<u>Insight</u>

Alzheimer Society

For people living with dementia

Fall 2023



Showing courage and raising your voice

The Alzheimer Society of B.C. is committed to changing the experience of people affected by dementia, ensuring that they have the confidence and skills to live the best life possible.

In this issue of *Insight*, our Leadership Editor, Myrna Norman, celebrates the positive change many British Columbians living with dementia are experiencing when they feel included and supported in their communities. We also interview a person living with Lewy Body dementia who talks about the power of photography and we share the Society's engagement in policy discussions to address the challenges faced by people living with dementia.

We're highlighting the latest dementia events and invite you to join us for the webinar series on "Flipping stigma," a conversation to help flip the script on stigma associated with dementia. We're also thrilled to invite you to attend our latest programs for people living with dementia, available in English and Chinese.

We would like you to consider sharing your story and advocating for people living with dementia. By sharing your story, you can help create opportunities for people with lived experience to engage with local government representatives while supporting the Society to drive forward action and change. Learn more on page 7.

Dementia support is now available in the Yukon!

In partnership with the Government of Yukon, the Alzheimer Society of B.C. extends dementia support and education to Yukon-based community members living with dementia and their care partners, as well as health-care providers. Learn more on page 5.

In this issue:

Message from MyrnaPage 2ResourcesPage 4InterviewPage 3AdvocacyPage 7

Celebrating change in our communities



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

Thank you, all! I have had the most extreme honour of sharing my thoughts with you. Connecting, sharing and welcoming: these are just some of the actions that British Columbians – with or without a dementia – are taking to help us stay part of our communities.

With the acceptance of our communities, we are learning to re-engage in our neighbourhoods. We are going out for dinner with friends. We are going to movies. We are having short holidays and, thanks to you, feeling less fear and stigma.

We are not hiding in our homes. We are going out. We are answering the telephone. We are telling others about our experiences. We are finding ways to live well with our diagnosis. Our communities are beginning to understand and this helps.

We are paying attention to folks who appear lost. We are involving folks living with dementia in local park activities, in buddy support calls and in transportation. We are becoming less judgemental when we see differences. Benches are popping up to allow us to rest. Signage is clearer. Bollards and yellow paint help us to see the street corner. Clerks in stores seem to have more patience. We certainly appreciate the changes our communities are making so we have inclusiveness everywhere.

It may be that we are celebrating differences!

– Myrna Norman

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

The powerful benefits of photography for mental and physical health



Anyone who sits down with Cliff Jennings and flips through his photo album will get to hear him tell the story of each photograph. He purchased a second-hand Pentax Spotmatic – his first camera – when he moved to Whistler, B.C. in 1965. He used it to capture moments and memories from his early adventures as a heli-ski guide and hiker who co-founded Whistler Search and Rescue. There are also stories and photographs from when he met his wife Vivien working at a local hotel in the developing ski resort. Together, they established a life in Whistler and have been married for over 50 years.

In the fall of 2020, the pair sold their lakeside cabin and exhaustion rapidly affected Cliff's health. After being admitted to the hospital, where they ran many tests, Cliff was diagnosed with Lewy Body dementia. He spent the next 10 weeks on his hospital bed feeling socially isolated and physically deprived from the lack of exercise until he was transferred to a long-term care home in Squamish.

As soon as Cliff received his computer, he began researching Lewy Body dementia and read many studies indicating that physical and social activity appear to help

reduce the risk of developing cognitive decline and dementia. "I want to learn more about dementia," says Cliff. "I tell people I'm self-medicating by helping others learn about the disease. I just like helping people."

Photography is Cliff's exercise. Passionate about photographing family, wildlife and mountain scenery, he finds doing photography helps him clear his thoughts. "My mind is kept sharp taking photos and then editing them after," he explains. "My exercise is taking my camera for a walk, hike or ski."

Today, Cliff looks forward to attending the social programs held at his care home and walking on flat trails with his family where he can be seen equipped with his latest camera, a Nikon D7500.

He reminds others on the dementia journey to keep socializing and mentally challenge themselves. "Find an activity you enjoy with a good support team," says Cliff. "I'm coping with the challenges by doing as much as I can and what has helped me was my family."

Challenge yourself!

Learn how our fitness and social program, Minds in Motion®, helps people living with any form of early-stage dementia. In-person and online options are available. Learn more at alzbc.org/mm.

What's coming up



Wednesday, November 22 2 – 3 p.m. PT.

To register, visit: alzbc.org/flipping-stigma

Upcoming webinar: Flipping stigma in action

For many people living with dementia, stigma and discrimination are undeniable realities.

The best way to challenge stigma and prevent discrimination is through education, awareness and advocacy. In the "Flipping stigma" webinar series, we will hear from the people living with dementia behind the "Flipping stigma on its ear" toolkit – a valuable resource created in collaboration with researchers at the University of British Columbia – to share insights on how to address stigma associated with the disease.

Join us for the webinar series, "Flipping stigma in action: Building confidence and competence in advocacy," as our guest speakers address how family, friends and health-care providers benefit from this toolkit. We will also discuss what strategies people living with dementia found useful when building skills and confidence as an advocate.



To register, call the First Link® Dementia Helpline:

English: 1-800-936-6033 Chinese: 1-833-674-5007

New way to socialize: Coffee and Chat

Coffee and Chat is our newest social program designed to help people living with early-stage dementia meet new people who are also on the dementia journey. The program provides the opportunity for participants to share experiences, laughter, and build friendships – the best of all is to have fun!

People living with early-stage dementia and caregivers (a family member, friend or care partner) are invited to join.

Participants can join weekly **in-person** sessions (in select locations) for 90 minutes or biweekly **online** meetings for 60 minutes. The program is available in English and Cantonese, and complements other early-stage dementia programs like the fitness and social program, Minds in Motion® and early-stage support groups.

Specialized support for Yukoners



In collaboration with the Government of Yukon, we have launched the First Link® Yukon Dementia Helpline providing Yukon-based community members – including people living with dementia and caregivers and health-care providers – access to dementia support services.

The First Link® Yukon Dementia Helpline is the first support service the Society is offering across the territory to help provide comprehensive support for seniors and caregivers, as well as supporting recommendations from the Government of Yukon's *Putting People First* and the *Aging in Place* action plans.

Anyone living with dementia or caring for someone either personally or professionally, as well anyone concerned about dementia or memory loss, is encouraged to call the helpline. Helpline staff can provide care and support to anyone facing dementia, at any stage of the journey: from diagnosis – or before – to end of life.

Yukoners can reach the helpline by calling the toll-free number: **1-888-852-2579**, available from Monday to Friday (10 a.m. to 8 p.m.) to access the help and guidance they need. All calls are confidential.

If you or someone you know in the Yukon is living with dementia or caring for a person living with dementia remember that you are not alone. We are here to support you to build the confidence and skills to live the best life possible.

More information will be shared soon as we continue to develop additional services to support the well-being of the community members affected by dementia in the Yukon.

For email inquiries: info.yukondhl@alzheimerbc.org

Learn more!

For more information and updates on dementia education and resources including webinars and online workshops, visit alzbc.org/yukon.

Engaging in policy discussions to enhance support

To help address the challenges people living with dementia and their caregivers face, the Society actively engages in policy discussions. We recently presented recommendations in person before the provincial Select Standing Committee on Finance and Government Services, highlighting the pressing need for a provincial dementia strategy and more support for British Columbians affected by dementia. The committee's report was published on August 3, 2023 and included the Society's recommendation to fund a provincial dementia strategy.

We also shared our feedback federally with a parliamentary committee assigned to review Bill C-295, proposed changes to the Criminal Code to address the abuse and neglect of people living in longterm care. Developed in consultation with people with lived experience, our recommendations included increasing funding in the long-term care sector to meet the new care standards introduced by the Health Standards Organization and the Canadian Standards Association. Alongside funding, we emphasized the need for a human resources strategy to address recruitment, retention and professional development of staff to improve quality of care for everyone living in long-term care.

People directly affected by dementia also shared their thoughts on spending priorities in advance of the next federal budget. Based on their input, we submitted two recommendations: allocate one per cent of dementia care costs to federal dementia research and prioritize diverse types of support, including financial assistance and programs for unpaid caregivers of people living with dementia as a part of a larger national caregiver strategy.

The Society will soon be working on policy submissions for two other issues on the horizon: the federal government's development of national standards on long-term care and Safe Long-Term Care Act. We will be reaching out to people living with dementia and caregivers to help inform our recommendations for the act. We will also respond to the federal Standing Committee on Health's invitation to make a submission on women's health issues. As with the other submissions outlined here, the Society will move this work forward in consultation with people living with dementia and their care partners.



Raise your voice

Help us advocate for a comprehensive dementia strategy, improved long-term care and enhanced support for caregivers. To join us and create positive change for people living with dementia in British Columbia and beyond, email advocacy@alzheimerbc.org.

6 ALZHEIMER SOCIETY OF B.C. | INSIGHT FALL 2023

What does advocacy mean to you?



Did you know that by accessing information and seeking support through the Alzheimer Society of B.C., you are advocating for yourself? Or that any time you share your story, you're contributing to advocacy efforts, raising awareness and dispelling myths? Advocacy can mean many different things and take many different forms.

For people living with dementia, advocacy is a powerful tool to challenge stigma, break down barriers and help influence policies. The simple act of sharing your experiences and challenges along the dementia journey can encourage local organizations and policymakers to consider the unique needs of people living with dementia, promote the development of dementia-friendly services and communities and influence research priorities.

Lending your voice to advocacy efforts helps create change at a personal, community or even a national level. By bringing unique perspectives and experiences to the table, people with lived experience can become advocates for change and help inspire others to do the same.

How can you share your story? We are currently expanding opportunities for our advocates to become more involved in our work. Over the summer, some of our staff met with different Members of the Legislative Assembly across the province to share what we hear from people with lived experience, influence policy changes and gain support on different Society initiatives.

We would like to create more opportunities for people with lived experience to engage with local government. We would love advocates with lived experience to join us at these meetings and share their stories with government representatives, while supporting us and driving forward action and change. Other opportunities to become involved may include supporting our community dialogue events and leading discussions in your local area or participating in the development of government policy submissions or briefing materials for MLAs by contributing your perspective of living with dementia.

If you are interested in learning more about advocacy, email us at advocacy@alzheimerbc.org.

Join the team!

Chair and committee volunteers are needed for the IG Wealth Management Walk for Alzheimer's, our signature fundraiser supporting people with dementia across Canada. Join us in planning this event and building community support. For more information, contact us at events@alzheimerbc.org.

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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.

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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 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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