



Even if I do.

Challenging stigma through awareness

January is Alzheimer's Awareness Month, an opportunity to break down the persistent stigma surrounding dementia and educate the public by sharing the unique experiences of people affected by the disease. It is also an important time to show people living with dementia that they're not alone. At the Alzheimer Society of B.C., the month marks the launch of the second year of our "Don't change" awareness campaign. The campaign aims to inspire British Columbians to continue showing up for the people living with dementia in their lives.

This issue also covers exciting work from a group of UBC researchers and dedicated people living with dementia who are sharing their expertise on how

to confront stigma. Learn more about the "Flipping stigma on its ear" toolkit inside.

The information section focuses on Alzheimer's Disease International's latest World Alzheimer Report, which explores how receiving a dementia diagnosis is experienced differently around the world. Alongside these findings, we share comments about the process of being diagnosed with dementia right here in B.C., from members of our early-stage support groups.

Finally, Myrna Norman interviews a caregiver and long-time advocate for people living with dementia about her experience supporting her husband with the disease.

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Tip table: Tips for living well at home from Myrna

- If you live on your own, cook your meals in the microwave so you do not need to worry about turning it off. The microwave keeps dinging at you until you open the door.
- If you get distracted while trying to drive with others in the car, pull over and let someone else drive.
- Keep a basket on your counter for your keys, glasses, purse – any of the things you need regularly.
- Put a whiteboard in a prominent place and write down appointment dates and times. Writing seems to reinforce our memories.
- Have someone take you for a walk every day if you can; otherwise

sit somewhere you can inhale the clean air and bright colours of your environment.

- If you get stuck with people's names, just use any name. At least you are making the effort!

Myrna Norman is a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia and a regular contributor to this newsletter. On page 4 of this issue, Myrna interviews Arvie Bourgeault, a former caregiver to her husband and advocate for people affected by the disease. Do you have tips or advice about living well with dementia? Share your ideas! Check out page 8 for details on how to get in touch.

Dementia awareness around the world: USA

Just outside of San Diego, California lies Glenner Town Square, a day centre that serves 200 people living with dementia. It is unique because it is decorated to resemble a traditional town from the 1950-60 period, when most participants of its programming were young adults. This was planned. People tend to form their strongest memories between the ages of 10 to 30 years old.

Treatment at the centre is based on "reminiscence therapy." This means prompts, such as old photos and memorabilia, are used to spark long-term memories and improve the mood of people living with dementia. The village

takes reminiscence therapy one step further by creating stores, libraries, diners and salons built and furnished to resemble an authentic square from the '50s and '60s. The stores even play music corresponding to the era!

When registering participants for the program, caregivers provide information about a person's past, including their career and hobbies, so daily activities can be tailored to each individual. The centre plans to update its surroundings periodically to reflect a new time period, relevant to the current aging population. To learn more, visit: <https://glenner.org/town-square>

Spotlight on diagnosis

Every year, the organization Alzheimer's Disease International (ADI) releases a report on a different topic, using a global lens. This year, the report focused on diagnosis, and included perspectives of people living with dementia, caregivers, clinicians, researchers and academics from around the world.

Key takeaways from the report

In the report, ADI estimates that there are over 55 million people living with dementia worldwide. They estimate this will increase to 78 million people by 2030.

ADI estimates that as many as 75 per cent of people living with dementia around the world have not yet been diagnosed. They predict this could be as high as 90 per cent of people living with dementia in low- and middle-income countries, where barriers to diagnosis are greater.

Barriers to receiving a diagnosis

People living with dementia and caregivers from around the world identified key barriers to receiving a dementia diagnosis through an online survey. The key barriers identified were:

- Lack of access to trained doctors (47 per cent)
- Fear of diagnosis (46 per cent)
- Cost (34 per cent)

As well, only 46 per cent of people surveyed felt they received enough information about dementia when they were diagnosed.

The report also highlighted the added barriers faced by racially-diverse Canadians, including:

- Difficulty accessing services in their own language.
- Structural barriers, such as systemic discrimination.
- Cultural barriers, such as increased fear or shame and stigma among their family or community.
- Cognitive assessment tests that are not tailored for diverse cultural groups or languages.

The report also explored diagnosis from the clinical perspective, making key recommendations to improve the experience of diagnosis and ensure more people around the world can be properly diagnosed and receive supports as early as possible.

Learn more

To read the full report, visit alzbc.org/ADI2021

To watch the webinar launch of the report, visit alzbc.org/ADIwebinar

Support group members share their experiences of diagnosis

We asked some of our early-stage support group members to share their own experiences with diagnosis. What they said reflected some of the barriers and range of experiences shared in this year's report. Here are some of their comments:

"I knew I was experiencing changes but was performing too high on the cognitive assessment tests to receive a diagnosis. It took continuous months of advocating, and all of the tests were exhausting and overwhelming. At one point I considered giving up on getting a diagnosis but decided to keep trying. Finally, my doctor referred me a specialized centre, and since then I've felt well supported."

"I didn't face any barriers in accessing a diagnosis. I was uncertain why the assessment happened in the first place, but I was aware of my memory changes and so I was relieved to receive a diagnosis."

"I still don't have an official diagnosis because my doctor and daughter don't think anything is wrong. I've stopped advocating for myself to get a diagnosis because my doctor does not take my concerns seriously, but I proceed with my self-diagnosis and seeking supports myself."

"COVID-19 created a barrier in getting an official diagnosis because I couldn't access an additional test in a timely manner where I live. However, my care team is proceeding with a probable diagnosis, and I feel confident in this."

We'd love to hear from you!

Would you like to share your experiences with diagnosis or living with dementia? Please contact us at insight@alzheimerbc.org.



Interview: Looking back on the dementia journey from a caregiver's perspective

Myrna Norman, a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia, recently interviewed Arvie Bourgeault, a caregiver to her late husband Bob. Arvie has been dedicated to helping educate others in her Maple Ridge community about the realities of living with dementia and caregiving. Arvie has advocated for people affected by dementia through her roles with the Dementia-Friendly Task Force, Seniors' Network Table and the CEED Centre in Maple Ridge.

Can you describe yourself in three words?

I am caring, patient and creative.

What was the effect of the diagnosis on you personally?

Heartache. I felt my best friend slipping away after 57 married years together.

Where did you find or not find the support you needed?

The onset was about 15 years ago. We didn't have the help we needed in the Okanagan. Eight years ago, Bob and I moved to Maple Ridge to be near our four children. They had enrolled in Shaping the Journey: Living with dementia®, a six-week education series offered by the Alzheimer Society of B.C. I arrived for the last two sessions and that was a glimmer of hope. Many challenges followed.



Arvie Bourgeault and Myrna Norman

Did you find enough time to care for yourself?

I cared for my husband at home so out of necessity I became pretty low maintenance. He required supervision. Our children were very supportive.

In hindsight, what would you say to others currently caring for a person living with dementia?

Join any support groups available; they will give you greater insight. It will be a social outing for both of you, where you will feel welcome and not judged. Continue to push to change the health-care system in so many necessary ways.

Interview: Looking back on the dementia journey from a caregiver's perspective, continued

What strategies did you use for toileting? For bathing? For handling disturbances due to anger?

Bob was able to manage quite well until the end when he was hospitalized. My purpose was to always preserve his dignity – he was a proud man, a man of that generation. The same with bathing. I would touch up his shaving if he missed a spot. Anger: he was a mellow person by nature. I used diversion, music and change of activity to bypass any occasions of frustration.

What was the biggest hurdle you faced?

Bob losing his driver's licence. We convinced him it was gone. He actually walked to his new doctor and came home with a letter signed by the doctor saying, "I think this man could drive." This doctor had no understanding of Alzheimer's disease, and my husband was a charming and persuasive man. I felt so defeated and had to start a difficult process over again.

Tell us a humorous story that took place during the journey.

We were returning home from a sightseeing day bus trip to Victoria. He was exhausted and thought we'd gone on a long voyage. (We used to travel a lot.) I realized on the walk home from the senior's centre that he didn't know where we were. He was thinking of me as the young girl he'd first met. After I got over the shock that he didn't recognize who I currently was, he was flirting with me

and trying to convince me to come home with him! I had to laugh. I told you he was charming! I knew we were at another crossroads.

How can the medical community improve its services to those in similar situations?

When we seek a diagnosis, they should treat caregivers with respect and listen to us and our knowledge of the person's behaviour. We had been married 59 years. I think I recognized the changes in his behaviour.

They should issue a coloured ID bracelet for people living with dementia when they are admitted to hospital, so any staff member would know they require different care. In my experience, staff members often don't respond to a call bell. I saw Bob suffer neglect until I arrived on site.

Can you name three positives as a result on your journey?

1. I value my own good health. It truly is your wealth.
2. I learned to be more keenly aware of the present, every single day.
3. I have worked hard to encourage my children, grandchildren and great-grandchildren to value each other and the love we share, and to tell each other so.

New resources aim to empower people living with dementia

Members of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia and others living with dementia are participating in a study aimed at taking action to address stigma and discrimination. This action group has created a toolkit of strategies and resources to help people living with dementia avoid being bystanders and act with confidence when confronted with stigma in their personal lives. They aim to educate and create social change.

The "Flipping stigma on its ear" toolkit website features audio clips of the group members, all of whom live with a form of dementia.

"You are hearing directly from them about their experiences in the community," said Jim Mann, a co-investigator of the study, along with researchers from the University of British Columbia. "You are hearing the questions and the solutions they have developed."

The website is being built in phases. The first phase shared resources tailored for people living with dementia, and the next phase, expected in early 2022, will be directed to health and social care providers. Action group members have identified educating this sector as a priority to help address stigma and discrimination.



Jim Mann

"It is a valuable tool for everyone to hear the first-person account of what it's like to live with dementia," says Jim, who also lives with dementia. "These members are talking about living well."

Access the toolkit, and future resources as the research continues, at flippingstigma.com.



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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?

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To subscribe:

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- Call 604-681-6530 or toll-free 1-800-667-3742



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