate that.

**Driving.** If your loved one is still driving, be the passenger frequently to check his or her capability. Dementia affects reaction time, spatial judgment, and decision making under pressure. Typical problems include

- not following right-of-way rules, for example at stop signs or when making a left turn
- getting flustered at intersections or stopping midstreet when feeling uncertain

You might suggest driving simpler routes and when traffic is less busy. Or facilitate rides from friends, public transit, etc. Eventually, call the doctor and ask for a driving evaluation.



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## Dementia and advance care planning



If the person you care for has received a dementia diagnosis, talk with them NOW about their wishes for medical care at the end of life. It's a critical time to update their advance care directive. For both your sakes, the sooner you start this conversation, the better.

### Are you hesitant to bring up the topic?

You may fear an angry response or denial that anything is wrong. Or perhaps you worry about depression. Try reframing the conversation:

- **Prior planning.** Often, advance directives have been included in estate-planning documents. Focus on updates and distributing to current physicians.
- **Work on your directives together.** Everyone needs an advance directive. Share what your thoughts are for your own directive (even if it's complete already). Then ask about your relative's wishes.
- **Consider it an act of love.** You want to know what kind of care your relative wants and what they most fear. With this, you can advocate for their preferences.

### Choose a decision maker

If nothing else, it's a good idea for your loved one to pick one person to be his or her medical decision maker. If the need should arise, this person would coordinate with the medical team to carry out your relative's end-of-life wishes.

### Start the conversation

- **Talk to your loved one shortly after the diagnosis.** Awareness is high, and your relative is more lucid than he or she will be in the months or years to come. The earlier you have the conversation, the more likely it will be that he or she has the capacity to sign needed documents.
- **Plan on several talks over time.** People with dementia are easily overwhelmed. Keep the conversations short and focused.

## The ability to make decisions

The right to choose for oneself is deeply embedded in our culture and the courts. It is one of those inalienable rights of adulthood.

Our legal system recognizes the need for health care decision makers to eventually step in and make medical decisions in the patient's stead. The person your relative chooses to do this is called the "health care power of attorney." The government also recognizes that finances may eventually have to be handled by someone else.

This role is called the "durable power of attorney." Sometimes these are the same person. Sometimes different.

Work with your loved one to select financial and medical decision makers. With a dementia diagnosis, do this sooner rather than later. Although a lawyer is not required to prepare the official documents, it's wise to consult with one.

### When to make the switch

If you are concerned about your relative's judgment, talk to the doctor privately. Physicians typically look at four aspects of the ability to make a sound decision. In the context of health care, for instance, can your loved one

- **understand the information.** Can he or she describe the diagnosis? The treatments being suggested?
- **appreciate the seriousness.** Can your loved one grasp the severity of the condition? Why a treatment could be helpful?
- **reason.** Can your relative weigh the pros and cons? Describe why he or she wants a particular treatment?
- **express a choice.** Will your loved one be consistent in his or her choice during repeated discussions?

If you think the person you care for is becoming unable to make wise decisions, meet with the family lawyer. If you are not an official decision maker, meet also with the health care power of attorney and the durable power of attorney. Alert them to your concerns and confirm their willingness to serve and the "triggers" needed to activate their roles.

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