Insight

Alzheimer Society

For people living with dementia

Spring 2024



Embrace community connections this spring

As daylight lingers and temperatures rise, let's embrace spring's invitation to participate in activities that build connections within our community. Consider marking your calendar on Sunday, May 26 for our annual fundraiser, the *IG Wealth Management Walk for Alzheimer's*, presented by Go Auto. With 20 communities taking part across the province, it's an opportunity to support a meaningful cause and get active outside. It's also a chance to build connections with others passionate about creating a better world for people affected by dementia.

Consider seeking out local gatherings, reaching out to a support group or

partaking in community activities aligned with your interests. The Alzheimer Society of B.C.'s First Link® dementia support is another great way for people living with dementia to access support, education and information at any stage of the journey. Learn more at alzbc.org/dhl or by calling 1-800-936-6033. Support is also available in Cantonese, Mandarin, Punjabi, Hindi and Urdu.

Connect with your local community on May 26

Find the *IG Wealth Management*Walk for Alzheimer's, presented by
Go Auto, closest to you. See page 5
to learn more!

In this issue:

Message from Myrna Personal reflection Page 2 Page 4 What's coming up Research

Page 5
Page 6

Don't wait for life to engage you: Tips to stay engaged



Myrna Norman is an advocate who often shares her expertise as someone living with the disease. She is a regular contributor to this newsletter.

Hi everyone,

Life happens. Other things happen, but we can use our powers of rationalization to change our responses to the happenings.

People living with a diagnosis of a dementia need socialization and 15 minutes of a caregiver's complete attention – perhaps sitting quietly holding hands or perhaps a gentle massage. Now of course, this is not meant for a caregiver that is not intimately engaged. But we are always so busy, that just 15 minutes of complete attention may provide benefits. It's certainly worth a moment to think about and to try.

Knowing your favourite music genre and taking the time to play it can also provide benefits.

Hugs, hugs and more hugs by anyone coming in for a visit turns out to be one of the best things. People living with dementia tell me that means so much to them

Go out for dinner or have it delivered. Watch a documentary that interests you.

It's now spring and the days are getting longer. Go for a long walk outdoors. Look for birds. Look for bulbs shooting from the earth. Maybe take a bus into the city. Change the scenery. Stimulation!

This summer, the Olympics will be held in Paris, France and it's the perfect opportunity to plan a get-together to watch your favourite events. Sports don't interest you? Plan a Barbie party or an Easter celebration!

My bottom line is, don't wait for life to engage you and your loved ones – go out and get life!

Sending you a happy spring season, Myrna

Join the conversation

Do you have advice or reflections about living well with dementia? Perhaps you are open to being interviewed to share your story in this newsletter. Add your voice to the pages of *Insight*.

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

Interview: The gift of sharing the dementia journey



Brian Ross knows how to help people.

Before retiring in Parksville, Brian worked as a lawyer for 40 years and a mediator for six years in North Vancouver.

"I have always liked helping people," Brian says. "I like bringing people with diverse interests together. I have happy memories of my career."

Five years ago, Brian, who has always valued the opportunity to share his insights and expertise, began struggling with memory retention and finding words. His wife Donna also noticed the changes. Concerned and upset, the couple began working together to find answers. Brian went through a series of tests and met with several specialists before eventually receiving a dementia diagnosis from the Djavad Mowafaghian Centre for Brain Health in Vancouver.

Since the diagnosis, Brian feels he's no longer in full control of his emotions, which has presented some challenges in his personal relationships. In the past, when Brian was faced with conflict, he could deflect. These days, conflict is harder to avoid.

"Sometimes it feels like everything is closing in on you. If I'm feeling overwhelmed, I sometimes snap, and my wife gets the brunt of that," he says. "If I say something inappropriate, she lets me know. I apologize, and we try again."

In addition to care and support from Donna, Brian has found understanding and connection in the Alzheimer Society of B.C.'s support groups, where he learned about living with dementia and the value of sharing his experience with others.

"I was initially very secretive about what I was going through," he says. "I thought people would think I was stupid. I opened up to close friends, then to people in the support group."

Much like the diverse groups of people Brian brought together in his career, the support groups provide a space for people with varying backgrounds and experiences to connect and learn from one another.

After a long, successful career, Brian has recently experienced one of his proudest achievements: speaking openly about his dementia journey. Now in retirement, being open about his diagnosis has become a new way for Brian to continue helping people.

"When I share, I hear other people's stories as well. It helps to share the journey."

Brian Ross is being honoured at this year's Oceanside IG Wealth Management Walk for Alzheimer's, presented by Go Auto. To read the full version of their story, or to register for the Walk, visit WalkForAlzheimers.ca.

Connect through creativity



A former lecturer and engineer, Don Cheeseman is a dementia advocate from Whitehorse, Yukon, living with the disease. In both his professional and personal life, writing has always been

important to Don, who documented his family history and captured stories when he lived in Central Africa. He finds great benefits in creative writing as a tool to practise mental exercise and stimulate his cognitive processes.

Don says he was once "there" – fully present and confident. However, as the days go by, he begins to feel he knows a little less each day. Although Don has never written directly about his own cognitive decline, he shares an excerpt from "When I Wander," a poem that strongly resonates with him.

A dementia diagnosis can generate thoughts and feelings you have not experienced before. Working creatively is an outlet to express a range of thoughts and emotions. It's also a way to connect with others who are going through a similar experience.

Consider whether partaking in creative hobbies, such as journaling, poetry, photography or painting could be helpful to you. Turn to page 8 to see how you can have your work featured in *Insight*!

When I shout out please don't ask me to be quiet...or walk by.

I am trying to tell you something, but have difficulty in telling you what. Be patient. Try to find out. I may be in pain.

When I become agitated or appear angry, please don't reach for the drugs first. I am trying to tell you something. It may be too hot, too bright, too noisy. Or maybe it's because I miss my loved ones.

Try to find out first.

When I don't eat my dinner or drink my tea it may be because I've forgotten how to. Show me what to do, remind me. It may be that I just need to hold my knife and fork I may know what to do then.

With all my thoughts and maybes, perhaps it will be you who reaches my thoughts, understands my fears, and will make me feel safe.

Maybe it will be you who I need to thank.

If only I knew how.

- Author unknown

What's coming up



Sunday, May 26

For more information and to register, visit: WalkForAlzheimers.ca

IG Wealth Management Walk for Alzheimer's

We are excited to announce the *IG Wealth Management Walk for Alzheimer's*, presented by Go Auto, will return to communities across B.C. on Sunday, May 26! Join us at a *Walk* event near you to show people affected by dementia they don't have to walk the journey alone.

Team up with your family, friends and coworkers and help us honour and remember people in your communities affected by the disease. Funds raised help to provide programs and services for families on the journey. The event also enables research into the causes of and cure for the disease.

Who will you walk for? Register as an individual or create or join a team.



Two Wednesdays, April 10 and May 15 2 – 3:30 p.m. PST

To register, visit: alzbc.org/LE-Partners (Part one)

alzbc.org/LE-Advocacy (Part two)

Lived experience: Working with lived experience partners

Lived experience partners help spread awareness about dementia by sharing their personal stories, experiences and perspectives. Meaningful engagement opportunities invite people directly affected by dementia to actively contribute to the Alzheimer Society of B.C.'s work.

In the first of a two-part lived experience webinar, we will feature a panel of people living with dementia and caregivers. They will share how partnering with the Alzheimer Society of B.C. has helped them find purpose and meaning on the dementia journey. Part two will focus on advocacy action planning. Staff will share how people with lived experience of dementia can support our upcoming advocacy projects while boosting their own skills and confidence.

Canadian perspectives on dementia: Highlights from the Landmark Study

Dementia is one of the most pressing health challenges facing Canada's aging population, but its scale and impact remain uncertain. The Alzheimer Society of Canada undertook the Landmark Study to address this knowledge gap. The study's primary aims are to:

- Increase awareness of the diversity of who develops dementia in Canada.
- Improve knowledge of dementia.
- Advocate for better dementia care.
- Create action among people, organizations and all levels of government to work together towards more inclusion, equity and diversity in dementia support and research.
- Push for change through more research investment, pushing back against stigma and creating policies to improve dementia care.

The first study report, released in 2022, updated projections for the number of Canadians forecast to be living with dementia over the next three decades. Should current trends continue, there will be a dramatic increase in the number of people living with dementia, and an accompanying rise in the number of care partners.

In January 2024, the second report, The Many Faces of Dementia in Canada, was released. The report highlights the diversity of people who will likely develop dementia in Canada over the next three decades. It focuses specifically

on Indigenous Peoples, ethnically- and racially-diverse groups, sex and gender differences in dementia as well as young onset dementia. In British Columbia:

- An estimated 1,530 Indigenous people were living with dementia in 2020. By 2050, a projected 5,900 Indigenous people will live with dementia, an increase of 286 per cent.
- By 2050, one out of every three people who live with dementia will be of Asian origin. This represents an increase of more than 700 per cent from 2020.
- By 2050, there will be 1.7 times as many people assigned female at birth who live with dementia than of people assigned male at birth.
- By 2050, more than 6,000 people under the age of 65 will live with dementia.

Together, we need to adapt how we help everyone – including Indigenous, racialized and younger people – live with dementia, while supporting equitable access to care, diagnosis and prevention tools for all.

Read the latest report

To read the latest Landmark Study report and learn more about what health-care providers, governments, researchers and people like you can do to change the future of dementia in Canada, visit: alzbc.org/landmark2.

You can make a difference



Storytelling is one of the most powerful ways someone living with dementia can take a stand against stigma, build connections in their community and help other people on

the journey know they aren't alone.

There are more than 85,000 people just like you who are living with dementia in B.C. today. Many of them have experienced stigma or felt isolated. Hearing stories of resilience and courage from other people facing dementia can help break down stereotypes and instill hope in others. We rely on the voices of people who have first-hand knowledge of the disease to help shape everything we do. Every story can have a far-reaching impact.

For Art Harrison, a person living with dementia and one of our lived experience partners, staying involved is important.

"That's where I'm getting my fulfillment now," Art says, "through living life and trying to open people's eyes a little bit about the disease."

Lived experience partners support our mission to ensure no one has to face the journey alone by sharing their experiences and insights. If you would like to learn more about how to get involved, please email us at livedexperience@alzheimerbc.org or visit alzbc.org/LivedExperience.

Help us make change through advocacy!

The Alzheimer Society of B.C. supports people affected by dementia in advocating for themselves or people who care for them when navigating the health-care system, as well as advocating for systemic change. To ensure our advocacy efforts truly reflect the diverse needs of people on the dementia journey across the province, we are offering new opportunities to partner with us.

Throughout 2024, we will be launching several short- and longterm advocacy projects and want to invite people living with dementia to take part in this important work. One key project is focused on the development and implementation of an election strategy for the upcoming provincial election. This strategy will prioritize the key issues that affect people living with dementia, their families and care providers. These issues include improving the diagnosis experience, supporting caregivers and improving cultural sensitivity and safety.

If you're eager to get involved but don't know where to start, join us on May 15 for a special webinar on advocacy action planning. This webinar will support you to build advocacy skills and confidence. You will also learn about some of our upcoming projects and how you can support them. Register for the webinar at alzbc.org/LE-Advocacy.

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

Contribute

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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:

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



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