

PERSPECTIVES

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Two Years Later

By Jennifer Snyder

Editor's note: Jennifer's first essay published two years ago in Perspectives can be found at: <http://goo.gl/ZqGXrD>. She has since moved to a continuing care retirement community.

The interesting thing about life is you don't know what's next. You think you know what's going to happen, but you really don't. I love it that you find you're doing something that you swore you'd never do and that you're not only doing it, but you're enjoying it! It's seeing both sides of the coin. I never thought I'd want to live with a bunch of old people but the people I've been getting to know are really fun people. One of the lovely things is that I don't have any feeling about what am I going to do next or feeling bored or lonely. It's just a feeling of here I am! And it's nice – no anxiety. That's what life has taught me. Don't hold on to expectations of what the future might be. It creates limitations in your future if you have a fixed idea about it, when perhaps you don't even know about other possibilities.

My memory is fading so much and I can't really remember exactly why I decided to move here, but it just happened and it seemed to go smoothly. All of my family

on Maui was moving back to the mainland, so we had to decide where I would go. I was feeling disconnected and foggy because I had little stimulus and structure living alone. One of my daughters is ten minutes away from where I live now. When I arrived, my children had moved everything in already and it was so nice to have my house all set up and to see my things. I felt at home right away. I love the beauty of it - the view of the mountains is wonderful, the darling kids at the preschool next door, and being

close to my daughter and her family. I have my own space – these two big rooms are mine. I can close the door and no one comes in except maybe to remind me of meals or an activity.

I feel I have enough independence and although I miss not having a car and being able to jump in it and go where

I want to, it's also very relaxing to not have the decisions – actually to see the positive in not having to make these kinds of decisions or choices. The hardest part was leaving my cat. He was such a good kitty. I could have brought him, but he would have had to live indoors in my apartment and I didn't want to do that to him. I do miss having a little animal around and I could have one, but I don't necessarily miss the responsibility. I know

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Two Years Later

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how consuming it is. I'd have kitty on my mind all of the time. So maybe it's time to focus now on human companionship.

It's not crowded here, but there are enough people. I'm interested in the other people and what's going on with them. I don't feel crippled by people doing things for me whereas in other times in my life, I felt I had to do things for myself. What I've tried to learn is to graciously accept help from others – to be thankful and not fight against it. Everyone is mixed in together here, so even if my memory gets worse or I need more help, it will be taken care of without having to move from my apartment. You don't want to criticize someone else and how they are doing because that could be you. So I don't have to panic about it or feel like I'd have to hide it if I needed more help.

One of my friends fell this morning and I heard her calling for help. I went out into the hallway but someone was already coming to help her. I don't ever feel like anyone is interfering, but if something happens, someone will be there. So it's a beautiful subtle thing they have going on – feeling cared for in an unobtrusive way. There is companionship and ease, but you always feel like you are still in control. It's a good feeling. I don't feel like people are watching me all of the time to see what I'm doing, but at the same time, they are. If I don't go to meals, they check on me and want to know if I'm OK.

But it's an art for the person who is giving help to people – to help but not overstep. You still want to have some control. They have to consider the other person. A caregiver has to be willing to give but also to step back, as needed. That's the tricky

part. It's as simple as asking, "Could I be helpful with that?" Or "Is it alright if I help you with this?" That's the part of learning with any relationship – how much should I do for you?

I make breakfast in my apartment, but usually eat lunch and dinner in the dining room. There is just enough structure here and mealtimes to participate in with other people. You reach a point when you don't want to cook for yourself anymore or figure out what you're going to eat. It's been gradual – my family has been helping me more and more along the way. But this is

"It's an art for the person who is giving help to people – to help but not overstep. You still want to have some control."

an extraordinary place because I've always felt it's so welcoming and open in the dining room. I haven't felt like a newcomer or out of place, or like I'm butting in. I don't know how

everyone succeeds in that, but they seem to do it. I don't hear a lot of people saying mean things about other people. But I'm pretty intuitive, so maybe I just don't find myself sitting at a table with negative people. I could have really resented having to go to the dining room for meals, but even when I was living alone I had the radio or television on during meals because I like the company.

It's important to be in a situation where you can love people and they will accept you and be loving in return. I feel it is a very loving and accepting place here. It's an open arms feeling. There is opportunity and newness, but nothing you *have* to do. I'm invited to do a lot of activities, but don't feel pressure. That would not work for me if I was being told what to do! Hopefully I give out a sense of love, but I need enough quiet time. I lose energy if I'm with people too much – I can feel scattered and depleted.

I'm really enjoying being creative and painting again. It's not that I'm doing masterpieces but it's just fun! When I first
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moved in, I started out with these coloring books for adults. I hadn't allowed myself to sit and color in a coloring book since my kids were young, but I used colored pencils in the books and it was fun! Now that I'm more settled, my own creativity is being freed up and I get so obsessed sometimes when I'm painting that I have to remember to get dressed and get down to lunch! I love the feeling of the creative muse taking over again. I jump into a stream and get carried along with the joy of creativity. It almost takes the place of a pet in that it's attention to something outside of me.



Jennifer's recent painting for grandson's wedding

It didn't feel complete living alone any more – I really enjoy not only sharing and talking with someone else, but all the little things that come with friendship. I don't feel any sense of push. At my age, I don't want to be pushed! There aren't a lot of "shoulds" like I should be doing this or that. It's nice to allow everything to just unfold. That may be a part of wisdom that comes with age – not fighting against life but going along with it a bit more. I have a belief that somebody on a different level is watching out for me. I have a feeling of my grandfather who raised me and my husband looking out for me and making sure it's all going OK. The comfort of it is so nice. It's support, and it's just right.

Reaching Out Around the Globe



The experience of Alzheimer's and related dementias affects individuals, families, and communities in every country on earth. Some countries are rich in resources, while others struggle to meet the educational and support needs of their citizens. Language barriers are often a challenge and it may be difficult to find educational materials written in the primary language of each country, or within each country's unique urban or rural multi-cultural communities where many languages may be spoken.

Alzheimer's Australia provides an excellent example of an organization that is committed to helping people with diverse cultural and language backgrounds. The national organization provides an excellent website with a wealth of information that can be easily downloaded in over 40 languages. Just click onto the language you need to view the available educational resources from this very helpful website.

<https://goo.gl/sOIrVK>

Another important resource for international support and services is Alzheimer's Disease International (ADI). Their website provides links to dementia organizations around the globe where individuals can click onto their country of origin or onto a country that speaks their language to find information on a website in their primary language.

<https://www.alz.co.uk/associations>

Or see ADI's "other languages" link at:

<https://www.alz.co.uk/other-languages>.

Awakening and Maintaining Your Five Senses



Part Two: HEARING

Over the course of five issues of Perspectives, we are exploring dementia and each of the five senses. In our last issue we discussed sight, and in this issue, hearing.

According to a recent statement from the Journal of the American Medical Association, 40 percent of people over 60 have hearing loss and that rises to 80 percent by age 80. Hearing loss can lead to social isolation, reduced activity, and increased risk of depression. The person with hearing loss and those around him or her can become irritable or frustrated with challenges in communication and the need for raised voices or ongoing repeating of phrases. Hearing loss makes the mind work extra hard to understand words or sounds, and there is also evidence that hearing loss can contribute to brain atrophy (shrinkage). Research suggests that the longer a senior lives with uncorrected hearing loss, the less able the brain may be to make sense of sounds. Poor hearing can cause safety issues if you can't hear a car when crossing the street, a teakettle whistling on the stove, a meeting with co-workers if you are still employed, or respond to an alarm in the event of an emergency.

Some people with dementia do not have hearing loss; rather they hear the volume of sound, but lose the ability to understand or interpret what they hear. This confusing and frustrating problem is called "receptive aphasia" and is more a

problem with the brain than the ears. Sounds come in, but the brain cannot always make sense of the sounds. For example, someone may say to you, "Please pass the salt." You can hear the words, but don't know the meaning of them so it's hard to respond. Or sometimes words or sounds are misinterpreted, so instead of passing the salt, you feel puzzled and do something else entirely unrelated to the request. Aphasia can also affect expression of language. For example, a person may mix up words because it becomes difficult to understand one's own speech.

Some tips for managing and maximizing your sense of hearing include:

- Have your hearing checked by an audiologist and wear hearing aides if needed. Be aware that it can take awhile to get used to a hearing aid, or you may need to be refitted or adjusted a few times. Don't give up!
- Keep hearing aids stored in the same place so you remember where you left them.
- If you do not have hearing loss, but have communication difficulties, see if your doctor will evaluate you for aphasia. This can help you and your loved ones better understand communication challenges and develop tools for working with them.
- Limit background noise during conversations. Turn down the TV, radio, or other distractions. If you eat out, try to find quiet restaurants whenever possible.
- Socialize with smaller groups so you can better track conversations.
- If you don't understand what someone says, it may not help for the person to speak louder. You may need to have the message repeated or rephrased to make it easier to understand.
- Sometimes having others use hand gestures is helpful. For example a care partner can point to the chair when suggesting you sit down.
- Exercise your hearing and your brain by listening to music that you enjoy or taking a walk and noting all of the different sounds you hear along the way.

RESEARCH UPDATES

The Need for Diversity in Research

Clinical trials are a partnership between researchers and volunteer participants who work together to answer questions about hopeful treatments or interventions in Alzheimer's and related dementias. To



ensure that answers are correct, these trials need diverse volunteers: women and men, African Americans, Latinos, Native Americans, Asian Americans, people with Alzheimer's or a family history of the disease, people with conditions that may lead to Alzheimer's, and healthy volunteers. For example researchers have identified that African-Americans and Hispanics face a significantly higher risk of Alzheimer's and other dementias. It is important to understand how and why, so it is essential for minority groups to participate in research. Also a medical or social intervention may work differently in different ethnic groups. Without adequate representation, questions about a treatment in a particular group of people may remain unanswered. The National Institutes of Health maintains a comprehensive list of clinical trials related to many medical conditions for people of all ethnic backgrounds. Click on the website, insert your diagnosis, and see what clinical trials may be recruiting in your area. <https://clinicaltrials.gov/>

Annual Alzheimer's Association International Conference Highlights

 This annual conference is the world's largest international gathering of the dementia research community. Scientists from around the world present findings about clinical trial results; advances

in detection, diagnosis and treatment; and what is state-of-the-art in all aspects of this ever-growing field of research. To read highlights from the 2016 conference held this summer in Toronto, Canada, see:

https://www.alz.org/aaic/releases_2016/wed_300_ET.asp

The Effects of Stress on the Brain

Feeling highly stressed can increase the likelihood that an elderly person will develop mild cognitive impairment, a condition that often leads to Alzheimer's disease. In a study led by Richard Lipton MD, and Mindy Katz, MPH, at Albert Einstein College of Medicine and Montefiore



Health System, researchers looked at the connection between chronic stress and "amnesic mild cognitive impairment" (aMCI), the most common type of MCI, which is primarily characterized by memory loss. In data collected from 507 participants age 70 or older who were enrolled in the Einstein Aging Study, they found that highly stressed participants were more than twice as likely to become impaired than those who were not. Stress was evaluated using a 14-item questionnaire, the Perceived Stress Scale (PSS). Seventy-one of the 507 participants were diagnosed with aMCI during the study. The greater the participants' stress level, the greater their risk for developing aMCI.

There is also research suggesting that stress could hasten the progression of Alzheimer's in those already diagnosed. Because stress is treatable through medical and lifestyle interventions, the results suggest that detecting and treating stress in older people might help delay or even prevent the onset of Alzheimer's. If you are concerned about your stress level, contact your doctor or your local Alzheimer's organization for support or guidance about stress management.

Memory Boosters

Helping Couples Connect

By Anne Hopewell

After my husband was diagnosed with Alzheimer's in 2000, we contacted our local Alzheimer's Society to learn about this disease. We became involved in education and support groups and what little social activities that were available. Unfortunately there were few structured social activities, so in 2012, with a few other couples we had met on this same journey, we created our own group, *Memory Boosters*, for people with dementia and their care partners. *Memory Boosters* meets twice a month in The Villages of Winston Park in Kitchener, Ontario, Canada.

We have worked to develop a program that would suit our needs and appeal to a wide variety of people. We wanted to pro-

bringing some "sweeties" and fruit, and we all have a chance to socialize. We also provide information on educational events, seminars, and opportunities for involvement in research at the University of Waterloo, Ontario, Canada. Many of our group members have been involved in these very worthwhile pursuits.

At the beginning of each meeting there is an opportunity for sharing information or discussing an issue that someone is dealing with so we can all be a sounding board and help that individual. One of the men was struggling with giving up his driver's license. He knew the time had come, but needed the peer help and support. He was grateful for this support and in turn, he was able to support others dealing with this difficult issue.

After this part of our meeting, we then have an activity or game such as: art projects, singing, bingo, line dancing, cookie



vide a safe and supportive environment where people could come and relax and enjoy themselves without worrying about being judged. As one participant with dementia said, *"Perhaps what makes this such a wonderful group is that everyone has an opportunity to contribute to the planning and managing of the club."*

We are all on the same journey and understand what others may be going through. Refreshments are a big part of our meetings and everyone takes a turn

decorating, nordic pole walking, bowling, and popular pot lucks. We reminisce and everyone enjoys sharing and getting to know one another better. We plan themed celebrations for special birthdays and anniversaries and holidays including Christmas, Valentine's Day, St. Patrick's Day, Halloween, and Oktoberfest with one of our members playing the accordion for us. In the worst part of winter we have a Caribbean Day with a steel band that everyone loves. This year we had a special

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Family Day so we could share with loved ones what we do at the club. Everyone had a great time and we plan to repeat this annually. Another participant with dementia says, *"Memory Boosters has given me an outlet to connect, expand friendships and try some activities I may otherwise not have considered."*

We have also organized outings including local museums, picnics, and hikes at local parks. We have gone to a butterfly center and visited two artist's studios to make pottery and glass fusion pieces. We were amazed at the results! This year we are going on a day trip that will be a dinner cruise along the Grand River. We are fortunate to live in a diverse community that has so much to offer. Every year we form a team and participate in our local Alzheimer's Society Walk. Last year, our team came in first place for fund raising and one of our members has been the top individual fundraiser for the past 3 years.

We began as a small group of friends that share a similar experience, but have now grown to nearly 40 members. Our main goal is to have some fun and also make sense of what is happening in our lives. We try to leave our troubles at the door and have some respite. Our participants provide the greatest testimony:

"I cannot tell you how much Memory Boosters has enriched our lives. A great group of people to socialize with."

"We don't have to look anywhere else, we have it all here."

"This has brought some fun back into my life and has inspired me to help others."

Memory Boosters Social Club has achieved everything it has set out to do and hopefully will continue to do so for many years to come!

For more information contact Anne at annehopewell70@gmail.com or visit the Memory Boosters Social Club on Facebook.

YOUR POETRY

In this column, we feature poetry written by a person living with dementia. We thank Bonnie Kraska for the following contribution.

Untitled

By Bonnie Kraska

I wake
I walk
I wander
And I while away the time
And in my head I ponder
*Who am I and what is mine?
Did I leave my child behind?
Or is she hiding in my mind?*

*Does my child know who she became
and are we still one and the same?
Is the sleeping child now blind
or is she hiding in my mind?*

*Did her dreams become my life
and were they dreams of fun or strife?
Did my life become her dream
or did my life stamp out that dream?*

*Do I waken from this dream-road
and wonder how it ends?
Do I marvel at the wonders
or fear the unknown bends?*

I greet my friend—
the me that's now—
*Hello my friend
Stay with me now!
This world is ours
There's much to see
We meet the mornings you and me
We meet each other, you and me.*

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