

THE PROGRESSION OF ALZHEIMER'S DISEASE - OVERVIEW

What is Alzheimer's disease?

Alzheimer's disease is the most common of a large group of disorders known as “dementias”. It is a disease of the brain, characterized by deterioration of thinking ability and of memory, caused by the progressive degeneration of brain cells. The disease also affects mood and emotions, behaviour and one's ability to perform activities of daily living. There is currently no cure for Alzheimer's disease nor can its progression be reversed. However, new treatments that will slow down or even stop the disease are expected within the next five to seven years. Moreover, present treatment options and lifestyle choices can often significantly slow the progression of the disease. Related dementias include Vascular Dementia, Frontotemporal Dementia, Creutzfeldt-Jakob Disease and Lewy body Dementia.

Alzheimer's disease typically follows certain stages which will bring about changes in the person's and family's lives. Because the disease affects each individual differently, the symptoms, the order in which they appear and the duration of each stage vary from person to person. In most cases, the disease progresses slowly, and the symptoms of each stage may overlap, often making the move from one stage to another quite subtle. The duration of the disease is usually seven to ten years but may be much longer in some people.

The Progression Series

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 family and caregivers. This overview provides a summary of the stages and information on end-of-life issues. It also includes a modified Global Deterioration Scale¹ (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*.

Approach to care

The approach to care that is reflected in this series is one that centres 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 deserves to be treated with dignity and respect.

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 mid stages of the disease can participate in decision-making and planning for the future and, with the person's wishes and values 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.

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

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". Following are brief descriptions of these stages.

1. Early stage

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 capabilities 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 term "early onset" which refers to people who have been diagnosed with Alzheimer's disease at a younger age than usual.

2. Middle stage

This stage brings a greater decline in the person's cognitive and functional 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 will become necessary.

3. Late stage

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

As 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 and attended to. Providing supportive care focuses on quality of life and comfort.

The Global Deterioration Scale (GDS)

In addition to hearing the terms "early", "middle" and "late" stage Alzheimer's disease, you may also hear health-care professionals use more clinical terminology and refer to the Global Deterioration Scale, also called the Reisberg Scale. The scale is used to measure the progression of Alzheimer's disease and divides the disease into seven stages. This scale is also used in diagnosing other dementias although the stages and symptoms vary from one dementia to another.



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 eg. managing finances, shopping, travel - Decreased knowledge of current events and recent events - Impaired ability to perform challenging mental arithmetic (for example, 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 eg. 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 eg. occasionally forgetting the name of a spouse or primary caregiver - Loss of awareness of recent events and experiences in their lives - Assistance is needed with activities of daily living eg. 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 impairments - 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

Modified from *Global Deterioration Scale*, Reisberg, 1982.



What's next?

No matter what stage of the disease the person is experiencing, information and support are important in 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 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 us at 416-322-6560 or visit our website at www.alzheimertoronto.org.

Resources:

1. Alzheimer Society. www.alzheimer.ca (of particular interest: "Alzheimer's Disease", "Alzheimer's Disease - The Progression of Alzheimer's Disease" and "Resources" sections).
2. Alzheimer Society of Canada. (1999). *Guidelines for Care*.
3. Alzheimer Society of Canada. *Safely Home Program*.
4. Alzheimer Society of Canada. (2008). *The Progression of Alzheimer's Disease—Overview; Early Stage; Middle Stage; Late Stage; and End of Life information sheets*.

Note:

This information 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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