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DEMENTIA FRIENDLY COMMUNITIES

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DEMENTIA FRIENDS
HAMILTON
IN OUR COMMUNITY

EDITION 4:

Let Compassion & Empathy be your Guide!

Living Well with Alzheimer's and Other Dementias:

A newsletter written by individuals who live with dementia

Communication 101

Different with Alzheimer's

By Doug Schweyer

I wonder how we can encourage those who are care partners and those who have Alzheimer's to better communicate with one another. My wife Joyce and I often talk about how to cope with my Alzheimer's. We have a few suggestions as to how we have begun at least to solve some of our challenges.

I have Alzheimer's and Joyce is my care partner. There are times when I don't feel like talking or I am in a particularly difficult mood. Joyce picks up on something I've said and replies, "do you know what that sounds like to me . . . like someone in an angry mood." I recognize that I have caused (at least in part) her reaction and we begin to problem-solve. After a couple tries, we start to understand each other somewhat better.

So, the typical question is, how are you feeling. I often cannot answer this. I usually start by saying, "I'm somewhat tired." Joyce might reply with, "did you sleep well?" which sometimes has me wondering if I have. *The truth is that I don't know, and it doesn't really matter*.

One of the things that people with Alzheimer's sometimes experience is an inability to get enough sleep. With this being the case, what can be done about it? Maybe there is a way to solve the problem – for example, medications or setting a regular time of going to bed. However, in my experience the solution may not be that simple. When you get to the bottom of it, the issue may not be sleep at all.

There are many changes with Alzheimer's – for those who have been diagnosed and also importantly, for care partners and others in our lives. Communication and being patient, compassionate and understanding helps Joyce and I continue to support each other as best we can in this chapter of our lives.

We have learned to pause, listen to each other, and try to understand what the other is really trying to say. This is part of the difficulty because sometimes my Alzheimer's prevents me from precisely defining how I feel. Instead of trying to solve an issue, Joyce might start by validating my feelings, saying something like, "I have trouble sleeping sometimes too." This helps to open the door for conversation so that we can communicate and maybe even get to the bottom of the issue at hand.

Now, this next topic is a difficult one, namely: how do we meet with relatives and friends, with honesty and truth? Being open and transparent is something that I believe is very important and something and I try to follow with everything in life. So, with everyone I meet, I try to inform them of my condition, letting them know why I might appear confused, telling them a little bit about how Alzheimer's affects me now and how it might in the future. This usually results in a short discussion. And then we can act relatively normal.

My advice is to be open about your condition and feelings, so family and friends can be comfortable and better understand how they might support you.

A Care Partner's Reflection: Patience, Compassion & Understanding

& sometimes just not having it!

By Joyce Schweyer

Hello again, as you know, I'm my husband Doug's care partner. I have a lot to learn about the job after reading and talking to Doug about how he feels. Some days I pass showing empathy and understanding, other days my patience just isn't there. It is then that Doug shows what a brilliant man he still is. He tries not to get in my way, and approaches me lightly, saying things like: "can I talk to you for a minute?", or "are you busy?" . . . shapes my impatience right up!

Doug is still in the early stages of Alzheimer's, but he has lost his short-term memory. Now for my problems adjusting to some of his quirks. The calendar is helpful to keep everything straight, but Doug asks over, over, and over again if he has the correct time. Where, O LORD, where do I find patience and humour to repeat each time as if it's the first, he asked (which is what I know I should do.)

My frustration level is tested when Doug's minor aches and pains are more important than my sciatica nerve pain. O LORD, help me to be compassionate, for he doesn't remember that I complained.

Our TV only has news channels. We watch the headlines over, and over again; Doug doesn't remember he listened to it before. Did I mention that he has control of the flicker and falls asleep when watching the news. O Lord, give me understanding, help me not to wake him and say what's on my mind. I know that repeating the news many times helps him to remember, but . . .

Doug has always been a good storyteller, but now his stories from the past get mixed up. When he looks to me for help, sometimes I say: "you're on your own" (not very nice of me), other times I finish the correct story. Sometimes I see that stubborn look he gets, and I know I should have been more understanding. O LORD, help me not to argue or correct my husband who has Alzheimer's!

SOOO. I will be taking more video courses to better understand my husband's disease. O LORD, I need all the help I can get. **I encourage other care partners out there to take all the courses you can and ask for spiritual help to guide you.**

About the Authors: J Douglas Schweyer is a retired pastor of the Evangelical Lutheran Church in Canada. Joyce Schweyer has had many jobs and calls herself a jack of all trades, but she calls being a helpmate to Doug the best job she has ever had. This year, Doug and Joyce celebrated their 60th wedding anniversary alongside their many children and grandchildren.

Involve your Care Partner in Medication Management

Ask your Pharmacist about a Dosette!

Doug: I have diabetes and take insulin several times a day, along with other prescription drugs that I must take on a regular basis. I rely on my wife and care partner Joyce to help ensure that I take my medications appropriately and on schedule.

My pharmacy also helps with medication management by providing a dosette that measures in advance all of my medications to take at any given time.

While there are days when my memory is better and I don't need help with my medications, keeping Joyce involved and in the loop with all aspects of my medication is very important for the days when I do!

Doing Things Differently with Dementia Friends

Dementia affects everyone differently - symptoms & challenges are different for each person & vary from day to day and moment to moment. We believe that it is important to try to find ways to adapt to these changes and, if possible, modify how we do things to find new ways to continue to live as well as we can!

Dear Diane

By Debbie Keay

This article is about you as my caregiver. Though sharing and showing you my gratitude and love in the role you now share with me, I wanted it in writing for you. It is also to let the world know what love is when a family member is diagnosed with what I refer to as an insidious brain change ~ aka. dementia. We have 40 years of caring for seven family members with Alzheimer's and Lewy Body, so we are well aware of what is wanted and needed in both roles. As the oldest sister, I am "supposed" to be taking care of you. As the youngest sister, you are taking care of me. You have made such a difference in my entire life and even more so now.

You have stepped up to the plate. Your empathy, compassion, sensitivity, and making me a priority is amazing.

Because I am still fairly functional and independent living on my own (well, what people see) you offer that extra security I am needing. You understand my disposition, quiet and sensitive. When something of a serious nature arises you never raise your voice (well almost). There was the one time when I wanted to start a bursary at a local college and under no circumstance was that going to happen. Instead, you suggested we get a park bench for our neighborhood park in mom and dad's name because they were the oldest living residents on the street and we lived at that park. What a brilliant idea. Argument averted because we listened to each other.

Over the years, you have seen my deterioration. You are always there for me, from rides to the veterinarian to attending physician appointments. You see me climbing the stairs to your house on all fours like a two-year-old because my mobility is gone. Trying to get me to a standing position is hilarious. Thank goodness you are strong like a bull. Too, with my shakiness I was always breaking cups and plates, etc. You didn't balk when this past month I asked if you and Donna could start coming to my place. Yes, we ate off paper plates and we laughed until we cried. You adapt to my needs.

One of the things that I love about you is that we do share a sense of humour, with our daily jokes and the nicknames you give to everyone (you have given me sooooo many). Do you miss running up and down the streets with water balloons as adults as much as I do, Mrs. A. on her front porch laughing at us.

When getting overwhelmed (which I don't share often) and I hesitate in doing things and haven't done laundry in six weeks or am behind in paperwork, you say "that's okay, there is always tomorrow". Just speaking it out loud is the incentive to get my you know what into gear. You are always on time with calling me and telling me to put my garbage and recycling out. You are my alarm clock, the gentle nudge that keeps me going.

I really appreciated you taking time off work to come to the bank with me so that I could put you on my finances preventing a lengthy Will. It took a while for you to find the time for a number of reasons but when at the bank and the tears flowed, I understood one of those reasons. It is not easy being a caregiver - watching someone you love, ebb away. I just wish when things get tough for you, you take care of you.

Another thing I appreciate about you is your stubbornness (my match). Oops I forgot; it is not stubbornness, it is determination. I want to thank you for giving me my independence and not telling me what to do.

I just thought of something that pertains to anyone I know. Please don't seek outside advice from family, friends and strangers. If you have questions, ask me first and I can direct you to any of my healthcare professionals. I had shared with someone about an Occupational Assessment I had because getting out of bed took 20 minutes and the list goes on. When sharing the outcome, the person went behind my back, sought information from a healthcare pharmacy with an occupational therapist, called me and proceeded to tell me this or that was wrong with the recommendation I had been given. I had to keep my frustration at bay, explaining that the person they spoke to did not know my medical history, had not done the assessment, did not know my environment and what I needed. Anyway, the call ended. The person was very well intended, but communication is such a key for me. Too much room for bad advice. Diane, you listen.

Not everyone with Alzheimer's experiences loss of reasoning, but some do. That is why I am trying to take precautions so that you are comfortable approaching me with concerns. The sooner things are dealt with, the less chaos and frustration. You are there every step of the way, not being critical or interfering but keeping my dignity intact. As for dignity, one of my health issues is incontinence and I have personal accidents multiple times a day even with diapers. You always ask if I need assistance, but ask first, allowing me the dignity to say "no". Diane, you are unflappable with me.

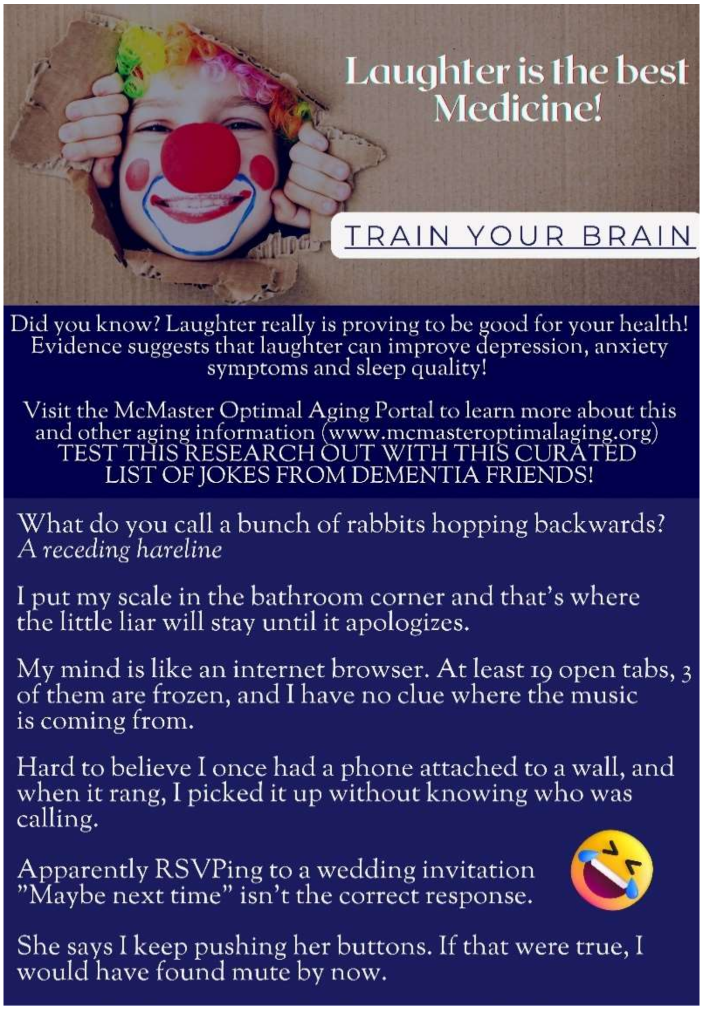
You are strong to the core, physically and help me carry things too heavy like kitty litter, 2 litres of milk, which you helped to problem solve by suggesting I buy 2 x 1 litres of milk. The little things you suggest are invaluable. And while I think of it, you don't mind when I call you three times in a row in a 15-minute period because I forget to tell you something. At the third ring, you jokingly say, "Now what?"

Diane, you are a gift to me, discreet, respecting my privacy, extremely sensitive, face my challenges (though I hope - don't think I have given you too many yet). You are a great listener. My day changes, sometimes hourly. You understand. You'll ask, what did you do today? "Slept". You're okay with that, never pressuring me to do this or that. You understand my initiation and motivation are becoming less and less.

Diane, you give me SECURITY.
Sensitivity
Encouragement
Compassion & **C**onsideration
Understanding
Respect
Independence
Tolerance (Really Acceptance but I needed a "T" word)
"Y" because you are my sister, and you love me.

So, Diane here you are teaching the world about being a caregiver. When I am no longer here and you are being challenged, pull this letter out and remind yourself who you are and show everyone what you are really made of, even in those moments where you feel vulnerable. Thank you for being there for me and your big heart. I am going to miss growing old with you. I love you too.

About the Author: Debra Anne "Debbie" Keay was diagnosed with early onset Alzheimer's in 2018 at the age of 58. Diane is a rockstar and loves cats.



Laughter is the best Medicine!

TRAIN YOUR BRAIN

Did you know? Laughter really is proving to be good for your health! Evidence suggests that laughter can improve depression, anxiety symptoms and sleep quality!

Visit the McMaster Optimal Aging Portal to learn more about this and other aging information (www.mcmasteroptimalaging.org)
TEST THIS RESEARCH OUT WITH THIS CURATED LIST OF JOKES FROM DEMENTIA FRIENDS!

What do you call a bunch of rabbits hopping backwards?
A receding hareline

I put my scale in the bathroom corner and that's where the little liar will stay until it apologizes.

My mind is like an internet browser. At least 19 open tabs, 3 of them are frozen, and I have no clue where the music is coming from.

Hard to believe I once had a phone attached to a wall, and when it rang, I picked it up without knowing who was calling.

Apparently RSVPing to a wedding invitation "Maybe next time" isn't the correct response. 🤣

She says I keep pushing her buttons. If that were true, I would have found mute by now.

Walk in my Shoes to Understand my Journey

By Phyllis Fehr

Today, I am asking you to step into the shoes of someone who lives with dementia to understand, appreciate, and support our individual journeys.

Begin by educating yourself and learning as much as you can about our diagnosis. I previously wrote about the different types and common symptoms of dementia *(see: "What Does my diagnosis Mean? (Dementia Friends- Issue 1)*. Try to understand as much as you can about our diagnosis to support our journey. It is helpful to understand that common symptoms and treatments will vary from diagnosis to diagnosis. But please remember that just because you have known someone who has lived with dementia, doesn't mean you know everyone who lives with dementia. We are people first and don't expect us all to have the same changes or needs.

It will also be helpful to understand where we are in our dementia journey. In our second newsletter, Debbie shares valuable insight to provide support through the different stages of dementia *(We Need A "hEARt" By Debbie Keay (Dementia Friends – Issue 2).* People refer to the stages of dementia in different ways; for example, Debbie references a 7-stage process, and you will hear others refer to three primary stages (early-middle-late). What is most important it not necessarily being able to identify our precise stage – we often identify with symptoms across many stages at any given time but having awareness around our personal journeys. Knowing what we are experiencing and being aware that this is constantly evolving will help you to better understand and support us.

Finally, talk to us. It is important to have open conversations as early as possible to understand what we want and how we wish to move forward when we might not be able to communicate this. This includes informal conversations – I encourage you to have lots of these, and more formal things such as possibly updating Power of Attorneys and Wills. You may wish to consider having a family meeting so that everyone is on the same page and in the loop. My husband and I have had conversations with all our children and grandchildren so that they are aware and understand how to support us and each other.

Help us continue to be ourselves and feel purposeful. Please do not to take over for us and support us to remain engaged for as long as possible. We have all heard the saying "if you don't use it, you lose it." This is so true for people living with dementia. Our family and friends often try to take on tasks or take over with some of the things that we have done for years and provide us with purpose and enjoyment. While taking over these tasks is usually done with good intentions to ease our burden or reduce risk (example: worrying that we will forget to turn off the stove when we are cooking), good intentions can be doing more harm than good.

Instead of trying to take over, please talk to us about your concerns. If there are ways to reduce risk so we can continue to do the things we enjoy, let's explore them. Support us to find ways to continue to contribute, feel purposeful, and be ourselves!

Now for some tips to help with some common issues and challenges:

Memory and Orientation

- Try using a calendar to help keep track of important events and appointments.
- Create a Reminder Board. A white dry-erase board can be useful.
- Try Sticky Notes on the Fridge.
- Label doors in the home so it's easier to find things (Examples: bathroom and cupboards).

Financial: I love to shop so we have put a monthly limit on my credit card and my Interact card, so I don't break the bank.

Safety/Security

- Consider adding an alarm system in your home that has an alert when the door opens.
- Purchase a watch or device with GPS tracking as a precaution and if wandering is a concern.

Safety in the Home

- **Falls prevention:** We made changes to make our home safer, such as getting rid of throw rugs. *Call Home and Community Care to request a visit from an Occupational Therapist to make home safety recommendations at 310-2222.*
- **Cooking:** My husband is very nervous about me using the stove, so he does all the prep and I come in and make the magic happen by adding spices or making the sauces. The other thing we do is he sits in the kitchen while I cook - this can get a little annoying as he frequently tells me what to do, but I am still able to enjoy cooking.

Other

- **Noise Reduction:** Many people who
- live with dementia have trouble with noise. I have purchased noise canceling earbuds for when I am in public spaces. I am looking forward to my sons-in-law birthday on Friday, the whole family is going out to dinner and axe throwing. I will prepare for this by taking my earbuds and with the knowledge and acceptance that I may not be comfortable with all the activities, but I can still enjoy the company and the antics that will go on.
- **Swallowing:** Some people who live with dementia have trouble swallowing and eating. I personally have a sauce or gravy with every meal to make it easier to swallow.

REMINDER: Living with dementia is NOT an individual journey. Just as we experience changes, challenges, and loss, so do our care partners, spouses, family members and friends.

About the Author: Phyllis Fehr is a wife, mother, grandmother, and great grandmother. Her career was as a Registered Nurse in both Intensive Care and Cardiac settings, as well as a sexual assault nurse examiner. Since being diagnosed with Alzheimer's 10 years ago, she has become an advocate for people living with dementia.

ABOUT OUR TEAM

We began Dementia Friends in our Community after coming together and bonding around a shared experience – living with Alzheimer's disease. In 2022, we launched our newsletter: *"Living Well with Alzheimer's."* Our goal is to create positive change for others who live with dementia, their families, and the community by sharing the perspective we have gained through our personal challenges and experiences.

Dementia Friends Hamilton is seeking NEW MEMBERS and WRITERS for our newsletter! If you live with dementia and want to learn more, join our team, or write for us, please contact Shelagh at 905-920-7721 or shelagh@hamiltoncoa.com

DEMENTIA FRIENDS
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DEMENTIA FRIENDS IN OUR COMMUNITY

Channeling our experiences living with Alzheimer's to challenge misconceptions and create supportive, inclusive communities!

www.coahamilton.ca/dementiafriends

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Spotlight on a Community Resource

CYCLING WITHOUT AGE (CWA)

Cycling Without Age provides people with mobility issues an opportunity to once again experience nature on a bike! The Dutch-inspired and Dutch-built three-wheeled trishaw is propelled by a trained pilot using an e-assist motor.

CWA Hamilton offers **no-cost rides** to those who are unable to cycle on their own. Rides in Hamilton can be arranged on Saturdays, Mondays, and some evenings, based on availability for up to one hour this summer (2023). *Rides can include a care partner or family member.*

To book a ride for you or a family member, e-mail cwapassenger@gmail.com

Would you like to be a volunteer pilot?

CWA is possible because of the contributions of volunteers!
Pilot training takes place every spring. Pilots must be confident cyclists, provide a vulnerable sector police check and undergo training.
Virtual information sessions will take place in March, with indoor on-bike training in April, and outdoor on-route training in May.

Email cwahamilton@gmail.com to learn more or visit https://cyclingwithoutage.ca/hamilton-burlington

CYCLING WITHOUT AGE

McMaster University

NewHope COMMUNITY BIKES