

Progression

Alzheimer Society

OVERVIEW

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. This overview provides a summary of the stages and information on end-of-life issues. It also includes a modified Global Deterioration Scale² (GDS), a tool commonly used by health care providers to measure the progression of the disease and to classify symptoms often seen at each stage. Detailed information on each of the stages, including suggestions for living with the disease, can be found in four separate companion sheets entitled *The Progression of Alzheimer's Disease – Early Stage; Middle Stage; Late Stage; and End of Life*.

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, 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.

Approach to care

The approach to care that is reflected in this series is one that focuses on the person living with Alzheimer's disease. By understanding a person's life experiences, support systems, personality and ways of coping, the individual's physical, social, emotional and spiritual needs can be better met. While the person's needs change as the disease progresses, the basic needs for overall health and security, stimulation, connection, self-esteem and affection remain. At the forefront of a person-centred approach to care is the belief that each individual with Alzheimer's disease, like all human beings, deserves to be treated with dignity and respect.

A key point to remember is although a person loses many abilities as the disease progresses, it is important to focus on the abilities that remain. People in the early to middle stages of the disease can participate in decision-making and planning for the future and, with the person's wishes and values

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

² Reisberg, B., Ferris, S.H., de Leon, M.J., and Crook, T. (1982). Global Deterioration Scale (GDS), *American Journal of Psychiatry*, 139:1136-1139.

expressed early on, living with Alzheimer's disease can be less stressful. Throughout all stages of the disease, enjoying pleasurable pastimes and activities, and spending time with friends and family are important in stimulating the brain and fostering a positive attitude.

The approach to care greatly influences the individual's quality of life. The Alzheimer Society has developed *Guidelines for Care* to explain to people living with Alzheimer's disease, their families and caregivers the special type of care that is most supportive of people with the disease.

Stages of Alzheimer's disease

The stages of Alzheimer's disease are commonly referred to as "early", "middle" and "late" and may be measured by the Global Deterioration Scale (GDS).

Brief descriptions of these stages follow:

1. Early stage (stage 2, 3 GDS)

The term "early stage" refers to individuals of any age who have mild impairment due to symptoms of Alzheimer's disease. Common symptoms include forgetfulness, communication difficulties, and changes in mood and behaviour. People in this stage retain many of their abilities and require minimal assistance. They may have insight into their changing abilities, and, therefore, can inform others of their experience of living with the disease and help to plan and direct their future care.

Please note that the term "early stage" refers to people of any age who have mild impairments as a result of Alzheimer's disease. This differs from the terms early or young onset which refer to people who have been diagnosed with Alzheimer's disease at a younger age than usual, typically under the age of 65.

2. Middle stage (stage 4, 5, 6 GDS)

This stage brings a greater decline in the person's abilities. Memory and other cognitive abilities will continue to deteriorate although people at this stage may still have some awareness of their condition. Assistance with many daily tasks, such as managing finances, shopping and homemaking may be needed. Usually by stage 6, help with dressing, bathing and toileting will eventually become necessary. Individuals in middle stage may walk alone from home and lose their way. Minimizing risk by using programs such as MedicAlert® Safely Home® is often helpful.

3. Late stage (stage 7 GDS)

In this stage, the person eventually becomes unable to communicate verbally or look after themselves. Care is required 24 hours a day. The goal of care at this stage is to continue to support the person to ensure the highest quality of life possible.

End of life

When the person nears death, comfort measures become the focus. As in the care of any person living with a terminal illness, physical as well as emotional and spiritual needs must be carefully considered. Attention to providing supportive care focuses on quality of life and comfort.

The Global Deterioration Scale (GDS)

Stage	Typical Symptoms
Stage 1: No cognitive decline (normal function)	<ul style="list-style-type: none"> - No memory problems
Stage 2: Very mild cognitive decline (may be normal age related changes or earliest signs of Alzheimer's disease)	<ul style="list-style-type: none"> - Memory lapses - Forgetting familiar names and locations of objects - These lapses are not typically obvious to others
Stage 3: Mild cognitive decline (early stage Alzheimer's disease can be diagnosed in some, but not all individuals with these symptoms)	<ul style="list-style-type: none"> - Mild forgetfulness - Difficulty learning new things - Difficulty concentrating or limited attention span - Problems with orientation, such as getting lost - Communication difficulties such as finding the right word - Loss or misplacing of valuable objects - Difficulty handling problems at work - Issues are noticeable to family, friends or co-workers
Stage 4: Moderate cognitive decline (mild or early stage Alzheimer's disease)	<ul style="list-style-type: none"> - Some memory loss of one's personal history - Difficulty with complex tasks e.g., managing finances, shopping, travel - Decreased knowledge of current events and recent events - Impaired ability to perform challenging mental arithmetic (e.g., counting backward from 75 by 7)
Stage 5: Moderately severe cognitive decline (moderate or mid-stage Alzheimer's disease)	<ul style="list-style-type: none"> - Major gaps in memory e.g., phone numbers or names of close family members - Help is needed with day-to-day tasks
Stage 6: Severe cognitive decline (moderately severe or mid-stage Alzheimer's disease)	<ul style="list-style-type: none"> - Continued memory loss e.g., occasionally forgetting the name of a spouse or primary caregiver - Loss of awareness of recent events and experiences in their lives e.g., not remembering what they had for lunch or their child's graduation - Assistance is needed with activities of daily living e.g., getting dressed, bathing - Difficulties counting - Personality and emotional changes such as confusion, anxiety, suspiciousness, anger, sadness/depression, hostility, apprehension, delusions and agitation - Obsessions such as repetition of simple activities - Disruption of normal sleep/waking cycle - Increasing episodes of incontinence
Stage 7: Very severe cognitive decline (severe or late-stage Alzheimer's disease)	<ul style="list-style-type: none"> - Severe cognitive impairment - Vocabulary becomes limited and verbal abilities eventually disappear - Loss of ability to walk independently and sit without support - Help is needed with eating and using the toilet; usually incontinent

What's next?

No matter what stage of the disease the person is experiencing, obtaining information and support are important to understanding and living with the disease. Information found in the five-part progression series can help to ease the way of the Alzheimer journey.

Help and support from the Alzheimer Society

Living with Alzheimer's disease at any stage can be 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). Please visit www.alzheimer.ca/stages

To learn more about the **MedicAlert® Safely-Home® program** or to register, please visit www.medicalertsafelyhome.ca.

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

Dementia and End-of-Life Care. Alzheimer Society of Canada (2016). This is an online, four-piece resource on dementia and end of life care. Available at www.alzheimer.ca/endoflife.

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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