

# Connections

Linking a community of dementia support



## Changing the conversation

“People waste a lot of bandwidth trying to disguise that they have dementia,” says Ken Walker, a dementia advocate and activist who has long fought for LGBTQ2IA rights with his husband, Mark Demers.

“Something we know from being gay is that shame can undermine relationships.”

Mark and Ken met through their activism, a passion they’re turning towards challenging the stigma associated with Alzheimer’s disease and other dementias. Ken, who lives with young onset dementia, first came to the Alzheimer Society of B.C.

as a volunteer support group facilitator and is now a spokesperson for this month’s national Alzheimer’s Awareness Month campaign entitled, “I live with dementia. Let me help you understand.”

Ken and Mark are two of many people across Canada sharing their story during the month of January to help change the conversation about dementia and educate people who may fear the disease or not know how to act around someone living with dementia. “I want people to understand that life can still be full when you’re living with dementia,” Ken says.

**Read and learn more**

To read their full story and learn about the campaign, visit [ilivewithdementia.ca](http://ilivewithdementia.ca).

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# Small actions have a major impact

For many of us, the beginning of a new year is time to take stock of our personal habits and set goals for the year ahead. The new year also marks the beginning of Alzheimer's Awareness Month, a time to listen to the voices of people affected by dementia, consider the role we all play in addressing stigma and make small changes in our daily lives. These changes can have a major impact on building more inclusive and supportive communities for people facing dementia.

When polled, most British Columbians say they would help someone living with dementia in need of assistance – but most admit they don't know how. This issue of *Connections* delves into how we can help close that gap with practical tips on when and how to offer your help to someone living with dementia. We're also introducing our first *Breakfast to Remember* fundraising event in Kelowna, an exciting new opportunity for business leaders in the Okanagan to lend their support, following the success of annual

*Breakfast to Remember* events in Vancouver and Victoria.

No issue of *Connections* would be complete without taking the time to recognize the people who are already leading the way in creating change for people affected by dementia. We'll profile Heather Inglis, a long-time caregiver who shares insight into the stigma her mother experiences, as well as the recipients of the Alzheimer Society Volunteer Awards. Dedicated to ensuring people affected by dementia are not alone, these are volunteers whose actions are truly making a difference across the province.

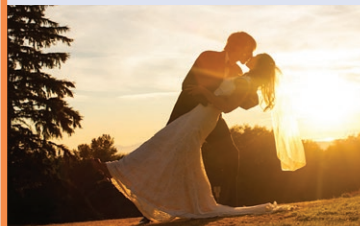


Maria Howard MBA, CCRC  
Chief Executive Officer  
Alzheimer Society of B.C.

## Events at a glance

We host signature events throughout the year to raise awareness and funds to help provide programs and services in communities around B.C. Here's a taste.

**Anything for Alzheimer's**  
Year-round



**Breakfast to Remember**  
February/March



**IG Wealth Management Walk for Alzheimer's**  
May



**Scotiabank Vancouver Half-Marathon & 5k**  
June



**Climb for Alzheimer's**  
September



**Charity Dinner for Alzheimer's**  
November



Learn more  
or get involved

For more information  
visit our events page:  
[alzbc.org/society-events](http://alzbc.org/society-events)

# Awareness: A caregiver's perspective



Heather Inglis and mother Gloria

*Heather Inglis is a former CUPE national representative and labour advocate who retired at the age of 51 to support her husband, who was living with liver*

*failure. Heather also supports her mother Gloria, who was diagnosed with Alzheimer's disease in 2013. Heather and her family live in Ashcroft, B.C.*

### Can you tell us a bit about Gloria?

My mom has never shied away from helping people. She and my dad used to run a publishing company but after he passed away, she decided to retire and became something of a super-volunteer. In 2008 she was named Burnaby's Citizen of the Year because of her work with various organizations, including victim support and volunteering at a hospice.

### What was your initial reaction to her diagnosis?

I was concerned for several years because of changes in my mother's memory, but she was managing and hiding it. It wasn't until October 2012 when we went on a cruise that I understood the extent of the changes. We were sharing a small stateroom, so everything was that much more apparent. There was one night when we were going to a formal dinner: Mom didn't want to go, but then completely forgot the conversation and got dressed up. I knew that we had to do something at that point.

### How did the rest of the family react?

My mother felt a lot of stigma, so we didn't tell the extended family for years. Eventually things changed enough that when I was going to see them, I couldn't be honest about my life without talking about it. Eventually she agreed to let me tell my cousins

and her brothers. When I did tell them, they didn't understand what it meant. That's been one of my biggest frustrations, actually: people don't understand the disease.

### How have other people in the community reacted?

Some long-time friends don't believe she has dementia. They don't see the evidence because they aren't around. One couple was quite excited because they received an anniversary card in the mail and I decided not to tell them that I sent it for her, because giving cards has always been something important to my mother.

### What support have you received from the Alzheimer Society of B.C.?

I've been incredibly lucky to have a support group for caregivers in Ashcroft, and for a while I was taking Mom to a support group for people living with dementia in Kamloops. The education has been wonderful, and I really appreciate the ongoing support. When I haven't been able to attend the group, I get calls to make sure I'm okay.

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

- Educate yourself. If you understand the disease – even a little bit – it helps.
- Be patient.
- Ask the caregiver how they are and if they need any help.

### Learn more

Heather is just one of many people standing up this January and saying, "I live with dementia." Read more stories at [ilivewithdementia.ca](http://ilivewithdementia.ca).

# Business leaders step up for *Breakfast to Remember*



Robert Cunningham is among members of Kelowna's business community bringing a new fundraiser to the city.

Business and community leaders play a significant role in changing the future of dementia in B.C. by supporting the Alzheimer Society of B.C.'s annual *Breakfast to Remember*

fundraisers – and this year leaders in the Okanagan have the opportunity to do the same. The events, which have to date taken place in Victoria and Vancouver, generate funds to ensure the Society can continue to support people affected by dementia as well as enabling dementia research. The inaugural *Breakfast to Remember*, presented by Valley Mitsubishi, will be held in Kelowna in March 2020.

“Every family in Kelowna either knows someone or has a family member affected by dementia,” says Robert Cunningham, Director of Sales for SGP Purchasing Partner Network in Western Canada and a member of the Kelowna organizing committee. “We should all be trying to support the cause.”

Among those who have been essential to the success of the event's fundraising model is Floyd Murphy, chair of the Vancouver organizing committee and representative for its founding sponsor, Murrick Group.

“Businesses bear a cost when they lose good people and when their employees who are caring for family members experience challenges,” Murphy says. “It is critical to create resources to support caregivers and ultimately find a treatment for this terrible illness.”

Stasia Hartley, Bayshore Home Health Area Director for Vancouver Island and chair of Victoria's organizing committee, sees the event as an opportunity to build a community of support for families facing dementia.

“When business owners learn more about how to build a dementia-friendly community, it has a positive impact throughout their network,” she says.

This year marks the ninth iteration of *Breakfast to Remember* in Vancouver and the seventh in Victoria, where Trillium Boutique Senior Living will once again present the event. The list of speakers is always impressive, and Kelowna is off to a great start, with soccer legend Bob Lenarduzzi delivering the keynote speech, alongside guest speaker Craig Burns, an advocate for people living with dementia.

## Get involved

To learn more, visit [breakfasttoremember.ca](http://breakfasttoremember.ca).

For sponsorship opportunities in Kelowna, contact Magda Kapp at [mkapp@alzheimerbc.org](mailto:mkapp@alzheimerbc.org).

Contact Janet Hutzul at [jhutzul@alzheimerbc.org](mailto:jhutzul@alzheimerbc.org) for Victoria and Vancouver opportunities.

- ***Breakfast to Remember* in Victoria, presented by Trillium Boutique Senior Living**  
Thursday, February 27, 2020  
Fairmont Empress Hotel
- ***Breakfast to Remember* in Vancouver**  
Thursday, March 5, 2020  
Fairmont Hotel Vancouver
- ***Breakfast to Remember* in Kelowna, presented by Valley Mitsubishi**  
Tuesday, March 10, 2020  
Coast Capri Hotel

# Chinese community hosts sold-out dinner for dementia

The *Charity Dinner for Alzheimer's* raised more than \$141,000.



On November 2, 2019 we held the second annual *Charity Dinner for Alzheimer's*. Organized by the Alzheimer Society of B.C. and caring volunteers from the Chinese community, the sold-out event was a huge success, raising more than \$141,000 to support more programs and services in Cantonese and Mandarin through our Vancouver and Richmond Resource Centres. This included a generous \$30,000 matching donation from the Ching and Yue families.

Thank you to all the donors, volunteers, sponsors and media partners who made the 2019 event a huge success! If you are interested in getting involved in the 2020 event, please contact Wendy Wong at 604-742-4903, or email [wwong@alzheimercbc.org](mailto:wwong@alzheimercbc.org).

卑詩省阿茲海默症協會於2019年11月2日舉辦了第二屆「關愛腦友記」慈善晚宴。是次活動是由卑詩省阿茲海默症協會及本地一羣熱心的華人合力舉辦，並獲得空前成功，共籌得超過 \$141,000 的善款，當中包括來自程氏及余氏家族的 \$30,000 配對捐贈，用作拓展華人社區的服務，包括透過溫哥華及列治文的資源中心以粵語及國語提供支援服務及教育講座等等。

感謝所有為是次慈善晚宴出心出力的各位善長、義工、贊助商及傳媒伙伴。如果你有興趣參與我們 2020 年的活動，請致電 604-742-4903 與 Wendy Wong 聯絡或電郵至 [wwong@alzheimercbc.org](mailto:wwong@alzheimercbc.org)。



## My mom.

Opera singer. Community carer.  
Farmer's wife. Volunteer. Warrior.  
Diagnosed with dementia in 2015.

## Who will you walk for?

Sunday, May 3, 2020

Register today at [walkforalzheimers.ca](http://walkforalzheimers.ca)



# Tips on how to help a person living with dementia

*It's the middle of winter and you are out walking on your lunch break. It's a chilly day and people are bundled in coats and scarves also enjoying the day. You notice a woman sitting on a park bench. She's only wearing a T-shirt and shorts and seems disoriented and scared. You realize she might be living with dementia.*

A recent poll conducted by Insights West showed that while the majority of British Columbians know someone living with dementia, 60 per cent say they are not confident they would know what to do if they encountered someone who needed assistance and might be living with dementia.

Dementia does not define a person: they are still the same person they were before their diagnosis. Many people living with dementia just need some support and compassion so they can remain active and engaged in their communities. This is where you can come in.

Here are some tips for how to help someone living with dementia, in whatever circumstance you might meet them:

- Get the person's attention. You could approach the person slowly from the front, make eye contact and wave.
- Identify yourself by name.
- Ask the person whether they need some assistance. If they say no but you are still feeling concerned, stay with them. Keep them company and try asking again in a different way.
- Ask questions that only require a yes or no response rather than open-ended questions. Give time to respond.

- Speak slowly and clearly and use gestures to illustrate what you're saying.
- Be respectful in your suggestions and questions. Offer to do something *with* the person rather than *for* them.
- Respond to their feelings, not just what they are saying. Remember that whatever they're experiencing is real for them.
- Avoid elder-speak like "sweetie" or "dear."
- Look to see if the person is wearing a MedicAlert® Safely Home® identification bracelet.
- If you are concerned about the person's safety, call 911 and stay with them until help arrives.

We can all play a role in making B.C. a safe and inclusive place for people living with dementia. By demonstrating compassion and understanding, we can help people living with dementia feel empowered and included.

Spread the word and start conversations to help people see dementia differently.

### Ask us

If you have questions about dementia, call our First Link® Dementia Helpline for information and support anytime **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

# World Alzheimer Report 2019

Alzheimer's Disease International (ADI) is the international federation of Alzheimer associations around the world and has an official relationship with the World Health Organization. ADI believes that the key to winning the fight against dementia lies in a unique combination of global solutions and local knowledge. Each year ADI releases a World Alzheimer Report which provides the most comprehensive data on dementia worldwide.

This past September, Alzheimer's Disease International released the 2019 World Alzheimer Report: Attitudes to dementia. The report reveals the results of the largest survey ever undertaken on attitudes towards dementia, with almost 70,000 people across 155 countries and territories completing the survey. This is an important piece of research, motivated by the belief that people living with dementia should be able to access support and services without experiencing stigma.

Some of the key findings of the report include:

- Every **three seconds**, someone in the world develops dementia.
- **Two-in-three people** still think dementia is a normal part of aging rather than a neurodegenerative disorder.
- Almost **80 per cent** of the general public is concerned about developing dementia at some point and one in four people think there is nothing we can do to prevent dementia.
- Approximately **35 per cent** of caregivers across the world said they have hidden the diagnosis of dementia from a family member.
- Over **50 per cent** of caregivers globally say their health has suffered as a result of their caring responsibilities even while expressing a positive feeling about their role.
- Stigma associated with dementia is preventing people from seeking the information, advice, support and medical help that could dramatically improve their length and quality of life.

## Key recommendations of the report include:

- Targeted public health awareness campaigns.
- Promotion of timely diagnosis and better post-diagnostic support.
- A global evolution of dementia-friendly communities, with people living with dementia and caregivers at the heart of their design, implementation and evaluation.
- Increased public advocacy for people living with dementia, amplifying the voice of lived experience.
- Increased advocacy focused on caregivers' experiences.
- Call for local governments to increase the funding, range and quality of community services for people living with dementia.

## Learn more

To read a full summary or to download the report, visit: [alzbc.org/ADIREPORT2019](http://alzbc.org/ADIREPORT2019)  
To view all previous World Alzheimer Reports, visit: [alzbc.org/ADIREPORTS](http://alzbc.org/ADIREPORTS)

# Meet our 2019 volunteer award recipients



Every year, the Alzheimer Society of B.C. nominates volunteers from across the province who epitomize what it means to be a volunteer for the Society.

### Kate and Gordon Sladen

#### Award of Leadership, inspired by Clyde & Lanny Slade

Based in the North-Central Okanagan, together Kate and Gordon have volunteered at support groups, public speaking events and at Minds in Motion<sup>®</sup>, 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

Motivated to support people affected by dementia and give back to his community, 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

A valued advocate armed with an arsenal of witty stories and timely anecdotes, Bob makes follow up calls to First Link<sup>®</sup> dementia support clients from the Society's Vancouver Resource Centre.

### Ken Walker

#### Award of Hope, inspired by Mike Crowe

Ken came to the Society as a support group facilitator in Vancouver and is now a member of the Society's Leadership Group of People Living with Dementia.

#### Read and learn more

Visit [alzbc.org/volunteer](http://alzbc.org/volunteer) to learn more about how to get involved as a volunteer.

## Questions about dementia or memory loss?



English: 1-800-936-6033

Cantonese or Mandarin: 1-833-674-5007

Punjabi: 1-833-674-5003

## First Link<sup>®</sup>

YOUR LINK TO DEMENTIA SUPPORT

Hours: Monday to Friday, 9 a.m. to 4 p.m.

Learn more: [alzbc.org/flhdl](http://alzbc.org/flhdl)

## About Connections

*Connections* is a quarterly print and digital publication produced by the Alzheimer Society of B.C. Articles cannot be reproduced without written permission.

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- **Email** [newsletter@alzheimerbc.org](mailto:newsletter@alzheimerbc.org)
- **Call** 604-681-6530; 1-800-667-3742 (toll-free)
- **Mail** to the Alzheimer Society of B.C.  
300-828 West 8th Avenue,  
Vancouver, B.C. V5Z 1E2

Help us reduce costs by subscribing to *Connections* by email.

### Are you a person living with dementia?

We also publish *Insight*, a publication for people living with dementia or cognitive impairment. For more information, visit [alzbc.org/insight-newsletter](http://alzbc.org/insight-newsletter).



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