



**Building a Strong
Foundation for Dementia Care**



Health-Care Provider Education

Alzheimer Society
BRITISH COLUMBIA

Acknowledgements

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Building a Strong Foundation for Dementia Care

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Introduction

Thousands of families across British Columbia are affected by Alzheimer’s disease or other dementias, and this number is growing.

The Alzheimer Society of B.C.’s ultimate vision is a world without Alzheimer’s disease and other dementias and that world begins with a more dementia-friendly society, where people affected by dementia are acknowledged, supported and included. But we can’t do it alone; it will take a dramatic shift in our culture to support people living with dementia, their caregivers and families. It will take a movement.

Health-care providers play a critical role in this movement by striving to increase the quality of care and quality of life for people living with dementia. The Society is here to help you build a strong foundation for dementia care by increasing your skills and confidence so that people living with dementia and their families live the best life possible.

A note on person-centred care and person-centred language: The Society subscribes to the definition of person-centred care outlined in *Guidelines for Care: Person-centred care of people with dementia living in care homes*:

Person-centred care is a philosophy that recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect and to participate fully in their environment.¹

In this manual we refer to “people living with dementia” instead of “patients.” “Patient” is a medically-oriented term, and we want to emphasize that the person living with dementia is more than their disease. Each is a whole person with a history and many years of experience. Each is a member of a network—of family, friends and acquaintances. Each is unique. Dementia does not change this.



1 “Guidelines for care: Person-centred care of people with dementia living in care homes.” Alzheimer Society of Canada. January 2011

Part 1: Understanding dementia

What is dementia?

Dementia is an umbrella term for a set of symptoms caused by disorders affecting the brain. Symptoms may include memory loss and difficulties with thinking, problem solving or language, severe enough to reduce a person's ability to perform everyday activities. A person living with dementia may also experience changes in mood or behaviour.

Dementia is progressive, which means the symptoms will gradually get worse as more brain cells become damaged and eventually die.

Dementia is not a specific disease. Many diseases can cause dementia, including Alzheimer's disease, vascular dementia (due to strokes), Lewy Body disease, head trauma, frontotemporal dementia, Creutzfeldt-Jakob disease, Parkinson's disease and Huntington's disease. These conditions can have similar and overlapping symptoms. For example, two people may be having difficulties with language that are caused by two different dementias. One of them may have Alzheimer's disease and while the other has vascular dementia.

Often, people will only receive a diagnosis of "dementia." But dementia in itself is not a diagnosis. A person living with dementia may be dealing with one or a number of progressive brain diseases. Alzheimer's disease is only one of these.

Sometimes, treatable conditions—such as vitamin deficiencies, thyroid disease, sleep disorders or brain tumours—may have symptoms similar to those of the progressive dementias. Reactions to prescription or over-the-counter medications are the most common cause of symptoms that are similar to dementia.

This is one of the reasons why the Alzheimer Society of B.C. encourages anyone concerned about their memory, cognitive functioning or overall health to see their doctor for a full medical assessment.

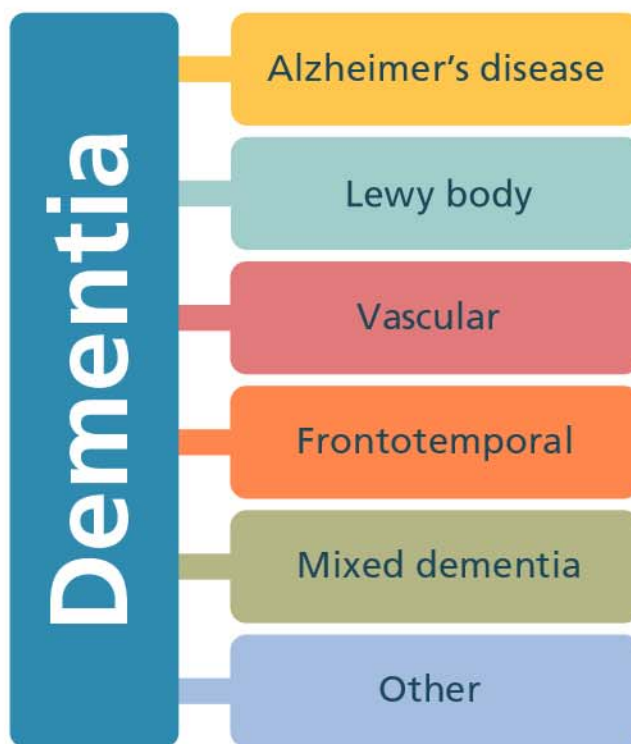


Figure 1: Alzheimer's disease and other dementias.

Normal aging versus dementia

Alzheimer’s disease and other dementias are not a part of normal aging.

Almost 40 per cent of people over the age of 65 experience some form of memory loss. When there is no underlying medical condition causing this memory loss, it is known as “age-associated memory impairment,” which is considered a part of the normal aging process. Brain diseases like Alzheimer’s disease and other dementias are different.

Age-associated memory impairment and dementia can be differentiated in a number of ways. Here are some examples:

Normal aging	Dementia
Not being able to remember details of a conversation or event that took place a year ago.	Not being able to recall details of recent events or conversations.
Not being able to remember the name of an acquaintance.	Not recognizing or knowing the names of family members.
Forgetting things and events occasionally.	Forgetting things or events more frequently.
Occasional difficulty finding words.	Frequent pauses and substitutions when finding words.
The person experiencing these symptoms may be worried about their memory; their relatives are not.	Relatives are worried about the person’s memory; the person experiencing these symptoms is not aware of any problems.

Note: This is not a diagnostic tool.

As a health-care provider you need to be aware of some of the red flags, but diagnosis is a job for the physician. If a person is worried about their memory, it is important that they talk to their doctor. It’s equally important to know that forgetting someone’s name or forgetting where they put something doesn’t necessarily mean that a person is getting dementia.



Delirium

Delirium is confusion that comes on quickly, often over a matter of hours. It may affect a person's thinking, attention and behaviour. Delirium is a serious problem that will often get better, but sometimes does not. Delirium is not the same as dementia. A person living with dementia can also experience delirium and, in fact, people living with dementia are more likely to experience delirium than people without dementia.

A person with delirium might:

- Have trouble paying attention or concentrating.
- Not know who or where they are.
- Experience a change in behaviour, such as:
 - Agitation (hitting or pushing, resisting care or not cooperating).
 - Restlessness (feeling a need to move around or feeling tense and "stirred up").
 - Lethargy (lack of energy), slowed speech and/or movements.
 - Change in sleep (for example, more awake at night and asleep during the day).
 - Any other change in behaviour or personality that is not normal.
- Experience changes to their perception, such as:
 - Seeing or hearing things that others do not.
 - Having paranoid beliefs, like thinking people are trying to hurt them or not feeling safe.
- Experience a change in mood, including feeling:
 - Anxious (being very nervous and fearful).
 - Depressed (feeling sad or upset).
 - Angry.
- Find it hard to express their thoughts or speak in a way that makes sense to others.
- Mumble or slur their speech.

Note: Symptoms may change throughout the day, and at times the person may seem like his or her "normal self."

As a health-care provider, it is important to be aware that the following factors may increase the likelihood of someone experiencing delirium:

- Being very sick
- Older age
- Dementia
- Dehydration
- Constipation
- Inability to urinate—or urinating only a small amount

- Urinary tract infection
- Recent hospital or long-term care home admission
- Pain following surgery
- Prior brain disease or injury
- Certain medicines

Delirium is treated by addressing the medical issues that are causing it, and also treating any troubling symptoms. Every person is different. Delirium might go away quickly or last for weeks.

The following table on the next page compares delirium and dementia, and adds a third “D” into the mix: depression. Particularly in the early stages of the progressive dementias, there are many symptoms that can also be indicative of depression. It is also true that many people with one of the progressive dementias are depressed, but if the depression is treated the cognitive difficulties remain.

The three Ds¹

	Depression	Delirium	Dementia
Definition	A change in mood which lasts at least two weeks and includes sadness, negativity, loss of interest, pleasure and/or decline in functioning.	An acute or sudden onset of mental confusion as a result of a medical, social and/or environmental condition.	Progressive loss of brain cells resulting in decline of day-to-day cognition and functioning. A terminal condition.
Duration	At least two weeks, but can last several months to years, especially if not treated.	Hours to months, dependent on speed of diagnosis and treatment.	Years (usually eight to 20).
Thinking	May be indecisive and thoughts highlight failures and a sense of hopelessness.	Fluctuates between rational state and disorganized, distorted thinking with incoherent speech.	Gradual loss of cognition and ability to problem solve and function independently.
Mental status testing	Capable of giving correct answers; however often may state "I don't know."	Testing may vary from poor to good depending on time of day and fluctuation in cognition.	May attempt to answer but not be aware of mistakes.
Memory	Generally intact, though may be selective. Highlights negativity.	Recent and immediate memory impaired.	Inability to learn new information or to recall previously learned information.
Sleep-wake cycle	Disturbed, usually early morning awakening.	Disturbed. Sleep-wake cycle is reversed (up at night, very sleepy and sometimes non-responsive during the day).	Normal to fragmented.
Hallucinations and delusions	Can be present in a severe depression. Themes of guilt and self-loathing, feeling others are better off than them.	Often of a frightening or paranoid nature.	Can be present. May misperceive. In Lewy body dementia, visual hallucinations are present.
Diagnosis	May deny being depressed but often exhibit anxiety. Others may notice symptoms first. Increased complaints of physical illness. Social withdrawal is common.	Diagnosis based on rapid onset of fluctuating symptoms. Can be mistaken for progression of the dementia.	Usually diagnosed approximately three years after onset of symptoms. Must rule out other causes of cognitive decline, e.g. depression or delirium.

¹ Delirium in the Older Person: A Medical Emergency. Island Health. 2014

Types of dementia

Alzheimer's disease

Alzheimer's disease is the cause of 60 - 80 per cent of dementias. It destroys brain cells, causing thinking ability and memory to deteriorate.

Dr. Alois Alzheimer first identified the disease in 1906. He described the two hallmarks of the disease: "plaques," which are numerous tiny, dense deposits scattered throughout the brain that damage brain cells at excessive levels, and "tangles," which interfere with vital processes, eventually choking off the living cells. When brain cells degenerate and die, the brain markedly shrinks in some regions.

The image in Figure 3 shows that a person with Alzheimer's disease has less brain tissue (right) than a person who does not have the disease (left). This shrinkage will continue over time, affecting how the brain functions.

There is currently no cure for Alzheimer's disease and its progression cannot be stopped or reversed. However, lifestyle choices and available treatment options can temporarily ease the symptoms for some people. For example, a person may find that taking one of the medications used for Alzheimer's disease helps them to feel more focused and less confused. People often talk about the "cobwebs" being cleared away—but if they stop taking the medication these symptoms return.

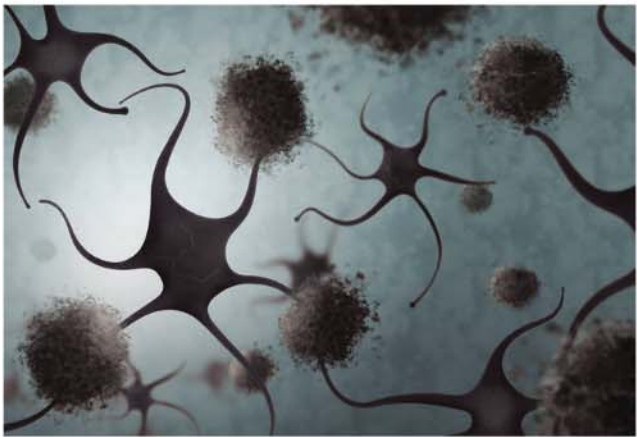


Figure 2: Plaques, numerous tiny, dense deposits in the brain, a hallmark of Alzheimer's disease.

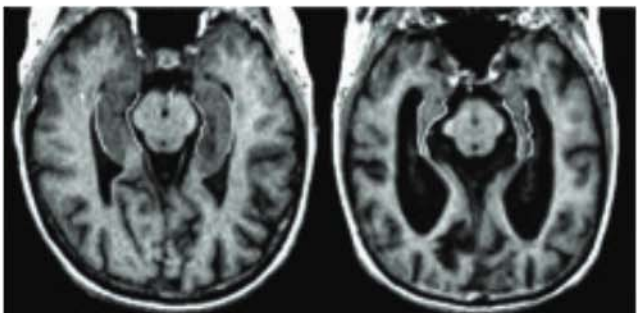


Figure 3: MRI images show the brain tissue of a person without Alzheimer's disease (left) and that of a person with the disease. Note the shrinkage in the brain on the right.

Stages of Alzheimer's disease

When a person has Alzheimer's disease, their brain cells progressively degenerate. The symptoms and the order in which the symptoms appear vary from person to person. The progression of Alzheimer's disease is often described in three stages. Generally, the disease progresses slowly, typically over several years, and the symptoms of each stage may overlap, making the transition from one stage to another quite subtle.

Early stage

- Mild impairment
- Forgetfulness
- Communication difficulties
- Changes in mood and behaviour
- Usually little assistance required to remain independent
- May be aware of changing abilities
- Need to plan for the future as soon as possible
- Support groups and education may be helpful

Middle stage

- Often referred to as "moderate"
- Cognitive and functional abilities have declined considerably

Late stage

- Often referred to as "severe" or "advanced"
- Verbal communication is minimal or non-existent
- 24-hour care is required
- Most people live in a long-term care home

End of life

- Increased mental and physical deterioration
- Symptoms worsen over time; comfort measures and quality of life become the focus
- Physical, emotional and spiritual needs must be carefully considered

Vascular dementia

- Also called multi-infarct dementia
- Occurs when brain cells are deprived of oxygen and die, due to blockage or rupture in the vascular system
- Stroke is a common cause of vascular dementia
- Strokes can be large or small, and can have a cumulative effect

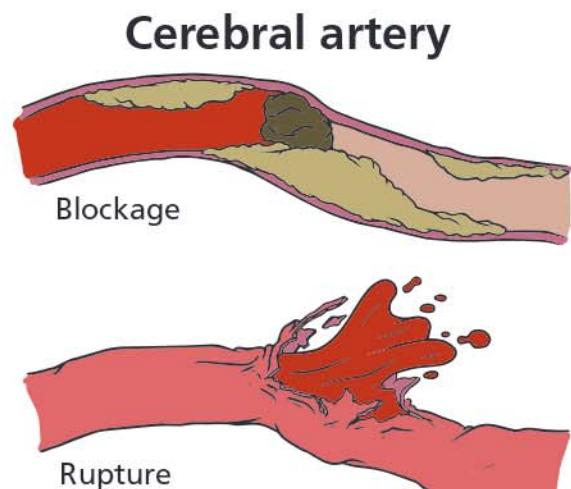


Figure 4: Stroke, caused by blocked blood flow in the brain or when a blood vessel leaks, is a common cause of vascular dementia.

- The difficulties a person experiences depend on the part of the brain that did not receive adequate oxygen (for example, if the temporal lobes have been damaged, language difficulties may result)
- Vascular dementia often comes on suddenly, but the difficulties a person experiences may happen in steps

Lewy body dementia

- Occurs because of abnormal deposits of a protein called alpha-synuclein inside brain cells
- These “Lewy bodies” interrupt the messages that travel through the brain’s neuro-pathways
- Usually affects the areas of the brain that involve thinking and movement
- Can occur by itself or together with Alzheimer’s disease or Parkinson’s disease and can include the following symptoms:

- Progressive loss of memory, language, reasoning and other abilities
- Difficulty finding the right word and keeping the train of thought
- Depression and anxiety
- Changes in alertness
- Sleeping changes/disturbances; e.g. acting out movements in R.E.M. sleep
- Apathy
- Visual hallucinations, typically of people, children or animals
- Parkinsonisms; e.g. rigidity (stiffness of muscles), tremors (shaking), stooped posture and slow, shuffling movements
- Sensitivities to medication, especially some sedatives and antipsychotics

- Usually progresses quickly

Frontotemporal dementia

- Tends to begin at a younger age than Alzheimer’s disease with onset occurring before 60 or 65 years of age.
- Ultimately, the person’s ability to function independently is significantly affected.

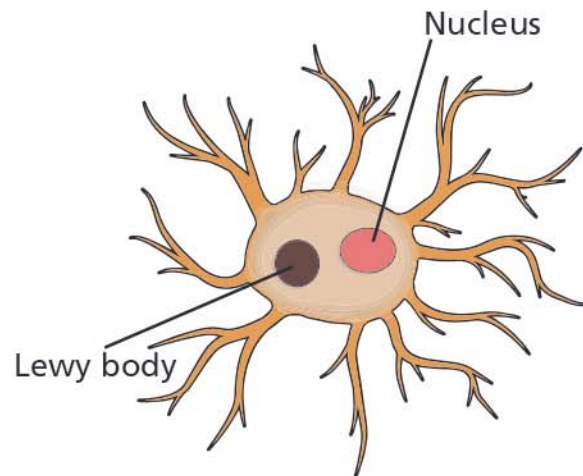


Figure 5: Lewy bodies, abnormal deposits of protein in the brain, interrupt messages along neuro-pathways in the brain.

Other names often used for frontotemporal dementia include:

- Semantic dementia
- Frontal lobe dementia
- Primary progressive aphasia
- Corticobasal degeneration
- Pick's complex/Pick's disease

Changes that may occur as a result of frontotemporal dementia include:

- Becoming withdrawn or disinhibited
- Loss of interest in personal hygiene
- Distractibility
- Overeating or compulsively putting objects in the mouth
- Incontinence
- Inappropriate social behaviour
- Loss of insight into the behaviours of oneself and others
- Changes in food preferences
- Blunted emotions
- Decreased energy and motivation
- Personality changes
- Problems with language can range from speaking less to total loss of speech
- Difficulty sustaining a train of thought or maintaining a conversation
- Often memory is not a problem in the early stages
- In the later stages of the illness, confusion, forgetfulness, swallowing difficulties and diminished motor skills are common

Mixed dementia

- Has characteristics of both Alzheimer’s disease and vascular dementia
- Researchers don’t know exactly how many older adults are currently diagnosed with a specific type of dementia actually have mixed dementia
- The combination of the two diseases may have a greater impact on the brain than either by itself
- If a person has both evidence of cardiovascular disease and dementia, the symptoms of which worsen slowly, mixed dementia may be the reason

Young onset dementia

- Defined as dementia beginning before the age of 65
- In Canada two to eight per cent of all people living with dementia are young onset
- Many of these people are in their 40s and 50s; they may:
 - Be working at the time of diagnosis
 - Have dependent children/parents living at home
 - Have significant financial commitments (mortgage, children, university fees, etc.)
 - Be physically fit
 - Be more aware of their symptoms
 - Find it hard to accept losing skills
 - Find it difficult to get information, support and services adapted to younger people living with dementia

Getting an accurate diagnosis of young onset dementia can take a long time. At least part of the reason for this is many people, including health professionals, aren’t aware that younger people *can* develop dementia.



In practice

Peter is 51 years old. He works as an accountant at a prestigious firm, is married and has two teenage children. For the past several months he has been making numerous errors in the audits he has done. He has always been very meticulous, so this is unusual for him. The firm has had complaints from clients, so they have had discussions with Peter and recently referred him to the Employee Assistance Program. Everyone has been assuming that there are problems at home which are affecting his work. This is not the case and Peter knows that something is wrong.

Mild cognitive impairment

People with mild cognitive impairment (MCI) may have problems with memory, language, thinking or judgment; for the majority of people, memory is most affected. These symptoms are more significant than the cognitive changes associated with normal aging. While the changes may be noticeable and measurable, they are not serious enough to interfere with daily life and independence.

MCI may increase a person's risk of developing dementia. However, some people remain stable and others may even show an improvement in cognitive abilities over time. Not everyone diagnosed with MCI goes on to develop dementia.

Understanding the brain

In order to be a compassionate and resilient caregiver it is important to accept that people living with dementia are experiencing the unstoppable progression of a disease. Understanding the progressive damage to the brain and how this is manifested is key to helping people living with dementia live the best quality of life possible.

Changes in a person's behaviour can be a sign of damage to certain areas of the brain. Below are descriptions of what each area of the brain does and how damage to that area can cause specific changes.

Limbic system

The limbic system links the lobes of the brain, enabling them to connect behaviour with memories. It is involved with memory, emotion and basic needs such as sleeping and eating. The limbic system tends to be affected early in the course of Alzheimer's disease.

Changes that may be seen:

- Difficulty finding objects and remembering where they were placed
- Suspicion
- Irritability, depression or anxiety

Hippocampus and temporal lobes

The hippocampus is where verbal and visual memories are processed and short-term memory becomes consolidated into long-term memory. The temporal lobes are involved in learning new things, language and reasoning and decision-making, among other functions.

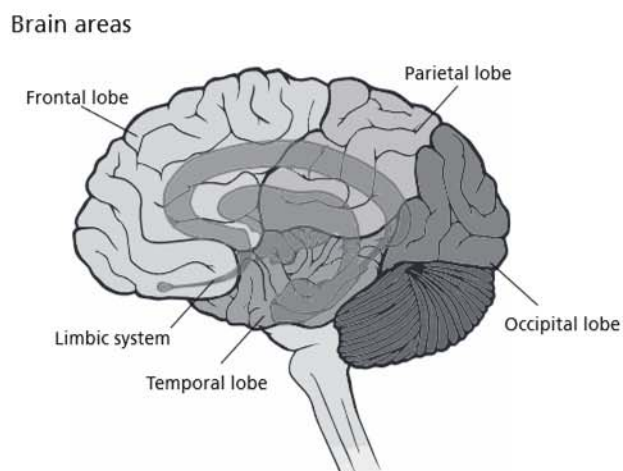


Figure 5: Areas of the brain, each one associated with a different set of functions.

Changes that may be seen:

- Inability to retain memory of the recent past
- Living in the present moment
- Loss of vocabulary
- Inability to recognize familiar faces, objects or places

Parietal lobes

The parietal lobes control our ability to put activities in a sequence. They allow us to use tools or perform tasks that require a logical order, such as starting and driving a car or putting on clothes. The parietal lobes also control our ability to understand spatial information, including where we, and other objects, are located within a specific environment.

Changes that may be seen:

The changes will vary depending on whether the left or right side of the brain is affected.

- Using words incorrectly
- Difficulty in understanding what others say
- Speaking in general terms rather than specifically
- Inability to express thoughts clearly in writing
- Difficulty handling bank accounts or paying bills
- Getting lost easily
- Difficulty putting on clothing
- Balance and gait difficulties

Frontal lobe

The frontal lobe helps us initiate activity and lets us plan and organize our actions. It also regulates our social judgment and behaviours, such as knowing what is appropriate in a situation, interpreting the feelings of other people and monitoring our own actions.

Changes that may be seen:

- Appears apathetic, uninterested
- Stops hobbies or other activities previously enjoyed
- Quickly loses interest in an activity, seems content to sit, does not respond to others
- Withdraws from others
- Is unable to stop an activity; repeats it over and over

Occipital lobe

The occipital lobe controls vision and the ability to see and combine colours, shapes, angles and movement into meaningful patterns. Although the occipital lobe is not usually directly involved in Alzheimer's disease, the surrounding visual areas that allow us to put the elements of vision together can be affected.

Changes that may be seen:

- Problems with depth perception
- Inability to see movement

Diagnosis

Diagnosing any of the dementias is a process of exclusion. In other words, physicians rule out what is *not* causing the problems. At this point there is no simple diagnostic test.

Ten warning signs

Here are 10 warning signs that indicate it is important to see a medical professional:

Warning sign	What is normal?	What may be a problem
Memory loss that affects day-to-day abilities	Occasionally forgetting appointments, colleagues' names or a friend's phone number and then remembering them later.	Forgetting things more often or having difficulty recalling information that has recently been learned.
Difficulty performing familiar tasks	Busy people can be so distracted from time to time that they may forget to serve part of a meal and only remember later.	Having trouble completing tasks that have been familiar to you all your life, such as preparing a meal or playing a game.
Problems with language	Everyone has trouble finding the right word sometimes.	Forgetting simple words or substituting words, making sentences difficult to understand.
Disorientation in time and space	Forgetting the day of the week or your destination — for a moment.	Becoming lost on your own street, not knowing how you got there or how to get home.
Impaired judgment	From time to time, people can make questionable decisions, such as putting off seeing a doctor when they have an infection.	Changes in judgment or decision-making: for example, not recognizing a medical problem that needs attention or wearing heavy clothing on a hot day.

Warning sign	What is normal?	What may be a problem
Problems with abstract thinking	Occasional difficulty with tasks that require abstract thinking— such as balancing a chequebook.	Significant difficulties with tasks that require abstract thinking; for example, not understanding what numbers are and how they are used.
Misplacing things	Temporarily misplacing a wallet or keys.	Putting things in inappropriate places: an iron in the freezer or a wristwatch in the sugar bowl.
Changes in mood and behaviour	Being sad or moody from time to time.	Varied mood swings— from calm to tears to anger— for no apparent reason.
Changes in personality	Subtle changes in personality over time.	Striking personality changes: can become confused, suspicious, withdrawn, apathetic, fearful or act out of character.
Loss of initiative	Occasionally tiring of housework, business activities or social obligations, but eventually regaining one’s initiative.	Becoming passive and apathetic and requiring cues and prompting to become involved.

If any of these symptoms is concerning, the next step is to see a family physician. In some cases, a referral to a specialist is warranted, but for most people, ongoing assessment and treatment is provided by the family physician.

At this stage in our knowledge, there is no one definitive test to diagnose Alzheimer’s disease or any of the other dementias. The diagnosis is made through a systematic assessment that eliminates other possible causes. The process may involve several of the following:



- Medical history
- Mental status exam
- Physical exam
- Laboratory tests, including blood work and possibly X-rays, EEGs (electroencephalograms), a CT (computerized tomography) scan, a SPECT (single proton emission computed tomography) scan, or a PET (positron emission tomography) scan
- Psychiatric and psychological evaluations

Treatment options

There is currently no cure for Alzheimer's disease and other dementias, nor is there a treatment that will stop the progression. Several drugs on the market and non-pharmacological treatments may help with some symptoms. A doctor or a qualified health-care professional should be consulted about any treatment or product being considered, including natural health products.

Drugs approved for Alzheimer's disease

There are several medications that can help with symptoms such as memory decline, changes in language, thinking abilities and motor skills. Although there is still no cure for Alzheimer's disease, people who respond to these treatments may experience improvements in their quality of life for several years.

Cholinesterase inhibitors

Three cholinesterase inhibitors are available in Canada to treat symptoms in people living with mild to moderate Alzheimer's disease:

- Aricept (Donepezil)
- Exelon (Rivastigmine)
- Reminyl (Galantamine hydrobromide)

Cholinesterase inhibitors help by improving the ability of impaired nerve endings to transmit messages from one nerve cell to another. Eventually, nerve endings degenerate and drugs are no longer effective. The drugs are prescribed for people with mild to moderate symptoms. Aricept has been approved for mild, moderate and severe Alzheimer's disease. All are variously used for people with other dementias.

Some PharmaCare coverage is available for cholinesterase inhibitors. Aricept is covered for the treatment of mild to moderate Alzheimer's disease as a Limited Coverage benefit through the Special Authority process. If the person cannot physically tolerate Aricept, Reminyl or the oral version of Exelon will be covered. (Exelon also comes in a patch form, and this is not covered.)

Please refer to alzbc.org/approved-drugs for information sheets with detailed information about each of these medications.

Ebixa

In our brains, information is passed from one nerve cell to another by chemicals called neurotransmitters. As Alzheimer's disease progresses, the neurotransmitter glutamate leaks out of nerve cells and is reabsorbed at levels that are dangerous to the cell. Ebixa (Memantine hydrochloride) works by blocking the reabsorption of glutamate into nerve cells. This drug has been approved for individuals with moderate to severe Alzheimer's disease.

Side effects

Both cholinesterase inhibitors and Ebixa may cause side effects including sleep disruption, headaches, nausea, diarrhea, constipation and drowsiness. Sometimes these side effects are short-lived, but for some people they persist and may result in the discontinuation of the medication.

Alternative therapeutic approaches

Some non-pharmacological therapies (such as music therapy, aromatherapy, pet therapy and massage) may be beneficial to people living with dementia. However, a lack of research prevents us from determining the effectiveness of many alternative treatments. The Alzheimer Society is funding projects in these areas in order to identify beneficial therapies for people with the disease.



When considering the use of natural health products, consider the following:

- Don't assume "natural" means "safe"
- Be wary of unsubstantiated health-related claims

Remember that herbal remedies can change the way prescription drugs work.

Dementia: The myths versus the reality

Myth: *Because someone in my family lives with dementia, I am going to get it.*

Reality: While genetics do play a role in the development of some forms of dementia, the majority of people who have dementia do not have a strong, known genetic link. Less than 5 per cent of all dementias are caused by genetics.

Myth: *Dementia only affects older people.*

Reality: While most people living with dementia are over the age of 65, a small number of people in their 40s and 50s can and do develop dementia. Most people do not develop dementia as they age; dementia is **not** a normal part of aging.



Myth: There's a cure for Alzheimer's disease.

Reality: Alzheimer's disease remains incurable. However, medications, support and care early in the disease can help manage symptoms and improve quality of life.

Myth: Memory loss means dementia.

Reality: People naturally forget things from time to time. When memory loss affects day-to-day function, it is important to visit a doctor to determine the cause. Many forms of dementia do not have memory loss as their first symptom so any unexplained changes in mood, behaviour or ability should be checked out by a doctor.

Myth: Dementia is preventable.

Reality: Dementia cannot be prevented, but there are things people can do to reduce their risk or delay the onset of symptoms. Strokes and cardiovascular diseases are involved in over 50 per cent of dementias. The risk can be reduced by maintaining physical activity and having good nutrition, controlling blood pressure and being socially active.

Myth: Vitamins, supplements and memory boosters can prevent dementia.

Reality: The research findings that link these substances to the prevention of dementia are inconclusive.

Myth: A diagnosis of dementia means life is over.

Reality: Many people living with dementia live meaningful, active lives for a number of years. Some people put their energy into public speaking and advocacy to help reduce the stigma that many people living with dementia experience.

Myth: All people who live with dementia become violent and aggressive.

Reality: Dementia affects each person differently and certainly not all become aggressive. Loss of memory and an increasing inability to understand what is happening around them can cause people living with dementia to express their frustration through their behaviour. Taking steps to make the environment as comfortable and calming as possible can avoid many upsetting situations for both the person living with dementia and people nearby. See page 25 for more information on responsive behaviours.

Myth: People living with dementia cannot understand what is going on around them.

Reality: This can vary from person to person and from time to time. Although the person's ability to communicate verbally may become impaired as the dementia progresses, it is possible to reach the person through other senses such as touch or listening to music. All people living with dementia have the right to be treated with respect.



Part 2: Understanding communication

Communication is a critical component of our lives; it enables us to express who we are and allows us to relate to one another. When we communicate, we convey messages or exchange information to share needs, opinions, ideas, beliefs, feelings, emotions, experiences and values. Of course, communication is more than talking and listening; it also involves understanding and interpreting.

A person-centred approach to communication

A person-centred philosophy views people living with dementia first and foremost as individuals with unique attributes, personal values and history.

A successful person-centred approach to communication is based on:

- Learning about dementia, its progression and how it affects individuals.
- Believing that communication is possible.
- Focusing on the person's abilities and skills.
- Reassuring the individual living with dementia and being positive.
- Meeting people living with dementia where they are and accepting their reality.

Quality of life for people living with dementia is largely dependent on their connection with others. Maintaining a relationship can be a complex and challenging process, especially when verbal communication is affected. **But it *is* possible!**

Ways to communicate

Information is conveyed in many ways:

- **Verbal:** Words we use and understand.
- **Non-verbal:** Body language (facial expression, posture and gesture).
- **Written:** Words we read and write.
- **Para-verbal:** Tone, pacing and volume of our voice.

How does dementia affect communication?

Dementia creates distinct challenges in how people express themselves and understand what is being communicated to them. This is the result of specific changes happening in the brain. Changes in the hippocampus and the temporal lobes may result in a progressive loss of vocabulary. As the parietal lobes begin to be affected, words may be used incorrectly and the person may have difficulty understanding what others are saying. It becomes difficult for the person to pay attention or to keep words flowing in a logical sequence. If English is not the person's first language, they may increasingly revert to the first language they learned.

These communication changes are common for people living with dementia:

- Difficulty finding a word.
- Creating new words for ones that are forgotten.
- Repeating a word or phrase.
- Difficulty organizing words into logical sentences.
- Cursing or using other offensive language.
- Reverting to a first language.
- Talking less than usual.

While dementia affects everyone differently, in general, it has a profound effect on language abilities and the way people living with dementia communicate. This language degeneration is known as *aphasia*.

People with aphasia have difficulty expressing themselves, finding the right words, understanding the words they hear, reading and writing. Communication can become increasingly challenging. Recognizing those changes will help the person living with the disease, their family and friends, and those who care for them, find ways to communicate more effectively.

Communication challenges during each stage of dementia

People living with dementia experience different changes to their communication abilities during the early, middle and late stages of the disease. As the illness progresses, they experience a gradual deterioration in their ability to express themselves clearly and understand what others say. *However, some form of communication does remain possible at every stage of the disease.* When all else fails people still maintain feelings, so communication on that level is possible.

In the **early stage** of most dementias the person often cannot find the right words – particularly the names of objects. The person may substitute an incorrect word, or may not find any word at all.

At this stage, the person may:

- Have difficulty understanding humour, jokes and fast talk.
- Be very concrete in their understanding of words and concepts.
- Have difficulty following multiple-step instructions.



In practice

Often people living with dementia become very concrete in their thinking. For example, Tony sees his wife sitting at the kitchen table, looking upset. He asks her what's wrong. She says, "Oh, nothing, sweetie. I'm just feeling a little blue today." Tony smiles and tells her not to worry—she is still the same colour as usual.

- Require increased concentration to follow conversations.
- Have trouble staying on topic.
- Need more time to respond to questions.
- Experience increased frustration.
- Have trouble finding the right word.
- Lose their train of thought more often.

In the middle stage, more words become lost, and the person needs to think longer before expressing thoughts. They may lose spontaneity; vocabulary may be more limited and sometimes the same word is repeated over and over again.

At this stage, the person may:

- Have trouble understanding everyday conversation.
- Frequently ask the speaker to repeat simple sentences.
- Find it difficult to follow long conversations.
- Have difficulty understanding reading materials.
- Repeat the same word or information over and over.
- Not be able to interpret facial expressions like a wink or the nod of the head.
- Have trouble explaining or understanding abstract concepts (for example, "I feel blue").
- Lose interest in talking or speak less.
- Have difficulty raising or lowering the voice.
- Have difficulty finishing sentences.
- Speak in vague and rambling sentences.



In the late stage, individuals appear to lose the capacity for recognizable speech, although words or phrases may occasionally be uttered and occasional flashes of lucidity may occur.

Non-verbal communication will become increasingly important. The person may:

- Be unable to understand the meaning of most words.
- Lose the capacity for recognizable speech, although words or phrases may occasionally be uttered. Language often does not make sense to others.
- Become totally mute.

Tips for communicating with a person living with dementia

Communicating well with someone who is living with dementia is not a skill that is learned overnight—it requires patience and practice. Remember to **connect not correct**.

Before you speak

- Enter the room or the person's space in a relaxed manner.
- Reduce distractions in the environment; for example, lower the volume of the TV.
- Make sure that the person has a working hearing aid and/or clean glasses, if prescribed.
- Make eye contact and use the person's preferred name when addressing them.
- Approach from the front, then move slightly to the side once you have caught their eye. If the person does not see you they may not respond to you, even if they can hear you.
- Get on their level. The person's peripheral vision is often compromised, and they increasingly see the world through a restricted range of view. When they can see you, they may be able to pick up relevant visual cues.



How to speak

- Get close enough so they can see your facial expressions and any gestures you may use.
- Speak clearly at a slightly slower pace and use short and simple sentences.
- Convey one thought at a time.
- Use close-ended questions which are focused and require a simple “yes” or “no” answer.
- They may have trouble recognizing people, so introduce yourself and explain why you are there. For example, “Hi, Mrs. Jones. I’m Kate. I’m here to help you get dressed, OK?”
- Show respect and patience. Avoid using childish talk or demeaning language. Don’t use endearments that are not appropriate to the relationship; for example, “sweetie.”
- Don’t talk about the person as if they are not there; try to include them in the conversation.

How to listen

- Be patient. Give the person time to process what you have said.
- Listen carefully to what the person is saying and observe verbal and non-verbal communications.
- Try not to interrupt the person even if you think you know what they are saying. If the person is having difficulty finding the right words, you can offer a guess as long as they appear to want some help.
- Make your communication a two-way process that engages the person living with dementia.
- If you don't understand what is said, avoid making assumptions. Check to see if you have understood what they mean.

Other ways of communicating

Use actions as well as words. For example, if it is time to go for a walk, point to the door or bring the person's coat to illustrate what you mean. Ask "Do you want a cup of coffee?" as you are holding the cup, and perhaps letting the aroma of the coffee reach their nostrils.

The more cues available to the person, the more likely it is they will be able to understand one of them.

Humour can bring you closer, can release tension and is good therapy. Laughing together over mistakes or misunderstandings can help. However, some people may see this as *you* laughing at *them*. If that is the case, humour is not advised.

If the person seems sad, encourage them to express their feelings. Show you care and provide reassurance. Always acknowledge their feelings. Even if the *facts* are wrong (or, more accurately, if they do not relate to current reality), the *feelings* are always right and need to be validated.

Part 3: Understanding behaviour

There is a reason for all behaviours and meaning behind them. This does not mean that a behaviour's meaning and cause are obvious. Part of being a good communicator with people living with dementia is being a patient and flexible "behaviour detective" rather than a judge.

Basic facts about behaviour

- A behaviour is often the expression of an unmet need which the person is unable to articulate in words.
- Some behaviours are a result of the disease.
- It is difficult to predict how behaviours will change in people living with dementia.
- We cannot teach people with progressive dementia to change their behaviour. We can influence the behaviour by modifying the environment and our approach.
- Sometimes, not reacting to the behaviour is the best solution.
- Applying logic and reasoning to help an individual manage behaviour problems does not work.
- Use your knowledge of the individual and your own creativity to address the behaviour.
- Caregivers need support and ongoing training to provide the best care possible.
- Strategies that are helpful today may not be helpful tomorrow.

Responding to different behaviours

When you are working with people living with dementia, there are many behaviours that might present a challenge to your training, knowledge and creativity. In this section we will look closely at four behaviours you will likely encounter often: delusions, reactive behaviour, repetitive behaviour and becoming restless in the evening.

Delusions and hallucinations

Hallucinations and delusions are symptoms of Alzheimer's disease and other dementias.



In practice

Mr. Peterson has a lovely gold watch that was given to him many years ago by his wife. Although he can no longer tell time using the watch, wearing it is familiar and reassuring for him. When the care aide enters his room in the morning to help him start his day, he screams at her and tells her to leave. "You stole my watch! You people can't be trusted." Maria, the aide, says "Oh, Mr. Peterson, you must be so upset! Let's see if we can find your watch."

When they find it under the pillow she says, "Oh this is wonderful! I found your watch. Can I help you put it on?" She doesn't point out that it wasn't her who hid it, nor does she get drawn into an argument that would go nowhere.

Delusions are false beliefs. Even if you give the person living with dementia evidence about something, they will not change their belief. For example, a person living with dementia may have a delusion in which they believe someone else is living in their house when they actually live alone.

Delusions can also be experienced in the form of paranoid beliefs, or accusing others of things that have not happened. For example, the person living with dementia may misplace an item and blame others for stealing it. Some people living with dementia may have the delusion that others are “out to get them.” For example, they may believe that their food is being poisoned.

Paranoia is a common aspect of delusions, resulting from a decreasing ability to separate fact from fiction.

Hallucinations are incorrect perceptions of objects or events involving the senses. They seem real to the person experiencing them but cannot be verified by anyone else. Hallucinations are a false perception that can result in either positive or negative experiences.

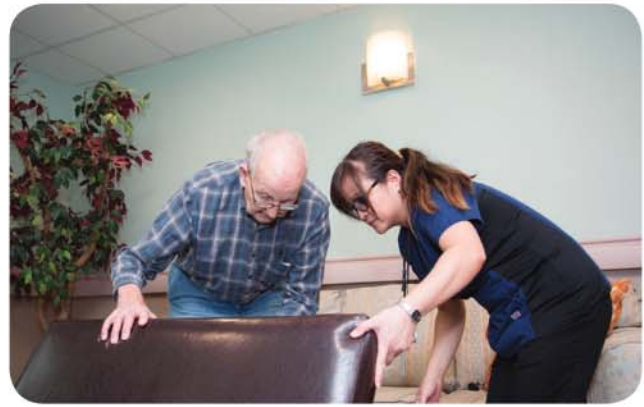
Hallucinations experienced by people living with dementia can involve any of the senses, but are most often either visual (seeing something that isn’t really there) or auditory (hearing noises or voices that do not actually exist). For example, a visual hallucination could be seeing bugs crawling over the bed that aren’t actually there. Of course, people also make “visual mistakes,” mistaking a housecoat hanging up for a person, for example, because they can’t see the object clearly. This can happen to anyone, and is not considered a hallucination.

Possible causes

- Different combinations of medications
- Unfamiliar people and environments
- Changes in routines
- Inadequate lighting
- Overstimulation of environment (too much noise, too many people, too many distractions)
- Sundowning, a form of disorientation and confusion that some people living with dementia experience in the late afternoon

Responding to delusions and hallucinations

- Try to determine if the person has any difficulty with hearing or vision.
- Make sure that lighting is adequate.
- Make sure that they are eating a well-balanced diet (malnutrition or dehydration can result in undernourishment of the brain).



- Try to make the environment comfortable (unfamiliar people or environments may be disruptive).
- Keep routines and schedules consistent.
- Try not to change the environment.
- Check for signs of physical injuries such as bruises or scrapes (a fall that was not witnessed by anyone could cause hallucinations).
- Determine whether the hallucination or delusion is bothering the person living with dementia. If it is pleasant, you may not wish to address it.
- Try to find a way to alleviate the distress. For example, if a person living with dementia lost their necklace months ago but believes it has just been stolen, help them look for it or distract them with another activity.
- Respond to the feelings and not to the issue. Rather than contradict them, acknowledge their concern.
- Do not get angry and avoid arguing. You will not win an argument with a person who is having a hallucination or delusion. Remember, the hallucinations and delusions are very real to them.
- Investigate suspicions that may be based on fact. It's possible that they really could be a victim.
- Use familiar distractions such as listening to music, exercise, playing cards or looking at photos.
- Reassure them.

Reactive behaviour

Reactive behaviours can be divided into two types: reactive physical behaviour (resisting care, throwing objects, damaging property, scratching, pinching, pushing, kicking and hitting) and reactive verbal behaviour (yelling, screaming, abusive language and swearing).

Possible causes

- A need to express feelings of resentment, anger, discomfort, frustration, fear, anxiety or depression.
- Physical symptoms, such as pain, constipation, fever, hunger, thirst, fatigue or a need to use the toilet.



In practice

Mrs. Chan has Alzheimer's disease. Until last month she was living with her daughter, Penny. Penny did not want her mother being cared for by "strangers," but two months ago Mrs. Chan fell and broke her hip. She needs to use a wheelchair and her dementia seems to have progressed. She is incontinent and needs more care than Penny is able to provide. They found her a lovely care home, but Mrs. Chan is more confused than ever and seems very depressed.

When the care aide tried to help her get dressed this morning, Mrs. Chan pushed her away. The care aide calmly said, "It's OK, Mrs. Chan. I'll come back later. This is hard, isn't it?" Ten minutes later she returned and Mrs. Chan let the care aide dress her and help her get ready for breakfast.

- An environment that may be too noisy, too crowded or too busy with activity.
- The person might be sensing high levels of stress from the people around them.
- As the disease progresses and memory becomes more compromised, reactive behaviours may occur when the person feels lost, threatened, unfamiliar with the people around them or frightened by their surroundings.
- Brain damage to the part of the brain that regulates judgement and the control of behaviour may lead the person to become uninhibited.

Responding to reactive behaviour

By understanding what causes certain behaviours and learning some ways to respond to them, you can reduce their frequency and intensity. If you notice the early signs of agitation and make appropriate changes to the person's environment, you may be able to avoid the reactive behaviour or reduce its intensity. Prevention is the ideal approach to reducing reactive behaviours, but preventative measures may not always work. Do not blame yourself if the person remains reactive. Think back to times when the person has become reactive. What events have led to their outbursts? Can you identify any common triggers? These could give you a clue as to what is troubling the person.

- **Watch for warning signs.** Does the person appear frustrated, anxious or frightened? Try to eliminate possible causes of stress.
- **Plan ahead.** If possible, encourage the person to participate in outings or activities at a time when they are usually rested. Allow for quiet rest periods throughout the day.
- **Lessen demands.** Keep the routine as simple as possible. Try not to rush.
- **Limit choices.** Too many options can be overwhelming.
- **Monitor the environment.** It may be affecting the person. They might react if the surroundings are too loud, crowded or unfamiliar. Moving to a quieter space might help.
- **Be mindful of personal space.** Being forced to accept help with intimate functions such as washing and using the toilet can be stressful. Give the person as much space, privacy and dignity as possible.
- **Regulate tone of voice.** As the person's language skills diminish, they will increasingly rely on *how* you say things rather than *what* you actually say. Maintain a calm and even tone of voice.
- **Take it step by step.** Explain things in simple sentences, breaking tasks down into easy, manageable steps. Offer help in a tactful way.
- **Focus on the positive.** Recognize achievements during any activity and do not criticize or continually point out errors.
- **Avoid confrontation.** Distract by suggesting an alternative activity.



- **Try again later.** The task is important, but your job is caring for people, not making them comply so you are able to complete all of your tasks in a set time.
- **Make well-being a priority.** Ensure the person gets enough exercise and sleep, has had enough to eat and drink and is comfortable. Limit distractions and avoid crowding the person.
- **Consult a physician.** Have physical problems and medication side-effects ruled out. Have vision and hearing checked.

Reactive behaviours may occur despite your best efforts—in fact, they probably will, at least occasionally. When they do:

- **Don't take it personally.** The person living with dementia does not mean to be reactive; they are not responsible for their behaviour or words. Don't argue or try to reason with them. Try to remain calm and use a soothing tone of voice. If necessary (and possible) walk away while you regain your composure. Try not to show that you feel annoyed or upset as this could cause the person to become more agitated. Debrief with other staff if an interaction is upsetting to you.
- **Focus on feelings.** Try to look past the person's behaviour and consider what they might be feeling.
- **Distract.** Offer an activity or a favourite snack. Try using music or a gentle massage to calm the person.
- **Protect the person.** Remove any sharp objects. Move the person away from stairs or objects that might be harmful.
- **Remove the trigger.** Whenever possible, try to gently guide the person away from whatever is upsetting them.
- **Comfort.** Offer a hug or to hold hands if this seems comforting for the person, and if it is appropriate given your relationship with the person.
- **Know when to walk away.** If the person becomes physical, give them plenty of space. Do not try to restrain them unless it is vitally necessary. You may need to leave the scene to prevent injury.
- **Call for help.** Call a co-worker, if possible. Your co-worker can help you with the person or can interact with other residents while *you* try to focus on the reactive behaviour.
- **Let it go.** Do not try to remind the person about an event after it has passed. They will most likely not remember and it was beyond their control. Forgive yourself if you did not respond the way that you would have liked to.
- **Talk to your co-workers.** Perhaps someone else has a helpful suggestion. Make sure that you have the opportunity to debrief with people who understand.
- **Seek medical advice.** If the behaviours are severe, pose safety concerns or do not improve despite your best efforts. For health-care providers who often work on their own, this is especially important.

Repetitive behaviour

Repetitive actions and repetitive questioning, as with any behaviour, have a cause. In dementia, damage to the front area of the brain can lead to perseveration. With verbal perseveration, the same thing is repeated over and over again, like a CD that skips. The person living with dementia likely has no insight or control over this behaviour.

Possible causes

- **Side effects of medication.** For example, moving the tongue in and out of the mouth repeatedly, is a side effect of medication.
- **Memory loss.** The person may not remember having asked the same question or having done the same activity.
- **Stress and anxiety.** This could be due to the person being unable to interpret sights and sounds. They may be unable to remember what has just happened or where someone is.
- **Inability to express a need or emotion.** Hunger might be expressed by repeatedly asking, "What's for lunch?" Being too warm could be expressed by pulling on one's shirt. The person may be feeling fearful or confused.
- **Frustration.** Perhaps the person is trying to communicate but is not being listened to or is unable to get the message across.
- **Inability to understand what is happening.** Even the simplest everyday chores may become unfamiliar, causing the person to repeatedly question what is happening.
- **Boredom.** The person may be under-stimulated and using repetitive behaviours to ease their restlessness.
- **Changes in the brain caused by dementia.** As the disease progresses, people living with dementia lose the ability to remember what they have just said or done. By repeating themselves, they are trying to gain a bit of control over their lives. Keep in mind that they may have said the same thing to you five times, but for them each time is the first time.

Responding to repetitive behaviour

- **Stay calm.** Use a calm tone of voice. Do not take the behaviour personally. The person living with dementia is likely unaware that they are repeating themselves. Take a break whenever possible.



In practice

John is attending an adult day program. He is dropped off by HandiDart at 9:30 a.m. and picked up at 3 p.m. Today he seems agitated. He is repeatedly asking staff when his wife is coming to pick him up. They reply calmly that the bus will come "later." However, he is getting increasingly agitated, so Steve, one of the staff, says "You look anxious, John. Do you think you might feel better if you help me wash the van?" John readily agrees, and works away until it is time for tea.

- **Address the feeling, not the question.** Repetitive questioning is often not a need for information but rather a need for reassurance. A hug or gentle touch on the arm or shoulder may help calm the person.
- **Redirect.** Try suggesting a favourite activity, such as a walk or listening to music, to divert the person's attention away from the repetitive behaviour.
- **Keep it simple.** Respond as briefly and simply as possible. Avoid telling the person that they are repeating themselves as this may only upset them. If changes in routine tend to upset the person, try telling them about any special plans just before the event. Sometimes simply ignoring the behaviour eventually works.
- **Write it down.** Try posting notes around their place in answer to their repetitive questions. For example, "Dinner is at 6 p.m." and, "Your slippers are in the closet." Use picture cards if the person has lost the ability to read.
- **Eliminate triggers.** If certain objects or activities tend to trigger the person's repetitive behaviour, try to avoid these situations. For example, if the sight of shoes by the front door always causes the person to start asking "Is it time to go now?" try storing shoes in a closet.
- **Brainstorm.** Memory aids like clocks, calendars and schedules may help orient the person. An audio or video tape made by a close family member may help with certain instructions, such as helping the person get up and get their day started. Be creative.
- **Replace.** If the person is making repetitive movements, try giving them something to occupy their hands and attention, like a simple puzzle or a stress ball.
- **Move on.** Allow the person sufficient time and then gently encourage them to move on with a soft touch on the arm or by pointing to the next step.
- **Seek medical advice.** Have a physician determine whether the repetitive behaviour may be caused by medication side effects, illness or other complications.

Sundowning

Note: "Sundowning" can suggest that a person's behaviour is a result of a problem with them and it is often considered unsupportive of a fully person-centred approach to providing care. When possible, use of term should be avoided and individual behaviours should be described. For the purpose of clarity, this section will refer to "sundowning" as it is still the most commonly used term.

The term "sundowning" is commonly used to describe symptoms that can be experienced by people living with Alzheimer's disease or other dementias. It is characterized by confusion, anxiety, agitation, restlessness or reactive behaviours and typically occurs late in the day, usually late afternoon or early evening.



Estimates on the prevalence of sundowning have been as high as 66 per cent among people living with dementia. Sundowning tends to peak in the middle stages of Alzheimer's disease and lessen as the disease progresses. It can be exhausting for the caregiver and often affects the person living with dementia's quality of life.

Sundowning seems to be related to a malfunction in the body's natural sleep/wake rhythms. It may also be related to an inability to deal with stress. There are several possible triggers:

- Fatigue (mental or physical)
- Disruption of sleep pattern
- Hunger or thirst
- Low lighting, shadows
- Boredom
- Over-stimulation

While completely preventing sundowning may be difficult, there are strategies that might make it less likely:

- **Increase exposure to light.** Sundowning typically occurs when natural daylight diminishes. Increase lighting at dusk to prolong the effect of daylight. It is also beneficial to spend time in outdoor sunlight at any time of the day.
- **Glasses and hearing aids.** The effect of low light on the person living with dementia is magnified by poor vision and hearing. Make sure that the person living with dementia is not in need of eyeglasses or hearing aids.
- **Check basic needs.** Is the person hungry or thirsty? Do they need to use the bathroom? Is the person uncomfortable? All of these may stimulate the tendency to sundown.
- **Plan activities early in the day.** Being active in the morning when the person is most energetic will help regulate sleeping patterns. Avoid physically or mentally demanding activities late in the day. Try to find the right balance between too much and too little activity.
- **Encourage afternoon naps.** For people living with dementia who appear tired in the afternoon, encourage a short nap (less than 30 minutes) early in the afternoon. This helps reduce the fatigue that is often associated with sundowning.
- **Exercise.** Regular exercise can help regulate the body and ease the mind. Avoid strenuous exercise late in the afternoon.



In practice

Mrs. Sidhu has moderate Alzheimer's disease, but she continues to live in her own home with the help of a live-in caregiver. Most days around 4:30 p.m. she turns on all the lights in the house and paces back and forth. Her caregiver has found through trial and error that it helps to have a basket of laundry for Mrs. Sidhu to fold. The caregiver asks her if she can help, then sets down the basket of towels. Folding them seems to calm Mrs. Sidhu, and the caregiver has a chance to finish making dinner.

- **Monitor diet.** Restrict sweets and caffeine consumption to the morning hours. Serve dinner early and offer only a light snack before bedtime.
- **Quiet afternoon.** Plan quiet and relaxing activities in the afternoon just before sundowning time. This can calm the person and prevent feelings of anxiety. Activities can include reading, listening to music, watching a favourite program on television or helping with familiar tasks, such as folding laundry or wiping the counter.
- **Change sleeping arrangements.** Allow the person to sleep in a different bedroom (if possible), in a favourite chair or wherever it is most likely to provide the best night's sleep. Try keeping the room partially lit with a nightlight to reduce the agitation that occurs when surroundings are dark or unfamiliar.
- **Provide a routine.** A regular routine helps the person living with dementia orient themselves in the day and provides a sense of security. It also helps regulate sleep patterns. Getting up, eating, exercising and going to bed at the same time every day reduces the likelihood of sundowning.
- **Provide a safe environment.** Make sure the person's living space is safe and secure. Remove dangerous objects. If the person wanders, restrict access to certain rooms.

When you are interacting with a person who is experiencing sundowning:

- **Reassure.** Comfort the person. Tell them, "I am here for you..." or "It is going to be OK..." Use a caring touch or a hug, if appropriate. Remind the person of the time, stay calm, avoid arguing and ask if the person needs anything. Use a calm and gentle tone of voice.
- **Distract.** Distract the person with a favourite object or activity. Engage them in a calming activity such as looking at photographs, taking a walk or singing softly.
- **Reduce stimulation.** Turn off background television and radio. Cover mirrors to avoid over-stimulation and to reduce the risk of confusion or even hallucinations. Talk softly, ask any visitors to leave and remove any stimuli that could cause anxiety.
- **Seek medical advice.** If non-medical alternatives do not work, medical intervention may help. A physician can assess the person for underlying physical problems that may be triggering the sundowning. Medication may be prescribed to help the person relax at night or to alleviate other symptoms.

Part 4: Understanding what families experience

Many health-care providers report that they feel reasonably secure in their ability to work with a person living with dementia, but they have a difficult time understanding and working with the person's family. Whether you work in community care, long-term care, acute care or any other setting, an understanding of what families go through on the dementia journey can help you enlist them as valuable partners in the care of the person living with dementia.

Caregiver stress

Providing care for someone with dementia takes a tremendous toll on one's physical and emotional health, yet many caregivers often don't recognize the warning signs of caregiver stress, or deny its effects on their health. Many caregivers tend to set their own needs aside while caring for the person living with dementia.

Providing care often leaves caregivers fatigued. Factors such as lack of sleep can reduce their patience or ability to provide the best care possible.

Stress is a normal part of caring for a person living with dementia. Caregivers can take steps to reduce it, but first it must be recognized. Warning signs of caregiver stress include:

- Not accepting that the person has the disease or that the dementia has progressed as far as it has
- Trying to control every detail of the person's care
- Anger at the person with the disease and others
- Emotional sensitivity
- Social withdrawal and depression
- Lack of sleep and exhaustion
- Lack of concentration
- Anxiety
- An increase in health problems



In practice

Mrs. Stein has been caring for her husband, who has Lewy body dementia, for five years. She has been reluctant to ask her friends or family for help. Mr. Stein's symptoms are challenging, and she doesn't want to burden anyone else with his care.

Two weeks ago, however, she had a minor heart attack. Her doctor told her this was her warning sign that she had to make some changes, or she wouldn't be around for much longer to care for her husband.

She hired a home support worker through a private agency. She was assured the worker had been trained to work with people living with dementia, but she doubted that the worker would know anything about Lewy body dementia. She questioned the worker in detail about everything that she did with her husband and never stayed away from home for the full three hours the worker was hired for. If her husband seemed unhappy when she returned home she would cancel the next home support visit.

Caregivers exhibiting stress may use community programs that provide respite and relief from caregiving, practical help with meals or housework and assistance with the care of the person living with dementia. You may be the first person to actually give the caregiver the opportunity to have a break — meet friends for coffee, go shopping. They may be incredibly relieved and grateful. But don't be surprised if instead, they seem critical and reluctant to leave you alone with the person living with dementia.

Caregiving tends to become all-consuming. The caregiver often gradually loses touch with friends, and their world shrinks. Despite exhaustion, their own health issues and difficulty coping with the demands of caregiving, they may hang onto the belief they are the best person to provide care for the person living with dementia. After all, they love the person and typically have a long history with them. Understanding some of their fears and concerns, and not taking the criticism personally, can go a long way towards building a good working relationship with family members.

“Because there’s a rotation of people all of the time, almost every day, I have to re-explain Mom’s needs. It’s a constant re-explanation. This is very exhausting to an already-exhausted full-time caregiver.”
– Family caregiver



In practice

Carol’s mother went to live in long-term care three months ago. Carol is finding it difficult to let go and visits every day, criticizing the staff for every little thing. Staff want to run and hide when they see her coming. Carol insists that she is only advocating for her mother, but she cries every day and sees her mother’s living situation as proof that she is a bad daughter.



Guilt

It is likely the person living with dementia will eventually require more care than the family caregiver can provide, even with outside help. Moving the person living with dementia to long-term care is one of the most difficult decisions a family member can make.

Caregivers often feel they are not doing enough, not doing things well enough or not spending enough time with the person, which can all create feelings of guilt. They may have promised the family member that they would never “put them in a home.” This is a promise they make to the person and to themselves. If it becomes necessary to break this promise they may feel they are betraying the person living with dementia, and guilt can become overwhelming.

As a health-care provider you may be on the receiving end of behaviour from the family. Acknowledging these complex feelings, or asking the care home director or social worker to talk to the family about what they are going through, can be the first step to developing a good working relationship with them.

Advising a family to not feel guilty, even if it is true, probably will not help. If they are being demanding or critical this is an opportunity to congratulate them for being such good advocates for their family member. Tell them it seems the person living with dementia was, and continues to be, cared for very lovingly by them, and that you will do your best to live up to their standards. But acknowledge that you will need their help to do so. As a team you are stronger, and the needs of the person living with dementia are more likely to be met.

“At this point there’s no cure. There’s not a t-shirt that says ‘I survived Alzheimer’s,’ but there should be one for the caregivers, because they’re the ones who are survivors of this disease.”

– Family caregiver

Grief

Caregivers often experience a continuous and profound sense of loss and subsequent grief as they live through the changes associated with the progression of the disease. The caregiver may be grieving the losses that are occurring in their own life as well as in the life of the person living with dementia.



Grieving is an up-and-down process. In the earlier stages, the caregiver may swing between despair and wild optimism that a cure will soon be found. They may even deny that anything is wrong with the person and try to suppress their feelings. Later, if they have accepted the situation, they may find that there are periods when they can cope well and make the best of things. At other times, they may feel overwhelmed by sadness or anger, or may simply feel numb.

Feelings like these are a normal part of grieving. These feelings may have a profound effect on the way family members relate to other people, including (and often specifically) people who are providing care for their family member. A grieving person may not look or act sad. Instead they may be angry, rigid, uncompromising and unreasonable—they may be people health-care staff do not look forward to seeing.

Recognize that grief and guilt may be behind many of the so-called “negative” interactions you as a health-care staff member have with the family. Sometimes all the person needs is recognition from you that you understand they are grieving.

Grieving in the final stages of dementia

Some caregivers find they have grieved the loss of the person for so long that they don't have strong feelings of grief when the person dies. Others experience a range of emotional reactions. These may include:

- Feeling numb
- Denial of the situation
- Shock and pain, even when death was expected
- Relief
- Guilt
- Sadness
- Feelings of isolation
- A sense of lack of purpose

What family members are feeling and how these feelings manifest may have a profound effect on how you perceive them. Just remember that there is no *right* way to grieve. As a health-care provider your support matters, but keep in mind that *you* may be experiencing grief over the loss of the person as well.



Families as members of the care team

The care team functions better when both families and care providers work together to support the individual receiving care. Both parties have the same goal: the well-being of the person living with dementia.

In order to work together effectively, families in general want the following messages to be conveyed to care providers:

- **Please respect our input.** This person is our family member. We have known them for our whole lives (in the case of a parent) or many years (in the case of a spouse). We know their history, likes, dislikes and how to calm them.
- **We may be experiencing many difficult feelings right now.** Whether you are home care or care home providers, part of us feels very bad that we are not able to provide all the care that our family member needs. As children, spouses and siblings, we feel this is our responsibility and by needing your help, we feel we are falling short.
- **Your care is not our care.** We want to believe that you are providing good care for our family member, but we mourn the fact that it is not the same as the care we provided. We understand that different care can still be good care, but it will take us time to accept this emotionally. Help us work with you to care for our family member. Let us know how we can best communicate our questions and concerns in a way that makes us a team in the care of our family member.
- **Thank you for being there.** We need you as much as the person living with dementia does. Now, let's work together!

Part 5: Additional resources

Language guidelines

The power of words

Language is our most powerful means of communication. Language used to describe Alzheimer's disease and other dementias has historically been largely negative, focusing on the losses experienced by the person living with dementia. While these losses are real, this negativity has contributed to the development and promotion of perceptions, interpretations and approaches to care that focus on weakness rather than strength, illness rather than wellness and victims rather than whole people.

By consciously using language in a more sensitive manner, we can avoid reducing individuals living with dementia to a series of labels, symptoms or medical terms.

Person-centred language

Person-centred language helps tackle the fear and stigma surrounding Alzheimer's disease and other dementias, in effect making the disease one that people are more likely to acknowledge and discuss. The preferred terms maintain dignity and respect for all individuals. The following principles are key to person-centred language:

Personhood

A standing or status that is bestowed upon one human being by others in the context of relationship and social being; it implies recognition, respect and trust.¹

Dignity and respect

Create positive conditions where people can live without fear of shame or ridicule; where they are treated with warmth and authenticity, listened to without judgment and given opportunity for self-determination and self-expression.

Acceptance and understanding

Accept each person with unconditional positive regard. Accept behaviour as a form of communication that expresses unmet needs or emotions. Help the person continue to enjoy basic personal freedoms.

Relationships

Support and preserve existing relationships. Support the person in the development of other positive relationships.

Recognition and individuality

Recognize the individuality of each person's life experiences, personality, values, beliefs and opinions. Respect and incorporate these factors in support planning.

Relationships of trust

Provide the conditions necessary to satisfy fundamental needs and create a climate for personal realization by providing a relationship based on trust. In a relationship of trust, the person knows confidences are respected, choice and control are maintained as much as possible, and the person will not be abandoned.

Person-centred language¹

Language to be avoided	Why should you avoid it?	Person-centred language
<ul style="list-style-type: none"> ○ Adult day care centre ○ Day care 	These phrases are more appropriate for children's services than for adults.	<ul style="list-style-type: none"> • Adult day centre/programs • Provincially-specific term • Support program
<ul style="list-style-type: none"> ○ Acting out ○ Aggressive behaviour ○ Agitation ○ Challenging behaviour ○ Difficult/problem behaviour ○ Hoarder/hoarding ○ Violent ○ Screamer ○ Sundowning/sundowner ○ Wandering/wanderer 	These terms are not specific. They suggest that the behaviour is a result of a problem with the person. They <i>label</i> , but give limited information.	<p>"Responsive" or "reactive" behaviours can be used, but specific descriptions are preferred:</p> <ul style="list-style-type: none"> • The person strikes out when asked to undress. • The person paces and appears upset. • The person becomes agitated and restless before dinner. • The person likes to walk. • The person got lost.
<ul style="list-style-type: none"> ○ Bib 	The term is reflective of products used in the care of children.	<ul style="list-style-type: none"> • Clothing protector • Apron
<ul style="list-style-type: none"> ○ Informal caregiver ○ Professional caregiver 	May offend people in the early stages who need people who will support them, not "caregivers." Caregivers may not identify themselves this way ("I am his wife, not his caregiver"). Terms not used consistently. Families may feel they <i>do</i> provide professional care.	<ul style="list-style-type: none"> • Ask caregivers what term(s) they prefer • Family member • Care partner • Care provider • Care team member • For health-care professionals, name the specific role; e.g. home support worker
<ul style="list-style-type: none"> ○ Cases 	People are not "cases." This term de-personalizes.	<ul style="list-style-type: none"> • People living with dementia/ person living with dementia, people we serve • Family member
<ul style="list-style-type: none"> ○ Deal with (as in deal with difficult behaviours) 	Sounds negative and punishment-oriented. Suggests exerting control.	<ul style="list-style-type: none"> • Describe the behaviour and think of suggestions for working with/responding to the person
<ul style="list-style-type: none"> ○ Demented ○ Demented person ○ Senile dementia 	Terms imply that the person is completely incapable	<ul style="list-style-type: none"> • Person with dementia • Person living with dementia • The person; the individual
<ul style="list-style-type: none"> ○ Diapers 	The term is reflective of products used in the care of children.	<ul style="list-style-type: none"> • Incontinence products • Incontinence briefs • Adult briefs
<ul style="list-style-type: none"> ○ Early onset dementia ○ Pre-senile dementia 	These terms can be confused with the early stages of dementia.	<ul style="list-style-type: none"> • Young onset dementia
<ul style="list-style-type: none"> ○ Feeders (and similar terms for other needs) 	Labels and de-personalizes.	<ul style="list-style-type: none"> • A person who needs support to eat or drink

¹ Adapted from Alzheimer Society of Canada's 2017 person-centred language guidelines

Language to be avoided	Why should you avoid it?	Person-centred language
<ul style="list-style-type: none"> ○ Handle (as in handle people living with dementia) 	Sounds physical and impersonal.	<ul style="list-style-type: none"> • Care for • Respond to the needs of the person living with dementia
<ul style="list-style-type: none"> ○ In denial 	Judgemental—often used to indicate that a person is not coping as well as one would expect. Implies a conscious choice to reject or refuse to accept reality. May actually be a part of the grieving process that needs to be addressed.	The listener's role is to validate the person's feelings, reflect back what they have heard, then ask the person to help them understand what they are going through.
<ul style="list-style-type: none"> ○ Loved one(s) 	Relationship between people and their family/friends may have been problematic and sometimes they are <i>not</i> loved ones— but it doesn't have to be for some people to be uncomfortable with the term. Sounds funereal.	<ul style="list-style-type: none"> • Person/people living with dementia • Name the relationship, (mother, husband, etc.) • Family member • Friend
<ul style="list-style-type: none"> ○ Non-compliant ○ Difficult ○ Refuses care ○ Uncooperative 	It is unreasonable to expect a person to comply with something he does not understand or that does not fit with his values. The person may be afraid and confused.	<ul style="list-style-type: none"> • Description of response and potential reasons for response
<ul style="list-style-type: none"> ○ Nursing home ○ Facility ○ Unit/wing ○ Institution 	Medically-oriented and historically has negative connotations. These terms are acute-care focused; not "home-like."	<ul style="list-style-type: none"> • Provincially-specific term • Long-term care home
<ul style="list-style-type: none"> ○ Patient 	Medically-oriented so should be used only within medical profession.	<ul style="list-style-type: none"> • Person/people living with dementia (or name specific type of dementia) • Person with lived experience
<ul style="list-style-type: none"> ○ Placement (care home placement) ○ Placement planning ○ Place/put 	One places or puts objects, not people.	<ul style="list-style-type: none"> • Moving to a long-term care home • Transition to a new home • Future care planning • Relocating to a long-term care home
<ul style="list-style-type: none"> ○ Sufferer ○ Victim ○ Burden 	Terms such as "victim" and "sufferer" add to the stigma and stereotypes surrounding dementia. They send the message that a life with dementia is not worth living, and that people living with dementia have nothing to contribute. Using the preferred terms maintains the person's dignity and focus on the person, not on their condition.	<ul style="list-style-type: none"> • Person living with dementia or name the specific type of dementia

Contact the Alzheimer Society of B.C.

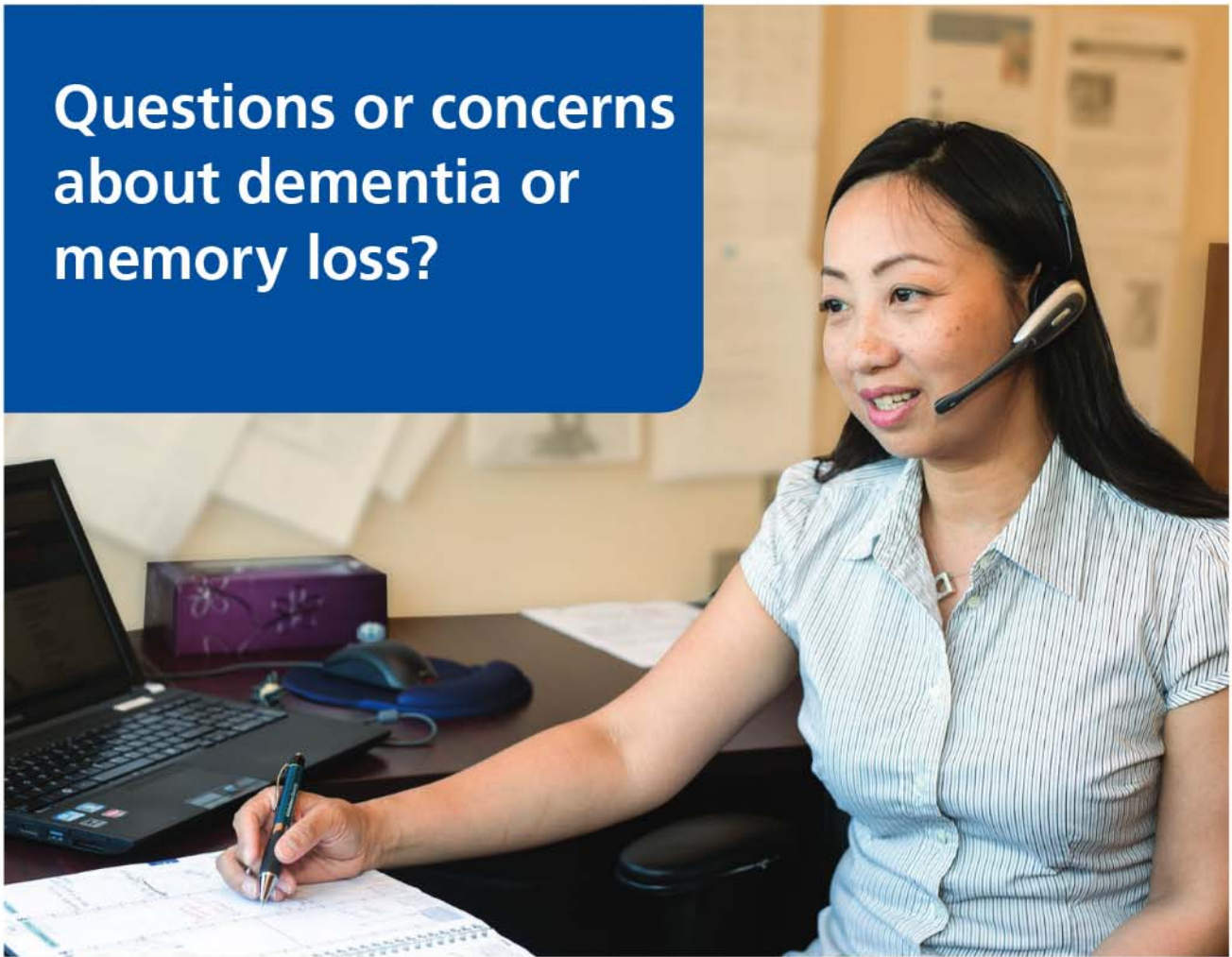
As a health-care provider, there may be times when your team is questioning how to respond to certain behaviours or situations. The easiest way to connect with us for any of your needs is via the First Link® Dementia Helpline at 1-800-936-6033, where trained staff and volunteers are ready to answer any questions or concerns about dementia or memory loss, or to connect you or anyone affected by dementia to the support they need.

Other resources:

- Alzheimer Resource Centres throughout the province, offering information, educational opportunities, support groups, a variety of print resources and one-on-one support.
- Dementia workshops, including in-person, online workshops and live or pre-recorded webinars, easily accessible via alzheimerbc.org and alzbc.org/tele-workshops.
- Online resources, including print resources for download and education specifically for health-care providers at alzheimerbc.org. Visit the “We can help” and “Tools for health-care providers” sections.
- First Link® formal referrals for health-care providers to connect individuals living with dementia and their care partners to Alzheimer Society of B.C. services and support. First Link® staff will contact the individual or designated contact person within five business days or after three weeks for those who are adjusting to the diagnosis. Referral forms available at alzbc.org/First-Link or firstlink@alzheimerbc.org.

Notes:

Questions or concerns about dementia or memory loss?



The First Link® Dementia Helpline is for anyone who:

- is interested in dementia
- is concerned about their memory
- has been diagnosed with dementia
- works with people living with dementia
- just wants to know more

First Link®

YOUR LINK TO DEMENTIA SUPPORT

English:

1-800-936-6033

Cantonese and Mandarin:

1-833-674-5007

Punjabi:

1-833-674-5003

Hours: Monday to Friday,
9 a.m. to 4 p.m.

Alzheimer *Society*
BRITISH COLUMBIA

