DEMENTIA connections

Fall 2020

YOUR GUIDE TO LIVING WELL IN CALGARY

VITAL VISITORS
WHY FAMILY CARE PARTNERS SHOULD BE CONSIDERED AN ESSENTIAL PART OF THE CARE TEAM

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

Power In ADVOCACY

Myrna Norman finds purpose and strength in supporting others


Branch Out Neurological Foundation
Leading the way to unconventional solutions in brain health.

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On the Cover:
Myrna Norman, photographed by Lindsay Elliott

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For each person living with dementia, an estimated 10-12 people are directly impacted. This photo shows some of the people in John Poole's family who have been affected by dementia.

WELCOME

THE COVID-19 pandemic has shone a spotlight on the serious deficiencies in how we provide care and social support for people impacted by dementia in both congregate and community settings. The recent outbreaks have also amplified issues faced by the health-care workforce that have long been known about and can no longer be ignored. There's an urgent and vital need to make things better.

Trying to balance the needs of care home operators, the health-care workforce, residents and family members throughout the pandemic has been difficult. Operators are trying their best to keep the virus out of their buildings. Consequently, families who provide an estimated 30 per cent of care in long-term care homes were locked out for several months. There are many heartbreaking stories about the impact of separation. Families are an essential part of the care team and can be educated on infection control and proper use of personal protective equipment. Family care partners must not be denied access during outbreaks or future waves of the pandemic.

With day programs, recreation, respite and most home care services cancelled, people impacted by dementia living in the community have largely been ignored. Many family caregivers referred to as "the invisible backbone of the Canadian health-care system" are struggling.

In loving memory of Duncan McLean.

The Next Chapter

This will be my last issue as editor, and I am very pleased to pass the reins to incoming editor, Carolyn Brandly. Carolyn has an exciting vision for the future of *Dementia Connections* magazine.

It has been my privilege to share stories of people impacted by dementia, and to use this magazine as a platform to raise public awareness, reduce the stigma of dementia, provide people living with dementia and their families with information about dementia, to showcase promising research and to serve as a reference for the dementia workforce.

I would like to express my sincere appreciation to editorial advisors Kimberly Shapkin, Sarah Salus, Ann Toohey and, posthumously, Duncan McLean, for their wisdom and input on the magazine content. Also, thank you to Meredith Bailey and Jill Foran of RedPoint Media for their patience and guidance.

Thank you for sharing your stories with us and for letting us know the positive impact of reading those stories.

With deepest gratitude,
Lisa

Lisa Poole
Founder and Editor
DEMENTIA CONNECTIONS

Poole family photo by Tricia Howatt Photography; Duncan McLean courtesy McLean family

DID YOU KNOW? **Dementia Connections *magazine is going Canada-wide!***

We are growing to support a national audience through expanded print and digital platforms beginning Spring 2021. Please take a few minutes to respond to our short survey that will help inform our expansion plans and enter your name in the draw for a $200 Visa gift card at the end of the survey. www.surveymonkey.com/r/DementiaConnections

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TRANSITIONS IN CARE

A new program engages medical professionals, people living with dementia, family members and care providers to reduce unnecessary emergency department visits

BY **Diane Bolt** PHOTO BY **Jared Sych**

Judy and Wayne Hykaway outside their care home in Calgary.

Wayne and Judy Hykaway began living with dementia in 2016 when Judy was diagnosed with age-related short-term memory loss and later with dementia. As Judy's condition progressed, the couple, who have been married for 47 years, sold their home and moved into independent living in Calgary's AgeCare Midnapore community.

In 2018, as Judy's condition worsened, the decision was made to move her into long-term care at AgeCare Sky-Pointe in northeast Calgary to be closer to their daughters. Wayne moved into supported living on the same floor.

> "I promised Judy that I would be with her each morning and stay until she fell asleep each night." —Wayne Hykaway

"I promised Judy that I would be with her each morning and stay until she fell asleep each night," says Wayne. "Our two daughters live nearby and come to visit often."

In July 2019, Judy was admitted to the emergency department (ED) as she was having difficulty breathing. With its overhead pages, bright lighting and lack of privacy, the ED can be anxiety-inducing, especially for someone living with dementia. Although Wayne says the treatment Judy received there was excellent, it was still a stressful experience for the entire family.

"My daughter spent the first night with Judy. There was so much noise and chaos that neither slept," says Wayne. "And, when I showed up in the morning, they were both in a panic."

Judy's tests returned few results except that she had perhaps aspirated some food and had mild pneumonia. The doctor suggested Judy be admitted for seven day's observation, which seemed too long to Wayne.

"All I could think was, 'They can't spend another night,'" he says.

Wayne wasn't alone in his concerns. Inpatient admissions are linked to an increased risk of infections, falls, delirium and functional decline. This is bad for patients and their families and can prove costly — a reduction in unnecessary transfers could save the province $7.44 million annually.

Thankfully, a new program is exploring how to address the issue. Alberta Health Services' (AHS) Transitions in Care project, which was launched in April 2019 and is scheduled to run until June 2022, educates health-care professionals, caregivers and family members about available options so that the person living in long-term care can be assessed and potentially treated at home rather than transferred to ED.

"Across Alberta [approximately] 28 residents are transferred from long-term care to emergency departments daily — that's over 10,000 residents a year," says Shawna Reid, a masters prepared registered nurse and a senior practice consultant with the Emergency Strategic Clinical Network, which is one of the Transitions in Care project's main partners. "Many to most of those will end up being triaged as less urgent or not urgent. Our primary outcome is a reduction in transfers from long-term care to emergency departments."

Transitions in Care, which was made possible thanks to a Partnership for Research and Innovation in the Health System grant (PRIHS), opens up communication among health-care providers in different departments, specifically between those in long-term care and emergency physicians. It also teaches caregivers, nurses and health-care staff to watch for very subtle changes in behaviours, body language, eating habits and so on, to catch health issues before they can progress. This information then helps inform the best patient-centred approach, whether that is to call a doctor, the AHS call centre RAAPID (Referral, Access, Advice, Placement, Information & Destination), the Community Paramedics (Mobile Integrated Healthcare), or, only if appropriate, transport the resident to the ED.

Wayne is already a member of the Resident and Family Council at AgeCare SkyPointe, a group that addresses quality of life concerns and enhancements for those living within the AgeCare community. When he heard about the Transitions in Care project in April, he applied to be part of it and was selected to share his insights and experiences. When Judy was admitted to the hospital three months later, Wayne's experience with the initiative helped him feel empowered to share his concerns with the emergency doctor. He felt it would be better to take Judy home, where she could be observed with familiar people caring for her. The doctor agreed and commended Wayne for advocating for his wife.

Today, Wayne is a member of many programs and projects across Canada, where he continues to share his experiences and insights.

"I get involved in these projects because I'm hoping to find people who can share advice about what has worked for them," he says "And, if I am going to spend time away from Judy, then I want to pay it forward doing something worthwhile and meaningful that will benefit not only my family but other families as well."

CHAMPIONING DEMENTIA CARE IN CANADIAN HOSPITALS

BY **Jennifer Friesen**

While standing in a darkened room filled with loud, abrupt noises, Dr. Shelley Peacock watched as a group of 20 health-care workers tried to complete tasks such as brushing their teeth or writing a letter. Some wore thick goggles and gloves, while others had braces on their limbs restricting their joints.

"Even though I wasn't participating, it affected me," says Peacock. "I remember feeling inundated with the noise and the banging and the chaos of it all. That's what it's like every day for people with dementia – it's not just the loss of memory, and sometimes we don't realize that."

The exercise took place in Edinburgh in 2019 as part of the Scottish National Dementia Champions Programme, which educates health-care professionals and family care partners on how to care, advocate and act as champions for those living with dementia. Peacock, who is a researcher at the University of Saskatchewan's College of Nursing, is adapting the program for Canada.

"We need to do a better job of making hospitals or acute care settings safer for people with dementia." —Dr. Shelley Peacock

Now in its 10th year, the Scottish program has trained more than 1,000 health-care professionals across the country. Over the course of six months, groups of 20 people take part in five days of training, which includes lectures, take-home assignments and hands-on exercises. People living with dementia and family care partners act as peer-educators. In 2018, the program was named one of the UK's 100 best breakthroughs for its impact on people's everyday lives.

Since 2019, Peacock has been working with colleagues from the University of the West of Scotland to adjust the program to meet Canada's unique needs and challenges.

This past February, Peacock and her team hosted a series of meetings over two days in Saskatoon for researchers and health-care professionals, as well as people living with dementia and care partners, to brainstorm ways to implement the project in the Canadian context. The sessions were made possible thanks to a $20,000 grant from the Canadian

DID YOU KNOW? ***In August 2020, the Government of Canada announced an investment towards 12 new community-based programs addressing the challenges of living with dementia. The projects will focus on addressing stigma, fostering communication and increasing the inclusion of people living with dementia within their communities. The $7.85 million was made available through the Dementia Community Investment fund. Learn more at Canada.ca***

Photo courtesy SHRF

Institutes for Health Research (CIHR)

“It’s fundamental that people with dementia and their family caregivers are educators as well,” she says. “The experts are actually people with dementia and carers.”

Canada’s size and differing healthcare systems between provinces and territories all play a part in adapting the program. But Peacock and her team are working to find “creative ways” to ensure it goes coast-to-coast.

The Canadian program will also focus more on acute care where training is most needed. Research shows that people with dementia who are older than 65 have an average of four other diseases. Consequently, they’re more likely to require acute care services where not everyone they interact with is educated about dementia care. By training healthcare professionals to be conscious of the disease, they can avoid complications that could arise in hospital.

The program is still in the planning stage, and Peacock and her research team are finalizing the information gathered in meetings. After more consultations, she hopes to gather further funding from CIHR to pilot the program in spring 2022.

“We need to do a better job of making hospitals or acute care settings safer for people with dementia,” says Peacock. “And one way to do that is to change practice.”

LANCET REPORT IDENTIFIES THREE NEW DEMENTIA RISK FACTORS

BY **Fabian Mayer**

RESEARCHERS ARE ADDING new pieces to the puzzle of dementia prevention. A large report published in July 2020 in *The Lancet* medical journal identifies three new risk factors that can play a role in the development of the disease. Excessive alcohol consumption, traumatic brain injury, and air pollution were all found to be new potential contributing causes of dementia.

The report comes out of updates to the Lancet Commission on Dementia Prevention, Intervention, and Care, which was originally created in 2017 by a group of two-dozen experts from around the world. The three new modifiable risk factors join nine others initially identified by the commission. These include less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes and low social contact. According to the paper, modifying these 12 risk factors may prevent or delay up to 40 per cent of dementias.

Dr. Kenneth Rockwood is a professor of geriatric medicine at Dalhousie University and sits on the commission. He says the blueprint for limiting the rise in dementia cases is becoming more and more clear just as many baby boomers begin to reach the age when most dementia cases are diagnosed (between 75 and 90).

“Generally, it looks like dementia risk is decreasing on an individual basis,” says Rockwood. “But because the population is ageing at such a rapid rate, this will still mean net very large increases in the risk of dementia.”

The report also analyzed existing literature from around the world. The quality and consistency of evidence for the three new risk factors has strengthened in recent years, allowing the commission to add them to the list.

Rockwood says the findings should affect dementia prevention on two levels: policy and individual. On the public policy side, governments can take steps such as implementing protocols to limit air pollution. Individuals, meawhile, may need to modify their own behaviour. This is especially important for adults who are at greater risk, such as individuals with a family history of dementia.

“We’re going to advise them, for example with respect to head injuries, that now would be the wrong time to pick a fight in league hockey. Wear your seat belt and if you’re riding a bike, wear a helmet,” says Rockwood.

When it comes to alcohol, the report suggests limiting consumption to no more than 21 units of alcohol per week. While some of the risk factors, such as having less education, need to be addressed early in life, researchers stress that most of the risk factors can be tackled at any age.

“It’s never too late to start a dementia prevention lifestyle,” says Rockwood.

12 MODIFIABLE RISK FACTORS FOR DEMENTIA

1. **Excessive alcohol consumption**
2. **Traumatic brain injury**
3. **Air pollution**
4. **Less education**
5. **Hypertension**
6. **Hearing impairment**
7. **Smoking**
8. **Obesity**
9. **Depression**
10. **Physical inactivity**
11. **Diabetes**
12. **Low social contact**

CREATING MOMENTUM

The Alberta Collaborative generated people-centred culture in continuing care

BY **Shannon Cleary**

With an extensive 30-year career in planning, continuing care operations and post-secondary education, Marlene Raasok has spent plenty of time defining and deciphering health-care nomenclature. Language has played an important role in establishing and guiding the modern shift from a medical, task-based model of care to a social, relationship-based model. However, the words we use lose their value if we don't all share in their meaning.

"Many times, we make comments without being clear on what they mean," she says.

Research shows that while many different care delivery approaches can have a positive impact on continuing care, the most successful organizations name their desired transformation and embed these new practices within their operation.

Raasok has also spent more than three decades advocating for and advancing change in how we support older adults to live well. Now retired and living in Alberta, Raasok acts as a senior advisor in Innovation, Entrepreneurship and Collaboration for the Schlegel-University of Waterloo Research Institute for Aging and, with her "free time," supported the Alberta Collaborative for Leadership for Person-Centered Living. The Alberta Collaborative, a grassroots initiative that began in 2016, joined "congregate living and care" leaders — care organizations, educators, researchers and families. Its mission was to support culture change in continuing care delivery and workforce development by identifying, defining and sharing the universal attributes of "people-centred practice."

"It was really important to have the time to reflect and hear from all of us, to put words that we often use into a practice with meaning," she says.

Photo courtesy Marlene Raasok

> "The same things that are important to residents and families are important to people working and volunteering. They are not just a vehicle to an end. They are collaborators in the journey."
> —Marlene Raasok

For three years, the Alberta Collaborative met three times a year and included several continuing care organizations, educators and researchers such as Bow Valley College, University of Lethbridge and University of Calgary's Brenda Strafford Centre on Aging, Alberta Health Services as well as family caregivers and advocates. Drawing from evidence and collective experience, the Alberta Collaborative identified the many attributes of "people-centred practice," which include moving from task-based work to relationship-centred approaches; anchoring individual preferences and priorities in their care; fostering understanding and inclusion of diverse needs of people across a range of ethnic communities; and valuing and supporting resident and employee linkages. The group presented these universal attributes to providers, policymakers, system-designers and educators through guidance documents, meetings and conferences.

"The opportunity to come together and learn from each other not only expands what we see, but creates momentum," says Raasok. "We can't get there from here if we don't all take it on."

Raasok says the first big shift in continuing care delivery was moving from a medical model to people-centred care, where residents were placed at the centre of the conversation. The model evolved to person-directed, often described as "nothing for me without me," where the individual's role was elevated as directing their care. Creating an environment of people-centred practice is the next shift, where those delivering the care are also included as partners.

"The same things that are important to residents and families are important to people working and volunteering," says Raasok. "They are not just a vehicle to an end. They are collaborators in the journey."

The Alberta Collaborative ultimately sees people-centred practice as everyone coming together to be at their best, to live with well-being and to work with meaning.

Raasok says the Alberta Collaborative's efforts have already generated change. In May 2020, the group published FACES, supported by LEADing attributes for organization success, an infographic and guidance tool for organizations to understand and apply people-centred practices. The concepts were used by Bow Valley College to incorporate people-centred practice into its Health Care Aide Training Program for the 2020-21 academic year.

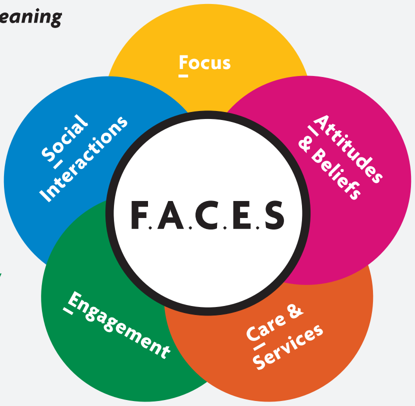
"These insights can guide organizations in thinking about what we create, and how we enable the best possible outcomes," says Raasok.

FOR OUR BEST IN CONGREGATE LIVING & CARE

People LIVE with WELL-BEING and WORK with Meaning

Social interactions enable joy, purpose and safety
- Community involvement
- Environments for living
- Access to technology

Engagement creates understanding and community
- Language for understanding: quality of life, quality of care and safety
- Cultural sensitivity
- Communication, collaboration and learning



Focus brings clarity about expectations
- Knowing each person
- Preferences for quality of living
- Dignity of choice making

Attitudes & beliefs guide what we do
- Relationship-centered
- Emotional intelligence

Care & services support needs and well-being
- Strength-based; flexible
- Teamwork with families, care partners and volunteers

L.E.A.D

Leadership
- Co-creates internally and with service partners.
- Is visible; champions changes with learning for continuous improvement.
- Facilitates a culture of respect, dignity, service quality and safety.
- Is engaging, removes barriers, celebrates success.

Enables Teams
- Co-creates work designs for consistent carers with flexibility to meet care needs; teams working together close to points of service.
- Inspires talent and contributions of employees, families/care partners and volunteers.
- Fosters a healthy environment: free from abuse, balancing safety expectations and risk for all.

Acts with Shared Information
- Co-creates information, including outcomes for resident/family experiences, quality of care, staff experiences and safety. Optimizes a range of communication and collaboration mechanisms; is transparent and balances individual privacy and collective interests for trusted and caring communities.
- Values differing perspectives, addresses concerns with clarity of processes and accountability.

Develops Capacity
- Is proactive in advancing promising practices and in developing relationships with referring partners and the community for mutual gain.
- Optimizes technology for connectivity among residents, care partners and with individual employees, teams and referring partners and for systems supporting effective, safe and efficient service delivery.
- Optimizes the physical environment for safety, quality of living and work effectiveness.

Infographic courtesy Marlene Raasok, adapted and reprinted with permission

Sheena and Paul Bates at their home in Calgary.

CAREGIVING IN UNCERTAIN TIMES

Families that support their loved ones with dementia face increased challenges during COVID-19

BY **Jennifer Dorozio** PHOTO BY **Mariah Wilson**

Family care partners of people living with dementia in the community often rely on programs and services that offer recreation, connection and respite. Since the outbreak of COVID-19, the focus has been mainly on hospitals and long-term care homes. But the outbreak and its resulting mandatory lockdowns, social isolation and disruption of programs and services have created escalating challenges for family care partners that continue to go largely unrecognized.

For Sheena Bates, a family care partner to both her mother, Rita, and her husband, Paul, the "before times" — as in what life was like before the pandemic seized the world — were very different.

Rita is 98 years old, lives with late-stage Alzheimer's in a long-term care home and uses a wheelchair. Paul, who is 63, lives with early-onset dementia. Before COVID-19, the family calendar was filled with visits to see Rita, as well as Paul's weekly day programs with the Alzheimer Society of Calgary's Club 36 and YouQuest. Both are programs that foster community and support for people living with dementia. Sheena and Paul also enjoyed regular meetings with a care partner social group called Memory P.L.U.S, run by Alberta Health Services.

> "Overall, they're absolutely struggling. The social isolation piece is huge for those in the community, as well as in long-term care." —Gwen McGhan

Photo by Colleen De Neve/ courtesy Gwen McGhan

On top of it all, Sheena worked part-time in the field of environmental monitoring.

But in March 2020, escalating cases of the virus resulted in province-wide lockdowns, meaning in-person connection and support ceased almost overnight.

"COVID-19 changed our schedule dramatically. There was huge isolation," says Sheena.

COVID-19's Impact

Along with the cancellation of face-to-face events and recreation programs, Sheena and Paul were isolated at home. Both Rita and Paul were considered high-risk for COVID-19, which made visits impossible.

The couple had previously tried video-calling Rita at her care home, but she had trouble focusing on the screen so they knew this was not an option. Sheena became concerned about the effects of isolation on cognitive health for both her mother and husband.

Meanwhile, Paul increasingly needed more emotional support and help with daily tasks. With day programs unavailable and faced with the demands of caring for Paul full-time at home, Sheena decided to step away from her job.

Later, when the rules around visitations lessened, in-person outdoor visits continued to be challenging. Rita had a hard time recognizing Sheena with her mask on in an unfamiliar environment and, to Sheena's dismay, her mother seemed to be deteriorating.

Supports Needed

Sheena's experience echoes many other family care partners' challenges in Calgary, says Gwen McGhan, an assistant professor in the Faculty of Nursing at the University of Calgary.

McGhan and a colleague, Deirdre McCaughey, an associate professor in the Cumming School of Medicine at the University of Calgary, have been researching the impact of COVID-19 on family care partners since the outbreak began. This summer, they surveyed 230 family care partners, from Calgary and surrounding areas, about their experiences.

"Overall, they're absolutely struggling. The social isolation piece is huge for those in the community, as well as in long-term care," McGhan says.

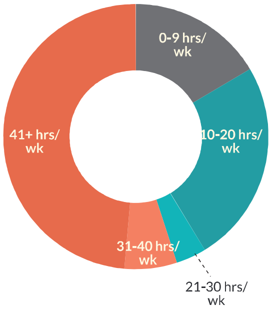
THE IMPACT OF COVID-19 ON FAMILY CAREGIVERS OF PEOPLE LIVING WTH DEMENTIA IN THE COMMUNITY

How have hours spent caregiving changed?

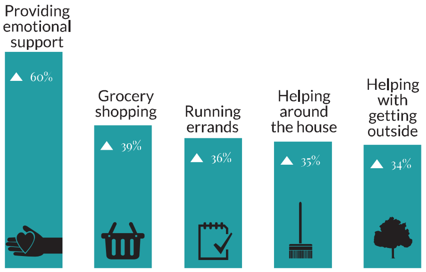
58% report an increase in time spent caregiving since the pandemic began

> I miss time to myself - now it's 24/7 care.

Almost 50% of caregivers are providing 40+ hours of caregiving each week - more hours than a full-time job



How have caregiving tasks changed?



Caregivers are performing these tasks more than usual since the pandemic began

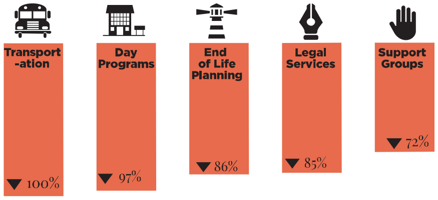
How have available resources changed?

Caregivers went from using an average of...

5 support resources before the pandemic to 1.6 during the pandemic

> I miss support. The dementia had just been diagnosed in the past 4 weeks. Everything hit mid-COVID ... the more help I needed the less that was available. Home care got canceled when our need was at its worst.

Biggest decreases in resources accessed:

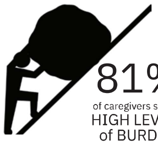


How are people with dementia and their caregivers coping?

72% of caregivers feel MORE ISOLATED

68% of caregivers feel MORE STRAIN

58% of caregivers report LOWER QUALITY OF LIFE



81% of caregivers scored HIGH LEVELS of BURDEN

> I worry that this will last longer than I can manage at home, alone, isolated.

> I worry about my Mother's isolation and reduced activity, which has worsened her short term memory loss

81% of caregivers report AN INCREASE IN RESPONSIVE BEHAVIOURS related to dementia since the pandemic began

Infographic courtesy of the University of Calgary, adapted and reprinted with permission.

While challenges vary, especially if the person with dementia is at home or in long-term care, McGhan says there are common concerns. Responses from study participants revealed that 69 per cent of care partners are feeling more isolated overall, and 58 per cent reported an increase in time spent caregiving since the pandemic began.

"Family caregivers are finding that their family member with dementia is really deteriorating because they haven't been able to have that engagement piece," she says.

As for family care partners, the lack of access to respite programs means care is often 24/7, which can lead to burnout. The fact there is no clear idea of when programs will be up and running again only adds to that stress.

"A big thing that we've been hearing is just frustration across the continuum [of care]," she says.

Currently, McGhan and her colleague are continuing to gather input from families across the province. They aim to develop meaningful recommendations for decision and policymakers based on direct feedback from family care partners to help improve their situation.

"Family caregivers are really critical to our health-care system, and they need to be supported," says McGhan.

A New Normal

As for Sheena, she is still figuring out what works for her, Paul and Rita in their new normal. Spending time outside, including walks, backyard visits and gardening, have all helped. But like all family care partners, Sheena needs more support and is trying to line up respite care again.

"I just keep reaching out, learning more and trying to stay engaged," she says.

TO WHOM I MAY CONCERN

An interactive theatre program gives voice to the dementia experience

BY **Fabian Mayer**

A performance of To Whom I May Concern.

Photo courtesy Laura Bowley

TO WHOM I MAY CONCERN (TWIMC) is an interactive theatre program that is a vehicle for people living with dementia to share their experiences with each other and the world. It was created by Dr. Maureen Matthews, a nurse and pyschotherapist based in Connecticut, in the early 2000s as a way for people to understand the experience of living with dementia. Partner and director Laura Bowley, who is based in Ottawa, joined in 2012 after reaching out to Matthews via Twitter. Bowley had personal experience with dementia — her mother passed away from vascular dementia. She says her family avoided talking about the disease, which made it difficult to get a diagnosis and plan for the future — something she doesn't want others to have to live through.

TWIMC's name was inspired by the stigma that people living with dementia often experience after a diagnosis.

"The idea is that when a person is diagnosed with dementia, they often become an 'it.' They tend to be objectified and lose their personhood," says Bowley. "People talk around them; they don't talk to them. The program empowers people living with dementia to reclaim their personhood, their 'I.'"

The TWIMC process takes about eight weeks from start to finish. Before participants hit the stage, whether virtual or physical, they share stories of living with a progressive brain illness such as Alzheimer's disease during weekly discussion groups. Besides trained TWIMC facilitators, no caregivers or family members are allowed in the sessions, which are currently being held virtually, enabling participants to speak freely and put feelings and emotions into their own words. Bowley says helping participants find their voice is an important goal, and benefit, of the program.

"They become comfortable talking about [their life] that way, finding out that they are travelling the same path, that they share a lot of experiences. It's very validating," says Bowley.

After about six weeks of meetings, facilitators take what was shared in the group and turn it into a script. The group then comes together a couple more times to review and discuss the script, make any changes and to rehearse.

! *DID YOU KNOW?* ***In 2017, TWIMC created a facilitator-training program as a way of expanding the program. Bowley says around 30 people have been trained to facilitate TWIMC programs so far. Virtual training programs run twice a year with the next one slated for Spring 2021.***

> The program empowers people living with dementia to reclaim their personhood, their ‘I.’” —Laura Bowley

Then, it’s showtime, a moment Bowley says most participants embrace.

“Usually the first thing they want to do [afterwards] is to do the performance again,” she says.

Scripts are typically arranged around five themes that come up in the discussion group: the diagnosis process, how participants have adapted, the reactions of family and friends, support they’d like from care partners and the community, and hopes and dreams for the future. Bowley says this last theme often surprises audience members.

“It’s very counter to what our perception is of dementia, that people are even thinking about the future,” says Bowley. “I think one of the things that strikes people who witnessed a performance or a video is that people living with dementia can have such insight into their diagnosis and into their lives.”

Most groups stay together and keep meeting even after the performance. Some participants, meanwhile, have gone on to become public advocates for people living with dementia.

“They see that they can still have an impact and they want to keep going,” says Bowley.

To learn more, visit towhomimayconcern.org

CREATIVE SOLUTIONS FOR JUSTICE

Dementia activists and allies from around the world are coming together through “Reimagining Dementia” to push for positive change

BY **Nathan Kunz**

SPANNING CONTINENTS, professions and lived experiences, the members of “Reimagining Dementia: A Creative Coalition for Justice” are focused on a unifying goal: do better for those impacted by dementia.

“We want to organize and mobilize a truly grassroots force that can move the conversation about aging and dementia in a positive, creative, inclusive, just and life-affirming direction.” says Reimagining Dementia coordinator Mary Fridley, a New York City-based organizer, activist and coordinator of special programs at the East Side Institute, an education and research centre.

Formally launched on September 8, the grassroots coalition includes more than 270 international members from varied backgrounds. Members include people living with dementia, care partners, artists, academics, advocates, medical professionals and more.

The coalition also released a “call to action” document that highlights its core principles —the need to challenge and transform dementia culture and treatment, amplify lived experience and advance the roles of art, activism and technology in care. Included in the document are a list of values that the coalition believes should guide dementia-related projects, programs, policies and approaches, but Fridley says how the coalition will operate has been left intentionally open. Members are currently working collectively to determine and guide those choices moving forward. Fridley says leading with creativity and the arts with opportunities for play, performance and improvisation will remain a central focus.

“What is taken away from people with dementia and, broadly speaking, people who may be limited in their physical, cognitive or emotional abilities is that we stop viewing them as human beings and as contributing members of society. It’s as if they are just here to be taken care of,” says Fridley, “And while I want them to have the best of care, they have much more to offer.”

Fridley says the fact that the coalition emerged when it did is no coincidence. Reimaging Dementia was formed during a pandemic in which older adults have been disproportionately impacted, and inspired by global calls for ends to racial, social, environmental and economic injustice.

“What we’ve seen is a movement of people around the world saying, ‘Enough is enough,’” says Fridley. “We can do better. We have to be more innovative and bold. We need to more creatively address the systemic problems that are impacting so many people.”

To learn more visit facebook.com/reimaginingdementia or reach out directly at ReimaginingDementia@gmail.com

SUPPORTING SUPPORTERS

Two support groups offer a lifeline for people living with frontotemporal dementia

BY **Jennifer Friesen**

Danielle Barrette-Marcuccio with her husband, John.

Photo courtesy Danielle Barrette-Marcuccio

DANIELLE BARRETTE-MARCUCCIO started to notice small changes in her husband, John Marcuccio's, behaviour seven years ago.

John was still playing competitive soccer, and his doctor continued to give him a clean bill of health. But Danielle noticed that he was having trouble remembering things, and that he was becoming increasingly disorganized and unusually sedentary.

FTD FAST FACTS

1. **The average age of diagnosis is 60**
2. **FTD represents an estimated 10-20% of all dementia cases**
3. **A hallmark of FTD is a gradual, progressive decline in language and behaviour**

These small changes began to grow, and, on September 9, 2015, John was diagnosed with frontotemporal dementia (FTD) — and was told he'd likely had it for a decade.

FTD often manifests when someone is 50 or 60, 10 years earlier than when Alzheimer's disease is typically diagnosed. Despite the fact that FTD represents an estimated 10 to 20 per cent of all dementia cases, the disease is under-represented and under-supported in Canada.

As a self-proclaimed "info-holic," Danielle poured herself into research and tracking clinical trials across North America. She travelled to Chicago in 2018 for a conference about FTD and was shocked to see how much information was available.

"It really struck me that there's so much going on in the U.S.," she says. "There's volumes of information, they have networks, but there's nothing in Canada. So, I thought, if I'm investing all this time and energy in finding everything, I'm going to be pooling and sharing that information with my fellow Canadians."

Danielle and John began going to monthly meetings of "Between Us," a young onset dementia support group hosted by The Dementia Society of Ottawa and Renfrew in late 2015. She noticed that after the meeting, participants continued to hang out in order to talk and connect. Inspired by this, she created a Facebook group, also called "Between Us," as a way to support and connect with those living with young onset dementia beyond the meetings.

The group became tight-knit, and members were soon meeting for regular vistis like picnics and nature walks.

"You could just sense it from the other spouses and family members that they needed meetings more than once a month," says Danielle. "So the group did evolve to include monthly dinners for spouses and other events, because there really is a need for that connection."

Following the success of the "Between Us" Facebook support group, Danielle felt it was mportant to create a group more focused on the disease specifically. She launched the "Canadians Living with FTD" Facebook group last May. Currently, the group has 133 members from across Canada who share Canadian resources, information, innovative ideas, research opportunities and establish networks in various communities while providing support to each other.

Working entirely on a volunteer-basis, Danielle frequently uploads important forms or documents, so people don't have to go looking for them.

"People have been pretty desperate to find each other," she says. "Not just in terms of gathering information and figuring out how things work in Canada, but just to connect, share and support one another."

Since COVID-19 has limited social interaction, both groups have continued to connect online, and the virtual support is useful.

"We're a network," Danielle says. "There's always someone who can help. Or, as one member Kelly from Ottawa recently stated, 'You will be so glad you joined this group… even if you don't share or post much, there is much to learn and a real sense of belonging.'"

Find Between Us - A Support Group for Those Living with Young Onset Dementia on Facebook.

ADVERTISING FEATURE

5 REASONS FAMILIES CHOOSE MEMORY CARE AT AMICA

With the health and safety of residents as a top priority, Amica is a trusted leader in providing exceptional care. This is especially important for people living with Alzheimer's. Changes in abilities and behaviour mean safety becomes an even greater concern. Knowing you or your loved one will be cared for by professionals certified in dementia and behaviour support is key.

CARE THAT IS PERSONALIZED

At Amica Britannia care is personalized – according to each resident's unique needs. Memory Care residents get enhanced care in dedicated Memory Care suites including support with bathing, dressing, medication management and more.

CARE THAT IS PROFESSIONAL

Each professionally trained staff member is highly qualified to ensure each Memory Care resident gets care that is knowledgeable, respectful and compassionate.

CARE THAT IS ALL-ENCOMPASSING

Not only is there a nurse and specialized support team on site 24/7 – our Memory Care residents also receive care with scheduled appointments from a visiting physician and physiotherapist, with access to foot care, a walker clinic and a hearing clinic.

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We use individualized support tools such as My Life Story Book and My Life Story Box as well as music therapy to help engage and comfort residents.

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At Amica Britannia, care is provided at every stage of life. If you're interested in learning if Memory Care is right for you or your loved one, book a private tour today

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RADIO RELIEF

Free radio service m4d Radio keeps the tunes flowing

BY **Colin Gallant**

Social-distancing and isolation are challenging, especially for people living with dementia. Losing the chance to connect with others during a time of heightened anxiety because of COVID-19 is particularly difficult.

To help address this, Music for Dementia, a national campaign based in the U.K. to make music available for people living with dementia, launched m4d Radio in June. Led by The Utley Foundation, a private charitable trust also based in the U.K., the campaign is a direct and positive response to the foundation's Commission report on Dementia and Music, which highlights the connection between access to music and quality of life.

"There was a real need to keep the music flowing," says Grace Meadows, programme director for Music for Dementia. "When we went into lockdown, musicians and music therapists couldn't go into care settings and we started to notice this was having an instant and very significant impact on people."

The free, 24-hour, web-based, ad-free radio service is a response to the reduced access to in-person music programs for people living with dementia. It is made up of five stations — The 30's and 40's, The 1950's, The 1960's, The 1970's and The m4d Mix — that have been carefully curated based on focus-group findings to include music that is attuned to the different moments that happen during the day.

For example, both gentle and energizing songs can help set the tone for the morning, and soothing music works for the mid-afternoon when sundowning may occur. Some of the music was even selected because it is suitable for the vocal range of an older adult to sing along with.

Meadows says the benefits of music have been observed in the realms of psychological health, physical health, self-expression and all-important social connection. Music has the ability to affect our state of mind and emotions, it makes us dance and sing, and lets us communicate wordlessly.

"I think about music being a kind of bridge that enables those of us without dementia to go into the world of those with dementia. We're not asking them to come back into our world, it allows us to visit them in their world, so to speak," says Meadows.

But it's not just people living with dementia who benefit from sharing music. Meadows says she's heard from care partners that they see people with dementia more fully when they are enjoying music together.

"Ultimately it brings people together in the here and now," she says. ◼

m4d Radio was heard by 30,000 listeners across 15,000 devices in its first month of broadcast. Listen for yourself at m4dradio.com

***DID YOU KNOW?* Established in 2010 and led by Dr. Eric Smith, the Prospective Registry of Persons with Memory Symptoms (PROMPT) gathers information on people seen at the University of Calgary's Cognitive Neurosciences Clinic at the Foothills Medical Centre. It is supported by the Katthy Taylor Chair in Vascular Dementia as well as donations to the U of C for dementia research. PROMPT is voluntary — participants provide consent to have their clinic information stored in a database for purposes of research and quality improvement. They can also indicate whether they wish to be contacted for future research studies including clinical trials. Learn more at brainandmentalhealthclinics.ca**

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CARING FOR YOUNG CAREGIVERS

The Young Caregivers Association's Powerhouse program combats isolation with virtual programming

BY **Nathan Kunz**

THE RESPONSIBILITY of caring for someone living with a chronic condition can be stressful and all-consuming, though the effects on children and young adults in support positions often go overlooked. The Young Caregivers Association (YCA) is looking to change that.

"We can't change their situations, but we can help them learn how to cope and deal with them. Then, we're hopefully setting them up to be stronger adults, being able to deal with caregiving as they continue to grow," says YCA executive director Michelle Lewis. "There's an undeniable need. And there's undeniable impact that services and support can provide these families."

Through Powerhouse — the name given to encapsulate the YCA's programs and services for young caregivers — the southern Ontario-based registered charity offers peer support gatherings, camps and counselling to young people under the age of 25 who play a role in support. Powerhouse's virtual supports can be accessed by young caregivers anywhere in Canada. While originally focusing on dementia caregivers, the YCA quickly expanded to children and young adults caring for someone with illnesses, disabilities, addiction and other ailments.

From the beginning, the central focus of all YCA Powerhouse programs has been combatting isolation and loneliness by bringing young caregivers together, allowing them to just be kids. As the COVID-19 pandemic hit Canada in early March, however, concerns surrounding the effects of staying at home began to arise.

"We had kids reporting that they were feeling even more isolated and lonely. They weren't able to get a break from caregiving because everybody was isolated at home," says Lewis. "[Transitioning quickly] was top of mind."

By March 13, 2020, the decision was made to cancel in-person events and move online to offer support. YCA staff worked to develop virtual Powerhouse programs in order to continue connecting young caregivers, all while making YouTube videos and remotely checking in with families in the interim.

Within a month, free virtual programs were up and running, and have continued to run through to the fall. Facilitated through Zoom video conferencing, programs include hour-long "Time for You" sessions to share experiences with caregivers of similar ages, along with all-ages "Fun With Powerhouse!" programs that include games and crafts, and the four-week "Caring and Connecting" program focused on breaking down barriers through peer connection.

The addition of online programs also contributes to expanding the group's reach, a trend Lewis hopes to continue. Further efforts are underway to work with provincial caregiver organizations in Nova Scotia, British Columbia and Alberta, and Lewis says she aims to one day have supports in place across Canada, ensuring no young caregiver is left to feel alone.

"We need to get to a place where all caregivers are respected," says Lewis. "And young carers are a part of that."

To learn more or register for virtual Powerhouse programs, visit youngcaregivers.ca or powerhouse.youngcaregivers.ca

YOUNG CAREGIVERS BY THE NUMBERS

1.9 million	**Canadians ages 15 to 29 perform unpaid care work**
5%	**spend 30 hours or more a week as carers**
19%	**care for 3 or more people**
27%	**care for parents**
47%	**are still attending school**
7%	**stopped attending school to focus on caregiving**

DID YOU KNOW? ***Unpaid care provided by young caregivers corresponds to an annual savings of $25,000 to $50,000 for the family and/or health-care system. Also, a majority of Young Caregiver Association participants are even younger than the national average, ranging from five to 14 years old.***

A PROACTIVE MODEL

MINT Memory Clinics provide compassionate, collaborative care

BY **Colleen Biondi**

Dr. Linda Lee has been a committed family physician in Kitchener-Waterloo for more than 30 years. Throughout her career, she began to recognize gaps in how people living with dementia and other memory disorders were cared for. After becoming aware of her patients' memory concerns, both Lee and her patients experienced challenges in accessing counselling supports, education,

> "If we can deliver the kind of care that older adults deserve, we will have done our job." —Dr. Linda Lee

in-home care and specialists like geriatric psychiatrists or cognitive neurologists. Waitlists and barriers to access — like patients having to drive long distances to multiple agencies — made the system far from user-friendly.

"I recognized how people living with dementia were being cared for," says Lee, who is also a researcher and associate clinical professor in the department of family medicine at McMaster University and a Schlegel Research Chair in Primary Care for Elders. "I decided what was needed was a model to address these issues through the primary care system."

In 2006, she opened the first of what are now called the MINT Memory Clinics in her hometown. MINT is an acronym for multispecialty interprofessional team, and that sums up its unique approach to partnership. One referral to a MINT clinic (there are now 115 of these no-cost sites operating in Ontario) will give the client and family access to a full assessment with a comprehensively-trained team of professionals such as family doctors, nurses, social workers and staff from local Alzheimer societies when available — at one time in one location. Unnecessary medicines may be described, and more appropriate ones may be prescribed, information is shared, strategies are organized, and follow-up plans are scheduled on the spot.

MINT IS AN ACRONYM FOR

Multispecialty Interprofessional Team

This progressive model is reaping personal and system benefits — 96 per cent of patients and caregivers surveyed said they would recommend it. An independent provincial evaluation showed clients using MINT clinics had fewer trips to the emergency department, fewer hospitalizations and stayed at home longer. Only 10 per cent needed referral to a specialist, instead of 100 per cent of people with dementia who were not associated with a MINT clinic. Now, wait lists for accessing dementia care are 50 per cent shorter with MINT clinics in place and wait times for accessing specialist care are shorter as these are reserved for only the most complex cases, says Lee. It is estimated that MINT clinics have provided service to over 50,000 individuals (patients and caregivers) to date.

And the MINT model is reaching diverse groups — clinics are located in Korean, Cantonese, Francophone and Indigenous communities (many staff are fluent in respective languages). The clinic has also served people who are homeless and those who live in rural environments.

Lee has developed a nationally accredited training program for MINT clinic team members. The five-day curriculum (three days of workshops; two days of on-site training), covers topics such as delirium, depression, dementia and other memory disorders, medication optimization, driving safety, lifestyle interventions and addressing caregiver needs. And, during the first two days of a new clinic's opening, Lee and her team provide one-on-one mentoring to help members work together as a highly functioning team.

This proactive care model provides ethical and compassionate help across the trajectory of the dementia experience, she explains. "It is about adapting the model — according to best practises and guidelines — to serve the client. There is a lot to consider for an accurate diagnosis, assessment and a comprehensive plan of management."

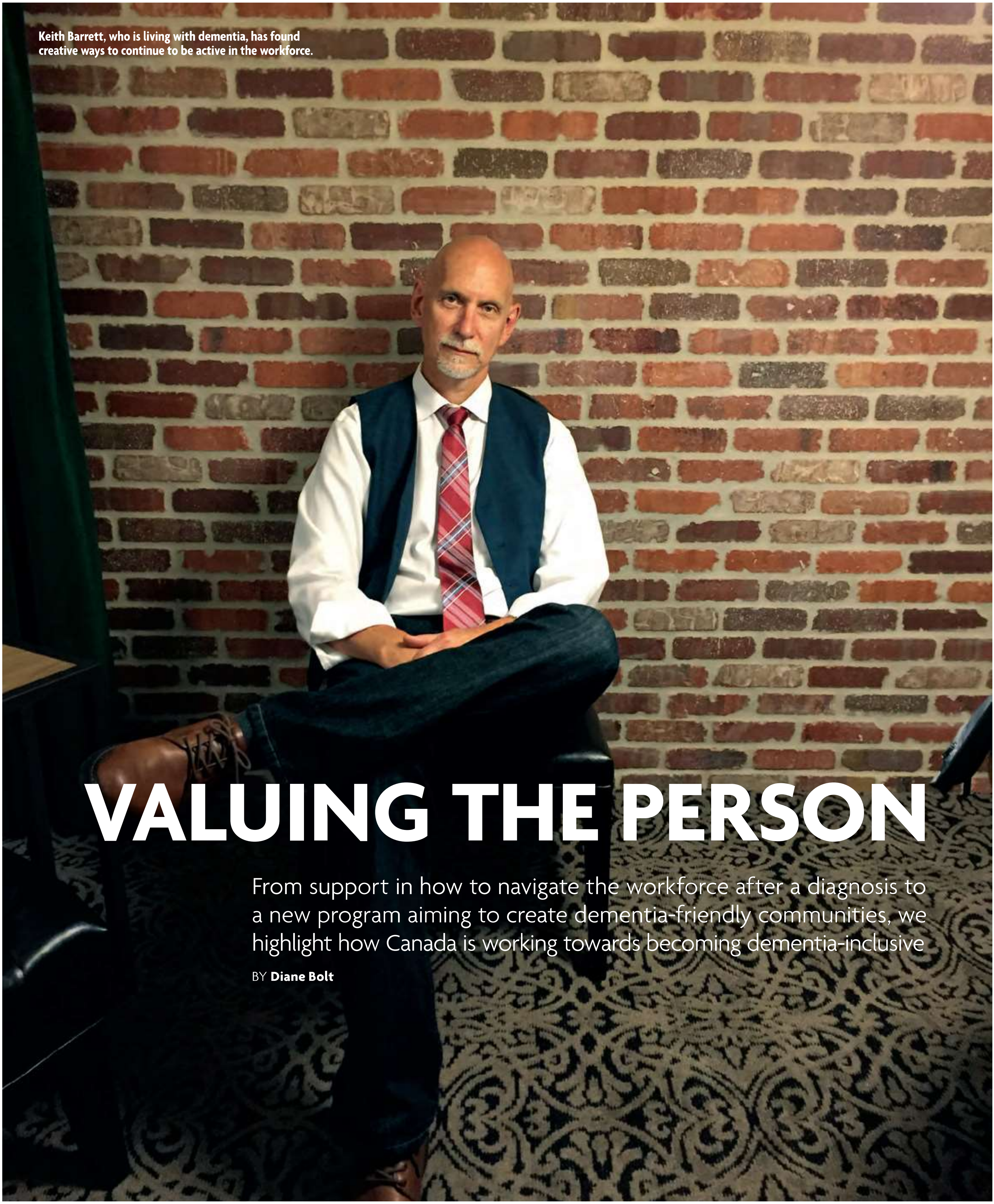
To Lee's knowledge, it is the first primary care initiative of its kind with published outcomes that demonstrate impact in improving health system capacity for dementia care.

Currently, Lee is expanding MINT clinics outside of Ontario. "We are excited to share this model of true collaboration," she says. Calgary is expected to open four test sites in the spring of 2021.

Lee is honoured to spearhead this drive moving forward. "Dementia affects people in such a life-changing way," she says. "If we can deliver the kind of care that older adults deserve, we will have done our job."

To learn more, visit mintmemory.ca

Facing page: istockphoto.com/ SDI Productions; this page: courtesy Dr. Linda Lee



Keith Barrett, who is living with dementia, has found creative ways to continue to be active in the workforce.

VALUING THE PERSON

From support in how to navigate the workforce after a diagnosis to a new program aiming to create dementia-friendly communities, we highlight how Canada is working towards becoming dementia-inclusive

BY **Diane Bolt**

RECEIVING A DEMENTIA DIAGNOSIS while still active in the workforce can add another stressful layer to adjusting to a new normal. For many, continuing to work may be necessary for financial reasons or because it's better for their well-being. Whatever the reason, navigating the landscape of the workplace while living with dementia is challenging.

Keith Barrett was 57 years old when he was diagnosed with young-onset dementia in 2016. At the time, he was a co-owner of a company called Partners in Parenting, a child, youth and family-centered support service based in Eastern Ontario. Barrett was responsible for financial and facilities management and human resources, which involved hiring, leading and training teams of people.

After his diagnosis, Barrett began experiencing challenging symptoms, including struggling to retain people's faces and names, as well as processing new information. But his new normal really hit home while he was doing a corporate training presentation.

"This was a presentation I gave once or twice a month and so I didn't need to have it scripted, but [suddenly] I couldn't maintain my sequence of thinking," he says.

In order for Barrett to continue in his role, he devised solutions with his business partner, Christine Rondeau, that included narrowing the scope of his responsibilities, implementing a cross-referencing system for his tasks and reducing his work week from 40 to 20 hours.

"I'm able to continue to work because Christine and Partners in Parenting supported my focus to be on my abilities and more narrowed to the financial side, and on what I could still do," he says.

Barrett has since sold his portion of the company to his business partner, but at the time, he was in somewhat of a fortunate position. As a co-owner, he felt empowered to work with his team to implement initiatives that allowed him to continue working — something that was beneficial for his well-being and the company.

"It shouldn't be an employer telling people what to do. The old adage applies that if you involve everyone in the decision-making, the better off the decision will be," says Barrett.

People living with dementia still have valuable knowledge, experience and skills to share and Barrett believes there are greater benefits for society as a whole to keep those living with dementia contributing to the workforce for as long as possible.

"The duty to accommodate is hard. It's hard for the person who needs the accommodation. It's also hard for employers to make it all fit. But that's the way our world is, and it's mutually respectful and, in part, helps to reduce the stigma surrounding dementia," says Barrett.

Alberta Employers Dementia Awareness Program

Monique Trudelle is the lead for Special Projects with the Alzheimer Society of Alberta and Northwest Territories. Trudelle is heading up the Alberta Employers Dementia Awareness Program, a pilot project that is part of the Government of Alberta's Dementia Strategy and Action Plan. The program is in its infancy but aims to increase awareness of dementia for employers and employees. Employers have a duty to accommodate legally under the Alberta Human Rights Act and, in some cases, under the Workers' Compensation Act.

"The aim is to build a practical guide so that employers have a one-stop-hub for information on how to support those living with dementia and their [care partners] and also help those living with dementia access the resources they need to approach their employer with their diagnosis," says Trudelle.

The project aims to create access to resources such as how to create a dementia-inclusive workplace, advice on combating the discrimination and stigma attached to dementia, respectful language to use and how best to support people living with dementia. It also may include example scenarios, like Barrett's experience adjusting his workflow.

"A dementia diagnosis doesn't necessarily mean a person can no longer do their job," says Trudelle. "It means that individualized accommodations need to be made — because there's no one-size-fits-all approach to supporting individuals living with dementia."

Trudelle hopes the program will raise employers' levels of understanding and knowledge regarding their duty to accommodate while also educating those living with dementia and their carers on their rights.

As for Barrett, he is excited to continue to work for as long as he is able.

"My decline is really slow and that's a good thing. If this is a trip, I'm going to take the long way around," he says. "You've got to just run with it."

> "It shouldn't be an employer telling people what to do. The old adage applies that if you involve everyone in the decision-making, the better off the decision will be." –Keith Barrett

Courtesy Keith Barrett

DEMENTIA-FRIENDLY CANADA: SAFE, VALUED AND EMPOWERED

LAUNCHED IN APRIL 2019, the Dementia-Friendly Canada project is a four-year initiative spearheaded by the Alzheimer Society of Canada in partnership with the Alzheimer Societies of B.C., Saskatchewan, Manitoba and Ontario. The project is funded by a $940,000 investment from Health Canada and the Dementia Community Investment, administered by the Public Health Agency of Canada. It aims to make communities more inclusive and approachable so Canadians living with dementia can feel safe, valued and empowered. With input from focus groups including people living with dementia, their care partners and community service agencies, the project builds on existing dementia-friendly initiatives across Canada.

For Maria Howard, the chief executive officer of the Alzheimer Society of B.C., community can be defined in many ways.

"A community can be a city, a town or it could be a library or book club. Being dementia-friendly means there's an awareness of how to support people living with dementia. It means creating a respectful and flexible place," she says.

Dementia-friendly support could mean providing designated shopping hours, developing a "dementia-friendly zone" logo for participating businesses to display, implementing easier-to-read signage and more accessible environmental design and providing education to debunk dementia myths and stigma.

Some of the highlights of the project for Howard have been how receptive people are to participate, as well as the level of government support.

"The fact that Health Canada and the Public Health Agency of Canada are behind this project [demonstrates] that Canada is taking a firm step forward in becoming a dementia-friendly country, which is what we should be given the number and frequency of people who are being diagnosed with dementia," says Howard. "We have to get to the place where the acceptance, support and acknowledgement of people living with dementia is normalized."

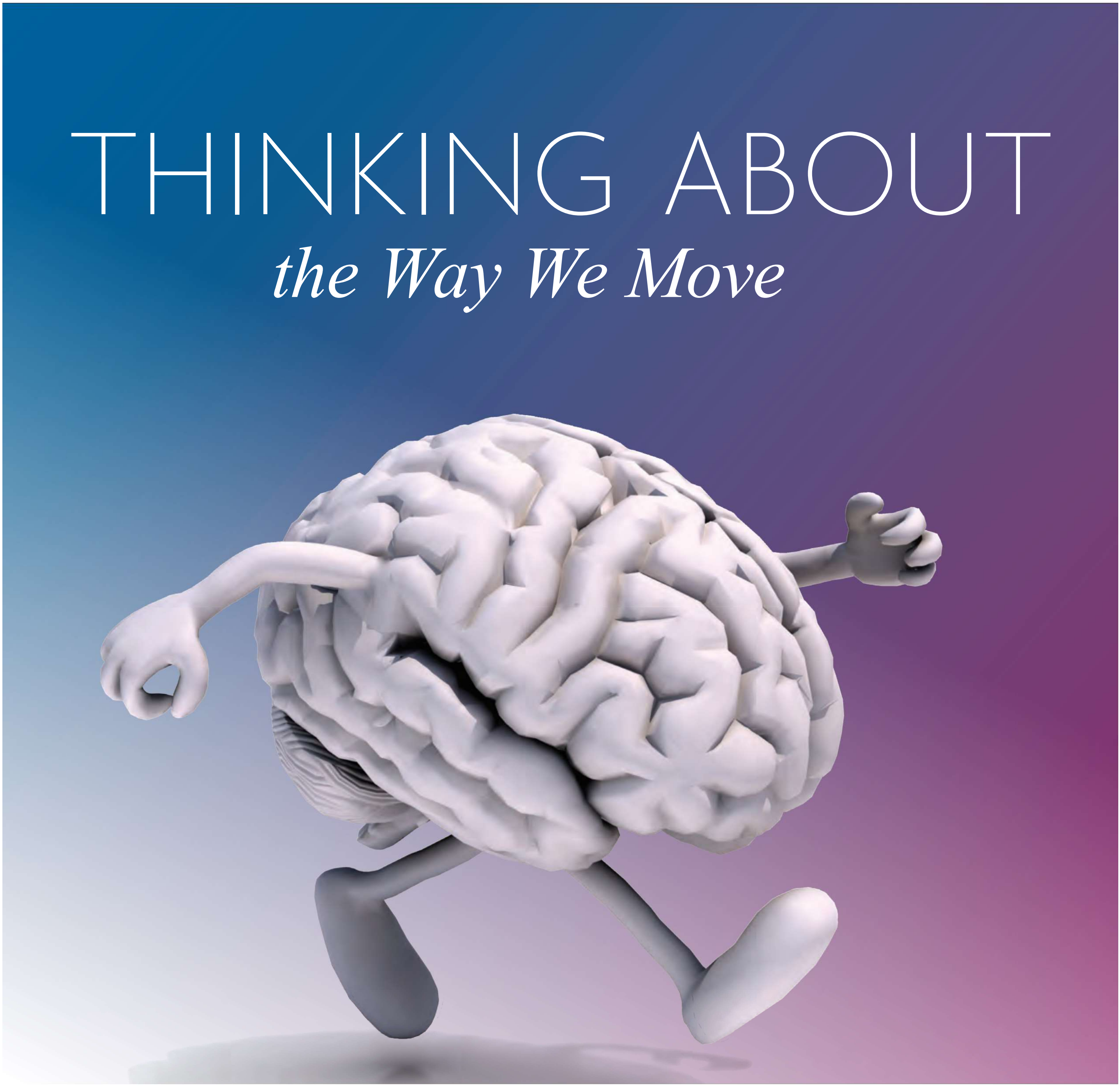
Photo by Flora Gordon

> "Being dementia-friendly means there's an awareness of how to support people living with dementia. It means creating a respectful and flexible place." –Maria Howard

DEMENTIA-FRIENDLY CANADA PROJECT GOALS INCLUDE:

- Training Canada's workforce through a mixed-method approach to ensure that people across diverse cultural, geographical and sector groups and the general public have access to practical information, education and tools about dementia.
- Promoting and enabling an understanding of dementia by incorporating the voice of people living with dementia, through awareness campaigns, and access to practical tools and resources.
- Achieving sustainability and scale-up Dementia-Friendly Canada by using research methods to assess the effectiveness of community-based interventions.
- Running the program in English, French, Cantonese and Mandarin.
- Rolling concepts out to other sectors, provinces, individuals and groups for a larger scale impact.

THINKING ABOUT *the Way We Move*



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Dr. Manuel Montero-Odasso is researching the connection between gait and cognition, as well as the potential effectiveness of lifestyle interventions that could limit the decline of both

BY **Karin Olafson**

Photo courtesy Dr. Manuel Monter-Odasso

For some, it might feel like walking requires no thought at all. But our gait — the technical term used to describe the way we move — isn't automatic.

"Mobility and cognition decline together in aging. They interact. If I see a patient with mobility problems [or] fractures, it's not uncommon that I detect undiagnosed cognitive problems," says Dr Manuel Montero-Odasso, a geriatrician based in London, Ontario. "And when I see a patient with cognitive problems or pre-dementia, it's not uncommon I diagnose mobility problems."

Montero-Odasso has studied the connection between gait and cognition since the 1990s. He is a professor in the departments of medicine, and epidemiology and biostatistics at Western University. He is also the director of the Gait and Brain Lab at the Parkwood Institute, which he started in 2010, and where he researches how gait changes can be a predictor for dementia, as well as how non-invasive interventions might reduce the risk of mobility and cognitive decline.

> ["Interestingly, in the '90s we thought that gait problems were a late complication of dementia, but studies show that [gait] changes are actually earlier indicators of cognitive impairment." –Dr. Manuel Montero-Odasso]

The connection between gait and cognition

The same part of the brain — the frontal lobe — controls both complex cognitive processes, like language, problem solving and emotion regulation and how we control movement.

In an article published in the *European Journal of Neurology*, Montero-Odasso explains this connection in greater detail: "Cognitive function, especially executive function and memory, rely on frontal-hippocampal and thalamic-striatal circuits [in the brain], which also control gait, spatial orientation and navigation."

Yet a changing gait does not lead to cognitive decline, nor does cognitive decline lead to changing gait. "We believe that both features are an expression of the same problem at the brain level," explains Montero-Odasso, but adds that the specific mechanisms connecting the two are still not fully understood.

The early indicators of cognitive decline

Changes in movement that might indicate cognitive decline include a slowing gait and smaller, shuffling steps.

"But that doesn't mean that everyone whose walk slows will [develop] dementia. And that doesn't mean everyone who develops dementia will start walking slowly," says Montero-Odasso. "Interestingly, in the '90s we thought that gait problems were a late complication of dementia, but studies show that [gait] changes are actually earlier indicators of cognitive impairment."

In fact, a decline in gait speed can precede cognitive decline by more than a decade. Through his research, Montero-Odasso incorporates something called dual-task testing. This assesses an individual's risk of progressing from mild cognitive impairment to dementia.

"In dual-task testing, you put stress [on the activity of walking] by adding an extra cognitive task," says Montero-Odasso. He tests his patients by having them walk up and down a corridor while simultaneously performing a cognitive task, like talking or doing calculations. Everyone's gait will likely slow down during a test like this, but it's the degree of change that can

GET MOVING

Incorporate more physical exercise into your day by exploring these walking routes in Alberta.

Henderson Lake Park, Lethbridge
Walk the 2.5-kilometre loop around the man-made lake and stop to enjoy the scenery in the Nikka Yuko Japanese Garden along the way.

Nose Hill Park, Calgary
Feel like you've left the city by exploring the many trails here. For great city views, try the Edgemount Ridge route.

Terwillegar Park, Edmonton
Admire views of the North Saskatchewan River. For a longer walk, take the footbridge across the river to Oleskiw River Valley Park.

be an indicator of cognitive decline.

"We found that in people over 65, a slowing down in gait of more than 20 per cent [during a dual-task test] means those people in particular are more likely to [develop] dementia," says Montero-Odasso.

He adds that if his patients decline in both gait speed and cognitive functioning, month by month over a six-month period, they are considered dual-decliners. A study he published earlier in 2020 in *Age and Ageing* found dual-decliners had a three-fold risk of progressing to dementia compared to non-dual decliners.

Can the risk of decline be reduced?

Currently, Montero-Odasso is leading a national trial to analyze the effects of combining physical exercise, cognitive exercises and vitamin D supplementation. His SYNERGIC Trial is tracking whether this combination of interventions could prevent both cognitive decline and mobility decline in adults living with mild cognitive impairment.

While the results of this trial — including recommended physical exercises, cognitive exercises and dosages for supplementation and exercise — aren't released yet, Montero-Odasso says there are steps that can be taken to reduce one's risk of both cognitive decline and mobility decline.

As well as incorporating dual-task gait assessments into any geriatric check-up, Montero-Odasso says that preventing mobility and cognitive decline should focus on lifestyle interventions. Emerging evidence shows up to 35 per cent of dementia cases could be prevented by modifying 12 lifestyle risk factors, one of which is physical inactivity.

"Sometimes you cannot prevent dementia entirely, but you can delay [some types] of dementia," says Montero-Odasso. "I think today, treatment for dementia is prevention and that prevention should be lifestyle interventions: having a healthy diet, doing physical exercise and doing cognitive training. Right now, we don't know how to prescribe that for older people, but we are in the state of research." ▮

RETRAINING GAIT

James McLoughlin is an associate professor in the College of Nursing and Health Sciences at Flinders University, based in Adelaide, Australia. With over 20 years as a neurological physiotherapist, McLoughlin uses mobility and exercise intervention to help retrain gait in his clients who experience cognitive changes.

"From what we know, safe mobility and exercise practice can help [slow physical and cognitive decline], especially when practised over the longer term," says McLoughlin. "[We] are very interested in providing exercises that work on specific skills that can carry over into real-life scenarios. [These] might also be very easily added into a more generic exercise program.

"By far the most common exercises we use early on are weight-bearing strength exercises," says McLoughlin. "It is important to remain strong in the legs especially, while also keeping the ability to have large enough quick steps that can save you in a stumble or trip."

Q+A

Dementia Advocacy Canada co-chair Mary Beth Wighton breaks down what it means to be an advocate

BY **Nathan Kunz** PHOTOGRAPHY BY **Peter McNeice**

FOR MARY BETH WIGHTON, being an advocate is at the core of who she is.

"I truly believe that I have dementia because I was meant to," says Wighton. "When we talk about, 'What do you think you're on earth for?' I think I'm on earth to be an advocate."

As founding member and co-chair of both the Ontario Dementia Advisory Group and Dementia Advocacy Canada (DAC), Wighton, who was diagnosed with frontotemporal lobe dementia in 2012, is passionate about using her position to help amplify voices with lived experience. She works to ensure that people living with dementia have a say in the matters that impact them daily.

Here, Wighton speaks about how she defines her work, the importance advocacy continues to hold and what she hopes to pass on to advocates who succeed her.

Q | How do you define advocacy?

A | We have different types of advocacy. You can be an advocate for yourself. You can be an advocate for others. You can be an advocate at a national or international level. But when we break down what it means, it's standing up for things that you believe are right — perhaps on a moral basis, perhaps just simply on a human rights basis. And that need is in all types of advocacy.

Q | What's the importance of being an advocate for yourself?

A | It is extremely important to advocate for yourself. You are your own expert. You must raise your voice and state what you need, want and have the right to. By doing this, you are taking the reins to your life and working to have others understand you. We cannot assume people know what is best for us unless we tell them. Self-advocacy takes practise and may be scary initially, but you can do it.

Q | What's the importance of collective advocacy through organizations like DAC?

A | When you band together and have a collective input on priorities, and people understand what those priorities are and what they're advocating for, it provides a stronger voice. If all of us go to the government, 465,000 people one at a time, then we're just 465,000 people one at a time. But if we stick together and we say, 'These are the three things that we want, and if we don't get it, then 465,000 people are not going to vote for you,' that gets a little stronger. So, we're able to have a larger impact, and maybe a more profound impact, than individually in activism.

Q | You've put in a lot of work as an advocate – why do you do it?

A | It has provided a sense of purpose for my life. I'm retired, so I get a fulfillment. It feels good to have a purpose every day. And often it is every day.

But with that said, I am cutting back and moving to full retirement. Because my dementia itself is changing, it's getting worse. And this advocacy comes at a cost — if I'm here with you, I'm not with my partner. That's the cost.

So, my advocacy is moving from, 'It makes me feel good,' to 'I need to help identify and promote other advocates so that us old dogs can retire and not feel guilty.' That's the challenge right now.

Q | Why should people get involved in advocacy work?

A | People should advocate because you can change something that you're not happy with. You can move things forward that perhaps are stagnant. And by raising your voice, you can move that beyond the metre. You can participate as an advocate because it will make you feel accomplished, and inside you know you've done something good — something you can be proud of. ■

ORGANIZATIONS FOSTERING DEMENTIA ADVOCACY:

Local

DEMENTIA NETWORK CALGARY

Founded in 2013, Dementia Network Calgary is a growing group of passionate, knowledgable stakeholders from across private, public and non-profit sectors. Focused on Calgary and area, DNC is taking a collaborative approach to tackling the complex issue of dementia.

National

DEMENTIA ADVOCACY CANADA

Co-chaired by Wighton along with *Dementia Connections* editor Lisa Poole, Dementia Advocacy Canada is a grassroots organization dedicated to influencing policy, informing program development and improving access to nationwide supports and services for those living with dementia and caregivers.

International

DEMENTIA ALLIANCE INTERNATIONAL

Dementia Alliance International aims to unify the voices of lived experience worldwide to urge government, private sector and medical professionals to take action in addressing dementia as an urgent global crisis.

Share your questions with us at feedback@dementiaconnections.ca

AN INDIVIDUAL CHOICE

Calgarian Duncan McLean, who was living with dementia, made the decision to access medical assistance in dying earlier this year. Here, he shares what choosing to die on his terms meant to him

AS TOLD TO **Nathan Kunz**

***In November 2019,** Duncan McLean began his journey towards accessing Medical Assistance in Dying (MAID).*

In 2017, at 55 years old, McLean was diagnosed with early onset Alzheimer's disease. He left his successful career in IT equipment sales and marketing and, in hopes of helping both himself and others living with dementia, took part in clinical trials and advocated for dementia care through fundraisers and other initiatives.

Following the difficult news that a promising drug trial he was participating in had been cancelled due to insufficient effective evidence, McLean weighed his options and began looking into MAID. Since 2016, eligible Canadians have been able to access MAID through the passing of federal legislation Bill C-14. The word "eligible," however, has been contentious, particularly within the dementia community, as imminent death as well as mental competence and the ability to make decisions immediately before the procedure remain a requirement. Advance requests are not available under current legislation, rendering most people living with dementia ineligible as they often lose their decision-making capacity long before they reach the required end-of-life status.

While McLean noted that he still felt healthy in many ways, he knew he wasn't going to get better. He made the decision to pursue his right to die, and proceeding months were spent carrying out the necessary safeguard steps, including speaking with independent physicians to confirm eligibility. Once it was determined he was eligible, McLean scheduled the procedure, an administration of drugs, for mid-July 2020.

Two weeks before his death, McLean spoke with Dementia Connections *about why he decided to exercise his right to medical assisted dying, and what the choice meant to him.*

Photos courtesy McLean family

McLean with his wife, Genevieve.

“I did notice that after the trial, things were starting to get a little bit harder than they were before, and then [started] realizing that there wasn’t really much anyone could do for me. I guess from my perspective, I didn’t want to end up going into a care home. If someone wants to do that, it’s their choice — I just would never want to do that. So that was my next play — what do I do? That’s when I started looking into this MAID thing.

“I had to go through quite a few people to get to where I wanted to be, and I felt like I actually was able to explain to them why I was doing this. And I sort of like the way MAID did it, because they actually did challenge me, which I think they should. But I got through that test.

“I had to go through a couple of doctors and a psychiatrist, and I had to walk them through what my life was like and what I wanted to do. And fortunately, they agreed. That was a big moment for me, because I didn’t want to have any hassles from other people. So that made me a bit happier, if you can call that happy.

“I’m not going to get better. That was the key for me — I knew that I wasn’t going to get better. And I also obviously wanted my family to continue their lives, because living with this is not good for anybody. Certainly, not for me, but also not for the other people in my family, who are sad, no question about it, but it’s time for them to move on, too. I probably could go on for a bit longer, but from my perspective, I’m not really interested in doing that.

“I believe in this. I think this is the right thing to do for the right person — I would not say, ‘You should do that.’ I would never tell anybody that. It’s a personal thing. I thought this through based on everything I tried. I really would have liked to overcome dementia, but there was nothing there, and there was no future for me. So that’s when I decided I’m going to deal with how I’m going to die. And fortunately, I think, I was allowed to do that.

“This is my journey. I don’t want to be viewed as the guy that’s doing something crazy, which I’m not. Or pushing other people to go ‘Oh, I should do that.’ Keep on making your own decisions — that’s all I can say to that.”

“No one pushed me. It’s an individual decision, and individuals will make their own decisions. And that’s the way it should be.”

Duncan McLean passed away July 14, 2020 with family at his side.

[“This is my journey. I don’t want to be viewed as the guy that’s doing something crazy, which I’m not. Or pushing other people to go ‘Oh, I should do that.’ Keep on making your own decisions.”]

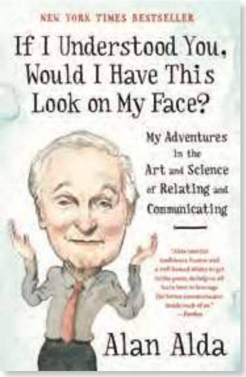
—Duncan McLean

4 BOOKS TO READ TODAY

BY **Meg Braem**

For This I am Grateful: Living with Dementia *By Christine Thelker*

Having worked as a nurse in dementia care, Christine Thelker felt that a dementia diagnosis was the worst news a person could receive. When Thelker's doctor told her that she had vascular dementia at 56 years old, she gave up her home, her car and her ability to drive along with her hopes and dreams. However, despite anticipating the losses ahead, Thelker decided, "I'm not done yet." Thelker found a new purpose as an advocate for others living with dementia through Dementia Alliance International. For This I am Grateful *recounts her discovery that life continues to be beautiful living with dementia.*



IF I UNDERSTOOD YOU, WOULD I HAVE THIS LOOK ON MY FACE?

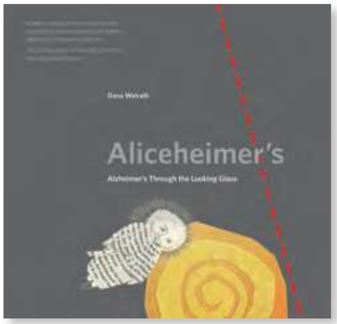
By Alan Alda

Best known for portraying Captain Hawkeye Pierce on the television series *M*A*S*H*, actor, screenwriter, comedian and author Alan Alda has spent decades exploring how people relate to each other. Motivated by his experience sharing medical knowledge as host of PBS's *Scientific American Frontiers*, he began exploring how to improve communication between doctors and patients. *If I Understood You* uses improv, storytelling techniques and scientific research to guide better communication with all the people in our lives.

WEEDS IN NANA'S GARDEN

By Kathryn Harrison

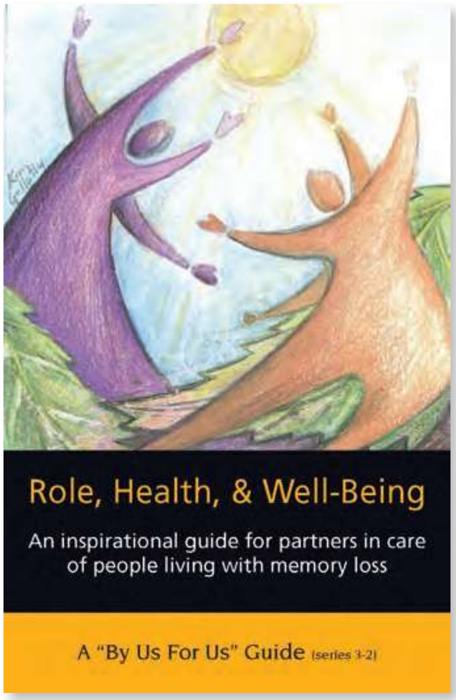
In this all-ages book, we meet a young girl and her grandmother who share a love of gardening, but one day weeds appear in their treasured plot. The girl discovers that her grandmother has Alzheimer's disease tangling her thoughts like the weeds do their flowers. Kathryn Harrison's beautiful illustrations help children understand and cope with the difficult changes that happen when a loved one has dementia. A donation from the purchase of each book goes to the Alzheimer Society of Canada.



ALICEHEIMER'S: ALZHEIMER'S THROUGH THE LOOKING GLASS

By Dana Walrath

In Dana Walrath's graphic novel, she creates a series of illustrated vignettes about the shared journey of mother and daughter living together after her mother, Alice, develops Alzheimer's disease. Using cut-up pages from Lewis Carroll's *Alice's Adventures in Wonderland*, Walrath rewrites what we think about aging, inviting us into a world of pirates, time travel and dead fathers who hover in trees. *Aliceheimer's* offers a unique glimpse into living in partnership with dementia.


Role, Health, & Well-Being

An inspirational guide for partners in care of people living with memory loss

A "By Us For Us" Guide (series 3-2)

BY US FOR US

This series of guides is written by people living with dementia for people living with dementia

When Brenda Hounam, who lives in Ontario, was diagnosed with Alzheimer's disease at age 53 in 2000, the disease was commonly thought to be something that only affected older people. Searching for resources, Hounam was dismayed to find there was no peer support near her, and the information available was only geared towards care partners rather than those experiencing the disease themselves. She also faced misconceptions such as the belief that those affected weren't able to be involved in their own care. Hounam decided to reach out to others with early-onset memory loss to find out how they took an active role in their well-being. Through her contacts with Alzheimer Society of Brant, the Alzheimer Society of Elgin-St. Thomas and the Murray Alzheimer Research and Education Program, as well as talking to several Ontario residents living with dementia, Hounam was inspired to develop the "By Us For Us" guides (BUFU). Hounam's vision was clear: to place importance first on the experiences, suggestions and tips from those directly affected BY dementia, FOR dementia. Over the years, hundreds of people from diverse backgrounds have contributed to the guides, offering insight into their unique experiences with the disease.

"It was my idea," says Hounam, "but everyone that has ever contributed in any way, that has the largest impact. The more experiences, tips and strategies that are mentioned in the guides, the better chance people reading the information have of connecting or trying suggestions. We are all unique individuals with [different] experiences and what we use to help us will be different."

By amplifying the voices of those affected, the guides create a community where people with dementia share knowledge enabling others to make empowered life choices.

"If you're speaking up for yourself, you're an advocate, for yourself and for everyone with dementia," says Hounam.

Physical copies and digital downloads of the guides are available at the-ria.ca/resources/by-us-for-us-guides

MORE ABOUT THE BUFU GUIDES

Since 2006, the By Us For Us guides have shared tips and strategies provided by people living with dementia and care partners. Typically running 30 pages, the BUFU guides are produced by the Murray Alzheimer Research and Education Program and cover topics suggested by people living with dementia ranging from finance to identity and self-worth. BUFU guides are organized into three separate series: People living with dementia, partnerships and care partners. Over the past 14 years, the BUFU development team has researched and written about themes such as safety when out and about, support matters, living safely, navigating food and mealtimes, enhancing communication and wellness, living and celebrating life through leisure, before/early diagnosis, living and transforming with loss and grief, memory workout and managing triggers. The guides are created through focus groups, interviews and questionnaire responses.

ECONOMIC STIGMA:
They will love you until they have to pay you

In her own words, Kate Swaffer shares her experience advocating for her worth

BY **Kate Swaffer**

Dementia and ageing are thriving industries, and as the global population of people over the age of 65 skyrockets, this will become more evident. There are more than 50 million people living with dementia globally, almost 10 million new cases every year, and one new diagnosis every 3.2 seconds.

There is big money in dementia, and yet, I am seldom offered a fee for my time when asked to join an advisory group, or contribute to a publication or policy review. When I have requested a fee, I've been told there isn't one and am then usually no longer invited. They do love you, until they have to pay you.

I have experienced economic stigma many times. In 2017, I was invited to be a keynote speaker at a conference in Australia, in which I requested a speaker's fee for my time and expertise. I was told that no speakers were being paid a fee so I accepted the invitation to support the organisation hosting the event. On day 2 of the conference, one of the other keynote speakers (without dementia) asked me if I had been paid. I mentioned that I'd been told categorically that no speakers were being paid. She laughed and said she and all other speakers (without dementia) were being paid. The message was clear; 'we' were not valued enough to be worthy of a fee, even though many delegates told us 'we' were a large part of why they had paid to attend.

I felt stigmatised, disrespected, and annoyed. When I called the CEO to discuss the matter, I was told that "of course we pay professionals an honorarium to respect them for their time and expertise".

People living with dementia should be respected for their time and expertise, too. Even though the vision and mission statements of many organisations claim that people with dementia are at the centre of their work, we are not fully or equally included, nor respected enough to be paid.

When organisations 'engage'

This page: istockphoto.com/ erhui1979; facing page: courtesy Kate Swaffer

“People living with dementia should be respected for their time and expertise, too. Even though the vision and mission statements of many organisations claim that people with dementia are at the centre of their work, we are not fully or equally included, nor respected enough to be paid.” –Kate Swaffer

people with dementia it presumably makes ‘us’ feel valued and included. This is not enough. In my twelve years of advocating for change, only the researchers from the University of Wollongong, and the University of Technology Sydney have agreed to pay for my time or expertise.

Sadly, there is always another person to groom as an advocate, who will initially feel thrilled to be engaged and feel valued, and not request payment. Many who are contacted to provide [free] advocacy for an organisation, will do it to have a sense of purpose and meaning again, and to feel like they are making a difference; I suggest most organisations are taking advantage of this [us]. It gives people back the life taken away via the Prescribed Disengagement® given at the time of, or soon after their diagnosis. But as soon as an advocate requests payment, or decides to voice something that is not the ‘corporate line’, they are quickly and easily replaced.

I’ve been told repeatedly, if I won’t do it for free, there are hundreds of others who will. Seriously.

There is a significant amount of resistance to paying us for our contributions, or even fully fund us to participate. I presented as an invited keynote speaker in Perth in 2015, and had to partly fund my travel costs. At this same event, I was also a speaker on a panel about dementia and employment. A representative from a large pharmaceutical company spoke about how they use ‘patients’ to inform their work. When I suggested they should pay them as consultants, in the same way they pay other experts, the response was negative. Around the world, organisatons and researchers are often required to include people with dementia in their work but are rarely willing to fund us. This includes Canada. I flew across the globe as an invited speaker at Canada’s National Dementia Conference in 2018 and was not paid for my time or expertise; worse, I had to personally fund a very significant portion of my travel expenses.

Many say they have been inspired to set up a new ‘dementia’ business because someone they loved had dementia, or are ‘inspired by people with dementia, such as the late Dr Richard Taylor’. In all the times I spoke with Richard, we both wanted PEOPLE WITH DEMENTIA to be the one’s speaking up and setting the ground rules and guidelines for their lives, not the people without dementia. It is why we co-founded Dementia Alliance International. He wanted us to speak for ourselves and despised the many who were using us for their own glory. We discussed this often, as I felt the same.

Prior to my diagnosis of dementia, I was paid for my work; since dementia, the economic stigma is such that most don’t respect me enough to pay me. The stigma will continue if those who proclaim to be inspired by someone with dementia, or who promote their businesses or research using their relationships with us, do not start to employ or pay us (or at least donate to an organisation such as DAI).


Kate Swaffer is the chair, CEO and co-founder of Dementia Alliance International.

We are a valuable ‘resource’, and provide significant contributions. Employing people with other disabilities took a long time, and, has a long way to go. For people with dementia, it is likely decades away too until organisatons start to employ us, or at least pay consulting fees.

This systemic and pervasive economic stigma discriminates against people with dementia. It also causes tension with newer advocates which, in turn, weakens the voice of the global community of people with dementia, resulting in fractured loyalties amongst dementia self-advocates.

It is doing us all harm. Even the oppressors. ◼

Anne Belliveau with her mother, Lois Buscher (Wiseman). Lois passed away in 2019.

Photo courtesy Anne Belliveau

Dementia Education is *Vital*

Anne Belliveau shares the story of her mother's experience living with dementia while undergoing treatment for cancer

BY **Anne Belliveau**

My 81-year-old mother was in the middle stages of dementia when she was taken from home to the emergency department at the Cobequid Community Health Centre in Lower Sackville, N.S.

After a worrisome 12 hours in there, we received the news: her large intestine was blocked due to a huge tumour. The tumour was just a portion of the cancer that had spread to all of her major organs.

Mom quickly forgot her diagnosis. We were devastated, and looking back, I blame the dementia for masking this disease, but that is a different story for another time.

Two days later, she went into surgery. The tumour could not be removed, so a colonostomy was performed and we were told she probably only had a few months to live.

I think it is imperative to note that I believe my mother received excellent care during her month-long stay in the hospital, and it was largely due to the excellent staff and a family that advocated for her continuously. However, we must not ignore important issues that require resolution.

Our first concern after Mom was transferred to a surgery ward was her safety. She did not remember where she was or why. She did not remember that she had a catheter or an ostomy bag with which she required assistance.

The family knew it was not safe for Mom to be alone. A family member was with her each day from 6:30 a.m. until 10 p.m. We had to convince the staff to arrange for a sitter for overnight care on more than one occasion.

> “I call on you to take my mother’s experience as one small example of the work that needs to be done to improve dementia care in our hospitals.” —Anne Belliveau

One night, she tried to get up on 16 separate occasions, and without support she would have fallen. For the first few days of her stay, our family spent a great deal of time educating the two charge nurses on Mom’s level of dementia. On many occasions, we experienced staff asking her questions that would affect her care, but due to the dementia, she would often fabricate an answer or answer inappropriately.

Although the charge nurses remained constant in Mom’s care, she had a different nurse with each rotation, and not all were educated on dementia or her abilities.

At one point, family asked for there to be a sign posted on her bed to inform all auxiliary staff that she had cognitive limitations.

Hospital staff felt this was an invasion of her privacy and therefore, this idea was not implemented. As a result, nurses, laboratory technicians, food service workers and transport clerks were not aware of, or educated in, ways to best communicate with her.

Mom would not have been able to complete menu request forms or sustain a level of eating that would prevent malnourishment if it were not for family.

Shortly after Mom’s surgery, the focus of her care was to build her strength, preparing her to return home. She was denied extended physical rehabilitation due to her dementia, as she would never be able to live independently.

Sadly, Mom did not regain all of her strength and was eventually released from the hospital one month later. She was transported home by ambulance to live for nine more months, bedridden, under the care of her family and an incredible team consisting of palliative care, Victorian Order of Nurses (VON) nurses, continuing care and continuing care assistants.

This came with its challenges, but again a story for another time.

I call on you to take my mother’s experience as one small example of the work that needs to be done to improve dementia care in our hospitals. Together, let’s demand it from our elected representatives.

Learn more about how to be an advocate for yourself and others on page 30.

BELLIVEAU’S 5 STEPS FORWARD

On June 17, 2019 the federal government released its first national dementia strategy. This is a first step in making care better, but the strategy focuses on home care, social programs and long-term care. Hospital care is not mentioned. At each turn of Mom’s hospital stay, there was an explanation to be given, a hurdle to jump through, or a possible difficulty to mitigate due to lack of communication, resources or education for staff when it comes to dementia patients.

These are the changes I believe are needed to improve hospital care for people with dementia:

① Create a safe “dementia-friendly” ward for patients with dementia.

② Assess how safe it is to leave a patient unattended.

③ Improve dementia education for hospital staff.

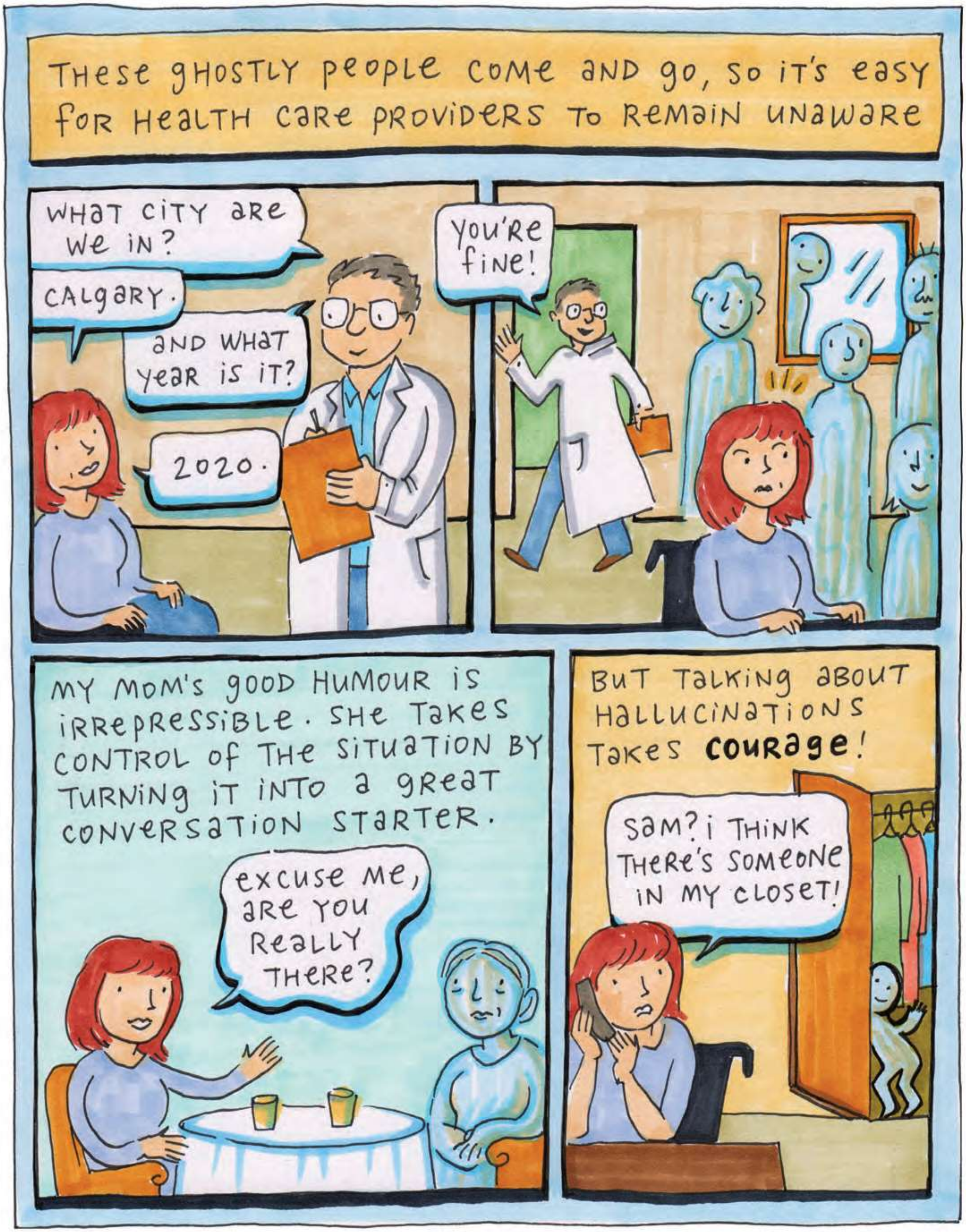
④ Create an effective means of communicating a patient’s level of cognitive ability among hospital staff.

⑤ Create small, dedicated care teams.

Conversations with my *Mother*

STORY BY **Sam Hester and Jocelyn Burgener** ILLUSTRATIONS BY **Sam Hester**

In our ongoing series, Calgary-based artist Sam Hester and her mother, Jocelyn Burgener, share their candid, heartfelt and oftentimes humorous conversations. Burgener served as MLA for Calgary Currie for two terms and is an arts advocate and author. She has been living with Parkinson's since 2003 and was recently diagnosed with dementia.


These ghostly people come and go, so it's easy for health care providers to remain unaware
What city are we in?
Calgary.
And what year is it?
2020.
You're fine!
My mom's good humour is irrepressible. She takes control of the situation by turning it into a great conversation starter.
Excuse me, are you really there?
But talking about hallucinations takes **courage**!
Sam? I think there's someone in my closet!


I JUST TRY TO STAY REASSURING AND CALM.
I'LL ASK THE NURSE TO CHECK, OK?
(IT'S OK KIDS, NANA'S OK!)
TALKING ABOUT IT HELPS HER TO REGAIN INSIGHT.
NOBODY THERE, YOU'RE OK!
THANKS!
I MISS JUST TALKING WITH HER ABOUT EVERYDAY THINGS.
HOW'S YOUR WRITING GOING?
NOT GREAT. MAYBE I NEED A GHOSTWRITER!
I ALREADY HAVE THE GHOST!
SHE'S ALWAYS BEEN A COMMUNICATOR, AND A CONNECTOR. SHE'S STILL USING THOSE SKILLS.
SHE CAN MAKE FRIENDS WITH ANYONE...
... WHETHER THEY ARE REAL OR NOT.
sh.

EMPOWERING TECHNOLOGY

BY **Sean P. Young**

A portable wheelchair lift and online games help ease social isolation

Lift2Go's modular design means customers can set it up easily in minutes without tools.

This page: photo courtesy Graham Smith; facing page: screenshots courtesy David Kaufman; istockphoto.com/ stockstudioX

1 *Increasing Independence*

Lift2Go is a portable wheelchair lift for temporary applications made by Calgary-based Adaptive Concepts Ltd. The modular design allows customers to transport and set up the lift, without tools, in minutes, giving people in wheelchairs, scooters and other mobility aids temporary access over stairs.

"It's a piece of equipment, but what it represents for the users is freedom, independence, mobility and, in some cases, the ability to be at home with loved ones," says Graham Smith, president, Adaptive Concepts Ltd.

Smith says his company saw a dramatic increase in the need for wheelchair lifts and ramps in Calgary in March 2020.

"When COVID hit, we heard from our colleagues at Alberta Health Services that they were struggling to get people out of hospitals to make room for COVID patients," he says.

To help people transition from hospitals to their homes, Adaptive offered a revolutionary pay-what-you-can lifting service, setting up temporary lifts at homes in the Calgary area.

"These were people who didn't need to be in hospital for medical reasons, it was simply they were in wheelchairs and there was no way to get them up five steps to their front porch," he says. "It felt great to give back to the community."

Smith says in addition to helping facilitate early hospital release, his customers are renting mobile lifts because they are postponing sending their friends or family members to long-term care facilities due to the pandemic. He also says that awareness about the negative effects of social isolation, particularly for those living with dementia, is increasing demand for his company's services.

"They're renting one of our lifts for as little as a few hours and because the deployment time and cost are so low, that becomes a practical thing."

To learn more about Lift2Go, visit lift2go.com. To learn more about a Mobilift, a portable lift solution that is offered by Adaptive Concepts' sister company, Adaptive Engineering, visit adaptivelifts.com. The Mobilift is different from the Lift2Go in that it doesn't disassemble and is a vertical platform lift vs. an inclined platform lift. Like the Lift2Go, the Mobilift can be set up at a single location anywhere from a few hours to a few months.

ABOVE Examples of Dr. Kaufam's Bingo and *Alice in Wonderland*-inspired online games.

RIGHT Participants who play online games show improvements in social connectedness.

2

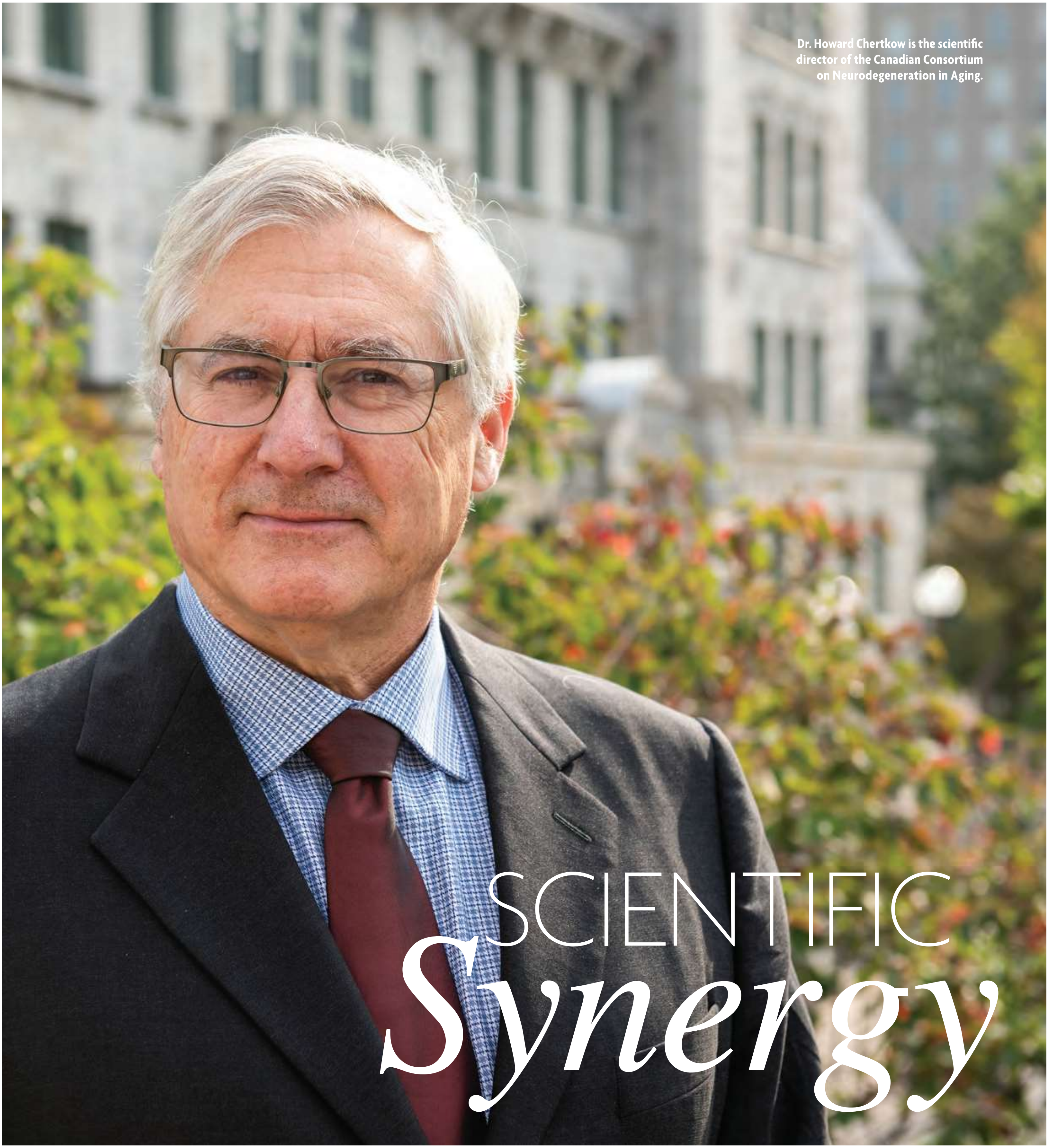
Online games helping reduce social isolation

A litany of evidence shows the benefits of mental fitness and social connectedness in reducing cognitive decline in older adults. An emerging field of study building on this research is exploring if digital games can help older adults avoid social isolation and improve their social-emotional health.

"I think of all the things that seniors can do to be healthy and happy, staying socially connected is the number one most important thing," says Dr. David Kaufman, professor emeritus, faculty of education at Simon Fraser University. "Our research is showing that digital games can provide social benefits to seniors."

Since 2013, Kaufman's team has studied hundreds of older adults across Canada at care homes, community centres and private homes, investigating the potential various digital games had in helping them combat social isolation. The team tested commercially available games like Nintendo Wii Bowling, and also designed their own "frame games" — custom digital versions of games like Bingo — that require the users to answer trivia questions periodically. The team even designed a virtual reality escape room game based on the children's classic *Alice in Wonderland*. Nearly all the games studied increased participants' social connectedness (on a scale) and reduced loneliness. Participants who played a Bingo frame game showed statistically significant improvements in social connectedness, as well as knowledge about nutrition and health, and reported an improved attitude toward digital games.

"A lot of seniors unfortunately are spending way too much time sitting in front of TV, which is a very passive activity," Kaufman says. "Having them play games can help foster connectedness and lessen feelings of isolation." ◼



Dr. Howard Chertkow is the scientific director of the Canadian Consortium on Neurodegeneration in Aging.

SCIENTIFIC *Synergy*

BY Elizabeth Chorney-Booth

Solving scientific problems related to dementia often takes teamwork and a collaborative approach. These two Canadian researchers are both part of the Canadian Consortium on Neurodegeneration in Aging, a national hub for dementia research

DR. HOWARD CHERTKOW

CCNA/CAN-THUMBS UP

Because scientists still don't know exactly what causes dementia or how to cure it, the field of dementia research has many moving pieces. Canadian universities and research hospitals are full of doctors and scientists studying varying theories concerning everything from genetics and brain chemistry on a molecular level to how diet and exercise can improve or delay symptoms. With so many different disciplines working on so many projects, it can be easy for individual labs to home in on their own specific areas of interest without connecting to the bigger picture of dementia prevention and care.

To address this, the Canadian Consortium on Neurodegeneration in Aging (CCNA) was established in 2014 to bring together country-spanning teams of scientists working in various areas of dementia research to collaborate and share information and resources. Currently, 19 national research teams are working in areas related to prevention, treatment and quality of life as they pertain to all forms of dementia. In 2019, the CIHR approved a second phase of funding for the CCNA, allowing it to take its framework to the next level.

"It's the idea that individual scientists don't really want to work alone. They want to collaborate with others interested in their topic," says Dr. Howard Chertkow, senior scientist at Baycrest's Rotman Research Institute in Toronto and the CCNA's scientific director. "In Canada, we're very collaborative. People like to work together, and they're willing to share. Canada is small enough that you can go out and create a national dementia research community."

This second phase has allowed the CCNA to move forward with a platform dubbed Canadian Aging and Neurodegeneration Prevention Therapy Study Using Multidimensional Interventions for Brain Support – Unified Platform (CAN-THUMBS UP). The title is a mouthful, but the acronym aligns with the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) and the American U.S. Study to Protect Brain Health Through Lifestyle Intervention to Reduce Risk (U.S. POINTER), making the finger reference relevant to the global research community.

CAN-THUMBS UP brings together 60 scientists from within the CCNA who will take a multi-disciplinary look at dementia prevention. Through the platform, researchers will be able to evaluate different perspectives and combinations of approaches to dementia prevention, connecting strategies involving diet, exercise and sleep therapy as well as potential medications. The idea is that combining research and data will help researchers come up with real solutions to dementia prevention to offer to the Canadian public.

"This is really the decade where the research could deliver important game-changing innovations in dementia prevention. We know that if we could delay the onset of dementia by five years, we would reduce the number of people with dementia in Canada by about 50 per cent," Chertkow says. "With the first five years of CCNA, we built our collaborative structure. Now we really want to go full speed to get some answers, some treatment and prevention strategies, and make those breakthroughs."

> ["We know that if we could delay the onset of dementia by five years, we would reduce the number of people with dementia in Canada by about 50 per cent." —Dr. Howard Chertkow]

Photo by Alex Tran

Photo by Doug Nicholson/ Sunnybrook

DR. ANDREW LIM

SLEEP AND DEMENTIA

Few things are as beneficial to our physical and mental well-being as a good night's sleep. Most anyone who experiences disrupted sleep — be it due to sleep apnea, anxiety induced insomnia or busy shiftwork — knows that barriers to good sleep can lead to bad moods, confusion and a host of physical problems. It's not surprising that sleep problems can play an even more significant role for people living with dementia.

For the last decade, Dr. Andrew Lim, an associate professor of neurology at the University of Toronto and a practising neurologist at Toronto's Sunnybrook Health Sciences Centre, has been studying how fragmented sleep impacts cognitive decline and the development and progression of various forms of dementia. Over the years, Lim has authored several studies, and he is the lead of the Canadian Consortium on Neurodegeneration in Aging (CCNA's) Sleep and Dementia team, along with the University of Montreal's Julie Carrier. The CCNA is a national hub for collaborative research on dementia.

"It's very clear that it goes both ways: fragmented sleep can be both a symptom of dementia, but it can also potentially be a contributor," Lim says. "So much so that the latest Canadian Consensus [Conference on the Diagnosis and Treatment of Dementia] guidelines on the management of dementia recommend that doctors ask their patients with dementia about sleep symptoms and treat diseases like sleep apnea in patients that present dementia symptoms."

Lim knows from his clinical practice that sleep issues can affect people with dementia. Behaviour like nighttime wandering can often be the deciding factor that causes families to place someone into long-term care. Studies have also shown there is a link between dementia and sleep apnea, which is often treatable.

Lim was an author on a 2013 study that followed the sleep patterns of over 700 older adults who were not diagnosed with dementia. The study concluded that those participants who suffered from sleep apnea or other sleep disruptions were more likely to develop Alzheimer's disease and other forms of cognitive decline as they got older. But sleep issues don't only affect older adults; Lim has also found that fragmented sleep can indicate that someone may develop dementia later in life.

This is not to say that poor sleep has a causal link to dementia — another neurological issue may be causing a patient's fragmented sleep patterns as well as the dementia symptoms. To investigate further, Lim has been working with the CCNA to look deeper into the brain's relationship between sleep and dementia. The next step will be studies, scheduled to start next year, that will introduce interventions for patients to see if treating sleep problems will decrease the likelihood of future cognitive impairment. Lim is also involved with studies that take a holistic approach to healthy sleep, diet and exercise, to see if a combination of healthy living pieces results in fewer or delayed instances of dementia.

"In the end we don't think that poor sleep is necessarily the sole or solitary cause of dementia," Lim says. "We think it's probably one of many factors that contribute. You probably have other factors that predispose you to dementia, and sleep is just one of them. But all of this is more reason to say to yourself that it may not be such a great idea to get only five hours of sleep a night."

["It's very clear that it goes both ways: fragmented sleep can be both a symptom of dementia, but it can also potentially be a contributor." —Dr. Andrew Lim]

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LIVING WITH *Dignity*

Small House care models offer personalized care and connection to community

BY **Shannon Cleary**

iStockphoto.com/ FrankRamspott

Numerous studies show that when continuing care homes reflect the layout, activities and personalized aspects of a typical house, it leads to positive outcomes for people living with dementia. For residents in small home models, benefits include less agitation, greater social engagement, maintenance of functional abilities, as well as positive impacts on staff. Meanwhile, for residents in traditional institutional and medical models of care, there is a risk of greater agitation and faster cognitive decline.

Carefor's Guest House in the Ottawa region of Ontario and THE GREEN HOUSE® Project in the United States are two "small house" care models that provide people living with dementia personalized care, a connection to community, and the opportunity to live independently and with dignity.

→

DID YOU KNOW? ***In September, Alzheimer's Disease International launched World Alzheimer Report 2020: Design, dignity and dementia; dementia-related design and the built environment. This in-depth and comprehensive report consists of two volumes and 84 case studies. It explores design principles, the role of design during a pandemic, innovators and pioneers, regional and cultural applications, the importance of including people living with dementia in the design process and more. The report's findings firmly state that dementia-related design is an essential, non-pharmacological intervention that directly impacts the quality of life for people living with dementia. Learn more at alz.co.uk***

1

Guest House (Short-Term Stay)

Robin Meyers is the director of community and personal support services for Carefor, a not-for-profit home health care and community support service for clients and caregivers in the Ottawa region of Ontario. Recently, a member of Meyers' team was picking up an older gentleman to participate in Carefor's community day program. Program staff had come to know him well, and right away the driver sensed something was wrong.

"When we arrived to pick him up, he just didn't seem himself," Meyers says.

Meyers' team learned that his wife, who was his primary caregiver, experienced a medical emergency the previous day and was taken to hospital by ambulance. For whatever reason, he was not brought along. Instead, he had been home alone for almost 24 hours, an incredibly stressful experience for both spouses. The team was spurred into action, with Meyers contacting the social worker involved and eventually visiting the hospital where his wife was admitted.

"I was able to tell her, 'Your husband is fine, he's with us,'" Meyers says. He was provided a private room in Guest House, Carefor's unique short-term respite model care home, until his wife was able to return home after her medical issue.

For people living with dementia, the ability to live at home for as long as possible depends on many factors, including access to safe and effective respite. In 2007, Carefor joined with the Perley and Rideau Veterans' Health Centre and the Dementia Society of Ottawa and Renfrew County to launch Guest House, a new model of short-stay respite care based in the community instead of in an institution. Its goal is to provide a familiar, household environment for people living with early to moderate dementia, where they can continue their daily routines when their caregivers require temporary breaks from their duties.

"It really is a home away from home for our guests," says Meyers.

The Guest House home is a standalone bungalow, built on the grounds of the Perley and Rideau Veterans' Seniors' Village in Ottawa's south end. The house has 12 private rooms, each with a private bathroom, as well as a common living room, kitchen, dining area and secure courtyard. Clinical health monitoring is not available in the program, but Guest House staff are able to assist and supervise medication requirements.

Meyers says the bungalow was designed with a "no-fail" layout, with directional cues built into the design. For example, sliding bathroom doors are within direct sight of the bed, prompting guests as soon as they wake in the morning. The home's two hallways are equipped with handrails, and each hallway leads back to the main common area regardless of which direction guests turn when leaving their room. Thresholds throughout the home are level, and the flooring in the common area is made of soft material to limit

Guest House has 12 private rooms as well as common areas such as a dining room, living room and kitchen.

Photos courtesy Susan Ryan/ THE GREEN HOUSE® Project

HOW IT WORKS

People living with dementia may stay overnight at Guest House for as many as 30 consecutive stays, up to a total of 90 overnight stays per year. Guest House also offers day stays for varying lengths between the hours of 8 a.m. and 10 p.m., and emergency stays for returning guests if beds are available. Guests are responsible for a co-payment of $40.24 for an overnight stay, or $20 for a day stay of one to five hours. The remaining balance is subsidized by the Government of Ontario and fundraising efforts by Carefor Health & Community Services.

bodily harm in the event of a fall. Everything about Guest House was built and operates to empower people living with dementia, says Meyers.

"Guests have the opportunity to accomplish tasks that they are able to perform," she says, such as gardening, assisting staff with baking or laundry, and participating in leisure activities, group discussions, games, art, music and modified exercises.

"Living with and supporting someone living with dementia isn't something we typically plan for, so having these types of resources obviously make a huge difference," says Meyers. "We do what we can to help people in our communities."

2

The Green House Model

Entering the world of long-term care placement can be a stressful passage for people living with dementia and their families. Susan Ryan, senior director for the Green House Project (GHP) in the United States, has accompanied many families on this journey throughout her almost 40-year career as a nurse and an advocate for elders. She recalls meeting a family in Arkansas whose beloved grandmother was living at home with her husband, her primary caregiver.

"Her dementia became more and more pronounced, to the point where she was no longer engaging with the outside world," says Ryan. "Her husband [told the family], 'I'm not putting her in a nursing home. There's no way.'"


The Green House Model creates opportunities for relationship building and meaningful connection.

This reaction is common, says Ryan, and one of the reasons GHP advocates for radical transformation of long-term care and post-acute care environments. One such initiative is The Green House Model, a care home that is small in size, has a low staff-to-resident ratio, reflects the architecture of its surrounding community, and is completely self-sufficient. It's not "home-like," it's a real home where meaningful life can happen.

"This is a model that, from a consumer perspective, you or I or our parents would want to live," she says.

Over the past 17 years, GHP has supported organizations to build more than 300 licenced Green House models across the United States, including four campuses with 34 Green House homes across them in the state of Arkansas.

Luckily, the granddaughter from the aforementioned family did find a Green House home for their beloved gran, where she has her own private bedroom and bathroom, and shares an open kitchen, dining and living area — the "hearth" — with 10-11 other residents. The homes are licensed and include 24-hour nursing care. Ryan visited the home in Arkansas a year after this grandmother moved in and noticed a profound change. The woman was dancing, singing and building relationships with residents and staff — including one staff member's newborn baby, whom she loved rocking during visits. Her husband, who visited his wife frequently, saw the change as well.

"He said, 'She's really engaging in life in a way that I could not get her to at home,'" recalls Ryan.

Outcomes like this are powerful demonstrations of what it looks like when older adults live with meaning, beyond just having their care needs met. Residents are in more control of their environment than they are within a traditional setting, from their schedules to their privacy to the temperature in their room. The Green House Model de-centralizes care delivery, such as dining and laundry and housekeeping, so the rhythm of care revolves around the residents and staff as opposed to institutional efficiency. The homes are equipped with clinical systems and regulatory standards, but that's not what you see when you walk in, says Ryan.

"When we see elements of the institution, that can reinforce that feeling of, 'I'm sick, I'm infirmed, I'm less than,'" says Ryan. Instead, residents of Green House Homes live "in common" with one another, in a normalized environment and as part of their communities and are seen as individuals with intrinsic worth. ◼

> ["This is a model that, from a consumer perspective, you or I or our parents would want to live." —Susan Ryan]

People understand without having to explain.

Bobby, Australia

Thanks to DAI we are all doing well.

Jane, USA

They are quickly becoming like a family to me.

Bill, Canada

I am so glad I found this amazing organisation.

Diana, USA

DAI saved my life.

Bonnie, USA

Everyone is really supportive.

Bill, Australia

They were life saving for me.

Christine, Canada

I felt so welcome like a warm hug.

Emily, Singapore

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

Mithrani, Australia

DAI gives me hope every day.

Natalie, Australia

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

Terrie, USA

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

Wally, USA

DAI is Life Changing, but don't take our word for it.

We could fill this magazine with comments like this. Dementia Alliance International (DAI) has members in over 50 countries, and many tell us it is life changing. DAI is run by members, who themselves all live with dementia. It provides online peer-to-peer support groups and social groups and many other services. Like our membership, all other services provided for members by DAI are free, and anyone with dementia can join.

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National Dementia Strategy's

WORK IN PROGRESS

More than a year after publication, Canada's national dementia strategy is being put into practice through collaborative projects and funding spread across the nation

BY **Nathan Kunz**

In June 2019, the Government of Canada's A Dementia Strategy for Canada: Together We Aspire *was launched. The first of its kind in Canada, this forward-looking strategy focuses on three overlying objectives:* ***preventing dementia, advancing therapies*** *and* ***finding a cure and improving quality of life*** *for people living with it. The 2019 federal budget is providing $50 million over five years to support implementation of the strategy.*

Now, more than a year and a half since the strategy's inception, we check in with the Public Health Agency of Canada, as well as Mary Beth Wighton and Jim Mann, to chart its progress. Wighton and Mann are advocates living with dementia who sit on the Ministerial Advisory Board on Dementia, which provides evidence-informed advice to the Minister of Health and contributed to the strategy.

Here are some of the key measures taken so far to implement the strategy:

1

OBJECTIVE

Prevent Dementia

NEED-TO-KNOW ACRONYMS:

Canadian Consortium on Neurodegeneration in Aging (CCNA)
A pan-Canadian research initiative with a primary focus on dementia, funded by the CIHR through a five-year $46 million investment.

Canadian Institutes of Health Research (CIHR)
The Government of Canada's health research investment agency.

Dementia Community Investment (DCI)
An annual $4 million fund dedicated to community-based initiatives aimed at optimizing well-being for people living with dementia and family/friend caregivers.

Dementia Strategic Fund (DSF)
A total of $40 million of the Budget 2019 will be administered through this fund focused on the implementation of its key elements, including awareness.

Public Health Agency of Canada (PHAC)
The lead federal organization on the National Dementia Strategy.

Examples of current initiatives

✓ With Dementia Strategic Fund support, the first round of projects dedicated to helping prevent dementia, reduce stigma and enable more dementia-inclusive communities are expected to begin in winter 2021.

✓ Dementia Community Investment funds are supporting initiatives for people living with dementia and caregivers. One such project, which was announced in August 2020, is the University of Manitoba's Living with Dementia in Rural First Nations Communities: A Health and Wellness Project. In it, the project is working with Indigenous communities in Manitoba to develop programming and increase awareness surrounding dementia.

✓ In 2019, a national platform studying dementia prevention in higher-risk individuals was launched. CAN-THUMBS UP (see pg. 48 for more), explores how combining preventative lifestyle factors can reduce dementia risk.

> *"The aspiration is a cure. We can't aspire any higher than that. But if you can't find a cure, let's just continue to find those risk factors, because that will ultimately lead to less people who need to be cured."*
>
> –Mary Beth Wighton

To learn more about the current state of the national dementia strategy's objectives and goals, read the 2020 Report to Parliament at canada.ca

Mary Beth Wighton by Peter McNeice; Jim Mann courtesy Alzheimer Society of Canada

2

OBJECTIVE

Advance therapies and find a cure

Examples of current initiatives

✓ Research funded through the Canadian Consortium on Neurodegeneration in Aging, which receives its funding from the Canadian Institutes of Health Research, has worked to advance knowledge on prevention, treatment and care for dementia. As a result, several research projects are currently underway across the nation, including:

- Dr. Sandra Black's project at the Sunnybrook Research Institute in Toronto, which is investigating how repurposing blood pressure-lowering drugs could delay the onset of dementia.
- A University of Toronto study led by Dr. Peter St. George-Hyslop, which is identifying potential molecular targets for treatments in neurodegenerative-disease-causing pathways.

> "I take heart that that progress is being made. It is not only looking to people with dementia 30 years down the road — it's looking to make life better for people living with dementia today." –Jim Mann

3

OBJECTIVE

Improve the quality of life of people living with dementia and caregivers

Examples of current initiatives

✓ Dementia Stategic Fund initiatives include stigma reduction projects, such as one with the Native Women's Association of Canada focused on reducing stigma in Indigenous communities.

✓ Dementia Community Investment fund community-based projects on quality of life include the University of British Columbia's Building Capacity for Meaningful Involvement of People with Dementia. The project explores a community development approach to support dementia-inclusive initiatives in arts, social activities, fitness and more.

✓ Under the strategy's "surveillance and data" pillar, projects addressing priority data gaps, including improving data on dementia caregivers, as well as dementia progression, stages and impacts, began in fall 2020.

> "There's a need for a better understanding from a systemic perspective — with a better understanding of dementia within the whole health services community. You can educate other people that there is a life after a diagnosis." –Jim Mann

Irene and Frank Palmer in 2001, a few years before Irene was diagnosed.

MAKING THE "Right" DECISION

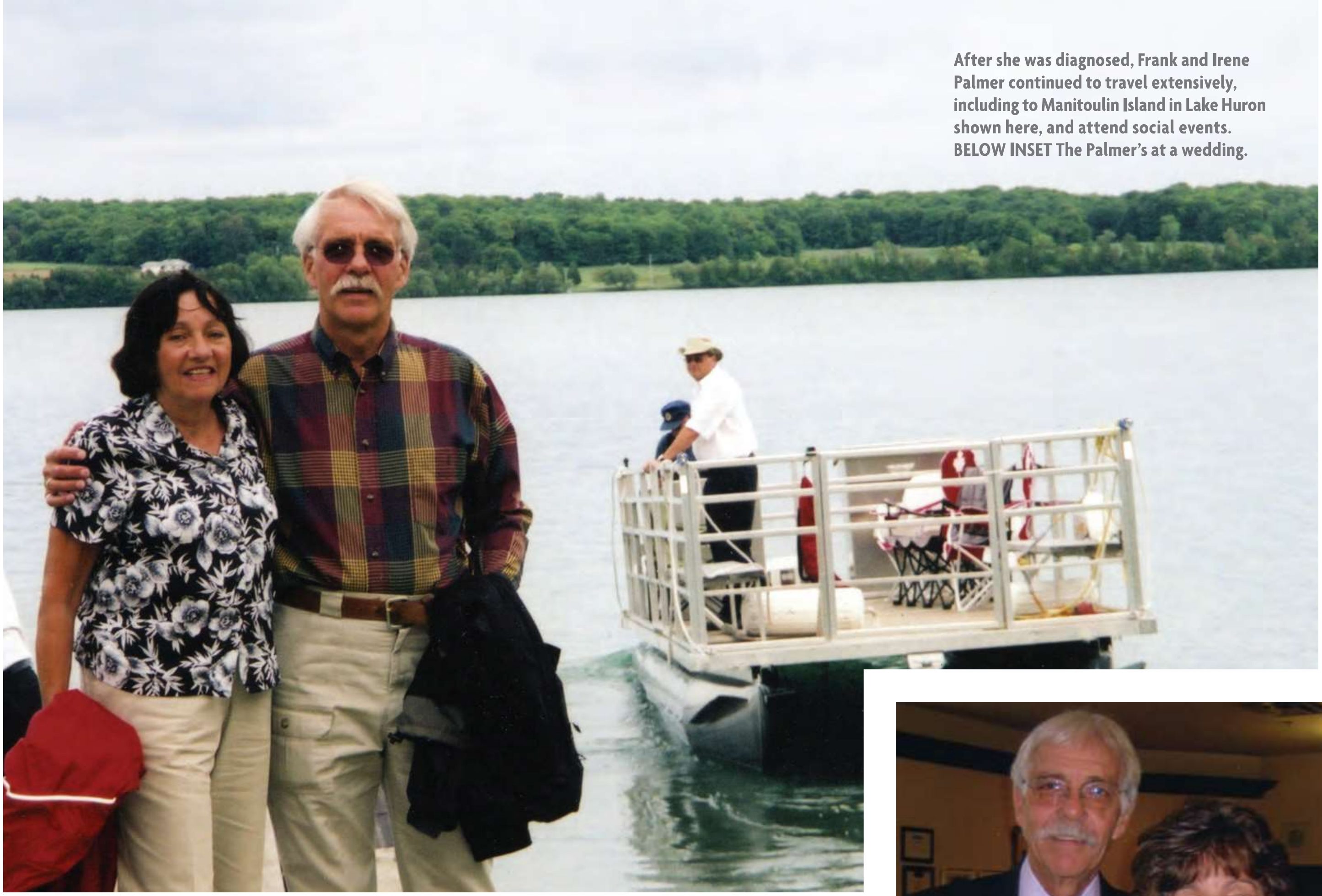
For many care partners supporting people living with dementia, choosing between long-term care or home care can feel like an impossible choice

BY **Elizabeth Chorney-Booth**

One of the biggest decisions people with dementia and their care partners face is choosing whether to stay at home or move into long-term care. Helping people remain at home is a pledge many care partners of people living with dementia make — often, their perception is that staying at home can offer more comfort, dignity and individualized support. But for others living with dementia, a long-term care home may be a better fit for their specialized needs. Regardless of where someone ultimately ends up, the quality of the care provided and if the relationship with the person or people offering care is healthy and respectful are key.

Neither choice is an easy one. In Canada, finding support — both financially and from a care perspective — to stay at home can be difficult. Meanwhile, concerns about the lack of personalized supports in long-term care, on top of the inadequacies revealed by recent COVID-19 outbreaks, are deeply troubling. Indeed, there are challenges and benefits to both options, and myriad factors to consider before making a choice. But for Torontonian Frank Palmer, the decision to care for his wife, Irene, at home was clear from the start.

Photo courtesy Frank Palmer; iStockphoto.com/ Swillkitch



After she was diagnosed, Frank and Irene Palmer continued to travel extensively, including to Manitoulin Island in Lake Huron shown here, and attend social events. BELOW INSET The Palmer's at a wedding.

Photos courtesy Frank Palmer

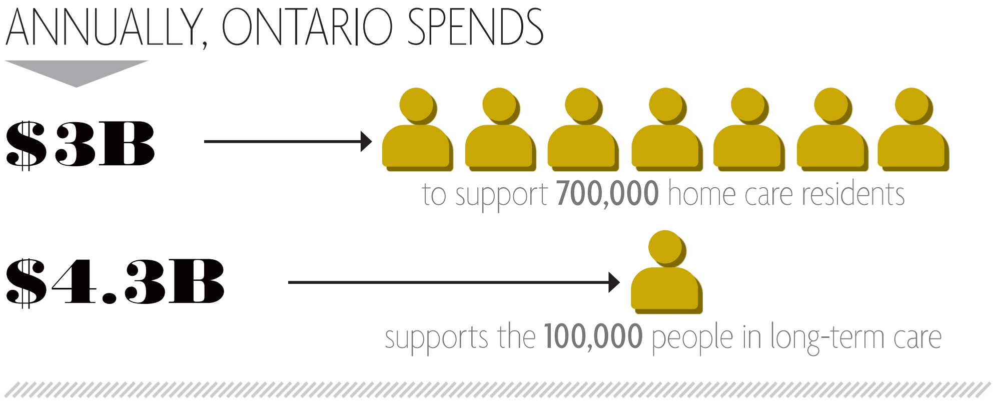
> "I just could not accept the conditions at many of the LTCs [long-term care homes] I looked at. I did not see dignity." —Frank Palmer

Frank and Irene's experience

After Irene's Alzheimer's diagnosis in 2004, Palmer wanted to challenge the assumption that eventually moving her into a long-term care home was unavoidable. Irene had enjoyed a successful career as an RN, and the couple had previously scouted care homes for her elderly mother, so the family was aware of the limitations of long-term care homes. Palmer was still working in the early days of Irene's dementia, but he felt like he had both the means and the fortitude to care for her at home even as her disease progressed.

"It had always been my inclination to keep her at home as long I could," Palmer says. "I just could not accept the conditions at many of the LTCs [long-term care homes] I looked at. I did not see dignity. I saw a lot of things I didn't like, even in the private LTCs. So, I was not prepared to do that with Irene."

In the beginning, Irene's symptoms were manageable. The couple continued to visit with family and friends, travel extensively and eat in restaurants. But in 2013, Irene had a major health crisis while travelling that landed her in the ICU in Florida, before she could be flown home to further recover in Toronto. Typically, hospitalization



can be the instigating factor that leads to a person with dementia moving into long-term care. Despite concerns from family, Palmer, who readily describes himself as "stubborn," insisted on caring for her at home.

After Irene returned from the hospital, Palmer set up a home care system that was essentially as comprehensive as what one would find in a long-term care home. Eventually, Irene had care professionals with her from 8 a.m. through to 10 p.m. Palmer did get some provincially funded agency help. Still, he also paid out of pocket for a lot of the care staff — which is similar to the idea of families of people in long-term care "topping up" care home staff with private caregivers. Palmer compares his role in managing and finding caregivers who fit his specifications to a full-time job. The price was comparable to what it would have cost to put her in a higher-end private care home. The difference, of course, was that home care required a lot more work on his part.

"I have for a number of years been telling people that I'm the CEO of my home address," Palmer says. "Luckily, I had the knowledge of how to do that, being a chartered accountant, but many families don't know how to do it."

A question of funding

A big part of the reason why home care can feel so challenging is a lack of financial support. According to an article published earlier this year in the *Globe and Mail*, when it comes to public funding, Canada has one of the lowest rates of home care support in relation to funding received by long-term care homes among G8 countries. The same article cites that in Ontario, $3 billion is spent annually on home care as opposed to $4.3 billion on long-term care. Yet there is an annual average of 700,000 Ontarians requiring care at home, compared to approximately 100,000 care home residents, meaning that that province is spending less on home care and spreading it much more thinly among a larger cohort of patients. Because of this financial prioritization of institutions, once people get to a point where they need round-the-clock support, a move into a care home can seem to be inevitable.

> "Especially with everything that's happened with COVID, this issue has been framed as a this or that: staying at home or going to a care home. I don't think that's...helpful."
>
> —Carrie McAiney

Rethinking how public funding is used by increasing or reallocating funds to home care could help ease the burden from care partners. But for many, funding alone isn't enough — the freedom to choose exactly how they use that financial support is key. Luckily, there are programs working to make aging in place more accessible. For example, Alberta Health Services Edmonton Zone Enhanced Home Living Client & Caregiver Supports Pilot is attempting to improve quality of life for both care partners and people living with dementia. Implemented in January 2019, the pilot is working with cohorts across the province made up of home care clients and care partners. Its three objectives include supporting caregivers' well-being, creating real choice for home care clients to stay at home and examining the impact of enhancing support services as opposed to health services. So far, the pilot has explored enhancing assessments, including to determine at-risk caregivers sooner. It's also increased services and funding, while still allowing care partners and home care clients the ability to choose the support they actually need. For example, participants can select the provider they want to use, whether private or public, such as a housecleaner or respite service, and invoice AHS monthly for reimbursement.

Finding support for care at home

An essential part of helping people stay at home longer is post-diagnostic support, often

Above: Frank and Irene Palmer at a friend's wedding in September 2017.

> "Even the day before she passed away, she still looked at us. She was smiling at us. She was still there."
> —Frank Palmer

the sooner the better. Recreational programming, support groups and caregiver training can all extend the time that a person with dementia can stay at home without going into a long-term care home.

But the period immediately after diagnosis can be overwhelming, and a lot of families don't feel comfortable reaching out. This is where Carrie McAiney, associate professor, Schlegel Research Chair in Dementia at the University of Waterloo Research Institute for Aging, appreciates programs like the Alzheimer Society's First Link program, where family doctors get permission to pass their patients' contact info to the Society, who can then be proactive about reaching out.

"It's important to get information into people's hands and help them with preparing and to understand what's happening and what to expect moving forward," McAiney says. "People often do wait to ask for help until they're really in a difficult state. At that point, it's hard to know how much a service can help. The potential benefit of having earlier intervention can be so much more helpful."

McAiney suggests that people newly diagnosed with dementia contact agencies like the Alzheimer Society as soon as they feel ready or ask their doctor or a nurse in their doctor's office for other local resources.

Making the "right" decision

While extensive home care works for some families, including the Palmers, it doesn't work for everyone, and families need to evaluate which options will best meet their individual needs. McAiney says that it's important not to position the choice as "care homes versus home care." One model is not universally better than the other, and that dichotomy can create guilt for families who choose what is seen as a less noble option. Both models can certainly fall short, especially when underfunded, but both can also offer excellent care and personal fulfillment for both the people with dementia and their care partners.

"Especially with everything that's happened with COVID, this issue has been framed as a this or that: staying at home or going to a care home. I don't think that's a helpful way to think about it," McAiney says. "Most people want their loved ones to stay home as long as possible and to do everything they can to ensure that will happen. But for a good percentage of people there can come a time when they need that extra support and it can be better and likely safer for the person to have a care circle around the clock."

As for Frank Palmer, he has no regrets. After spending seven years in an intensive home care environment, Irene peacefully passed away at home this past May. Although his grief is still fresh, Palmer knows that he did what was best for both of them. He feels like Irene lived for several years longer than she would have if she had left their home and also feels like they both enjoyed being together.

"In her later stages, yes, Irene sat at home," Palmer says. "But we could still talk, we could still tease each other, and we used to do that all the time. There would be smiles or chuckles out of her. Even the day before she passed away, she still looked at us. She was smiling at us. She was still there." ■

RESTORING TRUST:

COVID-19 and the Future of Long-Term Care

The decision to move someone into a long-term care home (LTC) can be a very emotional one for many Canadians, something that was tragically highlighted during the early months of the COVID-19 pandemic. In Canada, 81 per cent of COVID deaths occurred in LTCs, further eroding the public's trust in facilities that are often seen as being impersonal, overcrowded and unsafe. But even with an often-negative public perception, LTCs can also offer a level of safety, socialization and medical care that many older adults can't access in their own homes. LTCs are an important part of elder care in Canada — but there certainly is room for improvement and a need to win back the public's trust.

In April 2020, the Royal Society of Canada established a COVID-19 task force that included a working group of academics who created a policy briefing report on the future of long-term care called *Restoring Trust: COVID-19 and the future of long-term care.* The group determined that Canadian LTCs are in the midst of a workforce crisis, with many untrained, underpaid, and unregulated staff left caring for residents, many of whom have complex medical, emotional and physical needs that are not being met. The report outlines nine recommendations to improve LTC staffing, including establishing national standards, increasing federal funding, better compensating staff through both higher wages and more robust benefits and requiring better training and education for LTC staff.

> "If we don't treat the staff with dignity and respect, you can't expect them to treat residents with dignity and respect." —Dr. Pat Armstrong

"Staffing and training are absolutely at the core of the problem and we can't fix anything unless we address that," says Dr. Pat Armstrong, a professor at York University and a member of the team that put together the report. "But I don't think there's one magic solution. We have many ways of addressing the issue, but context matters and it will be different depending on where people are."

Armstrong wants to be clear that placing a loved one with dementia in an LTC shouldn't be seen as either a personal failure or a failure of Canada's health care system. Most experts agree that personalized care is what ensures the sense of dignity and quality life that people with dementia and their care partners fear will be lacking in an LTC, and better staffing is the best way to facilitate that individualized care. The task force presented the report to the Canadian government but there has not yet been an official response if any of the recommendations will be implemented on a widespread scale.

"We like to talk about care as a relationship and that the conditions of work are the conditions of care," Armstrong says. "If we don't treat the staff with dignity and respect, you can't expect them to treat residents with dignity and respect."

THE ROYAL SOCIETY OF CANADA'S NINE RECOMMENDATIONS FOR LONG-TERM CARE AT A GLANCE

1. The federal government must immediately order and act on a thorough, nationwide, data-based assessment of national standards for staffing in care homes.

2. The federal government must determine and implement national standards for training staff and allocating resources for infectious disease control, as well as create regulations for bringing on new staff and restricting visitors during an outbreak.

3. With federal funding, provincial and territorial governments must enact appropriate pay and benefits for direct-care aides and personal-support workers.

4. Provincial and territorial governments need to make full-time work with benefits available to all regulated and unregulated long-term care staff and evaluate the impact of "one workplace" policies currently in place.

5. Provincial and territorial governments must create and implement minimum education standards for unregulated employees, continuing education options for regulated and unregulated employees and proper training/orientation for external staff.

6. Provincial and territorial governments must support these education reforms for all staff.

7. With the support of federal funds, provincial and territorial governments must make mental health supports available to all long-term care staff.

8. The federal government's support must be contingent on the requirement of data collection from all aspects of long-term care, such as quality of life of residents and more.

9. The data collection process must be transparent and independent of the long-term care sector and governments.

not Just a Visitor

COVID-19 restrictions at long-term care homes exposed a grey area in the definition of "essential"

BY **Julia Williams**

ONE DAY IN MARCH, Jane Fisher* arrived at her husband Chris's Alberta long-term care home, a trip she had made almost every day for more than two years. She had a bag of freshly laundered clothing to drop off, and she was picking Chris up, as she did most days, to bring him home so they could spend the day together. But this time, she was informed she couldn't enter the building.

On March 17, 2020, Alberta's Chief Medical Officer of Health Dr. Deena Hinshaw, declared a state of public health emergency in response to the COVID-19 pandemic. Among other province-wide regulatory changes, the order ushered in new safety protocols intended to protect vulnerable populations in congregate care homes. These protocols included restrictions on who was permitted to enter such buildings (residents and staff) and who wasn't (almost everyone else). For non-staff, visitation access was limited to people whose family members were dying, or to visitors without whom "the essential care needs of the resident would otherwise be unmet," an unspecific guideline in which "essential care needs" could easily be interpreted to mean life-sustaining actions such as administering medications and feeding. Visitors like Fisher, who were not medical personnel or professional personal support workers, but who spent hours each day supporting someone with everything from care planning and hygiene to hugging and talking, were literally left out.

Fisher wasn't reunited with Chris, who has Parkinson's disease and dementia, for four months, when revised protocols allowed designated visitors into Alberta health-care facilities as of July 23.

"For the first six weeks, I was beside myself," Fisher says. "We've been married for 49 years and we've always been together. I didn't know how to cope with this."

While she understood and respected the need to prevent infection in the care home, she and Chris experienced significant distress while they were separated. They had almost daily FaceTime visits and she could wave to Chris through his ground floor window, but he suffered from boredom, depression and an increased level of confusion that persisted even after in-person visits resumed. "Me bringing him home daily to familiar surroundings was what helped him keep going," Fisher says. Without her steady

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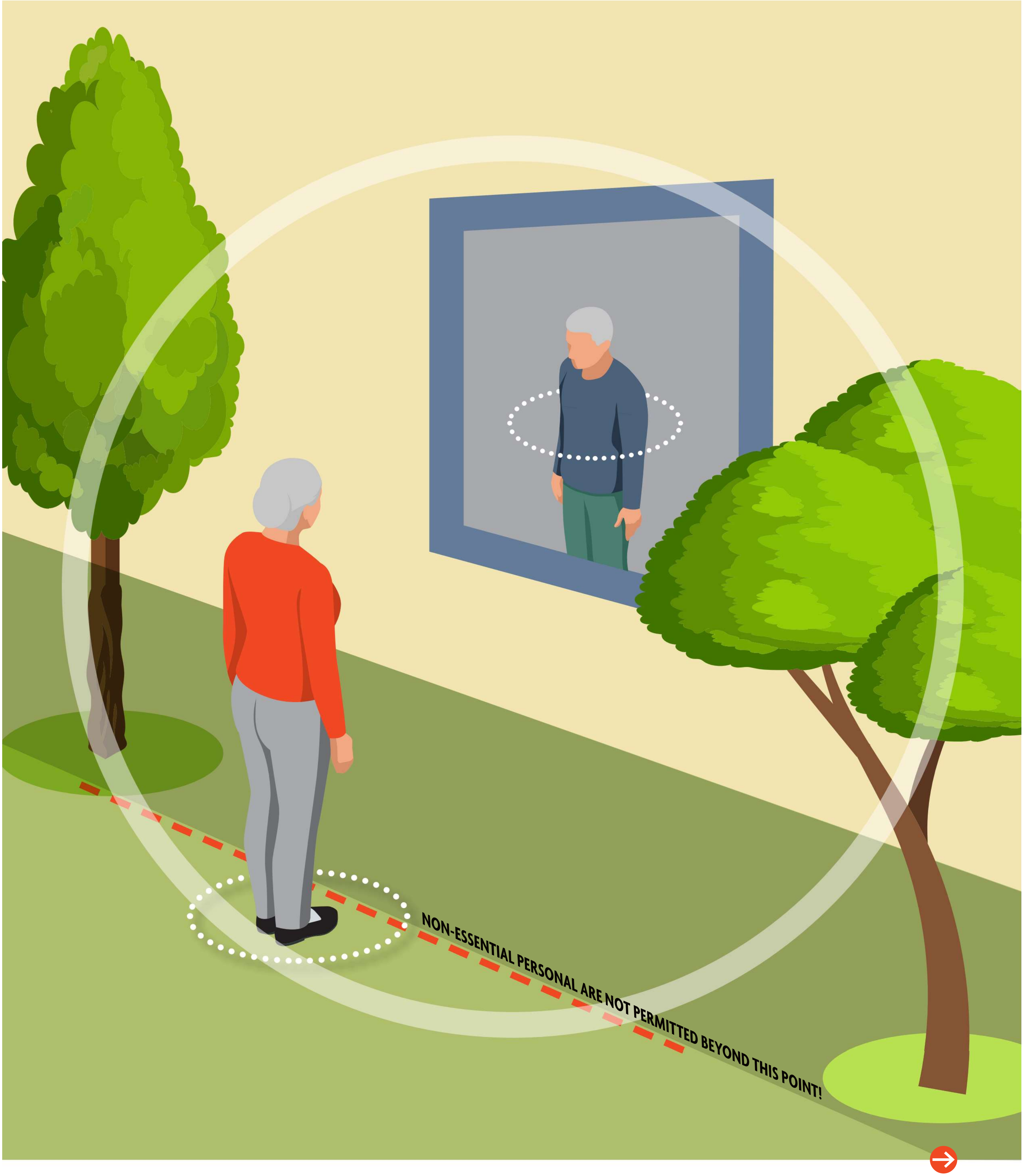
* Jane and Chris Fisher's names have been changed.


NON-ESSENTIAL PERSONAL ARE NOT PERMITTED BEYOND THIS POINT!

> "[Family care partners] are the invisible crutch that's been holding up this system for decades." —Vivian Stamatopoulos

presence, Fisher says Chris would get confused as to what year it was and which city he was living in.

As for Fisher, she felt rudderless and lost without Chris to care for. "I was depressed, and I've never been a depressed person. I wasn't used to being alone," she says. Two months into lockdown, Fisher wrote a letter to Dr. Hinshaw. "I wanted her to know how difficult it was," Fisher says. "I wanted her to know that we hated our lives."

Who defines essential?

The Fishers' story is not an anomaly: similar situations have occurred all over Canada since the coronavirus arrived and physical distancing became the new norm, especially in long-term care homes. Vivian Stamatopoulos, an associate teaching professor at Ontario Tech University who specializes in family caregiving, was a care partner for her grandmother and a passionate advocate for recognizing designated family members and friends as essential members of the care team. She describes the Ontario Ministry of Health March 13 memorandum, which recommended that visitors be excluded from care homes unless they were tending a dying relative or parent/guardian of an ill child or youth, as a travesty. "I knew the second that directive came down that it would spell disaster for residents," she says.

She believes she's been proven right. Now that family and friend care partners have been readmitted to Ontario continuing care homes (as of July 22), Stamatopoulos has heard multiple reports from people who say that isolation took a serious toll, that their family members or friends are not the same people they were four months earlier — that some residents appear to have given up the will to live.

The physical, mental and social benefits family and friend care partners can provide — and the detrimental consequences of isolating care home residents from these supports — have been a topic of scientific inquiry. Evidence shows that the presence of family/friend supports increases a patient's feeling of security while decreasing anxiety, confusion and even the likelihood of cardiovascular complications. The presence of family care partners helps to facilitate better communication between the resident and their health-care team, resulting in better care planning that leads to better health outcomes and quality of life. Isolating patients from the people who know them best can increase the risk of medical error, emotional harm and inconsistencies in care.

Long before anyone had heard of COVID-19, social isolation was known to raise a person's risk of developing dementia. The effect of enforced isolation during uncertain times on people already living with dementia — who often struggle with memory and planning, and who may find it difficult or impossible to communicate via video chat — is predictably negative. And it's not just care home residents who benefit from family support. Stamatopoulos says family care partners who were abruptly denied access to their family member or friend suffered feelings of

This page: photo courtesy Vivian Stamatopoulos; facing page by Jared Sych

CARER SUPPORT NEEDS ASSESSMENT TOOL (CSNAT)

INCREASINGLY, health-care professionals and educators are recognizing the need for a better support system for family/friend care partners. Many people who perform unpaid care work in Canada report increased levels of stress and depression, and doctors have observed that patient care is negatively affected when caregivers are distressed. Sharon Anderson, an expert in aging and family gerontology, says it's not caregiving that creates stress, it's overwork. "It's not having respite. It's being lonely and isolated," she says.

The Carer Support Needs Assessment Tool (CSNAT) is an evidence-based tool developed in the U.K. in 2007 that helps care partners forced helplessness, depression and a sense of lost identity.

The exclusion of family care partners during COVID-19 lockdowns is a consequence of the poorly defined role these individuals play in Canada's health-care system. Many people, especially those who live or work in long-term care homes, understand that family/friend care partners are anything but non-essential, but there has never been a formal distinction between casual, social visitors and those who provide significant, ongoing physical, mental and emotional support. Stamatopoulos says she's never heard an explanation for why care partners, many of whom spend 30 hours or more providing support each week, were deemed non-essential by default by the government. "They are the invisible crutch that's been holding up this system for decades," she says.

Identifying essential care partners

Kim Brundrit is the coordinator of Dementia Network Calgary, a community-based initiative committed to supporting people living with dementia. Brundrit is also a volunteer for the Canadian Red Cross, and when pandemic lockdowns began, she started to receive emails asking if she'd be willing to volunteer in Quebec and Ontario long-term care homes. Understaffed even before the pandemic, facilities in those provinces were desperate for workers (the crisis became so acute that more than 1,000 troops from the Canadian Armed Forces were deployed to help in Quebec's long-term care homes starting in May). Meanwhile, family/friend care partners were locked out. Brundrit started thinking there must be a better solution. What if it were possible to mitigate the risk of COVID-19 infection, while still allowing access to family/friend care partners? Would that not help to offset some of the staffing shortages and maintain quality of life for residents?

"I thought, if you can train me to work in a facility that has a COVID-19 outbreak, and I'm not a medical professional, why can we not train family care partners to go look after their loved ones?" Brundrit says. She and her team began the process of developing a training initiative for family/friend care partners in Alberta that would help to identify them as members of the core care team.

LEFT Vivian Stamatopoulos believes family/friend care partners should be deemed essential. RIGHT Kim Brundrit is the coordinator of Dementia Network Calgary.

> "If you can train me to work in a facility that has a COVID-19 outbreak, and I'm not a medical professional, why can we not train family care partners to go look after their loved ones?" —Kim Brundrit

With that goal, and under the guidance of facility operators and caregivers, Brundrit and her team applied for access to the Canadian Red Cross program, which is federally funded, to give family/friend care partners free training in personal protective equipment (PPE) and infection prevention and control (IPAC), so they could visit the person they cared for without contributing to the risk of a COVID-19 outbreak. The training would also

of people with long-term conditions to self-report on their own well-being. It's a questionnaire that identifies support needs in 14 key areas (or domains), from managing symptoms and sourcing equipment to addressing spiritual concerns or finding support to take an overnight break. The CSNAT uses a five-stage person-centred process that is facilitated by a practitioner and led by the care partner. Known as the "CSNAT approach," this process opens up a conversation between the care partner and health-care professional about how to address those support needs, which includes the creation of a shared action plan. Currently, about 60 Alberta health-care providers are trained to use CSNAT.

include communication tactics while wearing masks, especially when interacting with people with dementia. The training wouldn't be a mandatory requirement by long-term care homes, but Brundrit's hope is that it could provide an increased level of comfort and confidence that care partners would be able to keep both their friend or family member and the facilities safe and allow care partners continued access during an outbreak.

Recently, the Red Cross has announced the training is now available as an ongoing three-year certification program.

Hiring family members

Kensington Gardens, a 350-bed long-term care home in Toronto run by not-for-profit health services organization Kensington Health, was hit hard by a COVID-19 outbreak in March. The outbreak caused a severe staffing shortage as care workers got ill, went into isolation or confined their shifts to other care homes (many personal support workers work in multiple facilities at once). Abruptly, the home was down to roughly half its normal staff numbers.

Kensington Health president and CEO John Yip tried to address the staffing crisis by taking shifts in the dementia ward, redeploying staff from other clinics in the larger Kensington Health operation, hiring students on temporary contracts and recruiting nursing and personal support workers. Despite these efforts, Kensington Gardens was left with major staffing gaps, especially on weekends. Meanwhile, Yip was fielding calls from family members of residents, who insisted they were essential partners in care and were dismayed to have lost access to their loved ones. Finally, Yip's team brought him the solution to both problems, which had been staring them in the face: why not hire family members to work in the home?


John Yip, president and CEO of Kensington Health, hired family members to care for residents during the COVID-19 outbreak in March.

As it turned out, there were myriad legal and practical reasons why not. Yip had to consult with family members, the union and lawyers. He had to define the scope of care in this new role, as well as who to hire and how the hiring process should look. What would existing staff think? What would residents think? Transparency is one of the facility's goals, but is actually onboarding the family members of residents a little too much transparency? “We weighed all that in 24 hours,” Yip says.

The concerns were considerable, but none were unsurmountable. Yip's team successfully hired six family members of residents as temporary workers (for 90-day terms) and trained them at an accelerated pace. These new hires, called unit aides, were required to care for all 25 residents on the floor, not just their own family. They would not dispense medication or perform specialized tasks like lifting residents, but would be responsible for activities like socializing, setting up puzzles, arts and crafts and iPads, and lending

> “Family members are essential caregivers. They can be an asset to the entire floor.” —John Yip

CAREGIVER IDENTIFICATION BADGE

I am a CAREGIVER

In 2018, Ontario independent health policy think tank The Change Foundation introduced the Caregiver Identification (ID) Program and Family Presence Policy. The program, adapted from a similar “carer passport” initiative developed in the UK, uses a visual icon to identify designated family members and friends who provide essential care, and to ensure they maintain access to the person they care for who depend on their support.

The icon appears on Caregiver ID cards and in health-care settings (such as at patient bedsides). In addition to quickly identifying essential care partners, the program facilitates the integration of family members an elbow to help a resident walk around. Unit aides would always be supervised, and they would have to follow the Kensington Gardens code of conduct and privacy/confidentiality requirements.

The decision to hire family members was a desperate one, and Yip says it could have been prevented by significant systemic change that would raise staffing levels, improve compensation and training, and increase funding for infrastructure. "We shouldn't have got to this point as a sector," he says. Nonetheless, the unit aide program was a success. Yip observed these employees interacting with all the residents and treating them with the kindness and empathy they showed their own family. Their supportive presence contributed to the wellbeing of every resident, while mitigating the effects of the staff shortage. Unit aides were paid, but many chose to contribute their pay back to the Kensington Health Foundation.

Yip says this type of solution isn't necessarily a good fit for every care home, but he's interested how the unit aide program might evolve at Kensington Gardens post-pandemic. How can he engage family members better and offer them more comprehensive training? "Family members are essential caregivers," he says. "They can be an asset to the entire floor."

Looking to the future

Today, Jane Fisher is able to spend her days with Chris, with continued precautions, but she lives in dread of a second or third lockdown — a scenario that can't be ruled out in a province that has struggled to control community spread of COVID-19. Now that she's been through the first separation, Fisher thinks she might cope better, but she worries about her husband. "What will happen to him if he has to go through that again?" she says.

If the pandemic has one positive outcome, it may be that it helps to create a clearer understanding of the role family and friends can play in long-term care, and to ensure family care partners like Fisher retain access to the person they care for no matter what. In updated visitation guidelines published by Alberta Health Services on July 30, a "visitor" is defined as a social guest who is not involved in patient care, while a "designated family/support person" is defined as someone involved in the care and health matters of a resident, including assistance with feeding, mobility, personal care, emotional support, decision making and communication. It's a clear distinction, and it's a good start. ▮

DEFINING CARE

Dawn Baxter, a dementia consultant and support person for the Ministerial Advisory Board on Dementia for the Federal Minister of Health, is also a partner in care for Mary Beth Wighton, (pg. 30), who has young onset dementia. Baxter shares her definitions for common terms for support people.

Care partner/Partner in care
This term is preferred by many people because it clearly identifies a support person as a member of a larger care team, while affording dignity and respect to the person with dementia.

Carer
A broad, inclusive term that can include all members of a care team.

Caregiver
While commonly used, Baxter and Wighton consider this term problematic because it implies that care flows only in one direction.

Caretaker
Baxter and Wighton consider caretaker a pejorative term. It implies the person with dementia is simply a recipient of maintenance.

as partners in the health-care team. It clearly differentiates casual visitors from essential support people, who have historically been lumped into a single "family and friends' category that fails to recognize the physical and emotional role some visitors play in the wellbeing of patients and residents.

Christa Haanstra, executive lead, strategic communications for The Change Foundation, says the Caregiver ID program is intentionally flexible and designed to be implemented facility by facility. "There's no standard approach to implementation," she says. Supporting a family member with cancer, for example, is not the same as supporting a loved one with mental illness or dementia, who can't necessarily identify their caregiver. "You can be an essential caregiver even if the patient doesn't always recognize you," Haanstra says.

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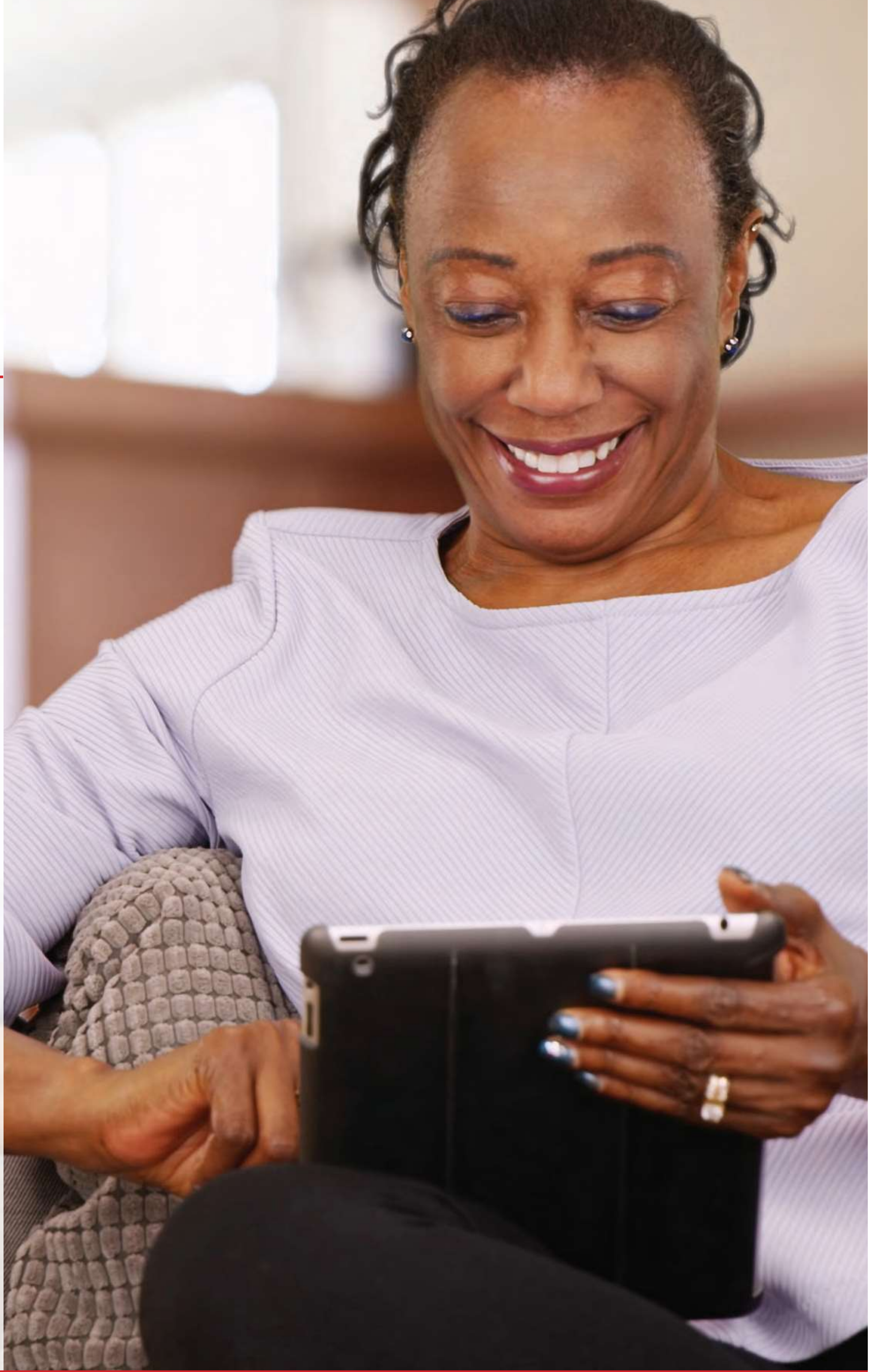

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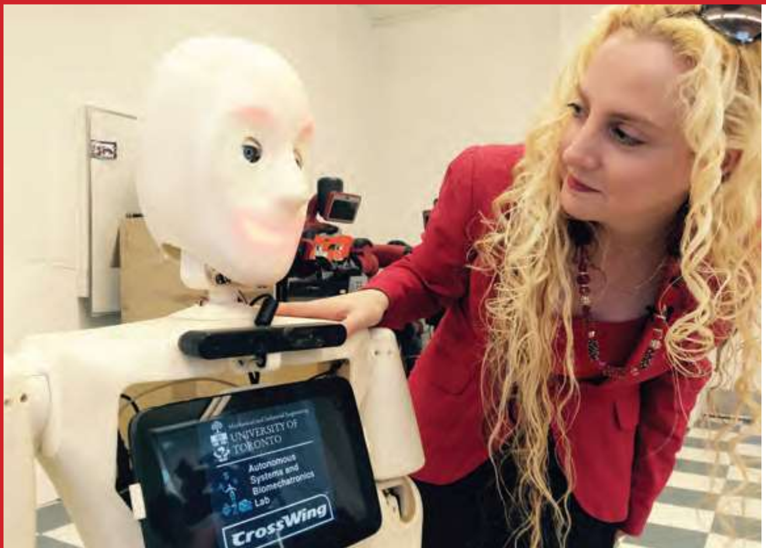

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GLOSSARY OF TERMS

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	●		$$$	C.A.R.E.S.; Person-Centered; Best Friends Approach™; Well-Being Model (integrates elements of GPA, PAC and more)	Long-term care; age-in-place; 24/7 nursing, in-house doctor; pets welcome
Auburn Heights Retirement Residence 21 Auburn Bay Street SE	allseniorscare.com 403-234-9695	●		$$-$$$	Person-Centered	Age-in-place; pets welcome, multiple amenities
Bethany Harvest Hills 19 Harvest Gold Manor NE	bethanyseniors.com 403-226-8200		●	$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Secure outdoor area; purpose-built for people with moderate to severe dementia
Bethany Riverview 200, 2915 – 26 Avenue SE	bethanyseniors.com 587-392-3999		●	$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Purpose-built for people with complex dementia care needs
Bow Crest Care Centre 5927 Bowness Road NW	reveraliving.com 403-288-2373		●	$	Dementiability Methods	
Brentwood Care Centre 2727 – 16 Avenue NW	intercarealberta.com 403-289-2576	●	●	$		Bistro on site
The BSF Bow View Manor 4628 Montgomery Boulevard NW	theBSF.ca 403-288-4446	●	●	$-$$$	Supportive Pathways	WanderGuard; long-term care
The BSF Cambridge Manor 253 Smith Street NW	theBSF.ca 403-536-8675	●	●	$-$$$	Supportive Pathways	
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 = The Brenda Strafford Foundation

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The BSF Wentworth Manor 5717 – 14 Avenue SW, Calgary	theBSF.ca 403-242-5005	●	●	$-$$$	Supportive Pathways	Age-in-place (multi-levels of care); secure outdoor area
Carewest Colonel Belcher 1939 Veteran's Way NW	carewest.ca 403-944-7800		●	$	Supportive Pathways	Priority to veterans; secure outdoor area; smoking permitted
Carewest Garrison Green 3108 Don Ethell Boulevard SW	carewest.ca 403-944-0100		●	$	Supportive Pathways	
Carewest George Boyack 1203 Centre Avenue NE	carewest.ca 403-267-2750		●	$	Supportive Pathways	
Carewest Rouleau Manor 2206 – 2 Street SW	carewest.ca 403-943-9850		●	$	Supportive Pathways; Complex Mental Health Care	Smoking permitted
Carewest Signal Pointe 6363 Simcoe Road SW	carewest.ca 403-240-7950		●	$	Supportive Pathways; Complex Mental Health Care	Dementia-specific design; smoking permitted
Chartwell Eau Claire Care Residence 301 – 7 Street SW	chartwell.com 403-269-3114	●	●	$-$$		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 587-392-2400	●	●	$$-$$$	Choice and dignity	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

RESIDENTIAL

Mayfair Care Centre 8240 Collicutt Street SW	mayfaircarecentre.com 403-252-4445		●	$	Person-Centred	Smoking facility
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	●	●	$$$	Supportive Pathways	Age-in-place; private, indepenent supportive living; dementia care
Providence Care Centre 149 Providence Boulevard SE	fatherlacombe.ca 587-393-1350		●	$	Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational programming; memory care, SL4 and 4D care
Revera McKenzie Towne Retirement Residence 20 Promenade Park SE	reveraliving.com 403-257-9331	●	●	$-$$$		Care included; multiple amenities including 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	●	●	$-$$	GPA; Best Friends Approach™	Age-in-place; pets welcome: swimming pool
Scenic Acres Retirement 150 Scotia Landing NW	reveraliving.com 403-208-0338	●	●	$-$$$	PAC; Supportive Pathways	Secure outdoor area; pets welcome, couples may live together
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
Southwood Care Centre 211 Heritage Drive SE	intercarealberta.com 403-252-1194	●	●	$	Butterfly Model	
St. Marguerite Manor 110 Evanspark Manor NW	covenantcare.ca 587-955-9788		●	$-$$	Person-Centred; Supportive Pathways	Couples may live together
St. Teresa Place 10 Redstone Place NE	covenantcare.ca 587-619-7116	●	●	$	Complex Dementia Care	Secure outdoor area; age-in-place; intergenerational progamming
StayWell Manor Village at Garrison Woods 174 Ypres Green SW	themanorvillage.com 403-242-4688	●		$$-$$$	Best Friends Approach™	Assisted living; memory care; enhanced care; palliation; respite care; rehab programs

RESIDENTIAL

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

The BSF = The Brenda Strafford Foundation

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 Approach
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	$34.95/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, $65/hr RN	Client-Centred
Qualicare Homecare	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
Senior Homecare by Angels	seniorhomecarecalgary.com 403-862-0129	LPN, HCA	$32.50/hr 4 hour minimum	GPA, Dementia-Friendly Approach

HOME CARE

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 Glenmore Park	6909 – 14 Street SW	403-258-7650	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	●	
Prominence Way Retirement Community	905 Prominence Way SW	403-727-9400	prominencewayretirement.com	●	●
Revera McKenzie Towne Retirement Residence	20 Promenade Park SE	403-257-9331	reveraliving.com	●	●
Rocky Ridge Retirement Community	10715 Rocky Ridge Boulevard NW	403-930-4848	rockyridgeretirement.com	●	●
Scenic Acres Retirement	150 Scotia Landing NW	403-208-0338	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)	8120 Beddington Blvd. NW	403-520-3350	carewest.ca	●	
Carewest Colonel Belcher	Adult Day Program	1939 Veteran's Way NW	403-944-7854	carewest.ca	●	
Carewest Glenmore Park	Living With Dementia program; Day Hospital program	6909 – 14 Street SW	403-258-7650	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	●	
JB Music Therapy – Memory Lane Chorus	Music program for people living with dementia and care partners			memorylanechorus.com		
Millrise Seniors Village	Wellness Day Program, Dementia Day Program	14911 – 5 Street SW	403-410-9155	retirementconcepts.com	●	
Monterey Seniors Village	AHS Adult Day Program	4288 Catalina Blvd. NE	403-207-2929	retirementconcepts.com	●	

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

ADULT DAY PROGRAMS

Newport Harbour Care Centre	Adult Day Program	10 Country Village Cove NE	403-567-5100	parkplaceseniorsliving.com	●	●
YouQuest at Calgary Jewish Community Centre (JCC)	YouQuest - An Active Community for Young Onset Dementia	1607 – 90 Avenue SW	403-255-7018	youquest.ca		●
St. Andrew's Presbyterian Church	Side by Side Fellowship (informal care) on hiatus. Virtual progams available	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. Virtual access is preferred.	403-290-0110	findsupport@alzheimercalgary.ca	8:30 a.m. to 4:30 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 via Zoom
Conversation Café	Dementia-inclusive get-togethers for caregivers and their partners currently online	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 Drive SW	403-253-2979	southwoodchurch.ca		Please inquire for meeting information
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 Drive 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

Myrna Norman with her dog, Norman.

Myrna's STORY

BY **Jennifer Friesen** PHOTOGRAPHY BY **Lindsay Elliott**

Between coaching softball, engaging city government to keep child resource centres open, raising her four daughters and supporting people living with dementia, Myrna Norman has always worked to advocate for others.

ON GROUNDHOG DAY — February 2, 1949 — a healthy baby girl was born in Saskatoon, Sask.

Her birthmother named her Leslie but was unable to care for her daughter at the time, so the newborn was placed under the care of family friends who called her Myrna.

Shortly after, Myrna's adopted family moved to British Columbia. Her father was a trucker, and Myrna remembers moving through the province often.

Myrna had always wanted to have lots of her own children, and she gave birth to four daughters within five years before marrying her now-husband, Dave, in 1995. Dave brought his two sons into their blended family, and the couple spent much of their free time fishing around their home in Nelson, B.C.

Myrna and Dave started Pillar to Post Home Inspection together shortly after getting married, which ran successfully for many years until Myrna started to struggle with the math when working on the company's bookkeeping.

She was diagnosed with frontotemporal dementia in 2008, and her doctor gave her eight years to live. Shocked and afraid, Myrna and Dave moved to Maple Ridge to be closer to their kids.

Now, 12 years later, Myrna is going strong. Her diagnosis changed to mild cognitive impairment in 2011, and, while she still struggles with her short-term memory, Myrna is committed to sharing her experience to help others.

"I had people give to me when I was growing up, and it's vital that I give back, that's just part of who I want to be," she says. "It was really crushing to think that I couldn't be a productive citizen. So I did everything I could do to help and stay involved. Now, I'm super, super busy. And I've pretty much been really busy since I decided to become an advocate."

As a member of 12 different committees, including Dementia Advocacy Canada, Myrna speaks publicly about living with dementia and helps with dementia support groups in her community. She participates in workshops and art projects at the University of British Columbia, and has had her poetry published by the university. In 2018, she also published a short children's book called *Sometimes my Nana,* to help children understand dementia and why their grandma might call them by the wrong name.

"By doing things like this, I'm able to stay as well as I am," she says. "I have some difficulties later in the evenings, but in other things I'm actually improving — and I swear it has to be my advocacy work."

Share your story with us at feedback@dementiaconnections.ca

Introducing Cambridge Manor

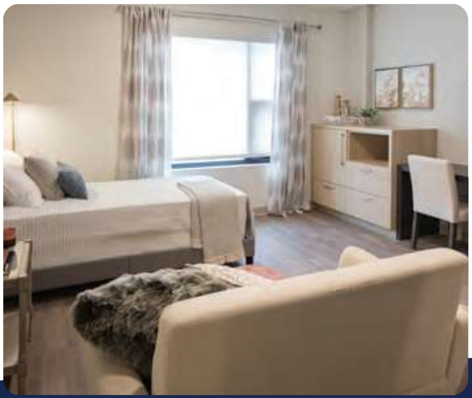
Cambridge Manor offers a true aging-in-place experience, based on personal needs, from Independent and Assisted Living to Enhanced Care and specialized Memory Care

Specialized Memory Care

Cambridge Manor offers a safe and secure community for seniors living with Alzheimer's or dementia. This main floor neighbourhood offers easy access to secure outdoor courtyard and gardens.

Additional supports in Memory Care include:

- Team members with specialized training and skills
- Specifically designed therapies, activities and events
- Daily reminders, prompting and cueing

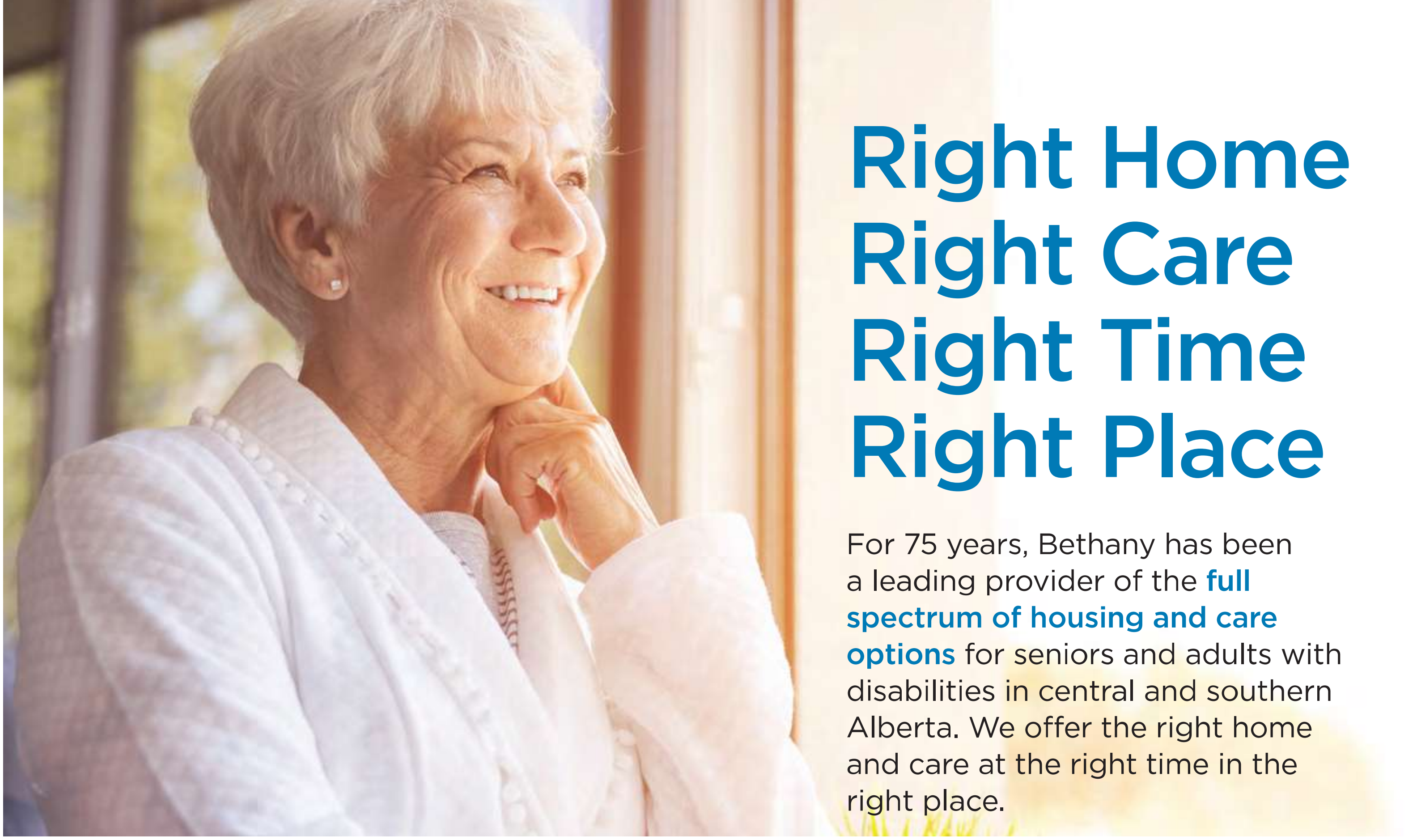


403-536-8675

cambridge@theBSF.ca

Visit us online at: cambridgemanor.ca | theBSF.ca

The Brenda Strafford Foundation is proud to lead the province's first Dementia Friendly Communities project and develop "A Guide for Creating Dementia Friendly Communities in Alberta."



Right Home
Right Care
Right Time
Right Place

For 75 years, Bethany has been 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.

Supportive Living and Long-Term Care

Bethany offers Supportive Living suites in a home-like setting to independent seniors. As care needs change, Designated Supportive Living offers 24-hour nursing support.

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:

403.210.4600 or **1.888.410.4679**

email: info@bethanyseniors.com

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