

Connections

Linking a community of dementia support



Research and resources during COVID

Researchers in B.C. have found ways to connect safely during the pandemic and continue their critical work to change the future of dementia. We are committed to doing the same, through our support of research and the ongoing development of virtual programs and services. We want anyone affected by dementia to know that they're not alone. Please connect with us through:

The First Link® Dementia Helpline: The Helpline continues to operate into the evening Monday through Friday (9 a.m. until 8 p.m.), with support available in Cantonese, Mandarin and Punjabi from 9 a.m. to 4 p.m.

Minds in Motion® online: We are now offering the fitness and social program online. Visit alzbc.org/MM for details.

Virtual support groups: We are continuing to roll out groups across B.C. If you are interested in participating, by phone or video, please call the First Link® Dementia Helpline for more information.

Webinars: Find recordings of recent weekly webinars on topics such as “Music and the brain – Key considerations for dementia” and “Lived experience: Strategies I wish I'd known” at alzbc.org/webinars.

Read and learn more

For a full catalogue of COVID-19-related resources for people living with dementia, caregivers and health-care providers, visit alzbc.org/COVID-19.

In this issue

Greetings

Caregiver story

Page 2

Page 3

Information

Events

Volunteering

Page 4

Page 7

Page 8

Moving towards a dementia-friendly future through research

The summer season began with signs of positive change, with increased vaccinations, loosened COVID-19 restrictions and a renewed sense of hope among British Columbians, including many people affected by dementia. While we continue to focus on all the ways we're able to provide new remote dementia support and look forward to the return of in-person activities of all kinds, we would also like to highlight essential work that has remained constant throughout the last year of pandemic restrictions: dementia research.

Research is key to changing the future of dementia. At the Alzheimer Society of B.C., we are proud of the progress we have made over the last year as research partners, investors and knowledge translators – including through collaborations that continued despite the challenges of the COVID-19 pandemic. This issue of *Connections* features tips for understanding research headlines and points to further resources to learn more about research, like our annual “A focus on research” publication which is available now.

Alongside the research news, we share feedback from caregiver support group members, as well as volunteers supporting Minds in Motion® online, programs which are both open to new participants. We also look back at all the creative ways communities have come together to fundraise over the last year and hear from Earla Leagault, a caregiver who found help on the dementia journey through a virtual support group.

As we look towards our vision of a world without dementia, we're so proud to support important dementia research that is improving lives today. We thank all our supporters for making dementia research, as well as all our dementia support and education, possible.



Barbara Lindsay

Barbara Lindsay, LLB
Interim Chief Executive Officer
Alzheimer Society of B.C.



First Link®
DEMENTIA HELPLINE

Questions about dementia or memory loss?

English: 1-800-936-6033
Cantonese or Mandarin: 1-833-674-5007
Punjabi: 1-833-674-5003

English: Monday to Friday, 9 a.m. to 8 p.m.
Cantonese or Mandarin and Punjabi: 9 a.m. to 4 p.m.



Accessing virtual support on the dementia journey

Earla Legault lives in Harrison Hot Springs and helps care for her mother, Joey, a retired nurse who lives with dementia. Earla was Joey's primary support throughout her journey, but has taken on a less active role since Joey recently transitioned from independent supportive living into long-term care. Earla is one of the many caregivers across the province attending virtual support groups, which are now open to new members.

When did your journey with dementia begin?

Mom was diagnosed five-and-a-half years ago through the Chilliwack Primary Care Seniors Clinic. She was looking after her daily living on her own, but didn't have attention to detail and needed help with her meds. She and I attended the Shaping the Journey education through the Alzheimer Society of B.C. together.

How did COVID-19 affect you?

It was awful at first. We phoned Mom a lot more. Whenever she was lonely before, she would go into the common area of her home, but with COVID, she couldn't. She likes keeping busy yet needed help initiating. Mom was bored and not getting enough exercise. COVID exacerbated her dementia and the isolation made it progress quicker. Because there weren't care staff around 24/7, her living situation became unsafe. Despite not being able to tour her new housing, she is safer living in care.

Did you attend a support group in-person before joining the virtual group?

I joined a caregiver support group that met regularly. Attending in-person wasn't quite working for me. I always used the First Link® Dementia Helpline. They're on speed dial. They're so helpful. Then I

learned about the tele-support group and I've attended regularly for a year. I like the call because I'm connecting with peers.

What's it like participating in a virtual support group?

Hearing other peoples' stories is really beneficial. You know their names and remember their familiar voices. I treat the group as a resource because I always learn something helpful that supports me in looking after my loved one and myself. I believe that when you're listening to your peers and hear them being vulnerable, it allows you to be vulnerable too.

What would you say to someone considering joining a group?

Try attending for three sessions. In that time, you hear other stories and learn more about the Society. In my experience, there is no handbook given to you on how to do this. You learn you're not alone. If you do join, make it a priority and look for respite care to attend. You owe it to yourself to get the support. You need that. I don't think of the caregiver support group as support; it's self-care. No one else is doing this for me.

What are you looking forward to this summer?

I plan to visit my mom, but I'm not going to be the caregiver. I'm going to be the daughter.



Joey and Earla

Join a virtual support group. Virtual groups of all kinds are opening regularly. To register, call the First Link® Dementia Helpline (see page 2 for details).

Virtual support groups: What participants are saying

Last year we started rolling out caregiver support groups across the province by telephone, and this spring, we were thrilled to add many more groups open to telephone or video participation, for both caregivers and people living with dementia. We are also now offering less-structured coffee and chat groups for people living with early-stage dementia. All groups are now open to new registrants. Call the First Link® Dementia Helpline for more information.

Not sure if a virtual group is the right fit for you? Here is what we heard from participants in our first tele-support groups, along with feedback we have used to strengthen the new groups on offer.

- “Being able to discuss the situation with others who truly understand makes me not feel so alone.”
- “[I like] being with my peers, who understand and are experiencing the same emotions.”
- “Connecting with people who have a common theme as me is SO validating, and keeps me motivated to carry on. Plus being with others who can relate to my journey and are able to understand with empathy as I do theirs, is priceless.”
- “It’s just a godsend knowing there are others out there going through the same crazy stuff; you totally understand what they are saying, and you know they absolutely get you.”
- “It is far more doable for me than attending in person, since my time as a caregiver is so limited.”

Support satisfaction

- 85 per cent of group members feel more connected to others in the same situation since attending the group.



- 98 per cent said the facilitator was able to manage the group and time effectively.
- 97 per cent of people said they feel comfortable or somewhat comfortable sharing their experiences in the group.
- 93 per cent would recommend participating in a virtual support group to others.
- 84 per cent of caregivers have benefited in some way from attending the virtual support group.

We also heard from participants that there was a need for other, more specialized caregiver support groups, including groups for: caregivers of people living in long-term care, Cantonese and Mandarin-speaking caregivers, LGBTQ+ caregivers and groups specific to caring for someone living with a specific form of dementia. We are pleased to share that all the aforementioned groups have been formed, with more on the way and open to new participants, as requested.

Learn with us

People are also staying connected through our online education. Of the support group members we heard from, 40 per cent had recently watched one of our weekly webinars. Webinars on a variety of topics related to caregiving and living with dementia are open to the public and shared weekly on our YouTube page. Learn more at alzbc.org/webinars.

Research: Deciphering the headlines

You may notice more eye-catching headlines related to dementia research in the coming months. Even during the pandemic, innovative research has continued. The Alzheimer’s Association Annual Conference (AAIC), taking place at the end of July, is a major international conference in the field and a key place for researchers to share new discoveries related to prevention, treatment and improvements in diagnosis for all types of dementia.



Whenever there are significant new findings in research, they often get picked up by the mainstream media. Of course, there is lots of high-quality journalism on research. However, sometimes when journalists are asked to interpret complex studies, or are rewarded for how much attention a story gets, we see headlines that exaggerate or sensationalize results to drive more clicks to their articles.

Come across an exciting headline? Here are some steps you can take:

- **Do an initial gut check.** Does it feel like the headline is informative, or is it seeking to cause an emotional reaction in the reader? Does it sound too good to be true?
- **Look beyond the headline.** Headlines can be oversimplified or exaggerated to grab attention. Read through the full text of the news story to get a more complete understanding.
- **Consider the source.** Does the source appear reputable? Is the author or associated organization listed? Does the website have any academic affiliations? Is it subject to peer review (for example, in an academic journal)? Does the website identify the original sources of the information?

Learn more about research

- Our annual publication “A focus on research” is now available at alzbc.org/research-2021. We break down the biggest dementia research stories of the year, share a guide to participating in research and tips for reading research headlines as well as a profile on local researcher Elyn Rowe.
- Watch our Dementia research 101 webinar with Dr. Julie Robillard at alzbc.org/dementia101.
- To learn more about how the Alzheimer Society of B.C. supports research, visit alzbc.org/BCresearch.
- Feel free to email us at research@alzheimerbc.org with any other questions.

Research: Deciphering the headlines (continued)

- **Check out the author.** Do a quick Google search. What are their credentials? Do they have qualifications to speak on this subject? For example, it's good news if the source you're reading is a doctor or a professor at a university, but it's still good to check what their area of expertise is. Another consideration: do they stand to gain financially in any way through sharing this information?
- **Cross reference with other sources.** Do a search of the topic and see if other sources support the findings.
- **When possible, read the original, full-text research article.** Many online news stories will link to the source. However, many journals require payment to access, but the abstract (summary) may still be accessible.
- **Consult the experts.** Connect with your family doctor, researchers or other health-care professionals you trust.

Research findings are often nuanced, with different factors to consider. For example, if a study was done on mice, it doesn't necessarily mean we'd find the same result in humans. We dive deeper into

some of these considerations in our “Deciphering research headlines” webinar that discusses best practices around research methods and how to spot misinformation. It also evaluates the evidence behind commonly-asked questions in dementia research, including those related to coconut oil, cannabis and the Bredesen Protocol. To watch the webinar, visit alzbc.org/researchheadlines.

New Alzheimer's disease drug receives FDA approval

The American Food and Drug Association has granted conditional approval for Biogen's investigational Alzheimer's drug, aducanumab, marketed as Aduhelm. This means that the drug will be made available for use immediately in the U.S., but Biogen will also complete an additional study on the drug's effectiveness to verify its clinical benefit. We will have to wait to see if Health Canada approves Biogen's application to use Aduhelm in Canada. Read more at alzbc.org/Aduhelm.

New resources available for helping someone with investment decisions

The Canadian Centre for Elder Law has released a study paper and new set of tools as part of the Inclusive Investing Project, developed to explore capacity and supported decision-making in the investment context.



One of the tools created is a booklet intended for friends and families looking to support a person living with dementia with their investment decisions. To read more, visit alzbc.org/inclusive-investing.

Fundraising together while we're apart

On March 11, 2020, Alzheimer Society of B.C. staff members were gearing up for a big day that week: the *IG Wealth Management Walk for Alzheimer's* campaign launch at the Vancouver Art Gallery. But instead of celebrating our flagship fundraiser together, we listened for updates from the World Health Organization, which had just declared COVID-19 a pandemic. That day marked the end of many plans, but the beginning of a new era in fundraising.

A new roadmap for events

The *Walk* went ahead in 2020, but it looked very different. British Columbians got active with their bubbles close to home throughout May, then joined Alzheimer Societies across Canada for a livestreamed event to share our stories and honour people affected by dementia. Following the *Walk*, we launched our first provincial *Climb for Alzheimer's* and were lifted by the excitement of seeing hikers participate in all corners of the province.

In the fall, in place of our annual *Charity Dinner for Alzheimer's*, we worked with our Chinese Advisory Committee and partner Fairchild Television to produce the Cantonese-language *Telethon for Alzheimer's*, where we reached a whole new audience. Last winter, almost one year after those first early days of the pandemic, we were inspired by a personal keynote talk from astronaut Col. Chris Hadfield at our virtual *Breakfast to Remember*.

This past May, we experienced another incredible *IG Wealth Management Walk for Alzheimer's* with communities rallying around people affected by dementia, sharing their stories online and generating critical funds. Thank you to all our supporters who took part and made the *Walk*, and all of our events over the last year, a success!

Dedicated donors and fundraisers

As we pivoted, independent supporters continued to show up in support of our mission. COVID-19



In honour of their grandmother Marilyn VanDongen, Jasmin Falk-Hurst and Taylor Minten raised more than \$10,000 for the *IG Wealth Management Walk for Alzheimer's* by selling lemonade in Kamloops this May.

restrictions prevented the *Forget Me Not Golf Tournament* from happening in May, but thanks to the generosity of our corporate sponsors who committed to providing the same level of financial support in 2020, we were able to invest the same funds into critical dementia research, support and education. Adhering to public health guidelines, other fundraisers took advantage of our new *Anything for Alzheimer's* virtual fundraising toolkit.

Donors also changed how they supported the Society, with some opting to make smaller monthly gifts, or giving during our holiday campaign when gifts were matched thanks to generous supporters. The pandemic also prompted others to include a gift for the Society in their wills. We are so grateful for the many ways people across the province continue to show up for people affected by dementia.

Climb with us in September!

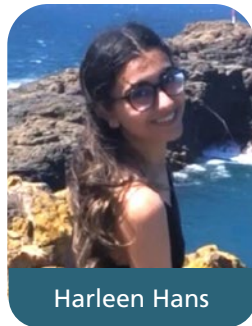
Join us at the *Climb for Alzheimer's* as we walk or hike to help provide dementia support and education between September 1 and World Alzheimer's Day on September 21. Learn more at climbforalzheimers.ca.

Volunteer for Minds in Motion®, online!

It has been a difficult year for volunteers who have missed giving their time to in-person support groups and Minds in Motion® sessions, activities that add purpose to their lives and help show people affected by dementia in their communities they're not alone. Last fall we launched our first sessions of Minds in Motion® online, and we are now accepting new participants and volunteers. Read on to hear what volunteers are saying about it.

“When in-person volunteering stopped due to the pandemic, I felt greatly disconnected. I missed the meaningful conversations with caregivers in support groups and felt something was missing when it came to my role as an active citizen. This, however, changed with online Minds in Motion®. Being virtually there for people living with dementia and their caregivers has allowed me to feel I am doing something meaningful again.”

- Harleen Hans



Harleen Hans

“It is gratifying to support the online Minds in Motion® program. You develop relationships and have a better understanding of how families are affected by dementia. The reward of the volunteer experience far outweighs your apprehension of stepping out of your comfort zone. It is extremely beneficial for families affected by dementia to participate in the online Minds in Motion® program so they receive the necessary support and realize they are not alone.”

- Ken Gillies

“It’s an absolute fun time, a time to share with others, laugh with others and get to know other people in the same situation. The facilitators are fabulous and will guarantee some fun sessions. Being a volunteer and able to help out is very rewarding, especially at the end of the session when we see people have enjoyed themselves and are looking forward to the next session.”

- Winsome Parris

To read more volunteer experiences of COVID-19, visit alzbc.org/COVID-stories. Email volunteer@alzheimerbc.org if you would like to take part.

About Connections

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- **Online** at alzbc.org/connections-newsletter
- **Email** newsletter@alzheimerbc.org
- **Call** 604-681-6530; 1-800-667-3742 (toll-free)
- **Mail** to the Alzheimer Society of B.C.
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Are you a person living with dementia?

We also publish *Insight*, a publication for people living with dementia or cognitive impairment. For more information, visit alzbc.org/insight-newsletter.



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