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Insight

Alzheimer Society
BRITISH COLUMBIA

For people living with dementia

alzheimerbc.org



Changing the conversation

The Alzheimer Society of B.C. is at the centre of a movement to build awareness, reduce stigma and encourage people to take action by changing the conversation about dementia. This movement wouldn't be possible without the people affected by dementia who choose to stand up and have their voices heard.

In this issue of *Insight*, we hear from two spokespeople for January's Alzheimer's Awareness Month campaign entitled, "I live with dementia. Let me help you

understand." Ken Walker, the 2019 recipient of the Alzheimer Society of B.C.'s Award of Hope, shares wisdom from a lifetime of activism. Craig Burns, a member of the Society's Board of Directors, gives advice to other people on the dementia journey. *Insight* Leadership Editor Mario Gregorio also opens up about his past experiences as a spokesperson for the campaign. Finally, we offer practical tips on how to ask for help.

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Mario: Living well with dementia

When I finished a presentation to a group of health-care providers, people newly diagnosed with dementia, caregivers and seniors, I saw a need to create more awareness about dementia. Having been an advocate for the Alzheimer Society of B.C. for more than 10 years, I am still puzzled when asked, “What is dementia?” It has been more than 110 years since Alzheimer’s disease, a form of dementia, was identified and given its name. This is followed with, “What is the difference between Alzheimer’s and dementia?” I get very excited when given the opportunity to help our community understand the disease.

A survey conducted by the Alzheimer Society of Canada found that one in four people do not want others to know that they have dementia. Misconceptions about the disease, as well as fear of being a burden to family and to society, create a sense of dread, loss, isolation and abandonment.

Three years ago, I became one of the faces behind the Alzheimer Society of Canada’s annual awareness campaign, “I live with dementia. Let me help you understand.” I ask people to look at me and see me as a person with dementia living well in my community. I ask them to hear my voice as I tell them that, with a little help, I am also able to live well in my own home. There were many hurdles along the way, but I am encouraged by so many people.

This fall, I shared my experience living with dementia at a workshop for health-care providers called “Come alive!” and in the September issue of



Mario Gregorio

Reader’s Digest. I am energized by the passion of professionals dedicated to providing person-centred care in long-term care homes, as well as the changing conversation about dementia in the media.

Together with the Alzheimer Society of B.C., I have given a face to the disease and allowed people to understand that we can make life easier for people living with dementia. With understanding, we can create environments that restore the dignity and autonomy of people like me – and you.

Mario Gregorio

Editor and member of the Society’s B.C. Leadership Group of People Living with Dementia

Asking for help

Dementia can affect many aspects of life, from budgeting to driving or cooking. It can be helpful to focus on your strengths but there can come a point in time when it is necessary to ask for help.

Some things that people living with dementia throughout B.C. have said they ask for help with include:

- “Remembering to take medications and phone numbers.”
- “Assistance in motivating me to get out of the house and be active.”
- “Transportation because I’m no longer driving.”
- “I ask my friends to understand that I can’t be around big groups anymore.”

Asking for assistance can be difficult. It’s hard to accept help for something you used to be able to do alone. But it’s important to remember that by asking for help you are taking active control over your life, rather than losing control.



When you ask for help, you’re taking active control of your life.

Here are some tips for spotting when it might be time to ask for help:

- You find yourself withdrawing from activities you used to enjoy but now feel uncomfortable doing. For example, you are not seeing friends because you feel uncomfortable going to busy restaurants or cafés.
- You are becoming increasingly frustrated when a task is taking you much longer to complete than it used to. By asking for help you can save time and still accomplish the task.
- You realize you are starting to make mistakes that could harm yourself or others, such as trouble driving or leaving the stove on.

There are lots of people and places you can seek help from, including:

- Family
- Friends
- Neighbours
- Local community centres
- Doctors/specialists
- Online groups/forums
- The Alzheimer Society of B.C.!

Let us help you

To learn more about how the Alzheimer Society of B.C. can help, contact your local Resource Centre or call the First Link® Dementia Helpline, Monday to Friday, 9 a.m. to 4 p.m.

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

Does Craig Burns fit the mould of someone who lives with dementia? There isn't one.



Craig Burns is a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia, as well as the Society's Board of Directors, roles he took on following a career in the charity and non-profit sector. Because of his previous personal experience as a caregiver to his mother, Craig was familiar with the Society's resources and was inspired to become a volunteer when he himself was diagnosed with dementia. He was the 2019 *IG Wealth Management Walk for Alzheimer's* honouree in Kelowna.

When were you first diagnosed with dementia?

I was having memory problems dating back to 2009. Initially my GP told me it was caused by work stress. In 2016 in my management duties at work, I was experiencing significant problems in organizing, compiling and analyzing work, scheduling and understanding my own spreadsheets. Confusion and anxiety became the norm. I met with a psychiatrist specializing in dementia who administered a series of tests over a four-month period. He then made a diagnosis of dementia, most likely Alzheimer's disease.

What was your initial reaction to your diagnosis?

With the diagnosis I was actually *relieved* to know that there was definitely something wrong. Someone now believed me! I soon retreated inwardly and had a very difficult time looking to the future. I knew what my mother had gone through, with her decline, need for long-term care and her eventual passing. It took some time for me to mentally face the challenges ahead.

How did your family react?

They knew I had been having memory problems and they then understood more fully when they heard of the diagnosis. My daughter Leigh attended the Society's workshops with me. She gained insight into the disease, what I was going through and how to support me. My son Dan has also been very supportive and knowledgeable. His career is in the health-care sector where he works with a variety of people, including those who are living with dementia.

How did other people react to your diagnosis?

My co-workers were very supportive. They did not know much about Alzheimer's disease, but asked appropriate questions. I went on sick leave, short-term then long-term disability, so it was a big change for them as well as myself. My past co-workers continue to support me, in conversations and coffee dates. I make the effort to keep in touch with them.

Other people have said, "Well, you look fine." I almost feel as if they don't believe me. Or, they say, "Oh I have memory

problems, too! It's part of normal aging." And that is the difficulty frequently. For many people, it's difficult to separate what is a disease and what is part of normal aging.

It's hard sometimes to inform and educate without somehow feeling like I'm pushing something that is not real. When people question my diagnosis because I don't show any signs of it, it reinforces the stereotype that Alzheimer's disease only affects the elderly. They may be picturing someone in the later stages of the disease. I don't fit that mould. I help them to see there *isn't* a mould.

Have you encountered stigma?

Staff within government departments have been mostly accommodating and supportive when I state that I live with dementia. Sometimes, though, when I state my status, some people just don't know what to say. They may just subtly change the subject. If the setting is appropriate, I try to help them understand. I want to inform them, not berate or judge them.

Are people's ideas about dementia changing for the better?

The public's awareness and knowledge are improving, yes. There still is much more to be done to educate as well as live in dementia-friendly communities. It takes all of us, people living with dementia, caregivers, friends and health-care professionals, to inform and educate

about the realities of dementia.

What advice do you have for someone living with dementia?

- Maintain your friendships and start some new ones.
- Get out of the house and go visit someone else who needs help with something in their life.
- Get active: walk, go to the gym, cycle, make crafts or play games.
- Join a new group or pursue an interest you have always wanted to. Today is the day!
- Live life 100 per cent and strive to be resilient!
- Maintain your sense of humour!
- If you live with dementia, discover the joy of "letting it go." It doesn't really matter, whatever it is.

Is there anything else you would like to say about your personal experience?

Being able to more effectively manage my depression has made a big difference in how I cope with dementia. Also, my personal faith has sustained me through my successes as well as through difficulties and failures, both personally and professionally. Because of this, I have an abiding confidence in what will be ahead in life.

Learn more

Craig is among people affected by dementia standing up and saying, "I live with dementia. Let me help you understand." as a part of the national Alzheimer's Awareness Month campaign. To learn more about the campaign, visit ilivewithdementia.ca.

Volunteer profile: Ken Walker, recipient of the 2019 Award of Hope

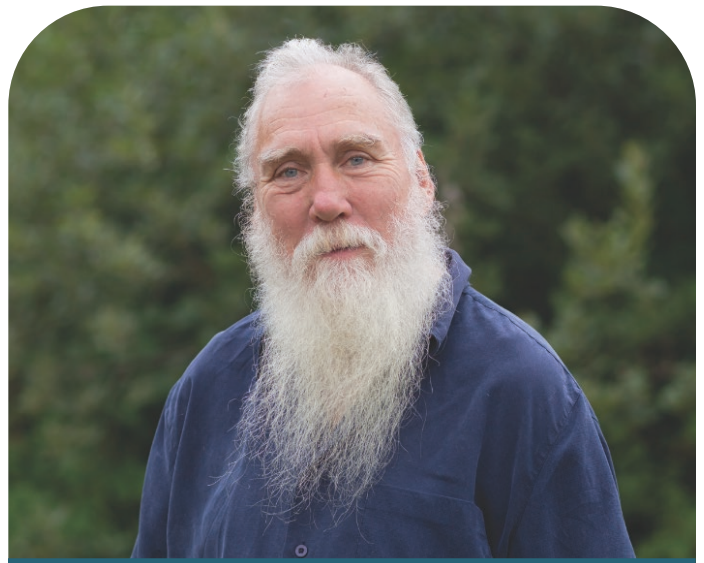
On the first day the provincial government was slated to begin televising its Legislative Assembly sittings in March of 1991, there was no shortage of action to catch on camera. Activists from ACT UP, a grassroots movement formed to fight the AIDS pandemic, filled the halls of the Legislature voicing opposition to the Province's position against funding HIV/AIDS medication at the time. Among the voices was Ken Walker, the only protestor carried out of the building that day after he Zap strapped himself to a chair.

Also there was Ken's now-husband Mark Demers, one of the activists who left voluntarily in the peaceful protest. Nearly three decades later, Ken and Mark reminisce about their early days creating change together. Those days are far from over.

Ken and Mark returned to the B.C. Legislature 28 years to the day after their protest with ACT UP, this time to advocate for the rights of people affected by dementia at the Alzheimer Society of B.C.'s luncheon at the Legislature.

"I want to leave the world a better place," says Ken, who lives with dementia. "That's at my core. I was like that even when I was five years old."

Ken, who has a background in group facilitation, began volunteering for the Alzheimer Society of B.C. as a support group facilitator long before he was diagnosed with young onset Alzheimer's disease. The experience gave him insight into what might be ahead, and the knowledge that there is no way of truly



Advocate and activist Ken Walker is the 2019 recipient of the Society's Award of Hope.

knowing, since individual experiences with the disease are each so unique. When Ken was diagnosed, the couple grieved for the lives they thought they would have – and soon leaned into the uncertainty ahead.

"We're back to a place in life where we don't have a plan," Mark says. "Once we were done grieving, we were OK about not having a planned future."

Ken returned to the Society seeking volunteer opportunities so that he could use his own experience to change the future for others affected by dementia.

"When I was diagnosed, I knew I was going to be wide open about it," he says. "Here I was, standing in front of people, and if I made a mistake, saying: 'I'm sorry; I have Alzheimer's.' "

As gay men who have gone through the process of coming out, Mark says, they saw the importance of visibility.

“We need to get out of the dark and be who we can be,” Ken adds.

While they believe in standing up and being seen, Ken and Mark acknowledge and empathize with those who may hide their diagnosis. Their view, though, is that the energy spent disguising dementia and hiding its challenges can be used instead to experience joy.

“When people treat dementia as a death knell, it takes away the opportunities that are around us all of the time,” Ken says. “I want people to know that with Alzheimer’s disease, we can have rich lives – it just takes preparation.”

Activism and advocacy weren’t something Ken turned to following his diagnosis. They have been integral themes of his life – and he honours them every day. Whether working to further rights of the LGBTQ2IA community, attending Vancouver’s climate action protests this fall – “at the back to give the kids the stage” – or participating in the national Alzheimer’s Awareness Month campaign to address the stigma of dementia, Ken never stops working to leave the world a better place.

“I’m still me,” Ken says. “The core of me is still the same.”

Ken is the Alzheimer Society of B.C.’s 2019 recipient of the Award of Hope which is given to people living with dementia who have demonstrated courage, leadership and support for others. To learn more about the Alzheimer’s Awareness Month campaign, visit ilivewithdementia.ca.

The Alzheimer Society of B.C.’s 2019 Volunteer Award recipients

Every year, the Alzheimer Society of B.C. nominates volunteers from across the province who define what it means to be a volunteer for the Society. Along with Ken, the 2019 award recipients are:

Kate and Gordon Sladen – Award of Leadership, inspired by Clyde & Lanny Slade

Kate and Gordon have volunteered at support groups, public speaking events and at Minds in Motion®, a fitness and social program for people in the early stages of dementia and a care partner. Kate is a former member of the Society’s Board of Directors.

Simon Grypma – Award of Community Service, inspired by Lola Turik

Simon has been the volunteer chair of the *IG Wealth Management Walk for Alzheimer’s* organizing committee in Nelson for eight years.

Bob Proctor – Award of Merit, inspired by Twigg White

Bob makes follow up calls to First Link® dementia support clients from the Vancouver Resource Centre.

Read and learn more

Visit alzbc.org/volunteer to learn more about how to get involved as a volunteer.

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- 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?

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