



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

Live a meaningful life with dementia

January is Alzheimer's Awareness Month, an opportunity to encourage organizations and people across the country to learn more about dementia and its impact on Canadians by sharing the unique experiences of people affected by the disease. Here in B.C., we'll be tackling the myth that a diagnosis of dementia is the end of a meaningful life. We'll be highlighting moments of joy and courage, tips and tools to support living well with dementia and hosting virtual events throughout the month. To stay connected throughout Awareness Month, visit alzbc.org/FullOfLife.

This issue of *Insight* features an introduction to the Alzheimer's Awareness Month campaign. We'll

also share the words of someone living with dementia who shares a day in her life. We'll share information about meaningfully engaging in research studies and knowing your rights as a research participant. We'll also profile two local researchers whose projects are focused on improving quality of life for people affected by dementia.

Finally, we'll share information about how you can take part in our in-person and online dementia programming, including an upcoming webinar that will focus on strategies for reducing the risk of people living with dementia getting lost.

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Join the conversation: Know your rights



Myrna Norman

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

The World Health Organization recently said, “Unfortunately, people [living] with dementia are frequently denied the basic rights and freedoms available to others. In many countries, physical and chemical restraints are used extensively in care homes for older people and in acute-care settings, even when regulations are in place to uphold the rights of people to freedom and choice.”

Everyone, regardless of whether or not they’re living with dementia, deserves to have agency and rights. I encourage all of you to educate yourself on your rights and help advocate for them. Some key resources include:

- The Canadian Centre for Elder Law: Call 604-822-0142 or visit bcli.org.
- The Canadian Charter of Rights for people living with dementia: visit alzbc.org/charter.
- The Alzheimer Society of B.C.: Visit alzbc.org/advocacy.

I need all your support to carry on. I’m getting tired but my passion is still raging.

Be kind to each other, Myrna Norman

Day in the life – A rant, by Rose Ong (Abridged)



Rose Ong

In fall 2022, I attended a forum in Waterloo, Ontario, filled with amazing work to help both caregivers and people living with dementia. I would like to share a story written by my friend, Rose, who spoke at the conference

and is living with dementia. She wrote a rant that she thought might help give her family an honest look into her brain.
– Myrna

Awake at 5:30 a.m. to take my pills, I rub my partner’s back and kiss the top of his head as he eats breakfast. He mentions things he knows I won’t remember. Yet,

he tries as much as I do to make the best of my condition.

I go back to bed for a few more hours. Sleep sends me to that mystical dreamland, leading me to a wandering world I don’t know, with someone I’ve never seen for a reason I can’t recall. It’s difficult to know how much you have forgotten when your mind is made of cheesecloth and memories are as soft as melted butter.

Awake after my dream, I drift to the bathroom. Confusion is waiting for me as I struggle to remember whether I should brush my teeth before I shower or should I – wait a minute – why is there no toilet paper? Whose shirt is hanging on the

doorknob? Why did I come here in the first place? Back to the toothbrush and it starts all over again. It takes me an hour to get out of the bathroom to move on with my day.

I turn on music because the television confuses to me. Background noise helps me focus. I go to the kitchen and look for the list I prepared the other day – where did I put my list? I look at my calendar to see if I've written something down. No.

I run to the coffee machine and make myself a cup of coffee. Nothing happens and I stand there staring at my cup before I realized I didn't turn the switch on. While the coffee brews, I work on making my matcha drink, forgetting which cabinet holds the glasses – found! I grab a large glass, add a scoop of matcha, brown sugar and pour milk over it all.

Suddenly, I remember my coffee and abandon this green drink. I know my coffee needs something but can't remember what! Oh yeah, brown sugar, coconut oil and cream. But then I see dishes in the sink. I must put them in the dishwasher before I forget. After 45 minutes of walking around in circles, I finally sit down and am left exhausted by all the mental effort put into making my breakfast.

The telephone rings and my next journey begins with a telemarketer for whom I don't have the time. I escape into one of my computer games. They don't mind how often I find myself distracted, confused or forgetful. And how did I miss that text from my sister, who checks up on me when I'm home alone?

A glance at the time and I find that my favourite show, *The Ellen DeGeneres Show*, started 15 minutes ago. I'll miss it if I don't change the channel but I can't find the remote. I wander around the room, searching under cushions and my granddaughter's toys for that "thing." I can't even remember its name. I burst into tears, when at last it appears.

The show usually reminds me to start on dinner and I text my husband for a reminder of what's on the menu tonight. "Could you make spaghetti tonight? There's beef in the fridge and squash in the drawer," he replies. As I return to the kitchen, I'm stumped with a new challenge – where did I (or he) put the pans? Did he put them away? I start opening cabinet doors, not really knowing what I'm looking for. I'll know when I see it – I hope.

Much of my day is based on hoping I won't get distracted. That maybe this time I won't forget. That I won't burn dinner tonight. But by this time of day, I'm weary with all the frustration and overwhelmed with all I try to do right. All I have energy to do is prepare for the meal and I text my husband to say I need to go lay down.

Every move, a second guess; every second guess, a distraction; every distraction, a new thought throws me into chaos.

Dementia, the big "D" word! We try to work around and often forget, the pain and, the loneliness of slowly losing that piece of yourself that makes you, you.

Rose Ong's story was abridged. To read the full story, please contact us at newsletter@alzheimercbc.org

This January we're flipping the script on dementia stigma for Alzheimer's Awareness Month



Lester has bravely accepted his dementia diagnosis

When someone receives the diagnosis of dementia, many things run through their head. *What will my friends think? How much time do I have left? Who is going to help?* One of the

most common thoughts is: *Does this mean the end of a meaningful life?* In fact, one in two people in British Columbia believe this to be true. However, while living with dementia is not an easy journey, we've learned from our community that there are unexpected moments of joy and many people can continue to live full and meaningful lives with support.

This January, we're once again recognizing Alzheimer's Awareness Month, focused on debunking the stigma associated with dementia. We're highlighting stories, tips and tools to support living well with dementia.

Among the people sharing their story this month is Granville in Sinclair Mills. A musician, artist, Vietnam War vet, father and raconteur, Granville pushes back on stigma: "What I'm trying to do is to feel good, even though I'm having to let go of more and more of myself." Granville finds ways to live a meaningful life every day, including through music. He's written a song, "The Day Will Come," that puts his own journey into perspective.

There's also Lester in Burnaby. Lester is a teacher who has bravely accepted his diagnosis, determined to learn all he can and share as many life experiences as possible with his wife Cindy. Joining an early-stage support group, as well as attending events and dementia-friendly research activities keeps him busy. "There's a lot I can learn from talking and listening to others who are on the same journey," he says.

Another person raising their voice this January is Jana in Cranbrook, a registered social worker and elected official within the Métis Nation of British Columbia, whose father Roy is living with the disease. After they received Roy's diagnosis, people in their lives dismissed it, saying it was just part of getting old and that he didn't really have dementia. Jana has leaned into her culture by becoming an advocate and bringing an Indigenous voice to the disease, to help create a better environment for Roy and others.

We hope you'll be inspired to find meaning in your own experience of the dementia journey. Join us in spreading awareness and take a stand against stigma.

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 the findings or co-present research results.

There are two types of research you can get involved in. **Quality-of-life research** typically 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?

If you are interested in finding 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

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

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. Findings will inform policy-makers and organizations involved in dementia-friendly initiatives about the specific needs of people living with dementia who live alone.

Follow us!

Alzheimer Society of B.C. regularly posts research opportunities on our social media pages.

Facebook: facebook.com/AlzheimerBC

Twitter: twitter.com/AlzheimerBC

Instagram: Instagram.com/AlzheimerBC

Learn more: Dementia-friendly cancer care webinar

On December 7, 2022, we were joined by Dr. Canning who shared her early findings in her study exploring how to develop a dementia-friendly care approach to

providing medical care for cancer patients. The recorded webinar is available to watch on our website at alzbc.org/Dr-Canning.

We'd love to invite you join us in person!



Since we resumed in-person programming – including our support groups, education workshops and Minds in Motion® – earlier this year, what we've heard from participants is how wonderful it has been to be able to come together, share their experiences and support each other face to face again.

If you're feeling ready, we invite you to join us in person again, too. You will have

an opportunity to connect without the distractions and pressures of home.

But don't worry if you're not ready for or are unable join a program in person. We are continuing to offer our programs online as well, to ensure people across B.C. – regardless of their situation – are able to access our services in a way that suits their needs. No matter who you are or where you live, no matter what challenges you face, you deserve to face the dementia journey with support.

If you or anyone you know is interested in our programs, check out what's coming up: alzbc.org/flbulletins.

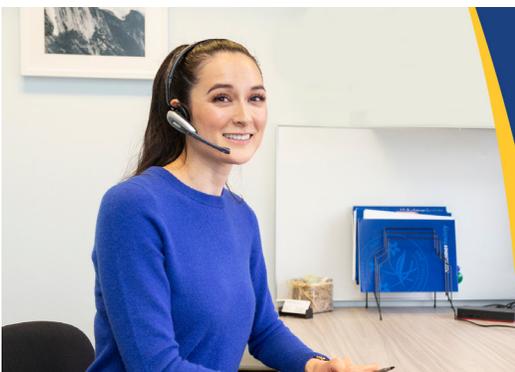
To learn more about our safety protocols, visit alzbc.org/COVID-safety.

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 our webinar with 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 lower the risk of them going missing.

This webinar takes place on Wednesday, February 15, at 2 p.m. PT. To learn more and to register, visit alzbc.org/webinar-Feb2023.



Alzheimer Society BRITISH COLUMBIA

For questions on memory loss or living with dementia, call the free, confidential **First Link® Dementia Helpline** (Monday to Friday):

| | |
|-----------------------|-----------------------------------|
| English | 1-800-936-6033 (9 a.m. to 8 p.m.) |
| Cantonese or Mandarin | 1-800-674-5007 (9 a.m. to 4 p.m.) |
| Punjabi | 1-800-674-5003 (9 a.m. to 4 p.m.) |

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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 English Helpline runs 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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