Finding a New Lease on Life

By Mary Gretsinger

Editor’s note: Three years ago, Mary Gretsinger, a retired teacher, was diagnosed with Alzheimer’s disease at the age of 66. She resides in British Columbia, Canada and was interviewed for “Insight – A Bulletin for People Living with Dementia” published by the Alzheimer Society of B.C. Mary shared how her love for playing the violin, walking, and her family have helped her embrace a new attitude toward life. We are grateful to Mary and the Alzheimer Society of B.C. for the opportunity to reprint her message from the Insight bulletin in this issue of Perspectives.

Has your outlook changed since you were diagnosed with dementia?

When I was first diagnosed, I concluded that my life was over. I went to bed for four days and cried for about that long. But then I thought about my husband, children and grandchildren and realized that this was a defeatist’s thinking. I am no longer upset by a label. The main thing for me was to get over the shame – to realize that’s just bologna.

Did anything else help you cope with your initial feelings?

I have played the violin since I was a child. One day after my diagnosis, I picked up my violin and played the very same concerto I had played at the Queen Elizabeth Theatre in Vancouver when I was just 16 years old. This experience showed me that I have a lot of living to do.

I read somewhere that music memory stays with you for a very long time. What good news to old musicians like me! Now, I am playing my violin more and my husband has even recorded tapes of me playing to share with friends and various dementia support groups. My drug of choice is the violin. If I’m feeling anxious, I pick up my fiddle. While I’m playing, I don’t have Alzheimer’s disease. I am enjoying life like I have never enjoyed it before. I consider my diagnosis a gift to me now, even though I sure didn’t feel that way in the first four days after my diagnosis.

What other activities do you enjoy?

I still keep physically active. Walking is almost more important than music for me...but not quite! I started walking for mood and fitness in 2006 and as of today, I’ve walked 10,852 kilometers! When I take my first step out the door, sometimes I start out thinking, “I can’t handle this disease” and about halfway out there, I

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start thinking, “Boy it’s a beautiful day.”

How has your family supported you since your diagnosis?

After my diagnosis, we had a family meeting with my husband, my children and grandchildren. My family now knows it’s okay to help me if I am having problems remembering. It also doesn’t hurt for the children to learn why granny might be trying to remember something and she can’t. My youngest grandchild asked me one day “Did you forget anything today granny?” Children are taught to be compassionate.

Do you have anything else you would like to share with people who have dementia?

Another great joy of mine is gardening. I’ve been trying to grow Shasta daisies forever, and yesterday, my first Shasta daisy arrived in my yard. My message to others is to keep growing Shasta daisies – if you will. I want people to know that dementia is not the end of the world, it’s just something that has been given to us.

It hasn’t destroyed my gardening. It hasn’t stopped me from playing the violin, or playing with the grandkids, or going camping and doing all kinds of things. I have a favourite line from a poem by Robert Browning that I have written down in my notebook: “For sudden the worst turns the best into the brave.” There are things I can’t do with Alzheimer’s disease, but that’s not the end of the world, and it’s making me brave.

Insight is a quarterly educational bulletin written for and by people with dementia published by the Alzheimer Society of B.C. To read back issues and to subscribe to the bulletin, see: https://goo.gl/xQNsBQ

TOO GOOD TO BE TRUE?

Editor’s note: The following content is edited from a National Institute on Aging (NIA) publication, “Beware of Health Scams.” To read or order any of the many informative publications available free from NIA see: https://order.nia.nih.gov/view-all-publications

Today, there are many ways to sell untested products – online, TV, radio, magazines, and newspapers are just a few examples. Actors portray doctors and patients on infomercials. It can be had to tell what’s an ad. The problem can be serious. Untested remedies may be harmful. They may get in the way of medicines prescribed by your doctor or be expensive and a waste of money. Question what you see or hear in ads or online. Media do not always check to make sure the claims in their ads are true or say if a celebrity is being paid to endorse a product. Ask your healthcare provider or pharmacist about a product before you buy it. Don’t let a salesperson talk you into making a snap decision. Look for red flags in ads or promotional material that:

Promise a quick or painless cure
Claim the product is made from a special, secret, or ancient formula
Use statements or unproven case histories from so-called satisfied patients
Claim to cure a wide range of ailments
Claim to cure a disease (such as Alzheimer’s or Arthritis) that hasn’t been cured by medical science
Promise a no-risk, money back guarantee
Offer an additional free gift or more of the product as a special promotion
Require advance payment and claim there is a limited supply of the product
My Happy Book
A Wonderful Idea from Cynthia Guzman
by Kristin Einberger

Cynthia Guzman was diagnosed with dementia on her 63rd birthday. Over the course of four years, she was eventually diagnosed with Lewy body dementia. Cynthia has advocated for those with dementia and their caregivers ever since her diagnosis. Much of this advocacy has been done through the Alzheimer’s Association. They have given Cynthia a voice, an audience, and a purpose in life. She served as an Early Stage Advisor for the Association for a year. Cynthia also traveled to Washington, D.C. for the 4th year in a row in April 2016, to speak with legislators during the National Advocacy Forum. Congressman Mike Thompson (D-CA) was so impressed with Cynthia’s work that he named her as Woman of the Year in Napa County, California.

Cynthia’s main purpose in life is to make the journey easier for people with dementia and their caregivers, and to advocate for a cure so that future generations will live in a world without dementia. Cynthia recently shared her idea for a Happy Book with me and we wanted to pass along this idea in the hope that it will bring some moments of joy to others:

One very special Thanksgiving celebrating with family and friends at my son’s house, I took quite a few photos, hoping to remember this wonderful day. Later, I put them all in a book. When I looked at the book later that day, it brought back wonderful memories and made me feel so good. I continue to look at this book often.

I add photos that are important to me, that make me happy, that bring joy to my life. I’m choosy about the photos, as I want them to all be the most special – people and events that make me happy now and that can be used by those around me as my disease progresses to share with me. I got to thinking – if a simple book like this makes me so happy, it would surely do the same for others dealing with dementia. It’s an easy thing to put together and the rewards can be huge. It is a visual reminder of good memories. Not only can it be used for the person with dementia, but it can also be a great tool in so many ways for caregivers and friends. During visits, they can use it to spark conversation and increase feelings of happiness between the person being cared for and the caregiver or friend. It can be a visual reminder of important people in the person’s life. It can also be used for caregivers – family or facility – struggling to take care of the person’s daily needs, such as showering and dressing, as it visually provides good feelings and can make the job at hand easier to perform.

I hope that you will consider making your very own “Happy Book.” Don’t make it too big or it becomes too difficult to hold. I have found that one that is 5 x 7 or 6 x 8 is the perfect size. Be sure to put photos in plastic, as this will allow them to be looked at over and over. Again, I recommend putting only your favorite photos in your book. For caregivers, you might consider adding favorite scents such as citrus or lavender to the book so that not only will there be visual memories, but those of smell also. This should be a very personal book, focusing on what makes you happy. I hope that your book will have as positive an impact on your life as it has on mine. Enjoy!!!

- Cynthia Guzman
HELPFUL RESOURCES

Over fifteen years ago, Kristin Einberger began working with people with early-stage Alzheimer’s and related disorders. Many wanted to find meaningful activity and ways to stimulate their thinking abilities. In 2007, she and a colleague, Janelle Sellick, published Strengthen Your Mind (Volumes 1 and 2), and years later created Sharpen Your Senses activity cards, as well as Strengthen Your Mind Program - A Course for Memory Enhancement. These resources are used by programs working with people with early memory loss, as well as by individuals themselves. Her and Sellick’s newest resource, Brain Flexers, is designed to exercise many areas of thinking such as memory, attention, focus, visual-spatial processing, and sequencing. Einberger states that Brain Flexers is divided into eight sections as follows:

Warm-Ups: Designed with success in mind, this is a way to help get a person comfortable with and excited about doing the remainder of the activities.

Sharpening Your Senses: These activities are aimed at stimulating all five senses through discussion, experiential activities, and reminiscence.

Language: A common complaint among older adults is the “tip of the tongue” phenomenon. This section has a variety of language activities designed to use memory strategies to help combat this and other losses incurred due to aging and memory loss.

Geography: This section spurs recall of travel experiences from long-term memory. The activities that involve navigating maps and determining distance or area exercise parts of the brain involved in visual-spatial reasoning.

Creativity: This section offers a variety of creative exercises that are new and unique and that use creativity to prompt our brains to think “outside the box.”

History and Culture: This section draws on participants’ long-term memories and promotes discussion and socialization.

Logic and Sequence: Problem solving is an important dimension of thinking. Activities in this section help to flex the brain by providing opportunities to figure out the who, what, when, where, why, and how of a variety of scenarios.

Music: Research has suggested the value of music in helping individuals to recall details of events that were previously forgotten. Music is a universal language and these activities provide opportunities to discuss and listen to music, to share memories, and to take part in activities which stimulate long-term memory and promote socialization and camaraderie.

All activities in Brain Flexers are meant to be fun and interesting, but also to provide a challenge. For questions or more information on how to order any of the above resources, contact Kristin Einberger at: keinberger81@gmail.com.
The Value of PET Imaging

Interim results were presented from the ongoing *Imaging Dementia—Evidence for Amyloid Scanning Study* (IDEAS), which is evaluating the use of brain amyloid PET imaging in the diagnosis and treatment of dementia. Amyloid is a protein found in the brain plaques associated with Alzheimer’s disease. Researchers reported results assessing changes in patient management and care in nearly 4,000 IDEAS study participants with mild cognitive impairment (MCI) or atypical dementia where there were challenges making an accurate diagnosis. After receiving the PET scan results, changes in medical management were seen in 67.8% of MCI patients, and 65.9% of people with dementia. This suggests that amyloid PET imaging may play a very important role in diagnosis and management of MCI, Alzheimer’s, and related disorders.

In related findings, a new study by the Karolinska Institute in Sweden found that in 135 people who were evaluated for memory problems, 68% had a change in diagnosis following a PET scan. PET scans are still rarely covered by medical insurance, but these new findings may provide scientific support for their importance in obtaining an accurate diagnosis.

Benefits of Goal Oriented Therapy

The GREAT Trial run by Linda Clare, PhD and researchers at University of Exeter is based on goal-oriented cognitive (thinking) rehabilitation, a program that helps people with early-stage dementia to function and maintain independence in daily activities. The study enrolled 475 participants from eight sites across England and Wales. Participants were randomized into a treatment group of working with an Occupational Therapist for ten sessions to achieve personally meaningful goals or into a control group who did not receive this intervention. Goals of those in the treatment group fell into categories including learning new memory strategies; improving attention and concentration; increasing activity; and reducing anxiety and stress. At the end of the study, researchers found that people who had received the therapy showed significant improvement in their goals when compared to those who did not get the therapy. A second phase of this study will take this therapy into health care settings so that more people can have access to the intervention.

Prevention

It is not uncommon for people with Alzheimer’s or a related disorder to be concerned about increased risks for offspring. Although genetics may play a role in some cases of dementia, there are many ways to offset other risk factors. Dementia prevention is a focus of much research and intervention. Findings were presented on a report published in the prestigious journal, *Lancet*, that identified nine modifiable risk factors that account for up to one third of the cases of dementia. The nine risk factors include: less early-life education; mid-life uncorrected hearing loss; obesity; hypertension; later-life smoking; depression; physical inactivity; social isolation; and diabetes. Addressing these risk factors may lower one’s risk for developing Alzheimer’s disease.
Learning To Be “Good Enough”

*MemoryWorks® at CaringKind*

By Maria Mursch, LMSW
(Manager of the Early Stage Center) and
Geri Taylor, RN, MPH
(Early-Stage Center Participant)

**Maria Mursch:**
The Harry and Jeanette Weinberg Early Stage Center at CaringKind in New York City was designed to meet the needs of people who have been diagnosed with Mild Cognitive Impairment, early Alzheimer’s disease, or a related dementia. The Early Stage Center serves people who are interested in meeting others who have similar experiences, and those who are learning to adjust to their diagnosis and changes over time. Geri Taylor has been a participant at the Early Stage Center since early 2014, and she was featured in the New York Times article “Fraying at the Edges” in spring 2016. She is a passionate advocate for people with early stage Alzheimer’s, and has chosen this forum to share her experience with CaringKind’s MemoryWorks® program.

MemoryWorks® is one of several core programs at the Early Stage Center. The primary goal of this weekly, professionally facilitated group is for participants to socialize and learn from others who have similar cognitive impairments, while working together on stimulating brain exercises including word puzzles, spelling games, and a variety of trivia questions. MemoryWorks® supports participants in feeling stimulated and successful, and provides a sense of camaraderie and cohesiveness. Participants report feeling a sense of relatedness to the others in the room who are sharing similar challenges. Many participants also report feeling better about themselves when their experiences are normalized and shared with one another. Here is Geri’s account of what she has learned from the group, in her own words:

**Geri Taylor:**
After attending the MemoryWorks® sessions for 3-4 years as my Alzheimer’s gets a stronger hold on my word-finding abilities, I have gained personal compensatory strategies to aid my conversational participation. Most importantly, the MemoryWorks® exercises give me greater confidence in conversation and independence.

I have increased emotional strength and acceptance of deficits, and I have embraced a new conversation style. For example: simpler sentences; fewer descriptive words (adjectives); fewer explanations of my thinking background. In essence, the MemoryWorks® activities reinforce the use of habitual word and expression choices. Its best outcome, as I see it, is pulling to the foreground alternate word choices frequently passed over. Hence, my appreciation for the “good enough” word choice as it maintains the fluidity of the conversation. And that fluidity allows the conversation to continue and I remain a participant. Alzheimer’s and my word finding symptoms do not become the topics or a distraction.

What I have learned:
1) Being in communication/conversation with others is most important, not that the thought is most properly expressed.

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2) “Good enough” is good enough. The perfect word is not as important as the intention to communicate feelings or thoughts.

3) Presence, body language and facial expressions are extremely important.

4) Faltering language is not the end of the conversation. Talking around and non-verbal expression is often just as effective as an exquisite sentence.

5) You and your intelligence are not exclusively packaged in your spoken communication.

In addition to learning this from interacting with family and friends, I feel this adaptation has been accelerated and enhanced by sitting with my Alzheimer’s peers. Together, we have gained confidence by seeing our peers’ intelligence and wonderful intention, and we gain confidence to weather our mistakes, word choices, stuttering, “ummmm”, and even the dreaded “blank.” The “dreaded blank” occurs when we so fixate on getting a particular word that the whole point we want to express is lost. “BLANK!” Recovery is often a laugh. This usually inspires someone to jump in. Let them or take it back graciously. However, we do not withdraw, but rather we “stay in the game.” More importantly, we take this with us into our daily lives.

Maria Mursch:
It has been my pleasure to lead Geri’s MemoryWorks® group and to support all of our early stage clients. As Geri so eloquently puts it, many of our participants learn how to accept what is “good enough” in order to participate actively in their lives while living with a cognitive impairment. For more information about the Early Stage Center, please visit www.caringkindnyc.org/earlyphasecenter or call the CaringKind 24-hour Helpline at 646-744-2900.

LETTER TO THE EDITOR

Hi Lisa,
We love your newsletter and use it in our Early Stage groups. I am interested to see that you are using the term “care partners” instead of caregivers. We have been slowly moving that way as well. I am interested in what made you decide on this move and how it is being received.

Thanks and keep up the excellent work.

Sincerely,
Arlene Huhn
Manager, Client Services & Programs
Alzheimer Society of Alberta and Northwest Territories

Hi Arlene,
How nice to hear from you. You raise a very important question. Language is always evolving and the terms “caregiver”, “carer”, and “care partner” are important examples of terms that may seem interchangeable but, in fact, have real and significant differences. In response to your question, I would like to devote an article in the next issue of Perspectives to this topic, but invite essential participation from our readers:

If you are a person with MCI, Alzheimer’s, or a related disorder, do you prefer the word “caregiver”, “carer”, “care partner”, or another term to describe the person or persons who may be helping you, as needed? Why do you prefer that term?

If you are an early-stage support group facilitator, please ask your support group participants the same question and write down each person’s response.

If you are a loved one assisting a person with dementia, what language do you prefer. Why?

If you are a professional, what term(s) do you use with the families you serve?

Please email all responses to Lisa Snyder at lsnyster@ucsd.edu and stay tuned!
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