

# Connections

Linking a community of dementia support



## Accessing services and preparing for the summer

The summer season welcomes us with warmer weather and an opportunity to adopt a slower pace, to step outside and connect with family and friends. It's also an important time for everyone to be aware of health protection measures during extreme heat.

Unfortunately, our province is experiencing a rapid increase in climate-related weather emergencies, including a heat dome, atmospheric rivers and wildfires. Emergencies and resulting evacuations can make it particularly challenging for people living with dementia to respond to and get the appropriate help they need.

### We are here to help:

- For tips on living well with dementia during warm weather and heat alerts, visit: [alzbc.org/warm-weather-tips](https://alzbc.org/warm-weather-tips)
- Watch our recorded webinar with Dr. Jennifer Baumbusch for strategies that will help people living with dementia and their families during these events: [alzbc.org/webinar-baumbusch](https://alzbc.org/webinar-baumbusch)

Call the First Link® Dementia Helpline, available Monday to Friday. Learn more: [alzbc.org/FLDHL](https://alzbc.org/FLDHL)

### Climb with us in September!

Join us at the *Climb for Alzheimer's* in September as we raise funds to help provide dementia support and education. This event is accessible to all. Learn more at: [alzbc.org/climb-alzheimers](https://alzbc.org/climb-alzheimers)

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# Research moves us forward

How can we combat stigma? How do people experience dementia – and what does that mean for how we should support caregivers and people living with the disease? What enhances quality of life? How can we reduce the risk of developing dementia? Research is key to helping answer these questions. Our commitment is to ensure that research on these important questions – and others – is available, understood and involves you. Our annual research publication, *A focus on research*, which details progress in these areas, is now available at: [alzbc.org/focus2024](http://alzbc.org/focus2024)

This issue of *Connections* features an interview with Dr. Sheila Novek, a researcher who focuses on the experiences of older adults, people living with dementia, caregivers and health-care providers in the community and long-term care. We also feature two caregivers who share what caregiving means to them as they navigate the dementia journey.

With a fall provincial election on the horizon, we're inviting you to get loud and get involved by

advocating for a funded dementia strategy to support people affected by the disease. You can also learn about our Partners in Giving program, what it means to be a monthly donor and how this powers our work.

Finally, in preparation for summer, we provide tips for people living with dementia and their care partners about how to travel safely to ensure comfort and enjoyment for everyone. While everyone can benefit from planning and taking extra precautions, such as preparing for weather emergencies, the Alzheimer Society of B.C.'s First Link® Dementia Helpline is available to provide the support and resources you need, when you need it. Learn more at: [alzbc.org/FLDHL](http://alzbc.org/FLDHL)

Have a happy and safe summer!



Jennifer Lyle  
Chief Executive Officer  
Alzheimer Society of B.C.



[alzbc.org/FLDHL](http://alzbc.org/FLDHL)

Questions or concerns about dementia or memory loss?

## First Link® Dementia Helpline

|   |                |
|---|----------------|
| English<br>(Monday to Friday, 9 a.m. to 8 p.m.)                 | 1-800-936-6033 |
| Cantonese and Mandarin<br>(Monday to Friday, 9 a.m. to 4 p.m.)  | 1-833-674-5007 |
| Punjabi, Hindi and Urdu<br>(Monday to Friday, 9 a.m. to 4 p.m.) | 1-833-674-5003 |

# No more what ifs



Jennifer Chandler (right), caregiver to her mother (left)

*Jennifer Chandler was navigating her mother's dementia journey, when she met a man whose wife recently passed away from the disease. In this story, Jennifer shares the gift the man gave to her through their conversations.*

I spoke with a man who had just lost his wife from complications associated with dementia. They had been married for 52 years, and though he admitted there was some relief after her long journey with dementia came to an end, his head lowered under the weight of his grief.

It wasn't that the feeling of grief was new because he had been experiencing that for years, but it was the "what ifs" and the "if I had only done" that began to eat away at him. He was questioning his decisions, especially the decision to transition her to a care home. It was clear that he had tried valiantly to care for her, but among other things, her actions posed safety concerns for herself. For example, he told stories about her becoming disoriented and his struggles to keep her safe during their outings together.

What struck me as we kept sharing our experiences as caregivers was that we both have lost so much time in our lives as we retrace our decisions, thoughts and conversations with respect to the people we are caring for. Those *should have, would have, could have* thoughts are killing us, but later that day I thought, this man has unknowingly given me a gift. I was able to see that we focus so much on what we think we are doing wrong rather than what we are doing right.

There are hundreds of good decisions, incredible feats of management and special moments together that exist on any given day.

From our talk together, I walked away thinking about the myriad of tasks and decisions that have worked well. I have challenged myself to reflect more on the circle of support and resources that I have sourced and have been shared since this journey began. When our loved ones finally move on, they have given us a chance to know more about how we define life and our humanity.

What we have accomplished as caregivers has been so important because it was all underpinned by the desire to love and care for someone right to the bitter end. Any decision made with that at its core can't be seen as right or wrong as it is wrapped in only the best of intentions. We each served, sacrificed and experienced loss all for one more precious moment to give and receive love.

To read Jennifer's full story, visit:  
[alzbc.org/Jennifer-Chandler](https://alzbc.org/Jennifer-Chandler)

If you would like to contribute your writing with us, email [newsletter@alzheimerbc.org](mailto:newsletter@alzheimerbc.org).



# Join our Partners in Giving program today!



Did you know that you can make a lasting impact on the lives of people affected by dementia simply by becoming a monthly donor to the Alzheimer Society of B.C.? Our Partners in Giving program offers you the opportunity to contribute to our cause in a dependable and continuous way, ensuring that we can plan ahead and make a lasting difference in the lives of individuals and families facing Alzheimer's disease and other dementias.

Joining Partners in Giving offers convenience and affordability for you as a donor. With just one decision, your monthly gift supports our work year-round, and you receive a single tax receipt for your cumulative donations – no matter the amount you choose to give each month.

Your monthly donation provides us with the financial stability needed to sustain our efforts now and into the future. Predictable income allows us to focus on our vision of a world without dementia and engage in long-term projects that truly make a difference. Additionally, your ongoing support reduces paperwork and administration costs, making it the most efficient and eco-friendly way to contribute.

As a member of Partners in Giving, you join a dedicated group of donors who share your commitment to the cause. Enjoy benefits such as regular Alzheimer Society of B.C. updates and event invitations, alongside knowing that your contribution empowers us to provide crucial resources. Your gifts fund support groups, education and information for people affected by dementia around British Columbia.

Together, we can envision a brighter tomorrow for people living with dementia and their care partners. Your contributions enable us to offer vital services and support, making a positive impact on countless lives.

Join our Partners in Giving program today by visiting our website to sign up and register your monthly donation. Together we can make a meaningful difference by helping give courage to anyone affected by dementia. If you have any questions, don't hesitate to reach out to Daria Polansky, Development Officer, Individual Giving and Stewardship, at [dpolansky@alzheimerbc.org](mailto:dpolansky@alzheimerbc.org) or 604-742-4936.

Thank you for your support!

## Thank you!

Thank you to everyone who supported us at the *IG Wealth Management Walk for Alzheimer's*, presented by Go Auto, on Sunday, May 26, as we came together to honour people living with dementia and the people who care for them. We hope to see you next year. Save the date for Sunday, May 25, 2025!

# Travelling with dementia



We all enjoy a change of scenery and a break from our regular routine, however, dementia can make getting away more challenging. If you're planning to take a trip – near or far – this summer, careful planning is important to ensure comfort and safety for both people living with dementia and their care partners. The following suggestions can help to minimize travel-related stress.

**Plan ahead:** Learn as much as you can about the place you'll be visiting so you can anticipate potential needs. If you are planning a long trip, consider taking a shorter trip ahead of time as a trial run. This will give you a good idea of the challenges you might face. Make sure to have a contingency plan in the event the holiday needs to be cut short.

**Ask for help:** Check with your airline or local airport to see whether they participate in the Hidden Disabilities Sunflower program. It's a tool created to help you voluntarily share that you have a disability or condition that may not be obvious and that you might need extra help or understanding in public spaces. Learn more at: [alzbc.org/hdsunflower](https://alzbc.org/hdsunflower)

If you feel it's appropriate, notify the airline that someone living with dementia will be flying with them. Consider requesting early boarding and arranging transportation to and from the gate. If you are staying at a hotel, let the staff know about your needs and explain some of the possible difficulties you might encounter.

**Keep it simple:** It can be helpful to stick to a familiar routine as much as possible when travelling. Consider choosing a destination in a similar time zone to help maintain a regular schedule. Wherever you find yourself, try not to overpack the itinerary with too many activities. Focus on enjoying just one or two things. This way, you can fully enjoy the experience without feeling stressed.

**Take time to rest:** Although exciting, travelling and sightseeing can be very tiring. Adjust your plans to match how you are feeling that day. Be sure to build in time for rest.

**Enjoy what's close to home:** There may come a point when travelling long distances is no longer the best option. However, staying close to home for the summer can still be fun! Consider a stay-cation at a hotel, plan a day at the beach, a picnic in the park or play local tour guide by having family and friends visit you.

## Additional resources

- Living well and staying cool in the heat: [alzbc.org/warm-weather-tips](https://alzbc.org/warm-weather-tips)
- Travelling with dementia: [alzbc.org/resources-travel](https://alzbc.org/resources-travel)
- Learn about heat-related illness and tips on how to stay cool outside. Download the guide from HealthLink BC at: [alzbc.org/HealthLinkBC-summer-guide](https://alzbc.org/HealthLinkBC-summer-guide)

## Watch our webinars:

- Travelling with dementia: [alzbc.org/webinar-travel](https://alzbc.org/webinar-travel)
- Great ideas on activities to enjoy during warmer weather: [alzbc.org/webinar-activities](https://alzbc.org/webinar-activities)

# Raise your voice this election



From left to right, dementia advocates Art Harrison, Lynn Jackson, Jim Mann and Mario Gregorio

In advance of this fall's provincial election, you can raise your voice and ask B.C.'s political candidates to commit to supporting people affected by dementia. The Alzheimer Society of B.C. is advocating for a funded dementia strategy which addresses the following priorities:

### 1. Helping break down stigma and social isolation:

Stigma can make people reluctant to seek help or delay a diagnosis – and it can contribute to feelings of isolation. Raising awareness can reduce stigma and foster supportive environments for people affected by dementia.

**2. Improving the diagnosis experience:** Early diagnosis of dementia is important so people can access appropriate care and support. Developing a clear pathway for dementia care, which includes coordinated supports throughout the dementia journey and increasing the number of geriatricians providing specialized care, will support this.

**3. Ensuring the right care is available at the right time:** Having a range of timely, appropriate and accessible care options throughout the dementia journey, from diagnosis to end of life, is essential to living well with dementia.

B.C. is a culturally and linguistically diverse province. Addressing the challenges outlined here and ensuring that initiatives are culturally relevant and safe is paramount.

### How can you make a difference?

1. Talk to your family and friends about the importance of dementia support.
2. Share information about dementia and what the Alzheimer Society of B.C. is doing on social media.
3. Write to your candidates to highlight the importance of supporting dementia-related initiatives.
4. Ensure you and others have the necessary information and support to vote.

These are just a few ways you can help raise awareness, advocate for change and improve support for all people affected by dementia in British Columbia.

### Get involved!

For more information on our campaign, including available resources and how you can get involved, visit: [BCVotesDementia.ca](https://BCVotesDementia.ca)



# Exploring the value of resident and family councils in long-term care



Dr. Sheila Novek

*Dr. Sheila Novek is a researcher in aging and a postdoctoral fellow in the School of Nursing at the University of British Columbia. Her research explores the experiences of older adults, people living*

*with dementia, family care providers in the community and long-term care. Below, Dr. Novek shares her insights from an ongoing study which focuses on people living in care, their families and the staff who engage with resident and family councils.*

## When did your interest in dementia-related research begin?

I've been doing dementia-related research since I was an undergraduate doing my honour's thesis. I was inspired by my personal experience of having my mother living with dementia at a young age, so I've continued research in dementia and long-term care ever since.

## What is a resident council and family council?

It is a group of people who live in a long-term care home, their families or representatives. They meet regularly to help improve the quality of life for everyone in the home by sharing their thoughts and representing the residents' needs and interests.

Although they've been around for decades, in 2022, the B.C. Ministry of Health introduced new regulations governing the operations of resident and family councils. Prior to this, minimal oversight existed, however, the COVID-19 pandemic underscored the importance of ensuring that residents and their families have a guaranteed voice in decisions affecting them.

## What do you enjoy most about your work?

My favourite part is getting to know and spend time with the councils. It's been especially moving to hear the residents' insights and realize how much they have to share and offer. It's also incredibly rewarding to see a council's energy and efforts lead to actual positive change in their care home.

## Can you share a success story?

A resident council I was doing research with advocated for an inaccessible courtyard to be repaved. It was so meaningful for these residents to be able to enjoy an outdoor space because of their efforts.

## What do you hope to achieve with this research?

We want to create a user-friendly report that highlights promising practices, offers helpful strategies and supports meaningful engagement. We ultimately hope the findings and recommendations we develop are of value to resident and family councils – as well as long-term care homes that want to support their councils.

- Learn more about Dr. Novek's research. Watch our *Research connects* webinar here: [alzbc.org/Research-Novek](https://alzbc.org/Research-Novek)
- For more information and helpful resources, visit: [iltccabc.ca](https://iltccabc.ca)

## A focus on research is now available!

Our annual research publication, *A focus on research*, is now available. This edition includes highlights of the remarkable B.C. researchers and innovative quality-of-life projects we support, dementia research news stories of the year and tips for reading about research. Read it here: [alzbc.org/focus2024](https://alzbc.org/focus2024)

# Gina McCulloch's volunteer journey



Gina McCulloch, volunteer support group facilitator, with her chocolate Labrador retriever Joey.

When Gina McCulloch started volunteering as a support group facilitator, she understood the needs of caregivers well. Gina cared for her mother for 15 years. For the first decade, Gina had little guidance to help her navigate the dementia journey.

“The problems were new and overwhelming,” Gina says.

Gina and her husband retired early and moved into her mother's basement to take care of her. It wasn't until years later, after her mother moved into long-term care, that Gina connected with the Alzheimer Society of B.C.

“The Society provided me with skills and knowledge to better meet my mother's needs, as well as my own,” Gina says. “We would not have progressed through the last five years of my mother's life as well as we did without the support I received. After my mother passed, I knew I wanted to help caregivers who were still on the journey.”

Read Gina's full story at: [alzbc.org/gina-mcculloch](https://alzbc.org/gina-mcculloch)

### Become a support group volunteer!

The Alzheimer Society of B.C. is in need of virtual and in-person support group facilitators like Gina! Learn more: [alzbc.org/Volunteer-Opportunities](https://alzbc.org/Volunteer-Opportunities)

## 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](https://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

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](https://alzbc.org/insight-newsletter).



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Charitable registration number:  
#11878 4891 RR0001