

LIVING WITH DEMENTIA



**Canadian Mental
Health Association**
Fort Frances
Mental health for all

Vision

Mental health and wellness in all communities.

Mission

To be a leader in the provision of advocacy, education, research and client-centered recovery-based services in the Kenora and Rainy River Districts.

Values

Collaboration

Empowerment and Self-Determination

Diversity and Social Justice

Accountability

Integrity and Transparency

Innovation

DISTRICT MENTAL HEALTH SERVICES FOR OLDER ADULTS PROGRAM

ABOUT THE PROGRAM

The Canadian Mental Health Association, Fort Frances Branch offers community-based geriatric mental health services in the Kenora and Rainy River Districts.

WHO IS ELIGIBLE

Seniors that are 60 years of age and older with a dementia or other serious mental illness, such as:

- Clinical Depression
- Mood Disorder
- Anxiety Disorder
- Schizophrenia
- Vascular Dementia
- Alzheimer's Disease or related Dementia
- Caregivers and care providers of seniors who have a serious and persistent mental health concern

The target population includes older adults living in community and facility-based environments including personal residences, supportive housing, chronic and acute care facilities and LTC homes.

THE PROGRAM PROVIDES

- Assessment and Cognitive Screening
- Counselling or Therapy
- Cognitive-Behavioural Interventions
- Care and Treatment Planning
- Referral and Advocacy
- Monitoring
- Education and Support to Caregivers
- Community Outreach and Presentations
- Geriatric Psychiatry

HOW REFERRALS ARE MADE

Referrals are accepted by any source including family, physicians, service providers and self-referrals. Contact information is on the back of this booklet.

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WHAT'S IN THIS BOOKLET?

You have been given this booklet because you or someone you care about has questions about dementia.

To answer these questions, this booklet contains a brief overview of a wide range of topics related to dementia.

Some of the information in this booklet may be important now, while other parts may be more useful later. Since this is a general guide, it's important to know that not everything in the booklet will be relevant to you and your unique situation.

Please continue to ask questions and talk to your Canadian Mental Health Association Fort Frances (CMHAFF) worker, your physician, and other care partners.

This book is dedicated to the clients and families that we are privileged to serve.

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WHAT IS DEMENTIA?

DEMENTIA is a word used to describe brain diseases that affect thinking, mood/personality, behaviour and physical abilities. In the same way that a fever is a symptom caused by another condition, dementia is the term for symptoms caused by another disorder.

THINKING

Dementia affects areas of thinking, such as:

- Memory
- Decision-making
- Problem-solving
- Learning
- Language
- Recognition
- Movement
- Organization
- Sense of direction
- Motivation
- Sensory perception
- The ability to care for oneself
- Sense of time

No two people are affected by dementia in the same way. Each person has strengths and challenges. Symptoms will depend on the area of the brain that is damaged and symptoms can change over time.

Examples of things that can become difficult include:

- Remembering messages and appointments
- Finding things
- Learning to use new things
- Sorting or paying bills
- Driving
- Finding words or naming objects
- Remembering recipes
- Doing things that require detail
- Planning things with more than one step
- Cleaning
- Taking part in conversations
- Organizing medications
- Starting a project or task
- Knowing the day or the time
- Getting around in unfamiliar places
- Daily activities like showering or laundry
- Recognizing people, places, or things

Every person with dementia is different.

In addition to affecting thinking, dementia also creates changes in:

MOOD/PERSONALITY

- Feeling more depressed, anxious, lost, confused, withdrawn, suspicious, frustrated or angry

BEHAVIOUR

- Repeating questions or stories
- Walking or pacing (wandering)
- Verbal or physical aggression/agitation
- Sleep problems
- Rummaging around for things
- Disinhibited behaviours (e.g. rudeness, inappropriate gestures)

PHYSICAL ABILITIES (ESPECIALLY IN LATE STAGES)

- Mobility problems (e.g. poor coordination and balance, trouble walking, falls, clumsiness)
- Loss of bladder or bowel control
- Loss of appetite, trouble swallowing and weight loss

STAGES OF DEMENTIA

Dementia is often progressive, which means that it will likely become more difficult to do things over time. Dementia is usually described in terms of stages:

EARLY STAGE DEMENTIA (MILD)

A person may be able to do a lot of things on their own and require minimal help. Signs and symptoms may not be easy to see, but include:

- Asking the same questions over and over
- Having a hard time finding words
- Having trouble with organizing finances or bills
- Medication mix-ups

MIDDLE STAGE DEMENTIA (MODERATE)

A person with middle stage dementia will rely more and more on others for everyday tasks. Signs and symptoms are more obvious, and can include:

- Struggling to name common objects
- Unable to learn new things
- May become lost when away from home
- Personality and behaviour change
- May be more silent or may become agitated
- May not recognize his/her own children
- May need reminders or prompts to complete tasks
- May have mobility and balance issues

LATE STAGE DEMENTIA (SEVERE)

A person in late stage dementia will need hands-on help with most things. Signs and symptoms of severe dementia may include:

- Unable to be left alone for long periods
- Confusion
- Significant communication issues
- Needing help to wash, dress, eat, use the toilet
- In time, the person may have a hard time to swallow, walk, stand or sit without assistance

ABOUT MILD COGNITIVE IMPAIRMENT

Some people have thinking problems that are more severe than normal aging but not severe enough to be called dementia. This is called Mild Cognitive Impairment (MCI). These minor problems in memory, concentration, speed of thought, language or problem-solving do not have a major impact on daily life or cause significant changes. Some people with MCI may develop dementia, but not all will. MCI does increase risk for dementia, but some people with MCI remain stable and some return to normal functioning.

ASK FOR HELP

It is important to ask for help if you experience or notice any changes, such as:

- Personality changes
- Changes in mood or emotion
- Seeing things that others can't see
- Being suspicious about people
- Not sleeping
- Problems with balance and/or falls
- Worries about who will look after you

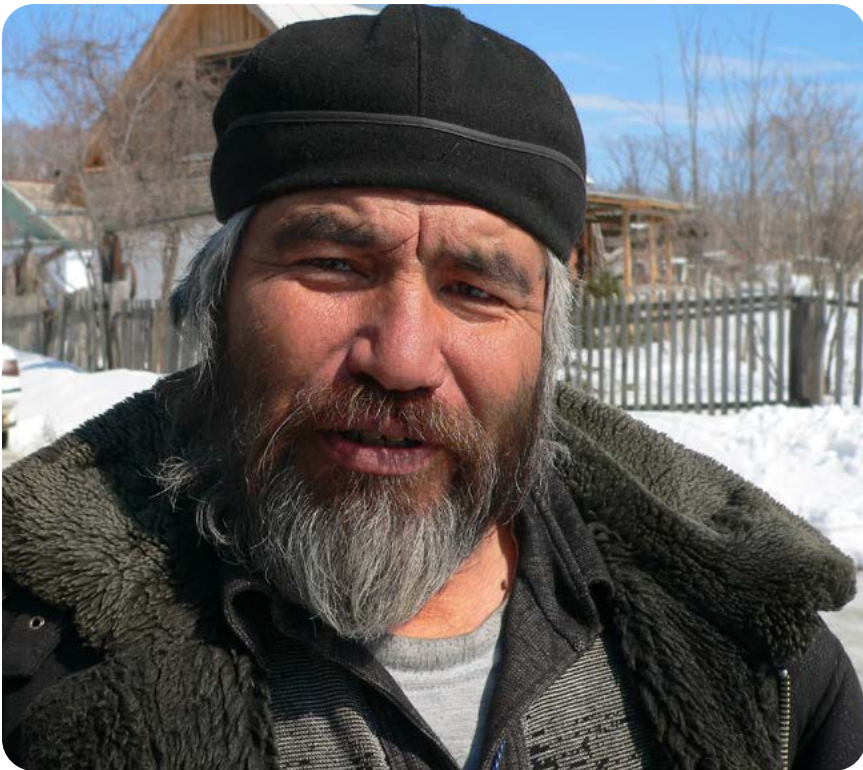
Sometimes individuals with dementia do not know that they are forgetting things or having difficulties. Family and friends are often the ones who recognize the changes. There is help for the caregivers too.

Helpful resources can be found at the end of this booklet.

CAUSES OF DEMENTIA

There are many different causes of dementia. Some are progressive and permanent, while others can be treated and reversed. It is very important to remember that dementia is not a normal part of aging.

Dementia can occur at any age but is most common in older adults (over 65). Dementia in younger adults (under 65) is often called Early Onset Dementia.



Conditions that may be reversible include:

- Depression
- Thyroid disease
- Vitamin deficiencies
- Infections
- Alcohol abuse
- Drug abuse
- Head traumas
- Dehydration
- Metabolic disorders
- Brain disease
- Drug reactions, medication side effects, overdose

Sometimes symptoms of dementia are not reversible and get worse over time. Many diseases can cause dementia in this way. The most common are:

- Alzheimer's disease
- Vascular dementia
- Mixed dementia
- Lewy Body dementia
- Frontotemporal dementia

ALZHEIMER'S DISEASE

Alzheimer's disease is the most common form of dementia.

- Early on, a common change is short-term memory loss
- Usually gets worse over time
- People with Alzheimer's disease are often not aware of the changes in their thinking
- Named for Dr. Alois Alzheimer, who discovered plaques and tangles in the brains of people with the disease
- Other biological features include brain cell death, brain shrinkage and loss of connection between brain cells
- Affects both men and women
- Is more common as people age
- Affects each person differently, but damage tends to start in the part of the brain needed for memory and progresses to areas needed for communication

VASCULAR DEMENTIA

Vascular dementia is the second most common form of dementia.

- Caused by brain damage from impaired blood flow to the brain
- Can develop after one or more strokes
- Can be related to heart problems or conditions that damage blood vessels
- Symptoms vary depending on what part of the brain has been damaged
- Motivation, personality, concentration, memory or mood can be affected
- Balance and walking can be affected due to paralysis, weakness or numbness
- Onset can be sudden or gradual
- Impairment can happen in steps with rapid deteriorations and periods of stability
- Controlling the factors that can increase the risk of heart disease and stroke may lower the risk of vascular dementia (e.g., diabetes, high blood pressure, high cholesterol, and smoking)

MIXED DEMENTIA

Mixed dementia refers to any dementia caused by more than one brain disease, but most often, it involves Alzheimer's disease and vascular dementia.



LEWY BODY DEMENTIA

Lewy Body dementia (LBD) is also relatively common.

- Early on, organization and concentration can be more affected than memory
- People with LBD are more likely to have good and bad days
- People with LBD can have significant changes in thinking and functioning over the course of a day
- In addition to thinking problems, people with LBD have some symptoms common in Parkinson's disease (e.g. stiffness, slowing of movements, stooped posture, poor balance)
- Visual hallucinations (seeing shapes, animals, people or children others can't see) are common in the early stages
- Risk factors are not well understood
- LBD is named after the doctor who discovered tiny round protein deposits in nerve cells of the brain known as Lewy bodies
- Years after Parkinson's disease is diagnosed, people can start to have symptoms similar to those of LBD

FRONTOTEMPORAL DEMENTIA

Frontotemporal dementia (FTD) is more rare and can be difficult to diagnose. It affects the frontal and temporal lobes of the brain.

- Early on, personality changes are common and may include extreme anger, odd behaviours, uncontrolled eating and loss of social graces
- Organization and getting tasks done is often a problem
- Bladder and/or bowel control may be lost
- A person may have problems with reading and writing
- Some kinds of FTD affect speech which can be reduced or lost; a person may stutter or mimic what they hear
- Speech and behaviour problems can appear separately at first but will overlap later on
- Memory and orientation to time are often unaffected in the early stages but will appear as the disease progresses
- Sometimes the brain cells in the affected area die and sometimes they get large and contain round, silver Pick bodies

OTHER DEMENTIAS

There are many more causes of dementia including:

- Creutzfeldt-Jakob disease
- Normal pressure hydrocephalus
- Huntington's disease
- AIDS dementia
- Posterior Cortical Atrophy
- Parkinson's disease
- Korsakoff syndrome
- Multiple Sclerosis
- Progressive Supranuclear Palsy
- Traumatic Brain Injury

Each of these brain diseases has a different combination of symptoms.

Dementia is not simply diagnosed by a blood test or a brain scan.

- The first step for your health care team to diagnose dementia is for them to learn about your experiences
- You will be asked about what is difficult for you, for how long, what medications you are taking and any other health conditions
- Family members or close friends may be asked about changes they see because dementia can interfere with recognizing one's own strengths and challenges
- Cognitive screening and memory tests are a common part of diagnosing dementia. These screening and assessment tools are used all over the world, but are not perfect
- Blood tests might be done to rule out other health conditions that can affect thinking
- A brain scan may be done but is not always required or practical

You can learn a lot from reading information on Alzheimer's disease, regardless of the kind of dementia.



TREATMENT OPTIONS

There is no cure for dementia at this time. Treatment focuses on helping the person with dementia, as well as aiding family members and other support networks.

EDUCATION

- Learning about dementia and the changes in the brain can be very helpful:
 - Written material (e.g. this booklet)
 - Websites (e.g. www.alzheimer.ca)
 - One-on-one education (e.g. from the Alzheimer's Society or CMHAFF)
 - Group sessions and presentations

HEALTHY LIFESTYLE

- Some ways to keep the mind and body as healthy as possible include:
 - Follow the Canada Food Guide
 - Walk, maybe with a friend
 - Do things you enjoy (e.g., music or games)
 - Participate in hobbies, sports and go to social events
 - Take care of spiritual health
 - Stop smoking
 - Sleep well

MEDICATIONS

- If there is another medical problem (e.g. depression), often it will be treated first
- Treating long-term medical problems (e.g. high blood pressure or diabetes) can help protect the brain from events like strokes
- Medication may help with some symptoms of dementia such as low mood, anxiety, hallucinations, aggression, agitation or sleep problems:
 - Antidepressants
 - Sleeping pills or sedatives
 - Anticonvulsants
 - Antipsychotics
- There are medications that may help with some cognitive symptoms or slow the progression of these symptoms. The treatment will depend on the type of dementia and symptoms:
 - Donepezil (Aricept®)
 - Rivastigmine (Exelon®)
 - Galantamine (Reminyl®)
 - Memantine (Ebixa®)
- All medications can have side effects, so it is important to discuss the risks and benefits with your health-care team
- It is important for someone to help supervise medications being taken as one of the changes dementia causes is not being able to organize (e.g. taking pills at the right time)

TIPS FOR A PERSON WITH DEMENTIA

ENVIRONMENT

Medication is not always needed. Caregivers may be given advice to reduce symptoms in other ways, such as:

- Changing the surroundings
- Giving support
- Talking or communicating in different ways
- Asking others to do certain tasks
- Optimizing the skills of the person with dementia

The Three “R” Technique

Reassure

that everything is ok or that they are safe

Redirect

to another activity or change the topic

Reminisce

about events or people they remember

- Get a good night’s sleep
- Pay attention to your surroundings
- Write things down
- Declutter
- Make a daily routine
- Use a daily diary
- Use a calendar
- Exercise each day
- See the doctor regularly
- Keep your mind active
- Socialize and enjoy the company of others
- Orient to time, place and people
- Repeat, repeat, repeat
- Use rhymes or tricks to remember things
- Use physical cues as reminders
- Use alarm clocks and timers
- Accept the help of others
- Stay involved in activities you enjoy



TIPS FOR CAREGIVERS

A person with dementia can be easily upset, as their brain no longer functions in an expected way. While it is normal to be frustrated, patience and asking for help go a long way. Here are some other tips:

- Do not ask, “Don’t you remember?”
- Provide a safe, simple and consistent environment
- Break tasks and language down into simple steps
- Provide a routine that includes exercise and activities that were enjoyed in the past
- Do not argue with the person
- Accept that you cannot change some of the person’s behaviour – we must change the surroundings or our approach
- Distract the person with other activities
- Reassure the person
- Allow the person to reminisce and tell stories they remember from long ago, even if you have heard it many times
- Practice patience

- Validate feelings
- Do not surprise the person
- Do not take the behaviour personally
- Pay attention to triggers – what happens before the behaviour? After? Can it be changed?
- Ask yourself if the solution will cause more problems
- Use good communication techniques:
 - Allow enough time to talk
 - Make good eye contact
 - Use visual cues
 - Use gestures together with words
 - Slow down
 - Repeat statements and questions
 - Use touch
 - Be aware of your body language
 - Give simple (two) choices only



It is not how much you do but how much love you put in the doing.

– Mother Theresa, missionary

SELF-CARE FOR CAREGIVERS

Caring for someone with dementia can be both rewarding and challenging. It is important for caregivers to look after their own health and take the time to participate in activities away from caregiving responsibilities.

- Regular exercise will help with stress
- Eating good food will help keep you healthy
- Getting enough sleep will help you feel well
- Give yourself permission to take time for yourself
- Ask for help when you need it
- Talk to a worker at CMHAFF Older Adults Program
- Join a caregiver support group (Alzheimer's Society)
- Learn about dementia
- Find out about the resources in your community that can help you and the person you care about

Some safety issues are important for everyone with dementia.

DRIVING

Driving is a complex activity. Most people with dementia will reach a time when it is no longer safe to drive. The health care providers will likely help you decide when it is time to stop driving and may be required by law to report to the Ministry of Transportation. The final say to suspend a driver's licence is made by the Registrar of Motor Vehicles. You may make your own decision to retire from driving before this step is reached.

- People with dementia are at increased risk for car accidents, even with a perfect driving record
- It may be necessary to test driving skills
- The time will come when it is no longer safe to drive
- It is important to prepare ahead for when you can no longer drive



GETTING LOST

Some people with dementia lose their sense of direction, wander and get lost. Practical things to consider:

- Wear bright coloured or reflective clothing
- Walk with someone
- Have identification with you
- Get an identification bracelet (e.g. *MedicAlert*® Safely Home at www.alzheimer.ca)
- Consider using location tracking technology (e.g. cell phones, GPS, etc.)
- Fill out the *Finding Your Way*® Identification Kit and keep it accessible (www.alzheimer.ca)
- Call the police as soon as possible

LIVING ALONE

Over time, persons with dementia who are living alone will need to have someone:

- Monitor medications
- Ensure meals are prepared and eaten
- Check that bills are paid
- Ensure personal care and hygiene are maintained
- Explore other safety risks

**At some point,
it is not safe to live alone.**



LEGAL QUESTIONS

A diagnosis of dementia can bring questions about your wishes and plans for the future. It is important to work on your plans early. A good place to start is with trusted family, friends or your lawyer.

SUBSTITUTE DECISION MAKER

- A substitute decision maker (SDM) is the person who will be able to make decisions for you if you are no longer able to do so
- If you do not legally choose an SDM there is a legal ranking of who will make decisions for you
- You can choose an SDM in a Power of Attorney and this person will be required to follow your known wishes, even if they are not in writing
- An SDM may be called on for a decision about where you live (e.g. long-term care) and what type of personal care you may have (e.g. clothes, hygiene, nutrition)
- To avoid misunderstandings, it is often best to talk about your wishes with your SDM, to put your wishes in writing, or tell your wishes to other people (e.g. family, friends, health care providers)

POWER OF ATTORNEY

- These are documents that let you choose someone you trust to make decisions regarding money and health matters. The legal documents that assign your *Continuing Power of Attorney for Property* and your *Power of Attorney for Personal Care* can be done by a lawyer or can be completed at home using the form provided by the Ministry of the Attorney General (www.attorneygeneral.jus.gov.on.ca)

ADVANCE CARE PLANNING

- These documents detail your wishes for the type of care you may want in the future (e.g. whether you would want to be on a breathing machine, to have CPR)
- Sometimes this is called *advance care directives* or making a living will
- There are many tools to help you plan (www.advancecareplanning.ca; www.dyingwithdignity.ca; www.speakupontario.ca)

WILL

- A will includes your plans for your money and belongings after your death. You can choose someone you trust to be your “*trustee*” or executor (the person who will carry out your wishes)

WHERE TO GET MORE INFORMATION

A NOTE ABOUT CAPACITY

The Ontario Health Care Consent Act identifies that a person is capable as follows:

“A person is capable with respect to a treatment, admission to or confining in a care facility or a personal assistance service if the person is able to understand the information that is relevant to making a decision about the treatment, admission, confining or personal assistance service, as the case may be, and able to appreciate the reasonably foreseeable consequences of a decision or lack of decision.” 2017, c. 25, Sched. 5, s.56.

In simpler terms, a person is capable of making their own decisions as long as they can understand the important information and can appreciate what is likely to happen if they make that choice.

The time to work on legal questions is now.

If left too late, it may not be possible to complete the necessary legal documents. The process then becomes much more complex and costly.

It can be very overwhelming when you or a loved one is diagnosed with dementia. You are not alone.

- The District Mental Health Services for Older Adults Program at CMHAFF – www.cmhaff.ca
- The Alzheimer’s Society – www.alzheimer.ca
- Your physician, primary care practitioner, Family Health Team, Health Access Centre and memory clinics
- *Finding Your Way*® Ontario – www.findingyourway.ca
- *MedicAlert*® Safely Home – www.alzheimer.ca
- Adult Day Programs and respite services
- Lawyers or legal representation
- Power of Attorney Kits: Service Ontario at 1-800-267-8097 or www.attorneygeneral.jus.gov.on.ca
- Advance Care Planning – www.advancecareplanning.ca; www.dyingwithdignity.ca; www.speakupontario.ca
- Home and Community Care Program
- Indigenous Cognition & Aging Awareness Research Exchange (I-CAARE) – www.i-caare.ca.
- Baycrest Centre For Geriatric Care – www.baycrest.org

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- Highway Traffic Act, Ontario Regulation 340/94/Drivers' Licences
- National Institute on Aging - www.nia.nih.gov/health/what-alzheimers-disease



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