Insight

Alzheimer Society BRITISH COLUMBIA

For people living with dementia

Fall 2025

Finding your guiding light

Each person's experience of dementia is different and unique to them; communicating your experience can help with connection and understanding. This issue, we share insights we heard from people affected by dementia in B.C. and the Yukon about the guiding words that have helped them to find hope, focus on self-care and inspire them to advocacy.

This thread of authentic self-expression is woven through this edition of *Insight*. Fred Keating welcomes us with musings on how his career in media has set the stage for his role as a lived experience partner. Ross Fetterly, a retired member of the Canadian Forces, share how he's navigating his dementia journey with young-onset Alzheimer's disease. We feature education opportunities designed by and for 2SLGBTQIA+ people affected by dementia. Celebrate the award-winning researchers in B.C. selected for this year's Alzheimer Society Research Program funding. Liz Amaral, our current Artist in Residence, shares her late husband David's "view from the inside" – a collaboration of journal entries and mixed-media artwork collected in a published book. We hope this collection of stories inspires you to connect with what makes you uniquely you this fall.

Lived experience partners support our mission to ensure no one has to face the journey alone by sharing their experiences and insights. To learn more about how to get involved, visit **alzbc.org/LivedExperience**.

In this issue:

Greetings from Fred	**Page 2**	Research	**Page 6**
Feature story	**Page 3**	Artist in residence	**Page 7**

The well-deserved rest

Fred Keating is a member of the Alzheimer Society of B.C.'s Lived Experience Partner Program.

My father loved what he did for a living. His recurring reminder to me was, "If you enjoy what you do for a living, you'll never work a day in your life!"

If I had a nickel for every time I heard that (and every time I have quoted it since), I'd be richer than Rockefeller!

His business card read: "Manufacturers Representative." A rather posh name for "travelling salesman." He did love to drive!

I, too, went into a business that I loved and worked at for 55 years. My career in media has allowed me to travel overseas and all around North America from the Arctic to the Yucatán Peninsula in Mexico.

I am one of the one in five people who every Monday would wake up ready to ride through the week! At least I was, until my diagnosis diminished my capacity to perform and succeed in a variety of common tasks. The hampering and complicating of my ability to handle the simplest of tasks on a computer or around the house was frustrating for me as well as family members. This preoccupation with my situation also rather quickly extinguished various sources of revenue.

I won't fib. I resent the loss of competence and the camaraderie.

Happily, that void has been filled with activities and opportunities offered by the Alzheimer Society of B.C. By participating in live presentations, online webinars and a host of educational activities, new friendships have been created and new information absorbed!

The Alzheimer Society of B.C.'s inclusive approach to participation and their ongoing support and education have increased my sense of confidence and competence.

Do I miss my former career? You bet. But I've got memories aplenty. I close my eyes and replay those adventures often. A comfortable chapter closed.

Celebrate your adventures! Appreciate them. Good, bad or horrific! They are yours forever.

Memories of Fred's illustrious career in media.

Life with dementia: Ross Fetterly's ongoing mission of service and resilience

Ross Fetterly

Ross Fetterly's 34-year career in the Canadian Forces took him around the world where he served in 38 countries – from managing defence budgets to teaching military economics to deployments in the Golan Heights and Afghanistan. After retiring from the Royal Canadian Air Force in 2017, Ross continued his work internationally, training senior officers in defence resource management and teaching as an adjunct professor at the Royal Military College of Canada.

Now he's navigating a new personal journey – young-onset Alzheimer's disease.

Now 65, Ross was diagnosed nearly two years ago. Despite being the fourth generation in his family living with Alzheimer's disease – his father, grandfather and three aunts were all affected – the diagnosis still came as a shock. "My wife noticed I was making small mistakes," he recalls. "She knew my family history and suggested we see a specialist."

After several tests and a debrief, Ross found himself at a crossroad. "My doctor cancelled my driver's license and called Ministry of Transport," says Ross. "It took a lot of freedom from me."

Although the loss of independence was difficult, Ross and his wife chose to adapt. The couple moved from Ontario to Victoria, B.C., to be close to family in a much more walkable city. "We just wanted to be next to our children and their family."

Today, Ross remains committed to staying active and connected. He walks weekly with a local men's group, participates in yoga classes and joins community center activities. He also attends monthly presentations at the Royal United Services Institute and serves as a member with the Canadian International Council. He has also found support through support groups with others diagnosed with early-onset dementia. "We have coffee, go for walks and just get to know some of the other men," says Ross.

His advice to others on the dementia journey is to be open, "I'm not shy about saying I live with dementia," says Ross. "It's a disease like cancer. Life still goes on. It's more challenging, that's all."

Learn about our social program, Coffee and Chat

A social program designed to help you meet new people, engage in social activities and have fun. For more information, visit **alzbc.org/coffee-chat**.

Words that stay with us

Tobias Jesso, Lived experience partner

A single moment can change your life and a single phrase can propel you forward. Recently, we asked people affected by dementia to share thoughts on hope, self-care and advocacy.

For some readers a reminder that each person's experience is unique can be a source of understanding: "If you've met one person living with dementia, you've met **one** person living with dementia." These words remind us to see the individual, not the avoid stereotype.

Lester and Cindy Gierach, a couple who are part of our Lived Experience Partner Program, agree. "You can live well with dementia for many years," a reminder that it is possible to maintain your quality of life for quite a while.

Another lived experience partner, Tobias Jesso, shared his guiding words on the importance of self-care for care partners. Reworking the timeless golden rule, "Do unto others as you would have them do to you," he reminds us to "care for yourself as you would care for your partner."

Care partners draw on the well-known metaphor from plane travel to reinforce the importance of self-care, "put your own oxygen mask on *before* assisting a travel partner."

For Sidra Qadeer, a Support and Education Coordinator at the Alzheimer Society of B.C., the guiding words that fuel her are, "Change the narrative from *decline* to *dignity*." To other staff members, she often says, "People living with dementia are not losing out on life. They're living life with dementia. That's what the conversation needs to be about."

Changing the conversation may also take place with small asks that make a big difference. This is something that guides Pat Hanrath, a caregiver and lived experience partner in the Yukon.

"It's okay to tell people what you're concerned about and ask for answers," says Pat. The change you ask for – whether in home support, to a health care professional, or in long-term care – may help not only the person you care for, but many others in the future.

Thank you to everyone who shared their guiding words.

We're inviting you to share a guiding message or idea learned from us that has stayed with you – something that offered strength, shifted perspective or became a mantra during difficult moments. Your message may be featured in future articles or campaigns. Contact us: **dementiaeducation@alzheimerbc.org**

New course will focus on better care for 2SLGBTQIA+ people living with dementia

Through consultations with community members and community organizations, we're developing a new course to support more appropriate care for 2SLGBTQIA+ people living with dementia.

When interviewed for a video developed by the BC Care Providers Association, Chris Morrissey – a fierce 2SLGBTQIA+ advocate who has since passed away, spoke to the importance of queer-positive care. She described why it is critical that care workers who support 2SLGBTQIA+ clients have a queer positive mindset.

Knowing a care provider is queer positive is, "the most important thing for me in terms of someone coming into my home to provide care," she continued.

Queer-positive care – the provision of health and social services that affirm, respect and centre queer individuals' needs – is essential.

Five key themes emerged in the consultations:

Re-closeting and safety concerns: Many 2SLGBTQ+ seniors fear long-term care because they may feel pressure to hide their identities due to fear of discrimination or mistreatment. Trauma of earlier experiences may be deeply felt.

Spiritual and emotional care: Many 2SLGBTQIA+ older adults value spiritual care but affirming supports are not always available.

Symbolism versus action: Visual signs of inclusion (like rainbow flags) are welcomed, but inclusive hiring, clear policies, and ongoing training are also essential.

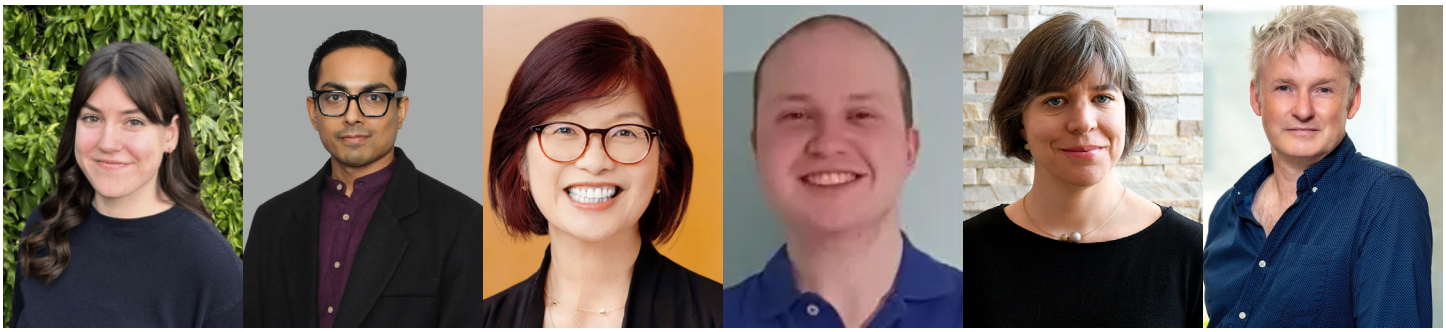
Dementia-specific considerations: Dementia may affect expression of identity, relationships or intimacy. Care teams need empathy, flexibility and cultural humility.

Chosen family and legal barriers: 2SLGBTQIA+ people often build strong support systems with "chosen families," perhaps not recognized in care settings, advocacy, visitation, or end-of-life decision-making.

Many thanks to the community leaders and organizations who shared their wisdom and lived experience. We also appreciate the B.C. Care Providers' video with Chris Morrissey. The recording is available at **alzbc.org/queer-positive**.

We would like to recognize Chris Morrissey, whose incredible legacy you can read more about at **alzbc.org/memory-of-chris**.

2025 Alzheimer Society Research Program recipients announced



The Alzheimer Society Research Program (ASRP) is a collaborative initiative between the provincial Alzheimer Societies, the Alzheimer Society of Canada, other partners and our donors. This year, the ASRP has distributed $5.1 million to 37 researchers across the country, representing a truly national commitment to advancing dementia research from across the country.

To date, 108 projects in British Columbia have received over $11 million through the program. Congratulations to the six B.C.-based researchers awarded this funding for 2025. Their dedication and innovation are paving the way for a brighter future in dementia care and research.

Zoe Gilson, University of Victoria
Doctoral Award: Psychoeducation to reduce risk of cognitive decline: Testing an mHealth intervention.

Kishore Seetharaman, Simon Fraser University
Postdoctoral Award: Embedding dementia-inclusivity in built environment accessibility at the municipal level in Metro Vancouver: A universal design approach bridging aging, disability and dementia.

Lillian Hung, University of British Columbia
New Investigator Grant: A pilot randomized trial of a digital app, WhatMatters, to enable person-centred care.

Ryan Ripsman, University of British Columbia
Doctoral Award: Finding the weakest link: Identifying cell subtypes with Alzheimer's vulnerability in early-stage disease.

Veronica Hirsch-Reinshagen, University of British Columbia
New Investigator Grant: Deep histological and pathological phenotyping of sporadic dementia.

Douglas Allan, University of British Columbia
Proof of Concept Grant: A universal platform for high volume genetic modifier testing in tauopathy.

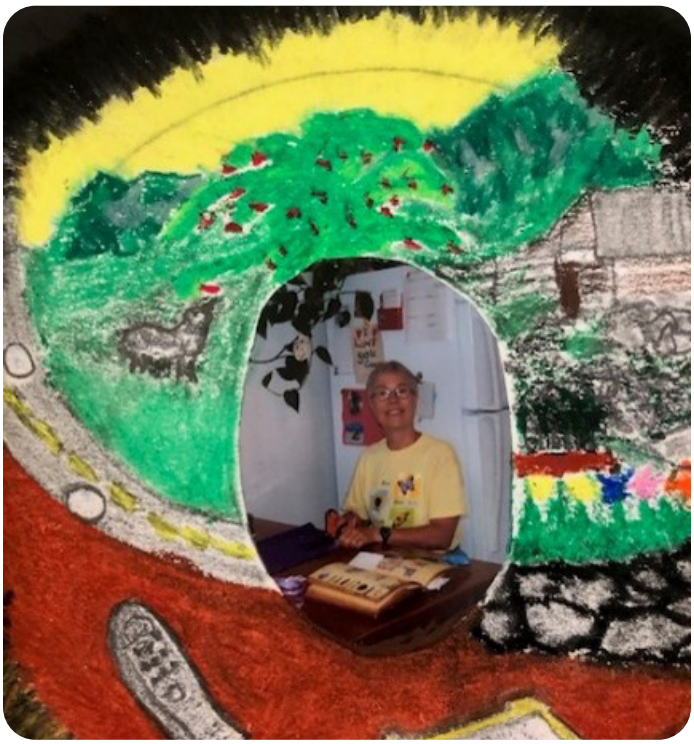
Interested in learning more?

To view the full project descriptions for all the 2025 recipients, visit: **alzbc.org/asrp2025**.

Artist in residence spotlight: *Love in a different way*

When David Amaral was diagnosed with dementia, he began journaling to document his progression and make sense of the symptoms he was experiencing. As an artist, he created visual representations of what was happening in his mind. Before his passing, his wife Liz promised to share his "view from the inside" to help others on the dementia journey. Below is an excerpt from Liz and David's book, featuring one of David's drawings and a journal entry.

An ever-shrinking world



"The picture is an attempt to define my peripheral vision.

I see clearly immediately in front of me as long as the view [is] uncluttered and familiar. Keeping a single focus really helps keep me comfortable. There is clarity there. In the lower part of the central area is a lot of brown. It depicts my sense of loneliness when Liz is not around (which is seldom). Inside the brown is our headset [handset] phone and my iPAD4. They represent our daily conversations to our daughters and the internet.

Along the road Liz and I have travelled looking for some cure to my failing cognitions [we] have tried many pills thus their presence.

My vision of what happened last week is quite blurred. My mental awareness of what is happening off our little farm is almost nonexistent and thus I colour the outside of the picture black. I acknowledge that Nelson and Castlegar [nearby towns] exist and how to get there and yet I feel a real disconnect."

Learn more about Liz and David's story

Liz and David's book, *Love in a Different Way: A Journey Through Dementia*, tells two stories: a loving wife thrust suddenly into the role of caregiver as she watches her life partner disappear into illness, and, through artwork and journal entries,the story of a loving husband who was trying to process and explain what was happening to him and ultimately say goodbye.

The recorded webinar, *Lived experience | The power of creative self-expression*, featuring Liz Amaral as a guest speaker is now available online at **alzbc.org/webinar-liz**.

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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 Helpline is available from Monday to Friday.

- English: 1-800-936-6033
  (9 a.m. – 8 p.m.)
- Punjabi, Hindi and Urdu: 1-833-674-5003
  (9 a.m. – 4 p.m.)
- Cantonese or Mandarin: 1-833-674-5007
  (9 a.m. – 4 p.m.)

  Email **info.helpline@alzheimerbc.org**

Are you a caregiver?

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

To subscribe:

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