



Dementia: End-of-Life Care

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The progression of dementia takes a heavy toll on the person with dementia—and on family and friends as well. Among caregivers, feelings of depression and fatigue are common. Many families experience a wide range of feelings through the course of the illness as they accept loss incrementally. Some experts refer to the experience as “dementia grief,” which recognizes the painful and gradual loss of a loved one as dementia advances.

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What do families and caregivers need to know about end-of-life care? First, it helps to understand what to expect with late-stage dementia. Secondly, families can ensure that individual preferences are honored with advance planning and legal documents. In addition, education about hospice care can help families make choices that honor comfort and dignity. Especially at the end of life, family members and other caregivers can use sensory connections to deliver comfort to a loved one with [late-stage dementia](#).

Late-stage dementia

“Family members and caregivers face the heartbreaking task of adapting to evolving dementia symptoms and accepting a gradual loss of function in those they love,” explains the blog on late-stage dementia.

Signs that a person with dementia may be reaching the end of life include being unable to move around on one’s own, being unable to speak or make oneself understood, and eating problems such as difficulty eating or swallowing, explains the [National Institute on Aging](#).

Planning ahead

When it comes to personal values and preferences, conversations with a person who has dementia are crucial throughout the course of the illness. Legal and medical planning are no exception. While conversations about end-of-life can be emotionally difficult for everyone, attention to planning helps ensure that an individual’s choices are honored.

The [National Institute on Aging](#) (NIA) recommends that families use advance directives to communicate a person’s healthcare wishes. Documents instructing care should be provided to healthcare providers. Families can have conversations to ensure all wishes are understood.

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These steps are essential to person-centered care. Ideally, conversations about directives happen early in the course of dementia. Examples of documents to consider are:

- a durable power of attorney for health care, authorizing a designated person to make healthcare decisions
- a living will, instructing the team about options related to end-of-life care
- a do not resuscitate (DNR) order, which instructs healthcare professionals not to perform CPR in case of cardiac or respiratory failure

The National Institute on Aging offers an in-depth [conversation guide for advance care planning](#), available in English and Spanish, that can guide families through important communications and meaningful decisions.

Hospice care

Hospice is a specialized form of interdisciplinary medical care designed not to cure illnesses, but rather “to address physical, psychosocial, and spiritual needs of the person,” explains the [Hospice Foundation of America](#). A person-centered care model, hospice revolves around individual’s goals and preferences, aiming to provide comfort, preserve dignity, and support the highest possible quality of life. It is particularly holistic, in that it provides extensive support for family members, as well as bereavement care.

Hospice care services can be provided wherever “home” is for an individual, such as in a skilled nursing facility. With a physician’s order, hospice is covered by Medicare as well as many private insurers. At times, a nursing home resident may benefit from continuing psychological care, especially from a practitioner with whom they have rapport. Behavioral issues related to advanced dementia may still be present, warranting specialized attention. For facilities served by GuideStar Eldercare, psychological care may complement hospice services provided on-site with an order from the hospice medical director.

Experts say that many families avoid or delay using hospice services, missing the benefits that hospice can provide. But in public perception, hospice may be equated with “giving up,” and many families are uncomfortable making the decision to involve hospice services. Yet “proper end-of-life care ensures dignity, comfort and control for patients in the later stages of Alzheimer’s disease or other types of dementia,” says [AgingCare](#).



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Comfort: sensory connections

At the bedside, a caregiver may wonder how to connect. Making sensory connections involving sound, touch, or sight is a meaningful way to deliver comfort to a loved one who is in the final stages of dementia. The National Institute on Aging offers these ideas:

- Be present. Simply being there can be more calming than you realize.
- Feel free to talk to a loved one, even if they are unable to respond.
- Hold hands, use the power of touch, brush a person's hair, or offer a soothing massage.
- Listen to favorite music or play audio with sounds from nature.

Support for caregivers

Because of the progressive nature of dementia, a caregiver may go through a range of feelings and reactions over time, and these feelings can be very difficult. Caregivers and families can carry deep burdens of stress and sadness as they gradually lose a loved one to dementia.

In the GuideStar care model, specialized clinical psychologists and licensed clinical social workers provide emotional support as they help families process what is happening—and support families as they face loss.

At the end of life, “It is not uncommon for those who took care of a person with advanced dementia to feel a sense of relief when death happens,” explains the National Institute on Aging. “It is important to realize such feelings are normal.” An advantage of including hospice services is spiritual support and continued support through the grieving process.

The end-of-life realities with dementia are deeply challenging. Being prepared can help caregivers take steps that will help support dignity and comfort in these painful times.

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