Alzheimer *Society*

Dementia

What to expect





What to expect

If you, or someone you care for, have recently been diagnosed with dementia, knowing what to expect and learning what has helped others can greatly improve your quality of life or the quality of life of the person you care for. There are many people living with dementia who are enjoying each day, as well as planning for their futures. Everyone living with dementia is different. They may experience dementia in different ways, and progress at different rates, however, there are some common things that a person may expect as their dementia progresses.

This brochure provides an overview of what to expect at each stage of dementia. However, some symptoms may appear in a different order to the stages described below. For more information, visit alzheimer.ca/stages.

What is dementia?

Dementia is a broad term that describes a set of symptoms such as memory loss, difficulty performing daily activities, and changes in judgment, reasoning, vision, movement, behaviour and emotions. While Alzheimer's disease is the most common type of dementia, there are many other types such as vascular dementia, frontotemporal dementia and mixed dementia. To learn more visit alzheimer.ca/otherdementias.

Dementia doesn't just affect older people. Sometimes people can develop "young onset dementia." This is when dementia symptoms start before the age of 65. To learn more visit alzheimer.ca/youngonset. There is currently no cure for most types of dementia. However, there are treatment options and lifestyle choices that can help with managing symptoms. If a person is living with cognitive impairment caused by another condition, such as thyroid, heart or nutritional disease, the dementia symptoms may be treatable.

In 2024, over 700,000 people are estimated to be living with dementia in Canada. By 2030, 187,000 people will be diagnosed per year (512 per day)¹.

The stages of dementia

Dementia typically progresses through certain stages, which are commonly described as "early," "middle," "late" and "end of life." For most people, dementia progresses slowly over a course of seven to ten years, but it may be much longer for others.

Stages are useful in helping us talk about and understand dementia symptoms. However, for each stage, the duration may be different for each person and the symptoms may overlap. Progression from one stage to another may also be difficult to notice.

Early stage

In the early stage, memory loss becomes noticeable to the person living with dementia and to those around them. Complex tasks such as managing finances and following a conversation may become challenging. For those who are still working, daily family and work commitments

^{1.} Alzheimer Society of Canada. (2022). Navigating the path forward for dementia in Canada: The landmark study report. alzheimer.ca/landmarkstudy.

may become more complicated. However, most people with early stage dementia can still complete tasks and require very little help.

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

- Reduce clutter to make things easier to find.
 Use labels, calendars, timers and medication organizers to help with reminders.
- To make conversations easier, ask people to speak slowly and reduce noise and distractions.

At this stage, you are in a strong and unique position to learn as much as possible and to have your voice heard. With an early diagnosis you can start treatments, to plan for your future and contribute to your community. You can help by connecting to your local Alzheimer Society and supporting their efforts, as well as assisting others living with dementia.

Taking care of your health is just as important for people living with dementia as it is for caregivers.

Middle stage

The middle stage brings a greater decline in the person's cognition and ability to perform daily activities. This stage is often the longest and everyone involved will need help and support.

As dementia progresses and affects different areas of the brain, restlessness, sleep pattern changes and hallucinations may also occur. Caregiver involvement increases and additional at-home help may be required. The person living with dementia may also need to move to long-term care.

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

- Changes in behaviour are a form of communication – try to determine the reason for the changes and what need or feeling the person is trying to express.
- Use visual and verbal cues to help the person understand (e.g. "Hi Mom. It's me, Pat. I've brought your grandchild Robin for a visit.")

Focus on remaining abilities. Consult an occupational therapist for advice on routines, activities and adapting the home to make it as safe and accommodating as possible.

Consider using a tracking device or GPS to help facilitate a safe return should a person become lost. For information, visit alzheimer.ca/trackingdevices.

Late stage

The focus of care at this stage is to support the person living with dementia to ensure the highest quality of life possible, both physically and emotionally. A person with late stage dementia may eventually become unable to communicate verbally, walk independently or sit without support. Care may be required 24 hours a day. If the person remains at home, added support will be needed. In many cases, the person may need to live in a long-term care home. For more information, visit alzheimer.ca/ltc.

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 support the person's strengths and abilities, and consider the person's history, likes and dislikes. Although a person in late stage dementia may not understand or respond as in the past, they can feel emotions and benefit from encouragement.

End of life

At the end of their lives, many people living with dementia are being cared for in a long-term care home. The person can still experience emotions, but may express them differently than they did in the past.

Knowing what to expect during this time can reduce the anxiety experienced by caregivers and help them avoid making difficult decisions in a crisis. Respecting the expressed wishes of the person living with



dementia 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. If appropriate, include prayers or rituals.
- Use a team approach, with caregivers and health-care providers working together, to maintain the highest level of comfort and quality of life for the person.

Caregivers 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 alzheimer.ca/endoflife.

Feeling grief and loss through all stages of dementia is normal. And everyone will grieve differently. Get the practical help and emotional support you need from your local Alzheimer Society at alzheimer.ca/find.

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 alzheimer.ca.

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