DEMENTIA

connections

Summer 2020

YOUR GUIDE TO LIVING WELL IN CALGARY

NURTURING THE SPIRIT
HOW FAITH COMMUNITIES WELCOME PEOPLE LIVING WITH DEMENTIA

DEMENTIA-INCLUSIVE INITIATIVES, ADVICE FOR CARE PARTNERS, INVALUABLE RESOURCES AND MORE

Beautiful MOMENTS

Felix Iroanyah finds joy in his family

Lisa Poole, shown here with her father, John, during a socially distanced visit.

WELCOME

THE COVID-19 PANDEMIC thrust the world into unprecedented circumstances, limiting our movements and forcing us to question every aspect of our health and social systems. This pandemic has been particularly harsh on people living with dementia and their families across Canada.

In many provinces, nursing home deaths were disproportionately represented, and Canada has the dubious honour of having one of the highest global death rates for this population. The Canadian Armed Forces' report detailing horrifying conditions of care in Ontario and Quebec must not be ignored nor forgotten.

Family members are essential partners in care, and yet, those who reside in congregate settings have been denied access to family during the pandemic. Read how technology helped bridge the gap for some, like Daniel and Janet Gaetano (pg 6), while waiting for the emergency measures to be lifted and family visits to resume. At the time of publication, it has been three months since family members have been allowed inside care facilities or people living inside were allowed out. Physically distant, outdoor visits while wearing masks are a poor substitute. No hugs or hand-holding are allowed.

For those who live in the community, home care, recreation programs and most forms of respite have been cancelled. Social isolation, which was already a concern, has increased exponentially. Some people with dementia struggle to understand and remember pandemic protocols and family caregivers have been left to cope with little support. Read how the Alzheimer Society of Calgary adapted quickly to provide remote communication including support groups and Club 36 Adult Day program activities (pg 18).

The pandemic has shone a spotlight on critical gaps in care, and this attention can be a driver to transform how care is provided and make our country more dementia-inclusive. We must do better as a nation to protect our most vulnerable and those who care for them.

Lisa Poole
Founder and Editor
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Correction: In the story "Food for Thought" in the Winter 2020 issue, we were remiss in stating that the title "nutritionist" is protected in Alberta and is reserved for regulated members of the College of Dietitians of Alberta.

In memory of Irene Palmer, beloved wife of Frank Palmer, who passed away on May 2, 2020.

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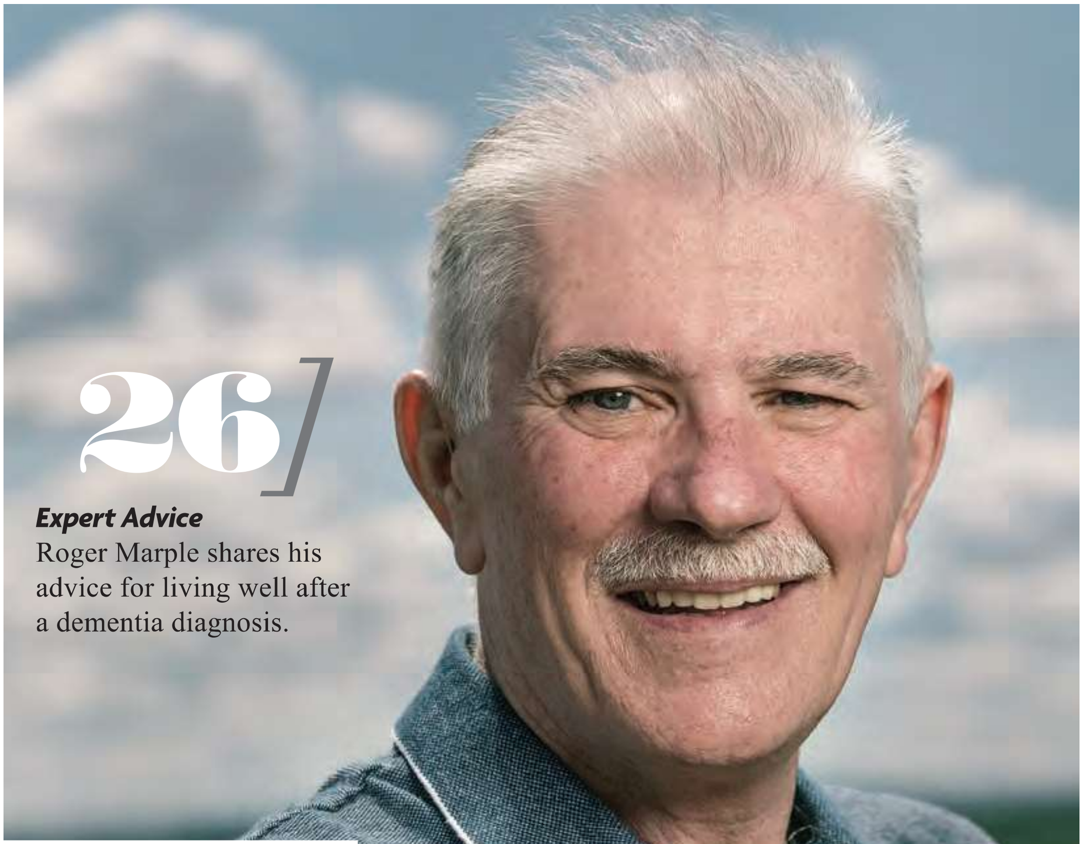

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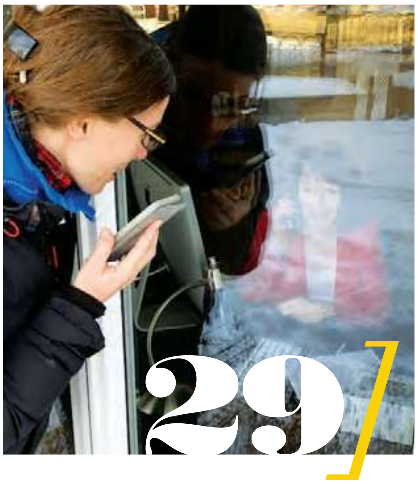

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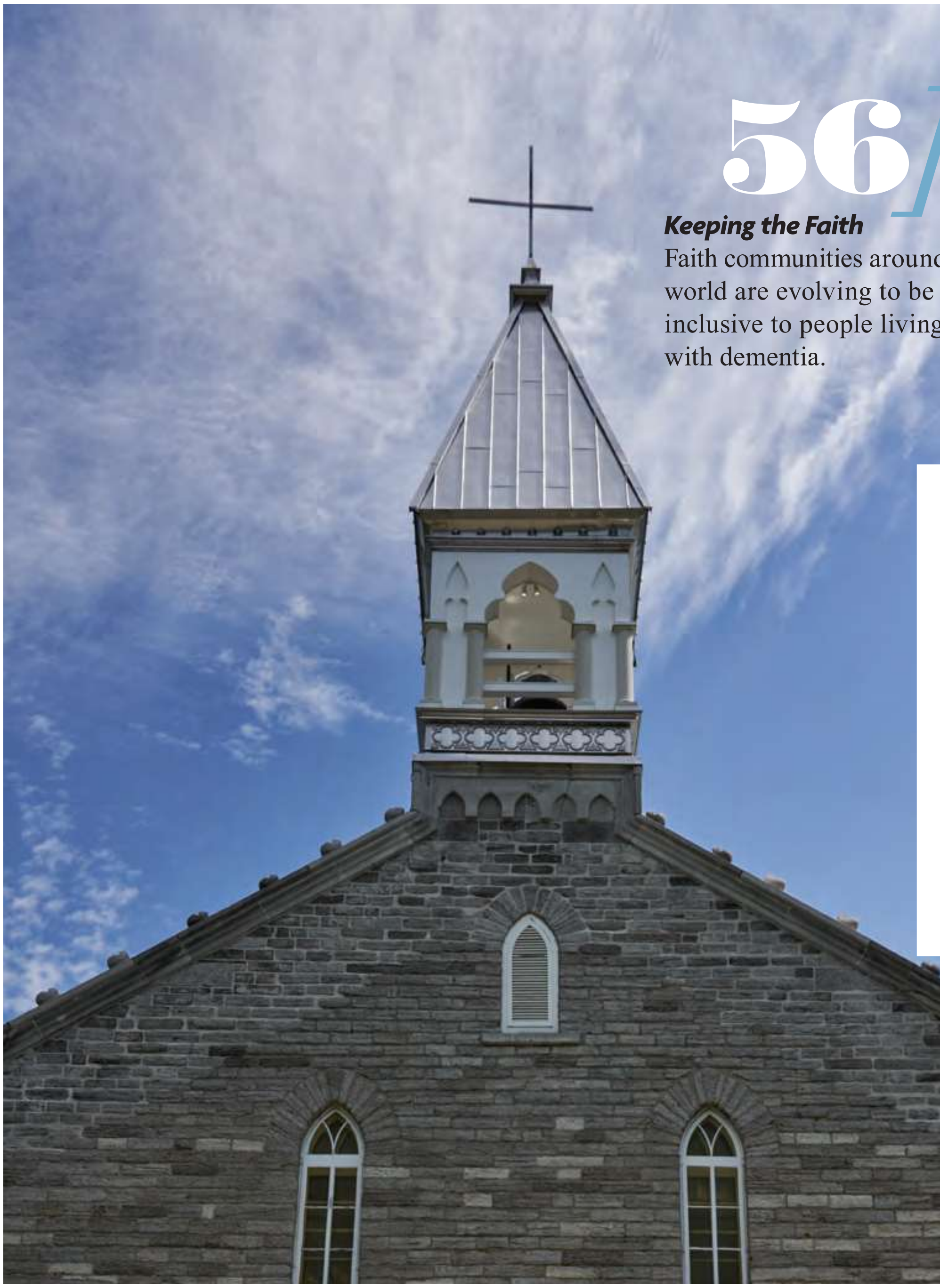

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CAREGIVING THROUGH COVID

Daniel Gaetano shares his experience caring for his wife, Janet, during COVID-19

BY **Nathan Kunz**

During the COVID-19 pandemic, family caregivers have seen their relationships with people in long-term care homes rapidly change. Emerging restrictions mean visiting residents has become increasingly difficult — if not impossible — while fears of outbreaks in care homes are a real concern.

For Daniel Gaetano, this fear became a reality when a confirmed case of the virus was reported at his wife's Calgary residence.

"You want to be there so you can see for yourself what's going on," he says. But you have to take what they're saying and [hope] they're doing a good job."

For the first year, Daniel made nearly daily visits, usually through the morning and into the afternoon to help with and share breakfast and lunch with Janet.

"I still felt the need to be with her," explains Daniel. "After I stopped working, basically that was my reason for being — to be with her and to be the person to care for her."

In early March 2020, concerns about the spread of COVID-19 had begun to escalate and it emerged that older adults, especially those living in care homes, were part of the demographic particularly at risk for the virus. On March 23, Daniel received notice that, to help keep residents safe, visitors would no longer be able to enter Bethany Riverview at all.

> "You want to be there so you can see for yourself what's going on, but you have to take what they're saying and [hope] they're doing a good job." —**Daniel Gaetano**

When Janet Gaetano was diagnosed with Alzheimer's disease in 2010, it began a major life transition for both her and Daniel. While Janet lived fairly independently for several years, her escalating care needs led Daniel to leave his job in accounting to focus on her care. Eventually, the decision was made to transition her into a care home. In February 2019, at the age of 61, she moved to the newly built Bethany Riverview.

On April 14, Bethany Riverview announced that one staff member had tested positive for the virus. Luckily, Daniel says, while the staff member worked on the same unit that Janet lives on, the two did not come in contact. Janet was tested for COVID-19 in late April and her results came back negative. At time of publication, three residents and three staff members had also been infected, but have all since recovered.

Although Daniel says he is confident in the care offered by Bethany Riverview, concerns naturally remain. "There's not anything that I can do. So, you wait to hear and hope that it's going to stay the way it is," he says.

Daniel is hopeful that the situation prompts the hiring of more full-time health-care aides and fewer casual employees working in multiple residences at the same time. Before COVID-19, having employees work between many care homes often meant inconsistent care for residents, but for many part-time and casual employees, the practice is often essential to make a living wage. During the pandemic, the practice appears to have contributed to the spread of the deadly virus to a particularly vulnerable population.

On April 10, Alberta's chief medical officer Dr. Deena Hinshaw ordered all staff working at multiple long-term care facilities to restrict their work to one site to limit possible spread.

Daniel notes that while COVID-19 has brought the issue to the forefront of conversation, he's always felt strongly that measures should be put in place to help ensure employees are able to work full-time at a single facility and, in turn, offer more personalized care. "I was always a proponent of that," he says. "There should be the same people working at the same place. But with this pandemic, it really reinforces that."

Photo by Emily Thomson, courtesy Bethany Riverview; screenshots courtesy Daniel Gaetano

Daniel Gaetano connects with his wife, Janet, over video chat.

In the midst of the pandemic, Daniel says being alone has allowed his mind to wander, and he's felt grief and loss in heavier waves than usual. To keep himself socially connected, Daniel has put together an unofficial schedule to check in and chat with family and friends regularly. He also says the relationships he's made with management and staff at Bethany Riverview have been helpful, as he is able to quickly get information on Janet's condition.

Beyond updates, Daniel says being able to see Janet, even if just virtually, has also been a refuge. Bethany Riverview has an iN2L touch screen monitor system that, along with allowing residents to engage with activities like movies and bingo, includes Skype capabilities. Since the lockdown began, Daniel has been able to schedule twice weekly video chats with his wife. Seeing that Janet is well has helped remedy his worst worries.

"Your imagination and your worries can take you down a really deep hole," says Daniel. "When you see her in the video chat, and you can see that she's smiling, she looks healthy, she looks alert, she can hear you and, in Jan's case, she's able to try to say things, you know then that she's in good spirits. It gives me the ability to see that she's okay."

BRIDGING THE GAP

People living with Down syndrome are at considerably higher risk of developing dementia as they age but have fewer supports in place to help

PHOTOS AND STORY BY **Jennifer Friesen**

Yvonne Dewar and her brother, Murray Adderley, at his home in Red Deer.

Ever since Yvonne Dewar moved to Calgary 22 years ago, she's brought her younger brother, Murray Adderley, to stay with her every few weeks. Adderley, who was diagnosed with Down syndrome at birth, lives in an assisted living home in Red Deer, Alta.

The youngest of four, Adderley has always been naturally sweet, loving, and social. But seven years ago, Dewar and her two sisters began noticing changes in their brother: he would often get stuck on an idea and needed things repeated.

Dewar recalls driving Adderley home to stay with her for a few days. As they pulled into the driveway he asked, "Who's house is this?"

"No, Mur, this is my house," she replied.

"Oh, you got a new house?" he asked.

"I'll never forget it," says Dewar. "We've spent a lot of time in this house, but suddenly he didn't remember."

In the following months, Adderley's sisters noticed other changes, including his withdrawal from social situations, which was very unusual for him. The signs and symptoms continued to mount, and he was ultimately diagnosed with Alzheimer's disease that same year.

"I just felt really, really sad," says Dewar. "[I thought] 'Is there not enough going on? Life has been challenging for him, and now he has this on top of it?'"

That feeling was echoed by their sister, Susan Franklin, who still lives in their hometown of Yellowknife.

"He hasn't had things easy, but we've always tried to make everything as wonderful in his life as we can," Franklin says. "But it was devastating."

Although distressing, Adderley's diagnosis wasn't necessarily unique. People living with Down syndrome have a high risk of developing dementia. Statistically, 75 per cent of people with Down syndrome 65 years of age and older are also living with Alzheimer's. People with Down syndrome are also more likely to have young-onset Alzheimer's. The reasons why aren't clear, but studies have shown that higher levels of plaques and tangles in brain nerve cells are a common feature associated with Alzheimer's. People with Down syndrome have been found to have significant levels of these plaques and tangles appear by as young as age 40.

In the seven years since Adderley was diagnosed, his family and caregivers have faced unique challenges that come from living with both diagnoses. With so many moving parts, between communication barriers and balancing medications, they work to the best of their abilities to decipher the root cause of the different conditions.

> "There's a lot of support through the Alzheimer's/dementia group, and lots of support for the Down syndrome group, but finding support for living with the two together is limited." —Yvonne Dewar

Additionally, there are currently no approved pharmaceutical drugs for this population in Canada, so the family is focused on keeping Adderley active and content.

"There's a lot of support through the Alzheimer's/dementia group, and lots of support for the Down syndrome group, but finding support for living with the two together is limited," says Dewar, who praises the help from Adderley's support workers and from the Alzheimer Society of Calgary. "Even in spite of having such a high percentage in this population, it's limited. I'm a little bit frustrated that there isn't more support or more training. It would be nice to talk to other people who are journeying through the same things."

Franklin adds that, outside of a small pamphlet she found at an Alzheimer's association and an article she saw 15 years ago, she hasn't seen anything else discussing the link between the two conditions.

"Having the knowledge is key, and that's what we want," says Franklin.

As Dewar sits with her brother on an early February afternoon playing Yahtzee and chatting about his favourite bands, she smiles and encourages him to talk about his upcoming birthday. Adderley's disease is still in the middle stages and he enjoys spending time with his family and neighbours, so the siblings discuss who he'll be inviting to celebrate with him. He'll be turning 59 this September and is planning to celebrate at his sister's Calgary home alongside friends, family and neighbours.

"I believe our parents up above are keeping a close eye on us," says Dewar. "We feel pretty blessed, so hopefully things will continue to be as good as they can be." ◼

CONNECTING THROUGH TECHNOLOGY

In the face of COVID-19, CABHI's annual conference went virtual

BY **Meredith Bailey**

When Len Carter, from Cambridge, Ont., heard that the Centre for Aging and Brain Health Innovation's (CABHI) annual What's Next Canada aging and brain health conference might be cancelled, he was devastated.

CABHI, which is spearheaded by Baycrest, is a collaboration of healthcare, science, industry, government and not-for-profit partners who aim to increase quality of life for older adults through innovation. Its annual conference features keynote speakers, engaging panel discussions, and presentations on the latest developments, research and improvements in aging and brain health today.

Photo courtesy Len Carter

Carter, who is living with dementia and is an active member of Dementia Advocacy Canada, was scheduled to present at the event as part of the Lived Experience Panel.

"I was really quite excited to speak about dementia myths and stigma, and when I heard it might be cancelled, I was depressed as hell," he says.

The conference, which was scheduled to be held at the Metro Toronto Convention Centre on March 11, was in limbo because of the growing spread of COVID-19. Hosting an in-person event could put participants and attendees at-risk.

"The health and safety of all presenters and attendees, and Baycrest patients and residents, who are a particularly vulnerable population, is of paramount priority," said CABHI's Managing Director, Dr. Allison Sekuler, in a press release.

With recommendations from the Toronto Region COVID-19 Healthcare Human Resources Working Group, the World Health Organization and the Centre for Disease Control, CABHI made a quick decision to host the conference virtually instead — an update that was good news to Carter.

"Magically, they decided to do it as a Zoom meeting," he says.

With two days' notice, CABHI lined up 43 speakers and offered nine hours' worth of online programming to more than 100 attendees. Speakers, including researchers, entrepreneurs, older adults and people living with dementia, participated in a variety of panels covering diverse topics such as technology and global partnerships on aging. The Lived Experience Panel, which featured Carter and fellow advocate Ron Posno, who is also living with dementia, as well as members of CABHI's Seniors Advisory Panel, explored how innovators can learn from users by inviting them to participate in the innovation process.

Carter says using technology was actually easier than an in-person presentation for participants on his panel.

"All of the participants on the panel felt much more comfortable on a video chat like Zoom than they might have been sitting in front of 300-plus people," he says. "We were able to have a really clear conversation."

CABHI's quick pivot to hosting a virtual conference allowed the conversation around living well with dementia to continue — something Carter was grateful for.

"It was a great opportunity for me to express my concerns about dementia stigma," he says. "I was able to tell a large group of people how devastating it is. If everybody understood what this thing is and weren't so afraid of it, we could all live much more normal lives."

> "All of the participants on the panel felt much more comfortable on a video chat like Zoom than they might have been sitting in front of 300-plus people. We were able to have a really clear conversation." —Len Carter

GUIDELINES FOR CARE

The Alzheimer Society of Canada's COVID-19 and Dementia Task Force supports medical professionals to treat people with dementia with respect and fairness

SPECIAL CONTENT FROM **the Alzheimer Society of Canada**

When Mario Gregorio was diagnosed with dementia 12 years ago, he was determined to continue to live his life fully.

As a volunteer for the Alzheimer Society of Canada, Mario, who lives in Burnaby, B.C., has educated thousands of people about the condition, and helped write the Canadian Charter of Rights for People with Dementia.

So, when the COVID-19 pandemic erupted, and news started coming in from Italy about doctors having to choose who got an ICU bed and who didn't, he got concerned.

> "Our rights are the same as those of any other citizens of Canada." —Mario Gregorio

"People with dementia are lumped in together with seniors in long-term care," he says. "So you are put on the bottom of the list."

Gregorio lives independently, like so many others who maintain a good quality of life after a dementia diagnosis. But he knew that in a pandemic, when scarce resources had to be rationed, doctors might not even consider people with dementia for critical care.

Unsurprisingly, the Alzheimer Society of Canada had the same idea. To help the medical community answer questions about how to treat people with dementia, the Society convened the COVID-19 and Dementia Task Force, a team of leading researchers, clinicians, and dementia specialists from across the country. Its goals:

- **to advocate for better care for Canadians living with dementia**
- **to reduce the stigma and discrimination against people living with dementia.**

The task force broke into teams that tackled different topics, including the question of how to allocate scarce resources in a pandemic. The objective was to help medical professionals make decisions in a crisis, and make sure they treat people with dementia with respect and fairness.

With the rapid spread of COVID-19, doctors and hospital administrators needed help with contingency planning, says Dr. Eric Smith, Professor of Neurology at the University of Calgary and Hotchkiss Brain Institute, who chaired the team that looked at the question of allocation of resources.

"We thought through how you would evaluate someone with dementia, along with people with other health problems to determine who might be offered critical care, including mechanical ventilation, versus which patients may not," he says.

The committee came up with a set of guidelines for doctors about allocating health-care resources that fit into three categories:

1. **Treat each person who has dementia as an individual, without making assumptions about their degree of ability or their quality of life.**

2. **Treat each person living with dementia with respect, be honest with them about what care is available, and provide the best care you can.**

3. **Encourage people with dementia to let their doctors and caregivers know what kind of medical intervention they would like if they become seriously ill: whether or not they want to be resuscitated, put on a ventilator, etc.**

Gregorio is also a member of the COVID-19 and Dementia Task Force. He says it's crucial for people living with dementia to speak up for themselves.

"Most of the articles I've read in the media assume that people with dementia are going to be excluded from medical care," he says. "This should not happen. Our rights are the same as those of any other citizens of Canada. We should not be put at the bottom of the list for treatment just because of our diagnosis."

Find out more about the Alzheimer Society of Canada's COVID-19 and Dementia Task Force and its recommendations at alzheimer.ca/covid19-taskforce

DEMENTIA, IMPROV AND SHARKS IN THE GARDEN

Calgary filmmakers explore improvisational theatre for people living with dementia through their documentary, *Garden Shark*

BY **Nathan Kunz**


Dawn Nagazina (middle left) and Anna Cooley (middle) with the *Garden Shark* creative team.

Dawn Nagazina had been studying improvisational theatre, or improv, at Company of Rogues Actors Studio in Calgary for nine months when she learned about the benefit of improv for people living with dementia. While looking for more ways to get involved in the improv community in early 2019, she heard about the Alzheimer Society of Calgary and Inside Out Theatre's Village Improv for Alzheimer's program. The program, which began in 2014, is offered as part of Club 36, an adult day program at Bethany Harvest Hills and AgeCare Seton. Participants living with dementia engage in improv exercises with professionally trained improvisors.

"When I learned of people living with dementia doing improv, I was just instantly excited," says Nagazina. "It's a space where we get to celebrate our individuality and you get to fail forward, but it's not really failing. Improv is about being in the present moment. And so, you don't need memory."

The Calgary-based filmmaker and actor says the concept immediately resonated with her, and she felt an urge to share it. That's where the idea for *Garden Shark* — a documentary exploring first-person accounts of the benefits of improv for people living with dementia — was born.

Garden Shark shows the effectiveness of improv, both as a recreational activity and communication tool, by following participants in the Village Improv for Alzheimer's program .

Unscripted and spontaneous, improvisational theatre as dementia care comes from a simple baseline — exercises rely on being in the moment, taking part and always trying to say, "Yes, and...". There are no wrong answers and the environment is usually light, supportive and, more often than not, filled with laughter.

Even the film's name comes from the freewheeling imagination that thrives in the practice. Nagazina explains in her pitch video that in improv, "if I want sharks in my garden, then I'm going to have sharks in my garden."

"It's just about giving people tools for communication, which everybody needs all the time every day, but it becomes more imperative when certain forms of communication become harder," explains *Garden Shark*'s director Anna Cooley, who joined the team shortly after the project received funding through Telus Storyhive's documentary competition in summer 2019.

Garden Shark was one of 30 Alberta and B.C. documentaries to be funded through Telus's annual competition. Winners are determined by a public voting period — like *Garden Shark* was — or by a jury of Storyhive team members and industry professionals. Nagazina, who previously worked as a professional engineer, says the widespread support in voting represented something of a collision of worlds.

Photo and video captures courtesy Garden Shark

Participants explore the risk-free, playful and hilarious environment created by Inside Out Theatre's improvisation program, Village Improv for Alzheimer's.

> "Improv is about being in the present moment. And so, you don't need memory." —Dawn Nagazina

"It was the first time I was asking for a lot of people in my creative world and my previous corporate world downtown to support this endeavor," says Nagazina. "The result was incredible."

For Cooley, whose grandmother lived with dementia for 10 years, the movie's focus resonated. She recalls her grandmother living particularly well with dementia, and, after hearing about the concept, she realized much of her family's communication with her grandmother echoed the methods in improv.

"I voted for this project every day that it was up because I knew the value of it," says Cooley. "Then I was thrilled when, a few weeks later, I was asked to direct the film."

In January 2020, a second push was made on crowdfunding site Indiegogo to host a free class for caregivers to learn improv skills along with people living with dementia. After a successful campaign, which garnered close to $10,000, the reactions of participants who took the free class, both caregivers and people living with dementia, became a centerpiece of the film, showing and teaching improv's benefits.

Now nearing completion, the team is looking to screen the doc at film festivals in Calgary and beyond. Following the festival circuit, they hope *Garden Shark* finds its way into medical schools and other training programs, as well as to those recently diagnosed with dementia.

"To show people living well, I think gives hope to both them and the people caring for them," says Cooley.

Garden Shark will premiere fall 2020 and will be available on YouTube and Telus OptiK TV. ◼

For more information, visit gardenshark.ca

DID YOU KNOW? ***In 2018, Texas businessman Dr. James Truchard gifted US$5 million to The University of Texas at San Antonio to establish the Oskar Fischer Prize. The initiative challenges the world's brightest minds to review the existing Alzheimer's disease research to-date and, through innovative thinking, synthesize it into one explanation for the cause of the disease. The prize is named for Oskar Fischer, one of the first scientists to publish descriptions of Alzheimer's disease in the early 1900s. Successful participants can win up to US$2 million. Funds will be awarded to winners in the spring of 2021. Learn more at oskarfischerprize.com***

CARING FOR THE CAREGIVER

Caregivers Alberta offers much-needed support to those providing care

BY **Colleen Seto**

One of the most important, yet often overlooked, roles is that of the caregiver. In Canada, millions of people act as caregivers for a friend or family member with a long-term health condition, a disability or age-related needs. With Canada's aging population projected to grow by 68 per cent in the next 20 years, the demands on caregivers will also increase.

Caregivers to a person living with dementia spend an average of 26 hours per week providing support. This work is largely unpaid and can be very stressful and physically and emotionally draining. Many caregivers of older adults living with dementia exhibit symptoms of distress, such as anger and depression, and a whopping 50 per cent will die before the person they are caring for.

Ultimately, caregivers also need care. Caregivers Alberta, an organization of caregivers for caregivers, offers much-needed support to those providing care to a friend or family member.

“Caregivers must be cognizant of their own needs,” says Johnna Lowther, provincial program lead for Caregivers Alberta. “Caregivers can get burnt out quite quickly, and we're here to try to prevent that.”

The non-profit organization provides programs and services such as one-on-one support through its caregiver advisor program, as well as new online programs.

“Caregivers can call, email or chat online with our advisor to get to the bottom of challenges they're facing,” says Lowther. “We take a step back and ask, ‘What are your needs as a caregiver?’ We listen and connect them to services, and we walk hand in hand with them on their journey.”

Caregivers Alberta acknowledges the work of caregivers and helps them to be part of a community, rather than working in isolation.

“We hear a lot from clients that it helps that they don't feel so alone,” says Lowther. “It can be hugely validating to hear and see that others are experiencing what you are.”

The organization also endeavours to make people more caregiver-aware.

“People don't always self-identify or recognize they're in that caregiving role,” she says. “By raising awareness of what a caregiver looks like and showing how you can support them, we help make sure that we prop up all of our caregivers.”

At least half of the organization's clients care for people living with dementia or cognitive loss. Lowther and her colleagues have been working to improve access and diversify support for dementia caregivers.

“We look at how they can have a more positive relationship with the person living with dementia so they can be a better caregiver,” explains Lowther. “Understanding the dementia diagnosis and how to communicate with a person living with dementia makes caregiving easier.”

Learn more at caregiversalberta.ca

DID YOU KNOW? ***In response to the growing demands on caregivers in the face of the COVID-19 pandemic, the Alberta Government announced $3 million in grants to Caregivers Alberta in April 2020. The funds will support the organization's programs including expanded hours for the Caregiver Advisor phone line, the development of a public awareness campaign on the importance of caregivers, the compilation of province-wide caregiver supports and more.***

FACING ISOLATION DURING COVID-19

Paul Lea shares what keeps him active and engaged

BY **Nathan Kunz**

On an average summer day, Paul Lea walks more than 10 kilometres. The 67-year-old Torontonian has lived well with his dementia diagnosis for several years, finding comfort in his routines as he continues to live alone. However, the COVID-19 pandemic has made the past months far from normal for everyone, Lea included.

"I don't like changes. I get frustrated," says Lea. "In the summertime, I have my music in my earbuds, and then I walk. It's my routine and I'm not sure when I'm going to be able to do that again."

Lea received his initial vascular dementia diagnosis in 2009 after suffering a stroke the year before. Though his journey has included challenges, he's remained active, noting that home reno projects in his bachelor apartment along with daily walks have kept him both mentally and physically engaged.

"I may be alone, but I'm not lonely," says Lea. "I normally say there's three of us here: me, myself and I, and I take care of the other two."

Lea was proactive in staying home and practicing social distancing early on in the COVID-19 pandemic. When the first Canadian case was reported on January 25, 2020, Lea, who also has diabetes and a mild case of chronic obstructive pulmonary disease, hunkered down and shelved his daily strolls as a precaution.

Despite his independent nature, Lea says he misses social opportunities previously offered by his walks. Others who struggle with independence may be feeling this to an even greater degree. Concerns related to loneliness in older adults were present before COVID-19. For example, the Government of Canada's 2013-14 *Report on the Social Isolation of Seniors* found that older adults living with mental health issues, including Alzheimer's disease or other related dementia, are at a greater risk of social isolation than those without. Isolation can lead to negative health behaviours, including drinking, smoking and not eating well, and can increase the risk of hospitalization by four to five times. Now, with isolation essential, these concerns are only heightened.

At the time of publication, Lea remains at home, save for trips to the doctor's office for appointments. DIY redecoration projects and spring cleaning have kept him engaged and moving, while playing video games on his Nintendo 64 has occupied his downtime.

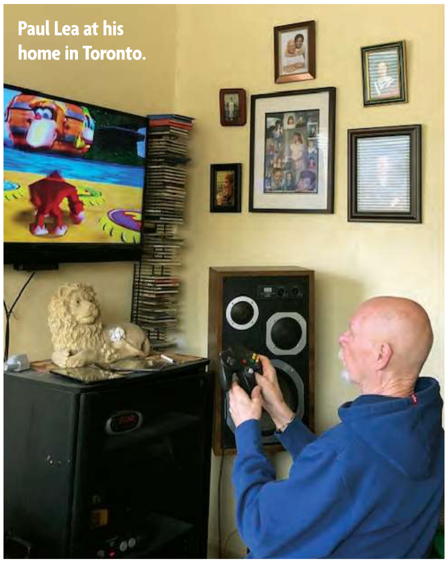
An active advocate and speaker on his experience with dementia, Lea has also found refuge in technology, which allows him to meet with various groups via Zoom video calls. While its part business-as-usual, the meetings can often create a much-needed escape from isolation and add a jolt of socialization.

As this interview wraps up, a dog bark sound from his Amazon Echo informs Lea of his upcoming weekly video conference with friends and fellow advocates living with dementia — a remaining routine he looks forward to.

"We have a real hoot. We joke that if people were to listen in, they'd say 'These people are nuts!'" says Lea.

While questions remain about the longevity of the pandemic, Lea has held on to a core approach that predates COVID-19 in his day-to-day life, recommending others in similar situations do the same: find a hobby, stay busy and look for the bright side.

"There's always a light at the end of the tunnel," says Lea. "No matter how minuscule it is, it's up to you to make it brighter."


Paul Lea at his home in Toronto.

> "There's always a light at the end of the tunnel. No matter how minuscule it is, it's up to you to make it brighter." —**Paul Lea**

Facing page: iStock/FatCamera; this page: courtesy Paul Lea

HOW PERSON-CENTRED LANGUAGE CAN CHANGE LIVES

BY **Colin Gallant**

A new report from Behavioural Supports Ontario (in collaboration with Alzheimer Society of Ontario and Ontario Centres for Learning, Research and Innovation in Long-Term Care (CLRI) has made a compelling case for how person-centred language can improve the lives of people living with dementia, complex mental health issues, substance use and/or other neurological conditions, as well as their care partners.

Published in 2018, the report, which is based on existing literature and was created with insight from an expert panel, including people living with dementia, shines a light on the idea that language and health are inextricably linked.

What is Person-Centred Language?

At its core, person-centred language is an appropriate, respectful, life-affirming and inclusive way to communicate (verbally and non-verbally) with people living with dementia and other neurological concerns. It is language that focuses on seeing the *person* first rather than their condition.

"Rather than saying or regarding somebody in terms of being a dementia sufferer," says Kate Ducak, project officer for the Ontario CLRI at the Schlegel-UW Research Institute for Aging and one of the co-leads of the project, "you throw in those extra couple words to say 'person living with dementia.'"

> "Rather than saying or regarding somebody in terms of being a dementia sufferer, you throw in those extra couple words to say 'person living with dementia.'" —Kate Ducak

Why is it Important?

Not only does language contribute to building a culture of respect, it can also reveal unconscious assumptions and biases. By thinking critically about what words mean and how they are used, we shift from taking language's impact for granted to recognizing — and altering — its effects. For example, Ducak says that when care providers for people living with dementia engage with the concept of person-centre language, even a little bit, it can help them see past those biases and begin to view the people they care for in a more human and whole way.

This can mean that instead of deciding someone is difficult because of their responsive behaviour/personal expression, care providers can start to recognize and then respond to the person's unmet need behind the responsive behaviour/personal expression. Those results are wide reaching.

"By making that little change within themselves, it starts a ripple of change, and that is what some people call culture change," she says.

Benefits for People Living with Dementia

Person-centred language can reduce stigma and discrimination related to the disease, foster dignity and empathy, and ultimately result in more precise and effective care. A person exhibiting signs of dementia may be less reluctant to see a doctor when stigma is reduced; being seen as more than just your disease can build trust and self-esteem; and care workers who look at a wholistic picture of someone living with dementia are more likely to see and address the non-disease issues they face.

How to Practice It

The easiest way to start implementing person-centred language is to visit BehaviouralSupportsOntario.ca/Pledge, where you'll find both big-picture methodology and step-by-step instructions. You'll want to start with these four steps: See the Person First, Build Trusting Relationships, Consider All Forms of Communication and Advocate for Person-Centred Language (see graphic).

"It requires a lot of self-reflection," says Tina Kalviainen, strategic communications specialist for Behavioural Supports Ontario and co-lead of the project. "Person-centred language does require some work, and we have to unlearn what we've been using to make sure we respect the person first."

THE PRIDE IS PRICELESS

A Toronto woodworking program allows men living with dementia to build friendships and confidence

BY **Hannah Kost**

Calling all handymen! The Alzheimer Society of Toronto has found a way to put carpentry skills to good use with Men's Shed, an eight-week woodworking program for men living with early- to mid-stage dementia.

The program is named after an international social movement for men that originated in Australia with a mandate to "advance the well-being and health of their male members and to encourage social inclusion." Men's Shed with the Alzheimer Society of Toronto has a similar objective: to foster friendships and build confidence through craftsmanship. The program began last September thanks to a $34,800 Seed grant from the Ontario Trillium Foundation.

"Research showed me that older male adults are finding it more difficult to make new friendships or to maintain their friendships. Seniors report that after a dementia diagnosis, their circle of friends shrinks," says Tina Krliu, community programs coordinator with the Alzheimer Society of Toronto.

"[Men's Shed] seemed like the best way to encourage our clients to meet new friends, share their experience, stay productive and contribute."

At the time of publication, the program currently has between 10 and 12 participants who meet every Tuesday at the Toronto Tool Library's Makerspace. With a full arsenal of equipment at their disposal, the group works together to craft a variety of projects that include wine racks, lamps and keychain holders. Woodworking experience can vary, the classes are supervised by volunteers, and caregivers are invited to join in, too.

Meanwhile, the nature of project-building inherently inspires teamwork and the friendships organically follow.

"They help each other out, they share their skills, their knowledge, and they make new friends. The friendships are naturally occurring and happen by working together on a project and through that camaraderie," Krliu says.

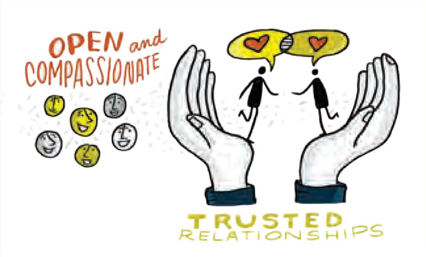
An added bonus for participants is that they have a physical manifestation of their capabilities to take home.

"It's very tangible. You've created this, and then you get home and you show your loved ones, 'Look, look what I did.' And everybody is amazed. They're praised for their success," Krliu says.

"We're bringing the self-esteem back to the men in our program, who [might] have been told that they can no longer use their tools because they have dementia. I think that pride when they see that final product is priceless. For me, it's heartwarming."

1. See The Person First

2. Build Trusting Relationships



3. Consider All Forms of Communication

4. Advocate for Person-Centred Language

Learn more at behaviouralsupportsontario.ca

Graphic courtesy Behavioural Supports Ontario; Men's Shed photo by Tina Krliu

THE ALZHEIMER SOCIETY OF CALGARY'S ADAPTATION TO COVID-19

The organization has put an emphasis on accessible resources and weathering the pandemic together

BY **Nathan Kunz** PHOTOGRAPHY BY **Jared Sych**

The Alzheimer Society of Calgary's Cindy Bond at her home in Calgary.

Like many organizations that regularly connect with clients in-person, the COVID-19 pandemic has created a period of major transition for the Alzheimer Society of Calgary. The Society is dedicated to offering support for caregivers, families and individuals living with dementia through day programs, workshops and gatherings, and the pandemic made it clear that in-person initiatives were too much of a risk. Instead, the Society moved quickly to create and add to its remote methods, adapting to the situation to continue its essential work for the population it serves — many of whom are older adults and particularly vulnerable to the virus.

"Staying connected and continuing to be adaptable is huge," says Alzheimer Society of Calgary Community Education Specialist Cindy Bond. "We're learning as we go and trying to stay ahead of the curve."

The non-profit acted fast as the pandemic began, with staff transitioning to working from home on remote initiatives. Central to the approach has been accessibility, with social workers fielding phone calls regarding questions and concerns for care, plus

**last name has been withheld at the request of the source* the addition of afterhours phone and Zoom video communication availability, Facebook Live chats and virtual support groups, which are now up and running.

For Theresa*, these resources have come in handy. Theresa has been active in Calgary's dementia community for several years, gathering information from events and publications to pass on to her father, who is the primary caregiver for her mother who is living with dementia.

Theresa says COVID-19 opened up new challenges for her mother, including heightened paranoia stemming from TV news coverage of the pandemic.

"As COVID began, my mom was becoming increasingly agitated," says Theresa, noting that watching the six o'clock news was previously a part of her parents' daily routine.

Out of concern, Theresa decided to make a call to the Alzheimer Society of Calgary, where a social worker suggested keeping her mother away from daily news coverage for the time being. After passing the advice along to her father, he came to the solution of recording favourite shows rather than watching live TV in order to help control media intake while still providing access to the programs she loves.

For Theresa, the ability to continue to access these avenues of support and figure out solutions, even if just temporary, has been empowering.

"It's a very potent form of communication. It can alleviate, remediate, mitigate situations and offer solutions," says Theresa of the direct communication option offered through Alzheimer Calgary. "It's [about] having a sense of purpose and taking action."

Elsewhere on the Alzheimer Society of Calgary site, resources such as webinars have replaced in-person events for the time being. While content is often tailor-made through listening to concerns, researching solutions and consulting expert community collaborators, Bond also notes the effectiveness of looking to locations like the UK and Germany to see how they're dealing with similar concerns. "Sometimes it's not reinventing the wheel," says Bond.

Day program adaptations have also been made. Activities like music, bingo and exercise classes offered through Alzheimer Calgary's day program, Club 36, have moved online through video calls, creating opportunities for socialization in a particularly isolating time. According to Bond, the day program staff have been able to regularly check in and interact with all of their members, and have delivered food to many, throughout the pandemic.

"What we do know from the research consistently is that mental health and physical health are directly impacted by isolation," says Bond. "Bringing [people] even closer into that community of care and heading that for them is truly our mission at this time."

> ["Bringing [people] even closer into that community of care and heading that for them is truly our mission at this time." —Cindy Bond]

With the uncertainty of the pandemic still in place, fluidity has been essential to the Alzheimer Society of Calgary's response. Though transition is not always completely smooth, Bond says a willingness to adapt and be there for the community remains at the core of the organization.

"We're not afraid to make mistakes, that's part of our growth and learning," says Bond. "We're trying new things and [watching if it] worked. And if it doesn't, we're on to something else. We're here, we're not going anywhere — we're in this together."

For more information, visit **alzheimercalgary.ca**

QUICK TIPS FROM THE ALZHEIMER SOCIETY OF CALGARY DURING COVID-19

- Stay connected with those who are close to you.
- Keep engaged by learning something new, exercising, maintaining routine and continuing to do things that keep you safe.
- Get groceries delivered.
- If worried, take action. Worry is only helpful if we can take action.
- Remember that we have more control than we realize, and we are all in this together.
- Educate yourself but limit media exposure — pick reliable sources for information.
- Be kind to yourself.
- Don't ignore your physical health (talk to your health professionals).
- Don't ignore your mental health (reach out to a health professional or a counselling agency).
- Plan ahead — get wills, Enduring Power of Attorney and Personal Directives updated or done. Plan meals and activities.
- Take a break and breathe. Find moments that give you peace.
- Help others if you can.
- Connect with us for tips and strategies around challenges.

MINDFULNESS & BRAIN HEALTH

……

Being in tune with your body and mind can have ample health benefits

BY **Jennifer Dorozio**

Mindfulness may be having a moment in popular Western culture today, but people have been utilizing this ancient practice and experiencing its various benefits for centuries. Many of the methods practiced in the West originated in Asia and may bring to mind visions of a Tibetan monk in seated meditation or someone performing the techniques of yoga or Aikido. A growing body of research suggests that practicing mindfulness can have a positive effect on anxiety, depression, the immune system and more.

What is Mindfulness?

In Western cultures, mindfulness is often a catch-all phrase that includes the idea of using mental techniques to increase awareness in the present moment. The practice involves focusing on your environment, bodily sensations and thoughts and feelings without placing judgement or expectations on them. Often the energy is on the breath. It is both a meditation exercise and a way of being that people can adopt into their lives. Being mindful can look like following a 10-minute guided meditation app, taking a yoga class, or simply being in nature with the intent to observe and clear the mind.

Mindfulness-Based Stress Reduction

Dr. Mabel Hsin is a medical doctor who began focusing on wellness care and mindfulness teaching full-time after seeing its powerful effects in one of her young patients. The patient, who was in his late twenties, was under pressure in his job and, as a result, battled with severe anxiety and gastritis. He had tried therapy, counselling and multiple medications with little effect and could barely get out of bed. As a last resort, he took part in an eight-week-long Mindfulness-Based Stress Reduction (MBSR) program. The effects were significant. Through the program, the patient began experiencing less pain and didn't need as much medication. He was also able to go outside again and developed the courage to leave his job and apply elsewhere. "It was just tremendous improvement," Hsin says.

Inspired, Hsin, who regularly practices Aikido, a form of martial

iStock/sergio34; iStock/amtitus; iStock/George Peters

MINDFUL MOVEMENT ***"Mindfulness is not just about meditation," says Hsin. You can bring mindfulness into almost any movement by being present in the moment. Activities like walking, dancing, running and more can be made "mindful" by noticing your breath, physical sensations and the environment without judgement or expectation.***

arts in which she holds a black belt, began training to teach MBSR in 2017. After becoming a qualified MBSR teacher in 2019, she made the decision to leave her clinical practice behind

The MBSR program was developed in 1979 by Jon Kabat-Zinn at the University of Massachusets Medical School in the U.S. Now taught across North America, the program is broken into weekly in-class two-and-a-half-hour sessions. Outside of class, participants also study the history of mindfulness, its health benefits and different types of meditation. The program's goal is to teach students how to handle stress by integrating mindfulness skills into their day-to-day lives.

Today, Hsin teaches MBSR to cardiac patients at the Southlake Regional Health Centre in Ontario, as there is a strong link between anxiety and an increased risk of heart attacks. She also works with Altitude HCM, which helps companies build healthy workplaces through assessing and developing emotional intelligence in their employees.

Mindfulness and Dementia

As mindfulness is linked to being good for your brain and body, there is some discussion about whether it could help delay, or prevent, the onset of dementia. Hsin believes that practicing mindfulness can alter a person's physiology for the better and says science backs up its benefits. "Not only am I seeing it first-hand, I'm also seeing the scientific data," she says.

For caregivers, who are under a lot of pressure and stress, a mindfulness practice can help them avoid burnout. It also teaches strategies for responding, rather than reacting, to challenges.

For people who are living with early-stage dementia and mild cognitive impairment, the practice may be useful for acknowledging complex emotional patterns they may be feeling and uncovering anxiety triggers in order to reduce stress.

Prevention Practice

When it comes to dementia prevention, Hsin says the study of mindfulness is fairly new, but there are known benefits that could improve overall brain health. Besides increasing general happiness, it is known to reduce anxiety, which is important as stress and anxiety are risk factors that may lead to a dementia diagnosis later in life. There is also preliminary research in the field of epigenetics, the study of gene behaviour, on stress reduction and how it affects gene expression in humans. While still relatively new, this research could potentially prove that taking measures to reduce stress and modifying other lifestyle factors, like diet and exercise, could determine whether or not dementia presents itself as people age. Lastly, mindfulness has been shown to slow aging in the brain, which means practitioners could potentially stay healthier longer.

MINDFUL BENEFITS

Here are some of the studied benefits linked to consistent mindfulness practice.

- Improved sleep
- Reduced anxiety and stress
- Increased brain functions like memory
- Better focus
- Better emotional regulation
- Feeling happier in life
- Decreased inflammation
- Healthier heart function
- Stronger immune function

THREE MEDITATION APPS TO TRY TODAY

1 **Headspace**
Includes hundreds of guided meditations for a variety of situations and needs.

2 **Calm**
Offers guided practices from two to 30 minutes long as well as seven-day to 21-day programs for beginners.

3 **Aura**
Allows you to personalize your meditations based on your mood.

PATIENT-ORIENTED RESEARCH IS CHANGING HEALTH CARE FOR THE BETTER

BY **Sam Gryba**

Photo courtesy Dr. Maria J. Santana

DR. MARIA J. SANTANA is passionate about patient experience. As a clinical pharmacist, health services researcher, patient and family-centred care scientist and assistant professor in the department of Pediatrics and Community Health Sciences at the University of Calgary, understanding what matters to patients and their families has always been the focus of her work. It also led to her role as the provincial lead for patient engagement for the Alberta Strategy for Patient-Oriented Research Support Unit (abSPORU), an initiative led by the Canadian Institutes of Health Research (CIHR).

First announced in 2011, SPOR is a national initiative that funds, develops and improves health-care policies through patient-oriented research. As part of the initiative there are 11 provincial and territorial SPOR SUPPORT units across the country including abSPORU.

What is Patient-Oriented Research?

SPOR defines "patient" as an all-encompassing and inclusive term to describe individuals who have personal experience with a health issue, as well as informal caregivers, including family members and friends.

Every individual has their own unique needs, values, and preferences. Health practitioners involved in patient-oriented research engage with patients to determine those specific needs, then examine the care that is currently available and modify it to incorporate those needs. Essentially, through SPOR, patients are invited to be partners in the research process.

"As a practitioner, as a clinician, there are a lot of things that we could do better, but there is only one way to make it better, and it's working with the patients and their families," says Santana. "We ask them, 'What is important to you?'"

How does AbSPORU work?

The Alberta SPOR SUPPORT Unit (AbSPORU) was created in 2013, and is jointly funded by Alberta Innovates and CIHR. Its research is supported by seven platforms including data, consultation and research services, pragmatic clinical trials, methods support and development, career development, knowledge translation and, lastly, patient-engagement, which Santana leads. Each platform provides valuable assets to the research, such as the development of training programs for researchers and health practitioners, tools to better analyze datasets, resources for patients for clinical trial participation and more.

The patient engagement platform is a critical aspect of AbSPORU, as one of its guiding principles is that researchers and health-care providers collaborate with patients and their families throughout the entire research process. As the provincial lead for patient engagement, Santana ensures this happens so that research results are always relevant to the patient.

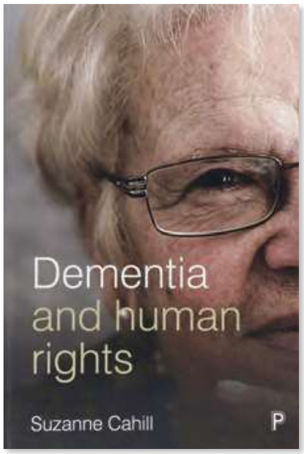
How does AbSPORU benefit people living with dementia?

Living with dementia can have a significant impact on quality of life. There are also social determinants to be considered such as access to care and housing. Patient-oriented research addresses these concerns by engaging with people living with dementia, as well as their families and caregivers. Currently, there are several provincial research teams supporting patient-oriented research in dementia. For instance, Santana's patient engagement team works with Dr. Carole A. Estabrooks, who is the scientific director of Translating Research in Elder Care (TREC) program. TREC is focused on developing solutions to improve the quality of care and life for residents living in nursing homes and the quality of work life for their paid caregivers. TREC also hosts a citizen advisory group made up of people living with dementia and their caregivers who contribute to all aspects of its research.

What else should you know about AbSPORU?

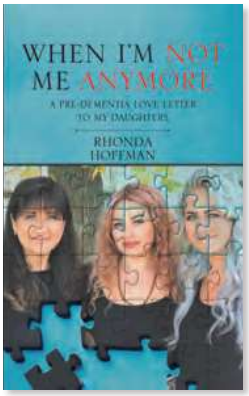
It is the goal of the AbSPORU Patient engagement platform to serve and connect communities across the province with researchers who are working to address what is important to them, says Santana. In Alberta, the patient engagement team recently launched an electronic platform called Albertans4HealthResearch to connect researchers and health practitioners with people and communities to work on patient-oriented research. This provincial network includes over 230 people in rural and urban areas. ■

4 BOOKS TO READ TODAY



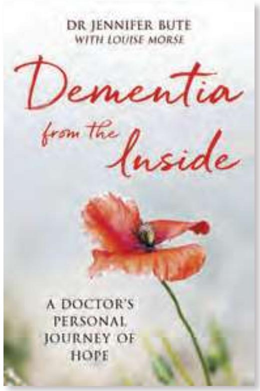
Dementia and Human Rights *by Suzanne Cahill*

The UN Convention on the Rights of Persons with Disabilities is a crucial tool to ensure that people with disabilities are afforded the same rights and freedoms as everyone else. Currently, dementia is not considered a disability, therefore, people living with it are not provided equal rights and freedoms. This concept is at the root of Professor Suzanne Cahill's book Dementia and Human Rights, *which uses human rights as a lens to explore the policy and practices currently in place for people living with dementia as well as what still needs to change.*



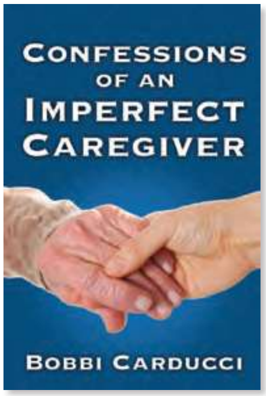
WHEN I'M NOT ME ANYMORE: A PRE-DEMENTIA LOVE LETTER TO MY DAUGHTERS *by Rhonda Hoffman*

Rhonda Hoffman spent years caring for her mother, Eileen, as she lived with dementia. The challenging and often painful experience served as inspiration for Hoffman's book *When I'm Not Me Anymore: A Pre-Dementia Love Letter to My Daughters*. The book is a road map filled with the knowledge Hoffman gained from the experience of caring for her mother. It is also an opportunity to chronicle her memories, feelings and thoughts with her two daughters in case she also one day finds herself living with dementia.



DEMENTIA FROM THE INSIDE: A DOCTOR'S PERSONAL JOURNEY OF HOPE *by Dr. Jennifer Bute with Louise Morse*

Dr. Jennifer Bute was working as a doctor in a large clinical practice that included people living with dementia, when she began to notice dementia-related symptoms in herself. In 2009, Bute was diagnosed with young-onset dementia. She resigned from her practice and began to learn whatever she could about how to slow the progression of the disease. Written with journalist Louise Morse, *Dementia from the Inside* is Bute's practical and inspiring account of what it's like to live with the disease. This book offers hopeful insight for people living with dementia.



CONFESSIONS OF AN IMPERFECT CAREGIVER *by Bobbi Carducci*

For seven years, Bobbi Carducci lived with and cared for her father-in-law, Rodger. During that time, she learned how to navigate the health-care system while supporting Rodger with his many health conditions, including schizophrenia, Parkinson's, age-related dementia and more. Her book *Confessions of an Imperfect Caregiver* chronicles those years with candour, humour and hope. Carducci's book is a reminder of the emotional and physical toll many family caregivers experience daily and highlights the compassion and love required to provide quality care.

Let’s speak up.

fix the funding formula

all-party dementia caucus

family care partner tax refunds or allowance

personalized care

single point of contact to navigate the system

family is an essential part of a care team

dementia inclusive communities

end the stigma

better post-diagnostic support

increase dementia specific skills and knowledge

It’s time to implement the National Dementia Strategy. Join us at:
www.dementiacanada.com

#MakeDementiaMatter

Dementia
Advocacy
Canada

Voices of Lived Experience

Q+A

Roger Marple shares personal tips for living well after receiving a dementia diagnosis

BY **Karin Olafson** PHOTOGRAPHY BY **Jared Sych**

WHEN ROGER MARPLE was diagnosed with Alzheimer's with vascular components at 57 years old, he was nervous about how others would perceive him. He felt ashamed and isolated himself. But, after experiencing frustrating encounters, such as being told hurtful dementia jokes and seeing a stranger at the grocery store checkout tell the cashier they were "having an Alzheimer's moment" while mimicking a seizure, Marple had had enough. For him, these encounters highlighted how many people believed dementia myths that perpetuated stigma.

So, the Medicine Hat local decided to speak up.

For the last five years, Marple has been an advocate for living as well as possible. A big supporter of dementia research, he's on the board of directors for the Alzheimer Society of Alberta and Northwest Territories and sits on the national advisory board for the Alzheimer Society of Canada. He's also active on Twitter, where he connects with research groups, organizations and communities working to improve life for people living with dementia.

Marple lives a full, busy life and inspires others not to isolate themselves or feel shame after a dementia diagnosis. Here, he shares insights and practical advice on how he lives life well.

Q | What's the first thing you recommend someone do after receiving a dementia diagnosis?

A | Getting a dementia diagnosis can feel very confusing, so I recommend people connect to First Link. It's a national program that helps individuals right after diagnosis connect with their Alzheimer Society to find support, learn about various services and get answers to any dementia-related questions. I also really like Dementia Advocacy Canada — it's bringing the dementia community together to speak openly and work towards common goals.

Q | Do you think that individuals should talk about their diagnosis?

A | Definitely. I've learned through experience that it's good to be open about your diagnosis rather than trying to hide it. Because I'm open, I've had people ask me questions about living with dementia. The conversation usually starts out with grief, but if I see a window, I'll change that conversation to a practical one. There are other times that I will just listen. Sometimes people need to vent. I'm okay with that and totally understand. It's led to some really positive and hope-filled interactions.

Q | Why do you feel that it's important to speak openly?

A | If we are going to achieve better funding for research and fight dementia stigma, it's going to be done by the voice of the many. The more we speak, the more positive change we'll see in a more expedited way. There are practical advantages, too. People that know I have dementia want to help me. For example, I frequent a restaurant and a waitress there knows I have dementia. When I leave, she scans my table to make sure I haven't forgotten anything. That kind of support makes your life easier.

Q | What can individuals do after a diagnosis to feel empowered?

A | Accept no one's preconceived definition of who you are living with dementia. Define yourself and what makes you who you are, [including] your hobbies, your interests and your relationships. I tend not to think about the challenges or how things will look down the road, and instead, focus on day-to-day life. I get involved in different things that have deep meaning for me — and I am busier now than when I was working! Keeping myself busy is important for me towards keeping my mind engaged in my day-to-day life.

Q | What tips do you often share to help others live well with dementia?

A | I helped the Alzheimer Society of Canada put together an information sheet with a range of practical memory aids, tools and day-to-day strategies. I use a combination of strategies and recommend people cherry-pick strategies that are relevant to them. For example, I've found the most powerful memory technique for me is visual: I hang my backpack on the door to remember it when leaving the house or I leave my laundry hamper in the middle of the living room so I won't forget to do my laundry. I also use technology and write notes for myself. [More details in sidebar.]

LIVING WELL WITH DEMENTIA: THREE PRACTICAL TIPS

GOOGLE HOME

Google Home is a voice-activated smart speaker. Marple tells Google Home to make note of important meetings or errands he needs to remember. Then each morning, the device provides a summary of the reminders relevant for the upcoming day.

TILE MATE

Marple puts this tiny Bluetooth tracker on items like his keys or in his bag. That way, he can track the item's location using the Tile app on his phone if he happens to misplace it.

WRITTEN REMINDERS

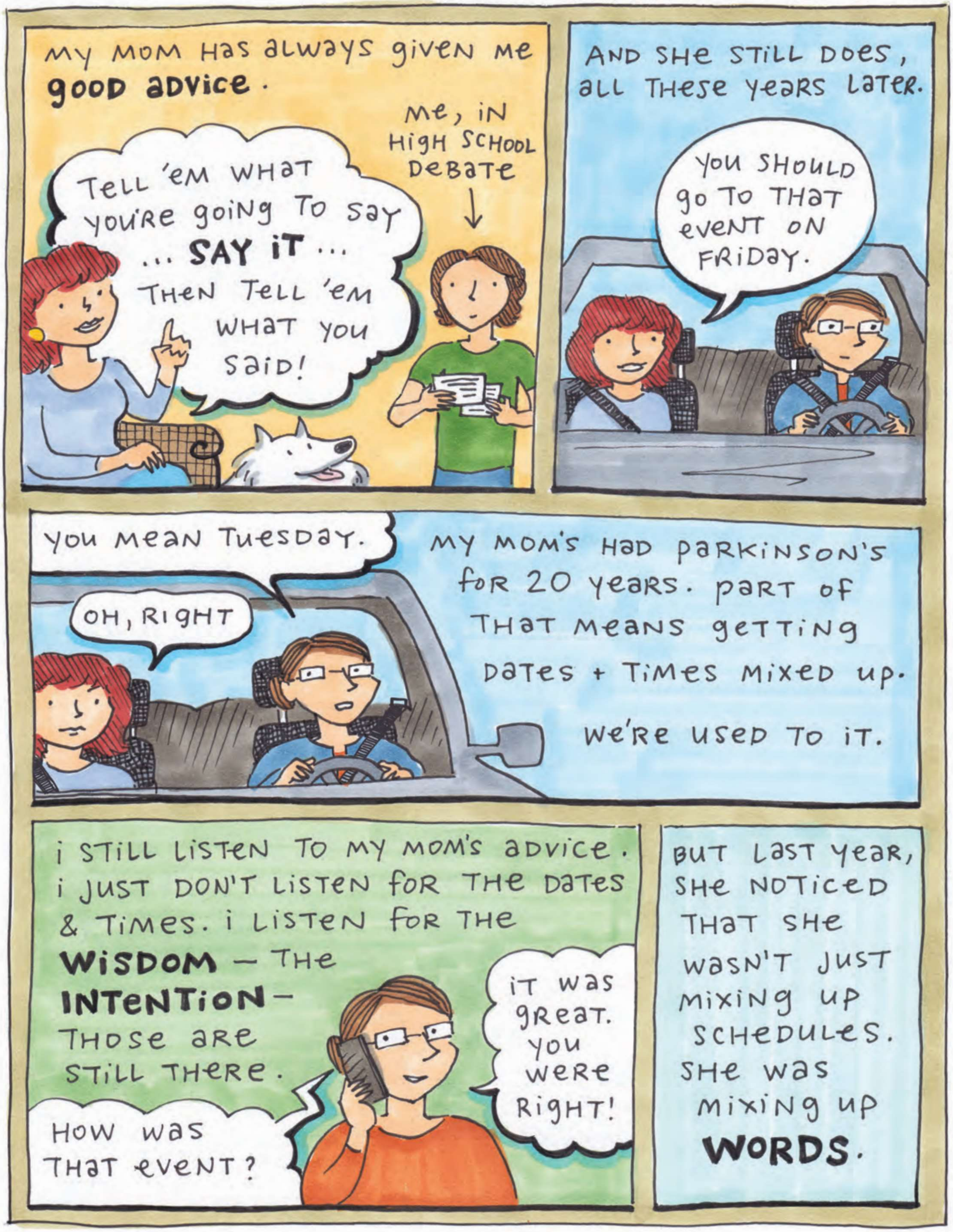
Marple writes reminder notes for himself on whiteboards and Post-it notes, but says erasing a note is just as important as writing it down. For example, he throws away a grocery list after the items have been purchased to avoid buying the same items again.

Share your questions with us at feedback@dementiaconnections.ca

Conversations with my *Mother*

ILLUSTRATIONS AND STORY BY Sam Hester

Sam Hester is a Calgary-based artist known for her vibrant and thoughtful comics. She is also a sought-after graphic artist and has created bespoke pieces for AHS, Dementia Advocacy Canada and many more. Jocelyn Burgener is mom to four children, including Hester, and "Nana" to six grandchildren. The 71-year-old served as the MLA for Calgary Currie for two terms, worked with the Calgary Chamber of Commerce and helped create the City of Calgary's Civic Arts Policy. In 2014, she wrote and self-published *Naked Under My Coat*, a book of poetry and prose. Burgener was diagnosed with Parkinson's in 2003 and lives in long-term care. In pre-COVID-19 times, she enjoyed Scrabble, bingo and connecting with friends and family, but these days she stays connected remotely through digital platforms. Hester shares their story here.


MY MOM HAS ALWAYS GIVEN ME **GOOD ADVICE**.
ME, IN HIGH SCHOOL DEBATE
TELL 'EM WHAT YOU'RE GOING TO SAY ... **SAY IT** ... THEN TELL 'EM WHAT YOU SAID!
AND SHE STILL DOES, ALL THESE YEARS LATER.
YOU SHOULD GO TO THAT EVENT ON FRIDAY.
YOU MEAN TUESDAY.
OH, RIGHT
MY MOM'S HAD PARKINSON'S FOR 20 YEARS. PART OF THAT MEANS GETTING DATES + TIMES MIXED UP.
WE'RE USED TO IT.
I STILL LISTEN TO MY MOM'S ADVICE. I JUST DON'T LISTEN FOR THE DATES & TIMES. I LISTEN FOR THE **WISDOM** – THE **INTENTION** – THOSE ARE STILL THERE.
HOW WAS THAT EVENT?
IT WAS GREAT. YOU WERE RIGHT!
BUT LAST YEAR, SHE NOTICED THAT SHE WASN'T JUST MIXING UP SCHEDULES. SHE WAS MIXING UP **WORDS**.


THE WORD JUST DROPS OUT OF MY CONSCIOUSNESS... AND I CAN'T BRING IT BACK TO LIFE AGAIN.
AT FIRST, I WAS DISMISSIVE
YOU JUST USED SOME PRETTY GOOD WORDS TO DESCRIBE YOUR "WORDLESSNESS"
BUT I GREW MORE CONCERNED WHEN WE VISITED THE EYE DOCTOR.
Q... Z ... P... X... J
A B C D E F G H I J K
THAT'S NOT A **VISION** PROBLEM. THAT'S A **COGNITION** PROBLEM!
SO... **DEMENTIA**? WHAT DO WE DO?
DOES A DIAGNOSIS EVEN MATTER?
NOT KNOWING IS TROUBLING. SO LET'S FIND OUT MORE!
YES– I WANT TO FIND OUT MORE. BECAUSE I STILL LISTEN TO MY MOM'S ADVICE.
AND THAT WAS THE FIRST CHAPTER OF OUR DEMENTIA STORY.
sh.

AMPLIFYING LIVED EXPERIENCE

Dementia Advocacy Canada's survey focuses on identifying and spreading what's working for Canadians right now

BY **Nathan Kunz**

Since its inception, Dementia Advocacy Canada (DAC) co-chair Mary Beth Wighton says the organization has worked to elevate voices of lived experience to the highest level of policy-making, inspiring real change in the process. DAC's recent online survey is an extension of its mandate.

"We never really have gone out and said to people living with dementia across Canada 'What's working?'" explains Wighton. "We need stuff now. And there's stuff working now. So, we just have to identify the things that are working now and get them out there."

DAC created the online survey to identify effective dementia-specific practices and programs in health-care systems across the nation available now.

Wighton, who was diagnosed with probable frontotemporal dementia in 2012, hopes to amplify perspectives of others living with dementia and care partners through the survey, leading to the potential spread of initiatives across the country. For example, if a program is identified to be working for someone living in Manitoba under their provincial health care, that insight could be more easily shared with Alberta policy-makers.

"We have to really cut through all those barriers and the silos and just say to everyone across Canada: if it's working, tell us about it. And if it's not working, tell us about it," says Wighton.

The five-question survey, which opened in November 2019 and takes roughly 10 minutes to complete, asks participants to relay information about different dementia-related practices, programs and resources they feel have been effective and ineffective. At the time of publication, the survey had been completed more than 1,000 times by Canadians living with dementia and care partners.

Wighton hopes the survey results spur real-time change for people living with dementia.

"To say there's something that's working in Nova Scotia, they've tried it in their different communities, and we can move it over to Southampton [Ontario] right now — that's powerful," says Wighton. "I just am so excited about where this is ultimately going to lead. It's going to change lives."

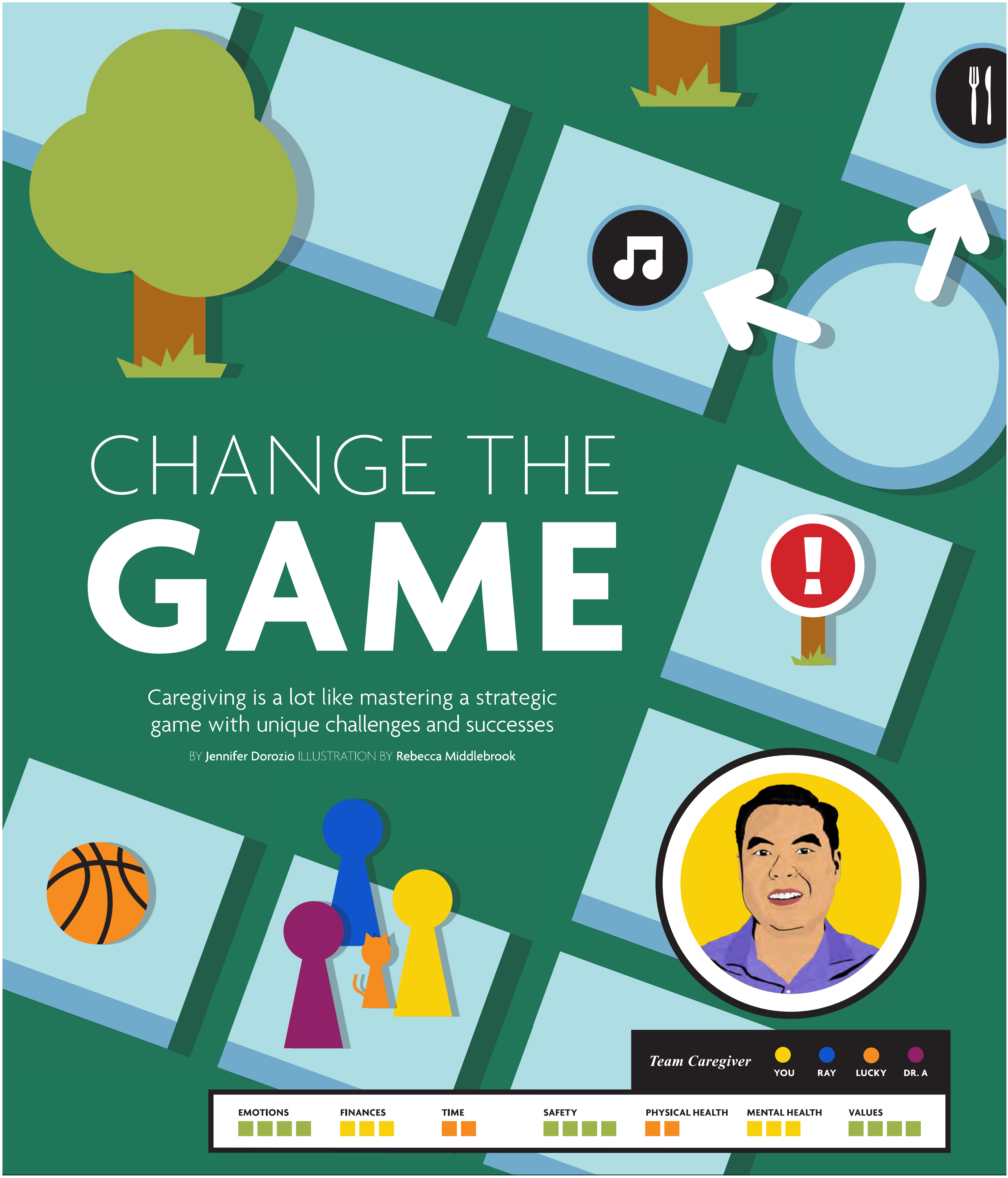
Initial results were gathered in May and are currently being evaluated, although the survey will remain open indefinitely for further completion and analysis. In order to ensure the best possible results, Wighton encourages everyone who hasn't yet to take part in the survey, either by completing it themselves or sharing it with anyone they know living with dementia or as a care partner.

As DAC continues to process survey results, Wighton says that individuals with personal experience will continue to be core advisors throughout the development and implementation of any future programs and services.

"This is about a team of people who want something to be the very best for people living with dementia, and care partners," says Wighton. "Every person on our team is important, and every person who does this survey is now considered part of our team."

Photo by Peter McNeice

To take the survey or review available results, visit dementiacanada.com



CHANGE THE GAME

Caregiving is a lot like mastering a strategic game with unique challenges and successes

BY **Jennifer Dorozio** ILLUSTRATION BY **Rebecca Middlebrook**

While caring for his father, only-child Ron Beleno quickly learned how exhausting and emotionally draining the work could be. His father, Reynaldo (Rey), lived with dementia for 10 years before passing away peacefully at home in Toronto in 2018. In the early years after his diagnosis, Rey still practiced a measure of independence — he took the bus and went for walks regularly. But one day, after a few years of living with dementia, he didn't return home from a walk and went missing for several hours. Ron called the police to help locate his dad safely, who had ended up nearby his former place of work. That jarring experience made Ron rethink his approach to caregiving.

"After that, I said [to myself], 'What do I need to help us take on this challenge?,'" he says.

Ron, who has always loved games — from video games to board games to sports – realized he could approach caregiving with the same strategic mindset he used to tackle a game.

> "We're all playing the same game, and the game is against the challenges that come with dementia." —Ron Beleno

"We're all playing the same game, and the game is against the challenges that come with dementia," says Ron.

Ron says the "gamification" of caring for his father helped with navigating the highs and lows of their years together more successfully. Here, he shares tips for gamifying the caregiver experience.

Get your head in the game

Dementia comes with many hurdles and can present a variety of obstacles, such as maintaining a person's safety, taking care of your own health, dealing with finances related to care and more. Instead of allowing yourself to be caught off-guard by these issues, start viewing them as obstacles to expect and prepare for.

"The shift is understanding that dementia is pretty much a game of challenges related to what each person wants in their lives," says Ron.

Work with your team

"Are you doing this as an individual superhero or as a member of a team?" Ron often asks the crowds in the caregiver workshops he speaks at in Canada and across the world. His point is you need support, and you will have more success when you're part of a team.

Ron's A-team included his father, his mother and their family cat, Lucky. He also purposely created the team to include health-care professionals, researchers, the Alzheimer's Society, local businesses and friends and neighbours.

"As challenges became heavier over time, [my dad's] ability to be a teammate became difficult, but it was my mom, myself and other team members who helped him and each other," says Ron.

Failures are opportunities

Nobody succeeds at everything all the time, and the inevitable failures that happen while caring for another person can provide valuable lessons.

"In the end, we're all going to have failures. But can those failures either be smaller failures [the next time] and can we get larger successes?," says Ron.

In the example of his father getting lost, Ron saw a learning opportunity and set up a safety net to support his dad to prevent it from happening again.

Set objectives

Most games, from soccer to Monopoly, have a clear objective: to win. While caregiving for another person, however, Ron says everyone's objectives will be different. The key is to start developing both personal and team goals, and then make choices that work toward them.

One major goal his family had was for Rey to age at home. Rey also wanted to stay socially active, continue to play music, cook and go out to restaurants. Ron achieved this by setting up their home to support his dad's wishes. The doors were equipped with chimes, while GPS tracking and support from neighbours and local businesses allowed Rey to continue to walk on his own safely for longer than expected.

Develop your skill set

Basketball players work on things like dribbling, defending and shooting to be successful. Similarly, caregivers need to develop their own arsenal of skills. Skills such as better communication techniques or learning how to advocate for patients are the types of things caregivers can cultivate.

Keep score

Ron says it was important to keep track of what he was investing his time, emotions and money in, and then monitor the return on that for his family.

"[At points during caregiving], my fear level was high, and my confidence was low. [I thought] what do I need to do to get better returns on that?," says Ron.

For Ron, the best investment was a GPS device that allowed his dad to walk safely alone. It gave Ron more peace of mind and offered his dad the ability to live well and continue to age at home.

PROTECTING *People*

The Decision-Making Capacity Assessment Model Toolkit honours patients first

BY **Sean P. Young**

Dr. Jasneet Parmar spent more than a decade developing the Decision-Making Capacity Assessment Model Toolkit (DMCA). This revolutionary resource, which was published online in 2019, is a practical, evidence-based guide that helps health-care workers document and assess, diligently and compassionately, a person's ability to make decisions for themselves. The toolkit's primary goal is to preserve autonomy, mitigate risk and assess decision-making capacity when it truly benefits the adult. For example, in terms of acknowledging the adult's decision-making capacity regarding where to live, the goal is to honour their preference, which is often to stay in their home for as long as possible.

Photo courtesy Dr. Jasneet Parmar

> "This is a clinical process based on legal and ethical considerations. It has really clarified what we as physicians and other disciplines need to undertake, and it protects the public." —Dr. Jasneet Parmar

The DMCA has been endorsed by Alberta Health Services and Covenant Health, the largest Catholic health-care provider in Canada. It has been adopted at hospitals, medical clinics, nursing homes and supportive living communities across Alberta.

"This is a clinical process based on legal and ethical considerations," says Parmar, an associate professor at the University of Alberta, AHS Medical Lead, Homecare and Transition, and the former Medical Director at Covenant Health. "It has really clarified what we as physicians and other disciplines need to undertake, and it protects the public."

A new process

Parmar began developing the DMCA for Covenant's Network of Excellence in Seniors' Health and Wellness in 2005. It was a collaborative effort with several key disciplines and stakeholders at the University of Alberta, and was created from years of consultation with a broad spectrum of care workers across the province. Back then, in order to determine if someone was incapable of making decisions for themselves, all a physician was required to do was fill out a simple one-page form. Then, if a person is legally declared "incapable," their ability to make decisions for themselves is taken away, and they can be moved from their homes to assisted living, often against their wishes.

The process seemed highly unethical to Parmar. From the consultations, it came to light that physicians, who were expected to provide these assessments, had no clinical process to follow, and their decisions could lead to the appointment of a guardian or trustee or the enactment of a personal directive.

"Other issues came to light, such as recognizing that people living with complicated medical conditions like dementia were at particular risk, as their decision-making capacity could be judged on hearsay or a test such as a MMSE (mini-mental status examination). There were system pressures to get these capacity assessments done to move patients to long-term care," Parmar says. "There were times when the personal directive would be established with the intent to enact it as soon as possible to get decisions made. As we explored these issues, a social worker reminded us that declaring someone lacking capacity is changing their legal status in society."

Having the ability to declare someone incapable of making decisions for themselves based on a short clinical visit and the word of a family member didn't sit well with Parmar. She set out to create a more compassionate clinical process that was people-centred and honoured the wants, needs, and desires of the person first. The DMCA model operates under the principles that "all adults are presumed capable of making their own decisions until the contrary is demonstrated" and that "the onus is on the assessor to demonstrate a lack of capacity, not on the patient or client to demonstrate capacity."

Exploring triggers

"With this model, we always look at if a capacity interview is even warranted," Parmar says. "The DMC assessment process needs to be followed before an adult is subjected to a DMC interview."

Parmar says the DMCA includes Capacity Interview and Capacity Assessment Process Worksheets that start with the triggers of why the physician is being asked to assess capacity. The worksheets help them determine if the person is making decisions that will result in significant harm to themselves or others. The DMCA process then thoroughly evaluates the person's decision-making capacity across seven domains (social, health care, legal, associates, accommodation, financial & estate, and education & work).

Parmar says one trigger that comes up frequently is someone's ability to manage their finances. She says families often ask for someone's capacity be assessed because they are worried about the financial choices their family member is making. But, sometimes, through the DMCA process, it is revealed that the person in question fully understands the consequences of their decisions.

"We should always try to honour people's values. We sometimes get very protective and want to move them to a safe setting to avoid risk. However, people may choose to live at risk," Parmar says. "A poor choice does not equate to lack of decision-making capacity. Everybody makes poor choices from time to time."

Determining values

Under the DMCA process, declaring a person incapable is only done after proper screening, including cognitive and functional testing, consultation with care team members, and when less intrusive and restrictive interventions fail to reduce risks. Parmar says establishing an enduring power of attorney and personal directive, covered under the Personal Directive Act in Alberta, while someone still has capacity is very beneficial. These legal declarations mean that the person's values are understood by everyone involved in their care. In the event they lose capacity, enduring power of attorney and personal directive ensure they still have an active voice in determining any future decisions.

"You should absolutely establish these while the person still has capacity," Parmar says. "It's quite a process to apply for guardianship or trusteeship after the person is declared incapable. It can add a lot of stress for the families involved."

The DMCA not only determines if someone is incapable of making decisions, it works to assess their financial picture, which is crucial in creating a plan for assisted living, should it be required. It can also help families better plan for safeguarding the person's finances, automating bill payments, or determining if they need to appoint a guardian, establish a trusteeship or instruct an enduring power of attorney.

"It's very important because you cannot do a capacity assessment without knowing what that person's finances look like and what legal agreements are already in place," Parmar says. "And if the person is taking risks and has capacity, then we need to support the adult and their family to help solve these problems. Trying to declare adults who are making poor choices as lacking capacity is not the solution in such situations."

DMCA'S BASIC OVERVIEW OF STEPS

1 Pre-assessment: The adult's attending team determines if there are significant triggers that merit an assessment. This is an action or inaction that could potentially put the adult at risk, such as failing to pay bills or regularly getting lost when taking a walk.

2 The team will determine if the patient is medically and psychologically stable before performing cognitive and functional tests.

3 If an adult's accommodation is in question, the health-care team, family and patient will brainstorm ways to continue to keep the adult safe in their home. This could include using GPS devices when taking a walk.

4 Only if the problem(s) cannot be resolved and the adult remains at unacceptable risk will the psychologist or a DCA (designated-capacity assessor) proceed with the formal capacity interview. ▣

DYNAMIC DEVICES

BY Sean P. Young

Two new technological innovations improving quality of life

The TELUS LivingWell Companion wearable device helps people age at home safely.

1

TELUS LivingWell Companion

Launched in 2018, the TELUS LivingWell Companion Personal Emergency Response Service (PERS) is a wearable device that offers access to 24/7 emergency assistance and optional fall detection. The service starts at $25 per month with no equipment fees and comes in "Home" and "Go" versions. The Go version includes built-in GPS and works anywhere in Canada with cellular service, while the Home version works inside the home and requires a landline.

In an emergency, users can press the call button to enable two-way communication with a trained operator who can contact up to three family members or friends and, if necessary, dispatch emergency services. When triggered, the optional fall detection feature automatically connects to an operator who will dispatch emergency services if there is no response.

"People living with dementia have a higher risk of falling, and, while family members make every effort to help [them], a fall or medical emergency can occur at any time," says Juggy Sihota, VP, Consumer Health, TELUS.

In 2019, TELUS acquired DirectAlert, a Quebec-based PERS company with more than 15 years of experience providing emergency response services across Canada. The acquisition makes TELUS the largest Canadian-owned provider of personal medical alert services, enhancing a key offering in its TELUS Health line of products, which includes virtual care.

"LivingWell Companion is one of TELUS Health's many services empowering Canadians to take control of their health," Sihota says.

Feedback from LivingWell Companion customers has been extremely positive.

"Some have expressed how it allows them to maintain an independent and active lifestyle and to continue doing the things they love while aging with dignity," Sihota says. "Others have told us it saved their life."

For more information, visit telushealth.com

This page: courtesy of TELUS Health; facing page: courtesy Steadiwear

2

Steadi-One

Steadi-One is a lightweight glove designed to reduce hand tremors. It uses the same earthquake-resistance technology found in high-rise buildings to stabilize the wrist and forearm while allowing for a full range of motion.

"We're seeing our customers gain their independence and confidence. They're getting back to doing the things they like best," says Emile Maamary, Steadiwear's (Steadi-One's parent company) CMO and co-founder.

Steadiwear's CEO and co-founder, Mark Elias, started working on Steadi-One more than three years ago. One winter afternoon, while Elias was visiting his grandmother for coffee, he noticed a slight shake in her hand. His grandmother has essential tremors, a condition that causes involuntary shaking. That day, as she took her first sip, her hands began to shake uncontrollably, causing her to spill her coffee and burn herself.

Shocked by this experience and at just how difficult daily activities were becoming for her, Elias consulted his aunt, a doctor who treats essential tremors. She told him treatment options were medications with side-effects, invasive surgeries, or botox injections, which all produced mixed results. Elias, a structural engineer by trade, was determined to find a better solution and began brainstorming ideas with his father, who is also a structural engineer.

"Mark's father specializes in high-rise structural damping for earthquake design," Maamary says. "They were able to expand this engineering application, and that's when Steadi-One was born."

Steadi-One combines a battery-free ball joint damper and a tuned-damper (steel rod that reduces the amplitude of mechanical vibrations) to stabilize the wrist and forearm when a hand tremor begins. Steadi-One has seen a success rate of 60 per cent in people who have used the technology and a clinical trial is currently underway to validate these claims. The device is registered as a Class I Medical Device in North America and has received grant support from both the federal and provincial governments in Canada.

Maamary says as sales continue to increase, Steadiwear's vision is to build a network of "assistive technology clinics" across North America where users can try before they buy as a way to continually improve the product.

"We want to make this as light and small and affordable as possible to help as many people as we can who are suffering from tremors," he says.

Steadi-One is a lightweight glove that stabilizes the wrist and forearm during a tremor episode.

To learn more, visit steadiwear.com

DID YOU KNOW? ***Sharing conversation virtually is nothing new to people living with dementia. Zoom (a video conferencing platform) has been a useful tool for social connection, information and resource gathering and educational opportunities long before physical distancing due to COVID-19 introduced it to much of the rest of the country. Zoom's blog has been featuring articles highlighting the benefits of the platform for people living with dementia as early as 2013.***

Available for free, Zoom is very user-friendly. It doesn't require a download and participants can join meetings by clicking on a link sent to their email accounts without an additional log-in. Besides Zoom, WhatsApp, Facebook Messenger and FaceTime are also free, easy-to-use video conferencing platforms.

FOR PEOPLE LIVING WITH DEMENTIA DURING THE COVID-19 PANDEMIC

01 Join a DAI online peer-to-peer support group today. www.joindai.org

02 Facetime, Zoom, or Skype with family and friends.

03 Follow ADI's up to date advice and resource page. www.alz.co.uk

04 Follow the World Health Organisation daily updates. www.who.int

05 Join your peers, family and friends at DAI's monthly Café Lé Brain & Webinars.

06 Contact your national Alzheimer's organisation.

07 Exercise daily.

08 Maintain physical distancing and stay safe.

Dementia Alliance International is providing additional support to members at this difficult time by hosting a number of extra online support groups and cafes.

Run by members, who themselves all live with dementia, DAI facilitates and provides these online peer-to-peer support groups and social groups for others with dementia through Zoom, for our members.

Like our membership, these and all other services provided by DAI are free. Anyone with dementia can join.

Online cafes, webinars and peer to peer support groups are ideal, especially now when we can no longer attend an "in person" group or event. Our Cafes and Webinars are open to everyone.

DAI

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

PAVING the *Way*

From comparing the effectiveness of therapies used in care homes to mapping the way metals interact with the brain, these Canadians are making waves in dementia research

BY **Elizabeth Chorney-Booth** PHOTOGRAPHY BY ◀ **Reynard Li and Carey Shaw** ▶

LEFT Dr. Jennifer Watt is a geriatrician at St. Michael's Hospital in Toronto. **RIGHT** A graphic based on Dr. Watt's study on effective treatments for people living with dementia, designed by Dr. Zahra Goodarzi (far right).

DR. JENNIFER WATT

Clinical research is important in the world of dementia care: having data based on how people respond to various therapies and methods of care gives medical professionals and caregivers real-world insight into how to best serve people living with dementia. But with so many researchers testing different approaches in different studies, it's nearly impossible to get a real handle on which therapies produce the most consistent results.

This is a problem that Dr. Jennifer Watt, a geriatrician at St. Michael's Hospital in Toronto and an assistant professor at the University of Toronto, set out to solve with a study that amalgamated data from 189 different research projects from around the world. Watt is the lead author on an October 2019 paper that compares the efficiency of both pharmacological and non-pharmacological interventions that deal with the complex behavioural and psychological symptoms of dementia. Specifically, Watt's systemic review looks at how effective each strategy is at addressing the symptom of agitated or aggressive behaviour in people living with dementia, which is often the result of an unmet need.

"Both myself and many of my colleagues have seen first-hand how different types of interventions can lessen symptoms of aggression or agitation, but we didn't have any good studies comparing the outcomes of medication and non-medicated treatments," Watt says. "That's why we embarked on the study that we did."

Watt's paper ranked the effectiveness of several potential interventions ranging from animal therapy (which ranked quite low) to outdoor therapy (the highest-ranking method on the list). Several drug treatments, like antipsychotics, ranked in the top third of the list. Still, given the potential side-effects of many of the listed medications, the ultimate finding is that caregivers should prioritize the high ranking non-pharmacological interventions such as massage, touch therapy and spending time outdoors.

Dr. Zahra Goodarzi, a fellow geriatrician and assistant professor at the Cumming School of Medicine at the University of Calgary, worked with Watt on the study. She designed an infographic depicting each treatment's efficiency so that caregivers can easily discern which interventions have had the most success, statistically speaking.

"We wanted to create something that would be useful," Goodarzi says. "The best part of it is that this is our best evidence. This is all of our knowledge distilled together and ranked."

Based on their clinical experience, both Watt and Goodarzi say they weren't surprised by how effective the non-pharmacological interventions ranked in the study. Based on first-hand experience, many care professionals

> "Both myself and many of my colleagues have seen first-hand how different types of interventions can lessen symptoms of aggression or agitation, but we didn't have any good studies comparing the outcomes of medication and non-medicated treatments. That's why we embarked on the study." —Dr. Jennifer Watt

What are the Effective Treatments *for* Agitation and Aggression in Persons Living with Dementia?

What were our steps for this study?

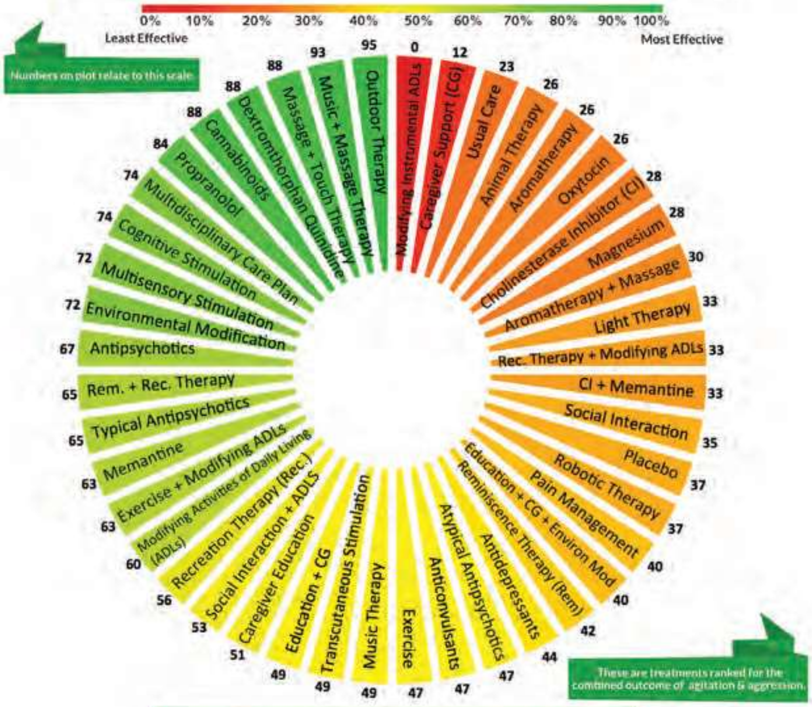
Step 1
Systematically searched and found *all* existing randomized trials

Step 2
Extracted all data from included studies

Step 3
Examined and analyzed all data comparing treatments

Step 4
Created a plot that ranks all treatments

Which treatments are best for agitation and aggression?



Numbers on plot relate to this scale

These are treatments ranked for the combined outcome of agitation & aggression.

What are the main findings?

This is the *first* study to compare data on medications and non-medication treatments for reducing symptoms of aggression & agitation in persons living with dementia.

Non medication treatments (e.g. outdoor therapy) and multidisciplinary care were *as or more efficacious* than medications for reducing symptoms of aggression and agitation.

There is no 'one size fits all' approach. This evidence helps persons living with dementia, care partners and health care providers choose therapies that are right for their specific situation.

Given the potential harms (e.g. stroke, mortality) associated with certain medications in persons living with dementia, our results suggest that multidisciplinary care and non-medication treatments (e.g. massage therapy, outdoor therapy) should be prioritized in treating symptoms of aggression and agitation.

Graphic and headshot courtesy Dr. Zahra Goodzari

> "We wanted to create something that would be useful, the best part of it is that this is our best evidence. This is all of our knowledge distilled together and ranked."
>
> —Dr. Zahra Goodarzi

have long advocated for a shift towards addressing the root causes of agitation and aggression by providing a sense of comfort and security through non-pharmacological therapies rather than eliminating those symptoms through drug interventions. But this is the first time that data has shown how effective these therapies are in comparison to medications. Watt is pleased that her study will validate what many caregivers have already been practicing.

"People have long believed that these non-medicated interventions work, we just never had the evidence to support what we believed," Watt says. "We can use this study to make a case for why we need to be using these non-pharmacological interventions clinically and why we need the resources to implement them successfully."


Kelly L. Summers is exploring how metals interact with the body.

KELLY L. SUMMERS

Kelly L. Summers doesn't specialize in matters of neurology, but she's working on research that may have a tremendous impact on the brains of people living with dementia. The PhD candidate from the University of Saskatchewan is most interested in the ways that metals interact with the human body, including how a metal imbalance can affect and impair brain function.

Summers' work is focused on the amyloid β peptide, a specific amino acid chain that can become misfolded in the brain, forming clumps on the outside of brain cells. These sticky clumps can trap metals, specifically copper, within them. Under the supervision of Drs. Ingrid Pickering and Graham George, professors at the University of Saskatchewan and Canada Research Chairs, Summers is studying how copper interacts with these peptides and how that interaction might contribute to the development of Alzheimer's disease.

Last year, Summers published a paper titled "X-ray Absorption Spectroscopy Investigations of Copper(II) Coordination in the Human Amyloid β Peptide." Summers and her team's findings may further our understanding of how the amyloid peptide binds to copper, which could indirectly predict how to remove the copper with drugs.

"One avenue that we explored is looking at how we could use some small molecule or drug that would be able to remove the copper where it's bonded with these peptides in the brain," Summers says. "There's been some promising results in mice where these drugs we've looked at seem really effective."

Summers isn't suggesting that the copper that binds to the peptides is completely responsible for Alzheimer's, but it could be part of a host of problems that contribute to the disease. Since the copper that sticks to the peptides is leached from other parts of the brain to create an imbalance, part of the research is to figure out how that imbalance may contribute to to the disease.

"This is one of the pieces of the puzzle and we know that the peptides shouldn't be there and the copper should not be stuck there," she says. "Whether that's happening because other things are going on or if it's the root cause of the disease, we don't yet know."

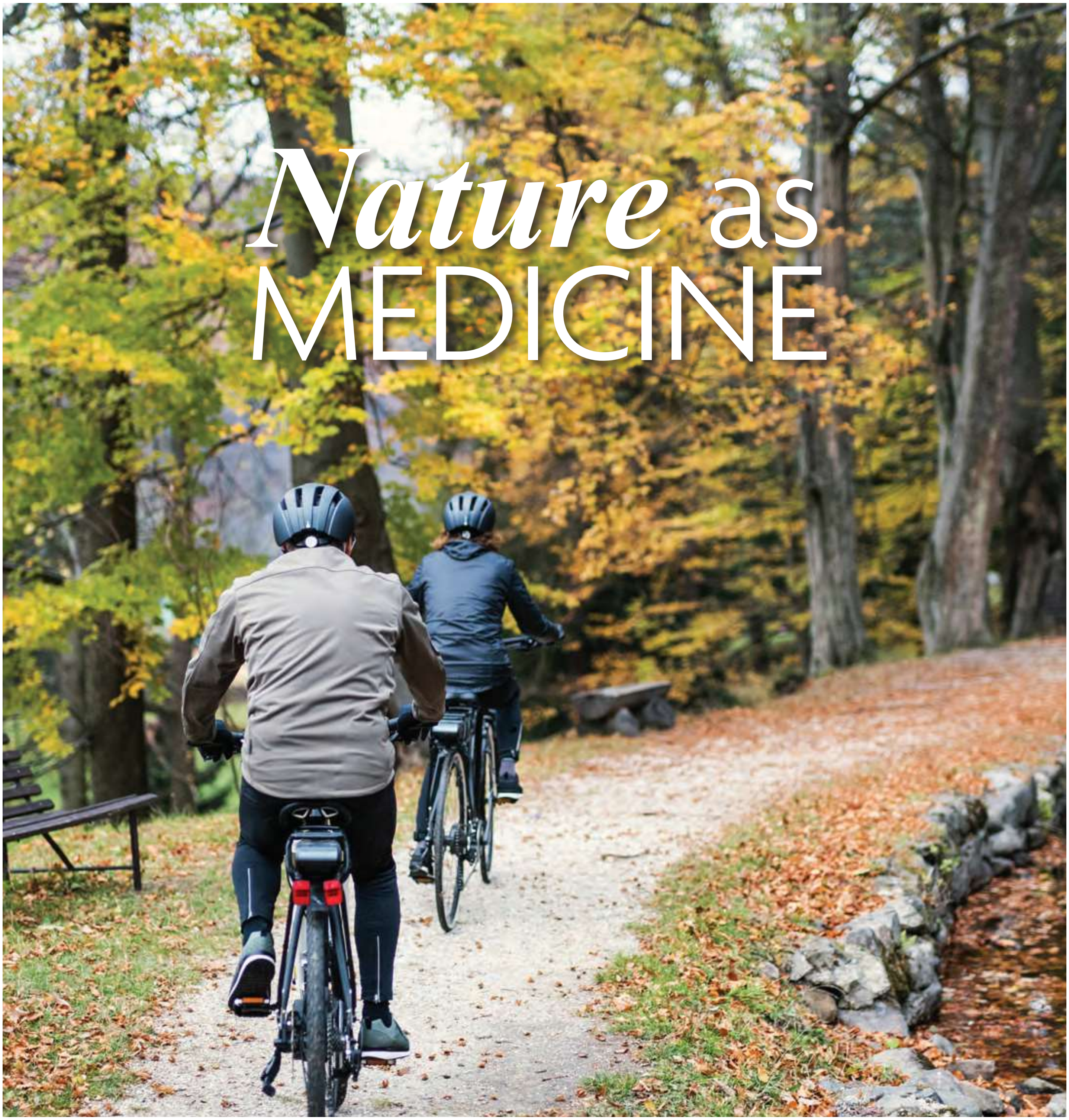
The ultimate goal is to develop a drug that either stops the copper from binding to these peptides or pulls the copper from the peptides to restore it to other parts of the brain.

In the lab, Summers is now working with an Alzheimer's model mouse and spectroscopy equipment, mapping out the copper in the animal's brain before and after it is treated with copper binding drugs. She is hopeful that the evidence from the mouse trials will help lead to a similar drug suitable for human use.

"There's some really interesting new evidence that shows that metals might have a role in how we store and form memories, so it makes sense to me that metals would have a significant role in the disease," Summers says. "If we can get those metals under control with some relatively simple drugs, it could have a fairly significant impact on slowing disease progression and making some of the cognitive symptoms less severe."

> ["If we can get those metals under control with some relatively simple drugs, it could have a fairly significant impact on slowing disease progression and making some of the cognitive symptoms less severe." —Kelly L. Summers]

Nature as MEDICINE



iStock/Halfpoint

Engaging with the outdoors, in both a rural and urban setting, is good for everyone

BY **Shannon Cleary**

Connecting with the great outdoors has a profound effect on human health. Studies show that a daily walk around the block can slow the progression of cognition decline. Sowing the ground that grows our food can influence and improve our eating habits. The babble of a running brook, the colours of a sunrise and other soothing scenes of nature are shown to reduce anger, fear and stress.

> ["It seems counterproductive that people living with dementia in an institutional setting or otherwise are not allowed to access the outdoors under the auspice of their safety." —Rebekah Churchyard]

The concept that engaging with nature benefits our physical, psychological and social well-being is hardly groundbreaking — bridging the gap between our natural and built environments has been a principle of good public policy for decades. With the proper access to it, a "prescription for nature" makes our communities healthier and people happier.

For people living with dementia, however, there are barriers to engaging with the outdoors in a safe and purposeful way. For example, pedestrian aids like crosswalks, which are designed to keep us safe, operate with the underlying assumption that everyone interprets the lights, buttons, signals and timers in the same way. In reality, crossing a busy intersection can be a dizzying and disorienting experience for someone living with dementia. While at an adult care centre, a vegetable garden may allow us to dip our fingertips in soil, but it can lack the purpose and productivity that really stimulates us and helps feed the human desire to fully engage.

Researchers are learning that improved and diverse opportunities for people living with dementia to engage with the natural environment can lead to better outcomes for individuals and their caregivers. But, providing these opportunities requires an understanding of how people living with dementia access the outdoors, what motivates a meaningful engagement with nature, and how health structures and policies in Canada can embrace alternative models of care to accommodate a population of our neighbours who are on the inside looking out.

Rural Connection

Rebekah Churchyard fondly remembers her grandfather's Christmas tree farm in Belwood, Ont. The rhythm of rural life was a familiar one to Churchyard and her family, who are still involved in the agriculture sector in southwest Ontario.

When her grandfather began experiencing signs of dementia in his mid-sixties, the disruption to his lifestyle and his sense of self was palpable. Churchyard and her grandmother, who was his primary care provider, quickly learned that the programs available for respite were concentrated in urban areas, hours away from the crops and silos that dotted her grandparents' familiar landscape. Churchyard also noticed that the programming was narrowly focused. Her grandfather struggled to derive meaning and enjoyment just (or solely) from activities like cards and bowling.

"There was very, very little programming with engagement with the outdoors," says Churchyard, who was studying social development at the time, specializing in gerontology and psychology. "He was very capable of working. It just wasn't safe for him to be operating [farm equipment]. But he could if he were supported."

Sadly, Churchyard's grandfather passed away at the age of 77. That sense of "something missing" in his care options inspired her volunteer work in social planning and project management. It also led her to research alternative concepts of care that would meet the needs of individuals like her grandfather, such as Green Care Farms (GCF).

GCF is a care model that uses farming practices and a connection with the earth to promote health and provide skill-building in diverse populations. Participants include people living with intellectual and developmental disabilities, people who are in recovery or transitioning back to community living, and — as piloted in places like the Netherlands — people living with dementia.

Currently, there are no such farms for people living with dementia in Canada,

RIGHT Rebekah Churchyard with her grandparents at their farm.
BELOW Rebecca Churchyard's grandfather, Ronald.

Photos courtesy Rebekah Churchyard

but Churchyard is dedicated to changing this. For the past few years, she has been working through the financial, legal and logistical complexities of bringing GCF for those living with dementia to Ontario. More important, Churchyard says, is to establish a sustainable, scalable system for GCFs in Canada.

"Access to the outdoors is a human right," says Churchyard. "It seems counterproductive that people living with dementia in an institutional setting or otherwise are not allowed to access the outdoors under the auspice of their safety."

Like Churchyard, Wim VanBeek and his wife, Anja, were inspired to open their own GCF when they discovered that much of the support for Albertans living with dementia was offered through institutions. Anja is a nurse with more than 25 years experience in home care as well as hospital settings and together, the VanBeeks are committed to improving the quality of life for people with dementia and disabiilties. The couple, who migrated to Canada from the Netherlands 12 years ago and have roots in farming, were already familiar with alternative care models like GCFs and identified that different options weren't available.

"How can we offer alternative care for the elderly and people with dementia so they can live longer in their current environment?" Wim says.

> “It’s about being exposed to nature, being active, eating healthy and adding value to the wellness of the client as well as the caregiver,” —Wim VanBeek

ABOVE **Wim and Anja VanBeek on their property in Northern Alberta.**

The VanBeeks eventually purchased a six-acre farmstead near their Northern Alberta community, and are currently in the process of converting their property to a GCF. While they’re still in the “proof of concept” phase, Wim imagines a typical day on the farm beginning with morning drop off, when clients and staff would gather to drink coffee and tea and prepare for the duties of the day. Tasks would then be divvied up: harvesting vegetables, weeding and planting, feeding the animals and more.

“Inspired by the dedication of caregivers, and our passion for economic development, our vision is to develop our hobby farm into a care-farm,” says VanBeek. “It’s about being exposed to nature, being active, eating healthy and adding value to the wellness of the client as well as the caregiver.”

Urban Connection

Whether we live in a remote community or an inner city, humans are equipped with a genetic need to connect with nature. Toronto-based urban planner Samantha Biglieri completed her PhD in Planning at the University of Waterloo in 2019. Her doctoral research focused on the importance of creating fully accessible, inclusive and meaningful spaces for people living with dementia. It included hours spent interviewing people with early-onset dementia on how they experienced their suburban neighbourhoods. Biglieri used GPS tracking to map the routes used by her volunteers. She accompanied them on “go alongs” to witness both the barriers they faced and the strategies they developed to overcome them. She was prepared to be surprised but was also impressed.

“They problem-solved,” says Biglieri. “For instance, participants used landmarks in different ways. ‘I turn right at the church’ or ‘I get off the bus when I see this bungalow.’”

NINE WAYS GREEN CARE FARMS (GCF) BENEFITS PEOPLE LIVING WITH DEMENTIA IN RURAL COMMUNITIES

① “Personhood” and remaining strengths are valued.

② Provides respite for care providers.

③ People can reside in their communities longer.

④ Supports agricultural industry.

⑤ Less time in passive or purposeless activities.

⑥ More physical effort can help with behaviours through using physical energy.

⑦ Rural community retains workforce in health care.

⑧ Improved physical, psychological and social well-being.

⑨ Participating in meal prep increases appetite.

> “There is a sense of independence and a sense of dignity that comes with being able to access your neighbourhood. People deserve to be able to go outside.” —Samantha Biglieri

These anchor points were sometimes distinct, like a brightly painted house or a garden of gnomes, or were common destinations, such as a hardware store or public library. Others held some sort of social connection: their children’s house, a recreation centre, or a coffee shop where the staff greets them by name. Even in older suburban communities that had similarly coloured homes, participants would still pick up tiny things in an environment of sameness, like a house with a leprechaun chair or a big red RV.

Participants would also go out of their way to avoid challenging experiences. During one “go along,” Biglieri recalled approaching a busy intersection with one of her participants and he explained why he didn’t use the controlled crossing: “He said, ‘There’s too much going on. I can’t deal with it,’” she says.

Instead, he crossed the road a few metres down from the flashing and beeping. To pay attention to one thing at a time, he crossed one direction of traffic, paused on the grassy median, and then crossed the other. Biglieri says participants would purposefully walk further, or on less direct side streets, to avoid too many inputs or startling sounds. Unfortunately, in some cases for people living with dementia, the solution eventually becomes to stay inside.

As an urban planner, Biglieri does see solutions in how we build and retrofit our communities in order to make them more accessible. For example, planning a grocery store within walking distance, building higher and denser instead of single and detached, slowing down arterial roads, creating commercial nodes within neighbourhoods and providing signs that lead to parks, shade and paths.

“There is a sense of independence and a sense of dignity that comes with being able to access your neighbourhood,” she says. “People deserve to be able to go outside.”

ABOVE, FROM LEFT Consciously planning accessible urban spaces allows more people to enjoy their neighbourhoods; easy-to-read signage with photos help make urban spaces easier to navigate.

BETTER URBAN DESIGN

Here’s how cities can evolve to better support people living with Dementia.

- Widen sidewalks.
- Paint raised sidewalks and level changes.
- Create shade canopies and rest stations with trees and frequent seating.
- Create easy-to-read signage with photos.
- Simplify intersections and plan pedestrian islands.
- Create unique designs for decision points, such has intersections, pathways and corners.
- Incorporate diverse age, ability and cultural groups in the planning and retrofitting of neighbourhoods.
- Revise land use plans and zoning to incorporate “dementia-inclusive” design.

Facing page: photo by Mies Van Beek; this page: iStock/South_agency; courtesy Lisa Poole

Level Up

Upskilling isn't just for professionals in the corporate world. For health-care workers, professional training and skill development is a chance to gain new knowledge and provide high-quality care.

BY **Karin Olafson**

FOR MANY, a toy car isn't worth a second glance. But for one Ontario health-care aide, who had recently completed training to learn new techniques for communicating with individuals living with dementia, noticing a toy car in his client's home was a game-changer.

The health-care aide (HCA), who had taken the Be EPIC person-centred communication training program, struck up a conversation with his client about cars. That conversation led to the client opening up about his physical needs for the first time, allowing the HCA to elevate the care he provided. But making this connection would have been much harder for the HCA had he not made an effort to upskill.

Canada's first national dementia strategy, released last June, states that having a "skilled workforce will… improve the quality of life of people living with dementia and caregivers." A skilled workforce is one that's continuously learning and incorporating current research and new, evidence-based best practices into their day-to-day work.

Upskilling — which is to say, teaching health-care workers new skills or providing training to develop skills that will enhance how they do their job — is essential in providing ongoing, quality care. Recent examples of upskilling across Canada have a common element: they're person-centred.

The Alzheimer Society of Canada calls person-centred care a relationship-based approach to caregiving. It's about care providers focusing on the needs of people with dementia, where care is "based on the values of dignity and respect, information sharing,

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participation and collaboration." It's about seeing people with dementia as people first, by going beyond their medical history.

Training the health-care workforce to think in this way means teaching soft skills that elevate relationship-building, communication and trust. These following businesses and post-secondary institutions are all providing new educational approaches to better prepare the health-care workforce to meet the demands of the future.

Be EPIC

Person-centred communication

BE EPIC is a person-centred communication training program created by Dr. Marie Savundranayagam, an associate professor in the Faculty of Health Sciences' School of Health Studies at Western University, and her research team out of that university's Sam Katz Community Health and Aging Research Unit. It aims to change the way the health-care workforce communicates with people living with dementia by training staff to focus on who the individual is, forging deeper, more meaningful relationships with their clients. The training is for health-care aides, or what Ontario calls personal support workers, and is made up of two sessions that total 10 hours of training, all taught by the Be EPIC research team.

Be EPIC integrates various theories, studies and evidence from the last 20 years, and is an acronym that reminds HCAs of the key elements that contribute to person-centred communication.

"E stands for 'environment' or surroundings, which offers lots of clues about the person with dementia's personal history, what matters to them, their likes and their dislikes," says Savundranayagam.

"P stands for 'person-centred communication strategies' meant to empower individuals with dementia to make their own choices and communicate them." For example, asking yes or no questions, or asking the person living with dementia to choose between two options. This type of questioning can be less cognitively taxing than asking open-ended questions.

"I stands for 'I matter, too.' That puts the focus on the caregiver. Sometimes there's a misunderstanding that person-centred care is all about the person receiving the care, but really, it's about the relationship," says Savundranayagam.

"C reminds caregivers to focus on the 'client.' Often they can tell you about what they like or don't like."

How is Be EPIC upskilling?

"We're [upskilling the workforce] so that they recognize their clients are persons with a wonderful, rich life history that needs to be acknowledged," says Savundranayagam.

BE EPIC QUICK FACTS

What's happening to upskill the workforce?
Be EPIC is a person-centred communication approach that teaches health-care aides to communicate with people living with dementia by creating meaningful relationships.

Upskilling health-care aides since: 2016

Where does training take place? At long-term care homes and care agencies across Ontario.

Number trained so far:
About 50 health-care aides.

COVID-19 AND THE VALUE OF PERSON-CENTRED CARE

By Be EPIC's Marie Y. Savundranayagam

IN THE BE EPIC TRAINING we start with the impact of both age-related and dementia-specific stereotypes on interactions with persons with dementia. A person-centered communication approach is foundational to all clinical care encounters and it is especially critical during a crisis. This approach values the dignity of persons with dementia and does not treat the most vulnerable among us as expendable. It values frontline staff, especially personal support workers, as key members of the health-care team and more importantly, as providers of meaningful social interaction and engagement for older adults. Our treatment of both older adults and the frontline health-care staff during the COVID-19 pandemic is a reflection of our existing stigmatizing views towards older adults. Let us use the lessons learned from COVID-19 to invest in the most vulnerable and progress as a society.

> ““We’re [upskilling the workforce] so that they recognize their clients are persons with a wonderful, rich life history that needs to be acknowledged.”
> —Dr. Marie Savundranayagam

“Caregivers can connect with the person by focusing on their identity and sense of self.”

Be EPIC also allows trainees to apply the communication skills they’ve learned immediately. During training sessions, learners interact with actors trained to respond in a similar way to someone living with dementia.

“We teach the trainees about the various communication strategies, and then we get into a simulated scenario,” explains Savundranayagam. “Then, the person who is engaging with the actor gets to reflect on [their reaction and response], and the actor comes out of character to talk about how they felt about the interaction. That [direct feedback] isn’t often something you get working in the field.”

Why is this important?

Savundranayagam and her team have found that Be EPIC participants are more confident communicating with people living with dementia compared with caregivers who haven’t taken the training.

“That’s important because, when workers are confident in their communication skills, then they are less likely to go into the encounter with fear or with stigmas,” says Savundranayagam. “They can address responsive behaviours and connect with the individual with dementia in a way that is meaningful to them.”

She adds that, with compassionate communication techniques, clients feel understood and listened to, increasing the likelihood of a reciprocal relationship and elevating the quality of care HCAs can provide.

AgeCare
Shifting the culture of care

IN 2018, the staff at AgeCare — a Calgary-based company that runs long-term care and supportive living communities for older adults in Alberta and B.C. — examined how they could improve the quality of life for all their residents, especially those living with dementia.

After learning from visiting experts at the Dementia Network

INSIGHT FROM AN AGECARE HEALTH-CARE AIDE

CHERYL BELLERAND, a health-care aide (HCA)who has worked at AgeCare Glenmore for 17 years, took AgeCare’s training program in 2019. She says the experience equipped her with the skills to further elevate the care she offers. Mainly, she’s learned how the language she uses every-day can influence her relationship with residents, and their families, and aid AgeCare’s culture shift.

“For example, we don’t use the word ‘diaper’ anymore,” says Bellerand, explaining that, instead, HCAs choose words that are more relatable and don’t feel humiliating or infantilizing for residents.

Bellerand says the training has given her the knowledge and confidence to encourage her coworkers and residents’ families to also examine the language they use and how it impacts residents. She draws from the training program to explain why it’s important to consider people with dementia as individuals and to choose certain words or actions to help them feel empowered. For example, when family members tell Bellerand they plan to visit to help her ‘feed’ a resident, she sees this as an opportunity to share what she’s learned.

“I tell them we try not to use that word anymore. Now, we assist residents with their meals,” says Bellerand. “I explain that we completed a training program and this [use of empowering language] is something we learned. We educate [families] when they come here to visit and they like that — families and staff have better relationships!”

The training reiterated to Bellerand that each resident is so much more than their dementia, but also that forging meaningful connections take time.

“Another thing I took away from the training program, and something I try to encourage among my coworkers, is to be patient,” says Bellerand. “If we have patience, HCAs will get more done and create more [of a relationship] with the residents.”

> "Families that visit and physicians that work in our dementia care neighbourhoods say they've seen a positive change in interactions between staff and residents." —Marilyn Willison-Leach

FACING PAGE EPIC founder, Dr. Marie Savundranayagam.

ABOVE, FROM LEFT Jennifer Grusing and Marilyn Willison-Leach with AgeCare.

Calgary's Dementia Re-imagined conference — including Claire Surr, a professor of Dementia Studies at Leeds Beckett University — and hearing feedback from AgeCare residents and their families, the business developed its own person-centred care model for residents living with dementia. This model doesn't have a name, but Marilyn Willison-Leach, senior-vice president, operations at AgeCare, calls it a company-wide culture shift.

"The important first step to take in shifting the culture and implementing our person-centred care model was to look at education," says Willison-Leach. "To achieve change, we had to [address] the knowledge, skills and attitudes that all our employees have toward people living with dementia."

How is AgeCare upskilling?

Instead of a formal, strictly classroom-style program, Jennifer Grusing, AgeCare's director, education and skills development, says AgeCare is taking an incremental educational approach.

"We wanted to develop an educational course that was going to stick," says Grusing, who created the program together with the AgeCare education and skills development team. She adds that all staff receive the training, not just those providing care. AgeCare educators created a five-module course, taught over five months, that helps staff absorb new information and then apply it. Registered nurses or licensed practical nurses who are in an educator role at AgeCare teach the course on-site.

"In the weeks in between each monthly module, staff have a workbook to read, questions to answer and can put what they learned into practice," says Grusing.

The course teaches employees about the personal, emotional and physiological factors that all play a role in providing compassionate, person-centred care. For example, one module touches on personal values, beliefs and stigmas. Another explores empathy and the importance of knowing a resident's life story and their interests. There's even a module on how dementia physiologically affects the brain. Grusing adds that the course design allows staff to interact with the course material through skits or by analyzing workplace interactions.

Why is this important?

Grusing and Willison-Leach both say the five-module training program provides staff with an in-depth understanding of life with dementia, helping them empathize with family members and connect with residents.

"Families that visit and physicians that work in our dementia care neighbourhoods say they've

AGECARE QUICK FACTS

What's happening to upskill the workforce? To help shift its care culture, AgeCare created a five-module course that teaches its staff about living with dementia and the various social, emotional and physical factors that go into providing compassionate, person-centred care.

Upskilling the workforce since: 2019

Where does training take place? For now, AgeCare is offering its education program at its seven communities that specialize in memory care; five are in Calgary, one is in Brooks, and one is in Strathmore.

Number of staff trained so far: 375 AgeCare employees.

Facing page: photo by Adela Talbot; this page: courtesy Jennifer Grusing

seen a positive change in interactions between staff and residents,” says Willison-Leach. “Mainly, I think [because of this culture shift], residents’ quality of life has changed because the primary focus has been put on their abilities.”

Bow Valley College

Training tomorrow’s health care aides

IN JANUARY 2020, Bow Valley College implemented the province’s new curriculum for its health-care aide (HCA) students.

The decision to update the provincial HCA curriculum came from the Government of Alberta, and the curriculum’s refresh was developed with input from government, educational institutions and industry representatives. Bow Valley College is one of the first post-secondary institutions in Alberta to adopt the updated HCA curriculum.

Doreen Stewart, the associate dean of applied health in the School of Health and Wellness at Bow Valley College.

How is Bow Valley upskilling?

Previously, the HCA curriculum was four months in duration. Now, students study this curriculum for eight months before graduation.

Doreen Stewart, the associate dean of applied health in the School of Health and Wellness at Bow Valley College, says students now have time to learn more theoretical content in-class. They spend more hours in the lab, where theory is put into practice in a simulated environment. Students also complete more clinical hours in a real health-care setting.

Specifically, students now spend 69 more hours in lab and obtain 120 more hours of in-clinic practice hours before entering the workforce. Students also spend 21 more hours learning theory related to the complex care they will provide as HCAs. These theoretical, in-class enhancements are peppered throughout the eight months of training.

“The course updates [focus on] cultural competency and sensitivity, reflection on our own perspectives, and development of communication skills to support diverse populations,” says Stewart. “And across all courses, there is an enhanced focus on developing person-centred communication strategies for individuals with dementia.”

Why is this important?

The enhanced curriculum will better prepare HCAs entering the workforce, as they’ll be armed with up-to-date theoretical tools and significantly more hands-on experience before graduating.

“Having a better understanding of some of those complex care needs will definitely improve the resiliency of the HCA workforce,” says Stewart. “And improved resiliency means they can better meet their clients’ needs without fatigue, stress or burnout. Our HCAs will be more work-ready upon graduation.”

> “Having a better understanding of some of those complex care needs will definitely improve the resiliency of the [health-care aide] workforce.” —Doreen Stewart

BOW VALLEY COLLEGE QUICK FACTS

What’s happening to upskill the workforce? The new provincial HCA curriculum has doubled in duration. During the enhanced eight-month certificate program, students learn more theory and complete more lab and clinical hours before joining the workforce.

Upskilling the workforce since: Bow Valley College’s first cohort began classes in January 2020.

Where does training take place? As well as running at Calgary’s Bow Valley College, any Albertan post-secondary institutions that deliver the HCA program will have to use the new, updated curriculum moving forward. **Learn more about any course changes due to COVID-19 at bowvalleycollege.ca**

Photo courtesy Doreen Stewart

Matthew Dineen outside of the St. Patrick Fallowfield Church in Ottawa.

Keeping the faith

Dementia-inclusive guidelines for faith centres help foster all aspects of well-being

BY **Elizabeth Chorney-Booth**

When Matthew Dineen's wife, Lisa, was diagnosed with early onset behavioral variant frontotemporal dementia in 2013 at the age of 43, the couple and their three children were shocked and devastated. Lisa moved into a long-term care home shortly after her diagnosis. Dineen, who lives in Ottawa, had been involved with dementia advocacy before Lisa's diagnosis and, after her diagnosis, he was a driving force behind the creation of Canada's national dementia strategy. He also became a member of Dementia Advocacy Canada (DAC), a grassroots group of people living with dementia and care partners.

As Dineen worked to champion, advocate for and support Lisa, he became aware that while doctors and caregivers were addressing her physical well-being, another very important part of who she is as a person wasn't necessarily being acknowledged. As practicing Catholics, the couple often turned to their faith to guide them through life, but after Lisa's diagnosis, Dineen found that many places of worship in Canada were not particularly dementia-aware.

When Susan Rae, a DAC member from Whitehorse, reached out to the organization for information on how she could make her local church more accessible to people with dementia, Dineen realized there were no current standardized guidelines for faith centres that wished to better serve the dementia community in Canada. So, in the spring of 2019, Dineen began to write a set of dementia-inclusive faith centre guidelines to share on the DAC website. For guidance, he largely turned to other countries including the United Kingdom and the U.S.

"There are no unified programs or guidelines in Canada," Dineen says. "For Lisa, even from a young age, church was like a second home. Why should people be made to feel like they don't belong when they have dementia? Being dementia-friendly is really about being valued and being allowed to participate in the religious community in any way they can."

Dineen is exploring how faith centres can reduce the stigma around dementia, clearly indicate that members with dementia are welcome at services, better communicate with people who

Photo by JVL Photography

may have trouble with memory and language, and offer personalized support to people with dementia and their caregivers. In working on these guidelines, Dineen has sought the advice of experts from around the world, who have helped him to identify strategies to assist faith leaders to make their centres safe and healthy environments for everyone.

Inclusivity within places of worship

Dementia inclusion in the United Kingdom is a bit further ahead than it is here in Canada. Charlotte Overton-Hart, an associate with Livability, a British disability charity that connects people with their community, says that about one in five churches in the U.K. have explicitly mandated measures to support parishioners with dementia and their caregivers. Within a church or other place of worship, this may mean ensuring that any signage can easily be interpreted by members with dementia and that buildings are physically accessible. It also includes specifically inviting parishioners with dementia and their caregivers to dementia-inclusive events like afternoon teas or coffee groups.

Overton-Hart differentiates between faith centres that are dementia-inclusive (taking measures to integrate those with dementia into the faith community) and dementia-specific (creating programing directed specifically at those with dementia), noting that people may appreciate one approach over the other depending on their individual circumstances. There's room for both, and centres should offer as many options as possible to be truly dementia-inclusive.

"Part of it is about articulating an invitation to people living with dementia so that they feel particularly welcome," Overton-Hart says. "If there's a service or a lunch club that specifically states it is dementia-inclusive, people may feel encouraged to keep coming as a regular member or even to come in for the first time."

Creating a sense of belonging

Being overtly inclusive is important, but places of worship also have a responsibly to not just include people with dementia, but to make them feel like valued members of the community. Many care experts already agree that a genuine sense of belonging created through meaningful relationships can be hugely beneficial to a person with dementia's well-being. Since many people

with dementia find themselves lonely or isolated after their diagnosis, places of worship can provide both practical human interaction as well as a deeper sense of spiritual belonging.

Professor John Swinton, a well-respected theologian, registered mental health nurse and the chair in Divinity and Religious Studies at the University of Aberdeen in Scotland, says that faith communities have a tremendous opportunity to practice the core tenants of their faith by going out of their way to embrace members with dementia. Swinton says this can be done by emphasizing elements like music and touch during services, but faith leaders should also reinstate the often-forgotten practice of reaching out to those with dementia via personal visitation.

"Going out and visiting people is just as important as drawing them in," Swinton says. "So many people, particularly with advanced dementia, are living in care facilities and are not able to get to a formal service. If you have a structure where people from the church or faith centre formally visit people, it reconnects them with the community. That's a tremendous gift for people to feel like they haven't been forgotten."

> "Faith transcends words, you don't have to use words to feel it or express it. People know when you're present with them and when you're assuring them of God's presence with them." —Kathy Fogg Berry

This page from left: courtesy Charlotte Overton-Hart; courtesy John Swinton; facing page: courtesy Lynda Everman

Inclusion through liturgical vestments

For some people living with dementia, the key that unlocks their connection to their faith might not be the words written in a book or spoken at a service, but something more visual or tactile, like a pastor's stole or a rabbi's tallit. With this in mind, Lynda Everman, author, editor and founding member of ClergyAgainstAlzheimer's, and her husband, Don Wendorf, have embarked on a project in which Everman crafts liturgical vestments, like stoles and tallit, for clergy to wear to signify their dedication to dementia inclusion. They call it the "Alzheimer's stole ministry and tallit initiative" and their work is documented in their book *Stolen Memories: An Alzheimer's Stole Ministry and Tallit Initiative.*

The colourful garments can be individualized to reflect the religious leader's own memories and touchstones while also increasing awareness around the importance of dementia inclusion. When clergy visit with people with dementia, the garment can spark stories and help develop connections.

FACING PAGE, FROM LEFT Charlotte Overton-Hart is an associate with Livability in the U.K.; professor John Swinton, a well-respected theologian from Scotland, encourages home visitations.

THIS PAGE, FROM LEFT Examples of garments from the Alzheimer's stole ministry and tallit initiative; **BELOW** Chaplain Kathy Fogg Berry's book is a guide for person-centred spiritual care.

Since 2018, Everman, who is based in Birmingham, Ala., has made almost 100 personalized stoles and tallits. She encourages other faith communities to start making them as well to spread the message of dementia inclusivity.

"To me, fabric does hold memories," Everman says. "When clergy wear their Alzheimer's stoles and [tallit], it sends a message of support to families facing dementia. It helps bring dementia out of the shadows so that we can talk about it and take action to mitigate the challenges posed by this difficult disease."

When words fail

As a long-time chaplain in American long-term care and hospice settings, Kathy Fogg Berry has seen first-hand how spirituality can bring meaning to the life of a person living with dementia, even if that person no longer has the ability to express that spirituality in words. Fogg Berry's book *When Words Fail: Practical Ministry to People with Dementia and Their Caregivers* is a guide for faith leaders looking to offer person-centred spiritual care.

Fogg Berry recommends that care facilities assess the spiritual needs of residents so that they can provide personalized services — be it prayer, theological readings, rituals, or spending time in nature — to make sure the person's spiritual needs are being met even if they're unable to articulate those needs. Even if the person is no longer verbal or able to remember certain things, the recognition of their faith can be very valuable.

"Our faith transcends words, you don't have to use words to feel it or express it," Fogg Berry says. "People know when you're present with them and when you're assuring them of God's presence with them."

Through connecting with these experts around the world, Dineen has learned that the way people connect with their faith communities is complex. He hopes to publish a set of dementia-inclusive guidelines for places of worship in Canada on the DAC website later this year.

"We are spiritual beings as much as we are physical beings," Dineen says. "We are connected to something greater than ourselves. Some people find that in the environment, for others it may be religion, but the spiritual part of the person is always there. And that's why this is so important."

> "We are connected to something greater than ourselves. Some people find that in the environment, for others it may be religion, but the spiritual part of the person is always there. And that's why this is so important." —Matthew Dineen

COMPOUNDING *Care*

What happens when both your parents have dementia at the same time?

BY **Julia Williams**

When Mary Huang fractured her foot at the end of 2019, it was a health crisis — but not for her. In her time-consuming care role for her parents, who both have dementia and other medical issues, Huang simply didn't have space in her life for an injury.

Huang's parents, Peter and Anna, were both diagnosed with mixed Alzheimer's disease and vascular dementia between 2017 and 2018. At the time, Huang, who is in her 50s, worked as a travelling consultant with major tech companies. When her parents received their diagnoses, she had a more flexible schedule than her brother and sister and no dependents, leaving her to take on the majority of care.

Huang is one of a small but growing demographic of Canadians who are caring for multiple family members with dementia at the same time. Caring for one person with dementia is a significant challenge, and caring for more than one compounds the responsibilities, as well as the stress, emotional load, logistical considerations and expenses.

How do you keep track of two (or more) people's medical issues, get them to appointments and act as their advocate? How do you find an appropriate living situation for your parents when their needs aren't the same? How do you navigate care options? What if family members with dementia pose risks to each other? Can you cover the cost of residential care, in-home care, medical support equipment and your own lost wages? How do you manage the distress, confusion and anger your family members with dementia may feel? How do you manage your own?

In June 2019, the Public Health Agency of Canada released its first national dementia strategy, a vision that will see the government spend $50 million over five years to advance dementia prevention, care and support and reduce stigma in this country. One of the strategy's areas of focus is to build the capacities of family/friend caregivers by supporting them through initiatives like tax credits (which already exist in some provinces) and improving their access to resources like dementia training, community supports and information about the health-care system. The strategy doesn't appear to mention caregiving situations where one person is caring for multiple family members with dementia, and this seems like an oversight.

Today, approximately nine older adults are diagnosed with dementia every hour in Canada, and that number will only rise. In 2014, people 65 and older represented 15.6 per cent of Canada's population, but population projections estimate older adults will make up 23 per cent of Canadians by 2030. The likelihood that a person may have two living parents who need dementia care in the future is increasing.

> "The emotional toll is tremendous. I felt split in two. Sometimes they needed care in different locations, and I felt like I had to choose between them." —Mary Huang

Lorrie Beauchamp's parents, Marcel and Beverly, were both diagnosed with dementia between 2013 and 2015. Marcel had a

Facing page from top: courtesy Ottawa Citizen, a division of PostMedia Network Inc., reprinted with permission; courtesy Mary Huang

Anna and Peter Huang are both living with dementia.
INSET Mary Huang is the primary caregiver of her parents.

mild form of vascular dementia and remained fairly independent, but when Beverly's Alzheimer's disease proved aggressive, the situation changed. At the time, Beauchamp, who today is a medical researcher and writer in her early 60s, had plans to semi-retire to Vancouver Island. Instead, in 2015, she put her career on hold, sold her Montreal condo and found an apartment two minutes from her parents' house in Laval, Quebec.

At first, Beauchamp planned to find her parents a suitable long-term care residence, but they were deeply attached to the home they'd shared for 45 years. What's more, Beauchamp, who is an active member of Dementia Advocacy Canada, was disturbed by the institutional nature of the dementia care units she visited.

"That's when I started to realize how inhumane the environment is for our seniors generally, and for people with dementia in particular," Beauchamp says.

It was decided: Marcel and Beverly would continue to live in their home, eventually requiring round-the-clock care. Beauchamp has four siblings, but like Huang, she was the one with the most flexible career and no children. She spent the next five years as her parents' primary carer.

Canada's dementia strategy reports that family/friend caregivers spend about 26 hours per week supporting a person with dementia and spend, on average, $4,600 per year on out-of-pocket care-related expenses. Add another person with dementia, and these numbers double (at minimum). Nor do the out-of-pocket expenses calculated here — which cover transport to medical appointments, prescriptions and household items, for example — account for the considerable cost of professional in-home care and long-term care fees.

When Beauchamp's mother began to need round-the-clock care, Beauchamp couldn't provide it alone. She hired in-home personal care workers to cover nights, and it cost her family more than $100,000 per year. She learned that Quebec offered tax credits for 35 per cent of these expenses, but upon closer inspection, she realized this was not the boon she'd hoped for. The annual limit for a dependent senior is $25,500, for a maximum tax credit of $8,925 per year — less than 10 per cent of the family's care expenses.

Huang, too, was astonished by the high cost of professional care. When she first researched options, she discovered that a private retirement home for both her parents would cost upwards of $10,000 per month. "That's $120,000 a year," she says. "How many families can afford that?"

She decided she would be the primary caregiver, despite the fact this would mean putting her career on hold. Because her parents' Ottawa home was no longer practical, given their medical needs, Huang managed the sale of their house and found them a single-level condo, where she could care for them with the help of in-home personal support workers.

Hiring support proved easier in theory than in practice. Unlike hospital or physician services, home care services are not publicly insured through the Canada Health Act; these services are delivered by for-profit and non-profit providers that differ from province to province. Some home care workers offer medical support and others only offer non-medical services, such as domestic help and cooking. Huang says the personal care workers she hired through agencies were usually casual part-time employees with multiple jobs. Turnover was so high that Huang had four different workers in six months. Some workers would visit for as little as 15 minutes and some didn't show up at all.

Canada's dementia strategy describes personal care workers as an integral part of the care team, but it acknowledges what Huang observed: staffing shortages, low wages and irregular work hours impact quality of care. Beauchamp learned that some agencies didn't provide any training (let alone dementia-specific training) and paid their workers only $12 to $14 per hour with no benefits, while charging clients more than double that amount. "People are getting paid more to clean your home," Beauchamp says.

Huang settled her parents into their condo with the intention to eventually find a long-term caregiver to move in with them and find another condo in the same building for herself. A few days before the sale of their house closed, Peter had a stroke that left him paralyzed

THIS PAGE Lorrie Beauchamp's parents, Marcel and Beverly.
FACING PAGE Lorrie with her mother.

on his right side. Now his needs were too significant for Huang and personal care workers to manage; he needed a long-term care facility. Through previous research, however, Huang knew that the wait-list system in place in Ontario would prove difficult to navigate. The median wait time for a bed for people coming from the community is more than 160 days. As Huang managed this setback, Peter was becoming increasingly upset about the loss of his independence, and he often directed his anger at her. To further complicate matters, Huang realized Anna was trying to care for Peter, neglecting her health and forgetting important details — most significantly, that Peter could no longer swallow solid food. Huang would have to separate her parents for their own safety.

During this time, tensions rose between Huang and her siblings, who she felt didn't offer reliable back-up support even as her care responsibilities became overwhelming. Huang was spending 60 to 70 hours each week caring for her parents, and it never felt like enough.

"The emotional toll is tremendous," she says. "I felt split in two. Sometimes they needed care in different locations, and I felt like I had to choose between them."

By spring of 2018, Huang was burnt-out. One day, she was pulled over in traffic while driving with her mother, and after a 10-minute conversation with the officer, she was handed a ticket and the number of a crisis line. She phoned, but it didn't give her the help she really needed: relief, even for a few hours, from her care responsibilities.

For Beauchamp, there were days she would come home and collapse, sobbing. Her siblings were a great source of support, but nonetheless, she struggled with anxiety and feelings of resentment, especially during the first year. She was responsible for endless administrative tasks: medical appointments, finding and managing nighttime care, researching government support programs and figuring out how the family would afford round-the-clock care. The house required ongoing attention too: repairs, accounting, grocery shopping and cleaning. All the while, Beauchamp was putting on a brave, positive face each day despite the sorrow of watching her mother lose her memories and her ability to speak. And, because Beverly needed so much support compared to Marcel, Beauchamp sometimes worried that he wasn't getting enough.

"It's the hardest thing I've ever done," she says. "I don't know how people survive this."

Beverly died peacefully at home, surrounded by family, at the end of 2018, and Marcel, now 93, is still in good health. Beauchamp, relieved of her full-time caring role, is living in Sooke on Vancouver Island — but she still feels the effects of those five years. Even now, every time Beauchamp's phone rings her heart starts pounding.

"Everything got hardwired into a form of PTSD," she says. But it wasn't her parents' illnesses that sent her into this state of crisis; it was the ongoing stress of caring for them with inadequate information and support. Beauchamp documented her caring experience in a blog called *Unforgettable*. In one post, she writes: "Alzheimer's is not sad. Dementia is not tragic…it is what we make it." She says if she had those five years to do all over again, she'd make it all about laughter, fun and silliness. Those things, rather than the myriad practical and logistical considerations, could and should be the focus of dementia care.

> "The two-parent scenario is going to become something that families will have to deal with." —Lorrie Beauchamp

Huang's parents are stable at the moment, her siblings have increased their support and her foot is healing. She regularly has joyful family meals with Peter and Anna. Like Beauchamp, it's not the disease she blames for the challenges of the last few years, it's a lack of clear strategy and communication of essential information.

"It's a very difficult system to navigate," Huang says. "People don't know the true choices they have."

The creation of Canada's national dementia strategy is a step in the right direction, but for Huang and Beauchamp, it's too little, too late. Beauchamp worries that it could be too late for her entire generation.

"The two-parent scenario is going to become something that families will have to deal with," she says.

A CLOSER LOOK AT LONG-TERM CARE

The transition into long-term care is a challenging one. Gathering as much information as possible can help smooth the way. Here, with the help of the Alzheimer Society of Canada's long-term care checklist, find some of the essential questions to ask before making the move.

Before Visiting

- Is the home subsidized by the government, or are you required to pay out of pocket?
- Are there specific units for people living with dementia?
- Are there additional costs for dementia care, and is the home upfront about what those include?
- Does the home offer tours, and is it easy to book one?
- Is there a waiting list for residents? Are there rules about who may receive priority on the waiting list, such as someone in a crisis situation?
- Is the home accredited and inspected regularly? Can you have access to a copy of the most recent report?

While Visiting

- Is the location convenient to access and visit?
- Is it clean and presentable, and does it feel welcoming?
- Are there quiet spaces for residents to meet with visitors?
- Is there clear signage to help residents navigate the space?
- Do residents have easy access to secure outdoor space?
- Do residents seem engaged and active?
- How many residents are there to a room?
- Are the bathrooms private or shared?

Staff Considerations

- Is staffing consistent, so that residents and staff can get to know one another?
- Do staff members treat residents with respect, empathy and compassion? Do they speak to residents like adults or children?
- Is the staff trained to support people living with dementia, and if so, what is the care approach?
- Is there a doctor on call?
- With the resident's consent, does staff regularly and consistently share information with family members?
- Is palliative care provided?
- Do staff members work between multiple care homes?

For more information, including the full long-term care checklist, visit alzheimer.ca.

DEMENTIA-RELATED
Services and Resources
for Calgary and Surrounding Area

GLOSSARY OF TERMS

Best Friends Approach™
Based on the concept of friendship; easy to practice and to understand.

Butterfly Household Model
A licensed care approach that includes increased staff levels, based on the concept of treating people with dementia as feeling beings.

C.A.R.E.S.
Incorporates U.S. national dementia care recommendations, features real-life scenarios, recognized by the U.S. Alzheimer Association.

Dementiability Methods
Methods are applied to help people with dementia function at their highest level.

Eden Alternative
Animals, plants and children are incorporated into the environment to provide engagement, meaningful activity and loving companionship.

Gentle Persuasive Approach (GPA)
An evidence-based training program that helps care providers deliver person-centred, compassionate care with a focus on four key areas: personhood, the brain and behaviour, the interpersonal environment, and gentle persuasive techniques.

Complex Dementia Care
Use of specialized approaches for individuals with complex behaviours associated with dementia.

Person-Centred Approach
Individual interests and abilities are the primary focus of care.

PALS
A not-for-profit pet program that brings animals into long-term care facilities.

P.I.E.C.E.S.
Based on the belief that responsive behaviours are words, gestures or actions that people with dementia use to express unmet needs.

Positive Approach to Care (PAC)
Care strategies and techniques integrate what is known about brain function and changes with therapeutic approaches to foster positive outcomes. Emphasizes the value of human connection when verbal communication and interaction skills are altered.

Supportive Pathways
Provides individualized, whole-person care in a supportive environment.

United Minds
Dedicated program facilitators tailor activities to abilities and interests to promote socialization and active participation.

WanderGuard
A tracking application designed to prevent persons at risk from leaving a building.

For more information
Best Friends Approach™ bestfriendsapproach.com | **Butterfly Household Model** dementiacarematters.com | **C.A.R.E.S.** hcinteractive.com/CDS | **Complex Dementia Care** bethany.com | **Dementiability Methods** dementiability.com | **Eden Alternative** edenalt.org | **Gentle Persuasive Approach** ageinc.ca | **P.I.E.C.E.S.** pieceslearning.com | **Person-Centred Approach** albertahealthservices.ca/assets/about/scn/ahs-scn-srs-aua-person-centred.pdf | **Positive Approach to Care** teepasnow.com | **Supportive Pathways** carewest.ca | **United Minds** unitedactiveliving.com

Subsidized: Please seek referral from Alberta Health Services Community Care Access at (403) 943-1920 or 8-1-1
Private Pay: Please contact facility for pricing and availability
$ = Less than $2,500/month $$ = $2,500-5,000/month $$$ = More than $5,000/month ***Confirm pricing with individual facilities**

RESIDENTIAL

FACILITY NAME	CONTACT INFO	PRIVATE	SUBSIDIZED	PRICE	CARE APPROACH	NOTEWORTHY
AgeCare Glenmore 1729 – 90 Avenue SW	agecare.ca/glenmore 403-253-8806		●	$	Person-Centred; Best Friends Approach™; Eden Alternative; P.I.E.C.E.S.; Supportive Pathways	Pet visits; secure outdoor garden
AgeCare Midnapore 500 Midpark Way SE	agecare.ca/midnapore 403-873-2600		●	$	Person-Centred; Best Friends Approach™; Supportive Pathways	Intergenerational child-care program; pet visits; secure outdoor garden; private-pay suites for spouses
AgeCare Seton 4963 Front Street SE	agecare.ca/seton 587-349-8444		●	$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet visits
AgeCare SkyPointe 179 Skyview Circle NE	agecare.ca/skypointe 587-619-1900		●	$	Person-Centred; Specialty Mental Health; Non-Violent Crisis Intervention	Intergenerational childcare program; cultural dining and activities; pet visits
AgeCare Walden Heights 250 Walden Drive SE	agecare.ca/walden 403-873-4700		●	$	Person-Centred; P.I.E.C.E.S; PAC	Intergenerational childcare program; pet visits; private-pay apartments for spouses
Amica Britannia 750 – 49 Avenue SW	amica.ca 403-476-8992	●		$$$	C.A.R.E.S.; Person-Centered; Best Friends Approach™; Well-Being Model (integrates elements of GPA, PAC and more)	Pets welcome; multigenerational programming; WanderGuard
Auburn Heights Retirement Residence 21 Auburn Bay Street SE	allseniorscare.com 403-234-9695	●		$$-$$$	Person-Centered	Age-in-place; pets welcome
Bethany Harvest Hills 19 Harvest Gold Manor NE	bethanyseniors.com 403-226-8200		●	$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Secure outdoor area; purpose-built for people with moderate to severe dementia
Bethany Riverview 200, 2915 – 26 Avenue SE	bethanyseniors.com 587-392-3999		●	$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Purpose-built for people with complex dementia care needs
Bow Crest Care Centre 5927 Bowness Road NW	reveraliving.com 403-288-2373		●	$	Dementiability Methods	
Brentwood Care Centre 2727 – 16 Avenue NW	intercarealberta.com 403-289-2576	●	●	$		Bistro on site
The BSF Bow View Manor 4628 Montgomery Boulevard NW	theBSF.ca 403-288-4446	●	●	$-$$$	Supportive Pathways	WanderGuard; long-term care
The BSF Clifton Manor 4726 – 8 Avenue SE	theBSF.ca 403-272-9831		●	$	Supportive Pathways	Long-term care; secure outdoor area; smoking permitted
The BSF Wentworth Manor 5717 – 14 Avenue SW, Calgary	theBSF.ca 403-242-5005	●	●	$-$$	Supportive Pathways	Age-in-place (multi-levels of care); secure outdoor area

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Carewest Colonel Belcher 1939 Veteran's Way NW	carewest.ca 403-944-7800		●	$	Supportive Pathways	Priority to veterans; secure outdoor area; smoking permitted
Carewest Garrison Green 3108 Don Ethell Boulevard SW	carewest.ca 403-944-0100		●	$	Supportive Pathways	
Carewest George Boyack 1203 Centre Avenue NE	carewest.ca 403-267-2750		●	$	Supportive Pathways	
Carewest Rouleau Manor 2206 – 2 Street SW	carewest.ca 403-943-9850		●	$	Supportive Pathways; Complex Mental Health Care	Smoking permitted
Carewest Signal Pointe 6363 Simcoe Road SW	carewest.ca 403-240-7950		●	$	Supportive Pathways; Complex Mental Health Care	Dementia-specific design; smoking permitted
Chartwell Eau Claire Care Residence 301 – 7 Street SW	chartwell.com 403-269-3114	●	●	$-$$		WanderGuard; secure memory living; couples may live together
Chinook Care Centre 1261 Glenmore Trail SW	intercarealberta.com 403-252-0141	●	●	$		
Evanston Grand Village 40 Evanston Way NW	evanstongrand.ca 403-274-6416		●	$	Supportive Pathways	Secure outdoor area; music and arts programs
Evergreen 2220 – 162 Avenue SW	reveraliving.com 403-201-3555	●		$$	Best Friends Approach™	Pets welcome
Extendicare Cedars Villa 3330 – 8 Avenue SW	extendicarecedarsvilla.com 403-249-8915		●	$	PAC; Supportive Pathways; Best Friends Approach™	Couples may live together; outdoor courtyard; PALS; WanderGuard; accept various levels of dementia; smoking permitted
Extendicare Hillcrest 1512 – 8 Avenue NW	extendicarehillcrest.com 403-289-0236		●	$	PAC	Couples may live together; intergenerational programming; PALS; Roam Alert
Father Lacombe Care Centre 270 Providence Boulevard SE	fatherlacombe.ca 403-256-4641		●	$	Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational programs; memory care
Holy Cross Manor 70 Evanspark Manor NW	covenantcare.ca 587-230-7070		●	$	Person-Centred; Supportive Pathways	Couples may live together
The Journey Club Seniors' Residence at Westman Village 176 Mahogany Centre SE	westmanvillage.com 403-313-5478	●		$$$	Butterfly Model; Person-Centred	Ground floor; secure neighbourhoods and outdoor area; age-in-place
Manor Village at Fish Creek Park 22 Shawnee Hill SW	themanorvillage.com 403-918-2127	●	●	$$-$$$		Age-in-place; in-house doctor; 24/7 nursing; all levels of care
Manor Village at Varsity 40 Varsity Estates Circle NW	themanorvillage.com 587-393-9999	●		$$-$$$		Memory care; pet friendly; couples may live together; balance tracking technology
Mayfair Care Centre 8240 Collicutt Street SW	mayfaircarecentre.com 403-252-4445		●	$	Person-Centred	Smoking facility

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McKenzie Towne Care Centre 80 Promenade Way SE	reveraliving.com 403-508-9808		●	$	Dementiability Methods	
Millrise Seniors Village 14911 – 5 Street SW	retirementconcepts.com 403-410-9155	●	●	$$-$$$	Supportive Pathways; Person-Centred	Independent and assisted living; near Fish Creek
Monterey Seniors Village 4288 Catalina Boulevard NE	retirementconcepts.com 403-207-2929	●	●	$	Supportive Pathways	
Mount Royal Care Centre 1813 – 9 Street SW	reveraliving.com 403-244-8994		●	$	Dementiability Methods	
Newport Harbour Care Centre 10 Country Village Cove NE	parkplaceseniorsliving.com 403-567-5100	●	●	$-$$$	Resident-Centred Care, GPA	Multi-sensory robotics; lakefront location
Prince of Peace Manor and Harbour 285030 Luther Rose Boulevard NE	verveseniorliving.com 403-285-5080	●	●	$-$$	Supportive Pathways; Best Friends Approach™	Secure outdoor area
Prominence Way Retirement Community 905 Prominence Way SW	prominencewayretirement.com 403-727-9400	●	●	$$$	Supportive Pathways	Age-in-place; dementia care, music and art programs
Providence Care Centre 149 Providence Boulevard SE	fatherlacombe.ca 587-393-1350		●	$	Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational programming; memory care, SL4 and 4D care
Revera McKenzie Towne Retirement Residence 20 Promenade Park SE	reveraliving.com 403-257-9331	●	●	$-$$$		Secure outdoor area
Rocky Ridge Retirement Community 10715 Rocky Ridge Boulevard NW	rockyridgeretirement.com 403-930-4848		●	$	GPA; Person-Centred; Supportive Pathways	Secure outdoor area; momentum tracking
Sage Hill Retirement Residence 6 Sage Hill Gardens NW	allseniorscare.com 403-455-2273	●	●	$-$$	GPA; Best Friends Approach™	Age-in-place; pets welcome: swimming pool
Silvera for Seniors - Beaverdam Community 2012 – 66 Avenue SE	silvera.ca 403-279-4623		●	$	Best Friends Approach™; Company-specific	Tailored to early stage dementia; independent living Silvera townhomes adjacent; Active Aging programs
St. Marguerite Manor 110 Evanspark Manor NW	covenantcare.ca 587-955-9788		●	$	Person-Centred; Supportive Pathways	Couples may live together
St. Teresa Place 10 Redstone Place NE	covenantcare.ca 587-619-7116	●		$	Complex Dementia Care	Secure outdoor area; age-in-place; intergenerational progamming
Scenic Acres Retirement 150 Scotia Landing NW	reveraliving.com 403-208-0338	●	●	$-$$	PAC; Supportive Pathways	Secure outdoor area; pets welcome
Southwood Care Centre 211 Heritage Drive SE	intercarealberta.com 403-252-1194	●	●	$	Butterfly Model	
StayWell Manor Village at Garrison Woods 174 Ypres Green SW	themanorvillage.com 403-242-4688	●		$$-$$$	Best Friends Approach™	Assisted living; memory care; enhanced care; palliation; respite care; rehab programs

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Swan Evergreen Village 2635 Eversyde Avenue SW	originway.ca 587-481-6638	●		$$-$$$	Person-Centred	Intergenerational programming; age-in-place; secure outdoor area; couples live together; AHS funded studios
United Active Living at Fish Creek 51 Providence Boulevard SE	unitedactiveliving.com 587-481-7907	●		$$	United Minds	Secure outdoor area
United Active Living at Garrison Green 3028 Don Ethell Boulevard SW	unitedactiveliving.com 403-685-7200	●		$$$	United Minds	
Whitehorn Village Retirement Community 5200 – 44 Avenue NE	originway.ca 403-271-2277	●	●	$	Best Friends Approach™	Monthly alzheimer support group
Wing Kei Crescent Heights 1212 Centre Street NE	wingkeicarecentre.org 403-277-7433		●	$		Chinese language & culture; age-in-place
Wing Kei Greenview 307 – 35 Avenue NE	wingkeicarecentre.org 403-520-0400		●	$		Chinese language & culture; age-in-place

OUT-OF-TOWN RESIDENTIAL

FACILITY NAME	CONTACT INFO	PRIVATE	SUBSIDIZED	PRICE	CARE APPROACH	NOTEWORTHY
AgeCare Sagewood 140 Cambridge Glen Drive, Strathmore	agecare.ca 403-361-8000		●	$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet visits; private-pay suites for spouses
Aspen Ridge Lodge 1100 – 20 Avenue, Didsbury	mvsh.ca 403-335-9848		●	$		Couples may live together
Bethany Didsbury 1201 – 15 Avenue, Didsbury	bethanyseniors.com 403-335-4775		●	$	Designated Supportive Living Level 4	Secure outdoor area; age-in-place
The BSF Tudor Manor 200 Sandstone Drive, Okotoks	theBSF.ca 403-995-9540		●	$	Person-Centred; Supportive Pathways	Intergenerational programming; secure unit and outdoor area; supportive living
Meadowlark Senior Care Home 203 Hillcrest Boulevard, Strathmore	meadowlarkcare.com 403-934-5294	●		$$	PAC	Secure outdoor area; age-in-place
Origin at Spring Creek 808 Spring Creek Drive, Canmore	originway.ca 403-678-2288	●		$$-$$$	Best Friends Approach™; PAC; Supportive Pathways	Secure outdoor area
Seasons High River 660 – 7 Street, High River NW	seasonsretirement.com 403-652-1581		●	$-$$	Embrace Today; C.A.R.E.S.; Person-Centered	Secure outdoor area; pets welcome
Silver Willow Lodge 2007 – 22 Avenue, Nanton	mosquitocreekfoundation.net 403-646-2660		●	$	Person-Centred; PAC; Supportive Pathways	Services provided by AHS

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HOME CARE

AGENCY	CONTACT INFO	STAFFING Qualifications	STARTING RATE	CARE APPROACH
A Friend Indeed	getafriendindeed.com 403-980-0199	Non-medical support for seniors	$31/hr 2 hour minimum	Best Friends Approach™; Supportive Pathways; COVID-19 safe visits
Alberta Health Services	albertahealthservices.ca 403-943-1920	OT, RN, HCA, LPN, PT	Free	Client-dependent
All About Seniors	allaboutseniors.ca 403-730-4070	RN, LPN, HCA, foot care, Companion	$30/hr 2 hour minimum	Best Friends Approach™
Bayshore Home Health	bayshore.ca 403-776-0460	RN, LPN, HCA, Companion	$28.75/hr 2 hour minimum	Supportive Pathways
Calgary Elder Care	calgaryeldercare.com 403-464-2455	RN, LPN, HCA, Companion	$32/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
CBI Home Health	cbi.ca 403-232-8770	RN, LPN, HCA	Call for pricing	Person-Centred
Classic LifeCare Calgary	classiclifecare.com 403-242-2750	LPN, HCA, Companion	$33.75/hr 2 hour minimum	PAC
Comfort Keepers (accredited with Accreditation Canada)	comfortkeepers.ca/calgary 403-228-0072	RN, LPN, HCA, Companion	$31.50/hr 2 hour minimum	Best Friends Approach™
Focus On Caring	focusoncaring.com 403-264-3839	RN, HCA	$31/hr 4 hour minimum	GPA
Global Senior Care	globalseniorcareservices.com 403-452-4555	RN, LPN, HCA	$28/hr 3 hour minimum	Best Friends Approach™
Granddaughters Personal Care Inc.	granddaughters.ca 403-828-0550	HCA, companion	$29-$35/hr 2 hour minimum	Best Friends Approach™; GPA; PAC; Gentlecare; Supportive Pathways
Home Care Assistance Calgary	homecareassistancecalgary.ca 403-301-3777	RN, LPN, HCA, Companion	$32/hr 3 hour minimum	Cognitive Therapeutic Method; Best Friends Approach™; Client-Centred
Home Instead Senior Care North	homeinstead.com/northcalgary 403-910-5860	HCA, LPN, RN, Companion	$32.95/hr 3 hours minimum	Dementia CARE Curriculum; Mobile Foot Care Services
Home Instead Senior Care South	homeinstead.com/calgary 403-984-9225	HCA, LPN, Companion	$33.95/hr 3 hours, twice a week	Nurse Directed Dementia CARE Curriculum; Mobile Foot Care Services
The Mad Tasker Complete Home Care	themadtasker.com 403-988-2471	RN, LPN, HCA, Companion	$30/hr 1 hour minimum non-medical, 2 hour minimum medical	Best Friends Approach™; Person-Centred
Nurse Next Door	nursenextdoor.com 403-454-1399	RN, LPN, HCA	$35/hr 3 hour minimum	Senior Home Care Services; Making Lives Better
Ohana Care Health Services	ohanacare.ca 403-300-2273	LPN, HCA, RN, RT	$35/hr 3 hour minimum	Best Friends Approach™
ParaMed	paramed.com 403-228-3877	RN, LPN, HCA, Companion	$26.75/hr HCA, $37.25/hr LPN, $60/hr RN	Client-Centred
Qualicare Family Homecare Calgary	homecarecalgary.com 403-209-2210	RN, LPN, HCA, Companion	$34/hr 3 hour minimum	Nurse Managed Care; Best Friends Approach™; GPA
Right At Home	rightathomecanada.com/calgary 403-869-8294	RN, LPN, HCA, PT, OT	$32.00/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
Samaritan Caregivers	samaritancaregiver.com 403-991-5202	LPN, HCA	$30/hr 3 hour minimum	Holistic care based on clients needs; promotes independence

HOME CARE

Senior Homecare by Angels	seniorhomecarecalgary.com 403-862-0129	LPN, HCA	$32.50/hr 4 hour minimum	GPA, Dementia-Friendly Approach
Supportive Outings and Services	soscaregiver.ca 403-816-0428	HCA, Companion	$29.95/hr 1.5 hour minimum	Companion Care; Supported Transport
Vinnette Morgan	vinnettemorgan@yahoo.ca 403-919-4052	Nursing Attendant	$25/hour	Client Dignity; Help Clients Stay at Home
Vytality at Home	vytality.ca 403-476-3680	RN, LPN, OT, HCA, Rec Therapist, Physio, Companion	$33/hr 2 hour minimum	Supportive Pathways; Person-Centred

OVERNIGHT RESPITE - Assessment Required

FACILITY	BUILDING ADDRESS	PHONE NUMBER	WEBSITE	SUBSIDIZED	PRIVATE
AgeCare Glenmore	1729 – 90 Avenue SW	403-253-8806	agecare.ca/glenmore	●	
Amica Brittania	750 – 49 Avenue SW	403-476-8992	amica.ca		●
Auburn Heights Retirement Residence	21 Auburn Bay Street SE	403-234-9695	allseniorscare.com		●
The BSF Clifton Manor	4726 – 8 Avenue SW	403-272-9831	theBSF.ca	●	
The BSF Wentworth Manor	5717 – 14 Avenue SW	403-242-5005	theBSF.ca	●	
Carewest Colonel Belcher	1939 Veteran's Way NW	403-944-7800	carewest.ca	●	
Carewest Sarcee	3504 Sarcee Road SW	403-686-8140	carewest.ca	●	
Chartwell Eau Claire Care Residence	301 – 7 Street SW	587-287-3943	chartwell.com		●
Evergreen	2220 – 162 Avenue SW	403-201-3555	reveraliving.com		●
The Journey Club Seniors' Residence at Westman Village	176 Mahogany Centre SE	403-313-5478	westmanvillage.com		●
Manor Village at Fish Creek Park	22 Shawnee Hill SW	587-392-2400	themanorvillage.com	●	●
Manor Village at Varsity	40 Varsity Estates Circle NW	587-393-9999	themanorvillage.com		●
Millrise Seniors Village	14911 – 5 Street SW	403-410-9155	retirementconcepts.com	●	●
Mount Royal Care Centre	1813 – 9 Street SW	403-244-8994	reveraliving.com	●	
Revera McKenzie Towne Retirement Residence	20 Promenade Park SE	403-257-9331	reveraliving.com	●	●
StayWell Manor Village at Garrison Woods	174 Ypres Green SW	403-242-4688	themanorvillage.com		●
United Active Living at Garrison Green	3028 Don Ethell Blvd. SW	403-685-7200	unitedactiveliving.com		●

The BSF = The Brenda Strafford Foundation ***Confirm dates and times with individual programs**

ADULT DAY PROGRAMS

FACILITY	PROGRAM NAME	BUILDING ADDRESS	PHONE NUMBER	WEBSITE	SUBSIDIZED	PRIVATE
AgeCare Glenmore	AHS Adult Day Program	1729 – 90 Avenue SW	403-253-8806	agecare.ca	●	
AgeCare Midnapore	AHS Adult Day Program	500 Midpark Way SE	403-873-2852	agecare.ca	●	
AgeCare Seton	Club 36 Adult Day Program	4963 Front Street SE	403-255-0700	alzheimercalgary.ca	●	
Auburn Heights Retirement Residence	Dementia Day Program	21 Auburn Bay Street SE	403-234-9695	allseniorscare.com		●
Bethany Harvest Hills	Club 36 Adult Day Program	19 Harvest Gold Manor NE	403-226-8201	alzheimercalgary.ca	●	
The BSF Bow View Manor	AHS Adult Day Program (including Dementia Program)	4628 Montgomery Blvd. NW	403-286-6166	theBSF.ca	●	
The BSF Clifton Manor	AHS Adult Day Program (including Early Onset and Dementia Programs)	4726 – 8 Avenue SE	403-204-9969	theBSF.ca	●	
The BSF Wentworth Manor	Adult Day Program	5717 – 14 Avenue SW	403-686-8602	theBSF.ca	●	
The Calgary Chinese Elderly Citizens' Association	Wellness Day Program, Dementia Day Program *Intended for clients who speak Chinese	111 Riverfront Avenue SW	403-269-6122	cceca.ca	●	
Carewest Beddington	Comprehensive Community Care (C3)	308 – 8120 Beddington Blvd. NW	403-520-3350	carewest.ca	●	
Carewest Colonel Belcher	Wellness Day Program	1939 Veteran's Way NW	403-944-7854	carewest.ca	●	
Carewest Sarcee	Comprehensive Community Care (C3)	3504 Sarcee Road SW	403-686-8140	carewest.ca	●	
Carewest Signal Pointe	Carewest Signal Pointe Adult Day Program	6363 Simcoe Road SW	403-240-7953	carewest.ca	●	
Father Lacombe Care Society	Wellness Day Program	270 Providence Blvd SE	403-254-6288	fatherlacombe.ca	●	
Millrise Seniors Village	Wellness Day Program, Dementia Day Program	14911 – 5 Street SW	403-410-9155	retirementconcepts.com	●	
Monterey Seniors Village	Wellness Day Program	4788 Catalina Blvd. NE	403-207-2929	retirementconcepts.com	●	
Newport Harbour Care Centre	Adult Day Program	10 Country Village Cove NE	403-567-5100	parkplaceseniorsliving.com	●	●
YouQuest at SAIT	YouQuest - An Active Community for Young Onset Dementia	1301 – 16 Avenue NW	403-255-7018	youquest.ca		●

***Confirm dates and times with individual programs**

ADULT DAY PROGRAMS

St. Andrew's Presbyterian Church	Side by Side Fellowship (informal care)	703 Heritage Drive SW	403-255-0001	standrewscalgary.ca		●
Varsity Acres Presbyterian Church	Side by Side Fellowship	4612 Varsity Drive NW	403-288-0544	vapc.ca		●
Wing Kei Care Centre	Wellness Day Program, Dementia Day Program *Intended for clients who speak Chinese	1212 Centre Street NE	403-277-7433	wingkeicarecentre.org	●	●

CARE PARTNER SUPPORT

PROGRAM	PROGRAM DETAILS	PHONE NUMBER	E-MAIL	HOURS	DATES
Alzheimer Society of Calgary	Contact the Society for program details	403-290-0110	findsupport@alzheimercalgary.ca	7:30 a.m. to 7 p.m. Mon-Thurs; 8 a.m. to 4 p.m. Fri	Monday to Friday excluding stat holidays
Calgary N.E. Dementia Support Group	Dementia-specific support	403-273-2371	Call Jean, at number listed	7 p.m.	Last Thursday of each month
Conversation Café	In-person and virtual dementia-inclusive get-togethers for caregivers and their partners	403-290-0110 x 237	kim@dementianetworkcalgary.ca, dementianetworkcalgary.ca	Dates and times available on website	
Dementia Caregiver Support	Dementia-specific support Southwood United Church, 10690 Elbow Dr. SW	403-253-2979	southwoodchurch.ca	1 p.m.	1st Monday of each month
Memory P.L.U.S.	Learn coping strategies in a safe, fun environment. For those with early-stage dementia and their care partners	403-955-1674	family.caregivercentre@ahs.ca	2 hr Sessions	Due to COVID-19, program on pause until safe to meet in-person.
Young Onset Dementia Support Group	For people with dementia (diagnosed under age 65) and their caregivers Southwood United Church 10690 Elbow Dr. SW	403-975-6685 403-283-9537	cindy@youquest.ca, call for first time participants	7 p.m. to 8:30 p.m.	1st and 3rd Tuesday of each month (subject to change)

***Confirm dates and times with individual programs**

Share your questions and comments with us at feedback@dementiaconnections.com

Felix Iroanyah with his daughter, Ngozi, at his home in Mississauga.

Felix's STORY

BY **Jennifer Friesen** PHOTOGRAPHY BY **Wade Hudson**

Born in Nigeria in 1939, Felix Iroanyah has followed his passion for education across the globe. Since settling in Toronto in the early 1970s, his love for learning and for his family has never wavered.

FELIX IROANYAH left his home in Nigeria for England when he was 19 to attend school. While there, he achieved a PhD in economics and philosophy. He moved to the U.S. in the late 1960s to work at Columbia University before moving to Toronto in 1971. He sent for his fiancée, Adanma, to come to Canada from Nigeria in 1972, and the couple married a year later. They had three children, Chuck, Azu and Ngozi. In 1985, the tight-knit family moved to Mississauga. Together, they spent their days working and laughing together, even in the face of hardship.

After working for the Ontario government and then starting his own business, Felix took a job in cabin services at Air Canada, where he stayed until he retired in 2006.

Felix's passion for education is shared by his family. Ngozi is currently finishing her PhD in health policy and equity studies at York University, and, at 57 years old, Adanma graduated with a bachelor of theology in June 2000. Unfortunately, she passed away suddenly that December, and Felix slowly began to act a little differently. Following an assessment in 2008, he was diagnosed with early stage Alzheimer's disease.

"It was a sombre moment for the family," says Ngozi. "It continues to be difficult to see him struggle with it."

While Ngozi says it remains difficult to see her father struggle, she sees he's found happiness in his own way.

Today, Felix is living with advanced Alzheimer's, and can often be found with a smile on his face. Always laughing and offering high fives, he lives in his Mississauga home with his new wife and his son, Azu. He loves walking, going for drives in the car and interacting with friends at the Alzheimer Society's day program he attends.

"Dementia is different for everyone … and, even with dementia, there are beautiful moments I have with my father," says Ngozi. She recalls taking Felix and her stepmother out for a Father's Day dinner after graduating from her master's program. When they first sat down, Felix seemed off in his own world, but as soon as she told him that she had graduated, his focused on her.

"His eyes shifted, it was like the cloudiness cleared for a moment, and he looked at me and said 'congratulations,' and then he was gone again," she says.

For Ngozi, these small connections are meaningful.

"It's about knowing that it's not all sad. The moments when I rest my head on his lap and he strokes my hair, or when I look at him and his eyes soften and he smiles at me, are beautiful. Those are the moments that still warm my heart. There are still so many beautiful moments you can have with people living with dementia."

Share your story with us at feedback@dementiaconnections.ca

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Right Care
Right Time
Right Place

Bethany is a leading provider of the **full spectrum of housing and care options** for seniors and adults with disabilities in central and southern Alberta. We offer the right home and care at the right time in the right place.

Affordable Housing and Campus of Care for Seniors

Seniors can age in community as their care needs change at **Riverview Village** in southeast Calgary. We offer affordable rental suites for independent seniors, as well as highly complex dementia care and long-term care at our new purpose-built Bethany Riverview located on-site. We also have a wide variety of affordable housing complexes throughout Calgary.

Life Lease Community

Sundance on the Green is a community for independent seniors who enjoy active living. Purchase a spacious suite through our Life Lease program, which is a home-ownership arrangement offering peace-of-mind with a guaranteed buy-back of the lease agreement.

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Bethany's care centres are home to almost 1,000 residents who require long-term care in central and southern Alberta. Our programs provide professional services to those who require 24/7 care.

For more information, please contact us:

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