Insight

Alzheimer Society

For people living with dementia

alzheimerbc.org



Changing the experience

The Alzheimer Society of B.C. is committed to changing the experience of people affected by dementia, ensuring that they have the confidence and skills to live the best life possible.

First Link® dementia support is the Alzheimer Society of B.C.'s suite of programs and services designed to help people affected by dementia. First Link® helps people living with dementia to better understand the diagnosis and become equipped to cope with the changes to come.

In this issue of *Insight*, we introduce Mario Gregorio, our new Leadership Editor, who passionately advocates for better support for people living with dementia. We will share exciting news about the recently released national dementia strategy and hear from a person living with dementia who receives support through First Link® dementia support. Finally, we'll hear how volunteering with First Link® helps a person living with dementia stay connected to and engaged in their community.

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Greetings from our Leadership Editor



Mario Gregorio with
Federal Minister of Health,
the Honourable Ginette Petitpas Taylor.

When I was first diagnosed with dementia 11 years ago, I found myself afraid of the future, ashamed that I'd brought this disease into my family and – because of self-imposed withdrawal – alone. Despite billions of dollars spent looking for a magic pill, there is still no cure and stigma about the disease lingers in our culture.

Sometimes it feels like that stigma overwhelms the efforts to dispel the myths and misconceptions of the disease – but I want you to know that everyone can find their own way to speak up.

One way that I've chosen is by participating in Canada's National Dementia Conference, held in Ottawa in May 2018, and as part of an advisory committee with the Alzheimer Society of Canada.

The conference brought together a diverse group to identify challenges related to dementia, discuss opportunities for collaboration and share ideas for a national strategy. It was heartwarming to hear the applause of other participants as we each grabbed the microphone and

shared our experiences, frustrations and our hopes for the future of dementia care.

The conference was a key step in developing Canada's national dementia strategy, which was released on June 17, 2019.

After reading the strategy a few times, I created my own acronym to help me remember the goals of the report, AWE:

- Awareness
- Wiping out stigma
- Education

At the conclusion of the conference in May 2018, the Canadian Minister of Health, the Honourable Ginette Petitpas Taylor addressed the participants. She encouraged us all to "dream big." We have to think big and dream big if we want to change the experience of dementia for all people in B.C. and across Canada.

Mario Gregorio B.C. Leadership Group of People Living with Dementia

Become an advocate

The national dementia strategy would never have been possible without the work of dementia advocates across the country. The Alzheimer Society of B.C. will continue to advocate for an action plan to translate these goals into measurable progress. If you want to join us, please visit alzbc.org/advocate.

Canada's national dementia strategy



On June 17, the federal government announced A Dementia Strategy for Canada: Together We Aspire, Canada's first national dementia strategy.

How did the strategy happen?

With this strategy, Canada joins 31 other countries committed to making dementia a national priority. A result of years of tireless work by advocates across the country, this is an important step forward for all Canadians affected by dementia.

In May 2018, the National Dementia Conference took place in Ottawa. Policy makers, people living with dementia, caregivers and other stakeholders shared their experiences to inform the national strategy. This group included Alzheimer Society of B.C. CEO Maria Howard and Myrna Norman, Mario Gregorio and Jim Mann from the Society's Leadership Group of People Living with Dementia.

"A national dementia strategy is important in helping to increase understanding of the disease, reduce stigma and inform people how to maintain their brain health."

– Jim Mann, dementia advocate

What is the strategy trying to achieve?

The strategy's vision is a Canada where all people living with dementia and caregivers are valued and supported; quality of life is prioritized; and dementia is prevented, well understood and effectively treated. To achieve this vision, the strategy outlines three national objectives:

- 1) **Prevent dementia:** Supporting research into preventing dementia as well as environments that encourage healthy living.
- 2) Advance therapies and find a cure:
 Increasing the amount of dementia research and ensuring that research is patient-oriented and includes people affected by dementia in the process.
- 3) Improve the quality of life of people living with dementia and caregivers: Reducing stigma, encouraging dementia-friendly communities and accessible and equitable care.

What comes next?

This is an exciting and significant milestone for Canadians living with dementia. In the coming months, the federal government will publish an implementation plan outlining the concrete ways it intends to accomplish these goals.

Learn more

To read Canada's full national dementia strategy, visit: alzbc.org/full-nds

Making every moment count



Jim Mitchell is a people person who likes to live life to the fullest. Originally from England, Jim immigrated to Canada in 1974 with his wife Margaret and their two small children. Today, Jim lives at home in Kamloops where he enjoys various activities such as painting in oils and acrylics, fishing, travelling and spending quality time with his family.

Recently, Jim shared his experience of Minds in Motion®, a social and fitness program for people in the early stages of dementia.

When were you diagnosed with dementia?

I was diagnosed with dementia about a year and a half ago. I noticed I was getting confused about things. It was difficult for me to use the telephone and make decisions over the phone, especially if it was to do with anything technical or financial. I'm a retired electronics technician and worked as a service manager for a major service depot. When I started to lose my ability to do things with electronics, it was very frustrating. When I went to the doctor, I was tested and learned I was in the early stages of the disease.

How did you get connected to the Society?

The doctor recommended I get in contact with the Society to see if there were things I could get involved with – and that's how I was invited to attend Minds in Motion®.

How has attending Minds in Motion® affected your day-to-day life?

I have been attending Minds in Motion® for a year now. It gives me an opportunity to interact with other people living with dementia. I hope they introduce this

program across Canada because it will benefit others tremendously.

What do you enjoy most about Minds in Motion®?

The exercise part of the program led by the fitness instructor is brilliant. I like to participate, so that if the instructor loses count during the exercises, I can jump in and remind her. She loves that.

We also have brain exercises where we have 20-question quizzes and split up into teams. We all really enjoy that. A lot of the time I put together quizzes and brain teasers so I get to lead the activity and it works out just great. It gives Corrina, our Minds in Motion® Coordinator, a bit of a break. Last Christmas I gave everybody a sheet with pictures of Christmas carols, and everyone had to figure out which carol it was by looking at the picture.

This past week, we made race horses. We used all sorts of materials such as wool, socks and toilet plungers – we had a lot of fun checking those out. We made horse's heads out of all those bits and pieces and then we raced them across the gymnasium using the throw of dice to move ahead on a grid. Sometimes, we

have our coffee break after the exercises and sit around the table and share things about ourselves. It's wonderful! It's something we look forward to. It gives you something to think about.

What would you say to someone who has recently been diagnosed with dementia? I would say get involved with something like Minds in Motion® and give it a chance. The more people understand dementia, the better. Many people are surprised when I openly share with them I live with dementia. You still have to carry on and make the most of life.

I like to know that every day, whoever I meet, they're going to be smiling and laughing before we part company. That's

Learn more

Minds in Motion® is a social and fitness program available as part of First Link® dementia support. It is open to people in the early stages of dementia to attend with a care partner. Read more about the program: alzbc.org/mim

what I like to do. I just be myself. We all have our ups and downs, but I try to make the most of every situation, keep on smiling and try to make each day as pleasant as I can.

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Learn more: Connect to First Link® dementia support by calling the First Link® Dementia Helpline at 1-800-936-6033 or visiting a resource centre near you: alzbc.org/help-near-you

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Peter Wynn is helping others on their journey



Three months after he was diagnosed with Mild Cognitive Impairment (MCI), Peter Wynn and his wife Sylvia Bergen chose to retire and move to Penticton from the Lower Mainland to be closer to their family. It was a hard decision to make and after 30 years with a career that gave him a sense of purpose and helped him feel valued, Peter found himself looking for something new that would be meaningful. He found that something when he connected to the Alzheimer Society of B.C., joining a support group and becoming a volunteer at the South Okanagan and Similkameen Resource Centre.

Reaching out to the Society in these two ways – getting support and getting involved – has been very beneficial for Peter. It's given him a better perspective on his diagnosis. "I didn't have a clue about dementia," he says. "Some people are lost and don't know what comes next – but coming to the Society can help you learn about the disease."

Support groups for people in the early stages of dementia are just one of the many options for people affected by the disease offered as part of First Link® dementia support. Peter meets with his group once a month. "I tend to sit back and listen to my fellow group members; I listen for situations that my wife and I have dealt with, and then offer my experience – because we've been through the same thing."

Peter's support group has helped him understand that the disease has its medical complications, but the impact goes beyond that. "It also has an effect on your social life – it's different for everyone."

The impact on your social life is why staying engaged with your community

can be so vital, and why volunteering has also been such an important experience for Peter. With 60 per cent of people living with dementia in the community rather than in long-term care, staying engaged is vital to preventing feelings of isolation.

Peter volunteers one morning every week at the resource centre, where he answers phones, takes messages and greets people coming in for support. "Peter helps to add a warm and welcoming face to the Society. His compassion and connection with others creates a safe and inviting atmosphere for guests in our Early Stage Support Group," says Mary Beth Rutherford, Support and Education Coordinator for the region. "Peter approaches his role with a great deal of professionalism. He is open about his experience and looks to help others on their journey."

For Peter, volunteering offers a sense of inclusion and camaraderie, as well as an opportunity to keep his mind actively engaged in new and challenging tasks; all things that are critical to healthy living. Peter says, "I like knowing there are more active volunteers than the ones I see on a

regular basis. They are out there and it's nice when the team gets together for a special event."

"I want others to understand how important it is to seek help if you're noticing changes in yourself or in a loved one. Contact your doctor or convince your friend to contact a doctor or your local Alzheimer Society. Go get the info that can help you."

You can learn a lot by attending support groups, and the social benefits of

volunteering contribute to improved mental health. As Peter says, the first step is working with health-care providers to get a diagnosis.

Want to become a volunteer?

To learn more about how you can volunteer for the Alzheimer Society of B.C., email volunteer@alzheimerbc.org.



You are not alone: The Alzheimer Society of B.C. offers support groups for people in the early stages of dementia. Find out more about local support at alzbc.org/help-near-you

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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, including people living with dementia, their caregivers, friends, family, health-care providers and the general public.

• English: 1-800-936-6033.

Punjabi: 1-833-674-5003

Cantonese or Mandarin: 1-833-674-5007

Hours: Monday to Friday, 9 a.m. to 4 p.m.

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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