

CARE Compass

Helping Navigate the Later Stages of Dementia



Common Medical Issues in Late-Stage Alzheimer's Disease

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.

In late-stage Alzheimer's disease, the brain gradually loses its ability to control many basic bodily functions. At this stage, care often shifts from managing memory and thinking problems to providing physical comfort, preventing complications, and supporting quality of life.

Common Medical Complications

Aspiration Pneumonia

- The most common cause of death in advanced Alzheimer's disease.
- Difficulty swallowing (dysphagia) can cause food, liquids, or saliva to enter the lungs.
- This can lead to serious lung infections requiring medical attention.

Urinary Tract Infections (UTIs)

- Often occurs due to loss of bladder control.
- May cause sudden increases in confusion, agitation, or changes in behavior (delirium).

Dysphagia (Difficulty Swallowing)

- Makes eating and drinking difficult.
- Can lead to weight loss, malnutrition, dehydration, and weakness.
- Increases the risk of aspiration pneumonia.

Immobility

- Many individuals eventually become unable to walk or sit independently.
- Can result in:
 - Muscle weakness and contractures
 - Joint stiffness
 - Pressure injuries (bed sores)

Incontinence

- Loss of bowel and bladder control is common.
- Requires careful skin care to prevent irritation and infection.

Decreased Eating and Drinking

- Eating and drinking much less- there brain does not sense hunger or thirst
- Loss of appetite is part of the disease progression
- Avoid forcing fluid or foods

Hyperorality

- Putting objects into the mouth or chewing on non-food items
- This does not indicate they are hungry or thirsty
- Do not assume they need food with this specific behavior
- Provide safe chew options

Sleep Changes

- Increased need for sleep 8 hours→10 hours→ 12 hours→16 + hours daily
- Frequent daytime napping
- Sleep helps the brain recover and maximizes waking time

Seizures

- Nearly 50% of people with late-stage dementia may develop seizures
- This can look like
 - Blank Staring
 - Unresponsiveness
 - Repetitive Behaviors
- What To Do
 - Turn the person onto their side
 - Protect them from injury
 - Time the seizure
- If the seizure lasts longer than five minutes, call 9-1-1

Muscle Changes and Contractures

- People can develop
 - Muscle stiffness
 - Spasticity (involuntary muscle contraction)
 - Contractures (tightening of the muscles)
 - Myoclonus (sudden jerking movements)
- These changes are part of disease progression
- Forcing arms or legs straight can be painful

Other Medical Concerns

Constipation

- Often caused by reduced movement and decreased fluid intake.

Falls and Fractures

- Changes in balance, coordination, and depth perception increase fall risk.

Pain

- Individuals may experience pain from arthritis, pressure sores, constipation, or other conditions. Because communication abilities decline, caregivers should watch for nonverbal signs such as:
 - Grimacing
 - Restlessness
 - Agitation
 - Withdrawal
 - Changes in behavior

Key Caregiving Reminder

Prompt recognition of infections, swallowing difficulties, pain, dehydration, and skin problems can improve comfort and help prevent serious complications. Care goals in late-stage Alzheimer's focus on safety, dignity, comfort, and quality of life.

Websites With More Information

The link below should route you to the National Institute on Aging website reviewing tips about care in the late stage of Alzheimer's.

<https://www.nia.nih.gov/health/alzheimers-caregiving/care-last-stages-alzheimers-disease>

The link below should route you to the Alzheimer's Association website for late-stage caregiving.

<https://www.alz.org/help-support/caregiving/stages-behaviors/late-stage>

TIPS:

- ❖ Watch closely for nonverbal signs of discomfort or pain. Check out our Learning to Assess Pain Scale video:
<https://www.youtube.com/watch?v=0oet5amhguk&t=3s>.
- ❖ Keep a journal if you feel there is medical concern.
This can include:
Eating and Drinking, Medications, Sleep Patterns, Toileting and Incontinence, Skin Integrity, Pain and Comfort