

# Connections

Linking a community of dementia support



Yes, I live with dementia.

Let me help you understand.

I have frontotemporal dementia and Alzheimer's disease. I enjoy painting landscapes. I am an award-winning volunteer. I am Myrna.

## Alzheimer's Awareness Month

*This January, people across Canada are standing up and saying, "Yes, I live with dementia."*

"We all deserve dignity," says Myrna Norman, who was diagnosed with frontotemporal dementia and Alzheimer's disease in 2008.

Myrna – a member of the B.C. Leadership Group of People Living with Dementia – is one of many Canadians who are talking about their experience during Alzheimer's Awareness Month this January. They are addressing the stigma and discrimination that people living with the disease experience. "I have

friends who no longer wanted to see me," Myrna says, when asked about her experience of the stigma. But people living with dementia can continue to make great contributions to their communities when given the chance. "People talking about dementia is a positive thing," says Myrna.

What does Myrna want people to learn to do this January? "Become educated, be patient, be empathetic."

Read and learn more

Want to hear more about the experiences of people living with dementia? Visit [ilivewithdementia.ca](http://ilivewithdementia.ca).

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# It's time to start a conversation

Welcome to the winter issue of *Connections*, the Alzheimer Society of B.C.'s publication for people who are affected by or concerned about dementia.

Our vision is for a world without dementia; until that day comes, we are working toward building a dementia-friendly society where people affected by the disease are welcomed, included and supported. This is particularly timely, as January is Alzheimer's Awareness Month, when we come together to amplify the voices of people who are directly affected by the disease – people living with dementia, their caregivers and their families – and help the movement grow.

This issue includes tips for caregivers on navigating health-care services. Read about a couple who experienced the diagnosis of young onset dementia very early in their relationship and about one of our star volunteers. You can also find out about the *Investors Group Walk for Alzheimer's* coming to a new community this spring.

You can help to eliminate stigma and empower people living with dementia; by demonstrating compassion and understanding, you can help them feel safe and included, which in turn can allow them to continue contributing to their communities.

Throughout January – and beyond! – start conversations with people and help them see dementia differently. Maybe share your copy of *Connections* as a starting point. It may seem like a small step, but along the way you'll be building a province that is safe and inclusive of people affected by dementia.



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



**Investors Group Walk for Alzheimer's**  
May



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



**Climb for Alzheimer's**  
September



**Coffee Break®**  
September/October



**Learn more or get involved**

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

# The healing power of caregiving

*When symptoms of dementia start before the age of 65, we use the term young onset dementia. There are 16,000 Canadians under the age of 65 living with young onset dementia. People living with young onset dementia face unique challenges. BJ Doyle, a caregiver, shares his story of two people who met, fell deeply in love and ended up changing one another's circumstances because of young onset dementia.*

There was never any doubt in my mind I'd be sticking around when my partner of six months, Judy, suddenly announced in February 2012 that she had been diagnosed nine months earlier with young onset Alzheimer's disease.

I was utterly shocked that an otherwise seemingly healthy Judy had already been officially diagnosed as being in the early stages of dementia since the relatively young age of 53. Sitting across Judy's dining table that evening, speaking with her daughter Angela over the phone, I struggled to keep my mind from racing. What was I about to launch into?

I was able to stay present and fully absorb the scope of what was being said, as Judy displayed her selfless attitude in between sobs of heartache. As completely terrified as she was that the reality of her condition might provoke me into running scared after only knowing one another for half a year, it was clear that between Judy's words and Angela's, I was witnessing something that was stopping me in my tracks: people reaching out and humbly, quietly, asking for help.

The seeds of intrinsic loyalty, I suppose, were already being sown even before I realized I was about to transition into the role of caregiver. That process – from initially managing Judy's financial obligations,



**BJ and his partner Judy.**

liaising on her social commitments and eventually handling all aspects of health, nutrition and personal care – would be, for myself, not unlike the breaking of an early dawn; by the time you notice it's arrived, you realize it has been happening for some time.

Unlike a lifelong union between two people with one partner suddenly becoming ill, I had to remember that I wasn't thrown into this. I was choosing it. As a new caregiver, I quickly found out caregiving is as much about taking care of yourself as it is about giving care. It was like an emotional blank cheque that, through a leap of faith, I would somehow find within me to write over the coming months. Nevertheless, our journey together had begun.

People say I do a lot for Judy, but in fact it's what she has done for me that is remarkable. It's worth it, for instance, to (discreetly) clean up a kitchen's worth of mess after Judy has offered to help dry dishes if it means preserving what's left of her autonomy.

Allowing for mistakes, presenting choices, re-phrasing questions and demonstrating patience all come into play daily. Neil Young once spoke about his own father being in the grips of dementia: "It's quite something to see your loved ones living in the moment."

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## Caregiver story

And the experience of being blessed with having Judy in my life has made me realize that such things as love, gratitude and acceptance truly are important. Each day is a gift; any day can suddenly bear unexpectedly great surprises; laughter truly is the best medicine, and that staying present in the moment is the key to everything. Above all, a huge takeaway that I never could have prepared for is discovering over time that there's a healing power that comes with sacrifice.

Judy often says, as recently as in the past week: "I'm doing the BEST that I can." Hearing those words

People say I do a lot for Judy, but in fact it's what she has done for me that is remarkable.

makes me realize that we both are. And whatever that "best" happens to be on any given day, is always going to be good enough. It has to be.

Read DJ's full story: [alzbc.org/bj-doyle](http://alzbc.org/bj-doyle).

### Share your stories with us

To submit personal stories, photography or original poems, email us at [newsletter@alzheimerbc.org](mailto:newsletter@alzheimerbc.org). Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.

## Caregiver tips

# Navigating health-care services throughout the caregiving journey

A variety of services are available for people living with dementia and caregivers within the formal health-care system and through community agencies. Navigating your way through these services and accessing them when the time is right, however, can feel overwhelming.

### When should I access health-care services?

The decision to access support services isn't always easy. It's often filled with questions, expectations and emotions. These may make it difficult to reach out.

It is best to reach out sooner rather than later. Even if it's determined to be too early for the person living with dementia to use support services, they are at least entered into the system and assigned a case manager. This is beneficial because you have direct contact information. When the situation changes, be proactive and make sure to inform your case manager.

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## Caregiver tips

### How do I decide which health-care services to use?

Ideally the person living with dementia will have input on this, although in some cases the disease may have progressed beyond the point where they are able to express their wishes to the full extent.

When possible, we encourage families to start the conversation with the person living with dementia when they are in a position to make decisions about their future – often well before the system of care is accessed. When the time comes to access these services, you can be confident that you are respecting and following the person's preferences.

### What makes the decision to access health-care services so challenging?

For some caregivers, it can feel like the decision to access services is a choice between two equally undesirable alternatives. On the one hand, as caregiver, you may feel exhausted and it may become necessary to have additional support and time for yourself. On the other hand, the idea of having one or more people in your home providing support can feel uncomfortable.

Accessing support is also an indication that the disease is progressing – and admitting this can be very difficult to do. You have a finite reserve of emotional and physical energy. It's not unusual for caregivers to become ill during the journey. It's important to look after yourself and stay as healthy as possible, for your sake and for the person living with dementia.

### How can I find out more about the system of care?

For more information about accessing health-care services, including how to discuss and encourage

the use of services with the person living with the dementia, visit your local Resource Centre, call the First Link® Dementia Helpline or learn from home by watching the Society's tele-workshop "Navigating the system": [alzbc.org/navigating-the-system](http://alzbc.org/navigating-the-system).



### Connect with support and learning

First Link® dementia support is for people living with dementia and their care partners at any stage of the journey. Call the First Link® Dementia Helpline at 1-800-936-6033 or visit the [We Can Help](#) section of our website.

**You're invited**  
**BREAKFAST TO**  
**REMEMBER**  
February 22, 2018 VICTORIA  
Fairmont Empress  
[breakfasttoremember.ca](http://breakfasttoremember.ca)

Keynote speaker – Jack Knox  
*Times Colonist*

Guest speaker – Bob Lenarduzzi  
President, Vancouver Whitecaps

Sponsorship opportunities available.  
Contact: Hart Dashevsky  
Phone: 604-742-4925  
Email: [hdashevsky@alzheimercbc.org](mailto:hdashevsky@alzheimercbc.org)

**Alzheimer Society**  
BRITISH COLUMBIA

An aerial photograph of a harbor with many boats docked at a pier. In the background, there are buildings and a lighthouse on a small island. The sky is blue and the water is a deep blue.

# Cranbrook is joining the Investors Group Walk for Alzheimer's!

*The 2018 Investor's Group Walk for Alzheimer's is returning this May. Read about our newest Walk and the special volunteer committee chair who is helping to make it possible.*

In early 2017, the Alzheimer Society of B.C. completed expansion of First Link® dementia support into the East Kootenay region. To mark the importance of providing support to families in the region, we are proud to announce that in 2018, Cranbrook – home to our East Kootenay Resource Centre – will join over 20 communities across the province with its own *Walk*!

The *Investors Group Walk for Alzheimer's* is Canada's biggest fundraiser for Alzheimer's disease and other dementias. It's a fun and family-friendly way to create a movement while sending a message of inclusion and hope to the estimated 70,000 British Columbians currently living with dementia and the people who care for them.

Each *Walk* is led by a dedicated volunteer committee. Rebecca Dix, a family support worker for Axis Family Resources, is chairing the volunteer committee for the inaugural Cranbrook *Walk*.



Rebecca Dix

Rebecca was inspired to get involved after her grandmother was diagnosed with vascular dementia. "When I heard about the opportunity, I thought 'What

better way to get involved in my community and help families affected by dementia.'"

Rebecca hopes the event will raise awareness. "On May 6, people can expect to have a great time

getting involved with a cause that affects millions of individuals and families worldwide!"

By attending an *Investors Group Walk for Alzheimer's* event you are joining a community of courage that will change the face of the disease, build support and ultimately usher in a world without dementia. Join us, and make memories matter.

## Walk or sponsor someone else

The *Investors Group Walk for Alzheimer's* takes place on Sunday, May 6, 2018 in over 20 communities around B.C. Funds raised stay in B.C. and support programs, education and services in your community. They also help support research into the causes and the cure. Visit [walkforalzheimers.ca](http://walkforalzheimers.ca) to read your local honouree's story and learn how you can register and fundraise.

**You're invited**  
**BREAKFAST TO REMEMBER**  
March 7, 2018 VANCOUVER  
Fairmont Waterfront Hotel  
[breakfasttoremember.ca](http://breakfasttoremember.ca)

Keynote speaker – Jason McLean  
President and Chief Executive Officer  
of McLean Group

Sponsorship opportunities available.  
Contact: Hart Dashevsky  
Phone: 604-742-4925  
Email: [hdashevsky@alzheimerbcc.org](mailto:hdashevsky@alzheimerbcc.org)

**Alzheimer Society**  
BRITISH COLUMBIA



**WALK FOR  
ALZHEIMER'S**  
MAKE MEMORIES  
MATTER™

# 70,000 reasons to make memories matter!

Join us for the *Investors Group Walk for Alzheimer's* across B.C. on Sunday, May 6, 2018.

It's a fun and family-friendly way to create a movement while sending a message of inclusion and hope to the estimated 70,000 British Columbians currently living with dementia and the people who care for them.

**Event locations:**

- |                            |                          |                                  |
|----------------------------|--------------------------|----------------------------------|
| Abbotsford                 | Nanaimo                  | Smithers                         |
| Barriere and area          | Nelson                   | Tri-Cities & Ridge Meadows       |
| Burnaby & New Westminister | North Island (Courtenay) | Vancouver                        |
| Cranbrook                  | North Shore              | Vernon                           |
| Fort St. John              | Penticton                | Victoria                         |
| Fraser Valley (Chilliwack) | Port Alberni             | White Rock, North Delta & Surrey |
| Kamloops                   | Prince George            |                                  |
| Kelowna                    | Richmond & South Delta   |                                  |

**Register and fundraise today!**

Funds raised for the *Walk* will support programs, education and services in your community. They will also help enable research into the causes and cure.

**Alzheimer Society**  
BRITISH COLUMBIA

**1-800-667-3742**  
**walkforalzheimers.ca**

# Linda Healy: Behind the scenes at the Kamloops Resource Centre



For Linda Healy, the best part of volunteering for the Alzheimer Society of B.C. is “seeing people overcome the stress they have when they first walk through our door, and the relief they feel in knowing that they are not alone.”

If you’ve called the Kamloops Resource Centre, chances are you’ve heard Linda’s friendly voice. For almost 15 years, Linda has been a calming presence for the people reaching out for support.

Starting in 2003, Linda trained in one-to-one support for individuals and families living with dementia and has quietly become a mainstay of the Kamloops team. She volunteers three days a week in a variety of roles, but she’s much more comfortable talking about her

colleagues than herself, crediting “the camaraderie of the staff and other volunteers” for her long service.

While Linda is modest about her contributions, Tara Hildebrand, Support and Education Coordinator, is not. “Linda is involved in everything from one-to-one support to organizing support groups and workshops – and that’s even before you get to her work as Kamloops Committee Chair for the *Investors Group Walk for Alzheimer’s*,” Tara says. “Her wonderful sense of humour and the gift of her presence help us ease the heaviness that comes with the difficult conversations we have, which is incredibly important for the people we support.”

It takes a team to support British Columbians affected by dementia. Thank you, Linda, for being an essential part of our team.

### Read and learn more

Please visit the [Volunteer section](#) of our website to learn more about volunteering with the Society or call 1-800-667-3742.

## 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.

### Contact us to contribute content or to subscribe to receive *Connections* regularly.

- **Online** at [alzbc.org/connections-newsletter](http://alzbc.org/connections-newsletter)
- **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

You can help us reduce our costs by choosing to receive *Connections* by email.

### Are you a person with dementia?

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

### Need additional support?

The First Link® Dementia Helpline is a confidential province-wide support and information service for anyone with questions about dementia, including people living with dementia, their caregivers, friends, family, professionals and the general public.

**Email:** [supportline@alzheimerbc.org](mailto:supportline@alzheimerbc.org)

**Phone:** 604-681-8651; 1-800-936-6033 (toll-free)  
Monday to Friday, 9 a.m. to 4 p.m.