What’s Next, God?

By Reverend Cynthia Huling Hummel

I have a strong family history of Alzheimer’s. My mother and her brother had Alzheimer’s, and their mother (my grandmother) had some form of dementia. I started experiencing memory problems in my 50s. I had problems with names, with remembering faces, or remembering what I read in books. I wrote everything down and checked it off because otherwise I couldn’t remember if I had actually done the tasks. I felt totally defeated when I couldn’t remember the books of the bible. Heck, even the third graders in my church could do that.

In 2010, I decided to enroll in the Alzheimer’s Disease Neuroimaging Initiative (ADNI) through the University of Rochester. (Editor’s note: See http://www.adni-info.org/). I was hoping that the study might not only help me understand what was going on with my brain but also advance research. Thanks to many tests, which included PET scans, MRIs, a spinal tap, and many cognitive tests, I finally had an answer. I was diagnosed with amnestic mild cognitive impairment (MCI) likely due to the earliest signs of Alzheimer’s disease.

In speaking to my doctors and talking about the probable progression, I made a decision to leave full time ministry, but it broke my heart! I was devastated because I loved being a pastor, but the reality was that I couldn’t do it anymore. But when adversity strikes, we can be bitter or we can be better by looking for the blessings.

I can’t read books any longer, but I can still read newspaper articles or short stories. So I gave away over 500 books when I left the ministry. I couldn’t remember them and they just reminded me of my disability instead of my ability. I try to focus on my abilities. – what I still can do, not what I can’t do. There are lots of things we can’t do as our lives change and we age, so let’s focus on what we can do.

When we get bad news, it is tempting at times to wonder, “Why is this happening to ME?” Chaplain David Martin, Director of Pastoral Care at Robert Packer Hospital wrote, “Rather than asking, ‘Why me,’ the better question to be asking is: ‘What now?’ How is God going to use this adversity?” I’m going to have to get a tee-shirt printed that says, "What’s Next, God?" on it. A woman in my church named Bertie said that God was clearing

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my plate so that I could have a new ministry. Shifting gears now, my new ministry is Alzheimer’s.

I have started a new chapter in my life. I saw an ad in the newspaper for an 8-week class through the Alzheimer’s Association and so I signed up. When I got there, I sat in the parking lot and I cried. I was feeling so sorry for myself and my situation. But I had an epiphany thanks to my mom and the lessons she imparted to us—lessons about not feeling sorry for ourselves, that everyone has their cross to bear, and that into every life a little rain must fall. She taught us to step up to a challenge, and do what we could do to make a difference. I could sit back and wait for someone else to do something or do it myself. So I decided to volunteer for the Alzheimer’s Association. I trained to be a peer-to-peer educator and a support group facilitator. I volunteered to help with the caregiver retreat and to be a speaker in and around my community to let people know about the programs and services available through the Alzheimer’s Association. In 2015, I was selected to serve as one of 12 National Early-Stage Advisors for the Alzheimer’s Association for a year’s term and to be a voice for those living with Alzheimer’s.

I went to a clinic that the doctor recommended for people with brain injuries that helps people who are cognitively challenged to live independently by making adjustments. So part of this is learning to adjust to our reality. I keep a very detailed calendar. I send myself email and text messages. I leave myself voice messages. I have lots of different ways to cue myself to remember things. I set the alarm on my phone with a message because I lose track of time. I’ll use the kitchen timer. I have a sign on my door of all the things I have to remember before I leave the house. Some days I have good days and some days I trip up over my own tongue. It’s sort of like a faulty switch or wire in a lamp. You go to turn it on and the lamp doesn’t come on and then you jiggle the wire a little bit.

The only way that we will find a cure for Alzheimer’s is to fund research—and for individuals to step up and participate in research. I am now in the seventh year of the ADNI study. I learned last year, that I have an abnormal tau protein in my brain and my diagnosis was changed from MCI to Alzheimer’s.

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So I feel even more motivated and energized to do what I can, for as long as I can, to help as many as I can. It’s my mission. It’s what I am called to do. Sometimes well-meaning people will say, “Oh you are so brave.” Oh please! I’m not really brave, but I am bold. I know that what I do can, and will, make a difference.

I have two grown children and one of the ways we’ve dealt with Alzheimer’s as a family is that we’ve talked about it openly and made plans. We’ve talked about end of life issues. Too often people don’t want to have these discussions.

One of the things to be aware of if you have a loved one with Alzheimer’s is to keep an environment that is calmer. Many who live with Alzheimer’s cannot take a lot of noise. As much as I love family gatherings and being out with my friends, the noise level often stresses me out. I sometimes have to disappear into a quiet room to escape from the commotion. I get agitated when the conversation

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is happening over a loud TV program, radio broadcast, or in a noisy environment like a restaurant. Turn off the background entertainment and dial things down for the person with dementia.

Over the years, I have observed care partners taking on tasks that the person with dementia used to handle. There is a balance between being supportive and taking over too soon. When care partners take over something that the person with dementia can do, I believe that unintentionally sends a message “you are no longer capable” and eventually the person with dementia loses that skill or ability. Look for clues on when to step in and help. Otherwise, you may crush our spirit. Don’t answer for us. Give us the time to answer questions directed at us. Yes, it may take us longer. People with Alzheimer’s need to feel valued. We need to feel that we still make a difference. When we help others, we help ourselves.

I’m praying all the time for the people I love, for my family and friends, and for a cure. But it’s not enough to pray for it. We are called to partner with God and do what we can. For me that means participating in clinical trials. For others it might be putting our faith into action – giving respite to a neighbor who needs an hour to go out shopping and sitting with their spouse who has Alzheimer’s. We need to invite people with cognitive difficulties to be part of our faith services, to reach out to someone who may be having memory problems – to be a person who lives out their faith by walking with someone on this journey.

I am a fighter and I am doing everything that I can to fight this disease. My goal is to raise money for research and for support for those of us who have been diagnosed. Together we can make a difference. Together we will end Alzheimer’s!

A Caribbean Cruise for People with Dementia and Their Care Partners

November 11th-18th, 2017

Radio host, Lori La Bay, founder of “Alzheimer’s Speaks” is coordinating a unique seven-day symposium and cruise filled with fun, life lessons, coping skills, and insights to assist all on board with understanding and meeting the needs of those living with dementia. During this cruise, participants will get to know others with dementia and their care partners and hear tips and tricks for living graciously from both professionals and those diagnosed. On-board programs include morning meditations, music therapy sessions, discussion panels, and Memory Cafés where participants socialize and discuss a range of subjects. Lori Le Bay describes her intended experience as one where participants “hear others’ dreams, struggles, and joys while feeling a true sense of comfort knowing that others understand, accept, and support you.”

The cruise leaves from Fort Lauderdale, Florida and stops include the Bahamas, Puerto Rico, St. Thomas, and a private island, Half Moon Cay. To read more about this Caribbean Cruise, see the Alzheimer’s Speaks website at: https://alzheimersspeaks.com/cruise-with-us

For more information about pricing, details of the itinerary, and registration, contact Kathy Shoaf at 219-608-2002 or Kathy.shoaf@cruiseplanners.com.
Travel Strategies and Tips

Travel is a meaningful activity for many people with Alzheimer's or a related disorder. "When I travel to a new place, it takes my mind off of all my worries," says Al. "I see new things and have different kinds of experiences than I do at home. I feel part of something bigger than my usual little world."

Alzheimer's may have little impact on your enjoyment of travel but you might need to modify plans somewhat. Memory challenges and being out of your normal routines increases your risk of losing things or becoming fatigued or disoriented. Many people continue to travel on longer vacations or tour foreign countries, but if such trips become too challenging, shorter weekend trips can be satisfying. You may enjoy a visit to a familiar destination such as the home of family or close friends. Consider taking a few small trips to see how you adjust before embarking on a longer trip to an unfamiliar place.

When you plan for travel the following tips may be helpful:

• Simplify your travel itinerary. See fewer places in greater detail so you have more time to get accustomed to new surroundings. Some people enjoy small cruise ships because the boat provides a consistent place for sleeping and eating with the opportunity to dock at different ports for day trips.
• Schedule in “down time” during your trip when you are not on the go and can rest.
• Have identification with you at all times. Check with your local Alzheimer's organization for programs to enroll in such as Medic-Alert/Safe Return so you can receive assistance if you get lost or become separated from your group.
• Consider wearing a watch that includes GPS tracking so a loved one can trace your location if needed. If you carry a phone many cell phones have this tracking option, as well.
• Bring a nightlight for your hotel bathroom so you can find your way to the bathroom more easily in the dark.
• Pack lightly! Too many items and bags create more opportunities to lose things.
• Ask your doctor about a mild sleep aide to use if needed. Disrupted sleep and jet lag can increase confusion and disorientation. Do not use over the counter sleep aids without a doctor’s approval as they can increase confusion.
• Drink plenty of fluids. Travel (even in cool climates) can be dehydrating resulting in worsened memory and confusion.
• Keep a simple diary or take photographs to help you recall each day’s events and help you recall your trip when you return home.
• Write good old-fashioned postcards to friends and family. Ask them to keep them for you so you can have them as mementos upon your return home.
• Consider telling other travelers or tour guides that you have Alzheimer's or a related disorder, or simply that you have memory problems. This may put everyone more at ease and allow others to help you if needed.
• Bon Voyage!

This article is reprinted from Living Your Best with Early-Stage Alzheimer's by Lisa Snyder. Available at: https://goo.gl/osIB6x
Awakening and Maintaining Your Five Senses
Part Five: TOUCH

Over the course of five issues of Perspectives, we have been exploring dementia and each of the five senses. In our previous four issues we discussed sight, hearing, smell, and taste. In this final article in the series, we explore the sense of touch.

Touch is the first sense to develop in the womb and may be one of the most enduring of the five senses well into late life. Touch can be a powerful form of communication, and persons experiencing any stage of dementia do not lose their ability to respond to caring touch. Our sense of touch is engaged throughout the day and night, so it is important not to overlook this important sense.

Tiffany Field, PhD and colleagues reviewed research that looked at the effects of massage therapy on the body's biochemistry. They found that in many different medical conditions and stressful life experiences, massage has been shown to reduce stress by decreasing levels of the stress hormone, cortisol. Even the simple act of holding hands with a loved one while out on a walk or watching a movie together on the couch.

Consider the following tips for engaging your sense of touch:

- Reach out and touch while outdoors (while paying attention to avoid toxic or spiny plants). Is there soft new growth on a bush, textured bark on a tree, or a welcoming lawn to sit on in a park?
- Don’t underestimate the simple act of holding hands with a loved one while out on a walk or watching a movie together on the couch.
- Research suggests that petting a dog or cat can reduce blood pressure and have a calming effect. If you don’t own a pet, some communities have visiting pet therapy programs. Or a neighbor’s friendly dog might enjoy the attention!
- Consider working with a licensed massage therapist who can do gentle bodywork to reduce any stress and evaluate any areas of pain. Take care of your care partner and encourage him or her to seek massage therapy as needed, too!
- Have a loved one place some small familiar objects of varied textures in a bag. Close your eyes and reach into the bag. Pick an object and try to identify it just by touch. How does it feel?
- Think about the many ways you experience touch each day. What experiences are pleasant? How might they happen more often? Are there experiences that are unpleasant? If so, how can those be reduced or modified?

Not all touch is a positive experience, however. Certain health conditions can impact the sense of touch including poor blood circulation, some neurological disorders, and diabetes. Also, skin becomes drier and more fragile as we age, so touch may need to be gentler or can incorporate soothing or hydrating skin lotion. As dementia advances, it may be harder for a person to verbally describe pain or unpleasant sensations, and it is important for care partners to be sensitive to any body language or facial expression that may indicate pain.
RESEARCH UPDATES

Phone-Based Study Recruiting People with Dementia with Lewy Bodies and Caregivers

The purpose of this study is to get input from those that have dementia with Lewy bodies (DLB) and their care partners on certain study questionnaires. The questionnaires are used in clinical trials to assess recent symptoms that may affect the behavior of those living with the condition.

A person with DLB and their care partner will participate in two telephone interviews (and an optional third telephone interview) which can be done from their own home. Each telephone interview will take one-to-two hours to complete. There is no medical treatment involved in this study. Participant pairs will receive a $100 payment ($50 each) to compensate for their time for two interviews, or a $200 payment ($100 each) to compensate for their time for three interviews.

If you are over age 50, English speaking, and you and your care partner are interested in participating in this study, contact the primary investigator, Aaron Yarlas, by phone at 401-642-9245 or by email at ayarlas@qualitymetric.com.

Effects of Diet Drinks on the Brain

Recent data derived from the Framingham Heart Study and published by Matthew Pase, MD and colleagues at Boston University has found that people who drink sugary beverages frequently are more likely to have poorer memory, smaller overall brain volume, and a significantly smaller hippocampus (a region of the brain responsible for memory). Their follow-up study was more specific in the effects of diet sodas on the brain. Dr. Pase states, “We also found that people drinking diet soda daily were almost three times as likely to develop stroke and dementia. This included a higher risk of ischemic stroke, where blood vessels in the brain become obstructed and Alzheimer’s disease dementia, the most common form of dementia.” Although the researchers suggest that people should be cautious about regularly consuming either diet sodas or sugary beverages, future studies are needed to test whether giving people artificial sweeteners causes adverse effects on the brain.

Reference: Boston University School of Medicine website

Congress Approves Increased Funding for Dementia Research

Bipartisan members of Congress recently approved an additional $400 million in funding to the National Institute on Aging (NIA) for Alzheimer’s related research as part of a $2 billion increase in this year’s National Institutes of Health (NIH) budget. This encouraging and essential support of Alzheimer’s research does not, however, address the Trump administration’s request to cut National Institutes of Health (NIH) funding by 18% in 2018. NIA is one of the 27 Institutes and Centers of the NIH and is the primary Federal agency supporting advances in Alzheimer’s research across the country. [https://www.nia.nih.gov/]

NIA also oversees Alzheimer’s Disease Education and Referral (ADEAR) that is focused on education and support for people with dementia and their families. See ADEAR’s informative website at: [https://www.nia.nih.gov/alzheimers]
“AROMA DE CAFÉ”
The First Spanish-Speaking Memory Café in Massachusetts

We thank Martha Medina and Angeline García, facilitators of Aroma de Café, for generously sharing their experience in order to give others an example of a Spanish-speaking café. We also recognize the vision and hard work of the Executive Director of the Lawrence Council on Aging, Martha Velez, and her colleague Laura Alefantis, for bringing this café into being.

The Lawrence Council on Aging started the first Latino Memory Café through a grant given by the Massachusetts Association of Councils on Aging (MCOA) at the Lawrence Senior Center on July 21, 2016 with five participants with dementia and their caregivers. In keeping with the cultural theme, we decided to call our café “Aroma de Café” (The Aroma of Coffee). The community has come to know and respect the Lawrence Senior Center for its warm, welcoming atmosphere that provides a supportive, diverse, and safe environment for elders, their families, and caretakers. The Senior Center is centrally located in the heart of Boston, surrounded by elder housing. There is access to public transportation for anyone that wishes to attend. Currently, the majority of elders that attend the Senior Center are primarily Latino; however the Senior Center strives to offer a place that is inviting, culturally sensitive, and inclusive to everyone who enters through its doors.

Finding Spanish-speaking elders and their care partners who would be appropriate participants was not difficult, since many attend the Senior Center for other programs. Our ongoing struggle is around the stigma attached to Alzheimer’s that complicates our outreach efforts. Culturally, Latinos are often private people, especially about Alzheimer’s or dementia. These are treated as a “family matter” to be dealt with in the home, and families rarely seek outside support.

This is why it is important to offer Aroma de Café at the Senior Center, a place that our Latino elders and their family members have already familiarized themselves with through other daily events and programs. Many have established relationships with staff, volunteers, and other elders that likely were developed before any symptoms of Alzheimer’s began to surface. Our “Aroma de Café” has a unique atmosphere due to the high level of family participation. We also think it could be beneficial for Personal Care Attendants and Home Health Aides to participate in these activities with their clients.

Aroma de Café meets once a month for two hours. Time is split between doing a facilitated activity and informal socializing. Typical activities are based in the creative arts, such as making collages, storytelling, or dancing. The creative arts utilize brain functions that tend to endure as dementia advances. Because there is no right or wrong way to do them, they encourage participants to feel successful. The focus is on joy, connection, and what the person can do. The rule of thumb in our café is that staff and volunteers don’t raise the topic of dementia unless guests do. This way the door is open to guests who have not been diagnosed, do not accept their diagnosis, or simply need a break from thinking about it.

A Spanish language toolkit for developing your own memory café can be found at: http://www.jfcsboston.org/GuiaCafeDeMemoria
You can find the toolkit in English at: http://www.jfcsboston.org/MemoryCafeToolkit
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**Perspectives** is published by:

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**Perspectives** is published quarterly and is supported by the National Institute on Aging grant P50 AG05131. Copyright 2017. Electronic formats may be printed for personal or professional use, but please do not reprint newsletter articles for other publications without permission. Electronic subscription is free of charge.

All articles, unless otherwise cited, are written by Lisa Snyder, LCSW. For citation purposes, refer to the article author, title, and the newsletter's complete name.

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