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*

SECTION 1:
THE BRAIN AND DEMENTIA

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

**What is Dementia?**
A medical term.

**CAUSES**
- Alzheimer’s Disease
- Vascular (multi-infarct) Dementia
- Lewy Body Disease
- Other

**SYMPTOMS**
**BRAIN DAMAGE**
Death of brain cells & impaired function of remaining cells

**DEMENTIA**
A cluster of symptoms related to a decline in cognitive abilities

**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.
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 4
- Vascular dementia page 5
- Lewy Body Dementia page 6
- Frontotemporal Dementia page 7

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 behaviour
9. changes in personality
10. loss of initiative

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.

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 (VaD) is the result of either single or multiple strokes. A stroke is defined as a loss of blood flow that causes brain damage. VaD usually has a sudden onset and immediately follows a stroke. VaD may follow a stepwise progression—functioning can deteriorate, stabilize for a time, and then deteriorate again. The cognitive symptoms may vary, affecting some areas of the brain more or less than others (e.g. language, vision, or memory).

**Who gets Vascular Dementia?**

VaD is the second leading cause of dementia, affecting both men and women. VaD often co-exists with Alzheimer’s disease; this condition is called “mixed dementia”.

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Alzheimer Society | 5 |
Is there treatment?
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 calculation. 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 does Lewy Body Dementia affect?**
Lewy Body Dementia is more common in men than in women.
Is there a treatment for Lewy Body Dementia?
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. The average course of the disease is 7-8 years.

Is there a treatment for Frontotemporal Dementia?
Presently, there is no known cure for Frontotemporal Dementia and its progression cannot be slowed down.

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 binder with you and write down what your physician says is causing your dementia:


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:

- brainstem
- cerebellum
- cerebrum

The parts of the cerebrum are sometimes called “lobes”. The cerebrum is also divided into two distinct sections, called “hemispheres”, the right brain and the left brain.
Parts of the Brain and What They Do

**Frontal Lobe:**
- enables us to plan and organize actions
- enables us to look ahead in time, to schedule tasks and devise ways to achieve goals
- initiates our activities
- enables us to be insightful and have the ability to moderate feelings and monitor our behaviours
- houses our style of being in the world—our personality
If your frontal lobes are affected, you may have noticed:
(œ check which ones affect you)

☐ greater fluctuations in your attention span than before—
   maintaining your concentration requires greater effort
☐ challenges with complex tasks involving multiple steps
   (medical term = apraxia)
☐ shifts in your ability to make decisions, especially under pressure
☐ changes in how you feel about yourself
☐ greater difficulties in moderating your feelings and moods

*What symptoms have you noticed?*

| ______________________________________________________________________ |
| ______________________________________________________________________ |
| ______________________________________________________________________ |
| ______________________________________________________________________ |
**Temporal Lobe:**
- controls new learning and short-term memory

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

- changes in your ability to learn new information
- lapses in your short-term memory
  (medical term = amnesia)
- problems remembering recent events
  (e.g. remembering appointments, or details of a doctor’s visit)
- fluctuations in your vocabulary skills
- changes in your ability to recognize familiar faces, objects, or places

*What symptoms have you noticed?*
**Parietal Lobe:**
- enables us to use words and numbers correctly
- enables us to understand spatial information—telling us where we are and where other objects are in our surroundings
- enables us to place activities in sequence
- enables us to use tools

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

- communication difficulties such as finding the right words, mixing up words, or using the wrong words (medical term = anomia)
- changes in your ability to express thoughts and feelings (medical term = expressive aphasia)
- difficulties following conversations and understanding what others have said (medical term = receptive aphasia)
- difficulties understanding what you have read (medical term = alexia)
- shifts in your ability to express thoughts clearly in writing (medical term = agraphia)
- increasing challenges handling bank accounts or paying bills
- trouble following directions; getting lost more easily
- beginnings of balance and gait difficulties or mild coordination problems (medical term = ataxia)

*What symptoms have you noticed?*

____________________________________________________________

____________________________________________________________

____________________________________________________________
Occipital Lobe:
- impacts elements of 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:**
- 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

*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:

▪ contacting the Alzheimer Society of B.C. to join a support group or call the Dementia Helpline (see Section 7).

▪ contacting the Alzheimer Society of B.C. to access education programs.

▪ www.alzheimerbc.org
  Visit the Alzheimer Society of B.C. website for information about dementia and available programs and services.