

## Getting involved!

On May 1, 2016, thousands of British Columbians in 23 communities across the province gathered together for the *Investors Group Walk for Alzheimer's*. People with dementia, caregivers, family, friends and community partners walked to honour the over 70,000 individuals in B.C. who are living with Alzheimer's disease or another form of dementia.



Participating in events like the *Walk* is just one way people with dementia can continue to be engaged in their communities. This summer issue of *Insight* highlights some of the different ways you can stay involved and active – through summer activities (page 1), having your say in setting Canadian dementia research priorities (page 5), participating in one of the Society's early stage support groups (page 6), or even consider joining the Alzheimer Society of B.C.'s Board of Directors (page 2).

## People with dementia share their perspectives

Summer is the warmest season of the year and a time when many people like to do outdoor activities and go on vacation. Recently, groups of people living with dementia around the province discussed their favourite summer activities. Their comments are shared below.

- "I like to spend all summer on the lake at our cabin."
- "I am going to try to grow tomatoes and lettuce."
- "Nothing!"



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- “I stay close to air conditioning...”
- “Fishing.”
- “Take a trip in our new RV.”
- “Walking outside.”
- “Drinking cold beer.”

- “Paddle in a kayak.”
- “I like to spend time in the garden or with my dog.”
- “I plan to travel to northern Lake Ontario.”
- “I go to the park and have a picnic lunch.”
- “Swimming in Kalamalka Lake.”
- “I will do some exploring on Haida Gwaii.”
- “Enjoying the community festivals.”
- “I like to take things easy.”

What activities bring you meaning and joy during the summer season?

## Get involved with the Alzheimer Society of B.C.’s Board of Directors!

Volunteers play an important role in the Alzheimer Society of B.C.’s efforts to support the thousands of British Columbians affected by dementia. The members of the Society’s Board of Directors are a dedicated group of volunteers who jointly guide and oversee the strategic priorities of the Alzheimer Society of B.C. In recognizing the value of having the voice of people with dementia included,

the board would like to invite a person with dementia to join them as a member.

Jim Mann is a dementia advocate who was diagnosed with Alzheimer’s disease in 2007. Jim served as a member of the Society’s Board of Directors for six years. Recently, Jim shared his previous experience as a board member with *Insight*.

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### **Why did you decide to join the Board of Directors?**

First off, I enjoy board work – the policy, the global view and the strategic planning. But I also viewed the invitation to join the board as important in ensuring the voice of a person with dementia was heard and acknowledged. I have said for years that if we – people with dementia – don't tell our story, how else will people learn about the 'real' story of dementia? So, at the board level, how else will the Society's governors know what programs and services for people living with dementia are needed without their voice at the table?

### **What did you enjoy about being a board member?**

Almost everything. Strategy development, working with and getting to know the talented staff, the other board members and the business people who volunteer their time to help move the Society forward. Being a board member had its challenges, like trying to keep up with some of the discussions around the table, inserting my thoughts and opinions and staying attuned to the issues that matter. But that's what being a board member is about – influencing the work of the Society for today and for tomorrow, for those in support groups today and for



Dementia advocate Jim Mann, a previous member of the Alzheimer Society of B.C.'s Board of Directors.

those not yet diagnosed, for those living with a dementia in big cities and those living in rural areas.

### **Why is it important to have a person with dementia be on the Board of Directors?**

This is our Society and people living with dementia are a major recipient of its services. In order for the Society to better appreciate where it should be going with the various programs and services it offers, the voice of its user group, so to speak, should be at the table. We hear the phrase 'nothing about us without us' – this extends to the boardroom table where policy is developed and debated and the business of the Society is examined.

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Who better to participate actively in these conversations but the person most impacted? It goes without saying, doesn't it?

### **What advice do you have for other people with dementia who want to get involved in dementia advocacy?**

Just do it! Advocacy is and can be many different things to many people. It is writing a letter to the editor, your provincial representative (MLA) or expressing an opinion. But advocacy can be more. It is speaking about your

experience of living with dementia to your neighbour, or your local store keeper. Advocacy is education, really.

Not everyone has seen dementia close-up so they don't understand the disorientation, the misunderstanding, the periodic difficulties that occur when we are out and about so who better to educate than us, people actually living with dementia! For those of us no longer employed, we now have a (non-paying) job as educators, and the community is our classroom.

#### **Join the Alzheimer Society of B.C.'s Board of Directors**

If you are a person living with dementia in B.C. who is interested in joining the Alzheimer Society of B.C.'s Board of Directors call 604-742-4917 or email [KKinahan@alzheimercbc.org](mailto:KKinahan@alzheimercbc.org).

## **Alzheimer's Drug Therapy Initiative: Decision announced**

Since 2007, the Alzheimer's Drug Therapy Initiative (ADTI) has provided eligible B.C. residents with PharmaCare coverage for a class of medications called cholinesterase inhibitors used in the treatment of Alzheimer's disease. The ADTI was developed in B.C. to gather evidence on the effectiveness of these medications. The ultimate aim was to determine whether or not the medications should be listed on the Provincial PharmaCare Formulary.



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In April 2016, the Ministry of Health announced their formal decision regarding the ADTI. Highlights of the decision include:

- People already receiving coverage through the ADTI will experience no changes to their medications or access to coverage.
- People who meet the criteria and are trying the medications for the first time will be prescribed donepezil. Should they not be able to physically tolerate donepezil they will be able to try galantamine or the oral version of rivastigmine. In all cases they will be prescribed the generic forms of these medications.

The decision to ensure this medication for Alzheimer's disease is still accessible through PharmaCare is a positive one for people with dementia and caregivers.

Each person will experience Alzheimer's disease medications differently. If you have questions about medications or coverage, it is important that you connect with your doctor or pharmacist.

The Society is grateful to the many people with dementia who contributed their thoughts and feedback about the medications. Lynn Jackson is just one of the many individuals who got involved in this advocacy effort. Below, Lynn shares her thoughts on the decision.

“Over the years, I and many others have advocated so hard for this to finally happen. I have seen time and time again how this medication has helped some people in my early stage support group and I am pleased about this decision.”

### Have your say: Help set dementia research priorities in Canada

Do you want to help shape the future of Canadian dementia research? The [Canadian Dementia Priority Setting Partnership](#) study asks Canadians for the questions they would like to see answered by dementia research. The responses will be prioritized to produce the “top ten” Canadian dementia research priorities.



Please share your knowledge and complete the questionnaire at [www.alzheimer.ca/researchpriorities](http://www.alzheimer.ca/researchpriorities) or call 604-742-4933 (toll-free 1-800-667-3742) to have a copy of the survey mailed or faxed to you.

## Staying involved after a diagnosis

Barbara White was diagnosed with Alzheimer's disease four years ago. Recently, Barbara shared a note with *Insight* which highlights how participating in one of the Alzheimer Society of B.C.'s support groups helped her along her journey with the disease. For more information about the Society's [early stage support groups](#) for people living with dementia, please contact your [local Alzheimer Resource Centre](#) or call the [First Link® Dementia Helpline](#) at 1-800-936-6033.

### A message from Barbara

My name is Barbara White, and for the past four years I have been living with Alzheimer's disease. After my diagnosis, I joined an Alzheimer Society of B.C. early stage support group and we have bi-weekly meetings each month. I learned how to build up my confidence. I also learned how to challenge the stigma towards myself and other people who have Alzheimer's disease. By joining the support group, I have been shown that I am not alone in having this disease.

My husband Wayne is a great supporter as he has become my caregiver. He attends monthly caregiver support group meetings. He learns



Barbara at the 2016 *Investors Group Walk for Alzheimer's*.

about how to help me cope with my Alzheimer's disease.

In 2014, I was chosen to be the honouree for the *Walk for Memories* (now the [Investors Group Walk for Alzheimer's](#)). My goal as an honouree was to make people who have Alzheimer's disease or another dementia aware that there is help available within their community.

I have not lost my great sense of humour. I must state to everyone who has Alzheimer's disease or another dementia, please keep having fun by laughing with friends and family. If you keep busy and keep laughing a lot in your life you will live longer!

## Contribute to Insight

Do you have a topic you would like to see covered in *Insight*? Do you have content you would like to publish in *Insight* such as personal stories, photography or original poems?

If so, please contact the Alzheimer Society of B.C.

- Email [Insight@alzheimerbc.org](mailto:Insight@alzheimerbc.org)
- Send mail to the address below, care of *Insight*.  
300 - 828 West 8th Avenue  
Vancouver, BC V5Z 1E2

All submissions will be considered based on theme and space. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.

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- Visit our **website** at [alzbc.org/Insight-bulletin](http://alzbc.org/Insight-bulletin)
- **Call** 604-681-6530 or toll-free at 1-800-667-3742
- **Email** [Insight@alzheimerbc.org](mailto:Insight@alzheimerbc.org)

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## Call the First Link® Dementia Helpline

A confidential province-wide support and information service for anyone with questions about dementia, including people with dementia, their caregivers, family and friends, professionals and the general public.

- **1-800-936-6033**  
Lower Mainland 604-681-8651  
Monday to Friday, 9 a.m. to 4 p.m.
- **Email** [supportline@alzheimerbc.org](mailto:supportline@alzheimerbc.org)

## Are you a caregiver?

The Alzheimer Society of B.C. also publishes *In Touch*, a bulletin for caregivers of persons with memory loss.

To subscribe:

- Visit our **website** at [alzbc.org/In-Touch-bulletin](http://alzbc.org/In-Touch-bulletin)
- **Call** 604-681-6530 or toll-free at 1-800-667-3742
- **Email** [In-Touch@alzheimerbc.org](mailto:In-Touch@alzheimerbc.org)



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