SHAPING THE JOURNEY: living with dementia®

Help for Today. Hope for Tomorrow...
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Revised January 2015
The journey with dementia poses many challenges. For families on the journey, having an understanding of what they face can make all the difference. The Alzheimer Society of B.C. is dedicated to helping families build the knowledge, skills and confidence to live well with dementia.

Thanks to the generosity of donors and funders, and the commitment of our volunteers, the Alzheimer Society of B.C. is able to offer a variety of services designed to give people the help they need, when they need it, and in ways that work for them.

Contact the Dementia Helpline (1-800-936-6033 or in the lower mainland 604-681-8651) for more information about:

- **Alzheimer Resource Centres** - your access to information, support, programs and services, and referrals to community resources.

- **Information Bulletins** - to connect and inform caregivers (*In Touch*) and people with dementia (*Insight*).

- **Education Programs** - for information about diagnosis, day-to-day living, positive approaches to care, strategies for managing the challenges and how to prepare for the future.

- **Support Groups** - for caregivers and for people with early symptoms of dementia.

or visit our website at

www.alzheimerbc.org
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Visit the Alzheimer Society of B.C. website at www.alzheimerbc.org
WELCOME

You have been provided with this *Shaping the Journey: living with dementia*® workbook because either you, or someone in your family or circle of friends has been diagnosed with an illness that is causing dementia.

While this workbook is written for people with dementia, you will still find the information useful if you are a family member.

This workbook has valuable information that will help you in considering some important issues. It offers personal planning tools and details on how to connect with the Alzheimer Society of B.C.

You are starting on a journey and you are not alone. The Alzheimer Society of B.C. is your link to a community of services and support.
HOW TO USE THIS BINDER

This workbook is designed as a participant’s workbook for the education series *Shaping the Journey: living with dementia®* or as a self-help workbook. It is written in an easy-to-read manner. However, you do not have to undertake it in its entirety. If you plan on using it as a self-help workbook, work at your own pace. It is not necessary or advisable to complete the entire workbook in one sitting. You can look at a section, or even a few pages at a time.

Remember that you can access more information and support from the Alzheimer Society of B.C. Contact information for the Society is in Section 7 of this workbook.
ACKNOWLEDGEMENTS

The Alzheimer Society of B.C. wishes to thank Betty Andersen, M.A. (Registered Clinical Counsellor) and the Society’s team of staff who helped develop these materials.

We give special recognition to those who participated in the Shaping the Journey: living with dementia® pilot project and gave us their suggestions on ways that this booklet could be improved.

We also wish to thank a number of others who have agreed to have their work included in this workbook. Where appropriate, the author is acknowledged in a footnote.
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

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”.


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:

(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.
A degree of denial is essential. Like somebody drinking hot coffee, we sip the truth of our condition carefully and gently.

—J. W. Anthony*

* J. W. Anthony. "Ideas about Alzheimer's", reprinted with permission from Perspectives - A Newsletter for Individuals with Alzheimer's or a Related Disorder, Vol. 3, No. 4, May-July 1998. Published by the University of California, San Diego, Shiley-Marcos Alzheimer's Disease Research Center. Contact Lisa Snyder at isnyder@ucsd.edu for a free email subscription.
In this section of the workbook, you will learn about:

- the impact of receiving a diagnosis of a life-threatening illness
- what other people have found helpful
- telling other people about the diagnosis
- getting support

Receiving a diagnosis of dementia can be overwhelmingly frightening. Every person reacts differently to an unwelcome diagnosis. There is no right way or wrong way to react.

We can think of the reaction to hearing bad news as having five phases. These phases can be experienced and re-experienced in any order. There are no time limits to the range of reactions and emotions that people go through when receiving catastrophic news.

1. **Shock and Numbness**
   A diagnosis of dementia can come as a shock, even if you have been half expecting it.

2. **Disbelief and Denial**
   “This can’t be happening to me/us!” “It isn’t as bad as the doctors say.” In the beginning, denial can be a positive force. We use denial to shield ourselves from news that is too painful to bear, as we adjust inwardly to our new reality.

3. **A ‘hurricane’ or a ‘roller-coaster ride’ of uncomfortable feelings of anger and frustration; a trajectory through emotional devastation**
   It takes time to sort through the many reactions and emotions including frustration and anger at the situation, at the disease, at others, and even at oneself. However, some people experience a sense of relief to know there is a medical reason behind the changes they have noticed in their thoughts and actions.
4. Despondency and Sadness
   Everyone will experience periods of feeling:
   ▪ helpless and powerless in the face of the implications of the diagnosis—confronting one’s limitations.
   ▪ intensely sad when considering all the losses this disease has caused and may cause as time goes on—the healthy, happy years that are past and the lost years of the future.
   ▪ worried and fearful: “What’s going to happen next?”

5. Acceptance
   Accepting the problem rather than avoiding it, and then realizing that the situation must be adjusted to rather than actively changed. Acceptance will involve recognizing and becoming reconciled to the limits of the body.

How well do these five phases match your experience?

Understanding and acknowledging these wide-ranging reactions and emotions can help one to cope with the situation. Keep in mind that how one lives with these intense reactions and emotions depends on their personality and coping style.
There are many ways besides talking to process feelings, such as:
- writing in a journal
- painting or becoming involved in other artistic hobbies
- following your faith and other spiritual pursuits
- exercising
- reading poetry, philosophy, self-help, and other books
- listening to music
- taking time to reflect

**Note how you might choose to process your feelings.**

**TELLING OTHERS ABOUT YOUR DIAGNOSIS**

Who you tell about your diagnosis and how you tell them is an intensely personal part of any journey with an illness. There are a few things you may want to consider:

- Disclosing your diagnosis to those closest to you who may be able to give you help and support is important in facing the challenges of dementia.

- The degree of closeness or importance of the relationship with your individual colleagues, friends, and family may be a factor in deciding who to tell.

- You do not need to tell anyone unless you want to.
My Social Network Map
Write in each box the names of the people you meet in the following categories—see example below.

An example of how to complete your network map:
I meet my friend Emily every week.
I meet my sister Gail every day.
I meet Paul at the book club once a month.
I see Tony when I volunteer at the library every other week.

<table>
<thead>
<tr>
<th>Daily</th>
<th>Weekly or more often</th>
<th>Approx. every 2 weeks</th>
<th>Monthly or less often</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td>Gail</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>Emily</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neighbours</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Activities where I met people</td>
<td></td>
<td></td>
<td>Paul</td>
<td></td>
</tr>
<tr>
<td>Work or organizations I belong to</td>
<td></td>
<td></td>
<td>Tony</td>
<td></td>
</tr>
</tbody>
</table>

In this example, Gail and Emily are much closer to MYSELF than Tony and Paul.
<table>
<thead>
<tr>
<th></th>
<th>Daily</th>
<th>Weekly or more often</th>
<th>Approx. every 2 weeks</th>
<th>Monthly or less often</th>
<th>Rarely</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family</td>
<td></td>
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<tr>
<td>Friends</td>
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<tr>
<td>Neighbours</td>
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<tr>
<td>Activities where I met people</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Work or organizations I belong to</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Consider that the closer people are to the box that says **MYSELF**, the more important it may be to tell them about your diagnosis.
ARE YOU FINDING IT HARD:

- **TO UNDERSTAND AND EXPRESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA?**
  
  **YES/NO**

- **TO TELL YOUR FAMILY AND CIRCLE OF FRIENDS?**
  
  **YES/NO**

If the answer is yes to any of the previous questions, you may want to write down what it is that you are finding hard. You can use your list to help you when talking about your situation with family and friends. This list can also serve as a reminder of the questions you might want to address when contacting the Alzheimer Society of B.C.
Consider:

▪ contacting the Alzheimer Society of B.C. to join a support group (see Section 7)
▪ contacting the Alzheimer Society of B.C. to access education programs
▪ subscribing to *Insight*—a bulletin by and for people with dementia from the Alzheimer Society of B.C.
▪ visiting a website where people with dementia chat, such as:

**www.alzheimer.ca**
This is the official website for the Alzheimer Society of Canada. Of special interest is the section on “Creative Space”—a place where people affected by Alzheimer’s disease or a related dementia can express themselves through creative writing and artwork.

**www.alzheimer.ca/english/creativespace/intro.htm**

**www.dasninternational.org**
This website is organized by the Dementia Advocacy and Support Network, a group of individuals with Alzheimer’s disease or related disorders. In the “Articles and Books written by DASNI People” section, you will find essays and talks by persons with dementia.
Argue for your limitations, and sure enough they’re yours.

—Richard Bach

SECTION 3: MAINTAINING YOUR HEALTH
MAINTAINING YOUR HEALTH

IN THIS SECTION OF THE WORKBOOK, YOU WILL LEARN ABOUT:

▪ important health numbers such as blood pressure
▪ the importance of what you eat and drink
▪ the importance of exercise, with suggestions
▪ the importance of managing stress
▪ how depression can be a problem
▪ suggestions on working with your doctor

The brain is an organ of your body and is affected by your general health.

Having an illness that is causing dementia makes it even more important to take care of your health. This will be vital in enhancing your quality of life.

There are many elements of living that contribute to general health, also referred to as “wellness.” Some of these will be outlined in the following pages.

HEALTHY NUMBERS
There are some critical health numbers that you should be monitoring with your physician to make sure you stay as healthy as possible.

Where do you stand on the healthy numbers scale? Is your...

▪ Blood pressure…less than 120/80?
▪ Blood sugar…less than 7.0 mmol/L?
▪ Cholesterol…less than 200 mg/dL?
▪ Weight in proportion to your height?

If you have doubts about these numbers, speak to your physician.
NUTRITION

A healthy diet that is good for your heart and circulation is also good for your brain! High cholesterol is thought to lead to stroke and brain-cell damage. Diabetes is also thought to significantly increase your risk of developing dementia.

The Canada Food Guide Recommendations:

Recommended number of Food Guide Servings per day:

<table>
<thead>
<tr>
<th>AGE IN YEARS</th>
<th>19-50</th>
<th>51+</th>
</tr>
</thead>
<tbody>
<tr>
<td>SEX</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Females</td>
<td>7-8</td>
<td>7</td>
</tr>
<tr>
<td>Males</td>
<td>8-10</td>
<td>7</td>
</tr>
<tr>
<td>Vegetables &amp; Fruit</td>
<td>7</td>
<td>7</td>
</tr>
<tr>
<td>Grain Products</td>
<td>6-7</td>
<td>6</td>
</tr>
<tr>
<td>Milk &amp; Alternatives</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Meat &amp; Alternatives</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
### What is one Food Guide Serving? Look at the examples below:

| Vegetables & Fruit |  
|--------------------|--------------------------------------------------|
| ▪ **fresh, frozen or canned vegetables** 125ml (1/2 cup) |  
| ▪ **leafy vegetables**  
| » cooked: 125ml (1/2 cup) |  
| » raw: 250ml (1 cup) |  
| ▪ **fresh, frozen or canned fruits** 1 fruit or 125ml (1/2 cup) |  
| ▪ **100% juice** 125ml (1/2 cup) |  

| Grain Products |  
|----------------|----------------------------------|
| ▪ **bread** 1 slice (35g) |  
| ▪ **bagel** ½ bagel (45g) |  
| ▪ **flat breads** ½ pita or ½ tortilla (35g) |  
| ▪ **cooked rice, bulgur or quinoa** 125ml (1/2 cup) |  
| ▪ **cereal**  
| » cold: 30g |  
| » hot: 175ml (3/4 cup) |  
| ▪ **cooked pasta or couscous** 125ml (1/2 cup) |  

| Milk & Alternatives |  
|---------------------|--------------------------------------------------|
| ▪ **milk or powdered milk** (reconstituted) 250ml (1 cup) |  
| ▪ **canned milk** (evaporated) 125ml (1/2 cup) |  
| ▪ **fortified soy beverage** 250ml (1 cup) |  
| ▪ **yogurt** 175g (3/4 cup) |  
| ▪ **kefir** 175g (3/4 cup) |  
| ▪ **cheese** 50g (1 ½ oz.) |  

| Meat & Alternatives |  
|---------------------|--------------------------------------------------|
| ▪ **cooked fish, shellfish, poultry, lean meat**  
| 75g (2 ½ oz.)/125ml (1/2 cup) |  
| ▪ **cooked legumes** 175ml (3/4 cup) |  
| ▪ **tofu** 150 g or 175ml (3/4 cup) |  
| ▪ **eggs** 2 eggs |  
| ▪ **peanut or nut butters** 30ml (2 tbsp) |  
| ▪ **shelled nuts and seeds** 60ml (1/4 cup) |  

| Oils & Fats |  
|-------------|--------------------------------------------------|
| ▪ Include a small amount—30 to 45ml (2 to 3 tbsp)—of unsaturated fat each day. This includes oil used for cooking, salad dressings, margarine and mayonnaise. |  
| ▪ Use vegetable oils such as canola, olive, and soybean. |  
| ▪ Choose soft margarines that are low in saturated and trans fats. |  
| ▪ Limit butter, hard margarine, lard, and shortening. |
EXERCISE
Make it regular, varied, and enjoyable! Exercise can help keep your weight and blood pressure down.

The variety of physical activity can be as important as the type of exercise.

Exercise has a positive effect on your emotions because of the chemicals that are released when you exercise.

Find something you enjoy. Exercise does not need to be a chore.

- Get off the bus one stop earlier and walk the rest of the way.
- Take the stairs instead of the elevator.
- Join an “Aquasize” class – it’s social and fun
- Stand up while talking on the phone.
- Stretch to reach items in high places and squat or bend to look at items at floor level.
- Take dance lessons (you can move and listen to music that you enjoy).
- Enjoy nature while walking – and perhaps a friend or their dog will join you.
- Join a recreational club that emphasizes physical activity.
- Participate in charity walks and raise money for good causes while you exercise.

Making a commitment to exercise with another person can help with your motivation and enjoyment.

You can ask family or friends to give you memberships or passes to exercise activities as holiday or birthday gifts.
You might like to write down a few forms of exercises that you would find enjoyable and the names of people you would like to ask to exercise with you—your exercise buddies.

<table>
<thead>
<tr>
<th>Exercise I Enjoy</th>
<th>Possible Exercise Buddy</th>
</tr>
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<tbody>
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<td></td>
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<td></td>
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</table>

**HYDRATION**

The brain relies on an adequate amount of water in your body (hydration) to function properly. If you are already having problems with brain function, keeping your brain properly hydrated is even more important.

You should drink at least six cups of water per day. There are some drinking bottles that can help you to measure your intake. They are often given out free at events—perhaps you can pick up a drinking bottle for yourself.

An illness that causes dementia can reduce one’s sense of thirst—so drink the recommended six cups of water even if you do not feel thirsty.

**ALCOHOL**

Health care professionals strongly recommend that alcohol consumption either be eliminated or significantly restricted if you have an illness causing dementia.

Consuming alcohol in combination with prescribed medications may be a bad idea. Talk this matter over with your physician.

MENTAL EXERCISE

Be mentally active! Make it your business to find things that challenge your memory and thought processes—this will help strengthen the connections between your brain cells.

There are always new experiences to try, so be proactive and find something you enjoy.

There are a number of puzzles you can access for free—either in the free newspapers that come to our homes or on the internet.

Ask your family and friends to get you the kind of puzzles you enjoy as holiday or birthday gifts.

STRESS MANAGEMENT

A lot of stress is not good for the brain.

If you are having challenges with your memory and ability to organize things, it is important that you balance this with time spent relaxing and reducing stress.

You might like to ask a friend or family member to help you develop and master stress management skills (listed on pages 37-39).

There are some excellent tapes and CDs that you could listen to. Many pharmacists and health stores sell relaxation tapes. You should be able to find one that appeals to you.

Stress Management: Breathing

1. Natural Breathing

Ideally, adopt this breathing technique as your normal daily breathing pattern, whenever you are not physically active.

- Gently and slowly inhale through your nose, filling only your lower lungs (keep your upper chest still as your stomach moves in and out).
- Exhale slowly.
- Continue this slow, gentle breathing with a relaxed attitude, concentrating on filling only the lower lungs.

**I AM GOING TO USE THIS:**  **YES/NO**

### 2. Calming Breath
Incorporate this breathing technique into your daily life. Use it six to eight times a day to reduce the build-up of normal tensions.

- Exhale all the way.
- Take a deep breath, filling your lower lungs first followed by your upper lungs.
- Slowly exhale, saying “relax” (or a similar word) under your breath.
- Let your muscles go limp and warm; loosen your face and jaw muscles.
- Remain in this “resting” position physically and mentally for a few seconds, or for a couple of natural breaths.

**I AM GOING TO USE THIS:**  **YES/NO**

### 3. Calming Counts
Use this technique anytime to encourage your body’s calming response.

- Close your eyes and take a long, deep breath.
- Exhale slowly while saying the word “relax” silently.
- Take ten natural, easy breaths. Count down with each exhale, starting with ten.
- While you are breathing comfortably, be aware of any tensions in your body. Imagine those tensions loosening.
- When you reach one, open your eyes again.

**I AM GOING TO USE THIS.**  **YES/NO**
Stress Management: Muscle Relaxation

1. Brief Muscle Relaxation

Use this technique anytime you want to release muscle tensions and quiet your mind.

1. Close your eyes and sit quietly, letting go of any distracting thoughts (20 seconds).
2. Bend your arms and then cross them in front of your chest. Tighten your fists, arms, shoulders, chest and back, and lift your shoulders up to your ears, while you're breathing (10 seconds). Now relax (15-20 seconds).
3. Crunch your face up, wrinkle your nose, squint your eyes, purse your lips and bite down on your teeth (10 seconds). Now relax (15-20 seconds).
4. Take a deep breath, pull in your stomach and tense your lower back. Hold your breath while counting to six. Then exhale slowly. Now relax (15-20 seconds).
5. Extend your legs and tense them, while pointing your toes toward your head (10 seconds). Now relax (15-20 seconds).
6. Repeat Steps 2 to 5.
7. Sit quietly—clearing your mind and focusing on your breathing or on a pleasant scene in your mind—as you invite your body to feel relaxed, warm, and heavy (1 minute).
8. Open your eyes, feeling refreshed and at ease.

I AM GOING TO USE THIS. YES/NO

2. The Ten-Second Grip

Use this technique anytime you want to release muscle tensions and quiet your mind.

- Cross your arms in front of you, or grab and squeeze the arm rests of your chair, tending your upper and lower arms. Tense your stomach and leg muscles as well. Hold that position (10 seconds) while you continue to breathe.
Then let go and take a Calming Breath.
- Repeat the above two actions twice more.
- Shift around in your seat shaking your arms, shoulders, and legs loose. Gently roll your head a few times.
- Close your eyes and breathe gently (30 seconds). Let your body feel warm, relaxed, and heavy during this time.

I AM GOING TO USE THIS.  YES / NO

3. Stop Your Negative Thoughts
Use this technique to interrupt recurring negative thoughts and worries.

- Listen for your worried, self-critical, or hopeless thoughts.
- Decide that you want to stop them (“Are these thoughts helping me?”).
- Reinforce your decision through supportive comments (“I can let go of these thoughts.”).
- Mentally yell “Ow!” or snap a rubber band on your wrist.
- Begin Calming Counts.

I AM GOING TO USE THIS.  YES / NO

DEPRESSION

Having a bad day, feeling blue or down, sadness and grief are part of our life experience. They occur because of natural changes in biological cycles and as emotional responses to difficult life experiences.

Coping with these feelings is best handled by acknowledging them, talking about them with friends and family, and keeping them in perspective.

However, there can be a gradual transition from these ups and downs to clinical depression—which is actually an illness of the brain. This illness becomes more common as we age.
Signs of clinical depression

Use this chart as a checklist:

*Note: This is not a diagnostic tool*

- difficulty concentrating
- no longer experiencing pleasure in things formerly enjoyed
- sleep disturbances
- changes in eating habits—usually a decrease in appetite and food losing its taste, or in some cases, overeating
- feelings of guilt, helplessness and/or hopelessness
- increase in self-critical thoughts
- thoughts of suicide
- increased isolation from friends
- increased alcohol/drug use

If you experience most of the above symptoms for more than two weeks, there is a possibility that you may be suffering from clinical depression. If you think you may have clinical depression, speak to your physician. Untreated, it usually continues to get worse. However, with treatment, some people can recover from it. It is possible to have both clinical depression and dementia at the same time. Do not assume that the symptoms of clinical depression are a part of the dementia and therefore have to be tolerated. Clinical depression is treatable with medication and counselling.
WORKING WITH YOUR DOCTOR*

Your doctor can be one of the most important sources of support throughout your journey with Alzheimer’s disease or a related dementia. There are a few points to keep in mind to make this relationship more successful:

Preparing for your visit

▪ Book your appointment at a time of day when you are usually at your best. Make sure the person in the doctor’s office who makes the appointments is aware of why you need an appointment at a specific time of day.

▪ The typical doctor’s office schedules 10 minutes per appointment. If you think you need more time with the doctor because you have a long list of questions and concerns, let the office staff know when you are scheduling your appointment. They may be able to give you a longer appointment or book a second one.

▪ Write down your questions and concerns before your appointment because it is hard to remember them when you are feeling stressed. This is especially true for people with memory loss. List your concerns in order of importance—this ensures that important issues are addressed first.

▪ It can be a good idea to take a support person with you. You will feel more confident knowing someone is there to support you and provide assistance when needed. A support person can be there:
  » to be a second set of ears
  » to keep notes if you find writing difficult
  » to be a back-up to your memory if you forget something
  » to help your doctor understand what you are trying to say
  » to provide, if needed, details of the changes they may have noticed in you
  » to make sure, if needed, that all issues and questions are dealt with before you leave the office.

* Adapted from the Alzheimer Society of Canada booklet and video “Working Together”, developed with an unrestricted educational grant from Pfizer.
Talk to your support person ahead of the scheduled visit about what your expectations are during the appointment. Review the issues you wish to raise with the doctor so you can both be prepared.

Important information to take to your appointment:

» On your first visit to a doctor, you might want to bring all of your medications with you. For subsequent visits, let the doctor know about any new medications you are taking, including over-the-counter medications.

» Bring notes about your symptoms: Have they changed? Are they the same? Are there any new ones?—include when they started, what is happening, and how they affect the way you function.

» Bring a list of past and current medical problems as well as results of any lab tests and scans you may have had.

» It is common for people living with Alzheimer’s disease or a related dementia to experience feelings that are difficult to handle. If these feelings intrude too much in your daily life, note them down and be sure to let your doctor know. Write down what you feel and when the feelings arise.
At the doctor’s office

- It is a good idea to keep a note of what your doctor says so that you can review it at home, or share it with family members.

- Writing the answers on the same sheet that you wrote down the questions you prepared can help you to keep track. It can also ensure that the information is easy to find. Before you leave, review with the doctor the information you have recorded.

- If you find it difficult to listen and write at the same time, ask your support person to record or write down the information.

- As an alternative, you can use a hand-held tape recorder to record the conversation with your doctor (provided the doctor agrees to being taped) or to record the information as soon as you leave the office.

Communicating with your doctor

- You may have definite ideas of what a doctor should do for you. It is reasonable for you to expect that your doctor is:
  - a good listener
  - honest
  - explains things to you in a way that you can understand
  - directs you to support services

- Your doctor will also have expectations of you. These might include that you will:
  - be honest—share all information related to an issue including your reactions and how it affects your day-to-day life
  - be cooperative with your treatment plan or tell him/her if you deviate—for example, reporting that you have stopped taking a prescribed medication
  - ask questions if you do not understand something
Getting on-going support

- Let your doctor know when you are happy with the treatment and care you are receiving. Positive feedback is always helpful.

- If you disagree with a suggested course of treatment and wish to get a second opinion, politely ask for a referral to another doctor or specialist.

- You may think that your doctor is not listening to your concerns. As a first step, you should try to talk to him or her about it honestly and diplomatically. Often, an open conversation will resolve the issue.

Things to note down for discussion about your relationship with your doctor:

» **What is your specific concern?**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

» **What are the positive aspects of the relationship?**

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
» **What in the relationship is not working?**

» **What can change to make it work?**

- If the relationship does not improve, you might consider changing doctors to get the ongoing care and support you need and deserve.

- Remember that there are other community resources. Using the same pharmacist to dispense all of your medications can be an extremely helpful safety measure. You can talk to your pharmacist about side effects of medication and interactions between medications—both prescription and over-the-counter. The pharmacist may also recommend a daily or weekly pill container that will help ensure you take your medications as prescribed.

- [www.nia.nih.gov/alzheimers](http://www.nia.nih.gov/alzheimers)  
  This site offers valuable updates on Alzheimer’s disease research and news from the Alzheimer’s Disease Education and Referral Center.

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**Use a weekly dispenser for pills!**
As an Alzheimer’s survivor, I have no reason to hold back or to be ashamed of having Alzheimer’s. I am open to sharing what is happening in the experience and advocating for a better understanding of the disease.

—T. Raushi*

Section 4: Life After Diagnosis

* Raushi, T. Perspectives - A Newsletter for Individuals with Alzheimer’s or a Related Disorder, Vol. 7, No. 4, May-July, 2002, pp. 1-3. Published by the University of California, San Diego, Shiley-Marcos Alzheimer’s Disease Research Center. Contact Lisa Snyder at lsnyder@ucsd.edu for a free email subscription.
SHAPING THE JOURNEY: living with dementia

LIFE AFTER DIAGNOSIS

IN THIS SECTION OF THE WORKBOOK, YOU WILL LEARN ABOUT:

▪ the kinds of changes that follow a diagnosis of an illness that causes dementia
▪ suggestions for dealing with these changes
▪ the feelings that follow a diagnosis of an illness that causes dementia
▪ suggestions on dealing with these feelings
▪ practical suggestions to help with the emotional side of living with dementia

COMING TO TERMS WITH A LIFE I DID NOT PLAN

Enduring life’s inevitable changes can be challenging. Human beings have a built-in ability to adjust to change. In adjusting to change, we experience a psychological process described as “transition.” It can require true courage to weather this process.

We can think of change as moving from one state (an end) through a transition phase to a new beginning.

<table>
<thead>
<tr>
<th>ENDING</th>
<th>transition “NEUTRAL ZONE”</th>
<th>NEW BEGINNING</th>
</tr>
</thead>
<tbody>
<tr>
<td>• what is left behind</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• what ceases to be</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• letting go</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• loss (grief, anger, “blues”)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• movement from old to new</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• risky (apprehension)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• uncertainty (tension)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• boundaries are fuzzy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• new roles/work</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• involves a shift in attitude/perspective</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• alignment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• gain</td>
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</table>
Transition can also be called a transformation. Alzheimer’s disease and related dementias have been described as life-transforming conditions. Things will not be the same. You will need to come to a decision about how to live with your new reality.

We adjust more readily to changes/transitions that are:
▪ our choice
▪ have a net gain (more gains than losses)
▪ final

The changes that happen with Alzheimer’s disease and related dementias do not follow this pattern. There are, and will continue to be, a multitude of changes in many aspects of one’s life that will require adjustment. There are, and will be, a variety of reactions to and feelings about the ongoing process of adjustment and readjustment.

Before thinking about the changes you are facing, it is important to think about who you are right now.

Thinking about your “self,” list as many labels as possible in answer to the question: Who am I? For example: father, architect, partner, sister, singer, writer, peacemaker, friend.
Here are some ways people talk about the changes that come with Alzheimer’s disease or a related dementia:

- **Changing abilities**—“Certainly I miss the abilities that I am losing; daily I am reminded of the losses.”
  
  *T. Raushi.*

- **Sense of mastery**—“The worst feeling is that of not being able to trust myself.”
  
  *Sheila*

- **Changing activities and roles**—“We do not take well to uselessness. Retirement and illness challenge us to redefine what it means to be of use and to have a purpose.”
  
  *W. Lustbader*

- **Noticing shifts in key relationships**—“In the economy of illness, the supply of friends tends to shrink. Peripheral friends drop away, since such relationships are reliant on contexts in which little effort has to be exerted.”
  
  *W. Lustbader*

- **Changing sense of self and place in a now “unsure” world—no longer able to maintain illusion of constancy**—“It’s a strange world I’m trapped in…On a bad day, even my solutions have problems…There is so much frustration in my daily life…some days, I could just cry.”
  
  *Norma Selbie*

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*Raushi, T. The Alzheimer’s Survivor: Some Thoughts on Being an Alzheimer’s Survivor through the Eyes of a Person Diagnosed Early with the Disease: Perspectives - A Newsletter for Individuals with Alzheimer’s or a Related Disorder, Vol. 7, No. 4, May-July 2002, pp. 1-3. Published by the University of California, San Diego, Shiley-Marcos Alzheimer’s Disease Research Center. Contact Lisa Snyder at lsynder@ucsd.edu for a free email subscription.*
What changes are you noticing in yourself?

What are you still able to do and enjoy?

FEELINGS

When facing changes, and particularly as you move through the “Neutral Zone,” you will experience a variety of feelings. This is a necessary part of coming to terms with the changes.

Feeling (definition): A subjective response or reaction to a person or a situation.

Feelings are real and powerful. Although you cannot see or touch them, feelings can heavily influence your behaviour, your thoughts, and even your spiritual life.

No matter how much you try to suppress your feelings, try to make them go away, or pretend they do not exist or are relatively unimportant, they will eventually surface and clamour for your attention.
One of the most important components of the healthy transformation of your life is to find and come to terms with your feelings.

Your relationships can be affected, and you may not be able to think as clearly as you used to. At times, you may even fear that you are losing yourself. However, in finding your emotions you do not lose yourself, instead, you find yourself.

**Seven things to be aware of:**

1. Feelings are neither good nor bad, right nor wrong; feelings are messages to be interpreted.

2. Feelings do not last forever. No matter what you are feeling, eventually that feeling will lift and another emotion will take its place.

3. Everyone has a right to their feelings.

4. When you are overcome by a strong feeling, you do not have to act on it. Feelings are not dangerous but actions can be.

5. Feelings are not facts. Feeling a certain way does not necessarily reflect an accurate picture of the real world.

6. Denying a feeling does not make it go away.

7. It is important to acknowledge your feelings—even uncomfortable ones. Excessive self-judgment will block feelings. This is not helpful.

We typically think of feelings as falling into four categories. You may experience any or all of these emotions; and there are many degrees and shadings of each one: sadness, anger, joy, and fear.
When a chronic illness intrudes on your life, you may experience intense emotions. Strong feelings such as sadness, discouragement, and anger are common reactions to the implications of being ill. Emotional reactions can be intensified by the dementing illness. Your emotional reactions may seem stronger than before and harder to moderate.

Some of the uncomfortable feelings and reactions that people with Alzheimer’s disease and related dementias have identified as being part of their experience include:

- **frustration and anger** at the disease, sometimes at others, and even at oneself. There are four roots of anger:
  - fear—“What is going to happen next?”
  - frustration—“I can’t believe I can’t do that any more!”
  - intrusion—“I didn’t ask for this!”
  - injustice—“This isn’t fair!”

- **embarrassment and shame**—“I hate it when people see my mistakes.”

- **fear**—“What will happen to me?”

- **sadness and grief**
  Grief is a normal, universal response to all losses, including the loss of “what was” and the loss of “what might have been.” For example, you may miss the healthy person you once were, your feelings of confidence, your independence, your privacy, job satisfaction, untroubled family relationships, feelings of energy, a sense of happiness, and enjoyable hobbies.
▪ **Loneliness**
People with a serious illness may experience periods of intense and painful loneliness. Many people with dementia find it helpful to join a support group for people with early symptoms Dementia Support Group (see Section 7 for contact information).

▪ **Guilt**
You may think that you are somehow failing yourself and those closest to you.

*What feelings have you experienced?*

---

**TIPS FOR HANDLING FEELINGS AND REACTIONS**

Here are some techniques and strategies others have found useful:

▪ Recognize that your losses are important, not trivial.

▪ Admit your feelings to yourself and to others. Acknowledging and talking about these feelings is an important step towards emotional health. Consider speaking with a neutral person, such as a counsellor.

▪ Moderate intense reactions in the moment:
  » Cool down.
  » Stop what you are doing at the time.
  » Breathe! Take four or five slow, deep breaths.
  » Clear your mind by using a strategy such as counting to ten. This distracts you and buys some time to allow the thinking brain to re-engage.
Plan ahead: minimizing factors such as hunger or fatigue can help.

Self-soothe by:
» engaging in physical activities such as walking, running, dancing, etc.—whatever works for you
» laughing—look for the lighter side of the situation
» using relaxation techniques such as deep breathing, listening to music, playing with a pet, writing in a journal

Practice positive thinking. Remind yourself that feelings are not facts. When negative thoughts or unrealistic expectations intrude, switch to positive thinking.

Say consoling things to yourself such as “I can handle this.”

Develop the habit of positive self-talk to preserve self-esteem.* Self-esteem comes not only from the messages other people send you, but also from the messages you send to yourself via a subconscious voice in your head. Self-talk refers to that subconscious voice.

You have the power to override negative messages (i.e. “I’m stupid!” and “I’m not good enough!”) from yourself and others with positive self-talk. Examples of positive self-talk include:

» “There are people who love me and will be there for me when I need them.”
» “I deserve to be happy.”

First, consciously stop the negative thought. Then, replace it with a helpful or positive thought. Refer to page 39 in Section 3 on “Stop Your Negative Thoughts.”

STRATEGIES FOR COPING WITH FEELINGS

Strategies for coping with feelings include:
▪ positive self-talk
▪ journaling
▪ exercising
▪ engaging in enjoyable activities
▪ having an active social life

Positive self-talk
Be aware of your self-talk. Be mindful to not put yourself down, but to talk yourself up instead, with positive self-talk.

I AM GOING TO USE POSITIVE SELF TALK.  YES/NO

Write down some statements to repeat to yourself if you start to feel badly or feel the urge to put yourself down.

Who cares if you forget? There is no test at the end of the day. Enjoy!

Journaling
You can use a journal to help sort your feelings and to write down positive statements about who you really are (another way of practicing positive self-talk).

I AM GOING TO USE A JOURNAL.  YES/NO
If you do not have a journal, write down your plan to get one and use it.

---

**Exercising**
Exercise can relieve stress. It can give you time to think positive thoughts and make you feel good about your health and your body.

**I AM GOING TO EXERCISE.**  
YES / NO

Your exercise routine does not have to be strenuous, so commit to exercising at least three times a week. Below are some examples of exercises you can do.

» walking
» jogging
» swimming
» taking a fitness class
» other:
Engaging in enjoyable activities
Put aside some time everyday to do something enjoyable.

I AM GOING TO ENGAGE IN ENJOYABLE ACTIVITIES.  

YES/NO

Select some of the activities you enjoy, or add your own ideas.

- [ ] play a musical instrument  
- [ ] write in a journal
- [ ] take a walk outside  
- [ ] participate in a club or group
- [ ] listen to music  
- [ ] make crafts
- [ ] attend a support group  
- [ ] play a sport
- [ ] other ideas:
  

Having an active social life
Spend time with people who allow you to feel good about yourself. Participating in healthy activities, like those listed above, will help you improve your self-esteem.

I AM GOING TO HAVE AN ACTIVE SOCIAL LIFE.  

YES/NO

Stay involved with hobbies and interests.

Volunteer your time to help someone else!
List the people you will spend time with.


List some healthy social activities in which you will participate (e.g., visiting friends and family, dancing, etc.).


LOOKING AFTER THE PRACTICAL

People with dementia have provided a number of practical tips about how to cope with memory problems. Here are some of those ideas:

• Write HOT above the hot water tap in the shower or glue a red disk on the tap. Use arrows to indicate the direction to turn the tap ON.

• Carry your name, address and phone number in every sweater and coat pocket, or buy an i.d. bracelet on which to put this information.

• Put an oven mitt in the middle of the floor to remind you when the oven is on.

• Keep a day planner next to the phone to write down appointments.
ARE YOU FINDING IT HARD TO:

▪ COPE WITH RECEIVING YOUR DIAGNOSIS?
▪ PROCESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA?

YES/NO

If the answer is yes to either of the above questions, consider:

▪ contacting the Alzheimer Society of B.C. to join a support group (see Section 7)
▪ contacting the Alzheimer Society of B.C. to access education programs
▪ www.alzheimer.ca
  This is the official website for the Alzheimer Society of Canada. Of special interest is the section on “Creative Space”—a place where people affected by Alzheimer’s disease or a related dementia can express themselves through creative writing and artwork. www.alzheimer.ca/english/creativespace/intro.htm

▪ www.dasninternational.org
  This website is organized by the Dementia Advocacy and Support Network, a group of individuals with Alzheimer’s disease or related disorders. In the “Connecting with People” section, you will find essays and talks by persons with Alzheimer’s disease.
Disconnecting from change does not recapture the past. It loses the future.

—Kathleen Norris

Section 5:
Planning Ahead
Perhaps, till now, you have put off writing a will, or preparing other legal tools that will help your family deal with decision-making when you are no longer able to make your own decisions. However, a diagnosis of any serious health problem can bring you face-to-face with your own mortality. A diagnosis of Alzheimer’s disease or a related dementia highlights the need to think clearly about the short and long-term future. The time to plan is now!

**IN THIS SECTION OF THE WORKBOOK, YOU WILL FIND:**

- **Personal Planning - Along the Dementia Journey**: provides some examples of how personal planning may relate to different points along the dementia journey.

- **Ready, Set, Plan!**: a checklist to help you decide whether you and your family have dealt with some important planning issues.

- **Medical Profile - Admission to Hospital**: a place to document important medical and personal information that can assist in your care in the event that you need to go to the hospital.

- A section outlining some important considerations regarding driving.

Taking care of future planning is a gift that we can all give to our family and friends.

You need to inform someone in your immediate circle of family and friends about your decisions when you have made them—especially since you may be relying on them for help in the future.

Nothing in this workbook can replace you seeking independent legal and financial advice about your particular circumstances.

Another kind of planning: write a family history. Some stores sell books with questions that help you do this.
**PERSONAL PLANNING: ALONG THE DEMENTIA JOURNEY**

This chart contains some examples of how personal planning may relate to different points along the dementia journey. It is not a complete list of personal planning actions or situations.

<table>
<thead>
<tr>
<th><strong>Early stages</strong></th>
<th><strong>Middle stages</strong></th>
<th><strong>Later stages</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Consider building a personal support network.</td>
<td>Develop a relationship with your regional health authority’s Home and Community Care department. This may include a case manager.</td>
<td>Individuals appointed as Representative and Attorney are likely to begin making decisions on a person’s behalf.</td>
</tr>
<tr>
<td>Start conversations with your network on how to provide support when current arrangements are no longer safe (e.g. living arrangement, driving a vehicle).</td>
<td>Individuals appointed as Representative and Attorney may need to begin playing a significant role in decision making.</td>
<td>If plans are not made or are inadequate, a Temporary Substitute Decision Maker may be assigned to make health care decisions (temporary).</td>
</tr>
<tr>
<td>Develop a care plan with your physician and other health care providers.</td>
<td>Some people may begin using alternative methods of transportation due to driving cessation.</td>
<td>If plans are not made or are inadequate, a family member, friend, or the Public Guardian and Trustee of B.C. may be given authority to make health care, personal care, legal and financial decisions.</td>
</tr>
<tr>
<td>Consult a lawyer or notary, financial planner.</td>
<td>Explore options for respite care, home support, day programs, alternative housing or residential care.</td>
<td>If a person with dementia is living in residential care, the individual appointed to make health and personal care decisions has a role in developing a care plan.</td>
</tr>
<tr>
<td>Draft an <em>Enduring Power of Attorney</em> and a <em>Representation Agreement</em>.</td>
<td>Consider home adaptations to meet changing abilities.</td>
<td>Families and individuals appointed to make health and personal care decisions may need to advocate to ensure a person’s values and wishes direct end of life care.</td>
</tr>
<tr>
<td>Consider whether an <em>Advance Directive</em> meets your needs.</td>
<td>Review the Alzheimer Society of B.C.’s <em>Wandering Package</em> and incorporate strategies to promote safety.</td>
<td>If in place, an <em>Advance Directive</em> may be used in certain circumstances to inform end of life care decisions.</td>
</tr>
<tr>
<td>Write a will, choose an executor, estate planning.</td>
<td>Families and caregivers benefit from developing strategies for reducing their stress.</td>
<td></td>
</tr>
<tr>
<td>Register legal personal planning documents with the Nidus Personal Planning Resource Centre and Registry.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Become familiar with applicable tax credits.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ready, Set, Plan!

This checklist will help you to decide whether you and your family have dealt with some important planning issues. Have you thought about……..

<table>
<thead>
<tr>
<th>Financial and Legal Affairs</th>
<th>Yes</th>
<th>No</th>
<th>Where to get more information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensuring that someone you trust can access your bank account and safety deposit box</td>
<td></td>
<td></td>
<td>Bank or credit union, Lawyer, Notary</td>
</tr>
<tr>
<td>Making and registering a <em>Section 7 Representation Agreement</em> (if appropriate for your circumstances)</td>
<td></td>
<td></td>
<td>Nidus Resource Centre, Lawyer, Notary</td>
</tr>
<tr>
<td>Making and registering a will/review executor(s)</td>
<td></td>
<td></td>
<td>People’s Law School, Lawyer, Notary</td>
</tr>
<tr>
<td>Appointing a guardian for minor children</td>
<td></td>
<td></td>
<td>Lawyer or Notary</td>
</tr>
<tr>
<td>Reviewing beneficiaries in life insurance, RRSP’s, RRIF’s, pensions etc.</td>
<td></td>
<td></td>
<td>Financial or Investment Advisor</td>
</tr>
<tr>
<td>Informing your family of wishes/plans to avoid potential disputes. Making a list of personal items and who you’d like to receive them.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completing the <em>Authorizing or Cancelling a Representative</em> form for CRA (T1013 - gives permission for someone else to access your tax information)</td>
<td></td>
<td></td>
<td>Canada Revenue Agency</td>
</tr>
<tr>
<td>Applying for applicable tax credits</td>
<td></td>
<td></td>
<td>Canada Revenue Agency</td>
</tr>
<tr>
<td>Developing a financial plan. If you own a business, develop a business management succession plan</td>
<td></td>
<td></td>
<td>Financial Advisor</td>
</tr>
<tr>
<td>Reviewing insurance needs (e.g. house, life, car or long-term care insurance)</td>
<td></td>
<td></td>
<td>Lawyer, Notary or Financial Planner</td>
</tr>
<tr>
<td>Including a charitable gift as part of your estate planning</td>
<td></td>
<td></td>
<td>Lawyer, Notary, favourite charity</td>
</tr>
</tbody>
</table>

The content of the handout is provided as an information resource only and does not provide legal advice. Please consult your lawyer, notary and/or financial advisor to ensure your financial, estate, and health care planning is appropriate for your needs.
Have you thought about……

<table>
<thead>
<tr>
<th>Health Care and Personal Affairs</th>
<th>Yes</th>
<th>No</th>
<th>Where to get more information</th>
</tr>
</thead>
<tbody>
<tr>
<td>Making and registering a Representation Agreement</td>
<td></td>
<td></td>
<td>Nidus Resource Centre, Lawyer, Notary</td>
</tr>
<tr>
<td>Communicating end of life care choices to your representative and family (you may want to consider an advance directive)</td>
<td></td>
<td></td>
<td>Nidus Resource Centre, Public Guardian and Trustee of B.C., Lawyer or Notary, local health authority, physician</td>
</tr>
<tr>
<td>Labelling your keys, ensure there is a duplicate set in a known location</td>
<td></td>
<td></td>
<td>Family physician</td>
</tr>
<tr>
<td>Discussing with your family, plans for ceasing driving now/ in the future</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preparing a file with your important papers and information such as:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• your birth date and ID numbers (e.g. SIN, MSP, driver’s licence)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• names of financial and legal advisers, executor(s), individual(s) appointed through an Enduring Power of Attorney and a Representation Agreement</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• your health care professionals such as doctor and dentist</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• prescriptions, medical conditions, allergies and medications</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• phone numbers of family and other important people</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• location of Enduring Power of Attorney, Representation Agreement, will, etc.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• list of assets, deed(s), insurance policies</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• bank account and investment account numbers, location of safety deposit box, security codes for home safe, credit card information</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• passwords (e.g. email, computer, voicemail, etc.)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reviewing options for residential care and visiting potential sites</td>
<td></td>
<td></td>
<td>Your local health authority</td>
</tr>
<tr>
<td>Making a funeral plan</td>
<td></td>
<td></td>
<td>Funeral Service Association of B.C., Memorial Society of B.C.</td>
</tr>
</tbody>
</table>
### Medical Profile – Admission to Hospital

The following pages (page 69 to 72) provide a space for you to document important medical and personal information that can assist in your proper treatment and care in the event that you need to go to the hospital. You can remove these pages from your *Shaping the Journey: living with dementia* workbook and/or share their location with your family members.

#### BASIC INFORMATION

<table>
<thead>
<tr>
<th>Field</th>
<th>Information</th>
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<tbody>
<tr>
<td>Name:</td>
<td></td>
</tr>
<tr>
<td>Date of Birth (mm/dd/yyyy):</td>
<td></td>
</tr>
<tr>
<td>CareCard Number:</td>
<td></td>
</tr>
<tr>
<td>Home Address:</td>
<td></td>
</tr>
<tr>
<td>Home Phone:</td>
<td></td>
</tr>
<tr>
<td>Home Contact (Name):</td>
<td></td>
</tr>
<tr>
<td>Other Family Contact:</td>
<td></td>
</tr>
<tr>
<td>Relationship:</td>
<td></td>
</tr>
<tr>
<td>Ph:</td>
<td></td>
</tr>
<tr>
<td>Family Doctor:</td>
<td></td>
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<tr>
<td>Ph:</td>
<td></td>
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<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Community Nurse:</td>
<td></td>
</tr>
<tr>
<td>Ph:</td>
<td></td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Occupational Therapist:</td>
<td></td>
</tr>
<tr>
<td>Ph:</td>
<td></td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
<tr>
<td>Physiotherapist:</td>
<td></td>
</tr>
<tr>
<td>Ph:</td>
<td></td>
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<tr>
<td>Fax:</td>
<td></td>
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<tr>
<td>Other:</td>
<td></td>
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<tr>
<td>Ph:</td>
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<td>Specialist:</td>
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<td>Specialist:</td>
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<td>Fax:</td>
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<tr>
<td>Case Worker:</td>
<td></td>
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<tr>
<td>Ph:</td>
<td></td>
</tr>
<tr>
<td>Fax:</td>
<td></td>
</tr>
</tbody>
</table>
PERSONAL CARE / POSITIONING / OTHER RESOURCES

Health Issues: (Medical/ Surgical/ Emotional/ Psychiatric/ Allergies/ Tendency to Wander):
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Special Considerations for Treatment: (e.g. - is the person with dementia likely to be particularly anxious and confused by a visit to the hospital—explain)
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Positioning: (attach pictorial guidelines if complicated)
Information about particular sleeping positions or seating issues
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________
__________________________________________________________________________________________

Other important people involved in this person’s life:
Name: ___________________________ Ph: ___________________ Relationship: __________________________
Name: ___________________________ Ph: ___________________ Relationship: __________________________
Name: ___________________________ Ph: ___________________ Relationship: __________________________
Name: ___________________________ Ph: ___________________ Relationship: __________________________
Name: ___________________________ Ph: ___________________ Relationship: __________________________
EATING / COMMUNICATION / SIGHT / HEARING

Does this person have any food allergies? □ Yes □ No
If yes, please list all allergies: ____________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Does this person have coughing/choking episodes during meals? □ Yes □ No
Do they have swallowing difficulties? □ Yes □ No (if yes, what are the mealtime guidelines)
Food Texture: □ Regular □ Cut up □ Minced □ Pureed
Other Information: ____________________________________________________________

Does this person require a special diet? □ Yes □ No
□ Regular □ Cardiac □ PKU □ High Fibre □ Anti-reflux
Fluids: (if not regular ) □ Regular □ Thickened □ Thickening agent: ____________________________________________________________

How does this person communicate?
□ Verbal □ Non-verbal □ Yes / No Response □ Communication Aid
Please describe communication methods in detail: ____________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
Describe any unique way of communicating or behaving and the best way to respond:

<table>
<thead>
<tr>
<th>Behaviour</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</table>

Hearing Impairment: □ Yes □ No       Hearing Aid: □ Right □ Left □ N/A
Visual Impairment: □ Yes □ No       Glasses: □ Yes □ No       Contacts: □ Yes □ No
HEALTH ISSUES / CONSENT FOR TREATMENT / CURRENT MEDICATION

Lifts and Transfers Required:  □ Independent   □ Requires Assistance
Mobility Aids:    □ Wheelchair   □ Walker   □ Cane   □ Other: ________________________________
Bathing: □ Independent   □ Requires Assistance   □ Dependent
Dressing: □ Independent   □ Requires Assistance   □ Dependent
Oral Hygiene: □ Independent   □ Requires Assistance   □ Dependent   □ Dentures
Bladder Function: □ Continent   □ Incontinent   □ Incontinence Products: ________________________________
Bowel Function: □ Continent   □ Incontinent   □ Diarrhea   □ Constipation
Elimination Routines: □ Regular toileting every __ hours   □ Incontinence Pads (□ day □ night)
Sleep Patterns: □ Nothing unusual   □ Sleep disturbances: ________________________________
Safety Requirements: Information ________________________________
Skin Care: □ Pressure areas: ________________________________
  □ Wounds or sensitive areas: ________________________________
  □ Skin Products: ________________________________

* Representative or Committee: ________________________________

* Family member who is willing to be appointed TSDM by physician if this person cannot give informed consent for treatment:
  Name_____________________________ Ph: ___________________ Relationship: _______________________

* Person who is willing to be appointed a TSDM by the Public Trustee:
  Name_____________________________ Ph: ___________________ Relationship: _______________________

Current Medications—Keep this up to date

<table>
<thead>
<tr>
<th>MEDICATION</th>
<th>DOSE</th>
<th>ROUTE</th>
<th>FREQUENCY</th>
<th>LAST DOSE</th>
<th>SPECIAL CONSIDERATIONS</th>
</tr>
</thead>
<tbody>
<tr>
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</tbody>
</table>

Name_________________________ Signature_________________________ Date___________________
DRIVING
Dementia causes changes that will, eventually, affect a person’s ability to drive safely. Driving requires concentration, judgment, and the ability to reason and make decisions. All of these become impaired in people with dementia.

Dementia is a journey of losses. As one of the first major losses, driving is perhaps one of the most difficult to cope with. Managing this loss well can set the foundation for dealing with the other losses resulting from this disease.

If you have dementia, or support someone living with dementia, the following will provide information to help you manage this important safety issue.

Prepare to stop driving
Often stopping driving is one of the first losses you will deal with. Preparing yourself and those around you for this loss is key to handling this issue well.

In the early stages of dementia some people may continue to drive safely, others cannot. The following steps will help you prepare for the day you have to give up your keys:

- Talk – Many people feel angry or sad about having to stop driving. Discussing driving from the very beginning is important to handling this loss. Talk to your doctor, your caregivers, your family and friends. Let them know how you feel if giving up driving is going to be difficult for you.

- Assess – If you plan to continue driving, know that the illness may affect your ability to assess your own driving. Ask your family, friends and doctor to monitor your driving and to let you know when your driving abilities change. Your doctor can do a simple screening test and send you for a driving evaluation. A driving evaluation will let you know if it is time to stop driving.

- Plan – Plan for your retirement from driving. To ease the transition, plan for alternative ways to get around. Talk to your family and friends about driving you; and look at alternative transportation available to you. Try out the plan before you have to stop driving. This way you can see what works and what doesn’t before you need to rely on others.
Know when to stop driving

It is common for people to modify the way they drive as their abilities are affected by the physical changes of aging. But for people with dementia, it’s different.

Unlike the typical aging process, dementia affects your ability to know your own limitations. You might be aware of changes in your driving that suggest you are at risk such as:
- getting lost on familiar routes
- being unaware of driving errors
- missing traffic lights or road signs
- having near misses
- finding it difficult to stay in your lane
- noticing scrapes or dents on your car

One incident may not warrant concern. But over time, an increase in the frequency of unsafe driving behaviours requires attention. Often, because of changes due to your illness, you will not be aware of your own driving abilities. You might deny, make excuses or blame others for your unsafe driving behaviour.

You can ask your family members or friends to use this checklist to look for warning signs that indicate driving may no longer be safe. Because your illness is progressive, it is important to keep track of changes over time, so repeat this quick check often.

If you have concerns about your own or a family member’s ability to drive safely:
- Talk to your family about your concerns.
- Ask your doctor to do a screening test.

Driving warning signs

A diagnosis of mild dementia alone is not an automatic reason to stop driving. Families can use this list as an objective way to monitor any changes in driving skills over time. Written notes of observations can help you make informed decisions and may be useful in conversations with healthcare providers. Consider the frequency and severity of incidents. Several minor incidents or an unusual, major incident may warrant action. Look for patterns of change over time. Isolated or minor incidents may not warrant drastic action. Avoid an alarming reaction. Take notes and have conversations at a later time, instead of during or right after an incident.
### Driving Behavior Warning Signs

<table>
<thead>
<tr>
<th>Driving Behavior Warning Signs</th>
<th>Yes</th>
<th>No</th>
<th>When Noticed, How Often</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decrease in confidence while driving</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Difficulty turning to see when backing up</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Riding the brake</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Easily distracted while driving</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Other drivers often honk horns</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Incorrect signaling</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Difficulty parking within a defined space</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Hitting curbs</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Scrapes or dents on the car, mailbox or garage</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Increased agitation or irritation when driving</td>
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<td>☐</td>
<td></td>
</tr>
<tr>
<td>Failure to notice important activity on the side of the road</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Failure to notice traffic signs</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Trouble navigating turns</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Driving at inappropriate speeds</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Not anticipating potential dangerous situations</td>
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<td>☐</td>
<td></td>
</tr>
<tr>
<td>Driving Behavior Warning Signs</td>
<td>Yes</td>
<td>No</td>
<td>When Noticed, How Often</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
<td>-----</td>
<td>----</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Uses a “copilot”</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Bad judgment on making left hand turns</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Near misses</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Delayed response to unexpected situations</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Moving into wrong lane</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Difficulty maintaining lane position</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Confusion at exits</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Ticketed moving violations or warnings</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Getting lost in familiar places</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Car accident</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Failure to stop at stop sign or red light</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Confusing the gas and brake pedals*</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Stopping in traffic for no apparent reason*</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
<tr>
<td>Other signs:</td>
<td>☐</td>
<td>☐</td>
<td></td>
</tr>
</tbody>
</table>

*Stop driving immediately*
**Alternatives to driving**

Look at your needs. Each person’s transportation needs are different. Consider:

- Where do you generally want to go (e.g., appointments, shopping, social engagements)?
- How often do you need rides?
- At what time(s) do you generally need rides?
- How much can you afford/are willing to pay to get from place to place?
- Do you have any special needs regarding the transportation? (e.g., Do you use a wheelchair or walker? Do you need help right from your couch to a chair at your end destination?)

**Then look at your options:**

- Family and friends – You may know people who can help you get from place to place. The price is right and it could be a very convenient way to get around.

- Public transportation – For some, public transportation may be an alternative. Is there a bus stop near your home? There is a seniors’ fare discount for those 65 and older and a bus pass program for low-income seniors. Many buses are now wheelchair accessible. Persons with physical or cognitive disabilities who are unable to use public transit without assistance are eligible to use HandyDART. Find out what’s available in your community. Again, the price is right, but availability and convenience will depend on where you live and when and where you are going.

- Taxis – Convenient, but expensive. However, if you have a BC Transit handyPass or TransLink handyCard, the taxi-saver program provides a 50% subsidy.

- Special transportation services – Private, individualized, special transportation and accompaniment services are available in some communities. Service is often very convenient, available at any time, but more expensive than other options.

- Walking – Want to stay fit and go green? Do you live close to shopping, appointments, and other places you want to get to? Walking is a great way to keep fit and healthy. Check first with your doctor if you aren’t used to walking those distances. You can’t argue with the price.
• Community/Senior’s Centres – Many centres have pick-up transport services run by local volunteers. Some have planned outings with transportation included. Transportation costs are usually very reasonable but the services are not individualized (e.g. they may not be available on demand).

• Your own car – Just because you retire from driving doesn’t mean you have to sell your car. You might want to keep it so that it’s there for others to drive you wherever you need to get to. If you have a disability, you may be eligible for a special parking permit for people with disabilities.

• Deliveries and online shopping – Many grocery and other kinds of stores will deliver to you free of charge or for a small fee. Today, “catalogue” shopping has become easier with the arrival of internet shopping. It doesn’t get you where you want to go, but may help you acquire the things you need. Delivery charges are usually very reasonable.

• Other alternatives – Other options exist in some communities. For example, there may be transportation alternatives that will take you to and from medical appointments. Some municipalities have instituted special transportation programs.

No longer driving?
It doesn’t mean you can’t still carry on an active, engaged life. Getting together with a friend for lunch, visiting family members, playing a round of golf or a game of bridge or spending the morning at the local seniors’ centre are still important activities that you want to continue.

Continued mobility is the key
Some of us eventually choose to retire from driving. For others, it is no longer safe or possible to drive. And others may wish to continue driving part time. No matter what, most seniors want to remain active in their communities and that means they want to be mobile; able to get where they want and need to go at the right time.
Alzheimer’s Disease transferred me from what I call the trivial plane to the spiritual or personal plane. I had to face the absolute horror of the ‘A’ word, and I began a dialogue with my existence...

—D. Cohen*

SECTION 6: MAINTAINING YOUR SPIRIT

MAINTAINING YOUR SPIRIT

IN THIS SECTION OF THE WORKBOOK, YOU WILL LEARN ABOUT:

▪ the things that determine quality of life
▪ managing challenging symptoms
▪ maintaining hope when facing dementia
▪ the importance of spirituality as you face dementia

QUALITY OF LIFE WITH DEMENTIA

Quality of life is defined as a person’s sense of well-being that stems from satisfaction with areas of life that are important to them.

Morris Fridell writes, “But the greatest challenge to Quality of Life in Alzheimer’s disease is the darkness of the future... The spectre of the dark future of advanced Alzheimer’s disease is a significant challenge to Quality of Life in mild Alzheimer’s disease. The usual response is to make decisions that must be made...and then avoid thinking about the future. I believe that this approach tends to distort life and to be unsuccessful in eliminating fear.”

He then goes on to say, “The first step in recovery of quality of life is emotional safety. The goal is to recover from anxiety or depression and be strengthened in warding them off, to learn basic coping skills, to do basic advance planning, and to find some enjoyment in a simpler and more present-oriented life style.”

The following pages will highlight three key factors in maintaining your spirit so that you can still experience good quality of life:

▪ Managing Challenging Symptoms
▪ Hope
▪ Spirituality

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** Friedell, M. *Dementia Survival: A New Vision*. http://members.aol.com/MorrisFF/Vision.html
MANAGING CHALLENGING SYMPTOMS...IN ORDER TO IMPROVE QUALITY OF LIFE

Keep in mind that any changes caused by the disease are not going to happen to you suddenly. You will have time to adjust your lifestyle and to find help when you need it. Keep in mind that some days will be better than others. Do what you can on a given day.

Memory changes
Memory aids can help reduce the demands on your memory:

▪ Put important things like money, keys and glasses in the same place every time.
▪ Routine is important—have a regular way and time to do things.
▪ Do one thing at a time.
▪ Write reminders to yourself.
▪ Make a daily list of what you need to do and keep it realistic!
▪ Posting a weekly calendar of activities on the wall can be useful. Mark off days on a calendar.
▪ Keep important numbers by the phone where you can see them. Include emergency numbers, as well as your address so that you can refer to them quickly.
▪ Keep a day planner next to the phone to write appointments in. Get into the habit of checking it regularly.
▪ Label cupboards or drawers with words or pictures to remind you where things are kept.
▪ Carry your name, address and phone number in every coat pocket, or put the information on a bracelet
▪ Label photos with names of people important to you and the role they play.
▪ Mark the route to the bathroom with reflector tape to make night time visits less problematic.
▪ Put an oven mitt in the middle of the floor to remind you the oven is on.
▪ Noisy timers will remind you something is on the stove or in the oven.
▪ Electrical appliances used frequently should all have automatic shut-offs.
Ask your pharmacist about help with medication such as using bubble packs.
Try using talking clocks.
Tell people you have a memory problem—ask them to repeat or explain things.
Leave a set of house keys with a trusted neighbour.
Make a memory book of information that is important to you and keep it with you at all times. This book can be kept in a pocket (“pocket pal”) or hip pouch. It may contain:
» important phone numbers, including your own and any that may be needed in an emergency
» people’s names
» a list of things to do
» appointments
» a map showing the location of your home
» any thoughts or ideas you want to hold on to

Changes in abilities related to day-to-day living
When there is impaired processing capacity in the parietal lobes of the brain, it becomes more challenging to do things independently. To combat this you can:
Focus on the things you can do, not the things that have become too difficult.
Experiment with ways to modify activities. Flexibility is the key—find other ways to get the job done.
Research various aids that may be useful.
If you are having problems with one activity, try something else.
If something seems too difficult, take a break.
If you no longer enjoy reading, try talking books, audiotapes, and videotapes.
Take your time and ask others to give you time.
Ask for help and take it. Often people are wanting to know how they can help.
Ask others to assist with difficult tasks.
Check into services to help with household chores, meal preparation and banking.

Write a love letter sharing precious memories to your children, spouse and friends. Save for a future time.
Simplify your living space and your life.
Consider sorting out your closet and dresser drawers to make it easier for you to choose what to wear.
Consider purchasing clothing that is simpler to put on.

Changes in mood
- If you get frustrated when things are not going well, blame the illness, not yourself.
- If you are depressed or have other worrying feelings or thoughts, your doctor may be able to help.
- Sometimes talking to a counsellor who knows about dementia helps.

Changes in the ability to talk to others
Finding the right words to express your thoughts may become harder. Understanding what people are saying will also be difficult at times.
- Take your time.
- Tell people you have a problem with thinking, communicating and remembering.
- If you did not understand a statement, ask the person to repeat it.
- It is okay to ask over and over again.
- If too many people or too much noise bothers you, find a quiet place.
- If you lose a thought, let it go. It is okay if you forget—it may come back.

HOPE...AND THE EXPERIENCE OF ALZHEIMER’S

Hope is the belief in what is possible. It is what nourishes us during difficult times. With dementia, you can be struck by spells of discouragement, fear, or disillusionment. Hope may feel a bit elusive.
We hope because it is essential to our quality of life. When we hope, we are willing to get up more times than we fall down. We are willing to give ourselves one more chance, again and again. With hope, whatever the outcome, we can go on.

One reason to hope is an awareness of work underway to treat or cure Alzheimer’s disease. Scientists are continually researching new medications to slow disease progression and enhance functioning. New drugs are currently under investigation. In the last decade, there have been tremendous advances in research. Each new finding builds on previous ones. Scientists are optimistic that each advancement is moving towards prevention or a cure.

Another reason to hope is that those working in long-term care are developing far more loving, creative, and dignified ways of caring for individuals whose disease is very advanced. We can feel encouraged that in the future, we will be in the presence of loving and caring people who understand our condition and needs at all stages of the illness.

With the advances in communication technologies, people around the world are collaborating and sharing their discoveries, ideas, and experiences related to the many aspects of Alzheimer’s disease and related dementias. Everywhere in laboratories, community settings, support groups, households, and in our every day lives we can find seeds of hope.

**Finding Hope**

*Does everyone always hope?*

No. Hope fluctuates for every person. We can experience more or less of it on any given day or during any given period. When our hope is weak, that does not mean we are weak. Times of illness or unwanted change are particularly hard on hope.

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If I am low on hope or feel I have no hope, can my hope return? Yes. Sometimes, it is as if our hope has gone into hiding and one day it re-emerges. As with a physical injury, time and effort can help restore hope. Each of us must make the choice to reclaim our hope. It is not just handed to us. We must reach for it.

Here’s the critical question: How do I learn to hope? There are various ways you can learn to find, keep, and build hope. Some ways will work better for you than others. The only way you will know which ones work for you is by experimenting. Some ways will work better on certain days or at certain stages in your life. You will figure it out as you go along. Keep in mind that “hoping” is seldom an overnight success. It’s more like a lifetime adventure.

You might have to experiment to find a way that works for you.

▪ Throw the hope switch. Hope to hope.

▪ Notice signs of hope. Spring always follows winter.

▪ Listen to hopeful voices—talk to people with a positive attitude.

▪ Look back. Think about a time in your life when you felt especially hopeful. You can feel hopeful again. Why? Because you have done it before. You have had the experience of hope. You have got the makings.

▪ Expect to find hope where you least expect it—hope may find you.

▪ Break the silence that often accompanies times of low hope or no hope. You may break your silence by opening up to another or by writing for yourself. However you do it, you will head towards hope.

▪ Borrow hope from others, from your beliefs, from songs, readings, stories, movies, or even dreams.
Let out the artist or the clown in you.

Sometimes, when we are unable to feel hopeful, we need others to offer encouragement, or to shed a brighter perspective on a situation. This is the reason why people go to support group meetings.

Many find hope in seeing the growth and maturity of children and grandchildren that they helped usher into the world. They are an extension of life that continues on. In the face of one’s own illness or mortality, the company of family can inspire hope.

For those with limited or disconnected families, it can be comforting to establish a sense of extended community—a network of even one or two significant people whom you know will see you through the ups and downs, and with whom you can share your hopes and fears. True communication and understanding between people is one of the most powerful ingredients in a recipe for hope.

Some people put inspiring photographs or paintings on their walls or desks. Some hang posters with cheering thoughts or carry notes with affirming words.

Practice. Then practice some more. You practice by: naming hope whenever and wherever you find it; by highlighting hope as you come across it; by taking hope in; by expressing it; by preserving it.

Search for what is meaningful in your life. Right next to it you will find what gives you hope.
SHAPING THE JOURNEY: living with dementia

- Say “yes” to hope. No one plans to develop a chronic illness. But illness happens. Life does not always turn out the way we wish. When that happens, what do we do? Live with it? Fight it? Ignore it? Give in to it? There may be a reason to take any of these stances at one time or another. The hopeful response, however, is different. Hope says “yes.”
  » Yes, there is a way to handle everything.
  » Yes, I can deal with whatever that has been handed to me.
  » Yes, the unexpected can bring joy as well as sorrow.
  » Yes, misfortune can be a cause of growth as well as grief.

- Some people talk about living in the moment — access the potential for opportunity in each day.
  » Today, I can meet with friends.
  » Today, I am going to enjoy this quiet time when I can watch the world go by out of the window.
  » Today, I can go to my Tai Chi class.
  » Tonight, I can be warm by the fire.

Living with hope
“Searching to find what to be thankful for, I had to remind myself that anything with an end has a beginning. I could be thankful that we live in the 21st century, and now there is medication that helps many of us slow symptoms and I do have the benefit of an Early Stage Support Group. Medication has allowed me to continue functioning at a reasonably healthy level and while Mild Cognitive Impairment has progressed to Early Alzheimer’s disease — I still feel smart, inside.”
I continue to read (who cares if I make mistakes), walk, sing, and do word-finds because I believe it is important to keep busy. Remember the old adage, “If you don’t use it, you lose it.” I can no longer follow a recipe, but I can still whip up a mean stir-fry! My husband has become a greater support than ever before and bless him for his helpfulness. We now grocery shop as a team and he has taken on the responsibility for putting my pills into their weekly dispenser, then of course, he has to remind me to take them. One of the nicest things he has done for me is to hire a cleaning lady twice a month. This makes my life much easier. We still have a good life, only now we have to work around the challenges of Alzheimer’s disease."

**SPIRITUALITY**

The search for meaning and purpose during stressful life events knows no religious or spiritual borders. It is a quest as natural to the human condition as the quest for food and shelter.

People have a spiritual dimension in their lives. It is the essence of every person whether or not they have a religious faith. The ability of the human spirit to find meaning and purpose in life is remarkable—even amid tremendous challenges and hardships.

Human suffering can lead people in two opposite directions: promoting spiritual growth or diminishing the human spirit. Religion and spirituality offer pathways to find meaning in life, even after a diagnosis of a dementing illness. Like any terminal illness, a diagnosis of dementia brings with it a reordering of priorities. It can be a time to take stock of one’s life and focus on the legacy one wishes to leave behind. **

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* Contributed by an Early Stage Support Group Member, Kelowna, B.C.

“Having Alzheimer’s disease made me face ultimate realities, not my bank account. My money, my job and other parts of my life were trivial issues that restricted my growth, my spiritual growth. Alzheimer’s disease transferred me from what I call the trivial plane to the spiritual or personal plane. I had to face the absolute horror of the ‘A’ word, and I began a dialogue with my existence, a dialogue with my life and my death.”

If you have a spiritual life, it need not end with a dementing illness. It can be supported and affirmed. With appropriate physical care, you may need to look for support to:
- maintain faith practices and contact with faith groups
- express and demonstrate affection
- mark special occasions and make every day special
- talk about distress
- speak about your spiritual life

List some of the important people or resources to help you with sustaining hope and your spiritual life.

“So, like persons with incurable cancer or ALS [Amyotrophic Lateral Sclerosis], we with Alzheimer’s can come to a place where the disease is part of our lives but doesn’t define us. Then we can continue on with the basic tasks of our lives, with, say, singing our own songs or developing our relationship with God.”

** Friedell, M. http://members.aol.com/MorrisFF/LossOfSelf.html
ARE YOU FINDING IT HARD TO:

- COPE WITH RECEIVING YOUR DIAGNOSIS? YES/NO
- PROCESS YOUR FEELINGS ABOUT HAVING AN ILLNESS THAT IS CAUSING DEMENTIA? YES/NO
- FINDING AND MAINTAINING HOPE? YES/NO
- MAINTAIN YOUR SPIRIT? YES/NO
- MAINTAIN YOUR FAITH PRACTICES? YES/NO

If the answer is yes to any of the above questions, consider:

- contacting the Alzheimer Society of B.C. to join a support group (see Section 7)
- contacting the Alzheimer Society of B.C. to access education programs
Determine to live life with flair and laughter.

—Maya Angelou

Section 7: Contact Information
The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer’s disease and related dementias, to promote public awareness, and to search for the causes and cures.

**PROVINCIAL OFFICE**
300 – 828 West 8th Ave.
Vancouver, BC V5Z 1E2
Tel: 604-681-6530
Toll-free outside of the
Lower mainland: 1-800-667-3742

**THE DEMENTIA HELPLINE**
Lower mainland: 604-681-8651
Toll-free: 1-800-936-6033

**WEB SITE**
www.alzheimerbc.org

**LOCAL RESOURCE CENTRES**

**LOWER MAINLAND**

**Abbotsford/Mission**
214 - 2825 Clearbrook Rd.
Abbotsford, BC V2T 6S3
604-859-3889

**Chilliwack/Hope**
9291 Corbould St.
Chilliwack, BC V2P 4A6
604-702-4603

**Chinese Resource Centres**
Vancouver:
300 - 2425 Quebec St.
604-687-8299
Richmond:
290 - 7000 Minoru Blvd.
604-279-7120

**North Fraser**
103 - 5623 Imperial St.
Burnaby, BC V5J 1G1
604-298-0780
or 604-298-0782
**First Link®:** 604-298-0711

**North Shore & Sunshine Coast**
212 - 1200 Lynn Valley Rd.
North Vancouver, BC V7J 2A2
604-984-8348 or 1-866-984-8348
**First Link®:** 604-984-8347 or 1-855-984-8347

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<td>778-571-2390</td>
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<td>4 - 1475 Anderson St.</td>
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<td>BC</td>
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<td><strong>Vernon Resource Centre - by appointment only</strong></td>
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<td>Penticton</td>
<td>BC</td>
<td>250-493-8182 or 1-888-318-1122</td>
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<td><strong>East Kootenay</strong></td>
<td>1-800-936-6033</td>
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OUR VISION
Our ultimate vision is to create a world without Alzheimer’s disease and related dementias.

OUR MISSION
The Alzheimer Society of B.C. exists to alleviate the personal and social consequences of Alzheimer’s disease and related dementias, to promote public awareness and to search for the causes and the cures.