



Celebrating dementia research

While many people will experience a summer season different from past years due to COVID-19 restrictions, this season we're turning our attention to work that has continued throughout the pandemic: dementia research.

In this issue of *Insight*, we provide tips for interpreting research headlines and point to resources to learn more about research, including our annual publication, "A focus on research," available now. We are also pleased to share new resources for inclusive investing, messages from volunteers to the people they have missed supporting and a feature interview with Lester Gierach, who shares

his experience living with dementia to improve the future for others.

Stay connected virtually

We have virtual support available for anyone affected by dementia. This includes our social and fitness program Minds in Motion® online, telephone or video support groups for people living with early-stage dementia as well as caregivers and online resources, including weekly webinars. To learn more, or access any of our services, please call the First Link® Dementia Helpline (see page 8) or visit alzheimerbc.org.

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This is your platform: We invite you to make it your own

Welcome to *Insight*, the Alzheimer Society of B.C.'s newsletter for and by people living with dementia. Over the years, many courageous contributors have shared their personal experiences of living with dementia in the pages of *Insight* to support others living with the disease and address stigma. The publication would not be possible without their generosity and dedication. People have given their photography, poetry, personal writing and, most often, their time by participating in interviews with Society staff members who strive to accurately reflect their experiences in writing.



Myrna Norman

While we were planning this issue of *Insight*, a member of the Society's Leadership Group of People Living with Dementia stepped up and took on the role of interviewer to help ensure we're telling the stories you want to hear. We are excited to share Myrna Norman's conversation with Lester Gierach on page 4, and more interviews and contributions from her in the future. We hope this will inspire more of our readers to contribute to the newsletter – however they like.

Do you have a personal story you would like to tell, or questions you would like to ask other people living with dementia? Perhaps you have some tips on keeping well or managing stress during this uncertain time. Please send us your feedback, story ideas, art or interest in being interviewed. Everyone's journey with dementia is unique and everyone has a story to tell.

Get in touch

We welcome all ideas and contributions 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 your ideas or contributions to:
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

Research: Deciphering the headlines

You may notice more headlines related to dementia research in the coming months. The Alzheimer's Association Annual Conference (AAIC) takes place at the end of July. It is a key place for researchers to share new discoveries.

When new study findings are released, we often see the story picked up by a variety of media outlets. Sometimes when journalists are asked to interpret complex studies, we see headlines that may exaggerate or sensationalize results.

Here are some steps you can take to help you assess a headline:

- **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.** Read through the full text of the news story to get a more complete understanding.
- **Check out the author and the source.** Do a quick Google search. Do they have qualifications to speak on this subject? Even if the source is a doctor or university professor, it's still good to check what their area of expertise is.
- **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. 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.

Learn more about research

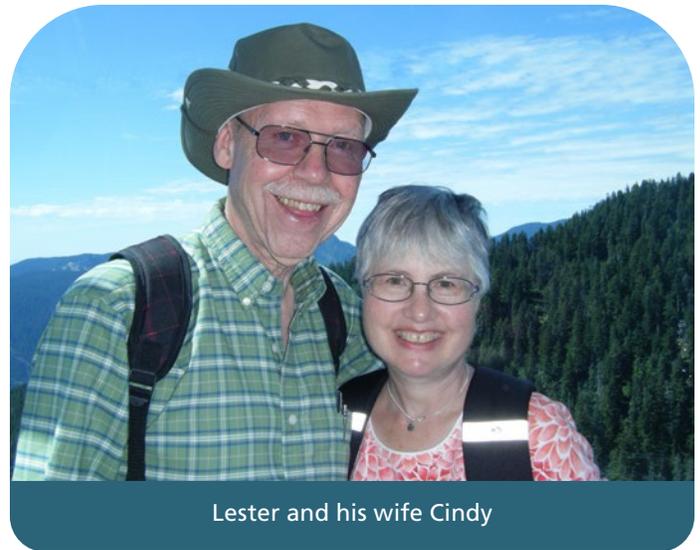
- Our annual publication, "A focus on research," is now available at alzbc.org/research-2021. We break down the biggest news of the year, share a guide to participating in research, tips for reading research headlines as well as a profile of a local researcher.
- Our "Deciphering research headlines" webinar looks at how to spot misinformation and evaluates the evidence behind commonly-asked questions. To watch the webinar, visit alzbc.org/researchheadlines.
- To learn more about how the Alzheimer Society of B.C. supports research, visit alzbc.org/BCresearch or email us at research@alzheimerbc.org.

New Alzheimer's 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. The drug will be made available for use immediately in the U.S., but 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.

Interview: Lester's journey living with young onset Alzheimer's disease

Following his diagnosis, Burnaby resident Lester Gierach began sharing his experience to connect with others on the dementia journey. He is a member of many groups and initiatives that involve people affected by dementia, including Burnaby's Dementia-Friendly Community Choir and dementia research at the University of British Columbia. In an interview with Myrna Norman, who lives with dementia, Lester opened up about his own journey in life and in living with dementia.



Myrna: What is your earliest memory?

Lester: My earliest memories are of Victoria where I lived in a child's paradise with my sisters and brothers. We would have fun together as a family at Beacon Hill Park or visit Butchart Gardens after church on a Sunday afternoon.

Myrna: What did you want to be when you grew up?

Lester: When I was growing up, I wanted to be someone like my father who was the pastor of a Lutheran church. When I was an adult, I decided what I really wanted to do was to teach at a Christian college, like Concordia College in Portland, Oregon. I later graduated with a Master of Science degree in Adult Education from the University of Wisconsin – Milwaukee.

Myrna: What was your profession?

Lester: After graduating from college, I enjoyed working at Milwaukee Area Technical College for many years, in Adult Basic Education. From 1987 – 1989, my wife Cindy and I moved to Beijing, China where we both taught English as a Second Language to adult students. In 1989, we moved to Taipei, Taiwan, where I became head of the English department at Christ's College. In 1990 we moved to Canada where I continued working with adult students.

Myrna: Who was the most influential person in your life?

Lester: One of the most influential people in my life is Richard Davidson, who graduated from Harvard University about the same time that I graduated,

Interview, continued

with a Ph.D. in Education Administration, from the University of Wisconsin. He is a professor of psychology and psychiatry at the University of Wisconsin – Madison, as well as founder and chair of the Center for Healthy Minds. His research and books often focus on mindfulness and meditation for both adults and children.

Myrna: What is your favourite book?

Lester: My most recent favourite books are called, *The Emotional Life of Your Brain*, by Richard J. Davidson, Ph.D. with Sharon Begley; and *Keep Sharp: Build a Better Brain at Any Age*, by Sanjay Gupta, MD.

Myrna: Who is the love of your life and how did you meet?

Lester: My wife, Cindy, is the love of my life. I met her 33 years ago in Milwaukee, Wisconsin. We met at a Lutheran church singles group activity in 1986. Cindy walked up to me and said, "Hi, my name is Cindy." The next time the group met together was for a picnic alongside Lake Michigan where Cindy and I had fun roller skating. The next day I called Cindy for a date and, of course, began falling in love.

Myrna: Can you think of a low point in your life when Cindy was there for you?

Lester: The lowest point in my life was when I found out that I had early-stage Alzheimer's disease, which was on

Valentine's Day, 2019. My gerontologist told me to "get my house in order."

Myrna: How do you cope with and live well with your diagnosis of Alzheimer's disease?

Lester: Since my diagnosis, we have been learning as much as we can about Alzheimer's disease. People who have this disease are encouraged to exercise and be socially active every day because it helps to slow down the progression of memory loss, keeping their brain active and functioning efficiently. So, before the COVID pandemic hit, we kept our eyes open for things to do, for places to go and people to meet with. Before the pandemic, I was socially active with coffee groups, church groups, taking part in UBC research, etc. During the pandemic, we have enjoyed many Zoom meetings with our church, seniors' groups, family, Alzheimer Society of B.C. webinars and even being part of a UBC research group.

Cindy: Each day is precious for us and we are learning how to live moment by moment.

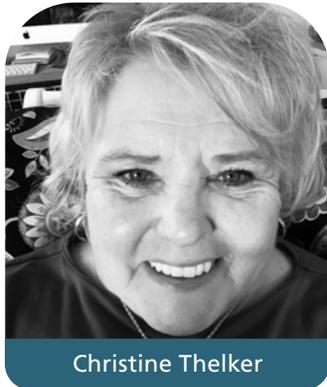
You're not alone

Read more first-hand experiences, including Jim Mann's monthly updates on living in the community with dementia during COVID-19, at alzbc.org/COVID-stories.

The city of Vernon is working to become dementia friendly

In June 2020, the City of Vernon passed a resolution to become age and dementia friendly, and work on this project is now underway. We look forward to continuing to collaborate with the City to build a plan that is responsive to the needs of people with lived experience and aligned with the City's vision.

Christine Thelker, an advocate living with young onset vascular dementia and member of the Age & Dementia-Friendly Committee in Vernon, brings her invaluable lived experience to this work.



- A quiet lane checkout, where we are not hurried or made to feel somehow inadequate when it takes us longer to figure out using our debit cards, find our money or bag our things.
- Early morning shopping hours (with no music and fewer people) create a friendly and easy shopping experience for people with disabilities and older adults.
- There are many more simple and inexpensive ways to assist people living with dementia or any other disability to have the ability to be more involved and included within their communities.

To learn more about dementia-friendly communities, visit our website at alzbc.org/DFC.

Christine recently shared her thoughts on what a dementia-friendly community means to her:

- Areas of no traffic. Having a car-free zone means I don't have to rush and risk falling. I don't have to be afraid, so I can manage to be out and do more for myself.
- Business owners and employees who are given training in things to watch for. For example, if I am standing in a store, I am not scoping the place to rob it. I may need assistance as all the noise in the store, such as the loud music, the general noise created by all the shoppers, the tills and the shopping carts, may have me overwhelmed.

New resources available to support you in 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 when it comes to making investments.

One of the tools created is a booklet intended for people living with dementia, to support you in understanding your investment decision-making rights. To read the booklet, visit: alzbc.org/investingtools

Volunteers share messages of support

Last year at this time, we shared messages from volunteers who provide direct, in-person support to the group members they miss. With in-person programming paused, it has been a difficult year for so many people, including for the volunteers who have been unable to engage in this meaningful activity and help show the members of their groups they're not alone. Below, we share more words of encouragement from these essential members of our communities. Read more messages from volunteers at alzbc.org/COVID-stories.

Landon Short, Minds in Motion® Assistant, Prince George

"It's hard to believe it is more than a year since the pandemic paused our Minds in Motion® program! Although in some ways it feels like much longer than a year since we have been able to get together in the way we were used to. It was this sense of community and developing connections with the amazing coordinators, volunteers and participants in the Minds in Motion® program that made me so happy to be a part of the program for over three years.



things seem to be slowly turning around for the better. So, we all just have to keep our heads up high and remember how resilient we all are with the knowledge we can get through this together, even if we are all still apart for now."

Vicki Taylor, Support Group Facilitator, Victoria

"This is a very challenging time for all of us but for those people who are facing a new diagnosis or dealing with progression of this illness, it must be incredibly isolating and stressful. I hope caregivers and people living with dementia will make use of the virtual community as best as they can. The First Link® Dementia Helpline is always answered by a kind and caring person. Hang in there until we can get back together in person.

"I have managed to keep busy with sewing for charity, making friendly phone calls to vulnerable seniors and volunteering at a vaccination clinic. For me, the key to staying healthy is getting outside. Walking is the best therapy and my dog is good at making sure that happens. Stay well everyone, and let's hope we can see each other in person soon."

Stay engaged!

Did you know, you can now participate in Minds in Motion® sessions online and early-stage support groups over the phone or online? Call the First Link® Dementia Helpline to register. See page 8 for details.

Subscribe

If you've enjoyed this issue of *Insight* and would like to receive it regularly, please subscribe. Help us reduce our costs by choosing to receive *Insight* by email.

- 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.

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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?

Connections is a quarterly print and digital publication produced by the Alzheimer Society of B.C.

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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