

Late-Stage Care

The late stage of Alzheimer's disease may last from several weeks to several years. Intensive, around-the-clock help is usually required.

For the person, it is important to focus on preserving quality of life and dignity. He or she should always be treated with compassion and respect.

Here are some care tips when the person is in the late stage:

Keep the skin and body healthy

A person with late-stage Alzheimer's disease can become bedridden or chair-bound. This inability to move around can cause skin breakdown, pressure sores and the "freezing" of joints.

Relieve body pressure and improve skin moisture by changing the person's position at least every two hours. Make the person comfortable and keep his or her body aligned. Use pillows to support arms and legs.

Learn how to lift the person. Avoid injury by seeing a health care professional about the proper way to lift and turn the person with dementia.

Use pillows or pads to protect bony areas such as elbows, knees, and hips. Apply moisturizer gently over bony areas; do not massage the lotion into these areas.

Maintain range of motion in the joints. "Freezing" of the joints (limb contractures) can occur when a person is confined to a chair or bed. Carefully and slowly move his or her arms and legs two to three times a day. See a physical therapist to learn the proper method for range-of-motion exercises.

Maintain bowel and bladder function

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

Set a toileting schedule. Keep a written record of when the person goes to the bathroom, and when and how much the person eats and drinks. This will help you track the person's natural routine, and then you can plan a schedule.

Use incontinence products. Adult briefs and bed pads at night can serve as a backup to the daytime toileting schedule.

Monitor bowel movements. It is not necessary for the person to have a bowel movement every day. If the person is constipated, add natural laxatives to the person's diet, like prunes or whole-grain breads.

Help the person eat and drink safely

The person with Alzheimer's may have trouble swallowing, which may cause food or drink to get into the airway and lungs. This can lead to pneumonia.

Allow plenty of time for eating. Mealtimes last longer now. Allow at least one hour for meals. Don't rush the person or force him or her to eat.

Make sure the person is in a comfortable, upright position. To help digestion, keep the person upright for 30 minutes after eating.

Choose soft foods that can be chewed and swallowed easily. The person may prefer bite-sized finger foods, like slices of cheese, tater tots or chicken nuggets. If he or she can no longer eat solid food, mash or puree it in a blender.

Make liquids easier to swallow. Swallowing problems put a person with dementia at higher risk for choking. Make liquids thicker by adding cornstarch or unflavored gelatin to water, juice, milk, broth and soup.

Prepare for choking. Difficulty swallowing can lead to coughing and choking. Be prepared for an emergency, and learn the Heimlich maneuver.

Monitor weight loss. While weight loss during the end of life is to be expected, it may also be a sign of inadequate nutrition, another illness or medication side effects. See the doctor to have weight loss evaluated.

Help prevent infections and pneumonia

The inability to move around in late-stage Alzheimer's disease can make a person more vulnerable to infections.

Keep the teeth and mouth clean. This reduces the risk of bacteria in the mouth that can lead to infection. Brush the person's teeth after each meal. Use a moistened gauze pad to clean the gums, tongue and other soft mouth tissues.

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.

Help prevent flu and pneumonia. The flu (influenza) can lead to pneumonia (infection in the lungs). It's vital for the person as well as the caregivers to get flu vaccines every year to help reduce the risk.

Recognize pain and illness

In the late stage, the person has more difficulty communicating pain. If you suspect pain or illness, see a doctor as soon as possible to find the cause. In some cases, pain medication may be prescribed.

Look for physical signs of pain, such as pale skin tone; flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body can indicate illness.

Keep track of the person's gestures, spoken sounds and the expressions on his or her face (wincing, for example) that may signal pain or discomfort.

Watch for changes in behavior. Anxiety, agitation, shouting and sleeping problems can all be signs of pain.

Residential and hospice care

A person with late-stage Alzheimer's often requires 24-hour assistance. This round-the-clock care can be too difficult for a sole caregiver. Moving the person to a residential care setting may be the best option.

Another option is hospice. The underlying philosophy of hospice focuses on quality and dignity by providing comfort, care and support services for people with terminal illnesses and their families.

To qualify for hospice benefits under Medicare, a physician must diagnosis the person with Alzheimer's disease as having less than six months to live.

End-of-life decisions

Ideally, discussions about end-of-life care wishes should take place while the person with the dementia still has the capacity to make decisions.

People with Alzheimer's have the legal right to limit or forgo medical or life-sustaining treatment, including the use of mechanical ventilators, cardiopulmonary resuscitation, antibiotics and artificial nutrition and hydration. These wishes can be expressed through advance directives.

Family members should not equate the refusal or withdrawal of treatment, including treatment for life-threatening illnesses (infections, hemorrhaging, heart attacks, etc.) as euthanasia or assisted suicide.

In fact, aggressive medical treatment may feel like torture to an individual who is in unfamiliar surroundings and does not understand the intentions of the care providers.

Related information; Late-Stage Care (PDF)

Medicare Hospice Benefit: Frequently Asked Questions fact sheet (PDF)

Hospice Foundation of America.

www.hospicefoundation.org

This site offers information on how to locate a hospice, questions to ask when selecting a hospice and resources related to hospice care and grief.

National Hospice Foundation.

www.hospiceinfo.org

This organization's site offers guidance in finding and selecting a hospice program. Medicare benefit information related to hospice services is also available.

National Hospice and Palliative Care Organization.

www.caringinfo.org

This site offers a variety of free resources on topics including advance care planning, hospice and palliative care, and grief and loss.