

Connections

Linking a community of dementia support



Managing dementia in difficult times

“I didn’t know what to expect” is a familiar refrain we hear from people – both people living with dementia and their caregivers – at almost every stage of the journey. Unpredictability often feels like the only constant of the disease, and everyone’s experience is so unique. Knowing you have a support network can be critical during difficult times.

This can be particularly important at times of the year that are stressful even when dementia isn’t a factor: when the seasons change, during the holidays, when our routines are interrupted, when things become hectic or complicated.

Knowledge is the most important tool for dealing with difficult times on the dementia journey. The more you know about the kinds of changes you might experience as the disease progresses, the better you and your family can prepare yourselves and develop strategies so you can face difficult and unpredictable situations with both feet planted on the ground.

Ask for help if you need it

The First Link® Dementia Helpline (1-800-936-6033) is available during challenging times – or anytime. Find help near you: alzbc.org/help-near-you

In this issue

Greetings & event calendar
Caregiver story

Page 2
Page 3

Caregiver tips
Get involved
Volunteer profile

Page 4
Page 6
Page 8

You don't have to face the difficult times alone

Welcome to *Connections*, our newsletter for people affected by or concerned about dementia. Our fall issue coincides with September – World Alzheimer's Month – when organizations around the world challenge the stigma associated with Alzheimer's disease and other dementias. The Alzheimer Society of B.C. is a part of this movement – and so are you! We're committed to a future without dementia; until that day comes, we are working together to build a dementia-friendly province.

Fall is a good time to think about change and plan ahead. This issue, you'll hear from a caregiver about her family's experience of the changes brought on by dementia, and two of our support group volunteers share their approach to giving support to people during difficult times. You'll find tips on navigating

the holidays with dementia and learn about opportunities to help raise funds to support people in your community – including the *Climb for Alzheimer's* fundraiser coming up on September 30.

Each issue of *Connections* is an opportunity to spread knowledge and grow our community of care. Share this issue with someone you know. Talk to them about meaningful ways to help us build a dementia-friendly province. This World Alzheimer's Month – and beyond – help us achieve our vision.



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



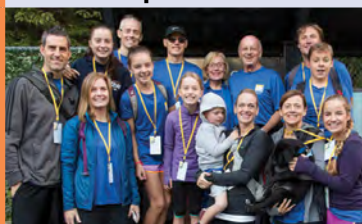
Investors Group Walk for Alzheimer's May



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

Managing dementia during difficult times: A caregiver's perspective

Jean Shirley, who is 81, cares for her husband Jim, who has been living with dementia since 2004. Jean shared how they respond to difficulties presented by the disease.

How did you first connect to the Alzheimer Society of B.C.?

I reached out to the Society for information and subscribed to the First Link® bulletin. That's how I first heard about Minds in Motion®, which we attend regularly in Langley. I've done some of the Society's dementia education and participate in a caregiver support group.

What are some of the challenges that you've experienced since Jim began to develop dementia?

In the beginning, the changes came slowly – it was just “small stuff,” such as Jim asking a question, forgetting and then asking again a few minutes later. That was the first thing I noticed, the first clue that there was a problem. As time has gone on, though, Jim began to have more general changes in memory and it became clearer what the issue was.

For a long time, the disease made slow progress, but I've noticed a significant decline in the last two years. Jim's biggest challenge is conversation. He enjoys being social but has trouble understanding what people are saying.

How do you cope with that?

We avoid group situations with a lot of strangers; with family, they know about Jim's dementia and the challenges that he's experiencing. We try to do family dinners because they make it easier for Jim to interact with other people. In smaller groups, Jim feels more



Jean and Jim at Christmas in 2016.

pressure to contribute to the conversation and often people don't seem to know what to say. In larger groups, there's less pressure for him to participate and for others to come up with something to say that he can follow. At a family dinner he can just sit back and listen.

Has connecting to the Society helped you face the changes?

Minds in Motion® has been enjoyable for both of us, particularly for Jim. It's an opportunity for him to get out and be social. I always sign up as soon as possible when new sessions start.

I've also really benefited from connecting with other caregivers at the support group. I can't talk to anybody – friends or family – about dementia, because they don't understand. You can't explain it to them. But in the support group, I can speak to and hear from other caregivers who understand what I'm going through.

Learn more

Want to find out more about support and education available in your community? Check the First Link® bulletin for your region: alzbc.org/bulletins

Caregiver tips: Holidays

September marks the end of summer and back to school. Fall and the holiday season – from Thanksgiving and Halloween to Hanukkah, Christmas or New Year's – is just around the corner. Holidays are an exciting time of celebration and connection with friends and family.

They can also be overwhelming. It is important to pace yourself and set aside quiet time to help ensure the well-being of both the caregiver and the person living with dementia. Here are some tips to help you have a successful fall and holiday season.



Visiting

Visiting family and friends can be enjoyable but can also be stressful for someone living with dementia. Here are some strategies to handle the stress:

- Try to anticipate what visitors will need to know if they will be staying with you – for example, not to leave the front door open if your family member is at risk of walking away and getting lost.
- If you are visiting an unfamiliar home, try to anticipate what you will need – for example, a sign on the bathroom door.
- Even in the flurry of holiday activity, try to stick to the person's routine as much as possible. For example, keep meal times and bed times the same. This can help calm and orient the person in the midst of all else going on.



Events

Holiday events and traditions can be an excellent way both to reminisce about old times and make new memories.

- Choose the occasions and traditions that are most important to you and your family and least disruptive for the person living with dementia.
- Consider having smaller gatherings and allow more time between events. For example, instead of having one large Thanksgiving dinner with everyone, consider having a few smaller dinners over a few days.
- Drinking alcohol in moderation may be fine for some people; however, keep in mind that alcohol can increase confusion and risk of falls. Consider serving non-alcoholic wine or beer.

Continued on page 5

Continued from page 4

Involving others

Ask friends and family for help! Don't feel like you need to manage everything related to the holiday season on your own. Some options might include:

- Think about hiring help for housework, care or cooking during the busiest times of the holiday season.
- Ask family members and friends to help with holiday preparations. Perhaps they can bring food, do some shopping or come early to set up. Practice accepting help if it's offered to you!

Involving the person living with dementia

Consider ways to involve the person living with dementia in holiday preparation and planning. Try to focus on the person's interests, skills and abilities. Some ideas include:

- Involve them in planning the menu for dinner. What are their favourite dishes?
- Ask them to help choose a holiday card to send out.
- If the person can no longer bake, perhaps they can still help by stirring batter or adding certain ingredients.

Self-care

It's important to remember to take care of yourself and ensure that the holidays are enjoyable for yourself as well. Things to keep in mind include:

- Take time to recognize the good work you do and how much you mean to the person you are caring for. Consider treating yourself.
- If people ask you what you would like for a gift, don't be afraid to offer some ideas for yourself; you deserve it! Some suggestions could be: gift certificates for restaurants, a homemade coupon for a free afternoon off or a spa treatment of your choice.



Encourage others

The holidays can be a difficult time of the year for families affected by dementia. Encourage the people in your life who may be visiting to learn more about the disease and how they can support you. The Alzheimer Society of B.C. offers opportunities for people to learn about dementia from home. Watch recordings here:

alzbc.org/education-recordings

**The First Link®
Dementia Helpline**

If you are living with dementia or have questions about the disease, call the First Link® Dementia Helpline at 1-800-936-6033. The helpline is available Monday to Friday, 9 a.m. to 4 p.m. Individuals and families in the South Asian community can receive culturally-specific support by calling the South Asian Dementia Helpline at 1-833-674-5003.

Be part of our team at the Climb for Alzheimer's

If doing the Grouse Grind® is on your bucket list, join us on September 30 for the seventh annual *Climb for Alzheimer's*, a fun, invigorating hike up the Grouse Grind® that raises funds to ensure families have access to vital programs and services while on the dementia journey. The *Climb*, which also helps advance knowledge through research, would not be possible without a dedicated group of passionate volunteers.

Sue Sami and Michael Buchan, volunteer co-chairs of the *Climb* committee, were inspired to get involved because of personal experience with the disease; Sue's father Prabhakaren lived with dementia and Michael's grandfather William is living with a diagnosis now.

Their multi-year commitment was inspired by the support they themselves have received; they know that fundraising is a vital way to support people affected by the disease. It's also an opportunity to raise awareness. "We want to educate our community about the disease and how they can get support," Michael says.

The committee's dedication is incredible. "It takes months of planning, recruiting and hosting pre-event fundraisers," says Sue. "Everyone on the committee is willing to give a helping hand," she says. "No matter how small or big the job is, you can count on volunteers to get it done." In addition to the organizing committee, approximately 40 volunteers help out on event day, arriving at 6 a.m. to set up

registration at the base of the mountain and the summit celebration at the peak. Volunteers handle everything from on-site logistics, registration and entertainment. "Watching it all unfold is priceless," Sue says. "It's amazing to see everyone come together to make the day special."

The committee is dedicated to ensuring that the event is accessible to everyone. People can participate and help fundraise without hiking the Grouse Grind® by registering for the Summit Stroll, a leisurely walk through the exhibits at the peak of the mountain. "On event day you see people from all walks of life, young and old," Michael says. "Most of them have a story to tell – that's when you realize you're not alone."

The *Climb* is an important part of ensuring that British Columbians affected by dementia are not alone on the journey. Fundraisers like the *Climb for Alzheimer's* give people an opportunity to become part of our movement.



Who will you climb for?

Register today as an individual or as a team and start fundraising by visiting climbforalzheimers.ca.

Make your coffee count with Coffee Break®!

You can make a difference to people affected by dementia this September and October by hosting a Coffee Break®. Coffee Break® is a simple and fun event that is as easy as inviting your friends, family and colleagues to enjoy a cup of coffee, tea or other treat in exchange for a donation. We'll even send you the coffee to get you started!

Your event can be exactly what you want it to be. You can make it big or small, by invite only, or open it up to the public. Whether it's a workplace, retirement home, school, community centre or in your living room, you can hold it wherever coffee or tea can be served and a donation collected!

When you host a Coffee Break®, you support Alzheimer Society of B.C programs and services to help people affected by dementia and help enable research into the causes of and cure for the disease. You'll be the crema of the crop!

Become a host

For more information or to order your complimentary host kit today, visit coffeebreakbc.ca or email coffeebreak@alzheimerbcb.org

The perfect holiday gift

With fall arriving and the holiday season fast approaching, support people living with dementia and their caregivers by making a gift to the Alzheimer Society of B.C.

Visit alzheimerbcb.org today to donate and to learn more about other ways to give, including:

- Joining our *Partners in Giving* monthly giving program
- Leaving a legacy gift
- Donating in memory or in honour of someone

To show your support, call 604-681-6530 or 1-800-667-3742, email giving@alzheimerbcb.org or visit alzheimerbcb.org.



Alzheimer Society
BRITISH COLUMBIA

From the facilitators: Finding support in difficult times

We provide over 100 support groups – both for people in the early stages of dementia and for caregivers – in communities across the province. This is only possible because of 135 volunteer co-facilitators like Janine Willemsen of Maple Ridge and Teena Love of New Westminster, who have been volunteering with us for more than five years.

“My role is to create and maintain a safe place for sharing all the emotions that caregiving brings up,” says Janine. “Often caregivers default to talking about the person they’re caring for; the group is a place where they can think about how *they’re* doing.”

Talking to other people affected by dementia can be an important resource when navigating challenges. “Caregivers are very sincere in what they want for the people they care for,” Janine says. “When it comes to the holiday season, it can be easy to have unrealistic

expectations.” In the support group, members encourage each other to be realistic. They remind each other that an event doesn’t need to be the same as it was in the past to be a success.

“Group members are good at reminding each other about the impact of changing seasons,” says Teena. “Differences in weather, light and length of day require finding and settling into new routines.”

For both Janine and Teena, the support groups are a place where creative solutions are valued. Members remind each other that even if the person you’re caring for is out of sync with the season or the event, it’s always possible to express and experience love.



Janine Willemsen



Teena Love

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.

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- **Online** at alzbc.org/connections-newsletter
- **Email** newsletter@alzheimerbc.org
- **Call** 604-681-6530; 1-800-667-3742 (toll-free)
- **Mail** to the Alzheimer Society of B.C.
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Vancouver, B.C. V5Z 1E2

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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.



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