

Connections

Linking a community of dementia support



Caregiving and self-care during COVID-19

COVID-19 has required us to review how we provide our support and education during a particularly challenging time for many people affected by dementia. While we may not be able to be with you in person, we want you to know you are not alone.

- The Society is rolling out tele-support groups across the province. If you are interested in participating in a tele-support group, please call the First Link® Dementia Helpline for more information.
- We have permanently extended the hours of the First Link® Dementia Helpline into the evening Monday through Friday.
- We are providing care and support by making more outreach calls to check in on First Link® clients.
- We are offering weekly webinars on topics of particular relevance to caregivers and people living with dementia at this time. Recorded webinars are also available in Punjabi.
- We have launched surveys of people living with dementia and caregivers – as well as of health-care providers – to hear directly from them about how we can meet their support needs at this time. (See next page to learn how you can participate.)

Read and learn more

For a full catalogue of COVID-19-related resources for people living with dementia, caregivers and health-care providers, visit alzbc.org/COVID-19.

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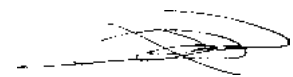
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Taking care of our caregivers

For many people living with dementia and the people who care for them, physical distancing measures to help stop the spread of COVID-19 have led to unforeseen challenges, mounting stress levels and an undeniable need for more self-care and support from those around them. As we move through another season and adjust to the “new normal,” it’s never been more important to take care of ourselves and our caregivers.

Just as every journey with dementia is unique, so are the experiences of caregivers and there’s no one-size-fits-all solution to helping relieve stress and provide much-needed support. If someone you know is caring for a person living with dementia and you’re not sure how to help them, try checking in and asking them what you can do. Listening is a great start. For caregivers, keeping well means practicing good self-care, recognizing the signs of burnout and asking for help. Call us. The Alzheimer Society of B.C. can be that lifeline.

In this issue of *Connections*, we outline self-care strategies and free mental health resources to help navigate this uncertain time. We also hear from Lloyd Jeck, a caregiver who shares the unique way he connected with his wife while unable to visit her care home, as well as a group of volunteers with messages of support for the caregivers they’ve been unable to see. No one knows exactly where the weeks and months ahead will take us, but we do know the only way there is together.



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



First Link[®]
DEMENTIA HELPLINE

Questions about dementia or memory loss?

English: 1-800-936-6033
Cantonese or Mandarin: 1-833-674-5007
Punjabi: 1-833-674-5003

English: Monday to Friday, 9 a.m. to 8 p.m.
Cantonese or Mandarin and Punjabi: 9 a.m. to 4 p.m.



We want to hear from you! As part of our ongoing evaluation of First Link[®] dementia support being undertaken by researchers at UBC, we have just launched a survey which focuses on the impact of the pandemic on people living with dementia and their caregivers. We invite you to complete this short survey and share your views and experiences with us: <http://bit.ly/firstlinkcovid>.

Staying connected from a distance



Lloyd and his wife Evelyn at her care home Christmas party in December 2019.

Lloyd Jeck and his wife Evelyn will celebrate their 62nd wedding anniversary this year. Evelyn is living with dementia and moved into long-term care in 2018. Lloyd is finding alternative ways of staying connected with Evelyn during the COVID-19 pandemic, including writing her poetry, shared on page 7. During this time, Lloyd, his family and friends also showed support by joining the online IG Wealth Management Walk for Alzheimer's and raising more than \$5,300 for people affected by dementia.

When did your experience with dementia begin?

We started noticing signs of dementia in 2012 and Evelyn was diagnosed with Alzheimer's disease in 2015. Initially after the diagnosis, we were still living in the country on a 24-acre piece of property. As time progressed this became problematic. I enjoyed being outside and Evelyn would become concerned if I was out of sight for too long. We bought two-way radios but eventually the buttons became confusing to her. So, we sold the acreage and bought a home right in town. Evelyn lived with me there until 2018 when she moved to a local care home.

How did you get connected to the Society?

It was through the local Resource Centre in Kamloops. Tara, the Support and Education Coordinator, would go to Clearwater occasionally for a caregiver support group with the Alzheimer Society of B.C. The group has been suspended due to the COVID-19 outbreak, but I still receive support calls from the Society.

What are some of the challenges you've experienced since the COVID-19 pandemic?

I find the isolation and lack of personal contact with Evelyn challenging. The last time I was able to visit Evelyn in the care home was March 19. We've had the occasional phone call and in recent days I've been able to visit her outside with a locked gate between us – that's certainly better than a phone call.

Sometimes it's confusing for Evelyn. It's difficult for her to comprehend all this. I do prefer visiting her inside because I can read to her. Before the outbreak, I was reading short stories to her, which she valued. I do appreciate this progression to visiting across the gate and I'm looking forward to being able to visit Evelyn in the room again soon.

Are you finding other ways of staying connected?

Since I've retired, I've written three books. I'm not really a poet, but I did put some words together for Evelyn. Being a schoolteacher, she has helped me tremendously in my speech, my writing and in my outlook on life. She has always been there to support me.

Initially when I wrote a poem during COVID-19, I was prohibited from visiting her – so I sent it to the staff via email. The poem was read to Evelyn several times. When I visited at the gate, I asked her about it and she seemed to remember.

What are some words of advice you have for other caregivers?

I've benefited from staying in touch with people from the support group. I know several of them quite well. I connected with one of them recently and we had a really good conversation. His situation is different from mine, but certainly he has been experiencing similar emotions. It's important to stay connected with people who understand, and I do appreciate the ones who keep in touch. We have to carry on right now and do the best we can.

Supporters look to monthly giving during times of economic change

Many people who donate to the Alzheimer Society of B.C. have had dementia touch their lives directly. Darwin, a donor in Burnaby who recently signed up to give monthly, is no exception. Many of his family members have lived with dementia, including his mother Minnie.

Giving monthly was a simple decision for Darwin.



Darwin

“Rather than making one payment, doing it this way isn’t a lot per month, and it will actually add up to more in the end,” he says. “You just set it up then you don’t need to think about it. Plus, I like that it helps give the organization a dependable budget each month.”

“Mom had [dementia] for a long time and spent the last years of her life in full-time care,” Darwin says.

“By the end, she had lost her speech and was unable to recognize anybody.”

Supporting work that helps alleviate stress for caregivers is a big reason he chose to support the Society. The dementia journey was stressful at times for Darwin and his family. He recognizes that stress itself can lead to medical problems, which is something he saw with his father.

COVID-19 has also emerged as a reason people may choose to donate on a monthly basis. It has created a less certain financial situation for many donors, who are choosing to switch to a smaller monthly donation in order to spread their giving out in a manageable way.

To learn more about monthly donations, please call 604-742-4906, toll free 1-800-667-3742 or visit alzheimerbc.org.

Have fun while fundraising from home!

With physical distancing a priority during the pandemic, many of you have asked about how you can continue to fundraise at this time. Hosting your own fundraiser through *Anything for Alzheimer’s* is a great way to continue supporting British Columbians living with dementia. Here are some ideas:

- Host a special event such as a virtual dinner party, book club or a coffee break via video chat, with participation by donation.
- Engage a local musician and livestream a concert, with tickets by donation.

- Hold a virtual scavenger hunt, a contactless bake sale or a front yard talent show with your family.
- Clean out your closets or the garage then sell your items in a virtual garage sale.
- Grow a beard, cut your hair or embark on a long-distance walk and collect pledges in support of your challenge!

Remember to personalize your message, share your event on social media, tag [@AlzheimerBC](https://twitter.com/AlzheimerBC) and use [#AnythingforAlzheimers](https://www.instagram.com/AnythingforAlzheimers) – and of course celebrate your fundraising milestones!

Register at AnythingForAlzheimers.ca.

IG WEALTH MANAGEMENT
WALK FOR ALZHEIMER'S

WALK ONLINE 2020

Thank you to all of our participants, donors, sponsors, patrons and volunteers who made the first *IG Wealth Management Walk for Alzheimer's* online a success!

On Sunday, May 31, Canadians showed that no matter what the world looks like, we are still united to support people affected by dementia.

Funds raised are instrumental to helping us provide support and education in communities across British Columbia.



National title sponsor



Provincial sponsors



RETIREMENT CONCEPTS

Regional sponsor



Media sponsors



Alzheimer Society
 BRITISH COLUMBIA

Recognizing caregiver stress and avoiding burnout

We've heard from many caregivers that this has been an incredibly stressful time. Many family caregivers find themselves caring for someone at home without their usual support networks or community programs. Others may worry about the safety of a relative who is living independently in the community with decreased levels of assistance or support, or those in long-term care homes where they are unable to visit.

Over time, this prolonged exposure to stress can negatively affect your physical and mental health, leading to burnout. If you are feeling this way, you are not alone.

Self-care tips

Stick to a routine. Both you and the person living with dementia will benefit from a regular and predictable daily routine. Maintain a consistent bedtime and get up at the same time every morning. Eat meals at consistent times. Schedule physical activity, rest times, social time and purposeful activities into each day.

- **Avoid information overload.** While it is important to stay informed on the news of the day, too much information can become overwhelming. Limit your news to reputable sources and consider setting a time limit or scheduling times into your daily routine to get caught up on the news.
- **Plan physical breaks and book respite time.** This may include asking your network of family or friends (dependent on physical distancing guidelines) or your case manager, if applicable, for support. Be sure to let your case manager know how you're really doing and speak to them about respite options available through home care.



- **Try relaxation techniques.** Activities such as visualization (picturing a place that is peaceful and calm), meditation, breathing exercises or progressive muscle relaxation (tightening and then relaxing each muscle group from one end of your body to the other) may help you relax. You can download free meditation applications for your smartphone such as Insight Timer, Smiling Mind, or Headspace which contain a library of guided meditations, relaxing music and talks.
- **Get support for yourself.** It is important that you get support for your experiences. Identify a trusted family member or friend who can be there for you when you are feeling overwhelmed, frustrated or tired and need a listening ear. Sometimes just knowing there is someone you can call for support is enough to boost your resilience. You may also choose to use formal mental health supports, such as the options listed here.

Free resources to support your mental health

- Our First Link® Dementia Helpline is available Monday to Friday, 9 a.m. to 8 p.m. to provide information and support at 1-800-936-6033. Service is also available Monday to Friday, 9 a.m. to 4 p.m. in Cantonese or Mandarin at 1-833-674-5007 and Punjabi at 1-833-674-5003.
- Connect with your family doctor, who may be able to provide a virtual mental health check-in.
- The British Columbia Psychological Association is offering a free Psychological First Aid Service for any B.C. resident (including health-care workers) experiencing stress, anxiety or uncertainty due to COVID-19. Fill out a form on their website at psychologists.bc.ca/covid-19-resources or call 1-604-827-0847 to access this service.
- The Canadian Mental Health Association has several programs as well as community counselling, mental health check-ins and peer support. Visit their website <https://cmha.bc.ca/covid-19/> for a full listing of resources.
- Call the Mental Health Support Line at 310- 6789 (no area code) to connect with your local B.C. crisis line without a wait or busy signal, 24 hours a day. Crisis line workers are there to listen and support you as well as refer you to community resources.
- Access Crisis Centre Chat at crisiscentrechat.ca to chat online with a crisis responder. It's available from noon to 1 a.m. every day.
- Anxiety Canada has created a free mobile application called **MindShift™ CBT** that uses strategies based on Cognitive Behavioural Therapy to help users learn to relax and be mindful, develop more effective ways of thinking and taking charge of anxiety.

Love Beyond The Water

Caregiver Lloyd Jeck (see interview, page 3), wrote this poem for his wife Evelyn, who lives with dementia in a care home that he has been unable to visit during the pandemic.

The winds that blow between us now
Were brought on by a terrible foe
One which has no fear no sureness
It cares not how it strikes us down.

Two spirits now in sep-rate domes
Leaves me now a broken soul
The days are long without your hand
Entwined in mine like treasured gold.

I know it hurts the pain cuts deep
For you and me we are apart
In sleep I dream of days gone by
And wish for those sweet times again.

The dawn will come the sun will shine
On you my dear and you'll be mine
Like times before the stars are there
And moonlight glow will light the way.

We then can walk in duo step
On sandy shores by waters tide
And far away beyond the waves
The goal we seek is there for us.

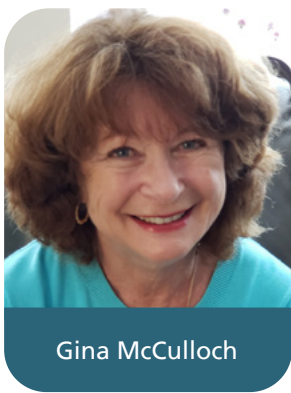
Our thoughts are there on mountains high
The clouds are soft behind our backs
Your eyes now turn and look in mine
Our hands entwine in perfect clasp.

The wind has died and chills no more
Warm waters here soothe weary souls
No longer do we stand alone
God brings us through to share again.

©Lloyd Jeck 2020

Volunteers send messages of support

Volunteers are at the heart of everything we do, and the meaningful relationships they build make our communities so special. While our in-person groups have been unable to meet in recent weeks, volunteers, including the caregiver support group facilitators below, have submitted letters discussing what they miss about their role and messages to the group members they miss. Read the full letters at alzbc.org/COVID-stories.



Gina McCulloch

“My thoughts frequently turn to our group members as we are no longer able to lean on each other for support and understanding. I hope each of you realize that while we aren’t together in body, we are still together in spirit. I easily recall each member and the issue that was weighing on their mind

at our last get-together. We volunteers remember you. We share your journey even though we can no longer sit beside each other.”



Sandra Hentzen

“As a volunteer, I look forward to meeting with family caregivers and listening to the shared experiences. I miss being present with brave and caring individuals as you go through this heart-wrenching journey with positivity and growth. Stay strong, stay safe, make sure you practise self-care more now than ever. I think of you often and look forward to connecting with you all.”



Janis Wright

“I want all support group members to know that we volunteers are thinking of you during this challenging time, wishing we could be there for you. I miss the camaraderie, the laughter, as well as the tears. We connect in a meaningful way because there is a special closeness that develops when people feel safe enough to share their fears. I miss all of you!”

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.
300-828 West 8th Avenue,
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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