



EMPOWERING DEMENTIA-FRIENDLY  
COMMUNITIES

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online and in other languages.



EDITION 3: Living well wherever home is  
means something different for each one of us!

## **Living Well with Alzheimer's and Other Dementias**

A Newsletter Written by Individuals  
who live with Dementia



## A Family's Reflection: Living Well with a Loved one who has Alzheimer's

By Phyllis Fehr & Family

My family's love and support during my journey through dementia has been key. The support I've needed has varied and I know will continue to change through my journey. At this point, I am living with young onset Alzheimer's and am doing well.

**But I wonder: how is this affecting the rest of the family?** Today you will read just that from a number of my family members from the age of 70 down to age 8. Let's get started.

### My husband (70 years of age)

Over the last 10 year I have learned so much.

- You must be patient. When you ask a question, it may take 10 to 30 seconds, sometimes longer before you get an answer.
- Provide support but don't smother. Give your partner the opportunity to succeed and have that feeling of accomplishment when they do.
- When you meet friends in public, greet them with their name so that your partner doesn't feel embarrassed if they don't remember.
- You need to be able to adapt as each day will be different. Some days will be quite normal, and others will be very challenging.

**We get through by remembering the love we have for one another. We realize that there will inevitably be a decline, but we don't dwell on this. We live for today.**

### My grandson (9 years of age)

My nanny has dementia but I still make sure she is alright and she is alright and if she's hurt I make sure that she gets better so then that when she gets better she doesn't get hurt again.

### My daughter (40 years of age)

Hi, my name is Candice. I am a mother, a health care aide and most importantly a daughter. My mother was diagnosed young, with early stage dementia. She was an ICU nurse who saved lives and I was proud and looked up to her. Now she is CHANGING THE WORLD and I aspire to be more like her! Being the daughter of someone with Alzheimer's is not easy, no matter how progressed the disease is.

Let me explain. I'm the passenger in her journey. I watched her go through tests and lose family and friends as soon as she received her diagnosis. I watch her struggle with losing her independence and with things that are changing. As her daughter, this breaks my heart and there is little I can do. I can be supportive and help come up with ideas to simplify things to make life easier. I can help come up with things to make it less obvious when out in public.... But I am just the passenger who is along for the ride and have no control.

My mother has taken her diagnosis and decided it does not define her. She is using this to make changes locally, nationally, and internationally! I AM SO PROUD! I know the day will come that she will forget who I am and my children. This will be the worst day of my life, but I know it's inevitable. I can try and prepare myself and my family, but it won't be enough. **This disease doesn't just affect the patient but the whole family who are just passengers.**

### My stepdaughter (47 years of age)

I was asked "What is it like having a stepparent with dementia?" Phyllis has been in our family for over 40 years, so to say she's a stepparent doesn't really fit. She is way more and the title doesn't do her justice. We are lucky in a sense because of her knowledge from her background as an ICU nurse. She saw the signs and symptoms of dementia very early, which helped her find a great team for her medical care.

When you don't live with someone, it's not always easy to see the everyday signs. We do see differences in our family gatherings. Our parents' house was always the place to be for Sunday dinners, BBQ's, and social gatherings. These things still happen, but now the guest list is smaller, and they are less often. During the gatherings, we see Phyllis where she is most comfortable (in her special spot) because the noise of the people, the stress of entertaining and the searching for answers to questions being asked during conversations, and recovery time after is hard on her.

**We know that the road ahead will not be easy but is a road we will travel together as a family.**

**About Phyllis:** Phyllis Fehr is a wife, mother, grandmother, and great grandmother to a large, blended family. Since being diagnosed with Alzheimer's disease 10 years ago, Phyllis has become an advocate for people living with dementia. While Phyllis has accepted her journey with open arms, she knows that living with dementia does not affect her singly and she is grateful for the understanding, support and love she receives from her family who are going through this journey with her every day.

### My granddaughter (26 years of age)

Having a grandmother with dementia while I live on another continent is hard. I have the chance that my grandmother's dementia is progressing well and that she still remembers a lot. But I know one day it will get worse and the fact that I'm not able to visit her as much as I would like to while she is still herself scares me.

However, I'm glad that we can video call and talk whenever we want to. I'm so lucky that she can watch me grow up and become the woman that she'd always wished I'd be.

**Without her in my life, I would be a completely different person, for that, I am forever grateful.**

### My foster son (49 years of age)

As a stepchild, I have noticed some, but so far, have not seen a huge difference in mom's decline. I am a firm believer that the amount of speech writings and being involved with spreading the word about dementia and Alzheimer's has kept her mind active and focused. I do know that once she starts declining significantly, we can get help with classes on how to cope. **We will be there to support her in any way we can.**

### My granddaughter (8 years of age)

My nanny has dementia and I still love her and she gives me love to. We spend time together for a while.

**ATTENTION: BUSINESSES, ORGANIZATIONS, GROUPS & EVERYONE WHO WANTS TO LEARN MORE!**

Join us for a **FREE** workshop to learn how we can work to create dementia-friendly communities!



Hear about first-hand perspectives and experiences of a person with dementia



Gain useful tips on how to interact and work with people with dementia



Earn a Dementia-Friendly Education Certificate in 1-hour to use for professional development



[www.facesofdementia.ca](http://www.facesofdementia.ca)



## Supporting one another through Alzheimer's and all of life's challenges

By Doug & Joyce Schweyer

**Not everything living with Alzheimer's - or anything in life- is black and white. We often identify our role as either the "caregiver/care partner" or the "person with dementia/Alzheimer's disease", often assuming that it is the "person with dementia/Alzheimer's disease" who requires care and support from the other. While this may be true some of the time, it is not the full story. People who live with dementia can still be capable, caring, and supportive partners in their relationships.**

Doug and Joyce are a great example of this. They have been married for 60 years. They are committed to one another, and they are aging together - adjusting, adapting, and supporting one another, alongside their family and support system through all that life throws at them. This includes Alzheimer's disease for Doug and a variety of other health challenges for Joyce.

*Doug:* I was diagnosed with Alzheimer's disease in 2020. I have written about my diagnosis and journey living with Alzheimer's over the past two years in previous editions of our newsletter, which you can read at [www.FacesofDementia.ca](http://www.FacesofDementia.ca).

The last year has brought on quite a few changes in our lives through my journey living with Alzheimer's disease, and also through health challenges that my wife Joyce has been experiencing. As a family, and as a couple married for over 60 years, Joyce

and I have done our best to adapt and made significant adjustments to cope with these challenges, while supporting one another to live as well as we can each day.

*Joyce:* What happens when the person with Alzheimer's disease is taking care of the "caregiver?" We never thought of that, even with serious health problems, I was never going to become 'helpless.' After all, I can do anything I want to if I want to, and I'm going to take care of Doug at home, so we can always be together. I had it all figured out and we had it all taken care of, but then something changed.

I couldn't get down on knees to do flower beds, a walker became a must, I had an upset stomach, was sleeping 24 hours a day, hated cooking and we had more burnt offerings than we could take. Depression and COVID were the nasty culprits. Doug tried to help me, but he has his own problems to remember. At least I could still drive, I thought...

Our family was watching and (with our agreement), our living arrangements changed in a hurry. In just 3 months, we sold our cottage home at St. Elizabeth's Village in Hamilton, sold/gave away a lot of my 60 plus years of treasures (I hope they are loved!) By the grace of God and with the help of family and friends, we permanently moved 80km west to Luther Village, a retirement community in Waterloo. All our meals are provided, there is a doctor on call, and on-site amenities at our disposal. We have grown to love the pool! We are still getting rid of some of our old treasures and as much as we appreciate the convenience of not having to cook, I do have fond memories of homemade bread, pizza, potato salad, and a lot of my favourites I use to make.

Now the car . . . I can still drive but had to give up my red car. Wiser family members didn't think I was a safe driver anymore, and in my heart, I knew they were right. We are happy at Luther Village, together hopefully for some time. We are well taken care of and even if I complain, I am thankful for all we have had and now.

*Doug:* Since moving to Waterloo, I have continued with our small group who is writing this newsletter. We are now down to 3 members, but

we are happy to share our experiences living with Alzheimer's disease, along with information about the disease and a puzzle and other interesting things to raise awareness and provide support to others. This writing will be my third contribution to the newsletter and Joyce's second. It's fun but also work! The good news is that we learn with each edition more about ourselves and from feedback, the format is well received.

During this time, I, along with the other members of this group have also participated in a Campaign: Faces of Dementia – sharing our stories about living with dementia through videos and portraits. Participating in this campaign has given each of us a chance to express ourselves to a larger group and those who see us or hear us should gain a new understanding of Alzheimer's disease and be helped if at some point they find themselves faced with Alzheimer's or become a care partner of somebody who is diagnosed with Alzheimer's.

*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. Doug and Joyce recently celebrated their 60th wedding anniversary alongside their many children and grandchildren.

Please help us share this newsletter! Share this newsletter ([www.FacesOfDementia.ca](http://www.FacesOfDementia.ca)) or contact us to receive printed copies. While you're there, please check out the Faces of Dementia Campaign to learn more about our personal stories living with Alzheimer's.

**FACES OF DEMENTIA**

HCOA  
Hamilton Council on Aging

Financial contribution from  
Public Health Agency of Canada  
Agence de la santé publique du Canada

**I am a sister.**

**I am a friend.**

**I am a writer.**

**I am a cook.**

**People living with dementia are more than their diagnosis.**

**Help us build dementia-friendly communities.**  
Learn more about free training workshops and how to support at:  
[www.facesofdementia.ca](http://www.facesofdementia.ca)

## Spotlight on a Community Resource

### HEALTH CONNECT ONTARIO

Ontario has relaunched HEALTH CONNECT ONTARIO (formerly Telehealth) to help Ontarians make healthcare decisions 24/7!

Health Connect Ontario is a free, secure and confidential service you can call or access online 24 hours a day, seven days a week to get health advice from a registered nurse or find health services or information.

Call Health Connect Ontario at 811 for health advice or information.  
Toll free TTY line: 1-866-797-000 OR visit  
<http://healthconnectontario.on.ca>

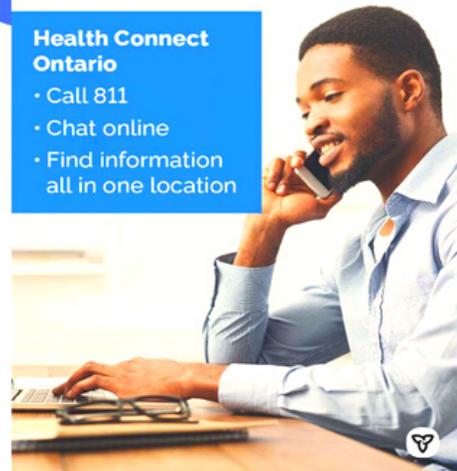
**811**



<http://healthconnectontario.on.ca>

#### Health Connect Ontario

- Call 811
- Chat online
- Find information all in one location





## Living Alone: Self-Compassion & Self-Respect

By Debbie Keay

When asked to write a piece on what it is like living alone with brain issues, my initial response was to write about the challenges and benefits of living with my Alzheimer's. I considered addressing how one adapts with the day-to-day events that need to be dealt with (e.g. Finances, Housing, Transportation, Physical Activity, Mental Health, Faith, Friends, Family, Shopping, Laundry, Cooking, etc.) and how I adapt to each situation. Each stage in my journey brings me deeper understanding and acceptance of further limitations. So, I wrote and wrote and wrote, but to me it was just regurgitating what so many have already said. Even though our journeys are individual we share many commonalities. In reflection of what I had written I decided to start again.

**I wanted to write about how important "Self-Compassion" and "Self-Respect" is.**

Living alone with Alzheimer's allows a lot of time for reflection, seeing with different eyes what was at my core. What a way to discover "self-compassion" and "self-respect". Described as patient, kind, loving and respectful of others, I had a moment of brilliancy (I have them occasionally).

The same things I give to others, I needed to give to myself (reinforced by my doctor - Dr. Steve). Let me tell you that I positively love living alone with my brain challenges.

**By having "Self-Compassion" and "Self-Respect" I found a new freedom I've never had before even though I've lived alone my entire adult life.**

I tell people I can do only 10% of what I used to do, but my friend of close to 40 years says she still sees me at 100% of who I used to be. She is right when it comes to the core of who I am. So let me take my core values of compassion and respect and apply them to me. Aha, another moment of brilliancy. **Freedom!**

- I have the *freedom* of not trying to hide how rough I might be feeling so not to worry others.
- I have the *freedom* to binge watch "Forged in Fire" at 2:00 am in the morning when I can't sleep after a night terror.
- I have the *freedom* to not have to dress up for work every day.
- I have the *freedom* to eat left over supper at 6:00 am for breakfast, yay for liver and onions (sorry Shelagh).
- I have the *freedom* to sleep to 1:30 in the afternoon unless I have zoom meetings regarding advocacy or appointments.
- I have the *freedom* to not have to answer to anyone I live with except my cat.
- I have the *freedom* to lop off my long hair without anyone trying to stop me. I just did it about an hour ago. A friend said I looked good until I turned around and said it was shorter in some areas. Hahaha - happens all the time!
- I have the *freedom* to let my laundry sit, which tells me I have too many clothes, so four boxes got sent to a thrift store.
- When I really can't sleep, I have the *freedom* to lie on my loveseat and watch the moon travel across my balcony doors. I question if it is the moon or the earth moving.
- I have the *freedom* to behave like a 4-year-old. I can stand in the rain with my arms out trying to catch raindrops on my tongue. I can question why we have eyebrows or why men have nipples if they don't breast feed. LOL (laugh out loud).

- I have the *freedom* to let my inner funny out and blame it on my brain filters slowly fading. Sometimes my filters are just fine but when I went with my friend Wendy to a drugstore there was a police officer picking out a card. I went up to him and thanked him for his service. Then I told him he was cute and asked him if he was married. He was about 30, I am 63.
- I have the *freedom* to sleep with my cat without anyone telling me not to let "the animals" on the bed.
- I have the *freedom* to go grocery shopping whenever I want and buy whatever I want, nobody asking me "Should you be eating that?" Sorry Dr. Steve.
- I have the *freedom* to not dress in the morning (hooray for zoom meetings) and wear whatever I want. You only need a head shot for a meeting. LOL.
- I have the *freedom* to do what I want, where I want to and when I want, without being told what to do or work around someone else's schedule, especially when my life energy is knee high to a grasshopper.

### **Sound selfish? No, it's self-preservation.**

Freedom has allowed me to KISS, (Keep It Simple and Smart). The "Smart" was something I heard from someone else. I have a meeting in 1 hour, but I am still in bed thinking about my day. Do I want to go shopping later? Maybe or maybe I'll just take a 4-hour nap.

Living alone is not easy by a long shot with challenges daily - emotional, physical, spiritual, and I wish in my heart of hearts that there could be someone to just hold me on occasion. With "Self-Compassion" and "Self-Respect" and grateful for my freedom, I can be my best so I can continue to be there for others. I still have the freedom to live independently despite what I may face in the future, and I am so very grateful for my blessings despite this ridiculous disease.

Some days I can give so much, others I am a sloth and find it hard to get out of bed. But I keep going - sometimes the energizer bunny, sometimes a snail trying to get across an 8-lane highway. I haven't been run over yet and if I am, I have a hard shell.

**Of course, living alone doesn't mean that I am lonely - not by a long shot!** The support of family, friends and even strangers who want to help is amazing! That leads me to another thought (my brain is always working, but weirdly.) *If I am never underwhelmed or overwhelmed, does that mean I am just "whelmed"?*

**To those who help me live the best I can under my circumstances, you are alive and well in my heart. If you are there, I am still here!**

Because I don't want to leave you on a somber note, my "funny" is taking over and I am being full of beans. There is an expression that people living with brain health issues hear all the time: "You don't look like you have dementia." I came up with a great comeback: "You don't look like have a yeast infection." Haven't said it yet, but if my filters go, well... you know how that will end.

*About the Author:* Debra Anne "Debbie" Keay was diagnosed with early onset Alzheimer's in 2018 at the age of 58. She uses her experience to advocate for community inclusion.

**TRAIN YOUR BRAIN**  
7-Day Toothbrush Challenge

*We challenge you to make a daily task a little bit more interesting!*

**Every day this week, try brushing your teeth with your non-dominant hand.**

If you are right-handed, use your left-hand. If you are left-handed, use your right hand. If you are ambidextrous, you could try using no hands! You may be surprised at how much you need to concentrate and challenge your brain to perform this routine task a little bit differently!

**Never Stop Learning!**

**Evidence suggests that by trying things differently and continually learning, your brain is challenged to create new pathways to think, adapt and create. Do things that you enjoy and keep active in mind, body, and spirit to optimize your brain health!**

# Tip of the Day

## **Don't sit through uncomfortable situations.**

**If you are overwhelmed by noise or people, take yourself out of the situation. Find a quiet room or space where you can "catch your breath."**



Team member Phyllis talks about how overwhelming crowds and noise have become since her Alzheimer's diagnosis. Phyllis consciously tries to minimize larger group gatherings, favoring one-to-one conversations or small family visits. She and many of her family members have a 'quiet room' in their home for her to go to if/when she is feeling especially sensitive to noise and people. She also recommends purchasing a good quality pair of noise canceling ear buds to carry, in case of an emergency - like in a restaurant!

### **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 do the things we enjoy!

## **WE WANT TO HEAR FROM YOU!**

**Dementia Friends in Our Community - Hamilton is seeking new members!** If you live with dementia in Hamilton, ON and would like to join our team or contribute to our newsletter, please contact Shelagh at [shelagh@hamiltoncoa.com](mailto:shelagh@hamiltoncoa.com) or 905-920-7721.

**To learn more, visit [www.FacesOfDementia.ca](http://www.FacesOfDementia.ca)**