



Getting to Know Dementia

**A Patient's Guide to
Diagnosis, Treatment,
and Care**

iCON
interCultural Online
Health Network



FACULTY OF MEDICINE
eHealth Strategy Office

We would like to acknowledge the *Alzheimer Society of B.C.* for their support of this initiative through the *Grant to Improve Dementia Care in BC.*

Alzheimer Society
B R I T I S H C O L U M B I A

Getting to Know Dementia

A Patient's Guide to Diagnosis, Treatment, and Care

| | |
|---|---------|
| Dementia is more than just forgetting. Do I have dementia? | Page 1 |
| Is dementia the same for everybody? | Page 3 |
| Why would I take medicine when there is no cure? | Page 9 |
| What kind of help is out there? | Page 11 |
| What will happen to my freedom? | Page 13 |
| Planning ahead: What do I do and when do I start? | Page 15 |
| Acknowledgements | Page 17 |
| Give us your feedback | Page 19 |

Is it dementia?

Recognition & diagnosis: One person's experience

Anne is 76 years old. She has owned and operated her own bakery for most of her life, and is still able to bake almost entirely from memory. Anne also enjoys telling vivid and detailed stories from her childhood.

One day, Anne faints and is taken to the hospital, where it is discovered that she has taken her blood pressure pills twice that day. Anne's daughter also notices that Anne can't remember the name of the nurse who has been with her all day. Other family members have also noticed that Anne's memory has been getting worse over time, and she's been having a hard time doing the things she usually does. Even so, her daughter is sure that Anne doesn't have any memory problems – she may struggle to find the occasional word, but she can still name her first grade teacher!

Anne's doctors were concerned about her. After some follow-up appointments and tests, Anne is diagnosed with early stage Alzheimer's.

1

Dementia is more than just forgetting. Do I have dementia?



Many seniors, their friends, and their family worry about getting dementia or Alzheimer's disease.

Dementia is *not* a normal part of aging, and not all seniors will develop dementia.

See a doctor if you or a loved one notice changes in your ability to function at work, in social settings or in day-to-day life.

What are the Signs?

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

1. Memory loss that affects day-to-day function
2. Difficulty performing familiar tasks
3. Problems with language (i.e., difficulty finding the right words and following a conversation)
4. Disorientation of time and place
5. Impaired judgement (i.e., cannot make the right decision)
6. Problems with abstract thinking (i.e., reduced ability to understand, think, remember and reason)
7. Misplacing things
8. Changes in mood and behaviour
9. Changes in personality
10. Loss of initiative

Talk to your doctor if you notice one or more of these happening to you in your life.

Diagnosing dementia is a process.

There is no single test to find the cause of your illness.

Your doctor will do an assessment to see if you have dementia, or will refer you for an opinion.

Knowing you have dementia.

The acceptance of a diagnosis is different for each person. For some older adults, it can be a long and difficult process and for some it is not.

“...She’s been having a hard time doing the things she usually does... she may struggle to find the occasional word, recall the previous day’s conversation, but she can still remember her first grade teacher!”

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 patients and their families to feel free to openly discuss their experiences and feelings during this time.

Many people will be around to help during this time.

These people include family, friends, doctors, and specialist such as psychologists, neurologists, geriatricians (a doctor who specializes in the care of aged persons), gerontologists, geriatric psychiatrists, nurses, social workers and/or occupational therapists.

Steps in Finding the Cause of Your Illness

1. Medical History

- Patient, family members and healthcare professionals will be involved in this process.

- Doctors may ask the following questions to the patients:
 - 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 medication?
 - Do you have a family history of dementia?

2. Mental Status Exam

- This test asks questions and includes exercises like drawing, writing and doing math.
- This test may be called the Mini-Mental Status Exam, or MMSE.

Some may find this test difficult, and some may not.
Try not to be discouraged. This test is 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 doctor may take your blood pressure, order blood tests and check your vision and hearing. Your doctor 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 a CT Scan or MRI. These provide detailed pictures of the brain.

Are all dementias the same?

Types of Dementias: One person's experience

Mr. Johnson was diagnosed with vascular dementia several years ago, when he suddenly started to become lost in familiar settings, couldn't recognize old friends, and became unsteady on his feet. Mr. Johnson was a smoker for most of his life and had high blood pressure. His doctors think he may have had a stroke which then led to his confusion. When Mr. Johnson was no longer able to be left alone, his wife quit her job to care for him.

Mr. Johnson's condition has been relatively stable and the couple was doing quite well until recently, when Mrs. Johnson started to behave strangely. She started forgetting to pay some bills, left the stove on, and had trouble remembering some words, even though she was always a very organized woman. Her children are confused since their mother never smoked, has normal blood pressure and exercises daily.

The children are worried, and decide to take their mother to the doctor where they are surprised to learn that Mrs. Johnson also has dementia! They ask the doctor how this can be – Mrs. Johnson's case is so different from that of her husband.

Is dementia the same for everybody?

No, not all dementias are the same and not everyone with dementia acts the same way. In fact, many different diseases or conditions can lead to different forms of dementia. The following are some of the most common forms/causes of dementia:

Alzheimer's Disease

This is a progressive and incurable disease. With Alzheimer's disease the brain is damaged by unknown factors. The damage starts in specific brain areas, but becomes widespread over time. Alzheimer's disease leads to a progressive loss of brain function, which eventually becomes so significant that it interferes with daily life. Memory loss is the most common symptom of the disease, though changes in mood, emotion, and behaviour can also occur. Each individual presents in his or her own unique way. The symptoms can be subtle at first. As a result of its progressive nature, people with Alzheimer's disease will eventually require full care in the final stages.

Vascular Dementia

Another leading cause of dementia is vascular dementia, which is sometimes difficult to distinguish from Alzheimer's disease; both cause similar symptoms, and can even occur together.

Vascular dementia is usually associated with diseases that interrupt blood supply to the brain causing a stroke. A person may develop vascular dementia following a single major stroke or multiple smaller strokes. Symptoms include trouble with decision making (also called executive function difficulty) and problems with walking and balance. Vascular dementia may not progress evenly but rather in a step like fashion related to further vascular events like small strokes. It is not always easy to identify in all patients. Some patients may not be aware that they have had a stroke. Your doctor may wish to consider brain scans to show the presence of strokes. Stroke prevention is similar to heart attack prevention. Quitting smoking and promoting exercises are important lifestyle changes. Treatment of high blood pressure, diabetes, high cholesterol, and heart disease also reduce your risk of stroke.

Mixed (Alzheimer's Dementia/ Vascular Dementia)

Despite being two separate diseases, vascular dementia and Alzheimer's disease often occur together as they are common diseases in the elderly. This is known as mixed dementia.

Alzheimer's disease has been described as the most common type of dementia with vascular dementia occurring less often. Recently, however, it has been realized that a mixed dementia is very common and probably not diagnosed as much as it could be. It may be that a mixed origin of dementia is in fact the most common cause. Persons with mixed dementia tend to have similar symptoms to those associated with Alzheimer's disease. They also tend to have risk factors for heart disease and stroke, and in some cases they may have a history of heart disease.

"My dad got dementia because of a stroke. My mom got dementia but did not suffer a stroke. There must be different causes for dementia."

Dementia with Lewy Bodies (DLB)

Persons with dementia with Lewy bodies tend to experience fluctuations in their mental abilities, attention and alertness. They may also experience detailed visual hallucinations, delusions and hand tremors. Some may experience repeated falls, combined with fainting or brief losses of consciousness. People with dementia with Lewy bodies also tend to be very sensitive to antipsychotic medications and can experience serious side effects even at low doses of these medications.

Parkinson's Disease Dementia

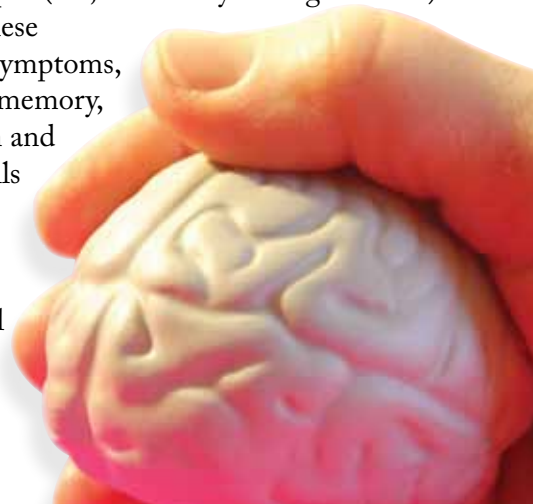
Parkinson's disease is primarily a movement disorder that causes the progressive loss of muscle function on one or both sides of the body, with varying severity. The most common symptom of Parkinson's is a tremor or shaking, usually in the hands. The tremor often worsens when the person

is under emotional stress. Symptoms also include difficulty with walking, coordination, and a 'mask-like' expression. Several years after the muscular symptoms appear, symptoms of dementia, similar to those of dementia with Lewy bodies and/or Alzheimer's disease, may appear. These symptoms include difficulties with attention, alertness, and memory loss.

Fronto-Temporal Dementia

Fronto-temporal dementia tends to affect people in

middle age. Symptoms tend to begin slowly and subtly but eventually progress to being more noticeable. Early in the disease, people with fronto-temporal dementia tend to experience changes in their character including one or all of the following: a loss of interest, inappropriate behaviour, difficulty planning their thoughts and difficulty making decisions for themselves (*failure of executive function*). Other changes might include a decline in hygiene, inflexibility in thinking (*mental rigidity*), becoming very distractible, placing inappropriate objects in the mouth (*hyperorality*), and constant repetition of a meaningless word or phrase (*perseveration*). Finally, there are also changes in a person's ability to use language, usually resulting in a reduction of verbal output (i.e., cannot say the right words). Despite these dramatic symptoms, a person's memory, perception and spatial skills (i.e., forming mental images) all tend to remain intact.



| Type of Dementia | Symptoms |
|---|--|
| Alzheimer's Disease | <ul style="list-style-type: none"> • memory loss • changes in mood, emotion, and behaviour • require full care at late stage |
| Vascular Dementia | <ul style="list-style-type: none"> • problems with decision-making, walking, and balancing • sudden onset |
| Mixed (Alzheimer's and Vascular) | <ul style="list-style-type: none"> • symptoms of Alzheimer's disease and stroke |
| Dementia with Lewy Bodies (DLB) | <ul style="list-style-type: none"> • fluctuations in mental abilities, attention, and alertness • visual hallucination • hand tremor • falls, fainting, or brief loss of consciousness • sensitive to anti-psychotic medication |
| Parkinson's Disease Dementia | <ul style="list-style-type: none"> • tremor or shaking in hands or face • difficulties with walking and coordination • 'mask-like' expression on face • similar to DLB, such as difficulties with attention and alertness |
| Frontal-Temporal Dementia | <ul style="list-style-type: none"> • loss of interest, loss of inhibition, or difficulties with decision making • decline in hygiene • mental rigidity • hyperorality • perseveration • reduction of verbal output |

| Causes/Origins | Treatments | Outcomes |
|---|---|---|
| <ul style="list-style-type: none"> tissue damage in specific area of brain. Damage spreads over time to other areas of the brain | <ul style="list-style-type: none"> change of lifestyle exercise decrease your stroke risk (see vascular dementia) medication | <ul style="list-style-type: none"> progressive disease even with treatment |
| <ul style="list-style-type: none"> problems with blood supply to the brain, such as stroke high risk factors including smoking, diabetes, high blood pressure/cholesterol, previous stroke, heart disease, inactive lifestyle | <ul style="list-style-type: none"> change of lifestyle low sodium diet low cholesterol diet quit smoking quit drinking exercise treat diseases that cause stroke medication | <ul style="list-style-type: none"> stable until the next stroke |
| <ul style="list-style-type: none"> similar to vascular dementia and Alzheimer's disease | <ul style="list-style-type: none"> change of lifestyle medication | <ul style="list-style-type: none"> progressive disease even with treatment |
| <ul style="list-style-type: none"> Lewy bodies, small spherical protein deposits found in nerve cells that disrupt normal brain functioning | <ul style="list-style-type: none"> change of lifestyle medication as above for vascular dementia | <ul style="list-style-type: none"> progressive disease even with treatment |
| <ul style="list-style-type: none"> associated with later stage of Parkinson's disease based on family history | <ul style="list-style-type: none"> change of lifestyle medication | <ul style="list-style-type: none"> progressive disease even with treatment |
| <ul style="list-style-type: none"> affected in middle-age mostly based on family history | <ul style="list-style-type: none"> change of lifestyle speech therapy medication | <ul style="list-style-type: none"> progressive disease even with treatment |

Delirium and Depression

In some cases a person may experience symptoms that are similar to dementia but are actually the result of *depression* or a condition called '*delirium*'. Both delirium and depression are *treatable* and can sometimes be completely *reversible*. For this reason it is important that they are not confused with dementia, which is an irreversible disease. Another complicating issue is that someone with dementia may also develop depression or delirium.

Delirium

Delirium occurs in association with a medical illness and is most commonly seen when seniors are in hospital, though family members may also notice it at home or in a nursing home. A person with delirium has a sudden and dramatic onset of symptoms lasting anywhere from a few hours to over a month. The severity of symptoms fluctuates. Most people with delirium are more confused in the evening, but they appear less confused with more lucid periods (mentally rational) during the day. Someone suffering from delirium can become disorientated to time, person and place. Both their short and long term memory are also impaired. A delirious person may also have disorganized and bizarre thoughts, hallucinations (usually experienced as seeing or hearing things that others do not), and may become paranoid, irritable, aggressive or fearful. Delirium is caused by another illness, medication or process interfering with brain function.

Delirium is very serious – it is a medical emergency because it can be associated with increased illness,

increased disability and death. It is important to be aware of delirium and speak to a doctor immediately if you suspect someone may be experiencing it. If the source of delirium is found and treated, the illness usually lasts a relatively short period of time.

Depression

Depression is a mood disorder that usually starts slowly and may coincide with life changes. In order to diagnose a major depression the

symptoms have to exist for at least two weeks continuously. If it is not diagnosed it may go on for months or years. Depression usually has a good response to therapy if treated properly. Unlike delirium, symptoms of depression are worse in the morning and improve during the day. People with

depression usually have normal alertness, orientation and long-term memories. Hallucinations are not common in depression. Recent memories can be impaired. Thoughts tend to be slowed with feelings of sadness and hopelessness. Some may think of suicide and make plans to hurt themselves. Such individuals need urgent medical attention.



| Other Symptoms Similar to Dementia | | | | |
|------------------------------------|--|--|--|---|
| Diseases | Causes/ Origins | Symptoms | Treatments | Outcome |
| Delirium | <ul style="list-style-type: none"> diseases, medication, or process interfering with brain function | <ul style="list-style-type: none"> sudden onset disorientation to time, person, and place short and long term memories are impaired disorganized, bizarre thoughts and hallucination paranoid, irritable, aggressive, or fearful sleep disturbance | <ul style="list-style-type: none"> finding the cause may require hospitalization safety measures can be put into place medication may be used to reduce the fear and agitation | <ul style="list-style-type: none"> usually return to status prior to illness delirium may last longer than the illness that caused delirium |
| Depression | <ul style="list-style-type: none"> mood disorder | <ul style="list-style-type: none"> recent memories are impaired feelings of sadness and hopelessness poor appetite sleep disturbance loss of interest and enjoyment thoughts of committing suicide hallucination (rare) | <ul style="list-style-type: none"> support, cognitive, behavioural and social therapies lifestyle modification medications electroconvulsive therapy and hospitalization may be required in severe cases | <ul style="list-style-type: none"> usually return to status prior to illness recovery time depends on when the depression improves |

Are there any medications for dementia? Will they cure my disease?

Medications for Dementia: One person's experience

Cindy 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 heard there is no cure but wonders if there is anything that could help her mother.

Her friend Jean is also caring for a parent with advanced Alzheimer's. Jean says her father can become agitated, and used to be paranoid and hallucinate. Jean got a prescription from her doctor and she says her father is much more settled. Cindy wonders what the medication was and if her mother should start taking it now as prevention?

Why would I take medicine when there is no cure?

1) Cholinesterase Inhibitors

The most common class of medications is known as *cholinesterase inhibitors*, which act on chemical messengers used by the brain. These drugs are approved for mild to moderate Alzheimer's disease. These drugs may be used for Alzheimer's disease and other types of dementia. With treatment, *one-third of patients will show an actual improvement, another third will have slower progression than without medication. The medication will have little or no effect on about one third of patients.*

The side effects are:

- nausea
- vomiting
- leg/muscle cramps
- sleep disturbances
- behavioural changes
- slower heart beat.

When taking these medications, it is important to keep a record of the symptoms and side effects. This will help your doctor decide if the medication is working, and if the dose or drug should be changed or stopped all together.

Treatment but no cure. There is no medication that will cure dementia. Instead, all available medications are aimed at treating the symptoms and not the underlying cause of the disease. As a result, *medication will not stop the progression of dementia.* These medications have side effects and may not be suitable for some patients.

2) Behavioural Problems

Medication will help manage the behavioural and psychological symptoms of dementia (BPSD) such as:

- hallucinations
- depression
- anxiety
- sleep disturbances
- aggression
- agitation.

Antipsychotics may be used to decrease disruptive behaviours as well as caregiver burden. 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.

Changing the environment

Changing a person's environment or routine, and improving caregiver knowledge, can reduce disruptive behaviours. Helpful strategies are:

- caregiver education and support
- art, music or pet therapy
- light exercise.

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.

However, if such attempts fail, medications may be required. It is important to remember that medications are usually a last resort, and are only used if:

1. alternative treatments are inadequate,
2. there is a risk of harm to the patient and others, and/or
3. the symptoms are severe enough to cause suffering and distress.

An exception to this is in the case of depression-related behaviours where medications may be

very beneficial and are not used as a last resort.

Whenever a disruptive behavior occurs, write down the *time, place* and what was *happening* at the time. This will help you and your doctor find possible triggers that can be eliminated or reduced. Your doctor may also wish to assess all current medications and possible psychiatric conditions, as either of these may cause disruptive behaviours.

“We couldn't figure out how to make her dad more comfortable, but turns out we just had to be more careful about his eating schedule.”

Antidepressants, mood stabilizers, and antipsychotics

If the above criteria are met, your doctor may prescribe a type of medication known as antipsychotics. These medications can treat aggression, hallucinations, paranoia, etc; however, they may be associated with significant side effects such as:

- increased risk of fall
- strokes
- heart attacks
- fatalities.

A discussion with the doctor is advised to review the goals of treatment.

Antidepressants and *mood stabilizers* may also help if the patient is depressed, and 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.



How can I get help and from where?

Caregiver Support and Community Care: One person's experience

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

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

What kind of help is out there?

Dementia can affect more than just your brain, and your doctor will want to know if and how it is affecting your day-to-day life and overall health. Your doctor 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 doctor is concerned, he or she can refer patients to the community health unit for further assessment.



Community Health Unit

A community health unit will often have a variety of experts such as *specialized nurses, social workers, dietitians, physiotherapists and occupational therapists*, who all assist people living with dementia. Community health units can connect patients and families with appropriate resources such as:

- home support
- home safety assessment
- safety in the community assessment
- adult day care
- respite care
- transition to alternate living situations.

Respite or relief care provides caregivers with temporary substitute care, giving them a break from daily care responsibilities.



Alzheimer Society of B.C.

Another excellent resource is the *Alzheimer Society of B.C. (ASBC)*. You do not have to have Alzheimer's disease to access their resources. The Society provides information, education and support to people who are living with dementia, as well as their friends and family. Services include and are not limited to:

- *early-stage dementia support groups*
- *caregiver education and support*
- *resource libraries*
- *help line*
- *websites*
- *pamphlets*
- *public policy and advocacy activities.*

The Society also maintains *Safely Home*, a national wandering registry that helps the RCMP locate and return someone who is lost. In addition to these services, the society may be able to suggest where to go for additional assistance.

"I didn't think there was anything I could get from ASBC, but now I don't feel so alone. My dad is happier now!"

Coping with Dementia in the Family

In addition to the person who is diagnosed with dementia, physicians will interview caregivers of persons living with dementia. Most caregivers will require some form of support for part or all of their caregiving experience. Caregiving, while rewarding, can also be demanding. Doctors are aware of the challenges that caregiving poses and they may ask questions in order to offer appropriate support and education to caregivers. This may involve referring caregivers on to the *Alzheimer Society, Home and Community Care*, or addressing health concerns directly.

"There are things you can do and there are experts out there who can help us."

If you are a caregiver, it is important that you feel comfortable discussing your concerns, challenges and coping skills. Your doctor is there to help.



Can I still drive and take care of myself?

Driving, Self-Neglect, Neglect, Abuse: One person's experience

Alice was diagnosed with Alzheimer's disease several years ago. She still lives on her own and continues with many of the chores and tasks she did before being diagnosed. This includes driving to get groceries.

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

She has also become increasingly religious and has started giving a lot of her pension to various charities. Her children are concerned that someone may try to take advantage of her generosity, especially as her Alzheimer's worsens. They need to start planning ahead but don't know where to start.

13



What will happen to my Freedom?

Driving

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

Doctors will use a variety of means to evaluate a person's ability to drive safely. For example, your doctor may wish to perform tests which 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 patients continue to drive after being assessed as being incapable of safe driving. Therefore, the ultimate decision to suspend a driver's license lies with the Office of the Superintendent of Motor Vehicles of British Columbia, and not the doctor.

Deciding to stop driving is a difficult decision, though it does not have to mean the end of one's independence. If you are concerned about your ability or a loved one's ability to drive, speak to your doctor about alternatives such as:

- *HandyDart*
- *HandyPASS*
- taxis
- *Taxi Savers*
- 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 doctor to keep your license since this may put both you and others at risk.

"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."

Abuse and Neglect

Abuse and neglect are unacceptable at any age. Doctors and other health care professionals are

trained to assess for and respond to actual or suspected cases of neglect, self-neglect, and abuse. When a doctor is concerned about one of these situations in their patients, they will usually refer this patient for further assistance.

If you are concerned that someone may be abused (intentionally or unintentionally), please contact any of the following resources for more information or support:

- the patient's family doctor
- local mental health team
- local community health unit
- the local emergency room
- Victim Link (24hr/7days support and referrals): 1-800-563-0808
- Public Guardian and Trustee of BC:
www.trustee.bc.ca
- Alzheimer Society of B.C.
- Dementia Helpline: 1-800-963-6033
- BC Coalition to Eliminate Abuse of Seniors:
www.bcceas.ca , 1-800-437-1940
- Community Response Network:
www.bccrns.ca

What You Should Know About Reporting Abuse or Neglect

In order to investigate situations of potential self-neglect, neglect or abuse, an organization must be formally designated to do so. The Public Guardian and Trustee of BC has designated the following community services: the five health authorities in BC, Community Living BC, and the Ministry of Child and Family Development. In most cases, these organizations will investigate and then encourage adults to seek support and/or legal actions. However, if an adult is deemed unable to seek support, the organization may intervene on their behalf. An adult may be deemed unable to seek support if: they are under physical restraint, suffer from mental or physical disability or have an illness or injury that interferes with their ability to self report. While watchful, a doctor may not have enough information to identify possible cases of abuse.

How do we plan ahead with a terminal illness?

End of Life Care: One person's experience

Jean, 82, was diagnosed with dementia ten years ago. Jean lives on her own, and her daughter Beth visits regularly to care for her. However, with three young children to also care for, Beth and her husband are feeling overwhelmed.

They know Jean will continue to need more care, and eventually she may have to move to a nursing home. Beth isn't sure how she'll know when to move Jean, or how to choose a nursing home.

Beth's husband is also worried about what will happen if Jean gets sick. Who of her four children will have to make decisions? Beth handles her mother's finances, but does that mean she makes her health decisions as well? Do they need an official document in place?

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

With Your Doctor

Every doctor seeks to provide care that honours the goals, beliefs and values of their patients. This becomes difficult when these preferences are unknown or when dementia makes patients no longer able to express themselves. Everyone should be looking at plans for the future, not just people with dementia. However, if you have dementia, then it is very important to talk about planning ahead and think about this very early on. *It is recommended that you and your doctor have an open and honest discussion about quality of life, the kind and intensity of care that you would like to receive and any important beliefs and values you may have.*

With Your Family

Some individuals may involve family or friends in this discussion so they are aware of these decisions. In particular, it is important to clarify your specific wishes with regards to *feeding and hydration, preference regarding artificial feeding methods, blood transfusions, cardio-pulmonary resuscitation (CPR), hospitalizations and intensive care unit admission*. Some may feel that these interventions may be applicable in earlier stages of dementia and not in later more severe stages of dementia.

Goals and Wishes

In addition to discussing your goals and wishes, it is recommended that you also put them in writing. With regards to health care planning, having a *representative* for personal decisions or signing an *advance directive* may be useful. Financial planning documents include *power-of-attorney* and a representation agreement. Advice from lawyers, notaries, and/or accountants may also be useful. An up-to-date will is also advisable. You can visit the *Nidus Personal Planning Resource Centre and Registry* (www.nidus.ca) for more information on how to deal with these procedures.

Power of Attorney

A power of attorney with an enduring clause is a *written document and not a verbal document*. The document designates a person to *make financial and legal decisions 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. However, you can also create a power of attorney to deal with *all* of your assets including real estate.

In order to protect a person who has dementia, it is important that he or she create an *Enduring Power of Attorney*, ideally before or early in a disease process, as this is the only power of attorney that can remain in place once a person is no longer mentally competent. If you are uncertain, or have questions about this, a public notary or lawyer may be helpful, especially if your finances are complicated.

Representation Agreement

A representation agreement is another legal document which *allows a person to nominate another adult to make their future personal care and health care decisions*. Your representative is required to have reasonable consultation with you before making any decisions.

There are two types of agreements:

Section 7, which entitles your representative to make *everyday decisions* (e.g., health care decisions with some limitations);

Section 9, which entitles your representative to also make personal care and *health care decisions of a broader scope*.

You are only required to see a lawyer or notary for agreements under Section 9; however, it is usually a good idea to seek legal counsel when making any type of representation agreement.¹

Living Wills or Advance Directives

These documents outline the medical treatment preferences for probable health circumstances that may occur in the future.

For more information contact the following organizations:

- Alzheimer Society of BC:
www.alzheimerbc.org &
Dementia Helpline: 1-800-963-6033
- Public Guardian and Trustee of BC:
www.trustee.bc.ca
- Nidus Personal Planning Resource Centre and Registry: www.nidus.ca

“It was hard to talk about the end of my grandmother’s life, but I am glad that we did because otherwise we wouldn’t know how to deal with her possible health outcomes... now we are able to do what my grandmother might have wanted us to do.”

¹Adapted from the Public Guardian and Trustee of BC: “How you can help people manage finances and legal matters when they cannot manage on their own” www.trustee.bc.ca/pdfs/STA/How%20You%20Can%20Help.pdf

Acknowledgments

A large number of very committed individuals participated in the development of this booklet, and we would like to gratefully acknowledge their expert advice and support.

We would like to acknowledge the primary financial support provided by the Alzheimer Society of B.C. We would also like to thank the BC Ministry of Health for their support.

Sincere acknowledgement to the members of the Content Advisory Committee who are listed below for their expertise in writing, reviewing, and editing the material.

Jay Bains MA, MEd, BSc

Program Coordinator,
Activity & Volunteer,
P.I.C.S. Assisted Living,
Surrey

Jas Cheema MA

Manager, Diversity Services,
Surrey Memorial Hospital

Dr. Martha Donnelly MD, CCFP, FRCPC

Director of Community Geriatrics,
Department of Family Practice,
University of British Columbia;
Director of Geriatric Psychiatry Program,
Department of Psychiatry,
University of British Columbia;
Assistant Professor ,
Department of Family Practice,
University of British Columbia

Dr. Soma Ganesan MD, FRCPC

Clinical Professor of Psychiatry,
Director Cross Cultural Psychiatry Program,
University of British Columbia

Dr. MaryLou Harrigan EdD, BSN

Heath Care Consultant
Harrigan Consulting,
Vancouver

Dr. Francis Ho BSc, MD, CCFP, FCFP

Clinical Professor Emeritus, Faculty of Medicine, University of British Columbia

Dr. Arvind Kang MBBS, FRCPC

Clinical Associate Professor,
Department of Psychiatry,
University of British Columbia;
Medical Director & Consultant Geriatric Psychiatrist,
Geriatric Psychiatry Program,
Riverview Hospital;
Consultant Geriatric Psychiatrist,
Lions Gate Hospital;

Vivian Lam

Support & Education Coordinator,
Alzheimer Society of British Columbia

Dr. Philip E. Lee MD, FRCPC

Assistant Professor, Division of Geriatric Medicine, University of British Columbia;
Associate member, Division of Neurology,
University of British Columbia;

Bernice K.W. Ma

Support and Education Coordinator,
Alzheimer Society of British Columbia

Carla Pajak, BSN, RN

Shiraz Ramji MSc, MSc, PBD

Family Gerontologist

Dr. Hetesh Ranchod MD, FCP(SA), FRCPC

Specialist in Internal Medicine and Geriatric Medicine,
Mount Saint Joseph Hospital;
Vancouver Community Mental Health Services,
University of British Columbia;
Guidelines and Protocols Advisory Committee,
British Columbia

Dr. Roger Y.M. Wong BMSc, MD, FRCPC, FACP

Clinical Associate Professor and Associate Program
Director, Department of Medicine,
University of British Columbia;
Associate Medical Director, Medical Services, Head,
Geriatric Consultation Program,
Vancouver Acute,
Vancouver Coastal Health Authority.

Michael Wilkins-Ho MD, FRCPC

Geriatric Psychiatry,
Clinical Assistant Professor,
University of British Columbia

Peter Ao, Kapil Kohli, Bill Lin, Jennifer Quan, Rupinder Sohal

DPAS Medical Students,
University of British Columbia

UBC eHealth Implementation Team



FACULTY OF MEDICINE
eHealth Strategy Office

Dr. Kendall Ho MD, FRCPC

Faculty Project Lead
Associate Professor,
Division of Emergency Medicine
Director,
eHealth Strategy Office,
Faculty of Medicine,
University of British Columbia

Dr. Helen Novak Lauscher PhD

Assistant Director of Research
eHealth Strategy Office,
Faculty of Medicine,
University of British Columbia

Elizabeth Stacy MA

Project Manager,
Research Coordinator,
Language and Community Engagement Portfolio
eHealth Strategy Office,
Faculty of Medicine,
University of British Columbia

Jasmin Abizadeh BA

Lead Researcher,
Content Development Lead
eHealth Strategy Office,
Faculty of Medicine,
University of British Columbia

Nelson Shen BEd, MHA

Multimedia and Communications Specialist,
eHealth Strategy Office,
Faculty of Medicine,
University of British Columbia

Feedback

Do you have feedback about this booklet?

We would like to hear your thoughts and suggestions. Your feedback will help us to make improvements to this booklet to ensure it's useful to you, your family, your friends, or others like you who are interested in this subject.

Please send your feedback by mail, email, or fax. Please indicate whether you are a caregiver, person with dementia, professional working in this field, or other.



Getting To Know Dementia

*eHealth Strategy Office
855 West 10th Ave
V5Z 1L7 Vancouver, BC*

*Email: icon.support@ubc.ca
Fax: 604-875-5083*



FACULTY OF MEDICINE
eHealth Strategy Office



FACULTY OF MEDICINE
eHealth Strategy Office

Getting to Know Dementia:
A Patient's Guide to Diagnosis, Treatment and Care
Fourth Edition, 2011

For more information or an electronic copy of this booklet, please visit us at:

iCON
interCultural Online
Health Network

www.iCONProject.org
www.eHealth.med.ubc.ca/dementia