## First Link<sup>®</sup> Bulletin Your link to dementia support

**October – December 2020** 

# Sundowning, late day confusion and sleep disturbances



As we step into autumn and the days are getting shorter, caregivers may experience noticeable changes in the behaviour of the person living with dementia. The change in behaviour, commonly known as sundowning, may cause someone to be confused, anxious, aggressive, agitated or restless later in the day.

Being unable to distinguish the day from night may cause disruption to sleep and wake patterns, while having little or no activity in the afternoon may lead to restlessness later in the day.

Caregiver sleeping cycles may also be affected, whether from a lack of sleep related to the stress of caregiving or being kept awake at night by the person living with dementia.

Learn ways to respond to sundowning on our website at <u>https://alzbc.org/2ZIAkh2</u>. Here are some strategies that you can try:

- Provide adequate lighting to lessen shadows when it begins to get dark.
- Allow for rest and naps between activities.

- See inside for dementia programs in Vancouver Island
- Maintain a regular eating and sleeping schedule as much as possible.
- Restrict the amount of caffeine and sugar consumed in the morning.
- Brisk walks or physical activity throughout the day may reduce restlessness or the need to wander later in the day.

Visit <u>https://alzbc.org/3hLncyv</u> for more information on how sleep affects dementia and for strategies that you can share with families affected by sleep issues. You can also access additional information and support by calling the First Link<sup>®</sup> Dementia Helpline.

Questions about dementia or memory loss?			
<b>First Link</b> <sup>®</sup>			
English	1-800-936-6033 9 a.m. to 8 p.m.		
Cantonese and Mandarin	1-833-674-5007 9 a.m. to 4 p.m.		
Punjabi	1-833-674-5003 9 a.m. to 4 p.m.		

# Thank you to everyone who participated in the *Climb for Alzheimer's* this summer!

This year, the *Climb* was held virtually across British Columbia. Participants united to raise funds and achieve a collective goal of covering 70,000 kilometres on trails around the province to show the 70,000 people living with dementia in B.C. they're not alone on their journey.

Thank you to everyone who supported and fundraised this event. Read more about what two participants experienced and who they honoured at the event.







#### Masami Yakata's story



Long-distance caregiving can be emotionally and mentally challenging. This is no different for Masami Yakata, who lives and works in Langley, B.C., while caring for her mother Masako who is living with dementia in Kyoto, Japan.

"It hasn't affected my everyday routine, but emotionally I'm feeling helpless," she explains. With the pandemic, she is unable to visit her family, which has heightened many of these emotions. "Every time I see my brother posting their struggles from Japan, I feel sick to my stomach not being there physically."

Feeling frustrated that she was unable to be with her family and provide help in person, Masami was keen to make a difference in some way. The opportunity struck her one day while on Facebook, when a friend who experienced a similar journey with their mother announced they were taking part in the *Climb for Alzheimer's*. She seized the opportunity and registered for the event straight away.

Masami set herself the goal to walk or jog 450 kilometres by September 21: World Alzheimer's Day. Since sharing her story on her fundraising page, her friends and family have been overwhelmingly supportive.

"I've been overwhelmed with gratitude," she says, "This disease has hit close to home for so many of us." To read the full story, visit: <u>https://alzbc.org/3gcJ7gP</u>.

#### **Talia Yorish's story**

Not many ten-year olds would consider fundraising on their birthday while climbing up the notoriously challenging Ground Grind<sup>®</sup> in North Vancouver. But young Talia Yorish is determined to make a difference and help the thousands of families across the province who are affected by dementia.

"Every year the *Climb for Alzheimer's* falls on or close to my birthday, so conquering Grouse Mountain is my own present to myself," Talia explains. "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."

Talia first took on the challenge in 2018 after witnessing how Lewy body dementia affected her grandmother, Mariam. Talia recalls how it quickly affected Mariam's memory and eventually, her ability to eat or go to the bathroom by herself.

This year's event has particular importance to her as, sadly, Mariam passed away this past April. Talia is taking part in the challenge this year to honour her grandmother.

"The *Climb* is a big challenge for me, just like the challenge that all families in B.C. that have a family member living with dementia face. There is no cure for dementia and I want to raise money to help this important cause and to find a cure. Every dollar counts! Let's kick dementia's butt!" To read the full story, visit: <u>https://alzbc.org/3kFWGYL</u>.



Talia Yorish and grandmother, Mariam







### Learn about dementia from anywhere in our live weekly webinars

Have your dementia questions and concerns answered by our specialist staff at our free dementia education webinars, now available weekly. Receive tips, learn strategies and share experiences with other participants. All you need is a computer, tablet or phone!

To register for our upcoming webinars or watch recorded videos from previous webinars, visit our website at <u>www.alzbc.org/webinars</u>.



Learn about dementia from anywhere by participating in our live webinars

Webinar	Date
<b>"Sundowning" (Late-day confusion)</b> – Learn the signs of "sundowning" caused by dementia and explore strategies for managing late day confusion.	Wednesday, October 7 2 – 3 p.m.
Brain health talk with Dr. Heather Palmer – Learn about brain health and how to maintain a healthy brain with guest speaker, Dr. Heather Palmer, Amica's National Director for Cognitive Well-Being.	Wednesday, October 14 2 – 3 p.m.
<b>Delusions, hallucinations and visual mistakes</b> – Explore strategies for responding to delusions, hallucinations and visual mistakes caused by dementia.	Wednesday, October 21 2 – 3 p.m.
More than a visitor: Care planning in a changing environment – Learn the rights and responsibilities of visitation and explore strategies to assert yourself as a valuable member of the care team.	Wednesday, October 28 2 – 3 p.m.
How to support a friend who has dementia or is a caregiver – Practical tips on how to offer support to a person living with dementia, their caregiver or family. For the general public.	Wednesday, November 4 2 – 3 p.m.
<b>Preparing for the holidays during COVID-19</b> – Explore strategies for adapting your plans to minimize stress.	Wednesday, November 18 2 – 3 p.m.
<b>Lived experience: Living with dementia during COVID-19</b> – Hear from people living with dementia as they share the impact of COVID on their lives.	Wednesday, November 25 2 – 3 p.m.
Virtual visits: Making the most of virtual visits – Explore strategies to maximize success when video calling.	Wednesday, December 2 2 – 3 p.m.
<b>Long distance caregiving</b> – Practical tips on providing meaningful caregiving support from a distance. For caregivers.	Wednesday, December 9 2 – 3 p.m.
<b>Driving and dementia</b> – Learn how dementia may affect a person's driving abilities and strategies to ease the transition for driving cessation. For caregivers and people living with dementia.	Wednesday, December 16 2 – 3 p.m.







Brain health tips with Dr. Heather Palmer this October 14



The brain is one of your most vital organs, playing a role in every action and every thought. Just like the rest of your body, your brain needs to be looked after. It's never too soon or too late to make lifestyle changes that will maintain or improve your brain health.

To learn more about brain health and what you can do to reduce your risk of dementia, join us on October 14 at 2 p.m. as we welcome Dr. Heather Palmer, Amica's National Director for Cognitive Well-Being, to talk about dementia risk and how to maintain a healthy brain. Register for this webinar at www.alzbc.org/webinars.

For more tips on how to support your brain health, visit: <u>https://alzbc.org/3cd00rk</u>.

#### Hear from our webinar participants!



"I learned so much and can really feel empathy towards people dealing with dementia in themselves and in their loved ones. You will be better equipped for whatever you face professionally and personally. The discussions that the webinars inspire amongst our attendees have been very community-building: they are not alone! - Cassandra V., library adult programming coordinator

"The webinar gave me the understanding that my reality and my mother's are no longer the same and I have to adjust my reality to keep her healthy, mentally and physically, and happy. The question and answer period were most interesting, giving an insight of what other challenges people are having and sharing ways of coping, conflict management and support. [The webinars] will remove negative emotions and replace them with understanding, coping strategies, support and the love that was once there." - Melissa C., caregiver



"It's been an overwhelming experience, but at least I have information that I can get. I'm grateful to have support out there. The webinars are fantastic and to be able to access them from your home is wonderful." - Linda H., caregiver







### Connect with other caregivers by phone through our tele-support groups

In response to COVID-19 and the temporary suspension of in-person support groups, the Alzheimer Society of B.C. will be offering regional and provincial telephone support groups for caregivers. Please see information below regarding the groups available to you and information regarding how to register.

Please note that the schedule is subject to change due to holidays or other conflicts. You will be notified by your facilitator upon registration.

### Vancouver Island tele-support groups

Tele-support group	Date	Registration		
Vancouver Island tele-support group Open to anyone in Vancouver Island who is currently caring for a person living with dementia.	<b>2nd Monday of the month</b> 7 – 8 p.m.	For information or to register, contact the First Link® Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
Vancouver Island tele-support group Open to anyone in Vancouver Island who is currently caring for a person living with dementia.	<b>3rd Thursday of the month</b> 10 – 11 a.m.	For information or to register, contact the First Link® Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
Vancouver Island tele-support group Open to anyone in Vancouver Island who is currently caring for a person living with dementia.	<b>4th Tuesday of the month</b> 2 – 3 p.m.	For information or to register, contact the First Link® Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
Provincial tele-support groups				
<b>Provincial long-term care tele-support group</b> Open to caregivers anywhere in B.C. who are caring for a person living with dementia in a long-term care home.	<b>3rd Tuesday of the month</b> 7 – 8 p.m.	For information or to register, contact the First Link <sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
<b>Provincial long-term care tele-support group</b> Open to caregivers anywhere in B.C. who are	4th Thursday of the month	For information or to register, contact the First Link® Dementia Helpline at		

caring for a person living with dementia in a<br/>long-term care home.2 - 3 p.m.Provincial young onset tele-support group<br/>Open to caregivers anywhere in B.C. who are<br/>caring for a person living with dementia who is2nd Tuesday of the month7 - 8 p.m.

For information or to register, contact the First Link<sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org

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currently under the age of 65.





Provincial tele-support groups				
<b>Provincial adult children tele-support group</b> Open to caregivers anywhere in B.C. who are caring for a parent living with dementia.	<b>2nd Wednesday of the month</b> 7 – 8 p.m.	For information or to register, contact the First Link <sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
<b>Provincial adult children tele-support group</b> Open to caregivers anywhere in B.C. who are caring for a parent living with dementia.	<b>2nd Thursday of the month</b> 6:30 – 7:30 p.m.	For information or to register, contact the First Link <sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
<b>Provincial BvFTD tele-support group</b> Open to caregivers anywhere in B.C. who are caring for someone with behavioural variant frontotemporal dementia (bvFTD).	<b>4th Monday of the month</b> 7 – 8 p.m.	For information or to register, contact the First Link <sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		
<b>Provincial general tele-support group</b> Open to caregivers anywhere in B.C. who are currently caring for a person living with dementia.	<b>3rd Thursday of the month</b> 2 – 3 p.m.	For information or to register, contact the First Link <sup>®</sup> Dementia Helpline at 1-800-936-6033 or by email at info.helpline@alzheimerbc.org		

# Caring for someone living with dementia in long-term care during COVID-19

The provincial government has announced changes to the visitor guidelines for long-term care and assisted living facilities. Under the phased approach beginning in July, one designated friend or family member will be able to visit.

Due to the restrictions on visiting long-term care homes, many people are unable to visit their family members as they usually would. Caregivers of people living in long-term care homes may experience frustration, anxiety, fear, sadness, grief, or guilt. Recognizing and acknowledging the feelings you are experiencing can help you to manage how you cope with this stressful situation.

Consider alternative ways of staying connected with your family member in long-term care:

- Can you talk to them on the phone or visit over Skype?
- Can the staff deliver a message for you?
- Can staff provide you with updates by phone or email?

We have created a three-part information sheet that may help you before, during and after your visit. Read more about this resource here: <u>https://alzbc.org/33BeHI9</u>.

For information on the updated visitor guidelines, please refer to the BC Centre for Disease Control's website: https://alzbc.org/3okahYi.

We invite you to share your visiting experience with us







