

LONG TERM CARE COMMUNITY COALITION

Advancing Quality, Dignity & Justice

PALLIATIVE & HOSPICE CARE FOR INDIVIDUALS WITH DEMENTIA: WHAT FAMILIES NEED TO KNOW

FACT SHEET FOR INDIVIDUALS LIVING AT HOME OR IN ASSISTED LIVING

When a loved one is in the later stages of dementia, families often have questions about comfort, care, and what to expect. Navigating these decisions can be emotionally difficult and overwhelming, especially when trying to balance medical needs with personal wishes. Palliative and hospice care can provide important support during this time, focusing on comfort, dignity, and quality of life. These services help manage symptoms and ease stress for both the individual and their family.

This fact sheet provides an overview of palliative and hospice care for individuals living with dementia. Early planning and open communication with healthcare providers can help families make informed decisions about care access the right resources. For more resources, please visit our website, <https://nursinghome411.org/dementia-care-in-the-community>.

What is Palliative Care?

Palliative care provides relief from symptoms and emotional stress at any stage of a serious illness, including dementia. It helps people live as comfortably and meaningfully as possible—while continuing with other treatments, if desired.

What Does Palliative Care Offer?

- **Purpose:** Focuses on symptom management, emotional support, and improving overall quality of life.
- **Who Provides It:** A multi-disciplinary team of physicians, nurses, counselors, and spiritual advisors (if desired).
- **Where It's Offered:** Available in the home, long-term care facilities, outpatient clinics, and hospitals.
- **Who Qualifies:** Anyone with a serious illness, including Alzheimer's disease and related dementias.

What is Hospice Care?

Hospice care is a specialized type of palliative care for individuals nearing the end of life. It focuses on comfort rather than curative treatment, helping people live their final months with dignity and as little pain as possible.

What Does Hospice Care Offer?

- **Purpose:** Focuses on alleviating pain and managing symptoms to ensure the individual is as comfortable as possible.

- **Who Provides It:** A multi-disciplinary team of physicians, nurses, counselors, and spiritual advisors.
- **Where It's Offered:** At home, in hospitals, long-term care settings, or dedicated hospice facilities.
- **Care Approach:** Curative treatments are discontinued to prioritize comfort and quality of life.
- **Who Qualifies:** Individuals with a life-limiting illness and a life expectancy of six months or less (if the illness follows its typical course).

Why These Services Matter for People Living with Dementia

- **Symptom Relief:** Helps manage pain, agitation, anxiety, and other distressing symptoms.
- **Comprehensive Support:** Multi-disciplinary teams provide care coordination, emotional support, and spiritual guidance.
- **Family and Caregiver Support:** Provides caregiver education, respite care, and grief counseling.

Start the Conversation Early!

Early planning helps ensure that care reflects your loved one's values and wishes. Talk with healthcare providers about options, ask questions, and revisit decisions as circumstances change.

How Do I Know When It's Time for Palliative or Hospice Care?

- **Palliative Care:** Appropriate at any stage of dementia to improve comfort and reduce stress—often alongside other treatments.
- **Hospice Care:** Appropriate in the advanced stages, when curative treatments are no longer helping and the focus shifts to end-of-life comfort.

Commonly Asked Questions

Q: Can my loved one still live at home while receiving hospice or palliative care?

A: Yes. Both types of care can be provided in the home or in assisted living.

Q: Is it too early to ask about palliative care?

A: No. It's never too early. In fact, starting palliative care early can improve comfort, reduce hospital visits, and help families plan with less stress.

Q: Can my loved one get palliative care even if they're still active?

A: Yes. Palliative care is not only for end-of-life. It can begin at any stage of dementia to manage symptoms and improve quality of life.

Q: Does accepting hospice care mean my loved one will die soon?

A: Not necessarily. While hospice care is designed for individuals with a prognosis of six months or less, some people live longer, especially when they receive good symptom management. Hospice can even be extended if needed.

Q: What if we change our minds about hospice care?

A: Hospice is a voluntary service. You can stop hospice at any time if your loved one's condition improves or you choose to pursue curative treatment again.