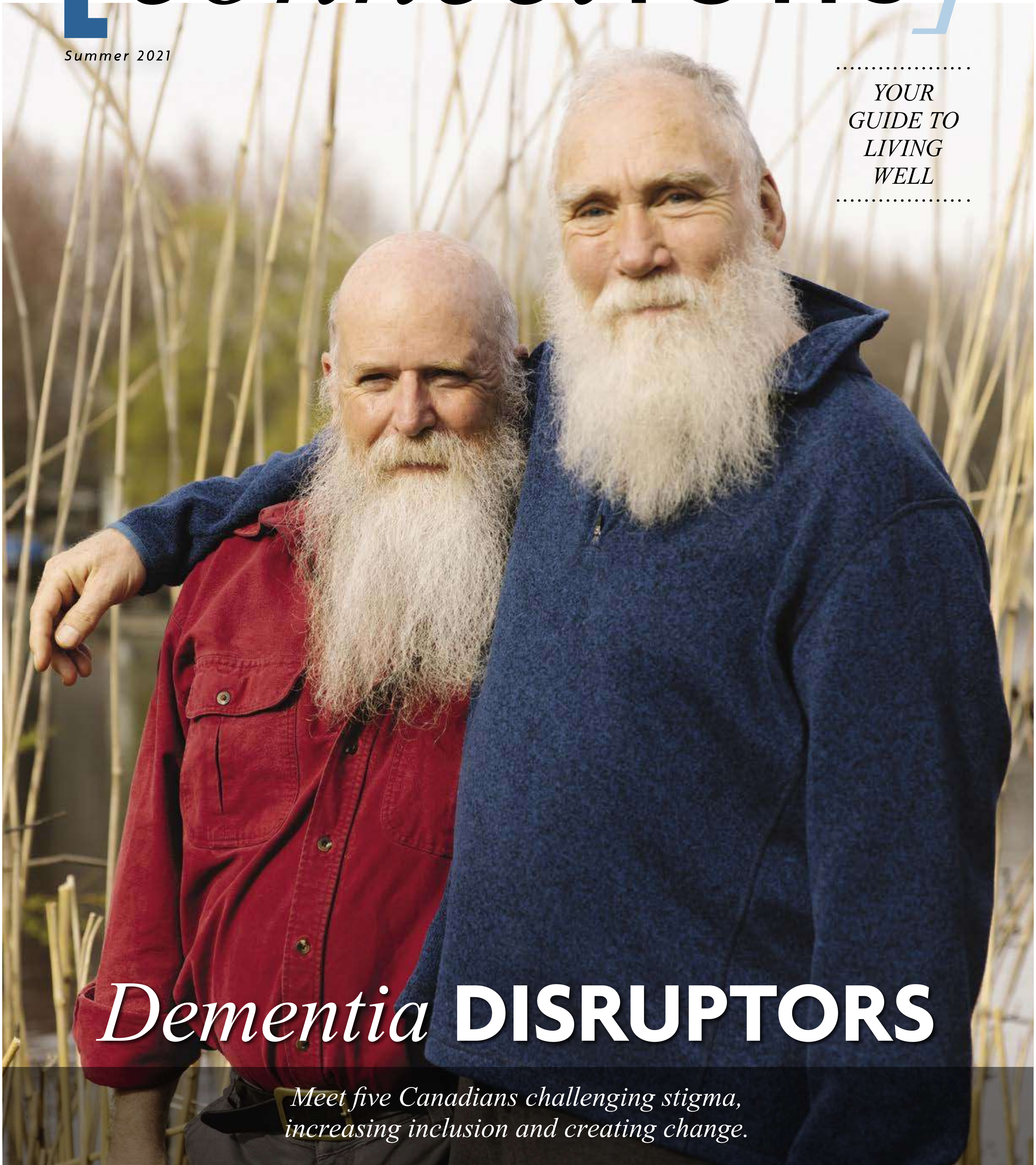
DEMENTIA
connections

Summer 2021

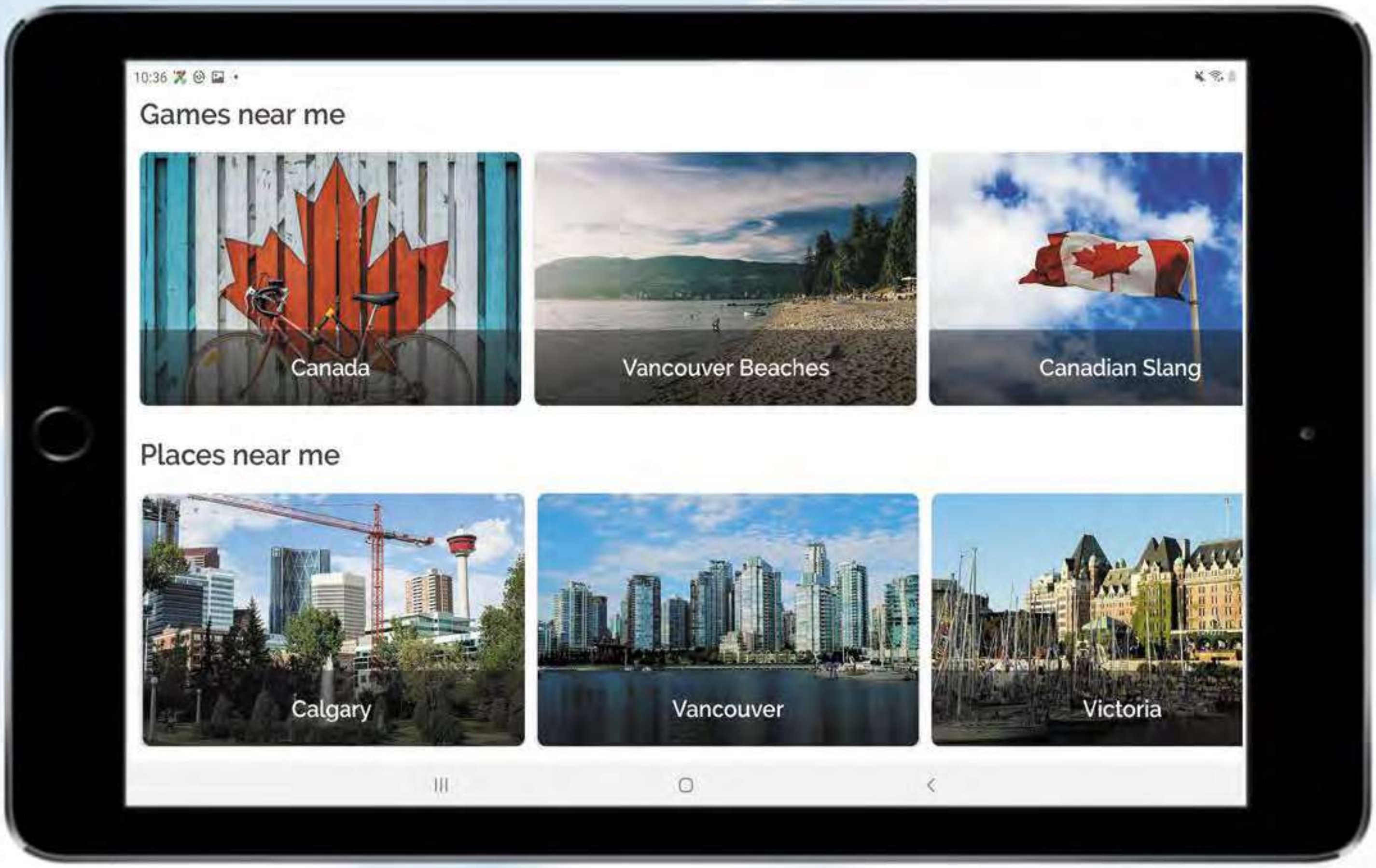


YOUR
GUIDE TO
LIVING
WELL

Dementia DISRUPTORS

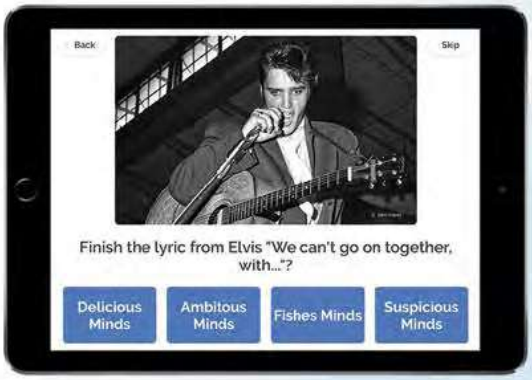
Meet five Canadians challenging stigma, increasing inclusion and creating change.

Play 100s of fun games for free



"Top 25 health & fitness apps."
- UK AppStore iPad charts (March - April 2021)

What is the name of this beautiful Canadian lake found in Banff National Park?



Finish the lyric from Elvis "We can't go on together, with..."?

Before its name was changed to the Calgary Tower, this iconic building was called the...

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Victoria, Vancouver, Kelowna, Calagry, Edmonton, Regina, Saskatoon, Winnipeg, Ottawa, Toronto, Quebec City, Montreal, Halifax, St John's and many more to come.

WELCOME

OUR VERY FIRST NATIONAL ISSUE, a brand-new website, new contributors and collaborators – *Dementia Connections* has so much to celebrate! I am honoured to build upon the powerful vision of our founder, Lisa Poole, and to expand *Dementia Connections* to serve people impacted by dementia across Canada. Special thanks to our Editorial Advisory Board members, and other contributors, who have shaped this issue.

COVID-19 has deeply affected the well-being of people living with dementia and care partners, and has exposed ageist beliefs and behaviours in Canadian society. The pandemic has also shone a spotlight on the incredible resilience of older adults, and I am hopeful that the pace of change to cultivate a more equitable and just aging society has been accelerated.

Our Summer issue is packed full of news of change. We focus on five formidable Canadian change-makers, Dementia Disruptors, who are challenging the status quo within the dementia community. In addition, we explore the often misunderstood concept of promoting quality of life through palliative care, and report on what opportunities for meaningful engagement and inclusion actually look like in practice. We've reformatted the Expert Advice column and welcome a geriatric physician and an occupational therapist to share their unique perspectives on preventing falls at home. Need some expert advice? Send us your questions connect@dementiaconnections.ca.

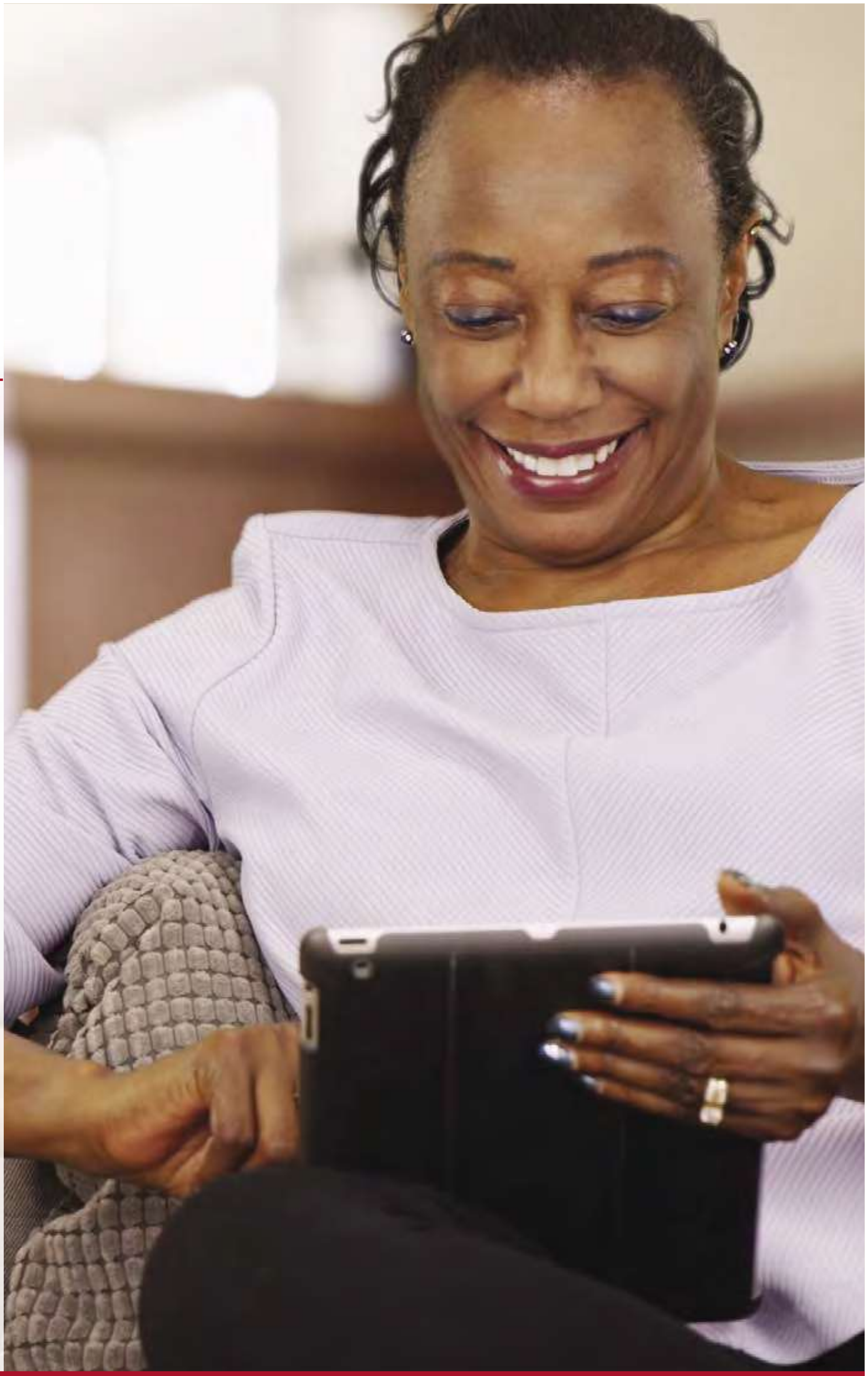
I am so glad to have joined the *Dementia Connections* community. I look forward to talking with you — and learning from you — about how to live well, despite dementia.

Carolyn Brandly, Editor in Chief
Let's keep in touch! ✉ editor@dementiaconnections.ca

PHOTOGRAPH: JUSTIN VEENEMA

AGEWELL

Canada's Technology
and Aging Network

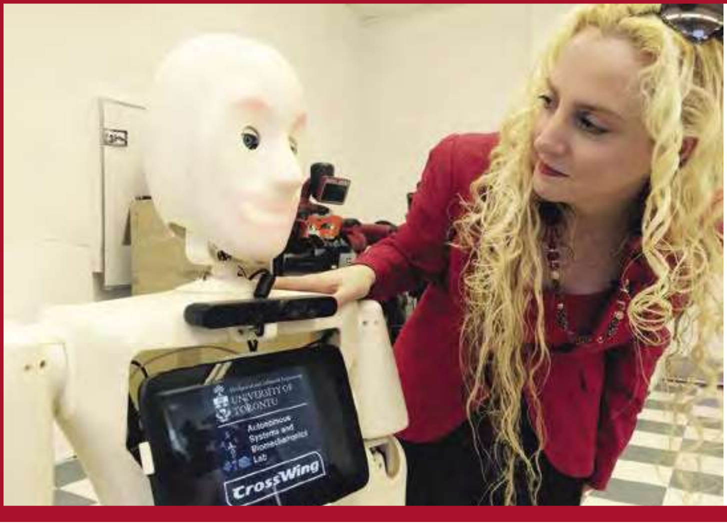


Introducing AGE-WELL.

We are a network dedicated to developing technologies and services that benefit older adults and caregivers.

AGE-WELL is the only pan-Canadian network bringing together researchers, industry, non-profits, government, older adults, and caregivers to create technology-based solutions to support healthy aging.

Learn about Casper, the socially assistive robot, and other technologies being developed by AGE-WELL researchers.



Be inspired at:
agewell-nce.ca

Join the AGE-WELL community!

NCE RCE

A CANADIAN NETWORK OF
CENTRES OF EXCELLENCE

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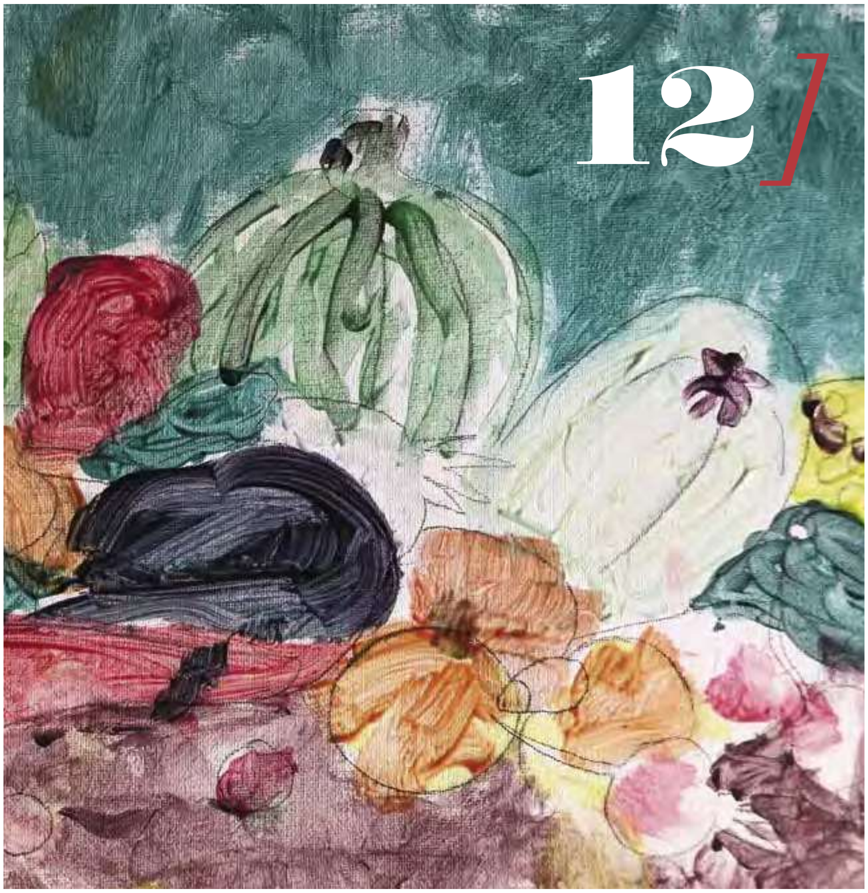

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✉ **Send an Email**

💬 **Share Your Story**

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Ken Walker and Mark Demers, photographed by Lindsay Elliott.

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Dementia Connections Editor in Chief Carolyn Brandly | **Published by Dementia Connections Canada Ltd.**, 303-45 Bastion Square, Victoria, B.C. V8W 1J1 **dcpublisher@dementiaconnections.ca** | Dementia Connections Canada Ltd. is a social venture on a mission to amplify the voices of people impacted by dementia & to share expert advice on how to live well with dementia. | **Managing Editor** Meredith Bailey | **Art Director** Veronica Cowan | **Contributors** Jocelyn Burgener, Elizabeth Chorney-Booth, Josianne Dufour, Lindsay Elliott, Jennifer Friesen, Colin Gallant, Sam Hester, Wade Hudson, Cailynn Klingbeil, Nathan Kunz, Fabian Mayer, Karin Olafson, Meaghan Young | **Printed in Canada by** International Web Express Inc. | **Advertising inquiries**, collaborate@dementiaconnections.ca | Statements, opinions and viewpoints expressed within this publication do not necessarily represent the views of the publisher. | Copyright 2021 by Dementia Connections Canada Ltd. | No part of this publication may be reproduced without the express written consent of the publisher. **Return any undeliverable Canadian addresses to Dementia Connections Canada Ltd.** | **SUBSCRIPTIONS** Print and digital available at DementiaConnections.ca/subscribe. For inquiries and address changes email connect@dementiaconnections.ca.

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Dementia Connections Magazine
@DementiaMag

Thought provoking! Caremongering and Assumptions of Need: The Spread of Compassionate Ageism During COVID-19

Caremongering and Assumptions of Need: The Spread of C...
Abstract. The Coronavirus Disease 2019 (COVID-19) pandemic has highlighted the pervasive ageism that exists i...
academic.oup.com

Kudos Letter

I work at Lakehead University, Centre for Education and Research on Aging & Health. We took a subscription to this wonderful and informative *Dementia Connections* magazine and required an invoice. I just want to say thank you for your diligence in helping me out! Very much appreciated and our finance dept has accepted the invoice and we are good to go!

Warm smiles and with appreciation...

Ruth
Ruth Wilford, Knowledge Broker
Centre for Education and Research on Aging & Health (CERAH)
Lakehead University

Many wonderful articles and resources! Thank you 🙏

@ldessie22So

We'd love to hear from you! Email us at connect@dementiaconnections.ca or reach out on social:
@DementiaMag dementia_connections_magazine @DementiaMag

EVEN MORE ONLINE AT DEMENTIACONNECTIONS.CA

- **Keep Dance in Mind: Dancing Can Keep Your Brain Healthy, Longer.** By Jennifer Dorozio
- **Tips and Tricks for Facilitating Zoom Interactions.** By Dr. Kate Dupuis
- **4 Books Written by People with Dementia.** By Dr. Carole-Lynne Le Navenec
- **The Need-to-Knows on Advance Care Planning and Directives.** By Nathan Kunz
- **Ending Misconceptions of Dementia.** By Christine Thelker

NEW!

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I am so glad I found this amazing organisation.
Diana, USA

DAI saved my life.
Bonnie, USA

Everyone is really supportive.
Bill, Australia

They were life saving for me.
Christine, Canada

I felt so welcome like a warm hug.
Emily, Singapore

It saved my sanity, I'm so thankful I found DAI.
Mithrani, Australia

DAI gives me hope every day.
Natalie, Australia

You never feel alone that's what you'll find at DAI.
Terrie, USA

I found out I wasn't alone and I didn't need to be ashamed.
Wally, USA

Is DAI the antidote for dementia?

We all know there is still no cure for dementia, and that research for a cure remains elusive. However, that is no reason for people to be treated as if they are at end stage of dementia straight after a diagnosis.

Dementia Alliance International is an international group which launched on 1 January 2014, whose membership comprises solely of people with a diagnosis of any type of dementia now from 49 countries. They are people of all ages, cultures, and demographic. Whether living alone, living with a partner, or living in a nursing home; everyone is welcome.

This innovative group offers online peer to peer support groups and cafes with other members where people are free to meet, laugh, talk and cry with people living with a diagnosis. The value of peer-to-peer support cannot be underestimated, and members of DAI consistently report it has been 'life-saving'.

So, if you have been diagnosed with dementia or know someone who has, it may be just the antidote needed to start living with dementia.

DAI
The global voice of dementia

email: info@infodai.org website: www.infodai.org www.facebook.com/DementiaAllianceInternational @DementiaAllianc

COVID-19: A DAY IN THE LIFE

Stephanie and Ron Ruckstuhl offer a glimpse of life during lockdown

By Jennifer Friesen

PHOTOGRAPH: MEAGHAN YOUNG, COURTESY STEPHANIE RUCKSTUHL

Stephanie Ruckstuhl moves a board game aside to sit next to her husband, Ron, as she settles into their living room on a January afternoon. Ron exhales as he readjusts the heating pad against the back of his chair.

"I think I pulled something when I tried to sit next to my wife yesterday," he says.

Since COVID-19 lockdowns began in Canada, the couple has been confined to their home in St. Andrews, New Brunswick, along with their 10-year-old daughter and Stephanie's parents, who live in the in-law suite downstairs.

It's been a challenging year.

As a nurse and instructor at New Brunswick Community College St. Andrews, Stephanie has transitioned to working from home during the week, but she's also the primary

> “COVID-19 has been a bit of a double-edged sword. I don’t have to get a caregiver for Ron...but at the same time it means I’m doing both jobs all day.”
>
> – Stephanie Ruckstuhl –

caretaker for Ron, who was diagnosed with early Lewy body dementia (LBD) at 48 years old.

“[COVID] has been a bit of a double-edged sword,” says Stephanie. “It’s nice because I don’t have to get a caregiver for Ron right now, but at the same time it means I’m doing both jobs all day, which is hard to separate sometimes.”

LBD is a type of dementia tied to changes in cognition, as well as sensory and motor function. It’s often difficult to diagnose. Stephanie says she first noticed a change in Ron in the summer of 2012 when his gait slowed down. A year later, he struggled to find an apostrophe on his keyboard to type the word “it’s.”

Stephanie knew something was wrong, but when they went to their family doctor, Ron was prescribed antidepressants. Ron’s mother was diagnosed with early LBD when she was 58, however, so Stephanie recognized these changes in Ron as similar to what his mother had gone through and kept pushing.

“I picked it up much earlier than other families would, only because of having somewhat lived it already,” says Stephanie. “I was concerned.”

Ron was diagnosed in February 2016 and left his job as a mortgage broker shortly after. He had week-long stretches of what Stephanie and Ron call “good days,” but his illness still took a toll.

“With Alzheimer’s, when people start losing functioning abilities or memories, it’s like a light on a dimmer switch, and it just goes lower and lower,” says Stephanie. “Whereas Lewy bodies is like a regular light switch: on or off.”

Six months before lockdown began last spring, Ron joined a men’s coffee group at a nearby nursing home, which he describes as a “high point” of his week.

“It was nice to be with people,” he says. “Just being a part of conversations and knowing what’s going on in the community.”

But the coffee group has been on hold since last March — as have most community activities and social programs.

This indefinite pause on activities has been difficult for the Ruckstuhls — and they’re not alone. Research shows that people living with dementia are not only more at risk for COVID-19, but increased isolation and reduced support resulting from physical distancing measures have hit them and their care partners particularly hard.

On good days, Ron and Stephanie play cribbage, the family plays board games together, or Ron visits his mother- and father-in-law downstairs. But the pandemic has left him feeling isolated. As well as their 10-year-old daughter, Ron and Stephanie have three adult children who live nearby, but restrictions have kept them apart.

“I miss my kids,” he says. “I feel like I’m cooped up all the time.”

Stephanie has struggled to find support for herself and Ron. Doctor visits have become phone calls, but they have a nurse who comes by monthly to check in and do Ron’s blood work. However, Stephanie says finding help was difficult even before the pandemic, due to the rarity of LBD.

“Even just with early-onset it’s still a big struggle to find supports,” she says.

Stephanie has turned to social media to connect with people affected by LBD from different support groups around the world. She hopes to start her own support group for people going through the same struggles they are, but says it’s been difficult to find the time.

“I’ve made it my mission to try and get something started,” she says. “But sometimes it feels like I have 20 cans of soup open on the stove and I’m not getting there to stir them all. The dishes aren’t done, the house is a mess, I haven’t showered today, and what am I going to make for supper?”

But today is a good day, and Ron doesn’t miss a beat.

“We’re ordering pizza,” he smiles.

How have you stayed active and connected during COVID-19?

Share your story with us at **connect@dementiaconnections.ca**

CREATING CONNECTIONS ACROSS GENERATIONS

When generations come together, everyone experiences social and emotional benefits

By Karin Olafson

Just over 20 years ago, Sharon MacKenzie had an idea. The B.C.-based teacher saw how French immersion was surging in popularity while working with the Vernon Public School District and questioned why immersion should be limited to language learning. She was interested in exploring something new: intergenerational immersion.

Intergenerational immersion, a term coined by MacKenzie, is when various age groups come together in each other's space — whether living, work or school — on an ongoing and regular basis. For everyone involved, the voluntary interactions are beneficial, purposeful and respectful.

Growing the concept began with the Meadows School Project. Starting in 2000, Kidston Elementary School students in grades five, six and seven joined residents and staff at Coldstream Meadows Retirement Community. For two months, the Coldstream Meadows residents and elementary students were immersed in each other's spaces.

"We set up a makeshift classroom in the retirement centre and had an open-door policy so seniors could come in at any time," says MacKenzie, adding that the project ran as a full immersion program until 2008. Residents spoke at the school as guest speakers and were involved in spelling bees among other initiatives, and students helped with the day-to-day running of the retirement community. But MacKenzie believes it was the one-on-one relationships that helped tackle isolation, loneliness and self-confidence issues for both generations.

PHOTOGRAPHS: COURTESY SHARON MACKENZIE

It turns out, MacKenzie was on to something. In 2019, a review titled "Successful Elements of Intergenerational Dementia Programs" published in the *Journal of Intergenerational Relationships* found that bringing generations together is mutually beneficial. It involved researchers from Maastricht University in the Netherlands and the University of South Australia. The review found that intergenerational dementia programs foster relationship-building, something that's particularly advantageous among older adults who commonly experience stigma and isolation. The review states these programs "may also provide empowerment, pleasure and prevent cognitive deterioration."

This is something MacKenzie observed during the Meadows School Project.

"No matter what the children were doing, the seniors would cluster and watch," says MacKenzie. "When the seniors and kids were together, it was fun. Actually, the care home's activity director said clients who wouldn't come down to her own activities — the singalongs or the ring toss — were suddenly crowding the activities

FRAILTY IS A CONDITION OF REDUCED HEALTH AND FUNCTION.

Older adults with frailty are more susceptible to large declines in health from minor illnesses such as the flu or falls and are more likely to be hospitalized, need long term care or die.

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CLOCKWISE FROM LEFT: Memories from the Meadows School Project

to be with the kids."

The 2019 review also found that increased dementia knowledge, such as that offered from intergenerational programs, "can make younger people feel more comfortable around people with dementia, increase levels of empathy and reduce misconceptions." Additionally, the review highlights that there is evidence of increased self-confidence and improved social skills in children. Again, MacKenzie witnessed this with her own project. She took photographs of each cohort at the beginning and end of the project and found, at the beginning, the students would sit at the seniors' feet in an almost formal way.

"At the end of the project, photos showed the kids supporting the residents. They would have their hands on the seniors' shoulders, assisting them and helping them," says MacKenzie.

In 2008, MacKenzie's involvement with intergenerational immersion evolved when she founded the i2i Intergenerational Society. As the volunteer not-for-profit's executive director, MacKenzie shares her research, resources and experience of intergenerational programming with educators, health-care professionals, government and interested community members. In the society's 13 years, MacKenzie has helped develop numerous intergenerational projects all across Canada.

The society doesn't teach a set program or encourage a specific intergenerational template; rather, the work is about encouraging creative ways to make intergenerational community connections.

"It's about taking what you already do and making it intergenerational by inviting groups to come together," says MacKenzie.

"Our society facilitates three levels of intergenerational connection, and immersion is just one of them," she says. "There's also a level we call 'Mama Steps,' where children and seniors come together once a week. 'Baby Steps' is where generations come together purposefully a few times a year. It has to fit your environment, how much time you have and the age groups you're working with."

The flexibility means it can easily be adapted during the pandemic. MacKenzie recommends shifting to facilitate connections through letter writing, Zoom meetups, phone calls or car parades.

"It doesn't replace that face-to-face time," says MacKenzie. "But it still provides both generations with a sense of social connection and purposefulness."

DID YOU KNOW?

Research published in July 2020 indicates that a blood test could detect Alzheimer's disease earlier. Two new studies, one led by a team in Sweden and one from the Washington University in St. Louis, measured a protein called ptau217, believed to be an early marker of Alzheimer's disease. The two studies used different methods to measure ptau217 in blood samples, but both predicted the study participants that had, or who would develop, Alzheimer's with close to 90 per cent accuracy.

Currently, an Alzheimer's diagnosis is often made through a clinical assessment of memory and cognition. Research is still in its early days, but the use of a blood test as a potential diagnostic tool could offer a more reliable, accessible and affordable option. **Learn more at nih.gov**

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Resources for individuals living with dementia and care partners

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Resources designed by people living with dementia and care partners to provide tips and strategies to enhance well-being and manage daily challenges.

Learn more at www.the-ria.ca

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Save The Date: May 26 to 27, 2022 | Calgary, Alberta

Walk with Me: Changing the Culture of Aging in Canada

Join older adults, care partners, policy makers, and researchers from all over the country to learn with and from each other about how to enhance the journey of aging.

Learn more at www.the-ria.ca/walkwithme

Walk with Me is co-hosted by the Schlegel-UW Research Institute for Aging and CapitalCare.

CHANGE BEGINS BY LISTENING

LGBTQI2S charity Egale is studying the experiences and needs of gender- and sexually diverse people living with dementia and their caregivers

By Colin Gallant

PHOTOGRAPH: COURTESY EGALE

The intersection of gender, sexuality, sexual orientation and dementia and dementia care is something we need to understand better. And a new study from Egale Canada is doing just that. Egale is Canada's leading organization for lesbian, gay, bisexual, transgender, queer, intersex and two-spirit (LGBTQI2S) people and issues. The study is called "From the inside out: The integration, optimization, and promotion of inclusive approaches to supporting LGBTQI2S PLWD and their unpaid primary carers." Egale, which is headquartered in Toronto, partnered with the National Institute on Ageing at Ryerson University on the study. Together, they're examining the experiences and needs of LGBTQI2S people living with dementia and their unpaid primary caregivers.

Celeste Pang, senior research officer, LGTBQI2S health, aging and housing for Egale, is the study's project co-lead. She says gathering data on and learning from personal experiences from both this segment of people living with dementia and their caregivers is "step one" in what will become a suite of educational resources and an awareness campaign created by Egale.

"We can't better support people if we don't actually understand what it is that they need and want," says Pang, an anthropological researcher who has studied LGBTQI2S aging

PHOTOGRAPH: COURTESY EGALE

experiences and care issues for nearly a decade. "I use the skill set that I have to amplify and to interpret what people tell me in ways that can lead to critical conversation about things such as dementia and dementia care."

This nationwide study, which kicked off in December 2020, consists of focus groups with LGBTQI2S people living with dementia and unpaid primary caregivers. Because the research is qualitative and exploratory, the sessions start out with questions like "How would you describe your experience living with dementia?" or "How would you describe your experience caring for someone living with dementia?"

It then moves into questions about the participants' specific experiences and what their individual wants and needs are.

Part of the reason LGBTQI2S people living with dementia require a study is that many social supports like health-care services have sometimes been inaccessible. For example, older trans individuals or people living with HIV may feel unwelcome because of past experiences with discrimination.

"Whether or not this is something an individual has experienced, this is a kind of community knowledge — that health-care and social services are not always safe spaces," says Pang.

The experience of unpaid care — and carers — for these populations can differ widely from cisgender, heterosexual populations as well.

"In Canada, we download a lot of the caregiving labour to unpaid caregivers. Often these people are thought of as family members, but especially in the LGBTQI2S community, they could be family members, [or] friends [or] community members," says Pang. "Who are these caregivers? What are their experiences and needs? How can carers be better cared for?"

The study organizers particularly encourage Indigenous, Black and people of colour participants to apply, as well as rural-based individuals. Historically, Pang says, studies on gender– and sexually diverse communities have been limited to white urban-dwellers, so there is a need to include a wider range of subjects to achieve meaningful understanding. ◼

YOUR VOICE MATTERS

Recruitment is still underway for the study, with results expected to be finalized this summer.

The online focus group is open to people living with dementia or unpaid primary caregivers of people who:

- Identify as lesbian, gay, bisexual, trans, queer, intersex and/or two-spirit
- Live in Canada
- Are 18-plus years of age
- Are capable of providing consent

Visit **egale.ca** to register for the study and to learn about recent findings and the study's subsequent awareness campaign.

MAKING NEW MEMORIES

An online painting class helps families connect

By Jennifer Friesen

LEFT Some of John Marcuccio's creations from the Masterpiece Painting class.

PAINTINGS: JOHN MARCUCCIO

Last summer, Danielle Barrette-Marcuccio and her husband, John, who is living with dementia, were feeling stir-crazy.

The Ottawa-based couple were five months into the first round of social isolation due to COVID-19. Like many others, they were looking for meaningful ways to spend their time while cooped up at home. Danielle decided to sign them up for something totally new: a painting class with Masterpiece Painting.

Organized by two Ottawa-based agencies, Carefor and The Dementia Society of Ottawa and Renfrew County, the Masterpiece Painting initiative is a monthly art class for people living with dementia and their caregivers. Once a month, art supplies are delivered to a maximum of 10 groups of two around Ottawa. The two-hour classes run from 11 a.m. to noon, and 1 p.m. to 2 p.m., to allow for a lunch break.

One July morning, paints, brushes and two canvases arrived on Danielle and John's doorstep. The couple joined a video call with an instructor and nine other partner participants to paint the Rideau Canal.

"Our daughter came over and she

> “It’s nice to see an activity that keeps him engaged, and it gives us a bit of fun and creates some nice memories.”
>
> – Danielle Barrette-Marcuccio –

got right into it, too,” Danielle says. “It ended up almost being more of a family activity.”

John was diagnosed with frontotemporal dementia in 2015 when he was 61. Danielle has been by his side as he moved into the advanced stages of the disease, and despite being largely non-verbal now, he took to painting immediately.

“He usually has a very short attention span, but when he started painting, he was completely engaged and stayed focused for two hours,” Danielle says. “I felt a little bit of relief and joy. It was exciting to see that he could do this. Sometimes it seems like everything is about things you can’t do, so it’s nice to add something to the list of can-do.”

Masterpiece Painting officially began last June, but the two agencies had been planning the classes for months before. The initiative was initially intended to be in-person, but as the pandemic took hold, it was moved online. Despite the change of venue, Carefor’s Robin Meyers says it’s the activity itself that matters.

“Over time, a lot of caregivers and people living with dementia have told us that they want to do activities with their family members,” says Meyers. “And they want to do things everyone does, not something just made for someone living with dementia — they want real activities that make you feel alive and to have fun together as a couple.”

Classes are led by instructor Gillian King, a professional artist who is currently in training to be an art therapist (art therapy is a discipline in which people are encouraged to express their thoughts and feelings through art). King lightly pencils in an outline of the month’s painting to make it easier for everyone to follow along.

Danielle says John doesn’t always like to stay inside the lines (or even on the canvas sometimes), but King always reassures them that their paintings are for them and they’re free to do what they like.

“Sometimes he’ll paint my hand,” Danielle says with a laugh. “But it’s nice to see an activity that keeps him engaged, and it gives us a bit of fun and creates some nice memories.”

Learn more about Masterpiece Painting and other remote and virtual programming at dementiahelp.ca

ABOVE John was completely enagaged by the painting classes.

RIGHT John and Danielle at home.

PHOTOGRAPHS: DANIELLE BARRETTE-MARCUCCIO

THE POWER OF WRITING

All across Canada, new letter-writing initiatives that launched in response to COVID-19 lockdowns aim to fight isolation and form friendships

By Karin Olafson

Zoom calls, WhatsApp messages and Instagram Live sessions aren't easy ways to connect with friends and family for all Canadians. In fact, for older adults living alone or in long-term care, the options for connection during COVID-19 are particularly limited.

But the simple act of writing and receiving a letter or email can be a powerful tool to ease feelings of isolation and loneliness. And during the pandemic, letter-writing initiatives have seen a resurgence across Canada.

Here are just three of those projects:

PHOTOGRAPH: DRAGONIMAGES, COURTESY ISTOCK

Caring and Connecting Pen Pal Initiative

Charmaine Holland, founder and president of Caring and Connecting Pen Pal Initiative, grew concerned for the older generation during the first lockdown. Holland, who is an aspiring geriatrician, thought a pen pal program could safely provide care home residents with social connection during the pandemic.

The initiative kicked off in March 2020 and has since partnered with almost 50 care homes across the country.

HOW IT WORKS:

"Our initiative focuses on virtual letters, which prevents unnecessary [risk] being introduced into the care homes. We receive letters from volunteers through email, then format them to be accessible to the average older adult," says Holland. The notes are then emailed to Caring and Connecting's partners.

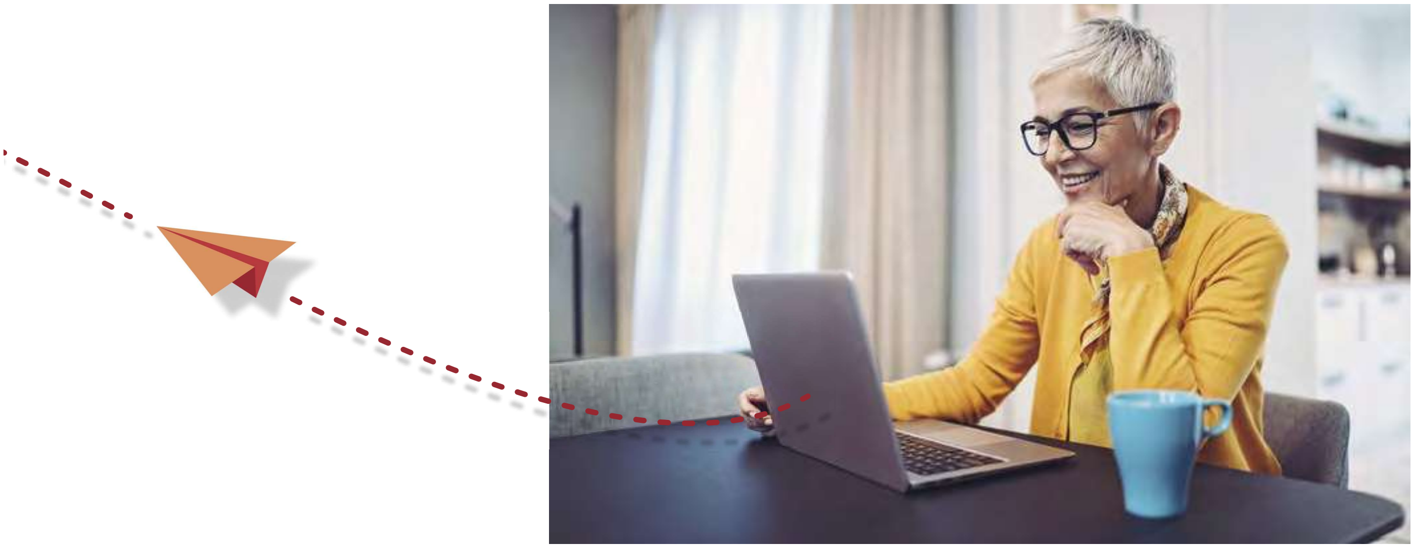
Currently, most letters are from community volunteers. "We tried our hardest to encourage two-way correspondence, but most seniors have been content simply reading their letters."

THE RESPONSE SO FAR:

Volunteers have written more than 1,000 letters since the project's inception. Holland has seen how personal submissions are, highlighting the desire to create meaningful connections.

"The writer takes the time to truly reflect … and children have included drawings," says Holland. These illustrations are a hit among recipients living with dementia.

✉ For more information email
caringandconnectinginitiative@gmail.com



The Grand-Letter Program

Ashi Saini is the program facilitator at Synergy, a Chestermere, Alta.-based charity that enables youth in the community to gather and find supportive resources. Saini wanted to connect girls ages 10 to 13 with older women in the community in hopes of reducing isolation for both age groups during the pandemic. With her goal in mind, the Grand-Letter Program launched in June.

HOW IT WORKS:
Saini connected with community groups like the Chestermere Whitecappers Association, a social group for Chestermerians ages 50 and older, to find local women interested in participating. Then, she created pairs to communicate via email. Saini provides weekly writing prompts, although some pairs communicate more often.

THE RESPONSE SO FAR:
"Most of the feedback from the youth has been that they really want to meet their pen pal," says Saini. "Some of them have gotten really close, to the point where they talk all the time."

For the older participants, the program has offered a unique opportunity to personally connect with and learn more about the younger generation.

"GRAND-LADIES" WEIGH IN

Older adults participating in the Grand-Letter Program out of Chestermere — or "Grand-Ladies," as they are affectionately known — explain what the weekly correspondence with a young person in their community has meant to them.

One participating Grand-Lady says, "I am really enjoying the exchanges I am having with my pen pal and am pleased to hear that some of the older hobbies I have, like cross-stitch and sewing, are being passed down to younger generations."

And another describes the weekly email from her young pen pal as "a breath of fresh air in her week." | Email **ashi@yoursynergy.ca** to learn more

Letters For Better Days

Vancouverite Megan Sadler co-founded Letters for Better Days with four other young women, Alejandra Gadea-Lopez, Alissa Phan, Nekisa Emadi and Tracy Ha. The group wanted to collect letters of hope for residents in long-term care homes in B.C. to encourage them during this tough time.

HOW IT WORKS:
This entirely digital letter-writing program was designed to minimize risk of exposure to COVID-19 and limit workload for care home staff. All letters crafted by writers are typed or scanned, then emailed to Letters for Better Days. The team collates all letters into one PDF, which is emailed to partners to print and distribute.

THE RESPONSE SO FAR:
Volunteers from across Canada, as well as England and Dubai, have written personal letters, and elementary school groups and companies have participated, too. Even fantasy novelist Neil Gaiman tweeted about the project.

"I read every letter we received, and some of them were so intensely personal. That personal touch benefits the recipient [and offers] brightness and joy," says Sadler. "A lot of seniors have said that they hope the letters never stop coming!"

Email **lettersforbetterdays@gmail.com** to learn more

PHOTOGRAPH: PIXELFIT, COURTESY ISTOCK

EXPLORING AGE ON STAGE

Over the past 20 years, the GeriActors & Friends theatre company has brought unique stories into the spotlight

By Meg Braem

When it comes to story creation, the GeriActors & Friends theatre company has a wealth of diverse life experiences to draw from.

During a rehearsal for an upcoming show, 78-year-old member Pearl Edwards shared how, when she was a girl in Trinidad, women gathered at the standpipe in her town to bathe their children, trade news and gossip before returning with buckets on their heads. Later, 86-year-old member John Grootelaar described when, as an eight-year-old, he sat on the roof of a truck and watched as allied planes flew over the Netherlands.

Through acting out vignettes like these, the "Geris," as they're known, share their rich experiences with audiences of all ages.

Founded in 2001, the Edmonton-based company has become internationally known for creating and promoting intergenerational theatre. The Geris range in age from 60 to 90 years old, with 'friends' — students and alumni from the University of Alberta — averaging about 22 years old.

The Geris' stories are entertaining but also challenge stereotypes, strengthen memory, develop skills associated with performance and articulate issues of aging. According to the Department of Human Ecology at the University of Alberta, older adults who engage in the arts receive a wide range of positive health outcomes including personal

CLOCKWISE FROM TOP RIGHT
The company from the play *We Decide*; GeriActors & Friends share a laugh; a scene from the play *Pink Nail Polish*.

PHOTOGRAPH: RYAN PARKER

control, self-esteem, physical health, functional independence, cognitive function and lower mortality rates.

How to make sure the arts are accessible to everyone, including those unable to make it to a theatre, has long been a question on founding artistic director David Barnet's mind. And with the pandemic restricting access to friends, family and social programs, the need for connection has never been more urgent. "We live in historic times," says Barnet. "We will use theatre to explore how they have changed us."

The company is embarking on a new creation process that will allow them to reach audiences in their homes. Funded by the Canada Council for the Arts as well as EPCOR's Heart and Soul Fund, the GeriActors & Friends recently completed a new play entitled *Way Back,* to be available through live stream and audio recording.

By exploring the theme "small human events set against the panoply of great world events," the Geris are sharing ideas and stories that will be the foundation of the piece. "We are bringing alive a past which would have faded away," says company member Diane Jonsson, describing how the Geris create.

Through the practice of creative aging, the company encourages older adults to express themselves. The Geris hope to entertain but also inspire audiences at home to share their own stories.

PHOTOGRAPHS: (TOP) RYAN PARKER; (BOTTOM) JEN SHAW

Way Back, written in collaboration with Meg Braem, will be performed virtually from May to June 2021 and in person from October to November (depending on COVID restrictions).

For more information on *Way Back*, as well as recordings of past GeriActors productions, visit **geriactors.ca**

> “There’s just so many more people living with dementia in our communities, and to be able to arm our youth with understanding, it can only make the world better.”
>
> – Barb Sutcliffe –

BRIDGING THE GAP

LIVING the Dementia Journey has been revamped to better connect young people and older adults

By Cailynn Klingbeil

LIVING the Dementia Journey, an award-winning training program for those who support people living with dementia, has been adapted for an important new audience: teenagers and young adults.

"Intergenerational programs will increase opportunities for youth and older adults living with dementia to connect, and bring generations together," says Neb Zachariah, project manager at The Schlegel-UW Research Institute for Aging (RIA), in Waterloo, Ont.

The youth program is being developed by the RIA's Supporting Inclusion through Intergenerational Partnerships, a five-year project to promote social inclusion among community-dwelling older adults living with dementia and their care partners in the Waterloo region. The training, designed for participants ages 14 to 25, is still in its pilot phase, with larger enrolment expected in September 2021.

Zachariah says that while older adults living with dementia have a lot to contribute to communities, social isolation can make it challenging for them to share their experiences and knowledge. At the same time, young people are looking for ways to be meaningfully involved in their communities.

"[The youth program] addresses the needs of both populations in a really helpful and mutually beneficial way," she says.

LIVING the Dementia Journey was created in partnership with the Murray Alzheimer Research and Education Program (MAREP), Schlegel Villages and the RIA in 2013.

Barb Sutcliffe, a registered nurse and senior manager of sales and marketing at the RIA, says the program was first developed to make sure the voices of people living with dementia were heard.

"There really wasn't any program out there that was hearing that voice and sharing it with people who were providing support for people living with dementia," Sutcliffe says.

The original program is offered two ways: a one-day interactive overview workshop and an advanced train-the-trainer workshop for people interested in becoming facilitators. Participants, including family care partners or those providing support at long-term care or retirement homes, gain awareness and understanding of what dementia is, how it progresses and its impact.

They also learn strategies to better communicate with, care for and listen to people living with dementia.

More than 2,350 people have completed LIVING the Dementia Journey, including those who take the two-day facilitator workshop and then continue to train team members in their organizations.

As well as content found in the original program, the youth program includes new material on how young adults can work with someone living with dementia through volunteering or future career opportunities.

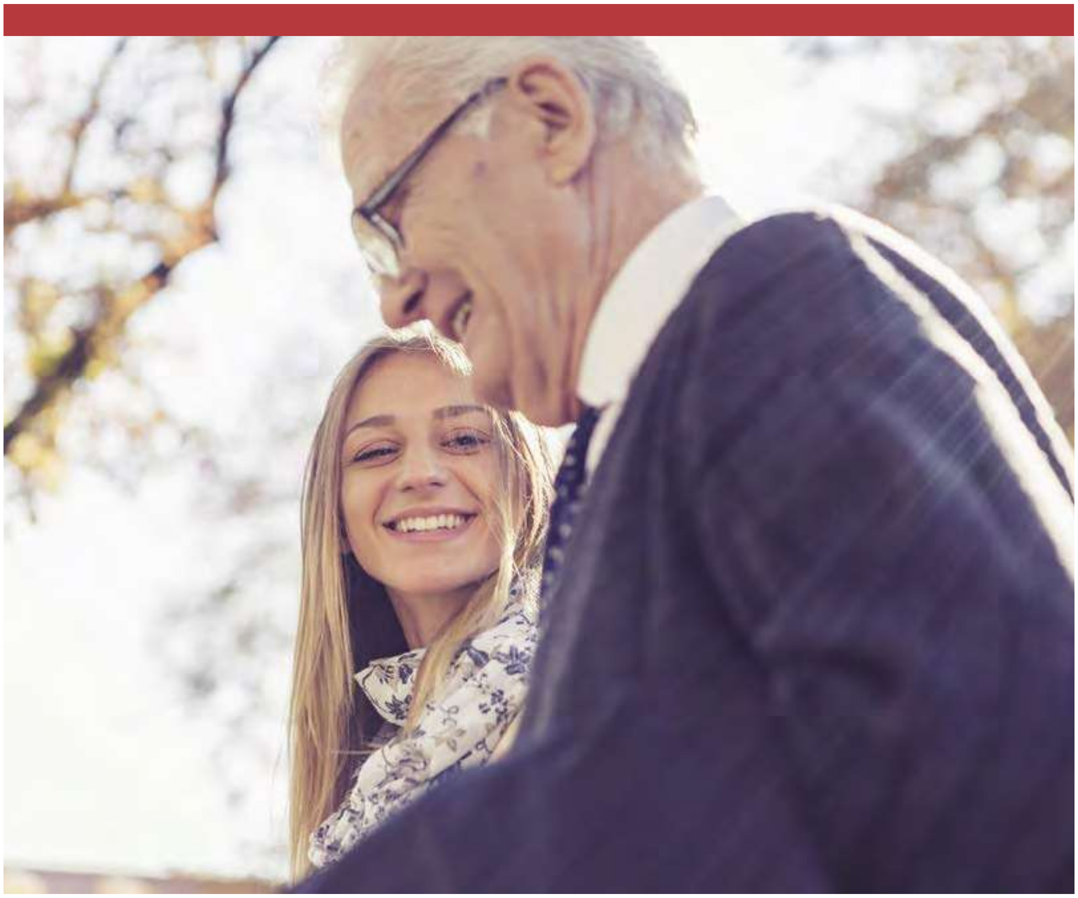
"It really is about equipping youth to engage with older adults. To see the value of working with [them], and to give them the confidence that they need to do it because we understand that there might be some apprehension or just misconceptions about older adults and people living with dementia," Sutcliffe says.

To adapt LIVING the Dementia Journey, the RIA worked directly with young people. A group took the existing workshop in February 2020 and shared feedback. Participants included Lucy Hur, a 17-year-old high school student from Waterloo. She enjoyed the experience so much that she's stayed involved by continuing to review content and share feedback and ideas.

"I really learned a lot," Hur says. "The program makes it more accessible for young people to be aware of what dementia really is."

Modifying the program for youth participants means a wider audience receives the same valuable training. The course has also been transformed to be delivered online, due to COVID-19 restrictions.

"There's just so many more people living with dementia in our communities and to be able to arm our youth with understanding, it can only make the world better," Sutcliffe says.



To learn more about LIVING the Dementia Journey including training opportunities, visit livingdementia.ca

PHOTOGRAPH: NOSYSTEM IMAGES, COURTESY ISTOCK

How family and friends can help support their loved one living with dementia and memory loss.

A diagnosis of dementia is a life-changing event, and not just for the person directly affected. Those closest to the person are profoundly touched as well. It's perfectly normal for all those involved to experience feelings of fear, denial and anger while adjusting to what's ahead. The road is long, so it's important for family members to learn how to cope with this new reality and effectively support their loved ones through the changes they will experience.

How can those caring for them help? Here are some suggestions:

1. Celebrate the person.

They may respond differently at times but inside, the person is the same. "It's so important to treat your loved one with the same understanding, respect and patience you showed them before they started losing their memory," stresses Elaine Wood, Vice President, Operations. "You don't want to lose sight of the individual," adds Jennifer Beninato, MemoryPlus™ Manager at Delmanor Elgin Mills.

2. Focus on the positive.

There's no point in being argumentative or trying to impress the person with logic. "They're looking to regain the control and power they've lost, so it's common for them to point the finger at someone else," explains Wood. "Be sure to be as agreeable and empathetic as possible, then redirect their attention elsewhere by starting a different conversation to get them thinking about something more positive.

3. Be flexible.

"Let go of your expectations and be prepared to change plans from day to day as time allows. Let your loved one take the lead as much as possible. Remember that the goal is enjoyment, not achievement," says Beninato.

4. Engage in activities they can still enjoy.

Keep your loved one as engaged as possible. "It provides comfort and support and allows the person to maintain more individuality and independence," explains Beninato. Remember what they've always loved to do: maybe it's baking, which you can now do together. Perhaps they loved to paint, exercise, play cards or games. "It's pleasurable to do activities with someone you love, as well as mentally stimulating."

5. Adapt the things they can no longer do on their own.

Be creative about introducing new ways to enjoy the things they did in the past. "If the person travelled, for example, look at old photo albums of trips and reminisce," suggests Beninato. Other examples: if they used to garden, take them for a visit to a garden centre to engage their passion for flowers. If they enjoyed shopping, consider a short trip to a favourite store. Or if they loved going to the theatre, get some videos of old television shows or movies and watch them together.

6. Take care of yourself.

Remember your own health is also a priority. "Take care of yourself so you have lots of patience and love to share," says Beninato. "Do things you enjoy: exercise, eat well, sleep well, find ways to relax like going for a walk or massage, engage in your own hobbies and interests, and take a break from caregiving to spend time with other family and friends."

To discover more about MemoryPlus™ at Delmanor Elgin Mills visit us online at Delmanor.com or call us at 905-770-7943

Sponsored Content

5 DEMENTIA YOUTUBE CHANNELS TO FOLLOW TODAY

By Karin Olafson

Alzheimer's Research UK

All the videos from this registered research charity challenge how people think about dementia. As well as easy-to-understand scientific explainers and interviews with researchers and celebrities, this channel shares personal stories of people living with dementia.

Find the channel: **youtube.com/AlzheimersResearchUK**

Dementia Alliance International

Dementia Alliance International (DAI), a global non-profit made up exclusively of people diagnosed with dementia, uses its YouTube channel to promote the rights and voices of those living with dementia. DAI's channel has been recognized as a top 20 Dementia YouTube Channel for the past three years. Find personal stories, videos featuring researchers, advocates and activists and more.

Find the channel: **youtube.com/channel/UC9OU-TO5MmvYPhmz6j7DYlg/**

What are your favourite channels? **@DementiaMag** or **connect@dementiaconnections.ca**

Dementia Careblazers

Every Sunday, American geropsychologist Natali Edmonds shares helpful tips, strategies and information to support family members caring for someone living with dementia. Find care partner self-care tips, helpful ways caregivers can respond to hallucinations and more.

Find the channel: **youtube.com/DementiaCareblazers**

Living Life With Lisa

Lisa lives with young onset dementia and uses her YouTube channel as a video diary, sharing her day-to-day experiences. Through highs and lows, Lisa shows that a dementia diagnosis can still mean living to the fullest.

Find the channel: **youtube.com/LivingLifeWithLisa**

Teepa Snow's Positive Approach to Care

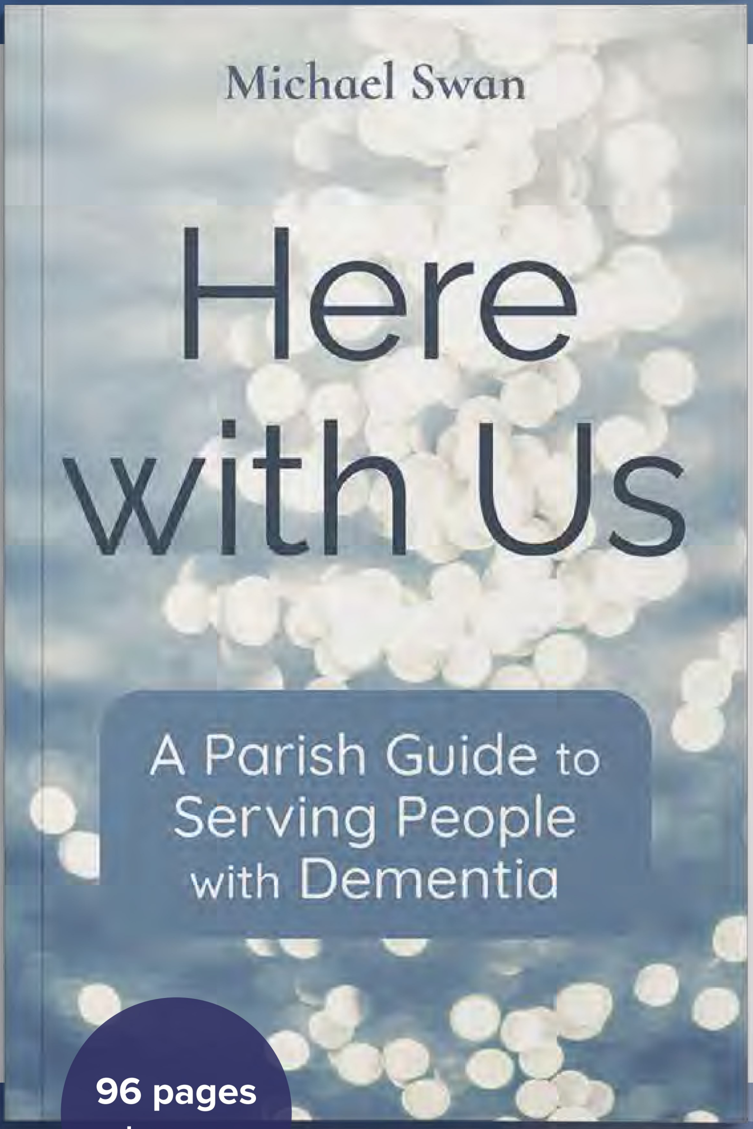
Teepa Snow is an American dementia care consultant and educator. Her compassionate caregiving tips, previously recorded public talks, and informative, short videos for people living with dementia all reinforce her positive, person-centered care approach.

Find the channel: **youtube.com/teepasnow**

VIRTUAL PET CONNECTIONS

PETS TOGETHER, a video project from the Animal Farm Foundation, allows anyone to book some time to connect with a dog, cat or even a horse — virtually, that is. The free video meet-ups are 30 minutes long, take place over Zoom, and are ideal for individuals or group settings.

For more information or to book a video session, visit **petstogether.org**



Michael Swan
Here with Us
A Parish Guide to Serving People with Dementia

FAMILY CAREGIVERS OF BC

www.familycaregiversbc.ca

At Family Caregivers of BC (FCBC), we frequently hear from unpaid family and friend caregivers about how rewarding they find their caregiving role. And yet, caregivers often face many practical and emotional challenges. The stress and uncertainty can lead to distress and burnout, potentially impacting caregiver health and their ability to continue providing support.

FCBC proudly and compassionately supports over 1 million people in British Columbia that provide physical and/or emotional care to a family member, friend of neighbour. FCBC supports caregivers by providing access to information, education and supports that enable caregivers to feel more confident and successful in their role. The free supports include:

- BC Caregiver Support Line – receive 1-1 telephone support, Monday through Friday at 1-877-520-3267
- Caregiver Learning Center – enjoy our podcast, articles, webinars, flipbooks and more https://www.familycaregiversbc.ca/caregiver-learning-center/
- Caregiver Support Groups – join our monthly virtual support groups https://www.familycaregiversbc.ca/family-caregiver-support-groups/
- Caregiver Connection Newsletter and Enews – sign-up and get resources to your inbox https://www.familycaregiversbc.ca/caregiver-connection/

According to our COVID-19 Impact Survey, over 50% of caregivers reported their mental health had declined since the COVID-19 Pandemic. FCBC is here to support caregivers with information, educational resources and supports.

THE POWER OF PARTNERSHIPS

Discover two initiatives that help raise awareness, reduce stigma and increase inclusion

By Diane Bolt

As the director of health of the Pinaymootang First Nation, a community located 240 kilometres northwest of Winnipeg, Gwen Traverse understands the unique health challenges people living with dementia and their caregivers face in rural settings. These issues include difficulty accessing health care to age in place, limited health literacy from informal caregivers, a lack of cultural sensitivity and awareness from some health-care providers, and difficulty securing funding for health and wellness programs.

Living with Dementia in Rural First Nations Communities: A Health and Wellness Project hopes to alleviate some of these challenges. The project, which is funded by the Public Health Agency of Canada, began in spring 2020 and is scheduled to run until March 2022. It is a partnership between the University of Manitoba and six First Nation communities, including Pinaymootang First Nation, Lake Manitoba First Nation, Opaskwayak Cree Nation, Norway House Cree Nation, Sagkeeng Anicinabe First Nation and Lake St. Martin First Nation.

"The project's three goals are to help informal caregivers and the person living with dementia lead a happy and fulfilling life, to mitigate risk factors in the community that affect dementia, and to mobilize the knowledge we have by developing training materials that

> "People in the city may not see how First Nations communities struggle in order to access better health care."
>
> –Gwen Traverse –

> "The project's three goals are to help informal caregivers and the person living with dementia lead a happy and fulfilling life, to mitigate risk factors in the community that affect dementia, and to mobilize the knowledge we have by developing training materials that can be shared with other Indigenous communities who may wish to learn from our experiences."
>
> – Dr. Reg Urbanowski –


PHOTOGRAPHS: COURTESY PINAYMOOTANG FIRST NATION HEALTH PROGRAM

FACING PAGE Team members connect with a community Elder. **THIS PAGE** Team members from the start up phases of the project in partnership with the University of Manitoba.

can be shared with other Indigenous communities who may wish to learn from our experiences," says Dr. Reg Urbanowski, the dean of the College of Rehabilitation Sciences at the University of Manitoba.

Urbanowski began working with a number of First Nation communities, including Pinaymootang First Nation, in 2016. He asked how the College could be of service to the community.

"Dementia in Indigenous communities is probably a good third higher than in the rest of the population, due to factors such as housing, residential-school trauma and health issues related to cardiovascular disease and diabetes," says Urbanowski. "And it's hitting people at a younger age and growing at a faster rate." (1)

During a gathering with the university in 2019, Traverse and her staff expressed interest to work on programming for people living with dementia in their community. Traverse also shared that Pinaymootang First Nation Health Centre considers itself a health and wellness hub for community members and people living nearby.

"I was so passionate and frustrated that I broke down crying," says Traverse. "People in the city may not see how First Nations communities struggle in order to access better health care."

This ongoing partnership between the University of Manitoba and Pinaymootang First Nation spurred the project's creation.

In July 2020, students from the university's physical and occupational therapy program visited Pinaymootang First Nation three times a week for six weeks to research the types of programs that might benefit those living with dementia. The students connected with people living with dementia and performed strength assessments, devised exercise regimens (such as chair exercises), and recommended strategies and equipment to increase self-care and independence. The students also helped develop a dementia toolbox of educational resources for caregivers.

Another project initiative in the development stage is called the Gift of Memories, which supplies tablets to people with mild to moderate dementia and their caregivers, so they can share life stories and experiences.

"It's a legacy piece that reasserts the value of people living with dementia and their history," says Urbanowski.

Today, the pandemic has slowed the project's progress, but Traverse, Urbanowski and their teams continue to work together to raise awareness and help reduce the risk factors associated with dementia.

(1) Learn more at i-caare.ca/factsheets
Indigenous Cognition & Aging Awareness Research Exchange. Kristen Jacklin, Wayne Warry, Melissa Blind, Sharlene Webkamigad, Louise Jones. "Signs and Symptoms of Dementia: A Indigenous Guide" (1126764, Industry Canada).

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BUILDING CAPACITY

PHOTOGRAPH: COURTESY BUILDING CAPACITY PROJECT

LEFT Main project partners from the Westside Seniors Hub and the Thunder Bay's Northwest Dementia Working Group at the project launch event at Kits Neighbourhood House. OPPOSITE PAGE Screenshots from Happy Memories Café's virtual events.

In the fall of 2018, the Public Health Agency of Canada's Dementia Community Investment (DCI) reached out to Dr. Alison Phinney with an invitation to submit an application for funding. The DCI is part of *A Dementia Strategy for Canada: Together We Aspire*, Canada's first national dementia strategy. The agency was looking for proposals to support community-based research interventions that improve the quality of life of people living with dementia and their caregivers.

Phinney is a professor in the School of Nursing at the University of British Columbia and co-director of the Centre for Research on Personhood in Dementia. She has long held inclusion, support and enacting positive change for people living with dementia as a career focus. Upon receiving the invitation from the Public Health Agency, Phinney remembered a conversation she'd had a few months earlier.

"I'd had a call in May 2018 from Westside Seniors Hub here in Vancouver. They wanted to bring [local] service providers together to promote the well-being of people living with dementia," says Phinney. The funding opportunity from the DCI felt like a perfect fit.

Phinney went back to the Westside Seniors Hub and pitched the idea of partnering on a community-based initiative to help people living with dementia and their care partners remain active and connected to their communities.

"They were game," she says.

Soon, the Building Capacity for Meaningful Participation by People Living with Dementia initiative was

> “We are looking at ways of engaging with people with dementia to create opportunities so that they can continue to be active in and contribute to their communities.”
>
> – Dr. Allison Phinney –

born. One of 18 ventures funded by the DCI, the four-year project is co-led by Phinney and her colleague Elaine Wiersma, an associate professor at Thunder Bay’s Lakehead University in Ontario and director of its Centre for Education and Research on Aging and Health.

The project looks at ways to promote self-advocacy and leadership and evaluate and adapt existing programs — such as social cafés, art classes and fitness programs — to be more dementia-inclusive in two project sites: Vancouver and Thunder Bay. It includes researchers from UBC and Lakehead University, as well as members of the Westside Seniors Hub in Vancouver and the North West Dementia Working Group in Thunder Bay. The project’s overarching aim is “to enable people living with dementia to participate in community life as full social citizens and to support the growth of innovative community initiatives that will foster inclusion and reduce stigma by creating meaningful opportunities for people with dementia to remain active and socially connected.”

In Vancouver, the South Granville Seniors Centre, which runs the Happy Memories Café, is one of the organizations the Building Capacity project supports. Douglas Dunn and his team facilitate the café, a social program for people living with dementia and care partners, which went virtual in mid-2020 with the project’s support. The team helps people living with dementia navigate the program’s video calls by pre-empting who will speak next and muting mics as needed.

“It was solely due to the Building Capacity funding that we were able to establish the program. We were allowed to spend funds mainly on staff wages and some pieces of tech (such as webcams and Zoom subscriptions),” says Dunn.

So far, expansion of the Building Capacity project has been slowed by the pandemic, but the intention is to build and share knowledge so that others can implement initiatives similar to the Happy Memories Café in the future.

“People living with dementia can still take on challenges and learn new things,” says Phinney. “We are looking at ways of engaging with people with dementia to create opportunities so that they can continue to be active in and contribute to their communities,” says Phinney.

DID YOU KNOW?

A new global initiative is working to accelerate progress of the discovery, testing and delivery of innovative interventions for Alzheimer’s disease. Officially formed in 2020, the Davos Alzheimer’s Collaborative is a partnership between the World Economic Forum and the Global CEO Initiative on Alzheimer’s Disease. The DAC’s six-year plan focuses on three areas: develop a diverse global study cohort, reduce the time and cost to bring new treatments to market and increase patient access to diagnosis, treatment and care.

Learn more at davosalzheimerscollaborative.org

Learn more about the Building Capacity project at **crpd.ubc.ca/building-capacity-project**

FALLING AT HOME AND HOW TO PREVENT IT

By John Sloan and Marni Tory | Illustrations by Josianne Dufour

For anyone, falling can be unsettling, but a fall can lead to significant injury for older adults. According to the Canadian Institute for Health Information, falls accounted for more than 80 per cent of hospitalizations for older adults between 2017 and 2018. The most common place for people to fall is in their own homes. For people living with dementia or cognitive impairment, the risk of falling increases. Luckily, from maintaining mobility to increased lighting, there are steps you can take to prevent a fall from happening in the first place. We asked the experts, Dr. John Sloan, a family physician and author who treats frail, older adults in their homes, and Marni Tory, an occupational therapist with Proactive Seniors, to weigh in on why falls happen and how to prevent them.

What tips and tricks do you use at home to prevent falls? Let us know on social, **@DementiaMag**, or email us at **connect@dementiaconnections.ca**

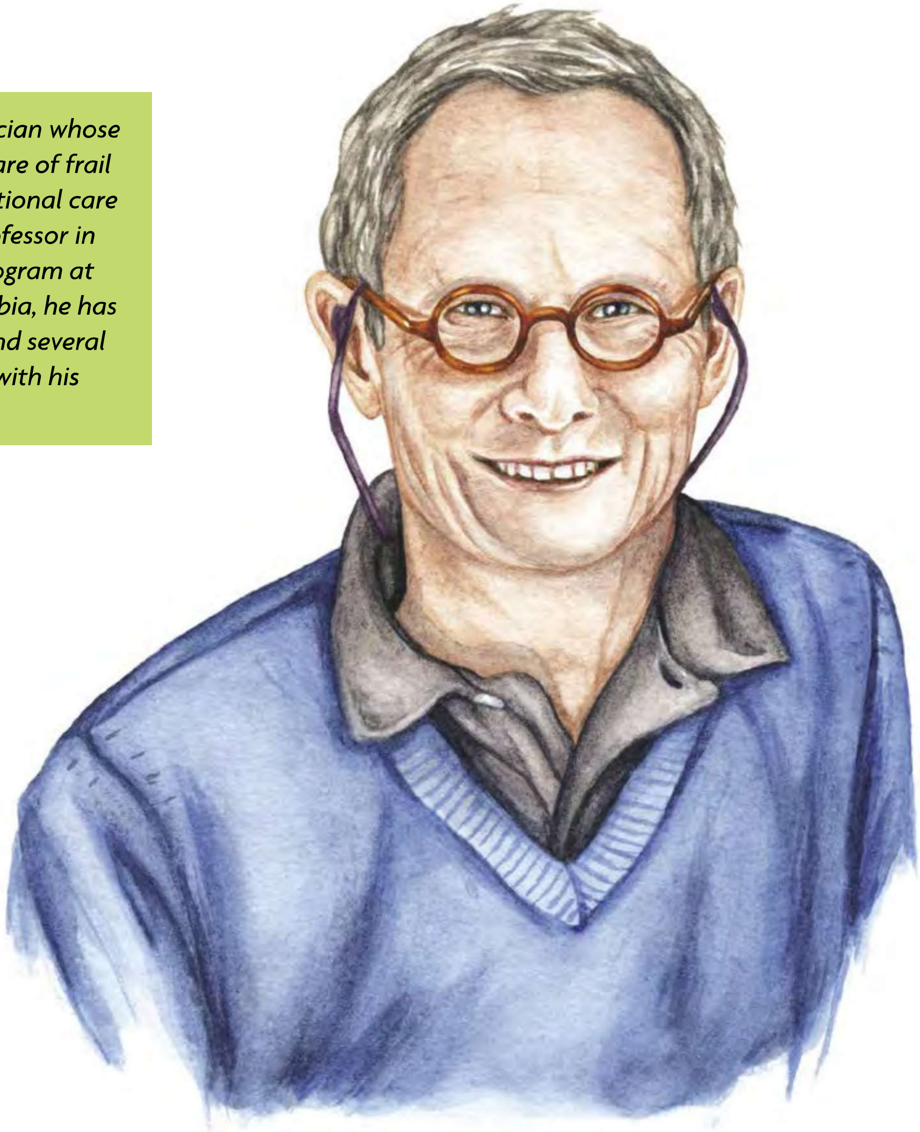
Why do falls happen? Q&A with Dr. John Sloan

Are older adults more at risk for falls at home? Definitely. Everything that maintains safe upright posture ages. Nerve impulses telling the brain about body position travel more slowly, along with the ones that signal muscles to correct deviations. Therefore an 80-year-old naturally "wobbles" more than she did when she was 30.

What are the main causes of falls for people living at home? Older people usually fall for several reasons, not just one. But some of those reasons are poor physical fitness, poor vision, hazards in the home, and diseases like arthritis, stroke, or heartbeat problems. But often overlooked is the prescribing of excessive medication, especially ones that cause blood pressure to drop when an older person stands up.

What are the most common injuries that result from falls? Fortunately, most [falls] don't cause any serious injury, [just] some sore spots that get better quickly. But broken bones (especially a hip) and head injuries (especially in people taking blood-thinners) are more dangerous consequences of falling.

Dr. John Sloan is a family physician whose practice is confined to home care of frail elderly people, avoiding institutional care of these patients. A clinical professor in the Primary Care Geriatrics program at the University of British Columbia, he has published numerous articles and several books on health care. He lives with his family in Roberts Creek, B.C.



What environmental or design changes can be made to prevent falls? Simplify the environment, especially on and around usual indoor pathways. Monitor and remove objects, electric cords, loose rugs or carpets, and toys. Maintain good lighting. Anything that makes getting from A to B easier reduces fall risk: everything on one floor, and bathroom near the bed, for example. Remove or pad sharp edges on tables.

What advice would you offer for people living with dementia and their care partners to prevent falls at home? Stay fit. With mobility, it's "use it or lose it." Remove hazards, dress sensibly (especially shoes) and assure adequate lighting. Although many elderly people find them embarrassing, assistive devices like canes or walkers can help. Carefully question the importance of medications that lower blood pressure (like any heart treatments) and cloud awareness (like sleeping pills). Both can increase the risk of falling.

What else is important for people to note regarding fall prevention? It isn't easy balancing the benefits of independence and exercise against the advice you usually hear, including my answers to these questions. Family members and health professionals may be afraid to let elderly people "live at risk," but defining what's reasonable is an individual project. Consider lifelong and natural preferences, and the kind of falls (sudden unexpected crashes, or falls where the person is able to get down to the floor safely).

→

Preventing falls by creating a dementia-inclusive home with Marni Tory, occupational therapist, Proactive Seniors

Why are falls more common for people living with dementia? Someone with dementia may have poor concentration or memory, causing them to forget their mobility aid or to use their wheelchair brakes. They may have decreased insight into their physical limitations or may misinterpret their environment and fail to recognize unsafe situations. Coordination difficulties, visual challenges, environmental hazards or medication side effects can make navigating the home difficult. They may have difficulty with depth perception, peripheral vision, judging distances or dealing with patterns and shadows. Unmet needs can also trigger someone to wander in search of a bathroom or the kitchen.

Marni Tory's tips for creating a dementia-inclusive home:

- Keep walking paths and stairs clear of clutter.
- Tape electrical cords to the wall.
- Provide tables to bring items like laundry baskets to eye-level.
- Place furniture to prevent creating obstacles without moving or taking away items that a person may grab for stability.
- Place mobility aids at both the top and bottom of the stairs.
- Secure shelves to the wall and place non-slip matting under furniture.
- Provide visual and wayfinding cues.
- Ensure adequate lighting. Proper lighting can reduce shadows, light the way to the bathroom and can assist with safety, especially on stairs.
- Automatic motion sensor lights are a good way to alert family that the person living with dementia is up and may need supervision.
- The bedroom and bathroom may need transfer poles, shower chairs, grab bars and raised toilet seats. Properly placed grab bars can be the difference between an independent safe transfer or getting stuck on the toilet.
- Highlight stair edges or top and bottom stairs with contrasting colours or tape.
- Redesign storage areas organizing commonly used items within reach.
- Manage floor surfaces, reducing glare and avoiding patterns.
- People living with dementia may have difficulty separating similar colours and setting objects and their backgrounds apart. Use contrasting colours to help with identification (toilet seats, tubs, doors, dishwashers, etc.). ◼

Learn more at **canadianfallprevention.ca/resources-and-links**

With over 20 years' experience in caring for seniors, Marni Tory is dedicated to the highest quality of life and care for people with dementia and their families.

She is an occupational therapist and Dementia Advisor with Proactive Seniors. Tory recently completed her master's of science degree in Dementia Care and is a certified Aging-in-place Specialist.

DEMENTIA DIALOGUE

Voices of Lived Experience

In our podcast, people living with dementia and care/life partners share their experiences. Peer listeners gain insights and strengthen their adaptive skills. Other listeners gain a deeper understanding of what it means to live with dementia and of the issues surrounding it. "

2021 PODCAST TOPICS:

- Spirituality and Dementia
- Arts and Dementia
- Dementia Friendly Communities
- LGBTQ2S+ and Dementia

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DEMENTIA DIALOGUE

BELOW The first National Meeting of the Irish Dementia Working Group in September 2019

PHOTOGRAPH: COURTESY THE ALZHEIMER SOCIETY OF IRELAND

HEAR OUR VOICE

A new guide identifies best practices for including people living with dementia in conferences, policy discussions, research and advisory positions

By Fabian Mayer

When it comes to lived experience, people living with dementia are the experts. But often they're not included in policy discussions or community consultations, even when the issue directly relates to their lives. Seeking input from people living with dementia is vitally important. However, it can involve some extra considerations.

The Irish Dementia Working Group (IDWG), an advocacy organization composed of people living with dementia, developed a user-friendly guide for individuals and organizations who wish to involve people living with dementia in their work or gain their views in a formal way. The guide, which was published in April 2020, was created with the support of the Alzheimer Society of Ireland and the Centre for Economic and Social Research on Dementia (CESRD) at the National University of Ireland, Galway. Kevin Quaid is the vice chair of the European Working Group of People with Dementia and a member of the IDWG. Quaid is also living with Lewy body dementia. He worked alongside dementia researchers, caregivers, and other people living with dementia to develop the guide. Quaid says bringing people living with dementia into big picture decision-making processes, research, advisory and policy creation around the disease is crucial.

"There was a light-bulb moment," says Quaid. "If we're talking about dementia here, there are so many types of it, who better to ask than the experts? And the experts are the people that have dementia."

The 23-page guide, called *Hear Our Voice!*, identifies best practices when formally involving people with dementia in policy, advisory, consultation and conference activities. Since its release, the guide has been adopted by the National Dementia Office of the Health Service in Ireland and accessed nearly 150 times online.

General Principles

Hear Our Voice! outlines a set of eight general principles that organizers and facilitators should consider in all interactions with people living with dementia. The principles include things such as seeing the person, not just their disease, as well as giving the person a voice, which may entail working within each individual's strengths.

"Regardless of the stage of the person with dementia, they have a voice [and] need to be listened to," says Quaid. "Sometimes they might go off on a tangent or stray from the topic, but if you listen, there are little gold nuggets. It's so important that they're not dismissed. And I think that's the core of *Hear Our Voice!*"

It is also essential to remain flexible. Individuals may have better and worse days or times of day; working within those needs as much as possible can help ensure meaningful contributions. Also, never make assumptions about what dementia looks or sounds like — dementia can vary greatly on an individual basis.

Communication and Information

Communicating with people living with dementia requires a thoughtful approach. Organizers should provide all details about the event or meeting such as the date, time, venue and event organizer contact details in

> "Regardless of the stage of the person with dementia, they have a voice [and] need to be listened to."
>
> – Kevin Quaid –

Hear our voice!

Guidelines for involving people with dementia in policy, advisory, consultation and conference activities

Co-produced by The Centre for Economic and Social Research on Dementia, The Irish Dementia Working Group and The Alzheimer Society of Ireland.

April 2020

CESRD Centre for Economic and Social Research on Dementia

REMEMBER THOSE WHO CANNOT

THE ALZHEIMER SOCIETY of IRELAND

PHOTOGRAPH: COURTESY THE ALZHEIMER SOCIETY OF IRELAND

Kevin Quaid is a member of the Irish Dementia Working Group and contributed to *Hear Our Voice!*

a written manner. When it comes to verbal communication during the event itself, avoid jargon and acronyms. Speak clearly and use short sentences when possible. Organizers should make doubly sure that participants know what is expected of them before and during the meeting or discussion. Quaid remembers attending one event where this point went overlooked.

"I was given a certain length of time to speak, and we had prepared [for that time]," says Quaid. "And 10 minutes before I was due to go on stage to speak, someone came up and said, 'Sorry you only have five minutes now.'"

A supporter quickly spoke up for Quaid, and he was eventually given his full time.

"When we have that kind of support, it makes us want to be involved. We look forward to being involved," says Quaid.

Venue and Involvement

There are several things one can do to ensure a venue is accessible and inviting to people living with dementia. Having someone to greet participants at the building entrance helps point participants in the right direction. Double-checking that there is signage to and from the washrooms is critical. If the event is being held virtually, ensure that the person with dementia has internet access and test it with them well before the start time. It's also important to try and start meetings on the hour; this is easier to remember than meetings that begin at quarter past or quarter to the hour.

Quaid recognizes that many of the suggestions aren't exactly complicated, yet they aren't always obvious.

"It's so simple that it's often the thing that's staring you in the face that you miss," says Quaid. "It all makes common sense, but 'common sense is not that common,' as my wife often says." ◼

To learn more about the guidelines and to read the full *Hear Our Voice!* document, visit **alzheimer.ie/wp-content/uploads/2020**

PHOTOGRAPHS: COURTESY KEVIN QUAID

ONCE UPON A TIME

How storytelling creates connection and benefits cognition

By Colleen Biondi

Storytelling is a beloved oral tradition that has educated, inspired and offered comfort since the beginning of time. Now, thanks to empirical research, storytelling has been linked to reduced cognitive decline in people living with dementia.

A randomized trial published in 2019 led by the Fujian Medical University in China looked at the impact of creative expression, such as developing a story, on communication, emotion, quality of life and cognition for people living with dementia. Facilitators used pictures to guide participants in the collective creation of a story using a U.S.-developed framework called TimeSlips, which is designed to encourage creative engagement among older adults as a way to add meaning to their lives

The results, reported in the journal *Neuropsychiatric Disease and Treatment*, showed that the intervention group — who participated in two facilitated storytelling sessions per week for six weeks — demonstrated "significant improvements in cognitive function" relative to the control group. Other benefits included an increase in quality of life and communication abilities and a decrease in depression. These benefits continued to be observed after one month.

These results are no surprise to Doreen Vanderstoop, president of Storytelling Alberta, a charitable organization that celebrates and promotes storytelling to a variety of audiences, including older adults, through its StoryShare program. In the fall of 2020, Vanderstoop began working with TimeSlips through the Alzheimer Society of Calgary. The

PHOTOGRAPH: COURTESY TIMESLIPS

PHOTOGRAPH: COURTESY TIMESLIPS

training involved six hours of theory and three practice sessions, along with mentorship sessions and a self-evaluation process. Vanderstoop became a certified facilitator in February 2021.

One of the initiative's approaches, as used in the study in China, is to bring an image into a storytelling session and ask "beautiful" questions of the participants to elicit their involvement. During one of those sessions, conducted with Alzheimer Society clients via Zoom during the pandemic, Vanderstoop used an image of a postman making a delivery. Questions included: What should we call the postman? Where does he live? What do you smell? Participants responded enthusiastically: They said his name is Joe, he lives in Calgary and they could smell the pine scent of winter.

Vanderstoop acknowledged and supported their storytelling efforts. "They have something to offer and are completely validated. You can see them light up," she says.

Now that she is a certified facilitator, Vanderstoop helps organize two TimeSlip sessions per month for people involved with the Alzheimer Society's programs and she is also actively seeking out opportunities to use this unique technique to serve people living with dementia in the broader community — all under the StoryShare umbrella.

"I am not a scientist," she says. "But we know that storytelling improves memory. It is about activating the mind and the imagination. That is where the power is." ◼

To find out more about TimeSlips, contact Ali Cada, director of adult day and creative programs at Alzheimer Society of Calgary. Visit **www.alzheimercalgary.ca** or **timeslips.org**. To learn more about StoryShare, reach out directly at 587-578-6790.

DID YOU KNOW?

Canada's first-ever 24-Hour Movement Guidelines offer an example of an ideal day-in-the-life for Canadians ages 65 or older. The guidelines, created by the Canadian Society for Exercise Physiology (CSEP), the Public Health Agency of Canada, Queen's University and ParticipACTION, were released in 2020. The document incorporates physical activity, sedentary time and sleep.

Takeaways include: move at least 150 minutes per week, limit sedentary time and aim to sleep at least seven to eight hours per night. Following the recommendations can lead to a lower risk of anxiety and depression, improved cognition and quality of life, and reduced risk of dementia.

Learn more at **csepguidelines.ca/adults-65**. For exercise tips visit **ParticipACTION.com**

SPOTLIGHT ON CARING

Exploring the challenges of caregivers during COVID-19

By Elizabeth Chorney-Booth

PHOTOGRAPH: JARED SYCH

Dr. Gwen McGhan is an assistant professor in nursing at the University of Calgary.

We're now over a year into the COVID-19 pandemic, and Canadians have seen how the virus has disproportionately affected older adults in long-term care. While much attention has been given to how our country could have better prepared care home residents and staff for the pandemic, an Alberta-based study shows that family caregivers have also faced significant struggles. Even with the vaccine rollout and the end of the pandemic hopefully in sight, the study has uncovered some findings that will be valuable for future health crises and even post-pandemic times when we all go back to some semblance of "normal."

The University of Calgary's Dr. Gwen McGhan, an assistant professor in the faculty of nursing and Dr. Deirdre McCaughey, an associate professor in the Cumming School of Medicine, started the first phase of their study in the late spring

> “Every family caregiver has their own unique situation and challenges that they may face.”
>
> **Dr. Gwen McGhan**

of 2020, during the initial part of Alberta’s pandemic shutdown. In partnership with Dementia Network Calgary and the Alzheimer Society of Calgary, along with guidance from a Community Advisory Committee including stakeholders and family caregivers, the researchers sent out a survey that was completed by 230 family caregivers in the Calgary area, primarily spouses and adult children of people with dementia. Half of the participants cared for their family member at home, while the others cared for people living in either assisted living facilities or long-term care homes. McGhan and McCaughey followed up in closer detail with some of the participants via a focus group and are now repeating the process with a second phase with participants from across Alberta. The second phase is also supported by the Alzheimer Society of Calgary and Dementia Network Calgary, along with the Alzheimer Society of Alberta and NWT, AbSPORU, Patient Engagement Platform and with funding support from the Drummond Foundation.

“One of the positives to come out of COVID-19 is that it’s going to put a spotlight on the caregivers and some of the challenges that they’ve been facing,” McGhan says. “Every family caregiver has their own unique situation and challenges that they may face.”

→

The survey focuses on four different aspects of the family caregiver experience:

- how well public health messaging was distributed to and accessed by caregivers during COVID-19
- how public health measures affected the experience and ability to provide care
- how the provision of care was affected
- how the pandemic has affected the well-being of family caregivers and people living with dementia

The responses led McGhan and McCaughey to draw up a list of recommendations that they hope will inform future health-care policy.

Dr. Deirdre McCaughey is an associate professor in the Cumming School of Medicine at the U of C.

PHOTOGRAPH: JULIA MACGREGOR

Three key recommendations emerged from the first phase of the study:

1. After many family caregivers reported losing important supports like homecare help and day programs during the pandemic shutdown, McGhan and McCaughey would like to see more consistency of supports provided during a future health care crisis.

2. They recommend that information about public health measures and how they may affect access to care facilities and resources be shared more clearly and consistently by public health officials.

3. They advise that governments avoid enacting a complete lockdown of care facilities, especially as a first option, so that family caregivers do not have to go months without seeing the people they care for.

The researchers hope that the additional phase will result in even more recommendations that can offer tailored resources to better support family caregivers in their essential role.

"We're working with our partners to ask these questions about what family caregivers need and how this information can help them," McCaughey says. "How do we support the agencies that support caregivers, and how do we try to craft policy recommendations? We're working really hard to try to have very broad and very tailored recommendations come from this study."

For more info visit **w21c.org/portfolio/impact-of-covid-19-on-family-caregivers-for-plwd**

VACCINES 101: STEPS IMMUNIZERS CAN TAKE TO SUPPORT A POSITIVE VACCINE EXPERIENCE FOR OLDER ADULTS WITH COGNITIVE IMPAIRMENTS[1]:

OFFER REASSURANCE
Just before and during the vaccination process, offer reassurance to the person. In addition to calming verbal reassurance, touch (e.g., put your arm on his or her shoulder or holding his or her hand) during the procedure can be very helpful.

USE DISTRACTION
Direct the person's attention into something else (e.g., "Let's look at some photographs together")

APPROACH FROM THE FRONT
Always approach the person from the front and use his or her name

ENSURE CALM ENVIRONMENT
Minimize noises and excessive activity around the vaccination area

AVOID COMPLEX EXPLANATIONS AND SPEAK IN CONCRETE TERMS

PAY ATTENTION TO NON-VERBAL INDICATORS OF DISTRESS
(e.g., facial expressions, arm movements)

EXPRESS EMPATHY FOR AND RESPOND TO THE EMOTION THAT IS EXPRESSED (e.g., "You are upset but it will be OK and I am here with you")

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[1] Alzheimer Society of Canada (alzheimer.ca)

ESSENTIAL TOGETHER

A program to reintegrate essential care partners has been launched by Healthcare Excellence Canada, a new organization formed by the merging of the Canadian Foundation for Healthcare Improvement and Canadian Patient Safety Institute

ABOUT THE PROGRAM
The COVID-19 pandemic has resulted in restrictive policies governing family and care partner presence in care homes that have been acutely difficult for residents, families and staff. A new program, Essential Together, aims to support policy makers, policy implementers and those who are experiencing policy to reintegrate, welcome and engage essential care partners as part of care teams.

WHO ARE ESSENTIAL CARE PARTNERS?
Essential care partners are active partners in care, providing the physical, psychological and emotional support, as deemed important by the resident (or substitute decision-maker).

Essential care partners can include family members, close friends or others who support the resident with decision making, care coordination and continuity of care.

HOW WILL THE PROGRAM HELP SUPPORT REINTEGRATION OF ESSENTIAL CARE PARTNERS? A SUMMARY:

- Encourages clear communication of mutual expectations and processes to identify, screen and update essential care partners
- Supports education of essential care partners about the use of personal protective equipment, hand hygiene and protocols to prevent and control infection
- Reinforces the importance of essential care partners through education of care home staff members
- Encourages clear communication and the execution of rapid appeals processes that can be initiated by essential care partners or care home staff

Learn more at **healthcareexcellence.ca/en/what-we-do/what-we-do-together/essential-together**

Has your care home committed to the Essential Together call to action to reintegrate essential care partners?
Let us know on social, **@DementiaMag**, or email us at **connect@dementiaconnections.ca**

VIRTUAL CONNECTION 101

From video conferencing to digital platforms for art classes, technology offers new ways to communicate and stay engaged

By Haley Rutherford

Since the pandemic began in March 2020, there has been a substantial increase in technology use within all age categories. In October of last year, Statistics Canada found 44 per cent of Canadians spent more money on technology since the onset of the pandemic, and 34 per cent of Canadians also spent more on their home and mobile internet connections.

Here, we highlight some newer technologies that continue to be helpful to daily life.

Haley Rutherford MSc, is the Executive Director at a private seniors home based in Calgary, AB. She has a passion for gerontology and loves seeing how technology can make an impact to those that use it in their daily lives.

VIDEO CONFERENCING

During the pandemic, we've been advised to stay home and limit our social circles. For many, this meant connecting with others through video conferencing. Virtual connection has become an important part of managing stress, contributing to our well-being and improving our ability to stay connected.

A video conferencing system that gained popularity during the pandemic is Zoom. In December 2019, about 10 million meeting participants used Zoom daily. In four short months, this number grew 30 times, reaching above 300 million daily meeting participants by April 2020.

PHOTOGRAPH: SEANSHOT, COURTESY ISTOCK

What is Zoom?

Zoom is a video conferencing platform that does not need any additional software and requires extraordinarily little technical knowledge. All you need is either a smartphone, a computer or a laptop.

How Does it Work?

There are two choices: either you are the inviter (host) or you're invited to join a call. If you are the inviter, you must send others an invitation to join you. This invitation includes the website details, and the meeting ID and a password. If you are an invitee, you must receive the meeting ID and password from the host. The passwords ensure that no one else can enter your Zoom call. If you've been invited to a Zoom call, once you enter the appropriate credentials, the software will download automatically. Then, just stay on your device until the call is over. One of the best things about this program for many users is the cost — it is free!

Learn more at **zoom.us**

FITNESS TRACKERS

With ongoing restrictions closing gyms and stopping fitness classes, our exercise routines may have diminished. Luckily, you can still stay motivated to sweat with the help of wearable fitness trackers.

Choosing your Device

Three of the more popular options are Fitbit, Apple Watch and Garmin. They range in price from less than $100 to more than $1,000 CAD and can monitor your sleep patterns and keep track of physical activity, including swimming, runs and walks.

What I like about these devices is that they track your steps, and you can have step challenges with your friends and families who have similar devices. You also receive badges and recognition for how far you go, and milestones achieved; if you walk 3,007 kilometres wearing Fitbit, it will share that you have walked the full length of Japan! This cool fact can be great motivation to keep going. Just make sure you remember to charge your device regularly.

Visit **fitbit.com**, **apple.com** or **garmin.com** to learn more

DIGITAL PLATFORMS FOR CRAFTING/LEARNING

During the early stages of the pandemic, there was a surge to start new hobbies. The pandemic also gave time for some people to do home renovations, learn to bake or take up crafting and art. These two platforms offer accessible ways to begin your new hobby.

Learn to Paint Online

For reasonably priced online art classes, check out **yaymaker.com**. This service provides online streaming classes that can be done from the safety of your home. Classes, like painting, knitting and more, are run on video conferencing platforms like Zoom. For example, during a paint nite class, an instructor leads participants through how to paint a pre-selected picture. There are a variety of options to paint scenery, animals, or landscapes.

Learn from the Experts

Crafters wanting to learn a new skill or enhance existing ones can tune in online to expert how-to videos, typically on **YouTube**. From learning how to play an instrument to expanding your knitting skills, you can find anything you want to learn online. These videos are usually pre-recorded and so you can't interact with the "expert" or ask questions in real-time if you get stuck, but it is a great way to explore and try a new hobby. And, like Zoom, it is free!

Technology, when used to improve both mental health and physical health, is a valuable tool, especially during a period of isolation.

What are your favourite digital tools? Let us know on social, **@DementiaMag**, or email us at **connect@dementiaconnections.ca**

PHOTOGRAPHS: (TOP) KALI9, COURTESY ISTOCK; (BOTTOM) GOLUBOVY, COURTESY ISTOCK

Learn useful tips and tricks for Zoom conversations at **dementiaconnections.ca**

CONVERSATIONS WITH MY *Mother*

In our ongoing series, Calgary-based artist Sam Hester and her mother, Jocelyn Burgener, share their candid conversations about life with dementia. In this issue, the duo captures the challenges of connecting virtually during COVID-19.

Story by Sam Hester and Jocelyn Burgener | Illustrations by Sam Hester


MAYBE I CAN GET THE GOLF CHANNEL...
MOM, IS THE PROBLEM WITH YOUR COMPUTER OR YOUR TV?
I THINK SOMETHING GOT UNPLUGGED
NO! DON'T UNPLUG ANYTHING!!
SAM... ARE YOU OK??
SORRY... IT'S JUST SO STRESSFUL, NOT BEING ABLE TO GO OVER THERE!
DON'T WORRY — I'M HERE TO HELP!


Now OPEN!

LET THERE BE LIGHT

These illuminating tips and tricks can help you create dementia-inclusive lighting at home

By Shannon Cleary

As we age, the structure of our eyes ages as well — our pupils reduce in size, our lenses become cloudy and less pliable, and our susceptibility to common eye conditions increases. These changes make it challenging to read small print, distinguish between colours, and transition between bright and dim spaces. In fact, adults over the age of 60 need roughly three times the amount of light to perform a task compared to the average 25-year-old. A poorly lit environment also increases our risk of falls, anxiety, depression and disruptive sleep-wake cycles.

People living with dementia also experience significant changes in vision. The brain interprets the visual information delivered along our optic nerve, and studies show that neurodegenerative conditions can result in a loss of depth perception and a difficulty distinguishing between two- and three-dimensional objects. What you might see as an impeccably polished wood floor may appear wet, slippery and dangerous to someone living with dementia. Or, shadows cast by a flickering streetlight can mimic menacing flames. Misperceptions like these can provoke fear, agitation and eventually a loss of independence.

Deb Bryson is co-lead for brainXchange's Design and Dementia Community of Practice (CoP), which has researched and developed recommendations for dementia-inclusive lighting environments.

"When I go into a home [as a geriatric consultant], it's quite often very dark," says Bryson. "I'm always saying to families, 'Can you make sure that the lights get left on until bedtime?' Families are puzzled when you bring that up. We don't often think about lighting."

Bryson says that addressing lighting in our homes can have dramatic effects on quality of life for minimal cost. Here are a few easy and effective ways to achieve dementia-inclusive lighting in your home.

ILLUSTRATION: SMARTBOY10, COURTESY ISTOCK

PHOTOGRAPH: NELLEG, COURTESY ISTOCK

NATURAL LIGHT

Bryson says daily exposure to natural light regulates our circadian rhythm (the internal clock that regulates sleep and wakefulness) and dictates our melatonin production. Even a few minutes a day outside is beneficial.

Indoors, Bryson suggests making use of large windows, atriums and skylights by positioning sitting areas and points of interest (like activity tables or aquariums) nearby.

AMBIENT LIGHTING

Larger rooms need more light sources, and lighting should vary in height (for example overhead lights, cove lights, wall-washers, task lights and baseboard lights at night) and direction. When shopping for bulbs, look for “cooler” lights for daytime use and warmer red or orange tones later in the day to promote better sleep/wake cycles. Also, use bulbs with an appropriate level of lux for the area you’re trying to light. Lux is a measurement of how much light is projected onto a given space. (One lux equals one lumen, a measure of brightness, per square metre.) For older adults, the recommended ambient lighting of general living spaces is 200-500 lx.

DID YOU KNOW?

In 2020, a team of researchers from Los Angeles’ Cedars-Sinai department of neurosurgery discovered parts of the retina, a sensory membrane that lines the inner surface of the back of the eyeball, that are more affected by Alzheimer’s disease than others. The team used special imagining to capture retinal images of study participants older than 40 who showed signs of cognitive decline. They could see buildup of a retinal protein in some participants, which can be an early indication of Alzheimer’s disease.

Learn more at **cedars-sinai.org**

CONTROLLING YOUR LIGHT SOURCE

DIMMABLE LIGHT SWITCHES allow you to customize brightness levels to the task.

ADJUSTABLE TASK LIGHTS help you control the location, direction and intensity of your lighting.

BIODYNAMIC LIGHTING mimics the natural progression of daylight by changing colour and intensity throughout the day.

Learn more about dementia-inclusive lighting practices at **brainxchange.ca**


ADJUST BLINDS TO AVOID GLARE

TASK LIGHTING

Bryson says adequate task lighting has a significant impact on independence and even appetite.

"Eating in a place that has good overhead light can improve eating habits," she says.

Areas where we perform visual tasks — like eating, preparing food or reading — require a lux level of at least 500 lx. Areas with low contrast, for example a blue puzzle on a dark table cloth, need up to 1,000 lx for aging eyes to properly distinguish colours and finer details.

Portable lamps or dimmable switches allow you to adjust and direct lighting, depending on the activity and the time of day.

NAVIGATIONAL LIGHTING

Adding lights to your hallways and stairs helps with safety and wayfinding, especially at nighttime. Plan to angle the lights to illuminate places like the edges of the floor, doorframes and handles. But use only what is necessary as too much light can impede vision.

TRANSITIONAL SPACES

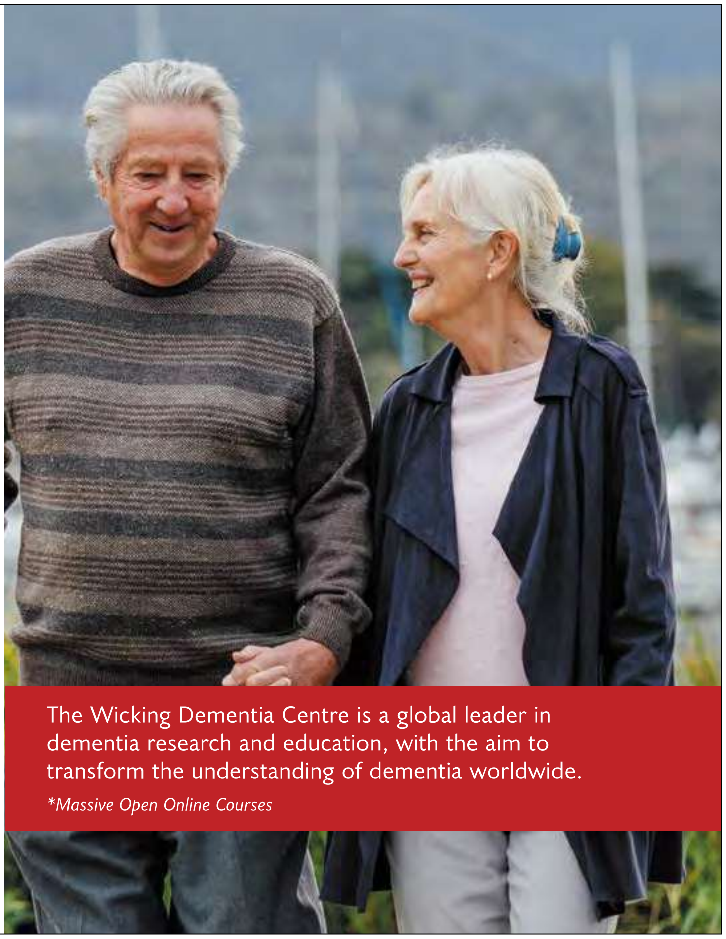
Anyone who's emerged from a dark building on a bright day, or flipped off a switch to cause sudden darkness, has experienced the adaptation our eyes undergo when confronted with lighting change. This adjustment takes much longer in aging eyes and can lead to falls, injury and confusion.

To avoid this, make sure your lighting is uniform from room to room. In transitional areas, such as entrances and mudrooms, make sure the lighting is even and adequate to illuminate both spaces.

GLARE

Glare, shadows and pooled lighting can create illusions that result in increased stress, anxiety and responsive behaviours in people living with dementia. Reposition lamps and light sources, cover highly reflective surfaces and adjust your home's curtains, blinds or shades throughout the day.

PHOTOGRAPH: ASBE, COURTESY ISTOCK



Transformational Caregiving

As caregivers we often feel isolated, stressed and exhausted.

We are encouraged to "take care of yourself first" — yet struggle to find ways to manage the guilt, grief and distress.

Book a Free 15 Minute Intro Call

katrina@katrinaprescott.com

Work with me to transform your caregiving experience and make it work for you:

- Save time and find short cuts navigating the system.
- Create a tool kit that will support you on your caregiving journey.
- Find alternative ways of getting the support and respite you need and deserve.
- Let go of guilt and learn how to be in the moment with the person you are caring for.

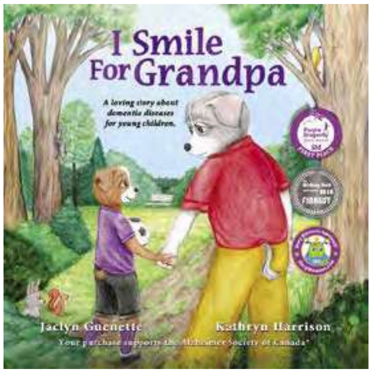
Katrina and her mother Kathryn Love
Photo Credit: Jesse Winters - The Globe and Mail

Katrina
Prescott

www.katrinaprescott.com

4 BOOKS TO READ IN 2021

By Karin Olafson



I SMILE FOR GRANDPA

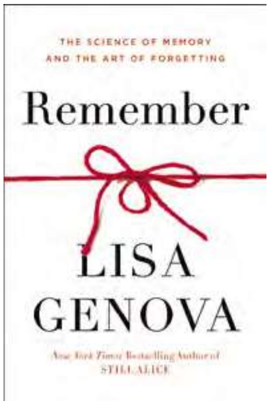
By Jaclyn Guenette and illustrated by Kathryn Harrison

This picture book explains dementia in a sensitive and child-friendly way. After Grandpa is diagnosed with dementia, Little Buddy learns that soccer games, camping and the other fun activities he loves doing with Grandpa won't be the same as before. He has questions, but his parents explain that Little Buddy will continue to have a special connection with Grandpa. This book is written for children ages three to seven, and offers them comfort and reassurance as they learn how a dementia diagnosis might affect their beloved family member. A portion of the profits is donated to the Alzheimer Society of Canada.

THE SMALLEST OBJECTIVE

By Sharon Kirsch

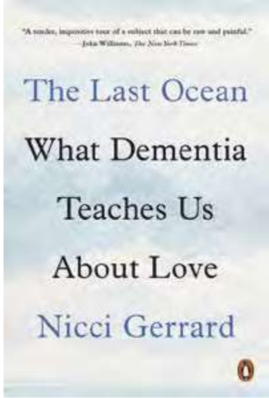
In this deeply personal memoir, Sharon Kirsch chronicles the challenges of witnessing her mother receive a dementia diagnosis. While she prepares to sell the family home in Montreal after her mother moves into assisted living, Kirsch discovers treasures that tell stories of her parents' past. She learns of family members she'd never met and of her parents' connection to the city itself. As well as candidly sharing her anxieties about being away from her mother at this time in her life, Kirsch discovers that recovering memories on someone's behalf can invigorate a sense of purpose.



REMEMBER: THE SCIENCE OF MEMORY AND THE ART OF FORGETTING

By Lisa Genova

Released in March, *Remember* is the first work of non-fiction from the author of the popular novel *Still Alice*. This time, Genova draws on her training as a neuroscientist to examine the science of memories, forgetting, and what can be done to protect our memories. *Remember* explores why some memories are forgotten within hours while others last a lifetime, how memory is affected by sleep and stress, and how dementia is a different kind of forgetting. Genova examines this topic in an easy-to-understand way, weaving relatable, personal stories in with the science.



THE LAST OCEAN: WHAT DEMENTIA TEACHES US ABOUT LOVE

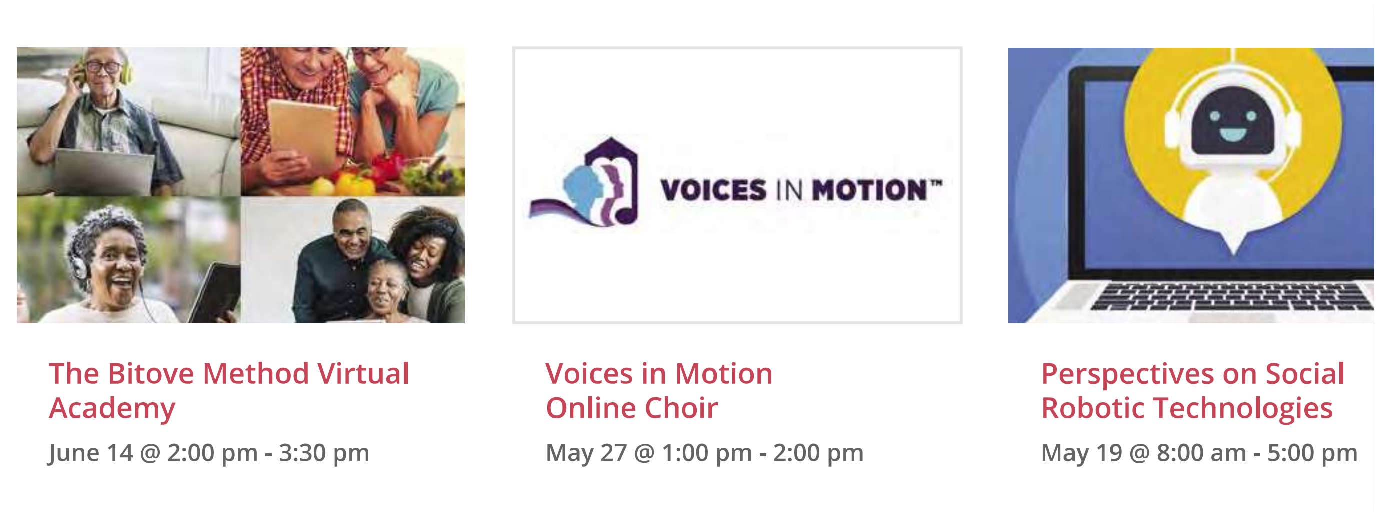
By Nicci Gerrard

After Nicci Gerrard's father, John, was diagnosed with dementia, he continued to live his life to the fullest. It was only after a challenging hospital experience that things became more difficult for John and his family. John passed away in 2014, and five years later, Gerrard published this lyrical, deeply personal book examining living with dementia, compassionate medicine, and end-of-life care. *The Last Ocean* is part memoir, part journalistic deep-dive, and part philosophical reflection on selfhood, identity and familial love.

What are you reading? Share your book suggestions with us on social, **@DementiaMag**, or email us at **connect@dementiaconnections.ca**

DEMENTIA

connections



The Bitove Method Virtual Academy
June 14 @ 2:00 pm - 3:30 pm

Voices in Motion Online Choir
May 27 @ 1:00 pm - 2:00 pm

Perspectives on Social Robotic Technologies
May 19 @ 8:00 am - 5:00 pm

CONNECTIONS LISTINGS

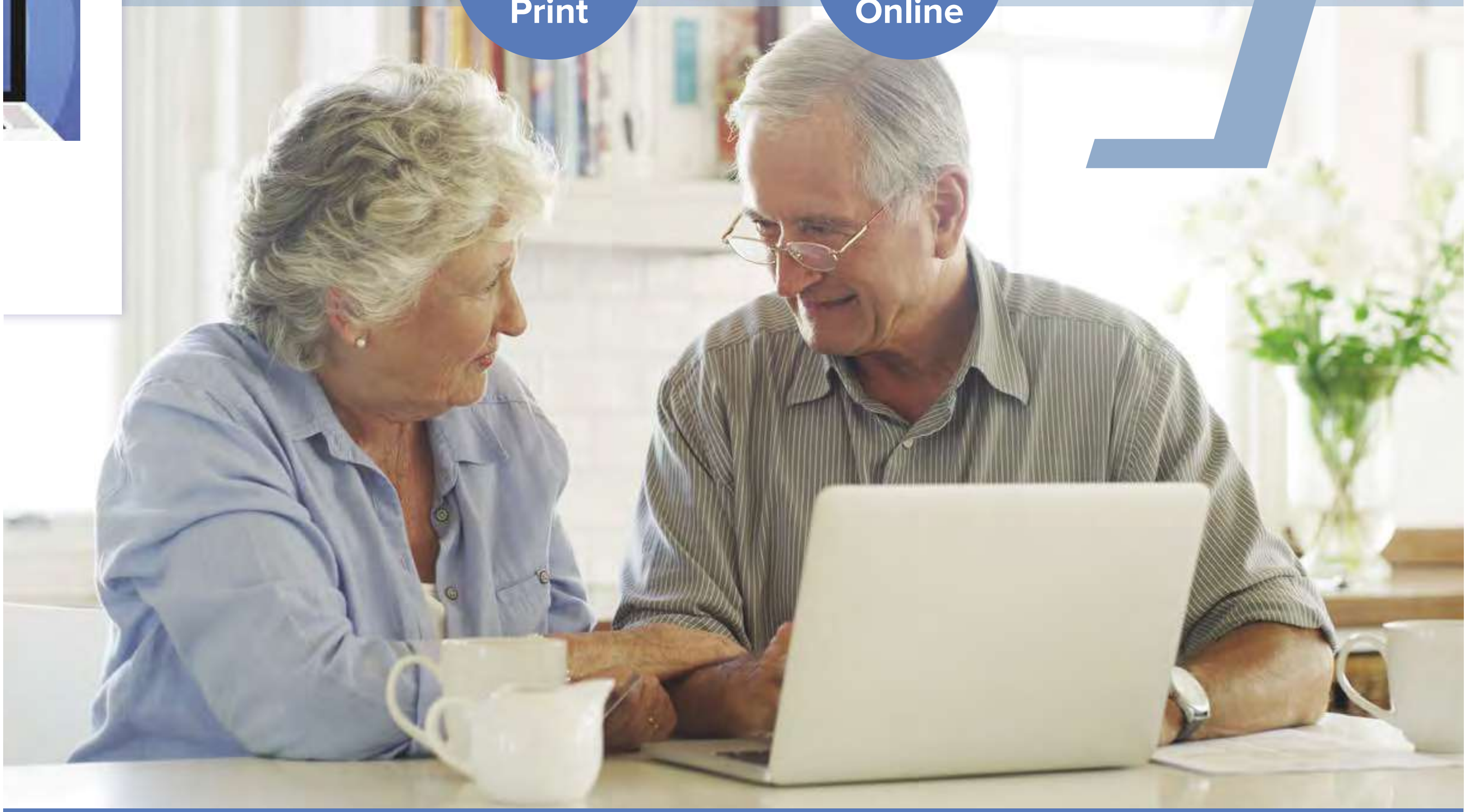
Join in, recharge, connect, learn and grow! Connections Listings enable people living with dementia and care partners to easily find ongoing opportunities to improve their overall wellbeing and quality of life. **Check out new listings online weekly and add your own!**

MORE THAN A MAGAZINE

MARKETPLACE

In the Dementia Connections Marketplace, we shine a spotlight on **dementia-specific** products, services and programs that can help make every day a little easier.

Print AND **Online**



Visit us today at DementiaConnections.ca

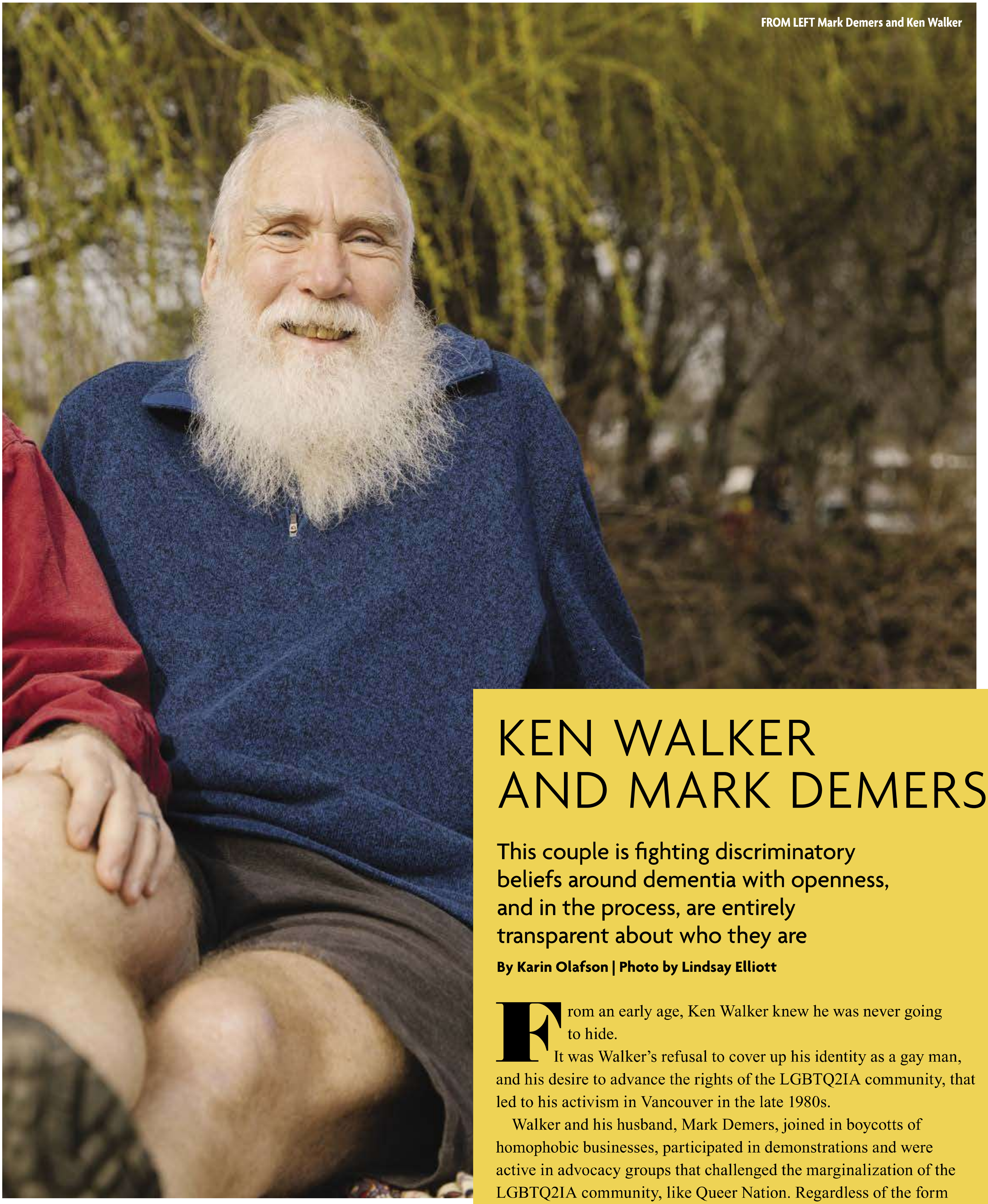
DEMENTIA DISRUPTORS

From big-picture government advocacy to intimate first-hand accounts, these Canadians are finding ways to challenge the perception of what it means to live with dementia

Sometimes, disrupting the status quo is the only way to create positive change. And for many people living with dementia — and their care partners — change is imperative, as the current state of dementia care simply isn't working. Luckily, there is a growing global movement working to create a more multi-faceted, candid understanding of what it means to live with dementia.

In our inaugural series, we highlight five Canadians who are questioning the norm. Through challenging stigma, increasing inclusion and rethinking traditional care approaches, these "dementia disruptors" are raising the voices of people living with dementia and their care partners.

Do you know a disruptor? Let us know on social, **@DementiaMag**, or email us at **connect@dementiaconnections.ca**


FROM LEFT Mark Demers and Ken Walker

KEN WALKER AND MARK DEMERS

This couple is fighting discriminatory beliefs around dementia with openness, and in the process, are entirely transparent about who they are

By Karin Olafson | Photo by Lindsay Elliott

From an early age, Ken Walker knew he was never going to hide.

It was Walker's refusal to cover up his identity as a gay man, and his desire to advance the rights of the LGBTQ2IA community, that led to his activism in Vancouver in the late 1980s.

Walker and his husband, Mark Demers, joined in boycotts of homophobic businesses, participated in demonstrations and were active in advocacy groups that challenged the marginalization of the LGBTQ2IA community, like Queer Nation. Regardless of the form their activism took, they always challenged injustice the same way:

by being open with those who held discriminatory beliefs and by being themselves.

"There was a lot of stigma around being gay and HIV became a focal point for that in the 1980s. We believed that people would be more accepting of gay people if they actually knew them personally," says Demers.

When Walker was diagnosed with young-onset Alzheimer's in 2015 at 58 years old, the couple decided to apply the strategies they used in their LGBTQ2IA advocacy to also "out" dementia. That is, Walker and Demers were committed from the beginning to be open about Walker's diagnosis.

"[Living with] dementia wasn't a discussion happening in [the LGBTQ2IA] community at the time of Ken's diagnosis. So, we had to initiate that," explains Demers. "There are a couple of people who don't know how to talk to Ken because they don't have any experience with dementia — and that is the point of being open. They will see a member of their community with Alzheimer's go through the whole process, and they will be better able to face it in their own lives if they encounter it."

They hope their openness also fights the stigma surrounding a dementia diagnosis and the misunderstandings around who dementia affects. They discuss Walker's diagnosis with national media outlets, raising awareness that life with dementia can mean a life well-lived. They're spokespeople for the Alzheimer Society of British Columbia and Walker is part of the BC Leadership Group of People Living with Dementia. Before COVID-19, they participated in the Alzheimer Society of B.C.'s annual luncheon at the Legislative Assembly of British Columbia, sharing their story of life with dementia for B.C.'s MLAs at the March 2020 event.

Simply, they are working to prove that dementia doesn't discriminate based on gender or sexual orientation, and that life with young-onset Alzheimer's doesn't look the same for everyone. And for Walker and Demers specifically, life with dementia hasn't put a stop to a lifelong passion for advocacy and speaking up.

"It's important to set examples when we can," says Walker.

And what do they do if someone doesn't understand dementia or feels uncomfortable?

"Just be kind," says Walker. "Have conversations. Talk about how we are all different in some ways."

HOW TO HAVE AN OPEN CONVERSATION ABOUT DEMENTIA

Ken Walker and Mark Demers share the approaches they use that enable genuine conversations about dementia.

DON'T HIDE WHO YOU ARE

Demers explains that Walker's approach is to publicly be himself and never hide who he is. "I think that not being open destroys people's lives," says Demers, adding that shame can be debilitating. "Ken's approach is to publicly be himself so that he can be a living contradiction to others' [prejudicial] beliefs."

ENCOURAGE LAUGHTER

Demers uses humour to help others feel free to ask questions. "If we're having a conversation with someone and Ken says something that really doesn't make sense [because of his young-onset Alzheimer's], we just joke about it and don't take it too seriously," says Demers. "That way people realize it's not taboo to talk about."

MAKE CONNECTIONS

Before COVID-19, Demers and Walker used the app Signup Zone, where friends and neighbours booked a time to visit and connect with them. "We would send out a calendar on Signup Zone for our friends and neighbours to come visit Ken," explains Demers. "Anyone who gets our email can sign up for a time to visit. By doing that, we are having an ongoing conversation with all of our friends about what's happening with Ken."

HOW KEN AND MARK ARE DISRUPTING THE DEMENTIA EXPERIENCE

This couple is "outing" dementia. Their approach to dementia education and rights is similar to how they fought oppressive beliefs of the LGBTQ2IA community: make it personal, not anonymous. Walker and Demers are modelling how they want the world to be: open, kind and ready to make personal connections.

REFORMING JUSTICE WITH HEATHER CAMPBELL POPE

As founder of Dementia Justice Canada, Heather Campbell Pope fights for a fairer justice system for people living with dementia

By Nathan Kunz | Photo by Wade Hudson

Heather Campbell Pope has dedicated the last four years to pushing toward law reform in the hope of ensuring that those with dementia in contact with the criminal justice system are taken care of, regardless of what they may have done.

"It is extremely important that people who are facing criminal charges receive a fair trial," says Campbell Pope. "[Advocating for people living with dementia] also means advocating for the rights of people when they've done terrible things."

Campbell Pope's work as founder of Dementia Justice Canada focuses on the time after arrest and before conviction — a period during which people living with dementia can languish indefinitely due to questions around their fitness to stand trial.

Campbell Pope explains that these individuals often fall under a model built for acute mental illness. The expectation is that cognition will get better ahead of trial, which is often the opposite case for those progressing through dementia. This can lead to years spent in facilities unfit to meet their needs. And a lack of guidance means that people interacting with individuals living with dementia, from police officers to care workers, can be lost on handling such situations.

"The justice system is not equipped to really handle these cases with the finesse and compassion that's needed when it's an elderly person with dementia," she says.

HOW HEATHER CAMPBELL POPE IS DISRUPTING DEMENTIA

Through dedicated advocacy at every level of government, Heather Campbell Pope pushes for a fairer system for individuals living with dementia who come in contact with the Canadian criminal justice system.

Working with older adults has long been central to Campbell Pope's career. A former lawyer, Campbell Pope articled for the Canadian Centre for Elder Law before establishing her own practice in British Columbia. She also spent time working with the BC Centre for Elder Advocacy and Support (now Seniors First BC) and the B.C. Ministry of Health's Seniors Action Plan team, as well as B.C.'s

leading long-term care industry association.

With her legal background and industry experience, Campbell Pope noticed critical shortcomings in providing justice for those living with dementia.

"I noticed a glaring gap in the law reform and policy discussion — and to some degree, in media coverage as well — about these cases that were sometimes fatal, where we heard the aggressor was arrested and perhaps even charged with a very serious offence. But then what happened to them?" says Campbell Pope, again noting that many fell into facilities unable to properly house them.

"I wanted to bring some centralized focus to these issues — to see where the system could improve in how they manage these tragedies."

Creating change at a large-scale level was the catalyst for founding Dementia Justice Canada in 2017. Since then, Campbell Pope has pushed for change through written advocacy around policy and law reform and engagement with politicians and senior officials at every level of government across Canada.

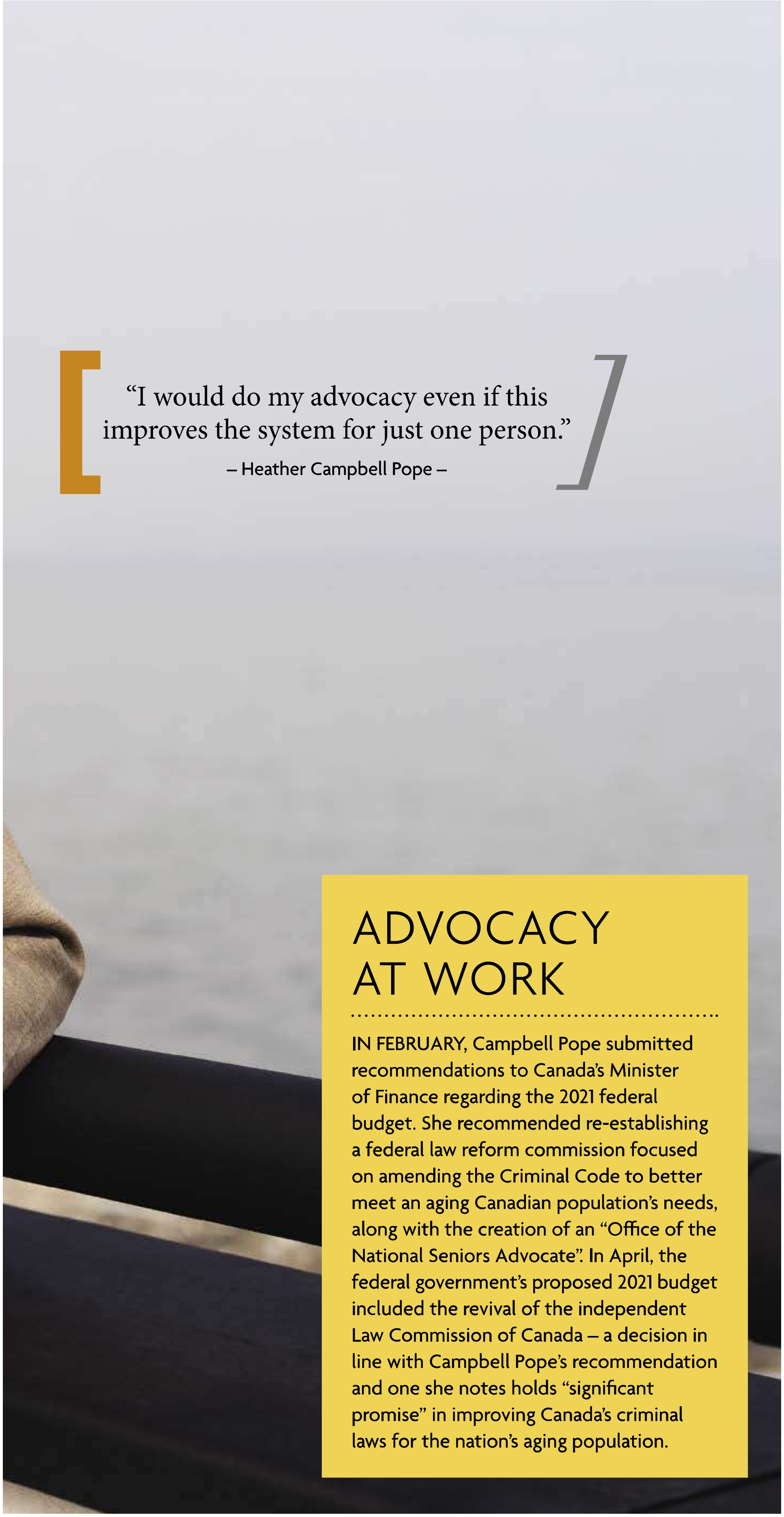
In February 2019, Dementia Justice Canada published *Nowhere to Live: Housing Vulnerability of Criminal Defendants with Dementia*, a report outlining recommendations on how to better serve the needs of those with dementia in contact with the justice system.

Within the report, Campbell Pope notes that, "At the macrolevel, our population is statistically insignificant, but at the individual level, the human cost is profound." Advocacy without headline-worthy statistics, Campbell Pope says, has presented challenges in Dementia Justice Canada's work, along with a common unwillingness from some others to delve into the dark side of dementia or use negative language that may go against the advocacy community's common scope.

Despite what can be an uphill battle, Campbell Pope's commitment to creating a fairer justice system continues.

"I would do my advocacy even if this improves the system for just one person," says Campbell Pope. "We don't know who that person will be, and he or she deserves a justice system that's prepared to handle their unique needs."

Learn more at **dementiajustice.com**



> "I would do my advocacy even if this improves the system for just one person."
>
> – Heather Campbell Pope –

ADVOCACY AT WORK

IN FEBRUARY, Campbell Pope submitted recommendations to Canada's Minister of Finance regarding the 2021 federal budget. She recommended re-establishing a federal law reform commission focused on amending the Criminal Code to better meet an aging Canadian population's needs, along with the creation of an "Office of the National Seniors Advocate". In April, the federal government's proposed 2021 budget included the revival of the independent Law Commission of Canada – a decision in line with Campbell Pope's recommendation and one she notes holds "significant promise" in improving Canada's criminal laws for the nation's aging population.

CHIPPING AT STIGMA WITH KIM BRUNDRIT

Through a collaborative approach and innovative initiatives, Dementia Network Calgary's Kim Brundrit has helped create an environment for Calgarians living with dementia to live better

By Nathan Kunz

Kim Brundrit clearly recalls the first time a guest announced they had dementia at a community event — a milestone for a condition that can be shrouded in stigma.

"I just felt like screaming and clapping," Brundrit says of the moment in late 2019. "It was the first time that someone felt comfortable enough to stand up and say that in a room full of people they didn't know."

Since 2016, Brundrit, who has a background in community engagement and policy development, has served as collective impact lead for Dementia Network Calgary. The Network is a group of individuals and organizations from the non-profit, public and private sectors that have united to create meaningful change for the dementia community.

Central to the Network's overarching goal has been challenging the common perception and stigma attached to dementia. A study Brundrit helped facilitate in the summer of 2019 showed that a majority of Calgarians thought that people living with dementia no longer live at home, a belief in stark contrast to the truth — 80 per cent of people living with dementia live in their community.

Dementia Network Calgary teamed up with Roger Marple, a Medicine Hat-based advocate living with dementia, on the "Dementia Lives Here" project to address the disconnect. With Marple as a guide, the initiative consists of a website populated with videos and blog posts that answer common questions and shed light on what living with dementia is like.

The Network knows the best way to reduce stigma is for people to interact with someone living with dementia. Marple is offering "Ask Me Anything" sessions online and the Network hopes to have them in person as soon as possible.

"Dementia's not fun, and we're not trying to make light of it," says Brundrit. "But we are trying to make

3 MORE STAND-OUT PROJECTS BY DEMENTIA NETWORK CALGARY

CONVERSATION CAFE
Safe, social gatherings for those touched by dementia along with their family member, caregiver or friends. No agenda, just conversation.

DEMENTIA RE-IMAGINED
A 2018 symposium featuring international experts and local stakeholders, designed to encourage conversation and inspire change around person-centred care for people with dementia.

COMMUNITY GATHERING
Quarterly gatherings (hosted prior to the pandemic) of people in the community to talk about dementia-related issues, gather knowledge, build advocacy priorities, test ideas and learn from the experts with lived experience.

PHOTOGRAPH: JARED SYCH

HOW KIM BRUNDRIT IS DISRUPTING DEMENTIA

Kim Brundrit is combatting community-wide challenges with innovative initiatives in pursuit of creating an environment where Calgarians impacted by dementia can live life well.

this an approachable conversation."

Finding collaborative and innovative solutions is at the core of Brundrit's work. She's worked with stakeholders throughout the community to spearhead projects for everyone impacted by dementia.

The cross-sector collaborative approach has been crucial to the Network's success, as exemplified by a project Brundrit helped bring to life amid rising cases of COVID-19 and lockdowns at long-term care facilities in 2020. Noticing a need for additional support in care facilities, as well as an increased need for emotional support for care partners who were unable to see the people they care for, Dementia Network Calgary, the Canadian Red Cross and the Alzheimer Society of Calgary teamed up to create a free online training program surrounding use of personal protective equipment (PPE) and infection prevention and control protocols (IP&C).

"We wanted family care partners to be in [long-term care facilities], but we needed to address the needs of keeping residents safe," Brundrit says of the thought process behind the program.

The program, which was extended into 2021, was a success, with participants reporting a dramatic increase in comfort and confidence when visiting care homes after the training.

Projects such as the PPE and IP&C program are examples of the Network's willingness to be reactive and offer quick solutions. But Brundrit says overarching goals such as chipping away at stigma is a long-term challenge. Along the way, however, Brundrit's work has helped inspire profound change.

Following the launch of "Dementia Lives Here," Brundrit received a call from a woman who had come across the webpage. After receiving a dementia diagnosis in November, she isolated herself and was reluctant to tell her family about the diagnosis. She told Brundrit she had planned to end her life after the holidays.

However, after seeing Marple share his experience, she decided she wanted to get involved with the cause.

While a task like dispelling stigma may not happen overnight, Brundrit says stories like these keep her moving forward to inspire further change.

"If that's all that happened out of this, that's amazing," says Brundrit. ◼

Learn more at **dementianetworkcalgary.com**

LISA RAITT

As a former Member of Parliament for Milton and former Deputy Leader of the Opposition, Lisa Raitt is using her previous position as a public figure to amplify the discussion around the challenges of caregiving. She shows that asking for help reduces isolation and that being vulnerable is powerful

As told to Karin Olafson

“I wasn’t always open and honest about my experience as a care partner for my husband, Bruce.

“In 2016, Bruce was diagnosed with young-onset Alzheimer’s at 56 years old. I hadn’t connected his symptoms with a diagnosis of Alzheimer’s, and we both felt denial and fear.

“At first, we kept his diagnosis completely hidden. That was Bruce’s choice: he was embarrassed and afraid of what others would think of him. But once Bruce and I accepted our reality, we decided we were going to live the best life we could. And we did, for a while. Later in 2016 we opened up about his diagnosis and we travelled and spoke publicly about young-onset Alzheimer’s.

"I was open about Bruce's diagnosis over Twitter, too. Last year, I shared a lot of the good stuff. My posts seemed to say, 'Our life is great and we're doing what we can.'

"But total openness about what was truly happening for us took time, and last winter, I knew I couldn't keep looking at his diagnosis with such optimism. For a while already, Bruce had been hallucinating and no longer understood he had Alzheimer's.

"His behaviour became aggressive. I learned that our experience with this stage of young-onset Alzheimer's — late stage six — was very similar to others' experiences.

"At that point, I knew I had to talk about it. I felt very strongly that I shouldn't sugar-coat what happens for a lot of families at this point of the diagnosis.

> "I knew I had to talk about it. I felt very strongly that I shouldn't sugar-coat what happens for a lot of families at this point of the diagnosis."
>
> – Lisa Raitt –

HOW LISA RAITT IS DISRUPTING THE CAREGIVING EXPERIENCE

Lisa Raitt refuses to sugar-coat her experience as a care partner for her husband Bruce, whose young-onset Alzheimer's led to aggression. By speaking candidly and being vulnerable, Raitt highlights that it is essential for a care team to have safety and a support network.

3 THINGS LISA RAITT WANTS CARE PARTNERS TO KNOW

1: UNDERSTAND THE STAGES
Raitt says it's important to educate yourself, be prepared and know what's coming next.

2: FIND SUPPORT
Raitt is part of a group based out of the United States called HFC, formally Hilarity for Charity. Once a week, she connects with other care partners whose spouses live with dementia to talk, trade stories and offer support.

3: ASK FOR HELP
If the person living with dementia shows aggressive behaviour, Raitt says to reach out for help. Know that it's a cry for help from them, but it is dangerous to you.

Find support through your local Alzheimer Society at **Alzheimer.ca**

"The number one reason I knew I had to be so real was because I was afraid of the aggression. I was seeking help, and by putting our reality out there, I ended up with tips and advice.

"I also want people who are in positions of power to understand what caregivers go through emotionally and physically. This New Year's Day, Bruce's behavioural responses had turned to full-on aggression out of the blue, and dangerously so. For our safety we called 911, and for now, he's in the Behavioural Neurology Unit at Baycrest Health Sciences where staff understand dementia. Caregiving is willingly and lovingly taken on, but the reality is it comes with exhaustion, stress and guilt. Before his hospital admission, I hadn't slept through the night in six months. I'm still sore.

"By being so honest, I came to realize I wasn't alone in experiencing aggression with this type of Alzheimer's. Now I am even more determined to make sure we show the negative side of dementia to increase awareness of what the care team experiences. If we're self-interested in making sure that things will be better for us personally in the future, then maybe we'll all fundraise more and rally together to effect change." ▣

Lisa Raitt and her husband, Bruce.

PHOTOGRAPH: COURTESY LISA RAITT

CONTINUE **YOUR STORY**

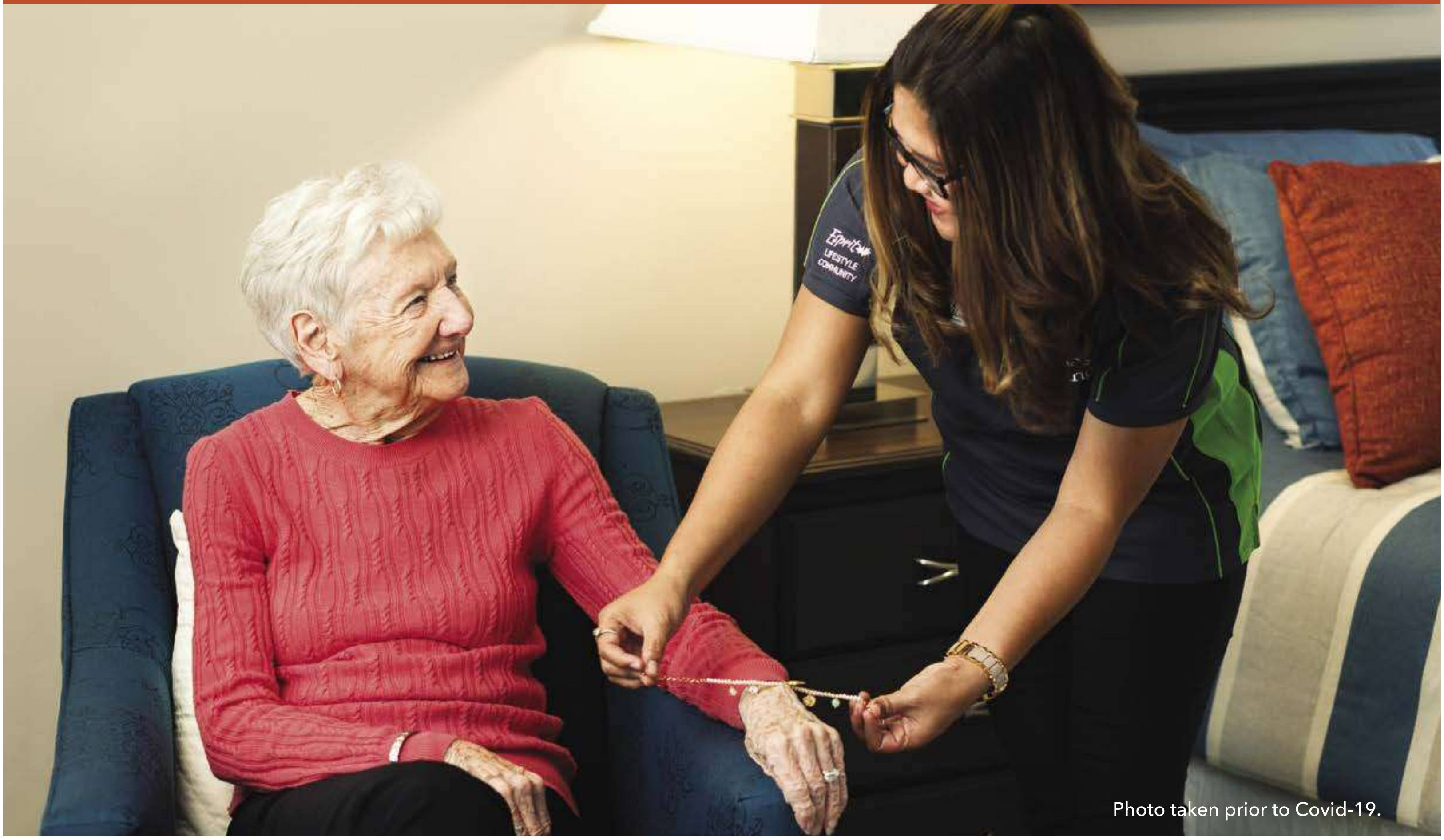


Photo taken prior to Covid-19.

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Independence in a Digital Age: Staying safe with software solutions

Its important now more then ever that we stay safe. Over the previous year we have learned a lot about what we can do both for ourselves and others when it comes to personal safety. One of the difficulties that the last year has brought has been the ability to stay safe, connected, and active all at the same time. There are many different solutions on the market that aim to provide people of all ages with additional security. Some of these items may be pendant panic buttons, hands free devices such as Google Home and reminder apps for taking medication. Today we will be diving into an application that aims to provide people of all ages and technology levels with extra security well at the same time providing their loved ones with peace of mind.

The technology we are discussing today is Hibou. Hibou is a software solution that aims to provide people of all technology literacy levels with tools to enhance their safety. Some of the features included are activity timers which allow you to go for a walk, ski your favorite slope, or just go for groceries knowing that someone is aware of what you are doing. Hibou also offers wellness checks allowing you to receive up to two daily wellness timers which are scheduled at times most convenient for you. These handy timers allow you to let your friends and family know that you are okay at just the push of a button. If you arent able to complete your wellness check Hibou will follow up with your loved ones and let them know that they need to check in on you. These are just a few of the fantastic features that Hibou has to offer. To learn more we talked to a few Hibou users, Ashely and her mom Donna who have been using Hibou for the past year.

Zach:

Hi Ashley and Donna, why don't you tell me a bit about yourselves?

Ashley:

Thanks Zach! My name is Ashely and I work at a grocery store in my hometown, and I am currently studying to become a Marine Biologist.

Donna:
My name is Donna, and I am a recently retired nurse. I like to spend my newly acquired free time hiking, bike riding and taking my dog Oscar down to the local beach.

Zach:

Donna, can you tell me how you use Hibou?

Donna:

I use Hibou almost every day. When I head out for a bike ride or down to the beach with Oscar, I set an activity timer with a description of where I am going and how long I am going to be gone. I love the extra peace of mind it gives me knowing my daughter would be contacted if something were to happen. I also have wellness checks configured in the morning and the evening. These allow me to quickly let everyone know that I am okay and safe throughout the day.

Zach:

That's fantastic Donna! Ashley, can you tell me a bit about how you use Hibou?

Ashley:

As I mentioned earlier, I am quite busy these days between my job and studying in school. Hibou is great because at anytime I can jump into the app and see what my mom is up to. Whether it is seeing that shes down at the local beach or that she has confirmed her wellness check in the evening it gives me that sense of relief knowing shes okay and out there enjoying her life. Before we had Hibou there was a lot of calling back and forth which was difficult for both of us and led to a lot of telephone tag. Hibou takes care of all of that for us now allowing us to stay connected, especially with everything going on in the past year.

Zach:

Its great to hear how both you and your mom have used Hibou to stay safe and connected. Donna, do you have any other family members using Hibou?

Donna

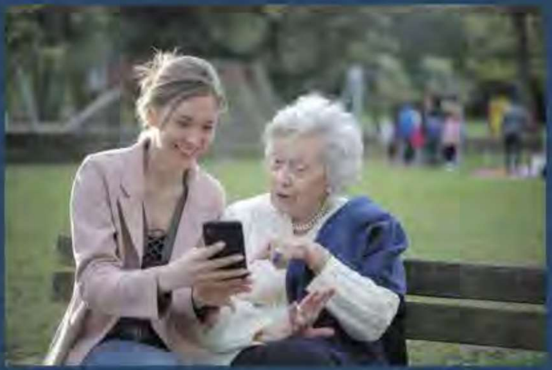
Yes! Once I saw the benefits of Hibou I was also able to get my mom connected to it. Shes a bit older and not so technology savvy so having the option to use Hibou with a touch-tone telephone was a life saver. She receives a call twice a day and confirms that everything is okay. One time she forgot to check in and I received a call promptly and on time from Hibou. When I followed up everything was okay, but I was impressed with how fast Hibou was able to notify me that something might be wrong.

Zach:

Phew! I am glad everything was okay and that Hibou could provide you with that extra sense of security. Thank you, Ashley and Donna, for taking the time out of your day to speak with me, it was great getting to speak with you and learn how you use Hibou.

Ashley and Donna:

No problem, thanks Zach!



HIBOU

If you want to learn more about Hibou and how it can help you and your loved ones, please visit hellohibou.com or call (604) 239-5909 for more information.

ILLUSTRATION: STELLALEVI, COURTESY ISTOCK

PALLIATIVE BEYOND PERCEPTION

Talking about palliative care can feel like an intimidating task, though starting the conversation now can result in a higher quality of life for years to come

By Elizabeth Chorney-Booth

When most of us hear the term "palliative care" we tend to think of people with terminal illnesses moving into hospice as they prepare to die, ideally as comfortable as possible and in a state of peace. But the term "palliative" takes on a different meaning when individuals are faced with the diagnosis of an untreatable progressive disease like Alzheimer's that will ultimately take them to the end of their life, even if that end is more than a decade away.

By *Merriam-Webster* dictionary definition, palliative care refers to support for a terminal or life-threatening illness that is "not intended to provide curative treatment but rather to manage symptoms, relieve pain and discomfort, improve quality of life, and meet the emotional, social, and spiritual needs of the patient." Since there is no known cure for dementia, this means a significant portion of dementia-related care is technically palliative — the goal isn't to eradicate the disease, but simply to improve and enhance the time that an individual has left.

For Dr. Kelli Stajduhar, a nurse and current professor at the University of Victoria's Institute on Aging & Lifelong Health and School of Nursing,

> The goal isn't to eradicate the disease, but simply to improve and enhance the time that an individual has left.

palliative care is an approach that informs caregiving rather than an add-on, especially as it pertains to people living with dementia.

"When I think of palliative care for people with dementia, palliative care really is a philosophy of care, not a place you go or a service," Stajduhar says. "When you think about it that way, the question that you ask is, 'What is it that we can do to enhance the quality of living up until the time a person dies?'"

It's no small question. Improving the quality of living for a person with dementia means drastically different things at different points along progression. In the early days of a diagnosis, palliative care might involve making sure that one sticks to familiar routines and gets plenty of rest. As dementia progresses, it could mean finding ways to access the activities that bring joy to life, such as spending time outdoors or regularly connecting with friends. Towards the end of life, a palliative approach may result in foregoing a transfer to an acute care hospital for life-saving treatment in favour of the comfort and familiarity of home or being in long-term care.

Personalizing Palliative

The philosophy also means palliative care plans are going to be personalized for every person, since no two people will have the same definition of "quality of life."

One of the challenges for care partners is how to respect the wishes of a person with dementia, even as their cognition declines to a point where they're unable to advocate for themselves. Ideally, a palliative care approach should begin as soon as a person receives a dementia diagnosis. This could involve a conversation with a family doctor about what the person would like to experience throughout the course of progression or an ongoing dialogue with family care partners. Knowing what kinds of interventions a person would be comfortable with, where they'd like to live if they need full-time care and what is most important to a person if they do enter a long-term care facility is the cornerstone of a palliative approach.

"Quality palliative care is really person-centred care on steroids,"

PHOTOGRAPH: IZUSEK, COURTESY ISTOCK

Stajduhar says. "Quality of life is about living your life in the way that you want. For caregivers, [it's about] knowing what people want for their physical health as they decline, as well as what they want for their mental health and spiritual health."

Skill and Art in Conversation

These conversations can be difficult to have, especially when people are new to their dementia diagnosis and perhaps not ready to think about the stage where they may be in long-term care or not able to speak or feed themselves, let alone able to contemplate their own death. Family care partners and doctors need to approach the topic of end-of-life care carefully (Stajduhar calls productive conversations about death "a skill and an art"), since words like "palliative" and "dying" can evoke significant fear in people who are already likely anxious about their diagnosis.

Katherine Murray is a certified hospice palliative care nurse with a master's degree in thanatology (the study of death, dying and bereavement) and the founder of Life and Death Matters, a company that develops and delivers palliative care education and resources. She says it's important to start these conversations early, as uncomfortable as they may be.

"We encourage patients and families to have conversations about the seriousness of their illness and to help the person talk about and clarify what is important to them," Murray says. "With advanced care planning, you can say what is important to you and have some of these conversations with your family and your loved ones and medical providers. And then you can get on with living."

No Time Like the Present

Michelle Pante is a licensed funeral director in British Columbia and the co-founder of Willow End of Life Education and Planning, an online-based company that helps people come to terms with their own mortality in a way that helps them clarify who and what matters most today. While death and end-of-life education and planning comprises Pante's work, she's also experiencing the issue of palliative dementia care first-hand, as both of her parents are currently at different stages of dementia progression. Pante's father lives in the family home with caregivers providing support 24/7 and

PHOTOGRAPH: PIKSEL, COURTESY ISTOCK

Myth Busting: People Living with Dementia ARE Able

Living with dementia naturally presents challenges, but the focus on changes overlooks the abilities that remain and new pathways for learning. Emphasizing ability shifts the focus away from the losses towards an opportunity to think about and support those with dementia more creatively.

Myth #1:

People with Dementia Can't Learn

Untrue. Learning is possible despite dementia! In our meaningful engagement classe we see people with dementia learning new ways of expressing themselves through art, movement & musical rhythm.

Myth #2:

People with Dementia Have Nothing to Offer

Inaccurate. People with dementia can still live purposeful lives. In our educational and interactive arts based classes, we see people living with dementia who are thriving. They feel comfortable to share their ideas, opinions and creativity in ways that help them engage not only with us, but also with their family and friends.

Myth #3:

Dementia Signals the End of a Meaningful Life

Incorrect. A person's wisdom does not go away with a diagnosis of dementia. Our professional artists leading the classes develop meaningful relationships with our members. Our artists are not only giving, but they receive from our members. We learn from each other.

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her mother has been in a long-term care facility for more than seven years. Pante wishes that someone had advised her to have a frank discussion with her mom about what she wanted her end-of-life care to look like early on. She feels like that conversation would have given her the power to make different choices as a family care partner.

"We didn't have enough advance care planning conversations because we didn't grasp or accept the expected progression of the disease and the fact that Mom would not be able to talk about her wishes as her disease advanced. Yes, the Alzheimer's caregiver's support group did provide a lot of insight but even there people did not talk about their experiences with end-of-life planning, death and dying," Pante says. "No one said, 'Mom, your capacity is going to change such that you will need help. Do you want to get help in the house and stay in the house or do you want to go somewhere else?' We didn't have that conversation. And that's partly because that's a really hard conversation to have. But you have to acknowledge it."

Naturally, the concerns surrounding palliative approaches to care become more urgent as people with dementia move to long-term care facilities or bring in full-time home care workers. If the person with dementia is unable to self-advocate at that point, Stajduhar suggests that families are very clear with care providers about what the person they care for would want. For example, suppose they'd rather not be put on a feeding tube or be given life-prolonging medication to treat other medical conditions as their dementia progresses. In that case, that should be made clear immediately.

Thinking about end-of-life is difficult, but since it is a certainty for all of us, acknowledging the palliative aspects of dementia care can make both those living with dementia and their care partners feel a sense of empowerment that can enrich the remainder of their lives.

"There's lots of research to support the fact that when we do that kind of planning, upstream and advance with people, the outcomes at the end of life are dramatically better," Stajduhar says. "You see more family involvement in care. You see fewer treatments that are not beneficial for people. You see better management of pain and other symptoms. You see a whole shift in orientation to care and to comfort."

4 ESSENTIAL TOOLS FOR END-OF-LIFE CARE

DR. KELLI STAJDUHAR says that even health-care workers can be nervous about taking a palliative approach to care, which means that people with dementia and their care partners often have to advocate for a palliative philosophy themselves. These resources can help put people on the right path when it comes to end-of-life care:

ADVANCE CARE PLANNING

A website full of resources to help individuals plan and record their wishes for care as their condition progresses.

🖥 advancecareplanning.ca

LIFE AND DEATH MATTERS

Katherine Murray's website offers educational resources, including her books *Integrating a Palliative Approach: Essentials for Personal Support Workers* and *Essentials in Hospice and Palliative Care: A Practical Resource for Every Nurse.*

🖥 lifeanddeathmatters.ca

DIGNITY IN CARE'S PATIENT DIGNITY QUESTION

The question of "What do I need to know about you as a person to give you the best care possible?" can help both caregivers and patients reframe the purpose and direction of their care.

🖥 dignityincare.ca/en/toolkit.html#The_Patient_Dignity_Question

WILLOW EOL 5-MINUTE LEGACY LOVE LETTER

This free tool includes a set of prompts to help individuals write letters to people they care about. There will be a time when you can no longer communicate in the same way with each other. Willow's Love Letter can help both those with dementia and family care partners express and share their love now, or it can be a keepsake for yourself or future generations.

🖥 willoweol.com

DEMENTIA DIALOGUE

Voices of Lived Experience

In our podcast, people living with dementia and care/life partners share their experiences. Peer listeners gain insights and strengthen their adaptive skills. Other listeners gain a deeper understanding of what it means to live with dementia and of the issues surrounding it. "

2021 PODCAST TOPICS:

- Spirituality and Dementia
- Arts and Dementia
- Dementia Friendly Communities
- LGBTQ2S+ and Dementia

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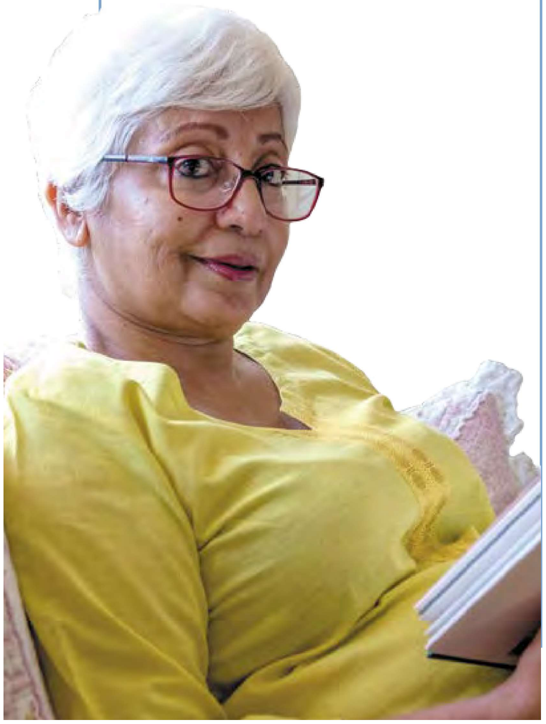
DEMENTIA
DIALOGUE


People living with dementia deserve better.

*Market*PLACE

Welcome to the
Dementia Connections
Marketplace.
Your spotlight on
dementia-specific
products, services and
programs that can
help make every day
a little easier.




Mobi


life for
families
living with
dementia is
made easier
with the
right plan
and support

Find more in our online marketplace at **DementiaConnections.ca /marketplace**

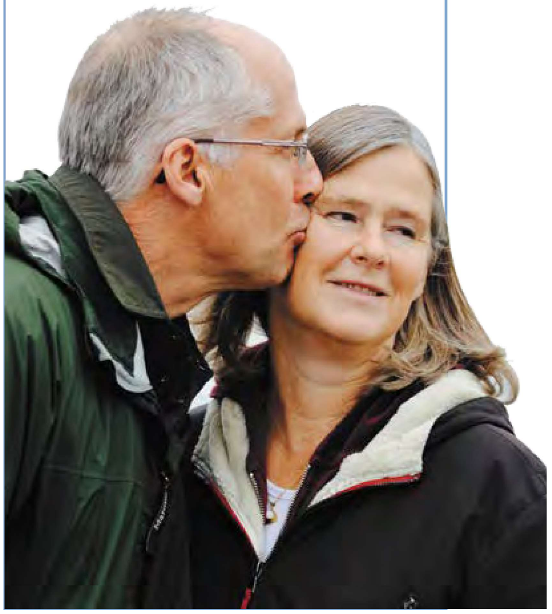
Eugeria.ca
eugeria.ca

Geri Fashions
gerifashions.com

My Scooter
myscooter.ca

Proactive Seniors
memorylanegames.com

VHA Home Healthcare
vha.ca



Walking for Wellness

When someone you love is diagnosed with dementia, it's common to try every strategy or supplement available to slow the progression of the disease and keep the person you know and love with you as long as possible. While there is still no cure for dementia there is a lot of promising research that can help both individuals with dementia and their caregivers continue to live healthy lives.

In a recent study published in the Journal of Alzheimer's Disease, a group of researchers from Texas Southwestern Medical Centre looked at the effects of a year-long aerobic exercise program (brisk walking). Middle-aged and older people with early signs of memory loss were able to raise their cognitive scores, saw an increase in blood flow to their brains and reduced central arterial stiffness. This is great news because it's an easy to implement intervention and the benefits surpass just the physical.

One chronic condition can often lead to a domino of chronic conditions. A diagnosis of Alzheimer's or Dementia is scary. When we're scared, our bodies release stress hormones – predominately, adrenaline and cortisol. Exposure to cortisol for extended period of time can lead to insulin-resistance (which can lead to diabetes), weight gain, and can trigger more serious mental health conditions like anxiety and depression. Now, one diagnosis of one person can lead to more chronic conditions for two or more people. The good news is that walking and getting physically active has the exact opposite effect – it can create a health and wellness cascade.

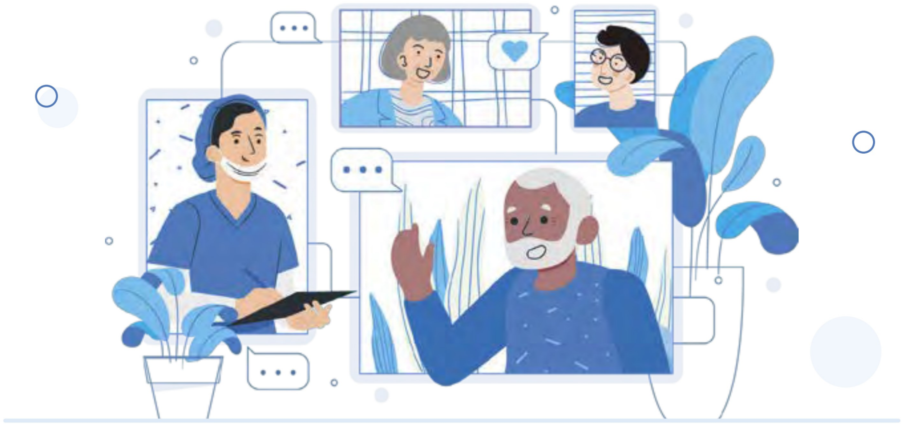
> ❞The good news is that walking and getting physically active has the exact opposite effect...❝

Both you and your loved one should aim to complete 150 minutes of moderate-to-vigorous aerobic activity per week. Aerobic activity is any activity that gets your heart and lungs pumping like walking, dancing, or cycling. An important part of this guideline to note is that you want to achieve a moderate-to-vigorous pace. This means that you're working at about a 5-7 on a scale from 1-10. At this intensity you could talk, but you shouldn't be able to sing. If walking briskly for 30-45 minutes five days per week sounds like a lot, remember that you have to start somewhere. Can you go for one 10-minute walk? Can you go for one 30-minute walk? Consult your doctor, start where you can, and slowly increase the time and speed of the walking to reach the moderate-to-vigorous pace and 150 minutes per week.

Emily Johnson
Founder and Creative Director
StrongerU Senior Fitness

Care2Talk

Video communications is not the future, it is the now!

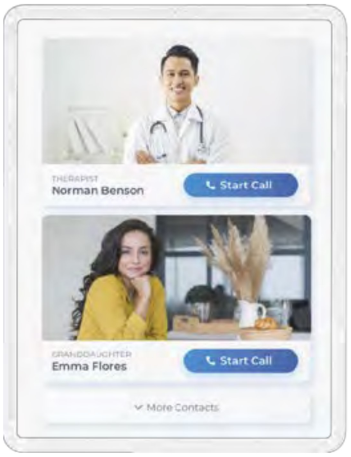


Care2Talk is an iOS/Android App which uses a specially designed interface on a mobile or tablet device to create an easy-to-use video chat tool for those with cognitive decline, or other impairments, which may make alternatives difficult to navigate.

This includes conditions associated with:

- Aging & Dementia
- Cognitive and Developmental Disabilities
- Brain Injuries
- Vision Impairment
- Physical Disabilities

We're currently working with the BC Care Providers & a few partnerships in the US to ease the communication hurdles between seniors and their family and friends.



Serving:

- Senior Care Homes
- Public Sector
- Peer2Peer, and
- Custom Enterprise Solutions

Benefits

- As Covid-19 hit us worldwide, the face-to-face connectivity was lost between seniors and their loved ones. Care2Talk restores this connectivity in order to help reduce **stress**, **anxiety**, and **depression.**

- Senior's well-being has been negatively impacted due to the lack of connectivity.

- Services like Skype or other video calling applications proved too confusing for many senior citizens to navigate and use.

- Care2Talk identified that there was a gap in services available to connect seniors or people with dementia or cognitive disabilities with their caretakers, family or friends.

- Allows for a better exchange of information since both speaker and listener are able to see and interpret body language and facial expressions.

Our Features

Simple touch video calling with CC
To initiate a videocall, just simply touch. Closed Capation is included as an option for all tablets.

Care2Talk's Web Portal
Designed for care homes in mind, simply manage all devices and payments in one location – our web portal.

Closed Network
Easy to share contacts information via email or text from anywhere around the world. Connecting just got easier!

Remote access
Administrators can easily make changes to contacts, view recorded conversations, or troubleshoot issues from anywhere in the world.

Ability for Integrations
Ability to integrate with care homes directly using their internal systems:

- Family and Friends outside the care home
- Friends within the care home
- Connect to admin (Care aide, front-end admin staff, kitchen, in-house doctor)

Unlimited onboarding training and support
Care2Talk will work with you to ensure full understanding of our tools and features with training videos, face to face (virtually), and full support from our IT team – white glove support!

Yearly updates
As technology changes, our Care2Talk customers will receive the latest version when rolling out updates at no additional cost

More information can be found at **care2talk.io**

FALL 2021

A sneak peek of our next issue

Subscribe today!
DementiaConnections.ca

APPS, WEARABLES AND SMART HOME SYSTEMS

Technology-enhanced solutions can support the independence, autonomy, and personhood of people living with dementia. Our Fall 2021 issue will explore the latest technology that is making a positive difference in the lives of people impacted by dementia.

CARE PARTNER WELL-BEING

The quality of care provided to people living with dementia is often a direct reflection of the well-being of the care partner. Care partner well-being in all domains is a growing issue of concern within the dementia community, and we'll dive deeper into this topic in our Fall 2021 issue.

THE HEALING POWER OF THE ARTS

Studies continue to show that when people living with dementia express themselves through art they reconnect to themselves and to the world around them. We now know that the ability to create art remains long after speech and language have diminished due to the neurological impacts of dementia.

Dementia Connections magazine is published quarterly, in spring, summer, fall and winter, each year.

JOIN OUR COMMUNITY

Dementia Connections is a community where people living with dementia, care partners, family members and friends, researchers, and other advocates stand together against dementia.

As a social venture, our purpose is to collaborate with people living with dementia, care partners and allies, to diminish silos and to co-design a new paradigm in which people with dementia are respected as whole persons, recognized as citizens with the right to participate fully in life, and empowered as change makers.

Dementia Connections is committed to amplifying the voices of people living with dementia and care partners, and to sharing the curated information and resources that will empower people impacted by dementia to live well on their own terms, with freedom from stigma.

Join our community. Speak up, share your knowledge, tell your story, give your opinion.

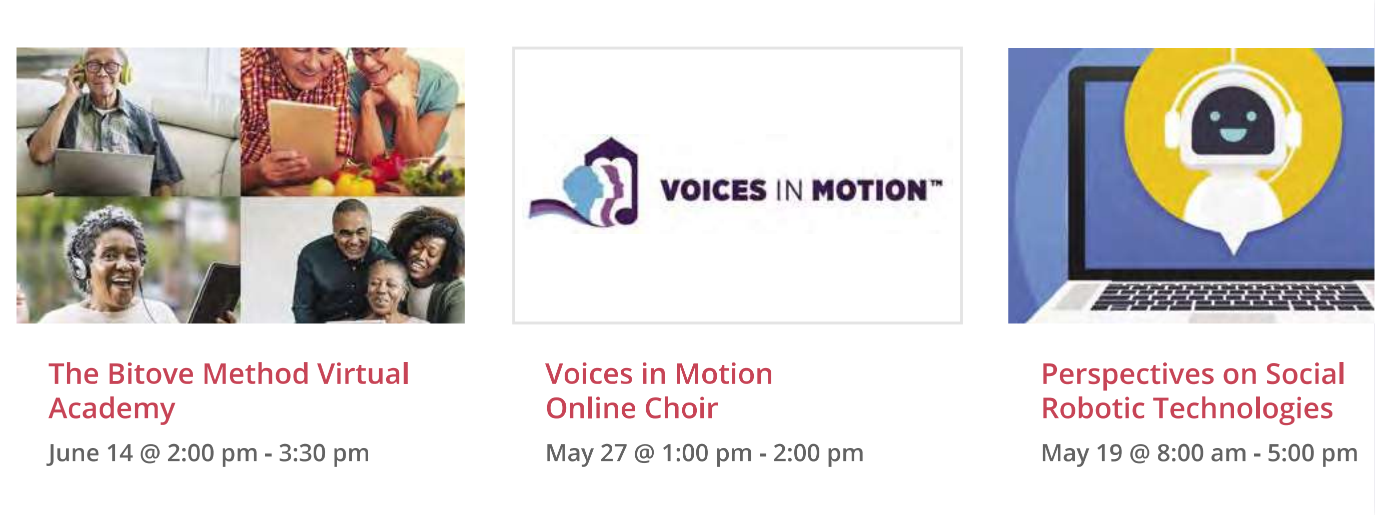
You are welcome here.
Join the conversation on social, @DementiaMag, or email us at connect@dementiaconnections.ca

PHOTOGRAPH: FSTOP123, COURTESY ISTOCK


Prominence Way
Retirement Community by Signature


Rocky Ridge
Retirement Community by Signature

DEMENTIA connections



The Bitove Method Virtual Academy
June 14 @ 2:00 pm - 3:30 pm

VOICES IN MOTION™

Voices in Motion Online Choir
May 27 @ 1:00 pm - 2:00 pm

Perspectives on Social Robotic Technologies
May 19 @ 8:00 am - 5:00 pm

CONNECTIONS LISTINGS

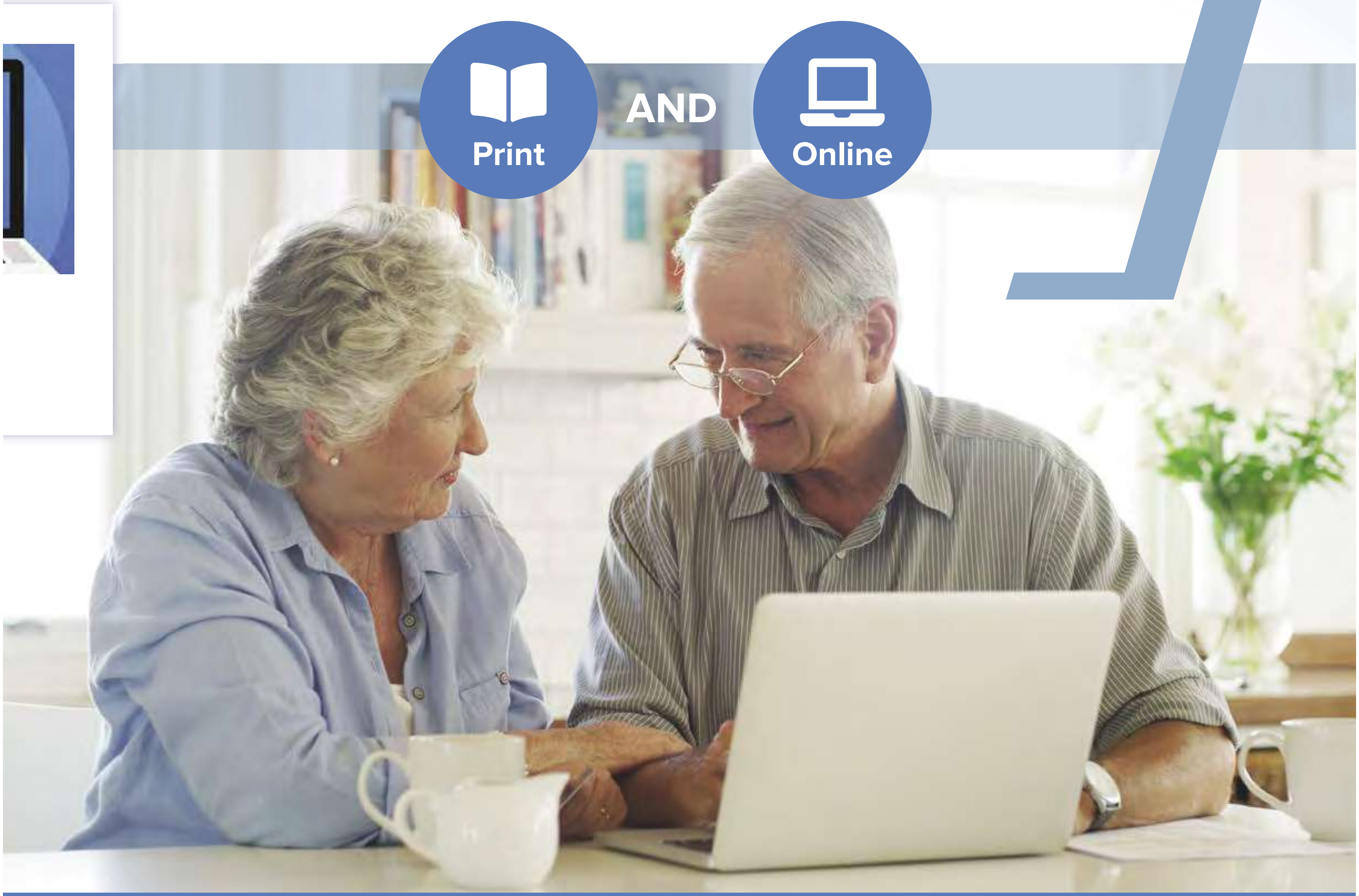
Join in, recharge, connect, learn and grow! Connections Listings enable people living with dementia and care partners to easily find ongoing opportunities to improve their overall wellbeing and quality of life. **Check out new listings online weekly and add your own!**

MORE THAN A MAGAZINE

MARKETPLACE

In the Dementia Connections Marketplace, we shine a spotlight on **dementia-specific** products, services and programs that can help make every day a little easier.

Print **AND** **Online**



Visit us today at DementiaConnections.ca

End the stigma

All party dementia caucus

Personalized Care

Human rights

Better post-diagnostic support

Increased dementia-specific skills and knowledge

Dementia inclusive communities

Family care partner tax refunds or allowance

Single point of contact to navigate the system

Family as essential part of a care team

Dementia
Advocacy
Canada

Voices of Lived Experience

Help us shape an inclusive Canada.

We are a grassroots group of Canadians living with dementia and care partners. Our mandate is to establish an active and respected role in decisions about government policies and programs that impact our lives.

Join us and share your story at DementiaCanada.com