

An Introduction to Dementia

*Helping you
chart a course*



Elizabeth Rhynold, MD
Kathi Hurley, RN BN MN
Cindy Hobbs, MD

An
Introduction
to **Dementia**

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This is a Canadian resource about dementia. The following email address is ONLY for comments about this booklet. It is not for patient-specific questions. You will not receive a response from a health-care professional.

Email: dementiacompass@HorizonNB.ca

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Dedicated to all the people
we have met whose lives
have been touched by dementia.
It has been our privilege to learn with you.



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Introduction

*“We never find answers
to the questions
we don’t ask.”*

By reading and asking questions you are already making an important effort to understand dementia. We hope this “Introduction to Dementia” is helpful and points you in the direction of other information.

We have labeled the questions we are most frequently asked: Frequently Asked Questions:

FAQ

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“What is dementia?” **FAQ**

Dementia is a word used to describe brain diseases that make thinking more difficult over time. These changes in thinking are only called dementia when they start to affect a person’s ability to do things or function.

Sometimes other terms are used instead of the word “dementia”:

- Memory problems, senility, major neurocognitive disorder, organic brain syndrome
- Sometimes the name of the brain disease is used instead of the word dementia (such as Binswanger’s or Pick’s Disease)

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Ways dementia can change thinking

No two people with dementia will have the exact same combination of changes in thinking. Here are some of the ways dementia can affect thinking:

• **Memory**

There are at least two main kinds of memory:

Short-term memory holds the information from the last few minutes or days. This is the kind of memory that is most often affected by dementia. Problems with short-term memory can make a person repeat questions or stories and misplace things.

Long-term memory is the ability to remember things from many years ago. People with dementia often have a relatively good long-term memory.

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• **Language**

Three aspects of language can be affected by dementia:

1. **Comprehension** is the ability to understand what is being said or read.
2. **Speech** is the ability to find the right words, to finish sentences and say thoughts out loud.
3. **Writing** is another important part of language.

Changes in the ability to communicate will vary depending on the effect the dementia has on each aspect of language.

• **Recognition**

People with dementia sometimes develop problems recognizing people they know or mistake people for someone else. This is not because of a problem with vision;

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instead, the brain has difficulty recognizing faces.

• **Sense of Direction**

Sometimes people with dementia can lose their sense of direction. This can happen when driving, when out on a walk or even in the house.

• **Organization**

Organizing is very important for doing tasks that have multiple steps or doing multiple things at one time (multi-tasking). Organization is an aspect of thinking that is frequently affected by dementia.

• **Motivation**

Often people with dementia have less drive or initiative. This is because motivation is an important area of thinking.

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Ways dementia can change function

Everyone has strengths and weaknesses. For example: some people find math easy but could never cook a meal for 16 people and have everything ready at the right time.

As dementia comes on gradually, it is often difficult to pinpoint the moment when dementia begins making it difficult to do things. When looking for changes in function it helps to think of how easy or difficult it was to do things two to five years ago.

Some of the things that can become more difficult early in dementia include:

- Remembering recent conversations and instructions (even when events from the distant past are easy to remember).
- Learning to use new appliances and gadgets.
- Sorting papers into piles to pay bills or taxes.

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- Driving to unfamiliar places.
- Remembering old recipes that were second nature.
- Doing jobs or hobbies that require a lot of exact measurements and concentration such as wood-working and sewing.
- Cleaning the whole house.
- Following and taking part in conversations with a group of people.
- Organizing a large number of medications.

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Causes of Dementia

“Aren’t memory problems just a normal part of getting old?”

FAQ

- Older adults may take slightly longer to remember facts and details. Memory problems that make people repetitive or make it difficult to get day-to-day things done are not a normal part of aging.

“What is the difference between dementia and Alzheimer’s disease?”

FAQ

- Dementia is a term used to describe changes in thinking that make it more difficult to get things done.
- There are many different causes of dementia.

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- Alzheimer’s disease is the most common type of dementia.

Below is a brief description of a few different causes of dementia. Not every person diagnosed with a specific brain disease will have the same combination of symptoms. Please talk to your health-care team if you have more questions about a specific kind of dementia.

Alzheimer’s disease

- Alzheimer’s disease usually gets worse gradually.
- Early on, the most common changes are in short-term memory. This can make people repeat themselves and misplace things in the house.
- Often people with Alzheimer’s disease are not aware of the changes that are happening to their thinking.

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Lewy body dementia

- Organization and concentration are often affected early on, more than memory.
- People with Lewy body dementia are more likely to have good days and bad days.
- In addition to thinking problems, people with Lewy body dementia often have some symptoms common to Parkinson’s disease including stiffness, slowing of movements and poor balance.
- Seeing things that others can’t see, such as people or animals (visual hallucinations), is common early on in Lewy body dementia.

Parkinson’s dementia

- Years after Parkinson’s disease is diagnosed, people can start having symptoms very similar to Lewy body dementia.

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Vascular dementia

- Following strokes people can have changes in their thinking. Some people have never had a noticeable stroke but changes to the blood vessels and blood supply to the brain gradually cause changes in thinking. These conditions are called vascular dementia.
- Motivation and personality changes are very common early on in vascular dementia.
- Balance and walking can also be affected early on.
- Vascular dementia is less predictable than Alzheimer’s disease because future strokes or poor blood flow to areas of the brain will cause thinking to get worse. There may also be periods of time when thinking stays relatively unchanged.

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Mixed dementia

- Any dementia that is caused by multiple brain diseases is called mixed dementia.
- If an autopsy of the brain is done following the death of people with dementia it is extremely common to find the changes of Alzheimer’s disease and vascular disease together.

Frontotemporal dementia

- This form of dementia is rarer and can often be difficult to diagnose. Symptoms can overlap with other dementias. Some of the more common changes include:
 - Dramatic changes in personality, including extreme anger, uncontrolled eating and loss of social graces are often more obvious than changes in memory.
 - The ability to organize and get work done is often a problem early on.

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- Some kinds of frontotemporal dementia affect speech.

Other

- There are many other kinds of dementia including Creutzfeldt-Jakob disease, normal pressure hydrocephalus (NPH), Huntington’s disease and AIDS dementia.
- Each of these brain diseases has a different combination of symptoms.

Often reading material and classes about dementia are designed for patients with “Alzheimer’s Disease”. You can still learn a lot from this information regardless of the kind of dementia.

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Diagnosing dementia

There is no blood test or brain scan that can diagnose dementia. This is especially true early on, when the changes are subtle and function is still close to normal.

How does your health-care team determine if there is dementia?

- The first step in diagnosing dementia involves lots of questions about what you are experiencing. Questions will likely include what you find difficult and how long this has been a problem. Your health-care team will likely review your medications and other health problems. They may also do a physical exam.

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- Often a family member or close friend will be asked to comment on any noticeable changes. This is not because your health-care team does not trust you. One of the changes that often occurs in dementia is the inability to recognize one’s own strengths and weaknesses. This is often called “lack of insight”.
- “Memory testing” is commonly a part of diagnosing dementia. One of the most common tests is the Mini Mental State Exam or “Mini Mental” which is a set of test questions that is scored out of 30. It is used all over the world and helps health-care providers get a snapshot of how good the memory is. This is not a perfect test. People who cannot read or cannot write may have problems with this test, while this test may be too simple for people with high education levels. The “Mini Mental” does not diagnose dementia. Other

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information is required to make a diagnosis of dementia.

- Sometimes blood tests are ordered to look for medical illnesses or nutritional problems that can impact thinking.
- Some people will get a CT scan or MRI of their brains. This is not required for the diagnosis of dementia. The decision to do a scan is between you and your health-care team.

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Treatment options in dementia

The treatment of dementia involves helping the whole person including the family and support systems when appropriate.

Education:

People diagnosed with dementia often benefit from learning more about the changes happening in the brain. Family and people supporting someone with dementia will also benefit from learning more about dementia. Forms of education include:

- Written material such as this booklet.
- Websites such as www.alzheimer.ca.

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- One-on-one education from a local Alzheimer Society office.
- Group sessions such as education classes and support groups available in many communities.

Healthy lifestyle:

There are many different parts of a healthy lifestyle. Here we outline some ways to keep the mind and body as healthy as possible.

- The Canada Food Guide outlines healthy eating choices.
- Walking is a safe and effective way to stay active. It may be important to walk with a buddy.
- It is important to continue recreational activities including hobbies, sports and social events which are enjoyable and keep your connection with the community.

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- Spiritual health can include knowing self, interacting with others, responding to nature and a relationship with God. Spiritual health may remain or become important for people with dementia.

Medications:

- If another medical problem is found, such as low thyroid function or depression, it is often treated first.
- Some people have long-term medical problems such as high blood pressure and diabetes. Treatment of these conditions can help to protect the brain from future damage from strokes.
- There are several medications available to treat the symptoms of dementia specifically. These are not a cure. Instead, the medications are used to slow down the decline in thinking and help maintain independence. As there are side

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effects to ALL medications, it is important to discuss the risks and benefits with your health-care team.

- Most of the time it is important for someone to help supervise the medications being taken to ensure they are being taken correctly. This is not because of lack of trust. It is often difficult to organize pills and take them at the correct time.

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Safety issues in dementia

A few key safety issues are important for everyone with dementia. These may not be an issue right now but may be in the future.

Driving

Driving is one of the most complicated activities we do during the day but we take it for granted!

- Even with a perfect driving record people with dementia are at eight times the risk of a car accident in the next year.
- In mild dementia, the risk of a serious car accident is 50 per cent higher within two years of diagnosis.

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At some time after being diagnosed with dementia it may be necessary to start formally testing driving every six months. There will come a time when it is no longer safe to drive. It is important to prepare for this ahead of time. **If you have concerns about driving please talk to your health-care team.**

Getting lost

Some people with dementia lose their sense of direction. This can lead them to go into other people’s houses. Other times people can’t get back from familiar places, such as a walk to the corner store. In order to decrease the risks of getting lost, there are some practical things that can be done:

- Wear bright colored clothing and a reflective vest.
- Go walking in pairs.

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- If a person with dementia could be lost - “minutes count”! Do not delay, call the police immediately to help with the search.

Supervision

If a person with mild dementia is living alone, it is important to have someone:

- monitor medications
- ensure meals are being prepared and eaten
- check that bills are being paid

Introducing this help early can make it easier to increase supervision with time.

At some point during the course of dementia it will not be safe to live alone. This is the case if you worry about what would happen during an emergency, such as a fire (would “911” be remembered?).

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Powers of attorney, advanced care directives and wills

Where do I start? **FAQ**

Your lawyer can help you lay out your wishes and plans for the future in the following important documents:

- **Enduring powers of attorney** – These are documents in which you give trusted individuals the power to make decisions regarding financial and medical matters for you when it becomes necessary.
- **Advanced care directives** – This document spells out your wishes for your future health care.
- **Will** – A will outlines your plans for your money and belongings after your death.

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When is the right time to see the lawyer? **FAQ**

Now!

What happens if I leave it too late? **FAQ**

Your lawyer has to be certain these documents are fully understood. If the dementia has become too severe and has affected thinking, it may not be possible to complete these documents. If these documents are not completed, the process is much more complicated and expensive.

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How dementia changes over time (stages)

The effects of dementia on the brain gradually change over time. These changes are often grouped into stages based on the amount of help a person with dementia requires on a daily basis.

Mild Cognitive Impairment (MCI)

Some people have changes in their thinking that make them take longer to complete tasks. Some people may not do as well as expected on memory testing. At this point these difficulties may not be considered dementia.

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Early stage dementia (Mild)

Early on in dementia a person may be able to do most things independently but some assistance is required. The earliest things to become more difficult include:

- organizing financial forms to pay bills and do taxes
- cooking meals from scratch
- driving the car to unfamiliar places
- taking multiple medications without reminders.

When a person starts needing help with some activities but is independent with everything else they are in the mild stages of dementia.

Middle stage dementia (Moderate)

With time, people with dementia begin to rely on others to do the shopping, cleaning, cooking, driving and banking. Around this

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time they may also start to need reminders or instructions for bathing, eating and going to the toilet. This is called moderate dementia.

Late stage dementia (Severe)

As we currently don't have a cure, people with dementia will eventually need hands-on help to get out of bed, bathe, dress and eat. This is often a time when it becomes difficult to get any words out and control the bowel and bladder. Swallowing without choking can also become a challenge. At this time the dementia is considered severe or late stage.

Information about later stages of dementia

The authors of this booklet have written two other booklets about dementia:

- The Dementia Compass
- Later in the Dementia Journey

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When to ask for help

It is never too early to ask for help! Your questions and concerns will change over time so it helps to always have a pad of paper ready when a concern comes to mind. It is important to talk to someone when any of the following changes or questions occur:

- Personality changes including getting angry or irritated with people trying to help.
- Seeing things other people can't see or being suspicious that people are stealing things or trying to break in.

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- Not sleeping or finding yourself thinking you wish you were not alive anymore.
- Problems with balance and falls.
- Worries about money, including: who will look after finances down the road; is there funding available to get help at home; how much will it cost if a move out of the house is necessary.

Who can help? FAQ

There are many people in the community helping people with dementia. Often your health-care team can point you in the right direction.

- Social workers have experience dealing with both the financial and the emotional sides of dementia.

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- Access to funding for help at home and beds in residential facilities (private care homes, special care homes and nursing homes) varies in each province. Again, social workers know how to access these services.
- The Alzheimer Society of Canada has offices in many communities. They are also available over the internet and by telephone (most provinces have a toll-free number). The Alzheimer Society of Canada helps people with ALL KINDS OF DEMENTIA!

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Where to get more information

Face-to-face advice can provide important information and support in difficult situations. Many communities have active support groups including:

The Alzheimer's Society

- Anyone with questions about dementia can contact the local Alzheimer's Society branch. **"It's not just for Alzheimer's Disease!"**

Caregiver support groups

- Ask a local social worker or check on bulletin boards at your local hospital.

Don't be afraid to reach out to your own family doctor, friends and family for help.

There are many online and written sources of information. We highly recommend these:

The Alzheimer's Society of Canada

- www.alzheimer.ca

Dementia Basics™ Online e-learning resource

- www.AlzheimerCalgary.com

Lewy Body Dementia Association

- www.lbda.org

The Association for Frontotemporal Degeneration

- www.theaftd.org/about

YouTube Inside the Brain: Unraveling the Mystery of Alzheimer's Disease

- www.youtube.com/watch?v=NjgBnx1jVIU

A Caregiver's Guide to Lewy Body Dementia

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National Institute on Aging: Caring for a Person with Alzheimer's Disease

- www.nia.nih.gov/Alzheimers/Publication

Alzheimer's Activities That Stimulate the Mind.

- Bazan-Salazar. McGraw-Hill.

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Other resources used in the preparation of
this booklet include:

Manuals, books and articles:

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- **The Driving and Dementia Toolkit. 3rd Edition.** Regional Geriatric Program of Eastern Ontario. 2009.
- **Getting to Know Dementia. A Patient's guide to Diagnosis, Treatment and Care.** University of British Columbia. 2010.

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Websites:

- www.rnao.ca
- Canada food guide:
<https://food-guide.canada.ca/en/>
- www.alzstore.com
- www.thiscaringhome.org
- www.thehartford.com/resources/mature-market-excellence/dementia-driving
- www.spiritualcare.ca



If you have noticed gradual changes in memory and thinking, it may be helpful to read about dementia. As time goes by you will likely have new questions. The Dementia Trilogy is a set of three booklets about dementia.



An Introduction to Dementia lists the earliest signs of dementia. It helps answer some of the more common questions like, “What is the difference between dementia and Alzheimer’s disease?”



The Dementia Compass offers some tips to help a person with dementia with their day-to-day activities. It also describes some personality changes that can be symptoms of dementia.



Later in the Dementia Journey provides helpful yet sensitive information to help focus on comfort in the later stages of dementia.

*Feedback about The Dementia Trilogy—
“Most noteworthy is the manner in which they were written: in simple language made easy to understand... the information provided has given us the power we need to face the future together.” Marie C.*