

Connections

Linking a community of dementia support



Join our community of care

We can't snap our fingers and cure dementia. We can't build a dementia-friendly B.C. overnight. It's going to take a movement.

In November 2017, we started a conversation – asking people close to the Society what a community of care means to them. We heard from advocates, volunteers and researchers. Most importantly, we heard from people living with dementia and from caregivers.

We want you – and all British Columbians – to be part of the movement.

Will you become a volunteer or an advocate? Will you join us in person for the 2018 *Investors Group Walk*

for Alzheimer's? Will you talk to people in your life and challenge stigma? Will you amplify the voices of people living with dementia as they tell their own stories?

Join us. Be part of the conversation. Be part of our community of care.

Get involved

To learn more about joining our community of care, visit <http://alzbc.org/get-involved>.

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Join the movement

Welcome to the spring issue of *Connections*, the Alzheimer Society of B.C.'s newsletter for people affected by or concerned about Alzheimer's disease and other dementias. With National Volunteer Week on April 15-21 and the *Investors Group Walk for Alzheimer's* on May 6, spring is an important time to talk about building a community of care.

Our vision is for a world without dementia; until that day comes, our more immediate vision is for a dementia-friendly society, where people affected by dementia are welcomed, included and supported. Building a community of care – a community engaged in moving away from fear and denial of dementia, dedicated to building a foundation of understanding and awareness – is how we make that vision a reality.

In this issue, meet someone who has walked the path from caregiver to volunteer to a member of

our amazing resource centre staff, and a volunteer who's shown us the impact someone can have on their community after diagnosis. Learn more about how you can support people when they are on the dementia journey. Read about the upcoming *Investors Group Walk for Alzheimer's*, happening in 23 communities across the province.

Each issue of *Connections* is an opportunity to change the conversation. Share it with someone in your life to help them better understand. Ask the people in your life affected by dementia how you can help them. Together, we can create a community of care.



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



Investors Group 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

Supporting your friend living with dementia

It is important to remember that receiving a diagnosis of dementia does not mean your friend will become different overnight. While the things you do together may change over time, this is still the same person. With the uncertainty and losses that can accompany dementia, it is important that your friend continues to feel valued and supported. Here are tips for supporting your friend:



During the early stages

- **Continue to be a friend.** The best thing you can do to support your friend is to reach out. Continue doing things that you enjoy together.
- **Do “normal” things.** Help your friend maintain an active and independent life for as long as possible. Remain involved in the community by going out for coffee, shopping or visiting the local recreation centre together.
- **Educate yourself.** Learn about dementia to help understand and prepare for the changes ahead. Call the First Link® Dementia Helpline (1-800-936-6033) or your local Resource Centre to find out about an introductory dementia education session near you.
- **Ask how you can help.** Ask your friend directly how you can support and continue to be a good friend to them.

During the middle stages

- **Adapt activities as necessary.** Focus on your friend’s remaining strengths and abilities. You may have to adapt yourself to their changing needs rather than expecting them to adapt to you.
- **Be patient.** Slow down if necessary. If your friend is being repetitive, avoid correction or criticism. Instead, try responding to their story as if it’s the first time you’ve heard it. This shows patience and understanding and will likely be appreciated by your friend.
- **Take the initiative.** You may need to take charge of the relationship. The person living with dementia may feel embarrassed by their symptoms and intimidated to reach out to you. Making plans can help reassure your friend that you are there for them. Your visits may become shorter, but it is important to continue to be a presence for the person.
- **Don’t take things personally.** Remind yourself that changes in personality, mood or behaviour are related to the illness.

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During the late stages

- **Give the gift of your presence.** At this point in your friend's dementia journey, a physical connection can be the best type of friendship. Just being there for your friend and providing them with company is often enough. You can do this by sharing a cup of tea, looking through old photo albums or simply sitting together. These visits may only last a short period of time but can be an uplifting experience for your friend.
- **Communicate creatively.** Be prepared to rely less on verbal communication. When you are communicating verbally, keep it short and simple. Give one message at a time and avoid condescending or childlike tones. Even if the person living with dementia loses the capacity for recognizable speech, you can continue to communicate through body language and the tone or pitch of your voice.

Supporting your friend who is a caregiver

Caring for someone living with dementia can take a toll on the physical and emotional health of caregivers and family members. Caregivers may begin to feel isolated, depressed and exhausted. A friend who can step in once in a while to help relieve stress is often appreciated.

- **Be a source of respite.** Caregivers may experience high levels of stress, so receiving regular breaks is important. If you can commit to helping on a regular basis – by mowing the lawn, doing the laundry, taking the person living with dementia on an outing or helping to find information and resources – you can help provide these breaks. Small gestures can go a long way.



- **Be a good listener.** Lend a non-judgmental ear and take time to really hear what your friend is saying. Try to offer advice only if you are asked – not every situation needs a “fix.”
- **Reach out.** Your friend may be hesitant or too busy to ask for help. Make it easy for your friend to ask for and accept your help. Ask them directly how you can help.
- **Accept that your friend will not have as much time as before.** Because of the demands of caregiving, your friend may gradually lose contact. Reassure them that you understand and that you're there whenever they are ready to reach out.

Connect with support and learning

First Link® dementia support is for people living with dementia and their care partners at any stage of the journey. Call the First Link® Dementia Helpline at 1-800-936-6033 or visit the [We Can Help](#) section of our website.

Watch a video about how you can support a friend affected by dementia:

<http://alzbc.org/support-a-friend>.

Supporting a friend: A caregiver's perspective

Dorothy Leclair has worked as a Support and Education Coordinator with the Alzheimer Society of B.C. for seven years. Her journey as a caregiver motivated her to volunteer and eventually become one of many staff members dedicated to improving the lives of people affected by dementia.

Q: What is your experience as a caregiver for a person living with dementia?

A: In 1999, my mother's behaviour began to change. We went to her doctor and she received a diagnosis of Alzheimer's disease. At the time she lived in a very rural area all by herself so she moved in with me and my three teenage children.

Q: How did you connect with the Alzheimer Society of B.C.?

A: I connected using what is now known as bc211 – an organization that specializes in providing information and referral regarding community, government and social services. I called the First Link® Dementia Helpline. I signed up for the *Family Caregiver Series*. The staff also put me in touch with a caregiver support group that I joined.

Q: How did you come to work at the Society?

A: After my mother went into care in 2007, I realized I could take the skills I had learned as a caregiver and share them with others. I volunteer as a support group facilitator. When First Link® dementia support began to roll out across the province, a number of jobs opened up with the Society.

Q: What support did you receive from friends or work colleagues?

A: Eighteen years ago, my colleagues didn't have the sensitivity some workplaces have today. I didn't have an inkling when I moved my mom into my home how quickly she couldn't be left alone. I had a job

and couldn't take time away, so I made the difficult decision to resign.

Friends had to learn with me.

Every week I had four hours of respite with a friend who knew to take the initiative in planning our get-togethers, and listened without trying to solve my problems.



Dorothy Leclair (pictured left), presents a volunteer award with Christine Penney, Chair of the Society's Board of Directors.

Q: Do you have any advice on supporting a friend who is a caregiver or is living with dementia?

A: If you are a friend of a caregiver, then become curious. Ask your friend how you can help. Let them know that you will listen and won't try to fix their problems. Realize that if you don't see your friend for great lengths of time it doesn't mean they don't care, they just don't have the energy. If you are really interested in helping, take dementia education with them. Call the First Link® Dementia Helpline (1-800-936-6033) to learn what is available. Ultimately, just be there for them.

Share your stories with us

To submit personal stories, photography or original poems, email us at newsletter@alzheimerbcc.org. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.

Celebrate the 2018 Investors Group Walk for Alzheimer's honourees!

The *Investors Group Walk for Alzheimer's* is a fun and family-friendly way to create a movement while sending a message of inclusion and hope to British Columbians currently living with dementia and the people who care for them. It will take place on Sunday, May 6, in 23 locations across B.C.

Each *Walk* is dedicated to an honouree: someone who has been affected by dementia, or who has valuably contributed to the lives of people living with the disease. The *Walk* provides the honouree family, and all participants, the opportunity to remember and honour people in their lives who have been affected by dementia, while standing with their community to show that they are united to end stigma surrounding the disease.

Michele Buchignani, whose family will be honoured at the Vancouver *Walk*, says, "My family and I are looking forward to connecting with other people who are coming together to help spread awareness and end stigma surrounding dementia. We are so grateful that we can be part of the Walk, and be the 'faces' of these committed and passionate individuals."

By attending the *Investors Group Walk for Alzheimer's* you honour the people who have passed and acknowledge the work that must be done to ensure help and hope for people living with the disease today.

Meet some of our honourees.

Kamloops

Louise Wiens is admired for her hard work, generosity and cheerfulness – traits that have guided her journey as a single mother of three,

music teacher, choir director, church devotee and champion curler. Since she was diagnosed with dementia, Louise has continued to apply her patience and positivity to her loves: family, music and leadership within her church.

"And all this with a smile," says her husband, John, "I admire and love her."

Louise and John have faced her diagnosis with the support of Support and Education Coordinator Tara Hildebrand who says, "Visiting with John and Louise showed me the profound love between them."



North Island (Courtenay)

Sandie Somers, a Clinical Nurse Specialist in dementia and seniors' healthcare, has built a career in service of people living with dementia and their caregivers. From working with the Alzheimer Society of B.C.

to secure provincial funding to launch First Link® dementia support on Vancouver Island, to developing award-winning educational tools for health-care providers that are used around the world, Sandie has transformed the experience of people affected by dementia.

"The Society itself and the wonderful people there are so responsive," Sandie says. "They're always at the other end of a phone call and there to support any initiative we bring to them."



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Vancouver

The Buchignani family has been supporting the Alzheimer Society of B.C. for nearly 30 years. Three generations of its volunteers have made an indelible mark on the organization – and a real impact on how British Columbian families experience the dementia journey.

Reg and Sally Buchignani were critical to the establishment and the success of several fundraising events, including a gala and the *Forget Me Not Golf Tournament*, the latter of which to date has raised more than \$10 million in support of the Society. Their daughter Michele has lent her leadership skills and business acumen to executive leadership roles within the provincial and national Societies.

After Reg's mother was diagnosed with Alzheimer's disease, their personal experience prompted them to volunteer – and has kept them engaged year after year.



“My grandmother's journey with dementia ended many years ago, but we've stayed committed to the Society's ultimate vision of a world without Alzheimer's disease or other dementias. If we can build a dementia-friendly B.C., we can make the journey a little easier for those British Columbians who are currently on it,” says Michele.

Get involved

The *Investors Group Walk for Alzheimer's* will take place in 23 locations across B.C. on Sunday, May 6, 2018. You can learn more about our honourees and register for the event by visiting walkforalzheimers.ca! Together, we make memories matter.



How would you like to be remembered?

When you make a gift to the Alzheimer Society of B.C. in your will, you help us create a brighter future for British Columbians affected by dementia. To learn more about creating your own legacy, please contact Leona Gonczy at 604-742-4926.

Once family and friends are cared for, we hope you'll remember the Alzheimer Society of B.C.

Alzheimer Society
BRITISH COLUMBIA

Join us in the Charity Challenge
Scotiabank Vancouver
Half-Marathon & 5k
June 24, 2018

Contact Katie Syroid at
604-742-4920 or ksyroid@alzheimerbc.org.



Peter Wynn: Staying active through volunteering

Living with dementia can mean re-evaluating what's important to you, and changing your life to maximize what you want from it. Peter Wynn relied heavily on his excellent memory in his work as a business analyst for the Worker's Compensation Board in Edmonton. When he began losing things and forgetting recent conversations, he spoke to his doctor. Peter treated his diagnosis of Mild Cognitive Impairment as an opportunity to reflect on what he wanted the next phase of his life to look like. He and his wife Sylvia decided to pack up and move to Penticton.

Once they settled in, Peter wanted to stay active, and Sylvia figured volunteering was just the ticket. When she discovered the local Alzheimer Resource Centre was walking distance from home, she sent Peter over to find out what he could do. Quite a bit, it turns out.



Support and Education Coordinator Mary Beth Rutherford with volunteer Peter Wynn.

Peter quickly became a mainstay at the South Okanagan & Similkameen Resource Centre in Penticton, answering the phone and putting visitors at ease. Peter and Support and Education Coordinator Mary Beth Rutherford haven't let his diagnosis decide how he can contribute; instead they put his unique skills to work. "Peter is a real gentleman and a professional. He could have been on radio: he speaks well when he is on the phone, he is very open about his situation and he makes people feel comfortable around him," says Mary Beth.

Thank you Peter for your enthusiasm and hard work!

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.

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

You can help us reduce our costs by choosing to receive *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-bulletin.

Need additional support?

The First Link® Dementia Helpline is a confidential province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, professionals and the general public.

Email: supportline@alzheimerbc.org

Phone: 604-681-8651; 1-800-936-6033 (toll-free)
Monday to Friday, 9 a.m. to 4 p.m.