

Connections

Linking a community of dementia support



Changing the experience

Receiving a diagnosis of dementia is life altering. To change the experience of dementia, the Alzheimer Society of B.C. offers First Link® dementia support, a suite of programs and services designed to help people affected by dementia.

First Link® began as a pilot program on Vancouver Island in 2007. Today, it has provincial reach, with people affected by dementia across B.C. able to call the First Link® Dementia Helpline, receive a referral from a health-care provider and access support and education to enhance their confidence and skills to live as well as possible.

First Link® clients receive regular, proactive contact from the Alzheimer Society of B.C. and we continue to

provide relevant support throughout the progression of the disease.

Learn more

We encourage anyone affected by dementia to connect with Society through First Link®. You can connect to First Link® by asking your health-care provider for a referral or by calling the First Link® Dementia Helpline:

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

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Imagine a better tomorrow with us

Welcome to the fall issue of *Connections*, the Alzheimer Society of B.C.'s publication for people affected by or concerned about dementia.

September is World Alzheimer's Month. This year we're focused on changing people's experience of the disease. In our effort to support people affected by dementia, we're always seeking ways to improve our programs and services. An evaluation of First Link® dementia support is underway, and we'd like to thank everyone who has already taken part. You are helping us help others.

In this issue, we'll hear how First Link® has helped a caregiver and meet one of our dedicated First Link® Dementia Helpline volunteers. We'll also learn about the national dementia strategy, a powerful tool to

improve the quality of life for people living with dementia across the country, and about leaving a legacy that will support other families on the journey.

It will take all of us to truly change the experience of the disease. We hope reading the stories of people connected to First Link® will inspire you to become connected to the Society, maintain your connection, or talk to others about the programs and services we offer.



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



IG Wealth Management Walk for Alzheimer's
May



Scotiabank Vancouver Half-Marathon & 5k
June



Climb for Alzheimer's
September



Charity Dinner for Alzheimer's
November



Learn more
or get involved

For more information
visit our events page:
alzbc.org/society-events

First Link[®] – a caregiver's perspective



Phil and Maxine

Maxine Albertson lives in Kamloops with her husband Phil, diagnosed with Alzheimer's disease in 2016. Maxine shared her thoughts about First Link[®] and what the new National Dementia Strategy might mean.

When did your experience with dementia begin?

We started noticing issues in 2012, the year Phil retired. We went on holiday to the Dominican Republic. I had been working long days and he had been home alone, so I hadn't noticed much difference in his behaviour. When we got there, everything was strange and different. He couldn't remember how to get to the buffet or to the bedroom. The doctor thought he might be having a stroke or an aneurysm. Over the next few years, things gradually got worse.

Early in 2016, I asked the doctor if there was anything else we could do; she suggested some memory tests. Phil went for a CT scan and within a week he was diagnosed with Alzheimer's disease.

How did you get connected to the Society?

Our doctor didn't know about First Link[®]. They gave us the diagnosis and that was it. I read a lot, so I started scanning the internet. I came across a link for the Alzheimer Society of B.C. and learned there was a Family Caregiver Series in Kamloops. I went to four sessions to learn about the disease. We received an information package that I shared with our doctor's office, so they could refer other people to First Link[®].

What do you like about First Link[®]?

We both attended the Healthy Brain session and have been attending Minds in Motion[®] for the last two

years. I really enjoy it. Phil enjoys the social aspect. I like the physical activity; it gives me one day a week where I can do more than just walk. It's also very good for us to compare stories with other caregivers and to hear how they are going through the same things. I would love if we could go everyday. It's a safe thing we can both do together.

What do you think of the new national dementia strategy?

I think it's for sure something that needs to happen. More and more of the population is aging and we need to know how to keep ourselves healthy.

What do you hope the national dementia strategy might change or accomplish for people affected by dementia?

I hope the strategy will encourage doctors to refer people to First Link[®]. The doctor gives the diagnosis, but the Society is very good at practical suggestions. It is important to not wait, and to take advantage of all the resources available.

What would you tell other people to help them understand the caregiving experience?

Every day is a new day. Don't take it personally. When you're married to somebody or have lived with them for a long time, it's so easy to take things personally when they're upset. You must take it a moment at a time and you just do the best you can. There are lots of coping mechanisms you can learn to use. It's a journey and you have to try and keep your sense of humour.

Learn more

First Link[®] dementia support is the Alzheimer Society of B.C.'s suite of programs and services for people affected by dementia. To learn more, call the First Link[®] Dementia Helpline at 1-800-936-6033.

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.

With this strategy, Canada joins 31 countries with a commitment 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.

How did the strategy happen?

The road to this strategy has been long and people affected by dementia have pushed it forward.

The *National Strategy for Alzheimer's Disease and Other Dementias Act* received Royal Assent and became an Act of Parliament on June 22, 2017. The act directed the Federal Minister of Health to develop and implement a national dementia strategy (NDS).

In May 2018, the National Dementia Conference took place in Ottawa. Policy makers, people living with dementia, caregivers and other stakeholders shared their thoughts and experiences to inform the national strategy. Among the attendees were the Alzheimer Society of B.C.'s CEO Maria Howard as well as members of the Society's B.C. Leadership Group of

People Living with Dementia and its B.C. Leadership Group of Caregivers.

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, increasing awareness about ways to lower our risk of developing dementia and supporting environments that encourage healthy living.
- 2) **Advance therapies and find a cure:** Increasing the amount of dementia research, ensuring that research is patient-oriented and includes people affected by dementia in the process and that research gets adopted clinically.
- 3) **Improve the quality of life of people living with dementia and caregivers:** Reducing stigma, encouraging dementia-friendly communities, early diagnosis, accessible and equitable care, culturally-specific support, and support for caregivers.

What is a national strategy?

A national strategy is a nation-wide framework that aims to coordinate action across all sectors and levels of government. They generally have high-level goals such as improving quality of life and increasing awareness and research. It is a powerful tool to transform care and support.

How will the strategy make a difference for Canadians affected by dementia?

The national dementia strategy is a powerful tool to improve dementia care and support, making it a necessary step for Canada. The strategy ensures that all Canadians living with dementia, their families and their caregivers have the same level of access, quality of care and services, regardless of where they live.

Proven programs and supports will be scaled up and shared across jurisdictions to benefit everyone, from people living with dementia to their caregivers and health-care providers. The plan is an exciting and significant milestone for Canadians living with dementia, their caregivers and their families.

What comes next?

In the coming months, the Public Health Agency of Canada will publish an action plan outlining concrete ways the federal government will accomplish the goals.

Much work lies ahead to ensure that the strategy brings about immediate and lasting changes for Canadians affected by dementia but, for the first time, we have a national plan with a concerted and targeted approach to increase awareness, ensure timely diagnosis and intervention and enhance care and community supports.

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 a robust and sustainable action plan that will translate these goals into measurable progress. Please join us by visiting alzbc.org/advocate.



“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



Mario Gregorio with Federal Minister of Health, the Honourable Ginette Petitpas Taylor at the National Dementia Conference.

Learn more

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



Climb for **ALZHEIMER'S**

#climbforalzheimers

Climb with us!

Join us on Sunday, September 29
as we climb the Grouse Grind®
for people living with dementia.

Money raised will help support
people facing the uphill journey
every day.

Register now at
climbforalzheimers.ca



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Leaving a legacy



Judy Christensen,
Circle of Hope donor

Judy Christensen is very familiar with the dementia journey. Her mother Shirley, who passed away in 2004, lived with frontotemporal dementia. Later, Judy's father John was diagnosed with Alzheimer's disease. He passed away in 2014.

Although the family's experience of dementia was very difficult at times, Judy found it actually brought her closer to both her parents. Described by Judy as "emotionally distant," her father was never one to say

"I love you" or share his emotions. Having dementia seemed to break down his walls and revealed a sentimental and emotional soul.

"Towards the end, my dad told me: 'All my life I've never hated and I've never loved. I know love at last.' As hard as it was, for me, dementia actually had a silver lining," she says.

Judy attended an Alzheimer Society of B.C. education session, where she learned more about dementia and gained a better understanding of what to expect throughout the progression of the disease. She also immediately joined a local caregiver support group.

Judy decided to become a Circle of Hope donor by leaving a gift to the Alzheimer Society of B.C. in her will. "Dementia is a big concern of mine. It's so prevalent, numbers are so high, and I know I'm at risk. I wanted to do this to help the next generation."

Learn more

For more information about Circle of Hope, or if you have already left a gift in your will, call 604-742-4926, email lgonczy@alzheimerbc.org or visit alzbc.org/leave-legacy.

Make a difference in your community



Apply now for volunteer committee positions for the *IG Wealth Management Walk for Alzheimer's!*

The *Walk* is the Alzheimer Society of B.C.'s biggest fundraiser and supports people affected by dementia in your community and across British Columbia. We need motivated volunteers to plan the local events. A variety of organizing committee roles are available.

To learn more visit alzbc.org/walk or call 604-681-6530.

Together, we can make memories matter!

Christy MacLean: Staying on the line

When her mother was diagnosed with dementia, Christy MacLean knew that she wanted to give her all the support she could, but Christy didn't know what resources were available. Two years later, she continues to care for her mother, but she's become a resource herself: a volunteer for the First Link® Dementia Helpline.

“Whether people are calling for general information or for support, people just need a starting point. They just need someone to talk to,” Christy says. “You can feel like you're the only one going through it when you're caring for someone living with dementia. I see a lot of parallels in caring for my mom.”

Based out of the Greater Victoria Resource Centre, the First Link® Dementia Helpline is for anyone in B.C. who affected by or concerned about dementia. It's

also for people who work with people living with dementia.

Christy was a natural, having held various roles answering calls on information lines in the past – but you don't need to be a veteran to help meet the growing need for support and education. A background in first response, social work, counselling, gerontology or health care is an asset, but not mandatory, as an extensive training program is provided.

“My sister and I spent a lot of time dealing with doctors and trying to navigate the health-care system,” Christy says. “If I had been aware of the Helpline, I would have called for help.”



Christy MacLean

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.

Questions about dementia or memory loss?



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

First Link®
YOUR LINK TO DEMENTIA SUPPORT

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

Learn more: alzbc.org/fldhl

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
- **Email** newsletter@alzheimercbc.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

Help us reduce costs by subscribing to *Connections* by email.

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.



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