

Op-ed

FOR IMMEDIATE RELEASE

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**#StillHere to break down stereotypes about people living with dementia**



Alzheimer's Advocate Jim Mann discusses the state of dementia with UBC Centre for Brain Health Neurologist Dr. Howard Feldman at Vancouver's *Breakfast to Remember*, held on February 18, 2016 at the Fairmont Waterfront Hotel.

By Jim Mann

It was an honour to speak at the Alzheimer Society of B.C.'s *Breakfast to Remember* in Vancouver last week for two reasons. First, I had the privilege of speaking to the first *Breakfast* five years ago. The other reason, let's be honest, is the plain and simple fact that I'm still able to stand before an audience to continue my advocacy.

I'm just one example of the Society's January awareness campaign theme #StillHere. Even after my Alzheimer's diagnosis nine years ago this month, I am indeed *still here*.

That's one of the the myths I attempt to shatter through my presentations: the assumption often made that as soon as a person is diagnosed with Alzheimer's disease they immediately become incapable and incompetent.

Alzheimer's is a disease that many people know a little bit about and don't want to discuss. It will probably impact a majority of people in this province, but remains a mystery because of the many stereotypical images portrayed and the stigma that still exists.

Imagine for a moment that you and I meet for the first time. I introduce myself:

My name is Jim Mann.  
I live in the Lower Mainland of B.C.  
I am 67 years old.  
I have Alzheimer's disease.

*What do you see? Who do you see? Where is your focus?*

Do you zero in on my Alzheimer's as you look at me? Do you immediately think my cognitive abilities are limited? Do you avoid initiating a conversation with me because you assume I won't be able to understand?

Do you even believe me when I say I have Alzheimer's?

That's part of the complication. Alzheimer's and other dementias are cognitive and not physical. You don't see me paying only with bills because often I can't determine the value of coins. You haven't seen me leave the stove on too many times. You don't feel my panic when I become lost at the grocery store or in my own neighbourhood.

There's the stigma of the disease. That's why when I leave the house I wear a lanyard that reads: "Please be patient. I have Alzheimer's." I wear the lanyard to take control. If I get disoriented ordering a coffee, or if I am challenged at the counter trying to pay, the reason is clear, which hopefully lessens the clerk's stress—it definitely lessens mine.

Some people—both with dementia and others—question why I wear the lanyard. It is empowering. I want to be an active participant with my disease. As a business person remarked to a colleague when he told her he saw someone wearing a lanyard, "it's a great way to build awareness and reduce stigma."

Perhaps my business background as an advocate and a communicator play a role in my confidence in this task. It is also being—along with my wife Alice—my mother's care provider for many years. She had Alzheimer's. I saw stigma from peers in her independent apartment complex and some in the healthcare field. Since my diagnosis I too have seen stigma.

Losing friends when they're told of the diagnosis, having your own family immediately discount your opinion, the ignorance, the assumptions, *the stereotyping*. Like the time an emergency room nurse told me I looked fine when I insisted my wife accompany me to the examining room. Or the hospital clerk who laughed when I asked what day it was.

Staying active and having a purpose are vital to anyone. But I think it is even more important for someone living with dementia. In my support group I am the only one who uses transit. Most of us no longer drive. I also am the only one who uses the Internet to any great degree, which is how I access the bus schedule and get around.

Why am I telling you this? For a couple of reasons.

If you haven't already, many of you will come into contact with a person with dementia at home or at work, as an employer or employee. To know more about the disease will give you insight and help create a more dementia-friendly environment.

As our workforce ages, more workers will experience the effects of dementia and young-onset dementia will impact people in the prime of working life—in one's 40s or 50s.

The other reason I'm telling you this is because of a report from the U.K. Centre for Economics and Business Research. They predict dementia will impact business because employees will reduce hours worked or quit due to the demands of caring for people living with dementia.

More importantly for me personally is their note that two-thirds of people with dementia "would like banks and shops to have a greater understanding of the condition." Your personal support of the dementia cause and those who face the disease in all its forms is important and much appreciated.

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High resolution images available on request.

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## **About Dementia**

Dementia is a term that describes a general group of brain disorders. Symptoms include the loss of memory, impaired judgment, and changes in behaviour and personality. Dementia is progressive, degenerative and eventually terminal. Alzheimer's disease is the most common form of dementia accounting for almost two-thirds of dementias in Canada today.

## **About the Alzheimer Society of B.C.**

The Alzheimer Society of B.C. provides a provincial network of support and education for families impacted by dementia and people concerned about memory loss. Communities across the province count on the Society for support services, information and education programs, advocacy to improve dementia care in B.C., and to fund research to find the causes and cures. As part of a national federation, the Society is a leading authority on the disease in Canada.



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