

CARE Compass

Helping Navigate the Later Stages of Dementia



Moving to a Palliative Care Approach

This project was made possible by a generous gift.

The goal of the program is to help provide tools and information so that you can navigate the later stages of dementia. We hope that you find these videos and resources to be helpful and encouraging.

This program is designed to be a guide only for the compassionate care and support of your loved one and is not medical advice. If you have questions or concerns, always check with your doctor.

We also want to acknowledge that late-stage dementia can look very different from person to person. Sometimes the ideas we share may not work or work for a short time. That is okay. No one person is alike, and what works today may not work tomorrow. We hope to provide tools that can be options for you to try.

This guide contains links and other resources that may not be provided by the presenter but are added to the guide to provide additional information and support.

Moving to a Palliative Approach in Dementia

A palliative approach to dementia care focuses on comfort, dignity, and quality of life as the disease progresses. It does not mean giving up or stopping all medical care. Instead, it means adapting care to focus on what matters most to the person and their family.

Key points to remember:

- **Palliative care is not the same as hospice.** Palliative care can be introduced at any stage of dementia and can be provided alongside other treatments.
- **The focus may change over time.** In earlier stages, care may focus on maintaining function and independence. In later stages, some medications and interventions may become less helpful, and comfort may become the priority.
- **Treat the whole person.** A palliative approach considers physical, emotional, and spiritual needs.
- **Manage symptoms and discomfort.** Pain, anxiety, agitation, and other symptoms should be recognized and treated with the goal of maximizing comfort.
- **Support the caregiver, too.** Dementia caregiving can be extremely stressful. A palliative approach includes resources and support for caregivers and families.
- **Work as a team.** Care decisions may involve the person with dementia, family members, physicians, nurses, social workers, and other healthcare professionals.
- **Care can change gradually or suddenly.** Dementia often follows a gradual decline, allowing families to adjust care over time. A sudden illness, infection, stroke, or other medical event may require a rapid change in the plan of care.

Consider discussing with your healthcare provider:

- What are our loved ones' current goals of care?
- What treatments are still providing meaningful benefits?

- How can we best manage pain, anxiety, agitation, or other symptoms?
- What medications are no longer optimal in providing medical intervention and can be discontinued?
- Would a palliative care consultation be helpful at this time?

Websites With More Information

Palliative Care Education and National Resource Finder

<https://getpalliativecare.org/>

National Institute on Health- What is the difference between hospice and palliative care?

https://www.nia.nih.gov/health/hospice-and-palliative-care/what-are-palliative-care-and-hospice-care?mibextid=Zxz2cZ&utm_source=chatgpt.com

Making Decisions for Someone at the End of Life

<https://www.nia.nih.gov/health/end-life/making-decisions-someone-end-life>

Guardianship Resources

<https://www.justice.gov/elderjustice/guardianship-key-concepts-and-resources>

Tips

- ❖ Think about who would be assisting in making medical decisions for your loved one as physical care needs increase
- ❖ Collect and find paperwork that has your loved ones documented health care advocated or durable power of attorney
- ❖ Use caregiving communication apps on smart devices to deliver real time information with your loved one's care team members