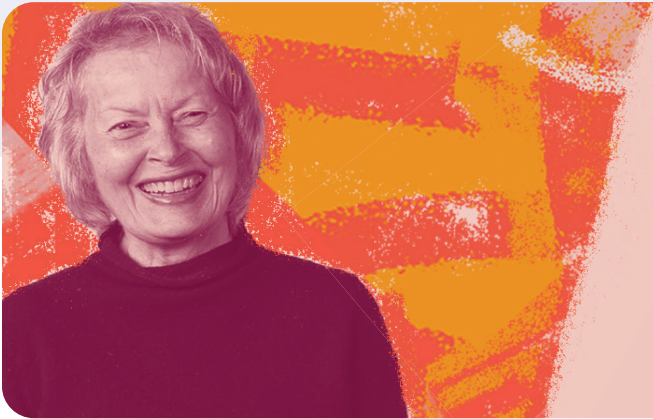


Connections

Linking a community of dementia support



Full of life with dementia

We can't change the progression of the disease, but we can change how we live today.

Learn to live well.

Alzheimer Society
BRITISH COLUMBIA

Taking a stand against dementia stigma

One in two British Columbians believe that a diagnosis of dementia means the end of a meaningful life. While living with dementia is not an easy journey, we've learned from our community that there are also unexpected moments of joy.

January is Alzheimer's Awareness Month, an opportunity for people across the country to learn more about dementia and its impact by sharing the unique experiences of people affected by the disease. This year we're focused on debunking the

stigma associated with dementia. We're highlighting community stories, tips and tools to support living well with dementia and hosting virtual events throughout the month.

While there's no cure, we can give support and courage for what's ahead. It takes courage to speak up about dementia. It takes courage to ask for help and to support friends and family members on the journey. By shifting people's perspectives, we become one step closer to creating a more dementia-friendly B.C.

Learn more ▶ To learn more about this year's Alzheimer's Awareness Month, visit: alzbc.org/FullOfLife.

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Community engagement creates impact

The beginning of a new year is a chance to celebrate our accomplishments and set new goals for the year ahead.

January is Alzheimer’s Awareness Month, an opportunity to raise awareness about dementia and show our support for the 85,000 people living with it in B.C. It takes courage to speak up, ask for help and support friends and family on the journey. Courage connects us all. This year we’re highlighting how people affected by dementia continue to live meaningful lives, helping those around them find joy, peace and happiness today. We encourage everyone to learn more about dementia and its impact on British Columbians – through listening, considering the role we play in addressing stigma and changing our attitudes about the disease and the people living with it.

This issue features an interview with Jana Schulz, a caregiver who is sharing her story to raise awareness. We also introduce researchers making an impact on

quality of life for people affected by the disease and share ideas on how to meaningfully engage in research studies as a participant.

We are excited to share details about the upcoming *Breakfast to Remember* – returning in-person to Kelowna, Vancouver and Victoria. As well, we invite you to attend our education workshops, including an upcoming webinar with a guest presenter who will focus on how to assist people living with dementia who are experiencing disorientation. Finally, we profile some of our champion fundraisers from 2022 and a volunteer who discusses her experience training to be an online support group facilitator.



Jen Lyle
Chief Executive Officer
Alzheimer Society of B.C.



First Link[®]
DEMENTIA HELPLINE

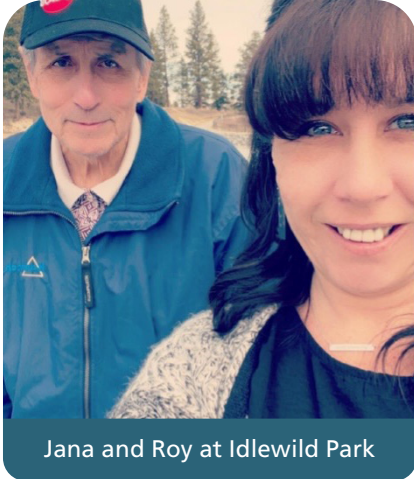
Questions about dementia or memory loss?

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.



Finding purpose and unexpected gratitude as a caregiver



Jana and Roy at Idlewild Park

Jana Schulz of Cranbrook, B.C. – a registered social worker, working as a regional dementia education coordinator for the East Kootenays and elected official within the Métis

Nation of British Columbia – feels caregiving has given her purpose. Since her dad, Roy’s, diagnosis, she feels like she has grown personally and professionally because someone she loves is living with dementia.

Jana started noticing changes to Roy’s behaviour and memory a couple years before his official diagnosis, when Roy was helping her husband build a fence. She knew something was wrong when her dad – who has a drafting engineer degree from the Southern Alberta Institute of Technology and would often turn to woodworking as a hobby – was having difficulty understanding the placement of the vertical and horizontal boards.

At first Roy and his family struggled to get the doctor to take his symptoms seriously. It wasn’t until they went to a new physician that they finally felt heard. In January 2016, he was given a diagnosis of early-stage Alzheimer’s disease, and a few years later, a second diagnosis of mixed dementia, including vascular dementia.

“At first, there was relief because we finally had a name to it,” Jana says. “But on the other hand, even though

we saw it coming and knew what it was? For me, it was *oh my gosh, what are we in for?*”

Since the diagnosis, Jana and Roy have spent countless hours together, often walking around their favourite spot, Idlewild Park. “There’s been a lot of laughter, storytelling and tears. He thought it was such an amazing place and I loved seeing him light up every time we go.”

During Jana’s journey, she has learned to lean more into her culture. She takes comfort knowing that Roy’s journey is bringing him closer to their ancestors and she’s brought an Indigenous perspective to the disease to help create a better environment for her dad and others. Through it all she’s found unexpected gratitude and joy.

Jana admits she and Roy didn’t used to be as close as they’ve been since his diagnosis. “I wanted to create memories and joy for myself. In a way it was selfish. But I made an effort to get to know my dad through each stage of the journey. I made the effort and Dad just kind of floated along with me, appreciative of the time together.” Even though her dad hasn’t recognized her in years, she still feels love when she sees him.

“It’s important not to lose yourself on the caregiving journey,” Jana says. “Despite all the challenges we’ve faced with the disease, there are so many moments that help shield me from immense amounts of grief. I don’t take those moments for granted.”

Learn more

To learn more about this year’s Alzheimer’s Awareness Month, visit: alzbc.org/FullOfLife

Participating in dementia-related research



Have you ever thought about participating in a research study? There are a variety of ways that people with lived experience can get involved. Your participation can provide researchers with valuable information about many different topics through surveys, interviews or focus groups. Another option is to participate in what's called an intervention: for example, taking a particular medication. Some research participants go even further and assist with study planning, help make sense of findings or co-present research results.

There are two types of research to get involved in. **Quality-of-life research** looks at ways to improve the lives of people living with dementia and caregivers. Examples include:

- Improving the quantity, quality and variety of community-based physical activities, healthy eating and wellness opportunities for people living with dementia.
- Identifying what helps or hinders physical activity for people living with dementia during Canadian winters.
- Understanding vulnerability and resilience among young family caregivers of people living with dementia.

By contrast, **biomedical research** focuses on investigating the causes, treatments and possible cures for dementia. Examples include:

- Evaluating the efficacy and safety of using a medication with people at risk for or at the earliest stages of Alzheimer's disease.
- Identifying the warning signs of cognitive decline in people who have experienced transient ischemic attacks (or temporary episodes of a stroke).

Remember, you are in control of what you choose to do. You can take part in research in a role that interests you. Participation is always voluntary: you will be provided with a clear description of what is expected of you, will never be pressured to participate and are free to withdraw at any time without giving a reason. This is known as free and informed consent and is a cornerstone of the research process.

Interested in finding out more?

To find out more about research studies in your area, or becoming involved in research, the following websites can be helpful:

Reach BC connects patient partners and health researchers in British Columbia. Learn more at reachbc.ca/volunteers.

Alzheimer Society of Canada Research Portal includes advertisements for research studies across the country. Learn more at alzheimer.ca/research.

Researchers are improving quality of life for people living with dementia



Dr. Shelley Canning

Each year, the Alzheimer Society of B.C. contributes to the Alzheimer Society Research Program (ASRP), a national partnership between provincial Alzheimer Societies and the Alzheimer Society of Canada. In 2021-22, two

researchers from B.C. received funding to look into ways to improve the quality of life for people affected by dementia.

Dr. Shelley Canning is a researcher at the University of the Fraser Valley working on a project called “Implementing a dementia-friendly care approach for cancer patients living with dementia.” The number of people living with both diseases is increasing and, unfortunately, these individuals typically have worse outcomes than people living with cancer alone. Dr. Canning aims to identify and address current care challenges by implementing dementia-friendly education and recommendations for the B.C. Cancer Agency. Anticipated results include decreased stigma, improved communication, more flexible care pathways and care environments that are easier to navigate.



Dr. Mariko Sakamoto

Dr. Mariko Sakamoto is a post-doctoral researcher at the University of British Columbia. Her project, “Dementia-friendly communities: Including the perspectives and experiences of people with dementia who live alone,” seeks

to understand the community-related needs of people living with the disease without a caregiver.

Dr. Sakamoto will explore how dementia-friendly communities can more effectively support social inclusion and well-being of people living with the disease. People involved in the research will help provide feedback on key pieces of the study and ensure the voices and perspectives of people with lived experience are considered. Findings will inform policy-makers and organizations involved in dementia-friendly initiatives about the specific needs of people living with dementia who live alone.

Upcoming webinar on reducing the risk of disorientation

As the population ages, the number of people living with dementia is expected to rise. Common symptoms like disorientation have become a growing concern. Join Noelannah Neubauer, Research Assistant in the Faculty of Health at the University of Waterloo and System Case Manager at Home Living Program in Edmonton, as she shares

her latest research on policies and strategies to assist people living with dementia who experience disorientation and reduce the risk of them going missing.

This webinar takes place on Wednesday, February 15, at 2 p.m. PT. Register at alzbc.org/webinar-Feb2023.

Breakfast to Remember returns to Kelowna, Vancouver and Victoria

We are excited to announce that *Breakfast to Remember* will return to Kelowna, Vancouver and Victoria in 2023. Aimed at increasing awareness among the business community, the events will bring together community leaders to highlight issues and realities facing people affected by dementia, an important factor in building dementia-friendly communities.

Each event will feature a keynote speaker from the business community and a guest speaker with a personal connection to the disease. Funds raised through ticket sales, sponsorships and donations help ensure barrier-free access to support services and education for anyone on the dementia journey. They also enable dementia research.

Volunteer committees are crucial for ensuring the success of each event in their communities. Floyd Murphy of Murrick Group, the founding sponsor of the Vancouver *Breakfast*, is the chair of the event’s organizing committee. “We’re thrilled to have our supporters connect in-person again,” Floyd says. “Everyone has a family member, friend or colleague who is affected by dementia. We should all be supporting the cause.”

Christa Castillo, Director of Community Relations for Trillium Communities and chair of Victoria’s organizing committee, sees the event as an

opportunity to build a supportive community for families facing dementia. “Creating a dementia-friendly community is important for people who are affected by dementia; it’s essential to their well-being for staying engaged in community life,” she says. “We can do our part as business owners and community leaders.”

Lauren Cornish, interim chair of Kelowna’s organizing committee, points out that the event is a meaningful way for supporters to come together and address the stigma associated with dementia. “By breaking down the barriers facing people living with dementia, we can ensure they’re living the best quality of life possible,” she says. “Supporters can help by learning more about the effects of dementia stigma and taking the next steps to reduce its impact.”

We are eager to welcome business leaders back for a morning of breakfast, networking and inspiration.



Floyd Murphy, chair of *Breakfast to Remember* in Vancouver

Breakfast to Remember, Kelowna

Presenting sponsor: Valley Mitsubishi
 Wednesday, February 22, 2023
 Coast Capri Hotel

Breakfast to Remember, Vancouver

Founding sponsor: Murrick Group
 Thursday, March 2, 2023
 Fairmont Waterfront

Breakfast to Remember, Victoria

Presenting sponsor: Trillium Communities
 Tuesday, March 7, 2023
 Fairmont Empress

To learn more, visit: breakfasttoremember.ca.

For sponsorship opportunities, contact Susan Rae at: srae@alzheimercbc.org.

Anything for Alzheimer's lets you fundraise your own way

Each year, dedicated individuals, businesses and community groups from across B.C. host fundraising events in their local communities in support of the Alzheimer Society of B.C. *Anything for Alzheimer's* is a fundraising program that helps you turn almost any idea into an event to raise awareness of and funds for the cause, as well as show people affected by dementia they are not alone.

Here are some of this year's highlights:

T-Bones Summer Prawn Skewer Fundraiser

The Ulveland family's T-Bone's Fresh Meal Market fundraises through their five Okanagan locations. After one of their parents was diagnosed with dementia, the cause is near and dear to the owners. Since 2015, their yearly fundraisers have raised more than \$102,000. Last summer's prawn skewer sale raised over \$5,300 and they are expecting to double the impact this winter.

United Floors Golf Tournament

This annual golf tournament is organized by United Floors locations on Vancouver Island. The Mayzes family started fundraising for the Society in 2001 and decided to further their efforts with the United Floors Golf Tournament in memory of Ken Mayzes, who lived with dementia. To date, they have raised a total of over \$37,000, including nearly \$6,500 in 2022 alone.

The Georgina Falt Memorial Mind Games Music Trivia

This music trivia fundraiser started in 2013 by couple Don and Theresa Bodger has raised nearly \$90,000. Named after Theresa's mother, who lived with dementia, the event weathered the cancellation of

in-person gatherings due to the pandemic by shifting online with an email game. Since returning in-person in 2022, they have raised nearly \$15,000.



Participants at the Georgina Falt Memorial Mind Games Music Trivia

This is just a snapshot of the many events thrown by British Columbians in support of the Alzheimer Society of B.C. We are truly grateful to all our community fundraisers for their tremendous creativity and willingness to do *Anything for Alzheimer's*. Thank you!

Thinking of hosting your own fundraiser?

To learn about how you can host your own unique event, and for fundraising inspiration, visit alzbc.org/A4A. Ideas include:

- Return-it Express – Bottle drive fundraiser
- Donate a Car – Donate your older vehicle
- Birthdays, coffee breaks, hikes, live streaming and more!

Volunteers provide virtual support to people facing dementia



When Donna Gallagher's parents were both diagnosed with dementia in 2016, she gave up her full-time job in Kelowna, packed her belongings and moved to Creston to become a full-time caregiver for them.

While caring for her parents and new to Creston, Donna found support at the Alzheimer Society of B.C.'s caregiver support groups. "Support groups gave me others to connect with," says Donna. "We were all on the dementia journey and learned so much from other caregivers." Donna cared for her parents for several years, until her mom passed away in late 2019, followed by her dad's death in early 2020.

In fall 2022, Donna learned the Society was expanding to over 70 support groups throughout the province and that volunteers were needed to facilitate them. Despite facing health complications of her own, Donna wanted to be able to support others affected by dementia. "I didn't know how I could possibly

volunteer, but I sent my application and figured I would go from there," she said. "Then I was contacted and given the option to facilitate online support groups."

Donna sees great value in having online options, which allow her to volunteer from home without her health concerns proving to be a challenge, while allowing people to access support from anywhere in the province.

To prepare for the role, Donna has been participating in support group training – including an in-person session and shadowing three virtual support groups – as well as reviewing dementia resources and watching recommended videos. "I always learn something new when I'm training and that makes it worthwhile."

The connection to a cause meaningful to her keeps Donna motivated to stay involved. "I want to see the disease cured and I know what the stigma is like – I witnessed it with my parents."

To learn more about how you can volunteer with us, visit alzbc.org/volunteer.

About Connections

Connections is a quarterly print and digital publication produced by the Alzheimer Society of B.C. Articles cannot be reproduced without written permission.

Contact us to contribute content or to subscribe to receive *Connections* regularly.

- **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.
300-828 West 8th Avenue,
Vancouver, B.C. V5Z 1E2

Help us reduce costs by subscribing to *Connections* by email.

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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