

Progression

Alzheimer Society

LATE STAGE

This document is one in a five-part series on the stages of Alzheimer's disease and is written for the person with the disease, their family¹ and caregivers. The late stage of the disease is featured in this sheet. For information on the other stages of the disease, please see the following sheets in the series: *The Progression of Alzheimer's Disease – Early Stage; Middle Stage; and End of Life*. For a general overview of the disease, its stages and the approach to care, please see the *The Progression of Alzheimer's Disease – Overview* sheet.

What is Alzheimer's disease?

Alzheimer's disease is a disease of the brain where abnormal proteins collect in brain cells. Alzheimer's disease causes symptoms of dementia such as memory loss, difficulty performing daily activities, and changes in judgement, reasoning, behaviour, and emotions. These dementia symptoms are irreversible, which means that any loss of abilities cannot come back.

Alzheimer's disease is a common form of dementia; however, there are many others. Other irreversible dementias include vascular dementia (due to strokes), Lewy Body disease, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease, and Huntington's disease.

These conditions can have similar and overlapping symptoms, and many of them can only be diagnosed with certainty by autopsy of the brain.

There is currently no cure for Alzheimer's disease. However, there are treatment options and lifestyle choices that may slow it down. Researchers continue to look for ways to prevent or stop Alzheimer's disease and bring back lost abilities and memory.

The late stage - what to expect

In the late stage of the disease (also referred to as "severe" or "advanced Alzheimer's disease"), individuals experience increased mental and physical deterioration and need 24 hour care. Individuals in the late stage:

- Experience severe impairment in memory, ability to process information and orientation to time and place.
- Lose their capacity for recognizable speech, although words or phrases may occasionally be uttered; nonverbal communication will become increasingly important.
- Need help with eating and using the toilet and are often incontinent of urine and stool.
- Lose the ability to walk without assistance, then the ability to sit without support, the ability to smile, and the ability to hold their head up. The brain appears to no longer be able to tell the body what to do.

¹ The term family includes anyone in the supportive network of people with dementia.

- May have impaired swallowing.
- May lose weight.

Because the person with late stage Alzheimer's disease cannot initiate activity alone, family and caregiver involvement is necessary, and in many cases, the person will need to live in a long term care home, or, if at home, with added support.

Whether at home or in a long term care home, the goal for late stage Alzheimer care should be enhancement of the quality of life – to be at the highest level of well-being possible – physically, mentally and emotionally.

Activities should be tailored to remaining strengths and abilities, taking into consideration the person's life history, likes and dislikes.

Suggestions for providing care in the late stages of Alzheimer's disease

1. Connect through the senses

Even if the person can't communicate verbally or no longer recognizes you, they likely will still be able to communicate in other ways and feel your affection and reassurance. People in the late stages experience the world primarily through their senses to maintain connections.

- **Touch:** Hold the person's hand. Brush their hair. Give a gentle massage to the hands, legs or feet. The person may find that stroking a pet or a soft fabric is calming.
- **Smell:** The person may enjoy the smell of a favourite perfume, flower or food which brings back happy memories.
- **Vision:** DVDs can be relaxing for people with Alzheimer's disease, especially ones with scenes of nature and soft, calming sounds.
- **Hearing:** Reading to the person can be comforting, even if they may not understand the words. The tone and rhythm of your voice may be soothing. What you say is not as important as how you say it. Speak gently and with affection. Your tone can help the person feel safe and relaxed. Read a favourite story or poem.
- **Play music** especially the type of music the person has enjoyed throughout their life. Music is a universal language that promotes meaning for most of us.
- **Get outside.** Sit in the garden, go for a short walk or if in a wheelchair, find a flat accessible route. Make it a daily habit! Time spent outdoors may help relieve anxiety and depression and encourage healthy sleeping patterns. When the weather is poor, consider sitting near a window or visit a greenhouse if one is available.

2. Reminisce

Reminiscing is a way to validate the "being" of a person and a way for the person to feel "I am here. I have a history".

- Fill a box with items that represent the person's interests, favourite activities, past work and happy memories from the past. Use these to connect to the person or foster conversation when the person is able.
- Look at photographs or DVDs of past events.
- Tell stories about past celebrations and enjoyable times.

3. Spirituality

- For many people, being part of a faith community is an important component of their identity. Tapping into the spiritual traditions which have been a significant part of the person's life can provide solace, continuity and a sense of self. Providing access to familiar rituals, symbols and music can trigger memories and connect with a person at a deeply emotional level when cognitive abilities have been severely impaired.
- Spirituality can take many forms. Often, connecting to nature, music, ritual or stories can fulfill a person's spiritual needs.

Care issues

Below are some of the physical care issues which often occur in the late stage. The following tips may help achieve maximum health and comfort. Consult your health care provider on specific techniques or if you have any questions.

1. Difficulty swallowing food and liquids

- Provide meals in a quiet and calm environment, away from television and distractions.
- Ensure the person is in a comfortable, upright position during and after a meal.
- Allow plenty of time for the person to eat; several smaller meals or snacks throughout the day may be easier to manage than three bigger meals.
- Foods that are soft or bite-sized may be easier to handle; be prepared for the possibility of choking as swallowing becomes more difficult.
- Encourage the person to feed themselves by giving visual cues or gently using hand-over-hand prompting. If the person needs assistance, offer the food and drink slowly - you may have to remind the person to swallow. Finger foods that do not require the use of cutlery can promote independence. Put one plate and utensil at their place to simplify the environment.
- Encourage fluid intake; substitute fruit juice, gelatin, sherbet, or thickened liquids if swallowing water is difficult.
- Record the person's monthly weight.
- Ask for a referral to a dietician to determine dietary needs and additional ideas for nutrition.

2. Caring for the skin and body

- If the person is bed-ridden or chair-bound, change the person's position at least every two hours to relieve pressure. Consult a health care provider about the proper technique to lift and turn the person.
- Protect bony areas with pillows and pads.
- Wash the skin gently and blot dry using minimal force and friction.
- Prevent "freezing" of the joints by maintaining the person's range of motion. A physiotherapist can demonstrate the proper technique for range of motion exercises.

3. Maintaining bladder and bowel function

- Set a toileting schedule.
- Eliminate caffeinated drinks, which stimulate urination.
- Provide adequate hydration during the day, but limit liquids at least two hours before bedtime.

- Use adult briefs, bed pads and mattress covers as needed.
- Monitor bowel movements.

4. Decreasing the risk of infection and monitoring for pain

- Pay careful attention to oral hygiene.
- Treat cuts and abrasions immediately.
- Make sure that the person receives an annual flu vaccine.
- People with late stage Alzheimer's disease may have difficulty communicating pain and family members and caregivers must learn other ways of recognizing pain and illness.

Watch for the following signs and report them to your health care provider:

- A pale or flushed skin tone; dry, pale gums; mouth sores; vomiting; feverish skin; or swelling of any part of the body
- Body language and nonverbal signs that may indicate discomfort (i.e. wincing, moaning)
- Changes in behaviour (especially anxiety, agitation, shouting, withdrawal and sleep disturbances)

Planning

1. Care

Refer to and follow any documents that the person with the disease has established to address his or her care wishes. If plans are not already in place, start the process as soon as possible. Establish who will be responsible for making care decisions. Follow the person's wishes, if you know them. Otherwise, decisions will need to be based on the person's lifelong values and desires and what you think the person would want. Your local Alzheimer Society can advise you about care issues and the kinds of professionals who can help to address them.

The person with the disease may be living at home with a family member, have help coming into the home or, in many cases, is residing in a long term care home. If you are caring for someone at home, you will need to have close connections to a physician and all or some of the following: visiting nurse, social worker, occupational therapist, home support services. They will be critical in working with you through this stage of the disease, helping you create a plan for the best care possible and meeting with you regularly to review the plan. Also, learn about the services that will be available as the person's disease progresses and both your needs change (home care services, respite care, community programs like Meals on Wheels and long term care homes). If considering a long term care home, learn what to look for and how to make the move as easy as possible.

If the person resides in a long term care home:

- Talk to staff about the person's unique interests, likes and dislikes to make sure they understand who the person was before the disease. Check out the All About Me booklet, a resource to share with staff to help them learn more about the person. The booklet can be found at alzheimer.ca/allaboutme.

- Keep current with the doctor and/or home's staff about the person's condition, care and treatment.
- Find out the key contacts for specific areas of caregiving (e.g., medical, social and spiritual).
- Tell staff your feelings and concerns, what help you need or questions you may have.
- Ask to have regular care planning meetings where family members and care providers can attend.
- Ask for a copy of the care plan.
- Discuss options for meeting the person's needs and preferences. Ask questions if you need terms or procedures explained.

2. Legal and financial

If not already in place, arrange financial and legal matters and establish who will be responsible for these functions. Follow the person's wishes, if you know them. If there are no explicit instructions for these matters, the family must make decisions taking into consideration the person's values, desires and what they believe the person would have wanted. Your local Alzheimer Society can advise you on what issues will need to be addressed and the kinds of professionals who can help with them.

More suggestions - taking care of yourself

Despite your best efforts, providing care will become more difficult as the disease progresses, and the person you are caring for becomes more dependent on you. This is a time when many family members need increased support for themselves. The following tips are to help family members take care of themselves.

- Avoid isolation and loneliness by maintaining social activities and contacts as much as possible.
- Take care of your own health, eat well and exercise.
- Learn what happens in this stage of the disease.
- Join a caregiver support group to connect with others living with the day-to-day issues of Alzheimer's disease and facing practical challenges, grief and loss.
- Be aware of the signs of stress and how it can affect your health and ability to provide care.
- Seek professional help if feelings of depression or anxiety are overwhelming.
- Be flexible about expectations.
- Try to be positive and keep a sense of humour.
- If the person you support is not in a long term care home, make time for yourself by using respite care options, professional home care services, family members or friends, volunteer caregivers and friendly visiting programs.

What's next?

Because Alzheimer's disease is progressive, you will continue to need more information and support. You may want to take time in this stage of the disease to think about what is important to you in the years that you live with Alzheimer's disease. The next sheet in this series is *The Progression of Alzheimer's Disease – End of Life*. Learning how the disease progresses and the changes that it will bring can help you to make plans for the future. However, only you can decide when is the right time to seek more information.

Help and support from the Alzheimer Society

Living with Alzheimer's disease at any stage can be very challenging. Whether you are the person with the disease or someone who supports them, it is normal to feel a variety of emotions including grief and loss throughout all stages of the disease. It is important to acknowledge your feelings, care for yourself and seek the practical help and emotional support that you need.

The Alzheimer Society in your community can provide educational resources to help you learn more about the disease, referrals to help you access the practical support you need, and one-on-one and group support to help cope with the emotional impact of the disease. Contact your local Alzheimer Society or visit www.alzheimer.ca.

Useful resources

The Progression of Alzheimer's Disease - Overview; Early Stage; Middle Stage; Late Stage; and End of Life information sheets. Alzheimer Society of Canada (2016)

Guidelines for Care: Person-centred care of people with dementia living in care homes, Alzheimer Society of Canada (2010).

Shared Experiences - Suggestions for those with Alzheimer's Disease. Alzheimer Society of Canada (2013). Also available in audio files at www.alzheimer.ca/sharedexperiences

All About Me. Alzheimer Society of Canada (2013). This fillable PDF booklet gives information about the individual's needs, preferences, likes, dislikes and interests. Available at www.alzheimer.ca/allaboutme

Day-to-Day Series - Communication. Alzheimer Society of Canada (2010)

Day-to-Day Series - Personal Care. Alzheimer Society of Canada (2010)

To learn more about the ***MedicAlert® Safely-Home® program*** or to register, please visit www.alzheimer.ca/en/Living-with-dementia/Day-to-day-living/Safety/Safely-Home.

Ambiguous Loss and Grief for family members. Alzheimer Society of Canada (2013)

The Alzheimer Society of Canada offers a wide variety of free information sheets and brochures. To learn more, please visit our website at www.alzheimer.ca/brochures.

Note: This information sheet provides guidance but is not intended to replace the advice of a health care professional. Consult your health care provider about changes in the person's condition, or if you have questions or concerns.

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Alzheimer Society of Canada
20 Eglinton Avenue West, 16th Floor, Toronto, Ontario M4R 1K8
Tel: 416-488-8772 1-800-616-8816 Fax: 416-322-6656
E-mail: info@alzheimer.ca Website: www.alzheimer.ca
Facebook: facebook.com/AlzheimerSociety Twitter: twitter.com/AlzSociety

