



Getting to Know Dementia

A Guide to Diagnosis,
Treatment, and Care



**BRITISH
COLUMBIA**

Supported by the Province of British Columbia

iCON
interCultural Online
Health Network



THE UNIVERSITY OF BRITISH COLUMBIA

Digital Emergency Medicine

Department of Emergency Medicine | Faculty of Medicine



Message to the Reader

In 2015-16, more than 419,000 Canadians, 65 years and older were living with dementia. Of these, two-thirds of patients were women. There are approximately nine seniors diagnosed with dementia every hour and 78,600 new cases of dementia per year.¹ A recent report found that the number of individuals affected by dementia may increase by 72% in the next 10 years. Certain ethnic minorities, women and those living with uncontrolled chronic conditions such as diabetes and hypertension, were also reported to be at a higher risk for developing dementia¹. However, healthy diet and lifestyle changes can help reduce your risk of developing dementia, no matter what age you start making these changes.

The Chinese-speaking community in Canada may have a lower level of knowledge about dementia and perceive more barriers when seeking help.^{2,3} While increasing age can be a risk factor for dementia, dementia is not a normal part of normal aging. Changes in your or your loved one's personality and memory may not always be age-related and paying attention to the early signs and symptoms of dementia can help you/your loved ones get timely medical attention. Please do not wait until you/your loved one's symptoms worsen before talking to your primary care provider.

Through this booklet, we aim to provide information about why memory loss related to dementia is not a result of normal aging and is not something you should feel ashamed about. Trusting your family members and your primary care provider with any symptoms you are experiencing is not a sign of weakness. While it can be tough to deal with society's views on dementia, it is important for us to educate ourselves on how our mental health is as important as our physical health.

While dementia is not curable, early diagnosis can lead to a better outcome through better management of symptoms with medications and non-medication therapies. It can also give you more time to prepare and plan for the future. This may mean handling your finances, deciding on the kind of care you want to receive and making the most of your time spent with loved ones. If you or your family members notice changes related to dementia in your mood and behaviour, please do not hesitate to seek professional help. You are not alone in this journey and there are people that can help.

Please note: This booklet is a compilation of best practices put together by content experts and its use is meant for general information purposes. The information presented in this booklet does not replace the advice of a health care provider. Please talk to your health care provider before implementing any changes to your lifestyle or medications.

1. The information presented in this section has been adapted from: Canada, P. (2019). A Dementia Strategy for Canada: Together We Aspire: In Brief - Canada.ca, from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy-brief.html>
2. Koehn, S., McCleary L., Garcia L., Spence M., Jarvis P., Drummond, N. (2012), Understanding Chinese–Canadian pathways to a diagnosis of dementia through a critical-constructionist lens, *Journal of Aging Studies*, 26(1). doi.org/10.1016/j.jaging.2011.07.002.
3. Ho, B., Friedland, J., Rappolt, S., & Noh, S. (2003). Caregiving for relatives with Alzheimer's disease: Feelings of Chinese-Canadian women. *Journal of Aging Studies*, 17(3), 301–321. doi.org/10.1016/S0890-4065(03)00028-8



Getting to Know Dementia

A Guide to Diagnosis, Treatment, and Care

Dementia is more than just forgetting. Do I have dementia?	Page 3
What is the difference between normal aging and dementia?	Page 5
What are the risk factors of dementia? How can I maintain the goal of a healthy lifestyle and brain?	Page 7
How do I get diagnosed?	Page 11
Are there different types of dementia?	Page 13
What are the different stages of dementia and what can I do to manage them?	Page 16
Are there any medications for dementia? How do they help?	Page 19
Planning ahead: What do I do and when do I start?	Page 23
Abuse and neglect	Page 26
How can caregivers get help and from where?	Page 27
Resources	Page 33



Recognition and diagnosis:

One person's experience

Mun Yee (Mary) is 76 years old. She has owned and operated her own Hong Kong style café for most of her life. She also enjoys telling vivid and detailed stories from her childhood.

One day, Mary faints and is taken to the hospital, where it is discovered that she has taken twice the dose of her blood pressure pills twice that day. Mary's daughter-in-law notices that Mary cannot remember the name of the nurse who has been with her all day. Other family members have also noticed that Mary's short term memory has been gradually declining over the past year or so. She has trouble remembering what she ate for breakfast. She has also been having a hard time doing the things she usually does, such as leaving the burner on, taking medications twice instead of once, trouble remembering which groceries to buy, trouble using the TV remote, misplacing keys, forgetting her appointments, and asking the same question repetitively to family members. Her daughter-in-law reports that Mary doesn't have significant memory problems – she may struggle to find the occasional word and may misplace items often, but she can still name her first grade teacher! All this time, her family thought Mary was just forgetting because she's getting older.

However, Mary's doctors are concerned about her. After some follow up appointments and tests, Mary is diagnosed with early stage Alzheimer's disease.



(Shutterstock, n.d.)

Dementia is More than Just Forgetting. Do I Have Dementia?

Many older adults, their friends, and their families worry about getting dementia. Dementia is not a normal part of normal aging. Dementia is a broad term used to describe the impact of diseases or injuries that affect the brain and the vascular system.¹ Dementia is a chronic, progressive condition, which not only affects memory but also awareness of the time, place or people around us, language and math skills, behavior, decision making, judgement, personality and day-to-day function. However, it is important to know that not all adults will develop dementia.

See a health care provider if you, your family, friends or caregivers notice changes in your ability to do things, loss of skills you had before or trouble remembering new information in social settings or in day-to-day life.

¹ Adapted from: Canada, P. (2019). A Dementia Strategy for Canada: Together We Aspire: In Brief - Canada.ca, from <https://www.canada.ca/en/public-health/services/publications/diseases-conditions/dementia-strategy-brief.html>



What are the Signs of Dementia?

The Alzheimer Society of Canada lists the following as signs of dementia:

1. Memory loss affecting day-to-day abilities.
2. Difficulty performing familiar tasks such as using a stove, the TV remote, or the phone.
3. Problems with language, such as difficulty finding the right words and trouble following a conversation.
4. Disorientation in time and place leading to confusion and getting lost. For example, forgetting the way home from the grocery store or the temple/church.
5. Impaired judgement, such as difficulty making the right decision.
6. Problems with abstract thinking and planning. This may show up as trouble planning a family event, a reduction in ability to think, remember and reason.
7. Misplacing things, losing keys, forgetting where you left your jacket or purse.
8. Changes in mood and behaviour, for example, feeling more irritable or anxious or changing emotions in a short period of time.
9. Changes in personality that are different from your usual self, for example, becoming aggressive or unkind when you've never been that way before.
10. Loss of initiative and decreased socialization, such as staying in your room and away from family, no longer making family decisions that you used to before.

Talk to your health care provider if you or your loved one experience any of these signs.

What is the Difference Between Normal Aging and Dementia?

Dementia is not a part of the normal aging process. As people age they experience some form of changes in brain function, which are considered normal aging. However, significant changes in brain function may be signs of early dementia. One of the biggest risk factors for dementia is simply aging. This can make it difficult to distinguish whether the changes that we experience in our brain function and memory after age 65 represent normal aging, or signs of early dementia.

The following section illustrates some of the key differences between normal aging and dementia.

Short term memory

Normal aging: A person forgets small details from a year ago, such as what they wore on a given day, or what was talked about over tea. They are still able to recall dates and events.

Dementia: A person forgets more important details from more recent events such as whether medication was taken in the morning or where they were walking. They may leave the stove on or misplace money. Longer term memories are often still okay in early stages.

Learning new things

Normal aging: A person has difficulty learning complex information, such as using a new phone. They are, generally, still able to remember how to use day-to-day things such as the stove or washing machine.

Dementia: A person forgets information that was previously learned, like using the phone, TV remote or toaster, which they have used many times before.

Language

Normal aging: A person has some trouble finding the right words to describe something; vocabulary and comprehension remain intact.

Dementia: A person has difficulty finding words more often. This can result in frustrating conversations with starts and pauses. They sometimes use inappropriate words to describe something. Vocabulary becomes very limited.

Names and recognition

Normal aging: A person forgets the name of someone they have only met once or twice, or the face of someone they have not seen for a long time.

Dementia: A person forgets the names of close relatives or friends; in advanced dementia, people can have trouble visually recognizing their loved ones.

Insight

Normal aging: A person often feels their own memory is slipping, even if others don't notice their difficulties.

Dementia: A person often denies being forgetful, and may even get offended if others start noticing their memory difficulties. They may make up stories to cover their memory loss in earlier stages. In some cases, there is no self-awareness of the memory loss.

Judgment

Normal aging: A person's judgment is the same as before.

Dementia: A person's judgment and decision making become affected; decisions are often poor and result in actions without consideration of consequences. For example, dressing in summer clothes during the winter or in the rain, or difficulties in managing financials and properties, or unusual behavior towards loved ones (becoming more argumentative).

Change in personality/ behavior

Normal aging: A person's baseline personality and behavior remain unchanged.

Dementia: A person's personality can appear to completely change. They may become more aggressive, get angry or irritated easily; they can be argumentative, very emotional and at times blunt. They may lose social skills, and may come across as less thoughtful.

Perhaps the most important difference of all is that dementia progressively (with time) affects a person's ability to live and function independently. Significant memory loss or brain changes that affect daily living are not part of normal aging.

It is important to speak to your health care provider if you suspect dementia in yourself or a loved one. If ignored, dementia can eventually reduce quality of life and can even affect a person's safety in later stages.





What are the Risk Factors of Dementia? How Can I Maintain the Goal of a Healthy Lifestyle and Brain?

The following information has been adapted from the Alzheimer Society of Canada: “Heads Up for Healthier Brains” brochure <https://alzheimer.ca/sites/default/files/documents/heads-up-for-healthier-brains.pdf> and “Meal Times” brochure https://alzheimer.ca/sites/default/files/documents/Meal-times_Alzheimer-Society-Canada_0.pdf

Generally, dementia is caused by progressive changes in the brain. Age is the biggest risk factor for dementia, mainly in people over 65 years of age and in every third or fourth person over the age of 85 years old. Researchers have found however, that changes in the brain start about 20 to 25 years before symptoms appear.

There are some risk factors that are beyond our control. For example, lower levels of education in early life, being a woman, some ethnicities, losing your hearing during middle age, and having experienced a previous stroke, heart failure or heart disease can increase your risk of developing dementia. However, there are many risk factors, which can be controlled, and research indicates that reducing your individual risk has been shown to be beneficial at any age when it comes to prevention. Fortunately, there are actions we can take, not only to decrease our risk of these brain changes, but also to reduce/manage our risk of other chronic diseases.

It is very important to understand these risk factors and limit them over your lifetime to help lower your risk of developing dementia. They are outlined below along with healthy goals to minimize your risk.



Diabetes

Uncontrolled type 2 diabetes makes a patient twice as likely to develop dementia.

Goal: Keep blood sugars well controlled, with Hemoglobin A1c less than 7%.

Among people 75 years of age or older, Hemoglobin A1c less than 8% is reasonable. Talk to your health care provider about targets set for you.



Blood Pressure

High blood pressure, especially during midlife (45-65 years of age) puts strain on the arteries and blood supply to the brain. This increases the risk of developing dementia.

Goal: Generally, aim for blood pressure less than 140/90, or if you have diabetes, less than 130/80. Decreasing salt in your diet and regular exercise can help achieve this, along with medications as advised by your health care provider.



Cholesterol

High cholesterol levels also affect the blood supply to the brain, increasing risk of dementia.

Goal: Generally, aim to keep total cholesterol under 5.2 mmol/L. Keep HDL (“good cholesterol”) above 1 mmol/L, but ideally above 1.5 mmol/L. LDL (“bad cholesterol”) should be kept as low as possible, depending on the other conditions you may have. An ideal level of LDL would be below 2 mmol/L, but speak to your health care provider to determine your targets.



Lack of Physical Activity

Not staying active and exercising increases the risk of many serious illnesses, including heart attacks, stroke, diabetes and dementia.

Goal: Aim for at least 30 minutes of strenuous physical activity per day, at least four days per week. Brisk walking is acceptable for older adults. Speak to your health care provider about what is appropriate for you.



Alcohol

Excessive alcohol use harms brain cells and increases the risk of dementia.

Goal: Keep alcohol use to occasionally at most. Avoid daily consumption (more than two drinks per day) and avoid binge drinking.



Smoking

Smoking increases the risk of several types of dementia, especially if you continue to or start smoking after the age of 65.

Goal: Quit smoking. It is never too late, as risk levels for many conditions will decrease with every smoke-free day after quitting, even if you have smoked for many years.



Obesity

Obesity, especially in middle age, increases risk of dementia.

Goal: Generally, men should aim for a waist circumference below 102 cm, and women below 88 cm. Ask your health care provider to measure your Body Mass Index (BMI). Keeping BMI under 25 is ideal. Make healthy food choices by eating a diet full of dark coloured fruits and vegetables. Increase omega 3 oils in your diet by cooking with canola oil and eating fish (e.g., steamed fish). Spinach and blueberries have antioxidants that protect your body from damage and are good for you.



Poor Hearing

Our brain needs input from all our senses, such as seeing, tasting, smelling, touching and hearing. New research shows that reduced hearing can actually lead to the brain becoming smaller.

Goal: See your health care provider as early as possible if you notice any hearing difficulty.



Depression and Social Isolation

There is a link between not staying in contact with friends and family, and depression, which can increase your risk of developing dementia. Many patients with early dementia also have depression.

Goal: Stay connected socially to help you stay connected mentally. Social interaction (minimum twice a week) appears to have a protective effect against dementia. The more engaged you are, the better.

- Call your friends and family regularly to stay connected with them. Get to know your neighbours and plan activities together, such as walks around the neighbourhood.
- Spending time with others who have a positive attitude towards life can improve your mood and make you feel connected.
- Volunteer at local places, such as the temple/church or be active in the workforce.
- Join a group or start your own group! If you have a hobby you enjoy, you can invite friends and neighbours over to read together, knit together or even do arts and crafts together.

If staying engaged in your relationships and the community does not help, we encourage you to speak to your health care provider about changes in your mood as early as possible, as several treatment options are available.



Lack of Brain Exercise

Research has shown a link between exercising the brain and a lower risk of dementia. This suggests that keeping the brain active and stimulated is protective against dementia.

Goal: Keep your brain active by exercising it using the following tips:

- Try something new. Join a class with friends, visit a park with your family. You can also learn a new language, a new recipe, how to use the computer or other hobbies, such as knitting or gardening.
- If you have a task you do every day, change the way you do it. For example, try brushing your teeth with your left hand if you always use your right hand.
- Ask your young grandkids or other family members or friends to play games with you. Card games that involve thinking or calculations, chess, and jigsaw puzzles are some examples of games that can exercise your mind.



Head Injuries

Severe or repeated head injuries, such as those occurring in contact sports, including kabaddi, boxing, wrestling or high-speed outdoor activities, can lead to brain changes that may be linked with dementia.¹

Goal: Always wear a helmet for dangerous activities. Play safely.

To summarize, keeping happy, social and proactive about your health can help decrease your chances of getting dementia. Reduce stress by practicing relaxation, meditation or other stress reduction techniques. See your health care provider regularly, both for checkups and any specific health concerns. Your health care team is an important partner in maintaining your health.



Consult your health care provider for more information if you think you might be at risk of developing dementia.



(Shutterstock, n.d.)

¹. Adapted from the Alzheimer Society of Canada: “Challenge Yourself” <https://alzheimer.ca/en/Home/About-dementia/Brain-health/Challenge-yourself> and “Day to Day Living” <https://alzheimer.ca/en/Home/Living-with-dementia/Day-to-day-living>



How Do I Get Diagnosed?

Diagnosing dementia is a process.

There is no one test to know if you have dementia

Your health care provider will do an assessment, which can sometimes involve a number of steps, including a referral to a specialist if needed. There are multiple causes of dementia-like symptoms that need to be considered before getting a correct diagnosis of dementia.

Knowing you have dementia

The acceptance of a diagnosis is different for each person. Some people need a longer time to accept getting a diagnosis of dementia.



What Can I Do?

Get the help and support you need from friends and family, or from professionals and/or organizations. When you find out you have dementia you may feel relieved, shocked, sad, or in denial. It is important for people living with dementia and their families to feel free to openly discuss their experiences and feelings during this time.

Stigma or feelings of shame around dementia can hurt and discourage people living with dementia and their families from getting a diagnosis, accessing the services they need or telling others. Stigma and stereotypes lead people to think that living a satisfying life ends with the diagnosis of dementia. It is possible to continue to live well with the disease especially if diagnosed in early stages. Refer to the Alzheimer Society to learn more about stigma.

People will be around to help during this time. These people include family, friends, doctors, and specialists such as psychologists, neuropsychologists, neurologists, geriatricians (a doctor who specializes in the care of older adults), gerontologists, geriatric psychiatrists, nurses, social workers, genetic counsellors, and/or occupational therapists.



Steps in Getting a Diagnosis



1. Medical History

- People living with dementia, family members and health care professionals will be involved in this process.
- Problems with driving, forgetting to take or not being able to remember taking your medications, being repetitive in conversations, and forgetting recent conversations or events can be signs of dementia and should be brought to your health care provider's attention.
- Health care providers may ask the following questions to people living with dementia:
 - What are the symptoms?
 - When did the symptoms start?
 - How do the symptoms affect your life?
 - How are you feeling emotionally?
 - Do you have any worries or thoughts that bother you?
 - Are you taking any prescribed/over-the-counter/herbal medication?
 - Do you have a family history of dementia?
 - What are your other medical problems?



2. Mental Status Exams

In the Mental Status Exam you will be asked questions to assess your memory and brain function. Some of these tests are available in multiple languages. Please ask your health care provider for language options if English is not your first language. Some may find these tests difficult, and some may not. Try not to be discouraged. Tests are a part of getting you the help you need. These tests help your doctor with the diagnosis and treatment.



3. Physical Exam

A complete physical exam may show if a physical condition is the cause of your dementia. A health care provider may take your blood pressure, and also check your vision and hearing. Your health care provider may also evaluate your gait (i.e., manner of walking and running), balance, sensation, reflexes and speech.



4. Specialized Tests

Sometimes, more specialized tests are needed such as blood tests, electrocardiogram (ECG), computed tomography (CT) scan or magnetic resonance imaging (MRI). These provide detailed pictures of the heart and brain. These tests provide information about any reversible factors that are causing your symptoms.

Are all dementias the same?

One person's experience

Mr. Man Kit (Peter) Lau was diagnosed with vascular dementia several years ago when he suffered a stroke. He was suddenly starting to become lost in familiar settings, sometimes wasn't able to recognize old friends and was becoming unsteady on his feet. Peter smoked cigarettes for most of his life and had high blood pressure.

Peter's condition had been relatively stable and he was doing quite well until recently, when his wife, Amy, started to show strange changes. She was starting to forget to pay bills, leave the stove on, have trouble remembering words, and misplace items even though she was always a very organized woman. Her children became confused, as their mother has normal blood pressure, has never smoked and has no other health issues. They are worried and decided to take their mother to the doctor, where they are surprised to learn that Amy also has dementia! They ask the doctor how can this be? Mrs. Lau's case is so different from that of her husband's.



(Shutterstock, n.d.)

Are There Different Types of Dementia?

In the story on the left, we can see that Amy is experiencing a different type of dementia than her husband Peter. Not all dementias are the same. The image on the next page depicts the different types of dementia. While the symptoms listed in each box are associated with certain types of dementia, they should not be used to diagnose dementia yourself. If you experience any symptoms associated with dementia, see your health care provider for a diagnosis.

There are other types of dementia, which are not listed here. For more information:

<http://www.alzheimer.ca/en/bc/About-dementia/Dementias>



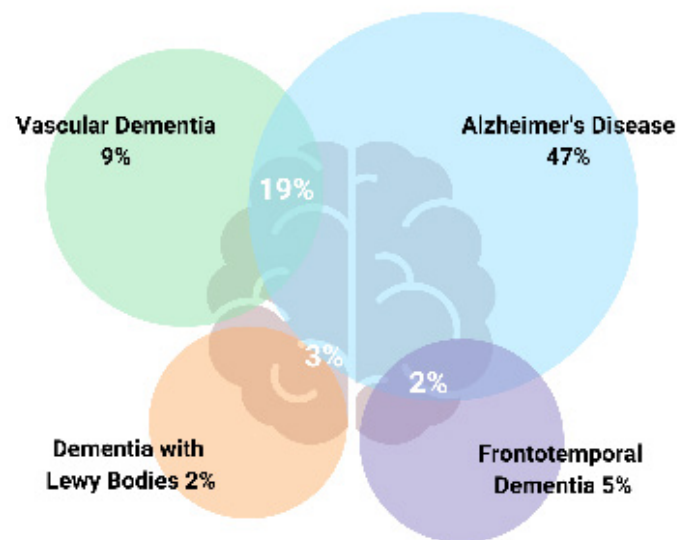
Alzheimer's Disease

There are various types of dementia, the most common of which is Alzheimer's disease. It makes up two-thirds of all dementia cases, and a majority of cases are seen in people over the age of 65. Less than 1% of patients under 65 years of age, even with a strong family history of dementia, can be diagnosed with young onset dementia. Symptoms typically indicative of Alzheimer's dementia (most consistent with Mrs. Amy Lau's symptoms) include difficulty remembering recent conversations, names or events, changes in mood, emotion and behaviour and eventually not being able to function independently.

Vascular Dementia

Problems with blood supply to the brain, such as a stroke, can lead to another type of dementia called vascular dementia. Symptoms typically indicative of vascular dementia, include difficulty with decision making, walking, finding the right words, recognizing familiar faces and places, balancing and driving (most consistent with Mrs. Amy Lau's symptoms).

Sub-types of Dementia



Sub-types of Dementia- commonly seen in Canadian memory clinic. Excerpted from Cognitive Impairment - Recognition. Diagnosis and Management in Primary Care (2014).

Dementia with Lewy Bodies

Dementia seen in association with Parkinson's disease is Lewy Body Dementia. Symptoms include visual hallucinations (seeing things), hand tremors, falls, fainting, vivid dreams and Parkinson's movement.

Frontotemporal Dementia

Another type called Frontotemporal Dementia is seen at a young age with a strong family history. Symptoms include constant repetition of meaningless words or phrases, decline in hygiene and self-care, loss of interest, and inflexibility in thinking.

There are other types of dementia not mentioned here, for additional information on types of dementia please visit: <http://www.alzheimer.ca/en/bc/About-dementia/Dementias>



Stages of Dementia

Dementia can be described in “stages,” which refers to how far a person’s dementia has progressed. Defining a person’s disease stage can help with determining the best management and appropriate support for patients and caregivers. Most often dementia stages are referred to as – mild (early stage), moderate (middle stage) and severe (late stage). Dementia affects people in different ways. Each person will progress through stages differently and many stages might overlap.



Healthy

A healthy person without dementia is able to perform many activities of daily living, such as:

- Dressing
- Bathing
- Eating
- Communicating with friends and family
- Managing their finances
- Choosing weather-appropriate clothing

Mild (Early Stage)

During the early stage, people may still be able to continue with their activities of daily living. Due to the limited impact of dementia on their daily life, people may even be unaware of a diagnosis of dementia. Friends, family members or others close to the individual or the individual themselves may notice:

- Increased forgetfulness
- Difficulties with communication
- Changes in mood and/or behaviour
- Changes in ability to manage activities of daily living

Moderate (Middle Stage)

During the moderate stage, people or their loved ones may notice a greater decline in their functional and cognitive abilities. At this stage, people may require some assistance with daily tasks, such as:

- Driving
- Banking
- Shopping
- Meal preparation
- Homemaking
- Dressing
- Bathing and toileting

Severe (Late Stage)

The late stage of dementia may also be called the “severe” or “advanced” stage. As the late stage progresses, activities of daily living may become difficult for people to manage on their own and they may require care 24 hours a day, even with basic functions such as:

- Eating
- Toileting
- Simple communication

If you are in this stage, please do not hesitate to rely on your loved ones for support when you need it.



What are the Different Stages of Dementia and What Can I Do to Manage Them?

Healthy

A healthy person without dementia is able to perform many activities of daily living. People without dementia are able to talk to family and friends, remember where they keep their personal belongings, manage their finances and choose weather-appropriate clothing. They are also able to perform many other tasks on their own, such as dressing, bathing and eating.

However, people living with dementia have difficulty carrying out these activities. As their dementia progresses, they will find that they need more and more support in carrying out their daily tasks.

Mild (Early Stage)

The term “early stage” refers to individuals of any age who have mild changes in memory and function. People in this stage may be able to continue their activities of daily living with minimal assistance, which may explain why some people are not aware that they have dementia during this stage and may not get diagnosed until a later stage. Common symptoms include forgetfulness, communication difficulties, and changes in mood and behaviour, specifically depression and anxiety. Depression and anxiety can be managed by educating patients and families, along with involvement of a doctor. Friends, family or others close to the individual may begin to notice difficulties. A person living with dementia may have insight into their changing abilities, and, therefore, can inform others of their symptoms and experience of living with the disease.

What Should I Do?

- Talk to your health care provider as soon as you start noticing symptoms. There are medications that may help (please refer to page 19).
- Maintain a healthy lifestyle, including physical activity, healthy eating, socializing, and familiar and meaningful activities.
- Make sure to carry your name, address and phone number in every sweater and coat pocket, or buy a bracelet to put this information on, in case you experience difficulty with finding your way home.
- If you experience difficulty with managing your medications, talk to your pharmacist about blister packs and pill boxes to help you remember when to take your medications because it is important to take your medications on time.
- Improve the safety of your home by installing night lights, a working furnace and functioning smoke detectors. Ensure that appliances, such as the stove and oven, are turned off after use. If you have difficulty with this, one option is to install an automatic stove turn off device.
- Be realistic about your ability to drive. Talk to your health care provider about how your symptoms can impact your ability to make safe decisions on the road. (Please refer to page 18).
- Arrange financial, legal and care matters and decide who will be responsible for these functions. Make a Representation Agreement (in B.C.) or Power of Attorney to say what you want for your future care (Please refer to page 24 for more information).
- Learn about the services and resources that are available in the community (for homecare, community centres and programs and other resources, please refer to page 27).
- Attend early stage support groups facilitated by the Alzheimer Society of B.C.

Moderate (Middle Stage)

One may experience a further decline in memory and functional abilities in this stage. Even though cognitive abilities deteriorate, people at this stage may still have some awareness of their condition. With these changes, assistance with many daily tasks, such as driving, banking, shopping, meal preparation, homemaking, dressing, bathing and toileting will eventually become necessary. While this can be a very difficult time for the individual, family members may also be deeply impacted. With increasing need to provide care, everyone involved may need help and support, for which resources are available (Caregivers please refer to 'Caring and Supporting People Living with Dementia' section on page 27).

What Should I Do?

- Simplify your daily regimen with things like choosing clothes, dishes that you can make easily and trying to use the same route to get to places.
- Remembering to take your medications on time can be a challenge in this stage. Set daily alarms or ask your loved ones to help you with this task. Many pharmacies also offer a delivery service to make sure you receive your refills on time.
- Communication may not be as easy in this stage. Please take the time you need to express yourself and tell others you may need more time.
- Take a friend or family member with you to your health care provider's appointments to help improve communication and clarify information.
- Home Health Services can provide you with possible assistance in some daily functions such as bathing, meal set up, and medication supervision if deemed appropriate. Contact Home Health for an assessment (Please refer to page 26 for more information).
- Forgetting your way home can happen. Contact the Alzheimer Society to register yourself or your loved one with the MedicAlert® Safely Home®. For strategies to prevent this, please refer to the caregiver section on page 27.
- Consider using a nutritional service or having family members help with cooking. Discuss alternate meal options with your family as you may have trouble cooking as dementia progresses.

Severe (Late Stage)

The late stage of dementia may also be called "severe" or "advanced" stage. As the late stage progresses, the individual may require care for 24 hours a day and will have to rely on loved ones for help. Basic functions such as toileting, eating, and even communicating can become quite difficult for a person living with dementia to do on their own. While coming to terms with this can be tough, it is important for people in this stage to strengthen their support system and not hesitate in reaching out to near and dear ones for help when needed. Preparing for this stage by communicating with family and planning ahead in earlier stages to direct finances and health care decisions is extremely important.

Can I still drive and take care of myself?

One person's experience

Mr. Lok Yin (Lucas) Lee was diagnosed with Alzheimer's disease several years ago. He still lives on his own and continues with many of the chores and tasks he did before being diagnosed. This includes driving to get groceries.

Lately though, his children have noticed some new dents on his car, but Mr. Lee denies having any accidents. His children know driving is an important part of his sense of independence but they worry about his safety.

He has also become increasingly religious and has started giving a lot of his pension to various charities. His children are concerned that someone may try to take advantage of his generosity, especially as his Alzheimer's worsens. They need to start planning but do not know where to start.

"I was really devastated when I learned that I had to stop driving, but now I know there are more options. It's a good thing because otherwise I may have hurt someone."



(Shutterstock, n.d.)

Driving

Dementia affects the brain's ability to function properly, leading to impaired judgement, reflexes and perceptions. Therefore, dementia often affects a person's ability to drive safely. The decision about when to stop driving must be discussed as soon as the signs and symptoms of dementia begin to appear.

Health care providers will use a variety of means to evaluate a person's ability to drive safely. For example, your doctor may wish to perform tests that evaluate your attention, your judgement, and your ability to understand where objects are in space. They may also speak to friends and family in order to learn about your driving habits and history. Doctors are legally bound by the Motor Vehicles Act to report if people living with dementia continue to drive after being assessed as being incapable of safe driving. The ultimate decision to suspend a driver's license lies with RoadSafetyBC, and not the doctor.

Deciding to stop driving is a difficult decision, though it does not have to mean the end of your independence. If you are concerned about your ability and/or a person living with dementia's ability to drive, speak to your health care provider about alternatives such as: HandyDart, HandyPASS, taxis, Taxi Savers, and bus passes.

Above all, it is important to be honest and open for your safety and that of others. Do not withhold information from your health care provider to keep your license since this may put both you and others at risk. To register for HandyDart services at no charge visit www.translink.ca (Metro Vancouver) or www.bctransit.com (B.C., excluding Metro Vancouver).

Why would I take medicine when there is no cure?

Medications for dementia: One person's experience

Reena cares for her mother who has early Alzheimer's disease. She has heard about a few miracle pills for treating Alzheimer's but is not sure if she can trust them. She has heard there is no cure but wonders if there is anything that could help her mother.

Her friend Mira is also caring for a parent with advanced Alzheimer's. Mira says her father could become agitated easily, get very suspicious and started seeing things. After Mira received a prescription from her doctor however, she says her father is much more settled. Reena wonders what the medication was and if her mother should start taking it now as prevention.



(Shutterstock, n.d.)

Are There Any Medications for Dementia? How Do They Help?

There are treatments but no cure. There is currently no medication that will cure dementia or reverse the symptoms. This is why it is very important to be diagnosed and start treating dementia early. Even though medications don't cure dementia, they can slow down the functional impact of dementia and may even improve your quality of life. When starting these medications, it is important to discuss goals of treatment and monitor for both benefits and side effects while using them. It is important to remember that medications are only part of what can be used to treat the symptoms of dementia. Making sure that a person's living situation, other medical conditions and medications are not contributing to cognitive or behavioral symptoms are also an important part of treating dementia.



Medications for Dementia

1) Cholinesterase Inhibitors

The most common class of medications for dementia are known as cholinesterase inhibitors, which act on chemical messengers used by the brain. These drugs are approved for mild to severe Alzheimer's disease. These drugs may be used for Alzheimer's disease and other types of dementia.



With treatment, one-third of people living with dementia will show an actual improvement, another third will experience some degree of symptom easing, and one-third will either deteriorate or have no effect.

While these medications are usually well tolerated, some common side effects are:

- Nausea
- Diarrhea
- Leg/muscle cramps
- Slower heartbeat
- Sleep disturbance, especially if taken at night

2) Memantine

Memantine can be used to treat moderate-to-severe Alzheimer's disease both alone or in combination with a cholinesterase inhibitor. Those who cannot take cholinesterase inhibitors may be able to take memantine. The use of memantine has been associated with a moderate benefit for symptoms of dementia; however, there does not appear to be any benefit of memantine in those with mild Alzheimer's disease. Side effects of memantine include:

- Confusion
- Dizziness
- Drowsiness
- Headache
- Insomnia
- Behavioral changes



3) Behavioural Problems

While not recommended as a first choice, medications might help manage the behavioural and psychological symptoms of dementia (BPSD) such as:

- Hallucinations
- Depression
- Anxiety
- Sleep disturbances
- Aggression
- Agitation

It is essential to always assess a person's environment and physical condition for things that contribute to BPSD such as:

- Feeling pain
- Feeling hunger
- Trouble breathing
- Being too warm or too cold
- Feeling afraid or threatened

Antipsychotics may be used to decrease behaviours associated with anxiety, anger and aggression that can include verbal outbursts (shouting, swearing, or name-calling) and involve physical attacks. Before starting any behavioural medications, it is important to weigh the risks of the drugs against the person's behaviours. All drugs have potential side effects and some may be more harmful or worrisome than the symptom being treated.



Whenever these kinds of behaviours occur, write down the time, place and what was happening at the time. This will help you and your health care provider find possible triggers that can be eliminated or reduced. Your health care provider may also wish to assess all current medications and possible psychiatric conditions, as either of these may cause reactive-disruptive behaviours.

4) Antidepressants, Mood Stabilizers, and Antipsychotics

A type of medication, known as antipsychotics may be prescribed if you are experiencing the above mentioned behaviours. These medications can treat aggression, hallucinations, paranoia, etc.; however, they may be associated with significant side effects such as:

- An increased risk of falls
- Strokes
- Heart attacks

A discussion with your health care provider is advised to review the goals of treatment.

Antidepressants and mood stabilizers may also help if the person living with dementia is depressed, as these drugs may be very beneficial with minor side effects. Deciding which medications to use and when, is a complicated decision that must be made on an individual basis.



5) Natural Health Products

When considering the use of natural health products, think about the following to minimize your risk:

- Do not assume “natural” means “safe.”
- Be cautious of unconfirmed health related claims.
- Herbal remedies can change the way prescription drugs work. Be aware of interactions with other medications and tell your health care provider and pharmacist about any herbal remedies you may be taking.

It is recommended to use blister packages and caregiver supervision to improve safety and compliance to medications.

PharmaCare coverage of cholinesterase inhibitors

PharmaCare covers Donepezil (brand name, Aricept®) for the treatment of mild to moderate Alzheimer’s disease as a Limited Coverage drug through its special authority process. A doctor usually reassesses patients’ cognitive abilities every six months to ensure they are still benefiting from treatment. This drug does not cure Alzheimer’s disease but may slow its progression in some people in the mild to moderate stages of the disease. If a person living with dementia cannot tolerate donepezil, their doctor can request coverage for galantamine or rivastigmine (capsule only).



Planning Ahead: What do I do and when do I start?

With Your Doctor, Nurse Practitioner and Health Care Team

Every health care provider would like to provide care for their patients in a way that honours their patients' goals, beliefs and values. This becomes difficult if they don't know what their patients' wishes are or when dementia makes their patients no longer able to express their needs and wishes. Everyone should be looking at plans for the future, not just people living with dementia. If you have dementia, you are still presumed to be able to make your own decisions, but you may want to consider planning for the future very early on.



(Shutterstock, n.d.)



Talk to your doctor, nurse practitioner and health care team. Have an open and honest discussion about your quality of life, what matters to you, the type and level of care that you would like to receive, and any important beliefs and values you may have.

With Your Family

It is important to include your family or friends in these discussions so they are aware of your goals, beliefs, values and any decisions you have made or would make. For example, what would you want to happen if:

- ...You can't eat or drink on your own?
- ...The doctor thinks you need to go into the hospital?
- ...Your heart stops or you stopped breathing?

These conversations can be difficult and confusing but they are important to talk about ahead of time so your family can make decisions for you. Fortunately, HealthLink BC has information to help you make many of these decisions: <https://www.healthlinkbc.ca/tests-treatments-medications/treatments/advance-care-planning-should-i-receive-cpr-and-life-support>

Wishes and Instructions

In addition to discussing your goals and wishes, you should also put them in writing. You can appoint someone you trust, such as a family member or friend, known legally as a **representative**, to make personal and health care decisions for you when you are not able to do so yourself. It is important to make these decisions while you are capable, as dementia can impact your judgement as it progresses.

You can also complete a document known as an **advance directive**. This is a written document of your wishes regarding medical treatment. If you would like, you can also get advice from lawyers and notaries. There are some tools online to help you with making plans like these.



A provincial planning document, My Voice, is available on the Ministry of Health website (<https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>).

All health authorities have a variety of advance care planning resources and materials. Nidus Personal Planning Resource Centre and Registry (www.nidus.ca) has information as well.



Power of Attorney

An Enduring Power of Attorney is a legal written document that gives someone permission to make financial and legal decisions for you on your behalf. This can be as limited or as broad as you would like it to be. For example, you can give someone power of attorney for a specific bank account (your bank can give you a form), or to cash specific cheques. You can also create a power of attorney to deal with all of your assets, including your house.

An Enduring Power of Attorney is a unique type of power of attorney as it is the only power of attorney that can remain in place when a person is no longer mentally able to make decisions due to sickness or dementia.

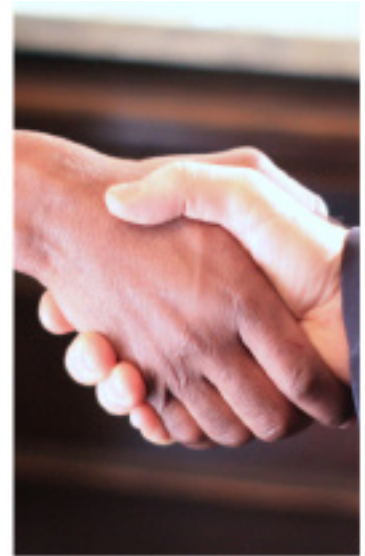
It is better to create an Enduring Power of Attorney before or early in a disease process. You can talk to a notary or lawyer if you have any questions about this and/or if your finances are complicated.



Representation Agreement

A representation agreement is another legal written document, which allows a person to nominate another adult to make his or her future personal care and health care decisions. Your representative is required to honour your wishes and instructions. There are two types of agreements: Section 7 (standard), which entitles your representative to make everyday decisions (e.g., health care decisions with some limitations); and Section 9 (enhanced), which entitles your representative to also make personal care and health care decisions of a broader scope.

To make a representation agreement, you can download the forms found on www.nidus.ca. You do not need a lawyer to complete these forms. However, if you would like some help with completing these forms, you can book an appointment through www.nidus.ca for a fee.



Advance Directives

These legal documents outline medical treatments a capable adult may or may not consent to in the future. For more information, contact the following organizations:

- Alzheimer Society of B.C.: www.alzheimerbc.org & First Link® Dementia Helpline: 1-800-936-6033
- Public Guardian and Trustee of B.C.: <https://www.trustee.bc.ca>
- Nidus Personal Planning Resource Centre and Registry: <https://www.nidus.ca>
- British Columbia Ministry of Health: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning>
- Fraser Health: <http://www.fraserhealth.ca/acp>
- Interior Health: <https://www.interiorhealth.ca/YourCare/PalliativeCare/ToughDecisions/Pages/Advance-Care-Planning.aspx>
- Northern Health: <https://www.northernhealth.ca/health-topics/advance-care-planning>
- Providence Health: <https://www.providencehealthcare.org/health-services/health-care-support-services/additional-services/advance-care-planning>
- Vancouver Coastal Health: <http://www.vch.ca/your-health/health-topics/advance-care-planning/>
- Vancouver Island Health: http://www.viha.ca/advance_care_planning/
- First Nations Health Authority: <https://www.fnha.ca/what-we-do/healthy-living/advance-care-planning>

“It was hard to talk with my grandmother, but I am glad that we did because otherwise we wouldn’t know what she would want and how to deal with her possible health outcomes... now we are able to do what my grandmother would have wanted us to do.”

¹ Adapted from the Public Guardian and Trustee of B.C.: “How you can help people manage finances and legal matters when they cannot manage on their own” <https://www.trustee.bc.ca/documents/adult-guardianship/How%20You%20Can%20Help.pdf>



Abuse and Neglect

Abuse, neglect, and self-neglect are unacceptable at any age. Doctors and other health care providers are trained to assess for and respond to cases of neglect, self-neglect, and of abuse. When a health care provider is concerned about one of these situations for their patients, they will usually refer the person living with dementia to another service or agency to receive help.

If you are concerned that someone you know may be experiencing abuse, neglect, or self-neglect then please contact the resources listed below to obtain more information and support:

- Victim Link (24 hours a day; 7 days a week support and referrals): 1-800-563-0808
- Seniors Abuse and Information Line: 604-437-1940, <http://seniorsfirstbc.ca/getting-help/when-to-call-sail/>
- First Link® Dementia Helpline 1-800-936-6033 (Alzheimer Society of B.C.)
- Home Health Service Line (1-855-412-2121)
- 2-1-1 or bc211.ca
- Designated Agencies http://www.trustee.bc.ca/Documents/designated-agency-responders/Designated_Agencies_Contacts.pdf

What You Should Know About Reporting Abuse?



(Shutterstock, n.d.)

There are several agencies in British Columbia who have been designated to respond to reports of abuse, neglect, and self-neglect of adults who may be unable to get help on their own due to a physical restraint, a physical disability, or an illness, disease, injury, or condition that affects their ability to get help on their own. The designated agencies are all of the health authorities, Providence Health Care, and Community Living British Columbia for adults who have developmental disabilities. These organizations will assess and investigate the situation to determine the best way to keep the adult safe. The identity of people who makes a report to a designated agency will remain confidential.

How Can Caregivers Get Help and From Where?

Dementia can affect more than just your loved one's brain, and your health care provider will want to know if and how it is affecting their day-to-day life and overall health. Your health care provider will want to discuss topics like maintaining good nutrition, exercise, quitting smoking and alcohol, driving safety, medication safety, kitchen safety, financial protection, bathing, housekeeping and socializing. If your health care provider is concerned, he or she can refer people living with dementia to the home health service line for further assistance. Relying on these resources does not mean you cannot care for your loved one. It means you recognize that sometimes the care required is complicated and can be emotionally difficult for you. Using these resources can help you manage your responsibilities.

Publicly-subsidized respite and adult day programs are accessed through your regional health authority's home and community care office. The fee for these services is based on your income.

In-facility respite provides short-term care for clients in a licensed long-term care facility. This supports caregivers by enabling a break and time away from caregiving while clients receive safe, professional care.

Adult day programs are also available for eligible individuals. Adult day programs are provided through an organized program of personal care, health care and therapeutic social and recreational activities in a group setting that meets client health care needs and/or caregiver needs for respite.

See page 33 in the Resources section for how to contact your local home and community care office. There may also be private pay adult day programs in your region.

The Alzheimer Society of B.C.'s First Link® program, available to people affected by Alzheimer's disease and other forms of dementia, assists caregivers to identify appropriate support services and to respond to common challenges that may arise at various stages when caring for people living with dementia. See page 33 for more information.

Family Caregivers of British Columbia is a non-profit organization dedicated to supporting informal and unpaid caregivers. They assist with navigating the health care system, offer education and information, facilitate emotional support groups, and operate a toll-free caregiver support line.

Family Caregivers of British Columbia:
<https://www.familycaregiversbc.ca>, 1-877-520-3267

What kind of help is out there?

One person's experience:

Mr. Pak Chung Lam, a widower, lives alone in a basement. His three children all live in different cities and are unable to care for Pak Chung's day-to-day needs. He was coping well, except lately his vascular dementia seems to be progressing.

Pak Chung's wife died last year and his children are worried that he may have had another small stroke since losing her. Pak Chung's wife used to do most of the cooking, so his children worry about what he eats, how he prepares meals, and how he buys food. Pak Chung also has high blood pressure and his children worry that he may be forgetting to take his medications. Without his wife, Pak Chung also seems less motivated and has stopped going to church and other social outings. His children are worried but do not know where to turn for help.



Caring and Supporting People Living with Dementia

Having dementia does not mean that the person is not intelligent anymore. It's just that their memory is affected. They should still get the same level of respect and love. It is important to recognize that a person living with dementia cannot change their behavior, nor should a caregiver attempt to force that change. Try to accommodate the behaviour, not control the behaviour. We must understand the disease, be patient, and accept who the person is in this moment. The reasons for someone behaving outside of character vary, but changing a person's environment or routine, and improving caregiver knowledge, can reduce their anxious or aggressive behaviours. Listed below are some practical strategies for caregivers to deal with behavioural and communication difficulties.



(Shutterstock, n.d.)



Communicating Clearly

- Ask simple questions and one question at a time; yes or no answers work best.
- Avoid asking questions with details that are difficult for them to remember, such as the date or grandchildren's names. Not being able to answer these questions might lower their self-esteem.
- Allow more time for responses and pay close attention to what they are trying to communicate.
- Maintain a calm and even tone of voice. A confrontational conversation should be avoided unless the situation involves a safety concern.
- Do not lose patience if your loved one keeps repeating things and don't tell them they have repeated it multiple times as it can hurt their feelings.



Memory and Impact on Life

- Encourage aids like calendars, diaries and telephone reminders.
- Keep keys, glasses, wallet in the same designated place ("landing spot") and label them.
- Accompany them to their appointments as they may have trouble keeping track of everything the health care provider says.
- Use Post-it notes around the house to answer recurrent questions. For example, "Dinner is at 6 p.m." and "Your slippers are in the closet".
- Put reminders on burners, taps and other household appliances, as well, to ensure they're turned off.
- Keep their daily routine as predictable and consistent as possible.
- Blister pack and supervise their medications if they are forgetting or mixing up medications.
- Consolidate their assets and simplify their banking. Talk to them about financial planning as early as possible.
- Talk to them about their future health care wishes while they are able to do so. Encourage them to have an advanced directive in place to prepare ahead of time.



Household Safety

- Monitor kitchen for mishaps (e.g., fires, burned pots); have stove unplugged or automatic stove turn-off device installed.
- Ensure functioning of smoke detectors.
- Assess home for other safety hazards (e.g., unsafe smoking, firearms in the home).
- Utilize 911 stickers for telephones.
- Consider a personal alarm service in case an accident happens.



Social Support

- Encourage your loved one to spend time with family and friends.
- Accompany them to temples/churches or parks for walks and socializing.
- Increased social support can motivate them to participate in physical and mental health activities.
- Talk to them about past memories and events in their lives by having meaningful and respectful conversations.



Forgetting, Getting Around and Transportation

- Limit fluids two hours before bedtime and use night lights in the home.
- Use devices that signal when a door or window is opened (bell placed above a door or an electronic home alarm).
- Ask your neighbours to alert the family immediately if person living with dementia is seen alone, confused or suspected of wandering.
- Encourage carrying identification when out alone; use an ID bracelet or register with the MedicAlert® Safe & Found Program.
<https://www.medicalert.ca/safe-and-found>
- Plan for alternate methods of transport, such as HandyDart, as driving abilities may deteriorate as dementia progresses.



Shopping

- Use lists when shopping; shopping assistance from caregiver.
- Use shop-by-phone or online shopping programs, if available.



Sleeplessness/Sundowning

- “Sundowning” is a state of increased confusion that many patients with dementia can go through. This occurs late in the afternoon and evening, as the sun goes down.
- Close the curtains and turn on interior lights to help minimize shadows and reduce confusion.
- Create a calm, quiet atmosphere without a lot of distraction and busyness during the evening hours.
- Increase daytime activities, particularly physical exercise. Discourage inactivity and napping during the day.



Food and Nutrition

- Let them cook if they can, to maintain their self-esteem but provide supervision to ensure burner safety.
- Talk to them about reducing or avoiding alcohol consumption as it can contribute to the confusion they are experiencing.
- Monitor for weight loss. If they are losing weight, talk to your health care provider or dietitian about special diets or nutritional supplements such as Boost and Ensure that can help meet their nutrition requirements.
- Consider meal support services (e.g., healthy delivered prepared meals or pre-prepared frozen foods).



(Shutterstock, n.d.)



Maintaining a Healthy Brain

- Encourage them to read newspapers in their first language, to keep them connected with events in Canada and from back home.
- Support them to keep their routine, for example, watching programs on television in the morning or evening.
- Grandchildren can also play games such as chess and cards with them or read stories to them.
- Take them to the health care provider regularly to maintain their physical and psychological health.



Connect with 'Better at Home' (betterathome.ca) if you need friendly visiting, transportation to appointments, light yard work, minor home repairs, snow shoveling, light housekeeping, or grocery shopping (phone numbers and services vary by community).

During the dementia journey, it is important to regularly assess living situations, as there may come a time when it is no longer safe for a person living with dementia to live at home. Decisions such as when to transition a loved one into a long-term care home are difficult to make. However, if adequate care cannot be provided or received, or if there is a risk for a person's safety, it may be time to consider alternative housing options. It is important to include health care providers, care partners, and the person living with dementia in the conversation. Talk about it early and decide together at what point would be good to change housing plans.

What works today, may not work tomorrow. The progressive nature of dementia and the multiple factors that influence reactive-disruptive behaviours mean that solutions that are effective one day may need to be modified the next day or may no longer work at all. Be creative and flexible in your strategies to address a given issue.

Caring for Yourself When You are Caring for Your Loved One

Coping with Dementia in the Family

Caregiving, while rewarding, can also be demanding. Health care providers are aware of the challenges that caregiving poses and they may ask questions in order to offer appropriate support and education to caregivers. Most caregivers will require some form of support for part or all of their caregiving experience. Health care providers may refer caregivers to the Alzheimer Society, Family Caregivers of BC, Home and Community Care, or address health concerns directly.

If you are a caregiver, you can always talk to your health care team. It is important that you feel comfortable discussing your concerns, challenges and coping skills. Your health care team is there to help.



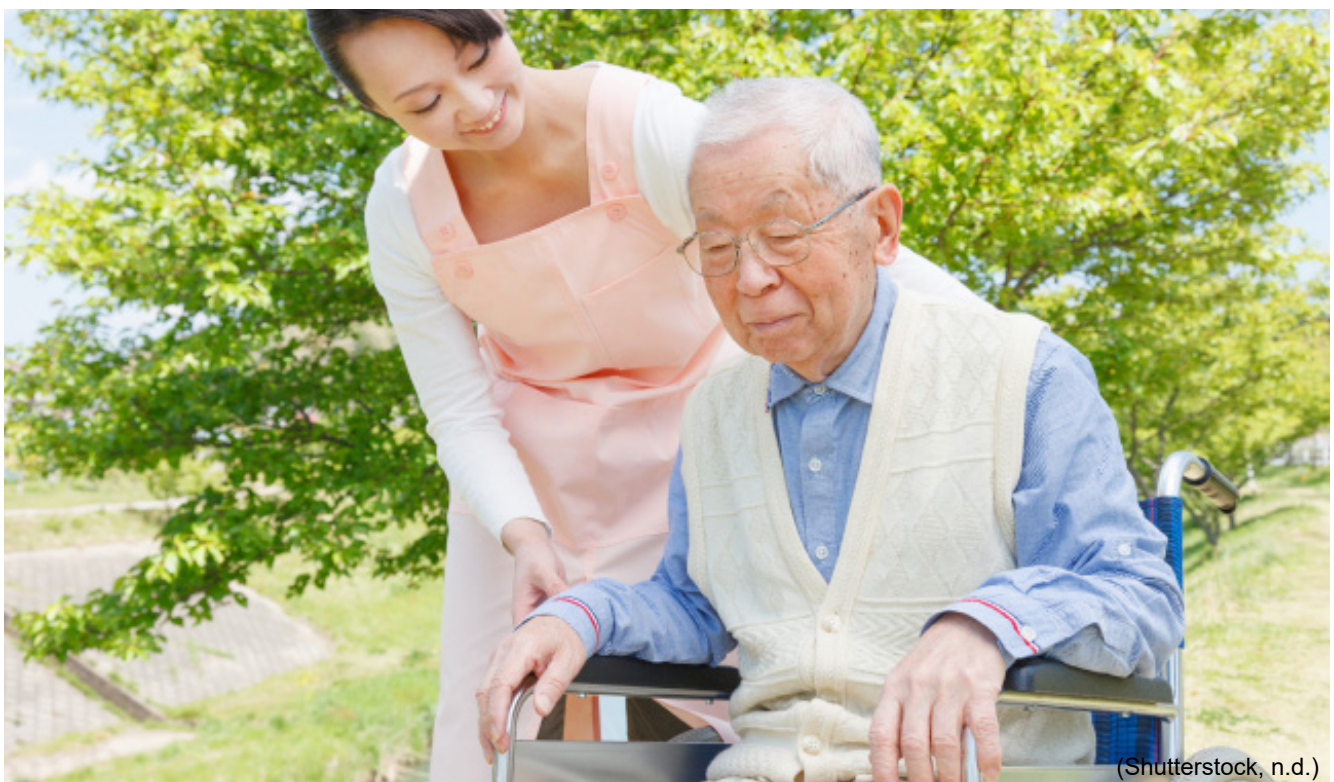
Self-care Tips for the Caregiver:

- Identify any personal health or other concerns that may be impacting you first. Ask yourself if there is something you need to do for yourself first.
- Caregiving can be an emotionally intensive experience. There can be a lot of stress associated with taking care of your loved one while balancing work, and home.
- Be prepared with stress relief strategies ahead of time. Recognizing why you are stressed and how you can reduce your stress is an important part of your well being.
- Ask other friends or family members for help. If you find it difficult to do everything on your own or if you need help with some things here or there, there are resources available for you. See the Information Based Resources section (page 38) for additional options for arranging help with care. Getting the support you need is a sign of courage and strength.
- Seeing your loved one go through a tough time can be disheartening. Talking to a doctor or a psychologist can help you cope with tough times and provide you with the emotional support you may need.

A Word About Feeling Guilty

It is normal to experience feelings of guilt during caregiving. These feelings may be triggered by thinking that you could be a better caregiver; thinking that you should not take any breaks for yourself; considering placement in a long-term care home; or feeling angry and frustrated. If you do experience feelings of guilt, you need to say to yourself:

- I am doing the best I can.
- There are some things I cannot control.
- It is the disease that causes behaviours to happen. Not my caregiving.





Resources

Support is available but resources may vary depending on the community you live in. Please contact your health care team for more resources available in your community.

Information for Support Services:

1. The Alzheimer Society of B.C.

The Alzheimer Society of B.C. is committed to building a dementia-friendly society, where people affected by dementia are welcomed, acknowledged and assisted by their community. First Link® dementia support connects people living with dementia, their caregivers and their families to support and learning opportunities at any point in the progression of the disease. First Link® is available in all communities across the province, and can be accessed in three ways:

- A referral from a health care provider or a community organization.
- By visiting one of the Alzheimer Society of B.C.'s Regional Resource Centres.
- By calling the First Link® Dementia Helpline (1-800-936-6033).

Individuals and families within the Chinese community throughout the province can receive language- and culture-specific support through the Chinese Dementia Helpline (1-833-674-5007).

In addition to the support and learning offered through First Link®, the Society strives to create general awareness about the disease and advocates for better quality of life for people living with dementia and for their caregivers.

To learn more about the Alzheimer Society of B.C. or about dementia, visit www.alzheimerbc.org.

2. Home, Transportation and Transportation Services:

a. Better at Home:

This organization partners with community services that can help with the day-to-day non-medical needs of older adults in British Columbia. Tasks vary by community but can involve gardening, shoveling, light housekeeping, companionship and grocery shopping. Please visit their website to find which organization in your community provides this service.

Phone: 604-268-1312

Website: <http://betterathome.ca/organization-directory/>

b. Home and Community Care Services:

Publicly subsidized home and community care services for eligible people are accessed through home and community care offices of the regional health authorities. There are criteria you must meet before a regional health authority can provide subsidized home and community care services, such as your care needs and if you have been residing in British Columbia for at least three months.

Home and community care offices can connect people living with dementia and families with appropriate resources and services for:

- Home Support
- Adult Day Programs
- Respite Services
- Care Management
- Long-Term Care
- Palliative and End-of-Life Care Services
- Home Oxygen Program
- Assisted Living
- Community Nursing Services

These services are designed to complement and supplement, but not replace, your efforts to care for yourself with the assistance of your family, friends and community. In most cases you will pay a fee for services based on your income.

The home and community care offices in the regions are:

Island Health: <https://www.islandhealth.ca/our-services/home-care-services/accessing-community-health-services>

- Victoria Community Access Centre (for South Island): 250-388-2273 / 1-888-533-2273
- Nanaimo Community Access Centre (for Central Island): 250-739-5749 / 1-877-734-4101
- North Island Central Intake: 250-331-8570 / 1-866-928-4988

Fraser Health: <https://www.fraserhealth.ca/health-topics-a-to-z/home-and-community-care>

- New clients – Home Health Service Line: 1-855-412-2121
- Current clients – Contact a regional Home Health Office: <https://www.fraserhealth.ca/health-topics-a-to-z/home-and-community-care>

Vancouver Coastal Health:

<https://www.vch.ca/en/health-topics/home-community-care>

- North Shore (North Vancouver, West Vancouver): (604) 986-7111, fax: (604) 983-6839
- Richmond: (604) 675-3644, fax: (604) 278-4713
- Vancouver: (604) 263-7377, fax: (604) 267-3419
- Bella Bella: (250) 957-2314
- Bella Coola: (250) 799-5311
- Powell River: (604) 485-3310
- Sea to Sky (Squamish, Whistler, Pemberton): (604) 892-2293
- Sunshine Coast (Gibsons, Sechelt): (604) 741-0726

Interior Health:

<https://www.interiorhealth.ca/health-and-wellness/child-community-and-home-care/help-with-living-at-home>

- List of Home and Community Care Offices (<https://www.interiorhealth.ca/YourCare/HomeCommunityCare/Documents/HCCOffices.pdf>)

Northern Health:

- The full list of Home and Community Care Offices can be found at the following link: https://www.northernhealth.ca/sites/northern_health/files/services/home-community-care/documents/health-offices-by-community.pdf

For more information, consult the Ministry of Health's Home and Community Care Webpage: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care>

Long-Term Care Services:

In July 2019, the Ministry of Health revised its access policy for publicly subsidized long-term care services, which increased choice for seniors in selecting a long-term care home. If you are eligible for publicly subsidized long-term care services, you are able to review your care options and choose up to three preferred care homes. When discussing your care options with your health authority care manager, they must give you a minimum set of information about the long-term care homes that can meet your needs. This information will assist you in choosing preferred care homes. While you are waiting for placement for your preferred care home, you will have the option to wait at home with additional supports, or go to an interim long-term care home while maintaining your position on the waitlist.

For more information visit: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/long-term-care-services>

c. Planning for Your Care Needs: Considerations in Selecting a Long-term Care Home

The Ministry of Health published a guide to help seniors and their caregivers select the long-term care home right for them.

For access to the guide: <https://www2.gov.bc.ca/assets/gov/health/accessing-health-care/finding-assisted-living-residential-care-facilities/residential-care-facilities/planning-for-your-care-needs-2021.pdf>

d. Transit Resources:

There are two transit services in B.C., and they vary based on your location. You can contact these transit services with any general questions that you may have about public transportation available in your area or to register for HandyDART services at no charge.

- TransLink - Metro Vancouver
Phone (HandyDART): 604-983-3680
Phone (General Info): 1-877-935-5669
Website: <https://www.translink.ca/>
- BC Transit – B.C. excluding Metro Vancouver
Phone (HandyDART): call your regional B.C. Transit office to organize service
Phone: 250-382-6161
Website: <http://www.bctransit.com/>

Resources for Caregivers:

3. Family Caregivers of British Columbia:

Family Caregivers of B.C. is a non-disease specific, non-profit organization dedicated 100% to supporting unpaid caregivers. The B.C. Ministry of Health provides funding for FREE family caregiver support across the province. Over 30% of the calls they receive are from caregivers caring for someone with dementia. Caregivers often need more than one source of support, so they provide information about Caregiver Support Groups, Caregiver Connection Newsletter and monthly eNews bulletins as well as online resources and webinars.

Website: www.familycaregiversbc.ca

Caregiver Support Line: 1-877-520-3267

4. Information on Health Authorities, Crisis Lines and Reporting Senior Abuse and Neglect

a. Health Authorities:

There are five health authorities in B.C., and they vary based on your location. You can contact these health authorities with any general questions that you may have regarding services available in your community.

- [Fraser Health](#)
Phone: 1-877-935-5669 (toll-free)
604-587-4600 (local)
Crisis Line: 1-877-820-7444
- [Interior Health](#)
Phone: 250-469-7070
Crisis Line: 1-888-353-2273
- [Vancouver Coastal Health](#)
Phone: 1-866-884-0888 (toll-free)
604-736-2033 (local)
Crisis Line: 1-604-872-3311
- [Island Health](#)
Phone: 250-370-8699
Crisis Line: 1-888-494-3888
- [Northern Health](#)
Phone: 250-565-2649
Crisis Line: 1-888-562-1214

b. Local Geriatric Mental Health Teams

These teams may have doctors, psychologists and nurses that can help you with any mental health condition you may be facing, including dementia. For information on these teams, please contact your health authority.

In Vancouver, there is an outreach team that is available to help. Please visit <https://vancouver.pathwaysbc.ca/programs/356> or call the Older Adult Community Mental Health and Addiction Referral Line (from Monday to Friday, 8:30 AM to 5:00 PM):

Phone: 604-709-6785

Fax: 604-709-6789

c. Seniors First:

This non-profit organization can provide you with support and resources if you are experiencing financial, legal or emotional abuse. They can also provide help with any legal action that you may want to take.

Website: <http://seniorsfirstbc.ca/>

Phone 1-866-437-1940 (8 AM to 8 PM daily)

d. S.U.C.C.E.S.S.:

S.U.C.C.E.S.S. is a non-profit organization that supports seniors in all stages of aging to maintain and high quality of life. S.U.C.C.E.S.S. offers a suite of programs for seniors in the Vancouver and Fraser Valley regions.

Website: <https://successbc.ca/service-categories/seniors/>

Phone: 604-684-1628



(Shutterstock, n.d.)

Information Based Resources:

a. British Columbia Ministry of Health:

This website has information about medical conditions, resources for patients and caregivers, information about drug coverage, advanced care planning resources, end of life care and many more. Please use the search bar to look up the specific information you are interested in <https://www2.gov.bc.ca/gov/content/governments/organizational-structure/ministries-organizations/ministries/health>

- For information about arranging for care: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/how-to-arrange-for-care>
- For information about home care: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/health-care-programs-and-services/home-care>
- For care options and costs: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost>
- For help locating an assisted living or long-term care facility in your community: <https://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/assisted-living>
- For caregivers: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/caring-for-seniors/caring-for-the-caregiver>
- For information about community services, long-term care, assisted living and hospice resources: [http://www.health.gov.bc.ca/library/publications/year/2007/Guide to Your Care Booklet2007 Final.pdf](http://www.health.gov.bc.ca/library/publications/year/2007/Guide%20to%20Your%20Care%20Booklet2007%20Final.pdf)

Please note that this guide was created in 2007 and may be updated by the Ministry in the near future. Please visit the [B.C. Ministry of Health Website](#) for more information.

b. HealthLink BC:

This website is affiliated with the B.C. Ministry of Health and can provide information about any medical condition as well resources available in the province.

Dementia specific information: Website: www.healthlinkbc.ca | Phone number: 8-1-1

- For patients: <https://www.healthlinkbc.ca/illnesses-conditions/dementia/dementia>
- For caregivers: <https://www.healthlinkbc.ca/illnesses-conditions/dementia/dementia-support-caregivers>

c. Health Gateway - Province of British Columbia

Health Gateway provides secure and convenient access to your health records in British Columbia. View your medications, health visits, immunizations and more, all in one place. Available on web and mobile app. Access your health information online: [Health Gateway - Province of British Columbia](#)

d. BC211:

This is a Vancouver-based non-profit organization that provides free information and referral to a full range of community, social, and government services, and operates 24 hours a day, 7 days a week. 2-1-1 is a confidential, multilingual telephone and texting service available in Greater Vancouver, Squamish-Lillooet, Sunshine Coast, Vancouver Island and the Gulf Islands.

Website: <http://www.bc211.ca/> | Phone or text: 2-1-1

e. B.C. Seniors' Guide:

The B.C. Seniors' Guide is an invaluable resource for seniors and caregivers, providing information about services and supports available throughout the province. Available in seven languages (print and electronic), the Guide has information about benefits, health, lifestyle, housing, transportation, finances, safety and more. Website: <https://www2.gov.bc.ca/gov/content/family-social-supports/seniors/about-seniorsbc/seniors-related-initiatives/bc-seniors-guide>



Acknowledgements

A large number of very committed individuals participated in the development of this booklet, and we would like to gratefully acknowledge their expert advice, contributions and support. This booklet is the Chinese edition to the “Getting to Know Dementia: A Patient’s Guide to Diagnosis, Treatment and Care” booklet, first published in 2011. The most recent clinical review of the booklet was completed in 2022.

We would like to thank and acknowledge the contributions of the authors of the 4th edition: Jay Bains, Jas Cheema, Dr. Martha Donnelly, Dr. Soma Ganesan, Dr. Mary Lou Harrigan, Dr. Francis Ho, Dr. Arvind Kang, Vivian Lam, Dr. Philip E. Lee, Bernicke K.W. Ma, Carla Pajak, Shiraz Ramji, Dr. Hetesh Ranchod, Dr. Roger Y.M. Wong, Dr. Michael Wilkins-Ho, Peter Ao, Kapil Kohli, Bill Lin, Jennifer Quan, Rupinder Sohal, Dr. Helen Novak Lauscher, Elizabeth Stacy, Jasmin Abizadeh, Nelson Shen, and Dr. Kendall Ho.

We would also like to thank the B.C. Ministry of Health Patients as Partners Initiative for their support and the Senior's Services Division for their review. Sincere acknowledgement to the Content Advisory Committee who are listed below for their content contributions and expertise in creating, reviewing and editing the material.

**Dr. Leena Jain MBBS, MD,
FRCPC, FACP**
Content Lead Geriatrician and Internal,
Medicine Specialist,
Fraser Health Authority

Dr. Peter O’ Connor, MD
Content Lead,
Clinical Assistant Professor,
Geriatric Medicine,
Fraser Health Authority

Jeevan Sangha, BSc
Fraser Health Authority

Sarah Metcalfe MPH, CAPM
Clinical Program Developer,
Fraser Health Authority

Cari Hoffman
Content Reviewer,
Regional Project Implementation
Coordinator,
Advance Care Planning,
Fraser Health Authority

Dr. Martha Donnelly MD, CCFP, FRCPC
Content Reviewer,
Associate Professor Emeritus,
Department of Psychiatry UBC,
Director of Community Geriatrics

Penny Slack MSc, CCRP
Research Coordinator,
UBC Clinic for Alzheimer Disease and
Related Disorders

Dr. Kendall Ho, MD, CCFP, FRCPC
Emergency Physician Professor,
Department of Emergency Medicine,
University of British Columbia

Harleen Chohan, PharmD, ACPR
Cultural and Community Engagement
Officer,
Digital Emergency Medicine, UBC

Sophia Khan, BA
Former iCON Program Manager,
Digital Emergency Medicine, UBC



Anne-Marie Jamin, MPH
iCON Program Manager,
Digital Emergency Medicine, UBC

Barbara Ho, RN
Chief Nursing Officer,
iCON Chinese Division,
Digital Emergency Medicine, UBC

Tellina Jahangiri, MBA
Communications Coordinator,
Digital Emergency Medicine, UBC

Alex Fung, BSc
Research Assistant,
Digital Emergency Medicine, UBC

Suzanne Ng, BKin
Senior Research Assistant,
Digital Emergency Medicine, UBC

Anisa Wong
UBC Work Learn Student,
Digital Emergency Medicine, UBC

Ben Rawluk
Alzheimer's Society,
British Columbia

Minika Chu, BA
Marketing and Communications
Coordinator,
Digital Emergency Medicine, UBC

Dr. Ashok Krishnamoorthy
Clinical Associate Professor,
Program Director,
Department of Psychiatry UBC

Dr. Sharon Koehn
Limited Term Clinical,
Research Professor,
Department of Gerontology,
Simon Fraser University

Baljeet Judge
Support and Education,
Coordinator- South Asian
Communities,
First Link® Alzheimer Society of B.C.

Michelle Yang, BSc
Research Assistant,
Digital Emergency Medicine, UBC

Cynthia Lung, BSc
Content Graphic Designer,
Digital Emergency Medicine, UBC

Hilary Low, BA
Research Assistant,
Digital Emergency Medicine, UBC

Annie Walters-Shumka, BSc
Research Assistant
Digital Emergency Medicine, UBC



Image Credit List

Author unknown. (n.d.). *Senior Asian Couple Enjoying Good Time*. Retrieved from: <https://www.shutterstock.com/image-photo/senior-asian-couple-enjoying-good-time-1562138032>

Author unknown. (n.d.). *Young Asian Female Hug Old*. Retrieved from: <https://www.shutterstock.com/image-photo/young-asian-female-hug-old-bedroom-1077633869>

Author unknown. (n.d.). *Asian Elderly Woman Sitting Alone*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-old-elderly-woman-sitting-alone-1800100207>

Author unknown. (n.d.). *Asian Elderly*. Retrieved from: <https://www.shutterstock.com/image-photo/portrait-image-60s-70s-asian-elderly-1186324837>

Author unknown. (n.d.). *Asian Senior Man Worry Lost Expression*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-senior-man-worry-lost-expression-1327336526>

Author unknown. (n.d.). *Asian Senior Couple*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-senior-couple>

Author unknown. (n.d.). *Elderly Person Doing Yoga Open Air*. Retrieved from: <https://www.shutterstock.com/image-photo/elderly-person-doing-yoga-open-air>

Author unknown. (n.d.). *Asian Senior Couple Jogging Nature*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-senior-couple-jogging-nature-park>

Author unknown. (n.d.). *Asian Senior Couple Calling on Phone*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-senior-couple-calling-on-phone-300181337>

Author unknown. (n.d.). *High Angle Rear View Lonely Asian*. Retrieved from: <https://www.shutterstock.com/image-photo/high-angle-rear-view-lonely-asian-1620317653>

Author unknown. (n.d.). *Asian Senior Man Sitting on Wheelchair*. Retrieved from: <https://www.shutterstock.com/image-photo/asian-senior-man-sitting-on-wheelchair-140084350>

Author unknown. (n.d.). *Old Man See Female Doctor Talk*. Retrieved from: <https://www.shutterstock.com/image-photo/old-man-see-female-doctor-talk-1436928695>

Author unknown. (n.d.). *Customer Service Good Cooperation Consultation*. Retrieved from: <https://www.shutterstock.com/image-photo/customer-service-good-cooperation-consultation-between-1121506268>

Author unknown. (n.d.). *Hands Caregivers Elderly*. Retrieved from: <https://www.shutterstock.com/image-photo/hands-caregivers-elderly-2005390415>

