

Alzheimer *Society*

Alzheimer's disease

What to expect



WHAT TO EXPECT

If you, or a family member, have recently been diagnosed with Alzheimer's disease, knowing what to expect as the disease progresses and learning what has helped others can greatly improve your quality of life. There are many people today who have been diagnosed with Alzheimer's disease who are enjoying each day, as well as planning for their futures. No matter what stage of the disease you or a family member is experiencing, information is important to understanding and living with the disease.

What is Alzheimer's disease?

Alzheimer's disease is a common form of a large group of disorders known as "dementias". It is a disease of the brain that impacts our short-term and long-term memory and our thinking ability as more brain cells become damaged and eventually die. The disease also affects our mood, emotions and behaviour, as well as our ability to perform daily living activities.

There is currently no cure for Alzheimer's disease, nor can we reverse the damage inside the brain. However, there are treatment options and lifestyle choices that can often significantly slow the progression of the disease.

As of 2016, more than half a million Canadians are living with dementia and each year, 25,000 more are diagnosed with the disease¹. Contact your Alzheimer Society for information and support to learn about living with Alzheimer's disease.

¹ A new way of looking at the impact of dementia in Canada. Alzheimer Society, 2012

The Stages of Alzheimer's disease

Alzheimer's disease typically follows certain stages, which are commonly described as "early," "middle," "late" and "end of life." In most cases, Alzheimer's disease progresses slowly over a course of seven to ten years but may be much longer in other cases.

Stages are useful in helping us talk about and understand the symptoms of Alzheimer's disease. However, it is important to realize that Alzheimer's disease affects each person differently. At each stage, the duration varies from person to person and the symptoms may overlap. Progression from one stage to another is usually quite subtle.

This brochure provides an overview of what to expect at each stage of the disease. For detailed information, please see the Alzheimer Society's 5-part series: *The Progression of Alzheimer's disease - Overview, Early Stage, Middle Stage, Late Stage and End of Life* available at www.alzheimer.ca/stages.

Early stage

In the early stage, memory loss becomes noticeable to the person with Alzheimer's disease and to those around them. Complex tasks such as balancing a bank account and social aspects such as following a conversation may become challenging. For those who are still working, daily family and work commitments may become more complicated. However, for the most part, people

with early stage Alzheimer's disease retain many of their abilities and require very little assistance.

Here are some tips to make your life easier during this stage:

- Reduce clutter to make things easier to find and use labels, calendars, timers and pill dispensers to help with forgetfulness.
- Make conversations easier to follow by asking people to speak slowly and reduce distractions.

At this stage, you are in a strong and unique position to learn as much as possible about the disease and to have your voice heard. An early diagnosis enables you to take advantage of medications and other means to slow down the disease, to plan for your future, and to contribute to your community. You can help by joining your local Alzheimer Society and supporting their efforts, as well as assisting others with the disease.

Remember, taking care of your health is just as important for people with Alzheimer's disease as it is for their families and caregivers.

Middle stage

A person's ability to perform daily living activities declines substantially during this stage. The middle stage is full of challenges, and everyone involved will need help and support.

As the disease progresses and affects different areas of the brain, various abilities are lost. Thinking and memory problems increase and a person will require help with many daily

activities. Restlessness, sleep pattern changes and hallucinations may also occur. Family and caregiver involvement increases dramatically and additional at home help or moving to a care home may be needed.

Here are some tips that may be helpful at this stage:

- Remember that all behaviour is a form of communication – try to determine what the person is trying to express.
- Use visual and verbal cues to help the person understand (e.g. “Hi Mom. It’s me, Bill. I’ve brought your granddaughter Ann for a visit.”)

Although a person loses many abilities as the disease progresses, it is important to focus on their remaining abilities. People with Alzheimer’s disease continue to experience emotions, although they may not be able to express them in the same ways they did before.

At any time during the disease, whether living at home or in a care home, consider registering with the MedicAlert® Safely Home® program. This program helps first responders identify the person who is lost and bring the family back together. For information, visit www.Medicalertsafelyhome.ca.

Late stage

The focus of care at this stage is to support the person with dementia to ensure the highest quality of life possible, both physically and emotionally. A person with late stage Alzheimer’s disease will eventually become unable to communicate verbally,

walk independently or sit without support. Care is required 24 hours a day. In many cases, the person will need to live in a care home. If the person remains at home, added support will be needed.

Here are some tips that may be helpful at this stage:

- Connect with the person through their senses of touch, taste, hearing, smell and vision. For example, music can bring pleasure and be soothing.
- Comfort the person with the sound of your voice as you read, tell stories and look at photographs together.

Activities should be tailored to remaining strengths and abilities, taking into consideration the person's history, likes and dislikes. Although a person in late stage Alzheimer's disease may not have the capacity to understand or respond as in the past, they are still likely to feel affection and benefit from reassurance.

End of life

At the end of their lives, most people with Alzheimer's disease are being cared for in a care home. The person can still experience emotions even though they are unable to express them.



Knowing what to expect during this difficult period can lessen the anxiety faced by family members and help them avoid making difficult decisions in a crisis. Respecting the expressed wishes of the person with Alzheimer's disease should guide all end-of-life care decisions.

Here are some tips that may be helpful at this stage:

- Tell the person that they are safe and cared for by speaking soothingly. If appropriate, include prayers or rituals.
- Use a team approach, with family and healthcare providers working together, to maintain the highest level of comfort and quality of life for the person.

Family members need to be mindful of their own health and emotional needs during this time, and later when the person passes away. For more information about end of life visit www.alzheimer.ca/endoflife

Feeling grief and loss through all stages of Alzheimer's disease is normal. And everyone will grieve differently. Get the practical help and emotional support you need from your Alzheimer Society.

The **Alzheimer Society of Canada** is Canada's leading nationwide health charity for people living with Alzheimer's disease and other dementias. Active in communities right across Canada, the Society:

- Offers information, support and education programs for people with dementia, their families and caregivers
- Funds research to find a cure and improve the care of people with dementia
- Promotes public education and awareness of Alzheimer's disease and other dementias to ensure people know where to turn for help
- Influences policy and decision-making to address the needs of people with dementia and their caregivers.

For more information, contact your local Alzheimer Society or visit our website at www.alzheimer.ca.

Help for Today. Hope for Tomorrow...[®]

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