

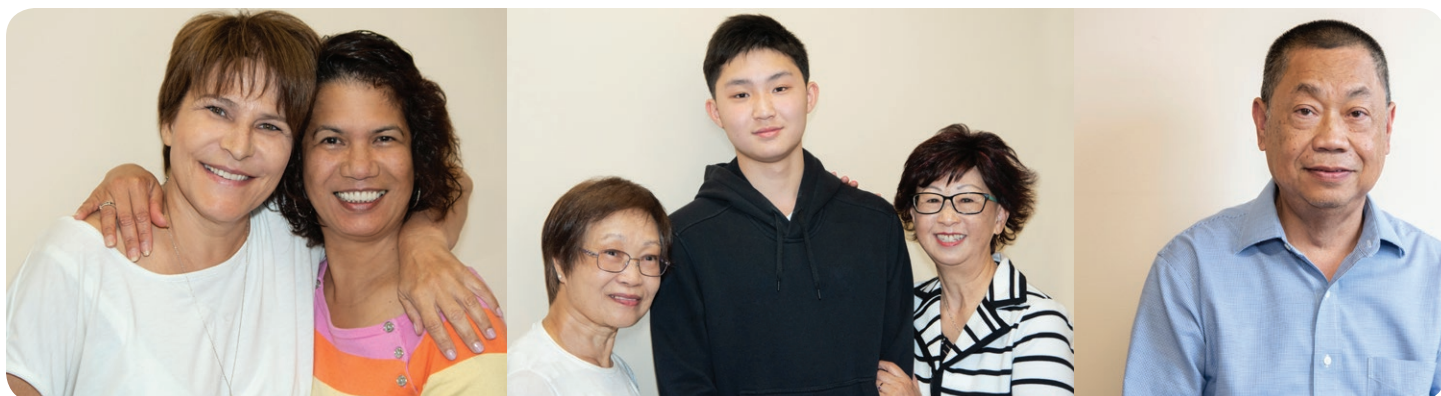
Spring 2019

Insight

Alzheimer Society
BRITISH COLUMBIA

For people living with dementia

alzheimerbc.org



A focus on dementia and human rights

We are building a dementia-friendly province. Central to this vision is the conviction that every British Columbian living with dementia is a person first and foremost, entitled to the same human rights as everyone else, as outlined in the Canadian Charter of Rights and Freedoms and the B.C. Human Rights Code. However, stigma and discrimination are huge barriers for people living with dementia, and often compromise their rights.

For this issue of *Insight*, we're focusing on how dementia and stigma affect human rights. Lynn Jackson, who is a member

of the B.C. Leadership Group for People Living with Dementia, shares a bit about her history of advocacy. Dudley Christian talks about his positive experience of inclusion. The *IG Wealth Management Walk for Alzheimer's*, which is coming up on May 5, is an important opportunity to bring attention to the rights of people living with dementia, and in this issue, you will meet Bill Blair, one of the honourees. We'll also be showcasing the Canadian Charter of Rights for People with Dementia, a key tool for people living with the disease to advocate for themselves.

In this issue:

What do human rights mean to Lynn? [Page 2](#)

The Canadian Charter of Rights for People with Dementia [Page 3](#)

Profile: Dudley Christian [Page 4](#)

Staying engaged through creativity [Page 5](#)

Participate in research to help others in your community [Page 6](#)

Walking to make change [Page 7](#)

What do human rights mean to Lynn?

When I was diagnosed with Frontotemporal Dementia, no support was readily available where I lived. Through the internet, I met people who had various forms of dementia and also didn't have any support. We decided to form an internet-based support group called Dementia Advocacy and Support Network International (DASNI). This was the beginning of my advocacy work for dementia.

In January 2002, I gave a presentation at the Alzheimer Society of Saskatchewan's provincial meeting about my diagnosis and how people could help. Every time I give this talk, or a copy of it, people invariably come back to me and say, "That is exactly what I'm feeling." Right from the beginning I knew talking about my diagnosis could be of benefit to other people. It was such a great feeling!

From there I became an advocate for people living with dementia all over the world. I have given presentations at conferences, done interviews in Japan, helped start a support group in France and been on the planning committee for the University of Waterloo's conference for people living with dementia. I also helped Lisa Genova write *Still Alice*.

I have been trying to combat the stigma of dementia mainly by talking about it. There is no cure for any of the dementias. This is scary. But if we don't talk about dementia, we will never find a cure.

Change has happened. At first, this change moved slowly but it's speeding up. We need to talk to our MLAs



and MPs. We need dementia-friendly communities.

Above all we need to continue talking about the various dementias. The people diagnosed with them are real people with feelings and needs.

It is important to advocate for people living with dementia because we need to feel that we are not alone. We the diagnosed still have the same human rights as before our diagnosis.

Lynn Jackson
B.C. Leadership Group of People Living with Dementia member

Become an advocate

By raising your voice and sharing your experience of the dementia journey, you can help other people in your community have a better experience. Learn how you can become an advocate:

<https://alzbc.org/advocate>

The Canadian Charter of Rights for People with Dementia

People living with dementia have the same human rights as every Canadian, as outlined in the Canadian Charter of Rights and Freedoms. The following charter:

- Makes sure people living with dementia know their rights.
- Empowers people living with dementia to ensure their rights are protected and respected and
- Makes sure that people and organizations that support people living with dementia know these rights.

People living with dementia have the following rights:

1. To be free of any kind of discrimination.
2. To benefit from all of Canada's civic and legal rights.
3. To participate in developing and implementing policies that affect their lives.
4. To access support so that they can live as independently as possible and be as engaged as possible in their community. This helps:
 - a. Meet physical, cognitive, social and spiritual needs,
 - b. Get involved in community and civic opportunities and
 - c. Access opportunities for lifelong learning.

5. To get the information and support they need to participate as fully as possible in decisions that



affect them, including care decisions from the point of diagnosis to palliative and end-of-life care.

6. To expect that professionals involved in their care are:

- Trained in both dementia and human rights,
- Held accountable for protecting their human rights, including the right to get the support and information they need to make decisions that are right for them,
- Treating them with respect and dignity and
- Offering equal access to appropriate treatment options as they develop health conditions other than their dementia.

7. To access effective complaint and appeal procedures when their rights are not protected or respected.

Learn more

Created by and for people living with dementia, the Canadian Charter of Rights for People with Dementia is a tool to help people advocate for themselves <http://ilivewithdementia.ca/charter>

Profile: Dudley Christian

Too often, people living with dementia experience judgment or feel excluded because there is a lack of understanding about the disease. People assume that a diagnosis of dementia means a person can no longer participate in their community. The reality is that people living with dementia are finding ways to remain actively involved. Dudley Christian is one of these extraordinary people. He was diagnosed with Posterior Cortical Atrophy in 2016. Dudley is a writer and poet who is sharing his voice and staying engaged with others.

Dudley immigrated to Canada from the Cayman Islands in the late 1960s. He worked as an engineer aboard cargo ships, sailing from port to port across the globe. When Dudley first met his wife Marilyn she was working in an Abbotsford post office. In Dudley's words, "I went to the post office after work and I said, 'I'd like to get a stamp ma'am.'" The two have been together ever since.

About eight years ago, Dudley joined the Holy Wow Poets Club. Having survived adversity growing up in the Cayman Islands, Dudley's experiences helped him create beautiful stories. He has self-published several books and even written songs. When asked why he joined the poetry club he says, "People kept saying to me, why don't you say something?"

Today, Dudley attends one of the Alzheimer Society of B.C.'s support groups for people in the early stages of dementia, a place where he can relax, get information and learn from



Dudley (left) at the 2019 Holy Wow Extravaganza at the ACT Arts Centre in Maple Ridge.



others. He also continues to participate in the poetry club, sharing his poetry and stories with others. For Dudley, the best part of being in the club is the camaraderie. "I enjoy getting together with other people and being able to talk to them one-on-one," Dudley says. "There is no questioning or no judgment."

Learn more:

For more information about the Society's early-stage support groups for people living with dementia, call the First Link® Dementia Helpline at 1-800-936-6033.

Staying engaged through creativity

The dementia journey can generate a range of thoughts and feelings. Creative hobbies like poetry can be helpful to you in managing those feelings and staying engaged. Dudley Christian shared with us a poem that he wrote in the early stages of dementia, when he observed an elderly couple at the table next to him.

She smiled and smiled

by Dudley Christian

She smiled and smiled again
'most to herself it seemed
Then marveled at the picture
She as a child had seen
Then she reached out her wizened hand
To grasp and hold his tight
The years had passed but everyone
The time was always right
Somehow, somewhere,
Some reason unbeknown
She thought only of the many years
She was loved by and loved him
Both hair of angel white wisps
Around enveloped full their face
As into her eyes his thought migrated
And back thru his he hers appreciated
Such light of love she touched him
A frail in age they struggled yet
Their only help in age of time
Each the other soundlessly
communicated

And love came back to them assist
Two who the years had seen full
Two in each other understood

Then now and always would
Her wrinkled hands grasped onto his
His gnarled bent fingers held
And caused a bond again to be
Their shared silent understanding
So many years past sixty now
Part eighty and even ninety
Their help the other did expect
And need not of outside pity
She smiled and did again
As so many years and years
Lent to him her supportive love
Her strength his ever needed
The years had wizened both
Yet never dimmed her eye's light
As his sparkled back as bright
Each so still in remembrance forever

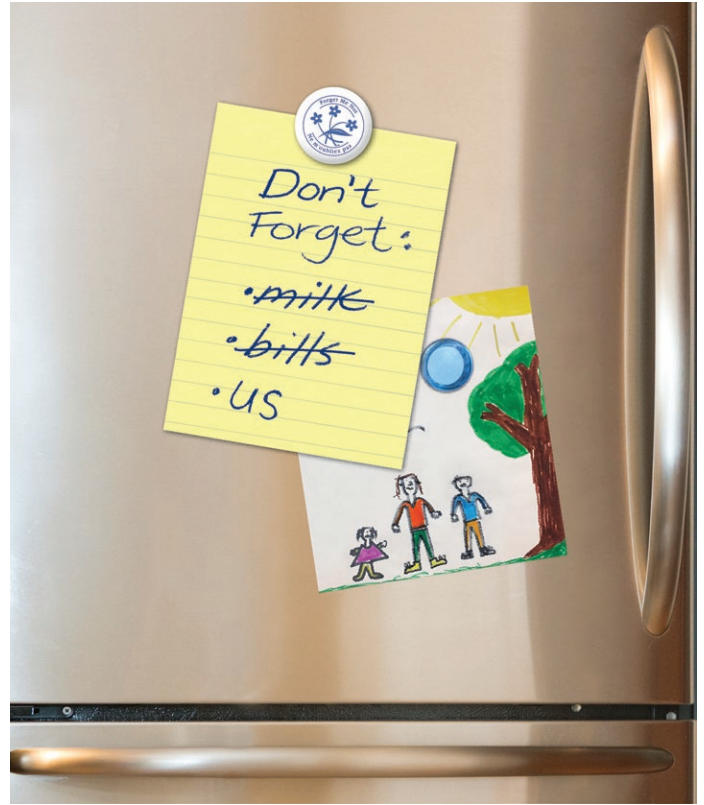
Share your creativity

We welcome artistic contributions from people living with dementia, including stories, drawings, poems and photography. If you'd like to submit, please email insight@alzheimerbc.org and we will consider your submission based on theme and space.

Participate in research to help others in your community

The Alzheimer Society of B.C. is committed to offering the highest quality services that meet the needs of the people receiving them. To ensure this, we have contracted researchers from the University of British Columbia to evaluate First Link® dementia support (including support calls, dementia education, support groups and Minds in Motion®).

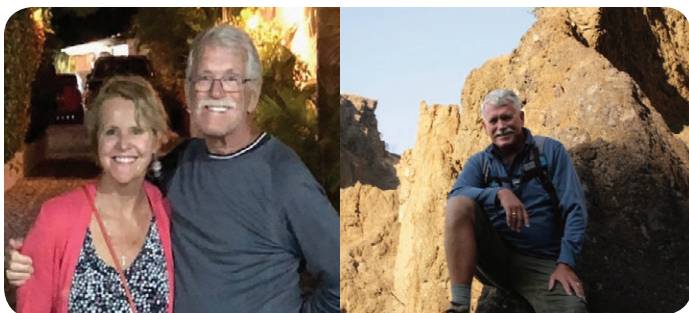
Your feedback is valuable and will help British Columbians affected by dementia. If you would like to participate to tell us how we can make First Link® services the most meaningful possible for people affected by dementia, sign up to be contacted by our external research partners by visiting:
<https://alzbc.org/FL-evaluation>



"If you are asked to participate in a research project, say yes! Researchers genuinely want to hear our experiences. ... [It] gives me hope that there are people striving to make the system better."
– Ellen Allan, First Link® client



Walking to make change



Bill Blair and his wife Wendy Nordick have faced numerous challenges since Bill was first diagnosed with Alzheimer's disease but have always maintained a philosophy to carry them through those challenges: "I don't need to be the best, but I try to be the best that I can be – including all my faults." Dedicated to advocating for people affected by dementia and helping others in their community, Bill and Wendy are this year's honouree family for the *IG Wealth Management Walk for Alzheimer's* in Kamloops, where Bill served as a judge for 26 years.

The *IG Wealth Management Walk for Alzheimer's* is an annual event that takes place in 21 communities across British Columbia. As a province-wide event, it helps increase awareness and creates an opportunity to talk openly how Alzheimer's disease and other dementias affect British Columbians.

Known for his judgment and his common sense, Bill didn't fit the stereotype of what someone living with dementia is supposed to look like. "There was skepticism," says Bill, adding that the consensus among his seven adult children was that his symptoms were the result of diet rather than dementia.

When dizziness, memory loss, lack of motivation and mood changes eventually led to a diagnosis of Alzheimer's disease, Bill and Wendy chose to be open about the new reality of their lives. Being open about their experience and learning about the disease through support groups and education provided by the Alzheimer Society of B.C. has been an important part of their journey.

"Life can be very good," says Bill, who continues to play bridge and SCUBA dive. "Whatever life has given you, you have to experience it as best you can. Go and look at the sunshine today. Go talk or listen to somebody. Be as content as you can with what you have."

Being open about our experience of the disease helps challenge the stigma that can prevent some people from receiving the support they need. As *Walk* honourees, Bill and Wendy are opening up these conversations: "We're not concerned with stigma. We want to overcome it by speaking out. I go out and tell people, 'My name's Bill. I have Alzheimer's disease.' Why not?"

Who are you walking for?

On May 5, join Bill, Wendy and thousands of British Columbians as they walk to end stigma and raise funds to support people affected by dementia. Register at <http://www.walkforalzheimers.ca>

Subscribe

If you've enjoyed this issue of *Insight* and would like to receive it regularly, please subscribe. Help us reduce our costs by choosing to receive *Insight* by email.

- Subscribe online at <https://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, 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 <https://alzbc.org/connections-newsletter>
- Call 604-681-6530 or toll-free 1-800-667-3742



Alzheimer Society of B.C.
300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

Phone: [604-681-6530](tel:604-681-6530)

Toll-free: [1-800-667-3742](tel:1-800-667-3742)

Fax: [604-669-6907](tel:604-669-6907)

Email: info@alzheimerbc.org

Web: www.alzheimerbc.org

Insight is produced by the Alzheimer Society of B.C. Articles cannot be reproduced without written permission.