

Connections

Linking a community of dementia support



Advancing knowledge in a dementia-friendly way

“Everybody has a story to tell,” says Dr. Gloria Puurveen, a researcher at the University of British Columbia. “It’s up to us to help them tell it.” Dr. Puurveen studies how people can live well through the progression of the disease, up to and including their end-of-life decisions. She was inspired by this work to explore how research itself could be dementia friendly.

To ensure a positive experience for participants, we must approach research with the same person-centred lens that we advocate for in care settings. Participants can contribute in meaningful ways, and researchers can reflect on how the lived experiences of people affected by dementia are represented and acknowledged.

“Dementia-friendly research dovetails with principles of ethical research,” Dr. Puurveen says. It can mean anything from how research questions are formulated to ensuring consent forms are simple and don’t require a high degree of health or research literacy. “It means always remembering that people affected by dementia are the heart of the research.”



Dr. Gloria Puurveen

Get involved

Find out more about dementia research in B.C.: alzbc.org/research-in-bc

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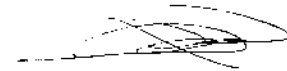
Furthering our understanding

Welcome to *Connections*, our newsletter for people affected by or concerned about Alzheimer's disease and other dementias. Summer is when dementia experts and researchers come together for annual events like Alzheimer's Disease International, the Alzheimer Association International Conference, or the University of British Columbia (UBC)'s Alzheimer Update. It is a great time to talk about how we support research.

Our vision is for a world without dementia. Until that day comes, our more immediate vision is for a dementia-friendly province. We support research to help achieve both of these visions, through the Alzheimer Society Research Program and the Ralph Fisher and Alzheimer Society of B.C. Professorship of Alzheimer Disease Research at UBC. We also support researchers to develop dementia-friendly methods.

In this issue, meet a caregiver who participated in research and a volunteer raising awareness. Learn how to prepare for challenges along the dementia journey. Read about our upcoming *Climb for Alzheimer's*, as the UBC's Dr. Teresa Liu-Ambrose talks about the importance of fitness.

Want to help us achieve our vision? Share *Connections* with someone in your life. Motivate them to find meaningful ways to help us build a dementia-friendly B.C. Each issue of *Connections* is an opportunity to spread knowledge and grow our community of care.

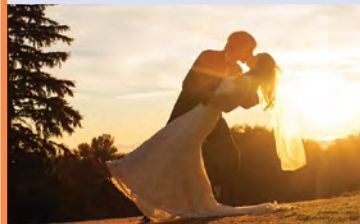


Maria Howard MBA, CCRC
Chief Executive Officer
Alzheimer Society of B.C.

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

Caregiver tips: being prepared

Emergencies can happen anytime. Instead of waiting for them to happen, it's best to prepare for emergencies before they occur. The tips below will help you prepare to respond appropriately in an emergency involving a person living with dementia.

Home safety

It's important to ensure that your home environment is safe to protect both the caregiver and person living with dementia. Here are some of the questions you might explore:

	Yes	No
Do I need to store the scatter rugs and secure the carpet to prevent falls?		
Are the stairways safe for the person I am caring for?		
Is the person living with dementia able to use the electrical appliances in the kitchen and bathroom safely?		
Should the hot water heater temperature be lowered?		
Are there any medications, cleaning substances or gardening chemicals that should be locked away?		
Do I need to be there when the person living with dementia has a cigarette? Should I hide the lighter and matches?		
Should I install locks on some of the doors? Do I need to change the position of the locks on the doors?		
Should I install safety equipment, such as grab bars, an elevated toilet seat or non-slip mat, in the bathroom?		
Does the lighting sufficiently eliminate shadows that may cause confusion?		
Are there items, such as pictures or mirrors, that may confuse the person living with dementia?		



First aid kit

A first aid kit should contain all of the essential supplies that will be useful for the person living with dementia and yourself during an emergency:

- Bottled water.
- Easy on/off clothes (a few sets).
- Copies of medical documents indicating the person's condition, along with a list of medications and supplies of medication.
- Incontinence products.
- Extra identification items for the person, such as an ID bracelet and clothing tags.
- Copies of medical documents that indicate the person's condition and current medications.
- Copies of insurance and social insurance cards.
- Waterproof bags to hold medications and documents.
- Favourite items, foods and liquid meals.
- Pillow, toy or doll to hold for comfort.
- Physician's name, address and phone numbers (including cell phone).
- Recent picture of the person living with dementia.
- Phone numbers for the First Link® Dementia Helpline (1-800-936-6033), and MedicAlert® Safely Home®.

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Emergency plan

Your ability to handle an emergency situation will be improved if you have a plan in place so you know what to do. It will also alleviate much of the stress that's associated with disasters. Things to keep in mind:

- Ensure that you have evacuation plans that address the particular needs of the person living with dementia. Connect with your nearest regional resource centre to see if help is available.
- If the person living with dementia lives in a care residence, find out about its disaster and evacuation plans.
- MedicAlert® Safely Home® is a 24-hour nationwide emergency response service for people living with dementia who wander or who have a medical emergency. Call toll-free at 1-855-581-3794.



Self-care

While preparing for an emergency is absolutely necessary for ensuring the safety of the person living with dementia and the caregiver, it's just as important to not neglect your own needs during and after an emergency.

- Take care of yourself by finding a good listener to hear your thoughts and feelings about the event.
- Take time to breathe, meditate and reflect.

Plan ahead

Responding in an emergency will be easier with advance personal planning, which will ensure the person living with dementia will have their health-care, financial and legal matters taken care of. For more information visit: alzbc.org/personal-care-planning.

The First Link® Dementia Helpline

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**.

Participating in research: A caregiver's perspective

Ellen Allen cares for her mother, Veslemoy Synnes, and has been connected with the Society since 2013. Ellen is a member of our caregiver advisory group and was invited to the Canadian Dementia Priority Setting Partnership Workshop in 2017. Funded by the Alzheimer Society Research Program (ASRP), the Canadian Dementia Priority Setting Partnership was devised as a forum for Canadians affected by the disease to provide input in order to help guide dementia research across the country.

What was the Canadian Dementia Priority Setting Partnership Workshop?

As part of the partnership, Canadians were surveyed on what they felt should be key dementia research questions; this resulted in over 8,000 questions, which were then narrowed down by a steering committee to a long list of 79 questions.

In June 2017, I took part in an all-day workshop in Toronto. A spectrum of individuals – including people with lived experience, social workers, academics, health-care providers and government officials – were asked to review the 79 questions and then distill them down to ten.

What were some of the highlights of being a participant?

I appreciated the chance to meet smart, dedicated and enthusiastic people who genuinely want to help make things better. It also reminded me that feelings I experience as a caregiver – frustration, inadequacy and guilt – are common.

What were some of the challenges you faced?

I had to overcome the concern that what I had to say may not be relevant, or that my experiences were not

representative of all caregivers. As well, I found some of the other attendees' credentials a little intimidating. However, the moderators were fantastic at making sure everyone felt their opinions mattered.



Is there anything you would have done differently?

I did my best to prepare ahead of the meeting. In hindsight, I could have spent more time gathering information from other caregivers in my community in order to share their voices as well. There were other caregivers in attendance with unique stories and we were all trying to share as many concerns as possible.

What are some words of advice you have for other caregivers?

If you are asked to participate in a research project, say yes! It may feel intimidating, but researchers genuinely want to hear our experiences and value our opinions. Even though there is a need for more research and there are systemic challenges, it is important to have a positive outlook. Caregiving can feel all-consuming, which can lead to obsessing over what is not available. Having participated in the workshop gives me hope that there are people striving to make the system better.

Learn more

Read the Canadian Dementia Priority Setting Partnership final report:

<http://www.alzbc.org/research-priorities>

Stay active and support people on the uphill journey

“Staying active is key to healthy aging,” says Dr. Teresa Liu-Ambrose, Canada Research Chair at the University of British Columbia’s Djavad Mowafaghian Centre for Brain Health and lead of the UBC Physical Activity for Precision Health Research Cluster. A great way to do this while also helping British Columbians affected by dementia is by registering for the *Climb for Alzheimer’s*, taking place on September 30.

The *Climb* is a fun, invigorating hike up the Grouse Grind® – but it’s also an opportunity to help us achieve our vision of a truly dementia-friendly B.C., where people affected by the disease are acknowledged, supported and included.

Dr. Liu-Ambrose is among the participants training for *Climb* this year, where she’ll also be talking to the crowd about her research that explores the important role fitness plays in healthy aging. Her career started out studying fall prevention for older adults, but she became fascinated by the impact of cognitive change on how people age, function and engage with others. Her interest became amplified by the experience of her uncle and other family members living with dementia.



Dr. Liu-Ambrose

“Your brain health is deeply connected to the health of your heart, your lungs and your muscles,” Dr. Liu-Ambrose says. Her work focuses on how to tailor

exercise programs for each individual’s needs, identifying how individual and environmental factors may magnify or minimize the effects of physical exercise on the brain.

“Evidence suggests physical exercise is beneficial for the brain, but like most therapeutic approaches, one size doesn’t fit all,” she says. “Some people may benefit from one type or combination of exercise or another.”

One size doesn’t fit all for exercise programs. Even if you don’t want to do the hike up the Grouse Grind®, you can still participate in the Summit Stroll. Participants of the Stroll will make their way around the walking paths and exhibits at the peak of Grouse Mountain at the pace that works best for them. Either way, you will be helping to ensure families can access vital support and education, helping advance knowledge through research and staying active in the process.

Broadly, though, we know that staying active can help us age in a healthy way. “Physical inactivity is a key risk factor that we can change,” says Dr. Liu-Ambrose. “Whether you’re doing the Grouse Grind® or taking a stroll, it’s all going towards helping your brain – and helping people across the province who are affected by the disease.”



Who will you climb for?

Register today as an individual or as a team and start fundraising by visiting climbforalzheimers.ca.

Fundraising one step at a time

On May 6, Brad Hoem ran his tenth-annual marathon, this year raising funds for the Society. “With my dad recently diagnosed with Alzheimer’s disease. I’ve learned firsthand about the challenging nature of this disease,” says Brad.

Brad’s learned a few things about fundraising, and understands how intimidating it can be. “For me, the

key was to get out early and just to ask,” Brad says. He contacted everyone he knew. “It sounds simple, but I think some people are hesitant to ask for support.”

Brad surpassed his goal, raising \$30,000 including matching donations from Macquarie Group. If you’d like to support Brad and see your donation doubled, visit his fundraising page: alzbc.org/brad-hoem.

Do your thing

Anything for Alzheimer’s makes it easy to take your unique idea and make it a fundraising success. Learn more at anythingforalzheimers.ca.

Thank you for walking, British Columbia!

Thank you for helping us raise over \$1,000,000! By participating in our annual *Investors Group Walk for Alzheimer’s* on Sunday, May 6, you’ve enabled us to provide support to people in our communities affected by dementia. Thank you to all participants, volunteers, *Walk* patrons, matching donors and sponsors!

By walking, you’ve joined our movement with thousands of people across Canada, showing no one is alone on the dementia journey and that we can truly make a dementia-friendly society a reality. Together we honoured people who have passed away from dementia, and have recognized the work that must be done to ensure help and hope for people living with the disease today.

Gifts made to the *Investors Group Walk for Alzheimer’s* contribute to vital Alzheimer Society of B.C. support and also help enable research into the causes of and cure for dementia. To make a gift today visit walkforalzheimers.ca.

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Susan Dixon: Threads that weave us together

Susan Dixon and her sister Nancy first connected to the Alzheimer Society of Manitoba over 20 years ago, when they began sharing caregiver responsibilities for their mother Dorothy, who was living with dementia. Support calls were a rare opportunity to talk openly about what was happening.

Moving to Kamloops in 1997, she connected with the Alzheimer Society of B.C. Since then, she has been an office volunteer, event organizer, Coffee Break® host, public speaker and support caller. She's also a long-time support group facilitator both for people in the early stages of dementia and for caregivers.

Susan and her sister kept a journal; last year, Susan showed the journal to her daughter Randi, who saw a story that needed to be told.

Both Susan and Randi work in theatre – Susan as a costume designer, Randi as a writer/producer/actor

and puppeteer – and this led them to write a play about their experience. “My mother taught me to sew, and I taught Randi,” Susan says. “We’re telling my mother’s story through my eyes, watching her struggle to sew my wedding dress. With dementia, threads get broken and lost – the thread of conversation, ideas, thought. My daughter and I wonder if another thread we’ll share is dementia in our own lives.” They hope that the play will be a new way of putting a human face on the disease.



Three generations: Dorothy, Susan and Randi.

Randi's photo © Perry Johnson Photography

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

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- **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

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Are you a person living with dementia?

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