

I read
all the available books
by other [people with]
Alzheimer's disease—
but they never had
quite the same problems
as each other, or as me.
It's not like other diseases,
where there is a standard
set of symptoms.
At least in the early stages
it seems to be as Individual
as the [person] themselves.

—C. Boden*

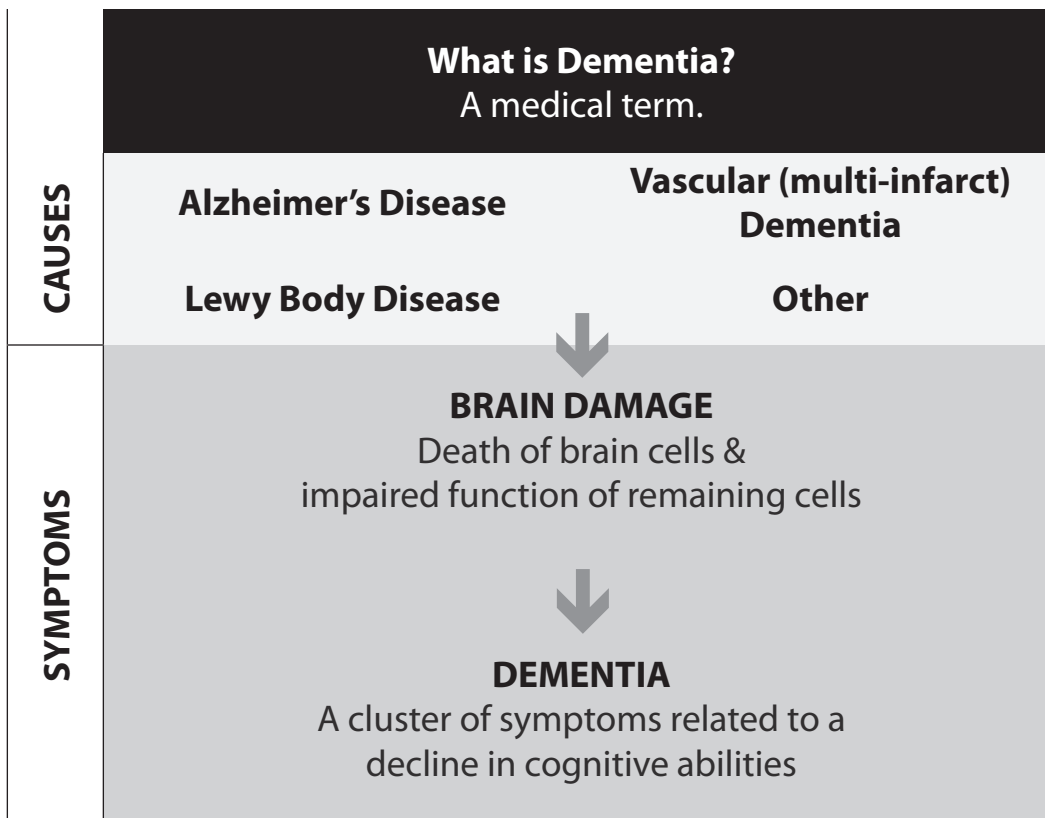
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THE BRAIN AND DEMENTIA

In this section, you will learn about:

- the definition of dementia
- the most common illnesses that cause dementia
- why diagnosis is important
- the parts of the brain and what happens as a result of illnesses that cause dementia
- what is not changed by dementia



Dementia is an umbrella term. There are numerous causes of brain damage that result in symptoms which are collectively known as dementia. The causes are given a name (diagnosis) when the symptoms follow a known pattern. Alzheimer's disease is the most common cause of dementia.

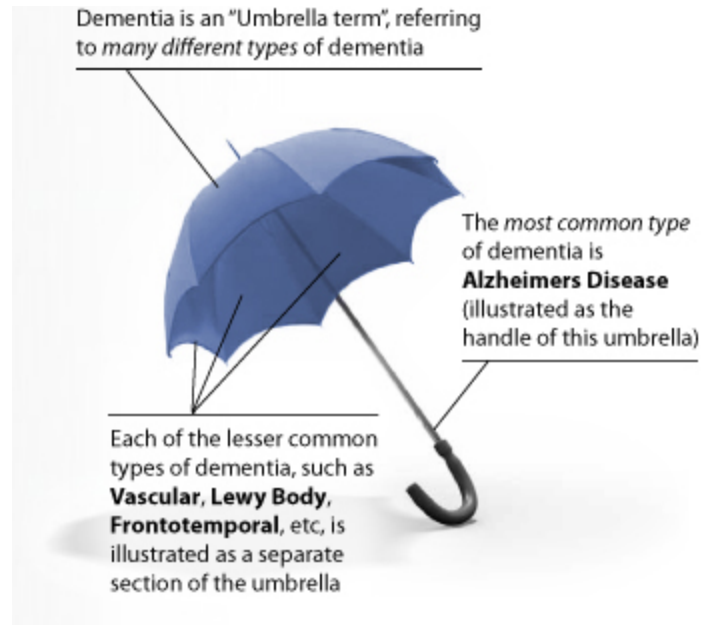


image courtesy of www.dementiajourney.ca

SYMPTOMS AND DIAGNOSIS

Your physician may have reviewed the details of your illness with you, but it is not always possible to give a precise diagnosis or reason why you have developed the symptoms of dementia.

ILLNESSES THAT CAUSE DEMENTIA

The following pages list some of the major causes of dementia. You may wish to read only the sections that apply to your diagnosis.

- Alzheimer's disease page 10
- Vascular dementia page 11
- Lewy Body Dementia page 11
- Frontotemporal Dementia page 12

Alzheimer's Disease

Alzheimer's disease is the most common cause of irreversible dementia. There are ten warning signs or symptoms:

1. memory loss that affects day-to-day function
2. difficulty performing familiar tasks
3. problems with language
4. disorientation of time and place
5. poor or decreased judgment
6. problems with abstract thinking
7. misplacing things
8. changes in mood and behavior
9. changes in personality
10. loss of initiative

Who gets Alzheimer's Disease?

Alzheimer's disease primarily affects those who are 65 and older, but it can affect people as young as 30. While both men and women are affected by it, two thirds of those who are 65 or older with the disease are women.

There is currently no single test that can tell if a person has Alzheimer's disease. Until there is a conclusive test, doctors may continue to use the phrase "probable Alzheimer's disease". However, be aware that doctors making this diagnosis are accurate 80 to 90 percent of the time.

Making the diagnosis can take time. It can be made in a family doctor's office, a memory clinic, or a hospital. The doctor may or may not want the person to see a number of health care professionals to help make the diagnosis. These professionals may include a psychologist, psychiatrist, neurologist, geriatrician, nurse, social worker, or an occupational therapist. These health care professionals will look for problems with the person's memory, reasoning ability, language and judgment, and how they affect day-to-day function.

Is there treatment?

Although there is no cure for Alzheimer's disease, there are treatments that may help alleviate some of the symptoms. You should discuss these options with your doctor.

Vascular Dementia

Vascular Dementia is the result of either single or multiple strokes. A stroke is defined as a loss of blood flow that causes brain damage. Vascular dementia usually has a sudden onset and immediately follows a stroke. Vascular dementia may follow a stepwise progression—functioning can deteriorate, stabilize for a time, and then deteriorate again. The symptoms vary, depending on which areas of the brain are affected (e.g. language, vision or memory, etc).

Who gets Vascular Dementia?

Vascular dementia is the second leading cause of dementia, affecting both men and women. Vascular dementia often co-exists with Alzheimer's disease; this condition is called "mixed dementia".

Is there treatment?

There is no cure for Vascular dementia. However, after a person has a stroke, medication may be prescribed to improve blood flow to the brain to reduce the risk of further strokes. A person may also benefit from different therapies to help with movement and speech, such as physiotherapy, occupational therapy, or speech therapy.

Lewy Body Dementia

Lewy Body Dementia is a form of progressive dementia identified by abnormal structures in brain cells called "Lewy bodies". The mechanism that leads to the formation of Lewy bodies is unknown.

In Lewy Body Dementia, there is a progressive loss of memory, language, reasoning, and other higher mental functions such as the ability to do calculations. The person may have difficulty with short-term memory, finding the right word, and sustaining a train of thought. An individual may also experience depression and anxiety. Visual hallucinations (seeing things which are not real) are common and can be worse during times of increased confusion. People with the disease may also make errors in perception (e.g. seeing faces in a carpet pattern).

Some features of Lewy Body Dementia can resemble Parkinson's Disease. These include rigidity (stiffness of muscles), tremors (shaking), stooped posture, and slow shuffling movements.

Who gets Lewy Body Dementia?

Lewy Body Dementia is more common in men than in women.

Is there treatment?

At present, there is no cure for Lewy Body Dementia. It is possible to treat some of the symptoms, such as depression and unpleasant hallucinations, with medication. Parkinson symptoms can also be treated. However, due to the multiple features of Lewy Body Dementia with Parkinson symptoms, treatment is often individualized, focusing on treating the symptoms in order of severity to avoid or prevent over-medication.

Frontotemporal Dementia (e.g. Pick's Disease)

Unlike Alzheimer's disease, which generally affects most areas of the brain, Frontotemporal Dementia is a progressive dementia that affects two specific areas of the brain—the frontal and temporal lobes. In some cases, brain cells in these areas can shrink or die. In other cases, brain cells get larger and contain round, silver "Pick's bodies." Thus, this type of Frontotemporal Dementia is called Pick's Disease.

Other examples of Frontotemporal Dementia include:

- Frontal Lobe Dementia
- Primary Progressive Aphasia
- Corticobasal Degeneration

In each situation, brain changes affect the person's daily functioning. Early symptoms often affect either behaviour or language (speech) or both.

In the early stage of Frontotemporal Dementia, behaviour changes or problems with language (speech) can appear separately. As the disease progresses, these two areas will overlap. Unlike with Alzheimer's disease, a person with Frontotemporal Dementia often remains oriented to time and has preserved memory in the early stages. In the later stages of the disease, general

symptoms of dementia arise, such as confusion and forgetfulness. Motor skills are lost and swallowing difficulties occur.

Who gets Frontotemporal Dementia?

Frontotemporal Dementia can affect both men and women. Although it can arise any time during adult life, individuals between 50 and 60 are most affected.

Is there treatment?

Presently, there is no known cure for Frontotemporal Dementia and its progression cannot be slowed down. The average course of the disease is 7-8 years.

MEDICATIONS

Although there is no cure for dementia, there are some medications that can help manage your symptoms. These medications called are “cholinesterase inhibitors” and there are three of them:

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

These medications work by increasing the amount of acetylcholine, a chemical in the brain that helps with memory and learning.

There is another medication called memantine (Ebixa®) that can be prescribed to people in the moderate or late stages of dementia. Memantine works on completely different chemicals in the brain. However, this medication is not covered by Pharmacare. If you have questions as your dementia progresses, talk to your doctor or pharmacist to find out whether this medication is an option for you.

If you are taking, or considering taking, one of these medicines, there are some points you should keep in mind.

- *Have Realistic Expectations.* These pills are not a cure. The medicines slow the progression of the disease, but the disease will continue to progress and eventually your condition will worsen.
- *They Do Not Always Work.* Some people do see an improvement in their functioning when

taking one of these medicines. That is why doctors prescribe them. However, this is not true for everyone. Some people actually get worse despite taking these medications while others see no change.

Watch Out for Side Effects.

- slowing of your heart rate (bradycardia) - which can cause you to feel sluggish or want to sleep all the time. Your family doctor will be keeping an eye on your heart rate, so be sure to see him/her regularly.
- stomach upset – if you are feeling queasy (especially if you are taking Aricept™ or Exelon™) that usually will go away on its own 2 to 4 weeks after starting the medications. However, if you have severe nausea or diarrhea or are too sick to eat you should contact your doctor as you may need to be switched to another medication.
- nightmares – although not a side effect that might be of great concern to some, nightmares can really reduce the quality of your sleep and hence your life. If you are on a once a day pill and are having nightmares, talk to your doctor or pharmacist about taking it in the morning and if taking it twice a day, take the second pill no later than 4 or 6 pm.

COMPLEMENTARY / HERBAL / NATURAL SUPPLEMENTS

Today many people are interested in complementary medicine and are looking for other things they can do to improve their health. Sometimes people think that if a supplement is herbal or natural that means it is safe. However, some natural substances are not safe (for example poison ivy or arsenic!). Other natural substances might be safe on their own, however, they can interact with your prescription medications. For example, St. John's Wort interacts with a LOT of medications making them leave your body faster than usual. So be sure to tell your doctor and pharmacist all the medications and supplements you are taking including:

- herbal/natural supplements
- vitamins/mineral supplements
- over the counter medications (like sleeping pills, Gravol®, cold/flu medication, etc.)

If you want to try an alternative treatment ask your doctor or pharmacist:

- 1) Will this interfere with any of my medications?
 - > If yes, then you should discuss why you want to take it more thoroughly with your health care provider. They may be able to suggest something else that will not interact.
 - > If no, then ask the next question
- 2) Is this safe?
 - > If the answer is yes, then you can feel comfortable trying it.

WHY IS DIAGNOSIS IMPORTANT?

Although diagnosis can be difficult, there are six reasons why it is important to know the cause of your symptoms of dementia:

1. People often feel a sense of relief when they get a proper explanation of what is happening to them and why.
2. The types of medications that are right for you may depend on the type of illness causing your dementia.
3. You will want to know what kinds of plans you should make for your future and for the people you care about.
4. Some of your symptoms may be treatable. For instance, you can get treated for depression even if you have an illness that is causing depression.
5. You may want to consider lifestyle strategies to maximize your health and wellness.
6. You may want to explain what is happening to you to the important people in your life.

Have you asked your physician to tell you what they believe is causing your dementia?

It can often be hard to remember what we are told by a doctor. When you ask this question or when you go to your next appointment, you might want to bring this workbook with you and write down what your physician says is causing your dementia:

My Dementia is caused by:

THE BRAIN

It is important for you to realize that the effects or symptoms you experience as dementia are caused by physiological changes in the brain. The changes in the brain's structure and chemistry will not happen all at once. They will happen over time and at different rates for each person.

You will have good days and bad days.

The symptoms you experience will depend on which parts of your brain are affected. As different parts of the brain are impacted, you may notice specific symptoms or changes in behaviour.

By knowing which areas of the brain are affected and what symptoms to expect, you can make the necessary adjustments to your lifestyle, taking into account your changing needs. By doing so, you will be able to continue with your daily routine.

Some people want to know more about the brain changes. Others do not.

If you **want to know more**, read on. If **not**, stop here and proceed to Section 2.

THE BRAIN CHANGES: WHAT IS HAPPENING TO ME?

Many of the symptoms you are experiencing are due to the changes in your brain which can affect mental and physical abilities including moods, emotions and behaviours. However, despite the limitations you may experience because of these changes, it is important to focus on what you can do, even in the face of shifting abilities.

The brain is the most complex part of the human body. This three-pound organ is the seat of intelligence, interpreter of the senses, initiator of body movement, and controller of behaviour. The brain is like a committee of experts. All the parts of the brain work together to complete even the simplest of tasks, but each part has its own special properties.

The brain is divided into three main areas:

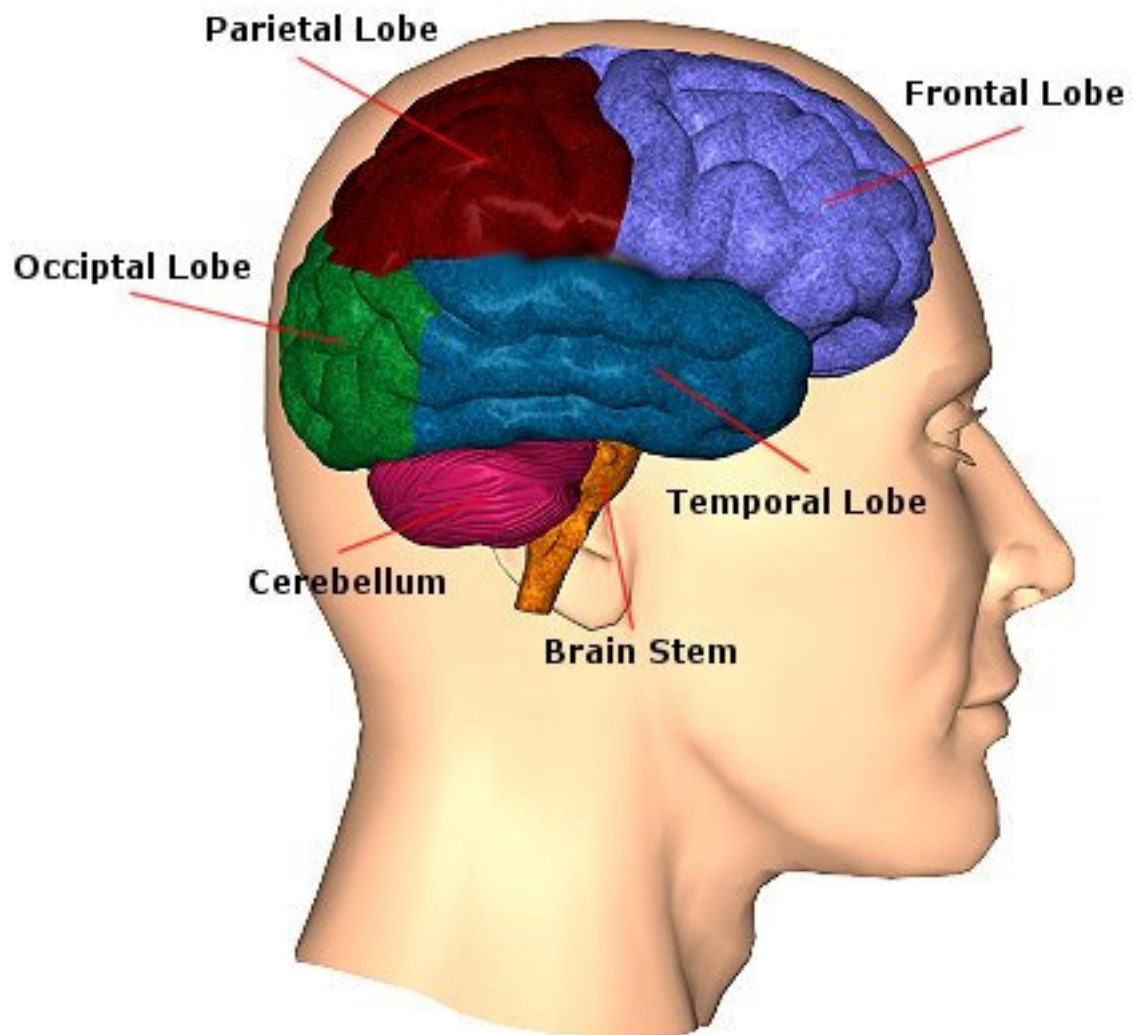
- brain stem
- cerebellum
- cerebrum

The **brain stem** connects the rest of the brain to the spinal cord and controls important functions like breathing, heart rate and blood pressure. (see picture on the next page)

The **cerebellum** helps maintain good balance and posture and helps co-ordinate body movements (e.g., swinging golf club, knitting, etc.). (see picture on the next page)

The parts of the **cerebrum** are often called “lobes”. The cerebrum is also divided into two distinct sections, called “hemispheres”, the right brain and the left brain. (see picture on the next page)

THE BRAIN



Frontal Lobe:

- helps to plan and organize our actions
- helps us to look ahead in time, to schedule tasks
- helps us set and achieve goals
- gives us the motivation to begin our activities
- helps us understand, monitor and change our behaviors in different situations
- helps us understand, monitor and control our feelings
- houses our “personality”

If your frontal lobes are affected, you may have noticed:

(check which ones affect you)

- difficulty focusing and concentrating on activities — paying attention requires greater effort
- problems doing things that have multiple steps such as making meals, paying bills, fixing things (medical term = apraxia)
- trouble making decisions, especially under pressure
- problems using judgment
- changes in how you feel about yourself
- greater difficulties in controlling your feelings and moods

What symptoms have you noticed?

Temporal Lobe:

- controls ability to learn new information and to “file” it in the brain for later use
- helps us speak and understand words

If your temporal lobes are affected, you may have noticed:

(check which ones affect you)

- changes in how you learn new information
- forgetting things that happened recently (medical term = anterograde amnesia)
- problems remembering things that you were planning to do in the future
(e.g. remembering appointments)
- difficulty finding the right words to express what you mean in while speaking and writing (medical term = expressive dysphasia)
- forgetting names of common objects, like kitchen utensils or appliances
(medical term = anomia)
- changes in your ability to recognize familiar faces, objects, or places
- difficulties following conversations, understanding what others have said, and understanding things that you read (medical term = receptive dysphasia)

What symptoms have you noticed?

Parietal Lobe:

- enables us to understand sensory information from the body – like telling us our hands are cold, hurt, or numb
- enables us to understand spatial information—telling us where we are and where other objects are in our surroundings
- enables us to use letters and numbers correctly
- enables us to find our way
- enables us to use tools

If your parietal lobes are affected, you may have noticed: (check which ones affect you)

- increased difficulty recognizing things by touch
- increasing challenges handling bank accounts or paying bills
- trouble following directions; getting lost more easily
- difficulties understanding what you have read (medical term = alexia)
- shifts in your ability to express thoughts clearly in writing (medical term = agraphia)

What symptoms have you noticed?

Occipital Lobe:

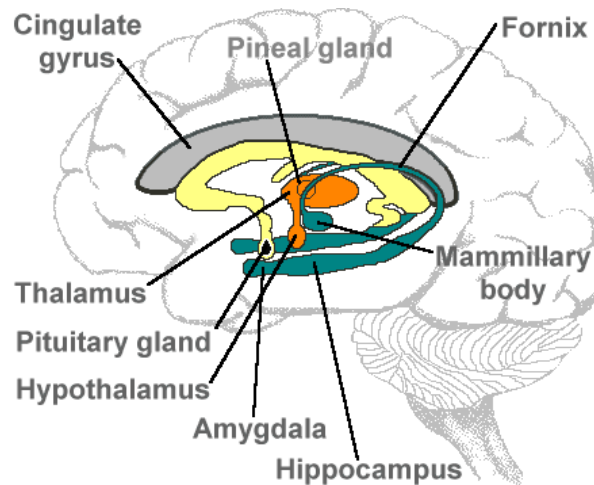
- has an important role in vision

If your occipital lobe is affected, you may have noticed: (check the box if it affects you)

perceptual difficulties—you may be looking straight at an object, but you cannot identify it. For instance, with looking at money, you may have difficulty telling one coin apart from another. (medical term = visual agnosia)

What symptoms have you noticed?

Limbic System



The Limbic System

- impacts our behaviour
- plays a role in basic instincts such as sleeping and eating
- plays a role in emotions
- impacts our sense of smell
- the hippocampus, which is part of the limbic system, is important for learning and short-term memory. This is the part of the brain where short-term memories are converted to long-term memories for storage in other brain areas. It is also where verbal and visual memory are processed.

If your limbic system is affected, you may have noticed:

(check which ones affect you)

- changes in your sleep patterns and appetite
- difficulties finding objects and remembering where they were placed
- irritability, depression, or anxiety. Keep in mind that anxiety and depression are often treatable—speak to your doctor if you would like help.

What symptoms have you noticed?

But you are more than your brain function! Consider that the glass can be half-full and half-empty at the same time.

What is in you that dementia cannot change?

Do you have more questions about dementia? **YES / NO**

Note your questions here.

For help with your questions, consider talking to your doctor, or contacting the Alzheimer Society of Nova Scotia (see section 7)