## Insight For people living with dementia

Alzheimer Society

Spring 2023



# A new season offers opportunity for positive changes

There are many ways to get active and find support this spring – including at the *IG Wealth Management Walk for Alzheimer's*, presented by Go Auto, coming up on May 28. We're excited to bring communities together while raising valuable funds to support people affected by dementia – and we hope you'll join us!

In this issue of *Insight*, we hear from our leadership editor Myrna Norman as she offers words of encouragement on finding meaningful activities to bring joy. We also introduce a couple who has benefited from the Society's webinars and who share tips for traveling safely with dementia. We're also showcasing poetry and thoughts from a community member living with the disease. Finally, we have updates on research, including what Canadians should know about the U.S. FDA's approval of the drug lecanemab. Learn what research shows about the cognitive benefits of exercise for people living with dementia and read about a researcher who launched the Choose to Move program, a fitness and social program for older adults.

Looking for ways to get active while supporting the Society? Join people across B.C. for the *IG Wealth Management Walk for Alzheimer's* on May 28. Learn more at walkforalzheimers.ca.

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## Taking control and finding comfort and joy



Myrna Norman is an advocate who often shares her expertise as someone living with the disease. She is a regular contributor to this newsletter.

Spring has sprung and we're welcomed to brighter days ahead of us. It's so joyous to watch nature! My lettuce seeds have already sprouted. Some of the bulbs outdoors are up and looking towards the sun. Even my rose bush has a beautiful bud. Do you find you have some comfort in the joy of spring? We all deserve to be happy, feel joy and have hope as our guiding light. Many of us living with Alzheimer's disease or another form of dementia are not given the possibility of hope when we get our diagnosis – but this is WRONG! Please be optimistic – things are happening around the world to offer treatment and even more.

Please spend your time looking for activities that bring peace, laughter and happiness to you. Bird watching, nature walking, doing something active, painting, learning a new language, sky diving – whatever it is, don't give up on yourself.

Unhappiness stunts. Happiness spreads. - Myrna

#### What we learned

In 2022, we asked for your feedback on our newsletters. As we prepare to relaunch them later this year, we would like to share a preview of the survey findings:

- Of the 408 respondents, 51 per cent were caregivers, 10 per cent were people living with dementia and 23 per cent were family members or friends of someone living with dementia.
- **75 per cent** reported they always or frequently read the newsletters.
- 58 per cent would like more frequent newsletters (monthly or bimonthly).

- Topics respondents were most interested in:
  - Information about living with dementia or caregiving (78 per cent)
  - Research updates (67 per cent)
  - Personal interest stories (43 per cent)
  - International perspectives (40 per cent)
  - Book suggestions/reviews (38 per cent)

Thanks to everyone who shared their input and stay tuned for changes!

### Webinars help navigate ways to travel safely

Living with dementia doesn't mean you need to stop participating in meaningful activities. Staying active is essential fuel for our spirits. In the case of Susan Walberg, a Vernon woman in the early stages of the disease, this means staying true to her passion for travel.

Susan was diagnosed with Alzheimer's disease in spring of 2022 and was introduced to the Society by her geriatric psychiatrist. Alongside her husband Garth, Susan explored the Society's website and found helpful resources on dementia, including webinars. "Webinars provided us a heads up on what to expect as the disease progresses," says Susan.

Last summer, Susan was preparing for a trip to visit her sister in Lethbridge, Alberta and turned to the Society's webinar on traveling safely with dementia for helpful tips and strategies like keeping a travel checklist, notifying the airline that someone living with dementia will be flying or writing down and bringing a list of emergency contacts. "My family was very apprehensive about me traveling on my own, but when they looked at the tips from the webinar, they felt reassured."

One suggestion Susan received was to phone ahead for special services. They learned that Garth was allowed to escort Susan through security and straight to her boarding gate. They also applied for a wheelchair for her. "I just smiled, because I wouldn't even have to walk – I just had to hold onto my purse," Susan says. Prior to her diagnosis, Susan wasn't typically an anxious traveller, but she understood that things might be different now. To keep herself grounded, she carried relaxation cue cards. "It helps with breathing or having some kind of mantra to change your focus," she says. Susan's flight was a success, and she was also thankful the Lethbridge airport was easy to navigate as she looked for her sister outside the arrival gate.

Recently, Susan and Garth visited Puerto Vallarta with their friends, carrying the travel checklist with them. "We've been before and it's a comfortable situation to be in a familiar area – that's key," says Susan. She adds that traveling with

friends makes the experience more meaningful: "We have a supportive group of friends – they can't solve your problems, but sometimes you just have to be heard and they're there to listen."



#### Learn more

- To watch the webinar on traveling safely with dementia, visit: alzbc.org/webinar-travel
- For helpful resources on traveling, visit: alzbc.org/resources-travel
- To access webinars on a host of other topics, visit: alzbc.org/ondemand

## What does the U.S. FDA approval of lecanemab mean for Canadians?



Lecanemab is a pharmaceutical drug that could potentially slow down some symptoms of early-stage Alzheimer's disease. Lecanemab is believed to reduce the amyloid plaques in the brain that are a hallmark of Alzheimer's disease.

In January 2023, following the release of early clinical trial results, the U.S. Food and Drug Administration (FDA) approved lecanemab (marketed under the name Leqembi) for use in the U.S.

#### Lecanemab trial results

The worldwide clinical trial began in March 2019 with 1,795 participants living with early-stage Alzheimer's disease, including participants from Canada. Lecanemab was administered intravenously every two weeks for 18 months.

Researchers measured participants' memory, orientation and problem solving, as well as looking at their home life, hobbies and personal care at both the start and end of the trial. Participants who were given lecanemab showed 27 per cent less cognitive decline in comparison to people given the placebo. It's currently unclear how such a finding affects the day-to-day lives of people with early-stage Alzheimer's disease, or for how long the impact persists. There are also side effects associated with lecanemab – most commonly, headaches and ARIA (amyloid related imaging abnormalities). ARIA side effects include brain swelling and brain bleeds that can be experienced as headaches, confusion, vision changes, dizziness, nausea and seizures.

Given the initial results and side effects, additional (longer) clinical trials are necessary to determine lecanemab's effectiveness and safety.

#### Lecanemab in Canada

To date, Health Canada has not approved lecanemab. Presently, the only way Canadians have access to lecanemab is if they are already participating in the ongoing clinical trial. No new participants are being accepted. It will likely be several years before anything is available to the public in Canada.

While lecanemab is not a cure, it "moves the needle" in terms of opening a door for future treatments. The Alzheimer Society of B.C. supports Health Canada's rigorous assessments of the safety and effectiveness of all drugs related to the treatment of dementia.

#### Learn more about the study

Read about the FDA's trial report from November 2022: alzbc.org/lecanemab-study

## The impact of physical activity on living with dementia



Incorporating physical activity into one's life is an essential part of cultivating good health. Studies have found that engaging in two to five hours of moderate to vigorous physical

activity weekly is associated with reduced risk of developing dementia. Research also suggests physical activity has a positive effect on the cognitive health of people already living with dementia.

Although it's not fully clear how activity has an impact on dementia, it has been suggested that it reduces cognitive decline by increasing the formation of neurons in the brain. Activity also reduces the likelihood of developing diabetes, hypertension and obesity, all of which are considered risk factors for dementia.

In addition to its cognitive benefits, physical activity has also been shown to increase opportunities for social interaction and improve sleep, mood and self-confidence. Physical activity also reduces the risk of falls by improving balance and mobility, important factors in enabling people living with dementia to live independently for longer. Care partners, too, benefit from activity: it reduces their stress and depression.

The Canadian Physical Activity Guidelines recommend adults engage in exercise for a minimum of 150 minutes per week. Activities can be spread across short sessions and can include walking, gardening, seated exercises, tai chi or yoga.

It's important to consider starting with physical activities that you find enjoyable, being mindful to take them at your own pace to avoid risk of injury. If you're starting a new activity, it's always good to check with your doctor.

#### Engaging the body and mind

As dementia progresses, a person's ability to participate in activities will change. For a list of suggested activities ranging from early to late stages of dementia, visit alzbc.org/activities.

#### Learn more!

Our recent webinar, with guest speaker Dr. Teresa Liu-Ambrose, explored the importance of physical activity in brain health. Dr. Liu-Ambrose is a physical therapist and a Canada Research Chair at the University of British Columbia, Department of Physical Therapy. She directs the Aging, Mobility and Cognitive Health Laboratory as well as Vancouver General Hospital's Falls Prevention Clinic.

To watch the webinar, visit alzbc.org/webinar-Dr-Liu-Ambrose.

### Meet the researcher: Dr. Joanie Sims-Gould



Dr. Joanie Sims-Gould

Dr. Joanie Sims-Gould is a scientist with the Active Aging research team, a Health Promotion Consultant and a Clinical Associate Professor in the Department of Family Practice at the University of

British Columbia. Her primary goal in each of these roles is to "add life to the later years."

With the Active Aging research team, one of her key accomplishments has been the design and province-wide implementation of the Choose to Move program. The free, province-wide program provides older adults with motivation and support to become more physically active and socially connected. The program involves working one-on-one with a trained activity coach who creates a tailor-made physical activity plan to meet your health and fitness goals. Currently, Joanie and her team are working on adapting the program to include more equity-deserving groups.

Joanie's interest in physical activity and social connectedness was borne out of her experiences with her grandmother, who lived with dementia. Her grandmother lived in northwestern Ontario, loved the outdoors and going for walks. However, as her dementia progressed, it became unsafe for her to walk alone. Joanie's grandparents connected with a local volunteer organization that provided respite services. Each week a companion would accompany Joanie's grandmother on a walk, whether by the lake or at the mall. Joanie believes it was one of the most important supports her grandparents received, as it contributed to her grandmother's sense of health and well-being, while offering a much-needed caregiving break for her grandfather.

Supporting her grandparents on their dementia journey has influenced Joanie's career path as an advocate for older adults. She's adamant that if the work in which she's engaged doesn't matter in the lives of her grandparents, then it's not worth doing.

#### Learn more

- For more information on Active Aging: www.activeagingrt.ca
- For more information on the Choose to Move program: www.choosetomove.ca

#### Upcoming webinar details

Join Dr. Joanie Sims-Gould for a presentation about the importance of physical activity and ways in which we can incorporate more physical activity into our daily lives, on May 24 at 2 p.m. To register, visit alzbc.org/Sims-Gould.

## Dementia around the world: Netherlands

#### The original dementia village

Hogeweyk, a village in the Netherlands, is a special kind of long-term care and home to 152 residents living in the advanced stages of dementia. This dementia village – which was the first of its kind – has stepped away from being a traditional medical care centre and created a community where people living with dementia are free to fully partake in society.

The village has only one entrance that is carefully monitored to ensure residents can wander the village without fear of becoming lost. Residents live a seemingly normal life but are actually under 24-hour care by staff. Each house accommodates up to seven residents and two caregivers. Hogeweyk is equipped with a grocery store, theatre, hair salon, post office and even multiple pubs. In reality, store workers are trained care providers disguised in street clothing to maintain the image of a typical village. The goal of this village is to keep residents active in the community, which is thought to improve their physical health, ultimately, leading to a better quality of life.



#### Poem

Oh my, my days are long

Unable to share memories of sweet days and songs.

My daily struggle with words and thoughts, frustration and sadness Who would have thought I would deal with this madness?

I look at faces and wonder who of all those folks are people I knew. My sense of humour, joy and laughter has

gone, so I'm told,

I guess I'm grateful I don't recall myself or

how I was in those days of old. I know my family at age 81 and know they support me with all that they can.

I have wonderful health and am thankful indeed,

My mind on the other hand is not up to speed.

Summer is coming and long winter days are behind

With the sun on my back, walks hand in hand

My family, my strength, will give me peace of mind.

- Maureen Craig

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- Subscribe online at alzbc.org/insight-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742

## 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.

- Email 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

## **Call the First Link® Dementia Helpline**

A confidential, province-wide support and information service for anyone with questions about dementia. Our English Helpline runs from 9 a.m. until 8 p.m., Monday to Friday. Cantonese or Mandarin and Punjabi Helplines are open from 9 a.m. to 4 p.m., Monday to Friday.

- English: 1-800-936-6033
- Punjabi: 1-833-674-5003
- Cantonese or Mandarin: 1-833-674-5007

Email supportline@alzheimerbc.org

## Are you a caregiver?

*Connections* is a quarterly print and digital publication produced by the Alzheimer Society of B.C.

To subscribe:

- Visit our website at alzbc.org/ connections-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742



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