



Keeping informed and active this spring

This issue marks one year since our lives changed so significantly due to the COVID-19 pandemic. It has been an incredibly difficult year for many people affected by dementia, but as the roll-out of COVID-19 vaccines ramps up and the weather improves, we are hopeful that brighter days are ahead.

In this issue of *Insight*, we answer some of the most-commonly asked questions related to COVID-19 vaccines we continue to hear on the First Link® Dementia Helpline. We also highlight feedback from our online Minds in Motion® sessions, a fitness and social program for people living with dementia and a

care partner that is now accepting new participants.

Guest editor Myrna Norman offers her optimism and advice for navigating the dementia journey, as well as some of her powerful poetry. Finally, we share an update from a new dementia-friendly research project.

Want to get active while supporting the Society? Join people across B.C. at our online *IG Wealth Management Walk for Alzheimer's* during the month of May. Learn more at walkforalzheimers.ca.

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Choose joy

Ever let those voices in your head castigate you for making a mistake? Ever brush your teeth with hair remover? Ever not respond to the “call of nature” and pay the price for not attending to your needs? Let’s not worry about the small stuff. Let’s go for the joy in our lives whether that is working in the garden, viewing the sunset, listening to an audiobook or walking at least 5,000 steps per day while taking time to smell the roses.

Having dementia has brought joy to my life in countless ways: painting on canvas, making a collage, writing poetry, writing books, having a voice to share with others, supporting and being supported by others. Sure, I wish I could still drive, host dinners, make cookies that tasted good and even remember when I last bathed. Life in all its forms is for living well. Live well with dementia.

Remember we still do have choices to make. We still have rights and responsibilities and those give us the options to find joy in our lives. If I can do it, imagine what you can do.

Myrna Norman is a dementia advocate and an active member of many advisory committees, including the Society’s Leadership Group of People Living with Dementia. She is passionate about combating the stigma surrounding dementia. Her book, *Dementia Strategies, Tips and Personal Stories* can be ordered by email at the.normans@shaw.ca.

I Am Not Afraid

by Myrna Norman

I was not afraid until
A bully showed his
ignorance
By attacking me.

I was not afraid until
My voice used a
language
Not familiar to me.

I was not afraid until
My independence was
Substantially curtailed.

I was not afraid until
My tasks became too difficult
to complete.

I was not afraid until
My presence was no
Longer requested.

I was not afraid until
Going for a walk
Became “wandering.”

I was not afraid until
My short-term memory
was gone.

I was not afraid until
Trying to keep up in a conversation
Became far too difficult.

I was not afraid when
I learned my journey
Could be happy.

I was not afraid when
My journey had a few dips
But I was able to proceed.

I was not afraid when
Advocating for People with Dementia
Became my life’s work.

I am not Afraid.



COVID-19 vaccines: Your questions answered

It has now been over a year since the coronavirus profoundly changed our lives, and its devastating impact has been felt deeply. We've heard people affected by dementia describe the COVID-19 vaccine as a light at the end of the tunnel.

Want to learn more about the vaccines? Here are the answers to some frequently asked questions.

Are the approved COVID-19 vaccines safe for people living with dementia to receive?

People living with dementia were not included in the clinical trials studying any of the approved vaccines. However, the trials did indicate that these vaccines are safe and very effective in older adults. Additionally, to date, no dementia-specific adverse effects have been reported to Health Canada, which we would expect to have seen by now as countries are focusing on vaccinating older adults. As such, the vaccines are strongly recommended by Health Canada for people living with dementia. For more information about the vaccines currently approved in Canada, please visit alzbc.org/vaccines.

What are the risks of receiving a vaccine?

Current data suggests that the approved vaccines have only mild side effects. People occasionally report fatigue, headache or pain at injection site (particularly after the second dose), but most experience no side effects at all.

As the vaccine has begun to be distributed globally, there have been some reports



of allergic reactions. However, all these people were appropriately treated and suffered no long-term effects. It is not unusual for some people to have allergic reactions to vaccines, but this remains very unlikely.

How will I know when I am eligible for the vaccine?

British Columbia's COVID-19 Immunization Plan is made up of four phases, which are primarily organized by age. B.C.'s Immunization Plan depends on many factors and information is subject to change. Visit the official website for the most up-to-date information at alzbc.org/immunization.

The Alzheimer Society of B.C. encourages people living with dementia to receive the vaccine as soon as it is available to them. If you have questions or concerns about the vaccine, we recommend connecting with your doctor or other health-care provider.

Keeping Minds in Motion®, online!

Sandee Hall lives independently in Kamloops and was among the first people to join an online session of Minds in Motion®, a social and fitness program for people living with dementia and a care partner. Sandee volunteers at the Brock Activity Centre and loves playing bridge, both in person, and online with local clubs since the onset of the pandemic. She has remained active and engaged virtually despite the challenges of physical distancing restrictions.



How did you first connect with the Alzheimer Society of B.C.?

When I moved to Kamloops in 2016, I started volunteering at the Brock Seniors Centre and someone there told me about the Medical Arts memory test and I jumped on it. It was through the testing that I was diagnosed with young onset Alzheimer's. When I was diagnosed, everyone was shocked. I didn't realize I had Alzheimer's. I thought I had some memory problems. That's when I got in touch with the Alzheimer Society. I was in a bit of shock. I was going through a long list of emotions, especially grief. When Tara Hildebrand [a Support and Education Coordinator for the Alzheimer Society of B.C.] reached out to me, I was able to express my concerns, fears and emotions, and I am able to accept the diagnosis now. Her support has been invaluable to me and my daughter.

What do you enjoy about Minds in Motion®?

I like talking to people. This was a chance to meet people with the same diagnosis as me. It's given me a chance to share experiences and make friends. We became friends right away. It's a wonderful way to keep our bodies moving and have fun. There are also games and trivia.

How has COVID-19 and the loss of in-person programming affected you?

I really look forward to Minds in Motion®. It's always on my calendar. The other participants are a huge part of my social life, as I can connect with them on a different level. They are like family to me.

How have the online Minds in Motion® sessions been for you?

I love them! The things that they can do with technology are amazing. We hear good music and exercise for 45 minutes then we still have the social aspect. It was very easy to adapt to the technology and there's support if we ever need it. The coordinators are fantastic and we have lots of fun.

What would you say to someone considering joining a Minds in Motion® group?

I would tell them it's one of the best things to join. It's an integral part of my life and it brings me joy. It's very helpful to be with your peers.

Minds in Motion® online: What participants are saying

This fall, the Alzheimer Society of B.C. began a pilot project to offer an online version of Minds in Motion®, a social and fitness program for people living with early-stage dementia and a care partner. Participants, like Sandee who is interviewed on page 4, shared what it was like joining the popular program in an online format. Here's what they had to say:

What do you like most about Minds in Motion® online?

- "The feeling of belonging and realizing that I am not unique in my current situation."
- "I love the social and exercise components. I have really missed the program and this works out wonderfully. It definitely fills the void."
- "Considering the COVID situation, it's very helpful."

- "Participation with other people."
- "The social connections."
- "The ability to connect with other people with similar physical/mental conditions and to provide support for each other."

Is there anything else you would like to share with us about your experience?

- "I appreciate the effort to keep Minds in Motion® in our lives during these isolating times."
- "We really enjoyed it."
- "The leaders were very personable, made everyone feel comfortable in this new age of being online."

Would you like to spring into setting healthy brain goals with Minds in Motion®? New sessions are beginning regularly. Learn more at alzbc.org/mim.



Researchers come together to study dementia-friendly communities

The Alzheimer Society of B.C.'s vision is a world without Alzheimer's disease and other dementias, and that world begins with a more dementia-friendly society where people affected by dementia are acknowledged, supported and included. The University of British Columbia's School of Nursing is working on a research project to help work towards this goal.

The study connects researchers, health-care providers, dementia advocacy groups, people living with dementia and their caregivers. The groups work together to develop a better understanding of dementia-friendly communities.

The study outlines a variety of challenges people living with dementia can face, including stigma, mental health challenges, difficulty accessing supports and financial need.

"Social inclusion and the work of this study is so important because people living with dementia need to be better heard and more included in society," said Lynn, one of the collaborators in the study and a person living with dementia. "We need to have a sense of purpose, which is essential to our life satisfaction. Although we have



the disease, we are people just like we were before diagnosis and need to be treated with the same respect as others."

By collaborating with health researchers and people affected by dementia, this research project has helped identify priorities that need to be addressed to build more inclusive, dementia-friendly communities. This information will be used to inform policy and help communities become more accessible to all.

This work was led by Assistant Professor Dr. Lillian Hung and Professor Dr. Alison Phinney, with funding from the Michael Smith Foundation for Health Research.

To learn the top research priorities identified through the project, watch their video at alzbc.org/DFCresearch.

Thank you for making Breakfast to Remember a success!

On March 4, people from around the province joined us for a *Breakfast to Remember* fundraiser like none other, featuring keynote speaker Col. Chris Hadfield, to raise funds to help provide support for people affected by dementia. Thank you to all our volunteers, sponsors, donors and guests – including Lynn Jackson, a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia, who opened up about how her life changed following a diagnosis of dementia.

“Living with dementia has made me think of my life in a whole new way,” Lynn said. “Over time, after accepting my disease, I wanted to be able to teach others and advocate for those diagnosed.”

Among others who spoke alongside Lynn at the event was Paul Blanchet, a Kamloops-based caregiver to his wife Linda, who lives with young onset Alzheimer's disease and emcee Dawna Friesen, anchor of *Global National*, who also shared her personal connection to dementia.



We are grateful for all speakers and supporters who furthered the conversation about dementia and helped us in our mission to change the future of the disease.

Dementia in the days of COVID-19: Jim's story

Jim Mann, a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia, regularly shines a light on the lesser-known impacts of COVID-19 on people living with dementia at home. Read ongoing updates and advice from Jim at alzbc.org/jimsstory.



How have you been handling the constant flow of information in the news that many people are finding overwhelming and stressful? Are there things you have done to help strike a balance or unplug?

It would be fair to think that because I have not been travelling or taking time to travel into town for meetings, that I

would be in total control in my home office. That, unfortunately, isn't the reality! It has taken me almost a year to better manage the flow of information and, believe me, it's a work in progress. There is a need to pick and choose what you read and what you save because, you are right, the flow of information is constant. As more and more groups and universities issue newsletters and as patient-oriented research becomes more accepted and pursued, there are more communication pieces distributed that could lead a person living with dementia to feel they are drowning in information. Like I suggested above, don't let this be a point of stress.

Be interested. Be curious. But keep it manageable.

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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
- 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
Vancouver, B.C. V5Z 1E2

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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