

A Guide to Supporting Loved Ones With

# Dementia or Cognitive Change



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Based on the research of Jackie Pool<sup>1</sup> and Thomas Kitwood<sup>2</sup>

# Understanding Dementia or Cognitive Change

# What Is Dementia?

Dementia is a symptom or series of symptoms of an underlying illness that affects the person on a global level. It can cause impairments cognitively (the ability to think), mentally (the ability to manage emotions) and physically (affecting balance and bodily functions). Typically, dementia initially presents with very subtle symptoms that, left undiagnosed, evolve into long-term changes in a person's overall functioning ability. Dementia is not a specific disease. Instead, it is a series of symptoms that affect memory, personality, thinking, behaviour and a person's ability to complete the everyday activities of normal living.

There are many types and causes of dementia, with over 100 different variations and root causes; Alzheimer's Disease is the most well-known. Other types include Young Onset Dementia, Lewy Body Dementia and Vascular Dementia, to name a few. Every day, more than 350 people in Canada develop dementia. This is more than 15 every hour.<sup>1</sup>

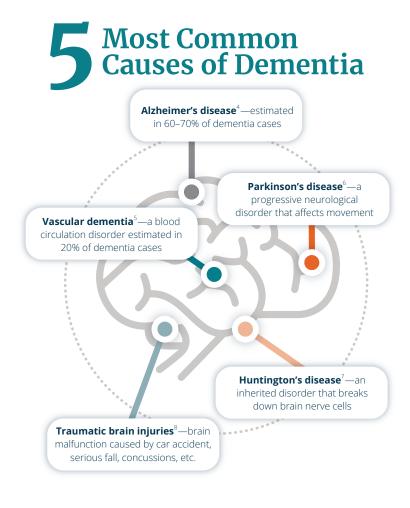
Symptoms of dementia, or cognitive change, can happen at any age, even in the very young. It can also be the result of other medical conditions such as stroke, acute or chronic infections, alcohol abuse, nutritional deficiencies and brain tumours, to name a few.

# **Normal Aging**

Aging is a normal process. How well we age depends on our genetics, lifestyles, overall health and risk factors. As we age, 40% of people will experience some form of memory loss after the age of 65 years<sup>2</sup>.

Memory loss alone is not an indication of dementia. If your memory loss does not affect your daily life or ability to complete tasks, you have no trouble remembering or learning new things, and there is no medical condition causing your memory problems, this is called "age-associated memory impairment." It is not dementia. Dementia is NOT normal aging. It is a cluster of symptoms resulting from other underlying medical conditions. According to the Alzheimer's Association<sup>3</sup>, at least two of the following core mental functions must be significantly impacted to be considered dementia:

- Memory
- 2 Communication and language
- Ability to focus and pay attention
- 4 Reasoning and judgment
- **5** Visual perception



<sup>1.</sup> https://www.carp.ca/2024/01/04/improving-cognitive-health/

<sup>2.</sup> https://alzheimer.ca/en/about-dementia/what-dementia/dementia-numbers-canada

<sup>3.</sup> Alzheimer's Association, What Is Dementia?, https://www.alz.org/

<sup>4,5,6,7,8.</sup> Alzheimer's Association, Types of Dementia, https://www.alz.org/alzheimers-dementia/what-is-dementia/types-of-dementia.

# 10 Warning Signs of Dementia

- Memory Changes that affect functional ability day-to-day
   Changes in diet, hygiene, cleanliness
- Difficulty doing familiar tasks
   Forgetfulness of recent events, changes in diet or eating habits
- Changes in language or communication
   Difficulty finding words or understanding
   a conversation (comprehension)
- Disorientation of time and place
   Not recognizing one's home or familiar places, loss of direction
- Impaired judgement
   Odd or inappropriate behaviours

- Problems with abstract thinking Problems navigating complex tasks
- Misplacing things
   Decline in planning and organization
- Changes in mood, personality, and behaviour Increased apathy, irritability, anxiety, confusion
- Loss of initiative
   Changes in interest, changes in hygiene
- Changes in understanding visual and spatial information
   Repeated falls or loss of balance and proprioception

You may have already witnessed these changes if you visit your loved one regularly. If these changes persist for an extended period or show up suddenly, it is essential to consult your loved one's family physician or a geriatrician as soon as possible. If you live far away from your loved one, it may be challenging to recognize and report a change in condition or behaviour. Professional caregivers, like those with Right at Home, are trained to recognize and report changes in the condition, behaviour, communication, and ability level of your loved one.

# **Diagnosing Dementia**

There is no specific test to diagnose dementia. In Canada, we have specialized memory clinics to support family healthcare providers in assessing and diagnosing changes in your loved one. A diagnosis of dementia typically requires a specialized healthcare team to complete assessments and lab and diagnostic tests to determine its presence and underlying cause. Family doctors are your first point of contact as they know your loved one's history and can help you determine if the noted changes may be caused may be caused by dementia. It is crucial to report all symptoms to your loved one's healthcare provider; this will allow for a more accurate diagnosis and, more importantly, a symptom-management plan to improve quality of life and overall safety. It is important to advocate for your loved one if you suspect dementia may be present, as it can affect someone as early as their 40s and 50s and therefore is often misdiagnosed by family physicians.

If your loved one does receive a dementia diagnosis, there are professional resources that can help your entire family navigate strategies to understand the different stages and the supports needed. Unlike traditional support programs, Right at Home's approach to dementia care and cognitive support is built on the belief that every person living with dementia or other cognitive changes has abilities to interact with their surroundings and to connect in new ways with their loved ones.



# Keys to Right at Home's Approach



### **Ability**

We create a care environment that empowers the client and their current abilities.



### **Personhood**

We incorporate the client's life history, routines and preferences into the Individualized Care Plan.



### Lifestyle

We collaborate with the client and family to set goals and create support activities in the areas of nutrition, socialization, wellness and awareness to minimize overall cognitive change.

# Is Dementia Preventable?

By controlling blood pressure, cholesterol and weight, it is possible for an individual to reduce the risks vascular dementia. However, preventing other dementias is a constant research goal, with many ongoing studies focused on identifying risk factors associated with dementia and determining how to treat some of the challenging behaviors and symptoms. Although there is no proven prevention for Alzheimer's disease and related dementias, in general, leading a healthy lifestyle may help address risk factors that have been associated with these diseases. (alzheimers.gov)

Know Your Risk Factors for Dementia			
High blood pressure	Heart disease	<ul> <li>Reduced social interaction (e.g., home alone, less contact with others)</li> </ul>	
Diabetes	<ul><li>Family history of dementia</li></ul>	Stress and depression	
Poor nutrition			

# Is Dementia Treatable or Curable?

Until the root causes of a person's symptoms of dementia are determined, it is not possible to implement a treatment plan. Remedies exist for dementia caused by metabolic and endocrine conditions such as hypothyroidism and nutritional conditions like vitamin B-12 deficiency. Studies suggest that it is possible to reverse symptoms of dementia caused by depression, adverse effects of drugs and substance abuse. While there are medications used to temporarily address a person's symptoms of dementia, there is no cure for Alzheimer's, Parkinson's and most other progressive dementias.

Researchers continue to feverishly study this widespread health crisis for possible answers and cures. Regardless of a person's symptoms or a formal dementia diagnosis, families and care providers can proactively address their loved one's symptoms and improve their quality of life by providing the right support.

# How Dementia Can Impact Families

# **Impact on Interactions**

Dementia and Mild Cognitive Impairment (MCI) impact how your loved one perceives and interacts with the world around them. This is the hardest part for families to understand and adapt to. Here are some examples of how the person affected by dementia may feel, based on the way they perceive the situation.

**Anxious -** You are feeling bored and restless at home, so you decide to go for a walk. But all the doors have been locked, and a stranger appears and tells you to sit down.

**Angry -** You are late picking up your children from school and are in a hurry. But, the person you are with will not let you go. OR You have loved ones and caregivers constantly monitoring you and feel under a microscope with no personal space.

**Vulnerable -** You open your door to a stranger who tells you it is time for you to take a bath.

**Frustrated** - You are trying to get dressed, but it seems someone has sewn up the sleeves on your shirt, removed some buttons from your jacket and hidden your shoes.

**Scared** - You are asleep in a chair in your home, when suddenly, you are awakened by a person you have never seen before who is trying to undress you.

**Confused** - You do not understand or remember where things are located or the order in how to do a task (dressing)

This is a small taste of what life can be like for someone affected by dementia.

In trying to help loved ones, we may accidentally cause fear, confusion, or frustration, which unintentionally brings out reactive behaviours. However, if we understand the effects the cognitive change has on our loved ones, we can limit these feelings and reactions.



# **Impact on Relationships**

Dementia can change a person's ability to communicate and interact with their surroundings. It can cause difficulty with...

### Communication

- Finding the right words
- Remembering names
- Staying on topic
- Coping with emotions
- Making inappropriate comments

# Recognition

- Recognizing faces
- Deciphering reality vs fiction or hallucinations
- Recognizing objects
- Recognizing or remembering family and friends

### Perception

- Seeing level changes like stairs and curbs
- Understanding anger or happy emotions
- Recognizing different textures
- Seeing at night
- Alterations in taste or smell

### Orientation

- Estimating distance
- Location awareness
- Seeing obstacles in one's path
- Disorientation in the home/ familiar environment
- Time and date awareness

These changes in ability CANNOT be controlled by the person affected by dementia and may lead to your loved one feeling upset, ashamed, frustrated or angry. This can cause them to withdraw and isolate themselves from others to self-control their environment. Establishing a predictable environment and a solid daily routine specific to your loved one's needs and interests is crucial to supporting their ability to function and be independent in their homes, thus lessening the frustration of adapting to constant change.

Our Right at Home professionals can assist you in creating an individualized Care Plan.

people have dementia worldwide. This number is expected to rise to 78 million in 2030 and 139 million in 2050.9

# Caring for a Loved One with Dementia

While each presentation of dementia or cognitive change is unique, there are techniques that can be used to enhance a person's quality of life. These techniques can also help families find new ways to connect with their loved one, despite cognitive change.



# Focus on Ability, Not Disability

As sons, daughters and spouses, it is incredibly challenging to watch the abilities of our loved ones decline because of dementia or cognitive change. Regardless of how advanced a person's dementia or cognitive change is, they still can interact with the people and environment around them. However, that interaction may be slightly different than families are used to and may require some adjustments or modifications.

Focusing on your loved one's abilities to complete daily activities and care activities, rather than compensating for their disabilities, honours their personhood and improves your loved one's confidence, engagement, emotional well-being, and physical well-being while potentially reducing your loved one's level of frustration, anger, apathy, and depression. This supports and empowers self-esteem and your loved one's ability to complete activities as independently as possible while giving family members ways to connect with their loved one as a family member rather than as a care provider.

**Emotional Physical** Confidence **Engagement Well-Being Well-Being** 

> **Frustration** Anger **Apathy Depression**

# **How Right at Home Defines Ability**

As your loved one's dementia or cognitive change progress, their ability to complete daily activities will likely change. Jackie Pool is an Occupational Therapist with more than 30 years of experience in dementia care, who partnered with Right at Home to complete our approach to dementia and cognitive support. Our program outlines four levels of ability for people living with cognitive change:



# **Planned Ability Level**

Able to plan activities and look for results, but may not be able to solve problems that arise



### **Sensory Ability Level**

Able to respond to sensory stimulation and complete single step activities, but may not have a conscious plan or the ability to create one.



### **Exploratory Ability Level**

Able to explore familiar activities and enjoy the experience of the activities, but may not look for a result from the activity



# Reflex Ability Level

Able to make reflex responses to direct sensory stimulation but may not be aware of their environment.

# 2 Pay Attention to Nutrition

Malnutrition can lead to many health problems, but a lot of people do not realize that poor nutrition can worsen symptoms of dementia or even make people appear less capable. Changes in taste, smell, perception of portion size or swallowing challenges may cause it.

Unlike diabetes or heart disease, people with cognitive change do not require a special diet. However, preventing malnutrition and undernutrition by helping loved ones with a balanced diet is important. According to the Government of Canada's Food Guide<sup>10</sup>, a balanced diet includes:



### **Vegetables & Fruits**

Broccoli, carrots, blueberries, strawberries, green and yellow bell peppers, apples, red cabbage, spinach, tomatoes, potatoes, squash and green peas



### **Protein**

Lean meat, chicken, variety of nuts and seeds, lentils, eggs, tofu, yogurt, fish, beans



### **Grains**

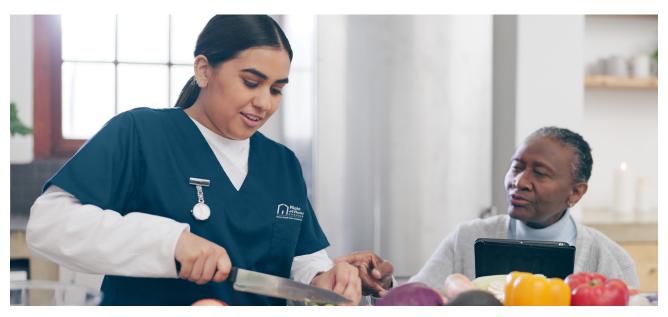
Whole grain bread, whole grain pasta, wild rice, red quinoa, brown rice

As you help your loved one with nutrition, remember that a "balanced" diet can mean different things for different people based on their preferences, cultural norms, or health conditions such as diabetes, hypertension, gluten intolerance or vegetarianism.

# **To Help Your Loved With Nutrition and Dining:**

- Limit distractions
- Keep a familiar place setting
- Prepare colorful foods

- Dine with your loved one
- use different solid-color plates, napkins and placemats



# **3** Help With Well-Being

People living with dementia or cognitive change often have challenges coping with their emotions. This often leads to stress, anxiety, anger or depression, which can increase symptoms of dementia.

# To Help Your Loved One Reduce Stress: Provide access to Encourage mobility fresh air Keep familiar photos and objects Support familiar sleeping and bathing routines

# 4 Support Their Perception and Safety

Cognitive change impacts your loved one's ability to function in their surroundings in ways they normally might. This means that stairs, rugs, clutter and lighting can cause new challenges for your loved one.

# To Help Your Loved One With Perception and Safety: Use contrasting, solid colors on walls, steps, beds, toilets and furniture Use night lights in bedrooms, hallways and bathrooms Remove items not necessary to the activity. Simplify the home, but maintain familiar organization and placement of items

# **5** Assist With Recognition and Orientation

Dementia and cognitive change impact your loved one's ability to recognize things in their environment, to make choices from a large set of information and to recall processes.

To Help Your Loved One With Recognition and Orientation:			
<ul> <li>Label objects, household rooms and dangerous items</li> </ul>	<ul><li>Present simple choices</li></ul>	<ul> <li>Remove items not necessary to the activity</li> </ul>	
Prompt the next steps in a process	•	<ul> <li>Use images or pictures to help recognize items, and remember foods, people and objects</li> </ul>	

# **6** Keep Communication Flowing

Often cognitive change causes communication challenges and relationship breakdowns in families. Because our identities are tied so closely to our relationships, cognitive change can lead to loss of self. Loss of self can result in isolation, depression and loneliness, which can worsen symptoms of dementia or cognitive change.

To Help Your Loved One Engage With the People Around Them and Communicate to the Best of Their Ability:			
<ul> <li>Touch their hand, arm or shoulder to gain attention</li> </ul>	<ul><li>Keep language simple</li></ul>	Make eye contact at eye level	
Use their name	<ul><li>Socialize in small, familiar groups or one-to-one</li></ul>		

You Can Also Help Your Loved One by Recognizing That Families Accidentally Create Barriers to Communication			
■ Impatience	<ul><li>Imposing our way  Multitasking  of doing things</li></ul>		
Guilt	Underestimating your loved one's ability		

# Managing and Supporting Responsive and Reactive Behaviours

A person affected by dementia sees and interprets what is going on around them differently due to a changes in perception and how the brain processes the information around them. Responsive and reactive behaviours can sometimes arise. The most common reason is an unmet need (example: hungry, thirsting, hot, cold, need the washroom). The person affected by dementia may use gestures, actions or words to respond to something negative or confusing to them in their social or physical environment. These changes can be upsetting for the person affected by dementia as well as their loved ones and those who support them.

## **Common Challenges**

- Aggression
- Agitation
- Wandering
- Restlessness

- Hallucinations
- Paranoia
- Making unexpected noises

# **Ensure the Health and Well-Being of Family Caregivers**

Caring for a loved one living with dementia is incredibly rewarding, but it can also be highly challenging. As you take on the additional role of family caregiver, it is important to maintain your mental and physical well-being and have awareness and strategies to perform when you feel overwhelmed and stressed.

To be the best loved one and family caregiver you can be, you should periodically evaluate your well-being and be prepared to ask for help when needed. Asking for help is not a sign of weakness but a sign of strength to maintain healthy relationships. It is important to ask for help, accept it when it is offered, and realize you don't have to do it alone.

Help can be temporary, such as respite support when you need a break or professional dementia care provided in the home by a specially trained professional caregiver.

As you care for your loved one, remember to take care of yourself by doing the following:

# **Maintain Your Relationships**

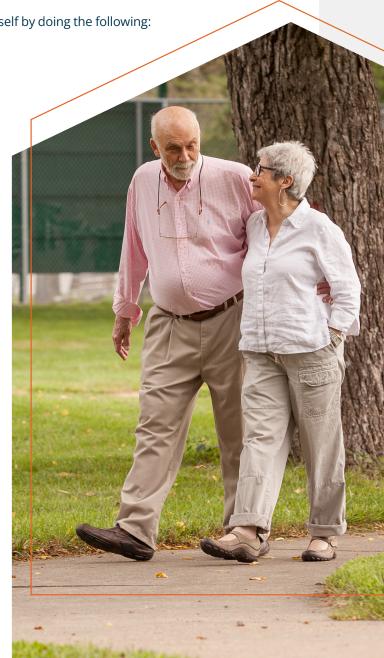
- Identify your internal support network, like friends and family members, that can help you through caring for your loved one.
- Identify your external support system, like a home care agency with bonded/insured caregivers, that can provide respite or professional in-home care when needed.

# **Self-Care And Emotional Well-Being**

- Make time for other friends and family members.
- Learn new ways to connect with your loved one.
- Make time to relax.
- Identify ways to relieve stress and stay healthy.
- Let go of guilt and address feelings of ambiguous loss and grief.
- Exercise when you can.

### **Establish A Routine**

- Give yourself permission to say yes.
- Give yourself permission to say no.
- Accept help when offered or seek it out if/when needed.
- Consider getting help to provide you with regular respite time to re-energize and re-focus.
- Have a support plan in place should you become suddenly ill or hospitalized.



# **How Right at Home Can Help**

Once you determine you need outside help, whether temporary respite assistance or a plan for ongoing support, Right at Home can assess the needs of your family and your loved one to create an individualized plan of care to fit the unique circumstances of your family. We offer caregiving services for almost any family in practically any situation, and we are trained to recognize changes in your loved one's individual behavior. We're committed to providing the care that's right for your loved one and giving you the peace of mind you deserve.



# **Develop a Custom Care Care**

When you call us, we'll ask questions to form a basic needs assessment and then set up an in-home visit. After our initial meeting, we will create a Custom Care Plan tailored to your loved one's specific needs and make detailed recommendations on services. Before implementing, we will review the Plan of care with you in detail, modifying it as you and your loved one see fit.



# **Caregiver Matching**

Once you approve the Care Plan, we match your loved one with the most appropriate caregiver possible by considering numerous factors: services needed, interests, and the personalities of both caregiver and client. Of course, if you ever have any concerns about a specific caregiver, we can promptly arrange a replacement.



## **Quality Care**

Every Right at Home Professional caregiver undergoes an extensive interview process, including background and reference checks. Professional Caregivers are trained and bonded/insured before ever caring for a client. Then, local Care Coordinators & Care Managers visit your loved one's home periodically to ensure things are going well and that caregivers follow the specifics of their Care Plan. They also assist in updating or adjusting as conditions change and evolve.



### **Dementia Care**

Right at Home's Approach to Dementia & Cognitive Support is recognized by the Alzheimer's Association® for incorporating the evidence-based Dementia Care Practice Recommendations in the following topic areas: Alzheimer's and dementia, person-centred care, assessment and care planning, activities of daily living, and behaviours and communication.



# Questions to Ask When Hiring a Caregiver

If you decide on home care, there are several questions you should ask the home care agency to ensure your loved one remains safe, healthy and happy:

Finding the Right Person	Right at Home C A N A D A • Home Health Care & Assistance	Other Home Care Providers
Are my caregivers trained and knowledgeable in working with people with Dementia?	Yes	Maybe
If I don't get along with my caregiver what can I do? Can I choose my caregiver?	Yes	Maybe
Are the caregivers understanding of how Dementia affects a person?	Yes	Maybe

Liability	Right at Home C A N A D A • Home Health Care & Assistance	Other Home Care Providers
Are the Caregivers Bonded / Insured	Yes	Maybe
Are background checks / police checks conducted on your staff?	Yes	Maybe
Is there a Care Manager who oversees the caregivers?	Yes	Maybe

Quality of Care	Right at Home C A N A D A Home Health Care & Assistance	Other Home Care Providers
Can my caregivers help with personal hygiene needs?	Yes	Maybe
Are the caregivers good communicators, patient, honest, reliable?	Yes	Maybe
How are the caregivers trained and supervised to ensure good quality care?	Yes	Maybe
What types of support and caregivers are out there for families and persons affected by Dementia?	Yes	Maybe
If a problem arises, can you help me address it?	Yes	Maybe

A trusted, professional, global home care agency, like Right at Home, positively addresses and manages each of these questions so you have peace of mind knowing your loved one is safe, secure and well cared for.





Call us for a free, no commitment assessment and to meet your community Care Planner.

1.855.983.4663 www.rightathomecanada.com



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