



Memory Cafe of the Red River Valley

PEOPLE WHO ARE FORGETTING SHOULD NOT BE FORGOTTEN

September 2024



IN THIS ISSUE

- Helping our caregivers - Maggie Ness
- My Message for Primary Care Providers - Kimberly Hinkel, PA- S
- *The Guest House* - Rumi
- Still Here, Still Me - Dr. Richard Taylor
- Remembering Lee and Roger
- For Our Health - Creating Your Centenarian Decathlon, Dr. Peter Attia
- Just for Laughs - Steve Froslie and Friends
- Alzheimer's Poetry Project
- Walk to End Alzheimer's, September 14th
- *To Test or Not to Test* - Alzheimer's Foundation of America
- Did you Know? Alzheimer's Association
- elbi - have you registered?
- September Meeting Schedule
- Sing From Your Heart Chorus update
- Toolbox for Caregivers, Parkinson's Foundation
- Ultrasound Showing Promise for Treating Alzheimer's Disease, University of Queensboro
- Insights for Family Caregivers, Healingwell.com

MY MESSAGE FOR PRIMARY CARE PROVIDERS

By Kimberly Hinkel, PA-S

"Memory Cafe provides a safe and supportive environment for individuals experiencing memory loss and their caregivers. It is a terrific organization that every primary care provider in the FM area should recommend to family members and patients who have received a new diagnosis of dementia."



Hi Memory Cafe Friends,

I want to talk a little bit about asking for help. This can be difficult for many of us but I would like to remind you that there are many people in our lives who would like to help you, we just need to ask AND accept. In the many avenues life takes us, we cannot travel them alone.

Below is an excerpt from Jolene Backey's book, Creating Moments of Joy book.

"Caregivers will need the help of others to get through this. They are on call 24/7 in their hearts, if not literally. They feel a deep personal burden about the needs they expect themselves to fulfill. So a helping hand might not be accepted..."

The caregiver: "No, you don't have to do this."

Your response: "Yes, I want to."

The caregiver: "No, I've never left him before."

Your response: "Just go. We will be fine."

The caregiver: "He might..."

Your response: "You don't have to worry. I got it."

The caregiver: "Well..."

Your response: "We will be just fine. Enjoy yourself."

The caregiver: "Are you sure?"

Your response: "Yes, I'm sure. Take as long as you need."

The caregiver: "I don't know."

Your response: "Well I do. Now scoot" (with a smile)

The caregiver hesitates... Your response: "Scoot."

Once the caregiver experiences that it is okay for someone else to help, they will be quicker to accept help the next time. The first time is the most difficult.

Caregivers are exhausted and don't have the energy to ask for help or even figure out how others can help. Keep it simple. Ask the caregiver what are the five ways we can help, and get them to be specific. It's important for someone to set up a help schedule. When we visit or help all at once, we are actually adding more stress.

Whatever might ease their journey... do that. Sometimes it's better when the caregiver is out of the house. It's too easy for them to feel guilty if they are watching you help. And when helping, reassure them by saying, "You are my friend, I care about you, so please let me help."

With gratitude,
Maggie

The mission of Memory Cafe of the Red River Valley is to recognize the intrinsic beauty and value of individuals living with memory loss while inspiring in them and their loved ones hope, joy, and a sense of empowerment.

The Guest House

By Rumi



This being human is a guesthouse.
Every morning a new arrival.

A joy, a depression, a meanness,
some momentary awareness comes
as an unexpected visitor.

Welcome and entertain them all!
Even if they're a crowd of sorrows,
who violently sweep your house
empty of its furniture,
still, treat each guest honorably.
He may be clearing you out
for some new delight.

The dark thought, the shame, the malice,
meet them at the door laughing,
and invite them in.

Be grateful for whoever comes,
because each has been sent
as a guide from beyond.

Dr. Richard Taylor



Richard Taylor, Ph.D. (decd. 2015), was a psychologist who was diagnosed with Alzheimer's-type dementia at the age of 61. He started writing short essays for his own benefit—trying to better understand what was going on inside of him.

He sought out others with dementia and began forming online chatrooms, which eventually grew into an international network. Through his writing and other communication efforts, he became a champion for individuals with early-stage and early-onset Alzheimer's disease, speaking regularly throughout the U.S. to avid audiences about the challenges of living with dementia.

He helped to found the Dementia Advocacy and Support Network International (DASNI)



Lee and her devoted husband, Gary, were regular attenders of Memory Cafe on Monday mornings. Lee was an amazingly cheerful and upbeat friend to all of us; she was so special! We miss her constant smile, gentle laugh, and frequent message to us, "I love you." Our thoughts and prayers are with Gary and their wonderful family.

STILL HERE, STILL ME

Voices of Those Living With Memory Loss

By Dr. Richard Taylor, *Alzheimer's from the INSIDE OUT*

Waiting for... (Excerpted)

When I first stumbled across Dr. Alzheimer in my brain, he was an occasional nuisance. He would empty a room full of memories here and there, and cause a couple of doors to stick, but I devised strategies to get around his tricks. Later, he became a frustrating pain in the ass. He would confuse my thought processes from time to time. I couldn't figure out things the way I had prior to meeting him. Now, he is a constant companion. Every day, every hour, every few minutes, I lose my train of thought. Not only do I lose it, I can't recall the name of the train, where I was going, or why I wanted to go there. Faces are merely familiar; the name is gone without leaving a trace. I am interrupted in my thought processes by improvised explosive devices left by Dr. Alzheimer. They explode between my ears but are not noticed by passer-bys outside of my head. My life is an on-going struggle to stay on track, to complete the thought, to find the right words, to hold myself together in the eyes of others when we are speaking. If a third person enters the conversation, I am simply lost. Now where was I? What were they saying? Conversations pass me by as I struggle to keep up, keep on track, and stay in the game.

Like the tramps in *Waiting for Godot*, I stand around hoping something will happen, someone will come and straighten it all out. In the meantime, my life goes nowhere; there seems little purpose other than to simply wait and watch. I direct my struggles to hanging on to yesterday. I am missing today and don't even want to think about tomorrow.

I don't think Godot is ever going to show up. Where is the meaning, the purpose, the happiness in being me today? The longer I wait, the more limited my cognitive options seem to be. But who or what am I waiting for? Me? To get better? To stop getting worse?

I am sure there is humor in my life, even now. I am sure there is unique meaning and purpose in my life, especially now. Maybe I shouldn't try so hard to find it; frustrate myself so much trying to understand it; disappoint myself so much trying to change it.

I am going to try standing around for awhile and see what it feels like, watch what happens. Maybe I should have done more of this in the past!

REMEMBERING OUR FRIENDS, LEE AND ROGER



Roger P.

Roger and his wife, Alice, and their daughter, Lori have attended Memory Cafe faithfully for several years. Roger always had a big, friendly smile on his face and was such a good friend to everyone he met. He became an excellent wood burner during Jerry and Janine's class and was so proud of his work. We will really miss our dear friend, Roger.



FOR OUR HEALTH CREATING YOUR CENTENARIAN DECATHLON OUTLIVE BY DR. PETER ATTIA (EXCERPTED)



Create your “Centenarian Decathlon” for a sustainable approach to exercise!

The most important part about exercising is to go from zero workouts to getting any regular movement at all. In one study, participants going from inactive to 15 minutes of daily, moderate exercise saw a decline in overall mortality of 14%. That’s huge! Unfortunately, most guidance around exercise is either too specific (“how to run your first half marathon”) or too generic (“just move more!”), Dr. Attia laments. That’s why he recommends you create your own “Centenarian Decathlon.” What’s that?

Your Centenarian Decathlon is a list of 10 exercises you’d like to still be able to perform when you’re 100 years old. What are they? They could range from walking for 10 minutes to taking 20 stairs in one go all the way to completing a 3-hour hike. Take some time to think of cool physical feats for a 100-year-old to accomplish, and write them down.

Regardless of whether your Centenarian Decathlon is ambitious or humble, the message is clear: Start working on those exercises now. After all, how can you expect to do something at 100 if you can’t do it at 40?

Pro tip: If you want to set more ambitious exercise goals, make up another decathlon for a closer decade of your life. If you’re 30 now, what would you like to be able to do at 50? And so on.

The exercise you dream of but never do is pointless. The exercise you do on a daily basis, no matter how small, is everything.

Alzheimer's Poetry Project (APP) alzpoetry.com

The mission of the Alzheimer's Poetry Project is to facilitate the creativity of people living with Alzheimer's disease and related dementia. We work with their care partners, healthcare workers, educators, and students to perform and create poems. We do not set boundaries in our beliefs in what is possible for people with dementia to create. By saying to people living with memory loss that we value you and your creativity, we are saying we value all members of our community.”



JUST FOR LAUGHS STEVE FROSLIE AND FRIENDS



Steve and his lovely wife, Linda.

When you are stressed, you eat chocolate, ice cream, cookies, cake and sweets. Why? Because stressed spelled backwards spells desserts.

Knock, knock
Who's there?
Wilbur Wright
Wilbur Wright who?
Wilbur Wright back
after this guitar solo!

Knock, knock
Who's there?
Omelet
Omelet who?
Omelet smarter
than I look.

There are times when my greatest accomplishment is keeping my mouth shut.

Why do you
feel
sophisticated
when you're in
the bathroom?
European

How many grad
students does it
take to change
a lightbulb?
One, but it
takes ten years.

From the Mind & Mouth of Yogi Berra:

‘Always go to other people’s funerals, otherwise they won’t come to yours.’

‘In theory there is no difference between theory and practice. In practice there is.’

‘When you come to a fork in the road, take it.’

‘If you ask me anything I don’t know,
I’m not going to answer.’

‘If you don’t know where you are going, you might wind up someplace else.’

QUOTE OF THE DAY

“I enjoy the process of doing things, and most of my feelings of accomplishment come from the middle, not the end, of projects.”

~ Dr. Richard Taylor, Alzheimer's advocate,
Alzheimer's from the INSIDE OUT (see p. 2) 3.



BUILDING SKILLS AND COMMUNITY



Saturday, September 14th
 Essentia Health Plaza at The Lights
 300 32nd Ave. W West Fargo
 Registration 9am
 Opening Ceremony 10am
 Walk 10:20am



Let us know if you'd like to sign up to be on our team or register using the QR link above.



- Only about half of Medicare beneficiaries with a diagnosis of Alzheimer's disease or dementia report being told of the diagnosis.
- Nearly half of Primary Care Providers sometimes choose not to assess patient cognition because treatment options are limited.
- Less than half of people with subjective cognitive decline have discussed their thinking or memory issues with a health care provider.

Source: Alzheimer's Association

HAVE YOU REGISTERED?



Get FREE on-demand support to ease the demands of dementia caregiving. elbi is an accessible mobile app that acts like a dementia specialist and support partner in your pocket.

Learn more at askelbi.com and register for FREE access here: bit.ly/tryelbi

“TUSEN TAKK” JERRY! (MANY THANKS)

We had such a special afternoon listening to Jerry Ness tell jokes and stories using the charming Norwegian wood figures he carved. It was absolutely delightful! Thanks, Jerry!



TO TEST OR NOT TO TEST?

Alzheimer's Foundation of America
 ALZ-TODAY-18.1_MECH-HR.pdf



The global genetic testing market was valued at \$8 billion in 2021, according to Precedence Research. Ancestry tracing sites have spurred the growth of personal-information seeking so significantly that genealogy has become the second most popular hobby in the United States, Science News reports.

Nathaniel A. Chin, MD, an assistant professor (CHS) at the University of Wisconsin-Madison, department of medicine, geriatric division, says “probably the most important question” involving this interest is what people should consider before getting tested. “It's not just a test that affects one person, just as Alzheimer's is not a disease that affects one person,” Chin says. “The key things to consider are: Why are they getting it? What are they hoping from the outcome? What is their motive?”

Secondly, people need to consider what they will do with the information if they prove to be at risk. Will they behave differently and make changes? Will they see themselves differently or worry that others do? What are the psychological consequences of knowing this information?

“Are there specific treatments based on your genetic risk? The answer is no,” Chin says. But while no therapeutic interventions exist now, great support groups do and joining a research study is also possible.

“Who are you going to talk to? Will you tell family and friends. Will your insurance company learn about it? Will it change your medical care? These are some of the questions that come up. One test leads to so many other questions. It's a ripple effect.”

“I would advocate that people need to consider how they will handle the information. That is the value of good counseling, to know what is involved. Counseling plays a huge role and should be mandatory.” It is not currently mandatory.

For initial exploration, Chin recommends the website genetestornot.org, which helps people think through the whole process of getting tested.

Chin said counseling about risks, particularly genetic risks, should be part of medical education. Medical providers play a critical role in terms of explaining risk, helping the patient consider the psychological effect the information could have and what the consequences of telling family and friends could be.



SEPTEMBER MEETING SCHEDULE

Questions? Call 701-404-6712

MONDAY SCHEDULE

Meet at Bethel Church (2702 30TH Ave S. Fargo)

Monday Schedule:

9:00-11:00 am - Coffee and Conversation Groups The Gathering Support Group for men and women recently diagnosed with MCI or early stages of neurocognitive impairment. Separate caregiver support groups for men and women care partners. Trained volunteers engage with your loved one with entertaining activities in a separate room during these support groups. Free. No reservation required for any Memory Cafe gatherings.

1:00 - 2:30 pm - Afternoon Programming:

- **2nd** - No Programming; Happy Labor Day!
- **9th** - Planning for the future: Assisted Living and Nursing Home options with Vickie Ness, LSW, (rescheduled from last month). Trained volunteers engage with your loved one in a separate room during education.
- **16th** - Creative Therapies with Kristen Young
- **23rd - 11:30 - 1:30** - Dine and Dance, Moorhead American Legion, 303 30th St. N. Moorhead
- **30th** - Fall Party & Games with Friends!

SING FROM YOUR HEART CHORUS

Thursdays, Sept. 5th and 12th, 1pm - 3pm (Social time 2:00-2:30pm) Bethlehem Lutheran Church (613 16th Street South, Fargo)

YOUNG ONSET DEMENTIA SUPPORT

Monday, Sept 23rd, 6:30 - 8 pm

Guest speaker - Sara Hentges, LSW, Fargo VA

Pizza will be served!

1122 1st Ave N. Fargo. Use west entrance on 12th St.

'DINE AND DANCE'

Monday, Sept. 23rd 11:30 - 1:30 pm

Moorhead American Legion

303 30th St N. Moorhead

Musicians - The Norsky Brothers, another favorite!

CrossFit at Memory
Cafe!



WEDNESDAY SCHEDULE

All meetings are 1-2:30pm at the specified locations

Wednesday Schedule:

4th - FALL KICKOFF CELEBRATION! Live music by the Golden Notes & Flowers from Hope Hope Lutheran church, South campus

11th - Huntington's Disease, Lynn Kotrba's caregiving journey; Harvest Hope Farm, support for families living with Huntington's disease. Hjemkomst Center, Moorhead.

18th - Laughter Yoga, Jan Nelson and Barbara Edin, HeartSprings Community Healing Center, Hope Lutheran church, South campus

25th - 9:30 - 11am - **Moving Ahead: Life After Loss Support Group*** For widows/widowers who have lost loved ones from dementia.

25th - 1 - 2:30 pm - **Caregiver Cafe Caregiver Support Group***

*Both support groups, on the 25th, meet at the Linger Laugh & Learn Center, 1122 1st Ave N, Fargo. Call 701-404-6712 for additional details.

VOLUNTEER MEETING AND EDUCATION

Tuesday, Sept. 10th, 1 - 2:30pm

Education - New tools for diagnosing dementia, Dr. Rodney Swenson, Neuropsychology Associates, Fargo.

'THE GATHERING' SUPPORT GROUP

Mondays, 9-11 am Bethel church. Newcomers welcome!



New support group for men and women recently diagnosed with early stage memory loss caused by any neuro-degenerative health condition. No reservation necessary.

Monday mornings
9 - 9:30 am!
See you there!



SING FROM YOUR HEART CHORUS

By Deb McTaggart, Director



Do you love to sing but worry you don't have the experience?

Many people hesitate to join a chorus for fear of not being good enough. Sing From Your Heart believes that everyone can sing from their heart and that the joy of singing together is what truly matters!

New to choirs? No problem! We welcome singers of all abilities in a supportive and encouraging environment.

Think your voice isn't what it used to be? We focus on the joy and beauty of singing together, not perfection.

Don't read music? That's okay! We can provide music binders with just the lyrics.

Sing From Your Heart is more than just a chorus, it's a community!

Just like many dementia-friendly choruses across the country, we believe in the power of music to connect and uplift. Many choruses have adopted the motto, "There is no wrong in this room," so consider joining Sing From Your Heart and experience the magic of singing together!

Join us this season!

We meet every Thursday from 1pm-3pm at Bethlehem Lutheran Church (613 16th Street South, Fargo). Our season is already underway, but it's not too late to join the fun! You are also welcome to visit and experience a rehearsal September 5th or 12th.

You can contact the chorus via our website, singfromyourheartchorus.org, by email: singfromyourheartchorus@gmail.com, or by phone 651-369-0629.

SAMSON'S FUNDRAISER UPDATE:

\$2555.00 RAISED SO FAR!

Samson is dedicating his hike on the Pacific Rim Trail (2,653 miles!) to his grandfather, Bill who was diagnosed with Alzheimer's disease last year.

Thank you Sam for supporting Memory Cafe!



A TOOLBOX FOR SELF-CARE

Parkinson's Foundation (parkinson.org)



Here are some tools for practicing self-compassion to help you maintain your physical and emotional health.

Identify Stress Triggers. A first step in self-care is identifying and acknowledging what causes your stress. Irritability, for example, may be triggered by certain situations, like having three things to do at once or having trouble getting your loved one out the door on time.

Acknowledge your right to feel emotionally off-balance.

Recognize the hidden grief component of your anger, anxiety, guilt and depression. Expect adaptation to, but not resolution of, your grief. Accept it and seek out support.

Determine your limits. What is your comfort level providing care? Everyone has limits. What are yours?

Build in regular breaks from caregiving and make them a priority. You cannot be a good caregiver to someone else if you don't take care of yourself.

Delegate. You may feel that you don't want to burden others, but in fact most people are willing to help if asked – they just need direction.

Often, in the rush of errands and medication schedules, quality time gets pushed to the bottom of the to-do list. Try prioritizing your list of caring responsibilities. Take on the most important ones yourself and try to find someone else – paid or unpaid – to help out with the less important ones.

Focus on the Positive. This may sound unrealistic in the midst of a difficult situation. However, we all harbor some degree of optimism and there are proven techniques for nurturing it.

Seek out joy in your relationship with the person with Parkinson's (or dementia). Your hands-on duties, such as bathing and dressing your loved one, might feel like work, but these tasks bring you together. Add some fun to your hands-on care: sing songs, tell jokes, share goals and dreams.

Develop a habit of participating in activities together outside of care tasks. Shared time as husband-wife, mother-daughter, siblings or other relationship – rather than as caregiver and care recipient – allows you to enjoy each other and build happy memories.

Treating yourself with care is not a luxury, but a necessity. It helps us rediscover the purpose and meaning in our lives.



ULTRASOUND SHOWING PROMISE FOR TREATING ALZHEIMER'S DISEASE

UQ News (University of Queensland)

May, 2024

University of Queensland researchers have found targeting amyloid plaque in the brain is not essential for ultrasound to deliver cognitive improvement in neurodegenerative disorders.

Dr Gerhard Leinenga and Professor Jürgen Götz from UQ's Queensland Brain Institute (QBI) said the finding challenges the conventional notion in Alzheimer's disease research that targeting and clearing amyloid plaque is essential to improve cognition. "Amyloid plaques are clumps of protein that can build up in the brain and block communication between brain cells, leading to memory loss and other symptoms of Alzheimer's disease," Dr Leinenga said.

"Previous studies have focused on opening the blood-brain barrier with microbubbles, which activate the cell type in the brain called microglia which clears the amyloid plaque. "But we used scanning ultrasound alone on mouse models and observed significant memory enhancement."

Dr Leinenga said the finding shows ultrasound without microbubbles can induce long-lasting cognitive changes in the brain, correlating with memory improvement.

"Ultrasound on its own has direct effects on the neurons, with increased plasticity and improved brain networks," he said. "We think the ultrasound is increasing the plasticity or the resilience of the brain to the plaques, even though it's not specifically clearing them."

Professor Götz said the study also revealed the effectiveness of ultrasound therapy varied depending on the frequency used. "We tested two types of ultrasound waves, emitted at two different frequencies," he said. "We found the higher frequency showed superior results, compared to frequencies currently being explored in clinical trials for Alzheimer's disease patients."

"By understanding the mechanisms underlying ultrasound therapy, we can tailor treatment strategies to maximize cognitive improvement in patients," Dr Leinenga said.

"This approach represents a significant step towards personalized, effective therapies for neurodegenerative disorders."

The research paper has been published in Molecular Psychiatry.

INSIGHTS FOR FAMILY CAREGIVERS

www.healingwell.com



- Allow your loved one to express herself verbally and creatively.
- Advocate for autonomy, choice, and independence. Don't always jump in and try to help. Let him do it himself.
- Create a healthy habitat, environment, and atmosphere.
- Encourage discussion of present and future. Don't only reminisce.
- Your loved one may have greater fear and concern with "looking stupid" or being embarrassed in public than in forgetting things.
- You will likely have to rearrange your lifestyle, perhaps retiring early or moving.
- Explore and implement legal and financial planning changes as soon as possible after consulting skilled professionals.

ADULT REMINISCING COLORING BOOK TRIAL

Deb's niece, Jennifer is a busy woman! She is a mother of three, an artist, Homeschool Co-op founder/director, and an active community volunteer in Morris, MN. She also cares deeply for the memory loss community. She will be sending us samples of an adult coloring book she recently published and is eager for our feedback!



Jennifer

"I created this coloring book especially for seniors because, while coloring is so popular now, there aren't many options out there just for them. The large, simple pictures are easy to color and all the images are nostalgic, helping seniors relax and enjoy a trip down memory lane. It's a wonderful way for grandparents to bond with their grandchildren, coloring together and sharing stories from the past. Coloring has countless physical and mental health benefits. It encourages mindfulness and creativity, helps eye-hand coordination, relaxes the body, and allows for a sense of pride and accomplishment. I hope you enjoy it!" Jennifer

Stay tuned for more information this month!

MEMORY CAFE TALENT



One of our greatest joys at Memory Cafe is learning how talented our participants are! Flora is an active participant of 'The Gathering' support group and she recently brought one of her gorgeous paintings to share. Great job, Flora!

CONTACT US: MEMORY CAFE RRV

PO Box 883, Fargo, ND 58107

701-404-6712

www.MemoryCafeRRV.org

hello@memorycaferrv.org

Memory Cafe of the Red River Valley

memorycafe_rrv



Jerry with his wood carved friends.

SPONSORS



Family and Employee Owned



MarshMcLennan
Agency



The Marv Bossart Parkinson's Foundation

ALEX STERN FAMILY FOUNDATION