

CARE Compass

Helping navigate the later stages of Dementia



Observing a Clinic Visit



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.

Making Medical Visits More Comfortable and Effective

Before the Visit:

Bring a written list of concerns and questions.

Include any changes in mood or behavior, sleep patterns, eating habits, walking or balance issues, recent falls, hallucinations or delusions, safety concerns (can they be alone), medication issues (refusing to take them, difficulty swallowing, etc.)

During the Visit

Caregiver input is essential. People living with dementia may have difficulty describing symptoms or remembering changes. Caregivers can help provide important information and support. Consider bringing a second support person. One caregiver can talk with the healthcare provider while the other helps reassure and comfort the patient.

Reducing Stress and Anxiety

Healthcare providers often adapt visits to the patient's comfort level by:

- Keeping visits focused and efficient
- Avoiding unnecessary testing
- Watching for signs of fatigue, restlessness, or anxiety
- Telehealth visits may be an option

Common Topics to Discuss

- Sleep difficulties
- Medication side effects
- Swallowing or choking concerns
- Behavioral changes
- Home safety

- Caregiver concerns and support needs

Medication Tips

If swallowing pills becomes difficult:

- Tell the healthcare provider.
- Ask whether medications can be changed to liquid, dissolvable, or easier-to-swallow forms.
- Never crush or alter medications without medical guidance.

Key Takeaway

Successful dementia care focuses on comfort, safety, and quality of life. Caregivers are valuable partners in the healthcare team and play an essential role in helping providers understand and address the patient's needs.

Resources:

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