

LATE-STAGE CARE

PROVIDING CARE AND COMFORT DURING THE LATE STAGE OF ALZHEIMER'S DISEASE

10 TIPS FOR LATE-STAGE CAREGIVING

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

CARING FOR A PERSON IN THE LATE STAGE

The progression to the late stage of Alzheimer's, which is sometimes referred to as severe Alzheimer's in a medical context, is a potentially lengthy process that can last from several weeks to several years. As the disease advances, the person's needs will change and deepen.

When a person is entering the late stage, he or she is less able to express preferences and to tolerate medical interventions. Ultimately, intensive, around-the-clock assistance is usually required. It's important to consult with your doctor to reevaluate care goals and 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 hospice care, which focuses on relief of physical suffering and maintaining quality of life.

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

BODY AND SKIN

In the late stage of Alzheimer's, 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 properly aligned. Use pillows to support arms and legs. Seek professional advice 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

Use pillows or pads to protect elbows, heels, hips and other bony areas. If you use skin moisturizer, apply it gently and do not rub it in.

Prevent “freezing” of joints

Joint “freezing” (limb contractures) can occur when a person is confined to a chair or bed. It can be 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 a doctor before beginning an exercise routine.

BOWEL AND BLADDER FUNCTION

If the person living in the late stage of Alzheimer's experiences urinary or bowel incontinence, 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

Identify the person's natural routine by keeping track of when the person uses the bathroom, and when and how much they eat and drink. If mobility is limited, 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. A bowel movement is not necessary every day. However, if the person goes three days without one, they might be constipated. Natural laxatives, like prunes or fiber-rich whole-grain bread, may help. Consult with the doctor if the constipation continues.

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 in the late stage of Alzheimer's who may have trouble swallowing. This may cause food or drink to be inhaled into the 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, but do try to figure out food preferences. The person may do better with smaller meals or snacks throughout the day rather than three large meals.

Comfortably seat the person

To aid digestion, keep the person 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

Place food on a spoon, gently wrapping the person's hand around the handle and guiding it toward his or her mouth. Finger foods are easiest to eat without assistance at this stage of the disease.

Assist the person with feeding, if needed

Offer food and 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. Avoid putting your fingers in the person's mouth — they could bite down.

Encourage fluid consumption

The person may not always recognize thirst and may forget to drink, which could lead to dehydration. If the person has trouble swallowing water, try fruit juice, sherbet or soup. Always check the temperature of warm or hot liquids before serving them.

Thicken liquids

A person living with dementia who has problems with swallowing is at higher risk for choking. 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.

Monitor weight

While weight loss during the end of life is 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 a doctor.

Know what to do if the person chokes

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

INFECTIONS AND PNEUMONIA

A person in the late stage of 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 that can lead to pneumonia. Brush the person's teeth after each meal. If dentures are worn, 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 mouth tissues. Do this at least once a day to help prevent tooth decay and gingivitis.

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

Influenza (the flu) can lead to pneumonia. It's vital for the person and their caregivers to get annual flu vaccines to help reduce the risk. A person can also receive a vaccine every five years to guard against pneumococcal pneumonia (a severe bacterial lung infection).

PAIN AND ILLNESS

Sudden behavior changes are often a result of pain. It's important to keep the person living with dementia comfortable, although this can be challenging because they have more difficulty communicating. If you suspect pain or illness, see a doctor 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 may signal pain or discomfort.

Be alert to changes in behavior

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

PERSONAL CONNECTION

Because of the loss of brain function, people in the late stage of Alzheimer's experience the world through their senses. While you may not be able to communicate through words, you can use other methods to show 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 hand, leg or foot massage. Gently brush his or her hair.

Stimulate the senses

The person may find joy in the smell of a favorite flower, food or scented lotion. They may enjoy how it feels to stroke a beloved pet or textured fabrics. If the person can walk with assistance or uses a wheelchair, they may enjoy gazing out the window or venturing outside to look at a garden.

Use your voice to soothe

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

Play music and videos

Choose music the person enjoyed when they were young, or that is related to the person's ethnic or spiritual background. Videos with nature scenes and soft, calming sounds can also be relaxing.

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.

Reminisce and share

Fill a box with photographs and other mementos, such as a recipe for a family dish or a military medal. Ask the person to choose an item so you can share a story about it.

RESIDENTIAL CARE

A person in the late stage of Alzheimer's disease often requires 24-hour assistance. This level of care may be too difficult for some to handle, especially a sole family caregiver.

Online caregiver resources

If you're looking for care options, seeking peer support or thinking about moving the person to a skilled long-term care setting, visit alz.org/care. Here you'll find reliable information and easy access to tools to help you plan and coordinate care and find support.

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