



tips & strategies

An inspirational guide
for people like us with early-stage memory loss

A "By Us For Us" Guide

introduction

This is the fifth guide in a series of practical and helpful resource booklets written by and for persons with early-stage dementia.

Contained in this guide are ideas and suggestions for living daily with an illness causing dementia. We are all individual and unique in how we live our lives. Because these tips and strategies were provided by individuals living with memory loss, they are unique and individual to that person – you need to alter them to fit you and your own life. We recommend that you work with the ideas for a few days and establish a routine that works for you – routines are a very important component of living with dementia. Don't give up on an idea before trying to alter it to fit your lifestyle – one person's idea may trigger ideas of your own – go with it – work through things to create your “new normal”!

Overall, visual aspects of anything we do are important. With memory loss you will find that visual cues are even more important now and will become even more so as time goes on. For example, the clothes we wear are often determined by what you first see in your closet – so stacking things too deep in your closet or dresser drawers will not work anymore. Be conscious of this and make the appropriate adjustments.

Allow sufficient time when implementing new routines or incorporating new strategies into your routine. Don't take on too much at once – implement one thing at a time. Prioritize and relinquish things that are not important. If our lives are too cluttered, functioning on a daily basis becomes difficult – like climbing a muddy, slippery slope, you need to find the flat spots. If not, the weight of all the tasks will pull you down the slope.

Tips and strategies overlap, so strategies come into play in how they work for YOU – don't give up! There is a way to make everything work for us as we live our “new normal”.

Brenda Hounam
Person living with dementia
Advocate and Spokesperson

This booklet is dedicated in loving memory to
my beautiful little granddaughter,
LEAH JENNIFER WHITNEY.

additional memory workouts

As we emphasized in the *Memory Workout* guide, it is important to continue to use cognitive activities to stimulate the brain. In addition to items listed in the *Memory Workout* guide, we offer below more suggestions to help you further ‘train your brain’. By devoting an hour each day and at least 3 to 5 times per week to these memory workouts, you will notice a change.

video and computer games

 There is a free game in Microsoft Windows called FreeCell. If you are not familiar with using a computer, ask a family member or friend to place a shortcut to the game on the desktop of the computer. If you are looking at investing in a game system, don't overlook purchasing used equipment and games that are available. Some older computer games are easier to play than the newer ones. Some suggestions would be to look in the classified section of your local paper, ask your grandchildren to borrow their game systems, etc.

television game shows

 Television game shows can provide an opportunity to interact with friends while testing your knowledge.

be creative

 The advantage of keeping a journal and writing your personal story becomes a great memory resource for yourself and also for your loved ones.

 Poetry writing is a great way to express all your emotions and can also create lasting memories. For example, Elaine Smith from the Alzheimer Society of Brant and the John Noble Home Day and Stay, LEAD Program wrote a poem for her new granddaughter that will be cherished forever.

*“Many tears were shed with gratitude that you were finally here.
Now, I have my little grandbaby to cherish and love.”*

(Excerpt written by Elaine Smith entitled, *Quinn Ionna Rose*)

-  In addition to learning to or playing an instrument, take it a step further and try your hand at creating a song or writing the lyrics to a song.
-  Make cooking and baking a more creative process by experimenting with the creation of new dishes.
-  Try your hand at various arts and crafts. Don't be afraid to try new projects. Research projects that can be created with minimal tools and for minimal expense, for example, chip carving or Swedish weaving. A great place to explore these options is at craft or woodworking exhibitions. Please see the resource section at the back of the guide for ideas and links to craft and woodworking websites.

keep learning

-  Learning a second language is a good way to stretch your brain. Consider learning the native language of a country you will be visiting on vacation, or even learning French before travelling to Quebec. Those living close to a First Nations community may consider learning their language. Don't overlook learning sign language. Your children or grandchildren may also enjoy practicing with you. The important fact is that you keep practicing. One way of doing this is by teaching others, for example, it has become very popular to teach infants and toddlers how to sign.
-  Learn how to use a computer. Have someone take you through the basic steps of turning on and off the computer and accessing different software programs. As you are learning by doing, write or have someone write detailed instructions that you can follow easily at a later date.
-  Learn to use a computer keyboard. There are books available to help you learn the proper finger positioning. Try typing with both hands on the keyboard and practice these skills by typing letters or emails to family and friends.
-  Use your non-dominant hand to do routine tasks, for example, if you are right handed, use your left hand to brush your hair, or eat your breakfast.
-  Don't underestimate your abilities. Participate in courses, workshops and other learning activities in your community to learn a new skill or activity or learn more information about a topic of interest to you.



Learn as much about the disease as you can; as one person with dementia put it: “Knowledge is power”.

memorizing



Read any magazine article or book and try to recall as much detail as possible.



Try to remember your daily routine without looking at your to-do list. Or, try to remember at the end of the day everything that you did.



Use a collection you have, for example, coins, stamps or spoons, and try to recall the details on how you came in possession of the item – where it came from, and in what year you acquired it. Write those details down to use as a way to reminisce.



Reading newspaper or magazine articles repetitively will help you retain the information, which you may find useful in social situations.

other ideas



Getting involved with children can be a great way to train your brain. From playing games, to reading stories and helping with homework, children can provide cognitive stimulation, socialization and physical activity.



Play darts. It can provide mental stimulation and requires you to practice your math skills as well as providing an excellent way to socialize with others.



Don't be afraid to try new things.

“I try to keep everything organized. I find my life easier that way. I use a calendar to keep track of my life. I have my husband to drive me and do all shopping with me. I can't do finances, my husband is my power of attorney and I have an accountant.”

– Maureen B., early-stage support group member,
Alzheimer Society of Guelph

for those in the workforce

In many situations people have noticed memory problems at work first rather than at home. This can be a blessing because it can initiate diagnosis and treatment earlier. If you are still working, you need to decide whether to tell your employer about your diagnosis. **Before making this decision, weigh out the situation, on a personal level and on a financial level, and do not let your emotions rule.** Rather, turn to someone you trust outside of your situation for advice, for example, a lawyer or financial advisor, and ask a family member or a friend to accompany you when you feel ready to share your diagnosis.

choosing to tell your employer

Some people are fortunate and have a good working relationship with their employers and, therefore, are not fearful of telling them about problems they are experiencing at work. Being proactive in telling your employer about your new situation allows you to remain in control, which can make the journey easier. Also, confiding in your employer can lead to a discussion on how to accommodate your work duties and schedule to fit your “new normal”.



If you are in a financial position, and your employer is agreeable, you may want to reduce your work hours. It is better to make the decision on your own to reduce your work hours than to be forced into it later. However, it is important to seek the advice of a lawyer or financial planner because reducing your work hours may have an impact on your overall benefits and pension especially if you are younger (not such a concern if you are closer to retirement).



Your employer may be agreeable to allowing you to job share, or share your role with another employee. The other person can provide support doing more challenging tasks, while you focus on tasks that are more manageable.

choosing not to tell your employer

Some people are not as fortunate and are fearful about telling their employer about their diagnosis. Whether or not you have disclosed your diagnosis to your employer, here are some ways to make your work day more manageable.



Avoid multi-tasking. Rather, stick to one task at a time. If that is not possible, limit multi-tasking as much as possible.



Write yourself detailed notes in your day-timer to remind you not only of appointments, but also the reason for the appointment, who will be attending, where the meeting will take place, and other important information related to the appointment.



Be more organized by writing and following a schedule.



Learn to say no. Stick to the basics and try not to take on jobs which are beyond your job description.



Maintain a good balance between work, social and family life.



Get lots of sleep and schedule regular breaks – it is vital now.



Watch your diet and avoid heavy meals. Try to exercise regularly.

“I know I’m still doing well because I’m still on the right side of the grass.”

– Jane Mederak, early-stage support group member,
Alzheimer Society of Brant

general tips and strategies for daily living

finances

-  Without giving up control of your finances, it is a good idea to have a trusted person who can help with some financial tasks, such as balancing your cheque book and making sure to remind you when a bill needs to be paid. It will be an individual decision however on how much or little control you want over your finances. Make sure to get your legal documentation in place.
-  Use a credit card rather than carrying large amounts of cash when making a purchase. When you do carry cash, make sure what you carry is in small denominations – nothing larger than a \$20 bill – and try to use the bill closest to the cost of the item. That way, if there is an error in making change the loss of money will be minimized.
-  Set up your finances to include automatic deposits and withdrawals for bill payments.
-  It is important early on in the process to think about and start the process of identifying a financial power of attorney and ensuring all the legal paperwork is completed. This will protect your wishes in the future.

safety and security

-  Register your phone number on a no-call list to minimize the amount of calls from telemarketers. See the resource section at the back of this guide for the link to make use of this service.
-  For those using a computer, be aware that banks or financial institutions will never request personal or banking information online. **NEVER GIVE OUT YOUR BANK ACCOUNT NUMBER OR BANK CARD PIN NUMBER TO ANYONE REQUESTING THIS VIA EMAIL.** Keep a note about this on your computer to remind yourself of this. See the resource section at the back of this guide for the link to a website that identifies common email hoaxes and computer viruses.

-  Be aware of sales people or those looking for donations who come to your door or call you on the phone. Some are reputable, however, some are not. If dealing with anyone who is requesting money or personal information, make sure you have a trusted person by your side. In order to minimize the number of individuals coming to your house, place a “No Soliciting” sign on your front door.
-  Consider getting the call display option on your phone.
-  Minimize the number of keys you carry just in case they are misplaced and do not put your name and address on your keys.
-  Try to shop at the same store so that employees can get to know you and you can build a trusting relationship with them. In addition, shop at stores that have a monitor on the cash register where you can see how much each item is, and how much change you are owed.
-  Carry a personal identification card with you in your pocket when you go for a walk or anytime you are not carrying a wallet.
-  Let people know where you are going.
-  Carry a cell phone and use the speed dial option with a list attached to the back of the phone.
-  Register for the Safely Home Program and wear your safely home bracelet at all times. It is an insurance policy and also acts as a form of personal identification. It can also provide your loved ones with peace of mind. See the resource section at the back of this guide for a link to the Safely Home Program website.
-  When using kitchen appliances or power tools, work cautiously and take it slowly, one step at a time. Consider working on projects with a friend.
-  One of the most difficult losses we experience with this illness is losing our driver’s license. In order to feel a sense of control over the situation but also to ensure you and others are safe, it is important for you to make the decision to stop driving yourself. This will be a difficult decision. Talk to others about it and determine how you will be supported when you decide not to drive any longer.

minimize stress

-  Slow down – if you do things too quickly, you may overlook safety, for example, when taking a bath or shower, take it one step at a time – this will give your brain a chance to catch up to your body.
-  Eliminate unnecessary noise and other stimulation – eliminate other distractions in the room, for example, turn off the music or television.
-  If you are involved in a gathering of people, for example, sitting in a restaurant, stay towards the outside of the group, or choose a table in a quieter location such as at the back of the restaurant or beside the wall. That way you will hear noise from one direction only and not from all around you.
-  Give yourself extra time to complete tasks or accomplish activities of daily living.
-  Try to deal with things as quickly as possible, do not worry so much, and try to maintain a calm home environment. Don't forget to take regular breaks.
-  Learn to rest when your body tells you.

visual cues

-  Signage can be written words or pictures. The written word can help to remind you to do things, for example, take your medication or turn off the faucet. Pictures can help label the contents of a dresser drawer or cabinet in the kitchen or workshop.
-  Write detailed notes to yourself.
-  Leave a pad and pen beside the phone in a visible location. Write down phone messages – remind the person on the phone to speak slowly so that you can write the message down.

 Use a large calendar to remind yourself of appointments and routine tasks, for example, garbage day or adding salt to the water softener. Consider colour coding your calendar – you can use different colours to outline your different appointments or activities, or you can use a different colour for each member of the household.

 Put pills in a visible location, if appropriate, or use a large visible sign to remind you to take your medication.

 Take pictures of items in the order you like to have them in or of outfits that go together. For example, a person with dementia completely re-designed her closet by putting clothing items that went together on the same hanger. She made sure she had pictures of all these outfits, which made it easier for putting things away after they were washed.

 Use post-it notes to keep you on track or remind you what you have to do.

develop routines

 Review your daily calendar every morning, and carry with you a notebook and a pocket day-timer. Share the content of your day-timer with your partner or other family members.

 Take your medication consistently at the same time every day.

 Try to plan to do more difficult tasks when you are the most alert.

 Put clothes away in your cupboard in complete outfits.

 Put items in consistent locations, for example, place your eye glasses on the night stand before you go to bed or leave your keys in the same location.

 Wear clothing with pockets so you have a place to put important information, for example, personal identification or your pocket day-timer.

entertaining

-  Keep your guest list to a minimum. Tell guests ahead of time when the party starts, but more importantly when it ends.
-  Be well rested and allow time the next day to rest.
-  If you want to entertain around mealtime, order in or arrange a potluck. If you are still cooking, keep the meal simple and the table setting basic.
-  You have to decide what you can or cannot do and do not be pressured into doing more.

electronic aids

-  Use a simple recording device to help you remember significant things.
-  If you have a cell phone, it can be used to stay connected, for example, by getting directions or when you need help while shopping. With a cell phone you can stay connected with someone who can guide you until you reach your destination or you find the item you want to purchase.
-  Use an alarm clock to remind you of appointments first thing in the morning or to help you know when to take your medications.
-  Timers can be very useful to help remind you of when to change the load of laundry, when you should check something in the oven, or in the workshop.
-  Having a large push button telephone will provide a larger space for writing names on the speed dial list. Having speed dial, call display, and an answering machine will make using your telephone easier.

“Whatever we are doing, we are doing for ourselves.”

– Carl Wilson, early-stage support group member,
Alzheimer Society of Sarnia-Lambton

general suggestions



Keep life simple.



Keep your sense of humour.



Plan ahead.



Communicate your needs to your partner, friends and family, and ask for and accept help.



Don't be ashamed – talk openly about your disease.



Check out transportation resources in your own community including organizations that offer volunteer drivers for medical appointments and grocery shopping.



Stay engaged, for example, volunteer in your community.



Attend a support group.



Create a memory box and start writing or taping your life story – this is a good way to share with others what is meaningful to you and what you want them to know about you.

“Learning to accept the current situation with its moments of negativity, limitations of memory and minor frustrations that it brings with it. Learning to realize all that has been good in my life, focussing on the good and positive aspects that I have experienced through family, friends. To appreciate the help that has been provided by the Alzheimer Society – my physician who is currently treating me – my family and friends – this is what is important in managing my daily life.”

– Dr. B. Epstein, early-stage support group member,
Alzheimer Society of Niagara Region

let your voice be heard

-  Advocate – speak-up on your own behalf and become a personal advocate, or advocate publically by speaking with local government officials. Persons with dementia are the experts – we need to teach the doctors and professionals about living with dementia.
-  Don't be afraid to confront other people's misunderstanding about the disease. We can play an important role in teaching others what it is really like to live with an illness causing memory loss and how they can better support us.
-  Offer to go and speak to students training to be doctors, nurses, personal support workers, recreation therapists, and so forth at your local college or university or to speak at local Alzheimer or other community events.
-  Stay active and healthy. Connect with your local Alzheimer Society chapter and day programs. There is a new program that several of the guide participants are involved in – the LEAD program (Leisure, Empowerment, Achievement and Dignity). It is held at the John Noble Home Day and Stay Program in Brantford, Ontario. This program is run weekly and has transportation to and from the John Noble Home. It offers time for a support session, social activities and a meal offered at the end of the afternoon events. The program structure is decided upon by the group participants and is flexible. Try starting a program like this in your area. Approach organizations and churches for assistance, perhaps they can offer a place for you to meet that might even have a kitchen that you can utilize. The first place to discuss this is at your local Alzheimer Society Support Group. An occasional social outing or special event through the chapter is a great start. **Start small and it can build.**
-  Encourage your local Alzheimer Chapter and others in your community to partner with you to develop *A Changing Melody*, a learning and sharing forum specifically designed by and for persons living with early-stage dementia. Please see the resource section for the MAREP website and information about *A Changing Melody*.

resources

www.chippingaway.com – woodworking website

<http://www.marymaxim.ca/> – knitting and craft store

<http://www.safelyhome.ca/en/> – register for the Safely Home Program

<http://vil.mcafee.com/hoax.asp> – list of the most common email hoaxes and viruses

www.LNNT-EDNCL.gc.ca – register your phone number for a do not call list that will minimize the number of telemarketing calls you receive

www.marep.uwaterloo.ca – information about MAREP and *A Changing Melody*

endorsement for the guide

The “By Us For Us” guides have been enormously helpful to me in my clinic as a Geriatrician. I have used the guides to help individuals and their families master powerful tools that they can draw on to ease the difficulties of living with a dementia. They have been very well received. I am thankful to have the “By Us For Us” guides as a resource.

*Sheri-Lynn Kane, MD FRCPC
Geriatrician*

Consistent with the previous four “By Us For Us” guides this booklet provides the person living with dementia, their family/friends, and the health care professional with practical daily living strategies. Sometimes it is hard to know where to begin so a resource such as this is very important. It enables the individual to select and try out strategies to maintain daily function, life roles, and independence.

In the introduction Brenda Hounam validates that change can be difficult, however, ideas, time, and support can lead to a successful “new normal”.

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acknowledgements

The “By Us For Us” contributors:

Alzheimer Society of Brant – Early-Stage Support Group, and the John Noble Home, Brantford – Day and Stay, LEAD Program members: Brenda Hounam, Gail Robinet, Elaine Smith, Clayton Wilson, Janet Dupuis, Gordon Sinclair, Maggie Fox, Jane Mederak, Pat Dale, Peter Haggarty, John Stulen, Stan Krol, Bonnie Broughton, Don McArthur, Mary Pongrac, and Marion Nelles

For their personal contributions, we would also like to thank:

Alzheimer Society of Guelph – “The Reminders Early-Stage Support Group” members: Maureen, Howard, Ron, Ted, Moe, Peter, David, and Brian

Alzheimer Society of Niagara Region – TLC Early-Stage Program members: Marie Somerton, Eileen Stevenson, Jim TeBrake, Dugald McColl, Dr.B. Epstein, Mary Colbey, Arlene Weaver, Pat Bennett, Margaret Ball and Helen Davis

Alzheimer Society of Sarnia-Lambton – Early-stage support group members: Joan Labelle, Carl Wilson, Bill Brown, Gavin, Stan, and Yvonne Braet

Those who took the time to fill out the questionnaires distributed by MAREP

There are many more who have offered support and input over the past few years, while this project was just a dream, who deserve credit, but wish to remain anonymous. You know who you are. Thank you!

“I occasionally enjoy greeting people who are new to our city. The benefits, social skills and introductions open doors and friendships and everyone benefits.”

– Clayton Wilson, early-stage support group member,
Alzheimer Society of Brant

Thanks also to:

- Natalie Suriano and Cathy Ross – Alzheimer Society of Brant
- Carol Howarth, Lisa Hayes and Cathy Ross – John Noble Home, Day and Stay, LEAD Program, Brantford
- Julie Mitchell – Alzheimer Society of Guelph
- Gina Bendo, Carolyn Dowd and Angela Gale – Alzheimer Society of Niagara
- Liz Sager – Alzheimer Society Sarnia-Lambton
- Lisa Loiselle, Sherry Dupuis, Bryan Smale and Jessica Lansfield – MAREP
- Guide Endorsements: Dr. Sheri-Lynn Kane and Marion Penko
- Cover Graphics: Brenda Hounam
- Creative services: Graphics, University of Waterloo

Operational expenses: One More Memory: “a song to touch the heart of Alzheimer’s disease”. Contact us at www.onemorememory.com, or Linda at lwestbrook@sympatico.ca.

Funding for this project was provided by the Homewood Foundation and the Murray Alzheimer Research and Education Program (MAREP), a major division of the Schlegel-UW Research Institute for Aging, Faculty of Applied Health Sciences, University of Waterloo.



Murray Alzheimer Research and
Education Program
University of Waterloo



HOMEWOOD
Health Centre

“By Us For Us” Guides – 5 guides in the series to date

- Memory Workout
- Managing Triggers
- Enhancing Communications
- Enhancing Wellness
- Tips & Strategies

we welcome your input

If you've been diagnosed with early-stage memory loss and would like to comment on this guide or suggest topics for future guides, please contact us at www.onemorememory.com.



To order additional copies of this guide or any other guides in the series, contact:

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