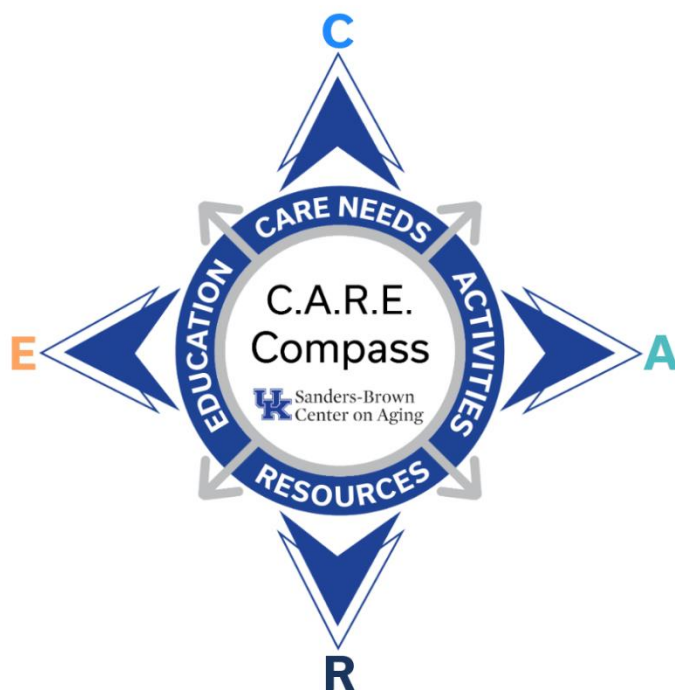


CARE Compass

Helping Navigate the Later Stages of Dementia



Importance of Clinical Care

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.

Importance of Clinical Care:

Shifting the Focus of Care

In the later stages of Alzheimer's disease, medical care is no longer focused on testing or diagnosis. Instead, the goal is to support comfort, dignity, and quality of life. Ongoing communication with healthcare providers remains essential to ensure your loved one receives the best care possible.

Care Options Beyond the Clinic

- Telemedicine: Video visits allow healthcare providers to check in, adjust treatments, and support caregivers without leaving home.
- Home-Based Medical Care: Some health systems offer in-home services. Ask your provider what is available in your area.
- Palliative Care: Focuses on managing symptoms such as pain, anxiety, sleep changes, and agitation while supporting both patient and family.
- Hospice Care: Provides comfort-focused care at the end of life and is often covered by Medicare and most insurance plans.

Preparing for Medical Visits

- Bring a current medication list
- Write down questions or concerns (changes in sleep, eating, behavior, etc.)
- Consider sending concerns ahead through a patient portal or written note
- If possible, have two caregivers present—one to assist the patient, one to speak with the clinician

Supporting the Caregiver

- You are not alone, support is available
- Healthcare teams can help manage symptoms and reduce caregiver stress
- Care can be provided at home, reducing the burden of travel and appointments

Key Message

Care in late-stage Alzheimer's should meet the patient where they are physically, emotionally, and medically—while prioritizing comfort and quality of life for both the individual and their caregivers.

Compassionate, comprehensive care is still possible—right from home.

Websites With More Information:

The link below should route you to the National Institute on Aging website reviewing Worksheets that are helpful when planning a doctor or medical provider visit.

<https://www.nia.nih.gov/health/medical-care-and-appointments/talking-your-doctor-worksheets>

Steps for Creating and Maintaining a Care Plan -A care plan is a form where you can summarize a person's health conditions, specific care needs, and current treatments.

<https://www.cdc.gov/caregiving/guidelines/index.html>

TIPS:

- ❖ Enroll in patient portals (Epic MyChart or Follow My Health) to communicate with providers. This can include sending a provider updates and requests (medication or appointment)
- ❖ Downloading a Pharmacy App, allowing you to order medication refills, or look up the current medication list.