

Caring for End-Stage Dementia



Dementia is the loss of brain function that occurs with certain brain conditions. It affects memory and makes it harder for a person to think clearly and communicate. As dementia slowly gets worse, disability increases. Over time, a person loses the ability to care for themselves. If your loved one has now progressed to end-stage (advanced) dementia, it may help to know what to expect and plan for what lies ahead.



Understanding end-stage dementia

Symptoms are different for each person. But in general, dementia has 3 basic stages. Each stage can last a few months to years. End-stage dementia is the last, and often most stressful, stage for both patients and families. Once this point is reached, your loved one's brain function will have severely declined. This will affect how the rest of your loved one's body functions. With end-stage dementia, your loved one may no longer:

- Recognize family members and friends
- Reason or have sound judgment
- Speak or understand language
- Have bowel and bladder control
- Eat or swallow correctly. You may have to consider tube feeding or using a device to provide nutrition. But many experts advise hand feeding instead.
- Walk correctly. They may need a wheelchair or may not be able to leave their bed.
- Do normal daily tasks, such as driving, handling finances, and making meals. They'll need constant care.

Advance care planning

It's important to try to plan ahead for care while your loved one is still mentally aware enough to make decisions. This can help your loved one stay away from treatments that they don't want or need. This care

planning usually takes the form of a written advance directive. This document outlines what healthcare your loved one does and doesn't want done when they're not able to speak for themselves. Your loved one should also have a healthcare proxy in place. This lists the person who'll make healthcare decisions for your loved one when they can't make or communicate those decisions.

Revisiting your loved one's care plan

Because of the extent of the physical and mental changes that can occur with end-stage dementia, your loved one's goals of care and treatment plan may need to change. Your loved one's healthcare provider and healthcare team can help guide you through this process. When meeting with the team, you and others included in your loved one's care may want to ask:

- How much longer does our loved one have to live?
- How can symptoms be managed at this time?
- What treatments might be helpful?
- What are the risks and benefits of these treatments?
- How will these treatments help with overall health and comfort?

These questions may lead to further discussions about end-of-life care. Although these discussions can be hard, remember that the goal is to provide the best care and quality of life for your loved one. Think about conversations you may have shared about the kind of treatments your loved one wants at the end of life. Think about their personal values or faith. Also ask for advice from those who share those values.

Considering care and placement options

With end-stage dementia, your loved one's caregiving needs will greatly increase. If you're still caring for your loved one at home, you may want to explore other care choices at this time. These may include:

- **Private sitter services.** A private sitter is a special type of caregiver. This person's main job is to watch and keep the person company. Sitter services are sometimes covered by long-term care insurance plans.
- **Placement in a nursing home or skilled nursing facility.** This type of facility helps with tasks of daily living. It also provides constant medical care. Trained healthcare providers, skilled nurses, and therapists are on site to help with care.
- **Hospice care.** This is end-of-life care that can be done in a skilled nursing facility, hospice center, or at home. Hospice care focuses on ensuring comfort and enhancing quality of life in the time your loved one has left. It also provides physical, emotional, and spiritual support for both patients and families.

Deciding whether to move your loved one to a facility or to end-of-life care can be upsetting. But know that you're not alone in this process. Your loved one's healthcare team can help address your questions and concerns. You can also get advice from a social worker, spiritual advisor, or attorney.

Getting support

Coping with your loved one's condition can wear you down over time. Grief, anger, fear, and worry—these are all normal emotions. Rather than dealing with your emotions alone, it may help to reach out to others. Talking with other family members and friends may help. Joining a support group for families and caregivers of loved ones with dementia may also help. You can get support from your loved one's healthcare team as well. You can also contact your county health department to find other local resources.

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