

Alzheimer's Disease or Other Dementias

Late Stage

Because Alzheimer's disease or other dementias are generally progressive, a person can transition from being fairly independent to being almost totally dependent over a short period of time. CAREGiversSM may be working with people in the late stage of dementia either in the individual's home or in living communities. In both cases, the CAREGiver will likely work side-by-side with family members and other providers. Late stage is the time when symptoms become more severe and the individual likely will require around-the-clock supervision and care. Late stage may last from several weeks to several years.

Possible symptoms may include:

- Difficulty walking
- Loss of ability to verbally communicate
- Incontinence
- Increased susceptibility to infections
- Extreme fatigue
- Difficulty swallowing
- Loss of appetite
- Lack of energy
- Minimal participation in activities
- Need for full-time help with activities of daily living (ADLs)
- Greatly diminished memory

HOSPICE AND PALLIATIVE CARE

As a person's dementia progresses, he or she will experience a gradual decline in health. When an immediate explanation for this health decline is not known, this is typically referred to as "failure to thrive". The symptoms from this progression commonly include weight loss, decreased appetite, poor nutrition and inactivity. The individual also can show signs of depression, dehydration and decreased cognitive function. When symptoms are more noticeable, the individual's doctor may conduct additional evaluations and eventually admit the individual to hospice care.

Often times when hospice care is discussed, there can be a misunderstanding that death is imminent. This is not always the case when a person is living with Alzheimer's disease or another dementia. Failure to thrive means that an individual, due to cognitive impairment, might struggle to improve and continue to experience a steady decline. He or she may be walking and talking, but also be at high risk for continued decline.

When an individual is receiving hospice care, a hospice team will generally coordinate medical oversight, service coordination and help with personal care. If the individual is receiving hospice care, you should introduce yourself to the team and generally follow its direction to the extent it is within your franchise office's scope of services. Contact the franchise office with any questions or concerns.

INDIVIDUAL CARE

Each person you care for has unique qualities. They may not do the same things they used to do, but they likely desire to maintain their usual routines.

Listed below are a few tips to help you support quality of life for a person in this late stage. Remember that these tips may not apply for every individual situation.

Use information from the individual's past

Even if an individual struggles communicating verbally, they may still enjoy old hobbies and pastimes, such as looking at scrapbooks, reading from a favorite book or holding and looking at some favorite possessions (ex., a handmade quilt, a childhood toy, or their collection of ceramic bunnies.) Depending upon their health situation, the person may still be able to enjoy some of his or her favorite foods, desserts or beverages (check with the family to be sure swallowing isn't an issue.)

Enjoy music

A person in the late stage may still enjoy singing (even if they don't know the whole song) or listening to favorite music. Most homes will have a music player of some kind (even the local cable television has music channels). If music isn't available and you think it would benefit the individual contact the franchise office for assistance.

Touch the spirit

Many people may have religious or spiritual traditions. Consider reading from the individual's favorite spiritual passage or singing a church or religious spiritual song that the individual has known or enjoyed.

Get outside

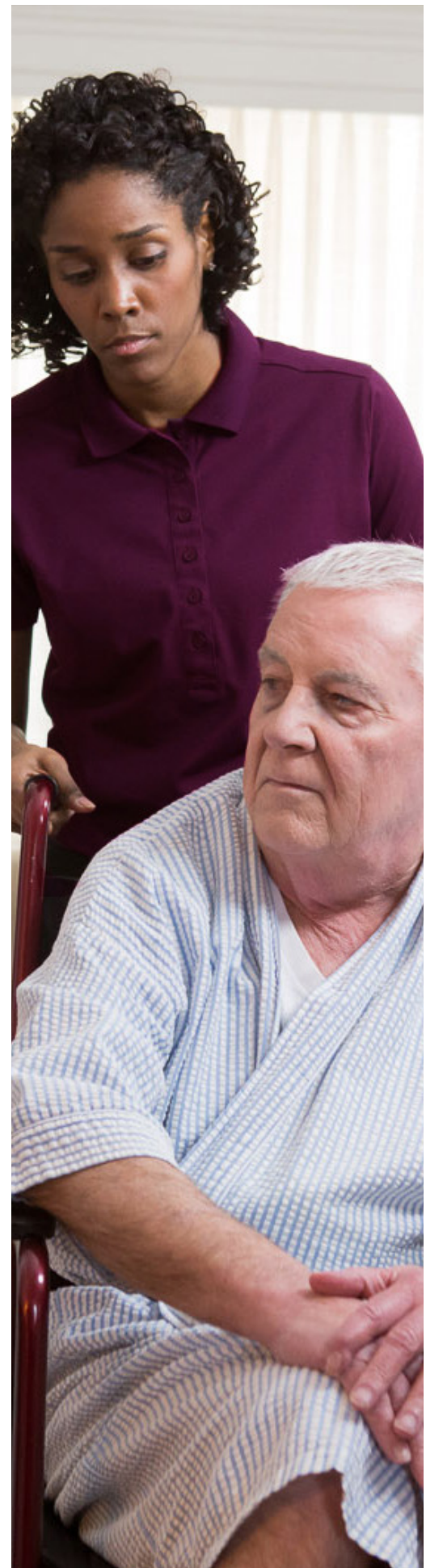
Even in the late stage, a person may enjoy sitting outside or on the patio on a beautiful day. Getting outside for some fresh air is sensory, can be spiritual, and may help to fight depression. Take care to have the person wear a hat if needed and/or be dressed appropriately for the weather. If the individual is in a facility, work with that team to coordinate any logistics (like a wheelchair) to help the individual spend time outside.

Show respect

If you think the individual doesn't understand you, ask for permission to do something. Never talk (or communicate nonverbally) in front of the person as if he or she isn't there.

Recognize, report and record

The individual's symptoms may worsen over time. If you recognize sudden changes in the individual's health, behavior, appetite, alertness or mood, immediately report your observations to the franchise office and record this information.



PERSONAL CARE

If the individual continues to live at home, you may be asked to assist with personal care. A key part of providing dignified care is helping the individual keep up with his or her personal care; for example, a bath, clean hair and clean clothes all can add to the individual's happiness and sense of well-being. Listed in this section are some personal care tips, across a variety of areas, to help you maintain the individual's routine.

EATING AND DRINKING

A person in late stage may lose her appetite or forget to eat or drink. It is important for the individual to stay nourished and hydrated; figure out the best way to encourage the individual to eat and drink. Listed below are some tips to assist with eating and drinking.

- Allow the person to do as much as they can on their own
- Cut food into smaller pieces
- Make finger foods
- If physician prescribed, add thickening agents to fluids
- Ensure the individual posture doesn't inhibit proper digestion
- Offer choices.
- Make the dining experience a social experience

If receiving palliative care, the individual may have a prescribed diet. It is important to help the individual follow this diet and immediately report any changes or concerns to the franchise office.

BATHING

Some individuals in late stage can be resistant to bathing. They may think they have already bathed or that they don't need a shower or bath (even if they have not had a shower or bath for days). Some persons with dementia seem to be afraid of water or getting their head wet. In some cases, bathing becomes easier if the individual takes sponge baths.

Listed below are some tips to assist with bathing.

- Give the individual as much independence as possible, and always explain your actions
- Be patient
- Ensure the room is a comfortable temperature
- Be reassuring and comforting
- Play the individual's favorite music (be sure to keep any plugged-in devices a safe distance from all water sources)
- Use the individual's favorite soap or lotions
- Watch for body language that may indicate pain or discomfort
- If the individual is unable to communicate, ask the family for personal preferences

GROOMING AND DRESSING

People in late stage Alzheimer's disease may lose the ability to safely perform familiar personal care tasks.

The individual's family may offer good information that can help you during grooming and dressing. Understand the individual's preferences so you can help to sustain his or her way of life. Knowing these preferences also can help you engage the person in conversation.

Listed below are some tips to assist with grooming.

- Be attentive to potential safety issues (ex., make sure the floors are not slippery, store all liquids and sharps/razors in a cabinet away from the person's sight, encourage use of grab bars)
- Get organized. The person with late stage dementia may have a very short attention span. Get your towels or personal care items all organized and ready to go before you start.
- Be a partner. This helps the person maintain dignity and feel part of the process.
- Keep the mood upbeat. If you are stressed and worried during grooming the person will pick up your mood. If you can be relaxed, confident and encouraging (ex., "we will get through this together") the individual will likely feel your mood and work with you instead of in opposition!

If you think the individual would benefit from home modifications, or if you need specific items to make the grooming experience better, immediately call the franchise office.

Listed below are some tips to assist with dressing.

- **Find out how the person dressed in the past.** Was she always well dressed and groomed and more formally dressed (ex., skirt and blouse), or did she like to keep it casual? Did the individual have breakfast in his pajamas and robe, or did he like to get dressed for breakfast? While a person in late stage may not be wholly aware of his or her appearance, efforts should be made to keep the person dressed as he or she would have wanted.
- **Simplify clothing.** In late stages of dementia, clothing with buttons and zippers may add difficulty to a person's routine. Work with the family to simplify the wardrobe.

TOILETING

The toileting process may become more difficult as the disease progresses. The individual may be fully incontinent and need to use absorbent undergarments. If the individual is able to walk, he or she may need assistance walking to the restroom and conducting personal hygiene.

Listed below are some tips to assist with toileting.

- Develop a routine
- Limit liquids before bedtime
- Plan ahead. The individual may have unplanned voids in the night. Use incontinent products, including briefs and pads.
- Respect the individual's dignity
- Avoid terms like "diaper" or "potty".

USE THE FIVE SENSES

Keeping an individual engaged can be challenging. Focusing on the five senses (touch, hearing, smell, sight and taste) may help.

- **Touch** - Providing a comforting touch, such as holding hands, can be a good way to communicate.
- **Hearing** - Build music and sound into the day. Look through the individual's CD collection or ask the family about his favorite music. Take in the outdoors and listen to the birds chirp or wind blow.
- **Smell** - Take a walk through a garden to smell flowers or find the individual's favorite perfume and let her wear it.
- **Sight** - Take a drive to look at landscapes and scenery. Look through photo albums, catalogues and magazines.
- **Taste** - Go through old cookbooks together and prepare the individual's favorite foods.

TAKING CARE OF YOURSELF

You may experience emotional feelings when an individual you have cared for no longer remembers your name or cannot do the same things she used to. You may experience sadness and feelings of loss as the individual care needs become more demanding.

Listed below are some tips for taking care of yourself.

- Do something that makes you happy
- Stay active with hobbies or other interests
- Exercise regularly
- Eat well-balanced meals
- Drink plenty of fluids
- Get plenty of sleep
- Practice relaxation techniques (ex., breathing exercises, yoga, stretching)

Call the franchise office if you need to talk to someone about your feelings of sadness or loss.

As clergy and social workers visit the individual, feel free to ask them for words of support after their visit with the individual. They may have wisdom to share with you.

OTHER RESOURCES:

Personal Care Skills

Hospice and Palliative Care Training