

DEMENTIA IN CANADA

1 IN 5 CANADIANS
 have experience caring for someone with a form of dementia

MORE THAN 500,000 CANADIANS
 live with dementia

56% OF CANADIANS
 concerned about being affected by Alzheimer's disease

Source: Alzheimer Society Canada 2017-2018 Impact Report

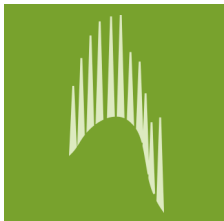
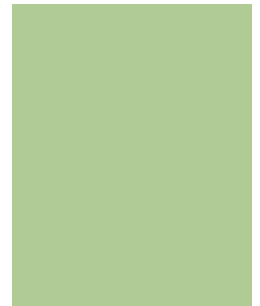


Labrador - Grenfell Health

DEMENTIA: WHAT TO EXPECT

"The disease might hide the person underneath, but there's still a person in there who needs your love and attention."

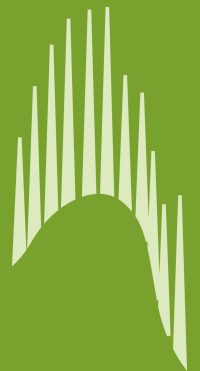
-- Jamie Calandrillo



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For more information, please visit:
www.alzheimer.ca/nl/en

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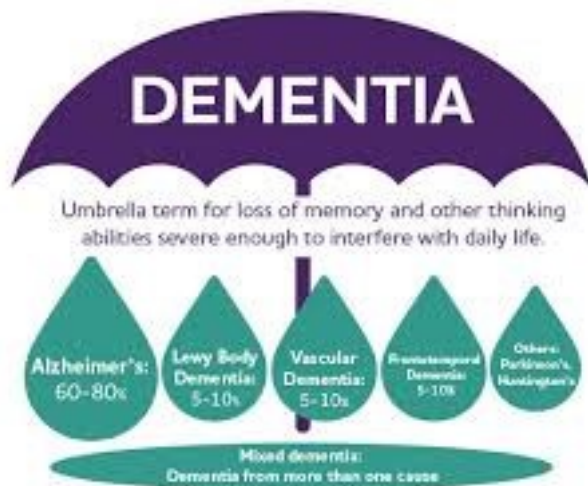
TYPES OF DEMENTIA

There are many types of dementia but some are more common than others. Alzheimer's Disease is the most common form of dementia, making up 60-80%. Other types include Lewy Body Dementia and Vascular Dementia.

Dementia with Lewy Bodies show symptoms of both Alzheimer's Disease and Parkinson's Disease. The person will walk similar to someone who has Parkinson's Disease which increases their risk of falling. The person will also show signs of memory issues and experience visual hallucinations.

Vascular Dementia can result after a stroke.

Every person is impacted differently with dementia and progress at different rates. This booklet aims to give you some idea as to what to expect so you can better prepare but timelines vary.



REFERENCES

<https://www.alzheimers.gov/life-with-dementia/tips-caregivers>

<https://www.webmd.com/palliative-care/caring-for-a-person-with-dementia>

<https://www.dementia.org/stages-of-dementia>

<https://www.elder.org/care-guides/living-with-dementia/>



ADDITIONAL RESOURCES

Communicating with people living with dementia | Alzheimer Society of Canada

<https://alzheimer.ca/en/help-support/im-caring-person-living-dementia/looking-after-yourself>

www.alzheimernl.org

<https://www.nia.nih.gov/health/alzheimers/living-with-dementia>

<https://www.elder.org/care-guides/living-with-dementia/>

<https://www.helpguide.org/articles/alzheimers-dementia-aging/living-with-dementia.htm>

Getting a new diagnosis of dementia is a lot to take in for the person as well as the family. Take some time to process the diagnosis and speak to healthcare providers about any questions you may have.

Dementia is a progressive condition and there is no cure. Dementia progresses at different rates in each person but the symptoms will continue to become worse over time.

There is no specific test for dementia. The diagnosis is determined based from a memory test and ruling out other conditions using blood work and CT scan. There may be more than one clinician who assess the person before a diagnosis is made. The reason for this a single appointment is only a snapshot in time and may not be enough to make a diagnosis.

There are medications that may help with memory but often only work for a short term and they do not work for everyone. Other non-drug treatments that may help include use of music, expressing through art, reminiscing, massage, and animal therapy.



SYMPTOMS OF DEMENTIA

Some symptoms include:

- Struggle to recall a familiar face or name
- Repeat the same questions, words or phrases, or have general problems with language
- Lose interest in hobbies they used to enjoy
- Become confused with the time of day and get lost in familiar places
- Lose track of their routine and appointments
- Find it difficult to focus on a hobby or TV program
- Show poor judgement, such as walk out into busy roads or pick up a hot pan
- Misplace personal items, like glasses and medicine
- Experience mood swings and become unusually anxious, upset or irritable
- Feel a constant need to walk around
- Become paranoid and delusional, or have hallucinations
- Be resistant to change, such as a new appliance
- Hesitate at doorways, curbs, or changes in flooring
- Struggle to swallow food and have weight loss
- Changes in bathroom habits
- Experience mobility problems
- Difficulties with thinking and problem solving
- Changes in personality
- Difficulty completing daily tasks

This list is not exhaustive and some symptoms can also relate to other conditions.

8. Sorting —Give person colored pom-poms and provide containers of the same color. Place pom-poms in the matching colored container. Use a deck of cards and sort by suit. Match pictures together or sort into groups such as pets and food.

9. Picture Puzzle—Enlarge a photo of the person or a close relative. Laminate it and cut into four odd pieces to put together. Alternatively: a colorful picture of a car, fruit or landscape also works well.

10. Activities relating to the individual's former life—For instance, a carpenter may enjoy sanding a nice piece of wood, a post office worker may enjoy stamping envelopes, a home-maker may enjoy arranging pots and pans on a shelf, fisherman may enjoy untying knots or mending 'nets' etc.

11. Reminiscing—Long term memory can be retained by people living with dementia even as the illness progresses.

12 Cup cake decorations—Buy a few dozen cup cakes. Make icing in two colours and put into piping bag.



12 ACTIVITIES FOR PEOPLE LIVING WITH ALZHEIMER'S DISEASE

1. Fiddle Box—Place items in a box and present it to the person two or three times a day for a 'feel, touch & explore'.
2. Music—Play folk or popular music from their younger days. Give the person a percussion instrument to add to the fun.
3. Rubber Tipped Darts Game—This can be played by one or two people, each having three darts to throw.
4. Threading Yarn or String—Buy large pasta loops for the person to string together with a thick yarn or thin rope.
5. Doll Therapy—The dolls should look like newborn babies. Buy a bassinet, a baby bath, a cot and lots of baby clothes.
6. Fabric box—Provide a large cardboard box with dozens of pieces of assorted fabric inside it; silk, lace, felt, velvet, acrylic and wool. Touch, feel and fold.
7. Beach ball—Buy a large beach ball and roll or kick it to each other while sitting.

DEMENTIA-FRIENDLY HOME

- Limit multiple changes at the same time as this will be confusing.
- Use signs and pictures to show the person's life story and help them to remember gaps.
- Open layouts are easier to navigate.
- Use colors to help with understanding. For example, red of toilet seats, blue for meal plates, a different color around door frames and edges of stairs.
- Remove mats or different patterned flooring as it can look like holes in the floor.
- Simple instruction signs can help but don't get too technical as this can cause more confusion.
- Remove flower patterns as they look like real flowers or other patterns that are bold and could be mistaken for something else.
- Good lighting reduces shadow and glare.
- Add handrails on stairs and in bathroom.
- Fall detection alarm buttons are available in our region through lifeline. This will alert a selected family member if a fall is detected. Speak with Social Work for more information.



HELP TO PRESERVE MEMORIES

Memories are still very important to a person living with dementia. More recent memories usually fade first but they hold on to older memories.

Photo albums and memory boxes can help keep memories strong. Talk and reminisce about the past. Remember your loved one is still the same person and things that mattered before still matter now.

DIET

Your loved one will likely need some help with eating a healthy and balanced diet. Make sure food is appealing as appetite starts to fade.

Get your loved one involved in preparing the meals especially if they were often in the kitchen in the past.

Don't overload plates during meal times and don't be too stuck on three meals a day. Often the person will eat less during meals but want to snack throughout the day. Have healthy snack options available for between meals.

Eating habits and tastes can change over time—this is normal.

Keep an eye out for any difficulties in swallowing and contact a speech language pathologist in your area to arrange an assessment if you notice any changes in swallowing.

TIPS FOR HANDLING TROUBLESOME BEHAVIOR

- We cannot change the person. A brain disorder is shaping who the person is becoming and how they act. You cannot change or control new behaviors but instead you need to learn to accommodate them. For example, if the person insists on sleeping on the floor, put the mattress on the floor so it's more comfortable.
- We can change our behavior and how we respond.
- Check with the doctor. Make sure the changes are not the result of another underlying condition or a reaction from medications.
- Behavior has a purpose. People with dementia cannot always tell us what they want or need. Taking all the clothes out of their closet each day may be filling the need to be busy. Give them something else to do to fill the need. It may take a few tries to figure out what need they are trying to fill and to find a replacement.
- Behavior is triggered. All behaviors happen for a reason. The root of changing the behavior is to disrupt the patterns.
- What works today, may not tomorrow. Adjustments may need to be made to current coping strategies or they may need to be changed completely.
- Get support from others. You are not alone. Talk to other caregivers as well.

COMMUNICATION TIPS

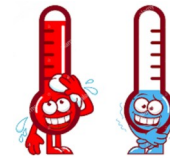
- Set a positive mood for interactions. Attitude and body language are very important.
- Get the person's attention. Limit noise and distractions. Say their name when you are talking to them to be sure they are paying attention to you before you start.
- Use simple words and sentences. Speak slowly and clearly.
- Ask simple questions. Yes/no questions work well. Ask only one question at a time.
- Listen with your ears, eyes, and heart. Be patient for an answer and if they are really struggling it's ok to suggest a word.
- Break down activities in smaller steps. This makes tasks more manageable and helps to maintain independence longer.
- When the going gets tough, distract and redirect. If your loved one becomes upset or agitated, try changing the subject or the environment (go for a walk).
- Avoid trying to convince them they are wrong. They easily get confused and anxious. Offer support and reassurance.
- Remember the good old days. Remembering the past can be soothing. Don't ask questions about things that happened recently but they will likely remember the past very vividly.
- Maintain a sense of humor. Individuals with dementia are usually still very social.

Dehydration is common and can cause increased confusion as well as urinary tract infections (UTI). Make sure water is always in sight.

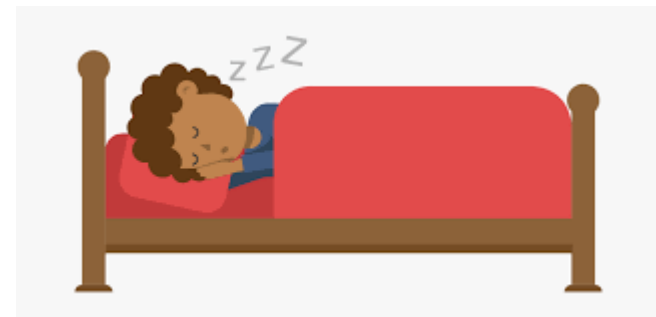
SLEEPING

Sleep patterns can get mixed up. Sleeping more during the day can lead to increased activity at night. Sometimes days and nights can get mixed up and the person will think it's time to get up and dressed when it's really time to get ready for bed.

Sleep patterns can be worsened with time changes or sudden changes in temperature.



Avoid caffeine and limit large meals in the evenings. Get some fresh air and exercise during the day. Relax before bedtime. These can all help keep a regular schedule for sleeping.



GENERAL DECLINE

Your loved one will gradually decline over time. The decline can include a change in communication, swallowing, mobility, and awareness of needing to use the washroom.



They may think they are hungry all the time or forget to eat completely.

There may be an increased risk of falling as the person may no longer remember how to walk. This is not a decrease in strength but a motor planning issue.

You may see personality changes as well as mood swings.

The decline may be gradual but may also have episodes of rapid decline associated with other health concerns or changes in environment. A stroke or heart attack may cause a rapid decline, so may a hospital admission or moving to a new living area.

Once diagnosed with dementia driving may no longer be safe. If your loved one is not ready to stop driving then they should be screened regularly by the doctor to ensure that they are still safe to be driving.



THINGS TO NOT SAY TO SOMEONE WITH DEMENTIA

- “Do you remember?” - This can make someone anxious if they don’t remember something they are expected to. Ask open ended questions instead such as “what was your favorite thing we did when I was growing up?”
- Don’t argue—Being right doesn’t matter just go along for the ride. Trying to correct will just lead to frustration.
- “You’re embarrassing me!” - They are having a hard time and are not trying to embarrass you.
- “Why are you doing that?” - They don’t have an answer why they are doing things like pick their skin. Give them something else to do with their fingers.
- “What shirt do you want to wear?” - Too many options. Show them 2 shirts to choose from. If they say one but point to the other, use the one pointed to.
- “That’s an orange, not an apple!” - It doesn’t matter! Just let them eat whichever one they picked.
- “You are home!” - They feel disconnected. Watch TV or have a conversation to help them settle.
- “You just ate!” - They often don’t remember they just ate. Have light snacks around to munch on.
- “We need to hurry!” - If your loved one is stressed or fearful it will only slow down the process. Be calm, support and comfort your loved one.
- “Here, let me do that!” - Have patience and let them finish. If they are having too much trouble then try and distract them and finish it yourself later. Find ways to help make tasks easier.