

Connections

Linking a community of dementia support



“Yes. I live with dementia. Let me help you understand.”

“I think it’s fair to say that most of us – if not all of us – have experienced the stigma of dementia,” says Jim Mann, member of the B.C. Leadership Group of People Living with Dementia. Jim, who was originally diagnosed with dementia in 2007, is one of many Canadians who are talking about their experience of living with dementia in order to challenge stigma during Alzheimer’s Awareness Month in January.



Jim Mann

As part of the campaign, we’re talking about the Canadian Charter of Rights for People with Dementia, a document created by a national advisory group of people living with the disease, including Jim.

“The charter is not meant to sit silently on a bookshelf,” Jim says. “I hope people will take some time this January to consider the far-reaching impact of the charter on people in their community who are living with dementia, and how it can inform how they think about the disease.”

Learn more

To read about Alzheimer’s Awareness Month and the Canadian Charter of Rights for People with Dementia, visit ilivewithdementia.ca.

Pictured above: Bill Chalmers, Sarah King and Esther Sarlo, 2019 Alzheimer’s Awareness Month spokespeople for Burnaby.

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Help challenge stigma

Welcome to the winter issue of *Connections*, the Alzheimer Society of B.C.'s publication for people who are affected by or concerned about dementia.

Our vision is a world without Alzheimer's disease and other dementias, and that world begins with a more dementia-friendly society, where people affected by the disease are acknowledged, supported and included. Every January we celebrate Alzheimer's Awareness Month, an important time to work towards our vision, change the conversation and challenge the stigma associated with dementia by amplifying the voices of people with lived experience.

In this issue, read about a caregiver's experience of stigma and dementia, along with tips on how to deal with that stigma. Learn about our upcoming *Breakfast*

to Remember fundraisers in Vancouver and Victoria. As well, you'll hear about some truly incredible volunteers doing amazing work.

Throughout January – and beyond! – start conversations with people and help them see dementia differently. Maybe share your copy of *Connections* as a starting point. It may seem like a small step, but along the way you'll be building a province that is safe and inclusive for people affected by dementia.



Maria Howard MBA, CCRC
Chief Executive Officer
Alzheimer Society of B.C.

Events at a glance

We host signature events throughout the year to raise awareness and funds to help provide programs and services in communities around B.C. Here's a taste.

Anything for Alzheimer's
Year-round



Breakfast to Remember
February/March



IG Wealth Management Walk for Alzheimer's
May



Scotiabank Vancouver Half-Marathon & 5k
June



Climb for Alzheimer's
September



Coffee Break®
September/October



Learn more or get involved

For more information visit our events page: alzbc.org/society-events

How stigma affects us

Stigma is a reality for many people living with dementia and their caregivers. Worrying about the judgment of others is one of their greatest barriers to seeking support and talking about their diagnosis. To help raise awareness of dementia and overcome the stigma attached to it, it is important for caregivers

How did your friends, family and people around you react when you told them about your family member/friend's diagnosis?



- “Some people were supportive but not everyone understands the amount of care it takes.”
- “They don't have knowledge or understand what dementia means.”
- “There was some distancing and avoidance.”
- “People were unsure how to talk to the person living with dementia.”

How would you suggest other caregivers respond when they experience stigma?



- “Try not to take it personally.”
- “Educate people about dementia.”
- “Let people know you need help.”
- “Explain. Help others understand the disease.”
- “Have a good cry and try to move on.”
- “Talk to other caregivers.”

to share their experiences with others and learn from those who have provided care in the past. We asked caregivers around the province to share their thoughts about their experiences of stigma. Here's what they had to say:

How have people behaved towards you as a caregiver?



- “One friend is trying to fix everything.”
- “My neighbour checks on me more often.”
- “Some people minimize the illness, saying that we all forget as we get old.”
- “People go out of their way not to talk about it.”
- “I get sympathy about the situation because I have given up my professional life to become a caregiver.”
- “I don't get the calls I used to get. I feel isolated. Friends don't know what to say.”
- “People can supply too many exhausting unsolicited suggestions.”

When people talk about dementia, are there words or phrases you don't want to hear?

- “I don't want to hear how sad it is.”
- “I don't like to hear it as a negative thing.”
- “I dislike when people joke about it.”
- “I get tired of the endless suggestions.”
- “I don't like hearing that it will get worse.”



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What would you tell people to help them understand what it's like to live with dementia?

- “Keep learning about the person and dementia.”
- “I find it difficult to explain. Every day is different.”
- “You have to accept it and learn as much as you can.”
- “It's a day-to-day existence. Sometimes there are not so great days but there are also enjoyable moments in between. Live in the moment.”



Learn more

We have developed ten advocacy fact sheets on advocating for a person living with dementia. Each fact sheet covers a different topic you may encounter along the dementia journey. To download the fact sheets or to learn more, visit: alzbc.org/become-advocate

Tips for overcoming stigma

- **Be open and honest.** When someone asks how you are doing, be honest with your answer. People may not realize how difficult things are for you.
- **Talk about dementia. Become informed.** Sharing accurate information is the best way to reduce stigma.
- **Help others understand.** Encourage people to learn more about the disease. The Alzheimer Society of B.C. offers free tele-workshops for people to learn about dementia at home: alzbc.org/learn-from-home
- **Talk to someone you trust.** It can be hard dealing with stigma alone. Sharing this part of your life with family and friends and letting them know when you need help and support can be of great comfort.
- **Stay connected.** A support group can be a safe place to share your struggles with people who understand. The Alzheimer Society of B.C. offers Family Caregiver and Early Stage support groups: alzbc.org/support-groups



Caregiver story

Challenging stigma: A caregiver's perspective

Fearon Blair lives in Kamloops with her husband Richard, who lives with both Alzheimer's disease and Frontotemporal dementia (FTD). Richard was diagnosed in June 2016 at the age of 71. Fearon shared a bit about their experience of the disease – both their own feelings of stigma and the positive response they've encountered from others.



How did you both react to Richard's diagnosis?
Richard showed very little reaction even though the situation was spelled out to him clearly by two different doctors. He would never discuss it with me, even though I believe he did understand what was happening and the implications. He has never shown fear of the diagnosis, although over the past year he's started to respond with anger in response to the challenges of the disease.

When we got the diagnosis of FTD, I was relieved we could finally acknowledge the changes I had been seeing, so we could start to deal with them. As the reality of it started to sink in, I started to feel different. I realized early on that I was grieving. I hadn't thought about the situation in terms of grief before, even when I saw others in the same situation, including my father-in-law, who cared for Richard's mother when she had dementia. I've come to accept things but the anger still bubbles up. As the demands of caregiving have grown, I've started to feel a little sorry for myself, too.

How have health-care providers treated you?

Other than one bad experience with a neurologist, I've been very impressed with the health-care providers we've worked with. Both of our general practitioners have been amazingly supportive. The people at the community clinic have made a difference through medications that have helped with Richard's reaction to frustration and his anxiety. All have shown concern for both of us.

How did the people around you react when you told them about the diagnosis?

I only told a few friends, and all of them were upset and sorry to hear about it. Because of Richard's connections in the community, the information's spread quite quickly.

Richard has one brother; when we told him, he expressed that he'd been living in fear of the diagnosis for himself, after their mother's experience. At first he was a bit inappropriate, making jokes about the changes in Richard's behaviour as the disease progressed. I had to discuss it with him, explaining that him making jokes about "our tragedy" was upsetting and that I would have stop including him if it continued. I think he was trying to deal with his own grief, and since our talk he's been more supportive – particularly when I've needed help dealing with some of Richard's behaviour.

Have you encountered stigma in response to Richard's disease?

While we've had relatively good experiences with friends, family and health-care providers, I've noticed the behaviour that comes with the disease can be difficult for people to deal with. When faced with some of Richard's symptoms – notably when he behaves inappropriately – people respond very quickly and badly. However, if you explain why this is happening most people respond well. In situations like grocery store line-ups, people are pretty understanding and not judgmental.

What are five things you would say to someone to help them understand dementia?

1. Because the brain controls so much of what we are, when problems develop, so many things change.
2. The disease progresses differently for each person.
3. The person living with dementia is doing the best they can in their situation.
4. The person living with dementia still needs to feel secure and loved.
5. It is a very challenging disease for caregivers and family members as well.

Share your story:

People willing to talk about their personal experience of the dementia journey can have a huge impact on how the disease is perceived and how people living with it are viewed. Help us build a dementia-friendly province by connecting with your local resource centre to talk about how your story can change perceptions:

alzbc.org/help-near-you

Join us for an inspiring Breakfast to Remember in Vancouver and Victoria

This winter, business and community leaders will gather to have breakfast, network and take a leading role to create change for people living with dementia – all before their work days begin. *Breakfast to Remember* fundraising events in Victoria and Vancouver are opportunities to fund dementia education, support services and research while addressing the stigma of dementia. Both events feature inspiring talks from local experts in business and dementia research.

Tomiko Yoneda, a PhD candidate in the Department of Psychology at UVic and an Alzheimer Society Research Program fellow, is one of those experts. The guest speaker at the Victoria fundraiser is a former First Link® Dementia Helpline volunteer who is using her unique background to inform her research into early screening assessments and treatments for dementia. Tomiko's volunteer experiences, including at Oak Bay Lodge, inspired her to investigate risk factors and early indicators of dementia and cognitive decline.

“As a volunteer at the Alzheimer Society of B.C., I gained insight into the many challenges that people

living with dementia and their caregivers face,” Tomiko says. “Contributing to the advancement of dementia-related knowledge with the purpose of improving quality of life for older adults and their family members is... my long-term ambition.”

Victoria's *Breakfast to Remember* is presented by Trillium Boutique Senior Living. The sixth iteration of the event comes to the Fairmont Empress from 7 – 9 a.m. on Tuesday, February 26.

Guests in Vancouver will hear from keynote speaker Caren McSherry, who is a TV personality and founder and CEO of Gourmet Warehouse. She will be joined by guest speaker Dr. Roger Wong, Executive Associate Dean of Education in the Faculty of Medicine at UBC, whose research focuses on hospital medicine in vulnerable older adults, including quality improvement in acute care geriatrics. The eighth-annual event is set for 7 – 9 a.m. on Thursday, March 7 at the Fairmont Waterfront.

For more details, or to purchase tickets, visit breakfasttoremember.ca.



You're invited
BREAKFAST TO
REMEMBER
VANCOUVER

March 7, 2019
Fairmont Waterfront Hotel
Vancouver

Alzheimer Society
BRITISH COLUMBIA

breakfasttoremember.ca

Meet the volunteers who make us great

The Alzheimer Society of B.C. honours volunteers who have gone above and beyond in their commitment to ensuring people affected by dementia live their best lives. We'd like to introduce you to the recipients for the 2018 Alzheimer Society of B.C. Volunteer Recognition Awards.



Award of Hope, inspired by Mike Crowe

Volunteers in this category are living with dementia and have demonstrated courage, leadership and support for others, as well as having acted as a role model while raising awareness.

Surrey resident **Doug McMorland** was diagnosed with vascular dementia in 2002. After several years as a client of the Society, Doug decided to use his experiences to help others. In 2011 Doug began co-facilitating support groups for people living with early-stage dementia. For seven years Doug has been showing how to live fully and courageously with dementia, both as a support group facilitator and a speaker at *Shaping the Journey: living with dementia...*® workshops.

Award of Merit, inspired by Twigg White

Volunteers in this category are chosen for their demonstrated commitment to the cause, empathy towards the needs of caregivers, and their sense of humour in the face of obstacles. Five volunteers from across the province were nominated for our Award of Merit this year.

Wendy Landree has contributed over 1,000 hours since she began volunteering at the Society's North & Central Okanagan Resource Centre in 2015. As a result of her health-care background, Wendy's role evolved quickly and she's taken on many aspects of organizing new resources and systems so that staff can focus on supporting families. She's being commended for her positive attitude, her commitment and dedication, and her willingness to try new things and grow with the Society.

Award of Leadership, inspired by Clyde and Lanny Slade

Volunteers in this category are agents of long-term change who have demonstrated strong leadership and vision. Two volunteers were nominated for our Award of Leadership.

After receiving support from the Society because both his mother and father-in-law lived with dementia, **Ron Angell** became a volunteer, taking on the role of

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You're invited
BREAKFAST TO
REMEMBER
VICTORIA



PRESENTED BY:



February 26, 2019

Fairmont Empress Hotel
Victoria

Alzheimer Society
BRITISH COLUMBIA

breakfasttoremember.ca

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a support group facilitator to help other caregivers better understand the journey. Ron has also served as the Chair for the *IG Wealth Management Walk for Alzheimer's* in Chilliwack since its founding, building a strong team of fundraisers and helping establish a Walk in Abbotsford.

Award of Community Service, inspired by Lola Turik

Volunteers in this category have demonstrated community leadership through their volunteer work at the grassroots level in rural or small municipalities.

Elise Willson first came to the Society for help in navigating the health-care system on behalf of her

mother. In 2006, she became a volunteer when she established the first support group for caregivers in Qualicum Beach. In 2009, Elise co-founded the Oceanside Dementia Education Task Team, a group dedicated to raising awareness and challenging stigma by screening educational videos about dementia twice a month in both Parksville and Qualicum Beach.

Our 2018 volunteer awards will be presented at Alzheimer's Awareness Month Open Houses in Vancouver, Surrey, Victoria, Kelowna and Prince George throughout January. The recipients will also be celebrated on social media.

Read and learn more

Please visit the [Volunteer section](#) of our website to learn more about volunteering with the Society or call 1-800-667-3742.

First Link®

YOUR LINK TO DEMENTIA SUPPORT

If you are living with dementia or have questions about the disease, call the First Link® Dementia Helpline at 1-800-936-6033. The helpline is available Monday to Friday, 9 a.m. to 4 p.m. Individuals and families in the South Asian community can receive culturally-specific support by calling the South Asian Dementia Helpline at 1-833-674-5003.



About Connections

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- **Email** newsletter@alzheimerbc.org
- **Call** 604-681-6530; 1-800-667-3742 (toll-free)
- **Mail** to the Alzheimer Society of B.C.
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Vancouver, B.C. V5Z 1E2

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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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