

# Connections

Linking a community of dementia support



Even if they do.

## Stay connected this Alzheimer's Awareness Month

For many people living with dementia and their caregivers, after a diagnosis, and as the disease progresses, it can feel like people around them are changing. Stigma associated with dementia can result in people making assumptions about someone's abilities or cause them to pull away for other reasons. People may feel unsure how to include or communicate with someone living with dementia.

This January, the Alzheimer Society of B.C. is recognizing Alzheimer's Awareness Month by highlighting the experiences of people affected by

dementia to say: "Don't change. Even if they do." The aim of the awareness campaign is to inspire people to reflect on the ways they will continue to show up for the people affected by dementia in their lives.

The best thing we can do to support people affected by the disease is not change, even if they do. Throughout January, learn how you can continue to show up while adapting to the changing realities of the disease. Keep visiting. Keep calling and FaceTiming. Find new ways to stay meaningfully connected. No one should have to face the journey alone.

### Read and learn more

To learn about the campaign and discover resources to help stay connected to people in your life who are affected by the disease, visit [dontchange.ca](https://dontchange.ca).

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# Diagnosis is often the first step towards support

January is Alzheimer’s Awareness Month, a time when we work to change the conversation about dementia and challenge stigma by sharing the stories of people affected by the disease in communities across the province. We are so grateful to the people who have stood up and raised their voices, especially at a time when so many people living with dementia and their caregivers continue to face stigma and discrimination. While each journey is unique, there are often similarities, including around the experience of diagnosis, which is the focus of the information pages in this issue.

We break down the latest findings in Alzheimer’s Disease International’s annual World Alzheimer Report, which focussed this year on the process of diagnosis. People around the world who are seeking a dementia diagnosis often face long wait times and stigma of all kinds, including from within their respective health-care systems, further complicating an already difficult journey.

We also feature an interview with Awareness Month spokesperson Charlene Allen, a caregiver who found

comfort in expressing herself through writing, as well as details on our upcoming *Breakfast to Remember* fundraiser, slated to take place virtually this March. Finally, as we start a new year of new possibilities, we’re excited to share our latest volunteer roles. All positions have brain health benefits and provide excellent opportunities to give back to your community and show people affected by dementia they’re not alone.

If you have questions or concerns about dementia, or would like support accessing services, please contact us. The easiest way to do so is by calling the First Link® Dementia Helpline where you can register or learn more about our programs and services, with options to connect to both virtual and in-person education and support.



Jen Lyle  
Chief Executive Officer  
Alzheimer Society of B.C.



**First Link®**  
DEMENTIA HELPLINE

## Questions about dementia or memory loss?

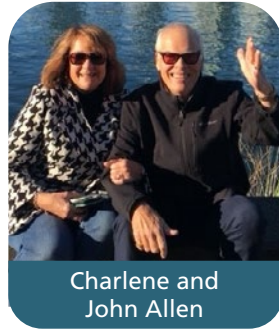
English: 1-800-936-6033  
Cantonese or Mandarin: 1-833-674-5007  
Punjabi: 1-833-674-5003

English: Monday to Friday, 9 a.m. to 8 p.m.  
Cantonese or Mandarin and Punjabi: 9 a.m. to 4 p.m.



# Staying positive through journaling

*Charlene Allen of New Westminster, B.C. is sharing her caregiving journey through journaling. Charlene's husband, John, was diagnosed with dementia six years ago.*



Charlene first noticed changes in her husband, John, when he became confused about house keys and started misplacing things around their home.

“At first, the doctor said, ‘Many people in their 60s forget things,’” said Charlene.

These incidents continued, particularly with navigation, which was something John was very good at, and Charlene saw a red flag. John took cognitive tests and was diagnosed with Alzheimer’s disease.

When Charlene was informed about John’s diagnosis, she recalled feeling frightened but also somewhat relieved because they had found the real cause of the symptoms, and they could start to make plans to prepare for the future.

The best way to support people affected by dementia is to maintain connections and show them that they’re not alone. The couple has been overwhelmed with care and encouragement from friends and family.

“I strongly believe that I did the right thing by telling everybody,” Charlene said, adding that communicating with others about her husband’s situation was important to her, so they knew what to expect. “I wasn’t feeling embarrassed. Friends and family showed more support, and it does bring out that kinder side of people when they understand the

reason for a person saying inappropriate things or other changing behaviours.”

The loss of in-person support due to COVID-19 restrictions was difficult for John and Charlene. When the couple needed to stay home, John would often walk away from video calls. Day programs were also on hiatus. Now that restrictions have been lifted, they have periodic support from home care workers and a small group of friends John interacts with.

Charlene first connected with the Alzheimer Society of B.C. through an educational workshop. She also attended webinars and met a few caregivers and since then, they have been supporting one another.

Charlene started sharing her caregiving experience with the people around her through journaling as a way for her to cope, stay positive, encourage others on the dementia journey and be encouraged herself.

“It is cathartic to write,” Charlene said. “This whole situation is terrible, and I know the disease is fatal. For the most part, I try to stay as positive as possible.” Here’s an excerpt from Charlene’s journal:

“I have received literally hundreds of beautiful cards, gifts, texts and other acts of kindness that admittedly most of us think but rarely express. I am touched daily by the hospital workers who smile and thank me for coming, the neighbours who stop to inquire about my husband and friends who call to tell me once again that we are in their daily prayers.”

Charlene is one of many British Columbians sharing their stories as part of Alzheimer’s Awareness Month this January. To learn more about the campaign, visit [alzbc.org/AAM2022](https://alzbc.org/AAM2022)

# Diagnosis: Takeaways from the Alzheimer’s Disease International World Alzheimer Report 2021

Every year Alzheimer’s Disease International (ADI), an umbrella organization of more than 100 Alzheimer Societies around the world, releases an in-depth report on a specific topic analyzed through a global lens. This year’s report, led by a team at McGill University, is entitled “Journey through the diagnosis of dementia,” and focusses on the experiences and best practices of dementia diagnosis through the lens of people living with dementia, caregivers, clinicians, researchers and academics.

## A global snapshot of dementia

The report estimates that there are over 55 million people living with dementia worldwide, and forecasts that this number will reach 78 million by 2030. Importantly, ADI also estimates that globally as many as 75 per cent of people living with dementia have not yet been diagnosed, with numbers estimated to be as high as 90 per cent in some low- and middle-income countries, where stigma and lack of awareness remain significant barriers to diagnosis.

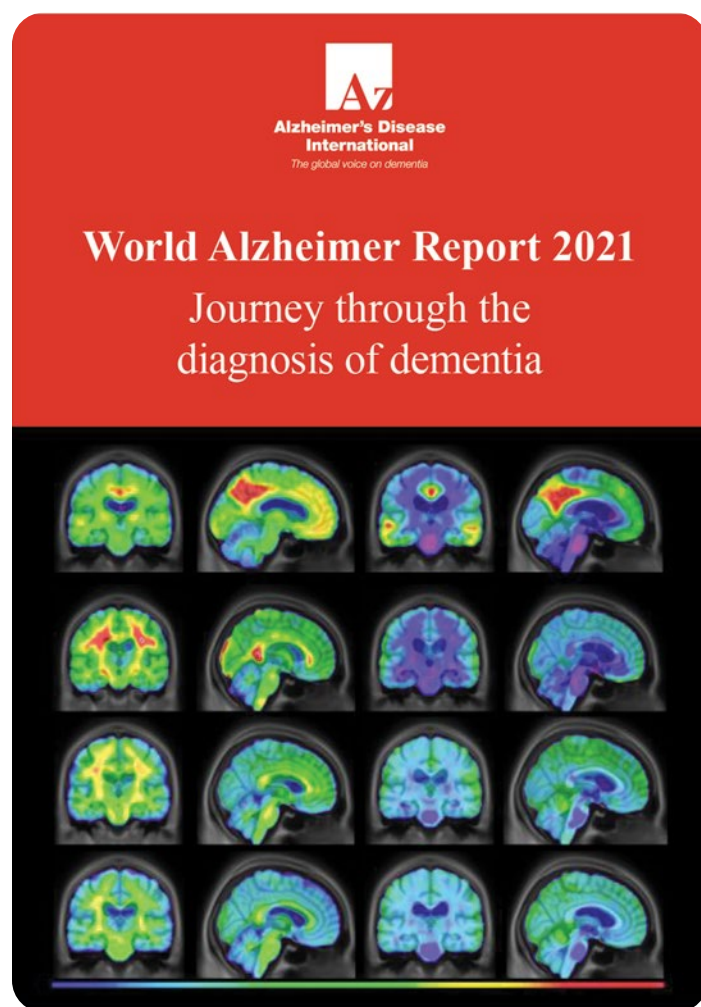
## Experiences of diagnosis

As part of the report, the authors issued an online survey to people living with dementia, caregivers and clinicians across the globe to better understand their experiences of diagnosis.

People living with dementia and caregivers identified that key barriers to receiving a dementia diagnosis were lack of access to trained physicians (47 per cent), fear of diagnosis (46 per cent) and cost (34 per cent). Only 45 per cent felt they were provided with enough

information when they were diagnosed, while many spoke of a lack of information at the point of diagnosis about specific types of dementia, the progression and available supports. Many said it took a long time to receive a diagnosis.

Clinicians were also asked about barriers they faced in providing a dementia diagnosis. They identified lack of access to specialized diagnostic tests (38 per cent),



lack of knowledge in making a diagnosis (37 per cent) and the belief that nothing could be done, thus making a diagnosis futile (33 per cent). Editor's note: This last point is a myth. Through our webinars and education series, the Alzheimer Society of B.C. emphasizes that the sooner someone can receive a diagnosis, the better, as accessing support and planning along the dementia journey is critical. These responses from clinicians highlight the continuing need for education and awareness to address stigma and remove a key barrier to diagnosis.

Clinicians also pointed out the impact of COVID-19 on access to diagnosis, with 83 per cent stating they believe the pandemic has delayed access to assessments for cognitive decline.

### Barriers to diagnosis for racially-diverse Canadians

The report also explores the experiences of Indigenous people and other racially-diverse Canadians when accessing a dementia diagnosis in Canada. Existing studies suggest that racially-diverse communities have a higher prevalence of dementia, and often face unique barriers, such as a lack of culturally-safe care and language supports. The report describes cultural barriers including increased fear or shame and stigma among family and communities, structural barriers such as systemic discrimination or difficulty accessing services in one's own language.

The report recommends creating cognitive assessment tests that are tailored to different cultural and language groups. The tests should also be validated (tested with different groups) to ensure that they are accurate at diagnosing dementia across diverse cultural groups. Importantly, rather than a one-size-fits-all approach,

the report recommends that all our approaches to dementia reflect the diversity seen across Canada.

Overall, the report provides a comprehensive look at diagnosis, including key recommendations to ensure more people around the world can be properly diagnosed and receive support as early as possible.

#### To learn more

To read the full report, visit [alzbc.org/ADI2021](https://alzbc.org/ADI2021).

To watch the webinar launch of the report, visit [alzbc.org/ADIwebinar](https://alzbc.org/ADIwebinar).

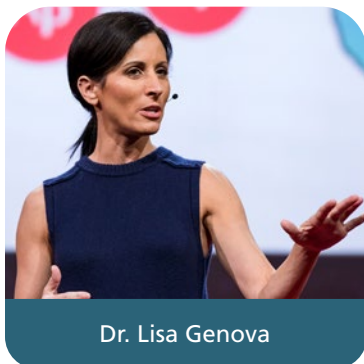
We also encourage you to read this quarter's edition of *Insight*, where we share quotes from our early-stage support group members on their own experiences of diagnosis.



# Breakfast to Remember set for March

## Neuroscientist and acclaimed author of *Still Alice* to speak at this year's event

This winter, people across B.C. will take action to support people affected by dementia at



Dr. Lisa Genova

*Breakfast to Remember*, a virtual fundraising breakfast event featuring a keynote address and live Q&A with Dr. Lisa Genova, neuroscientist, speaker and #1 international and *New York Times* bestselling author of *Still Alice*.

Lisa holds a Ph.D. in Neuroscience from Harvard University and has captured a special place in contemporary fiction, writing stories that are equally inspired by neuroscience and the human spirit. Her first TED talk on brain health has been viewed over five million times, with her most recent talk garnering more than one million in its first month alone.

“We’re thrilled to welcome such an inspiring and accomplished speaker to our breakfast,” said Jen Lyle, CEO of the Alzheimer Society of B.C. “Lisa Genova understands all the ways dementia can change a person’s life – as well as the neuroscience behind the changes and the actions we can all take now to improve brain health. With the number of people living with dementia on the rise, there is no better time to come together and learn while helping provide critical support needed today.”

Annual *Breakfast to Remember* events bring B.C. business leaders together to hear inspiring talks and help raise critical funds for Alzheimer Society of B.C. programs and services, including increased virtual programming. Funds raised also enable dementia research in B.C. Following the success of a sold out

inaugural virtual *Breakfast to Remember* in 2021, everyone in B.C. will once again have the opportunity to join the fundraiser to help show people affected by dementia they’re not alone.

We hope to once again see supporters and partners join us from all corners of the province to help ensure vital support and education is available for everyone on the dementia journey.

*Breakfast to Remember* is set for Thursday, March 3, from 7:30 – 9 a.m. Tickets include access to an exclusive research event, featuring a live discussion on the latest dementia research. To learn more, or to purchase tickets, visit [BreakfastToRemember.ca](https://BreakfastToRemember.ca).

### It's been a busy fundraising season!

Our 10th annual *Climb for Alzheimer's* took place virtually across British Columbia from September 1 - 21 when participants hiked, fundraised and showed people living with dementia that they are not alone. This year's event was a true hybrid, with enthusiastic climbers joining us at the Grouse Grind and helping to raise over \$90,000! The *Telethon for Alzheimer's*, broadcast entirely in Cantonese, took place on November 13 in partnership with Fairchild Media Group and raised over \$172,000! All funds raised will help ensure people living with dementia and their families are acknowledged, supported and included. Thank you to all the donors, volunteers, sponsors and media partners who made these 2021 events a huge success!

# A family's unconditional care on the dementia journey



Mary Gretsing

*Laura Doan is an associate professor at Thompson Rivers University whose mother, Mary Gretsing, has lived with Alzheimer's disease since 2017. Mary and her husband Bob are retired teachers who were dedicated to serving others in their community.*

*This story was written by Lisa Coriale, a long-time Kamloops resident and writer for the Kamloops Self-Advocate, a newsletter for people with diverse abilities. It is used with her permission.*

Mary Gretsing's family has come together to love and care for her, and give her as fulfilling a life as possible. Their example shows that love and patience are needed when caring for someone living with dementia. Mary was diagnosed with mild cognitive impairment in 2015. In 2017 she was diagnosed with Alzheimer's disease after recognizing early signs of confusion, forgetfulness and a lessening of her ability to take care of herself. Since then, she has lost her short-term memory and long-term memory, as well as the ability to communicate in the same way verbally. She now communicates through song and sounds.

"My mom is different now, but she is still my mom," says Laura, who encourages her to communicate through gestures as well. "My mom never gave up on me and I am not going to give up on my mom. My mom still loves people. She especially loves children and animals. She loves music. She loves to laugh. She wants to help and she cares deeply."

The example Mary modeled – through her advocacy for addiction services, teaching children who experienced trauma and putting into action all the things she was passionate about – taught her family to care unconditionally. Mary's husband Bob is her primary caregiver, which allows her to live at home. Laura and her siblings Rob Gretsing and Elizabeth Macrae also spend one-on-one time with her weekly. They receive support from their church community, a home care worker, who stops by weekly, and the Alzheimer Society of B.C., where Bob has attended a monthly support group for caregivers.

"My dad is probably the most patient man I know," Laura says. "Being patient with a person living with Alzheimer's is important. The changes that are happening in them are not within their control, so it is us who need to adapt."

Some of Mary's favourite activities are going for daily walks, drives and visiting her children and five grandchildren. They try to accommodate her needs as a family and give her as many options as possible. Many of their family activities have been adapted as Mary's abilities have changed. At this stage, she is slow to learn new things, so they ensure she is not expected to.

"While Mom no longer has access to her past and cannot plan for the future, she can still enjoy the now, so we should make the now count," Laura says.

Laura's advice for others caring for someone living with dementia is to communicate beyond words, be aware of changes and remain patient.

"We focus on what she can do, not on what she cannot do," Laura adds.

## The brain health benefits of volunteering

Our volunteer opportunities offer a variety of experiences associated with brain health benefits. The *IG Wealth Management Walk for Alzheimer's*, is currently seeking committee members across the province. Learn more at [alzbc.org/volunteer](http://alzbc.org/volunteer).

Volunteer position	Brain health benefits			
	Physical activity	Social engagement	Mentally stimulating	Learning
<b>Minds in Motion® assistant</b> Help facilitate a fitness and social program for people living with any form of early-stage dementia.				
<b>Support group facilitator</b> Create a safe and open space for people affected by dementia to share concerns and solutions.				
<b>Administrative assistant</b> Assist with admin duties to help staff deliver high-quality, personalized and reliable support.				
<b>Leadership Group of People Living with Dementia/ Leadership Group of Caregivers member</b> Join a group of passionate advocates who draw from lived experience to advise and inform the Society's work.				
<b>Event committee members</b> Join our dedicated and well-organized team of volunteer leaders to help plan the 2022 <i>IG Wealth Management Walk for Alzheimer's</i> .				
<b>Day-of-event volunteer</b> Interact with guests and support operations as a member of the team onsite during Society events.				

### 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.

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- Online at [alzbc.org/connections-newsletter](http://alzbc.org/connections-newsletter)
- Email [newsletter@alzheimerbcc.org](mailto:newsletter@alzheimerbcc.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?

We also publish *Insight*, a publication for people living with dementia or cognitive impairment. For more information, visit [alzbc.org/insight-newsletter](http://alzbc.org/insight-newsletter).



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