

late-stage care

Providing care and comfort
during the late stage
of Alzheimer's disease



Caring for a person with late-stage Alzheimer's

The journey to the late stage of Alzheimer's, sometimes referred to as severe Alzheimer's in a medical context, is part of the overall progression of the disease. It is a potentially lengthy process that can last from several weeks to several years. As the disease advances, the needs of a person living with Alzheimer's will change and deepen. Ultimately, intensive, around-the-clock assistance is usually required.

A person with late-stage Alzheimer's disease should always be treated with compassion and respect. It is important to focus on preserving quality of life, dignity and comfort.

When a person is entering the late stage, he or she is less able to express preferences and to tolerate medical interventions. It's important to consult with your physician to re-evaluate care goals and to make decisions about medical interventions, such as CPR, tube feeding and antibiotics. It's also important to discuss critical developments and decisions, such as admission to a nursing home, hospitalization and eventual palliative care, which focuses on relief of physical suffering and maintaining quality of life.

A person with late-stage Alzheimer's usually:

- › Has difficulty eating and swallowing.
- › Needs help walking and eventually is unable.
- › Requires full-time help with personal care, including toileting.
- › Is vulnerable to infections, especially pneumonia.
- › Loses the ability to communicate with words.



The Alzheimer's Association® suggests ways to provide care and comfort, and to maintain a connection with a person with late-stage Alzheimer's disease.

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This brochure provides guidance on the management of Alzheimer's and other dementias. It is not meant to replace a doctor's advice.

1. body and skin

In the late stage of Alzheimer's disease, the person typically becomes unable to walk. This inability to move around can cause skin breakdown (pressure sores) and joint "freezing."

To keep the skin and body healthy:

Relieve body pressure

Change the person's position at least every two hours to relieve pressure and improve blood circulation. Make sure the person is comfortable and that his or her body is kept properly aligned. Use pillows to support arms and legs. To avoid injury to the person and yourself, see a health care professional about the proper way to lift and turn the person.

Keep the skin clean and dry

The person's skin is fragile and can tear or bruise easily. Use gentle motions and avoid friction when washing. Clean the skin with mild soap and blot dry. Check daily for rashes, sores or breakdowns.

Protect bony areas

Because bony areas have little fat to protect them, use pillows or pads to protect elbows, heels, hips and other areas. If you use moisturizer on the person's skin, apply it gently and do not massage it into the bony areas.

Prevent "freezing" of joints

"Freezing" of the joints (limb contractures) can occur when a person is confined to a chair or bed. It's sometimes helpful to do range-of-motion exercises, such as carefully and slowly moving his or her arms and legs two to three times a day while the skin and muscles are warm, like right after bathing. Range-of-motion exercises are not for every individual and may not be appropriate throughout the progression of the disease. Consult with the doctor about the benefits of these exercises at various stages.

2. bowel and bladder function

A person with late-stage Alzheimer's disease may experience urinary and bowel incontinence for a number of reasons. If this occurs, see the doctor to rule out any medical problems, including a urinary tract infection or fecal impaction.

To help manage bowel and bladder function:

Set a toileting schedule

Keep track of when the person goes to the bathroom, and when and how much the person eats and drinks. This will help you learn the person's natural toileting routine. If the person is not able to get to the toilet, use a bedside commode.

Limit liquids before bedtime

Limit, but do not eliminate, liquids at least two hours before bedtime. Be sure to provide adequate fluids for the person to drink throughout the day to avoid dehydration.

Use absorbent and protective products

Using adult disposable briefs and bed pads at night can serve as a backup to the daytime toileting schedule.

Monitor bowel movements

It's not necessary for the person to have a bowel movement every day. If the person goes three days without one, however, he or she might be constipated. Adding natural laxatives to the person's diet, like prunes, or fiber-rich foods, such as bran or whole-grain breads, may help. Consult with the doctor if the constipation continues.

3. food and fluids

It's important for everyone to eat nutritious food and drink plenty of fluids. But this may be more of a challenge for a person with late-stage Alzheimer's because he or she may have trouble swallowing. This may cause food or drink to be inhaled into the airway and lungs, which can lead to pneumonia.

To help the person eat and drink safely:

Keep surroundings quiet and calm. Serve meals away from the TV and other distractions. If the person can eat at the table, use a simple setting with a plate or bowl, place mat, cup and utensils.

Allow enough time for meals

Don't rush the person or force eating. Find out which foods the person prefers. He or she may do better with smaller meals or snacks throughout the day rather than three large meals.

Comfortably seat the person

To aid digestion, make sure the person is in an upright position for 30 minutes after eating.

Adapt foods to the person's needs

Serve foods that can be picked up, chewed and swallowed easily and safely.

Encourage self-feeding

Sometimes a person will respond to cues to get started. Begin by putting food on a spoon, gently putting his or her hand on the spoon and guiding it to the person's mouth. Finger foods are easiest to eat without assistance in the late stage.

Assist the person with feeding, if needed

Offer food or drink slowly. Make sure it's swallowed before continuing. Alternate small bites of food with a drink. You may have to remind the person to chew or swallow. Don't put your fingers in the person's mouth; he or she could bite down.

Encourage the person to drink fluids

The person may not always realize that he or she is thirsty and may forget to drink, which could lead to dehydration. If the person has trouble swallowing water, try fruit juice, gelatin, sherbet or soup. To avoid burns, check the temperature of warm or hot liquids before serving them.

Thicken liquids

A person with dementia who has problems with swallowing is at higher risk for choking. Thicken liquids by adding cornstarch or unflavored gelatin to water, juice, milk, broth and soup. Or, buy food thickeners at a pharmacy or health care supply store. You can also try pudding or ice cream, or substitute milk with plain yogurt.

Monitor weight

While weight loss during the end of life is to be expected, it may also be a sign of inadequate nutrition or another illness, or the result of medication side effects. If weight loss is significant, consult with the doctor.

Know what to do if the person chokes

Difficulty swallowing can lead to coughing and choking. Learn the Heimlich maneuver to prepare yourself for an emergency. Check for classes at your local hospital or community center.

4. infections and pneumonia

A person with late-stage Alzheimer's disease is more vulnerable to infections because of his or her inability to move around.

To help prevent infections:

Keep the teeth and mouth clean

Good oral health reduces the risk of bacteria in the mouth that can lead to pneumonia. Brush the person's teeth after each meal. If the person wears dentures, remove and clean them every night.

Clean all soft tissues of the mouth

Use a soft toothbrush or a moistened gauze pad to clean the gums, tongue and other soft mouth tissues. Do this at least once a day to help prevent tooth decay and gingivitis (inflammation of the gums).

Treat cuts and scrapes immediately

Clean cuts with warm, soapy water and apply an antibiotic ointment. If the cut is deep, seek professional medical help.

Protect against the flu and pneumonia

The flu (influenza) can lead to pneumonia. It's vital for the person and his or her caregivers to get flu vaccines every year to help reduce the risk. A person can also receive a vaccine every five years to guard against pneumococcal pneumonia (a severe lung infection caused by bacteria).

5. pain and illness

Sudden behavior changes are often a result of pain. Promoting quality of life means keeping the person with dementia comfortable. This is more challenging at this stage of the disease because the person has

more difficulty communicating. If you suspect pain or illness, see a doctor as soon as possible to find the cause and get appropriate treatment. In some cases, pain medication may be prescribed.

To recognize pain and illness:

Look for physical signs

Pale or flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any body part can indicate illness.

Pay attention to nonverbal signs

Gestures, spoken sounds and facial expressions (e.g., wincing) may signal pain or discomfort.

Be alert to changes in behavior

Anxiety, agitation, trembling, shouting and sleeping problems can all be signs of pain.

10 tips for caring for a person with late-stage Alzheimer's

- 1 Treat the person with compassion and respect.
- 2 Focus on what the person can still do and enjoy.
- 3 Look for signs that the person might be in pain.
- 4 Get help from family and friends or professionals.
- 5 Encourage interaction with friends and family.
- 6 Communicate with sights, sounds, smells and touch.
- 7 Use music to engage the person.
- 8 Use a bendable straw to help with drinking.
- 9 If the person refuses to eat, find out why.
- 10 Contact the doctor if the person experiences significant weight loss.

6. personal connection

Because of the loss of brain function, people with late-stage Alzheimer's disease experience the world through their senses. While you may not be able to communicate with the person through words, you can use many other methods to show the person reassurance and love.

To keep the personal connection:

Comfort the person with touch

Touch can be a powerful connector. Hold the person's hand. Give a gentle massage to the hands, legs or feet. Gently brush his or her hair.

Stimulate the senses

The person may find joy in the smell of a favorite perfume, flower, food or scented lotion. He or she may enjoy how it feels to stroke a beloved pet or textured fabrics. If the person can walk with assistance or uses a wheelchair, he or she may benefit from going outside to look at a garden or watch birds. Gazing out the window may also be enjoyable.

Use your voice to soothe

It doesn't matter so much what you say — it's how you say it. Speak gently and with affection. Your tone can help the person feel safe and relaxed.

Play music and videos

Choose music the person enjoyed when he or she was young. Or use music related to the person's ethnic or spiritual background. Videos can also be relaxing. Choose one with scenes of nature that has soft, calming sounds.

Read to the person

Read a favorite story, poem, spiritual passage or blessing. The tone and rhythm of your voice can be soothing, even if the person does not understand the words.

Reminiscence and share

Fill a box with photographs and other items that reflect the person's interests, favorite activities or past work history. Ask the person to choose an item and share a story about it. Examples include a family photograph from a favorite vacation, a recipe of a traditional family dish or a military medal.

7. residential care

The amount of time needed to care for the person is one reason to decide to move to a new care setting. A person with late-stage Alzheimer's disease often requires 24-hour assistance. This around-the-clock care can be too difficult, especially for a sole family caregiver.

Alzheimer's and Dementia Caregiver Center

If you are researching your care options, looking for peer support or thinking about moving the person to a skilled long-term care setting, contact the Alzheimer's Association or visit our Alzheimer's and Dementia Caregiver Center at alz.org/care. This online resource center offers reliable information and easy access to resources, including: Alzheimer's Navigator®, Community Resource Finder, ALZConnected® and the Care Team Calendar to help you plan and coordinate care and get support.





alz.org/care

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- › Alzheimer's Navigator[®] – Assess your needs and create customized action plans.
- › Community Resource Finder – Find local resources.
- › ALZConnected[®] – Connect with other caregivers who can relate to your situation.



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alzheimer's association[®]

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's[®].

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