



Dementia: Guide for Patients and Caregivers

What is dementia?

Dementia is not just one disease. Dementia is a group of symptoms that gradually causes a person to have more difficulty thinking, making decisions, and carrying out daily activities.

Everyone forgets things from time to time, and it is normal for this to increase slightly with age. This is not dementia. Dementia is a disease; it is not a normal part of aging. Memory loss by itself does not mean a person has dementia. People with dementia not only forget important information, but they also have a hard time learning or remembering new things and making good decisions.

What is the difference between dementia and Alzheimer's disease?

Many different diseases or conditions can lead to different forms of dementia. Alzheimer's disease is one form of dementia and it is the most common and best known. Most people with dementia have Alzheimer's disease alone or Alzheimer's disease combined with other forms of dementia.

What are the signs of dementia?

The Alzheimer's Society of Canada lists the following common signs of dementia to look for:

1. Short-term memory loss that affects day-to-day function.
2. Difficulty performing familiar tasks.
3. Problems with language (e.g., difficulty finding the right words and following a conversation).
4. Disorientation of time and place.
5. Impaired judgement (e.g., cannot make the right decision, acting without consideration of the consequences).
6. Problems with abstract thinking (e.g., reduced ability to understand, think, remember and reason).
7. Misplacing things (e.g., placing an iron in the freezer or a wristwatch in the sugar bowl).
8. Changes in mood and behaviour (e.g., acting out of character by quickly changing from being calm to crying to angry within minutes).
9. Changes in personality (e.g., a calm, quiet person changing to someone irritable, suspicious or fearful).
10. Loss of initiative.

Talk to a health care practitioner if you notice one or more of these signs happening to you in your life or the life of a close friend or family member.

What are the risk factors for dementia?

The two risk factors for dementia that cannot be changed are age and genetics. However, it is possible to reduce the other known risks through lifestyle changes.

The following is a list of lifestyle choices to help reduce the risks of developing dementia:

1. Follow medical advice if you have high blood pressure, diabetes or other blood vessel diseases.
2. Limit alcohol and drug use.
3. Keep your mind active with puzzles, reading, or playing a musical instrument.
4. Keep active (e.g., go for walks, take a dance class, join a gym, go swimming or cycling).
5. Eat healthy meals.

How is dementia diagnosed?

Diagnosing dementia is a process. There is no single test to find the cause of the illness. It is important to talk with a doctor or nurse if you notice any of the signs of dementia happening to you or to a close friend/family member. This information will help with making a diagnosis and ruling out other conditions that mimic dementia. Some examples of conditions that mimic dementia and may respond well to treatment include:

- depression,
- medication interactions,
- infections,
- other diseases, such as heart and thyroid,
- alcohol dependency, and
- poor nutrition and dehydration.

It is important to find out the cause of the symptoms as early as possible because this will mean proper care, treatment and support, and will give enough time to plan for the future.

Is there a cure or treatment for dementia?

There is currently no cure for dementia. However, there are things to promote a higher quality of life for people with dementia. Behaviour and setting modifications have proven effective in treating some symptoms of dementia, as well as medications. But these medications can have several side effects. It is important to discuss with a health care practitioner what to expect from treatment. Talking about the risks and benefits of any medications will help to make decisions about treatment. Caregivers should be included as partners in treatment planning.

What do I need to know if I or someone I know has dementia?

Stay connected

A person with dementia can live a good quality of life for many years following diagnosis. However, when the affected person does not discuss early dementia signs with their health care practitioner, the diagnosis may be delayed and the onset may seem more sudden. Following diagnosis, many people with dementia continue to live at home, with help from family, friends, and professional caregivers. Staying connected to family, friends and interests is important to the health and well-being of a person with dementia. Over time it may become too difficult to provide care at home, and the person with dementia may need to move to a residential care facility. Caregivers and health care practitioners should make that decision together.

Get the help and support you need

Learning about dementia, discussing feelings and experiences, and planning for the future can help the person with dementia and those caring for them feel less anxious about what is happening. Learning about dementia helps with understanding and handling the changes caused by dementia. Plan to discuss your options and any questions you may have with your health care practitioner. A lot of information and support is available to help with this planning (see next page).

Dementia Information and Support Resources for Patients and Caregivers

► Information, Referral and Social Support Services:

- **Alzheimer Society of B.C.** – provides support and resources for patients, families and caregivers. Phone: 1-800-667-3742. Website: www.alzheimerbc.org.
 - o **First Step for Families** pamphlet – for families of those recently diagnosed with dementia. Online: www.alzheimer.ca/~ /media/Files/national/Core-lit-brochures/First_Steps_for_Families_e.pdf
 - o **First Link**® – is designed to connect individuals and families affected by Alzheimer’s disease or another dementia with services and support. Website: www.alzheimerbc.org/We-Can-Help/First-Link.aspx
 - o **Minds in Motion**® - is a fitness and social program for people with early stage dementia and a friend, family member or care partner. Website: www.alzheimerbc.org/We-Can-Help/Minds-in-Motion.aspx.
- **Alzheimer Society of Canada** – provides support and resources for patients, families and caregivers. website: www.alzheimer.ca.
 - o **Alzheimer’s disease: A Handbook for Care** – provides information and resources for caregivers. Visit: www.alzheimer.ca/~ /media/Files/national/Core-lit-brochures/handbook_for_care_e.pdf
- **Clinic for Alzheimer’s Disease and Related Disorders, UBC** – provides assessment and diagnosis of Alzheimer’s disease and related disorders for patients throughout B.C., including care and support for the affected individual. Physician referral is required. Website: www.vch.ca/alz/ialzheimer.html
- **Home & Community Care** – provides a range of health care and support services for people who have acute, chronic, palliative or rehabilitative health care needs. These services are publicly subsidized and are designed to complement and supplement, but not replace, a person’s efforts to care for themselves with the assistance of their family, friends and community. These services are provided through health authorities. Contact your health authority (visit www.gov.bc.ca/hcc/ and choose “How to Arrange for Care”).
- **SeniorsBC.ca** – provides information for seniors on a variety of topics ranging from elder abuse prevention, advance care planning, home & community care services, and financial & legal matters. Website: www.SeniorsBC.ca
- **University of B.C. Faculty of Medicine** – provides an online patient guide for dementia. Online: www.iconproject.org/dnn_icon/Portals/0/Docs/2011-06-08-GTKDEnglish-Web.pdf

► Driving/Transportation:

- **Drive ABLE Assessment Centres Inc.** – provides assessment of cognitively at-risk drivers. Phone: 1 877 433-1494. Website: www.driveable.com or www.candrive.ca.
- **Accessible Transit Options: HandyDART** – a door-to-door, share ride, custom transportation service. **TaxiSavers** – provides one-time trips when handyDART cannot accommodate travel needs. Vancouver website: www.translink.ca. Rest of B.C. website: www.bctransit.com.

► Elder Abuse:

- **The BC Coalition to Eliminate Abuse of Seniors** – provides information, training, community development and materials on abuse and neglect of seniors. In the Lower Mainland, phone: 604 437-1940. Phone toll-free in B.C.: 1 800 663-7867. Website: www.bcceas.ca.

► Nutrition:

- **Meals on Wheels** – a program where volunteers deliver hot meals to homebound seniors. Website: www.mealcall.org/canada/british-columbia/index.htm

▶ **Safety:**

- **Lifeline** – a personal response service that lets you summon help any time of day or night. Website: www.lifeline.ca
- **Safely Home® - Alzheimer Wandering Registry** – www.safelyhome.ca

▶ **Financial and Legal Issues:**

- **Representation Agreement** – permits an adult to name a representative for their health care decisions and some financial decisions. Website: www.trustee.bc.ca
- **NIDUS Personal Planning Resource Centre and Registry** – a non-profit, charitable organization that provides information to B.C. residents about personal planning, specializing in representation agreements. They also operate a centralized registry for personal planning documents. Website: www.nidus.ca/
- **Advance Care Planning Resources:**
 - o **B.C. Government** – provides links to guides and video on advance care planning, as well as links to health authority resources. Website: www.gov.bc.ca/advancecareplanning.
 - o **HealthLink BC** – provides information from a variety of government sources on advance care planning. Search for “advance care planning” on their website at: www.healthlinkbc.ca/.
 - o **My Voice** - an advance care planning guide to help individuals plan for their future health care needs. Online: www.health.gov.bc.ca/library/publications/year/2013/MyVoice-AdvanceCarePlanningGuide.pdf