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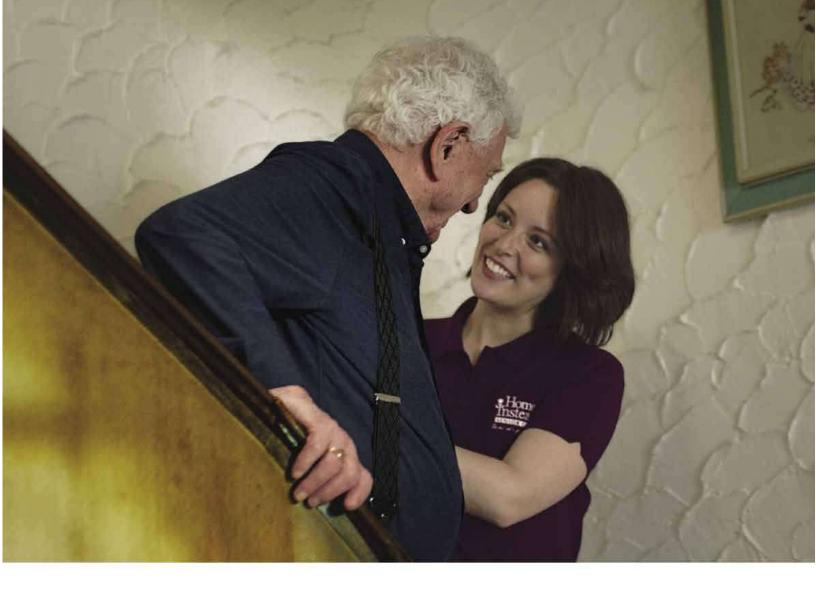
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Maddie S.

Stanley's CAREGiver



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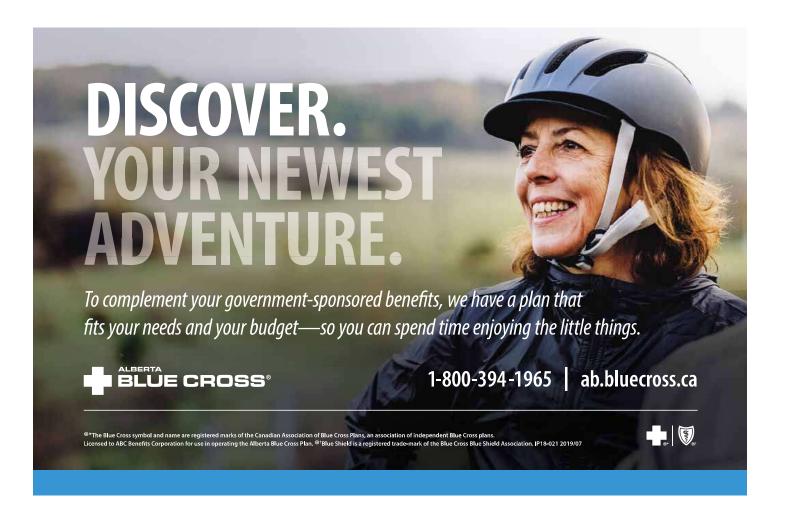
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Lisa Poole, shown here with her father, John. Photographed by Laura Colpitts Photography.

our national parties to be educated about dementia. Take every chance you've got to tell the candidates in your electoral district about the importance of implementing Canada's national dementia strategy without delay. Need a little guidance? Dementia Network Calgary has created advocacy tools to help you speak up. Learn more about the network on page 54.

Another way to share your experience is through participating in research. Research is critical. It will help us better understand how to prevent dementia, find a cure and optimize care. Increased funding and more volunteers are both needed, and to help point readers in the right direction, we've created a guide to clinical trials on page 50. In it, you'll discover what a trial entails and exactly how to get involved.

Your voice matters. This issue is packed with a variety of voices from across the dementia experience, including people living with dementia challenging stigma, care partners fighting for better care and researchers on the forefront of new discoveries.

There are many ways to get involved. You can write a letter to a politician, volunteer for a research project, join Dementia Advocacy Canada, or share your experience with us, in *Dementia Connections* magazine. Together we aspire!

# WELCOME

THIS PAST JUNE, Canada's national dementia strategy: A Dementia Strategy for Canada: Together We Aspire, was officially released. (Read more on page 8.) We are now one of 32 counties in the world with an official dementia strategy. Many people from multiple organizations were involved in the creation of this important, non-partisan document

and are deserving of our gratitude. It is now up to the rest of us to make sure that their vision is realized. Let's continue to speak up so that the urgent need for implementation of the national dementia strategy is widely understood.

As Canada heads into a federal election this fall, it is essential for political candidates from all of

Lisa Poole

Founder and Editor
DEMENTIA CONNECTIONS
lisa@dementiaconnections.ca

### Dear Lisa,

I just so happened to see Dementia Connections on a lunch room table and began flipping through it and the most beautiful medicine wheel caught my attention. I began reading and realized this is my team from Ontario who supported/mentored me during my master's degree!

It truly warmed my heart to see their amazing work with Indigenous communities in northern Ontario featured. It also highlights that the care we provide to individuals experiencing cognitive decline, or, as we say, "brain aging," differs amongst cultures. This team truly exemplifies what Indigenous community health collaborations are, and fosters the need for access to culturally appropriate care in Indigenous communities — a much-needed shift from the dominant approach commonly present.

It made my heart happy to see their work featured in the magazine!

# **Ashley Cornect-Benoit**

PhD student, Community Health Sciences, Population and Public Health, Cumming School of Medicine, University of Calgary

# Dear Lisa,

Putting your loved one into a long-term care facility is a hard thing to do. My husband spent more than four years in the Mount Royal Long Term Care Centre before he passed away. From the beginning of his stay, he felt like he was home and the staff made all of his visitors very welcome, too.

I also felt the care extended was excellent as he battled Alzheimer's. The atmosphere was friendly and laughter was a sound we often heard.

My family and I offer our sincere thanks to all of the staff at Mount Royal Care Centre. Every one of you played a big part in making Ward a happy person and were involved in his life right to the end.

Lorraine McLean and family

# Dear Lisa,

I enjoyed reading Dr. Wagg's article on incontinence. [Expert Advice, Spring 2019] I am especially interested in the name of the manufacturer of the pads that can hold up to one litre of urine without making your skin wet. I hope you can provide the name(s) of these products.

**Keith Keers** 

Dear Keith,

Thank you for your note! We reached out to Dr. Wagg with your query and have included his response below:

"There are large-capacity continence products on the market which have this kind of ability. They're body-worn, often with straps to secure them. There are a variety of manufacturers. There's more information at continenceproductadvisor.org/ products/pads/moderateheavybladderleakageinwomen/tshapepads, but most medical appliance stores will be able to help. They need to be applied carefully so they don't lie flat against the groin and are quite bulky, which is why some women don't like them." -Dr. Adrian Wagg

### Dear Lisa,

I ran across your magazine yesterday in a medical clinic and I am very impressed. Great articles, touching stories and you are addressing a key social issue.

It has been my passion for many years to get caregiving valued in society as genuine work, and to have federal funding for it, even when done by family members.

It seems to me that when we fund care of the young, sick, handicapped, frail elderly, those with dementia or the dying — but only in institutions — we ignore the huge value to the economy and the savings of family-based care. It should be an option, affordable to those who want it

You have a great magazine.
I learned a lot already.

**Beverley Smith** 

### Dear Lisa.

Congratulations on your fabulous publication, *Dementia Connections!* We salute your terrific initiative and implementation and appreciate your product! Cheeringly yours,

Linda & Steve

### Dear Lisa.

I am an aging/long-term care planning specialist with an intense interest in dementia — driven by a 14-year care experience with my father. I am speaking in Alberta shortly and have found your site/publication. I cannot tell you how impressed I am — the resources section alone is invaluable. Calgarians are so lucky to have this resource.

Karen Henderson

Share your story with us at feedback@dementiaconnections.ca.

Dementia Connections Editor Lisa Poole | Editorial Advisers Duncan McLean, Community Member; Paul Bartel, Alzheimer Society of Calgary; Kimberly Shapkin, University of Calgary Faculty of Nursing; Ann Toohey, University of Calgary - Brenda Strafford Centre on Aging | Published by RedPoint Media Group Inc., 100, 1900 11th St. S.E., Calgary, AB T2G 3G2, Ph 403-240-9055 redpointmedia.ca | President & CEO Pete Graves | Group Publisher Joyce Byrne | Publisher Pritha Kalar | Client Relations Manager Natalie Morrison | Editorial Director Jill Foran | Managing Editor Meredith Bailey | Art Director David Willicome | Graphic Designer Rebecca Middlebrook | Contributors Rodolphe Beaulieu, Colleen Biondi, Elizabeth Chorney-Booth, Shannon Cleary, Laura Colpitts, Jennifer Dorozio, Ron Freckleton, Jennifer Friesen, Remy Geofffroi, Victoria Lessard, Reynard Li, Karin Olafson, Mae Kroeis, Ron Posno, Drew Shannon, Jared Sych, Kristen Thompson, Jamie Vedres, Monique Wienedels, Mary Beth Wighton, Sean P. Young | Production Manager Mike Matovich | Audience Management & Reader Services Manager Rob Kelly | Printed by Transcontinental LGM | Advertising inquiries, info@redpointmedia.ca | Statements, opinions and viewpoints expressed within this publication do not necessarily represent the views of the publisher. | Copyright 2019 by RedPoint Media Group Inc. | No part of this publication may be reproduced without the express written consent of the publisher. Printed in Canada for free distribution. Return any undeliverable Canadian addresses to RedPoint Media & Marketing Solutions.













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# CANADA'S NATIONAL DEMENTIA STRATEGY IS BOLD AND BALANCED

Persons with dementia were active participants in its creation

eople living with dementia were included as equals in the creation of Canada's first national dementia strategy: A Dementia Strategy for Canada: Together We Aspire, released on June 17, 2019.

The strategy was informed by extensive consultations with individuals with lived experience and guided by the Ministerial Advisory Board on Dementia, whose members include two individuals living with dementia: Jim Mann, a retired executive entrepreneur and advocate from B.C., and Mary Beth Wighton, chair and co-founder of the Ontario Dementia Advisory Group from Ontario. Wighton is also co-chair of Dementia Advocacy Canada.

"This is a bold and balanced dementia strategy with human rights as a core principle," says Wighton, noting the government's commitment to follow through on promises to allocate at least one per cent of dementia care costs (currently over \$8 billion) to research funding.

The new dementia strategy emphasizes reducing stigma, prevention, access to timely diagnosis, rehabilitation, effective care coordination and the importance of a skilled workforce. It acknowledges care-partner challenges, including burnout and financial hardship as well as

low wages, lack of training and limited resources for personal support workers.

More than half a million Canadians are currently living with dementia and there are approximately 70 new cases of

dementia in Canada every day.

Implementation of the strategy is key.

Learn more about the strategy at Canada.ca.

Read more about Mary Beth Wighton on page 22.

# NATIONAL DEMENTIA STRATEGY AT A GLANCE

# Quality of life Diversity Human rights Evidence-informed Results-focused

# **National Objectives:**

Prevent dementia, including through advancing research, building the evidence base, expanding awareness of modifiable risks and supporting the adoption of healthy living behaviours.

# Advance therapies and find a cure,

including through increasing dementia research, developing innovative and effective therapeutic approaches and engaging people living with dementia and their care partners in therapy development.

Improve the quality of life of people living with dementia and their caregivers, including by eliminating stigma, promoting early diagnosis, addressing access to care, supporting care partners and building the capacity of

caregivers.

"This is a bold and balanced dementia strategy with human rights as a core principle." –Mary Beth Wighton



# GET INSPIRED

Fast facts about the Branch Out Foundation's Neuron Night

BY Kristen Thompson

# What is Neuron Night?

Held on Oct. 30 in Contemporary Calgary's art gallery space, Neuron Night is the Branch Out Neurological Foundation's annual event to challenge its grant recipients to get their research out of the lab and into the world in a TED Talk-style format.

"It is about developing the neuroscientists' ability to communicate their science to the public in an engaging way," says Crystal Phillips, Branch Out's co-founder.

# What is Branch Out?

The Branch Out Neurological Foundation is a charitable organization that supports research into innovative tech and non-pharmacological solutions for neurological disorders, including dementia, ALS, multiple sclerosis, depression and concussions. It also works to promote collaborations and helps get research and findings into the hands of the people who need it.

# What can I expect?

Besides cocktails and inspiring presentations, attendees at this science fair for adults will be given the opportunity to vote for their favourite speakers. The winner, as chosen by the audience, will receive up to \$1,000 to help further their research.

Neuron Night also features the "Your Brain on Art" auction, where local artists are paired with neuroscientists to create art inspired by their research. Art pieces will be on display and up for auction during the event, with all proceeds going to Branch Out.

Learn more at branchoutfoundation.com

# THE RIDE TO BETTER HEALTH

The Big Red Ride brings accessible cycling to Banff

BY Kristen Thompson

# What is it?

The Big Red Ride is a fully adaptive, four-seat, piloted, electric-assist bike from Holland. Located in Banff, it's used by a number of local community groups to improve the health of the town's aging population, as well as anyone marginalized by illness, disease, depression or loneliness. Each seat has a seatbelt and one can swivel for easy loading from a wheelchair or walker. One trained volunteer acts as the bike's driver and the other three riders can choose to pedal or use the electric-powered assist.

The Big Red Ride is a free program hosted by the Town of Banff and supported by Bow Valley Primary Care Network and Covenant Health rehabilitation team.

# Why was it created?

Physiotherapist Annie Tredray, who calls Canmore home, brought the bike to Canada and created the program in Banff.

"I created it to give the older adult population another opportunity to experience an adventure outdoors while socially connecting and also improving their physical and mental well-being," Tredray says.

# Who can ride?

The bike is available upon request for community seniors/adults in Banff. It hits Banff's streets every Tuesday and Thursday at 1:30 p.m. from June



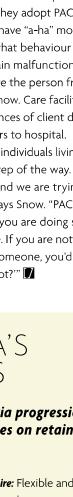
11 to Sept. 26 (weather dependent).

The bike is also available on a sign-out basis with trained volunteers for what Tredray refers to as "meaningful rides." For example, in the past, a group of patients going through chemotherapy took the four-seater for a cruise.

# Benefits for people living with dementia?

According to Tredray, the Big Red Ride would be a wonderful experience for those living with early-onset or moderate dementia because it offers a safe way to connect with others, while also getting some exercise.

"I think it's a societal responsibility to keep the aging population, and those with dementia, as active as possible in a fun and unique way," she says.





# CHOOSING RESPECT

Teepa Snow's Positive Approach to Care better serves people living with dementia

BY Colleen Biondi

hen Teepa Snow was a little girl, her grandfather, who was living

with dementia, came to stay with her family. That experience planted a seed of empathy and respect that has informed her 40-year calling as a care provision partner.

Snow began working in health care as an occupational therapist doing handson, clinical therapy with people living with neurological impairment, including dementia, brain injuries or strokes.

The North Carolina native went on to become a teacher, consultant and

researcher with programs such as the University of North Carolina at Chapel Hill's School of Medicine's Program on Aging.

Through her work, she recognized that people with dementia were not being well-served — care approaches were more controlling than caring and were dictated more by deficit than by asset. The emphasis was on compliance, rather than conversation.

Snow became committed to changing the culture and practice of dementia care. Since the mid-2000s, she has travelled the world promoting a framework of practice that helps loved ones and professionals serve people with dementia in a more respectful way. It is called Positive Approach to Care (PAC).

"We don't have a cure for this thing [dementia]," she says. "But there are better ways to manage it. With the right environment, expectation, cueing, timing and support, you can get a very different outcome."

PAC is a humanistic and inclusive way to engage people who are compromised by cognitive decline. It emphasizes relationships based on authenticity, empowerment, compassion and curiosity. PAC works with people in the strength of the moment and focuses on what capacities they have retained, instead of those they have lost.

For example, people living with dementia often have challenges processing verbal information and finding the right words. Discussions can be fraught with confrontation and frustration. So, if they are struggling with conveying a message, Snow suggests saying, "You want something? Tell me more about it." That message offers encouragement, fosters a partnership between the two parties and moves the conversation forward. Snow suggests continuing with, "Is it something to eat or something else?" etc.

All questions should be accompanied by physical demonstrations (showing the individual an apple, pretending to put on a sweater) that provide context. "Vision intake is often better preserved than auditory processing," Snow says.

PAC trainees (typically care facility staff and spouses or care partners) report less stress and more positive well-being when they adopt PAC practices. They often have "a-ha" moments when they learn that behaviour is related to the brain malfunctioning. "They can separate the person from the dementia," says Snow. Care facilities report fewer incidences of client distress and fewer transfers to hospital.

PAC celebrates individuals living with dementia every step of the way.

"It is your life and we are trying to help you live it," says Snow. "PAC is not a strategy where you are doing something **to** someone. If you are not doing something **with** someone, you'd better be asking, 'Why not?"

# TEEPA'S GEMS

# This dementia progression model focuses on retained abilities:



**Sapphire:** Flexible and easy to change



**Diamond:** Clear, but rigid, with moments of brilliance



**Emerald:** Watching, talking and doing with imperfections



**Amber:** Ruled by momentary sensations



**Ruby:** Either still or moving; challenged by transitions



**Pearl:** Hidden in a shell, with moments of awareness



# When it comes to Memory Care, one thing matters more than anything else: You.

The Journey Club is all about achieving the highest quality of life possible. When it comes to Memory Care, that's more important than ever. The Journey Club Memory Care Program is part on the world-renowned Butterfly Care Homes program. This unique, person-centered care program is based on the Feelings Matter Most model. It is about establishing compassion as the central priority and moving away from the emphasis on nursing tasks and procedures. The Butterfly Care Homes at The Journey Club are real homes, places to be celebrated, where there are passionate leaders, heartfelt staff, engaging environments and true family involvement.



# The Butterfly • Dementia Care Program

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- Each resident is assessed and receives a personal care plan to support their holistic personal care
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- Regular and rigorous quality audits for care, programming, and accommodations

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The Journey Club.ca



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# FUNDRAISING INSPIRATION

BY Karin Olafson

Interested in fundraising for dementia research, treatment and care, but not sure where to start? Get some inspiration from these four Canadians who found creative and effective ways to raise money by combining their fundraising efforts with their personal passions. Whether that passion was athletic, artistic or in the garden, their efforts got people donating big.



# Maxime McLean, Duncan McLean and Alyx Stariha: The Runners

When Maxime McLean's father, Duncan, was diagnosed with early onset Alzheimer's in 2017, she knew she wanted to find a way to raise money for an organization that provided resources, information and

support to her family.

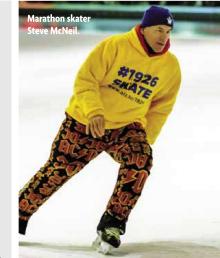
Despite not considering herself a runner, McLean took on two challenges this year: she registered to race her first half marathon, and she created a team to participate in the Scotiabank Calgary Marathon Charity Challenge, an online fundraising program that helps support Canadian

charities as part of the race. McLean collected pledges for the Alzheimer Society of Calgary.

This past May, she successfully completed the 21.1-km distance at the Scotiabank Calgary Marathon, and her team, which included her father (who ran the 10-km distance) and Alyx Stariha, a family friend, raised almost \$4.000.

"It's really important for me to give back so the Alzheimer Society of Calgary can keep doing what they're doing to help other families going through this," says McLean.

Read more about Duncan McLean and his experience with clinical trials on page 50.





# Steve McNeil: The Marathon Skater

Steve McNeil, a Torontobased amateur hockey referee, completed his first 19-hour and 26-minute outdoor skate in 2012 as a tribute to his mother, Eunice, who lived with dementia. The skate's length acknowledges the year Eunice was born — 1926 — and it also symbolizes the endurance required by caregivers.

In 2013, McNeil turned his skate into a fundraiser for the Alzheimer Society of Toronto.

Every winter since 2013, he's skated the distance while blasting AC/DC as a tribute to Malcolm Young, a member of AC/DC who lived with dementia and passed away in 2017.

This past winter, he took the challenge Canada-wide. McNeil travelled to the seven



Canadian cities that have an NHL team, including Calgary and Edmonton. McNeil skated for 19 hours and 26 minutes at an outdoor rink in each city. He also raised funds for each city's Alzheimer Society branch, including \$3,000 in Calgary, where on Feb. 16, 2019, he skated on the outdoor rink at Thomson Family Park in -33°C and a blizzard.

It was during his Calgary skate that AC/DC-member Angus Young, Malcolm Young's brother, learned that their music inspired McNeil during his endurance skates, so the band donated \$19,260 to the cause.

McNeil has no plans to make his fundraiser easier. This coming winter, he hopes to complete his marathon skate in all 10 provinces — and to do it with his skates unlaced.

"It's to show how difficult a day in the life of a caregiver is," says McNeil. "Their day is a lot harder than me having to skate 19 hours and 26 minutes without tying up my skates."

Learn more at 1926skate.com



# **Bruce Horak:** The Performer

Toronto-based theatre and visual artist Bruce Horak's one-man show, Assassinating Thomson, premiered in 2013 at fringe festivals across the country. He brought it to Calgary this past February.



Left: Bruce Horak's Assassinating Thomson. Below: Ron Freckleton and Sarah Salus, director of philanthropy and engagement, the Alzheimer Society of Calgary, with dahlias.

The show, co-presented by Lunchbox Theatre and Inside Out Theatre, explores the mysterious death of the Canadian painter Tom Thomson juxtaposed with Horak's own story — as an infant growing up in Calgary, he battled a rare cancer of the eye and currently lives with less than 10 per cent of his vision.

As part of the performance, Horak live-painted a portrait of the entire audience, which was auctioned off after each show, with the proceeds going to charity.

During the show's fourweek run in Calgary, Horak raised \$3,600 — the paintings typically sold in minutes which he donated to support arts programming at the Alzheimer Society of Calgary.

"I have a passion for visual and theatrical art, and my maternal grandparents both had dementia, so I thought this was a really great direction to go," says Horak.

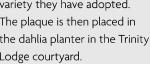


# **Ron Freckleton:** The Gardener

Ron Freckleton began growing dahlias when his wife, Joan, was diagnosed with dementia. After Joan passed away in 2014, Freckleton brought photos of his dahlias to his new home at Calgary's Trinity Lodge Retirement Residence. Management was impressed, and he was soon asked to grow dahlias in the lodge courtyards.

Two summers later, Freckleton had the idea to use his gardening skills to raise money for the Alzheimer Society of Calgary, and, in 2017, the Adopt a Dahlia project was born.

Dahlia-lovers pay \$10 to support the project. That investment gets their name typed onto a laminated plaque, along with the dahlia



Freckleton grows more than 20 varieties of dahlia — and more than 50 dahlias in total — meaning some planters can be full of plaques with the names of enthusiastic dahlia adopters. Last year, his Adopt a Dahlia project raised \$1,700, a total he's expecting to exceed this year.

"I have such fun with Adopt a Dahlia, and it's such a worthwhile cause," says Freckleton.

Learn more about Ron Freckleton's experience as a care partner on page 36. [1]



variety they have adopted. The plaque is then placed in the dahlia planter in the Trinity Lodge courtyard.

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# SPEAKING UP

Canadians living with dementia are banding together to influence change

BY Karin Olafson

ementia Advocacy
Canada is an initiative
that aims to amplify
the voices of Canadians
who are living with dementia, and the
voices of care partners.

The grassroots movement was created so that Canadians who know dementia best can work together to influence dementia-related policies, improve access to supportive services and have an active and respected role in decision-making, policy and program development.

The idea for the movement started in May 2018 at the National Dementia Conference in Ottawa, which included people living with dementia and care partners from across the county. Several attendees met over a few beers and recognized their shared common interests and value as a distinct and separate entity. In January 2019, Dementia Advocacy Canada emerged from those initial meetings and currently has more than 150 members.

"I tell people that I'm the expert. I'm the one living with dementia," says Myrna Norman, a B.C.-based member of the Dementia Advocacy Canada executive. "It's my passion to see change and I can offer ideas as to what therapies and practicalities can truly help individuals living with dementia."

Norman is one of five members of the executive, four of whom live with dementia. All five members were in Ottawa during the 2018 National Dementia Conference for the movement's beginnings.

As a member of the executive, Norman helps drive the movement's organizational framework by ensuring all members work together and are included in its decision-making. The executive also connects members with each other, either through in-person meetings in different cities when possible, but largely through video conferencing and social media.

Dementia Advocacy Canada's spring 2019 survey, which was shared with those living with dementia and care partners, confirmed its top priorities:

- A single point of contact to mitigate the difficulty navigating a fragmented system.
- **2.** Regulation of personal support workers and standards of excellence in dementia care.
- **3.** Rehabilitation to live as well as possible with a dementia diagnosis.

"People with dementia and care partners are speaking up. We understand that we can change the policy. We understand that we can influence the government and we can improve health-care services across Canada," says Norman.

That includes Canada's rural north.

Susan Rae is a Dementia Advocacy

Canada member who lives in Whitehorse.

Yukon. Her husband, Dr. Andrew Kaegi, a retired physician, lives with dementia and Rae is his care partner. After his diagnosis, Rae had trouble finding any information, resources or supports. She felt isolated and like there weren't any policies or programs in place to help people living in Canada's remote areas.

"Through Dementia Advocacy Canada, I feel like I'm a voice not only for caregivers, but a voice for Northern Canada," says Rae. "Each location in Canada will be unique in its needs. Up here, what we do to support individuals with dementia and care partners will likely look very different from a big centre. But people living with dementia and their care partners in remote areas can speak up and share what it is we actually need."

Rae adds that Dementia Advocacy
Canada is an integral connection to a support network. She's accessed resources about hosting dementia-friendly meetings and has received advice on how to help stop her husband from misplacing his hearing aids — both supports she hadn't found in her hometown.

Looking to the future, both Norman and Rae hope to see more Canadians who are impacted by dementia join the grassroots movement.

"For the grassroots movement to succeed, we need to speak up," says Norman. **17** 

Learn more at dementiacanada.com



DID YOU KNOW? For people who wear them, losing one or both hearing aids can be a common problem. New tracking technology, such as Made for iPhone (MFi) hearing aids, pair hearing aids with an app on your smartphone. If aids are misplaced, the app can track their last known location. Visit canadianaudiologist.ca for more information.

# LISTEN UP!

These two dementia-related podcasts should be on your playlist



# LIFE WITH DEMENTIA

### BY Mae Kroeis

Life with Dementia, which first aired in January 2019, is a podcast run by the Dementia Association for Awareness and Support, a registered charitable non-profit organization.

Each 30-minute episode features a guest's experience with dementia. Guests can include people living with dementia, care partners and spouses, and researchers and physicians.

Information from the podcast includes tips based on the personal experiences of people living with, or caring for someone with, dementia, as well as insights from research and more.

# Who is behind it?

The Edmonton-based Dementia Association for Awareness and Support is run by a triad of women connected by their

From left: Beth Mansell, Heather Barnhouse and Johnna Lowther.



passion for providing support services for family caregivers of people with dementia.

The non-profit includes Johnna Lowther, who has worked in recreation therapy in aging services for over 20 years and spearheads and hosts the podcast; Beth Mansell, who has personal and professional experience with dementia through her work with Sage Seniors Association; and Heather Barnhouse, a lawyer who is also a caregiver to a family member living with dementia.

# Why is it important?

Lowther believes that people living with dementia and their care partners should feel empowered to live a better life and that the *Life with Dementia* podcast can help.

"I hope it will change the lived experience of someone living with this disease. For that to happen, it requires us as a society, community or individual to learn techniques to better support those people or their caregivers," says Lowther.

Lowther invites listeners to share their feedback, topic

ideas or guest suggestions through the podcast's social media pages on Twitter and Facebook to make sure the podcast serves the listeners' needs.

Listen at thedementiapodcast.org, @thedementiapod



Based out of Ontario, *Dementia Dialogue* is a podcast for and about people living with dementia and their care partners. It provides an intimate perspective of the experience.



# Who is behind it?

David Harvey, the podcast's producer and host, and former chief of policy and programs at the Alzheimer Society of Ontario, first formulated the idea when he was collaborating on a research project called "Mapping the Dementia Journey." The

project was a joint effort between a team of researchers led by Dr. Elaine Wiersma and the Alzheimer Society of Ontario. Its goal was to create an outline of the significant points of the dementia experience as divided into four main categories: changing and adapting, the system journey, relationships and community, and focusing on me.

# Why is it important?

"The human voice is a powerful instrument of communication. There's an intimacy and a strength," says Harvey. "One of the things I like about the podcast is that it's relatively easy for people to do. You can [listen to] it while you're going somewhere, or you might be waiting for somebody. People can play it and replay it, so if you don't grasp the point the first time, then you can listen to it again. That's particularly important for people that might have some cognitive impairment."

# What will I hear?

In September 2018, *Dementia Dialogue* made its debut. The first season is six episodes long, each episode about 20 minutes in length, and explores the theme "changing and adapting"— one of the four components of the "Mapping the Dementia Journey" project.

Keep an eye out for the next season, which debuts this fall and focuses on "the system journey," looking at key interactions with health-care and social service systems.

Listen at dementiadialogue.ca

# GOING DEEPER

Why MAID is failing people living with dementia

FEATURING GUEST WRITER Ron Posno PHOTO BY Monique Wiendels

n the spring 2019 issue of Dementia Connections magazine, the article "Death and Decisions" by Julia Williams explored the issue of access to Medical Assistance in Dying (MAID) legislation for people living with dementia. It included interviews with Dr. Samir Sinha, director of geriatrics at Sinai Health System and the University Health Network in Toronto; Dana Livingstone, whose mother passed away from complications related to dementia; and Ron Posno, who is living with dementia. Currently, people with dementia are excluded from accessing MAID. Posno believes that every Canadian has the right to a medically assisted death. Here, Posno, who is 80, dives deeper into his perspective as to why MAID, in its current form, is failing people living with dementia.



Ron Posno at home in London. Ont.

federal government was forced into the creation of the Medical Assistance in Dying law (MAID) by the Supreme Court

FROM MY PERSPECTIVE, the

of Canada with its Carter Decision in February 2015. Basing its findings upon the Canadian Charter of Rights and Freedoms, the Court essentially said every Canadian has the right to a medically assisted death, and then the Court directed the Government of Canada to legislate such

law within one year.

The government asked the Supreme Court for more time, and a large number of experts from across the country were asked to bring forward recommendations ASAP. The Supreme Court gave the government four more months, and the government assigned the experts' recommendations to a panel of MPs and senators for review. This second review panel largely supported the experts'

recommendations and — this is critically important — both panels supported the use of advance requests (ARs). Neither mentioned anything to do with the concept of "foreseeable future," nor the need for "late-stage protection," nor any requirement "to protect the vulnerable."

On June 17, 2016, Bill C-14 (MAID) was passed by the House of Commons, possibly the most compelling health legislation since the passage of Medicare in 1966. And yet, MAID failed because it *did not follow* the directions of the Supreme Court and it failed to permit access for people with dementia.

In its original direction to the Government of Canada, with respect to the creation of MAID, the Supreme Court did not say people with dementia are vulnerable and need protection. It said, "Every individual is equal before and under the law and has the right to the equal

We should have access to a real MAID law, and a more informed, dementia-friendly Canada.

nd a.

protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability." (Carter Decision, February 2015)

In spite of such clear and definitive direction, people with dementia are still excluded from MAID.

Five months after MAID was passed, the federal government hired the Council of Canadian Academies (CCA) — a not-for-profit organization that asks the best experts in their respective fields to assess the evidence on complex scientific topics of public interest to inform decision-making in Canada — to study the problems of MAID and report back by December 2018.

Dr. Samir Sinha [who was one of the sources in *Dementia Connections*' story, "Death and Decisions"] is known as a passionate spokesperson for senior health. He is also a member of CCA. Sinha sees MAID as "a complex ethical issue." As an example, he offers from the CCA report: "Removing a requirement for express consent [i.e. removing late-stage protection] immediately prior to the MAID procedure raises the possibility that a person might receive MAID against their wishes."

This statement is an example of pure speculation. I am a person with dementia. I was assessed almost three years ago, and, if my dementia progression devolves as expected, I will have maybe 10 or more years before I am incapable of rational thought. If an AR process was in place, I could apply early in my

progression, and, if it came to be that I wanted to change my rational mind, I would have time to withdraw the application. That's not speculation; that's the reality of people living with dementia. We don't need "late-stage protection." We do need an improved MAID.

# Here are the four real failings of MAID:

**1** • Foreseeable future. MAID is limited to deaths in the "foreseeable future," but does not clarify what or when that is.

**2.** Late-stage protection or express consent. Who are we protecting, physician or patient? How can an "ask" be accepted from a patient in the throes of pain, or in the late stages of dementia?

\*\*No provision for advance request/directives. Why? Who are we protecting? Why must an application be withheld to just before a cogent death, contrary to existing, mandatory requirements for do-not-resuscitate orders?

• Protection for the vulnerable. Late-stage protection creates vulnerability; people with dementia are most vulnerable during late-stage progression of dementia, but most are capable of cogent fluency for 10 years or more after initial diagnosis.

Real, rational solutions are available. We just need calm, rational decisionmaking. Dump the first two failings. They are so obviously wrong, they don't require detailed explanation for removal. Provision of advance requests need not be difficult. We already have — right across this country — a citizen's right to a "do-not-resuscitate" application procedure. It does not discriminate, other than by consideration of mental competency. People with dementia can apply — while they are still cogent. If they are not able, then a properly designated attorney or a substitute decision-maker may apply on behalf of the person in need. ARs could be provided. The legal precedent is there, and the procedure is well-established; just follow the steps.

So, let's go ahead. Dying With Dignity Canada (DWDC) has a petition going around in which it has proposed legitimate, well-considered and relatively easy changes to MAID. Of the more than half million people with dementia in Canada today, possibly 400,000 could make an informed and cogent choice. They don't have to choose MAID, but that choice should be available.

Waiting is destructive; proceeding is constructive. We should have access to a real MAID law, and a more informed, dementia-friendly Canada.

Let's do it now.

Learn more at dyingwithdignity.ca



# THE CENTRE FOR AGING + BRAIN HEALTH INNOVATION

The impact of an inventive approach to innovation

BY Victoria Lessard



n innovative idea might begin with a metaphorical light bulb flickering on, but, more often than not, there are many, many steps

in between identifying a problem and coming up with a successful solution. Based in Toronto, the Centre for Aging + Brain Health Innovation (CABHI) aims to bridge that gap in seniors' health care.

Created in 2015 through funding from the Government of Canada through the Public Health Agency of Canada, CABHI helps support the development and commercialization of aging and brain

innovations from early ideas, to testing and validating products, to helping a product scale and get adopted in the health sector. Some of the services CABHI offers include funding, project management, knowledge dissemination, networking, feedback from the CABHI Seniors Advisory Panel and more.

CABHI focuses its efforts on four gaps it has identified in innovation in seniors' health. These include filling a niche in providing resources for underserved point-of-care innovation; improved speed between innovations in getting from bench to end users; increasing the success of Canadian companies engaged in the aging brain health and dementia care markets through their services so that these innovations can become procured and more widely adopted; and providing support for underrepresented communities in seniors' care

CABHI has several programs that focus on the various stages of the innovation process, often in collaboration with other partners, including National Bank. Programs include the Spark Program, where health-care workers can develop their ideas for improving seniors' care, and the Industry Innovation Partnership Program, which connects companies and seniors' care organizations to test innovations.

Mel Barsky, director of business development, says CABHI's unique approach to innovation is its emphasis on perspective.

"CABHI developed a partnership model that optimizes the innovation process through co-development, ensuring that end users'—

"We know our approach can make a meaningful difference for older adults and their caregivers." –Mel Barsky

for example, older adults, caregivers or health-care providers — perspectives are integrated into decision-making, priority-setting, user testing and dissemination," says Barsky. "In a 2018 survey of CABHI stakeholders, 91 per cent of industry respondents, 92 per cent of researchers and developer respondents, and 100 per cent of health-care respondents said it would be difficult to access similar services or assistance elsewhere."

Essentially, CABHI takes a needs-specific approach to innovation in seniors' health. It identifies where the greatest stop-gaps are in the innovation process — both for individual innovators and in seniors' health care overall — and helps to fill them. One of the key ways it does so is by making sure that innovators receive feedback from those organizations and the people their project/product is aiming to help.

So far, CABHI's unique approach has led to the launch of more than 210 projects and over \$84 million in project funding in less than five years. This year also saw CABHI's introduction of What's Next Canada's inaugural Innovation Day on March 20. The day was a part of the annual Rotman Research Institute Conference in Toronto. The focus of What's

Toronto

Next Canada was to provide learning and networking opportunities for innovators.

In addition to a number of exciting guest speakers and panellists, one of the highlights of the day was the pitch competition, hosted by NBC News anchor Richard Lui. Nine companies competed and were judged on the potential transformative ability of their pitch. The 2019 CABHI Innovation People's Choice Award was given to U.S.- and Canadian-based Catalyst Healthcare for "spencer," a device that helps manage medication. And the 2019 CABHI Innovation Award went to San Francisco-based Darmiyan for its work on early dementia detection.

CABHI is continuing on its upward trajectory—it already partners with seven provinces, including Alberta, and is working on partnering with two more and a territory. CABHI is also continuing to expand on an international scale, with three partnerships that will be announced in the near future.

"We know our approach can make a meaningful difference for older adults and their caregivers, for seniors' care organizations, for innovators, and for the health system," says Barsky. "We will continue to build our community of innovators."

HERE ARE THREE
EXCITING PROJECTS
THAT ARE CURRENTLY
WORKING WITH
CABHI:

**YouQuest** Based in Calgary, YouQuest is a day program where people living with early onset dementia can go for community, support and activities.

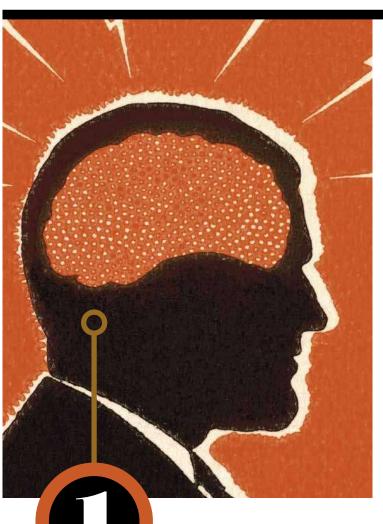
**RetiSpec** Toronto-based RetiSpec is working on a way to identify biomarkers of Alzheimer's disease in the human eye through the use of artificial intelligence in order to identify the disease early on.

**COMPAs** An app that is being developed at the Integrated University Health and Social Services Centre in Montreal, *COMPAs* includes photographs, songs and videos of important moments and periods in the user's life in order to encourage memory and communication.

# THREE PREVENTION PRACTICES TO START TODAY

BY Kristen Thompson

From protecting yourself and eating better to making sure you're getting enough sleep, the following studies look at some of the things you can do to help reduce your risk of dementia



Watch Your Head

Head trauma can have a number of long-term effects, ranging from worsened sight to permanent brain damage. A recent study out of Umeå University in Sweden found that traumatic brain injuries

(TBI), such as concussions, can also be a risk factor for dementia.

Published in the *PLOS* medical journal in January 2018, the study revealed that the risk of a dementia diagnosis was highest in the year following the injury, and the participants who experienced a TBI were four to six times more likely to

receive a dementia diagnosis than those who hadn't.

The study also found that participants who had more severe or multiple brain injuries over their lifetimes had a higher risk of developing dementia at an older age, and, though this risk may decrease over time, it is still evident more than 30 years after the trauma. The results of the study remain consistent when looking into family medical records and genetic risks for dementia.

The researchers caution that the study's outcome does not necessarily mean that all people who have suffered from a brain injury will be diagnosed with dementia, and there is no evidence that one mild TBI increases the dementia risk.

However, a growing body of evidence does suggest that repeated mild TBI, experienced by athletes who play football or hockey, for example, could be linked to a greater risk of a chronic traumatic encephalopathy dementia diagnosis.

# **START NOW**

Avoid head trauma by wearing a helmet while bike riding or participating in sports, and buckling up while in a moving vehicle.



# **Drink Responsibly**

The amount of alcohol you drink has a significant effect on your body, and according to a 2017 study, drinking too much or too little could also increase your risk of dementia.

A team of researchers from the Université Paris-Saclay, and University Montpellier in France, in collaboration with scientists from University College London in the U.K., set out to discover the connection between alcohol consumption in mid-life to old age and the risk of dementia.

The 23-year-long study included over 9,000 participants between the ages of 35 and 55, and found that both abstaining from alcohol and drinking heavily (more than 14 standard U.K. alcohol units per week) in mid-life raised the risk of dementia when comparing the results to participants who drank light-to-moderately.

While the study doesn't encourage those who do not drink to start drinking, it does

Illustrations left to right: iStock/CSA Images; iStock/CSA-Printstock; iStock/CSA-Archive



caution that excessive alcohol consumption can increase the chance of being diagnosed with dementia in later life. Although the reasons why excessive alcohol consumption is linked to an increased dementia risk aren't specifically known, one factor could be that drinking large amounts of alcohol can prevent neurons from regenerating.

Alternatively, some evidence suggests that light-to-moderate drinking plays a protective role in brain health

by reducing inflammation and clearing away toxins.

Ultimately, the study "encourages the use of a lower threshold of alcohol consumption in such guidelines, applicable over the adult life course, in order to promote cognitive health."

### **STAY MODERATE**

Alberta Health Services recommends consuming no more than 10 standard-sized drinks a week for women, and 15 for men.





# Get a Good Night's Sleep

The benefits of a good night's sleep on your overall brain health are many. Sleeping seven to eight hours a night allows for brain healing and storing of the day's memories. It also helps your body rest and heal for the day ahead.

A group out of Johns Hopkins University and the University of California compiled a report in 2014 based on multiple studies on the role of sleep and brain health. The goal was to determine the impact of lack of sleep on cognitive decline and an increased dementia risk.

The report indicates that a poor sleep schedule, meaning less than seven hours a night

or inconsistent sleep patterns, is a risk factor for developing dementia, but that the underlying associations of how lack of sleep affects the risk of dementia are not clear. Does lack of sleep cause or compound dementia or are sleep issues caused by an existing undiagnosed dementia?

Either way, the report states, "Healthy sleep appears to play an important role in maintaining brain health with age, and may play a key role in [dementia] prevention."

# **DIVING DEEPER**

A 2018 study, conducted by the U.S. National Institute of Health, specific to Alzheimer's disease, found that losing even one night of sleep can increase amyloid proteins in the brain. A buildup of this protein is linked to both impaired brain function and Alzheimer's disease — good reason to clock at least eight hours of sleep every night.

# Photo by Peter McNeice

# CHANGING OUR LIVES FOREVER

Mary Beth Wighton was diagnosed with frontotemporal lobe dementia at 45 years old. Today, more than six years later, she is a vocal advocate for inclusivity for people living with dementia. Here, in an excerpt from her upcoming book Dignity + Dementia: Carpe Diem, Wighton shares when she was first diagnosed during a doctor's appointment with her partner, Dawn.



BY Mary Beth Wighton

Sept. 5, 2012, St. Mary's Hospital, Kitchener, Ont.

As I drove us to the 9 a.m. meeting with the geriatrician, many thoughts ran through my head.

"Here we go, another appointment with another doctor," I thought. "One more stupid test. I hate when they ask me to write down the clock time because I know what time it is." And, "I'm looking forward to my Timmy's coffee."

Dawn and I arrived at the hospital, grabbed a coffee and headed to the waiting room. I asked myself, "How can I only be 45 years old and be sitting here?" It really bothered me that, after years of battling serious depression, memory loss and behavioural changes, no one had provided me with a sound medical diagnosis. That was all about to change.

Nurse Julie began the mini-mental state examination (MMSE). Sure enough, there were the questions about time. I muttered to her that I don't have a problem with time. We continued. Finally, the last 30 questions lay in front of me. My mind was tired, and it had become hard to stay focused. I didn't have the brain power to answer any more questions. Finally, we were finished. After asking Dawn and me a few more questions about my health, she disappeared to tally the results.

Soon, the door opened, and nurse Julie appeared with the doctor. Everyone sat down. The doctor immediately started to discuss the results of the MMSE. Six months ago, I had taken the same test and scored 24. Today, my score was 18 — an obvious, significant decrease.

I'm not sure of all the things she discussed, but I do remember this: "You have Frontotemporal Lobe Dementia, or FTD."

"Whoa," I thought, "no one has ever used those words before.

I knew I was cognitively impaired, but what was this FTD thing?"

The doctor went on to explain more about FTD, including that my amount of education will help. More blurred talk.

"FTD is a rare form of dementia and is incurable," the doctor said.

Dawn and I looked at each other. Could this really be happening? More blurred talk.

"You will not be able to drive anymore, effective immediately."

"What?" I thought. "Okay. This is now serious."

More blurred talk.

I stopped hearing the rest of the conversation. The only thing I could hear in my head was, "You can't drive. You don't have a driver's licence!"

I started to see red. I flew out of my chair and threw some papers in the garbage. I stormed out of the office, trying my best to slam the door shut. I tried a few times.

I continued to the hospital hall and stopped. I began to pace up and down, mumbling to myself. "How could this be? How can I have dementia? How can my licence be removed? How can I have dementia?"

My cellphone rang, and it was Dawn asking where I was, if I was okay, and for me to come back. "No!" I said. "I'm not coming back into the room because I don't want to hear any more."

I continued to pace.

Eventually, Dawn came out of the examination room and approached me in the hall. We said nothing and I handed my car keys to her. We headed out towards the car. Dawn proceeded to take my usual seat at the wheel, and I took her usual seat as a passenger. FTD had changed our lives forever.

Let's not dream of a world free of neurological disorders.



# This page: courtesy Bryan Gilks; facing page: Dineen family photo by Maryalice Mullally; Union Jack iStock/imagesunlimiteduk

# the future is Dementia Friendly

Learn more about a toolkit designed to make Alberta communities more inclusive, and how physical activity continues to benefit people living with dementia

BY Jennifer Dorozio

# Dementia Friendly Communities Project Toolkit

A more dementia-friendly Alberta? There's a toolkit for that.

The Brenda Strafford Foundation's (BSF) 2016 Dementia Friendly Communities Project was a two-year pilot program that ran in Calgary's Westhills communities and the Town of Okotoks. The project aimed to empower communities to reduce the stigma of dementia and build capacity to enable people to age in place. The project also planned to create a comprehensive guide to enable its findings to spread to communities across Alberta. To achieve that, the Dementia Friendly Communities Project Toolkit was released this month.

The toolkit was developed out of lessons learned from the pilot's programs. The BSF partnered with organizations and city services, such as the Calgary Public Library and the Town of Okotoks, to hold Conversation Cafés (a community gathering space for people living

with dementia), awareness talks and dementia-sensitive employee training pilot programs. For instance, high school students in Okotoks learned about dementia through the insight of a clinical neuropsychologist, as well as potential career opportunities to work with people living with dementia.

After observing what initiatives worked and what didn't, recommendations were created for how to create dementia-friendly communities.

The toolkit — funded in part by the Government of Alberta (Seniors and Housing), Alberta Innovates, Alberta Health Services and The Brenda Strafford Foundation — is an all-purpose, dementia-inclusive guide that includes case studies, best practices and research in the form of text, infographics and videos.

"The intent was to develop a toolkit that could be used in any community, any neighbourhood, or any city and town, to give them strategies on how to make their communities more dementia-friendly," says Bryan Gilks, cochair of the Westhills Dementia Friendly Communities Project.

The toolkit can be used by anyone, including care partners and advocates who want to engage with people living with dementia in their communities in a more sensitive and meaningful way.

The toolkit is broken up into tangible steps to follow and includes case studies of sectors that often interact with people living with dementia, including first responders, health and community agencies and more.

"We wanted to ensure it was as user-friendly as possible by transparently sharing everything that we've learned over the past few years so that folks can embark on their own journey," says Navjot Virk, research and innovation practice manager with The Brenda Strafford Foundation and project manager of the Dementia Friendly Communities Project.

A first responder, for example can watch a video explaining how to recognize someone who is living with dementia in a crisis situation and learn appropriate interaction techniques.

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Learn more at thebsf.ca



"The intent was to develop a toolkit that could be used in any community, any neighbourhood, or any city and town, to give them strategies on how to make their communities more dementia-friendly." —Bryan Gilks



DID YOU KNOW? The Calgary Fire Department (CFD) Community Safety Team won an award in the safety category for its work with the Dementia Friendly Communities Project at the City of Calgary's 2019 One City awards—an annual celebration of City staff. Through the project, the CFD ran dementia awareness training, implemented the Home Safety Program for people living with dementia, and more.

# Sharing the Joy of Dance with People Living with Dementia

In 2012, Matt Dineen's wife, Lisa, began exhibiting troubling symptoms such as a drastic change in her job performance and a lack of desire to contribute to household affairs. Less than a year later, at 43 years old, she was diagnosed with behavioural variant frontotemporal dementia, a form of dementia that leads to significant changes in personality, behaviour and complex thinking. The diagnosis was devastating for the whole family, including the couple's three children.

"I don't think words can capture how painful it is," Matt Dineen says.

In 2013, Lisa moved into Carleton Lodge, a long-term care facility in Ottawa (where the family is based), because of the rapid progression of her illness.

Dineen began advocating for the rights of people living with dementia, including through the Dementia Society of Ottawa and Renfrew.

In May 2018, at the National Dementia Conference, Dineen saw a presentation of Canada's National Ballet School's Sharing Dance program. Through a variety of opportunities, the broad focus of Sharing Dance is to share the joy of dance with as many people of all ages and abilities as possible.

Dineen knew he had to bring Sharing Dance to Lisa.

"Lisa loved dancing. She was the life of the party. I just thought, 'She



Matt and Lisa Dineen with their three children.

deserves this, and I am going to do everything that I can to make it happen," says Dineen.

The program has many different iterations taught across Canada — including NBS Sharing Dance Parkinson's and NBS Sharing Dance Kids. The presentation Dineen saw was for Sharing Dance Seniors, a joint venture between NBS and Baycrest Health Sciences, a Torontobased health-care and research centre. Sharing Dance Seniors is also part of a study spearheaded by researchers at Manitoba's Brandon University and Trent University in Peterborough that explores the ways in which dance contributes to the social inclusion of people living with dementia and their care partners.

In Sharing Dance Seniors, classes are led by NBS instructors via video stream, with trained local community staff and volunteers present, helping to facilitate. The program offers two levels, based on the cognitive and physical ability of participants. Level 1 is dementia-friendly and

is danced from a seated position, where care partners and loved ones can join in and dance to the beat. Level 2 is slightly longer and offers standing options.

"We all still have the capacity to experience joy. [In class], you can watch the transformation that happens, and you see the smiles on [people's] faces," says Rachel Bar, manager of health and research initiatives at the NBS, who helped design Sharing Dance Seniors.

After reaching out to the NBS, Dineen wrote a proposal to the City of Ottawa to bring the program to Ottawa's four long-term care facilities, including Carleton Lodge. And, this past April, Lisa attended her first Sharing Dance class there along-side two of her three children.

"It was one of the finest accomplishments of my life being able to get that [program] in," says Dineen. "She was beaming and singing along with the music."

Learn more at nbs-enb.ca



# BE A GOOD SPORT AMBASSADOR

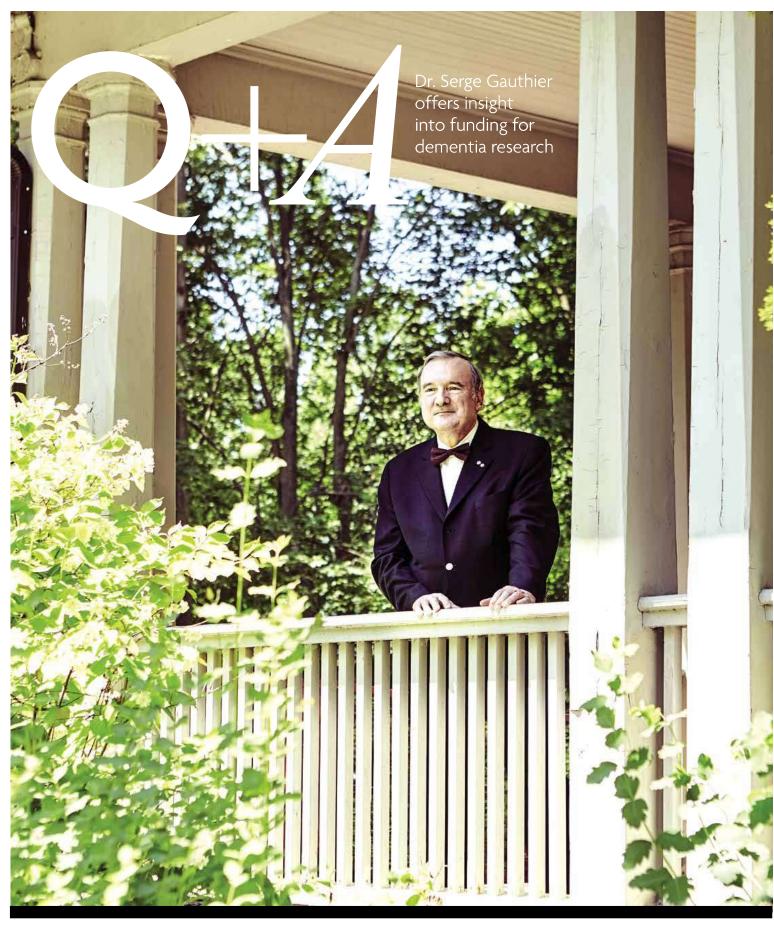
Sport England and the Alzheimer's Society of the U.K. want people living with dementia to continue to enjoy participating in and benefitting from sport in their communities.

With this goal in mind, in February 2019 the Dementia-Friendly Sport and Physical Activity Guide was published.

The guide gives any person, community-based activity group,

recreation facility or sports organization an opportunity to learn more about dementia and how to support and include people living with dementia in sport.

It includes things like step-by-step actions that training staff at public recreation centres can take to help make people with dementia feel more comfortable while there, and a checklist to make physical environments used in sports — such as leisure centres and sports clubs — more dementia-inclusive.



BY Elizabeth Chorney-Booth PHOTOGRAPHY BY Rodolphe Beaulieu

**AS A PROFESSOR** and the director of the Alzheimer's Disease and Related Disorders Research Unit at the McGill Centre for Studies on Aging in Montreal, Dr. Serge Gauthier has not only faced the challenges presented by the mysteries of dementia itself, but also the funding hurdles that researchers routinely encounter. Even if a researcher has a great idea for a project and volunteers willing to participate, public funding bodies do not have enough money to go around and private funding is not always available. From Gauthier's perspective, a shortage of funding isn't the only thing that's preventing researchers from better treating and preventing dementia, but it is certainly a factor.

Here, he reflects on the state of dementia research funding in Canada.

Q | How is research like yours typically funded in Canada?

A | We apply for [both public and private] grants. Many researchers have been very successful thanks to agencies such as the Weston Brain Institute [Canada's largest private funder of research on brain diseases linked to aging]. If it were only up to the federal body, the CIHR [Canadian Institutes of Health Research], we wouldn't get sufficient funding.

You often need to go outside of the country — sometimes we have to apply for funds in the U.S. and Europe.

Here in Quebec, private-public partnerships have worked well, especially when private money has been matched by funding from the government.

- Q | Do you feel like dementia research is properly funded in Canada?
- A | The answer is a balance of yes and no. There has been sustained funding from the federal government and the provincial bodies. And, more importantly, for the past five years we've had

a consortium in Canada called the CCNA or the Canadian Consortium on Neurodegeneration in Aging. [It] has major funding from the CIHR [and is in] partnership with the Alzheimer Society of Canada and two or three smaller provincial funds. It's just been re-funded for another five years. But the amount that was given [\$50 million] is half of what is needed. That's why my answer is yes and no. We have the funding, but it's not enough.

There was a Senate report in 2016 about funding for research on dementia and Canada. It should be in the order of \$100 million per year, which is about one per cent of the cost of the disease. Right now, we're about halfway there.

- Q | As our population continues to age, will there be increased public demand for a fully funded national dementia strategy?
- A | In all the countries where the population is aging to be over 80, the need for increased funding is going to be a significant factor. The good news is that people who are baby boomers, age 65 to 75, are very keen on prevention and [will] volunteer for research.

The bottleneck is, we don't have enough staff. [For example], we don't have enough scanners to scan the brains of the volunteers. So the funding would be for support staff, special equipment and researchers.

- Q | In Canada, we've seen a lot of success with funds and awareness being raised for heart disease. Can we expect the same for dementia?
- A | People who [have] not died of a heart attack or a stroke [when they were] younger are now at risk for dementia, so yes. A lot of research is going to be translated into clinical practice quickly in Canada, perhaps faster than elsewhere. A working group began creating a national dementia strategy two years ago. [It was released this past June.] It was created by an all-party bill that went through unanimously, so we can be confident that the national plan will be followed through by whoever wins the upcoming federal election. But we'll have to remain vigilant.
- Q | Why is a well-funded national strategy so important?
- A | Dementia will soon become the most expensive health condition. In some parts of the world, it's estimated that it will cost the entire [amount] of [a country's] current health-care budget. So, if we can reduce the numbers of people with dementia by 20 per cent within one generation, by delaying the onset of symptoms by five to 10 years, that will make a big difference.

Share your questions with us at feedback@dementiaconnections.ca.

# Navigating the Maze

Calgarian Lynne Kearns shares the story of her husband, Bill, and his challenging health-care journey

he journey from a

BY Elizabeth Chorney-Booth PHOTOGRAPHY BY Jared Sych

dementia diagnosis into a full-time residential care facility is never an easy one on either the person living with dementia or their care partner. When Lynne Kearns's husband, Bill, was diagnosed with dementia she was devastated, but Bill's decline ended up being far more difficult and heartbreaking than she could ever have imagined.

The dementia caused severe changes in Bill's behaviour, which made it impossible for him to transition into a nursing home. Bill's journey reveals many gaps in our health-care system, and Lynne hopes that, by sharing his story, she can raise awareness and help advocate for better end-of-life care for people living with difficult-to-manage, complex dementia.

# Meet Bill

Lynne met her husband, Bill Kearns, when they were both just teenagers — she remembers him as a charismatic and fun-loving young man with dreams of becoming a dentist. After Lynne finished university, while Bill was still in dental school, the two married and went on to have three children and seven spirited grandsons. Highly personable and extraordinarily generous, Bill had an ability to make people feel at ease. He was adored by his family and appreciated by his friends, neighbours and patients, and pretty much everyone else who had the opportunity to get to know him.

"He was lovely. He was a wonderful partner, and we had a very good life together." Lynne says, reflecting on their marriage of 52 years. "He had a special facility to communicate easily and a great ability to diffuse tension. He was just a great guy."

# The Beginning

As they reached their senior years, Bill and Lynne pursued their passion for travel, exploring destinations around the world, and spending time with their growing brood of grandsons in between trips. Lynne lights up when she looks at photos of Bill on their travels. But those days of adventure were cut short in 2010 when, after experiencing some other health issues resulting in open-heart surgery, Bill was diagnosed with dementia. Lynne cared for him at home for six years, but as his symptoms increased, keeping him at home became difficult. Ultimately, it was more than she could handle.

"His behaviour was very challenging," Lynne says. "He didn't just fade away into the sweet night. In retrospect, there had been signs he had dementia before, but after the surgery, it was undeniable."

"One of the behaviours that kept me in a high state of alert was that Bill, being very fit and recovering easily from the heart surgery, could run again, and run he did. He wouldn't keep a locator bracelet or anklet on, and he would regularly disappear. I sometimes got my bike out, or took the car if I couldn't locate him on foot, but when I found him he'd see me approaching and run faster in the opposite direction. Or he would take his bike, before I gave it away, and go long distances. Sometimes, in desperation, I would call the police to locate him. He also experienced a rapid loss of language, and being unable to communicate verbally was frustrating for him."

# Escalation

Lynne reached a point where she was exhausted by those six years of caregiving, and it no longer felt safe to keep Bill at home. After careful consideration, she decided to place him in a private care facility. Things, unfortunately, did not go as planned.

"Before placement, I explained in detail what his symptoms were," Lynne says. "And they said, 'Oh, we can manage that." But they couldn't, and he was only there for three nights.

"I hadn't had any freedom for a very long time, and my sons and daughters-in-law encouraged me to attend a piano concert the third evening Bill was in care. Various family members stayed with him through supper and then made sure he was settled. I turned my phone off and enjoyed the music. When I turned it back on after the concert, there were several messages telling me to call immediately.

"Bill had some kind of an episode at the home. I still don't know exactly what he did. He was fine when my kids left, but the staff said he became extremely agitated shortly after and, having zero tolerance for these types of behaviours, they turned him out at 9 p.m. that cold November night. Out of desperation, we took him to Rockyview Hospital, where he was eventually admitted to Unit 47, an acute-care ward. He didn't leave Unit 47 until he died ten and a half months later."

# **Questioning Care**

Bill's placement at Rockyview was never intended to be permanent. After assessment, Lynne was eventually told







Lynne and Bill with friends on the Sinai in Egypt. the only placement option for Bill was the Managing Dementia with Expertise (MDE) Unit at Bethany Calgary. This became a catch-22, since the hospital environment aggravated his symptoms even more, and placement in the MDE Ward, for which there was a waiting list, became more and more elusive.

"Bill's physician and the entire staff on Unit 47 were terrific, but properly which all lead to dead ends."

Bill spent day after day in a small, poorly configured hospital room whose only window looked directly onto a brick wall. There were no windows to the outside world for Bill anywhere on Unit 47. The common space for the entire ward was being used as a hospital room for another difficult-to-place dementia patient, so no social or recreational space of any kind existed on the unit. Occupational, art or music therapy of any description was non-existent.

"The longer Bill remained in the hospital, the less likely he was going to be placed, because he was getting increasingly agitated. This resulted in him being restrained, both chemically and physically, which led to further decline," Lynne says. "I can't prove it, of course, but I think Bill went downhill more quickly in the hospital than he would

unsuitability of an acute-care ward for Bill and patients like him and identifying what was, in her words, "a gaping Alberta Health Services system failure." But, despite Lynne's efforts, no one did anything to improve Bill's situation before he died. She doesn't blame the staff at Rockyview or even the private care facility, but firmly believes that AHS must find better alternatives for caring for and housing people living with dementia who exhibit difficult behaviours.

"I don't think the doctors and nurses liked the way things were," Lynne says. "We had a terrific doctor. The staff was wonderful, but I felt utter frustration in not being able to enact any kind of positive change toward making Bill's final days more humane."

He passed away on Unit 47 on Sept. 27, 2017.

"It was heartbreaking, and it was unacceptable. And there was nothing I could do about it. It felt like I, too, was in a maze. I was shunted from one person to another within the Alberta health-care system over a long period of time, and, when months into this process, I was referred back to an employee I had spoken with much earlier and who hadn't been of any assistance then, it became painfully obvious that the path I was on was hopeless. I couldn't get answers anywhere, and it was clear that there was no possibility of a humane end of life for Bill. In spite of all my efforts, I couldn't access a decisionmaker. Something needs to change."

"We had a terrific doctor. The staff was wonderful, but I felt utter frustration in not being able to enact any kind of positive change toward making Bill's final days more humane." —Lynne Kearns

caring for patients with complex dementia is really challenging in the best of circumstances, and almost impossible on an acute-care hospital ward," Lynne says. "Imagine being terribly confused and then being trapped in a place where there are bells and whistles going off constantly and computers and stretchers cluttering the halls,

have in a more appropriate placement. It was a miserable decline, and it was a miserable ending for a wonderful person who deserved so much better."

# **Aftermath**

After Bill had been in the hospital for about four months, Lynne wrote a letter to Alberta Health Services detailing the

and and an ambanda an

# GOING DEEPER

The crux of the problem Lynne Kearns had in housing Bill was the unpredictability of his symptoms. Dr. Allen Power is an educator, public speaker and author whose life's work has been promoting the idea that medical

professionals look at people living with dementia as whole human beings.

While he doesn't like the term "complex dementia," Power does say that facilities need to shift their expectations surrounding "difficult" symptoms, rather than expecting residents with dementia

to behave differently. Power suggests that care partners seek out care homes that approach residents as individuals.

When touring a care home, Power suggests noting these questions: Is staff respectful? Do they boss people around? Is there consistent staffing for personal care, or do "strangers" come in to provide intimate care every several weeks? Are the residents treated like adults, or children? Can they get outside daily? How do they refer to people's distress and other expressions? What is their level of use of psych meds?

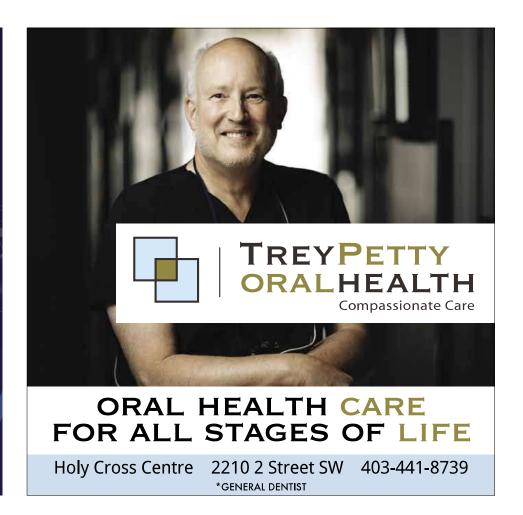
# Improve your loved one's care

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Share your story, share strategies for care and advocacy, and make connections.

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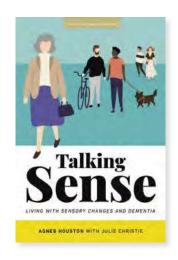


Visit this link to raise awareness of frontotemporal degeneration (FTD) and all forms of dementia:



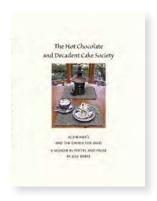
https://www.theaftd.org/world-ftd-awareness-2019-2020

# 4 BOOKS TO READ TODAY



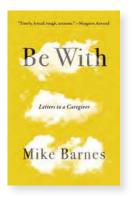
# Talking Sense by Agnes Houston

When Agnes Houston was diagnosed with young-onset dementia in 2006, she found there was not enough information on how to support people living with sensory changes associated with dementia. Houston, who is a vocal advocate for people living with dementia, began a decade-long journey researching her experience and chronicling how sensory changes impacted her life. Houston's book, Talking Sense: Living with Sensory Changes and Dementia, written with Dr. Julie Christie, is a guide for health professionals, care partners and more to better understand and support people with sensory challenges. Talking Sense is available as a free download from the dementiacentre.com website.



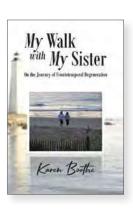
# THE HOT CHOCOLATE AND DECADENT CAKE SOCIETY by Jule Briese

In Qualicum Bay author Jule Briese's book, The Hot Chocolate and Decadent Cake Society: Alzheimer's and the Choice for MAiD (a memoir in poetry and prose), she shares snapshots of life from the first year following her husband, Wayne's, Alzheimer's diagnosis. Bries also tackles the tricky topic of the current state of Canada's MAID legislation. Briese's book can be purchased by emailing tranquilshorescreative@gmail.com, and partial proceeds will be donated to Dying with Dignity Canada.



# **BE WITH by Mike Barnes**

In Toronto author Mike Barnes' book, *Be With: Letters to a Caregiver*, he shares four letters addressed to an unnamed caregiver who is caring for a loved one living with Alzheimer's. Barnes draws from his personal experience caring for his mother, Mary, who was living with the disease at the time. Meant to be read in snippets, such as on the bus or at the doctor's office, the book highlights the trials and insights of living with dementia and how to simply be with and enjoy the people we love.



# **MY WALK WITH MY SISTER**

# by Karen Boothe

After significant changes in her behaviour, Karen Boothe's sister, Brenda, was diagnosed with frontotemporal degeneration (FTD) at 56 years old. Also known as frontotemporal dementia, FTD is rare and involves the degeneration of the frontal and/or temporal lobes of the brain. Karen became Brenda's primary caregiver and, in her book, My Walk with My Sister: On the Journey of Frontotemporal Degeneration, she shares how she learned to love, accept and care for Brenda after her diagnosis.

Get involved at www.dementianetworkcalgary.ca

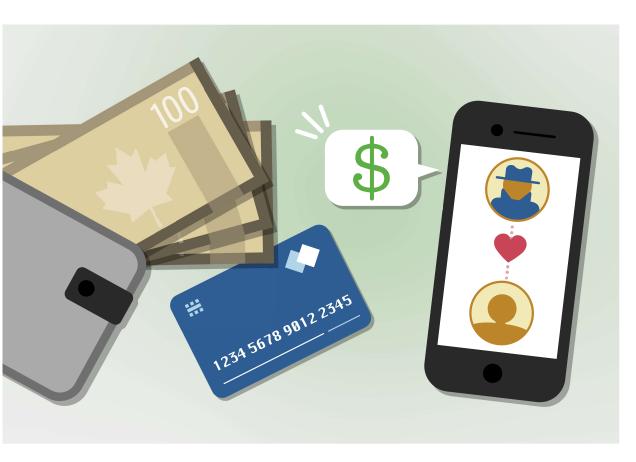




Alzheimer Society

# THE NATURE OF THE SCAM

BY Sean P. Young



or as long as there has been money, there have been unscrupulous people trying to steal it. Scammers look for any vulnerability they can to gain an edge, and sometimes that makes people living with dementia prime targets.

"Anyone with reduced cognitive function is especially at risk for financial abuse," says Jill Chambers, president and founder of Financial Concierge Inc. "It may affect their executive functions, so they're not able to understand clearly what is being asked of them, or to easily make decisions."

Chambers, a certified financial planner who also holds a degree in nursing, started Financial Concierge in 2018. The service is

"Don't feel bad about being scammed. Very intelligent, well-educated people fall for these things all the time. These people are good at what they do." —David McKee

designed for seniors and their care partners to handle the day-today complexities of their financial lives: document organization, bill payment and statement reconciliation, power of attorney, and estate administration. Chambers says approximately 90 per cent of her clients have been victims of financial abuse, and, most of the time, it's by family members.

"That's the first thing I take my clients through when they are thinking about giving someone power of attorney," she says. "Is that person trustworthy? And are they

even capable of doing it?"

Chambers says seniors often find they have limited options when it comes time to appoint an executer who they can trust to take over their finances. This lack of options and isolation makes them vulnerable because if they do get taken advantage of, "they're not going to report the person to the police, they're just going to endure it," she says.

But what about when the scam is coming from outside the house? Isolation often plays a role in many of the scams seniors fall victim to from strangers as well, Chambers says.

This page: Rebecca Middlebrook; facing page left to right: iStock/primulakat; iStock/Gunay Aliyeva; iStock/Vit\_Mar

"The majority of the people that have landlines are going to be seniors, and they may be socially isolated and pleased to have someone to chat with on the phone," she says. "That makes them an easy mark."

There are many things you can do to protect yourself or a loved one from financial abuse. David McKee, community engagement coordinator with the Better Business Bureau in Calgary, says care partners who notice something is off in their loved one should consider if they have been financially abused.

"If they seem agitated or like they don't want to talk about something, it might be because they are going through something like this," McKee says.

He adds that, while the scams he dubs "the classics" are still common — like someone impersonating a Canada Revenue agent on the phone to steal money or an identity — seniors are targeted from places we often don't consider.

"Online dating is a big area for fraud. It's not just young people using it, everyone is on there now," he says.

Chambers and McKee agree that any transaction involving wire transfers, sensitive information (like a SIN number) or writing cheques to someone's personal account for an investment or service should be looked at as highly suspicious. Chambers adds that having a care partner listed as a point of contact with their loved one's bank can be critical in stopping a scam that is underway.

"If the bank flags something suspicious going on in your account and your capacity is diminishing and they don't have anyone else to contact, they are basically helpless to stop it," she says.

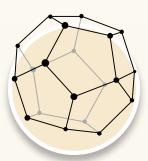
McKee says the embarrassment of being duped can often make a

# SPOT THE SCAM

Calgary's Better Business Bureau's David McKee says most scams follow similar patterns: "Once you can spot these traits, no matter what the themes are, you can usually see it's a scam." Here's what McKee says to look for:







# Time constraints or limited availability

You've won a cruise that you don't remember entering a draw for. But, if you want this \$8,000 luxury trip through Europe, you must send \$50 to the caller so they can process the tickets today. This is a common example of how scammers use a person's fear of missing out to steal their money or their identity. "If it's got to happen 'right now' or it's gone, you should be suspicious," McKee says. "You don't have to do anything 'right now.' Ask before you give."

# Emotional manipulation

Scammers will often call impersonating government or collections agents and scold the person for avoiding taxes or missing payments. This immediately puts the person on the defence and makes them more susceptible to making a panicked decision. "If they're scolding you or it's hostile in nature, they want to keep you off balance," McKee says. "People are often reactive and they're panicking because they haven't seen this kind of thing, so really all you have to do is just slow things down."

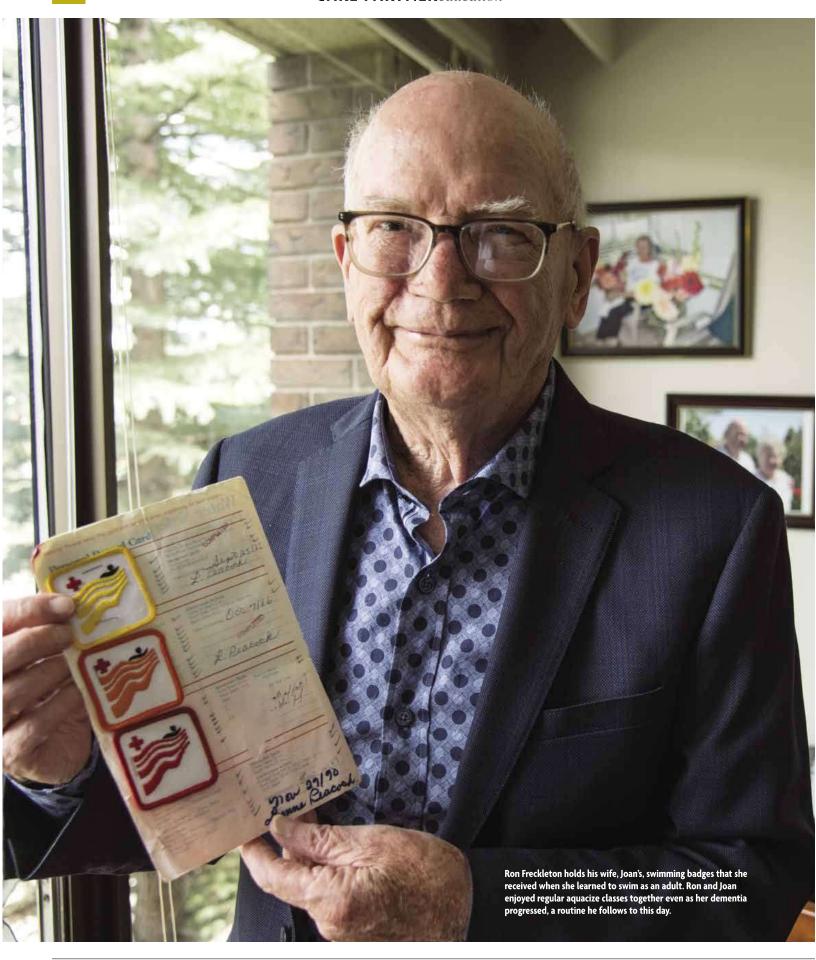
# Multilayered

Sophisticated scammers will call elderly people impersonating their "favourite grandson" in need of money. "Then you supply the name and they're off to the races," McKee says. The scammer often uses a "boiler room" technique from there, McKee says. A second person will call impersonating a doctor or police officer who corroborates details explained in the first scammer's call. "It gets very three-dimensional after that, so it becomes harder to know if you're in the middle of a scam," McKee says.

bad situation much worse and that talking about what happened is the first step to fixing the situation.

"Don't feel bad about being

scammed," he says. "Very intelligent, well-educated people fall for these things all the time. These people are good at what they do."



# My Lovely Joanie

Calgarian Ron Freckleton spent 10 years caring for his wife, Joan, who was living with dementia. Here, he reflects on that journey and shares some insights he learned along the way.

BY Ron Freckleton PHOTOGRAPHY BY Jared Sych

y dear wife, Joanie, died at 11:11 a.m. on Easter Sunday, April 20, 2014. Joanie had been living with dementia for 10 years, and I had been her sole caregiver.

In those early years, both of us faced a whole new world. For Joanie, it was a world of confusion and fear. My world — one of desperation and despair. Over time, I gradually learned to live with and care for a loved one with dementia.

Although I have no professional education on the subject, I feel that my 10-year journey through dementia with my lovely Joanie qualifies me to offer advice to the family caregivers of loved ones with this debilitating condition.

### **Dealing with a Diagnosis**

I hope you have sought professional advice on ascertaining your loved one's condition. Not having it diagnosed does not mean that it does not exist. Denial does not

delay its progression. The behaviour of people living with dementia will vary according to the type of dementia that they have. The part of the brain that is affected by dementia dictates what behavioural traits will become evident. It is important that you do not feel that there is a stigma attached to dementia. It is a disease of the brain, pure and simple.

# **Practicing Compassion**

Short-term memory loss is often one of the first symptoms of dementia. Your loved one may repeat questions or statements. For instance, "What day is it today?" If you feel exasperated hearing the question repeated and answer, "I've just told you," your voice and body language may cause your loved one to become aggressive and hostile. Pretty soon, both of you will feel ill-tempered and a very poor tone will be set. A stony silence will hurt you more than your loved one. I found it easier to answer the

repeated question with a goodhumoured reply. "It's Wednesday, all day, and it's Thursday all day tomorrow." My voice and tone indicated that everything was fine. What did it cost me to repeat my answer each time the question was asked? Nothing, absolutely nothing.

We're all human; there will be times when you are not at your best and lose patience with your loved one. He or she will forget your squabble in a moment — their lack of short-term memory will ensure that. But the harsh words you both may have shared will be with you for a long time. That's something for you to think about. Bite your tongue when you can't say something nice. You'll be the benefactor.

## Go with the Flow

If your loved one is content to spend their days doing little things that make no sense to you, but are of interest to them, go with the flow. That should be your mantra: "Go with the flow."

[Once,] Joan, using scissors, cut 20 \$5 bills in half. Her thinking was, probably, that she would double her money. Her smile when she showed me her handiwork was

Caregivers, please be aware of your own health, both physical and mental. It is just as important as your loved one's.



just lovely. How could I be mad at my Joanie? I was genuinely amused as I did the repair work.

You will learn that trinkets become treasures, things of little value become very precious. Many quiet hours can be spent just touching them. Encourage your loved one, show them that you share the love of their possessions. You may see it as an obsession; think of it as a pastime.

Quiet times with someone living with dementia are a blessing. Some of the best days of my life were spent sitting with my Joanie. Me, talking about good times in the past, Joan listening. I could tell if she was really remembering just by her comments. Sometimes she was, sometimes she wasn't. It didn't make any difference, we were happy together. I learned that the precious memories I spoke of were therapeutic for me and comforting for Joan.

# Maintaining Social Connections

Something that gave me pleasure was the way Joan behaved in social occasions when she was around people other than myself. She



Joan and Ron Freckleton in November 2013.

greeted everyone as though they were the best of friends. She didn't distinguish between store clerks and medical specialists; everyone was a recipient of her charm and warm smile. I was careful not to interfere with her interactions. Social interaction was important to me. We needed to maintain contact with family and friends. A support group is important, necessary and can never be too large.

## **Connecting with Your Doctor**

As Joan's dementia progressed, her behavioural pattern changed, and I learned new skills. Our family doctor was my mentor. I recommend that all family caregivers keep in close contact with their GPs. If your doctor does not have experience with geriatric care, I suggest that experts be consulted.

I was fortunate that our doctor's special interest was geriatrics. He insisted that we visited him each month. He was monitoring my health as well as Joanie's. Each visit garnered valuable advice. He explained that "white lies" and promises that you can't keep were okay. Constantly repeated requests by your loved one, for something not possible, will easily be assuaged by saying, "We'll do it tomorrow," or something similar. The request will be forgotten tomorrow. No harm done. Our doctor's major message was to keep your loved one as happy as possible.

## **Finding Resources**

My advice to all family caregivers is: please accept all the help offered to share the care of your loved one. I should have taken advantage of Alberta Health Services' [resources] a lot sooner. The home care services that are available will enable you to grab a few hours of respite. You will find

that you can entrust your loved one to a professional's care and know that they will be in good hands.

Another helpful organization is the Alzheimer Society of Calgary. A portion of the society's funding goes into research, but its major commitment is to the support and well-being of dementia clients and their family caregivers. The society also puts great emphasis on awareness and education. The frequent information sessions and seminars that it presents are often the first steps that caregivers take in their quest for answers. The numerous programs and the available activities are invaluable to dementia clients. The respite that the caregivers gain is so necessary to their own well-being.

# **Caring for the Caregiver**

I made many missteps along our long and winding road. I wish I could retrace and replace them. I hope some of my words will help you avoid the pitfalls that were part of our journey. My biggest error was not seeking help in a timely fashion. As the years ticked by, I had become adamant that I was the only one Joan would accept as a caregiver companion. I continually declined the offers of help from friends and family. My love for Joanie made me blind to my own welfare. I was sacrificing my own health and well-being by taking on the sole responsibility of caring for Joan.

I know now that I was wrong. Our family doctor recognized that I needed to get professional caregivers involved in Joan's daily life. His advice led me to the actions that I should have taken years earlier.

Caregivers, please be aware of your own health, both physical and mental. It is just as important as your loved one's.



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# **SMART CONNECTIONS**

From robots to online community spaces, these innovations foster relationships

BY Sean P. Young

**Mylo**Candace Lafleur's life changed dramatically six years ago when

she had a major stroke. "Suddenly, my whole world flipped; there was this massive loss of independence," she says.

At the time of the stroke, Lafleur was living and working in London, England, with her husband and one-year-old twins. The native Edmontonian was in a stroke ward for several weeks, and, when she was released, she struggled with everyday tasks, such as using her phone.

"My husband had to be home [to care] for me or the hospital wouldn't even discharge me," she says. "It really changed my perspective."

Lafleur began searching for technological tools that could help her regain some of her independence but she couldn't find anything close to what she needed.

"It was mostly remote controls with oversized buttons," she says.

Out of this experience, Lafleur came up with Mylo.

"Mylo is a home monitoring and



companion robot aimed at helping people get out of hospitals faster and stay in their homes longer," she says.

Four years ago, after she recovered, Lafleur moved to Ireland to take her

MBA at Trinity College, which she completed in 2017. During that time, Lafleur, who had no experience with tech, assembled a team to design Mylo.

While she says Mylo can be assistive to anybody, the team dedicated itself to creating a robot that offers practical and genuinely needed assistance to people living with dementia and their families. This was done partially to narrow the team's scope, and "partially because my neurological autoimmune disease [which

# Huddol

Huddol (pronounced "huddle") taps into the power of many to help users overcome their health challenges. First

launched in Quebec in 2017, it is a free online community that brings caregivers, health-care professionals and organizations together.

"Huddol combines the lived experience of peers with the knowledge of professionals in one community," says Mark Stolow, Huddol's founder and CEO.

Users can ask for help, share a story or provide advice to other users on health topics they have experience with. For example, health-care professionals and families living with dementia can interact to help each other find the best advice specific to their situation, as well as local resources. As part of the site's giving economy, Huddol members earn virtual HDL tokens for their support of one another. These tokens can be redeemed to get discounts on health offers in Huddol's Wellness Marketplace.

"Rather than it being a more passive search, we wanted it to be about asking for help and getting help," Stolow says. "Our community comes to your doorstep to help you."

To join Huddol's free community, visit Huddol.com.

caused her stroke] is likely to lead to developing dementia myself," Lafleur says.

Her team interviewed more than 100 families living with dementia and then compiled a list of the common issues and challenges they faced, including isolation and loss of employment.

"We took those stories and we made a robot, as you do," she says.

Every Mylo comes with a health monitoring watch — Fitbit Versa. Lafleur's team worked with Fitbit so the watch pairs with Mylo and can detect falls and checks the person's heart rate once every 30 seconds. Mylo can alert caregivers or emergency supports if its companion has a medical event. It also has an anti-wandering function, is a personal assistant, and works as a two-way video communication device that allows caregivers to connect with their loved ones whenever they want. All these functions can help manage the stress of caring for someone and the stress of being cared for.

Mylo is currently available in Ireland, the United Kingdom and most of Western Europe, and Lafleur says she is looking for a Canadian distributor. She says in-home trials and initial purchases in Ireland have been incredibly positive.

"Families with a Mylo report feeling more optimistic and their relationship ties are stronger."

Part of Mylo's success may be its approachable cat face. The team tried several versions during trials at care homes before finding the right fit.

"We tried a little girl face, a little boy face, a dog — nothing," Lafleur says. "As soon as we made him a cat, he drew a crowd. We got the same reaction in a few more places, so now he's a cat."

Meet Mylo at heyMylo.com.



#### DementiaTalk

DementiaTalk is a not-forprofit online space where people living with dementia, their families, care partners and friends can share and discuss information.

"We wanted to create a way for people to connect and get information, no matter where you live," says DementiaTalk co-founder Christine Prysunka, who also leads online services for the Alzheimer Society of Alberta and Northwest Territories.

In 2017, Prysunka partnered with Fadi Khalil, a partner at OVERT Information Systems who, inspired by the dementia experience in his own family, volunteered his time to create this new virtual community. Groups on all sides of the dementia experience are already collaborating on the platform — free from the influence and distraction that often shows up on social media.

"We take privacy very seriously. We don't allow any advertising, and we're not asking for money," Khalil says. "This is a safe place for people to have a discussion, to get support from the community."

Check out DementiaTalk at dementiatalk.org.

 $\overline{DID\ YOU\ KNOW?}$  North America's first smart-tech care home for people living with dementia is being built in Hamilton, Ont. Inspired by the Dutch model of dementia care, Ressam Gardens will include AI and smart technology to monitor and improve resident well-being.



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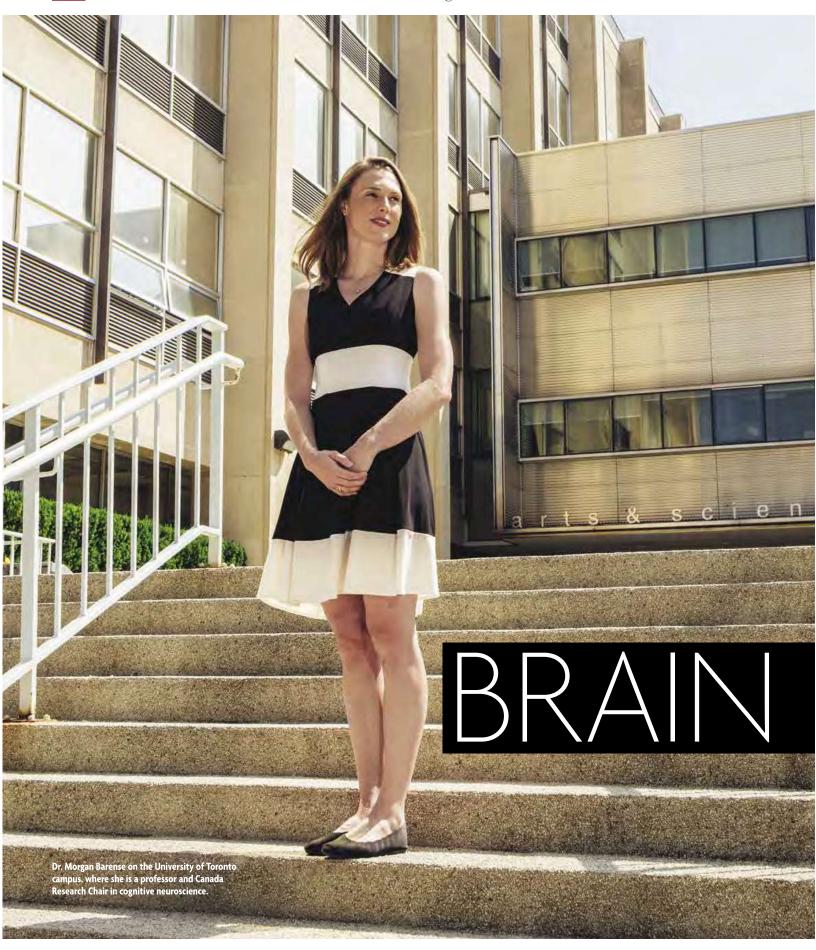
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# DR. MORGAN BARENSE

ost people routinely use their smart phones as memory aids. We'll use the record function to take audio notes or reminisce over past events via the "Memories" function on Facebook. But can smart phone technology also help people living with dementia hold on to their memories?

That's the question Dr. Morgan Barense first discussed with a colleague over lunch in 2014.

Now, almost six years later, Barense, a professor and Canada Research Chair in cognitive neuroscience at the University of Toronto, and her lab team have created a mobile device app that acts as an external hippocampus, helping those in the earlier stages of dementia to successfully retain memories.

The hippocampus is located in the temporal lobe, the inner folds of the bottom of the brain. One of its functions is to help us process experiences and turn them into memories. It's also typically one of the first areas to be impaired by Alzheimer's disease, which can result in memory loss

and affect the ability to make new long-term memories. Barense and her colleagues thought that if they could mimic the memory functions of the hippocampus, the effects of dementia could be delayed.

With funding from the Canadian Institutes of Health Research and the Centre for Aging and Brain Health Innovation, they set to work on an app dubbed the *Hippo-camera*. It allows users to use video to record, label and replay an event they would like to remember, such as a birthday party. The brain is then helped to retain the event as a long-term memory through repeatedly watching the video on the app.

"The idea is, if we can circumvent the hippocampus and get these memories to the rest of the brain,

users stand a fighting chance of remembering them at least in some form," Barense says.

The *Hippocamera* is much more than a video app. To mimic the hippocampus, Barense and her team built features into the app that compress and replay the videos at an accelerated rate, similar to the way the hippocampus naturally replays memories. The events are also separately labelled and clearly distinguished from one another.

Perhaps most importantly, the user also needs to regularly rewatch each event to convert it into a long-term memory. To facilitate this, the app senses when users are idle, which can often be when they'd naturally reminisce about recent events, and vibrates their phones to remind them to review the recorded memories several times throughout the day. Barense is still researching exactly how many times an event should be watched in order for the rest of the brain, including the neocortex (the outer part of the brain), to integrate it into long-term memory.

Barense's testing has shown that using the *Hippocamera* app enhanced users' hippocampal function, creating a 25-per cent boost in what she calls "episodic richness," which is the ability to re-experience a memory rather than simply recalling its basic facts. Barense is hoping that continued testing will also provide evidence that using the app may have a preventative effect and even slow the progress of dementia.

"The app makes memories better, but it's also good for brain health because you're juicing up the circuits in a way that's going to help them be protective from the disease," she says.

Barense hopes to have the app commercially available by the end of 2019.

"Not only does it make memories better, but it's also good for brain health because you're juicing up the circuits in a way that's going to help them be protective from the disease."

—Dr. Morgan Barense

# DR. ROBERT SUTHERLAND

iguring out why some people develop dementia and others don't can give scientists a better idea of how to potentially treat the disease.

For the past three years, Dr. Robert Sutherland, a professor and chair of the department of Neuroscience at the University of Lethbridge and the director of the Canadian Centre for Behavioral Neuroscience, has been working with his colleagues, Drs. Bruce McNaughton and Majid Mohajerani, to study something called cognitive reserve.

Cognitive reserve seemingly protects people from developing symptoms of Alzheimer's, even if their brains show markers of the disease.

"The idea is that some people have processes in the brain that provide them with resilience against Alzheimer's disease," Sutherland says. "Their brains acquire the disease, but they're still able to manage in the face of the disease process in their brain. We call that means of resilience 'cognitive reserve."

Why some people have more of this protective cognitive reserve than others is still unknown. Research shows that people who have higher levels of education, more complex language skills and the ability to speak multiple languages tend to have higher levels of cognitive reserve. Since Sutherland can't test the causation of this on humans (for instance, we don't know if university graduates pursue higher education because they have high cognitive reserve or if they have high cognitive reserve because of that brain stimulation), he's conducting his experiments on mice.

In the lab, Sutherland has put the

human Alzheimer's disease into the mice's genomes and introduced enrichment (the mouse equivalent of getting a PhD or learning to speak Italian) to see if the "educated" mice will develop protection against cognitive deterioration in ways that the "non-educated" mice do not. Sutherland is watching to see how the connections within the mice's brains change with additional cognitive reserve.

The work is still in the research stage, but the hope is, if Sutherland can figure out exactly how the cognitive reserve function is protecting a mouse's brain from Alzheimer's and how it can be increased, scientists can eventually develop means of treatment that either prevents or even reverses Alzheimer's in human patients.

"The ideal outcome would be that we come up with some kind of therapeutic approach, say a pill, that restores youthfulness in the

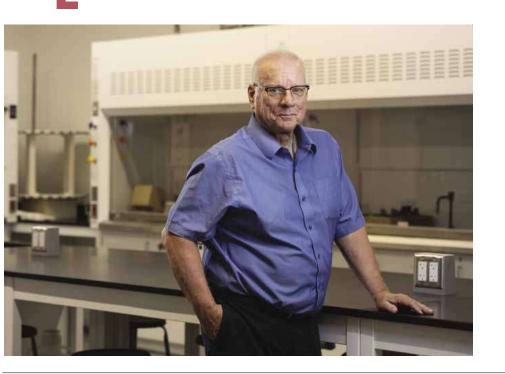
cortex and allows the cortex to be rebuilt," Sutherland says.

Even if that outcome doesn't present itself immediately, Sutherland's work could

have significant impact. Simply proving that a lifetime of challenging one's brain with education or cognitive "exercise" can decrease instances of Alzheimer's would be a result that all of us can apply to our own lives.

"The lowest level ambition that we would have in this project is to understand the causal connection between things like childhood education and cognitive stimulation and Alzheimer's disease," he says. "The translation potential for that is that we get that information out to families and schools and in government policy to try to make it a key part of dementia prevention strategy."

"The lowest level ambition that we would have in this project is to understand the causal connection between things like childhood education and cognitive stimulation and Alzheimer's disease." —Dr. Robert Sutherland



BY Jennifer Friesen ILLUSTRATIONS BY Remy Geoffroi

on Fenn was sitting in his Toronto office in 2003 when he received a phone call from the police in London, Ont.

"Does anyone you know drive a white Chevrolet convertible?" the constable asked. Fenn immediately recognized it as his mother's car, and the officer continued. "We found it in the middle of an intersection between Oxford and Waterloo, and we found your business card in the glovebox."

The next few hours were a whirlwind. Fenn quickly called his dad in London to check in, and discovered that his mom, who was living with Alzheimer's, had simply left to run some errands. She must have become confused at some point, and Fenn's dad, who was her primary caregiver, eventually found her walking down a nearby street.

Later, Fenn and his family met with his mother's medical team in London, and it was decided that Fenn's mother needed to move into a care home.

"It was a tough day for me, and for the rest of my family," he says.

Being the closest to home out of his siblings, Fenn became the "designated

driver" for his parents' health care, which, in turn, kickstarted a new life mission for him. Fenn knew many people, including his parents and his friends' parents, who wanted to stay in their homes

as they aged but needed access to information and support in order to age in place safely.

In 2004, after decades spent working in media and marketing, Fenn founded the communications company Caregiver Omnimedia, which focuses on providing vital information about aging in place, in terms of home care and modifications for individuals and their caregivers.

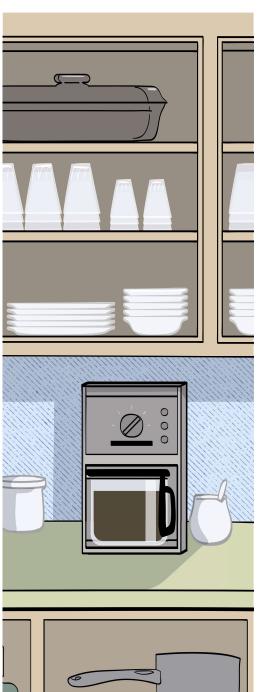
"I knew very quickly that the biggest problem we had with family caregiving was information," Fenn says. "That was why I wanted to form this company. I wanted to ramp up communication and move things forward."

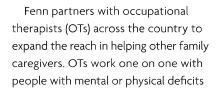




"I knew very quickly that the biggest problem we had with family caregiving was information." —Don Fenn

This page: courtesy Don Fenn; facing page: courtesy Marnie Courage







"[Aging in place] means having access to the health care and social support that you need to live safely and independently." —Marnie Courage

and their caregivers to find solutions to barriers in their everyday lives. Through a consultation process, OTs, along with renovation contractors, go into homes and help make plans to modify a space for people who want to continue to live at home and are seeking accessibility.

Marnie Courage is a Winnipeg-based OT and CEO of Enabling Access Inc., and she says that aging in place involves melding safety, security and happiness for everyone in the home.

"Aging in place means a lot of different things to a lot of different people," says Courage. "But it means having access to the health care and social support that you need to live safely and independently in your home or community for as long as you wish, or are able. This is both for the individual and the caregiver."

In addition to Caregiver Omnimedia's consultations and workshops, Fenn started a home modification council that is working to streamline the aging-in-place process for individuals and their caregivers. Currently, OTs, renovators and home builders are all hired individually, but they're moving forward to formalize a process for families so everyone is on the same page for the individual's needs. His vision is a "network across"

the country" to help family caregivers modify their homes in order to create safe and accessible spaces for their aging or disabled loved ones — and there are a lot of people looking for this help.

According to the Canadian Mortgage and Housing Corp., 85 per cent of aging baby boomers would prefer to age in place, even if there were changes to their health.

Margot Schulman has also been working to help family caregivers modify their homes through her interior design firm, Schulman Design. She started the Calgary business 22 years ago, after completing her degrees in interior design and gerontology. Even then, through her early work in care homes, she noticed that people were wanting to age in place, but the right spaces weren't being built.

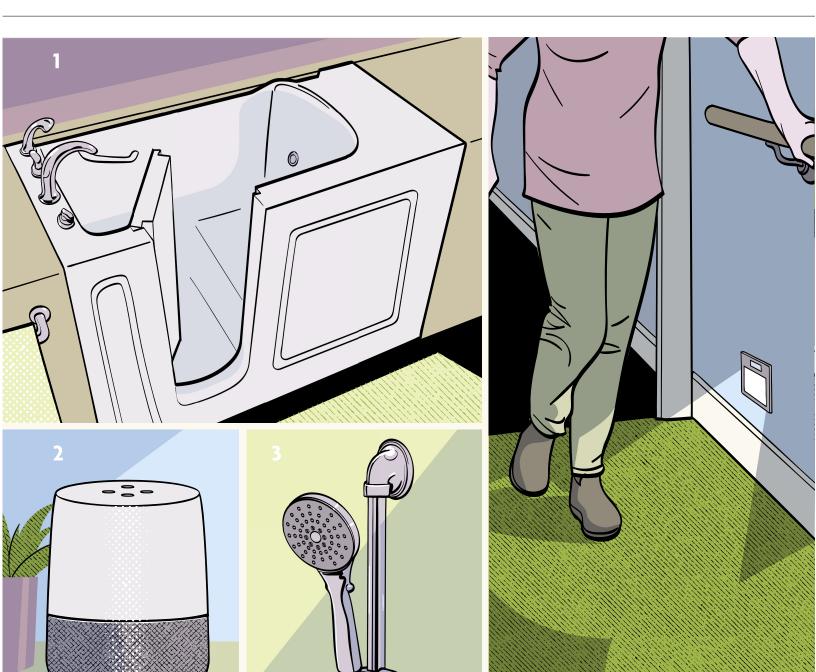
Schulman's brother, Dave, sustained a catastrophic head injury after a bike accident when they were in their early teens, so she says she learned very early how building design affects accessibility.

"Watching how these homes were designed, I just saw Dave's life shrinking," she says. "I didn't want his life to just be about the day-to-day, waiting for care. What I realized is that buildings have such an impact on how people feel,





DID YOU KNOW? Low-income Albertans with mobility challenges can apply for grants to modify their homes through the Government of Alberta's Residential Access Modification Program (RAMP). To make modifications, eligible participants can receive up to \$7,500 per year each year, or up to \$15,000 per person within 10 years. Learn more at alberta.ca/residential-access-modification-program.aspx.



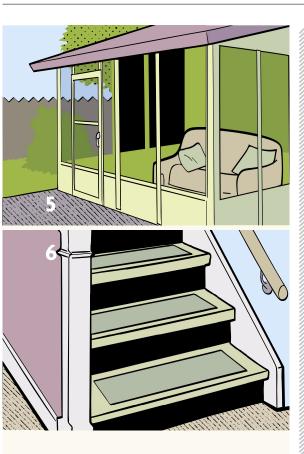
# HOME MODIFICATION TIPS FROM THE EXPERTS:

"Universal design should work just as well if you're six or you're 60. A barrier-free shower is useful for everyone, even if it is an investment." –Don Fenn

"Taking sensors and overlaying them into the common smartphone for Google Home or Alexa, you can make a motion detector, so, if the loved one wanders, the device says, 'Oh, Joan, go back to bed,' with the loved one's voice. It helps everyone sleep."

—Marnie Courage

"Renovating the bathroom with grab bars and handheld shower wands is major. Having a shower wand that has a pause button to promote independence to control turning water on and off is terrific for individuals and caregivers." –Margot Schulman



"Have sensors put into bedrooms, so as soon as someone gets out of bed and needs to use the washroom, there's automatic motion detecting lights that go on and lead them to the bathroom. It helps prevent falls." –Marnie Courage

"Try to find places where the sensory impact is quiet. It's important to be outside and have fresh air, and understand the shift of the seasons. Patios are popular because of this." –Margot Schulman

"Having contrast on steps is very important for visibility. Having tape on the edges of where steps are, or the counter versus backsplash, just creating real differentiation in colours is helpful." –Marnie Courage



"The feeling of well-being and the feeling of being at home are non-negotiable for life."—Margot Schulman



how they work and how they interact. I realized that the feeling of well-being and the feeling of being at home are non-negotiable for life."

Schulman says people's homes should reflect their values and personal histories, so that people living with dementia can have a sense of personal choice while still staying safe. The goal is to increase inclusivity in every building.

For example, Schulman recommends the simple remedy of removing cupboard doors or installing glass or metal mesh inserts in cabinets in the kitchen for those who love cooking and still have the capacity to help. It removes the question of where the mixing bowl is, and offers visual cues to keep the person engaged.

"We know that if someone is using their hands, then they're using their brain," Schulman says. "We want people to feel engaged in their day in a way that sparks joy."

Of course, safety is a paramount concern for home modifications.

Fenn, Courage and Schulman all agree that safety is a main interest while working on home modification solutions — and it's not without cause. A 2014 report from the Public Health Agency of Canada states that falls result in 85 per cent of injury-related hospitalizations for seniors, and more than one-third of seniors who are hospitalized for a fall are discharged to long-term care —

almost double the amount who were living in that kind of care when they fell.

Simple changes, such as putting handrails on the wall of frequently used routes, can help to keep a loved one safe. More advanced modifications can include lights leading the way to the washroom, automated floor lights in the hallway or smart homes that set off an alarm if a door leading outside is opened.

With Enabling Access Inc., Courage has found that washrooms and front entrances are the two main places that need modifications. Many homes in Calgary have a few steps leading to the front door, so she has suggested including a second handrail or melding a ramp into the landscaping so that it's both aesthetic and functional.

Additionally, grab bars, non-slip floors and wheelchair-accessible showers can be seamlessly incorporated into contemporary designs.

In a home where one person is caring for another with dementia, all three experts agree that, in addition to safety, compassion and empathy are essential for aging in place.

"I think it's the same for everyone," says Courage. "Home is where the heart is. Our longer-term memories are often connected with the senses surrounded to the home: the smells, the sights, the feel and the sounds. We should all have that security of home."

Schulman photo by Jager & Kokemor Photography



sent her an article on dementia.

The piece profiled University of Calgary researcher Dr. Marc Poulin and his study, "Brain in Motion I." Its objective was to assess the effects of exercise on brain health, including cerebrovascular and cognitive functions with the help of research participants.

At the time, McGrath's mother was living with dementia, and

McGrath clicked on a link at the

her father was his wife's primary

bottom of the article, curious about participating in the study. For one, McGrath met the criteria: she was between the ages of 50 and 80, and, due to the diagnosis of a first-degree relative, she was at increased risk of developing dementia. Two, the study meant engaging in a more physically active lifestyle. Who wouldn't benefit from becoming more physically active? And three, well, it was for a greater good.

"My mom has dementia, research is the key, so let's sign up," she thought.

It turned out the "Brain in Motion I" study was no longer recruiting active participants, but, one year later, the follow-up study, "Brain in Motion II," began recruiting. McGrath volunteered, becoming a self-described "guinea pig" for dementia research.

# What is a Clinical Trial?

Clinical trials are research studies that include human participants. In a clinical trial, which is one of the final stages of the research process, investigators introduce an

caregiver.

intervention — an experimental medication, behaviour, or technology, for example — and examine its safety and effectiveness on humans with the help of volunteer participants. There are different types of trials. For example, some explore treatment and some explore prevention, such as a randomized controlled trial like "Brain in Motion." All trials seek to establish therapies that cure, modify, prevent or manage the symptoms of any number of human disorders, from arthritis and asthma to cancer and Alzheimer's disease and related dementias.

The type of intervention varies by study. Many people associate experimental drugs with clinical trials, but an intervention can also be a medical device, procedure, vaccine or non-pharmaceutical treatment such as education, technology, diet or exercise. A study out of the Université Laval and University of Alberta is examining the value of companion dogs and service dogs for people with mild to moderate dementia.

Clinical trials are key to identifying a cure or disease-modifying therapy for dementia. Dr. David Hogan is the academic lead of the Brenda Strafford Centre on Aging, and one of six members of a panel assembled by the Canadian Academy of Health Sciences to review the current state of knowledge about dementia and help in the development of a national strategy for Alzheimer's disease and other dementias. The panel identified 44 key findings that require consideration in the effort to improve the quality

of life and care of people living with dementia, including six dealing with research and innovation.

"Unless we do studies, we're not going to develop better treatments and better ways of preventing the illness," says Hogan.

According to ClinicalTrials.gov, a database of international privately and publicly funded clinical studies, there are approximately 80 active clinical trials in Canada studying new treatments for Alzheimer's disease, specifically.

Clinical trials rely on human volunteers, but recruiting and retaining study participants can be a challenge. Researchers struggle with bridging the communication gap between the scientific community and the public, and, even when people are aware and willing, not all volunteers meet inclusion criteria or live near a study location. Low enrolment numbers can limit what researchers are able to interpret from the results.

Dementia research faces an even larger recruitment hurdle than other disorders. People living with dementia often need a caregiver to act as a study partner, and must have the capacity to consent themselves or provided legal authority to a caregiver. Alzheimer's disease also has a slow, decades-long progression that is not well-understood, making it difficult for investigators to study interventions at the pre-symptomatic stage.

# Making a Commitment

When Joanne McGrath was selected for the "Brain in Motion II" randomized controlled trial in

"Unless we do studies, we're not going to develop better treatments and better ways of preventing the illness." —Dr. David Hogan

"My mom has dementia, research is the key, so let's sign up." —Joanne McGrath .....

2018, there were eight other participants in her group. The study is examining an older population of people who are at an increased risk for Alzheimer's disease and related dementias. Primarily, it seeks to understand how exercise improves brain blood flow and cognition, such as thinking, memory and reasoning skills.

Every Monday, Wednesday and Friday evening for six months, McGrath left her home in Cochrane, Alta., and drove to Calgary's Shane Homes YMCA at Rocky Ridge for one hour of supervised exercise. Exercise, she emphasizes, not just activity. Participants had to maintain a percentage of heart-rate reserve, which is a percentage between resting heart rate and the maximal heart rate. The intensity was assessed using heart rate monitors.

McGrath and the other participants in her aerobic group were also expected to exercise at home once a week. Their output was tracked on a wearable heart rate monitor — McGrath dubbed hers "Jiminy Cricket."

At the end of the six-month aerobic exercise period, none of the nine participants had dropped out. (The study continues to monitor participants for one year and aims to study 250-300 people.) Participants of a trial may leave at any time — they're volunteers, after all — so McGrath was proud of her group of strangers-turned-"guinea pigs"-turned friends. She was also grateful for the accountability that





a supervised exercise program provided, something she discovered she needed in order to prioritize her physical health. And contributing to research on dementia, something that affects her family and so many in Alberta, was the catalyst for it all.

"A lot of people are touched with dementia in their lifetime," says McGrath. "It's hard to find someone who's not."

## Do Your Research

"We support and actually encourage people to be interested in clinical trials," says Christene Gordon, provincial lead of client services and programs with the Alzheimer Society of Alberta and NWT. Gordon says, while they are not "active brokers" in connecting researchers with participants, the society does provide its client base with contact information of studies that are actively recruiting.

...... "If it's something that makes sense, that fits my lifestyle and can be beneficial for others, I would look at it, for sure." —Duncan McLean

> Gordon's team also provides clients with a thorough checklist from the Alzheimer's Society of Canada to help them make an informed decision. She says that clients often hear about experimental treatments or research from news coverage,

but don't know where to go from there. Gordon says potential volunteers shouldn't be afraid to ask researchers questions. (See below.)

# Managing Expectations

Clinical trials seek to establish whether a treatment is effective for humans or not — in the case of identifying a disease-modifying drug therapy for Alzheimer's disease, it has more often been not. The very nature of this exercise can lead to disappointment for investigators, sponsors and participants.

Duncan McLean was diagnosed with early onset Alzheimer's in 2017. His physician informed him of a worldwide clinical trial for an Alzheimer's disease treatment, which, at the time, was seeking participants for its third and final phase before market. The treatment involved an antibody shown to remove beta-amyloid plaque from

> the brains of individuals with early Alzheimer's disease. McLean was a good candidate for the trial and agreed to participate.

"Why wouldn't I?" he says.

For about 17 months, McLean received monthly infusions, as well as his standard care. His commitment to the clinical trial included a series of MRIs, weight tracking and memory recall testing. McLean

does not know if his infusions were the experimental treatment, or if he was part of the placebo group, but he did experience a relatively stable period throughout his participation.

"It wasn't burdensome; I didn't have any side-effects," he says.

Disappointingly, the trial was cancelled after an independent data monitoring committee determined the trial was unlikely to meet its objectives. There was no risk to participants, its investigators made clear, but the interim results were not telling researchers to "keep going."

"I went into it with my eyes open," says McLean.

Although he was disappointed the trial was cancelled, and with it the momentum of the most promising drug Alzheimer's research has had in years, McLean says he would still consider participating in another clinical trial in the future.

"If it's something that makes sense, that fits my lifestyle and can be beneficial for others, I would look at it, for sure," he says.

# Idea to Impact

"The brain is the most complicated thing in the universe," says Ty McKinney, research director for Calgary-based Branch Out Neurological Foundation. Branch Out has raised almost \$3 million for alternative brain research, supporting studies that use innovative technology and non-pharmaceutical solutions



# **QUESTIONS TO ASK** BEFORE VOLUNTEERING FOR A CLINICAL TRIAL FROM THE ALZHEIMER SOCIETY OF CANADA:

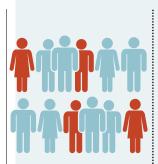
- Has the study been reviewed by an ethics board?
- What's the purpose?
- Who's funding?
- Who can participate?
- Who's excluded?
- Can I continue to take other medications?
- Who is responsible for my care during the study?
- What are the known risks?
- What is the type of study?
- Is there a placebo?
- How will it be decided what participants are assigned?
- How will I hear about the results?
- When will I hear?

like nutrition and physical activity to assess and manage disorders.

McKinney says there are shortterm benefits to participating in and raising awareness of clinical research. For example, there is a strong body of research to suggest that exercise may lessen cognitive impairment and reduce dementia risk. While these studies continue to assess the why and the how, individuals can still add exercise to their lives as a potential diseasemodifying behaviour.

Branch Out also seeks to accelerate the process from "idea to impact," referring to the significant amount of time it can take an idea to go from a lab to demonstrating scientific merit to mainstream medical practice. This process can take a decade or more, and can feel overwhelming and far removed from the day-to-day life of someone living with dementia.

"Participating in research might sound kind of scary because it sounds like you're being tested on in some capacity, but not all research has that sort of risk factor," McKinney says. "In many ways, it can be positive, because people end up learning more about the disease and the brain itself, while directly contributing [to] the science that may end up developing a new treatment."



How is a clinical trial different than an observational study?

In an observational study, researchers do not interfere with the subjects. An example of this is the Victoria Longitudinal Study (VLS), a longterm investigation of human aging through the University of Alberta and the University of Victoria. The study, which began in the 1980s, allows researchers to track and analyze participant data and identify possible trends.

In a clinical trial, investigators introduce an intervention — medication, behaviour or technology — and examine its effects.



Clinical trials have inclusion and exclusion criteria for participants.
Participants must have the capacity to consent or must have provided consent to their substitute decision-maker.

For dementiaspecific clinical trials, participants can include:

**ADULTS** with no dementia or cognitive impairments

**ADULTS** at increased risk for Alzheimer's disease or related dementias

**ADULTS** with a diagnosis of Alzheimer's disease or related dementias

**CAREGIVERS** of those living with dementia

# DISPELLING MYTHS AROUND CLINICAL TRIALS



# MYTH: "They don't need participants."

Recruiting and retaining volunteers for dementia research is a challenge. Studies are often in need of patient participants, healthy participants or both. Low enrolment numbers can limit researchers in interpreting the results.

# MYTH: "Tests are invasive and inconvenient."

Testing can include surveys, cognitive tests and memory recall, fitness tests, brain mapping and imaging, and biomarker specimen analysis (blood, salvia samples, etc.) Researchers often strive to make it easier for participants to volunteer by accommodating flexible schedules or offering compensation for expenses such as travel and parking.

# MYTH: "There are too many risks."

Risks vary by study, and it is up to each individual and their care team to weigh the potential benefits and risks before participating in a clinical trial. Using the checklist provided by the Alzheimer's Society of Canada will help inform the process.



# **START HERE:** THREE PLACES TO FIND A CLINICAL TRIAL

Talk to your health-care provider about potential risks and benefits before participating in a study.



Alzheimer Society Research Portal alzheimer.ca



Participate in Research University of Calgary research.ucalgary.ca



NeuroCAM Connect
Branch Out Neurological Foundation
branchoutfoundation.com

# Dementia Network



# Calgary

Meet the organization that believes Calgary can be a supportive, innovative community where people impacted by dementia can live life well

BY Jennifer Dorozio PHOTOGRAPHY BY Jared Sych

ive years ago, Barb Ferguson, executive director of the Alzheimer Society of Calgary, and her team took stock of Calgary's growing resources for people living with dementia and their care partners. While they saw great potential, and the opportunity to bring various stakeholders together to coordinate efforts, they realized something was missing.

At the time, more than 42,000 Albertans were living with dementia and that number was growing. Ferguson and her team believed that, to tackle the needs of that growing population, Calgary needed a hub where individuals and organizations across many sectors could collaborate, innovate and advocate.

With this vision as a guide, Ferguson enlisted 22 stakeholders from diverse groups representing families and care partners, private care facilities, funders, community organizations, health services, post-secondary institutions, and government — all interested in tackling "the complex problem of dementia" jointly.

Stakeholders included representatives from Alberta Health Services, AgeCare and the University of Calgary, among others.

The group first met in January 2014, officially forming Dementia Network Calgary (DNC).

That same year, the Steering Committee, comprised of the original 22 members, met again to develop a strategy road map for dementia and their vision for Calgary: "The Calgary community is a supportive, innovative environment where people impacted by dementia can live life well."

The Alzheimer Society of Calgary is the backbone organization of DNC. In that role, the Society provides coordination, communication and mobilizes funding.

DNC employs a specific approach

to engagement called a collective impact model. It brings together collaborators from different sectors to address large, complex issues. Ferguson describes this fresh approach as "following the energy" of what is needed when it comes to dementia supports.

"It's really about tackling critical community issues in a collective way, believing that not one person or organization can solve difficult problems," says Ferguson.

# 3-2-1, Action!

In order to help people living with dementia live life well, DNC identifies priorities through engagement with impacted individuals and stakeholders and addresses these priorities through "action teams."

These teams usually consist of a leader (either from within DNC or an outside partner) and a group of DNC volunteers. The teams meet regularly to brainstorm and carry out goals, and sometimes team up with community partners to see them accomplished. After a goal is met, action teams either disband or evolve.

For example, in 2017, one goal was to support people in the dementia community develop more interpersonal relationships and experience less isolation. To address it, community gatherings and Conversation Cafés were created.

"[We were hearing that] people felt that there was nowhere that felt safe for them and their care partners to go and just be normal," says Kim Brundrit, who is DNC's coordinator and one of its only employees. Brundrit, who helps care for a family member with dementia, understands this need for community interaction first-hand.

At community gatherings, which

"It's really about tackling critical community issues in a collective way, believing that not one person or organization can solve difficult problems."—Barb Ferguson





happen multiple times a year, an expert in the field of dementia shares knowledge and then engages the crowd in an interactive question period. Past speakers have included researchers familiar with the latest assistive technology, as well as experts on how to age at home.

Conversation Cafés take place in spaces like pubs and coffee shops and provide safe zones for people with dementia and their care partners to socialize and connect. Brundrit remembers that, after one café, a woman shared that she and her husband, who was living with dementia, hadn't left the house for three months before that day.

"[The woman] said, 'I felt so alone and ashamed, [then] I came here and there's all these people who are in the same situation. I feel like I can go out and do something again," says Brundrit.

# Thinking Strategically

On a relational level, if people affected by dementia can feel like they belong to a community, then DNC views that as success. But, in keeping with its original goal of being a place "where people impacted by dementia can live life well," the network also meets to discuss higher level strategic planning for the city and beyond, including becoming involved in government by advocating to local politicians.

A political advocacy action team was created in 2017 to help interested parties campaign the Alberta government for better dementia care and support. At the time, some DNC representatives even met with then-Health Minister Sarah Hoffman to push for the release of the *Alberta Dementia Strategy and Action Plan*, a multitiered approach to dealing with the growing crisis of dementia within Alberta.

The plan was released in 2017 and highlighted the need for better primary care for people living with dementia and more social awareness of the condition.

"The strategy had been in the works for years, and it was kind of just sitting on a shelf somewhere," says Brundrit. "Through advocacy, we were able to lean on the government to release it so that people could start working on it. It was a huge success."

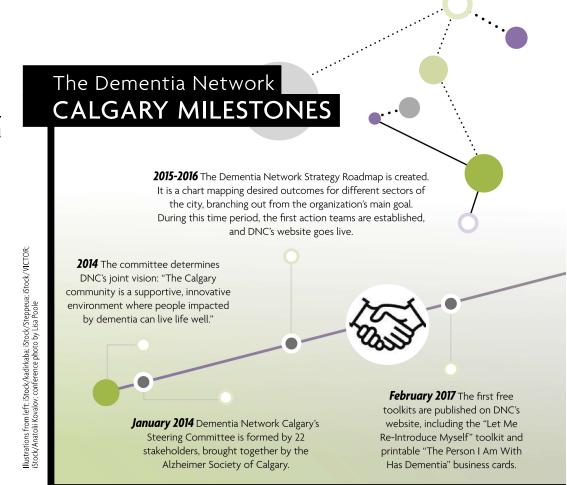
Just recently, prior to the 2019 provincial election, an action team hosted a public, all-party political forum about the future of dementia care in Alberta. A landing page on DNC's website offered an advocacy toolkit that included lists of current candidates, statistics that outlined the need to take

action on dementia care, tips on what to ask a candidate that comes to your door and more.

Maybe the largest impact DNC has had to date, in terms of scale, was its successful creation of Dementia Re-imagined, a sold-out conference attended by more than 500 people in June 2018.

Held at Mount Royal University, the inaugural event hosted three world-renowned dementia researchers who shared their expertise on shifting the culture of care from task-based to a relationship-based model.

"We wanted to leave people with a sense of hope, [telling them that] you're part of a community, you're not alone in this and that you can be active participants in what is happening," says Brundrit.



In July 2019, Dementia Re-Imagined: Continuing the Conversation took place and was similarly well-attended. It furthered the dialogue around care culture and featured returning world-renowned experts Daniella Greenwood and Dr. Allen Power.

"I am very proud of all that the network has accomplished this past year," says Ferguson. "We want to build a movement around dementia in Calgary and we are already realizing greater engagement from a variety of stakeholders."

Inspired by discussions at the first Dementia Re-imagined conference, DNC is now examining how to shift care culture locally, specifically how to implement consistent staffing models in care facilities and improve staff training standards.

Through its newly formed Social Innovation Lab, DNC will convene long-term care facility operators, DNC stakeholders and other dementia community influencers in order to test out potential solutions such as new staffing models via pilot projects throughout Alberta.

"Hopefully, we will end up with some successes that we can implement on a large scale once they are proven," says Brundrit.

# Following the Energy to the Future

Despite success within the organization, both Brundrit and Ferguson agree there is still much to be done in reaching DNC's original vision for Calgary, but believe they are moving in the right direction.

"Our strategic goal keeps me

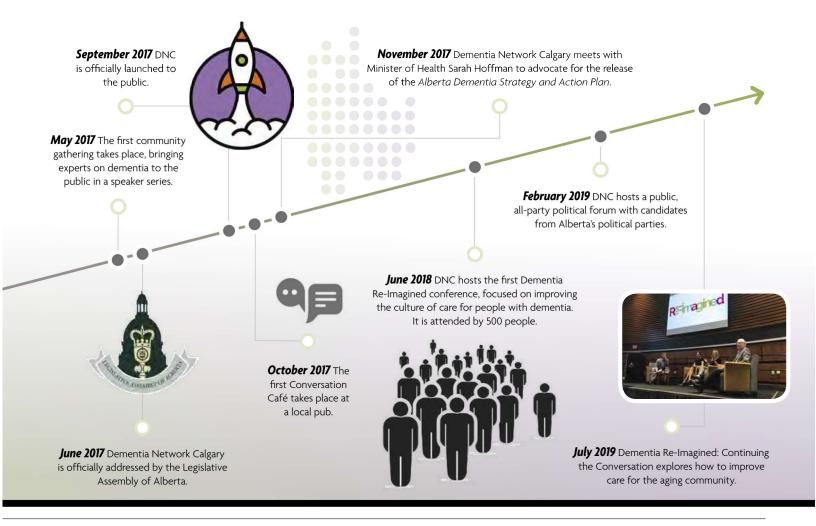
going," says Ferguson. "My belief is that [DNC] is how we're going to make sustainable change. It's about doing things differently."

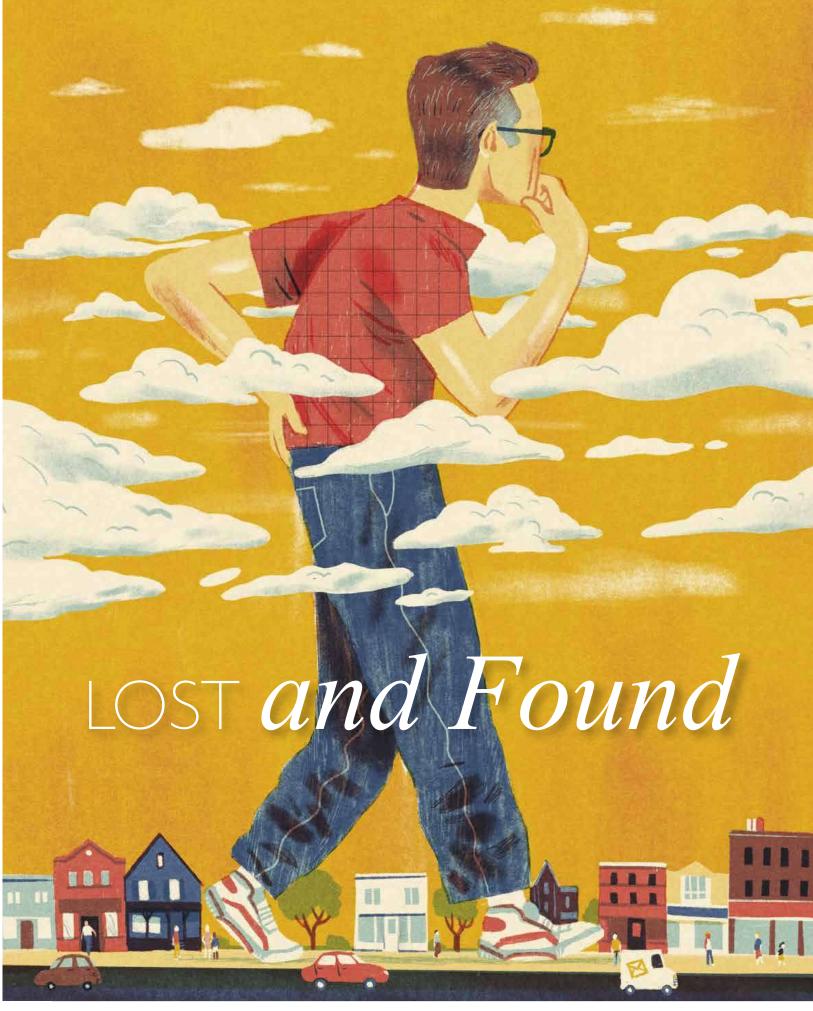
DNC has received interest from other jurisdictions looking to follow its model to achieve community impact and is happy to share resources and provide support.

Next up, DNC is preparing materials for public advocacy during the October 2019 federal election, drawing from the same framework developed for the recent provincial election.

"I see amazing possibilities here [in Calgary]," says Brundrit. "I think we could be a real world leader in [dementia] work."

Learn more at dementianetworkcalgary.ca





For individuals living with dementia, walking can be a useful way to stay physically active and socially engaged, but getting lost is a real risk. These proactive safety strategies and new, more effective community response methods can help balance protection with autonomy.

BY Karin Olafson ILLUSTRATIONS BY Drew Shannon

t was a warm summer day in 2009
when Paul Lea left
his Toronto home
for the grocery store
a few streets away.
He'd done this walk countless
times before, but, this time, Lea
strayed from his usual route and
took a turn into a side street.

When Lea turned the corner, it was as though he'd stumbled into a new city. Nothing looked familiar. He had no idea how to get home. He was lost, and he felt utterly anxious and alone.

It was Lea's neighbour who found him, sitting on the sidewalk and suffering a panic attack. He was three blocks from his apartment.

# Not all who wander are lost

When Lea was first diagnosed with vascular dementia earlier in 2009, he was afraid to go outside in case he got lost. Lea certainly isn't alone. In fact, it is relatively common for individuals with dementia to get lost, and often safety strategies aren't implemented until after a scare.

According to data collected from the Calgary Police Service,

191 seniors ages 65 and older were reported missing in 2018 in Calgary alone. And government statistics show that close to 46,000 Albertans are living with dementia. A frequently cited statistic is that 60 per cent of individuals with dementia wander, although what that truly means is debated. Paul Bartel, the manager of Learning and Support Services at the Alzheimer Society of Calgary, explains that, even though individuals with dementia can get lost, there aren't accurate numbers reflecting the regularity.

"Does this 60 per cent statistic mean they have gone for a walk, gotten lost and come back? It's unclear if this number means that 60 per cent of individuals with dementia have been reported lost, and it's unclear if the number reflects people who get lost more than

once," says Bartel. "The source of this statistic is also unclear."

This lack of clarity is why some prefer the terms wayfinding or walkabout. Commonly, people confuse wandering and getting lost as one and the same; in reality, an individual with dementia won't always get lost while wandering.

The reasons an individual with dementia will wander are numerous. Often, walking is a familiar activity and it can be a way to escape an upsetting situation or express a desire. Bartel adds that going for a walk isn't necessarily something to prevent; there are the physical benefits of exercise and the mental benefits of being outdoors. Simply, anyone can get lost, but the issue is that those living with dementia are at greater risk of getting lost — and that is when wandering can become unsafe.

Anyone can wander and anyone can get lost, but the issue is that those living with dementia are more at risk of getting lost — and that is when wandering can become unsafe.





# Starting a global conversation

Worldwide, the number of individuals living with dementia is projected to reach 152 million by 2050. Dr. Noelannah Neubauer, a post-doctoral fellow in the faculty of applied health sciences at the University of Waterloo, believes international collaboration exploring the topic of wandering will yield the most effective results.

In 2018, during her PhD research in the faculty of rehabilitation medicine at the University of Alberta, Neubauer connected over Twitter with Katie Gambier-Ross, a PhD student out of the University of Edinburgh doing similar work.

"We learned that, even though there's not that many researchers like us in this field, none of us were speaking to each other," says Neubauer. "Instead of us all recreating the wheel and each doing our own work, Katie and I thought that we should have a group that represents this issue internationally."

Neubauer and Gambier-Ross co-founded the International Consortium on Dementia and Wayfinding, a platform that connects people from around the world who are working to promote safe wandering, educate the community about wandering and find ways to effectively respond when people living with dementia do get

lost. Since the first meeting in January 2018, there have been 15 online and in-person meetings with representatives from eight countries. Simply, the Consortium is about information sharing, connecting researchers with anyone else whose lives are touched by dementia in order to take the conversation beyond the academic realm.

# Finding a safety strategy that's just right

In December 2017, as part of her PhD work at the U of A, Neubauer developed a series of guidelines related to wandering. Easy to use, the guidelines offer proactive strategies around dementia-related wandering intended to direct intervention and manage the risks of getting lost. The first of their kind, the guidelines can be found online, including on the findingyourwayontario.ca website.

Neubauer found that there are so many strategies meant to keep individuals with dementia safe while wandering that the sheer volume of options becomes difficult to navigate.

"There is no one-size-fits-all safety solution," says Neubauer. "There are more than 300 types of high-tech solutions [like GPS devices] and low-tech strategies [like ID bracelets] out there, and it took me almost five months to come across them all."

Neubauer's guidelines streamline these strategies and outline which are recommended depending on

whether the individual with dementia's risk of getting lost while wandering is low, medium or high.

"There's this awful paradox where individuals with dementia or their care partner don't see a risk of getting lost at all, and so no safety strategy is applied until something happens," says Neubauer. "Then the care partner sees the wayfinding behaviour as so risky that they put all these strategies in place that restrict independence."

Neubauer has coined this risk perception the "Goldilocks Principle on Dementia and Wayfinding" and says an "all or nothing approach" isn't effective. The goal is to find a personalized and proactive safety strategy that is just right.

# **Implementing** safety solutions

Ron Beleno's father, Rey, was diagnosed with Alzheimer's in 2007. After the diagnosis, Rey would leave his Toronto home for the nearby plaza to buy a coffee and visit the stores. He had a routine that kept him happy.

"Once in a while, my mom would call to say that he was an hour late and wasn't back yet. But he always came home," says Beleno.

One summer evening, Rey didn't come home from his walk. Hours passed and he still hadn't returned. The incident resulted in an hours-long police search. Late that night, Rey was found 12 kilometres from his home, near his former place of work. After the experience, Beleno became an advocate for using technology to support aging in place.

Advances in tracking technology — think specialized tracking apps like Life360, and GPS devices like GPS insoles — means care partners like Beleno can still support their loved ones' independence,









but keep them safe should they get lost. Beleno gave his father two GPS devices; both were attached to two sets of the same keys. He also set up a few geofences, a virtual boundary defined by GPS that triggers an alert if Rey went beyond the virtual barrier — specifically, in Rey's case, a safe distance of 500 metres.

"He could still go and walk, but I was alerted if he left the safe vicinity," says Beleno. "There were still incidents of him getting lost, but they were safe incidents because we could track him."

Beleno's strategy toward promoting safe wandering is something Neubauer hopes to reinforce with her guidelines: "Within the guidelines is the push for people to have multiple safety tools," says Neubauer. "For example, if GPS fails, to also have a low-tech strategy so then there's something else at play."

# When vulnerable seniors go missing

But even the most cutting-edge safety technologies can fail. The GPS charge might die or the user "We are looking at how we bring the community together to support caregivers and police by being on the lookout." —Kim Savard

might leave the house without their tracking device. During Beleno's experience as a care partner, he found GPS devices to be expensive, and his father sometimes forgot the purpose of the device's different buttons. And, for someone not quite as tech-savvy as Beleno, the set-up of GPS devices and geofences can be challenging.

Because of these limitations, an effective response strategy needs to be in place should individuals with dementia go missing, and a police search is just one piece of that. The Consortium has highlighted the various response strategies in the works around the world, which will eventually be listed on its underconstruction website, helping members build on what already exists.

Kim Savard, program manager

at Carya, a social services agency in Calgary and participant in the Consortium, is a co-founder in the Calgary Coordinated Community Response to Missing Seniors committee. Building on the committee's work and taking what she's learned of other countries' response strategies through the Consortium, she believes the most effective response methods involve a wider network than just the care partner and the police.

"We know we need to focus on the prevention piece so people don't go missing and the education piece around what to do if you find somebody who does go missing," says Savard. "In terms of the response piece, we are looking at how we bring the community together to support caregivers and police by



# RESPONSE STRATEGIES AROUND THE WORLD

The International Wayfinding Consortium is shining a light on effective response strategies around the world, inspiring Calgary stakeholders to build on what's already in place.

#### **Herbert Protocol**

This initiative comes from the West Yorkshire Police in the U.K. Care partners fill in a form with vital information like a photograph, places the person has previously been located

while wandering and weekly habits. If needed, these details can help police with a fast search. Interest in introducing this same strategy in Calgary has surfaced.

## **Purple Alert**

This app from Alzheimer Scotland engages the community's help when a vulnerable senior goes missing. Registered users receive an alert when someone goes missing, and can then help authorities search for that missing person. Calgary was one of three Canadian cities participating in a test of something similar — an app called Community-Area Silver Alert App or C-ASAP — in June 2018, and improvements are currently being made.

# MedicAlert

This strategy is from the U.S., but now has an international presence. Users register online to receive an ID bracelet engraved with their medical needs. Should a user go missing while wearing the bracelet, first responders can call MedicAlert to receive the wearer's supplied medical history. MedicAlert also alerts the missing person's family. In January 2019, the Calgary Police Service partnered with MedicAlert.

being on the lookout. We are also focusing on the follow up after a missing incident to provide connection to resources [and] support."

The engaged community element was integral for Beleno's father. It wasn't technology or a strategic response strategy that helped police find Rey. Ultimately, it was a passerby who noticed something was wrong and called paramedics and police for help.

Wandering isn't necessarily something to be prevented, but awareness of the possibility that someone living with dementia can get lost — and that getting lost can end tragically — needs to be

discussed openly so proactive safety strategies can be put into place.

After his scare that summer morning, Paul Lea has adopted an active approach to his safety and his independence. Lea's strategy is to always carry his iPhone, ready to type in his home address to guide him home if he does feel lost.

RISK OF GETTING LOST Based on Noelannah Neubauer's PhD thesis, these strategy guidelines can help reduce the chances of getting lost for people living with dementia at home: Risk Level Medium High **Unplanned Absence** ☐ You live alone ☐ You are lost in the □ Initial signs present or ☐ You live with family but diagnosis of dementia are often home alone ☐ You leave home and walk community ☐ You live with family and ☐ You go out regularly with alone often have them around 24/7 family/friends ☐ You walk away from ☐ You don't go outside ☐ You exercise when friends/family if you are without someone else out with them stressed ☐ You are often overwhelmed or anxious **Strategies** Education and awareness • Use locating technologies Call 911 or go to a local • Exercise with a partner (GPS etc.) Develop a preventative or wear a locating device business for help · Adopt the buddy system strategy plan Create an easily accessi-Keep your home address Talk to your care ble list of where you used so you never walk alone saved on your phone or provider ASAP to work/live • Seek community supon a card in your pocket Wear an identification ID • Have someone check in ports (i.e. home care) and use Google or Apple or bracelet\* with you regularly Maps to redirect yourself • Register under a vulnerhome able persons registry if Have a friend or family available\* member you can call. Can transition to lesser or greater levels of risk at any moment Need to apply education and proactive strategies as soon as possible so safe wandering can still be encouraged Learn more at findingyourwayontario.ca



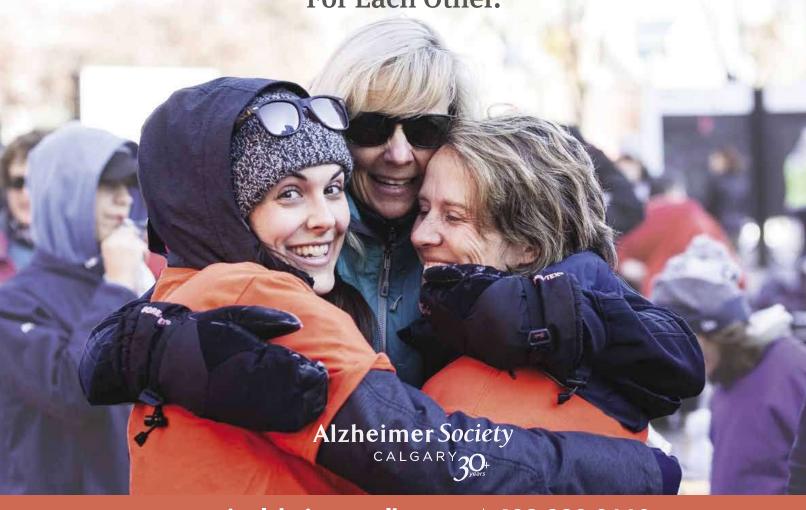
ALZHEIMER

# WALK & RUN

THANKSGIVING SUNDAY **OCTOBER 13, 2019** 

1 km walk | 5 km walk | 5 km run | 10 km run

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# Dementia redefined at the United Nations

Dementia Alliance International (DAI) hosted a Side Event on Dementia: the leading cause of disability at the 12th Session of the Conference Of State Parties (COSP12) on the Convention on the Rights of Persons with Disabilities (CRPD) in New York, which will have far reaching benefits for all people with dementia, now and into the future.

Ms. Catalina Devandas Aguilar, the UN Special Rapporteur on the rights of persons with disabilities opened the session. Our disabilities may be more invisible than others, but we are still being denied our rights, 71 years after the adoption of the Universal Declaration of Human Rights.

Through collaboration with the United Nations, the World Health Organisation, the Australian Government, the International Disability Alliance, Global Rehabilitation Alliance, Alzheimer's Disease International, Human Rights Watch and World Hospice and Palliative Care Alliance, we focused on full and equal access to the CRPD and dementia as a disability.

Together, we are working to ensure change:

- Reduce stigma, discrimination and isolation
- Equal and affordable access to Universal Health Coverage including Rehabilitation
- Access to the CRPD
- Stop Institutionalization and segregation
- Stop all forms of abuse, including chemical and physical restraints

We will continue to campaign towards others understanding dementia is a condition causing acquired cognitive and other disabilities, and for full and equal access to the CRPD and other Conventions. Equal health and disability services are essential for maintaining independence and dignity, for longer, and whilst dementia is a terminal condition, we should not all be 'dying at diagnosis'.



Speakers from left to right:

**Antony Duttine,** Regional Advisor in disabilities and rehabilitation, Pan American Health Organization/World Health Organization (PAHO/WHO)

Christine Thelker, Dementia Alliance International, Board Member

Kate Swaffer, Dementia Alliance International, Chair/CEO

Bethany Brown, Researcher, Older People's Rights,

Disability Rights Division, Human Rights Watch

**Arlene Pietranton,** American Speech-Language-Hearing Association **Jan Monsbakken,** Global Rehabilitation Alliance





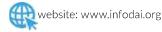


# 24 hours a day, 365 days a year, DAI works hard to advocate for people living with dementia. But, we need your help.

Dementia Alliance International is a not for profit 501c3 charity run by and for people living with dementia. Dementia Alliance International offers people diagnosed with dementia hope, to keep living and to reclaim their pre-diagnosis life. Dementia Alliance International needs your help today. Donate or partner with us today:

https://www.dementiaallianceinternational org/donate-or-partner/







# DEMENTIA-RELATED Services and Resources

for Calgary and Surrounding Area

# GLOSSARY OF TERMS

#### Best Friends Approach™

Based on the concept of friendship; easy to practice and to understand.

#### **Butterfly Household Model**

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 the highest level they're capable of.

#### **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 personcentred, 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 therapy 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<sup>TM</sup> 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
<b>AgeCare Glenmore</b> 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 therapy; secure outdoor garden
<b>AgeCare Midnapore</b> 500 Midpark Way SE	agecare.ca/midnapore 403-873-2600	***************************************		\$	Person-Centred; Best Friends Approach™; Supportive Pathways	Intergenerational childcare program; pet therapy; secure outdoo garden; private-pay suites for spouses
<b>AgeCare Seton</b> 4963 Front Street SE	agecare.ca/seton 587-349-8444			\$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet therapy
<b>AgeCare SkyPointe</b> 179 Skyview Circle NE	agecare.ca/skypointe 587-619-1900	***************************************		\$	Person Centred; Specialty Mental Health; Non-Violent Crisis Inter- vention	Intergenerational childcare program; cultural dining and activities; pet therapy
<b>AgeCare Walden Heights</b> 250 Walden Drive SE	agecare.ca/walden 403-873-4700	***************************************		\$	Person-Centred; P.I.E.C.E.S; PAC	Intergenerational childcare program; pet therapy; private-pa apartments for spouses
<b>Auburn Heights Retirement Residence</b> 21 Auburn Bay Street SE	allseniorscare.com 403-234-9695			\$\$\$	GPA	Age-in-place; pets welcome
<b>Amica Britannia</b> 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 Butterfly, GPA and PAC)	Pet therapy; mutigen- erational programming; WanderGuard
<b>Silvera Beaverdam</b> 2012 – 66 Avenue SE	silvera.ca 403-279-4623			\$	Best Friends Approach™; Company-specific	Tailored to early stage dementia; independent living Silvera townhome adjacent; Active Aging programs
<b>Bethany Harvest Hills</b> 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 peopl with moderate to sever dementia
<b>Bethany Riverview</b> 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 peopl with complex dementia care needs
<b>Bow Crest Care Centre</b> 5927 Bowness Road NW	reveraliving.com 403-288-2373			\$	Dementiability Methods	
<b>The BSF Bow View Manor</b> 4628 Montgomery Boulevard NW	theBSF.ca 403-288-4446			\$-\$\$\$	Supportive Pathways	WanderGuard; long-term care
<b>The BSF Clifton Manor</b> 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

<b>The BSF Wentworth Manor</b> 5717 – 14 Avenue SW, Calgary	theBSF.ca 403-242-5005	•	•	\$-\$\$	Supportive Pathways	Age-in-place (multi-
5/1/ – 14 Avenue Svv, Calgary	403-242-5005					levels of care); secure outdoor area
<b>Carewest Colonel Belcher</b> 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; P.I.E.C.E.S.	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
<b>Chartwell Eau Claire Care Residence</b> 301 – 7 Street SW	chartwell.com 587-287-3943			\$-\$\$		WanderGuard
<b>The Edgemont</b> 80 Edenwold Drive NW	reveraliving.com 403-241-8990			\$\$-\$\$\$	PAC	
<b>Evanston Grand Village</b> 40 Evanston Way NW	evanstongrand.ca 403-274-6416			\$	Supportive Pathways	Secure outdoor area; music and arts programs
<b>Evergreen</b> 2220 – 162 Avenue SW	reveraliving.com 403-201-3555			\$-\$\$		Pets welcome
<b>Extendicare Cedars Villa</b> 3330 – 8 Avenue SW	extendicarecedarsvilla.com 403-249-8915			\$	PAC	Couples may live togethe outdoor courtyard; PALS WanderGuard; accept various levels of dementia; smoking permitted
<b>Extendicare Hillcrest</b> 1512 – 8 Avenue NW	extendicarehillcrest.com 403-289-0236			\$	PAC	Couples may live together; intergener- ational programming; PALS; Roam Alert
Father Lacombe Care Centre 270 Providence Boulevard SE	fatherlacombe.ca 403-256-4641			\$	Person-Centred Approach; Supportive Pathways	
<b>Holy Cross Manor</b> 70 Evanspark Manor NW	covenantcare.ca 587-230-7070			\$	Supportive Pathways	Couples may live together
Intercare Brentwood Care Centre 2727 – 16 Avenue NW	intercarealberta.com 403-289-2576			\$		
Intercare Chinook Care Centre 1261 Glenmore Trail SW	intercarealberta.com 403-252-0141			\$		
Intercare Southwood Care Centre 211 Heritage Drive SE	intercarealberta.com 403-252-1194			\$	Butterfly Approach	
<b>Manor Village at Varsity</b> 40 Varsity Estates Circle NW	themanorvillage.com 587-393-9999			\$-\$\$		Purpose built; pet friendly; couples may live together; tracking system in place

RESIDENTIAL						
<b>Manor Village at Fish Creek Park</b> 22 Shawnee Hill SW	themanorvillage.com 403-918-2127	•		\$-\$\$		Secure outdoor area
<b>Mayfair Care Centre</b> 3240 Collicutt Street SW	mayfaircarecentre.com 403-252-4445	•		\$-\$\$		Smoking facility
<b>McKenzie Towne Care Centre</b> 80 Promenade Way SE	reveraliving.com 403-508-9808	•	•	\$	Dementiability Methods	
<b>AcKenzie Towne Retirement Residence</b> 10 Promenade Park SE	reveraliving.com 403-257-9331		•	\$		Secure outdoor area
<b>Millrise Seniors Village</b> 4911 – 5 Street SW	retirementconcepts.com 403-410-9155	•	•	\$\$-\$\$\$		
<b>Monterey Seniors Village</b> 1288 Catalina Boulevard NE	retirementconcepts.com 403-207-2929	•	•	\$		
<b>Mount Royal Care Centre</b> 813 – 9 Street SW	reveraliving.com 403-244-8994		•	\$	Dementiability Methods	
<b>Newport Harbour Care Centre</b> 10 Country Village Cove NE	parkplaceseniorsliving.com 403-567-5100		•	\$	Supportive Pathways; Best Friends Approach™, Resident-Centred Care, GPA	Multi-sensory robotics; lakefront location
Whitehorn Village Retirement Community 5200 – 44 Avenue NE	originway.ca 403-271-2277	•	•	\$-\$\$\$	Butterfly Model; Best Friends Approach™	
Prince of Peace Manor and Harbour 285030 Luther Rose Boulevard NE	verveseniorliving.com 403-285-5080		•	\$	Supportive Pathways; Best Friends Approach <sup>TM</sup>	Secure outdoor area
<b>Providence Care Centre</b> 149 Providence Boulevard SE	fatherlacombe.ca 587-393-1350			\$-\$\$	Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational pro- gramming; age-in-place purpose built for peopl with complex dementia care needs; WanderGua
<b>Rocky Ridge Retirement Community</b> 0715 Rocky Ridge Boulevard NW	rockyridgeretirement.com 403-930-4848		•	\$	GPA; Person-Centred; Supportive Pathways	Secure outdoor area; momentum tracking
<b>Sage Hill Retirement Residence</b> S Sage Hill Gardens NW	allseniorscare.com 403-455-2273		•	\$	GPA	Age-in-place; pets welcome
<b>5t. Marguerite Manor</b> 10 Evanspark Manor NW	covenantcare.ca 587-955-9788	•	•	\$-\$\$		Couples may live together
<b>St. Teresa Place</b> 0 Redstone Place NE	covenantcare.ca 587-619-7116		•	\$	(Components of) Butterfly Approach; Best Friends Approach™; Complex Dementia Care	Secure outdoor area; age-in-place; intergener ational progamming
Scenic Acres Retirement 50 Scotia Landing NW	reveraliving.com 403-208-0338		•	\$	PAC	Secure outdoor area; pets welcome
<b>StayWell Manor Village at Garrison Woods</b> 174 Ypres Green SW	themanorvillage.com 403-242-4688			\$-\$\$\$	Best Friends Approach™	Assisted living; memory care; enhanced care; palliation; respite care; rehab programs
<b>Swan Evergreen Village</b> 2635 Eversyde Avenue SW	originway.ca 587-481-6638	•		\$-\$\$	Best Friends Approach™	Intergenerational programming; age-in-place; secure outdoor area; couples may live together

RESIDENTIAL						
<b>United Active Living at Fish Creek</b> 51 Providence Boulevard SE	unitedactiveliving.com 587-481-7907	•		\$-\$\$	United Minds	Secure outdoor area
<b>United Active Living at Garrison Green</b> 3028 Don Ethell Boulevard SW	unitedactiveliving.com 403-685-7200	•		\$\$\$	United Minds	
<b>The Journey Club at Westman Village</b> 176 Mahogany Centre SE	westmanvillage.com 403-313-5478	•		\$\$\$	Butterfly Model; Person-Centred	Secure outdoor area
Wing Kei Crescent Heights 1212 Centre Street NE	wingkeicarecentre.org 403-277-7433		•	\$		Chinese language & culture; age-in-place
<b>Wing Kei Greenview</b> 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			
<b>AgeCare Sagewood</b> 140 Cambridge Glen Drive, Strathmore	agecare.ca 403-361-8000		•	\$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet therapy; private-pay suites for spouses			
<b>Aspen Ridge Lodge</b> 1100 – 20 Avenue, Didsbury	mvsh.ca 403-335-9848		•	\$		Couples may live together			
<b>Bethany Didsbury</b> 1201 – 15 Avenue, Didsbury	bethanyseniors.com 403-335-4775		•	\$	Designated Supportive Living Level 4	Secure outdoor area; age-in-place			
<b>Meadowlark Senior Care Home</b> 203 Hillcrest Boulevard, Strathmore	meadowlarkcare.com 403-934-5294	•		\$-\$\$		Secure outdoor area; age-in-place			
<b>Origin at Spring Creek</b> 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			
<b>Silver Willow Lodge</b> 2007 – 22 Avenue, Nanton	mosquitocreekfoundation.net 403-646-2660		•	\$	Person-Centred; PAC; Supportive Pathways	Services provided by AHS			
<b>The BSF Tudor Manor</b> 200 Sandstone Drive, Okotoks	theBSF.ca 403-995-9540			\$	Person-Centred; Supportive Pathways	Intergenerational programming; secure unit and outdoor area; supportive living			

HOME CARE				
AGENCY	CONTACT INFO	STAFFING Qualifications	STARTING RATE	CARE APPROACH
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, 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
CBI Home Health	cbi.ca 403-232-8770	RN, LPN, HCA	\$33.76/hr 1 hour minimum	
Calgary Elder Care	calgaryeldercare.com 403-464-2455	RN, LPN, HCA, Companion	\$32/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
Caring Hands Home Health Calgary	caringhandscalgary.ca 403-999-3336	RN, LPN, HCA, Companion	\$25/hr 3 hour minimum	Treat Clients as Family Would
Classic LifeCare Calgary	classiclifecare.com 403-242-2750	LPN, HCA, Companion	\$33.75/hr 2 hour minimum	PAC
Comfort Keepers	comfortkeepers.ca/calgary 403-228-0072	RN, LPN, HCA, Companion	\$31.50/hr 2 hour minimum	Best Friends Approach™
Ohana Care Health Services	Ohanacare.ca 403-300-2273	RN, LPN, HCA, Companion	\$30/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	LPN, HCA, personal experience	\$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	\$30/hr 2 hour minimum	Cognitive Therapeutic Method; Best Friends Approach <sup>TM</sup> ; Client-Centred
Home Instead Senior Care North	homeinstead.com/northcalgary 403-910-5860	HCA, LPN, Companion	\$32.95/hr 3 hours minimum	Dementia CARE Curriculum
Home Instead Senior Care South	homeinstead.com/calgary 403-984-9225	HCA, LPN, Companion	\$33.95/hr 3 hours, twice a week	Nurse Directed Dementia CARE Curriculum; Mobile Foot Care Services
The Mad Tasker	themadtasker.com 403-988-2471	RN, LPN, HCA	\$30/hr 1 hour minimum	Best Friends Approach™; Person-Centred
Max Home Care	maxhomecare.ca 587-352-1010	HCA	\$27/hr 2 hour minimum	
Miraculum Homecare	miraculumhomecare.com 403-452-6399	RN, LPN, HCA	\$28/hr 3 hour minimum	Family Care Focus
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	\$30/hr 2 hour minimum	Best Friends Approach <sup>TM</sup>

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ParaMed	paramed.com 403-228-3877	RN, LPN, HCA, Companion	\$55/hr	Client-Centred
Qualicare Family Homecare Calgary	homecarecalgary.com 403-209-2210	RN, LPN, HCA, Companion	\$33/hr 3 hour minimum	Nurse Managed Care; Best Friends Approach™; GPA
Right At Home	rightathomecanada.com/calgary 403-869-8294	RN, LPN, HCA, Physio Therapy	\$32.00/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
Senior Homecare by Angels	seniorhomecarecalgary.com 403-862-0129	LPN, HCA	\$29.95/hr 2 hour minimum	Client-Dependent
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 403-488-7991	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	•					
The BSF Clifton Manor	4726 – 8 Avenue SW	403-272-9831	theBSF.ca	•					
The BSF Wentworth Manor	5717 – 14 Avenue SW	403-242-5005	theBSF.ca	•					
Carewest Colonel Belcher	1939 Veteran's Way NW	403-944-7800	carewest.ca						
Carewest Sarcee	3504 Sarcee Road SW	403-686-8140	carewest.ca	•					
Chartwell Eau Claire Care Residence	301 – 7 Street SW	587-287-3943	chartwell.com		•				
Evergreen	2220 – 162 Avenue SW	403-201-3555	reveraliving.com		•				
McKenzie Towne Retirement Residence	20 Promenade Park SE	403-257-9331	reveraliving.com		•				

FACILITY	PROGRAM NAME	BUILDING ADDRESS  W  S  E	PHONE NUMBER	WEBSITE	SUBSIDIZED	PPIVATE
AgeCare Glenmore	AHS Adult Day Program	1729 – 90 Avenue SW	403-253-8806	agecare.ca/glenmore		
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	Young Onset 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	III Riverfront Avenue SW	403-269-6122	cceca.ca		
Carewest Beddington	Comprehensive Community Care (C3)	308 – 8120 Beddington Blvd. NW	403-520-3350	carewest.ca		
Carewest Colonel Belcher	Wellness Day Program	1939 Veteran's Way NW	403-944-7854	carewest.ca		
Carewest Sarcee	Comprehensive Community Care (C3)	3504 Sarcee Road SW	403-686-8140	carewest.ca		
Carewest Signal Pointe	Carewest Signal Pointe Adult Day Program	6363 Simcoe Road SW	403-240-7953	carewest.ca		
Ohana Care Health Services	Ohana Care Day Program	156 – 8888 Country Hills Blvd.	403-300-2273	ohanacare.ca		
Peace of Mind	Peace of Mind Adult Day Program	#26, 5440 4 Street NW	587-887-4900	peaceofmindcare.ca		
SAIT	YouQuest - A Wellness Community for Young Onset Dementia	1301 16 Avenue NW	403-255-7018	youquest.ca		
st. Andrew's Presbyterian Church	Side by Side Fellowship (informal care)	703 Heritage Drive SW	403-255-0001	standrewscalgary.ca		
arsity Acres Presbyterian Church	Side by Side Fellowship	4612 Varsity Drive NW	403-288-0544	vapc.ca		
Ning Kei Care Centre	Wellness Day Program, Dementia Day Program *Intended for clients who	1212 Centre Street NE	403-277-7433	wingkeicarecentre.org		

<sup>\*</sup>Confirm dates and times with individual programs

CARE PARTNER S	SUPPORT				
PROGRAM	PROGRAM DETAILS	PHONE NUMBER	E-MAIL	HOURS	DATES
Alzheimer Society of Calgary	Contact the Society for program details	403-290-0110	findsupport@alzheimercalgary.ca	8:30 a.m. to 4:30 p.m., Monday to Friday	
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
Calgary South Dementia Support Group	Dementia-specific support	403-271-9570	Call Claire, at number listed	10 a.m. to 11:30 a.m.	2nd and 4th Thursday of each month
Conversation Café	Monthly meet-up for people with dementia and their care partners	403-290-0110 x 237	kim@dementianetworkcalgary.ca, dementianetworkcalgary.ca	2 p.m. to 4 p.m. on Tuesday and Wednesday, 10 a.m. to 12 p.m. on Thursday	2nd Tuesday of each month, 3rd Wednes- day, 4th Thursday of each month
Dementia Caregiver Support	Dementia-specific support Southwood United Church, 10690 Elbow Dr. SW	403-253-2979	southwoodchurch.ca	l p.m.	1st Monday of each month
Living with Dementia	12 topics by professional facilitators Carewest Glenmore Park Day Hospital, 6909 – 14 St. SW	403-640-6480		Call to confirm	Call to confirm
Memory P.L.U.S.	Safe, fun, social activities for those with mild dementia and their care partners	403-955-1674	family.caregivercentre@ahs.ca	2 hr Sessions	Fall/Spring sessions 12-week program
Young Onset Dementia Support Group	For people with dementia (diagnosed under age 65) and their caregivers Southwood United Church 10690 Elbow Dr. SW	403-975-6685 403-283-9537	cindy@youquest.ca, call for first time participants	7 p.m. to 8:30 p.m.	1st and 3rd Tuesday of each month

\*Confirm dates and times with individual programs

# Questions? Feedback? Stories to Share?

Write to us: feedback@dementiaconnections.ca
Connect with us online at: dementiaconnections.ca



# NEIL'S Story

AS TOLD TO Jennifer Dorozio PHOTOGRAPHY BY Jared Sych

Neil Godfrey is a geoscientist by profession, outdoorsman by hobby and, as he discovered in his early 40s, an oil and watercolour painter by passion. Early in his retirement, at the age of 60, Godfrey began to notice troubling symptoms, including struggling to file his taxes and read his watch. Eventually, Godfrey was diagnosed with posterior cortical atrophy — a rare form of Alzheimer's disease that affects, among other things, spatial perception and calculation. Now 63, Godfrey is still a man of many interests, especially when it comes to connecting with his wife, Joanne, three children and six grandchildren. As he continues to adjust to his new normal, Godfrey prioritizes activities and people that bring him joy, value and purpose. To challenge stigma and raise awareness, Godfrey regularly shares his experience living with dementia, including with students at the University of Calgary, local churches, seniors' groups and, now, Dementia Connections magazine.



I [was] a double 'E' extrovert, and now [since the diagnosis],

I'm probably a small 'e' extrovert. Now, what brings me joy is relationships,

[including] my wife, my family, my friends, my grandkids and grand-dog. And sushi dates, skiing, hiking, camping, painting and the mountains. Oh, and a good night's sleep — my neurologist told me that a

night of good, deep sleep is really good for people with dementia.

"Life is good. I stay very active, but I have simplified my life. I keep a very detailed agenda and focus on familiar things.

"I've never had [anxiety before] in my life, so, in the last two years, that's new for me. I manage my anxiety by managing stress, paying attention to what causes me stress and avoiding it. I just make [social] decisions and say 'yes' or 'no,' and I'm not afraid to do that, whereas before, I would just do everything.

"[The advice I would give to someone with dementia] is to embrace it, accept it and simplify your life. Being socially active is really important. Buddies call me and say, 'Let's go for sushi, let's go skiing,' or I'll pursue people for coffee, and I love that. Do not isolate. Now, I think it's an era where you can say, 'I've got Alzheimer's, and it's okay.'

"[I have learned through all this] to be kind to your care partners, and I say care partners because there's more than just my wife caring for me; there are friends and whomever.

"I edit my life by focusing on what I can do, not what I can't do. What gives me hope every day is my strong Christian faith in Jesus Christ. He is my anchor and the peace in my storm.

"[Dementia] is an important topic. I've done speaking tours and am still doing them. I do it because it's so important to this generation to have an awareness of dementia. I self-diagnosed, and I encourage people to go to their doctors [and advocate for themselves]. If you have [a] dementia [diagnosis], you should educate yourself. [After a diagnosis], you should still be public, and you should still enjoy your life."

Share your story with us at feedback@dementiaconnections.ca.



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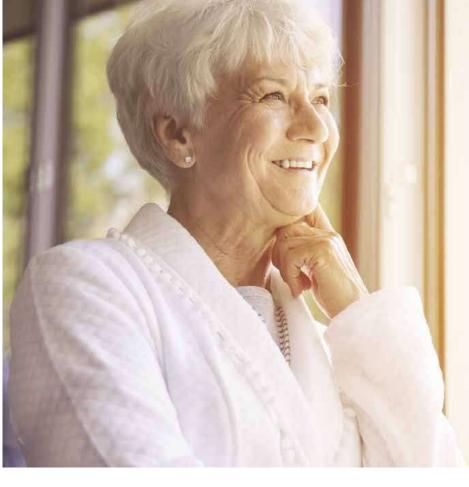
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# Right Home Right Care Right Time Right Place

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

# **Affordable Housing and Campus of Care for Seniors**

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

# **Life Lease Community**

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

# **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 1000 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

