



Changes in long-term care and planning for the future

While people in B.C. continue to establish new routines amid the COVID-19 pandemic, for many people affected by dementia, including those affected by accessing care and restrictions to care home visits, this remains an exceptionally difficult time.

This issue of *Insight* takes a closer look at long-term care in B.C. and progress made in defining dementia-friendly care homes. We hear from Jim Mann, *Insight's* former editor, with an update on his advocacy as it relates to long-term care and offer resources to support advance care decision making. We also showcase reader

poetry submissions and ways you can get involved to support other people living with dementia by sharing your experiences.

As we move forward during this unprecedented time together, we're continuing to make increased support calls and asking anyone in need of help to please reach out to us on the First Link® Dementia Helpline. We will continue to host weekly webinars on topics of particular relevance during this time and update our catalogue of COVID-19-related resources at alzbc.org/COVID-19.

We're here for you. Please contact us.

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Research is transforming long-term care

We are pleased to share this guest editorial from Jim Mann, a dedicated advocate for people living with dementia, former Insight editor and member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia.

Here we are in autumn and many of us are still making adjustments to this new normal. It does take some getting used to, but I think we're all pretty resilient, so I'm confident we'll make it work for our own individual situations.

The University of British Columbia recently announced that this November at its fall convocation, I would be awarded an honorary Doctor of Laws degree. (I was overwhelmed when I got the letter from UBC and I am, still, overwhelmed!) Last year, I was invited to be a Visiting Community-Based Scholar at the university's W. Maurice Young Centre for Applied Ethics, where I focused on dementia research and issues of consent and ethics. UBC's write-up noted my passion for countering negative stereotypes and promoting inclusivity, both of which apply to people living with dementia in long-term care, which is this issue's theme.

I appreciate the opportunity to be the guest editor for this issue of *Insight* and I thank Mario for the invitation.

We hear and read a lot about peoples' desire to age in place and certainly, new technology is transforming this desire into reality. With sensors, better communication tools to keep in touch



Jim Mann, longtime advocate for people living with dementia

with relatives and friends and gadgets – I'm sure that's the technical term! – to keep us safe in the kitchen and elsewhere in our home, I'm confident in saying we have never been more safe.

But, for some of us, for various reasons, there will come a time when we will have to transfer to long-term care.

We are fortunate that long-term care today has had the benefit of a great deal of research which is inspiring a culture shift. Many recommendations and innovations from this research have been adopted and incorporated, making living in care more person-centred. In many homes, there isn't a standard wake-up time, more activities are planned and there is more flexibility throughout the day.

There is a growing recognition that each resident is an individual with their own unique history, wishes, likes and dislikes.

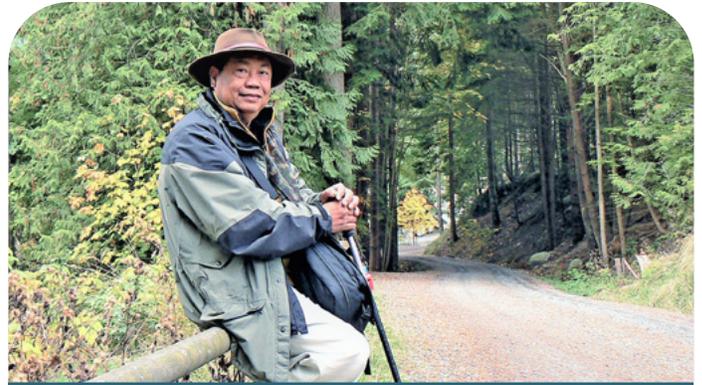
Now that's progress!

A call from my doctor changed the way I look at the future

The pleasant banter with my doctor ended abruptly when he asked what my plans are, should I be infected with COVID-19. Although I thought about this issue much earlier in the pandemic, the conversation caused uneasiness when I realized that I had to make a decision that would have a profound effect on me and my family.

As a member of the Canadian Consortium on Neurodegeneration in Aging, a group of researchers working to improve the prevention, treatment and quality of life among people affected by dementia, as well as the Alzheimer Society of Canada's COVID-19 Task Force, I have come to understand the ramifications of medical care after one is infected with COVID-19. I felt the need to consult a trusted health-care provider to help me understand the complex issues involved: that is, to either accept or refuse coronavirus-related medical treatment.

I sat down with a family member who has worked for several years as a health-care provider in a hospital setting, holding the hands of elderly patients who are in the final stages of their lives. I came to understand the importance of making decisions while I still have the ability to make relevant choices. She explained to me the importance of putting my thoughts on paper about my future care, my choice for an substitute decision-maker and my wishes, should I be unable to communicate them. A substitute decision-maker (SDM) is a person you choose in advance to make health-care decisions for you in the event that you can't make them for yourself.



Mario Gregorio, editor of *Insight* and member of the Society's Leadership Group of People Living with Dementia

Spending a few hours in the evening searching the internet turned out to be quite absorbing and allowed me to gather information that helped me create a plan I believe is best for me. It also allowed me to explore options for long-term care, should I become unable to look after myself.

After a few weeks, I phoned my doctor and asked him for the legal forms that allow him to understand and execute my instructions for medical care. I reassured him that I have discussed my wishes with a substitute decision-maker who also signed the document.

Confronting one's mortality is difficult. It is said that when we are born, the only guaranteed thing is that we are going to die. We strive to live life to the fullest and enjoy what the world has to offer. As we travel through the many roads that lead to the final journey, the gift of peace of mind for our loved ones requires our thoughtful consideration. Now is a good time to make a plan.

See page 5 for advance care planning resources.

Spotlight on long-term care

The COVID-19 pandemic has shone a spotlight on long-term care and the devastating outcomes experienced by many families across Canada. It has sparked important conversations, and more Canadians are paying close attention.

We have heard stories about the gaps and shortcomings in long-term care, the difficulties of isolation, as well as the dedication and resilience of health-care providers. The Society is engaging with these issues in various ways: by understanding the experience of those in care through our work with advocates, supporting families we are connected to and by looking for ways to ensure that concerns raised by families and shared in the media are being addressed.

In B.C., approximately two-thirds of people in long-term care are people living with dementia. We believe people living with dementia have the right to enjoy the highest possible quality of life and quality of care. A care home that values and puts into practice a person-centred philosophy of care is considered best practice in dementia care.

What is person-centred care?

Person-centred care:

- Recognizes that individuals have unique values, personal history and personality.
- Recognizes that each person has an equal right to dignity and respect, and to participate fully in their environment.



Here are a few examples of what person-centred care could look like in a care home:

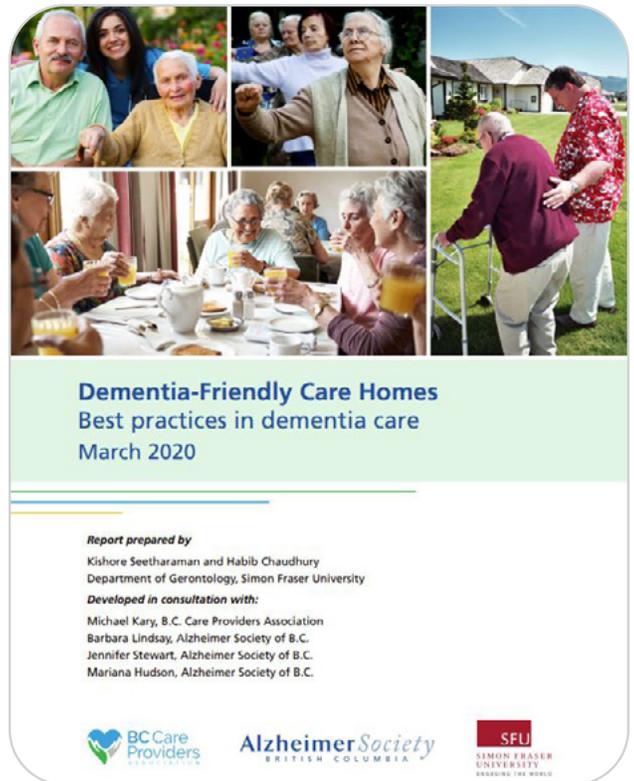
- Supporting people to engage in meaningful activities they enjoy, tailored to their interests.
- A health-care provider taking extra time to understand a person's individualized wishes and goals of care, while supporting them in their decision-making.
- Collaborating with families and involving them in the life of the care home.
- Considering residents' cultural backgrounds, such as providing familiar foods and supporting cultural celebrations.
- Ensuring the physical layout of a care home is comfortable, home-like and easy for residents to navigate.
- Leaders ensuring consistent staffing schedules to promote relationship-building between staff and residents.

We encourage you to think about what person-centred care may look like for you, and to share your thoughts in discussions with family, friends or your care team.

Dementia-friendly care homes

Earlier this year, the Alzheimer Society of B.C. collaborated with the BC Care Providers Association and the SFU Department of Gerontology to create a report titled, "Dementia-friendly care homes: Best practices in dementia care." This report provides suggestions on how care homes can be more dementia friendly, including both physical changes and in education, training, staffing and care practices.

To read the full report, visit:
alzbc.org/DFCH-report



For a global, cross-cultural perspective on dementia-related design and the built environment, check out Alzheimer Disease International's World Alzheimer Report 2020, "Design, Dignity, Dementia: dementia-related design and the built environment," at: alz.co.uk/research/world-report-2020

Advance care planning resources

- The Alzheimer Society of B.C.'s personal planning resources, available at: alzbc.org/personalplanning
- The Memorial Society of B.C.'s End-of-life planning and other resources, available at: memorialsocietybc.org/resources
- Various resources and support are available through the Nidus Personal Planning and Resource Centre at: nidus.ca
- Support, education and other resources, including an advance care planning toolkit, are available through Dying with Dignity Canada at: dyingwithdignity.ca/education



Keeping social while distancing: Marcia's story

Marcia Gresch is social, compassionate and a natural communicator who worked in the airline industry for 27 years. After she was diagnosed with dementia five years ago, she continued to stay heavily involved in her community, including as a Green Coat (customer service ambassador) volunteer at Vancouver International Airport – until the COVID-19 pandemic hit and her volunteering was put on hold. For Marcia, keeping active and staying socially engaged was vital to preventing feelings of isolation.

“Before COVID-19, I was going everywhere, and it was great,” Marcia says. “You can’t just sit at home. It’s important to stay involved. Still, I dislike having to do everything online these days. I have a hard time with that, even though I’ve worked with a computer practically my whole life.”

While Marcia can no longer volunteer or participate in activities as she usually would, she is still finding ways of staying connected to neighbours and friends.

“We go out, we meet when we can, and everybody practises social distancing. Everybody around the neighbourhood is talking, which is a good thing. I also still go to my church group on Saturdays. Everyone sits in different couches, we bring food and we eat together. It’s great! If I didn’t have that I’d go bananas.”

As for what advice she has for others, Marcia says, “You have to keep in contact with other people. Use the phone if you can’t physically meet them – just stay connected. Keep talking and keep sharing.”

A message to our community

After seven years with the Alzheimer Society of B.C., CEO Maria Howard is starting a new chapter in her career as CEO of Family Services of Greater Vancouver, a registered charity supporting families in need, or in crisis or with trauma.

In her time at the Society, Maria was instrumental in making change for people affected by dementia. We’re grateful for her vision and passion – and wish her the best as she continues her work to make life better for British Columbians.

Share your experience to help others affected by dementia

Are you a person living with dementia interested in sharing your voice to make a difference? We’re looking for new members for our Leadership Group of People Living with Dementia. These group members meet with us regularly to provide important guidance on Society

programs and initiatives. We also connect our members with external advocacy opportunities, such as research, academic conference panels and with other events.

Email advocacy@alzheimerbc.org to learn more.

Comfort in poetry: Sharing words of support



Myrna, Maple Ridge

For Myrna Norman, a member of the Alzheimer Society of B.C.'s Leadership Group of People Living with Dementia, poetry continues to be an outlet as she navigates the new challenges of restrictions put in place to stop the spread of COVID-19.

Myrna began writing poems before the pandemic began. They offer a window into her experience as someone who lives with dementia.

The Lady and the Hug

She wasn't walking aimlessly
But she knew no one there
An event for Seniors at the church
Called the Seniors Health and Wellness
Fair.

Her eyes not searching for
acknowledgement
Although her heart wished it so
Just someone to share a smile with
To prove she was not alone.

It happened,
A woman came up to her
And asked if she could embrace

They hugged and hugged and hugged
again.

As the hug continued
A tight and warm embrace
The Lady began to sob,
Her shoulders heaving, but with joy.

We Seniors, said the Lady
Once our kids are grown
Are lonely and sometimes alone
And ever longing for someone to hug.

Norma, Kelowna

Untitled (D-E-M-E-N-T-I-A)

Does anybody hear me? Sometimes I talk
inside.

Everybody has somebody, so why do I feel
so lonely?

Mention my name and hold my hand. It
makes me feel warm inside.

Even on a blue day, I can feel hopeful.

Nowadays life can be confusing, yet it
usually lifts.

Time is fleeting, so let's make this moment
special.

I am still me and hope you know how
much I love you.

Alzheimer Society – You have my back.
Thanks for caring.

We want to hear from you! Send your
submissions to insight@alzheimerbc.org
or see back page for mailing address.

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- Subscribe online at alzbc.org/insight-newsletter
- Call 604-681-6530 or toll-free 1-800-667-3742

Contribute

We welcome contributions, such as personal stories, photography or original poems, from people living with dementia. Please provide your name, mailing address, phone number and/or email address if you would like to be contacted. All submissions will be considered based on theme and space.

- Email 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

Call the First Link® Dementia Helpline

A confidential, province-wide support and information service for anyone with questions about dementia. Our English Helpline hours have been extended and now run from 9 a.m. until 8 p.m., Monday to Friday. Cantonese or Mandarin and Punjabi Helplines are open from 9 a.m. to 4 p.m., Monday to Friday.

- English: 1-800-936-6033
 - Punjabi: 1-833-674-5003
 - Cantonese or Mandarin: 1-833-674-5007
- Email supportline@alzheimerbc.org

Are you a caregiver?

Connections is a quarterly print and digital publication produced by the Alzheimer Society of B.C.

To subscribe:

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