

Winter 2019

Insight

Alzheimer Society
BRITISH COLUMBIA

For people living with dementia

alzheimerbc.org



“Yes. I live with dementia. Let me help you understand.”

January is Alzheimer’s Awareness Month, an opportunity to challenge the stigma experienced by people living with dementia. Throughout the month, thousands of Canadians will be standing up to share their stories to challenge negative attitudes and misconceptions. When we reduce stigma, people living with dementia can live better.

Among Canadians sharing their story is Chris Kensit from Duncan, B.C. This

issue, Chris reflects on how stigma has affected her experience of the dementia journey while advocate Jim Mann shares his thoughts on the Canadian Charter of Rights for People with Dementia, recently created by a national advisory group of people living with the disease. You can also learn about the impact of music on the experience of dementia and someone living with dementia who has helped build a better community through volunteering.

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What does the Charter mean to Jim?

Over the years since my diagnosis of Alzheimer's disease in 2007, I have read an increasing number of articles about "nothing about us, without us" and about meaningful engagement of people living with dementia. The increasing volume of people calling for this meaningful engagement is helping the message be heard and responded to in a variety of ways. The Alzheimer Society of B.C. sees the engagement of people living with the disease in a meaningful way as an essential aspect of building a dementia-friendly province.

That said, this engagement isn't limited to the Society, or any organization, researcher or volunteer. Rather, it extends to our life in a broader context.

I think it's fair to say that most if not all of us at one time or another have experienced the stigma of dementia. And we have seen or heard the stereotypes that reinforce the assumption that, once diagnosed, you immediately become incapable and incompetent, immediately going into long-term care.

One way to help challenge this stigma is to formalize our expectations and make it clear that we – as people living with dementia – have rights.

Formalizing expectations is something that advocates living with dementia from across the country took on as members of the Alzheimer Society of Canada's advisory group of people living with dementia, when we developed a Canadian Charter of Rights for People with Dementia.



The advisory group is very proud of our charter, which highlights the right to be treated with respect and dignity, as well as having the chance to access support to thrive as much as we want within our communities.

Recently, I said that the charter is not meant to sit silently on a book shelf. I think it's fair to say all of you won't let that be an option. Please take some time to consider the far-reaching impact of our charter for you and others living with dementia in and around your community. This is a proud achievement for all of us.

Jim Mann
B.C. Leadership Group of People Living with Dementia

Learn more about the charter:
Read the full Charter of Rights for People with Dementia and how you can help it make an impact by visiting:
<http://www.ilivewithdementia.ca>

Staying engaged through creativity

The dementia journey can generate a range of thoughts and feelings. Creative hobbies like music can be helpful to you in managing those feelings and staying engaged.

Before his diagnosis in 2016, Granville Johnson – honouree for the upcoming *IG Wealth Management Walk for Alzheimer's* in Prince George – was able to take part in many musical activities and wore many hats. Granville has been writing poetry and stories for most of his life; at one time, he was also a professional dancer, specializing in improvisation. While dancing, he began drumming a bit with the bands that would back him up. Slowly, he began drumming more than he danced.

Because it is so central to his day-to-day thoughts, dementia has in some ways become the focus of his musical ideas. When he is drumming, Granville is able to lose himself in the moment and find space away from the disease.

At the same time, dementia has reenergized Granville's creativity. He practices music daily now, and has discovered a new sound for himself. He uses music to express the "unreality" of his experience with dementia.

"It's important to be true to yourself," Granville says. "Find whatever it is you enjoy and focus on getting on with it. If it is something new or something you haven't practiced in a long time it will be scary, but don't be afraid to open yourself up and be vulnerable. Ask yourself: *where do I go from here?*"

To listen to Granville's song, "The Day Will Come", visit <https://alzbc.org/the-day-will-come>

- Written by Granville Johnson
- Produced by Chin Pranam Injeti and Shallom Johnson
- Lead vocal, djembe: Granville Johnson
- Backup vocals: Shallom Johnson
- Keyboard, bass, percussion: Chin Pranam Injeti
- Slide show: Granville Johnson



Personal reflection

Chris Kensit was diagnosed with dementia in August 2015, at the age of sixty-five. Living on her own in Duncan on Vancouver Island, Chris is a passionate advocate who is a member of the B.C. Leadership Group of People Living with Dementia. For Alzheimer's Awareness Month, Chris shared her experiences of the stigma she's experienced after receiving her diagnosis.

How did you react to your diagnosis?

I went home and had a good cry. I cried hard. Because my mother lived with dementia – and now my sister is living with it as well – I had intimate knowledge about what the progression of the disease and its symptoms was going to look like, and that made it incredibly difficult for me. I have a science background, and found that doing research made it a bit easier to cope. I ended up finding a lot of meaning in the works of Christine Bryden, a woman who was diagnosed with young onset dementia at the age of 46. While she's written a lot, I have gotten a lot out of her book *Dancing with Dementia*.

How have health-care providers treated you?

While my general practitioner has been incredibly supportive and generous, he wasn't very well-versed in dementia and didn't have many resources to draw on. Because I started doing my own research when he diagnosed me, I started to bring in studies and materials I'd found. He likes to tease me about being his teacher but the whole process has become a very collaborative one.

I've been referred to a few neurologists; my first experience was with someone

who didn't listen to what I had to say about what I was experiencing. Eventually I got a referral to Dr. Alexandre Henri-Bhargava in Victoria and that has been a much better fit.

How did the people around you react when you told them about your diagnosis?

My daughter – who's 47 now – has had a lot of difficulty accepting and understanding what my dementia means. My son (52), though – he's been so supportive. We've laughed a lot and there's a great deal of respect. He is very good at being attentive without being intrusive.

A lot of people who have been long-term friends have withdrawn, though. I feel like they don't want to look in the mirror



Chris with her son David.

or think about what they might have to face. I have a small posse of tight-knit friends who have stayed strongly connected with me; I'm going to be getting hip replacement surgery soon and already have three friends – some of whom I've known for more than fifty years – already scheduling their shifts looking after me.

Have you encountered stigma with your disease?

I don't think I've encountered *stigma* was much as I've encountered a lack of understanding about the disease – and a lack of patience. People need to understand that living with dementia means experiencing certain challenges, particularly around memory, and that they need to find solutions rather than getting fed up with someone when they're struggling.

I am reminded of an experience I had with a locum I dealt with, who became impatient with me when I couldn't remember a medication I'm on and gave me a conflicting prescription. It ended up being a bit of a challenge to iron out the situation and I wish she'd been patient with me so that we could have found a solution.

What would you say to someone to help them understand dementia?

I would say that experience with dementia changes on a daily basis. In *Dancing with Dementia*, Christine Bryden compares having dementia to having a kaleidoscope in your brain; one small distraction and the whole picture changes. Living with dementia means practicing daily mindfulness. You have to keep your life simple and break every task down into steps.

I would also want to say that dementia is extremely isolating. People living with dementia still need to be able to stay active and engaged to alleviate depression.



Chris Kensit (right) participating in the Society's Experience of Dementia Across Cultures event in Fall 2018.

Become an advocate

Everyone has a role in speaking up about dementia. Advocacy starts with the willingness to share your story to help others understand. Learn how you can become an advocate here:

<https://alzbc.org/advocacy>

Introducing your 2019 IG Wealth Management Walk for Alzheimer's honourees!



As the 2019 *IG Wealth Management Walk for Alzheimer's* approaches, we would like to share with you some incredible members of communities across B.C. who have been affected by dementia or who have made an invaluable contribution to the lives of people living with the disease.

Here are your 2019 honourees:

Abbotsford – Tom Smith and his daughter Samantha

Barriere and area – Lorraine Chambers

Burnaby & New Westminster – Leila Jamal and New Westminister Seniors Specialized Clinic

Chilliwack – Wendy Eyre-Gray

Courtenay – Linda Hodgkin

Kamloops – Bill Blair and Wendy Nordik

Kelowna – Craig Burns

Nanaimo – Donna Armstrong

Nelson – All caregivers

North Shore – The Lenarduzzi family

Pictured above: Among the 2019 honourees are Craig Burns, Christine Mills, Leila Jamal, Linda Hodgkin and Granville Johnson.

Penticton – Klaus and Trudy Kotzian

Port Alberni – All caregivers

Prince George – Granville Johnson

Richmond – Jack and Kim Evans

South Delta – Ron and Geramy Powell

Tri-Cities – Arvie Bourgeault

Vancouver – Christine Mills

Vernon – Margaret Stecyk and family

Victoria – Peter Woods

Whistler – Chantel Jackson

White Rock, North Delta & Surrey – Elaine Friesen Carter

Find out more about your local honouree by reading their story at <http://www.walkforalzheimers.ca>. Together, we make memories matter!

On Sunday, May 5, 2019, we invite you to walk with your community and in honour of someone in your life who have been affected by dementia. Who will you walk for? Register today at <http://www.walkforalzheimers.ca>.

Volunteer profile: Doug McMorland

The Alzheimer Society of B.C. is a volunteer-driven organization, with over 750 volunteers who work alongside our 85 employees to support British Columbians living with dementia, their caregivers and families. Dedicated individuals, in communities throughout B.C., volunteer in a wide variety of activities that expand and strengthen our ability to provide quality programs, support and services.

Volunteering is also a great opportunity for people living with dementia to both remain active and socially engaged, as well as challenging the stigma surrounding the disease.

In 2001, Doug McMorland was diagnosed with Alzheimer's disease at the age of 60. Eighteen years later, Doug is still determined to make a difference for his peers living with dementia.



allows Doug to ask the right questions at the right time. He knows when to share his own experiences to help everyone participate in the conversation."

Still, Doug thinks his volunteering is a little selfish: "I am meeting good people and enjoying my time. Volunteering at the support group is as good for me as it is for the participants."

Doug started co-facilitating an early stage dementia support group in Surrey shortly after he was the Walk honouree for the 2011 White Rock/Surrey *IG Wealth Management Walk for Alzheimer's* (formerly *Investors Group Walk for Alzheimer's*). Doug sees that his presence at the support groups gives hope to others: "There are still things you can do. It's not all sadness. Stay involved – people need to be out and active. I could sit at home and feel sorry for myself, but there is a lot out there."

This past August, Doug moved out of his home to a care residence. He is determined to keep volunteering at the monthly support group and is currently working out the best transit option to get there. Doug keeps his life focused on what he can do, not what he can't.

Become a volunteer:

Want to be a volunteer for the Alzheimer Society of B.C.? Email volunteer@alzheimerbc.org.

Alzheimer Society of B.C. staff person Avalon Tournier, who is Doug's supervisor, knew he would be an excellent co-facilitator as soon as she met him at a Christmas gathering. "I could see how insightful Doug was, and that is what

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- 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.

- Phone 1-800-936-6033
Lower Mainland: 604-681-8651
Monday to Friday, 9 a.m. to 4 p.m.
- 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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