

Navigating and enjoying the summer

As the warmth of the summer sun brightens our days, it brings about opportunities to relax and explore outdoors. Some of us eagerly plan trips to take advantage of the weather, while others prefer to soak in the sun closer to home. Wherever you are, take this issue of *Insight* along as one of your summer reads.

In this edition, we feature the inspiring story of someone who faces life's challenges with resilience, as well as practical tips for safe summer travels. We're also highlighting the work of a researcher who is collaborating with people living with dementia to better understand the needs of people living independently in the community. Packed

with information and inspiration, we hope this issue contributes to the joy and brightness of the summer months. Consider reaching out to *Insight* to share how you spent your summer! Turn to [page 2](#) for details on how you can submit your story or pictures.

Stay safe during summer heat

Tips for living well and staying cool in the heat:

alzbc.org/warm-weather-tips

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

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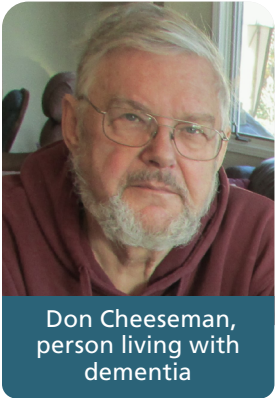
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Greetings



Don Cheeseman, a retiree who now resides in Whitehorse, is living with dementia and a member of the Alzheimer Society of B.C.'s Lived Experience group (turn to page eight to learn more!). Though

Don sometimes finds himself losing the initiative to step out of the house, he still puts a tremendous effort into taking part in mentally stimulating social activities.

My journey with dementia has had a profound impact on my life, my writing and storytelling. Firstly, it's challenging for me to bring to mind family adventures and memories. Secondly, encompassed by my own dwindling writing capacity, I find it difficult to write supportive and uplifting prose, when a list of personal failures may be a more prominent subject within my recent memory.

Despite the obvious challenges, I continue to refine and reshare my older writing with new venues. I try to remain engaged in activities that stimulate my brain, like Scrabble, running a weekly group chat and providing constructive feedback on other writers' works.

I have tried to adapt my lifestyle to manage, minimize and hopefully slow the effects of dementia. These adaptations facilitate eating less red meat, more physical and mental exercise and most difficult for me, more socializing.

My wife, and constant support, keeps a routine with minimal change, a strategy that helps me cope with my daily life. She takes my shortening patience and calms it with laughter. She checks my small labours and keeps me from forgetting cooking food or worse. Her support is never ending and she is truly the hero of this story.

I hope this summer you will find yourself immersed in an activity you can enjoy with your partner, family member, friends or neighbour. Challenge your mind and find ways to maintain brain health – whether it's gardening outdoors, visiting a local park, playing an instrument or painting. Do what brings you joy and laughter!

– Don Cheeseman

Get in touch

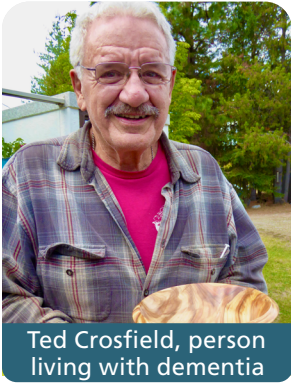
We welcome contributions from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted.

Email your ideas or contributions to:
insight@alzheimerbc.org

Call 604-681-6530 or toll-free
1-800-667-3742.

Mail to the Alzheimer Society of B.C.,
care of *Insight*:
300-828 West 8th Avenue
Vancouver, B.C. V5Z 1E2

The art of positivity with Ted Crosfield



Ted Crosfield has spent most of his adult life in Ootischenia, B.C. Ted and his wife Linda recently embarked on a new chapter, trading in their hectare of land for a more manageable

place in Nelson. Ted reached out to Insight to share the lessons he's learned about resilience, finding your passion later in life and how positivity can prevail in the face of significant challenges.

A former pilot in the Canadian Air Force, Ted's life took an unexpected turn at 22. While attempting aerobatics during a training mission, he experienced a plane crash and severely injured his leg. After spending months in hospital, Ted made the difficult decision to amputate his leg, which greatly impacted his outlook on life.

"The most significant thing was the complete inability to imagine a future," Ted says. "I went from being a pilot in the Air Force to pumping gas at the service station."

However, Ted adjusted to his new life, and eventually went back to school, earning a degree at Simon Fraser University. Later, at Selkirk College, he discovered his talent in wood turning – a method of shaping wood by rotating it on a lathe. Just one year later, he was hired on as Instructional Assistant, a position he held on and off over 14 years. Over the years

that followed, Ted perfected and gained confidence in his craft.

"When I got into wood turning, I decided I was artistic, but all I had to do was take away the 'ic' and I was an artist."

Over two decades, Ted has created over 1,300 signed pieces. His work has been selected in juried art shows and is collected internationally. Although Ted's diagnosis of dementia a few years ago led him to give up wood turning, he hasn't let the new challenge alter his spirit.

"Focus on what you have left, not on what you've lost – that's basically what I live by."

Ted appreciates the support from the Alzheimer Society of B.C.'s First Link® dementia support. The regular phone check-ins to see how he's doing are particularly important to him.

He has also found great support from his family, especially his wife Linda. "She is an amazing help," he says. "We know we have the right thing."

Ted vows to continue to live life to the fullest and stay positive.

"I said a long time ago that I wanted to live fully, as if every moment is my last, because I've gone through such traumatic experiences, like the plane crash. But I'm here. I've got it, so I better enjoy it."

To view more of Ted's work, visit: tedcrosfield.ca

Travelling with dementia



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

Plan ahead: Work with a family member or friend to learn as much as you can about the place you'll be visiting so you can anticipate your needs and potential challenges. If you have a travel agent, make sure they are aware of your needs. Arrange for assistance at airports or train stations and create an itinerary to alleviate stress and enhance the overall experience. Entrust your travel companion with important documents such as your passport and medical information. It can help you focus on your needs during travel. Finally, if you are planning to visit friends and family, tell them about the changes you have experienced since your last visit and offer suggestions for how they can be supportive.

Keep it simple: When you travel, it can be helpful to stick to a familiar routine as much as possible. Choosing a destination in a similar time zone can help you maintain a regular schedule. Consider avoiding peak travel time when crowds are larger and wait times are longer. Additionally, don't overpack your itinerary with too many activities. Focus on enjoying just one or two things well. 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 day to match how you are feeling. Be sure to build in time for rest. After all, vacations are supposed to be relaxing!

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 the following ideas for a fun 'stay-cation:'

- **Have family and friends visit you:** If you are no longer travelling long distances, consider having family and friends come to see you. During their visit, you can play tour guide for the day and show them your favourite hometown sites.
- **Go to the beach:** You don't need to travel to an exotic location to enjoy a day at the beach. Our province boasts wonderful ocean and freshwater beaches. So grab your beach umbrella, towel and don't forget the sunscreen!

- **Plan a picnic in the park:** Do you have a favourite park you like to visit? Next time you go, consider packing a picnic basket with some tasty summertime snacks. Parks are also perfect for engaging in light activities like throwing a Frisbee or bird watching. If you are up to it, invite family and friends to join in on the fun!

People living with dementia share their travel tips:

“Know where your care partner is at all times.”

“Get help from the airport; ride the cart to the gate or ask for a wheelchair – then you don’t need to walk long distances.”

“Have your care partner pack with you.”

“Keep it simple! Don’t over-schedule.”

“Bring something for quiet moments – like an adult colouring book.”

“Carry a ‘Please be patient, I have dementia’ card with you.”



For more helpful links and resources on travelling with dementia, visit: alzbc.org/resources-travel

Raise your voice this election

In advance of this fall’s provincial election, you can raise your voice to ask for improved dementia support. We want election candidates from all parties to address the social, economic and emotional needs of people affected by dementia by committing to three priorities:

1. Helping break down stigma and social isolation.
2. Improving the diagnosis experience.

3. Ensuring the right care is available at the right time.

Writing to your candidate to highlight the importance of supporting dementia-related initiatives and ensuring you and others have the necessary information and support to vote are just a couple of ways you can help make a change.

For more information on our campaign, visit: BCVotesDementia.ca

Get involved: Designing dementia-friendly communities for people who live on their own

Some people affected by dementia who participate in research take comfort in the hope that their involvement contributes to our understanding of the disease, improving the lives of others. This engagement can provide a sense of purpose and opportunities to stay active and engaged in the community.

Dr. Mariko Sakamoto, an Assistant Professor in the School of Nursing at the University of Victoria, has a great opportunity if you'd like to get involved in meaningful research. She is looking for people living with dementia who live alone in the community to join a participatory research study. Participants will form an Action Group and engage in online workshops with the goal of developing an in-depth understanding of the needs of people with dementia who live on their own.

Below Dr. Sakamoto and co-researcher, Lynn Jackson, share more about the research study.



Dr. Mariko Sakamoto is a researcher and has been a registered nurse for over 25 years. Her work to date has brought attention to the challenging issues and transitions that people living with dementia experience in our health-care system and in Canadian society.

Can you explain what happens during a co-design workshop?

These workshops are meant to be engaging, participatory and enjoyable — where the goal is to collectively design and create some type of outcome that is meaningful and important to the people who participate. Our goal is to co-design an action plan to inform future dementia-friendly community planning — as well as future research.

Do participants have to attend in person?

No. We expect that five online workshops lasting 60-90 minutes will take place approximately every two weeks. Participants must be able to join an online Zoom meeting, but the research team can provide a tablet and support to help people connect online!

Can you share your insight or experience of partnering with people living with dementia in research?

I've learned so much. I was lucky to be able to work on the Flipping Stigma project, and this has influenced how I approach research. All the work I do is community-engaged and participatory in nature. This means that I co-research, co-design and co-create with people with lived experience. I've found that this can lead to powerful and meaningful outcomes.



Lynn Jackson began her career as a Registered Nurse. She is a proud member of the Métis Nation B.C. with sixth-generation roots stemming from the Manitoba Cree. Lynn

was diagnosed with dementia in 1999. Her current interests include advocating for people living with dementia and increasing awareness of Alzheimer's disease and other dementias.

What inspired you to become involved in this co-design research study?

It's important for the people being studied to be a part of the research team and be able to give their input from lived experiences. I want to be able to find out from others how they are managing as well as help others with my experiences. Also, because I have a diagnosis of dementia and live alone, this study was a good fit for me.

What is your role in the action group?

My role is as a member as well as a co-researcher – so I wear two hats. Along with working in partnership with Mariko, I'm involved with the gathering of information and adding my input into the workshop sessions.

Why would you recommend others affected by dementia get involved?

As well as having a lot of fun with the group, you will be helping yourself and others who live alone now and in the future.

I always say that if I am helping others, I am helping myself as it keeps my brain active which is necessary in helping to stave off the decline of my brain disease.

If you'd like to join the Action Group or learn more, please email dfcproject@uvic.ca or call 250-472-4835.

To learn more about the Flipping Stigma Toolkit, created by the Action Group, visit: flippingstigma.com

Our 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

David's journey: Becoming a lived experience partner



David Nickel, lived experience partner

Lived experience partners help spread awareness about dementia by sharing their personal stories and perspectives. Opportunities for meaningful engagement invite people directly affected by dementia

to contribute to our work with their unique insights and perspectives.

David Nickel is one of our new lived experience partners. He lives with his wife in Chilliwack, in a house that overlooks the river. He loves to play golf and visits his local gym four or five days per week. David was diagnosed with dementia four years ago. Shortly after his diagnosis, he connected with the Alzheimer Society of B.C. and joined an early-stage support group for people living with dementia.

"The group was very useful," David says. "It helps to share what I'm going through."

Recently, David decided to become more involved with the Alzheimer Society of B.C., so more people could learn from him and how he is navigating life while living with dementia. In January, he was one of four panelists featured in a lived experience webinar. Participants shared how they live life to the fullest on the dementia journey.

"I've always liked to share," David says. "Telling my story gives me a way to

contribute and connect with other people in the dementia community."

When people with lived experience of dementia share their stories, it reduces stigma and discrimination and helps people on the dementia journey feel less alone. Lived experience partners may be invited to participate in committees, webinars, advocacy opportunities and more. The voices of lived experience partners give us firsthand knowledge of what it's like to live with the disease and how to best support people on the journey.

David is looking forward to finding more ways to participate as a lived experience partner, which might include sitting on a committee or an advisory position.

"I certainly don't mind telling my story when somebody wants to listen," says David. "I try to have a good sense of humour about all of it. If I forget to play a few holes while playing golf, I get a better score!"

If you would like to learn more about our Lived Experience Partner Program, please email livedexperience@alzheimerbc.org or visit: alzbc.org/livedexperience

To watch the lived experience webinar, visit: alzbc.org/LE-webinar2024