

# **DAY by DAY:**

A guide for people diagnosed with a  
condition causing early stage memory  
problems



Today is a gift to learn from and enjoy.  
That is why it is called the “present.”

The material in this publication was adapted from the booklet, *Just for You: For Persons Diagnosed with Alzheimer's Disease*, published by Alzheimer Canada, and also excerpts were used from the book *Alzheimer's: The Answers You Need*, by Helen D. Davies and Michael P. Jensen, published by Elder Books.

## What Causes Memory Problems?

Normal aging changes can cause problems with memory, however, these changes are not enough to interfere with a person's ability to manage their life and function day by day. When memory problems *do* become severe enough to present a challenge, we use the word *dementia*. Dementia is a general term that describes a group of symptoms related to the loss of cognitive function, i.e., problems with thinking, reasoning, and memory that interferes with daily living. Many problems that cause dementia are treatable or are a result of another condition, so it is critical to identify the cause by seeking a complete diagnosis from a physician or neurologist.

There are also many conditions that cause progressive dementia. Alzheimer's Disease is not a normal part of aging, but it is the most common cause of progressive dementia in persons 65 and older. Other causes include vascular (multi-infarct) dementia and Lewy Body dementia (a condition that causes symptoms of both Parkinson's and Alzheimer's within a year of each other). All of these conditions generally advance very slowly, taking years to progress. Although everyone is affected somewhat differently, for most people these conditions can result in:

- Problems with new (short-term) memory
- Difficulty concentrating or making decisions
- Forgetting words or losing your train of thought easily
- Difficulty doing tasks or taking a lot longer to do them than usual
- Getting confused or disoriented
- Frequently misplacing familiar objects

## What can I do about it?

On the following pages are some things people with dementia experience and suggestions that might help.

But first, it is important to know that:

- The changes you are experiencing are because of the disease
- You will have good days and bad days with your memory. This type of fluctuation is normal
- The disease affects each person differently and symptoms vary among people
- Some of the suggestions in this book might work for you and some may not
- Experiment! Trying different ideas will help you find out what works best for YOU

- Take control! By learning about dementia, you and your family will be able to better manage the disease
- You are not alone! There are people who understand what you are going through and who can help you
- YOU are the best advocate for yourself! Tell people what things help and do not help, and educate them about the changes you are experiencing

## About Memory Loss

- While you may clearly remember events from long ago, recent events are often quickly forgotten
- You may have difficulty keeping track of time, people, and places
- You may have times when you forget appointments or people's names
- Trying to remember where you put things might be very frustrating at times

### **SUGGESTIONS THAT MIGHT HELP:**

- Try to do only one thing at a time
- Be patient with yourself
- Be as organized as possible
- Ask your friends/family to give you more time to respond and to give you as much information as possible in the conversation
- Write it down before you go – e.g., what you want to buy at a store, your favorite foods at a restaurant
- Label cupboard, drawers, or other work spaces with words that describe their contents. For example, “dishes,” “nails,” “socks”
- Always keep a note pad with you to write down things you want to remember (or utilize the best system that works for you)
- Always keep a note pad by the telephone to capture important information
- Post important telephone numbers in large print by the phone
- Ask your family to remind you of important things, like when to take medications or doctor's appointments
- Marking off days on a calendar is one way of keeping track of time
- Try to maintain a similar routine from day to day
- Reduce your stress whenever possible, including letting your family do those tasks that increase your stress, for example, paying bills
- Create a special place in your home -- your own “shrine” where you can keep important, or often used, things such as keys, a clock, calendar, and anything else you want to keep track of
- If you lose something, try to remain calm and move on to something else for a while rather than obsessing over it and increasing your stress

## About Getting Lost or Disoriented

There may be days when places that are usually familiar to you may seem unfamiliar. For example:

- You may not recognize which way to turn
- A familiar street may not look the same

### **SUGGESTIONS THAT MIGHT HELP:**

- Carry with you directions for where you are going – the address and phone number may also be helpful. Some people can utilize GPS systems with great success, others cannot. With the help of your family, experiment with devices that might work the best for you
- When you think you are lost, don't keep trying to find your way – stop and ask for help. Don't be afraid to ask for help. Explain to people that you have a memory problem and need assistance.
- Take someone with you when you go out
- Always carry identification with you, with your name, address, phone number, and an emergency contact name and phone number
- Avoid traveling at night, in bad weather, or to unfamiliar places
- Frequent the same places (stores, restaurants, drugstores, gas stations, etc) to familiarize yourself with them and their staffs. Don't be afraid to ask them for their help if you need it
- Learn how to be a passenger. It's kind of others to be willing to drive you

## About Talking to Others

- Finding the right words to express your thoughts may become harder at times, and finding the exact word you're searching for might be difficult
- Understanding certain words that other people are saying might also be difficult sometimes

### **SUGGESTIONS THAT MIGHT HELP:**

- Try to accept your diagnosis and be comfortable talking about it; this will put others at ease as well
- Try to relax and take your time
- Tell people you have a memory problem and ask them to repeat what they said
- IT IS OKAY to ask again, even many times – that part of your brain is not working correctly and asking someone to repeat will often be necessary
- If too many people or too much noise bothers you, find a quiet place
- If you lose a thought, just let it go. It is okay if you forget it; the thought will come to you later.
- Try to develop a positive attitude and don't stress about it because stress only increases memory problems.
- Try to maintain your sense of humor

## About Daily Frustrations

You may find it harder to do things that you once did easily. For example:

- Picking out clothes to wear
- Following a recipe
- Managing money
- Driving a car

### **SUGGESTIONS THAT MIGHT HELP:**

- Take a break or “time out” when you get frustrated
- SLOW DOWN! Give yourself time and don’t let others hurry you
- Admit you are upset. Then let it go.
- Know that misplaced items will turn up eventually
- If you need help, ask
- Use calendars, watches, and daily lists as memory aids.
- Or, if a watch increases the pressure to rush, choose NOT to wear a watch
- Be patient with yourself
- Be patient and kind with yourself and just do the best you can

# Why Do I Feel This Way?

Experiencing the changes caused by dementia may cause you to have feelings you are not used to having. Dementia tends to heighten emotions, so that you feel things more deeply. Your feelings will vary – the feeling you experience one day may be gone the next day. Having these feelings is normal, but it is important that you share them with those you love or someone you feel comfortable talking to.

Below are some feelings that people with dementia often say they experience. They are only a sample, and it does not mean you will experience any, or all, of them. There are also some suggestions that others with dementia have found to be helpful in dealing with these feelings.

## **“I WORRY MORE THAN USUAL.”**

- Some of the things you may be worried about are: What is going to happen? How quickly will things progress?
- It is important to talk to your family and friends about what worries you. Even if there are no definite answers, talking almost always helps.
- Most people find that doing an activity that they enjoy-- like walking or doing a hobby, or taking care of a pet--help them to keep a positive outlook and to keep them relaxed.
- What things have you done in the past to help you when you feel worried or anxious? Try some of those same things now, like listening to your favorite music, reading , or exercising.

## **“I SOMETIMES THINK I AM GOING CRAZY.”**

- You are NOT going crazy. The changes in your brain are neurological changes that are causing you to have problems thinking clearly.
- Telling those around you how you feel may provide some comfort and relief. Talking to those around you will also help them to know when you need help and when you don't.
- Consider becoming an advocate and educating others about what it's like to experience dementia, such as a group at your church

## **“I SOMETIMES GET INTO A BAD MOOD.”**

- With the changes you are dealing with, it is not surprising that you may not always be in a good mood. On those days, try to remember that having good and bad days is part of dementia, and that tomorrow will likely be a better day
- Try to focus on doing something you enjoy or that will lift your spirits

**“I SOMETIMES FEEL ANGRY.”**

- Why is this happening to me? What did I do to deserve this? These questions are natural.
- Feeling angry is okay
- Talking to someone might help – a family member, friend, pastor, another person with memory loss, your doctor, or a counselor who know about dementia.

**“I SOMETIMES FEEL SAD.”**

- When someone is faced with a diagnosis, it is natural to feel sad at times. Again, talk to those around you. Let them know how you feel.
- If you can't seem to get rid of this sadness, talk to your doctor. He/she might be able to prescribe medication that can help you feel better.
- Watching a funny movie or TV show might help take your mind off yourself for a while. Keeping your sense of humor is very important.
- Do something you enjoy or find meaningful
- Stay as involved as you can with the things that interest you.

**“I'M REALLY EMBARRASSED WHEN THINGS GO WRONG.”**

- When something goes wrong, like not being able to find the right word in the middle of a conversation or doing something incorrectly, go easy on yourself. Explaining to people that you have memory problems often helps. People can be very understanding.
- Your memory problem is due to a neurological condition and is no fault of your own.
- Lighten up and be kind to yourself
- Everyone has memory glitches at times; try to keep a sense of humor about it

**“I SOMETIMES FEEL VERY LONELY.”**

- You may think the people around you don't understand what you're feeling, so you may feel alone. Sharing this feeling with people who care about you might help.
- Explain what you know about dementia to your friends, or have someone else do it. If they understand more about what you are going through, they might be better able to help or understand. Also, tell them how much their visits mean to you.
- If friends/family don't call or visit, call them

**“I GET SO FRUSTRATED!”**

- No wonder! Facing the challenges caused by this disease can frustrate even the most patient person.
- Again, talk to people about why you are frustrated. See if there is anything

you can do, or the people around you can do, to decrease frustration. Try some of the hints in this book.

- Keep your sense of humor – it sometimes helps to laugh at things that might otherwise frustrate you

**“I DON’T LIKE IT WHEN OTHERS TAKE OVER THE THINGS I ALWAYS DID.”**

- When you see your tasks being taken over by others and this frustrates you, talk to those taking over the task. Is this a task you are still able to do? Or, are you still able to do some part of the task?
- Sometimes people “take over” simply because they are trying to be helpful. When friends/family offer to help, suggest specific ways they may be of assistance. Let them know what you do – and don’t – need help with.
- You are more important to your family than just the tasks you do. The things you DO are not as important as the relationship you share with your family and friends.
- Try to let go of those duties you cannot do so well or that present some sort of safety concern (e.g., driving). Let other people help.

**“I FEEL GUILTY OR EMBARRASSED ASKING FOR HELP.”**

- We all value our independence. Few of us like to rely on others for help. But over time, we all find it necessary to ask for help in some areas.
- You don’t need to feel guilty or embarrassed when you need help. Just as you feel good when you can help others; it makes others feel good when they are able to offer assistance to you. It’s part of the “give and take” of being a person.
- Talk about your feelings, but try to accept the help you need.

Emotional reactions like these are normal because you are facing many new challenges and adjustments. Each of us has his/her own way of dealing with our feelings. The important thing is to find ways of coping with these feelings that make YOU feel better.

## How Else Can I Take Care of Myself?

There is not yet a cure for conditions causing progressive dementia, such as Alzheimer's disease, but there are many ways that you can maintain a rewarding, active, and enjoyable life. The goal is to keep yourself healthy, as stress-free as possible, and functioning at your maximum capacity. The following tips, shared by other persons with dementia, may help to make your life easier or even slow down the dementia:

### **STAY IN GOOD PHYSICAL CONDITION:**

Dementia can drain your physical and mental resources. The mind is sharper when the body is healthy:

- Exercise regularly (in consultation with your doctor)
- Take a nap when you are tired and make sure you get a good night's rest (Fatigue increases memory problems)
- Eat properly (cut back the high cholesterol, high fat foods)
- Have regular check-ups and take medications, as prescribed
- Do not smoke
- Cut down or eliminate alcohol, as both can worsen dementia symptoms
- Have your eyes and ears checked regularly and wear hearing aids or glasses if you need to

### **MAINTAIN A STABLE LIVING ENVIRONMENT:**

Condition your brain by having a stable, routine living environment. Avoid confusing surroundings.

- It might be helpful to make a simple "to do" list each morning, with one or two things you wish to accomplish
- Remove distractions and do one thing at a time
- Leave familiar objects in the same location
- Don't hurry yourself or let others hurry you
- Take a break when you are getting tired or frustrated

### **KEEP YOUR BRAIN ACTIVE:**

Exercise your brain like you exercise your body!

- Continue to do activities that you still enjoy
- Continue to socialize with friends and family and don't isolate yourself
- Invite guests in and accept invitations out
- Attend movies, concerts, and other activities you enjoy
- Write or record your life story
- Do volunteer work
- Stay as involved as you can in the things that interest you

### **HAVE A POSITIVE ATTITUDE:**

An open and positive attitude is necessary to keep your brain in the best possible shape.

- Maintain your sense of humor – do things that make you laugh
- Maintain your spiritual life. If you belong to a church, keep attending, or keep doing whatever spiritual practices bring you peace, comfort and strength
- Enjoy nature
- Do not be afraid to try
- Do not feel sorry for yourself
- Do not be embarrassed to have memory problems; discuss it openly with family and friends and let them know how and when they can be of help
- Do those things that give you enjoyment or relaxation more often (for example, listening to music, taking a bubble bath, playing with a pet, watching sports on TV, etc.)
- If you're feeling sad much of the time, talk to your doctor about medications that can help restore your positive approach to life

### **AVOID STRESSFUL SITUATIONS:**

When we're stressed out, our mental energy goes into coping with the stress, not with meeting our other needs. Stress makes memory problems worse.

- Try to eliminate, as much as possible, those things that give you stress (for example, crowded places, unpleasant or difficult tasks, etc.)
- Slow down and give yourself enough time
- We all have a certain time of day that we are at our best. Save the more complex or strenuous activities for this time of day.
- Avoid quarrels
- Try deep breathing when you feel stressed. This will allow you to get more oxygen to your brain
- Move to a quieter room
- Listen to music that calms you down
- Count to ten

## Should I Tell My Friends About My Diagnosis?

One of the worst things for memory is STRESS. When you don't share your diagnosis openly with family and friends, it increases your stress, as well as their stress. It makes sense to talk over with your loved ones the changes you are experiencing, as this will greatly ease the stress and pressure of trying to hide changes from them.

Simply explain to friends/family what your doctor has diagnosed you with and the effect it is having on you. Tell them what you would like from them as family members and friends. For example, tell them when you would like help and when you don't need help. The best way to educate others and help yourself is by speaking openly about dementia and trying to put others at ease. YOU are your best advocate! Others will learn and take their cue from you.

Continued social contact is also very good for you. Continue to enjoy your friends just as before, but make it easier on everyone by talking openly about your diagnosis.

## How Hard Should I Try to do Things?

There is a difference between pushing yourself to the best of your ability and frustrating yourself by trying to do something that is too difficult. The rule of thumb is you should stop trying when you feel yourself becoming frustrated. You gain nothing by pushing yourself to the point of anger and frustration and will only make the situation harder for yourself and others.

## What Should I Do If I'm Having a Bad Day?

You probably know if you are having a bad day even before you get out of bed. A technique that can turn a bad day into a good one is to take your time before getting up. Laze in bed for a while. Have a glass of orange juice before rising. Let your family know that you are having a bad day and need to take things more slowly. And don't push yourself to accomplish too much until you're feeling better.

## What Should I Do If I Cannot Find the Words to Say What I Mean?

Not being able to find the words to say what you mean is very frustrating. Try to remember that YOU are the one putting pressure on yourself to find the word, and one of the things that blocks your memory is that pressure. The best way to find the right word is to relax, and:

- Take your time. Let a few minutes pass if you need to. Think through what you want to say and try again.
- Find another word that means the same thing, or start your sentence over with a fresh approach.
- Consider going into another room and speaking into a tape recorder or writing your thoughts down. You have taken a break and a change of scenery by leaving the room. By recording your thoughts or writing them down when you are alone, you won't feel the pressure of a conversation.
- Have someone from your family there (or a friend), who is ready to help. Work out a cue, like nodding or pointing your finger when you want them to suggest a word or help you to complete your sentence.