Insight

For people living with dementia

Alzheimer Society BRITISH COLUMBIA

Winter 2024



Building community: Alzheimer's Awareness Month

This January marks another Alzheimer's Awareness Month, when we will continue to work to dismantle the stigma surrounding dementia and celebrate moments of joy as we show that it's possible to live well with the disease. This year, we are highlighting how our programs foster a supportive community for people on the dementia journey.

Throughout the month, we're hosting virtual events and sharing practical tips for living well with dementia. In this issue of *Insight*, you can learn a bit more about Alzheimer's Awareness Month and how you can help nurture a stigma-free future and a stronger community for everyone affected by the disease.

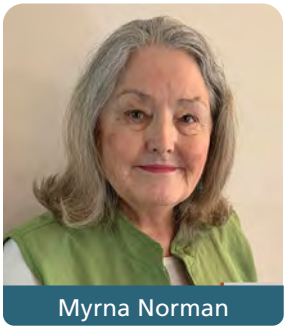
Learn more:

To learn more about this year's Alzheimer's Awareness Month, visit **alzbc.org/fulloflife**.

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Accepting hope and joy


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.

Dementia is a loss of cognitive functioning, thinking, remembering and reasoning changes to an extent that it interferes with a person's daily life.

Resilience is the process and outcomes of successfully adapting to difficult and challenging circumstances in life experiences, especially mental and emotional traumas.

Coping mechanisms are tools we can use to adjust to life's ups and downs; however we can do so much better. Most of us are aware of specific strategies we use to at least "get through a difficult time."

In my personal struggles, it seemed to me that my expectations of hope, joy and happiness were more rooted in fictional concepts – like Disneyland – than what mattered deep inside of me. My idea of a good life was one that was given to me by others, based on my behaviours and my acceptance of their values.

How do we get from resilience and dementia to opportunities of hope, joy and contentment? What can we learn about ourselves to encourage and to accept hope, joy and contentment?

Positive emotions include hope, interest, joy, love, gratitude, amusement and satisfaction. Happiness is often a fleeting emotion but contentment is a mindset we can all learn and gain so much from.

This Alzheimer's Awareness Month, we're also being reminded of how British Columbians affected by dementia can continue to live full and meaningful lives – that there is joy, peace and happiness. I'm challenging you to participate in conversations that matter to people affected by the disease this month. Just do it. Accept hope, joy and contentment. It's your life.

– 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

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.
alzbc.org/fulloflife



January is Alzheimer's Awareness Month

Alzheimer Society
BRITISH COLUMBIA

Support groups provide a sense of belonging



The dementia experience involves change, loss and uncertainty. There are unique challenges, transitions and changes for the person living with dementia, as well as their caregiver. Grief is a response to any personally-significant loss at any stage of dementia. It can be experienced and re-experienced in five different stages: denial, anger, guilt, sadness and acceptance.

The Alzheimer Society of B.C.'s early-stage support group provides people living with dementia a safe place to share experiences, learn from their peers and find help navigating the many changes associated with the disease. The following are some of the common topics discussed in support groups, along with quotes from participants on the dementia journey.

Procrastination

"I feel like I'm becoming a procrastinator – I just can't seem to get things done or I'm always sidetracked and have too many things on the go."

The need for more rest

"I need to lie down to rest my brain and body, even if I'm not sleeping. It allows me to sort through what needs to be done versus what I think I should be doing."

Expectations

"There are expectations that people have of me and expectations that I put on myself. It makes me feel stressed, anxious and hopeless."

Feeling more emotional

"I feel 'less than,' and I'm uncomfortable with being so emotional."

Grieving

"Acceptance is hard; I don't think I will ever really accept it. Sometimes it can appear that I have accepted it and come to terms with it on the outside, but it's always there – kind of nagging."

People living with dementia find a sense of belonging and feel they are all equals when attending a support group. Participants have benefited from learning through their peers and get a sense of hope that they can live a good and meaningful life. To learn more about early-stage support groups, visit **alzbc.org/support-groups**.

Learn more!

Watch our webinar "Coping with change, grief and loss" and explore strategies to help you cope in the face of changes. Visit **alzbc.org/webinar-grief**.

For more resources on grief, download the handout: **alzbc.org/grief-handout**

What's coming up



Wednesday, February 21 from 2 – 3 p.m. PT

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

Research focus: The "why" behind the "Flipping Stigma on its Ear" toolkit

Join us for the final webinar of the four-part "Flipping stigma" series, with a focus on research. Representatives from the UBC research team, along with action group members living with dementia, will discuss the importance of participatory action research. They will also address the underlying stigma and misconceptions of dementia that exist in the research field today. We'll conclude the series with a look at the "Flipping stigma" toolkit's global impact and what's next for the "Flipping stigma" team.



Two Wednesdays, January 10 and 24 2 – 3 p.m. PT

Learn more at alzbc.org/fulloflife.

Alzheimer's Awareness Month panel discussions

Don't miss our two upcoming webinars led by extraordinary individuals: Jim Mann, an advocate living with dementia, will moderate the first panel discussion on living life to the fullest on the dementia journey. Jana Schulz, a caregiver and registered social worker, will lead the final panel on the importance of finding a supportive community within our programs and services. These webinars promise unique insights and valuable perspectives. Don't miss these inspiring conversations that will empower and enlighten you, as we come together to build a more compassionate and inclusive future.



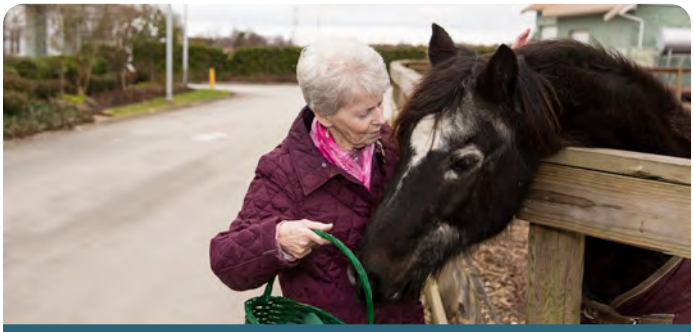
For more information, call the First Link® Dementia Helpline:

Punjabi: 1-833-674-5003
Chinese: 1-833-674-5007

New! Minds in Motion® programs in Fraser region

Minds in Motion® is a fun and engaging fitness and social program designed for people living with early-stage dementia and care partners, to stimulate both the mind and body. We are now expanding the program to the Punjabi- and Cantonese-speaking communities so they can socialize and express how they feel in the language they are most comfortable with.

Unlocking the power of volunteering for your brain health



See if you can transform your passions and hobbies into meaningful volunteer opportunities!

Volunteers play an essential role in the Alzheimer Society of B.C.'s work to support people affected by dementia. Volunteering is a great way to make a difference, not only in the lives of others, but in your own life as well. Recent research (Proulx et al., 2017) found that formal volunteering with organizations like religious or charitable groups (rather than informal help for family and friends) is linked to better cognitive function.

The cognitive connection

Proulx and colleagues analyzed the survey responses of more than 11,000 participants 51 and older. The results showed that engaging in formal volunteering in mid to later life is linked to higher levels of cognitive function, especially in areas related to working memory. Working memory can be thought of as the brain's notepad, where you temporarily store and process information for understanding tasks and problem-solving. The link between volunteering and cognitive function appeared stronger for females than males. While people with better cognitive function tend to be more likely to volunteer in the first place, this tendency is only a small part of the association between volunteering and cognitive function (Kail & Carr, 2020).

Healthy habits

Volunteer activities provide older adults with an opportunity to increase social interaction, physical activity and cognitive stimulation. Moving forward, volunteering could be used as a lifestyle intervention for maintaining brain health among older adults and may one day be used as an intervention to slow down cognitive decline related to dementia (Kail & Carr, 2020).

To learn about other tips and strategies to help you lead a healthy, balanced lifestyle that reduces your risk of dementia, visit **alzbc.org/BrainHealthyTips**.

References:

https://doi.org/10.1093/geronb/gbaa101
https://doi.org/10.1093/geronb/gbx110

Focus on research

Interested in learning how the Alzheimer Society of B.C. supports research, highlights in dementia-related research and enhancing your research literacy? Be sure to check out our annual publication *A focus on research*, to be released in early 2024. Visit **alzbc.org/support-research**.

Sharing your voice: The drive for meaningful engagement opportunities


Jim Mann

The Alzheimer Society of B.C. has established a committee for engaging volunteers with lived experience of dementia. This committee is made up of a group of our staff, people living with dementia and family caregivers. The purpose is to ensure the voices of people with lived experience inform all aspects of our work.

The committee is pleased to announce the development of a framework guide outlining our commitment to meaningfully engage with people affected by dementia.

Jim Mann has long been a respected leader and partner in much of the work at the Alzheimer Society of B.C. Jim has contributed his knowledge and experience living with dementia to numerous projects. He is also a proud member of the Alzheimer Society of B.C.'s committee for engaging lived experience volunteers.

When Jim was first diagnosed with Alzheimer's disease in 2007, there were not many opportunities for people living with dementia to volunteer. Thanks to Jim and other determined dementia advocates, the Alzheimer Society of B.C. has begun to push aside preconceived notions of what dementia looks like and what people living with dementia are capable of.

"It's from watching us and hearing us tell our stories that perspectives began to shift," Jim says.

Meaningful volunteer opportunities for people living with dementia are incredibly important. "Being diagnosed with dementia," Jim says, "your confidence can take a hit." For Jim, opportunities that inspire him to learn and better understand his diagnosis are the definition of empowerment. "Learning is part of being an effective volunteer. It will make you feel good. You will build your confidence as you learn. You can take control of your diagnosis."

Jim encourages others living with dementia to get involved in a way that feels comfortable to them. He stresses the importance of having a variety of roles for people to choose from that maximize their unique strengths. We all have something to contribute!

To learn more about the Alzheimer Society of B.C.'s lived experience initiative visit **alzbc.org/LivedExperience**.

Granville shares how volunteering has been a meaningful part of his dementia journey:

"Dementia has given me a cause: being able to present myself through my art with the purpose of advocacy. Discovering that – wait a minute – I can actually help here!"

– Granville Johnson, person living with dementia

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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?

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