Alzheimer's disease and other forms of dementia

Getting a Diagnosis Toolkit

This toolkit can help you prepare to talk with your doctor or health provider about a possible dementia diagnosis.

Symptoms of dementia may include frequent loss of memory, difficulty with day-to-day tasks, and big changes in mood and behaviour. People may think these symptoms are part of normal aging, but they aren't. If you notice any symptoms or changes in abilities, behaviour or communication, it's important to see a doctor. It is possible that a treatable condition, such as depression, drug interaction or infection, could be causing such changes.

- ❑ Review the 10 Warning Signs — are there changes in abilities, behaviour or communication? There is no set number of warning signs that need to be experienced before you visit your doctor.
- ❑ Complete the Preparing for Your Doctor's Visit form. Where possible, provide specific examples:
  - What symptoms have been noticed?
  - When did they first appear?
  - How have the symptoms changed over time?
- ❑ If you have questions, contact your local Alzheimer Society.
- ❑ Make a doctor's appointment and share the reason for your visit.
- ❑ Review the Getting a Diagnosis information about what to expect at your appointment.
- ❑ Take your completed Medications, Medical History and Questions to Ask Your Doctor form to your appointment.
- ❑ Take your completed forms and notes to your appointment.

  If you receive a diagnosis of dementia, ask your doctor to refer you to the Alzheimer Society's First Link® program. Or call your local Alzheimer Society to self-refer.

If you need help or have any questions please reach out to the Alzheimer Society of Toronto at info@alz.to or 416-322-6560. You can also find help at alz.to/get-help-now

10 Warning Signs

1. **Memory changes that affect day-to-day abilities**
   It is normal to sometimes forget meetings or co-worker names only to remember them a short time later. But a person living with dementia may forget things more often. Or it might be hard for them to remember information they just learned.
2. **Difficulty doing familiar tasks**
   Busy people can be so distracted sometimes that they may forget to serve part of a meal, only to remember it later. But a person living with dementia may have trouble doing tasks they have done all their lives, such as preparing a meal or playing a game.
3. **Changes with language and communication**
   Anyone can have trouble finding the right word. But a person living with dementia may forget simple words. Or they may use the wrong words, making them hard to understand.
4. **Disorientation in time and space**
   It is common to forget the day of the week or your destination — for a moment. But a person living with dementia may become lost on their own street. They may not know how they got there or how to get home.
5. **Impaired judgment**
   Sometimes, people may make bad decisions such as putting off seeing a doctor when they are not feeling well. But a person living with dementia may not recognize a medical problem that needs attention, or wear heavy clothing on a hot day.
6. **Problems with abstract thinking**
   Sometimes, people may have difficulty with tasks that require abstract thinking, such as balancing a chequebook. But a person living with dementia may experience challenges with understanding what numbers are and how they are used.
7. **Misplacing things**
   Anyone can temporarily misplace a wallet or keys. But a person living with dementia may put things in inappropriate places, such as an iron in the freezer or a wristwatch in the sugar bowl.
8. **Changes in mood, behaviour and personality**
   Sometimes people feel sad and moody, or experience changes in their behaviour. But a person living with dementia may experience more severe changes. For example, they may quickly become tearful or upset for no obvious reason. They may be confused or suspicious and withdraw from others. They may act differently from what is normal for them.
9. **Loss of initiative**
   It is normal to lose interest in housework, business activities or social obligations sometimes. But most people regain their initiative. A person living with dementia may become passive and disinterested. They may need cues and prompts to become involved.
10. **Challenges understanding visual and spatial information**
    A person living with dementia may have problems with vision, depth perception and movement. They might not see objects in their way when walking. Or they might have challenges placing items on a table.

Adapted from *10 Warning Signs* (Alzheimer Society of Canada, 2018) and *Warning Signs of Dementia infographic* (Alzheimer Disease International, 2017).

Preparing for your doctor's visit

Fill out this checklist. Share it with your doctor. Answer any questions your doctor asks. Be honest about changes in your life — or changes that you've noticed in someone else.

Do you or someone you care about have any of these problems?

1. Attention
- ❑ Being easily distracted
- ❑ Losing focus in conversation

2. Memory
- ❑ Asking the same questions over again
- ❑ Repeating the same information many times
- ❑ Losing things
- ❑ Leaving the stove on, tap running or door unlocked
- ❑ Forgetting meetings or the current month

3. Language
- ❑ Having problems remembering people's names
- ❑ Struggling to use common words
- ❑ Using the wrong words
- ❑ Finding it hard to follow a conversation with many people
- ❑ Having trouble with simple spoken and written instructions

4. Vision and space
- ❑ Not recognizing faces
- ❑ Getting lost in familiar places
- ❑ Having difficulty finding the way when driving or walking

5. Judgment
- ❑ Having problems planning daily activities (like managing money, or going out alone)
- ❑ Not knowing what to do if there is a fire or if someone becomes sick
- ❑ Having problems with driving or using appliances

6. Coordination
- ❑ Can't put actions in order (like taking the right steps to make a cup of tea)
- ❑ Having problems using utensils to eat or using tools to groom

7. Mood
- ❑ Feeling sad or frustrated a lot
- ❑ Losing interest in doing things

8. Personality and behaviour
- ❑ Seeing or hearing things that other people do not
- ❑ Being suspicious (like thinking people want to hurt you)
- ❑ Becoming upset or frustrated fast
- ❑ Seeing changes in your personality
- ❑ Being impolite, or acting out of character
- ❑ Having strange food cravings

9. Daily function
- ❑ Hard to finish familiar tasks (like bathing, or getting dressed)

Medications and medical history

Take your medications to your appointment; include any prescription drugs, vitamins or supplements.

If you are seeing a new doctor, prepare a list of your current medical conditions.

More questions to ask your doctor

What tests will I need to take?

How long will it take to get a diagnosis?

Do I have any other conditions that could cause my symptoms or make them worse?

Would you suggest that I see a specialist?

When should I come back for another visit?

Sources:
Masellis, M. & Black, S. E. (2008). Assessing patients complaining of memory impairment. *Geriatrics and Aging, 11*(3), 169-178.
American Alzheimer's Association. (2022). *Visiting your doctor*.
American Alzheimer's Association. (2022). *Working with the doctor*.

Alzheimer Society

Getting a Diagnosis

No single test can tell if a person has dementia. The diagnosis is made through an assessment that eliminates other possible causes. Until there is a conclusive test, doctors may continue to use the words "possible or probable dementia."

A family doctor or a specialist can make the diagnosis, and it may take time. The doctor may or may not refer you to other health-care professionals. These may include a psychologist, psychiatrist, neurologist, geriatrician, nurse, social worker or occupational therapist. They will look for problems with your memory, reasoning, language and judgment, and how these affect day-to-day function.

The process involves:

Medical history
You and your caregiver will be asked questions about your symptoms now and in the past. There will be questions about past illnesses and about family medical and psychiatric history.

Mental status exam
This tests your sense of time and place. It also tests your ability to remember, express yourself and do simple calculations. It may involve exercises such as recalling words and objects, drawing and spelling, and answering questions such as, "What year is it?"

Physical exam
The exam will focus on the brain and nervous system. Other body systems that can affect brain function, such as blood pressure, and heart and lung function, will also be examined. The doctor will also test muscle tone and strength, coordination, eye movement, speech and sensation.

Laboratory tests
Blood work will be ordered to help detect problems such as anemia, diabetes and thyroid problems that might be adding to symptoms. In some medical centres, the following tests may be used, but they are not always necessary for a diagnosis:

- **CT** (computerized tomography) scan and **MRI** (magnetic resonance imaging) take images of the brain.
- **SPECT** (single proton emission computed tomography) shows how blood is circulating to the brain.
- **PET** (positive electron tomography) shows how different areas of the brain respond during activities like reading and talking. This scan is usually done after 45 minutes of rest.
- **Sleep tests** measure brain activity to determine levels of cognitive performance and brain aging.
- **Psychiatric and psychological evaluations** may be helpful in ruling out illnesses such as depression, which can sometimes cause symptoms similar to dementia. Neuro-psychological testing can evaluate memory, reasoning and writing.

Adapted from *Getting a Diagnosis* (Alzheimer Society of Canada, 2018).

We thank the Care of the Elderly Member Interest Group for their generous contribution to the development of this resource. To provide feedback on this resource, please email publications@alzheimer.ca.