

## What is Alzheimer's disease?

Alzheimer's disease is a type of dementia—an illness of the brain that affects a person's ability to carry out daily activities. Memory, emotions, mood, behaviour and language are all affected, and because the disease is progressive, the symptoms worsen over time. There are many forms of dementia, but Alzheimer's disease is the most common among older people.

In the disease's early stages, people most often notice **memory problems**<sup>1,2</sup> that can be severe enough to interfere with their ability to work or carry out everyday tasks. It's normal for people to forget some things as they get older—mild forgetfulness or the occasional difficulty in finding a word is not necessarily cause for alarm. But in Alzheimer's disease, the change is more dramatic. People tend to forget things that they used to remember, like **names, words, and where they've put everyday objects**. More importantly, this difficulty is persistent, progressive, and severe, and there is usually a noticeable, rapid decline in cognitive skills. If you become concerned about such changes in yourself or someone you care about, it's important not to delay and consult a physician as soon as possible.<sup>3</sup>

## How widespread is the disease?

Alzheimer's disease is the most frequently seen form of dementia<sup>4</sup>—and it's frighteningly common in older people. Today in Canada, over 450,000 people over the age of 65, and 1/3 of those over 85, have Alzheimer's disease or a related disease.<sup>4</sup>

What's more, as the country's 10 million baby boomers grow older, the number of people with the disease is expected to rise considerably.<sup>5</sup>

## What are the risk factors of Alzheimer's disease?

Because the cause of Alzheimer's disease is still unknown, it's difficult to predict who will develop it in the course of their lifetime. Some risk factors, however, are known, the most important of which is age. In fact, after age 65<sup>6</sup> the frequency of all types of dementia just about doubles every five years. By the time a person reaches age 85, they're at a 35% risk of dementia.

People diagnosed with Alzheimer's disease may worry that they have passed the disease to their children, but this usually will not be the case. There are two types of Alzheimer's disease. One is a familial type. It is passed from one generation to another through a dominant gene. If one of your parents has this type of the disease, you *always* have a 50% chance of inheriting the gene and then developing the disease. The familial type of Alzheimer's disease is very rare and is seen in only 5-10% of cases. About 90% of cases are the sporadic type of Alzheimer's disease. You can develop this kind of Alzheimer's disease even if nobody in your family has had the disease, although having a family history still affects your chances of getting the disease, compared with someone with no Alzheimer's disease in their family—the more family members who are affected, and the closer they are to you, the higher the risk for the disease.<sup>6-8</sup>

An important thing to note is that although dementia is different from "normal forgetfulness," there is a step before the disease occurs, a sort of in-between stage, called mild cognitive impairment. Some experts now feel that in some cases, mild cognitive impairment in an older person is a "pre-state"—that could lead to Alzheimer's disease.<sup>9</sup>

## Are there ways to prevent Alzheimer's disease?

Since most cases of Alzheimer's disease are of the sporadic type and difficult to predict, it isn't an easy disease to prevent.<sup>8,10</sup> Some research suggests that keeping the mind active can protect against cognitive decline with age, pointing to the "use it or lose it" theory when it comes to brain cells. Scientists are exploring the possibility that keeping the brain active can protect it from Alzheimer's disease or slow down some of the symptoms when the disease begins.<sup>10</sup> If this is so, the theory is that it will take longer for a condition such as Alzheimer's disease to destroy brain cells and produce symptoms.

There is a growing amount of evidence that concludes that keeping an active lifestyle can help prevent Alzheimer's disease, or at least reduce the risk of developing it,<sup>10</sup> but there is agreement that many healthy activities, despite a diagnosis of the disease, should be a part of everyone's overall lifestyle and aging strategy.

## What are the signs and symptoms?

Alzheimer's disease progresses through three general stages, from a mild, early stage, through a moderate, mid stage, to a severe, late stage. It starts slowly, and in fact, when the disease begins affecting the brain, there are no outward signs or symptoms.

### Mild stage

In mild Alzheimer's disease, the main thing that occurs is a decline in cognition. This means that the ability to think, reason, recognize and interpret is affected, and mild forgetfulness is typically the first noticeable sign of the disease. People living with the disease, as well as their families, friends, co-workers, and medical practitioners, will start to notice the signs, such as problems with concentration. Language and communication difficulties may appear, such as trouble finding the right word when speaking, and difficulty keeping up with a conversation or reading. Poor planning, poor judgment or becoming lost even in familiar settings may also begin to show. Personality changes may become noticeable, including becoming more withdrawn, anxious, or suspicious.<sup>2</sup> Changes in personality, as well as behaviour, begin to appear. As a result, people seem less like themselves—and the challenge, at this point, is to try to connect with them in new ways that engage and stimulate them. A general apathy and lack of interest are characteristic of all three stages of the disease, but they begin here. Additionally, people and their loved ones may initially be in denial about what is actually happening. Once the disease has been diagnosed by a doctor, though, it's important to monitor the emotional well-being of that person and offer them support and reassurance. In early Alzheimer's disease, a person can usually still function independently and may participate in their health decisions and planning for their future care despite the fact that memory loss and other cognitive deficits become noticeable.<sup>2, 11</sup>

### Moderate stage

In mid-stage Alzheimer's disease, the person becomes more dependent on caregivers as mental abilities decline, personality changes, and physical problems develop. For instance, the person can still bathe, use the toilet and dress, although he or she might need help to do so. Symptoms such as the loss of ability to identify familiar people, disorientation about time and place, agitation, depression, irritability, and rarely, aggressivity, may all appear at this time. It is important for caregivers to give the person with the disease the chance to do as much as their remaining abilities allow them on their own. This can be done by simplifying the task at hand by dividing it into easier, smaller steps, and by maintaining the routines the person is used to.<sup>2</sup>

## Severe stage

In late-stage, severe Alzheimer's disease, a person will eventually be unable to walk, talk, sit up, or control their bowels or bladder, making them completely dependent on their caregivers for help in basic activities of daily living.<sup>2</sup> They also suffer from a number of other diseases and conditions that have nothing to do with Alzheimer's disease but can be life-threatening; pneumonia, for instance, is a significant cause of death among people with the disease. At this point, the main objective is to make the person feel as comfortable as possible by alleviating pain or any distressing symptom that they may be experiencing.<sup>2, 12</sup>

## How is the disease diagnosed?

In its early stages, Alzheimer's disease can be difficult to diagnose. But early diagnosis is key for a number of reasons, including the chance that the symptoms may be those of a different disease or condition altogether—one that may be curable. And if the diagnosis is, in fact, Alzheimer's disease, early detection will allow more time for long-range planning, decision-making, and caregiving arrangements, as well as an early start in treating some of the disease's more manageable symptoms. Importantly, the medications and lifestyle changes that slow down Alzheimer's disease work best the sooner they are started.<sup>13</sup>

The first step to diagnosis involves testing a person's memory and their ability to think clearly. The Mini-Mental Status Examination (MMSE) is a commonly used test and it just takes a few minutes to complete. What's more, it can be repeated over time to see if there are any changes.<sup>14</sup>

A doctor or other healthcare professional will perform a physical examination as well as carry out a series of laboratory tests to help determine if it is dementia, as well as rule out any other causes.<sup>15</sup> In some cases, a doctor may order a CT or MRI scan to examine the structure of the brain. In Alzheimer's disease, there is often visible atrophy or shrinking of the brain that has occurred.<sup>15</sup>

## How is Alzheimer's disease treated?

Receiving a diagnosis of Alzheimer's disease is disturbing—for both a patient and their loved ones. In fact, the disease affects all members of a family, from the spouse to the children and even grandchildren.<sup>16</sup> A crucial part of treatment involves educating the whole family about the disease state, and helping them understand and come to terms with what the future holds. In most cases, the person with Alzheimer's disease will be primarily looked after by one other person—most often a spouse or adult child—and this caregiver may need significant support.<sup>17</sup> Respite care (admitting the person with dementia to hospital or a nursing home for a short time) can offer that caregiver a much-needed break and can often be arranged by the family physician or other healthcare provider.<sup>18</sup> What's more, support workers can teach caregivers behaviour management strategies that can be very effective in dealing with the behaviour and mood problems (like agitation, depression, restlessness or aggression) that a person with Alzheimer's disease may experience.<sup>2</sup>

As for medication, it has come to play an important role in the management of the disease, as it has been shown to be effective in treating some of the disease's symptoms.<sup>19</sup> There's a great deal of research into Alzheimer's disease, so treatment options are getting better all the time.<sup>20,10</sup> One commonly used type of drug, cholinesterase inhibitors, works on the brain chemicals that carry nerve messages.<sup>21</sup> In most patients, this leads to benefits in cognitive functioning, as measured with tests such as the MMSE. These medications are likely to lead to an improvement in symptoms or reducing the rate of their progression.<sup>19</sup> It's important to always keep in mind, though, that the earlier the disease is detected, the better, because treatment can begin sooner.

The management of AD can challenge even the most skilled and experienced healthcare professionals. Yet there is still much they can offer: a thorough assessment and diagnosis, symptomatic treatment if appropriate, support and information for patients and their caregivers, and a referral to community resources such as the Alzheimer Society of Canada.

## Living with Alzheimer's disease

A diagnosis of Alzheimer's disease can come as a shock to some, while others may experience a sense of relief because they can finally identify the symptoms they have been experiencing.<sup>7</sup> Being diagnosed can cause a range of emotional responses, including denial, anxiety and frustration over the effects of losing ones' cognitive abilities. Depression is also common following diagnosis. These are all normal reactions, and communicating with family, friends, and other people about the disease and its emotional impact may help in dealing with these feelings.<sup>7</sup>

Many people diagnosed with Alzheimer's disease may feel reluctant to tell others about it. But talking about it can help with coming to terms with the diagnosis, as well as opening the door for people to offer their support. It may also help others understand the reasons for changes in the behaviour of the person with the disease.<sup>7</sup>

By learning more about it, people living with Alzheimer's disease can help understand and accept it, making it possible to better cope with their condition.<sup>7</sup>

Since the progressive changes caused by Alzheimer's disease don't all happen at once, one coping strategy that people with the disease and their caregivers can use is to focus on the things they are still able to do. In early stage, the loss of abilities is often mild. With a little help, people with Alzheimer's disease can continue living nearly as independently as they did before. Medications that help with the symptoms of the disease work best when begun at this early stage.<sup>7,13</sup>

There are many ways to maintain a healthy and active lifestyle despite a diagnosis of Alzheimer's disease. Maintaining hobbies is a fun way to stay active, and mentally challenging activities can be as simple as trying to avoid using a calculator, playing stimulating games such as cards, doing puzzles, or watching movies. Activities can be tailored to the person's level of ability.

Staying physically and emotionally healthy go hand-in-hand with quality of life, and keeping the body active is just as important as keeping the mind active. Making healthy choices includes eating well, limiting alcohol or giving up drinking, going out and doing something enjoyable every day, scheduling regular check-ups with the doctor, and getting enough rest—including taking naps. Maintaining emotional health can mean keeping in touch and spending time with loved ones, or joining a support group and sharing with others.<sup>7</sup>

Planning for the future is an important part of coping with Alzheimer's disease. This includes taking care of paperwork, financial matters, living arrangements, and health and personal care plans.<sup>7</sup>

In late-stage Alzheimer's disease, it is important to remember, more than at any other time over the course of the disease, to provide comfort and preserve the person's dignity, privacy and safety. All decisions regarding end-of-life care should respect the person's wishes as much as possible. If there is no advanced directive, or if they have not or could not be expressed, you can take into consideration his or her beliefs and values to make a decision that would be as close as possible to the one he or she would have made. Doctors and healthcare teams are there to help decide what is best for the person, and it is important to talk to them at this stage—sticking with best treatment practices gives people with late stage Alzheimer's disease their best chance at remaining secure, contented, and connected.<sup>12</sup>

## Empowering both the patient and the caregiver

Caregiving can take a physical and emotional toll, and caregivers should take steps to look after themselves<sup>16</sup> Each day brings new challenges as they learn how to best support their family member's changing abilities and new behaviours. As the end of life approaches, he or she may require constant care.<sup>2</sup> At that point, caregivers may have to decide whether to hire a full-time healthcare professional to help at home, or whether it's best to resort to a care facility. The guidance of a physician or a long-term care team will be needed.

It is important that the caregiver tries to remain connected to those around them. Organizations such as the Alzheimer Society can provide support, advice, and referrals to suitably located and affordable facilities. Additionally, the local Alzheimer Society can give referrals to support groups and other community resources to help navigate through the progression of the disease.

## Resources, Patient Associations & Congresses

[www.onmemory.ca](http://www.onmemory.ca)

**Toll-free tel.:** 1-888-80MEMORY (1-888-806-3667)

On Memory is a valuable resource that provides information, tools and support for people living with Alzheimer's disease as well as their family and friends.

### Alzheimer Society of Canada

20 Eglinton Ave. W., Ste. 1600  
Toronto, ON M4R 1K8

**Tel:** 416-488-8772

**Toll-free:** 1-800-616-8816 (valid only in Canada)

**Fax:** 416-488-3778

**E-mail:** [info@alzheimer.ca](mailto:info@alzheimer.ca)

**Web:** [www.alzheimer.ca](http://www.alzheimer.ca)

The Alzheimer Society offers information and support for patients and loved ones affected by Alzheimer's disease, and can put you in touch with support and resources at a local level.

[www.alzheimercoffeebreak.ca](http://www.alzheimercoffeebreak.ca)

Coffee Break is the Alzheimer Society's major annual fundraiser where friends, co-workers and customers gather in communities across Canada to raise funds for local Alzheimer Societies.

[www.dementiaguide.ca](http://www.dementiaguide.ca)

The Dementia Guide provides helpful information and tools created by people who understand what it's like caring for someone who has Alzheimer's disease. Their goal is to provide up-to-date information for you to use to create your individualized care plan for symptom management and communication with physicians and family members.

[www.safelyhome.ca](http://www.safelyhome.ca)

Safely Home is a program that aims at helping people with Alzheimer's disease maintain their independence by assisting them if they become lost.

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