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Winter 2020

YOUR
GUIDE TO
LIVING
WELL IN
CALGARY

AROUND
THE WORLD
EXPLORING
THE GLOBAL
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EXPERIENCE

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AND MORE

Staying ACTIVE

Marjorie Many Wounds-Many Guns finds joy in nature



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Maddie G.

– Maddie G.
Stanley's CAREGiver



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



WELCOME


JANUARY IS ALZHEIMER'S AWARENESS MONTH in Canada. It's the perfect time to reflect on the results of a recent survey conducted by Dementia Network Calgary, which revealed that the vast majority of all respondents feel people living with dementia are stigmatized and isolated. The survey found 18 per cent of all respondents would hide a dementia diagnosis. These survey results echo similar findings from a 2017 survey by Alzheimer Society of Canada, which found 1 in 5 people would avoid seeking help for as long as possible, if they thought they had dementia.

Stigma and a lack of public awareness result in fear, shame and social isolation for people impacted by dementia, and can also affect the care they receive. As

our population ages and dementia prevalence increases, it will be impossible to provide enough long-term spaces to meet demand, and most people living with dementia will remain in community. At the same time, there is a projected global health-care workforce shortage. To address this widening gap, we must build community capacity so family, friends and neighbours understand how they can help people impacted by dementia live as well as possible. One potential solution is small-scale care, embedded in community. See page 42 to learn more.

Awareness is key to understanding how to reduce the risks of developing dementia. Turn to page 20 to learn about the link between brain health and what we eat.

Awareness will also be improved by more research. Alzheimer Disease International (ADI) urges that at least one per cent of the overall global cost of dementia should be spent on research. Currently, Canada lags behind other countries in research funding. See page 58 for more information about ADI.

More than 17,000 people live with dementia in Calgary, and eight new people are diagnosed every day. By reducing stigma, raising awareness and advocating to fully implement both the Alberta Dementia Strategy and Action Plan and the national plan, *A Dementia Strategy for Canada: Together We Aspire*, we can make Calgary a supportive, innovative environment where people impacted by dementia live well. 

Lisa Poole
 Founder and Editor
 DEMENTIA CONNECTIONS
lisa@dementiaconnections.ca



Dear Lisa,

I wanted to compliment you on your excellent publication, *Dementia Connections*.

The mix of practical information, stories of families managing dementia and the excellent design of the publication is so accessible to people affected by dementia and the general public.

Thank you so much for preparing such a useful resource, I look forward to reading more issues of *Dementia Connections*.

Regards,

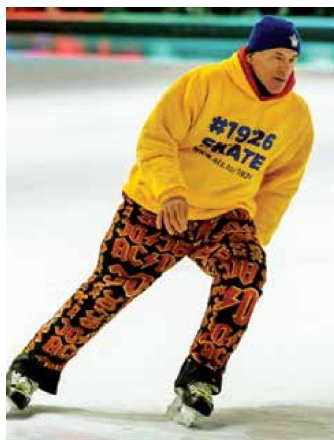
**Catherine Freeze,
MEd, RD, CDE**

Department of Health and Wellness,
Charlottetown, PEI

Dear Lisa,

Thank you for your magazine. The phrase: “help facilitate a positive attitude to the condition of dementia,” really made my heart soar. [Find it on dementiaconnections.ca under the “helpful links” tab.] Too much symptomology, along with fear and shame of the condition, is out there.

Thank you,
Irene Brannan



Dear Lisa,

I would like to thank all the staff there for everything you guys do for the dementia community across the country. Also, thanks for taking the time to write about my fundraising. I can hardly

wait to get back to Calgary. I’m currently working on plans for this year. I would like to skate in all 10 provinces at a military base in each province as a tribute to our military families battling with Alzheimer’s and dementia who face bigger challenges being stationed abroad.

Thanks again,
Steve McNeil

A story about Steve McNeil’s fundraiser, *1926 Skate*, ran in the Fall 2019 issue of *Dementia Connections*. Learn more about McNeil on dementiaconnections.ca

Dear Lisa,

We’ve just come from the CC [Conversation Café] at Lake Bonavista where we had 23 people in attendance today! Nine of them were new to the café and most had heard about it through *Dementia Connections* magazine. There was great discussion and lots of information-sharing. For those of us who are regulars, and getting to know each other well, the camaraderie and support is very noticeable. Our lovely young server, Mary Jane, says she loves our get-togethers there and is hearing things that are helping

her understand her grandmother’s situation with dementia. It sure feels like a happy, cohesive group! Lots of laughter, too.

Nancy & Jo

Dear Lisa,

My name is Jule Briese and I have begun to offer a new course called Hot Chocolate & Decadent Cake — Dementia & A Choice for MAiD. It is for people living with dementia and their companions. It is an 8-hour course offered in four, 2-hour sessions or can be facilitated as a two-day retreat. It is limited to eight participants. The course is experiential and offers opportunities for reflection as well as small group discussion.

For more information, people can contact me by e-mail, tranquilshorecreative@gmail.com, or by phone, 250-752-4996.

Jule Briese

Qualicum Beach, BC

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

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Pink and Teal and Read all Over

The *Pass Me By* graphic novel series considers the dementia experience in layers of life and colour

BY Colin Gallant

When Kyle Simmers and Ryan Danny Owen started working on the five-part *Pass Me By* graphic novel series, they knew that complicated work lay ahead. Though Simmers had worked on a few pages from 2015 to 2017, the project took its full form when Owen came aboard in the summer of 2017. They wanted to tell the story of Ed, a queer man in his 70s living with dementia, and they wanted to do it in a way that properly reflected that Ed was a complicated person no more defined by his dementia than any other part of himself.

“[*Pass Me By*] is a split narrative between Ed’s experience in contemporary life dealing with this disease — and family and agency and control — and then, back in the 1970s, when he went on tour with a glam rock band, sort of subverting your expectations of this bachelor living in a rural Canadian context,” says Simmers.

A visual artist whose pronouns are “they” and “them,” Simmers was inspired to create *Pass Me By* based on their own experiences growing up in a small town where they remember both a lot of joy and also the pain of not fitting in. Shortly after Simmers’s grandmother was diagnosed with dementia, they began an early version of *Pass Me By* to help channel their feelings through art.

It was around this time that Simmers met Owen through the Alberta College of Art + Design (now Alberta University of the Arts), where they were both students. Owen was dealing with illness in his own family — his mother’s cancer diagnosis — and wound up helping to storyboard and write dialogue for *Pass Me By*. In July 2018, the pair launched a Kickstarter campaign to finance the project. At the end of the 30-day campaign they had raised \$9,131 — nearly double the \$5,000 goal. The following February, the *Pass Me By* series was picked up by Alberta-based Renegade Arts Entertainment for publication and distribution.

As artists and writers, the collaborators were naturally drawn to the way visual storytelling can communicate differently than text-only works.

The key narrative device that makes *Pass Me By* unique is its use of colour. Aside from the requisite white, the only colours in the story are pink and teal rendered in different vibrancies, depending on the context. In their most simplistic function, the two colours indicate to the reader when Ed feels confidently cognizant or connected to a memory (pink) and when he’s feeling confused or frightened (teal).

As the creators strived to avoid reducing Ed to a diagnosis alone, they also avoided one-dimensional portrayals of memory. Plenty of frames make use




The *Pass Me By* graphic novel series tells the story of Ed.



of both colours in keeping with the fact that dementia experiences aren’t a binary of clear and foggy, good and bad, or any other polarized spectrum. The colour system also allowed the story to remain focused on Ed’s experiences and not become dominated by those around him.

“A lot of times, dementia narratives [become] about those who fall into caretaker roles. The person dealing with dementia a lot of times ends up losing the dignity of being a character in themselves,” says Simmers. “We really wanted to look at how that would feel to start to lose your faculty over yourself and not reduce Ed down to a victim.”

The first of the five-part *Pass Me By* series, *Gone Fishin'*, is available now through Renegade Arts Entertainment and both Simmers and Owen are hard at work on the next instalment. 

Learn more at renegadeartsentertainment.com

Neuro Nexus

This annual design competition aims to spur medical innovation

BY Fabian Mayer

The human brain is incredibly complex. Unfortunately, so are many of the diseases and disorders that affect it. Understanding and treating neurological conditions, including everything from depression to dementia, is one of the great challenges facing medicine today. Launched last spring, Neuro Nexus is an annual multidisciplinary design competition confronting that challenge head-on.

Hosted by Innovation 4 Health, a student organization at the University of Calgary that focuses on health-care innovation through fast-paced hack-athon-style events, the competition asks doctors, researchers, health professionals and community members to identify specific problems associated with a range of neurological disorders, as well

as bottlenecks in neuroscience research. Those issues include things like predicting and monitoring the effectiveness of medication for personalized approaches or developing new therapeutics. Small groups of students from universities across Calgary who are studying in fields such as engineering, medicine, sciences and business, collaborate in hopes of solving one of the issues.

“We connect people who know a challenge with people who have the skills to address it in a meaningful way,” says Kathryn Simone, Innovation 4 Health co-founder and biomedical engineering PhD candidate.

Teams of five to seven people have just six weeks to come up with their approach to the problem and three days in the University of Calgary’s Schulich School of Engineering Maker Multiplex to build a prototype.

Neuro Nexus culminates in a “Demo Day” where teams show off their ideas and compete for awards and funding. Former *Daily Planet* host Jay Ingram emceed the inaugural edition of the event at Calgary’s new Central Library in May 2019.

“It was the largest event we ever did,” says Simone, who organizes

similar challenges in other areas of medicine for Innovation 4 Health. “The show of support from the community was really quite powerful.”


The grand prize was awarded for a set of inflatable cuffs designed to limit brain damage from strokes by applying pressure to a patient’s extremities. In the data analytics category, an app called *Carelytic* took the top prize. The app is made for caregivers supporting people living with dementia. It allows caregivers to track things like diet, medications and behaviour, thereby identifying potentially clinically significant patterns. Other categories include clinical impact, research impact and people’s choice. Successful teams use the cash prizes, totalling \$17,500, to continue developing their prototype, some entering accelerator or incubator programs with an eye to eventually bringing their idea to market.

Pujarati Roy, *Carelytic*’s team spokesperson who’s in the third year of her bachelor of science degree at the U of C, says winning at Neuro Nexus was valuable on multiple levels.

“Winning at Neuro Nexus was able to secure *Carelytic* some funding, but even more valuable was the outreach and support we gained throughout the event. We were able to network with amazing people and it made us extremely hopeful that we can accomplish our goal,” Roy says. “We are currently in the design phase and working alongside medical practitioners to create a better fit with current patient care.”

Innovation 4 Health plans to expand Neuro Nexus in 2020 by opening up the competition to students and professionals from across Alberta. The team is also considering adding artificial intelligence as another competition category.

“People want to apply their skills to meaningful problems,” says Simone.

The 2020 Neuro Nexus competition will begin this spring. 

Learn more at innovation4health.com



Photo by Meredith Bailey

The *Carelytic* team, counter-clockwise from top left: Prince Okoli, Gabrielle Gonzaga, Jennifer Trinh, Roxanne Howard, Pujarati Roy. (Missing: Angela Li, Sam Josha)

THE BUURTZORG METHOD

This Dutch approach provides community solutions to home-care needs

BY Jennifer Dorozio



From its humble beginnings in a small city in the eastern Netherlands, a method of home care called Buurtzorg has inspired countries around the world to put patient care first.

Jos de Blok, the creator of Buurtzorg — which is Dutch for “neighbourhood care” — worked as a nurse and manager for a home-care organization for several years. In 2006, he and a small team of nurses began practising a more direct approach of community-based care for

individuals in need of home-care assistance in the small Dutch city of Almelo.

“My idea was that we could improve the quality of health care by giving health-care workers, [specifically] the nurses, the autonomy and ownership of deciding what has to be done and how [to] do it,” says de Blok.

In a radical shift away from care practices caught up in bureaucracy and procedures, de Blok created a home-care method that prioritizes direct patient care.

“My idea was that we could improve the quality of health care by giving health-care workers, [specifically] the nurses, the autonomy and ownership of deciding what has to be done and how [to] do it.” —Jos de Blok

Buurtzorg’s hallmark is a consistent neighbourhood care team of about 12 professional nurses who provide home care to between 50 to 60 people within a designated area.

Each nurse meets with a patient and their caregivers, including family, to determine what they require during visits and follow-up. That nurse is then empowered to create a unique care plan appropriate for that person, collaborating with their team and other local health-care specialists, like physiotherapists and psychiatric nurses, when needed.

“It is this kind of circular process every time,” says de Blok. “The assessment and the holistic care is on hand, and the one who’s responsible for delivering the care is also responsible for planning and coordinating care.”

Nurses are expected to spend 60 per cent of their time on shift directly interacting with the client and addressing their needs, instead of reporting or attending meetings. During visits, nurses are equipped to provide a variety of services, as opposed to more traditional home-care methods where specific tasks are performed by specific people. For example, a nurse may clean out the fridge and have a cup of coffee with a patient during one visit and then subsequently do wound care while visiting on another day.

The approach is making an impact. In a study by KPMG, Buurtzorg ranked among the best home-care agencies in the Netherlands on measures of patient-reported experiences. A study by Ernst & Young found that the holistic approach of its nurses proved to have higher productivity during visits.

The Buurtzorg method is currently being used and tested in 25 countries, including Canada.

“All over the world we have neighbourhoods — it’s not about the city, it is about [creating] an environment,” says de Blok. ▣

FEDERAL FORUM ON DEMENTIA

Canada's federal parties weigh-in

Last September, Dementia Advocacy Canada (DAC), a grassroots group of people living with dementia and care partners from across the country, hosted an online federal forum on dementia. The intent was to learn, if elected, how and when Canada's federal parties would implement Canada's new national dementia strategy, *A Dementia Strategy for Canada: Together We Aspire*, which was released last June. The forum was hosted by DAC co-chair Mary Beth Wighton and moderated by André Picard, health columnist, for the *Globe and Mail*.

Representatives from the NDP, Conservative, Green and Liberal parties participated in the forum and weighed in on supporting front-line staff, the importance of advocacy and investing in dementia-related research. There was a consensus amongst the parties for MPs to form an all-party dementia caucus, and to implement mandatory dementia education for MP staff members.

Active engagement from Canada's federal parties regarding the strategy is a positive step forward, but continued advocacy is essential to ensure that the strategy is implemented. ▣

Learn more about DAC at dementiacanada.com

WHAT'S ON YOUR MIND?

CABHI's community discussion series calls on Canadians with lived experience

BY Meredith Bailey

The Centre for Aging and Brain Health Innovation (CABHI), led by Baycrest Health Sciences, is committed to providing market-ready health-care innovations for aging Canadians. Through its "What's on Your Mind?" community discussion series, the Ontario-based company is accelerating research by asking people directly what they need to live and age well.

This past November, CABHI, together with Dementia Advocacy Canada, hosted "What's on Your Mind?" in Calgary. It was the first time the event was hosted outside of Ontario.

The gathering, held at the Marda Loop Community Association, included people living with dementia, as well as care partners. Dr. Allison Sekuler, CABHI's managing director and VP of research for

Baycrest, led the lively discussion.

"We've actually interacted a lot with the community here in Calgary. But to come out and meet with people firsthand gives us a different perspective," Sekuler explained at the gathering. "Research should be driven by the individuals living it."

Participants shared their challenges with stigma, navigating the health-care system, accessing programming and the shortage of qualified health-care supports. The group brainstormed ideas such as introducing "dementia doulas" in hospitals. Several people living with dementia also shared the reality of their lived experience.

CABHI's goal is to capture themes from its community discussions and ensure it's on the right track with its innovations. In the next five years, it plans to build an advisory council with over a million people with lived experience to help inform the implementation of its programming.

"The reason we wanted to have a conversation with all of you, and to find out what you think, is because we want to move beyond research into action. We want to make a difference in the world," Sekuler said. ▣



CABHI's Dr. Allison Sekuler spoke at the Calgary event.

Learn more at cabhi.com



DID YOU KNOW? The U.K.'s first dementia-friendly ambulances were launched in the fall of 2019. The adapted vehicles include calming window screens, soothing music, twiddle-mitts and EMTs who have undergone dementia-friendly training.

INNOVATING HEALTH CARE

AGE-WELL supports aging Canadians through technology

BY Jennifer Friesen

It wasn't too long ago that fax machines and dial-up internet were seen as the pinnacle of technology. Back then, the concept of robots and "smart wheelchairs" would have sounded like little more than science fiction.

But now, Bridgette Murphy says, "here we are — it's happening."

Murphy is the managing director and COO of AGE-WELL, Canada's technology and aging network. Since launching in 2015, the network has created technologies,

policies and practices to assist older adults and their caregivers — and those technologies include smart wheelchairs and, yes, even robots.

AGE-WELL's administrative centre is based in Toronto, but it has partners and researchers across the entire country. AGE-WELL is federally funded by the Networks of Centres of Excellence program, a federal government initiative that funds large-scale research networks. As technology and innovation has snowballed over the past few decades,

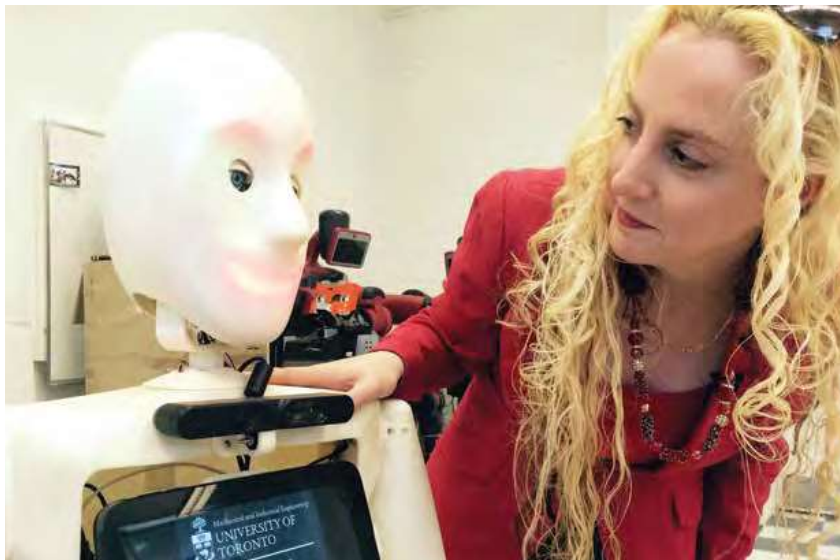
AGE-WELL believes it can be utilized to enrich the lives, health, safety and independence of aging Canadians.

"We're really looking at how technology can move the dial in many areas including cognitive health, dementia and independence," says Murphy. "I've seen technology have such a dramatic effect on a person's quality of life that it brought them to tears."

Murphy worked in research within the rehabilitation sector before teaming up with long-time colleague and scientific director of AGE-WELL, Alex Mihailidis. She explains that, as a senior scientist in this sector, Mihailidis saw the need for a more collaborative, multi-sectoral approach to developing technologies to support the aging population.

"It was a fragmented research community," Murphy says. "There were researchers working all across the country on the same things, but not necessarily together. This gap was really the impetus for us to connect everyone."

And it wasn't just researchers that AGE-WELL wanted at the table. In addition to its more than 250 funded and affiliated researchers from 42 Canadian



Dr. Goldie Nejat, AGE-WELL investigator and roboticist, at the University of Toronto with Casper the social robot.

Photo courtesy of AGE-WELL

AGE-WELL PROJECTS AND SUPPORTED START-UPS FOR PEOPLE LIVING WITH DEMENTIA

Automated Pain Detection System

A biomedical engineer and clinical psychologist collaborated on this system that uses facial recognition technology to assess pain levels in individuals

living in long-term care who may be unable to articulate pain. Learn more on page 38.

Wandering Detection and Diversion System

Using motion, contact and bed

sensors, this technology is activated when someone living with dementia wanders out of bed at night. It can be personalized to activate a night light, play a voice message by a loved one or alert a caregiver.

WinterLight Labs

Through a one-minute sample of someone's speech, this technology can detect and monitor dementia and other cognitive impairments more efficiently than traditional handwritten tests.

universities and research centres, it has also partnered with caregivers, aging Canadians, and nearly 400 industry, government and non-profit partners.

“We knew that we couldn’t just do research for research’s sake,” says Murphy. “If you’re going to develop a technology for someone with dementia, someone with dementia needs to be a part of that process.”

Over the past five years, AGE-WELL has worked to bridge that gap through collaborations, research projects, training programs and more. The network connects Canadians living with dementia and other age-related conditions or challenges with researchers, policy-makers with innovators, and engineers with entrepreneurs.

Through its combined knowledge base, AGE-WELL develops and aims to accelerate the delivery of technologies designed to assist the aging population. By funding research projects and opening up its network to innovators, AGE-WELL has helped to produce multiple start-up organizations with products for this demographic.

In the network’s first year of operation, it funded an idea for a smart wheelchair that uses a blind-spot sensor detection system to help prevent collisions and ensure safety. The project became a start-up called Braze Mobility, and the technology has now been commercialized.

AGE-WELL also funded a few robotics programs, including social robots that prompt people living with dementia to complete tasks like brushing their teeth or getting dressed. In the future, robots will be able to make virtual medical visits possible so aging adults can stay at home for longer.

“Cognitive health and dementia have always been priorities for us,” says Murphy. “And that has really been validated by what we’ve heard from older adults and caregivers across the country. By hearing their stories, we know that technology can help meet the needs of Canadians and improve their lives.” ■

ALZHEIMER’S DISEASE DRUG RECEIVES A NEW LIFE

Biogen has reversed its decision on aducanumab, submitting the drug for FDA approval

BY Nathan Kunz

Seven months after initially calling off the worldwide trial for a potentially groundbreaking early Alzheimer’s disease treatment — called aducanumab — U.S. biotechnology company Biogen has reversed its decision. It plans to submit the drug for approval in early 2020.

At press time, Biogen, who developed the drug with Japanese pharmaceutical manufacturer Eisai, has announced its intention to move forward with a U.S. Food and Drug Administration (FDA) Biologics License Application in early 2020.

“There is some promising evidence from these trials of aducanumab that we might have the first drug that can slow down the progress in Alzheimer’s disease,” says University of Calgary professor of neurology Dr. Eric Smith, who was a co-investigator at the Calgary site of the trial.

If approved, aducanumab would be the first disease-modifying therapy option on the market for those living with Alzheimer’s disease — meaning a treatment that slows the rate of decline.

The aducanumab trial was initially called off following an interim

“futility analysis” in late March 2019. In what Smith calls an “unusual situation,” Biogen reversed the decision in October after further analysis showed positive results in participants with early Alzheimer’s. These positive results came from a larger dataset made available after discontinuation that included more data from patients randomized to the higher doses of the drug.

According to Biogen, “Patients who received aducanumab experienced significant benefits on measures of cognition and function, such as memory and language.”

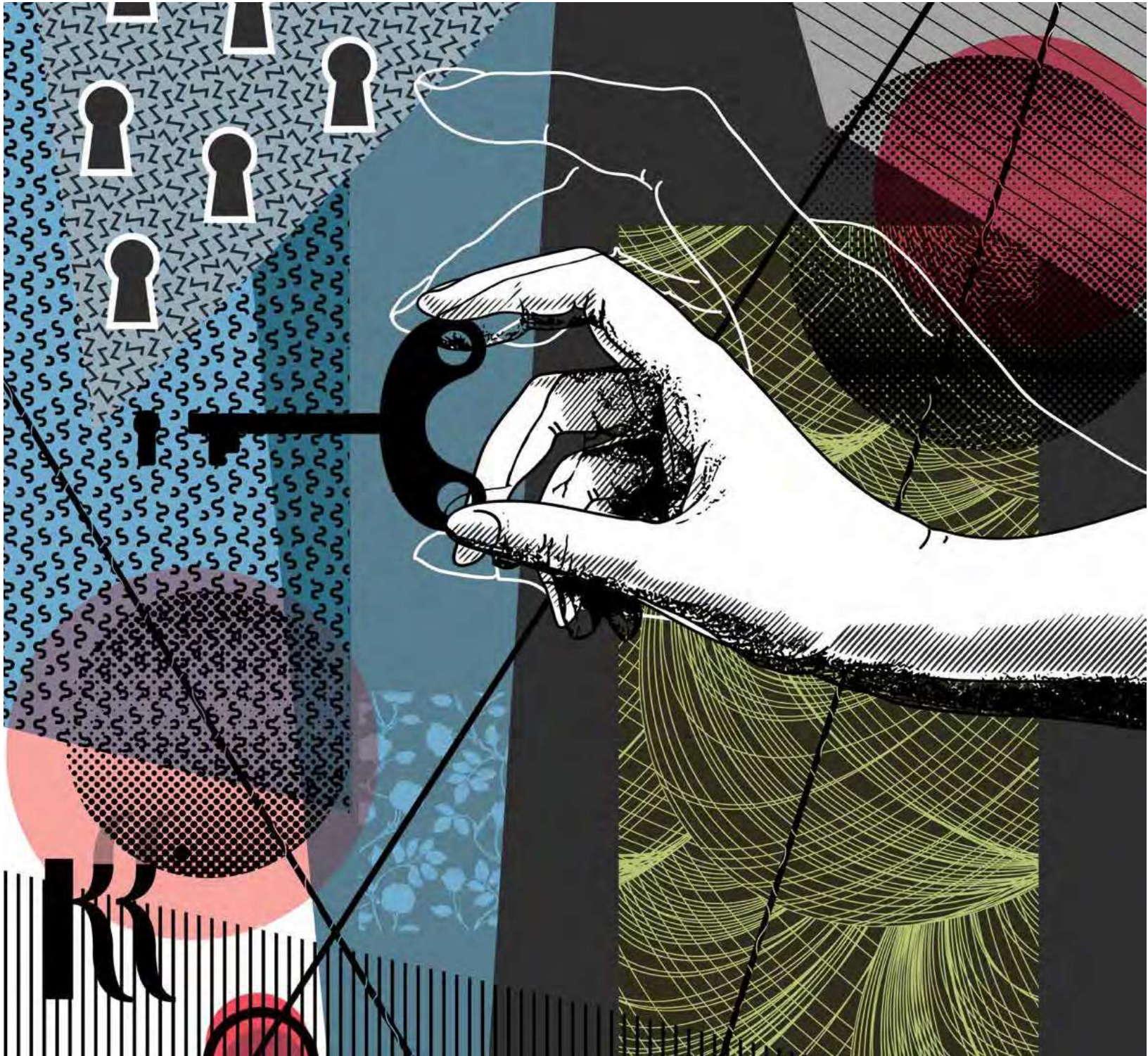
At the moment, the future of aducanumab is still uncertain. Smith notes that the results of the trial have yet to be published in any peer-reviewed medical literature. Also, Smith suggests that, due to the unusual circumstances regarding the reversal, the FDA could require another trial using the higher dose that yields positive results.

Calgarian Duncan McLean, a participant in a previous Biogen trial who is living with dementia, is encouraged by this new development. “It’s a positive thing that Biogen is going to continue their research,” he says. ■

UNLOCKING DOORS

Decreasing segregation and isolation in long-term care can increase quality of life

BY Elizabeth Chorney-Booth



Caring for people living with advanced stages of dementia often involves some kind of segregated living situation. Traditional care homes often put residents living with dementia in designated memory-care wings, locked away from the rest of the facility's population.

The idea is that, if left to roam, residents living with dementia may become confused, go missing, or cause harm to themselves or others. But a growing number of experts are arguing that the real harm comes from restricting these residents' movement. The concept of

city of Waterloo Research Institute for Aging. "The biggest one is a civil rights issue. By segregating them, we're essentially saying that this population can't live around the rest of us anymore."

Kate Swaffer, chair and CEO of Dementia Alliance International, a U.S.-based charity that represents the global voice of dementia, is deeply committed to deinstitutionalisation and desegregation of people with dementia. Swaffer, who is living with dementia, also believes dementia villages are simply another form of segregation, and are little better than a "ghettoization of people with dementia,"

Plus, mingling with residents without dementia can help keep one's cognitive abilities sharp.

"When it comes to locking doors, people focus on physical safety, which is a real concern," Power says. "But security can also be about psychological or emotional security. Being in a locked-in, confined space decreases that sense of psychological or emotional security."

Power says that removing the doors between memory-care wings and the rest of a care home is a good first step. While separate memory-care areas tend to be the global trend in the industrialized world, some communities, like

"When it comes to locking doors, people focus on physical safety, which is a real concern, but security can also be about psychological or emotional security. Being in a locked-in, confined space decreases that sense of psychological or emotional security." —Dr. Al Power

"unlocking doors," that is, allowing people living with dementia some level of personal freedom, may actually improve their quality of life.


When experts talk about unlocking doors, they don't usually mean allowing care home residents to walk out the front door and come and go as they please. Rather, advocates for resident freedom are looking at measures as simple as desegregating memory-care residents or creating fenced-in outdoor areas that residents can access any time.

"There are a lot of reasons why I don't think it makes sense to have separate living areas for people with dementia," says Dr. Al Power, Schlegel chair in Aging and Dementia Innovation at the Univer-

rather than a solution to assisted living.

Power, who has long been an advocate of shifting the culture of dementia care to focus on the person rather than the disease, says the idea of segregating residents with dementia has only been around since the '70s. Part of the reason this became popular was that care homes realized the power of marketing specialized memory-care wards. He says that not only is there no clinical evidence that segregation is better for people living with dementia, but there's actually plenty of evidence that suggests it can be detrimental to a person's mental well-being. Locked doors can create a sense of imprisonment, as well as feelings of anxiety and distress.

United Active Living in Calgary, are already giving all residents full access to the entire property, and United's community at Fish Creek offers an enclosed outdoor space. Power has seen other facilities in the U.S. and Europe that also allow full access to enclosed outdoor spaces. He thinks it's possible for facilities to eventually consider unlocking their front doors as well, employing staff to accompany residents as they go for a walk, or using GPS technology to keep them safe. As with all dementia care, Power would like to see each patient's needs addressed on an individual basis.

Ultimately, unlocking doors is about treating people living with dementia with dignity. 

DID YOU KNOW? In 2016, the University of Nottingham in the United Kingdom was officially recognized as the first ever dementia-friendly university by Alzheimer's Society UK. The university is committed to reducing stigma, creating innovative employment practices for people living with dementia, increasing dementia-awareness education and contributing to meaningful research.

IMAGINE THIS

Get to know Alberta's IMAGINE Citizens initiative, a group of Albertans working together to give patients a voice in their own health care

BY Jennifer Friesen

The IMAGINE Citizens initiative officially launched in 2015, but, according to Judy Birdsell, chair of the initiative, “We didn’t actually know it was a launch when we did it.” Birdsell says it started as a conversation among 10 Calgary and area residents who felt let-down or misinformed by the health-care system and who wanted to talk about what needed to be done to improve the future of health care in the province.

What is IMAGINE Citizens?

As a citizen-led initiative, IMAGINE is working to bring Albertans’ voices together to improve the current health-care system.

and information about how the health system works to inform its activities. For example, IMAGINE embarked on a project with funding from Alberta Health in which it worked with a diverse group of Albertans over several months to make recommendations related to some key policy directions related to primary health care. Birdsell says the resulting report’s recommendation of having more consistency between how patients and others discuss primary care has influenced the way key groups like Alberta Health now talk about primary health care.

“Our primary purpose is to help Albertans learn and become effective voices in shaping the future of health care. We have the deep belief that

“Our primary purpose is to help Albertans learn and become effective voices in shaping the future of health care.” —Judy Birdsell

IMAGINE was formalized as a provincial society in October 2018 in order to help establish its independence and raise money for its work. It is comprised almost entirely of volunteers, including a board of eight people, 40 core members who lead projects and a community of about 600 others across the province.

IMAGINE’s operations committee meets once a month to coordinate its projects.

Often working with the University of Calgary’s O’Brien Institute for Public Health, IMAGINE aspires to use evidence from research, input from Albertans

citizens need an independent voice in health care because there’s no organized way for patients and citizens to have a voice,” Birdsell says. “This work will lead to better health and experiences for all of us, regardless if we have cancer, diabetes or dementia.”

Health Care 101

In 2017, IMAGINE helped launch a project called Health Care 101, where it reached out to 200 Albertans to ask what could help them be better informed on health care. One area

that was important to Albertans was understanding who was in the system and their roles. Birdsell was shocked that a majority of Albertans were unable to explain the difference between the ministry of Alberta Health and the health authority of Alberta Health Services. IMAGINE, working with several partners, used the information it gathered to create *Health Care Basics for Albertans*, an informative module available on its website. There are three more modules currently under development.

Looking forward

By fusing citizen needs deeper into current conversations, IMAGINE is bringing the patient and citizen perspective to policies, health-care conferences, meetings and research projects. By having a seat at the table, IMAGINE volunteers (including patients and affected family members) are able to advocate for improvements in the health system.

Sharing knowledge with Albertans is always ongoing for the volunteer-run group, but the next steps involve learning from the stories they hear and advocating together for a change in policy to reflect the needs they hear about. By sharing knowledge through online platforms such as the Health Care 101 initiative, or by meeting with government officials, such as Alberta Health, IMAGINE is working to both empower the voices of patients and advocate for that voice among policy-makers.

How to get involved

Birdsell says IMAGINE doesn’t “look or feel like many organizations,” when people want to get involved. When someone is interested in helping the cause, IMAGINE works to find the best fit for them.

“We don’t have a list of job descriptions yet,” she says. “We’re still very organic in how we do things.”

Learn more at imaginecitizens.ca

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EXPAND YOUR CARE TEAM

These health-care providers are three of several who offer valuable services to people living with dementia

BY Meredith Bailey ILLUSTRATIONS BY Hayden Maynard



1

Occupational Therapist SPECIALTY AND QUALIFICATIONS

An occupational therapist (OT) is trained to support a client's physical, mental, emotional and social needs. In order to practice in Alberta,

OTs must have a university degree in occupational therapy, at least 1,000 hours of supervised clinical practice and be registered with the Alberta College of Occupational Therapists.

WHAT THE JOB ENTAILS

OTs work collaboratively with clients to help them continue to engage in meaningful day-to-day activities, such as driving or preparing a meal.

OTs work in a variety of settings including schools, hospitals, long-term care facilities and in clients' homes.

BENEFITS FOR PEOPLE LIVING WITH DEMENTIA

Working with an OT can be useful for someone living with early-stage dementia to maintain a sense of independence in their own homes. For example, an OT could work with a client to assess the safety and function of their kitchen. OTs could suggest things like identifying and labelling the contents of kitchen drawers and cupboards to allow for easier navigation to prepare meals. Read more about the role occupational therapists play on page 60.

2

Dietitian

SPECIALTY AND QUALIFICATIONS

Dietitians are specifically trained food and nutrition experts. In Alberta, a registered dietitian (RD) is recognized by the College of Dietitians of Alberta. RDs must have completed a four-year bachelor's degree with a focus on food and nutrition, as well as supervised practical training.

WHAT THE JOB ENTAILS

RDs work closely with a person's health-care team to address their individual diet and nutrition needs.

RDs also conduct research, direct nutrition programs and can be responsible for shaping public health policy.



Illustrations © Hayden Maynard, IZi Art Inc.



**BENEFITS FOR PEOPLE
LIVING WITH DEMENTIA**

RDs can help support people living with dementia to continue to eat healthy, nourishing

foods regularly. RDs can offer solutions for people who may struggle to feed themselves or require extra assistance at mealtimes.

**Speech-Language
Pathologist**


SPECIALTY AND QUALIFICATIONS

Speech-Language Pathologists (S-LPs) are highly trained to evaluate, diagnose and treat a variety of language, communication and swallowing issues. S-LPs have a minimum of a master's degree in their field, and they work with patients of all ages, from infants to older adults. To practice in Alberta, they must be registered with the Alberta College of Speech Language Pathologists and Audiologists.

WHAT THE JOB ENTAILS

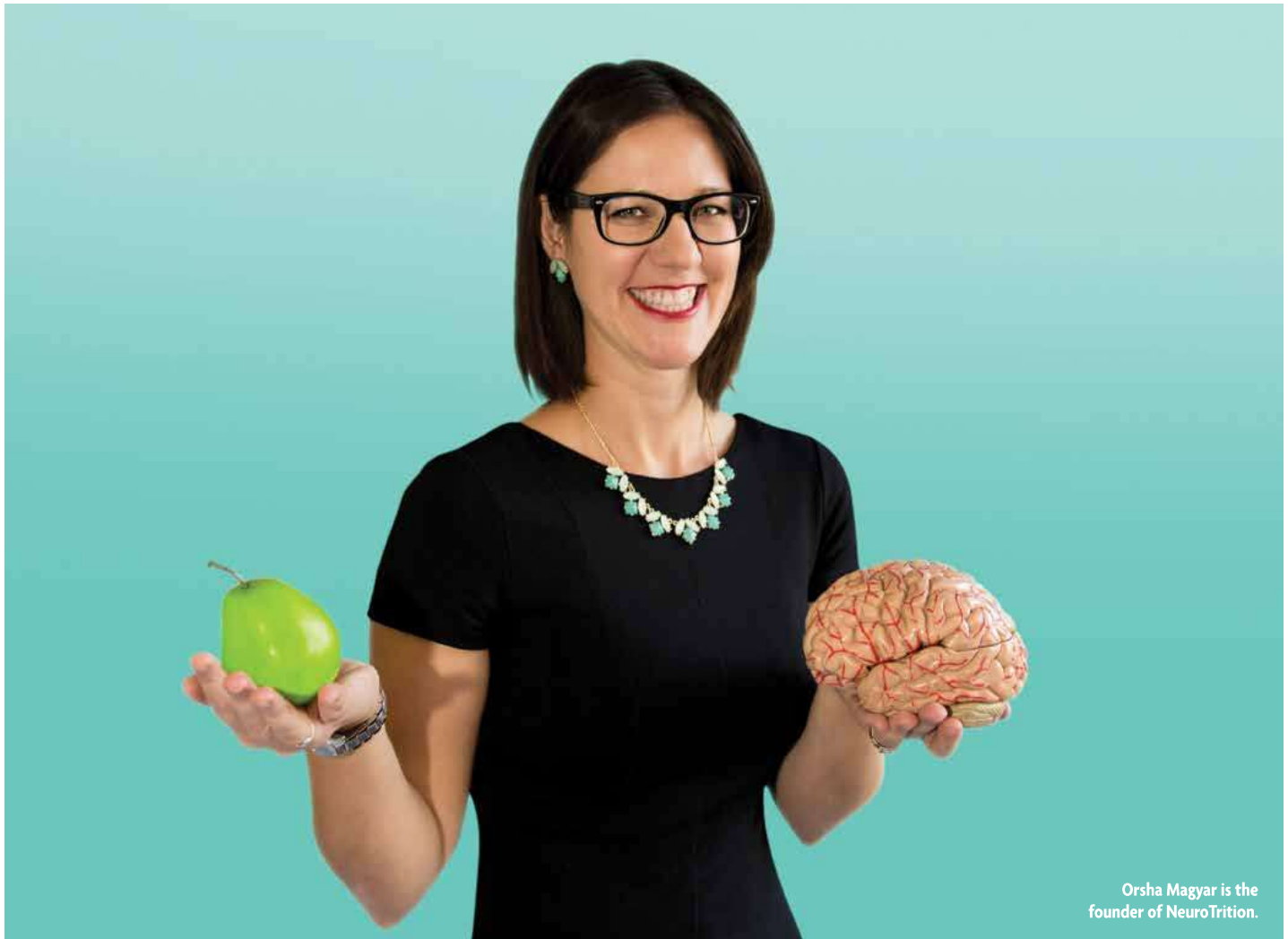
S-LPs are communication experts. They cover a broad scope of issues, from stuttering and literacy challenges to effective social skills and eating concerns.

**BENEFITS FOR PEOPLE
LIVING WITH DEMENTIA**

S-LPs can be an integral part of a person living with dementia's care team. Working with an S-LP can help people with dementia continue to communicate as effectively as possible. S-LPs can also help manage dysphagia, or swallowing difficulties, which increases quality of life. 



DID YOU KNOW? *In 2018, Scotland created its first dementia-inclusive park in the city of Stirling. Located in King's Park, one of the city's most popular, the project was spearheaded by the non-profit Paths for All. Dementia-inclusive updates include a handrail along a steep path, improved bathroom signage and new benches.*



Orsha Magyar is the founder of NeuroTriton.

FOOD FOR THOUGHT

NeuroTriton focuses on optimizing the link between our brains and our diets

BY Jennifer Dorozio

A love of neuroscience and the know-how for helping people lead healthier lives brought Orsha Magyar out of the lab and into the kitchen to found her Calgary-based company, NeuroTriton.

Magyar, who has a bachelor's degree in behavioural neuroscience and a master's degree in neuroscience from the University of British Columbia, spent 10 years in academia studying brain function.

While completing her master's thesis

at UBC in 2008, which focused on neural circuits and neurochemicals that underlie brain and mental health, Magyar began asking big questions of her field, separately from her thesis.

She wondered if solutions beyond prescription medicine existed for mental and neurological conditions, such as anxiety, depression and dementia.

"If someone has a brain condition or mental illness, we give them certain meds for it," says Magyar. "While I'm not against medication, I started wondering,

'Could there be tools besides medication to help people's brains?'"

This line of questioning led her to begin researching alternative ways to address mental and neurological issues, and it was then that Magyar discovered holistic nutrition.

After finishing her master's, Magyar leapt into studying nutrition and became Certified in Holistic Nutrition (CHN) from the Canadian School of Natural Nutrition. She was determined to uncover science-based approaches to making

“What we eat has an impact on things like cognition and memory and even our mood and mental health.” —Orsha Magyar

people’s lives better through diet.

“What we eat has an impact on things like cognition and memory and even our mood and mental health,” says Magyar. “The link is real between junk food and poor memory, cognition and poor brain aging.”

In 2010, Magyar founded NeuroTriton with the goal to take complex, research-proven findings and synthesize them into nutritional recommendations for clients to live healthier and longer lives.

“First and foremost, I’m a scientist, and it’s really helped my company compete in a somewhat saturated space,” she says.

Magyar works with a team of nearly 20 people, including science writers, “neuro chefs,” nutritionists and more, to find diet-related solutions fit to individual clients’ needs.

NeuroTriton offers “Brain Food Menus” tailor-made for individuals hoping to optimize their cognitive functions, and a series of targeted “Brain Building Programs” for specific and common problems like insomnia and shift work or stress and emotional eating.

The company also works with clients dealing with mental health conditions like anxiety and depression, as well as neurological conditions such as multiple sclerosis, Parkinson’s disease and those living with dementia. It works with clients’ family members who are at risk of developing these conditions, too.

There are several factors tied to aging that can affect brain performance. As we age our metabolism slows down and so does our production of stomach acid, meaning we can’t absorb and assimilate as many vital macronutrients and micronutrients needed to keep the body and brain running smoothly. Most importantly, as we age the flow of blood, including blood that carries glucose to the brain, can decrease. Glucose, or blood sugar, is essential fuel for the brain and glucose levels directly affect learning, thinking and memory.

General aging also leads to a reduction in the diversity of the good bacteria in the gut, which Magyar says can lead to brain inflammation.

A key factor, especially for clients living with dementia, is that as humans

age they produce less acetylcholine, a vital memory neurotransmitter that the nervous system uses to activate muscles in addition to memory.

“One of the biggest things I advocate for is early diagnosis [of dementia or cognitive impairment] so that medications, supplements and nutrition can be started to slow down progression,” says Magyar.

For patients with cognitive impairment of any kind, Magyar works to increase brain-boosting nutrients into their everyday diet that they may otherwise lack due to aging and lifestyle factors, such as poor eating habits. Specifically, those nutrients include omega-3, anti-inflammatory and antioxidant nutrients, healthy fats and pre and probiotics.

Brain health — including improved memory, mood and general alertness, as well as the ability to keep learning — can be maintained, says Magyar, but, in the case of dementia, working preventatively is key. Diet cannot reverse dementia, but it may help stave off the onset of dementia and lessen its symptoms, especially early on.

“We can start reducing the risk [of dementia] right away,” she says.

[Learn more at neurotriton.ca](http://neurotriton.ca)

11 VITAL BRAIN NUTRIENTS FOR DEMENTIA PREVENTION

1 Vitamin B12 Found in Greek yogurt, nutritional yeast, certain fish, meat, eggs and sea vegetables.

2 DHA (docosahexaenoic acid) Found in certain fish, algae, hemp, chia, flax and pumpkin seeds and walnuts.

3 Medium-chain triglycerides Found in coconut, cheese, yogurt and butter.

4 Turmeric Add this yellow spice to hot drinks.

5 Phosphatidylserine Found in meat, mackerel and cod, white beans and barley.


6 Acetyl-L-carnitine Found in seafood, lean meats, poultry, eggs, beans, peas, nuts and seeds.

7 Vitamin E Found in almonds, hazelnuts brazil nuts, sunflower seeds, avocado, spinach, Swiss chard, red pepper, mango and kiwi.

8 Alpha-lipoic acid Found in red meat, organ meats, broccoli, tomatoes, spinach, Brussels sprouts, yams, carrots and beets.

9 Probiotics Found in fermented foods like kimchi and also in sourdough bread and raw sauerkraut.

10 Vitamin D Vitamin D3 is high in foods like fish, eggs, cheese, and lichen, whereas D2 is high in mushrooms and sea vegetables like seaweed.

11 Antioxidants Found in fruits and vegetables and Brazil nuts. 

HERE WE GO AGAIN

Mary Beth Wighton was diagnosed with frontotemporal lobe dementia in 2012 when she was 45 years old. Today, she is a vocal advocate for inclusivity for people living with dementia. In an excerpt from her upcoming book, Dignity + Dementia: Carpe Diem, Wighton shares how she has navigated unexpected symptoms and worked to create a supportive care team.



Some days are easier than other days. Today has not been easy. I had an appointment with my geriatrician this morning. The last time I saw her was when she diagnosed me with frontotemporal lobe dementia (FTD). I walked out of that appointment before it was finished. I did the same thing today.

When the appointment started, the doctor told [my partner] Dawn and I that we were there on the request of my family doctor. He was concerned about my aggressive behaviour.

About one week ago, we had a scary episode while in the car. While travelling in the evening back from Dawn's folks' place, which is about an hour drive, something snapped inside me. There were four of us in the car. Dawn was driving, our friends Brianna and Shayla were in the back, and I was in the passenger seat. I knew something was going wrong and I told Dawn to get us home quickly.

No sooner had I said that, then a black cloud descended on me. I began to repeatedly hit the passenger window with my closed fist. This went on for a while. Dawn tried to talk me down, but I kept doing it. I then began to try and kick the front window. At some point, Dawn stopped the car and I was moved into the back seat with Brianna and Shayla took the passenger seat. My erratic behaviour escalated as I also started to yell obscenities out of the window.

I don't remember all of what happened but was told of my actions the next day. It lasted for about an hour. We were extremely lucky that I did not cause a serious accident. Everyone was very shaken up by the incident. Bruising on my knuckles and hand had already begun.

I laid on the couch the entire next day. Not only was I feeling very tired, but I was also extremely worried about the previous night. I had put my family in danger. This weighed heavily on me. I decided that I needed to find out if this was common for people diagnosed with FTD. I went on a website forum I had

recently discovered: ftdsupportforum.com.

This site is for people with FTD and their caregivers. I began to search the entries to learn if others had experienced this before. Much to my relief and dismay, I found many entries about challenging behaviours of an FTD car passenger.

From what I could gather, a car ride can overstimulate someone with FTD. There were many suggestions from both parties on how to try and get around this stimulation. Some ideas were: move to the back seat, use ear plugs, don't have a radio on, put up a window shade, etc. I shared this information with Dawn, and we strategized on how to help me be a safer passenger.

It was because of this incident, and some others, that I found myself sitting in front of the geriatrician. She told us she was very concerned about this behaviour. She also found it odd that I could share with her some of the strategies I found on the web. She thought that was unusual for someone with dementia. She suggested to Dawn that, if this happened again, she should take me to the emergency ward in the hospital to get evaluated by a psychiatrist.

Dawn and I tried to tell the doctor that the erratic behaviour I had displayed was common in FTD. The doctor continued with her suggestion to go see a psychiatrist if it should happen again.

Dawn and I have already been down the long and winding road of working with psychiatrists to help in healing me and it is not the correct road. We will stay focused on moving towards the resources we believe can and will help us.

I realized today how incredibly important it is to not only be well-educated about FTD, but to also push back on individuals who we believe are not taking us on the right course of action.

When putting together a team to help me on my journey, I must have people onboard whose strategy I agree with. It is critical for my team to have synergy and listen to me. **■**

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All in the *Family*

How to help kids maintain a close relationship with a loved one who is living with dementia

BY Julia Williams PHOTO BY Laura Colpitts Photography

From Left: Krista Poole with her husband, Mark Schiefler, daughter Eva, father, John, and daughter Sophia.

One summer day, seven-year-old Eva Schiefler went outside to water the plants and was delighted when her granddad turned her chore into a family water fight. On another occasion, her granddad transformed a game of carpet bowling into a game of his own invention — bowling soccer. “Everything with my granddad is a surprise,” says Eva, who is now 12 years old. For those people who know and love him, the mischief, playfulness and laughter have always been a big part of who her granddad is.

Eva’s granddad, John Poole, was diagnosed with vascular dementia in 2012. As his illness has progressed, his daughter Krista Poole has made sure that her daughters, Eva and 15-year-old Sophia, remain involved in his life. Since John was a very involved grandparent, this was a natural thing. Krista and her husband, Mark Schiefler, knew from the beginning that they wanted to be open with their children about their granddad’s illness.

“As a family we made a decision early on to keep life as normal, active and happy as possible for my dad. We didn’t

want him to become defined or limited by his dementia diagnosis. Instead, we wanted to be open about it and to push boundaries to normalize dementia for those around us,” she says. “We informed ourselves; we talked a lot as a family about what was most important and what we found hardest. Sophia and Eva have definitely been on this journey with us and with Dad.”

No matter how John’s illness has changed his circumstances, the family has kept him closely connected, but it’s required them to be adaptable. For instance, they needed to rethink their fun, noisy dinner gatherings when it became clear that John was overwhelmed in these situations. When John, now 80, lost his ability to communicate clearly, the family needed to find new ways to communicate with him.

“We focus on making sure he has the best quality of life, and this means meeting him where he is at. He still smiles

“I don’t think I ever found a resource for children around dementia that was as valuable as our lived experience.” —Krista Poole

when we play balloon volleyball together, he likes getting outside and saying hello to passersby. There are still things we can enjoy together,” Krista says.

The Alzheimer Society of Canada estimates that 564,000 Canadians are currently living with dementia, and that 1.1 million people are affected directly or indirectly by the disease. Compared to other serious illnesses like cancer or multiple sclerosis, a dementia diagnosis can be a source of shame and stigma in a family; sometimes even the person who receives the diagnosis is reluctant to disclose or discuss it. When a disease is poorly understood by adults, it’s no surprise that kids can get left out entirely.

According to Sarah Salus, director of philanthropy and engagement for the Alzheimer Society of Calgary, reluctance to discuss dementia is rooted in a widespread lack of education about the disease. It’s a complex disease and sometimes people are not sure how to explain it to children.

“Some people are inclined to brush off a diagnosis or sweep it under the carpet,” she says. “If you try to hide it from your kids or prevent them from seeing that person [living with dementia], it is going to be weird for them.”

Krista included her daughters from the get-go, and, as things became more complicated, used a mixture of expert advice, common sense and advice from peers who’d had similar experiences. She says dementia-education resources helped the family overall, but didn’t really help inform them in how to involve their children. “I don’t think I ever found a resource for children around dementia

Water fight photo courtesy Krista Poole



John and Eva play in the yard.



that was as valuable as our lived experience,” Krista says. Her family has never focused on what her father is losing: John is still John.

“My dad still loves his family, a good meal and laughing. He still loves being active. That just looks very different now,” she says.

Gail Elliot, a leading gerontologist and dementia specialist, is the founder and CEO of DementiAbility Enterprises Inc., an Ontario-based organization that provides dementia-education resources including workshops, books and online tools for professionals, caregivers and people living with dementia. In 2012, Elliot co-authored an activity book called *Frank and Tess – Detectives!* for children aged five to nine who have a parent with frontotemporal degeneration dementia (FTD). The book includes age-appropriate scientific and behavioural information.

Elliot says a good place for families to start is at alzheimer.ca, which has some introductory information aimed at children.

Dementia is generally defined as loss of memory, but Elliot points out that memory is complex. That’s one reason why it’s difficult to come up with a one-size-fits-all best practice for teaching children (or indeed adults) about diseases that affect cognition — because these diseases manifest differently in different people. Typically, for a person living with dementia, their declarative memory (recalling facts and events) gets worse as it progresses, but procedural and emotional memory is usually spared much longer. Elliot says what a person was like in the past will usually be very similar to how they are in the present, depending on where and how severe the damage is in the brain. They still love the same people

Krista has also made this observation. Her daughters are less nervous than the adults are about trying new things and laughing when their granddad is around, and their laughter is contagious.

“The kids are often showing us what my dad is capable of still doing,” Krista says. As Eva puts it, “It’s kind of just seeing what our granddad likes to do, rather than forcing him into anything.”

Kids can even help ease some of the frustration that accompanies cognitive decline. Krista’s daughter Sophia was often better than adults in the room at understanding John when his communication challenges began.

“When he used an unusual word for something, we were stuck on that word, while Sophia was more in tune with the sentiment,” Krista says. “She would say something like, ‘Granddad’s sock is bothering him,’ and then a knowing look would travel between them. My dad looked so relieved that someone finally understood him.”

Sophia says she may have been less conscious of changes in her granddad than the adults were, which made it easier to handle what came up. “I wasn’t really looking for a difference,” Sophia says. “Eva and I have grown up with the idea that Granddad does have dementia. It’s what we’re used to.”

While there is no single way to involve children in the life of a person with dementia, Elliot says one thing is certain: when young people and people living with dementia interact, magic can happen.

Salus agrees. The Alzheimer Society of Calgary is working with high schools to get young adults to volunteer in the art program of Club 36, a day program for people with dementia. “That kind of experience is so valuable,” she says.

Salus feels hopeful when she sees younger children donating their birthday money to organizations like hers and weaving empathy and philanthropy into their lives. Dementia awareness is rising — and that’s good news for everyone, including children. ■

“Kids live more in the moment than adults do. Adults are always thinking, ‘What if I say the wrong thing?’ People with dementia tend to live more in the moment, too.” —Sarah Salus



Sarah Salus and her sons, Matthew (left) and Oliver.

and can often perform practiced skills such as reading, baking or working on a car, but, as Krista observed, these skills may look different or take longer.

Elliot uses what she calls the WOW model to teach people how to interact with someone living with dementia in a positive way: **W**ho is the person, past and present? **O**bservations? **W**hat are you going to do?

In this, children may have a natural advantage. Salus notices this ability to be present in her own sons, ages 10 and 12, when they interact with their great-grandmother, who is living with dementia.

“Kids live more in the moment than adults do. Adults are always thinking, ‘What if I say the wrong thing?’” Salus says. “People with dementia tend to live more in the moment, too.”

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Q + A

Agnes Houston shares how her dementia diagnosis disrupted her sensory experience

BY Elizabeth Chorney-Booth PHOTOGRAPHY BY Marc Millar

WHEN AGNES HOUSTON was first diagnosed with early onset dementia 13 years ago at the age of 57, she knew that memory loss was inevitable, but she didn't expect her sensory experience to be disrupted. Early into her diagnoses, Houston started experiencing intense changes with her vision, hearing, taste and other senses — she was constantly hit with a sensory overload that made coping with dementia even more difficult than she'd imagined.

Not getting answers from her doctors, Houston took to learning more about how dementia can affect one's senses, earning a Churchill Fellowship research grant to travel from her home in the U.K. to explore the topic in Canada and Ireland. This spring, Houston published a book titled *Talking Sense: Living with Sensory Changes and Dementia*, co-written by Dr. Julie Christie. Here, Houston explains how sensory changes can confuse and overwhelm people living with dementia, often affecting their ability to socialize and enjoy life.

Q | In your experience, are most people unaware that dementia can affect people's senses in addition to memory?

A | I've found that professionals in both the vision field and the auditory field don't know that people with dementia can have sensory issues. The professionals and nurses in the dementia world aren't knowledgeable about it either. That's what made me go on this quest — I was being told by the professionals who were looking after my dementia that my sensory issues had nothing to do with dementia. But I was meeting other people with dementia and they were having similar symptoms and getting no help, so I knew that something wasn't right.

Q | How do these sensory changes affect day-to-day life?

A | It's sensory overload — the brain is being forced to make sense of too much. Crossing the road is a challenge, for example. Alongside the noisy traffic, the weather and environment make it difficult to judge the speed of traffic and I've been bumped by a car. Going into noisy environments like diners or cafés is difficult because the scraping of chairs on hard surfaces, the coffee percolators, and the chatter and music

build up and I cannot think. These experiences were making me isolate myself and I was losing connection to family gatherings, coffee times with my gym buddies, and my ties to my neighbourhood and local community.

Q | Dementia always requires people to make many adjustments to their lives. What are some adjustments that are related specifically to these sensory issues?

A | I use adaptations and aids. My audiologist made me a mould for my ear — it's like putting your hands over your ears and takes away a lot of the noise. I also got noise-cancellation headphones, which help with conversations. If I go to a restaurant, I'll ask them if they've got a quiet place, and tell them why. If you're caring for someone, phone up and ask when the quietest time is and book a quiet table. That way you're creating a safe environment to have a family meal or a nice meal with your pal.

For sensory changes related to taste and [resulting] food likes and dislikes, I keep a food diary. I try to have fun with it and when I go out for coffee, I'll try different drinks to see if I could expand my choices. That helps me feel like I have some control over it.

Q | What can health-care professionals do to support people living with sensory changes?

A | Professionals need to listen to the person with dementia and discuss what action they can take so that the person can live the life they want to. I've been dealing with this for 13 years now, and when I started, I felt like the lone voice, but I'm not the lone voice anymore. We just need the research done to back it up — that's the next step, research to prove that this is what we're going through. ▣



To learn more about sensory changes related to the dementia experience, you can access a free, downloadable copy of *Talking Sense* at dementiacentre.com.

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

DID YOU KNOW? *The Edmonton Philharmonic Orchestra's Spring Concert is an inclusive evening of live music. Held on March 16 from 7 to 8 p.m. in the main auditorium at the Edmonton General Hospital, the concert showcases dance music such as the waltz and the tango. Guests, including families and people living with dementia, are invited to move freely about the space or sit and enjoy the music. Learn more at edmontonphilharmonic.com.*

SAYING “Yes”

Mark Johnson was the primary caregiver and support for his wife, Shirlianne, who was living with dementia. Choosing to move past stigma, they both found hope, energy and comfort in connecting with friends and playing an active role in their community. Here, in his own words, Mark reflects on his experience loving and caring for Shirlianne (Shirl) before she passed away in 2014.

Normally, I am asked to talk about Shirl’s diagnosis and the clinical side of her care. Also, the experience of home care and when Shirl moved into assisted living and the emotions that go with making those decisions.

But there is a big piece to this disease that few people talk about: the importance of community and building a grassroots dementia-friendly community. This is key, because after seeing the doctor for 30 minutes every six months, the other five months, 29 days and 23 hours were spent living in our community.

Asking for Help

When Shirl was first diagnosed, I found both of us withdrawing. We stopped going to things like company barbecues, parties and

get-togethers. We were unsure of how to approach the topic of Shirl’s diagnosis. Shirl was worried that people would think she was strange and certainly we had some self-imposed stigma about her disease.

We would use any excuse to avoid being around people. And if people asked us how we were doing and if we needed help, we would say, “No! We’re fine.”

Saying “Yes”

I had been asked to play soccer with a team and I turned it down because I didn’t feel it was appropriate leaving Shirl for long periods, but I really wanted to play. Then, one day, when I was coming home from work, my next-door neighbour Marilyn asked if she could help. But this time, instead of saying, “No, I am okay,” I said “Yes.” If Marilyn could sit in with

Shirl for an hour each Friday evening, I could go and play soccer.

Marilynn, being Marilyn, suggested I stay a bit longer and have a beer with the guys. So, every Friday, I would pick up cakes and make a pot of tea, and Shirl and Marilyn would sit down and watch *Say Yes to the Dress*. Meanwhile, I would run like crazy chasing a ball and then have a beer. This small thing worked so well and helped me so much. It was an amazing respite. And Shirl and Marilyn enjoyed one another so much that when I came home, Shirl would sometimes say, “Oh, you’re home?” like the fun had come to an end.

When you play soccer, there can be lots of functions to go to, but I was still hesitant to attend. When I explained that we couldn’t go because it could be awkward with Shirl’s diagnosis, my team said,

Shirlianne and
Mark Johnson.



“No!” The team said they would work at making Shirl feel comfortable and would understand what to do to make sure she had a good time. They were clear that, whether Shirl lasted 15 minutes or three hours, it wasn’t an issue.

Widening Support

Two of the guys from my soccer team knew Shirl because she

would walk around the area with our little black dog, Ossie. They said they’d keep watch to make sure Shirl and Ossie were okay. That gave me the idea to get photocopies of Shirl and Ossie done, clip my business card to the paper and give it out along Shirl and Ossie’s walking route.

After that, sometimes we would go for a walk together and people

would wave and say, “Hi, Shirl.” I would ask, “Do you know these people?” Shirl would say, “No, but they’re nice,” and wave back.

Sharing Support

Our friends from B.C. didn’t shy away from us either, because they knew Shirl well. Every January, we would go to Mexico with them for two weeks and have lots of



Shirlianne and her dog, Ossie.



Everyone I met on this journey wanted to do the right thing for Shirl, and that's what I draw strength from.

fun. For us, there was also the benefit of their shared support for Shirl's care. In the summer, we would also go to their house in B.C. and even took a few trips to California and Vancouver Island. It was the best respite ever! To be around friends and also share in the responsibilities for Shirl made me feel really good.

Finding Perspective

There was plenty of stress and fear that went with this diagnosis, but the people around us, and the Alzheimer Society, helped me and made me more resilient.

I remember a psych nurse coming to the house once and giving Shirl a cognitive test. Afterwards, the nurse said that Shirl had done so badly on the mini mental and Montreal Cognitive Assessment tests that I should look at long-term

care. The nurse said it was time. When the nurse left, I called the Alzheimer Society and they suggested that I look at how Shirl was functioning and not the test.

So, I decided we needed a holiday away. I booked four weeks back home in England and two weeks in Mexico.

Living Well

I wanted Shirl to live well with dementia and I believed that could only happen if people around her lived well with her dementia, too, and they did! People around Shirl were patient and understanding and that helped me keep her at home a lot longer, probably 12 to 16 months longer.

When Shirl did go into long-term care, she went downhill really fast and passed away 18 months later. I believe that Shirl went downhill

because she lost the things that mattered to her most: Ossie, me, her friends, her community and engagement with that community. And on a personal level, I was no longer resilient — I was broken.

Coming Full Circle

Sometimes, we look for solutions in four-storey care homes and not among the grassroots of our community. Today, I am very lucky to work for the Alzheimer Society of Alberta and Northwest Territories and see the effects of community in my job.

One day, a gentleman named Jim phoned me at the society. He wanted information, as his friend had just been diagnosed and Jim was determined to understand how he could better engage with and support his friend. As I was getting his address to send a package out, I realized he lived on my street. Without prompting him, he told me a story about a young lady on his street who had been diagnosed with Alzheimer's and her little black dog. Jim said, "I would always wave and say 'hi' and tell her what a nice little dog she had." He said he wished he'd understood more about her experience, as he wanted to be more helpful to her.

Everyone I met on this journey wanted to do the right thing for Shirl, and that's what I draw strength from. We need to continue to educate our communities and build a positive experience for people to live within them. ▣

DID YOU KNOW? *Opened in 2015, Memory & Company in Markham, Ont., is the first boutique respite hotel in the world designed specifically for people living with dementia. The hotel offers 24/7 supervision by trained support staff and nurses as well as gourmet meals and activities such as movie nights, animal visits, fitness and more. Learn more at memoryandcompany.com.*

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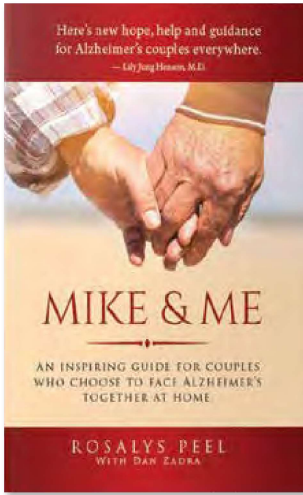
This not-for-profit organisation is run by people living with dementia for people with dementia.

DAI provides hope; hope to reclaim your pre-diagnosis life. Peer-to-peer groups where you can meet and talk to other people who have been Prescribed Disengagement® upon diagnosis, plus online cafes and educational webinars.

DAI is free to join, so have a look at our website and become a member. www.join dai.org

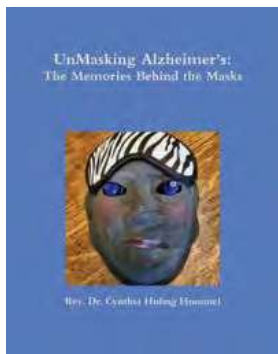


4 BOOKS TO READ TODAY



Mike & Me: An Inspiring Guide for Couples Who Choose to Face Alzheimer's Together at Home by Rosalys Peel

When Rosalys Peel's husband, Mike, was diagnosed with Alzheimer's disease, she couldn't find any "couples" resource books to help them keep Mike at home and out of a care facility. So, she wrote her own. *Mike & Me* highlights how to approach each day living with, as opposed to dying from, Alzheimer's. For 10 years after Mike's diagnosis, he and Rosalys travelled, raised their granddaughter, maintained their romance and found new ways to communicate. This practical and inspiring book offers new perspectives on how to live well with dementia.



UNMASKING ALZHEIMER'S: THE MEMORIES BEHIND THE MASKS

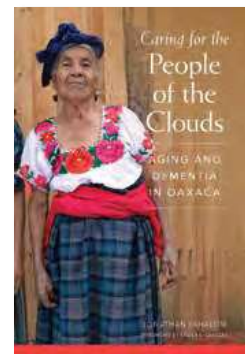
by Rev. Dr. Cynthia Huling Hummel

Written by retired Presbyterian minister Rev. Dr. Cynthia Huling Hummel, this self-published book is a collection of photographs that feature 36 masks Hummel created along with her reflections on, and hopes for, how to live well after an Alzheimer's diagnosis. Hummel, who holds a doctorate in ministry, was diagnosed with mild cognitive impairment in 2011, which has since progressed to Alzheimer's disease. As a vocal advocate for Alzheimer's research, she regularly participates in clinical studies and encourages others to do the same. Half of the proceeds from the sale of *UnMasking Alzheimer's* will be donated to the Alzheimer's Association.



BIRD-BENT GRASS: A MEMOIR, IN PIECES by Kathleen Venema

In 1986, Kathleen Venema accepted a teaching assignment in Uganda. While she was there, her mother, Geeske Venema-de Jong, promised to write her letters. Throughout the late 1980s, Kathleen and her mother exchanged some 200 letters. Twenty years later, Geeske was diagnosed with Alzheimer's disease and the letters became a tool for Kathleen to help prompt Geeske's memory and continue to nurture her intellect and curiosity. Through excerpts from their letters, as well as conversations, journal entries and emails, *Bird-Bent Grass* offers a complex and moving exploration of memory, illness, love and connection.



CARING FOR THE PEOPLE OF THE CLOUDS: AGING AND DEMENTIA IN OAXACA by Jonathan Yahalom

In psychologist Jonathan Yahalom's book, *Caring for the People of the Clouds*, he explores how family caregivers approach caring for a family member living with dementia in rural Mexico. Specifically, Yahalom reveals his research on the Zapotec people, or "People of the Clouds," an Indigenous group who live in eastern and southern Oaxaca, Mexico. Yahalom reveals that in rural Mexico, it's believed that Alzheimer's doesn't exist because local people lack the stresses that people in the modern world face. *Caring for the People of the Clouds* explores how the Zapotec people care for their "forgetful elders." 📖



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A HEAD START

BY Sean P. Young

New technologies are empowering people living with dementia



1 Embodied Labs
Erin Washington, co-founder and head of customer experience at Embodied Labs, used her personal life as fuel to help create a virtual reality experience that lets caregivers see what life is like with dementia. Washington and her younger sister, Carrie Shaw (also Embod-

ied Labs' CEO and founder), were care partners though most of their 20s for their mother, who was diagnosed with early onset Alzheimer's disease at age 50.

"One thing that we always wondered was, 'What was this disease like from her point of view?'" Washington says. "And, if we could experience [that] from

a sensory point of view, how could that make us better care partners?"

Family caregivers and professionals and students at long-term care facilities and academic organizations can now experience a snapshot of life with dementia using Embodied Labs virtual reality (VR) technology.

First, users take a pre-assessment about their existing knowledge of dementia. Then, they log onto Embodied Labs' platform, put on a VR headset and take a six-to-nine-minute journey as Dima, a Lebanese American immigrant living with symptoms of Lewy body dementia and Parkinson's disease, or Beatriz, a middle-aged woman, as she progresses through early, middle, and late stages of Alzheimer's disease. Afterwards, users reflect on how the VR experience changes their understanding of dementia.

Washington says people who have undergone the experience often report big improvements to their care practice.

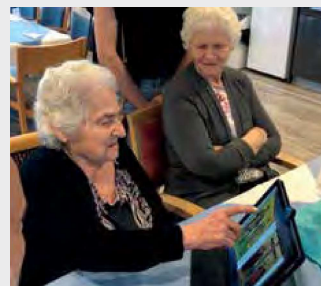
"They better understand why the person [living with dementia] might be irritated or agitated, making them more patient, insightful and understanding in their approach to care," she says.

Learn more at embodiedlabs.com

2 Deva World by Mentia
Deva World creates a virtual-gaming experience designed specifically for individuals living with cognitive impairment — and it does not require VR headsets. People living with dementia and their care partners can visit *Deva World* via tablet, where the objects they interact with are specific to the user — music they love can be preloaded onto the record player; artwork they admire is displayed on the walls; even the photos inside the albums are from the player's past.

As the player and their caregiver interact with the objects in *Deva World*, real-world connections are strengthened.

"Everything inside the world is grounded on enrichment strategies for well-being that you would expect to get in a high-end care



environment," says Mentia CEO and co-founder of *Deva World*, Mandy Salomon.

The experiences in *Deva World* are informed by dementia-care best practices and the goal is to create a sense of agency in the player through interacting with objects and places and seeing the results of their actions. Salomon says the caregiver also gains a better understanding of the person behind the disease.

For more information, visit Mentia.me

3 Careteam

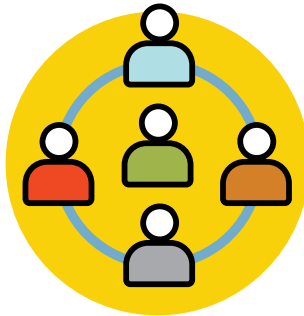
Careteam is a new type of health-care collaboration platform that brings the user, their health-care providers and personal support team together.

“You see a patient in the appointment room for a few minutes, but what really matters is all these moments in between and what people do with the information provided at the appointments,” says Dr. Alexandra T. Greenhill, founder, CEO and chief medical officer at Careteam Technologies.

Greenhill created Careteam to enable health-care providers to more efficiently coordinate care and support patients between hospital, home and community settings.

The platform securely stores, organizes and updates the user’s care plan and allows them to create a flexible team of people who can all help the user stay on track with their health goals.

The clinical team can share information with



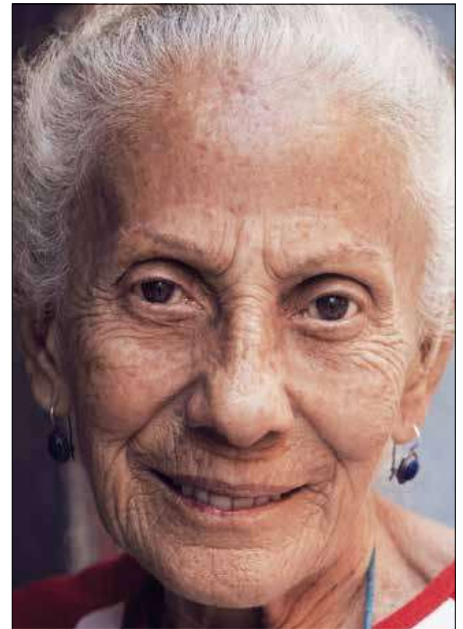
everyone on the user’s care team and can track the team’s progress in completing assigned tasks. Staying on track and handling the “grunt work” between visits

greatly improves a person living with dementia’s quality of life and gives family members and caregivers a focused sense of purpose.

“An example of this is when a person is first diagnosed with dementia. While they wait to see a specialist, that specialist can send them a list of things that everyone can help with,” Greenhill says. “[Things like] getting the MedicAlert bracelet or a checklist on how to ensure that the house is safe.”

Currently, the platform has been rolled out at four hospitals in Ontario and British Columbia.

Learn more at careteam.tech



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4 HAnalytics Solutions

When Shaneel Pathak’s wife, Heing, was diagnosed with stage 4 cancer six years ago, he witnessed the power effective information management had on her experience.

“We had a lot of information chaos going on at the time,” Pathak says. “But she was tracking all her information, analyzing it, graphing it, taking photos — and all this helped her, not just to improve quality of life, but also in the treatment decisions.”

Inspired, Pathak and his business partner, Cory Kapsner, created HAnalytics Solutions, a Health Analytics platform, in 2015.

HAnalytics’ suite of tools includes an easy-to-use journal module where users and their caregivers can log symptoms, metrics, lab results and side-effects. Pathak says the journal produces reports that can be shared



with health practitioners.

“It makes the conversation easier with your practitioner because patient-derived information is readily available, so you don’t have to recall it from your memory, which is what most people do,” he says.

The second component of the tool is a health library application that allows users to bookmark relevant disease information to better understand the best treatment options available for their specific symptoms. The tool can also be used to connect

with peers who are also living with dementia to discuss commonalities.

Users can also grant secure access to caregivers for help managing their care. [V]

Learn more at hanalyticssolutions.ca



Spotlight on *Care*

These two Canadian researchers are improving quality of life for people living with dementia

BY Kaitlyn Hanson PHOTOGRAPHY BY ◀ Laughing Dog Photography AND Kiriako Iatridis ▶

DR. CAROLE ESTABROOKS

Dr. Carole Estabrooks, professor in the faculty of nursing at the University of Alberta and the scientific director of Translating Research in Elder Care (TREC) program, is passionate about improving the quality of long-term care in Canadian nursing homes with a focus on the four western provinces.

“Nursing homes, I would argue, have probably the most vulnerable citizens in society — even more vulnerable than children, because, in many ways, they often don’t have their advocates anymore,” says Estabrooks.

An increasing number of older adults enter a care facility later than they may have 10 or 20 years ago, and this creates an increasingly complex and dependent population living in long-term care.

“People are coming later and later into nursing homes,” Estabrooks says. “They are coming further along in their journey, their dementia is more severe and other chronic illnesses are taking their toll.”

Adding to that complexity is the fact that many care aides also constitute a vulnerable population. In urban areas, more than half of care aides have immigrated to Canada and speak English as a second language. The workforce is predominantly female and, on average, is older than in other health-care settings. Also, almost 30 per cent of the care aides in Alberta specifically hold more than one job.

“You have this highly vulnerable population of people in nursing homes being looked after by another potentially vulnerable population,” Estabrooks says.

Created in 2007, TREC is an ongoing multidisciplinary, multi-site research program situated in

Alberta, B.C. and Manitoba, but with individual studies in a number of provinces and team members from across the world.

The program explores how to improve quality of care and quality of life for long-term care residents, enrich the work life of care aides and enhance efficiency. As part of its research, TREC is involved in multiple projects, including a large observational and longitudinal study, randomized controlled trials, and network studies. It also has a number of advisory committees.

To gain insight into ensuring resident and care-aide well-being, TREC’s longitudinal TREC Measurement System (TMS) has been collecting data on residents, staff, care units and facilities since 2007. In addition to quarterly standardized observations on functional and clinical outcomes for nursing home residents, regular surveys and interviews are carried out with front-line staff to assess their general physical and mental health, as well as the quality of their work life and work environment. The data collected from TMS is being used to continue to understand and improve the long-term care sector, create best strategies and inform policy.

Many front-line staff members have valuable experiential knowledge that is not always utilized to its full potential, which is where TREC’s randomized controlled





DR. THOMAS HADJISTAVROPOULOS

For Dr. Thomas Hadjistavropoulos, improving the quality of life for people living with dementia has long been a priority — and the key, he says, may lie in more effective management of pain.

Hadjistavropoulos, who is a registered doctoral psychologist and the Research Chair in Aging and Health at the University of Regina, where he is also a professor of psychology, says that when individuals living with severe dementia experience pain, it is often missed or undertreated.

Further complicating the issue, he adds, is the fact many consider the self-report of pain to be the “gold standard” for making decisions about pain management.

“Dementia, when it progresses, leads to a decline in both cognitive and linguistic abilities,” he explains. “People cannot report the pain, and the signs of pain can be misattributed to other causes, then we have unnecessary suffering.”

Hadjistavropoulos has focused his research primarily on pain assessment, and his research team developed the Pain Assessment Checklist for Seniors With Limited Ability to Communicate (PACSLAC). The specialized assessment tool, which is now in its second version, has been utilized by professional caregivers of older adults living with severe dementia for more than a decade.

“We have shown that when [a pain-assessment tool] is used regularly by staff, pain levels go down in the residents because pain is identified and presumably treated,” he says.

→ trials, such as Safer Care for Older Persons (in residential) Environments (SCOPE), can provide a useful framework for support.

To participate in SCOPE, units appoint care aides to lead local improvement teams, and provide them with support as they work with the research team and other local teams over a 12-month period to implement local quality-improvement initiatives, learn about measuring progress, etc. A SCOPE pilot study (phase one of a larger trial), that concluded in February 2017, involved care aides from seven different nursing homes in Manitoba.

Participants worked in teams to make improvements in the areas related to residents’ mobility, pain or responsive behaviours of dementia. The pilot study indicated that care home residents benefited from initiatives that encouraged them to move more, and that care aides gained greater confidence in their work.

“We’ve had astonishing success with it,” says Estabrooks. “We observe improvements in empowerment and engagement, and [care aides] start to solve problems that are meaningful to them and the residents.”

“You have this highly vulnerable population of people in nursing homes being looked after by another potentially vulnerable population.” —Dr. Carole Estabrooks

The team also developed several guidelines about the frequency of pain assessment and the timelines of treatment. Assessments should be carried out a minimum of once per week by caregivers, and more frequently if pain is suspected.

Hadjistavropoulos says that while caregivers in long-term care understand the benefits of regular assessments, they have also expressed challenges in carrying them out at the recommended frequency.

“They say, ‘We’d love to do it a minimum of once a week, but we don’t have the resources to do it. We don’t have the nursing staff to do it,’” Hadjistavropoulos says.

The notion that resources can be an obstacle to carrying out regular pain assessments was the inspiration for his current project, an automated pain-detection system.

The plan is that the vision system will be positioned in a care home resident’s room and use an artificial-intelligence system programmed to recognize common behaviours in people who are experiencing severe pain.

Because a person living with severe dementia may not be able to communicate the pain they are experiencing verbally, the vision system will be able to recognize grimaces and other facial expressions associated with pain. It will then alert the nursing station to check on the resident when those behaviours are identified.

Although the idea of using computer vision to identify pain behaviours is not a new one, Hadjistavropoulos says researchers in the past have struggled to create an algorithm that works in less-than-ideal conditions, such as when patients may not be facing the camera directly.

“People [with dementia] cannot report the pain and the signs of pain can be misattributed to other causes.”

—Dr. Thomas Hadjistavropoulos




“We wanted something that would work as people go about their daily routines,” he explains, adding that his partner and co-lead on the project, Toronto Rehabilitation Institute scientist Dr. Babak Taati, is making further calibrations to the algorithm so that it is better able to distinguish between facial expressions, such as grimaces or frowning, and the features of older patients, such as wrinkles.

Although the system will involve cameras, it will not record the patients as they go about their regular activities. Instead, it will process the images as they are captured by the camera and will analyze them for signs of pain.

“It will be very similar to a heart rate monitor that keeps track of how often your heart is beating,

but does not keep any information about what you were doing while your heart rate was increasing or decreasing,” he says.

The work is supported by the AGE-WELL Network of Centres of Excellence. Hadjistavropoulos hopes that a prototype of the pain-recognition technology will be ready for field testing within the next year.

As part of his work toward improving pain care for seniors with dementia, Hadjistavropoulos has also launched a campaign aimed at sharing evidence-based information about pain assessment. 

More information can be found at seepainmoreclearly.org or on Twitter using the hashtag #SeePainMoreClearly

Small Cooperative *Living*

These smaller housing models make a big impact



BY Shannon Cleary

Before Faye Kirbyson, an older adult living with dementia, moved into a Daughter on Call elder care home in Brandon, Man., she was not eating. It was one of the concerns Faye’s family brought to Gail Freeman-Campbell, the organization’s founder and CEO. In those first few days, while the other five residents engaged in grocery planning and shop-

ping, or potato peeling and mashing, Faye declined her seat at the “family” table. At first, instead, she walked non-stop until she was exhausted. After about a year in the home, Faye would sit in front of the TV and staff would bring her food to eat there.

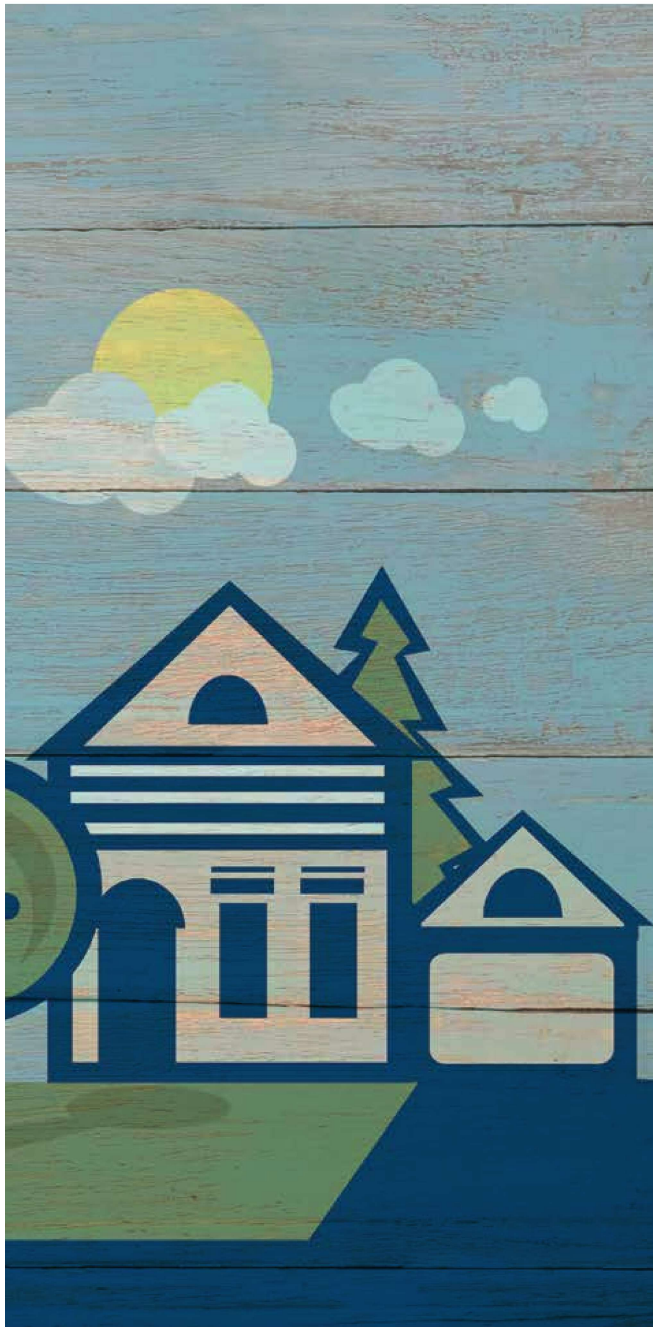
It’s common for people living with dementia to refuse to eat, to be able to sit still long enough to eat, or to eat a balanced diet on their own. What’s

unique to each individual, Freeman-Campbell says, is the need that is not being met.

What was Faye’s unmet need?

“Turns out, she used to be extremely physically active,” says Freeman-Campbell. “She had a purpose to move.”

Care providers, who staff the Daughter on Call care home 24/7, began leaving fresh food on the kitchen counter, encouraging Faye to eat as she moved



Facing page: iStock/DistinctiveDesign; this page courtesy ExquisiCare Inc.

around her home throughout the day.

“We called it ‘Faye’s Perch,’” says Freeman-Campbell. It worked. This simple accommodation empowered Faye to eat and be active on her own terms.

Faye is a resident — and the namesake — of Kirbyson Home, Daughter on Call’s first cooperative elder care home. The 3,000-square-foot bungalow was purpose built in 2017 in a residential community in Brandon. It has six private bedrooms,

“I just don’t buy that because someone has health-care needs, they need to be in a large environment.”
—Dawn Harsch

each with an ensuite bathroom, and a shared kitchen, living room, dining room, fenced yard, garden and hair salon. Kirbyson Home is one of five Daughter on Call elder care homes currently accepting residents, with six more similar bungalows under construction in Manitoba. Freeman-Campbell’s waitlist includes families with immediate needs, those who are anticipating an eventual need, older adults who submit an application pre-emptively on their own behalf and more.

“People want options,” she says. “As long as my phone is ringing, I will keep expanding.”

Small-Scale Living

When we imagine long-term health care for our aging population, we’re more likely to think of a hospital-like setting than a home in a residential neighbourhood. But many care homes are challenging that assumption, including ExquisiCare Senior Living in Edmonton. ExquisiCare has three 10-bedroom estate homes in the Edmonton area, two of which are specifically designed for people living with dementia.

When Dawn Harsch, president and CEO of ExquisiCare, was in nursing school studying to become an RN, she worked in a long-term care ward with six beds to a room, separated by curtains. Harsch remembers thinking, “There’s got to be a better way than this.”

Harsch says care home models like ExquisiCare provide the same high quality of care, safety and innovation as traditional models, accommodating resi-



ExquisiCare Senior Living in Edmonton has three 10-bedroom estate homes.

dents at the beginning of their dementia journey to end-of-life, all while keeping seniors in the community.

“I just don’t buy that because someone has health-care needs, they need to be in a large environment,” says Harsch.

In a smaller environment, we are more accountable for one another and our seniors can live more purposefully. At one of her Edmonton homes, Harsch describes a gentleman who carries the groceries in from the driveway, which she discovered is something he had done in his own home for decades. When prospective families arrive to tour the house, he proudly embodies the role of host.

“He clearly feels like it’s his home,” she says.



“Yes, their needs are met. But there’s more to their world than just needs.” —Tamar Krebs

Rhythm of a Home

Most households have a familiar rhythm. Its cues are much more familiar to us than those of a larger, institutional environment. Small cooperative-living models seek to reinforce these cues and integrate residents into the running of the home to the extent they are interested and capable. Some residents enjoy meal planning and prep, others might fold laundry, garden or, in the case of some Daughter on Call homes, care for the home’s companion dog.

The shared living spaces are open to everyone, but tasks are completely optional. For residents who are further along in their dementia journey, the sensory stimulations in a home-like setting still have therapeutic meaning: the smell of a meal as it is being prepared can increase appetite and the flexibility

of a household schedule can allow for more personalized eating, sleeping and activity patterns.

Be Our Guest

The move into full-time care is a vulnerable time for families. Small care homes can remove the friction that visiting a large facility may cause and often allow guests to visit at any time. Often there are no specified visiting hours, and families not only get to know the other residents, but also the other families and caregivers in what can otherwise be an isolating experience.

Global Initiatives

As the proportion of older adults grows in every population around the world, so does society’s motivation to reimagine senior living. Reigershoeve,

in the Netherlands, is a smaller-scale model for people living with dementia, with four group homes of six to seven residents on a small Dutch farm.

In the United States, The Green House Project partners with health-care providers to transform the way we create long-term and post-acute care. Its mission to “eradicate institutional models, destigmatize aging, and humanize care” has inspired care models around the world.

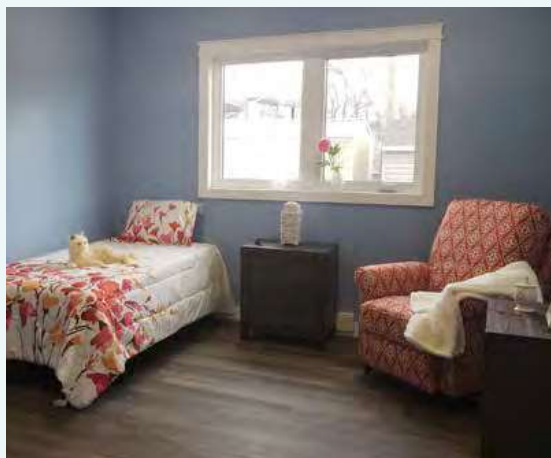
Purposeful Living

Tamar Krebs is the founder and Co-CEO of Group Homes Australia, which has 11 care homes, each with between six and 10 residents and a high carer-to-resident ratio.

The homes are equipped to provide modern medical care, but are designed with period-sensitive decor.

“The visual environment is part of the therapy itself,” says Krebs.

The shared living spaces encourage



THREE BENEFITS OF SMALL HOUSING:

Empowerment

A home-like setting allows residents to participate in the day-to-day rhythm of a household, and is an opportunity to provide purpose and value.

Personalization

Private bedrooms, bathrooms and even the shared living spaces are decorated as a home first. Residents can personalize their space while still accommodating medical equipment as needed.

Community

Building small cooperative homes in our communities destigmatizes aging and allows older adults to live in the communities they helped to build.



Group Homes Australia encourages residents to engage in day-to-day activities.

“A lot of things that we do in a hospital can be done in a home.”—Erik Landriault

socialization and allow residents to engage in the day-to-day activities that bring them purpose and meaning. Krebs believes it’s important for seniors to live in an environment based on their common interests and hobbies, rather than just medical needs.

“Yes, their needs are met. But there’s more to their world than just needs,” says Krebs.

Is Small-Scale Living for Everyone?

Breaking our idea of the traditional health-care model can be challenging for some families. Daughter on Call CEO Freeman-Campbell says that some families sometimes still want a medical model, with uniformed staff and routines based on clinical care.

“We’re conditioned to fix, and, when we can’t fix, we think it’s a failure,” says Freeman-Campbell.

Small-scale living can also feel very intimate — while residents have personalized, private bedrooms and bathrooms, the shared living spaces are meant to foster social connectivity and interaction. Freeman-Campbell watches closely for signs that new residents are adjusting, such as taking part in household tasks and activities.

“Then we know they’ve accepted it as a home,” she says.

The Future of Care

Society in general has become less accepting of the institutionalized model of care. In fact, personalized care and home-like settings are increasingly being

incorporated into large-scale facilities.

Erik Landriault is the former director of innovation at SE Health in Toronto. SE Health is a national social enterprise providing home care, health solutions and health education. Landriault’s former team, SE Futures, explores the “home-hospital” model of care. SE Futures supports health innovations that disrupt the idea that good care must only be equated with a hospital.

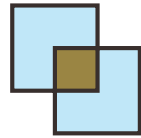
“A lot of things that we do in a hospital can be done in a home,” says Landriault. Traditionally, medical care required expensive technologies, and highly trained individuals to operate those technologies. With so many advancements in technology, surgeries and community supports, Landriault says a future where seniors feel empowered to age at home is possible.

“There is an increasing awareness that it benefits everyone to shift power back into the community,” he says.

Community Asset

In Edmonton, one of the most rewarding impacts Harsch has witnessed is how neighbours have embraced care homes in their communities. She expected a small amount of NIMBY-ism (an acronym for “Not in My Back Yard”), but her fear has been assuaged by the positive response in the Edmonton communities. Residents are getting to know their neighbours and are empowered to feel like part of a community, not excluded from it. At Halloween, a favourite time of year in the care home, ExquisiCare residents hand out full-size candy bars to trick-or-treaters.

“Seniors are craving love and respect,” says Harsch, something she feels is uniquely provided in small-scale living. “It allows our seniors to live in and enjoy the communities they worked so hard to create.”



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The Dementia Experience *Around the World*

According to Alzheimer's Disease International: "Someone in the world develops dementia every 3 seconds." In 2017, that translated to close to 50 million people across the world living with dementia. It is a disease that doesn't discriminate — every single country in the world is impacted by it. Diagnosis may be on the rise, but so too is global awareness of it. Currently, there are 32 national dementia plans, which the World Health Organization would like to increase to 146 by 2025. Now, more than ever, people living with dementia are speaking out to reduce stigma and advocate for their rights, long-term care facilities are challenging traditional care models to increase quality of life for residents, and bright minds across the world are hard at work to find a cure. From global organizations fuelling research to people living with dementia navigating multiple languages, we take a closer look at dementia across the globe.



Global Statistics

A snapshot of the international numbers and specifics related to dementia today



Canada

1 in 5 Canadians have experience caring for someone living with dementia.

564,000+ Canadians are living with dementia.

25,000 The estimated number of new cases of dementia being diagnosed in Canada annually.

\$10.4 billion The annual cost to Canadians to care for those living with dementia.

65%  of people diagnosed with dementia over the age of 65 are women.

U.S.

6 Alzheimer's disease is the 6th leading cause of death in the U.S.

5.8 million Americans are currently living with dementia.

16 million+ Americans provide unpaid care to people living with dementia.

Mexico

3.5 million The projected number of people in Mexico who will be living with dementia by the year 2050.

Costa Rica

2014 The year Costa Rica launched a national Alzheimer plan, the first low- or middle-income country to do so.

Argentina

5 Alzheimer's is the fifth-leading cause of death in Argentina.
2016 The year Argentina launched the National Strategic Plan for a Healthy Brain, AD and other Dementias. It was the first plan in Latin America to focus primarily on risk reduction.

G20



Dementia featured heavily at the G20 Health Ministers Meeting held this past October in Okayama, Japan. The meeting brought together health ministers from 19 countries and the European Union, along with guest countries and organizations, to discuss high-priority issues of global health. All members committed to addressing the biggest health and social crisis the world faces today: dementia. The resulting Okayama Declaration of the G20 Health Ministers Meeting included several vital commitments around dementia. **ARTICLE 29** of the document states: *“We commit to developing and implementing multi-sectoral national action plans, adopting integrated approaches on dementia in line with the Global Action Plan to improve the quality of care and the quality of life of people with dementia, their families and caregivers.”* **ARTICLE 30** addresses prevention, early detection, diagnosis, intervention and strengthening primary health care, as well as supporting healthy aging. *“We also recognize the importance of including older persons with disabilities in efforts to support healthy and active aging, including the provision of social and health services in line with the UN Convention on the Rights of Persons with Disabilities.”*

Asia

2015 The year Japan spearheaded its New Orange Plan for dementia, which includes campaigns to raise public awareness and create trained “dementia supporters” within communities.

9.8 million The number of people living with dementia in 2015 in east Asia, the highest rate in the world.

1 in 5 people in Japan are projected to be living with dementia by 2025.

Scotland

In **2018**, Scotland’s Dementia Champions Programme was named one of the U.K.’s best breakthroughs for its impact on people’s everyday lives. The intensive eight-month program teaches health and social-care professionals to see, hear and feel the experiences of people living with dementia by working closely with them, their caregivers and families. Today, there are more than 850 Dementia Champions working in Scotland.

Europe

15% is what the Netherlands, a world leader in elder care, spends of its gross national product on health care, including elder care.

2001 The year that France launched Europe’s first national dementia plan.

7.5 million the number of people living with dementia in western Europe, the second highest in the world.



Africa

7 The number of developing countries that STRiDE (Strengthening responses to dementia in developing countries initiative) is building research capacity and providing evidence on dementia care for, including two in Africa, South Africa and Kenya.

Australia

2005 Australia was one of the first countries in the world to create a national dementia plan when it launched *Dementia Initiative – making Dementia a National Health Priority* in 2005.

447,115

Australians are living with dementia.

1.5 million Australians are involved in caring for someone living with dementia.





Dementia Care

With the number of people in the world living with dementia projected to reach 82 million by 2030, the need for creative approaches to enhancing quality of life grows ever stronger. These eight approaches from around the globe are an example of some of the innovative ways to offer quality care to individuals with dementia.



Intergenerational living in the Netherlands.



Netherlands

Intergenerational Living in Care Homes

In 2012, Gea Sijpkens, CEO of the Humanitas care home in Deventer, Netherlands, invited university students to live at the care home among the elderly residents, rent-free. The only condition: students had to socialize and be generally neighbourly with the older residents for a minimum of 30 hours per month. That could include preparing meals for residents, taking them around town on a recumbent tandem bike, and simply chatting, telling stories and sharing quality time together.

Today, six students live in Humanitas alongside more than 100 elderly residents, about 70 per cent of whom live with dementia.



United Kingdom

Sharing a Love of Literature

Dr. Johanna Harris, a senior lecturer in the English department at the University of Exeter, knows the power of a good story. In 2011, she pioneered the Exeter Care Homes Reading Project. English students from the university volunteer to visit different care homes in Exeter to read out loud to the residents. More than 100 English students volunteer each year to share the power of literature with care home residents, including those living with dementia.

Staff from participating care homes have seen the project spark conversation, trigger long-term memories in residents, create a sense of familiarity and calm, and inspire a more social atmosphere.

Using Sport to Reminisce Together

The Sporting Memories Network program is present in care homes, community venues and hospital units across England and Wales. Trained volunteers encourage program participants over the age of 50, many of whom live with dementia, to recall and share their favourite sporting memories. That might mean remembering a monumental past win at a big tournament like Wimbledon or the FIFA World Cup, or recalling the fun they had participating in a particular sport. Photographs, sports memorabilia, radio sound bites and physical activities (like "New Age Curling," an iceless version of curling) are all used to trigger memories and initiate the sharing of stories.



France Mail and More

As well as delivering the mail, France's postal service, La Poste, runs a program called *Veiller sur mes parents* ("Watch over my parents"). Through the program, which was introduced in 2017, postal workers connect and visit with elderly men and women along their routes every day, except Sunday. Subscribers, usually relatives of elderly residents, pay a monthly fee to La Poste and are alerted through an app after every visit if their relative is well or in need of assistance. No minimum visit time is mandated, but postal workers tend to spend between six and 15 minutes chatting with each person.



Germany Choosing Your Own Care

Germany is one of only a few countries in the world that offers an insurance system for long-term care.

Created in 1995, the Long Term Care Insurance (LTCI) program provides long-term care allowance benefits to persons who are defined as "frail" by Germany's Social Security Code. There are three levels and kinds of care, including family care, professional home care and informal

care. People who choose the informal care option receive a cash allowance monthly; otherwise, care providers are paid directly by the program.

LTCI gives people who need care the autonomy to hire people they know at times that are convenient for them. Since its creation, LTCI has reduced dependence on government provided health care and helps mitigate health-care workforce shortages.



USA Living a Normal, Everyday Life

Dr. Bill Thomas founded the Green House Project care home model back in 2001. He believed that individuals with dementia should live in real homes, not institutions or home-like facilities. He advocated for a care home model where seniors could experience privacy, dignity and autonomy just as they would at home. Residents live in small houses with 10 to 12 others, there's an open kitchen and an inviting living room, and everyone gets a private bedroom and washroom. Residents have independence and control over their environment, choosing when they'd like to go to bed, when they'd like to eat and whether they'd like to walk around the Green House neighbourhood.

Today, there are nearly 300 Green House homes across the U.S.



Japan With the Help of Robots

The Shin-tomi Nursing Home in Tokyo uses 20 different robots to support frontline staff in their day-to-day tasks, like Tree, a robot that helps residents walk and move. The robots are also companions for residents, like Pepper, a friendly humanoid robot that is roughly four feet tall, can guide exercise and dance classes, and can engage in basic conversations. Animal-like robots, such as the baby harp seal, Paro, or robotic cats, respond to residents' touch by moving or making noise, and are proven to be calming for residents.


In the spring of 2017, a research team with the Japan Agency for Medical Research and Development found that robots that interact with humans increased the independence and activity of 34 per cent of seniors at care homes. And today, roughly 5,000 care homes across Japan are analyzing how best to incorporate technology to support care for individuals with dementia.

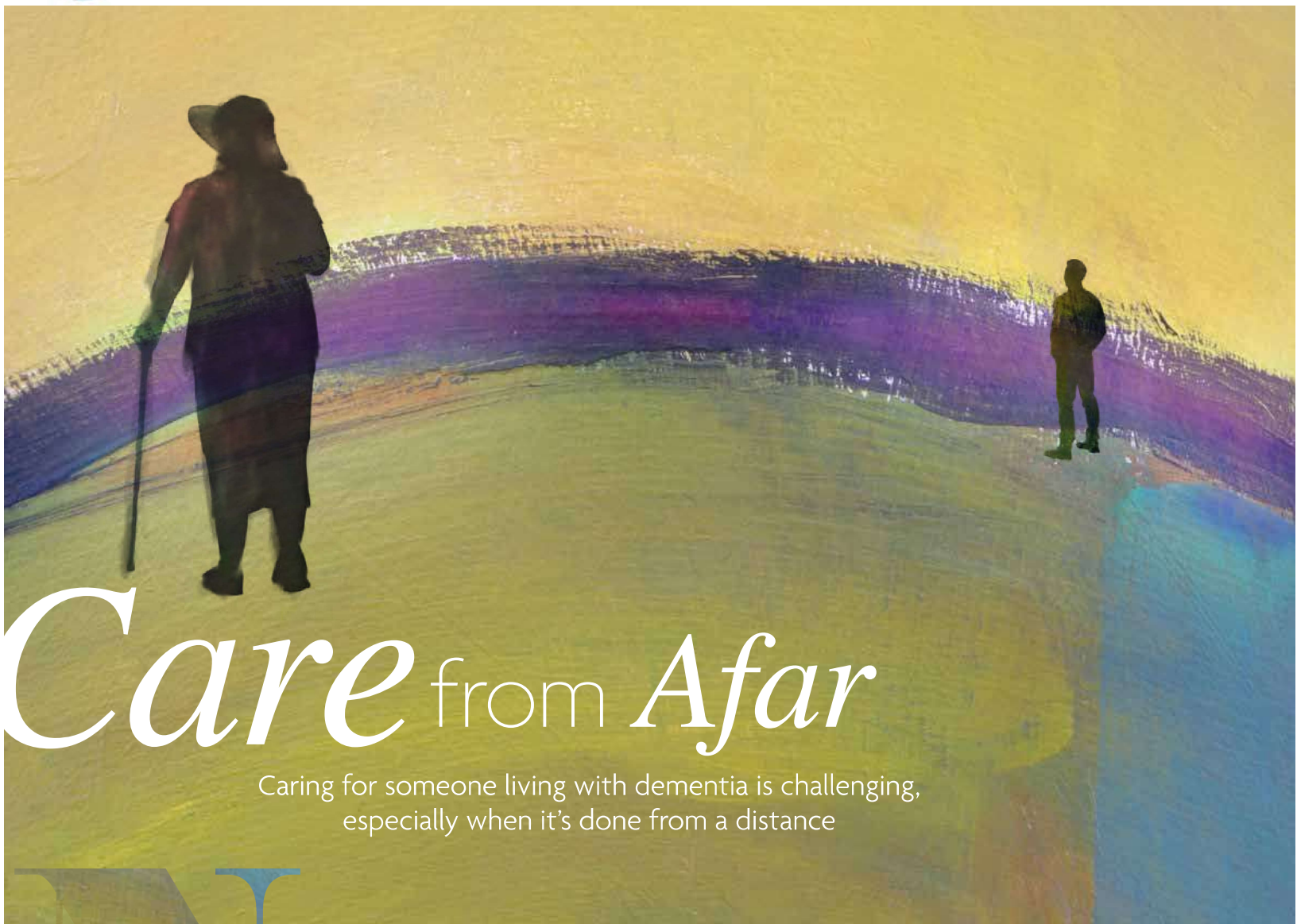


IKEA's prefab homes are designed for people living with dementia.



Sweden Welcome Home

IKEA is launching prefab homes designed for people living with dementia. The furniture giant is working with BoKlok, an affordable housing company it owns together with Swedish construction firm Skanska, to create the homes. Queen Silvia of Sweden is also a major partner in the project and sits on the steering board. Dementia-inclusive elements include removing mirrors from bathrooms, replacing modern buttons with old-fashioned knobs on appliances and incorporating nature and shared common spaces. The goal of the affordable housing project is to support aging members of the population to stay at home longer. So far, a pilot home with six apartments has been built with more scheduled in the coming year. 



Care from Afar

Caring for someone living with dementia is challenging, especially when it's done from a distance

Navigating the role of caregiver for someone living with dementia can be made all the more difficult when the barrier of distance is added. But, while facing the obstacles of varying time zones and health-care systems, paired with the emotional toll of separation, can be difficult, taking on the task is doable, especially with the right supports in place.

Dementia Connections spoke with three Canadians with experience as long-distance caregivers to learn more about how they overcame the challenges associated with caring from afar and the advice they want to give to others in similar positions.

Ian and Julie Goldman

Living away from home was not a new situation for Ian Goldman when his mother started exhibiting early symptoms of dementia. Raised an only child in Leeds, England, Goldman first moved away from the United Kingdom in the late 1970s, settling into his current place of residence in Toronto in 1986.

His mother, Julie, was notably independent in the intermittent years, living in the family home in Leeds on her own for several years after her husband passed away in 2001.

Goldman says his mother started

displaying signs of dementia in 2009. It began with frequent repetition during phone conversations, difficulties handling cash and often sleeping in a chair rather than her bed (later believed to have been a result of Julie imagining guests were visiting her home).

At the time, Goldman was returning to the U.K. every year or two and speaking with his mother frequently and openly by phone, though he says having trusted family and other community members nearby was crucial in staying informed. Their visits and calls also gave Julie a feeling of connection and caring.

“If you can get an ally, a pair of eyes and ears on the ground, it’s such a big help,” says Goldman. “Especially if you’re the sole care manager for your loved one, as I was.”

As his cousins began to report an increased number of panicked phone calls and other uncharacteristic actions from his mother, Goldman decided to take a proactive approach. During a visit for Julie’s 80th birthday, Goldman organized online bill payments, set up meetings with the family doctor, and initiated an email arrangement with the doctor in order to stay informed while he was back in Toronto. He also introduced in-home personal care visits, which his mother initially resisted, but eventually came to accept.

Technology also played a major role in facilitating Julie’s care. Having previously received power of attorney from his mother, Goldman was able to streamline dealing with finances through online banking, and he corresponded with agencies and health-care professionals both through email and video-conferencing. In addition, Goldman, along with his wife, also accessed educational e-learning tools through the Alzheimer Society of Toronto and attended small group sessions in order to better understand the natural journey of the illness.

Among the lessons Goldman learned through the Alzheimer Society was the importance of considering the toll of stress on caregivers.

“By early 2017, Mom’s situation was deteriorating, and I was dealing more and more with agencies and medical institutions and trying to figure out what exactly was happening,” says Goldman. “Some



“If you can get an ally, a pair of eyes and ears on the ground, it’s such a big help. Especially if you’re the sole care manager.” —Ian Goldman

of that was distressing to me, and extremely frustrating. [The]Alzheimer courses on caring for the caregiver were helpful, too.”

While Goldman’s personal journey would end with the passing of his mother in October 2017, he continues to give back through research, contributing his lived experience to the Canadian technology and aging network AGEWELL and the Centre for Aging and Brain Health Innovation. He also volunteers for organizations such as the Alzheimer Society of Toronto, including its Minds in Motion program, offering presentations and facilitating sessions that relay his experiences, displaying first-hand that the journey of long-distance caregiving may come with obstacles, but is far from unmanageable.

Greg and Ruth Stephenson

Greg Stephenson says his mother, Ruth, hid the early stages of the gradual onset of her dementia well, which made the news of her getting lost on her way to church a shock.

Ruth had driven from her home in Mill Bay, B.C., to the north end of Vancouver Island and back again, unable to find her exit. Once back in Mill Bay, she got into a car accident, at which point her family was informed of what had happened. Luckily, Ruth suffered only minor injuries but, following the accident, she underwent testing and her doc-



Above: Ian Goldman with his mother, Julie, in 2010, before the significant onset of her dementia.

tor found that severe respiratory issues were limiting oxygen to her brain. While the respiratory issues were corrected, Ruth’s doctor also informed the family of an underlying Alzheimer’s disease diagnosis, which was expected to progress quickly.

At the time of the accident, Stephenson was living in Calgary, but had siblings living nearby who were able to ease the transition period following Ruth’s diagnosis. Earlier conversations Stephenson had had with his mother further helped when faced with the decision of securing either in-home care or moving her to an assisted-living facility.

“I had known from conversations with her before that, were she not able to live independently, she didn’t really want to live in her own home,” says Stephenson.

He and his siblings made the decision to move Ruth into Sunrise of Victoria, a private assisted-living facility with a dedicated floor for residents living with dementia. While his siblings would eventually move away from the





island, Stephenson says the transition into becoming the primary caregiver was eased by decisions he and Ruth had made prior to the diagnosis, such as securing power of attorney to act on his mother's behalf financially.

From there, Stephenson says the facility was fantastic when dealing with care, leaving no worries in terms of his mother's comfort or happiness. Still, the distance was difficult emotionally.

"I was never worried about her being unhappy because I knew she was happy with her situation. But



I wasn't there as much as I wanted to be," says Stephenson. "Had I been in the same city, I could have visited her daily. And I wasn't able to do that. That was hard."

Stephenson made time for visits, often on a monthly basis, coordinating trips to Victoria with doctor's appointments whenever possible in order to be involved when medical news was delivered. When he was unable to visit, Stephenson says daily phone calls filled the gaps, with the contact — regardless of length or subject matter — meaning the world to both sides.

"When I would talk to her, she didn't always know who I was, but she always knew that I was special," says Stephenson. "The

conversation — sometimes it'd be long, sometimes short, and it would often be quite disjointed, but she always enjoyed talking to me.

"That kind of daily contact and the chance to just talk to the woman who raised me was always a comfort."

Martin and Bill MacDonald
Calgarian Martin MacDonald and his father, Bill, were separated

by much of the country when early symptoms of Bill's vascular dementia became noticeable. During semi-frequent trips to Bill's home in London, Ont., MacDonald noticed his father was starting to eat less frequently and was experiencing deterioration in memory and motor skills, such as driving abilities.

The signs of early symptoms led MacDonald and his brother, who lives in the Bahamas, to convince their father to move into a private assisted-living home in London. While the move worked for a while, it became evident that the progression of Bill's condition was leading to unforeseen difficulties in the long-distance caregiver relationship. MacDonald says that, although neighbours and family friends were able to give occasional updates, the stress of not knowing when he may receive news of Bill getting lost or facing other troubles began to take a toll.

"It was frustrating. You just never knew when you were going to get that phone call," explains MacDonald. "Helplessness is probably the best word."

Eventually, costs started to add up. Between trips to visit the London facility and extra care required due to the progression of the condition, Martin made the decision

"Had I been in the same city, I could have visited her daily. And I wasn't able to do that. That was hard." —Greg Stephenson



Above right: A portrait of Ruth Stephenson, painted by long-time family friend Karin Olsson.

TIPS FOR MANAGING A LONG-DISTANCE CAREGIVER ROLE

1

Ask for Advice

The prospect of managing a long-distance caregiver role may seem isolating, but reaching out for help from services or finding someone with lived experience can alleviate some of the stress.

When struggling with questions regarding moving his father to Calgary, Martin MacDonald connected with someone who had navigated a similar situation through Chartwell Fountains of Mission Retirement Residence.

"When I spoke with her, it was really reassuring," says MacDonald. "[Finding the opportunity to access] that experiential learning from somebody who's already gone through it would be my advice."

in early 2016 to move his father to Calgary. “We were going back and forth, and, after a year and a bit, we said, ‘We just can’t keep doing this,’” says MacDonald.

MacDonald admits the decision came without knowing what would be required in the move. Initial assumptions of securing an Alberta Health Care Insurance Plan (AHCIP) ahead of the move led to dead ends when MacDonald was informed his father would need to be present to register. MacDonald’s worries were remedied, however, when he reached out to Chartwell Fountains of Mission Retirement Residence to inquire about a room for his father, and they assured him they could help in the transition.

Through AHCIP, coverage from an Alberta plan commences three months after residency is established in the province when moving from within Canada. In the intermittent months, services accessed by the individual are covered by the Alberta government, who then bills the province of origin. This means that, in someone like Bill’s case, while waiting for Alberta coverage, services accessed would be billed back to Ontario through their health-care insurance plan there.

Despite hesitation, MacDonald



“It was frustrating. You just never knew when you were going to get that phone call. Helplessness is probably the best word.” —Martin MacDonald



From right: Martin MacDonald with his son, Trevor, and Bill.

was able to coordinate the three hours per day of care his father required through Alberta Health Services (AHS), allowing Bill to live comfortably in Calgary among his family until his passing in October 2016. While the move did come with its challenges, MacDonald says having his father nearby and able to create memories with his grandchildren was something he doesn’t take for granted.

“It was incredible to have him out here,” says MacDonald. “And I think it meant the world to my dad, too.”

DID YOU KNOW? Once a week, 130 Safeway and Sobeys stores across Alberta are offering a sensory-friendly shopping experience for customers who may be sensitive to sensory overload. During designated hours, the stores dim lighting, turn off loudspeakers, lower scanner noises and avoid cart collection. Sensory-friendly shopping days and times vary, depending on location. Visit your local Safeway or Sobeys to learn more.



Keep in Contact

Having a trusted support system nearby, whether it be family, friends or health-care professionals, can be vital

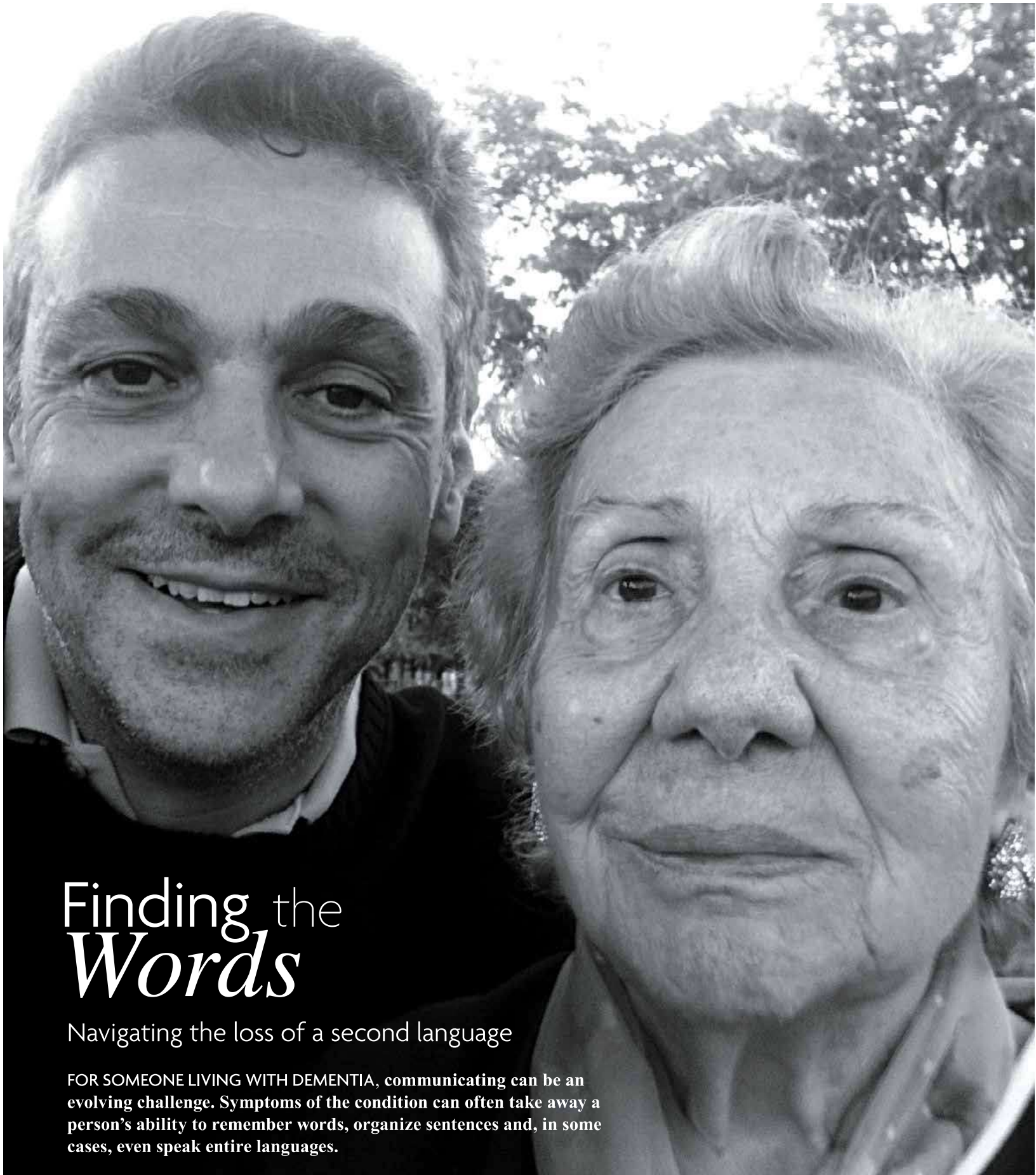
in staying informed. Ian Goldman says maintaining relationships throughout the community in Leeds, such as trusted neighbours and local social service agencies, allowed him to stay up-to-date on his mother’s condition.



Keep Everyone Involved

Staying in contact with others within the person with dementia’s support system alleviates pressure and ensures that everyone feels they’ve contributed in a time of drastic transition.

“Talk to as many people as you can, and try to move forward as a family,” says Greg Stephenson. “Not everyone can be involved in the same way, but if everyone feels involved at some level, at the end of the process, everyone can feel that they contributed and that they made their loved one’s life as enjoyable as possible and as rich as possible.”



Finding the *Words*

Navigating the loss of a second language

FOR SOMEONE LIVING WITH DEMENTIA, communicating can be an evolving challenge. Symptoms of the condition can often take away a person's ability to remember words, organize sentences and, in some cases, even speak entire languages.

Padmaja Genesh is a learning specialist with the Alzheimer Society of Calgary. She says all types of dementia tend to make communication harder.

“As the disease is progressing, the ability to communicate will diminish gradually,” says Genesh. “People living with dementia will have difficulty expressing themselves and also difficulty understanding others.”

People who speak multiple languages, specifically immigrants to Canada who learned English at a later stage in their life, tend to lose their vocabulary and revert back to their native language. Genesh says it is believed this happens because English is more recently acquired knowledge compared to their native language, making it more likely to be forgotten.

This presents unique challenges for families who immigrated to Canada from another part of the world. For example, finding services in the mother tongue is often difficult, adding to the sense of isolation that can come with the dementia experience.

“Even in the middle stage [of the disease], the person can revert to their first language, especially for immigrants,” says Genesh. “Sometimes, even the kids might have been raised here and not speak that language at all.”

“People living with dementia will have difficulty expressing themselves and also difficulty understanding others.”

—Padmaja Genesh



Finding Solutions

Nectarios Charitakis has experienced some of these struggles first-hand. His parents moved from Greece to Montreal in the early 1950s and his mother was diagnosed with dementia in her final years. As his mother’s dementia progressed, she lost all her ability to speak English and French and reverted back to Greek.

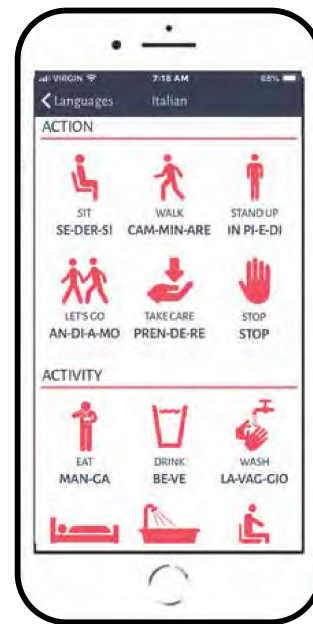
“Eventually, my mom’s bed was surrounded by all these yellow Post-it notes that had words translated phonetically from Greek into English, just to help the nurses communicate with my mom,” says Charitakis.

Charitakis has since founded uCaret, an organization that helps families get in touch with, and hire, caregivers. He says the experience of caring for his mother made him think of the countless people, families and caregivers across Canada struggling with similar problems around language.

Working from the Post-it notes, Charitakis created a series of posters that included phonetic translations of key words from a variety of languages for caregivers. The posters — available to download for free on uCaret’s website — feature icons of actions such as eating, washing and sleeping, with the foreign words spelled out phonetically underneath in 12 different languages.

Charitakis soon started getting requests from caregivers for something similar in a smaller format, so he began developing the *CareLingo* app. The app translates 35 activities of daily living and about five crucial phrases into 14 different languages.

“You can pull out the app, show someone the picture for ‘stand’ and touch it and it will actually



Opposite page: Nectarios Charitakis with his mother. Left: Screen shot of the *CareLingo* app. Simply point, touch an icon and the word is spoken in the person’s language.

say the activity in whatever language,” says Charitakis. “This app is specifically designed around home care. There’s other translation apps, but this is designed around activities of daily living.”

A second version of the app, currently in development (the beta version was released in December), will use voice-to-voice translation to incorporate a real-time translation feature. Caregivers or people living with dementia can speak directly into the app and it will translate the words into the desired language.

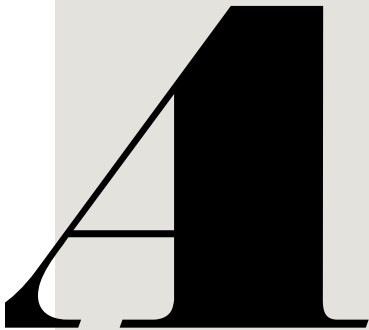
Currently, the *CareLingo* app costs \$2.79 to download and is available for both Android and iPhone.

Learn more at ucaret.net

DID YOU KNOW? Speaking two or more languages can improve cognitive reserve and can play a protective role against dementia or delay its onset. In a Canadian study, people who were bilingual were diagnosed with dementia, on average, four years later than people who spoke only one language.



Alzheimer's Disease International



LZHEIMER'S DISEASE INTERNATIONAL (ADI) is a key player in the fight against dementia. Created in 1984 and based

in London, England, the non-profit supports the national work of 100-and-counting member associations and federations by hosting global and regional conferences, and through supporting research.



“[Making dementia a priority] has been a huge focus for us over the last 10 years.” —Chris Lynch

ADI's Goals and Objectives

ADI's vision is to make dementia a global priority. “This has been a huge focus for us over the last 10 years,” says Chris Lynch, ADI's deputy CEO and director of policy, communications and publications. And that push is a timely one. Currently, there are 50 million people living with dementia around the world and, according to the World Health Organization (WHO), that number is expected to triple by 2050.



ADI advocates at high-level meetings with members. For example, at a recent sit-down, India's minister of health committed to developing a national dementia plan. It holds conferences (this year's global conference is in Singapore) that offer members, researchers, scientists, health-care professionals, carers and people living with dementia a chance to stay abreast of the latest research, network and develop relationships. It also runs Alzheimer University — three-to-four-day workshops that cover topics such as capacity-building, policy development and advocacy — for staff and volunteers of membership groups.

In 2017, ADI played an instrumental role in the creation of *The Global Action Plan on the Public Health Response to Dementia*. This public document was spearheaded by the WHO and launched at the World Health Assembly that same year.

The plan consists of seven pillars:

1. Dementia as a public health priority
2. Dementia awareness and friendliness
3. Dementia risk reduction
4. Dementia diagnosis, treatment and care
5. Support for dementia carers
6. Information systems for dementia
7. Dementia research and innovation.

“The emphasis now is on the realization of that plan by helping member agencies develop their [own] national initiatives,” says Lynch. “A good national response will tackle all seven action areas.”

2019 Survey Results

In the spring of 2019, ADI launched a global survey about attitudes related to dementia. Almost 70,000 people responded to the survey, including the general public, health-care professionals, caregivers and people living with dementia.

Key findings included:

Two in three people thought dementia is caused by normal aging (this is untrue), and one in four people thought there is nothing to do to prevent dementia (this is also untrue).

Additional themes included:

Stigma, ill-preparedness of medical personnel to serve the population and extreme stress and illness of caregivers. Case studies related to marginalized groups, like the homeless, people living in prisons and the LGBTQ community, were also shared.

What's Next?

ADI is committed to research that improves the lives of people living with dementia and is a key partner in a number of global projects. One of those current projects, called STRiDE (read more on page 49), explores ways to build capacity for dementia-related resources and support in lower- and middle-income countries.

ADI is also continuing to advocate strongly for drug development. “There is a global desire and push for a drug-based treatment for dementia,” adds Lynch. “We are desperate for a breakthrough.”

Learn more at alz.co.uk

Dementia Alliance International

IN 2008, A MONTH BEFORE HER 50TH BIRTHDAY, Kate Swaffer was diagnosed with young onset dementia.

After the shock wore off, Swaffer, who lives in Adelaide, Australia, got into action mode. She found writings by the late Dr. Richard Taylor, which encouraged her to reclaim her life. But soon she discovered there were few resources available for anyone with dementia. People newly diagnosed were told to “go home, give up and get their end-of-life affairs in order.”

This was unacceptable to Swaffer. Post-diagnosis, the university she was attending at the time of diagnosis advised her to continue her studies. With disability assessment and support, she completed two undergraduate degrees. This led her to realise she had the right to rehabilitation, which she began demanding from her health-care professionals. She then pursued a master’s degree — focusing on dementia care.

“I was tired of people saying what was right for me and how I was feeling, and not once asking me. We needed a group of people with the condition to manage their own affairs.” Essentially, Swaffer says she became an “accidental activist.”



“I was tired of people saying what was right for me and how I was feeling, and not once asking me.” —Kate Swaffer

In 2014, Swaffer and seven other individuals living with dementia formed Dementia Alliance International (DAI), a U.S registered charity, with a global outreach.

DAI’s vision:

“A world where all people are valued and included.”

As well as offering peer support, research information and webinars, DAI represents the global voice of people living with dementia. Board members — like Swaffer, who is the organization’s chair and CEO — advocate at strategic meetings including at the World Health Organization and the United Nations.



At these venues, the group tackles high-level issues such as the prevalence of “Prescribed Disengagement®,” the lack of human rights for people living with dementia and the need for disability status, disability support, rehabilitation and support to continue to live in the community.

Prescribed Disengagement:

— a term trademarked by Swaffer —refers to being advised to disengage from your pre-diagnosis life, your plans and your dreams. It creates a sense of hopelessness for everyone, which negatively impacts a person’s sense of self and their quality of life. Instead, the emphasis should be on capacity, resilience and support.

When it comes to work, Swaffer believes that people living with dementia should have access to disability plans and supports to help them succeed and contribute to the workforce. These may include adaptive technologies like voice-recognition software, assistance with note-taking and/or counselling. Outside the workplace, they should have access to rehabilitation services like speech therapy and disability assessment and support to maintain independence for longer.

Thanks to major advocacy work by DAI, there have been a few positive developments for people living with dementia. In 2017, for example, human rights were included in the Global Action Plan on the Public Health Response to Dementia adopted at the World Health Assembly.

Moving forward, DAI is committed to supporting people to remain in their jobs or volunteer, and live in their homes for as long as possible. It is focused on better global collaboration, including financial support to back national action plans, and it will continue to call for an end to stigma. There is still much work to be done and DAI intends to be at the forefront helping to create a more hopeful world for people living with dementia. ▣

Read more about rehabilitation on page 60.

Learn more at dementiaallianceinternational.org



Reaching Out *for Rehab*

Rehabilitation supports and enhances everyday functioning, meaning it could improve quality of life for individuals living with dementia. So why isn't it more accessible?

CHIRSTINE THELKER lives an active, independent life. She travels often and participates in Pilates classes several times a week. But every so often, her ankle gives her a little trouble. She has some

difficulties with her balance and her coordination, too, which is common for individuals like her who live with vascular dementia.



Thelker, who lives in Vernon, B.C., knows that without rehabilitation to strengthen and balance her musculoskeletal system, these physical issues will only get worse. And if they do get worse, that would affect her ability to approach the everyday activities she loves, altering the life she leads.

Thelker was diagnosed with vascular dementia four years ago, but it's only in the last two years that physiotherapy became a regular part of her health-care routine.

"When my doctor gave me the dementia diagnosis, I felt lost and isolated," says Thelker. "There was no medical follow-up for me."

It was only when she discovered Dementia Alliance International, a global support, education and advocacy group comprised of



individuals living with dementia, that she learned rehabilitation services like physiotherapy were even an option for individuals living with dementia. And that chance discovery changed Thelker's life.

Rehabilitation focuses on strategies that maintain or improve functional ability and independence through maximizing an individual's capacity. Most likely all individuals will require rehabilitation at some point in their lives. Simply, rehabilitation is any form of care that enables an individual to keep up activities for everyday living.

What that means specifically differs from person to person: one person's everyday can be vastly

different from someone else's, which is why rehabilitation therapy is such a broad form of health care. Physiotherapy, occupational therapy and speech therapy are just some forms of rehabilitation, yet all rehabilitation services will contribute to a person regaining or maintaining independence, recovering from a physical setback or improving their functioning in daily life.

Since beginning regular physiotherapy sessions two years ago, Thelker's balance is better and her core is stronger, making daily activities like lifting laundry and carrying groceries easier and reducing her risk of falls. And, Thelker adds, she just *feels* better.

In Thelker's case, rehabilitation therapy is a form of preventative medicine, lessening her risk of physical setbacks that aren't directly related to her dementia, such as falling and breaking a bone. But rehabilitation can also be restorative, says Dr. Katherine McGilton, a senior scientist at the Toronto Rehabilitation Institute University Health Network. One area of her research focuses on the rehabilitation of older adults living with dementia after a hip fracture, and she has found evidence of

“We need to help people with dementia be productive, functional, independent people for as long as possible. We need to help them live better.”

—Christine Thelker



the positive effects of inpatient rehabilitation for older adults with dementia.

A 2013 study McGilton worked on found that providing inpatient rehabilitation lowered the individual with dementia’s chance of being admitted to a long-term care facility after they were discharged from the rehabilitation facility.

“Our research found the more rehab, the better the [physical] recovery for individuals with dementia,” says McGilton. “Walking

involves your procedural memory and some of our clients actually began walking sooner than clients who don’t have dementia. Clients without dementia are really worried about the pain and so don’t want to walk and begin rehab exercises.”

Despite these promising findings, neither preventative nor restorative rehabilitation therapies are widely accessible to individuals with dementia. Often that’s because rehabilitation isn’t posi-

tioned as an option at the time of a dementia diagnosis. McGilton’s research also highlights a lack of accessibility. In a 2016 study by her colleague Dr. Dallas Seitz, it was found that, of the 11,200 individuals with dementia who experienced a hip fracture, 40 per cent received no rehabilitation. And, of those who did, only 27 per cent received inpatient rehabilitation, the level of rehab shown to have the best outcomes for people living with dementia.

Left: Christine Thelker with her physiotherapist, Kathy Drysdale. Above: Thelker and Drysdale at The Cobblestone Clinic in Vernon, B.C.



“The savings were between \$20,000 to \$30,000 per patient, per year, when we get older adults with dementia into a rehabilitation bed as opposed to going into long-term care.”

—Dr. Katherine McGilton



One of the biggest barriers at play is stigma, or the “why bother” attitude that exists.

“We actually make assumptions that someone is physically declining because of their dementia. And [health professionals] tend to keep people with dementia out of rehab because of their cognitive status,” says McGilton. “There’s the belief that because a patient with dementia won’t remember what they were taught yesterday that they can’t be rehabilitated. In truth, what we’ve found is your level of physical functioning prior to the fall, rather than your cognitive status, is an indicator of how well you will do in rehabilitation post-fracture.”

Above: Dr. Katherine McGilton, senior scientist at the Toronto Rehabilitation Institute University Health Network.

Another barrier is cost, particularly with preventative rehab. Christine Thelker recognizes that receiving rehabilitation therapy can be a financial struggle for many individuals with dementia, as the public health-care system doesn’t cover many of these therapies. In Canada, rehab therapies can cost between \$75 and \$150 per session without insurance coverage, making these therapies out of reach for some individuals without employment and private health insurance.

When it comes to inpatient rehabilitation, McGilton says that teaching health-care providers how to effectively rehab individuals with dementia does require experts like advance practice nurses to teach staff how to do it well so there is a cost. Yet, there are also long-term cost savings by making rehab more accessible.

“A health economist on my team looked at the cost savings of rehabilitation,” says McGilton. “The savings were between \$20,000 to \$30,000 per patient, per year, when we get older adults with dementia into a rehabilitation bed as opposed to going into long-term care.”

But, because there are so few inpatient rehabilitation beds in the Canadian health-care system, that “why bother” mentality means people with dementia are overlooked.

“There are not enough beds for the demand,” McGilton says. “It becomes an issue of how many beds do we need to meet the needs of this growing segment of the population and how do we improve access when we do.”



In June 2019, Christine Thelker travelled to New York to attend the 12th Conference of States Parties to the Convention on the Rights of Persons with Disabilities. She sat in a room full of United Nations representatives and spoke about living with dementia, why dementia should be recognized as disability, and the rights to which this group is entitled, including access to rehabilitation.

These days, Thelker continues to advocate for individuals with dementia to receive equal access to health care, including access to rehabilitation therapy. She says that rehabilitation should be offered as a standard part of treatment protocol, not because it will cure anyone’s dementia, but because it is ethical to provide health-care options.

“We don’t say ‘why bother’ to people with cancer because there is a risk their cancer could come back in five years. We don’t say, ‘We’re not sure if this drug trial will work, so we won’t try,’” says Thelker. “Why is it okay to approach people with dementia with that attitude?”

Thelker continues her rigorous rehabilitation regimen today. She knows she has to work hard to keep her body functioning well so she can continue to meet the demands of her day-to-day life on her own terms. And it’s an option she wants everyone with dementia to access.

“We need to help people with dementia be productive, functional, independent people for as long as possible,” says Thelker. “We need to help them live better.”

Photo courtesy Dr. Katherine McGilton



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Creating a Dementia-Inclusive Community

A CLOSER LOOK AT LONG-TERM CARE

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

Q

Before Visiting

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

Q

While Visiting

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

Q

Staff Considerations

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

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

DEMENTIA-RELATED Services and Resources

for Calgary and Surrounding Area

GLOSSARY OF TERMS

Best Friends Approach™

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

Butterfly Household Model

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 person-centred, compassionate care with a focus on four key areas: personhood, the brain and behaviour, the interpersonal environment, and gentle persuasive techniques.

Complex Dementia Care

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

Person-Centred Approach

Individual interests and abilities are the primary focus of care.

PALS

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

P.I.E.C.E.S.

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

Positive Approach to Care (PAC)

Care strategies and techniques integrate what is known about brain function and changes with therapeutic approaches to foster positive

outcomes. Emphasizes the value of human connection when verbal communication and interaction skills are altered.

Supportive Pathways

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

United Minds

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

WanderGuard

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

For more information

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

Subsidized: Please seek referral from Alberta Health Services Community Care Access at (403) 943-1920 or 8-1-1

Private Pay: Please contact facility for pricing and availability

Ⓐ = Less than \$2,500/month ⒸⒸ = \$2,500-5,000/month ⒸⒸⒸ = More than \$5,000/month *Confirm pricing with individual facilities

RESIDENTIAL

FACILITY NAME 	CONTACT INFO 	PRIVATE 	SUBSIDIZED 	PRICE 	CARE APPROACH 	NOTEWORTHY 
AgeCare Glenmore 1729 – 90 Avenue SW	agecare.ca/glenmore 403-253-8806		●	\$	Person-Centred; Best Friends Approach™; Eden Alternative; P.I.E.C.E.S.; Supportive Pathways	Pet visits; secure outdoor garden
AgeCare Midnapore 500 Midpark Way SE	agecare.ca/midnapore 403-873-2600		●	\$	Person-Centred; Best Friends Approach™; Supportive Pathways	Intergenerational childcare program; pet visits; secure outdoor garden; private-pay suites for spouses
AgeCare Seton 4963 Front Street SE	agecare.ca/seton 587-349-8444		●	\$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet visits
AgeCare SkyPointe 179 Skyview Circle NE	agecare.ca/skypointe 587-619-1900		●	\$	Person Centred; Specialty Mental Health; Non-Violent Crisis Intervention	Intergenerational childcare program; cultural dining and activities; pet visits
AgeCare Walden Heights 250 Walden Drive SE	agecare.ca/walden 403-873-4700		●	\$	Person-Centred; P.I.E.C.E.S.; PAC	Intergenerational childcare program; pet visits; private-pay apartments for spouses
Auburn Heights Retirement Residence 21 Auburn Bay Street SE	allseniorscare.com 403-234-9695	●		\$\$-\$\$\$	Person-Centered	Age-in-place; pets welcome
Amica Britannia 750 – 49 Avenue SW	amica.ca 403-476-8992	●		\$\$\$	C.A.R.E.S.; Person-Centered; Best Friends Approach™; Well-Being Model (integrates elements of Butterfly, GPA and PAC)	Pet visits; mutigenerational programming; WanderGuard
Silvera for Seniors - Beaverdam Community 2012 – 66 Avenue SE	silvera.ca 403-279-4623		●	\$	Best Friends Approach™; Company-specific	Tailored to early stage dementia; independent living Silvera townhomes adjacent; Active Aging programs
Bethany Harvest Hills 19 Harvest Gold Manor NE	bethanyseniors.com 403-226-8200		●	\$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Secure outdoor area; purpose-built for people with moderate to severe dementia
Bethany Riverview 200, 2915 – 26 Avenue SE	bethanyseniors.com 587-392-3999		●	\$	Supportive Pathways; GPA; P.I.E.C.E.S.; Complex Dementia Care	Purpose-built for people with complex dementia care needs
Bow Crest Care Centre 5927 Bowness Road NW	reveralliving.com 403-288-2373		●	\$	Dementiability Methods	
Brentwood Care Centre 2727 – 16 Avenue NW	intercarealberta.com 403-289-2576		●	\$		Bistro on site
The BSF Bow View Manor 4628 Montgomery Boulevard NW	theBSF.ca 403-288-4446	●	●	\$\$-\$\$\$	Supportive Pathways	WanderGuard; long-term care
The BSF Clifton Manor 4726 – 8 Avenue SE	theBSF.ca 403-272-9831		●	\$	Supportive Pathways	Long-term care; secure outdoor area; smoking permitted

The BSF = The Brenda Strafford Foundation

RESIDENTIAL

The BSF Wentworth Manor 5717 – 14 Avenue SW, Calgary	theBSF.ca 403-242-5005	● ●	\$-\$	Supportive Pathways	Age-in-place (multi-levels of care); secure outdoor area
Carewest Colonel Belcher 1939 Veteran's Way NW	carewest.ca 403-944-7800	●	\$	Supportive Pathways	Priority to veterans; secure outdoor area; smoking permitted
Carewest Garrison Green 3108 Don Ethell Boulevard SW	carewest.ca 403-944-0100	●	\$	Supportive Pathways	
Carewest George Boyack 1203 Centre Avenue NE	carewest.ca 403-267-2750	●	\$	Supportive Pathways	
Carewest Rouleau Manor 2206 – 2 Street SW	carewest.ca 403-943-9850	●	\$	Supportive Pathways; Complex Mental Health Care	Smoking permitted
Carewest Signal Pointe 6363 Simcoe Road SW	carewest.ca 403-240-7950	●	\$	Supportive Pathways; Complex Mental Health Care	Dementia-specific design; smoking permitted
Chartwell Eau Claire Care Residence 301 – 7 Street SW	chartwell.com 403-269-3114	● ●	\$-\$		WanderGuard
Chinook Care Centre 1261 Glenmore Trail SW	intercarealberta.com 403-252-0141	● ●	\$		
The Edgemont 80 Edenwold Drive NW	reveraliving.com 403-241-8990	●	\$\$-\$\$\$	PAC	
Evanston Grand Village 40 Evanston Way NW	evanstongrand.ca 403-274-6416	●	\$	Supportive Pathways	Secure outdoor area; music and arts programs
Evergreen 2220 – 162 Avenue SW	reveraliving.com 403-201-3555	●	\$\$	Best Friends Approach™	Pets welcome
Extendicare Cedars Villa 3330 – 8 Avenue SW	extendicarecedarsvilla.com 403-249-8915	●	\$	PAC; Supportive Pathways; Best Friends Approach™	Couples may live together; outdoor courtyard; PALS; WanderGuard; accept various levels of dementia; smoking permitted
Extendicare Hillcrest 1512 – 8 Avenue NW	extendicarehillcrest.com 403-289-0236	●	\$	PAC	Couples may live together; intergenerational programming; PALS; Roam Alert
Father Lacombe Care Centre 270 Providence Boulevard SE	fatherlacombe.ca 403-256-4641	●	\$	Person-Centred Approach; Supportive Pathways	Secure outdoor area; intergenerational programs; memory care
Holy Cross Manor 70 Evanspark Manor NW	covenantcare.ca 587-230-7070	●	\$	Supportive Pathways	Couples may live together
Manor Village at Varsity 40 Varsity Estates Circle NW	themanorvillage.com 587-393-9999	●	\$\$-\$\$\$		Memory care; pet friendly; couples may live together; balance tracking technology
Manor Village at Fish Creek Park 22 Shawnee Hill SW	themanorvillage.com 403-918-2127	● ●	\$\$-\$\$\$		Age-in-place; in-house doctor; 24/7 nursing
Mayfair Care Centre 8240 Collicutt Street SW	mayfaircarecentre.com 403-252-4445	● ●	\$		Smoking facility





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McKenzie Towne Care Centre 80 Promenade Way SE	reveraliving.com 403-508-9808	● ●	\$	Dementiability Methods	
McKenzie Towne Retirement Residence 20 Promenade Park SE	reveraliving.com 403-257-9331	● ●	\$		Secure outdoor area
Millrise Seniors Village 14911 – 5 Street SW	retirementconcepts.com 403-410-9155	● ●	\$\$-\$\$\$	Supportive Pathways; Person-Centred	Independent and assisted living; near Fish Creek
Monterey Seniors Village 4288 Catalina Boulevard NE	retirementconcepts.com 403-207-2929	● ●	\$	Supportive Pathways	
Mount Royal Care Centre 1813 – 9 Street SW	reveraliving.com 403-244-8994	● ●	\$	Dementiability Methods	
Newport Harbour Care Centre 10 Country Village Cove NE	parkplaceseniorsliving.com 403-567-5100	● ●	\$\$-\$\$\$	Resident-Centred Care, GPA	Multi-sensory robotics; lakefront location
Prince of Peace Manor and Harbour 285030 Luther Rose Boulevard NE	verveseniorliving.com 403-285-5080	● ●	\$\$-\$\$\$	Supportive Pathways; Best Friends Approach™	Secure outdoor area
Prominence Way Retirement Community 905 Prominence Way SW	prominencewayretirement.com 403-727-9400	● ●	\$\$\$	Supportive Pathways	Secure outdoor area; intergenerational programming; age-in-place; dementia care, music and art programs
Providence Care Centre 149 Providence Boulevard SE	fatherlacombe.ca 587-393-1350	● ●	\$	Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational programming; memory care; SL4 and 4D care
Rocky Ridge Retirement Community 10715 Rocky Ridge Boulevard NW	rockyridgeretirement.com 403-930-4848	● ●	\$	GPA; Person-Centred; Supportive Pathways	Secure outdoor area; momentum tracking
Sage Hill Retirement Residence 6 Sage Hill Gardens NW	allseniorscare.com 403-455-2273	● ●	\$\$-	GPA; Best Friends Approach™	Age-in-place; pets welcome
St. Marguerite Manor 110 Evanspark Manor NW	covenantcare.ca 587-955-9788	● ●	\$\$-		Couples may live together
St. Teresa Place 10 Redstone Place NE	covenantcare.ca 587-619-7116	● ●	\$	(Components of) Butterfly Approach; Best Friends Approach™; Complex Dementia Care	Secure outdoor area; age-in-place; intergenerational programming
Scenic Acres Retirement 150 Scotia Landing NW	reveraliving.com 403-208-0338	● ●	\$	PAC	Secure outdoor area; pets welcome
Southwood Care Centre 211 Heritage Drive SE	intercarealberta.com 403-252-1194	● ●	\$	Butterfly Approach	
StayWell Manor Village at Garrison Woods 174 Ypres Green SW	themanorvillage.com 403-242-4688	● ●	\$\$-\$\$\$	Best Friends Approach™	Assisted living; memory care; enhanced care; palliation; respite care; rehab programs
Swan Evergreen Village 2635 Eversyde Avenue SW	originway.ca 587-481-6638	● ●	\$\$	Person-Centred	Intergenerational programming; age-in-place; secure outdoor area; couples may live together
United Active Living at Fish Creek 51 Providence Boulevard SE	unitedactiveliving.com 587-481-7907	● ●	\$\$	United Minds	Secure outdoor area

RESIDENTIAL

United Active Living at Garrison Green 3028 Don Ethell Boulevard SW	unitedactiveliving.com 403-685-7200	●		\$\$\$	United Minds	
The Journey Club at Westman Village 176 Mahogany Centre SE	westmanvillage.com 403-313-5478	●		\$\$\$	Butterfly Model; Person-Centred	Secure outdoor area
Whitehorn Village Retirement Community 5200 – 44 Avenue NE	originway.ca 403-271-2277	●	●	\$	Butterfly Model; Best Friends Approach™	
Wing Kei Crescent Heights 1212 Centre Street NE	wingkeicarecentre.org 403-277-7433		●	\$		Chinese language & culture; age-in-place
Wing Kei Greenview 307 – 35 Avenue NE	wingkeicarecentre.org 403-520-0400		●	\$		Chinese language & culture; age-in-place

OUT-OF-TOWN RESIDENTIAL

FACILITY NAME 	CONTACT INFO 	PRIVATE	SUBSIDIZED	PRICE \$	CARE APPROACH 	NOTEWORTHY 
AgeCare Sagewood 140 Cambridge Glen Drive, Strathmore	agecare.ca 403-361-8000		●	\$	Person-Centred; Supportive Pathways; GPA	Intergenerational childcare program; pet visits; private-pay suites for spouses
Aspen Ridge Lodge 1100 – 20 Avenue, Didsbury	mvsh.ca 403-335-9848		●	\$		Couples may live together
Bethany Didsbury 1201 – 15 Avenue, Didsbury	bethanyseiors.com 403-335-4775		●	\$	Designated Supportive Living Level 4	Secure outdoor area; age-in-place
Meadowlark Senior Care Home 203 Hillcrest Boulevard, Strathmore	meadowlarkcare.com 403-934-5294	●		\$-\$		Secure outdoor area; age-in-place
Origin at Spring Creek 808 Spring Creek Drive, Canmore	originway.ca 403-678-2288	●		\$\$-\$\$\$	Best Friends Approach™; PAC; Supportive Pathways	Secure outdoor area
Seasons High River 660 – 7 Street, High River NW	seasonsretirement.com 403-652-1581		●	\$	Embrace Today; C.A.R.E.S.; Person-Centered	Secure outdoor area; pets welcome
Silver Willow Lodge 2007 – 22 Avenue, Nanton	mosquitocreekfoundation.net 403-646-2660		●	\$	Person-Centred; PAC; Supportive Pathways	Services provided by AHS
The BSF Tudor Manor 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 
A Friend Indeed	getafriendindeed.com 403-980-0199	Non-medical support for seniors	\$31/hr 2 hour minimum	Best Friends Approach™; Supportive Pathways
Alberta Health Services	albertahealthservices.ca 403-943-1920	OT, RN, HCA, LPN, PT	Free	Client-dependent
All About Seniors	allaboutsensors.ca 403-730-4070	RN, LPN, HCA, foot care, Companion	\$30/hr 2 hour minimum	Best Friends Approach™
Bayshore Home Health	bayshore.ca 403-776-0460	RN, LPN, HCA, Companion	\$28.75/hr 2 hour minimum	Supportive Pathways
CBI Home Health	cbi.ca 403-232-8770	RN, LPN, HCA	Call for pricing	
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™
Focus On Caring	focusoncaring.com 403-264-3839	RN, HCA	\$31/hr 4 hour minimum	GPA
Global Senior Care	globalseniorcareservices.com 403-452-4555	RN, LPN, HCA	\$28/hr 3 hour minimum	Best Friends Approach™
Granddaughters Personal Care Inc.	granddaughters.ca 403-828-0550	HCA, recreation aide, companion, 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	\$32/hr 2 hour minimum	Cognitive Therapeutic Method; Best Friends Approach™; Client-Centred
Home Instead Senior Care North	homeinstead.com/northcalgary 403-910-5860	HCA, LPN, RN, Companion	\$32.95/hr 3 hours minimum	Dementia CARE Curriculum
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	thematasker.com 403-988-2471	RN, LPN, HCA, Companion	\$30/hr 1 hour minimum non-medical, 2 hour minimum medical	Best Friends Approach™; Person-Centred
Max Home Care	maxhomecare.ca 587-352-1010	HCA	\$27/hr 2 hour minimum	
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, Companion	\$35/hr 3 hour minimum	Best Friends Approach™

HOME CARE

ParaMed	paramed.com 403-228-3877	RN, LPN, HCA, Companion	\$26/hr HCA, \$37/hr LPN, \$60/hr RN	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, PT, OT	\$32.00/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
Senior Homecare by Angels	seniorhomecarecalgary.com 403-862-0129	LPN, HCA	\$32/hr 4 hour minimum	GPA, Dementia-Friendly Approach
Supportive Outings and Services	soscaregiver.ca 403-816-0428	HCA, Companion	\$29.95/hr 1.5 hour minimum	Companion Care; Supported Transport
Vinnette Morgan	vinnettemorgan@yahoo.ca 403-919-4052	Nursing Attendant	\$25/hour	Client Dignity; Help Clients Stay at Home
Vytality at Home	vytality.ca 403-476-3680	RN, LPN, OT, HCA, Rec Therapist, Physio, Companion	\$33/hr 2 hour minimum	Supportive Pathways; Person-Centred



OVERNIGHT RESPITE - Assessment Required

FACILITY 	BUILDING ADDRESS 	PHONE NUMBER 	WEBSITE 	SUBSIDIZED	PRIVATE
AgeCare Glenmore	1729 – 90 Avenue SW	403-253-8806	agecare.ca/glenmore	●	
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		●
Manor Village at Fish Creek Park	22 Shawnee Hill SW	587-392-2400	themanorvillage.com	●	●
Manor Village at Varsity	40 Varsity Estates Circle NW	587-393-9999	themanorvillage.com		●
McKenzie Towne Care Centre	80 Promenade Way SE	403-508-9808	reveraliving.com	●	●
McKenzie Towne Retirement Residence	20 Promenade Park SE	403-257-9331	reveraliving.com		●
Millrise Seniors Village	14911 – 5 Street SW	403-410-9155	retirementconcepts.com	●	●
StayWell Manor Village at Garrison Woods	174 Ypres Green SW	403-242-4688	themanorvillage.com		●
United Active Living at Garrison Green	3028 Don Ethell Blvd. SW	403-685-7200	unitedactiveliving.com		●
The Journey Club at Westman Village	176 Mahogany Centre SE	403-313-5478	westmanvillage.com		●

The BSF = The Brenda Strafford Foundation

*Confirm dates and times with individual programs

ADULT DAY PROGRAMS







FACILITY 	PROGRAM NAME 	BUILDING ADDRESS 	PHONE NUMBER 	WEBSITE 	SUBSIDIZED 	PRIVATE 
AgeCare Glenmore	AHS Adult Day Program	1729 – 90 Avenue SW	403-253-8806	agecare.ca/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	Dementia Day Program	21 Auburn Bay Street SE	403-234-9695	allseniorscare.com		●
Bethany Harvest Hills	Club 36 Adult Day Program	19 Harvest Gold Manor NE	403-226-8201	alzheimercalgary.ca	●	
The BSF Bow View Manor	AHS Adult Day Program (including Dementia Program)	4628 Montgomery Blvd. NW	403-286-6166	theBSF.ca	●	
The BSF Clifton Manor	AHS Adult Day Program (including Early Onset and Dementia Programs)	4726 – 8 Avenue SE	403-204-9969	theBSF.ca	●	
The BSF Wentworth Manor	Adult Day Program	5717 – 14 Avenue SW	403-686-8602	theBSF.ca	●	
The Calgary Chinese Elderly Citizens' Association	Wellness Day Program, Dementia Day Program *Intended for clients who speak Chinese	111 Riverfront Avenue SW	403-269-6122	cceca.ca	●	
Carewest Beddington	Comprehensive Community Care (C3)	308 – 8120 Beddington Blvd. NW	403-520-3350	carewest.ca	●	
Carewest Colonel Belcher	Wellness Day Program	1939 Veteran's Way NW	403-944-7854	carewest.ca	●	
Carewest Sarcee	Comprehensive Community Care (C3)	3504 Sarcee Road SW	403-686-8140	carewest.ca	●	
Carewest Signal Pointe	Carewest Signal Pointe Adult Day Program	6363 Simcoe Road SW	403-240-7953	carewest.ca	●	
Manor Village at Fish Creek Park	Programs offered through The Academy of Aging	22 Shawnee Hill SW	403-918-2127	themanorvillage.com	●	●
Millrise Seniors Village	Wellness Day Program, Dementia Day Program	14911 – 5 Street SW	403-410-9155	retirementconcepts.com	●	
Monterey Seniors Village	Wellness Day Program	4788 Catalina Blvd. NE	403-207-2929	retirementconcepts.com	●	
Newport Harbour Care Centre	Adult Day Program	10 Country Village Cove NE	403-567-5100	parkplaceseniorsliving.com	●	●
Peace of Mind	Peace of Mind Adult Day Program	#26, 5440 – 4 Street NW	587-887-4900	peaceofmindcare.ca		●
SAIT Wellness Centre	YouQuest - A Wellness Community for Young Onset Dementia	1301 – 16 Avenue NW	403-255-7018	youquest.ca		●

*Confirm dates and times with individual programs

ADULT DAY PROGRAMS

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

CARE PARTNER SUPPORT

PROGRAM 	PROGRAM DETAILS 	PHONE NUMBER 	E-MAIL 	HOURS 	DATES 
Alzheimer Society of Calgary	Contact the Society for program details	403-290-0110	findsupport@alzheimercalgary.ca	8:30 a.m. to 4:30 p.m., Mon-Thurs; 8 a.m. to 4 p.m. Fri	
Calgary N.E. Dementia Support Group	Dementia-specific support	403-273-2371	Call Jean, at number listed	7 p.m.	Last Thursday of each month
Conversation Café	Dementia-inclusive get-togethers for caregivers and their partners	403-290-0110 x 237	kim@dementianetworkcalgary.ca, dementianetworkcalgary.ca	Dates and times available on website	
Dementia Caregiver Support	Dementia-specific support Southwood United Church, 10690 Elbow Dr. SW	403-253-2979	southwoodchurch.ca	1 p.m.	1st Monday of each month
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.	Learn coping strategies in a safe, fun environment. For those with early-stage dementia and their care partners	403-955-1674	family.caregivercentre@ahs.ca	2 hr Sessions	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 (subject to change)

*Confirm dates and times with individual programs

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



Marjorie Many Wounds-Many Guns and her husband, John Megahy.

Marjorie's STORY

BY Stephanie Joe PHOTOGRAPHY BY Jared Sych

Marjorie Many Wounds-Many Guns was born in 1928 to parents Sara Many Wounds and Tom Many Guns on the Tsuut'ina Nation (even though she is a member of the Siksika Nation). She spends her days doing puzzles with her husband, John, and taking daily walks.

PUZZLES LINE THE WALLS of the Siksika Elders' Lodge on the Siksika Nation where Marjorie Many Wounds-Many Guns and her husband, John Megahy, have been living since 2015. Together, the couple completed each puzzle, and even more puzzles wait to be glued and displayed.

Puzzles and crosswords are a part of Marjorie's daily routine. Her husband believes they help her memory. She began showing signs of dementia in 2014 at the age of 86.

The couple share a suite at the lodge, which is filled with pictures of loved ones and a younger Marjorie and John.

They met 50 years ago as nurses at the Glenmore Auxiliary Hospital in Calgary. She had been married before when they met and had five children from her first marriage, and John had three of his own. Together, they would parent two more children, all while working full-time as nurses. They also raised a grandson who became a police officer and is now a safety inspector.

Marjorie was one of the first Indigenous nurses in Alberta, and she went on to train in psychiatric nursing at the Goderich Psychiatric Hospital in Ontario. She was very active in the community and loved to be outside.

"I went swimming, horseback riding, skating and skiing," Marjorie says. "I was active the whole way through [my youth]."

"Today, I still like to walk — I'm active."

Marjorie takes daily walks within the lodge and, if it's nice enough outside, she'll take a walk around the grounds with the help of a nurse. She still has an appreciation for nature and believes in being active on a daily basis.

"Look at that beautiful tree," Marjorie says as she looks outside during a particularly windy day. "If it was in front of my window, I would be looking at it all day. That's all I'd do for entertainment." 📺

Share your story with us at feedback@dementiaconnections.ca



Dementia
Advocacy
Canada

Voices of Lived Experience

We are a grassroots group of Canadians living with dementia and care partners.

Our mandate is to establish an active and respected role in decisions about government policies and programs that impact our lives.

Let's speak up.

- > Book a meeting with your newly elected MP
- > Ask about their connection to dementia and tell them about yours
- > Make sure they know about Canada's National Dementia Strategy
- > Ask them to support the creation of an All-Party Dementia Caucus
- > Take a photo with your MP and send to admin@dementiacanada.com

**Canada needs
an All-Party
Dementia
Caucus.**

Join us at:

www.dementiacanada.com



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.

Supportive Living and Long-Term Care

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

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

For more information, please contact us:

403.210.4600 or **1.888.410.4679**

email: info@bethanyseniors.com

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CREATING CARING COMMUNITIES