Insight

Alzheimer Society

For people living with dementia

Winter 2021





Changing the future through awareness

January is Alzheimer's Awareness Month and this year the theme is "Changing the future." The Alzheimer Society of B.C. is asking British Columbians to consider simple actions they can take to support people affected by dementia today, and to change the future of dementia in the province. For people living with dementia, it's an opportunity to hear from others on the dementia journey and learn ways to access or ask for support.

This issue of *Insight* features ideas on how manage stress through mindfulness, ideas for activities for keeping in touch with friends and family, as well as an interview with Ron Restrick, an Alzheimer's

Awareness Month spokesperson who shares how he manages living with mild cognitive impairment by staying active. We also go inside an art exhibition exploring what it means to live well with dementia through art and *Insight* editor Mario Gregorio looks back on the last 12 years since he was diagnosed with dementia.

While we celebrate our successes and look to the future, we also recognize that for many people, this continues to be a challenging time. We are asking anyone in need of help to please reach out to us on the First Link® Dementia Helpline.

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It's so nice to hear from you again

Mario Gregorio is Insight's editor and member of the Society's Leadership Group of People Living with Dementia.

I often joke that the loneliest piece of equipment in my house is the telephone because nobody calls. Since my neurologist gave me a diagnosis of vascular dementia 12 years ago, I am still doing well.

I like to believe that my hunger to find out more information about this disease that causes so much unnecessary pain and suffering allowed me to understand the challenges and to find creative solutions. I stumbled on the word **neuroplasticity**, which means the ability of the brain to change through growth and creating new connections.

In retrospect, I am now able to be at peace about what is happening around me. It is not my family's fault, nor my friends' lack of caring that made them stop visiting. It is just that they do not know how to respond. The greatest challenge is the sense of abandonment and aloneness, the loss of connections with friends and grief for lost opportunities.

An acquaintance once observed that since his diagnosis, he gets the impression that instead of being thought of as a smart, funny and very interesting person, people assume that he is different now, no longer competent. Unsure he understands what they are saying, people talk slowly, simply or worse, loudly. This is very hurtful to him.

Because of the misinformation about dementia, we lose the person for the disease. Often there is a feeling of distaste and puzzlement rather than empathy and understanding from people after learning that someone in their life has been diagnosed with dementia.



In January, for Alzheimer's Awareness Month, the Alzheimer Society of B.C. will explore the theme of "Changing the future" for people living with dementia. Key to this is staying connected with people living with dementia. You can read tips for how to be included in the lives of friends and family on page 5, and to learn more about the January Awareness Month campaign, visit alzbc.org/future.

Mindfulness activities for stress-relief

Mindfulness is a popular concept at the moment, but what does it really mean? Mindfulness is simply paying attention to the experience of the present moment through our senses without judgement. While we all possess this ability, it can become easier with practice – like strengthening a muscle.

Studies have found engaging in mindfulness practices like meditation can reduce stress and help you to feel calmer throughout the day.

Mindful breathing

Take slow, long, deep breaths and feel your stomach expand. Notice the feeling of your breath moving in and out of your lungs and through your nose. You may wish to simply notice your natural breath or try a technique like "square breathing," inhaling for four counts, holding your breath for four counts, exhaling for four counts and pausing for four counts. You can do this practice anytime, anywhere.

Mindfulness meditation

Find a comfortable position, either sitting in a chair or lying down. Close your eyes and focus your attention on your breath. When your mind wanders, gently bring your attention back to focusing on your breath and the present moment. You may wish to set a timer for 5-10 minutes, during which time your goal is to stay focused on the meditation.

You can also find free guided meditations online through websites such as InsightTimer.com, HeadSpace.com, through their smartphone applications or on YouTube.



Mindful activities

Many activities during our day are automatic – we do them while thinking about something else. Any daily activity can be made mindful by focusing on the present moment. When drinking a cup of tea, for example, take a moment to notice the weight and warmth of the mug in your hands, sense the muscles you use when lifting the mug to your mouth, notice the smell and really savour the taste. When listening to music, notice the the different instruments and vocals, including the range and different tones.

To learn more about managing stress, call our First Link® Dementia Helpline or visit our website: alzbc.org/managing-emotions

British Columbians pledged their support through powerful awareness campaign

A weekend getaway before you drifted apart from your travel buddies. A dinner party when you still got the invitation. A call from a friend when you really needed to talk to someone.

People living with dementia often lose these vital social connections because the people in their lives don't know how to respond to a diagnosis of dementia. Friends or family don't know what to say, or how to include the person living with dementia in their life, so they drift apart.

This fall, the Alzheimer Society of B.C. ran a powerful awareness campaign aimed at inspiring people to reflect on the ways they will continue to show up for the people in their lives who are living with dementia. The campaign, entitled "Don't change. Even if they do." challenged British Columbians to find ways to keep connected, especially during this time of increased isolation. With an estimated 60 per cent of people with a diagnosis of dementia living in the community instead of in long-term care, keeping these relationships is essential to the well-being of people facing the disease.

"We know that people living with dementia and their caregivers are facing more social isolation than ever," says Alzheimer Society of B.C. interim CEO Barbara Lindsay. "We want everyone to step up and show their support for people living with dementia in their communities. Keep visiting. Keep calling or FaceTiming. Even during COVID, we need to maintain our connections to people living with dementia to show that they're not alone."

As a part of the campaign, the public visited dontchange.ca and pledged how they would continue to stay connected to people affected by dementia. From dropping off fruit to watering plants, visitors to the site pledged to continue making small gestures that have a major impact on keeping friends and family supported and included.



To read pledges made during the campaign and view powerful campaign videos, visit dontchange.ca.

Staying connected during COVID-19

The appointment of a Minister for Loneliness in the UK highlighted a growing concern about the welfare of seniors and people with disabilities. Countries like Japan, the Netherlands, Australia and Canada have recognized loneliness as a social issue that needs to be addressed due to the growing number of seniors in society. The pandemic has identified the gaps in the delivery of care in long-term care homes, where the impact of loneliness and isolation has been undeniable.

How can we help ourselves and our family members, friends or neighbours cope with this sense of grief and loss from increased isolation? Although the challenge seems daunting, our creativity and common sense allows us to develop ways and means of reaching out.

Activities to try

It's never been more important for British Columbians to stay in touch with the people affected by dementia in their lives. For people living with dementia, here are some ideas about the ways we can ask to stay connected to our family members and friends. (Note, not all of these suggestions may be possible for everyone given current COVID-19 restrictions.)

- Make a five-minute telephone call once a week. It is a good idea to schedule it before midday.
- Arrange for Skype or Zoom virtual parties, holidays and family gettogethers. Encourage grandchildren to make short video calls.



- Take part in activities together, such as:
 - Craft, photography or other art classes
 - Tai chi, meditation or laughter yoga sessions
 - Music learn how to play an instrument like the ukulele or join a choir
 - Hobbies, such as building boats in a bottle or stamp collecting
- Take short morning walks around the neighbourhood together.
- Create a memory box of treasures, and try including:
 - Old photographs or photos of places you've visited
 - Souvenirs from trips or childhood memorabilia
- Order in or share simple meals together.
- Visit with a pet, borrow one from a friend or look at photos of animals together.

Being active and keeping connected through COVID



We can help change the future by staying connected. Ron Restrick of Maple Ridge lives with mild cognitive impairment and is sharing how he stays connected with the

people in his life as a part of Alzheimer's Awareness Month. Ron retired from a career with the B.C. railroad and now lives independently. He enjoys spending time being active outdoors, travelling, crossword puzzles and keeping in touch with neighbours, friends and family.

When were you first diagnosed with mild cognitive impairment?

I went to see my doctor with my son last fall. My son wanted to talk about it, so he took me to the clinic and they did some memory tests. I was having trouble doing certain things. They didn't say it was mild cognitive impairment at the time. They saw things that were noticeable to them, but that I had grown used to.

What was your initial reaction to the diagnosis?

It was difficult to understand. Why me? Little things are difficult – finding things, like my glasses, but I'm used to it now. I still feel pretty good. I go out and I hike. Those things are important to me, because they were before this took place.

How have people responded to your diagnosis? Have they stayed in contact or have you found that people have pulled away?

Everybody was on board. My friends are still there. Everybody calls me and we go and do things. I've had two marriages and I'm still close to everyone, my children and my siblings. There's a place for me.

Have you found that COVID-19 has changed how you stay in contact with people?

I'm upset that it has caused problems for my family, but it hasn't interfered with me at all. I get my food, go for walks and hikes. I still talk with my family and friends on the phone.

How do you like to stay connected to the people in your life?

I like to say hello to neighbours while I'm running around the block. It's a part of who I am. I enjoy people. It doesn't matter if they're old or young. Everybody knows me. Life is good. Sometimes I do get frustrated when I can't find something, but it's not troublesome. People are very cognizant of this. When I get these pieces of something that I can't remember, my friends have patience and offer tips.

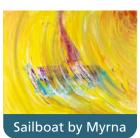
What Alzheimer Society of B.C. programs and services have you used?

I was a part of an early-stage support group (before it was put on hold due to COVID-19). There were 14 of us. I loved it. I had a lot of fun with them. There were some really nice characters. I made a connection. There are a lot of good people out there.

Engaging in research: Online art exhibit shares the experience of living with dementia



At the Alzheimer Society of B.C., we encourage people living with dementia and their care partners to seek opportunities to be involved in research as



a way to continue learning throughout life and to stay socially engaged. It is also a form of advocacy, source of hope and way to engage in the community. In our work with researchers, we emphasize the importance of dementia-friendly research: research that meaningfully engages and partners with people living with dementia and their care partners as participants, co-researchers and advisors.

A wonderful example of dementiafriendly research is the online art exhibit "In there out here: Art making space to live well with dementia." The exhibit showcases the work of people living with dementia and their care partners through various media including painting, collage, photography, masks, poetry, sculpture and a short film. The featured art shares insights on what the participants would like the world to know about their dementia journey. This work was led by Associate Professor Susan Cox and Postdoctoral Fellow Gloria Puurveen at the University of British Columbia's W. Maurice Young Centre for Applied Ethics, with funding from the Alzheimer Society Research Program, the Canadian Institutes of Health Research and the Michael Smith Foundation for Health Research.

The project began with interviews with people living with dementia and their care partners. It included a series of arts-based workshops that explored the meaning of living well with dementia. This project is also a wonderful example of resilience in the face of the difficulties of the COVID-19 pandemic, as the group adjusted to Zoom workshops partway through the project and shifted to an online exhibit for the artwork.

Explore the incredible artwork created by this group as well as interactive art activities you can participate in at artmakingspace.com.

Participate in dementia research

By participating in research, you can help shape the future of dementia in Canada. REACH BC is a new online platform where volunteers interested in participating in research can connect with health researchers and browse research opportunities across British Columbia. To access the REACH BC portal and learn more, head to reachbc.ca.

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- Subscribe online at alzbc.org/insight-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742

Contribute

We welcome contributions, such as personal stories, photography or original poems, from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

Email insight@alzheimerbc.org

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- Call 604-681-6530 or toll-free 1-800-667-3742
- Mail to the Alzheimer Society of B.C., care of Insight: 300-828 West 8th Avenue

Call the First Link® Dementia Helpline

A confidential, province-wide support and information service for anyone with questions about dementia. Our English Helpline hours have been extended and now run from 9 a.m. until 8 p.m., Monday to Friday. Cantonese or Mandarin and Punjabi Helplines are open from 9 a.m. to 4 p.m., Monday to Friday.

English: 1-800-936-6033

Punjabi: 1-833-674-5003

Cantonese or Mandarin: 1-833-674-5007

Email supportline@alzheimerbc.org

Are you a caregiver?

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To subscribe:

- Visit our website at alzbc.org/ connections-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742



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