



Late-Stage Caregiving En Español

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

What to expect

As the disease advances, the needs of the person living with Alzheimer's will change and deepen. A person with late-stage Alzheimer's usually:

- Has difficulty eating and swallowing
- Needs assistance walking and eventually is unable to walk

Get support

Late-stage care decisions can be some of the hardest families face. Connect with other caregivers who have been through the process on our online message boards.

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- Needs full-time help with personal care
- Is vulnerable to infections, especially pneumonia

Your role as caregiver

During the late stages, your role as a caregiver focuses on preserving quality of life and dignity. Although a person in the late stage of Alzheimer's typically loses the ability to talk and express needs, research tells us that some core of the person's self may remain. This means you may be able to continue to connect throughout the late stage of the disease.

At this point in the disease, the world is primarily experienced through the senses. You can express your caring through touch, sound, sight, taste and smell. For example, try:

- Playing his or her favorite music
- Reading portions of books that have meaning for the person
- Looking at old photos together
- Preparing a favorite food
- Rubbing lotion with a favorite scent into the skin
- Brushing the person's hair

- Sitting outside together on a nice day

Late-stage care options

Since care needs are extensive during the late stage, they may exceed what you can provide at home, even with additional assistance. This may mean moving the person into a facility in order to get the care needed.

Deciding on late-stage care can be one of the most difficult decisions families face. Families that have been through the process tell us that it is best to gather information and move forward, rather than second guessing decisions after the fact. There are many good ways to provide quality care. Remember, regardless of where the care takes place, the decision is about making sure the person receives the care needed.

At the end of life, 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

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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.

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

Learn more: [Residential Care](#), [Hospice Care](#) and [End-of-Life Decisions](#) (PDF)

Food and fluids

One of the most important daily caregiving tasks during late-stage Alzheimer's is monitoring eating. As a person becomes less active, he or she will require less food. But, a person in this stage of the disease also may forget to eat or lose his or her appetite. Adding sugar to food and serving favorite foods may

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encourage eating; the doctor may even suggest supplements between meals to add calories if weight loss is a problem.

To help the person in late-stage Alzheimer's stay nourished, allow plenty of time for eating and try these tips:

- **Make sure the person is in a comfortable, upright position.** To aid digestion, keep the person upright for 30 minutes after eating.
- **Adapt foods if swallowing is a problem.** Choose soft foods that can be chewed and swallowed easily. Thicken liquids such as water, juice, milk and soup by adding cornstarch or unflavored gelatin. You can also buy food thickeners at a pharmacy or health care supply store, try adding pudding or ice cream, or substitute milk with plain yogurt.
- **Encourage self-feeding.** Sometimes a person needs 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. Serve finger foods if the person has difficulty using utensils.
- **Assist the person with feeding, if needed.** Alternate small bites with fluids. You may need to remind the person to chew or swallow. Make sure all food and fluid is swallowed before continuing on with the next bite.

- **Encourage 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. Always check the temperature of warm or hot liquids before serving them.
- **Monitor weight.** While weight loss during the end of life is to be expected, it also may be a sign of inadequate nutrition, another illness or medication side effects. See the doctor to have weight loss evaluated.

Learn more: [Food and Eating](#)

Bowel and bladder function

Difficulty with toileting is very common at this stage in the disease. The person may need to be walked to the restroom and guided through the process.

Incontinence is also common during late-stage Alzheimer's.

To maintain bowel and bladder function:

Home Safety Checklist

Download, print and keep the checklist handy to prevent dangerous situations and help maximize the person living with dementia's independence for as long as possible.

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- **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. 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 throughout the day to avoid dehydration.
- **Use absorbent and protective products.** Adult disposable briefs and bed pads can serve as a backup at night.
- **Monitor bowel movements.** It is not necessary for the person to have a bowel movement every day, but if there are three consecutive days without a bowel movement, he or she may be constipated. In such instances, it may help to add natural laxatives to the diet, such as prunes or fiber-rich foods (bran or whole-grain bread). Consult with the doctor if the constipation continues.

Learn more: [Incontinence](#)

Skin and body health

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 "freezing" of joints.

To keep skin and body healthy:

- **Relieve body pressure and improve circulation.** Change the person's position at least every two hours to relieve pressure and improve blood circulation. Make sure the person is comfortable and properly aligned. Use pillows to support arms and legs.
- **Learn how to lift the person.** A care provider, such as a nurse or physical therapist, can provide instructions on how to properly lift and turn the person without causing injury. Make sure not to ever lift by pulling on the person's arms or shoulders.
- **Keep skin clean and dry.** Since skin can tear or bruise easily, use gentle motions and avoid friction when cleaning. Wash with mild soap and blot dry. Check daily for rashes, sores or breakdowns.
- **Protect bony areas.** Use pillows or pads to protect elbows, heels, hips and other bony areas. If you use skin moisturizer on these areas, apply it gently and do not massage it in.
- **Prevent "freezing" of joints.** Joint "freezing" (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 moving the arms and legs two to three times a day while the skin and muscles are warm, like right after bathing. Consult with the doctor before starting these exercises.

Learn more: [Bathing](#) and [Dressing and Grooming](#)

Infections and pneumonia

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

To help prevent infections:

- **Keep the teeth and mouth clean.** Good oral hygiene 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 them and clean them every night. Also, use a soft toothbrush or 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.
- **Protect against flu and pneumonia.** The flu (influenza) can lead to pneumonia (infection in the lungs). It's vital for the person with

Alzheimer's as well as 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).

Pain and illness

Communicating pain becomes difficult in the late stages. 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.

To recognize pain and illness:

- **Look for physical signs.** Signs of pain and illness include pale skin tone; flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body.
- **Pay attention to nonverbal signs.** Gestures, spoken sounds and facial expressions (wincing, for example) may signal pain or discomfort.
- **Be alert to changes in behavior.** Anxiety, agitation, trembling, shouting and sleeping problems can all be signs of pain.

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