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EDITION 5:

Accepting, Adjusting & Growing with CHANGE

Living Well with Alzheimer's and Other Dementias:

A newsletter written by individuals who live with dementia or A.B.C. (Acquired Brain Changes)

Transitioning out of using the term “dementia”

By Debbie Keay

My article is about transition of the word “dementia” to Acquired Brain Changes (ABC). What? You might ask. When and how did dementia get a new name?Well, the seed has been planted by M.I.C.E. Haldimand!

M.I.C.E. Haldimand (Memory+ Inclusive Communities Everywhere) is our sister team from Haldimand county - a group of citizens sharing their experiences with memory loss and cognitive challenges to create a more understanding and inclusive community for everyone!

Recently, M.I.C.E. spearheaded a campaign: Let’s Change the “D” Word: Dementia.

The World Health Organization estimates that there are approximately 55 million people worldwide living with dementia. Yes, that's the real number. I don’t have a statistic for the number of people who dislike the term dementia. However, I can tell you that there isn’t a single person I have spoken with who lives with dementia (and I’ve spoken with many) who considers this word positive or an accurate description of what we are living with.

And why would we? The word “dementia” can be traced to the Latin “dēmens” meaning out of one’s senses, insane, raving, or foolish.

Guess what, we are not out of our senses, but that's what people think (e.g., incompetent). People who are diagnosed with this insidious disease (my own description) are devalued by so many, from the community, family, healthcare, and other professionals, even ourselves. We misunderstand, have a negative perception, and often fear what dementia is and what it means.

But what does it really mean to live with “dementia?” First and foremost, people who live with dementia are all different – from our specific diagnosis (example: Alzheimer’s, Frontal temporal dementia, Lewy body, etc.), symptoms and journey, to who we are as human beings (which is still who we were.) We are generous, productive, intelligent, thoughtful, and accomplished, if allowed to be.

Last Spring, Doug, Phyllis, and I were privileged to present about living with Alzheimer’s disease to over 100 people at a local retirement community. At the beginning of our presentation (before we shared our diagnoses), we asked everyone to share the first words that came to mind with the word “dementia”. A very open and responsive group, they listed terribly negative words: sad, lonely, isolated, incapable, etc. At the end of our presentation, we went back to our original question. After learning that we lived with “dementia” and hearing our stories, we heard very different (positive) responses: capable, hopeful, loving, sensitive, intelligent. My point in sharing this is that people genuinely do not understand what it means to live with dementia.

We have seen countless campaigns aimed at challenging stigma and perceptions about dementia. At the same time, the very word that we are labelled with literally means “raving or insane.” How does this make sense?

Shouldn’t a word that is used to describe something that affects over 55 million people reflect who we really are? At the very least, the word that we choose to describe something so challenging should not create additional challenges for the very people who live with it. In my humble opinion, the biggest contributor to misunderstanding and stigma is the word DEMENTIA itself. And we need to do better!

So, back to M.I.C.E.’s campaign: Let’s Change the “D” Word: Dementia! What began as a casual conversation among friends turned into education for staff and team members about the word dementia and research about its usage internationally. ***Did you know that in 2004, Japan replaced the term 'chiho' (dementia) with 'ninchisho' (cognitive disorder) as part of a publicity campaign to challenge stigma?*** [1]

M.I.C.E. wanted to follow Japan's example. They had candid conversations with friends, colleagues, doctors and experts about the implications of changing the word dementia, which yes, we are fully aware implications exist and no, these do not justify keeping the word as it is for us – people who have been labelled with something so negative and who already have such an uphill battle to climb.

Beginning of 2023, M.I.C.E. engaged the community in a campaign to "Change the D word." Over the course of a few months almost 100 people responded to a survey with their selection of a new term for the word "dementia."

The most popular response that M.I.C.E. has now adopted to replace dementia is A.B.C. Acquired Brain Changes!

One of my favourite songs is by the Byrds, "Turn! Turn! Turn! (To Everything There Is A Season). Just beautiful. Some of the lyrics are so fitting "a time to break down." I know change takes time and does not meet without controversy. For instance, do you remember the "R' word that labelled people with learning disabilities or racist terms that were previously used freely and now fall under hate crimes?

Now it's time to get rid of the "D" word!

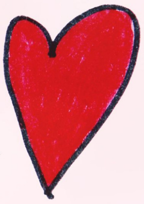
If you don't like A.B.C., that's ok. We are not tied to the term as much as using something other than "dementia." So, next time you think about saying "dementia', please say A.B.C. or something else! Yes, there will still be discrimination and stigma, but those of us living with it will give you a hug and say thank you for sharing our message of hope!

About the Author: Debra Anne "Debbie" Keay was diagnosed at age 58 with early onset Alzheimer's in 2018. Debbie is a proud team member of Dementia Friends Hamilton & M.I.C.E. Haldimand. She is a strong advocate for getting rid of the "D" word!

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!

Always
take care of
yourself first



Debbie: "I have always been somebody who takes care of everyone around me – FIRST. Until very recently, this was not a problem. Giving and giving back is a big part of who I am and gives me enjoyment in life.

I have noticed as my journey with Alzheimer's progresses and I also experience other health challenges, I physically do not have the energy to be involved in as much as I used to. I was involved in so much that I very often (unintentionally) skipped meals or medications and was physically exhausted at the end of a day!

One thing I am slowly learning is to say "No, thank you." I am starting to try to prioritize myself first and only do the things that I am physically able to and still get enjoyment from (examples: time with family, friends, work with this group and M.I.C.E.!) "Do for you and not just for others" is advice that I highly recommend that everyone consider and not just those who live with A.B.C. (dementia.) *After all, we really are better equipped to help others when we take care of ourselves*!

My next personal hurdle . . . truly learning to accept help from others!

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[1] Miyamoto M, George DR, Whitehouse PJ. Government, professional and public efforts in Japan to change the designation of dementia (chihō). Dementia. 2011;10(4):475-486. doi:10.1177/1471301211416616

Lessons to Accept and Grow through Life's Changes & Challenges

By Doug Schweyer

I want to tell you exactly how I got to this point with Alzheimer's. It's been quite a journey and today I want to share more about my journey of acceptance and change and the lessons that I have learned that I think are transferrable to anybody dealing and coping with any type of change or challenge in life. For the purposes of today's article, I am going to start at the beginning of my journey of change with a story that will be familiar to those I know and readers of this newsletter.

In May of 2019 I took the test for renewal of my driver's license because of turning 80 and passed it easily. In the meantime, my children and particularly my wife Joyce, noticed that I was shuffling my feet, that has never been the case and that I was a bit short of memory about events that I usually did without thinking. Joyce expressed her concerns and suggested that I visit our family doctor to get a medical opinion and I soon found myself visiting a dementia specialist at the hospital.

I went through a series of tests and things didn't go the way I had hoped, or suspected. Very different from my success with my Driver's Renewal Assessment, I couldn't even draw a clock, or remember five simple words. After these tests the doctor showed me a copy of the CT scan that had been taken about a year ago. She circled a part of the picture of my brain and asked me to tell her what I saw. I replied that there appeared to be a severed tube and she agreed and said that the picture showed evidence that I had experienced a mild stroke (TIA). The next thing she said was what really changed my life: "Based on today's tests, you are in the category of dementia and as of now I am authorized by the motor vehicle department to take your driver's license away."

Do I have any say in this shocking situation? Short answer no - unless I wanted to spend $750 dollars to appeal the decision with the Ministry of Transportation with no guarantee. So, I asked the doctor to let me see the results of all the tests and she gave me a few minutes to look them over and decide what to do next . . . It was hopeless. Looking at the tests, there is no way I would be a safe driver on the road. The decision was made easy, and I have never driven a vehicle again.

My wife Joyce drove us home and she continued to be our chauffeur until we moved into an assisted living facility. I have lost more of my short-term memory, but I am still able to contribute to society by telling it like it is, and with the other two friends and writers in this newsletter, we are sharing our truths to help others.

So, what has helped me to adjust and cope with the changes in my life? First, I am upfront and honest with everyone about the challenges that I experience so that they can try to understand and support me in my journey. The incredible support and understanding from my wife Joyce, family and friends has been my lifeline. I continue to learn as much as I can about Alzheimer's disease and do as much as I can to help with what I am going through by remaining active, engaged, and proactive in the decisions I make to contribute and find value in life. I have accepted my Alzheimer's and the changes that come with it are out of my control. Most of us are coping with some challenge in life and once you accept what is happening, you can learn how to live with it the best that you can.

My advice to others: "Accept what you are and live with it but don't say that this is the end of the world. Because it's not."

My turn to tell it like it is

By Joyce Schweyer

Now it's my turn to tell it like it is! Since Doug was diagnosed with Alzheimer's I was in the driver's seat and willingly stepped in to cart us around. I was free to shop where I wanted and say yes without having to ask somebody else for a ride. We had a RED Buick SUV, just what I (we) needed, even after we moved into assisted care.

Then came the pressure to get rid of my red car. It cost too much sitting in a parking lot to use once or twice a week, and then there were the comments: "Do you realize you almost side swiped a car? You would have missed that stop sign if I hadn't pointed it out. You don't know the new area. Your reflexes aren't up to par. You need shots in your eyes every 4 to 6 weeks because of macular degeneration. What if you have an accident?" After 3 months of hearing this from Doug and my family, I said Oookay and I gave up my little red car.

I couldn't watch the car being driven away; that was the day I lost my independence.

Our family are good at taking us to church and other places when we need a ride, but we are not independent. We use Mobility Plus, which is a very good service, but it must be planned and takes a lot of hurry up and wait. I'm not independent!

I like to shop at thrift stores and find a good bargain . . . Now, my go-to store is Amazon, for fast shopping from my chair. What is this world coming to?

And this is just my version of how it is . . .

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 July, Doug and Joyce celebrated their 61st wedding anniversary!

TRAIN YOUR BRAIN: Did you know that staying social is good for brain health?

Evidence suggests that by staying active, social, trying things differently, and continually learning, your brain is challenged to create new pathways to think, adapt and create.

Check out the new **City of Hamilton Social Participation Resource Guide** at www.hamilton.ca/seniors or pick up your copy at a local Senior Centre to learn about programs and services for older adults (55+) within the City of Hamilton.

Do things that you enjoy keeping active in mind, body, and spirit to optimize your brain health!

Patience and perseverance: change happens one step, one person at a time!

By Phyllis Fehr

Today I am going to talk about change. Through my journey living with dementia over the past 10+ years, and through my lifetime I have had the experience and often privilege to be a part of many "changes" and transitions – both personally and professionally.

Change can happen without us even realizing it is happening.
As an example, did you know that as we age, we start to eat less. This is a natural progression brought on by less activity and lower nutritional requirements. We don't realize that this is happening, it just does.

But there are times in our life that we make a conscious effort to make change happen. When we intentionally work towards any kind of change, there is often a process that we follow. To explain this process, I am referencing Loma Linda University's School of Medicine's Stages of Change. *(http://www.cpe.vt.edu/gttc/presentations/8eStagesofChange.pdf)*

Stage 1. Precontemplation: If you're in stage one, you won't recognize any need to change. Other people may express concerns, but you'll deny that a problem exists. Unless someone raises your awareness of the problem, you likely won't choose to do anything. As an example, if you have become complacent, your family may point this out and suggest you go for a walk.

Stage 2. Contemplation: When you're in stage two, you will recognize potential consequences of not changing, but you won't be fully committed to making a change. For example, somebody may recognize why exercise is important, but is still contemplating adding exercise to their lives.

Stage 3. Preparation: During stage three, a person creates a plan for change. Somebody in this stage may recognize that they are not getting enough exercise and plan to improve their activity. For example, they may try to fit a 30-minute walk into their daily routine, buy new runners or walking shoes. It is important to devote plenty of time and energy into creating a realistic plan that will set you up for your success.

Stage 4. Action: Stage four is where your change finally begins. You act! For example, somebody committed to going for a walk may ask a friend to join them.

Stage 5. Maintenance: Early into the action stage, you may be tempted to declare victory and think you're well on your path to success. But, if you don't consider how to maintain change over time, you may struggle with obstacles along the way.

During stage 5, it's important to monitor your progress and plan for possible problems and pitfalls that could cause you to revert to your old behavior patterns. For example, if it's time for your walk and raining outside, you may be tempted to skip today, but maintaining your new routine is important. Find simple solutions that enable you to follow through with your plan. For example, you could try using an umbrella, rain suit or walk indoors at an indoor track or the mall.

Now, I want to talk a little bit more about societal change. When we see things that need to change, we can either sit and do nothing about it or we can stand up and share our voice to advocate for change! A good example of this is what Debbie, Doug and I are trying to do with this newsletter to change how people think about living with Alzheimer's😊

How does advocacy work?

I would like to share a personal example to illustrate this. ***When I was first diagnosed with young onset Alzheimer's, one thing I knew was that I did not want to end up like my grandmother or my mother.***

When my grandmother and mother were diagnosed with Alzheimer's, they were brought home and hidden away, I thought this was appalling. It was a different time. People equated having dementia with being "crazy" or "insane." There was a real sense of shame that people with dementia and their family members carried with them for a disease that they had no control over.

I wanted better than this for myself. This feeling is what fueled my fire to challenge perceptions about Alzheimer's and inspire societal change to create inclusive communities.

I started slowly at our local Alzheimer's Society, challenging how programs for people with dementia should be informed (by those who live with it.) People listened and my voice grew stronger. I met other dementia advocates doing the same thing as me. We joined forces and our voices grew stronger. The impact of our collective voice has been amazing and only continues to grow. Together, we are making real change for others who live with dementia.

Thank you for being a part of the change!

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 11 years ago, she has become an international advocate for people living with dementia.

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Version 4 Jan. 18, 2023. This research study has been reviewed by the Hamilton Integrated Research Ethics Board under project #13387

McMaster University

Appendix 1 - Recruitment Poster

PARTICIPANTS NEEDED FOR RESEARCH:

Nature-based pilot project for
older adults living with dementia and their care partners

We are looking for volunteer participants for our study: Older Adults living with dementia (55+) and their care partners to participate in a nature-based pilot program for older adults living with dementia and their care partners. Participation includes: a 30-minute intake interview, monthly 2-hour nature-based activities (e.g. walking, nature-based art) in the Hamilton/Burlington area, pre/post-session mood questionnaires taking no longer than 5 and 15 minutes respectively for each session, and a 1-hour follow-up interview.

Potential participants will be asked some screening questions to determine eligibility to participate in this study.

For more information about this study, or to participate for this study, please contact:

Constance Dupuis
McMaster University: Gilbrea Centre for Studies in Aging
Telephone: 905-525-9140 ext. 24449 or
E-mail: dupuic1@mcmaster.ca

Research Team: Dr. Anthea Innes (Principal Investigator), Dr. Vanina Dal Bello-Haas (Co-Principal Investigator), Constance Dupuis (Co-Principal Investigator), Mason McLeod (Research Assistant), Equity Burke (Research Coordinator), María Belén Miguel (Research Assistant). McMaster University

This study has been reviewed and received ethics clearance by the McMaster Research Ethics Board, MREB#6580.

Appendix 1, Innes V2

Have your Say! Contributions from Dementia Friends

Living with Alzheimer's

By Robert Hollis, Guest Contributor

I believe attitude and desire are important aspects of living with Alzheimer's. YOU ARE STILL THE SAME PERSON YOU ALWAYS WERE. You can still function extremely well except for a few forgetful moments that you will remember eventually?

I like to make notes as I work through my day, but sometimes the words do not look right, and I have to think about them. "Word" spelling and grammar is a great tool if you are typing a letter. You can always carry a dictionary with you, but maybe this is taking it too far. Alzheimer's/dementia is a disease, but it does not stop you from having a real life, although at some point you may no longer be able to function the same. If you are like me, I am definitely not ready to stop yet.

I attend a program where people like me meet to talk about how they are coping and receive support. It is great to associate with people who can relate to our challenges. A funny thing I noticed was the majority of our group are left-handed, I hope this does not relate to a cause of this disease. (Ha Ha).

There are situations that I find discouraging, but that will not stop me. I find other ways to do what I need to do. This will not defeat me. I still have the strength to live my life to the fullest, and I will do that. **Be strong. Be resourceful. Please think like me. Your life is not over by a longshot.**

I recently joined a not-for-profit organization in my community. I volunteered to be on the donations committee, and I was recently elected as the treasurer, as well as part of the Board of Directors. My brain changes relate to giving back to people in need. I want to do more for the less fortunate. This gives me the desire to move forward.

My life is not over yet, and neither is yours. I want to be there if I can help someone. **Think Positive. Be Strong.**

Robert Hollis
~I am the same person I always was. But sometimes I just don't have same day delivery.

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.

We are seeking NEW MEMBERS & WRITERS for our newsletter! If you live with dementia and want to learn more or join our team, please contact us!

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