

Connections

Linking a community of dementia support



A focus on dementia and human rights

Central to the idea of a dementia-friendly province is the conviction that every British Columbian – and every *Canadian* – living with dementia is a person first and foremost. People living with dementia are entitled the same human rights as everyone else, as outlined in the Canadian Charter of Rights and Freedoms and the B.C. Human Rights Code. People living with dementia are protected in B.C. because dementia is considered a disability.

However, stigma and discrimination are huge barriers for people living with dementia, and often compromise their rights. Part of the reason the Alzheimer Society of B.C. exists is to advocate for the rights of people living with dementia, and to support

them in advocating for themselves. We believe people must be included in conversations and policy decisions that affect them.

We encourage anyone connected to the Society or to the issue of dementia to become an advocate for the rights of people living with dementia and for their caregivers.

Learn more

Created by and for people living with dementia, the Canadian Charter of Rights for People with Dementia is a tool to help people advocate for themselves:
ilivewithdementia.ca/charter

In this issue

Greetings & event calendar Page 2
Caregiver story Page 3

Health-care consent Page 4
Get involved Page 6
Volunteer profile Page 7

Change the conversation with us

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

Our vision is for a world without Alzheimer's disease or other dementias, and that world begins with a more dementia-friendly province, where people affected by dementia are acknowledged, supported and included.

National Volunteer Week starts April 7. It is a time to celebrate our many volunteers, from the Board of Directors to people staffing our First Link® Dementia Helpline.

In this issue, we're talking about advocating for the rights of people affected by dementia. You'll hear from a caregiver about the importance of inclusion. Krista James, National Director of the Canadian

Centre for Elder Law, writes about the complexities of health-care consent. Learn about how the *IG Wealth Management Walk for Alzheimer's* – coming up in May – is changing the conversation about dementia by raising awareness and addressing stigma. Finally, you'll meet a volunteer advocating for more services on Bowen Island.

I hope this issue will inspire you to find ways of advocating for people affected by the disease. Starting can be as simple as having one conversation. Help us make our vision a reality.



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

Inclusion: A caregiver's perspective



Robin Fennell

Robin Fennell lives in the village of Clinton, B.C. with his wife Blanche, who is living with Alzheimer's disease. Robin shares his thoughts about the challenges of living with dementia in a small community and the right of people living with dementia to be included.

When did your experience with dementia begin?

I knew a little bit about dementia, because I'd had relatives who lived with Alzheimer's disease. I'd also seen people in the community over the years – but it all started when my wife was diagnosed in 2015.

How has your community reacted to your wife's diagnosis?

There was disbelief as the disease progressed slowly at first and my wife was open about talking about it. She posted a letter around the community, explaining her diagnosis. People reacted with compassion and Blanche didn't change what she was doing; she'd go on a walk and someone would call to ask if I knew where she was. People looked out for her.

Later on, though, they started to exclude her. One thing about the disease is that you repeat yourself: When she tries to get into conversations at a coffee shop, people don't want to include her. That's very upsetting for me. She doesn't say anything, but I can see her disappointment.

Why do you think your community's reaction has changed over time?

Both the compassion and the exclusion are there at the same time. People will ask how Blanche is but they're the same people who are tired of hearing the same stories. I can see a slow pulling back. As time progresses it becomes more and more obvious.

What things have made you feel included? What would true inclusion look like to you?

I think it depends; I'm always included, but as Blanche's disease progresses, she doesn't go to as many functions any more and she retreats into safe spaces. We don't have as many things to do together, like curling or skiing. I would like to see more resources in Clinton, but that probably won't happen because there are only 650 people here.

While this is a small community, it's where Blanche feels comfortable. Every once in a while, I say we should move somewhere else, but this is her place. I try to make sure people are aware of this disease no matter where they are. Once they realize, the change of a person's face is amazing – from being impatient to patient. More awareness would really help. I've tried to talk to other people – even caregivers – but they don't want to talk about it.

How do you think we can better protect the right of inclusion for people living with dementia?

I think education is important. Basically, explain the disease and let people tell their stories, keeping the person with the diagnosis involved as much as possible. There's no limit on who can be educated – from a scientist to a plumber. I hear people say things like, "They've lost their marbles," all the time and education can help get rid of stigma. Talking about it is so important and everyone plays a role in this.

How can you help

Learn more about how you can advocate for yourself or other people affected by dementia to have the best possible experience by visiting: alzbc.org/advocate

Krista James on health-care consent

Krista James is the National Director of the Canadian Centre for Elder Law (CCEL), an organization dedicated to addressing the law and policy issues that impact us as we age.



Health-care consent is the idea that adults can only be given health care (including different treatment options or medications) with their agreement. This issue can become harder to navigate when people are living with dementia, as they often face both difficulties with understanding and discriminatory assumptions about their ability to participate in decision-making.

It is important for people to know about their rights. Under the law, consent must be:

- **Capable** – A person must be able to understand the information relevant to a particular decision and apply it to their situation in order to decide what they want to do. Legally, every adult is presumed to be capable of making their own decisions about everything – regardless of disability or disease. Very few people do not have capacity to make any choices. Capacity is also decision-specific, so a person might not have capacity to make a will but may still have capacity to make health-care decisions. Capacity also changes, and can be affected by stress or medications. People with disabilities should not be set to a higher standard than others. For instance, people may have capacity to consent to medical treatment even though they do not understand all the complexities involved in a surgical procedure.
- **Informed** – For a person to make a health-care decision, they need the relevant information. As a result, health-care providers have a professional obligation to take the time to speak with people

about the proposed health-care treatment, including potential risks and alternative treatments that might be available. People have the right to ask questions and receive clear and accurate information. This right also applies to situations where people must make decisions about reducing medication dosage or discontinuing medication.

- **Voluntary** – True consent is freely given, not a result of pressure. Health-care providers and families need to be aware of dynamics that influence choice. For some people, factors like authority or politeness limit their ability to say no, even when they want to. Some people are intimidated by physicians, or a desire to make choices that please others.

Difficulty communicating and understanding does not necessarily mean incapability to make decisions. Health-care providers and researchers have to accommodate these challenges. This support with communication and understanding is a requirement of both human rights law and health-care consent law.

Consent can generally be provided orally, in writing or inferred from conduct. The experience of dementia points to a need to be flexible about how people communicate consent. Importantly, informed consent also includes the right to change your mind and withdraw from a treatment or study.

Learn more

The Canadian Centre for Elder Law and the Alzheimer Society of B.C. have several resources, including a guide for people living with dementia on health-care decision-making law in B.C., an animated video and a report on the law and practice of health-care consent for people living with dementia, titled *Conversations about Care*. Read the report here: alzbc.org/health-care-consent

IG WEALTH
MANAGEMENT
**WALK FOR
ALZHEIMER'S**



My mom.

**Opera singer. Community carer.
Farmer's wife. Volunteer. Warrior.
Diagnosed with dementia in 2015.**

Who will you walk for?

Sunday, May 5, 2019

**Register today at
walkforalzheimers.ca**



Alzheimer Society
BRITISH COLUMBIA

Walking to make change

“I knew I wanted to be in this job since I was twelve,” says Leïla Jamal, occupational therapist at the New Westminster Specialized Seniors Clinic. “I had a significant hand injury at the time, which made me dependent on my mom for everything. In the same year I met my grandfather on my mom’s side and I just fell in love with him.” Leïla’s childhood experiences are where her advocacy for seniors began. That passionate focus on supporting seniors is what led to her nomination as the Burnaby and New Westminster honouree for the *IG Wealth Management Walk for Alzheimer’s*.



within community members’ homes to ensure independence and supporting people to “age in place” for as long as possible. Leïla often refers people to services like the Society’s own First Link® dementia support. “I am constantly learning about different kinds of dementia and new ways I can support people living with dementia,” she says. Being an honouree gives Leïla the opportunity to share what she knows and talk about the impact of dementia and other issues related to seniors.

Being an advocate for change is at the heart of being a *Walk* honouree. “The hope is that we can make a difference in the lives of people living with dementia and their caregivers.”

The *IG Wealth Management Walk for Alzheimer’s* is an annual event that takes place in 21 communities across British Columbia. As the Society’s largest fundraising event, it helps increase awareness and creates an opportunity to talk openly about the impact of Alzheimer’s disease and other dementias on British Columbians.

Leïla’s role as a honouree is enriched by her professional role – evaluating function and safety

Who are you walking for?

On May 5, join Leïla and thousands of British Columbians as they walk to end stigma and raise funds to support people affected by dementia. Register and start fundraising at www.walkforalzheimers.ca.

Join us in the Charity Challenge
Scotiabank Vancouver
Half-Marathon & 5k
June 23, 2019

604-742-4943 or events@alzheimerbc.org



Suzanne Allan: Advocating for a dementia-friendly Bowen Island



April 7 – 13 is National Volunteer Week and this year's theme is "The Volunteer Factor – Lifting Communities." The Alzheimer Society of B.C.'s more than 750 volunteers lift people affected by dementia in communities across the province every day. We are grateful to the volunteers who give their time in programs and services, events and advocacy. This support is essential to the help we are able to offer to the estimated 70,000 British Columbians living with dementia and their families.

Suzanne Allan is not one to face a challenge on her own. When her mother Barbara was diagnosed with Alzheimer's disease, she sought out other caregivers in her network who were supporting someone living with dementia. She ultimately began the first caregiver support group for Bowen Island.

Suzanne has been facilitating the support group for six years now and has seen the growing need to support people living with dementia on Bowen Island. During Alzheimer's Awareness Month in January, she organized education workshops – for caregivers and for the general public – and was struck by the number of people she hadn't known were caregivers.

The workshops are part of a movement to make Bowen Island more dementia friendly. "I think for families to live well with dementia, we need to help the broader community stop writing off the person when they hear of a diagnosis. We all need to recognize having dementia is a long journey. With greater awareness and a welcoming spirit from the community, people can continue living at home."

Just as she did not face the challenge of being a caregiver alone, Suzanne has gathered a team of



Suzanne with her mother Barbara.

passionate people seeking to increase services on Bowen Island. "Living in a small community, we have fewer options for people living with dementia and their caregivers. We are reaching out to potential partners to pilot an adult day program and hope to make that an ongoing service on Bowen Island."

Advocacy is building support for a different world, person by person and community by community. Suzanne is changing the world, both for caregivers who connect to each other through the support group, and for the community at large.

[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

Questions about dementia
or memory loss?



English: 1-800-936-6033

Punjabi: 1-833-674-5003

Cantonese or Mandarin: 1-833-674-5007

Hours: Monday to Friday, 9 a.m. to 4 p.m.

Learn more: alzbc.org/fldhl

Participate in research to help others in your community

The Alzheimer Society of B.C. is committed to offering the highest quality services that also meet the needs of the people receiving them. To ensure this, the Society has contracted researchers at the University of British Columbia to evaluate all First Link[®] dementia support services (support calls, dementia education,

support groups and Minds in Motion[®]). Your feedback is valuable and will help improve services for other British Columbians affected by dementia. If you would like to give feedback and be a part of this research project, sign up to be contacted by our external research partners by visiting: alzbc.org/FL-evaluation

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.



The Standards Program Trustmark is a mark of Imagine Canada used under license by the Alzheimer Society of B.C.

Charitable registration number:
#11878 4891 RR0001