

Connections

Linking a community of dementia support



Keeping well and coping with changes during COVID

As we move into another season affected by the COVID-19 pandemic, the Alzheimer Society of B.C. continues to look at the ways we're able to provide support. We want anyone affected by dementia, including families affected by restrictions to care home visits, to know that they're not alone. Please connect with us through:

First Link® Dementia Helpline: Following our expansion earlier in the year, the Helpline continues to operate into the evening Monday through Friday (9 a.m. until 8 p.m.), with support available in Cantonese, Mandarin and Punjabi from 9 a.m. to 4 p.m.

Tele-support groups: We are continuing to roll out groups across B.C. If you are interested in participating, please call the First Link® Dementia Helpline for more information.

Outgoing support calls: We are providing care and support by making more outreach calls to check in on First Link® clients.

Webinars: We continue to offer weekly webinars, including on such topics as: Accessing care services during COVID-19, Building caregiver resilience and Activities to do at home. Recorded webinars are also available in Punjabi. Visit alzbc.org/webinars for details.

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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Staying connected in long-term care

While British Columbians continue to establish new routines and adjust to changing guidelines in place to stop the spread of COVID-19, for many people affected by dementia, this remains an exceptionally difficult time.

We have heard directly from families on the difficult situations they find themselves in, especially when it comes to the restrictions around visitation in long-term care. Families want to ensure the person in care is safe by following the necessary infection and physical distancing protocols, while also taking care of their overall well-being by finding ways to stay connected. Following infection controls is paramount, but we know visitation restrictions and increased loneliness can have serious negative consequences for both people living with dementia, and the people who care for them.

This issue of *Connections* takes a closer look at long-term care in B.C., the challenges of staying connected with someone living with dementia in a care home and tips to help advocate for someone if you aren't comfortable with a decision made about their care.

We also hear from caregivers who stepped up for our first online *Climb for Alzheimer's* to create change while we're apart by hiking in communities across B.C. Finally, we're pleased to announce our upcoming *Telethon for Alzheimer's*, a new opportunity for members of the Chinese community to connect virtually and support other families. It will be broadcast nationally in Cantonese on Fairchild TV on November 7.

On a personal note, after seven years with the Alzheimer Society of B.C., I'll be starting a new chapter as I join Family Services of Greater Vancouver as its CEO. I'm so proud of the work we've done together, of the steps we've taken to improve the lives of people affected by dementia. Though I am leaving the organization, I am definitely not leaving the cause!



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.



Visiting in long-term care during COVID-19: A caregiver's perspective



Dick and Pat Fairbanks

The last few months have been challenging for people who live in care homes and their caregivers, unable to visit as they usually would due to COVID-19 restrictions. Dick Fairbanks from Lake Country is one of these people. Recently, Dick shared his thoughts about the challenges presented by the COVID-19 pandemic while caring for his wife, Pat, in long-term care.

When did your experience with dementia begin?

Pat was diagnosed with dementia about six years ago. The last two years Pat was living at home became very overwhelming. One night, I woke to find her bed was empty. Her shoes were still there but the flashlight was missing. Four hours later, we found her in the trash room. She moved into long-term care in March 2019.

Have you been able to visit your wife in long-term care since the COVID-19 pandemic began?

I haven't seen Pat for more than six months now. The care home offered me a chance to visit and sit across the table from Pat, but we'd have to wear face masks and wouldn't be allowed to touch each other. I know

what this would do to us. We've always held hands and shared a kiss and a hug. Now, I wouldn't be able to do that. I'm afraid it would upset her too much. So, I've stayed with the virtual meetings on Skype.

How do you find the virtual meetings?

Most of the time she knows I'm her husband, but she's forgotten my name now. She had two serious falls recently and ended up in hospital. Her face was black and blue, her right eye swollen and her dentures were broken in half. I could only keep her awake for two minutes at a time. Those things really tear me up. I wouldn't wish it upon my worst enemy.

Are there things that make you feel better during these difficult times?

When I feel distressed, I go for a ride on my scooter. Although I'm lonely, it satisfies me a little bit. I also read a lot because it takes my mind off things.

The staff at the Kelowna Resource Centre always leave me with a warm fuzzy feeling. They still phone me and always go that extra mile.

Do you have any tips or advice for other caregivers?

If I had one piece of advice, it would be to love them right to the end. They need it and you need it. If my experience could help one person, I'd be happy. That's what it's all about – we try to help each other over the bumps. It's a terrible disease but with support and help you'll get through it.

It is with great sadness that we share the news of Dick's passing shortly after this interview was written. We would like to send our deepest sympathy to Pat and their family at this incredibly difficult time.

Spotlight on long-term care



Here in B.C., the COVID-19 pandemic has disproportionately affected people living in long-term care, with devastating outcomes experienced by many families. The increase in media attention has shone a light on both the gaps and shortcomings of long-term care, as well as the incredible dedication and resilience of health-care providers working in difficult circumstances. It has sparked important conversations, here in B.C. and throughout Canada.

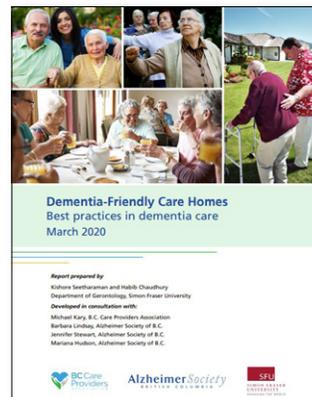
In B.C., approximately two-thirds of the long-term care population are people living with dementia. We know the restrictions around visitation, while important to control the spread of COVID-19, have been extremely difficult for families and people living with dementia, and bring with them a host of challenges and a range of emotions. The Society's view is that family members are an integral part of health-care teams.

We believe people living with dementia have the right to enjoy the highest possible quality of life and quality of care, and we are looking for ways to work with government and other community partners to ensure concerns raised by families and shared in the media are being addressed. We are listening, learning about the challenges and actively providing education to families, individuals and health-care providers.

The concept of person-centred care should be at the core of any reform efforts. Person-centred care recognizes that individuals have unique values, personal history and personality and that each person has an equal right to dignity, respect and to participate fully in their environment.

In this spirit, the Alzheimer Society of B.C. collaborated with the BC Care Providers Association and the SFU Department of Gerontology earlier this year to create a report titled, "Dementia-friendly care homes: Best practices in dementia care." Written prior to COVID-19, the report outlines a variety of recommendations that care homes can implement to improve the quality of life for people living with dementia. The full report can be accessed here:

alzbc.org/DFCH-report



Advocacy strategies when coping with changes

The changes to care home visitation rules limiting how and when you can visit your family members or friends can make you feel like you've lost control. There may be times when you find it difficult to accept this new reality. Other times, it may come more easily. Recognize that you are doing the best you can in incredibly difficult circumstances.

Advocacy strategies continued

If you find yourself in a situation where you aren't comfortable with a decision made about the care of someone living with dementia, such as changes to medication, routine or visitation, you may wish to consider the following strategies:

- Make sure you understand the whole situation. Ask questions, listen carefully and get all the details.
- Gather your thoughts before a conversation. Find out who has the power to change the situation, and ensure you are addressing your concerns to the right person. Make notes and focus on the facts as objectively as possible.
- Humanize the concern. Make sure the person you are talking to (or writing to) understands the effects of the situation on the person living with dementia and their family.

- Avoid arguing but be persistent. This can be hard to do. It's important to maintain positive and professional relationships with the care team.
- Express your appreciation. It is a difficult and stressful time for the health-care providers as well. They are doing the best they can in unprecedented times. Acknowledge those who help you.

Looking for more information on long-term care visits? We created a three-part information sheet with tips and considerations to help you before, during and after your visit. Read more at alzbc.org/visitingLTC

The BC Care Providers Association has also released a guide for supporting family visits during COVID-19, available at alzbc.org/bestvisit

We want to hear from you! How have your visits been going? Are there any issues you are facing? Connect with us to share your stories and experiences of long-term care during this time at advocacy@alzheimerbc.org.

Share your experiences to help others affected by dementia

Apply to our B.C. Leadership Group of Care Partners

Are you a care partner interested in sharing your voice to make a difference? We're recruiting members for our Leadership Group of Care Partners. These group members meet regularly with us to provide invaluable guidance on Society programs and initiatives. Email advocacy@alzheimerbc.org to learn more.

Participate in dementia research

By participating in research as a person directly affected by dementia or someone interested in making change, you can help shape the future of dementia in Canada. REACH BC is a new online platform where volunteers interested in participating in research can connect with health researchers and browse research opportunities across British Columbia. To access the REACH BC portal and learn more, head to reachbc.ca.

Climbing for Alzheimer's

Each September for the past eight years, committed supporters have climbed North Vancouver's Grouse Mountain for the *Climb for Alzheimer's*.

This year's event adapted to physical distancing protocols and, for the first time, people across the province took part by hiking in their community. From July 21 to September 21, hundreds of intrepid participants hiked to show the estimated 70,000 people living with dementia in B.C. that they are not alone on their journey and to raise funds for the Society.

Trails for this year's *Climb* ranged from Squamish's beautiful Crooked Falls, to the challenging Pierce Lake in the Fraser Valley. Other hikers explored local parks, traversed the seawall and even walked in their own backyard! Whatever way our hikers took part, each step contributed to this year's collective goal of 70,000 kilometres across B.C.

Some hikers set themselves their own personal challenge. Masami Yakata from Langley, B.C. hiked to honour her mother, Masako, who is living with dementia in Kyoto, Japan. Feeling frustrated that she has been unable to be with her family since COVID-19 began, Masami was keen to make a difference in some way and set herself a 300 kilometre challenge. Her friends and family were incredibly supportive, and she surpassed her \$150 goal – raising over \$1,000 in just four weeks!

"I've been overwhelmed with gratitude," Masami says. "This disease has hit close to home for so many of us."

One of the *Climb's* youngest fundraisers was Talia Yorish, who spent her eleventh birthday climbing the notorious Grouse Grind®. This is the third year that Talia has taken on the challenge to honour her



Masami Yakata and her mother Masako

grandmother, Mariam, who passed away from Lewy body dementia this year.

"My grandma was the funniest and she always made me laugh. She was always smiling and laughing until she left us and I'm thankful for all those memories," Talia says.

Talia has been one of the event's top fundraisers for two years in a row. She shares her motivation: "I want to raise awareness of the challenges and struggles that families affected by dementia have to face and show that these challenges can be conquered too."

Thank you to all our participants and supporters for their continued dedication! The funds raised through the *Climb for Alzheimer's* will allow us to provide programs and services to people affected by dementia, while enabling research into the causes and cure for the disease. With the number of people living with dementia increasing, this need is critical. Donations can be made until October 31, 2020. If you would like to donate, visit: climbforalzheimers.ca.

Thank you to the kind generosity of our sponsors, Neptune Terminals and Ecclesiastical Insurance, and our anonymous match donor.



Join us at home for the Telethon for Alzheimer's

When COVID-19 curtailed the Alzheimer Society of B.C.'s annual *Charity Dinner for Alzheimer's*, the Society's volunteer Chinese Advisory Committee as well as staff who support the event seized an opportunity to connect in a new way with the Chinese community. The team pulled together with media partners to plan the *Telethon for Alzheimer's*, an 80-minute Cantonese-language variety program to be broadcast nationally on Fairchild Television on November 7. The program features interviews with researchers and families affected by dementia, as well as vignettes from people making a difference in the lives of others living with dementia.

The telethon is a culmination of years of dedication from the Society's Chinese Advisory Committee, formed in 2016 to help grow language- and culturally-specific resources, as well as share knowledge and garner support from within the Chinese community.

"When we started, only people directly connected to the disease were aware of the Society," says Tony Yue, a founding member of the Advisory Committee.



Tony Yue

"We needed to make a major connection to the community."

While the Society has seen growth in the number of people accessing Chinese resources and support, there is still work to be done in removing language and cultural barriers. The telethon is chance to make important progress.

"The more people understand about the disease," Tony says, "the less fear they have."

Tune in to the *Telethon for Alzheimer's* Saturday, November 7, at 7:40 p.m. on Fairchild Television. Thanks to the generosity of anonymous donors, all donations made will be matched up to \$50,000. For every donation of \$50 or more, receive a limited-edition face mask from the Society while supplies last. Learn more at alzbc.org/TelethonForAlz.

For information and support in Cantonese or Mandarin, contact the First Link® Dementia Helpline at 1-833-674-5007, Monday to Friday, 9 a.m. to 4 p.m.

A record number of Canadians are making wills

A byproduct of COVID-19 is that many people are using their extended time at home to complete tasks on their to-do lists. Making a will is often at the top of the list, so it isn't surprising that a record number of Canadians have been creating and updating their wills.

Many Canadians are choosing to leave a charitable gift, as a planned gift, in their will. This is an amazing way to make a major impact and leave a lasting legacy, and many donors are surprised by the tax benefits of making a planned gift.

We are here to help with any questions you have about making this type of donation. There are many

ways you can use a portion of your assets to benefit both your family and the charity you care about. We also strongly recommend that if you are considering a planned gift you speak with a financial advisor to ensure you are making a donation best suited to your individual situation.

If you have questions about leaving a gift to the Alzheimer Society of B.C. in your will, please contact Leona Gonczy at 604-742-4926 or email lgonczy@alzheimercbc.org. If you have already included the Alzheimer Society of B.C. in your will, we'd love to hear from you. You can learn more about planned giving at alzbc.org/leave-legacy.

A message to our volunteers

As a charity, our efficiency, versatility and the quality of our programs relies on the diverse contributions of talented and dedicated volunteers. As volunteers, you strengthen our ability to grow and serve more people affected by dementia. Thank you for showing people on the dementia journey that they're not alone.

Staff and volunteers, as a team, make it possible to facilitate the programs and services needed to support people living with dementia and their caregivers. It is difficult not knowing how long the pandemic will continue to affect our community. Together, we share concerns about providing continued support during

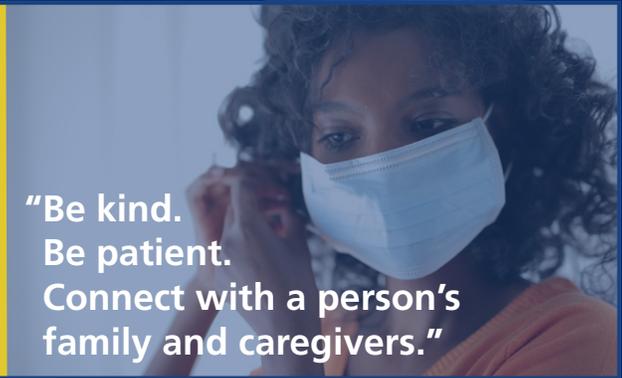
COVID-19 and are taking every measure to ensure the ways we provide this vital support are safe.

We recognize and value the powerful relationship we share. We look forward to when we can safely resume in-person programs and volunteer roles. During this time, we encourage volunteers to join us in staying up to date on the latest information and education about dementia, as well as how we are supporting people facing the disease through our online resources. To join our weekly webinars, access previously recorded videos or learn more about upcoming guest speakers, visit alzbc.org/webinars.

How can you help support family caregivers of people living with dementia?

Visit alzbc.org/HCP-COVID for health-care provider resources.

We want to hear from you. Share your experiences of caring for people living with dementia during COVID-19 at alzbc.org/HCPsupport.



"Be kind.
Be patient.
Connect with a person's
family and caregivers."

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
- **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

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.



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