



A BY US FOR US GUIDE

Memory Work Out

An inspirational guide
for people living with dementia

SERIES 1

Introduction

After I was diagnosed, I realized how very little information was available for people diagnosed with dementia. As a care partner for my father after he had a stroke, I knew how invaluable his occupational therapy was and I started to use similar activities for myself that included all the memory exercises that were of interest to me. I started doing these daily and by the time, I had been doing them for approximately a month, I started to notice that I was showing improvement. It was not monumental, but I was elated at any improvement at all. I have also noted that I have to do these exercises on a regular basis in order to maintain that level, but it has been well worth it as it has a direct effect on how I function on a daily basis.

By routinely doing this memory stretching, I wanted others to be aware of the benefits. I had difficulty in getting this message out until I approached some of my peers about the idea of putting out a series of guides on this idea and others that would be beneficial to all of us. I was blown away by the response from everyone as they all agreed that this was a project that was much needed.



“I have been doing mental exercises as therapy every day since I received my diagnosis. I know this is working for me. If you keep up with this, and you establish it as a routine, it will work. It’s like stretching your brain.”

(Brenda Hounam, Paris, ON)

Introduction continued

This project has given us all a purpose and sense of accomplishment that not everyone thought we could do. It is amazing what can be attained when people come together with the same purpose in mind. There were many of my peers that agreed with this approach and have offered their input and support over the years. I would like to thank them all now, as they are the ones that have encouraged me to find the strength to continue and bring this project to reality.

– Brenda Hounam, Paris, ON



“We are like the ‘Hummingbird Syndrome’ where we flit from object to object. Being involved in exercises that help us with our concentration is beneficial and extremely helpful for our day to day living.”

(Norm Wilson, St. Thomas, ON)

The warm-up

The importance of keeping your brain active is being documented in study after study. However, information on what mental exercises we should be doing, when and how often is not widely available.

Based on our personal experiences with dementia, we've created an exercise guide for your mind that has helped us to improve or maintain our memory on a daily basis – and our quality of life at the same time.

Looking after your memory means learning to think, see and feel better about yourself. It means that you can change the things you do and the way you do them – both in these daily exercises and in everything you do.

We hope to guide and challenge you to train your memory to function better. At the same time, we hope you'll enjoy these activities, gain strength and find them interesting and relaxing. Above all, we hope you will regain your confidence in doing everyday activities.

These exercises will not work exactly the same for everybody, because dementia affects everyone differently. But we do know if you don't use it, you're going to lose it. And we have found it works for us!

Jog your memory

All of the exercises in this guide were developed with the following three skills in mind and should encompass all three:

- ✓ Memory;
- ✓ Concentration;
- ✓ Problem-Solving.

In addition, we chose exercises that are:

- ✓ Affordable. We know that money can become an issue for many.
- ✓ Flexible. They can be done in the home.
- ✓ Inclusive.
- ✓ Independently-minded. Every activity inspires control over your own time without having to rely on your care partner. We can do it ourselves!
- ✓ Do-able. Most of us can do these exercises. The word “can’t” is not in our vocabulary anymore.



“I used to have to make copious lists, but now I can just jot something down.”

(Scott Millar, Toronto, ON)

Take your mind to the spa

Here are some tips and tricks for making the activities more successful. Use what works for you!

- ✓ Make sure you are in a **quiet space**, free from distractions. Set aside **one hour** or so of “you” time.
- ✓ Focus on your breathing to relax yourself before you begin. Breathe deeply and gently.
- ✓ Establishing routines is extremely important. It’s critical that you follow this routine at least **3-5 times per week**, but try to commit to a daily workout!
- ✓ **Treat it as a job** or as a workout. You need to put forth the effort, the same way you would a task at your place of employment.
- ✓ Choose activities you like to do. But also try things that are new; if you’re a puzzle person, take on a video game. A wide **variety** is very important in order to keep stretching.
- ✓ **Know your limits.** Push yourself, but not to the point where you become stressed. Pay attention to your warning signs that you’ve done enough for the time being – such as a tingling in your head or a headache.
- ✓ **Start easy.** As you get better, you can increase the difficulty level or try timing yourself to add an extra challenge or take on a new exercise.

Take your mind to the spa

continued

- ✓ **Reward your accomplishments.** Write down a list of all the things you CAN do.
- ✓ **Rest your brain.** If you find yourself struggling with a puzzle or activity and begin to feel frustrated, leave it for awhile – overnight even – and come back to it.
- ✓ Come at a puzzle or activity from a different angle. If something looks too tough, don't be put off. Just find a different way to tackle it or a way that works for you and it becomes simple. **Start slow and build your confidence** – and your brain power.
- ✓ It's all about your **personal best**. It's doing the best you can at the present time and that will change as you progress. You might do better tomorrow. You might have done better yesterday. What matters is that you are doing the best you can for this particular date and time.

Don't forget to listen to yourself...You might learn something."

(Don Hayes, B.A., MA, Brantford, ON)

Train your brain!

These exercises will get your brain moving, but feel free to come up with some ideas of your own. Pick the things you like to do and devote an hour every day, three to five times a week. You'll notice the difference!

Word and number games

Crosswords, word searches, word jumbles and Sudoku puzzles are all wonderful and fun ways to improve memory. You can modify these games to suit your needs by seeing how many words you can get in 20 minutes, rather than focusing too long on completing the puzzles.

Matching game

This is a variation of a card game called – appropriately enough – “Concentration” or “Memory.” Divide a deck of playing cards into sets of pairs (i.e. two red Kings, two black Twos, two red Jacks, two black Tens and so on...). You can start with just three sets (six cards) to begin and then gradually build until you can work with more sets. Shuffle the cards and place them facedown on the table. Turn over one card. Turn over another card, in an effort to find the match

for the first card. If it's not a match, turn them both back over. Turn over two new cards each turn, one after the other. Keep going until you are able to remember the positions of the cards when they are face down in order to match cards with their partners. Say the names of the cards aloud – “King bottom left, Queen top right.”

Train your brain! continued

Solitaire

There are many kinds of Solitaire games. Use a deck of cards or play on the computer.

Brain teasers

Remember the Rubik's Cube? It's great for people with dementia. It doesn't matter if you can solve it, just spend some time with it or see if you can get a row or a side. Other brainteasers include wooden, peg or wire games. Pick them up at garage sales, game stores or at Christmas time when they are being sold as stocking stuffers.

Jigsaws

Look for puzzles with fewer, larger pieces to start and as you improve increase the difficulty level. Buy them at garage sales or thrift stores.



“As most of us are aware, a lot of the literature and information concerning people affected from memory loss is relegated to the caregiver. Very little self-help information concerning the person affected with memory loss is available.”

(Rupert Inch, Port Stanley, ON)

Train your brain! continued

Video and computer games

Any video game that requires concentration, memory and problem solving – especially classics such as Tetris – help to work your brain.

Musical instruments

According to research, this is one of the most beneficial activities. Pick up a musical instrument and play, whether it's a flute, keyboard or a guitar. Even if you are only able to use one finger, it will still get you thinking.

Darts and billiards

Both are great ways to improve concentration, memory and problem solving. They're also a lot of fun!

Basic math

Play a numbers game like Yahtzee or dominoes by yourself. Or, set out some basic math problems, such as “making change,” to work on money skills.

Memorizing

- ✓ Read an article over several times and test yourself to see how much you can retain.
- ✓ Make a list of 10 items (e.g., things in the kitchen or workshop) and see how many you can recall.
- ✓ Study the objects in a room. Walk out and list how many things you can remember.

Train your brain! continued

Memorizing

- ✓ Place random objects on a tray and try to remember what was on the tray once you've covered it up or taken it away.
- ✓ Make a shopping list. See how many of the items you can remember on your own.

Help remembering

- ✓ Try breaking lists into smaller sections and sing them in 3/4 time.
- ✓ Use mnemonic devices such as HOMES (Huron, Ontario, Michigan, Erie, and Superior).
- ✓ Take an interest in the objects and words.
- ✓ Say things aloud. Repeat them several times.
- ✓ Come to your senses! Write things on your hand or another body part with your finger or try associating an object with a scent, past experience, or emotion.



“I am so excited about this project; it will be wonderful to show people what we still can do.”

(Sharon Smith, Brantford, ON)

Try something new

Don't be afraid to try something new. Start small and add a little more each time so you can get to a comfortable level. Once that level has been reached, add additional brain exercises.

- ✓ Learn your own new dance moves
 - Put on your favourite music.
 - Make up your own sequence of moves.
- ✓ Try different types of exercises
 - Zumba, Yoga, Tai Chi, martial arts (such a karate kata).
- ✓ Try any exercise that has a sequence of steps and movements.
 - Choose the order of moves that best suit you.
- ✓ Use your non-dominant hand to pick up items or to do different tasks. Try to use both hands equally.
- ✓ **Read aloud** to others or when alone. Saying words out loud strengthens your memory of those words.
 - Read daily calendar events or lists aloud several times.
 - Read to a friend.
 - Read story books to your grandchildren.

Try something new continued

- ✓ History enthusiasts can always expand their learning by researching past events.
 - Research family genealogy or cultural heritage (customs and ideas of people or societies).
 - If you want to research further, go online, visit a local library or cultural centre.
- ✓ Explore touch screen devices as they can be easier to use.

Always try to eat well. A healthy balanced diet helps to maintain brain function. When trying these suggestions, find the schedule that works best for you and your partner. You may need to clear the fog first thing in the morning while drinking your morning coffee or tea. Always pick a time that works best for you, maybe split the time between morning and afternoon. Dedicate time to be the best you can be each day and take it one day at a time.

Try to take part in a variety of activities that have some repetition. It is good to create a routine, but also mix it up every once in a while. Try to stay positive and enjoy the small moments! - don't say 'I can't'. It is trying your best that counts, not whether you succeed or not.

Draw upon your own personal and unique strengths, it helps to build your self worth. Appreciate your weaknesses and pay attention to your personal limits, (as these can change day to day). This will help you to decide what you need to work on.

What research says

Recent studies have shown that we CAN learn new strategies and stretch our brains by doing basic daily exercises and training. These exercises will extend well beyond into your daily activities. It's a new beginning of healing!

Studies conducted by researchers in Miami Florida, and supported by the National Institute on Aging (NIA), are demonstrating the importance of cognitive work, including cognitive training and rehabilitation programs. These studies suggest that people living with dementia can learn strategies for recalling important information and better performing tasks of daily living. Part of the training program involved face-name recognition, such as associating a prominent facial feature with a name, and using and referring regularly to a memory notebook to record important information, appointments, interactions, and events. The Miami Florida studies not only highlight the importance of “working the mind” but also the capacity for new learning in dementia.

Source: Alzheimer's Care Guide, August 2004



“Memory exercises are the first things I do each morning to ‘wake up my brain’. Courage is fear turned inside out!”

(Elaine Smith, Paris, ON)

What research says continued

Researchers investigating a theory called the “cognitive reserve hypothesis” are finding compelling evidence that there are individual differences in the way persons are able to tolerate changes to the brain associated with aging and Alzheimer’s disease. Those who have more engagement in activities, including intellectual activities, and rich life experiences appear to be better able to cope with changes to the brain than those who are less engaged in activities and life.

Source: Scarmeas, N., & Stern, Y. (2003).
Cognitive reserve and lifestyle.
Journal of Clinical and Experimental Neuropsychology,
25, 625-633.

Notes



“I learned that having memory loss is not the end of the world. There are still so many things I can do. What I CAN do, I WILL do.”

(Gail Robinet, B.A., M.Div., Burford, ON)

Brenda's story: The inspiration behind the By Us For Us Guides

When Brenda Hounam was diagnosed with Alzheimer's disease at the age of 53, she realized that very little information was available for people living with dementia. The dominant view was that people living with dementia could no longer learn and be involved in their own care. Brenda knew differently. In 2003, she was inspired to address this gap - to develop a series of resources specifically designed by and for people living with dementia. In 2004, she approached two of her peers with her idea and was surprised by the enthusiasm and support they offered. Through Brenda's contacts at the Alzheimer Society of Brant, the Alzheimer Society of St. Thomas, and the Murray Alzheimer Research and Education Program (MAREP), Brenda connected with various people living with dementia from all around Ontario to work on what came to be called, the By Us For Us (BUFU) guides. These guides provide tips and strategies for managing daily challenges and enhancing well-being for themselves and others living with dementia. Since the publication of the first guide, "Memory Workout", the following guides focused on issues raised by people living with dementia. The project has grown to include three series researched and developed in partnership with people living with dementia and care partners. The philosophy of the By Us For Us guides remains committed, placing importance first on the experiences, suggestions, and tips from those directly affected BY dementia, FOR those directly affected. Brenda has been a true inspiration and role model to her peers. Without her determination and perseverance, this project would not exist or have the international recognition that it does.

Resources

Alzheimer Society of Canada

Toll-free telephone: 1-800-616-8816

Email: info@alzheimer.ca

Website: www.alzheimer.ca

World Health Organization

Website: www.who.int

We also suggest that you check for other local, national and international resources.

Acknowledgements

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The refresh team

Brenda Hounam, Sian Lockwood, Hilary Dunn-Ridgeway and Michelle Stillman

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Sian Lockwood, Emma Bender, Hilary Dunn-Ridgeway and Michelle Stillman

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

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Endorsements

This “By Us For Us” Guide is a wonderful resource for two important reasons. First, a growing body of evidence strongly suggests that more frequent

participation in stimulating activities is associated with higher levels of cognitive function and reduced rates of cognitive decline. Stimulating activities and environments are particularly important for persons living with dementia. Second, and more importantly, this guide has been developed by persons with dementia who know better than any of us about the lived experience of dementia, their capabilities and needs, and what works best for them. I will definitely be spreading the word about this very useful guide!

Sherry L. Dupuis, Ph.D.

Director, Murray Alzheimer Research and Education Program;
Associate Professor, Department of Recreation and Leisure
Studies University of Waterloo

As a physician specializing in the care of individuals with cognitive loss, it has been a privilege to have the opportunity of reading this booklet before it went to print. It is truly an accomplishment for them individually as well as a team to organize and follow through with its publication. The fact that this booklet was prepared by individuals with cognitive loss who are trying to improve both their own function as well as providing valuable suggestions to others with dementia is a demonstration of how using your brain even with cognitive loss can improve one’s function. I am very impressed with the initiative and love that was put in to this piece of work by affected individuals.

Dr. E. Anne Braun

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About the By Us For Us Guides

The By Us For Us Guides (BUFU guides) are designed to provide people living with dementia/care partners the necessary tools to enhance their well-being and manage daily challenges. What makes these guides unique is that they are created BY people living with dementia/care partners, FOR people living with dementia/care partners. The guides include three unique series:

People Living with Dementia: Series 1

This series is written by people living with dementia and covers their experiences. It includes topics such as tips and strategies for managing daily challenges, memory exercises, and enhancing communication and wellness.

Partnership: Series 2

This series is written by both people living with dementia and care partners and covers the partnership experience. It includes topics such as safety, food and mealtimes, social connections, and coping with loss and grief.

Care Partner: Series 3

This series is written by care partners and covers their experiences of supporting a person living with dementia. This series includes topics such as before diagnosis, young care partners, roles, and health and wellbeing.

**To view other guides or order print copies, please visit the Schlegel-UW Research Institute for Aging website:
www.the-ria.ca**

We welcome your input...

If you are living with dementia or are a care partner and would like to comment on this guide, suggest topics for future guides, or participate in future guides, please contact Murray Alzheimer Research and Education Program (MAREP).

Connect with us!

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