CARE Compass

Helping Navigate the Later Stages of Dementia

Behavioral Disturbances

In Later Stages of Dementia

Sanders-Brown
Center on Aging

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.

Behavioral Responses – Late-Stage Alzheimer's

In the severe or late stages of Alzheimer's disease, behavioral responses are often the result of changes in the brain — especially in areas that control communication, perception, and emotional regulation. These reactions can vary, but commonly include:

Resistance to care
Pulling away, refusing assistance, pushing food away, or turning the head during meals or daily tasks.

Agitation or restlessness
Pacing, fidgeting, or becoming easily upset — especially in overstimulating or unfamiliar environments.

Increased confusion
Difficulty recognizing food, utensils, or even understanding what mealtime is for.

Difficulty recognizing bedtime, or the routine beforehand.

Difficulty knowing what day, month, or year

Difficulty recognizing loved ones; expects people to look like they did 30 or 40 years ago. Th

Withdrawal or disengagement
Loss of interest in eating, social interaction, or activities they once enjoyed.

Emotional distress
Crying, irritability, or sudden mood changes that may seem unprovoked.

Difficulty with sequencing (task breakdown)
Inability to follow the steps involved in eating — such as picking up utensils, scooping food, or chewing and swallowing in order.

Sensory-related reactions
Becoming overwhelmed by noise, lighting, or even the appearance of food, which can lead to refusal or agitation.

Changes in eating behaviors
Holding food in the mouth, spitting food out, overeating, or not recognizing when they are hungry or full.

It's important to view these behaviors as forms of communication rather than intentional actions. They often signal discomfort, confusion, fatigue, or unmet needs. Adjusting your approach — simplifying tasks, reducing stimulation, and offering reassurance — can help reduce these reactions and support a calmer experience.

Caring for someone in late-stage Alzheimer's disease can be incredibly demanding—especially when agitation becomes frequent. What I'd say to a caregiver in that situation is something like this:

First, **what you're seeing is part of the disease, not the person**. Agitation often comes from confusion, fear, pain, or being unable to communicate needs. Even if it feels personal in the moment, it isn't.

Second, **focus on comfort over correction**. At this stage, trying to reason or "bring them back to reality" can increase distress. Instead:

- Use a calm, gentle tone
- Keep sentences short and simple
- Offer reassurance rather than explanations
- Try to redirect attention (music, a familiar object, or a soothing activity)

Third, **look for triggers**. Agitation can be caused by things like:

- Physical discomfort (hunger, pain, needing the bathroom)
- Overstimulation (noise, too many people)
- Changes in routine
- Fatigue or "sundowning" (increased confusion later in the day)

Fourth, **create a calming environment**:

- Soft lighting
- Minimal noise
- Familiar items nearby
- Consistent daily routines

Fifth—and this is just as important—**take care of yourself**. This level of caregiving is exhausting. You're not failing if you feel overwhelmed. If possible:

- Ask for help from family or respite care
- Take short breaks when you can
- Talk to a support group (many caregivers find this incredibly validating)

Finally, **know when to seek medical guidance**. Sudden or severe agitation can sometimes be related to things like infections, medication side effects, or untreated pain.

Websites With More Information

The link below should route you to the National Institute on Aging website reviewing tips for managing agitation, aggression, and sundowning

https://order.nia.nih.gov/publication/tips-for-managing-agitation-aggression-and-sundowning

For more information about Treatments for adverse changes in behavior

https://www.alz.org/alzheimers-dementia/treatments/treatments-for-behavior

TIPS:

- Keep track via a notes app or in a small journal the adverse behaviors your loved one experiences. This helps when discussing care needs with medical providers.
  Make note of: time of day, activity at hand (e.g. eating or watching tv), the intensity of the behavior and the type of behavior (e.g. anxious or agitated).

- If you feel you or your loved one is in danger, keep a cell phone with you and take note of the bathrooms or bedrooms that have locks in case you need to barricade yourself and call 9-1-1.