

# DEMENTIA connections

Spring 2019

YOUR  
GUIDE TO  
LIVING  
WELL IN  
CALGARY

## SAFE TRAVELS

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AND TRICKS  
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MEMORABLE  
HOLIDAY AWAY

DEMENTIA-  
INCLUSIVE  
INITIATIVES,  
ADVICE FOR  
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INVALUABLE  
RESOURCES  
AND MORE

## FindingJOY

*Cathie Thrall has a full and colourful life*





The first morning I helped Stanley down the stairs, the third step creaked. That's when I found out his wife, Martha always told him to fix it. And now he's just glad he never did, because that's home. I love hearing Stanley's stories about home. And now I get to be a part of them.

*Maddie G.*

– Maddie G.  
Stanley's CAREGiver



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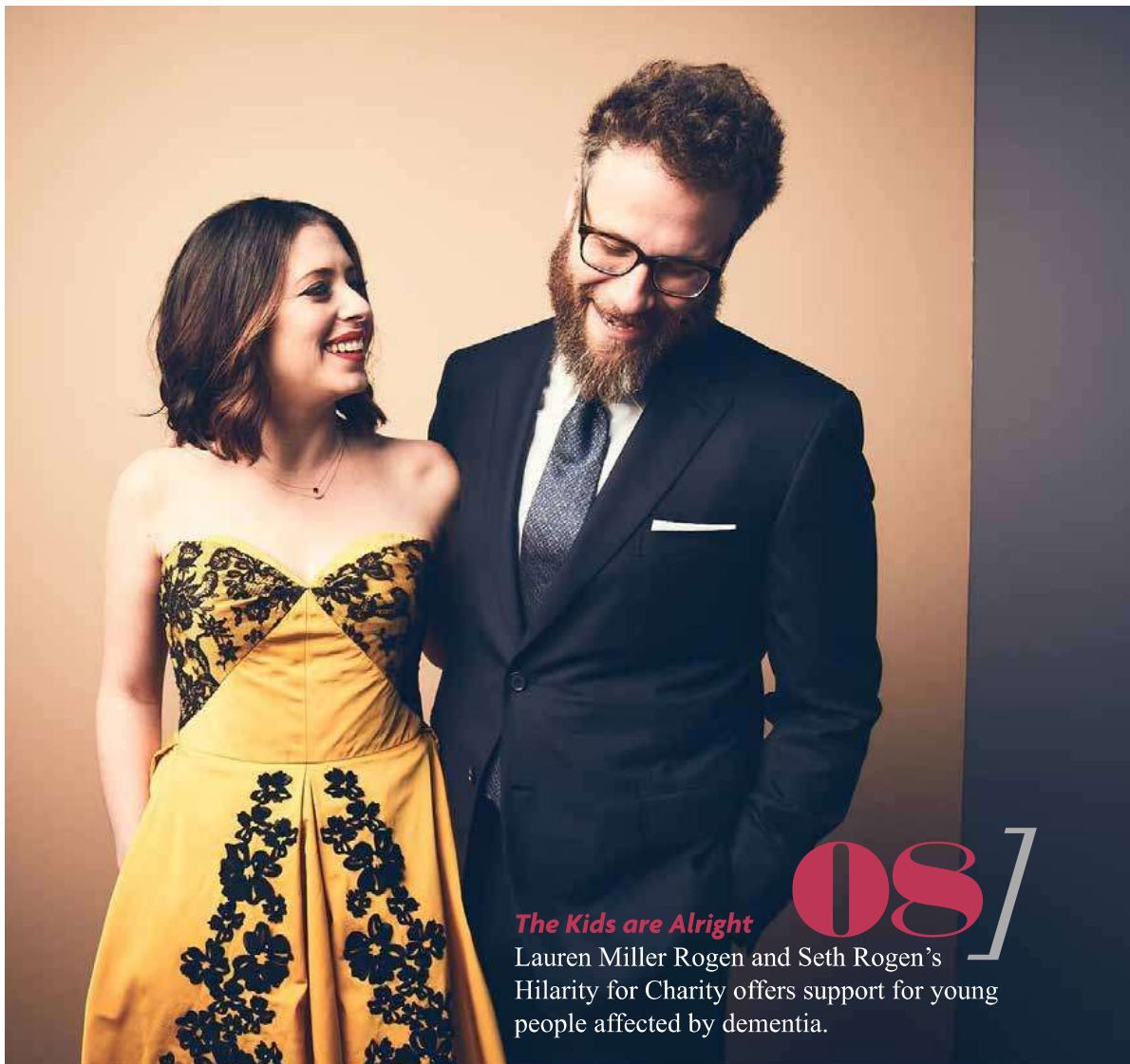
A listing of dementia-related services and resources, including public and private residential care facilities.

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

## WELCOME

PEOPLE AROUND THE WORLD are demanding better for those who are impacted by dementia. Alberta's upcoming provincial election and Canada's upcoming federal election are the perfect opportunities to speak up and educate politicians about the impacts of dementia on you and your family. Need ideas? Check out page 11 for suggestions for questions to ask candidates, provided by Kim Brundrit of Dementia Network Calgary.

Ron Posno and Dana Livingstone are two Canadians who have been

speaking up. They are challenging Canada's MAID legislation. See page 48 to better understand the complexities of this important and controversial issue.

Susan McCauley is another Canadian who is speaking up. McCauley, along with other respected dementia experts like Dr. Allen Power, are urging the medical community to discontinue using the label of Behavioural and Psychological Symptoms of Dementia (BPSD). See page 13 for more details.

This issue is also packed with stories about new innovations, promising research, risk reduction reminders and people who are helping those impacted by dementia lead the best life possible.

Keep sending your feedback — we love hearing your stories and suggestions! 📧

**Lisa Poole**  
Founder and Editor  
DEMENTIA CONNECTIONS  
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**WITH GRATITUDE** *Thank you for the memorial tribute in honour of Willem Kamphorst who passed away on September 29, 2018. We deeply appreciate your support.*





Hi Lisa,

Thank you so much for helping me out with this journey I have begun. Your magazine has a tremendous amount of information in it that is all the more valuable because it has such local sources. Kindest regards,

**Dementia Connections reader**

Hello Lisa,

Thank you for your insightful and interesting magazine.

Your work is much appreciated.

I have dementia in my family and will likely have it myself one day. As such, I'm very curious about the various stages a person who is diagnosed with dementia may experience.

Three specific things in the latest volume (Fall 2018) were of special interest to me:

1. "Nothing About Us Without Us" (page 18, the story of Mary Beth Wighton). Specifically, her mention of when she decided to stop doing her own banking



2. Q&A with Dr. David Hogan about driving (page 20).

This was superb! Especially the great question and the very clear answer to "What are the signs that it's time [...] to stop driving."

I was also encouraged with the sidebar: "7 tips for safe driving with dementia"—so it is possible! I want to learn more about it.

3. On the inside of the back cover page, there is an ad for Dementia Alliance International. The ad tells the story of

Kris McElroy. I found the last paragraph very encouraging:

"Today, a year later since his dementia diagnosis, Kris ... continues to live independently with the help and support of his devices"—wonderful!

**Gordon**

Hi Lisa,

Your website is amazing. It provides a lot of very useful information from different contributors resulting in a final product that is both very elegant and professional.

**Paul Thibault**

Hi Lisa,

My mom has dementia. A few nights ago I slept over at my mom's place. She came in and woke me up and asked about the kids. [She was] wondering when they were coming home? I told her I was there and her response was, "No silly, the little ones." I asked her who [she meant]. She said, "You know, Clint, Penny, Glen and Tammy." I told her, "I am Penny," and she asked how old I was. I told her, "54." She [said], "Oh wow! That makes me old." I explained to her that Tammy lives with her husband, Glen lives with his girlfriend and Clinton is in the hospital with his dementia. Mom remembered Clinton's in the hospital and not getting

out. So, after the small talk she settled down and finally went to bed. This is hard realizing that your mom doesn't realize the kids are all grown up and not living at home anymore.

**Penny Burton**

Hi Ms. Poole,

I happened to come across your magazine while searching the internet and wanted to tell you how informative and fantastic I thought it was. I live in New Jersey and I'd love to receive a magazine like this for free. In addition, it would be wonderful to see an issue including the certified recreation therapist and their role in being the qualified provider for recreation therapy in the home for people living with dementia.

Best,

**Karen Barrack, MA, CTRS, CDP**

Founding Partner,  
Life Vision Health, LLC

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

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Galvin Family Fund at the Calgary Foundation





# THE KIDS ARE ALRIGHT

BY Sean P. Young

*From global networks to exciting charities, a growing movement of young people is finding new ways to support each other and spark innovative ideas in dementia prevention, research and care*



Lauren Miller Rogen and Seth Rogen founded Hilarity for Charity in 2012. Opposite page: Hilarity for Charity is currently streaming on Netflix.

This page and facing page top: photos courtesy Hilarity for Charity and Getty Events; facing page bottom: photo courtesy Laura Bovi



**L**auren Miller Rogen, an actor, screenwriter and director, started Hilarity for Charity (HFC) with her husband (actor, writer, producer, and director), Seth Rogen, in 2012. The charity seeks to be “a resource for the millennial generation, to help bridge the gap in understanding the landscape of Alzheimer’s disease,” which speaks directly to Rogen’s own experiences. Her mother was diagnosed with Alzheimer’s when Rogen was 25. She also lost both her grandparents to the disease before her 19th birthday, and, like many young people in her situation, adjusting to life as her mother’s disease progressed was painful and difficult.

“It just wasn’t something I was prepared for, nor was it something any of my friends were even talking about,” she says. “I just felt very alone, and when I went online, it was a lot of sad, scary stories.”

Rogen tried to go to a support group, but the participants were all much older than her at the time, making it hard to connect and find common ground.

“Their situations are devastating as well, but I just couldn’t relate,” she says.

Rogen and her husband planned their



first HFC variety show fundraiser in 2012, a star-studded night that featured the talents of Bruno Mars, Paul Rudd and many more. The organization quickly evolved to become a global resource for young people wanting to join the fight against Alzheimer’s disease — which wasn’t a specific goal at the outset, Rogen says.

“At the time I don’t know if I understood we were going to do something that spoke to young people,” she says. “It was more I felt alone, and I knew I felt alone.”

HFC has raised more than \$10 million (USD) through its many programs including its annual variety show (the most recent version is currently streaming on Netflix starring comics such as Michelle Wolf and Tiffany Haddish). HFC’s initiatives include a home care grant program that offers respite for care partners, offered in partnership with Home Instead Senior Care (learn more on page 68), as well as university fundraising platforms and online support groups for young people.

Rogen says young people are breaking down the stigma surrounding Alzheimer’s and dementia by sharing their stories, and she is grateful HFC can help create better understanding and outcomes for millennials and their families.

“We’re connecting people who understand what it’s like to be starting out in their adult lives and dealing with a family member with Alzheimer’s,” she says. “We don’t need to feel alone. We wanted to do something to empower young people.”

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To learn more about Hilarity for Charity, visit [hilarityforcharity.org](http://hilarityforcharity.org).

## WORLD YOUNG LEADERS IN DEMENTIA



**W**hen Laura Booi, who is in her 30s and has a PhD in gerontology, couldn’t find a global network for emerging dementia researchers, she helped create one. In 2014, Booi co-founded WYLD, or World Young Leaders in Dementia, which describes itself as “a network of passionate young professionals working across disciplines and borders to develop innovative dementia solutions.”

“There was no group like this specifically for internationally-led dementia researchers and advocates,” Booi says. “None of us are being paid for it. We’re just coming together because we really believe in this, we enjoy each other’s company, and we get a lot from the collaboration and networking we offer each other.”

Currently working as an Atlantic Fellow with the Global Brain Health Institute at Trinity College in Dublin, Ireland, Booi connects virtually with dementia researchers, advocates, and care workers in the WYLD network to share the latest insights into dementia treatment, prevention,

and research. She says the enthusiasm the younger talent brings has helped WYLD grow quickly into a comprehensive group of subject matter experts that have informed dementia policy for the World Health Organization, the United Nations and the World Dementia Council, of which WYLD is an affiliate.

“We bring a lot of innovation, energy and creativity to the table,” Booi says. “If you are a millennial working in this space, you do have a lot to offer. Contact us, join our conversations.”

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Visit [wyldementia.org](http://wyldementia.org) to learn more.





From left: Roger Marple with premier Rachel Notley and MLA Bob Wanner.

## SPEAK OPENLY AND CHALLENGE STIGMA

Roger Marple is living with dementia, and he wants to talk about it

BY Karin Mantyka

**T**hese days, Roger Marple is more than willing to speak openly about his dementia diagnosis. He's matter-of-fact when he describes his boss's confusion about his deteriorating performance at work, and candid about how he finally went to a neurologist in 2015 to be told he had "Alzheimer's with vascular components."

He's also open about his initial feelings four years ago.

"I felt shame at first — and for quite

a while," says Marple. "I was in a pretty dark place when I was first diagnosed, and I did feel uncomfortable with the public's perceptions [of me]. And as time went on, I saw more examples of stigma for individuals living with dementia."


According to a survey conducted by the Alzheimer Society of Canada in November 2017, Canadians recognize that individuals living with dementia are subjected to various forms of stigma and experience it far more than Canadians living with other physical health

challenges. The survey found that Canadians believe stigma can result in individuals with dementia being frequently taken advantage of, socially rejected or avoided, ignored or dismissed. Yet despite this recognition, more than 50 per cent of Canadians surveyed admitted to using stigmatizing language, such as telling jokes about dementia.

Marple has seen first-hand how dementia stigma can lead to problems like social isolation, depression, shame and embarrassment. He's working hard to change that.

Recently, Marple started wearing a blue tie dotted with forget-me-not flowers — and encouraging others to wear one, too. These forget-me-not ties (and scarves for women) — a symbol meant to reduce dementia stigma and encourage positive conversation — are originally from the Alzheimer Society Lanark Leeds Grenville in Ontario. Marple brought the ties to Alberta. He meets with politicians and prominent researchers to talk about dementia and dementia stigma, invites them to wear a tie and snaps a photo. Marple then shares it on his Twitter feed to further awareness.

Marple also sits on the board of directors for the Alzheimer Society of Alberta and Northwest Territories, is on the advisory board for the Alzheimer Society of Canada and frequently presents on the topic of stigma. Marple hopes to encourage conversation, remove the negativity that clouds most dementia conversations and educate the public about what living with dementia is really like.

"If people respectfully challenge stigma, that is how we are going to start to change stigmatizing perceptions of individuals with dementia," says Marple. "My hope is that by speaking candidly, frankly and openly, other people will start feeling more comfortable speaking up." 

"If people respectfully challenge stigma, that is how we are going to start to change stigmatizing perceptions of individuals with dementia." —Roger Marple

Forget-me-not ties and scarves are available for purchase at [monarchclothes.com](http://monarchclothes.com). Learn more about Monarch Clothes on page 35.



# QUERIES FOR THE CANDIDATE

BY Mae Kroeis

**W**ith the upcoming provincial election this spring, your local MLA candidates want to understand the issues that are important to you, including questions and concerns about dementia care.

Kim Bundrit of Dementia Network Calgary says this is the perfect time to increase awareness about dementia and provide education. “[Now is the time to] make it an issue. Talk to everybody you can who is running or is in a campaign and put it on their radar so that when they get elected, they know more than they did before,” says Bundrit.

According to Bundrit, the best way to raise your dementia-related concerns with your local MLA candidate is to be specific and personal. Share why things aren’t working for you and your family, or why they are. Gauge the candidate’s level of understanding by their response and, if necessary, offer to provide education and additional information, available from your local Alzheimer Society. Lastly, Bundrit says to ask the candidate how they plan to address your concerns if they are elected.

## 8 QUESTIONS

Brundrit suggests asking your MLA candidate these specific dementia-related questions

*“If you are elected, what will you do to...”*

- 1 Improve access to support and care at every stage for people impacted by dementia (including their family and care partners)?
- 2 Ensure easy-to-follow pathways or patient navigators are in place for people impacted by dementia?
- 3 Ensure paid care providers are providing evidence-based, best practice care for people impacted by dementia?
- 4 Ensure training is available for the families and care partners of people diagnosed with dementia?
- 5 Reduce stigma and therefore isolation of people diagnosed with dementia and their care partners?
- 6 Support increased/consistent staffing in care homes?
- 7 Increase recreational opportunities for people impacted by dementia?
- 8 Meaningfully include people living with dementia in program development? 

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




## A NEW STRATEGY

**I**n June 2017, the National Health Minister was directed by Parliament to begin development of a national dementia strategy in tandem with provincial and territorial representatives. After two years of consultation, Canada’s national dementia strategy will be officially released June 2019.

### Why does it matter?

Currently, more than half a million Canadians are living with dementia and by 2031, that number is projected to double. Canada needs a comprehensive and coordinated approach to research, treatment and care in order to provide the best possible outcomes for people living with dementia and their families.

### A Community Investment

The federal government announced \$20 million over five years, starting in 2018/19, to support community-based projects that address the challenges of dementia. The initiative, called the Dementia Community Investment project, aims to optimize the health and well-being of people living with dementia and their care partners through the development of resources that support self-care, new dementia-friendly approaches in assisted-living communities, innovative approaches to reducing stigma and more. 

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



# A JELLY FOR YOUR THOUGHTS

Hydrating treats serve multiple purposes

BY Meredith Bailey

**W**hen Lewis Hornby's grandmother, Pat, who is living with dementia, was rushed to the hospital, his family was told to expect the worst. It turned out that she was severely dehydrated and, after receiving fluids, made a full recovery. A common concern for people living with dementia, dehydration can be caused by a variety of reasons, including

forgetting to drink, no longer feeling thirst, or struggling to use a cup.

Inspired by his grandmother's experience, Hornby decided to tackle the issue of dehydration for people living with dementia as part of his double master's program in Innovative Design Engineering at the Royal College of Art in London, England. He spent several weeks at his grandmother's care home and observed the residents' behaviour. He noticed that many struggled to eat with utensils but had fewer issues using their hands. Residents also understood and enjoyed the social nature of sharing a treat, such as eating a box of chocolates. Building on these observations, Hornby created Jelly Drops — sweet, colourful, ultra-hydrating, bite-sized gummies made up of approximately 90 per cent water.

Hornby's degree show garnered a lot of attention; he won the Dyson School of Design Engineering DESIRE Award for Social Impact, among others, and received multiple offers to trial Jelly Drops at care homes in the U.K. In October 2018, after a successful crowdfunding campaign, Hornby founded Jelly Drops as a company.


Nick Hooton, Jelly Drops CEO, says the gummies look like a treat, not medication, which helps create positive

interactions between people living with dementia and their care partners.

"It's designed in a fun, friendly way," Hooton says. "It's not designed as a medical intervention, but a talking point for carers and family members to engage with them."

The box opens easily, and each brightly coloured gummy is easy to see and pick up. "You can leave [the box] on the arm of a chair, and they can eat them as they wish," Hooton says. "It's an engaging, more independent way for people with dementia to hydrate."

The drops come in a variety of flavours, including lemon and strawberry, and are a little bit sweet but include little or no sugar. One box is equal to about three glasses of water.

The product is still in the development phase, and the company has recently partnered with a London university's food innovation lab to refine its recipe. Hooton says the goal is to begin mass manufacturing in the next year, with plans to expand into North America in the next few years. Meanwhile, Jelly Drops is looking for people interested in product trials or assisting with business partnership. 

Learn more at [jellydrops.co.uk](http://jellydrops.co.uk).



Lewis Hornby's grandmother, Pat, enjoys a box of Jelly Drops.



**DID YOU KNOW?** You can self-refer to AHS Home Care or even call on behalf of a friend or neighbour who might need some help. Call 403-943-1920 to learn more.



# CHALLENGING THE BPSD LABEL

BY Victoria Lessard

Over the past 10 years, Susan Macaulay says dementia has become her life. A fierce advocate for people living with dementia, Macaulay runs the website *My Alzheimer's Story*, where she discusses her own experience and shares resources for care partners. Macaulay also raises awareness about the overuse of antipsychotic drugs in dementia care, something she is passionate about changing after her mother's experience in a long-term care facility. Macaulay's voice is one of many in the call to re-examine how dementia care is thought of and facilitated — especially the use of the label BPSD.

BPSD stands for Behavioural and Psychological Symptoms of Dementia. This is the International Psychogeriatric Association's (IPA) categorization of behaviours that are determined to be



“Care workers and family members who are care partners need to put themselves in the shoes of the person living with dementia.” —Susan Macaulay

a result of dementia. The IPA further breaks down BPSD into two groups: psychological symptoms, such as anxiety or depression, and behavioural symptoms, such as aggression, wandering or screaming.

Geriatrician, author and public speaker Dr. Al Power argues that the categorization of these behaviours as symptoms of BPSD is fundamentally incorrect. “What the abbreviation says is that people do these [things] because they are symptoms of dementia. That's a flawed assumption,” says Power. “I see [dementia] as an enabler of distress rather than the root cause. By saying these are symptoms of dementia means that we ignore a host of relational and environmental factors that are coming into play during any interaction.”

Power uses an example of a cold shower to demonstrate — while someone without dementia would turn the knob to make the water warmer, a person living with dementia who is being given a shower and is not able to communicate in the same way might react by screaming.

“The dementia does make the person less able to cope or communicate, but the root cause is not the dementia, the root cause is the cold shower,” says Power. “We all have times when we get angry or frustrated or scared and for us that's part of the range of human expression. But for a person with dementia, these things become a ‘behaviour’ that somehow has to be ‘managed.’”

Macaulay witnessed this during her

“What the abbreviation says is that people do these [things] because they are symptoms of dementia. That's a flawed assumption.” —Dr. Al Power



daily visits to her mother's long-term care facility.

“What is often done [in the long-term care system in Canada] is people are medicated with antipsychotic drugs to make them more compliant because there aren't enough [care workers] or they aren't trained to engage properly with people who are living with dementia,” says Macaulay. “I saw all of that every day. It was distressing for both myself and my mom. She was given medications early in the morning and would be asleep for most of the day.”

Power and Macaulay would like to see the term BPSD removed from the language surrounding dementia care. Macaulay has a powerful survey on her website that uses the Nursing Home Behavior Problem Scale to ask respondents to consider what they would do in a similar situation. One such example is the ‘symptom’ of resisting care — Macaulay asks: “If a stranger tried to take your clothes off, would you resist?” Ninety-eight per cent of respondents said yes.

“Care workers and family members who are care partners need to put themselves in the shoes of the person living with dementia and ask themselves what they would do in the same circumstances,” says Macaulay. “That's the first step.”




# DEMENTIA QUESTIONS

BY Meredith Bailey

**I**n February 2018, Dementia Network Calgary hosted a political forum on dementia with four provincial party representatives.

Moderated by Lori Williams, associate professor, policy studies at Mount Royal University, the forum featured the UCP's Tany Yao, the Liberal Party's David Khan, the Alberta Party's Greg Clark and the NDP's Joe Ceci. Besides members of the panel, an additional five representatives from a variety of political parties attended the event.

Currently, more than 42,000 Albertans are living with dementia, and that number is expected to increase to 155,000 in the next 30 years. The panel addressed questions regarding the growing rates of dementia, including issues around long-term care, patient navigators, patient advocacy and models of care, caregiver pay and education. Despite the often-divisive state of Alberta's current political landscape, all members of the panel agreed that the question of dementia is a non-partisan issue and needs to be addressed in a meaningful way.

The forum was live-streamed on Dementia Network Calgary's Facebook page. 

Visit [Facebook.com/DementiaCalgary](https://www.facebook.com/DementiaCalgary) to watch the recording of the event.

## COMMENTS FROM THE PANEL



### **On improving care**

"We need a more ambitious dementia strategy. We need to look at the overall continuity of care and respite care. [We] need to improve home care, using a relational model of care, ensuring that the same caregiver comes more often than not, rather than somebody new every day."

—Greg Clark, MLA Calgary-Elbow, Alberta Party



### **On system navigation**

"Navigators can help greatly because of the personal connection that a person can have with the individual and the family to help them get through to understand the complex system that's in place, get better results, and bring up what they need."

—Joe Ceci, finance minister, NDP



### **On increased funding for home care**

"[We're] in favour of more funding for home care and respite care, so they don't have to go to expensive assisted-living facilities where they're going to feel alone and their condition will worsen because they're not around family members."

—David Khan, leader, Alberta Liberal Party



### **On education for caregivers**

"Investment in education for caregivers is an absolute must... we need to ensure they have the abilities and education to care for people."

—Tany Yao, MLA Fort McMurray-Wood Buffalo, UCP



**DID YOU KNOW?** In January 2019, the Canadian Academy of Health Sciences expert panel on dementia released its report outlining priorities for a national dementia strategy. The six-person panel, including University of Calgary's Dr. David Hogan, stresses the importance of quality of life for people living with dementia as well as improved quality and access to care. The report also highlights improved access to supports for caregivers and investment in dementia research. The report helps elevate the conversation around how best to adopt a national dementia strategy. Learn more about the specifics of the report at [cahs-acss.ca](https://cahs-acss.ca).






Colleen Pylypow, Sherbrooke's Manager of Volunteers and Global Events, and resident Malcolm Gilbert enjoying a game of baseball.

incorporates an elder-centred approach, in which residents have control over their care, and it encourages a varied and spontaneous environment. The philosophy encourages the use of the terms "elder" and "care partners" as opposed to "caregivers."

"If you've worked with people with dementia, you clearly understand it is a partnership. People agree or disagree with whether they're going to receive care or not receive care," notes Beatty.

The Sherbrooke Community Centre is home to 263 residents as well as day program participants. It has a community garden, art studio, gift shop, and more, all of which provide access to a healthy community environment where they can choose their activities and day-to-day experiences. Opportunities for intergenerational connections are provided from a daycare and a Saskatoon Public School grade six classroom that also operate out of the centre.

Beatty advocates that people living with dementia be part of healthy, normal communities as opposed to segregating them. She believes people living with dementia benefit when they remain connected to their relationships, nature, and varied activities. "In trying to make the world safe for people living with dementia, [we risk losing] the good parts of life, too."

Beatty offers trainings on the Eden Alternative several times a year. 

Learn more at [sherbrookecommunitycentre.ca](http://sherbrookecommunitycentre.ca) and [edenalt.org](http://edenalt.org).

## A HOLISTIC APPROACH

The Eden Alternative approach to dementia care focuses on the whole human being

BY Mae Kroeis

**W**ell-being is the cornerstone of the Eden Alternative philosophy.

Co-created by Americans Dr. Bill Thomas and Jude Thomas in the early 1990s, the Eden Alternative abandons the institutional approach to nursing home and dementia care and, instead, focuses on the human spirit as well as the human body in order to create a home where residents can thrive.

"Often, we were not taking into account the human spirit, and of course, for people with dementia, the human spirit is central because people with dementia live more

and more in their emotions," says Suellen Beatty, CEO of Sherbrooke Community Centre in Saskatoon, the first long-term care facility in Western Canada to formally register with the Eden Registry as an Eden Alternative home. (The Eden Registry is an international body that honours organizations committed to transforming traditional care approaches through the Eden Alternative philosophy.)

Developed especially for those living with dementia, who tend to be at a higher risk for loneliness, helplessness and boredom, the approach emphasizes the importance of companionship (from both humans and animals) in elder care. It also



## THE EDEN ALTERNATIVE IS GUIDED BY SEVEN DOMAINS OF WELL-BEING

### Identity

The elder's history, and who they are as a person is well-known.

### Autonomy

The elder is empowered to make as many choices as possible.

### Meaning

The elder has opportunities to find meaning from things that really matter to them.

### Growth

Elders can grow through meaningful activities.

### Connectedness

Elders feel connected to others, their environment and nature.

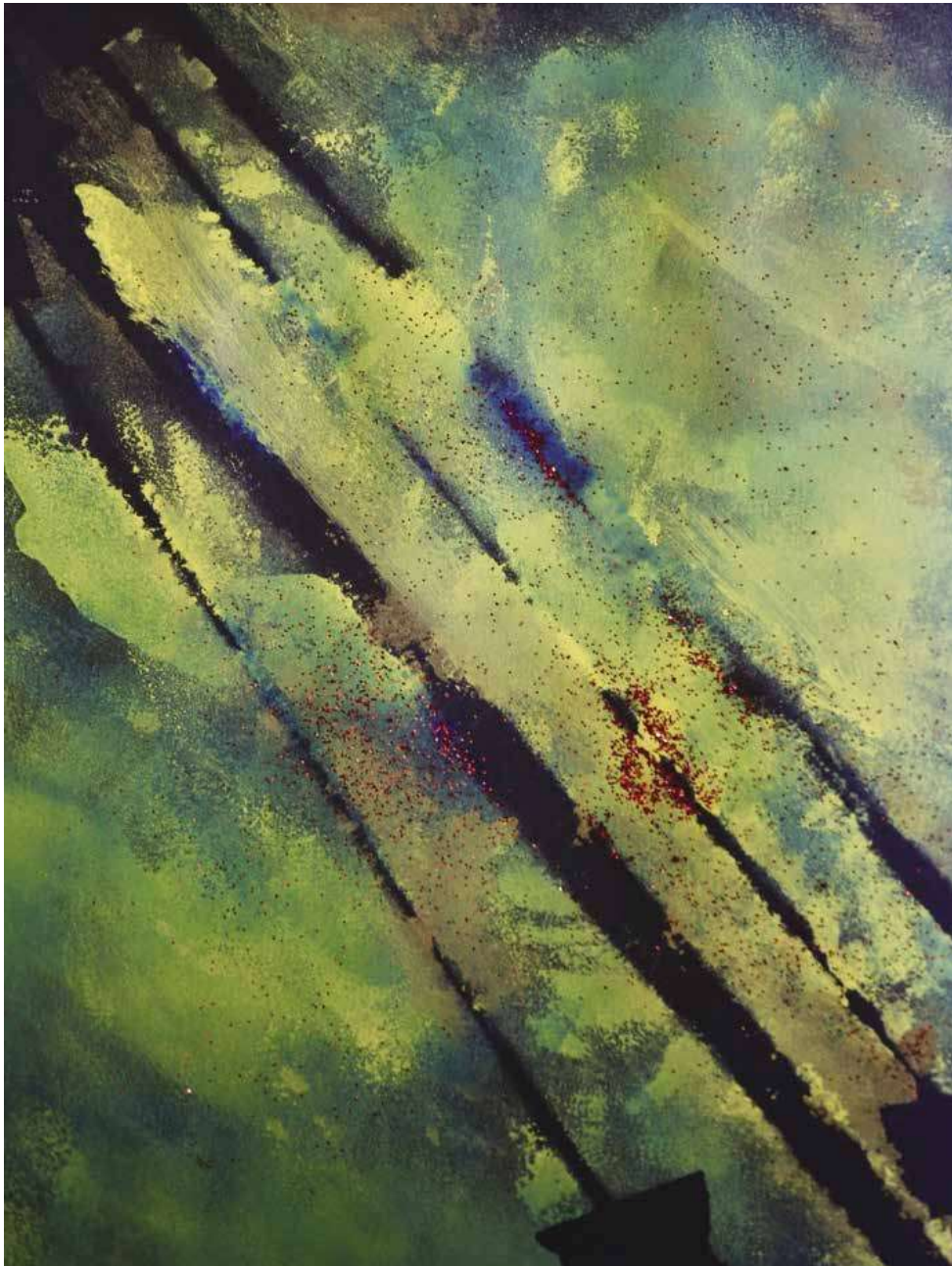
### Security

Elders feel psychologically, as well as physically, safe.

### Joy

Elders experience pleasurable moments.





Left: An abstract art piece created by an OMA participant.  
Below: Collaboration is key to OMA's success.



## OPENING MINDS THROUGH ART MILESTONE

BY Meredith Bailey

**I**n October 2018, the Alzheimer Society of Calgary became the first official Opening Minds through Art (OMA) training centre in Canada, which means more

facilitators can be trained to offer the in-demand program.

Created by Dr. Elizabeth Lokon of Miami University in Oxford, Ohio, OMA is a person-centred, evidence-based


intergenerational art program for people living with dementia. Over the course of eight to 10 weeks, participants co-create an abstract art project, which is presented in an art show.

"The mission of OMA is to bridge the gap and build empathy between younger generations and people living with dementia," says Ali Cada, director of Adult Day and Creative Programs at the Alzheimer Society of Calgary. "For people living with dementia, it allows them to be a teacher."

In Calgary, members of the Alzheimer Society's Club 36 partner with nursing students from the University of Calgary's faculty of nursing, but other facilities collaborate with different intergenerational groups, including middle-aged volunteers and high school students.

The program is designed to give participants living with dementia as many choices as possible in their art making.

"OMA promotes choices and autonomy and dignity for a person living with dementia," Cada says. "The testimony of the students, clients and care partners involved has been life-changing, which is why the program is so successful and effective."

Since the training centre opened, 24 new OMA facilitators have completed the program and a new training session is planned for this spring. 

Visit [alzheimercalgary.ca](http://alzheimercalgary.ca) for more information.

Photos by Ali Cada



# TRANSPARENCY IN LONG-TERM CARE

BY Mae Kroeis


**T**hanks to Private Member Bill 203: Long-Term Care Information Act, Albertans will have access to an on-line resource listing essential information about every long-term care facility and auxiliary hospital in Alberta.

The bill was put forward by MLA Kim Schreiner in Red Deer who, after a career in long-term care, knows how stressful and time-consuming it can be to choose a new home for a loved one. "This one-stop-shop online registry is to help alleviate that stress and make it an easier transition," says Schreiner.

Schreiner also saw how challenging it could be — especially for people with mobility issues, limited vision or cognitive impairment — to visit a facility. The registry aims to be as transparent as possible so people can access information from home in order to narrow down their choices.

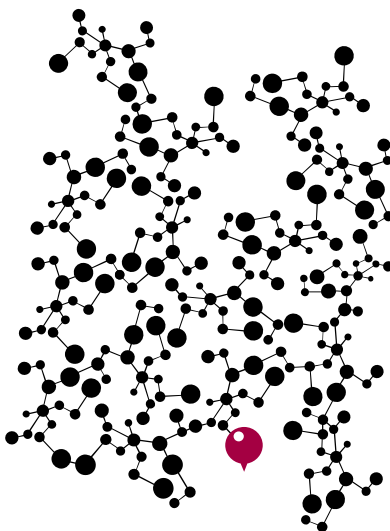
Updated regularly, the registry will include details such as contact information; accreditation status and any inspection results; accommodation charges and what those charges include; other available services such as laundry, foot care, a store, etc.; the number of beds in the facility; whether or not there is a counsellor; the language spoken by staff; memory care unit options and much more.

"We want to make sure our family member is in the perfect home for them," says Schreiner

The bill was passed in June 2018, so Albertans can expect to access the registry in the months to come. It will list more than 170 facilities across Alberta. 

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

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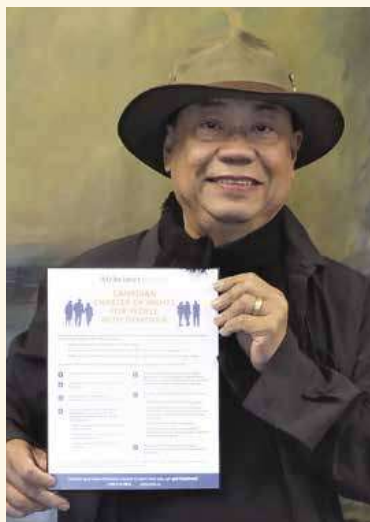
## A NEW ERA OF RIGHTS

**T**

*his past September, the Alzheimer Society of Canada launched the first-ever Canadian Charter of Rights for People with Dementia. The Charter will help people living with dementia, as*


*well as their families, address issues of stigmatization, unfair treatment or discrimination and the right to access appropriate care. For more than a year, the Society worked closely with an advisory group of Canadians living with dementia to determine the Charter's seven specific rights. That group included British Columbian resident Mario Gregorio. In a press release Gregorio says, "As a person living with dementia, it gives me confidence to know that I'm not alone and reassurance that my country, my health and social services and my family, friends and community are there to lend a hand. We, as a nation, need to play a leadership role to ensure that people with dementia are not marginalized."*

*The Charter gives people living with dementia the opportunity to advocate for themselves and ensures that their care partners and care providers know and defend their rights.*



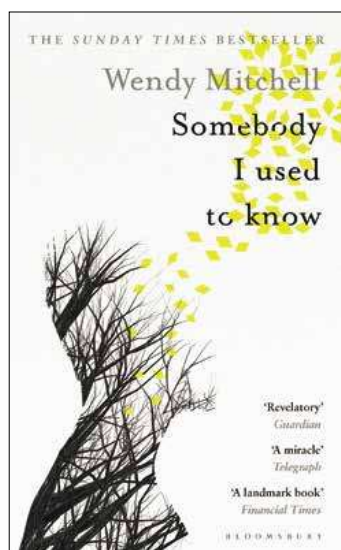
### THE CANADIAN CHARTER OF RIGHTS FOR PEOPLE WITH DEMENTIA INCLUDES THESE SEVEN RIGHTS

- 1 ]** To be free from discrimination of any kind.
- 2 ]** To benefit from all of Canada's civic and legal rights.
- 3 ]** To participate in developing and implementing policies that affect their life.
- 4 ]** To access support and opportunities to live as independent and engaged citizens in their community.
- 5 ]** To be informed and supported so they can fully participate in decisions affecting their care and life, from the point of diagnosis to palliative and end-of-life care.
- 6 ]** To expect that professionals involved in all aspects of their care are trained in dementia and human rights and are accountable to uphold these rights.
- 7 ]** To access effective complaint and appeal procedures when their rights are not protected or respected.

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



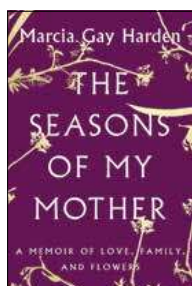
## FOUR BOOKS TO READ THIS SPRING



### Somebody I Used to Know *by Dr. Wendy Mitchell*

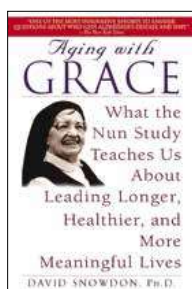
*This 2018 bestselling memoir is a revealing and honest record of one woman's dementia journey. At 58 years old, Wendy Mitchell was diagnosed with young onset dementia. Instead of losing hope, Mitchell chose to embrace her new life while continuing to outwit the disease as long as possible. Written with journalist Anna Wharton, Mitchell shares the story of her cognitive decline and her struggle to make sense of her rapidly changing world and sense of self. Somebody I Used to Know offers intimate, hopeful insight into the disease from the person living it. Today, Mitchell is part of the Three Nations*

*Working Group, is a regular presenter at conferences and contributor to dementia research, and continues to blog about her experience at [whichmeamitoday.wordpress.com](http://whichmeamitoday.wordpress.com).*



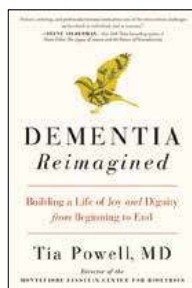
### THE SEASONS OF MY MOTHER *by Marcia Gay Harden*

Academy Award-winning actress Marcia Gay Harden adds author to her resume with her 2018 memoir *The Seasons of My Mother: A Memoir of Love, Family and Flowers*. In this lyrical book, Harden uses ikebana, the Japanese art of flower arranging, as a metaphor for the seasons of her mother's life and diagnosis with Alzheimer's. She also explores her own journey as an artist. Harden's honesty and humour paint a thoughtful and loving portrait of her family's Alzheimer experience.



### AGING WITH GRACE *by David Snowdon Ph.D.*

In 1986, epidemiologist and Alzheimer's expert David Snowdon began a scientific study into aging that involved a community of 678 Catholic nuns. Snowdon's 2001 book, *Aging with Grace*, reveals the fascinating data the project, nicknamed the "Nun Study," collected. Snowdon determined that a life lived in service to others may help us all live longer and healthier lives. Still relevant today, *Aging with Grace* offers practical tips for maintaining and nurturing a healthy brain.



### DEMENTIA REIMAGINED *by Tia Powell M.D.*

Part medicine and part memoir, physician and bioethicist Tia Powell weaves together the medical and cultural history of Alzheimer's disease with her family's personal dementia experience — Powell's grandmother as well as her mother were diagnosed with dementia. In *Dementia Reimagined*, Powell's goal is to shift the focus of the dementia conversation away from that of "cure" to "care." In this hopeful book, Powell offers her perspective on how life can continue to be meaningful and joyful after a dementia diagnosis. 📖



# YOU'RE *Welcome*

Calgary's inclusive offerings for people living with dementia continue to grow

BY Shannon Cleary



## **Memory Lane Chorus**

The Youth Singers of Calgary (YSC) and JB Music Therapy have partnered to create Memory Lane Chorus, an innovative choral program for people living with dementia and their care partners, family members and friends. During weekly 90-minute sessions, participants sing, socialize, and engage in music memory activities and therapeutic drum circles with certified music therapists.

Alida Lowe is the senior program, production and touring manager at YSC. She says the Memory Lane Chorus is tailored to participants' abilities and strengths, creating a safe and confidence-building environment. Lowe says the program intends to include both

new music and songs that hold special memories for its members.

The chorus began its first run in January 2019, with the capacity for up to 25 individuals living with dementia and 25 care partners and will end in April 2019 with a celebration and open house. The cost per pair is \$375.

Learn more at [youthsingers.org](http://youthsingers.org).

## **YouQuest**

John McCaffery was diagnosed with Young Onset Dementia (YOD) in 2007 at the age of 48. McCaffery was an active person before his diagnosis, but he and his wife Cindy soon learned that Calgary

had no relevant daytime support options for active people with YOD.

"I never met anybody or spent time with people my age who were having similar difficulties," he says.

So, Cindy McCaffery and social entrepreneur Myrla Bulman created YouQuest, a wellness community for an underserved population with unique needs and abilities. In 2018, YouQuest received \$50,000 from the Centre for Aging and Brain Health Innovation (CABHI) to develop and evaluate the community-based wellness pilot. YouQuest provides weekly, full-day support to Calgarians with YOD, and its partnership with SAIT Recreation provides a host facility that gives participants full access to SAIT's

Photo by Peter Gros



Wellness Centre. Pilot participants were selected based on a young onset diagnosis by 65 years of age (or prior symptoms and a later diagnosis), and their interest and ability to engage in the active public recreation setting.

The year-long pilot currently involves 10 participants and will continue through to September 2019.

“When the pilot project first started, very few of the participants knew each other,” says John McCaffery, who is on the board of directors for YouQuest acting as an advisor and informal participant in the program. “Now they’ve all come together. It’s nice to see the camaraderie and friendships that are developing.”

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

### Side by Side Program

Alice Post holds a few core beliefs: You don’t need a medical background to provide companionship to someone living with dementia; you don’t have to share the same religious beliefs to enjoy a moment of devotion; and you don’t have to carry a tune to join an afternoon singalong.

Post is the coordinator of Side by Side, an informal care program through St. Andrew’s Presbyterian Church. Side by Side started in 2012 and now runs at two locations in Calgary, on Wednesdays at St. Andrew’s and on Thursdays at Varsity Acres Presbyterian Church, each with approximately five to eight participants. Care partners are offered respite while their loved ones living with dementia are thoughtfully paired with program volunteers.

The volunteers and their companions take part in Brain Gym to stimulate brain function, guided spiritual nurture with a minister, gentle seated exercise, creative time for crafts and games, guest speakers, music therapy, refreshments and singalongs.



Post says the objective is to provide “unobtrusive support” in a relaxed environment, where participants build confidence and social connections through fellowship.

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

### The Open Orchestra

For those living with dementia, a trip to the orchestra can be a strenuous, sometimes startling event. That’s why the Calgary Philharmonic Orchestra (CPO) and Inside Out Theatre have partnered to create The Open Orchestra: A Sensory Friendly Concert, a modified presentation of music’s best-loved pieces. The

experience is part of Inside Out Theatre’s Good Host Program, an audience inclusion and accessibility program.

The CPO’s first “relaxed performance” took place in October 2018 at the Jack Singer Concert Hall and was directed by associate conductor Karl Hirzer. Dramatic sound effects, lighting and abrupt instrumental moments were edited, and guests were offered earplugs and a “visual story” brochure beforehand. Guests were also able to move freely about the theatre and make noise, loosening the etiquette often associated with attending the symphony. 

Visit [calgaryphil.com](http://calgaryphil.com) for The Open Orchestra’s upcoming dates and to learn more.



**DID YOU KNOW?** The Calgary Fire Department recognizes the complex needs of individuals living with dementia, including an increased risk of home fire hazards. Call 3-1-1 to request a free home safety visit from the Calgary Fire Department’s community safety officers.



# LOVING *Mom*

Calgarian **Samantha Palmer-Forrest** shares some of the experiences she's had while caring for her mother and offers insight into the challenges of being a care partner

PHOTO BY **Jared Sych**

**I** have been familiar with Alzheimer's disease my entire life, but for the past three years, it has become a part of my daily routine. My mom, Shawn, was diagnosed with early onset Alzheimer's in 2016 at the age of 56. I became her full-time caregiver at the age of 27.

My mother was the mom that all my friends wanted to have. The one you could talk to about anything. She raised my brother and me as a single parent and was always there for us when we needed her. My mom was kind, affectionate, social, bubbly and funny. I could always depend on her.

My mom started showing symptoms of dementia in the summer of 2015, when she was 55 years old. It began with increased forgetfulness and memory troubles. When she got lost driving to her family doctor's office, I knew something was wrong, and that this was not a normal part of aging.

My maternal grandmother passed away in March 2014 from complications related to Alzheimer's, and her mother, my great-grandmother, passed away in March 2003 from Alzheimer's. My mom

was showing symptoms that were very similar, and I knew in my gut that she had Alzheimer's, too.

My mom insisted that nothing was wrong with her. I made an appointment with her family doctor and she was referred to a cognitive clinic. My mom underwent a variety of tests and on April 1, 2016, she was officially diagnosed with Alzheimer's. I had already accepted that she was ill, but now it had become real and our lives would never be the same.

At the time my mom was diagnosed, I was a full-time online student living at home and I became her primary caregiver. Being her caregiver never felt like a choice, it was something I had to do to thank her for being a great mother and for always being there for me.

Following her diagnosis, my brother and I tried to do whatever we could for my mom, including trying to access all the resources we possibly could. This proved to be very challenging.

My mom receives Assured Income for the Severely Handicapped benefits (AISH) through the government. The program was hard to deal with from the very beginning. My mom's assigned caseworker

changed regularly, they were hard to contact, lost paperwork more than once, were slow to process it, and staff weren't always knowledgeable. It got so bad that my brother and I had to get a social worker to help us.

My mom also had a Dementia Care Team caseworker who worked for Alberta Health Services (AHS). She came to our house and did an assessment but there was little follow-up. Since she was part of AHS Home Care, my mom's caseworker did not continue with us when my mom was eventually placed in a facility. I think it would be more efficient and helpful if dementia support caseworkers were with the family from the diagnosis on, including through home care and during placement. Dementia support requires special training and knowledge that not everybody has.

We tried home care, but my mom absolutely refused to accept it. A different person came each time and mom was very concerned about strangers in her house. She'd cry and get angry and would sometimes lock herself in her bedroom. She wasn't able to get to know them or build a relationship. It should be the same person at the same time every week.

Health care aides weren't allowed to drive my mom anywhere. It would have been incredibly helpful if someone could have taken my mom out for recreation and socialization activities.

"It would be more efficient and helpful if dementia support caseworkers were with the family from the diagnosis on, including through home care and during placement."



Samantha Palmer-Forrest  
with her mom, Shawn,  
and brother, Alex, at  
Shawn's care facility.







As my mom declined, I became her almost constant companion and could not leave her alone for more than two hours. Being my mom's caregiver was a full-time job without pay and it affected my personal life greatly. Most people in their twenties are starting their own lives and families, but I was trying to take care of a parent, finish school, find a new career. I graduated from university in April 2018, but being my mom's caregiver dramatically reduced my job options.

Dating is complicated. I get asked

list for assisted living in November 2017. In August 2018, we got a call that a room was available in a care home. But unfortunately, we had to decline due to a lack of finances. We didn't know that we had to pay for my mom's room. We thought it was covered. More paperwork and assessments had to be done to be eligible to receive long-term care funding. Even then, the care home needed a certain amount of money up front. We thought we could get money from the bank for the interim but were denied. There was

“Caregivers need as much support as people living with Alzheimer's, which isn't always understood.”

whether or not I will get the same disease as my mother. It can be hard to explain to others exactly what it is, and how it impacts daily life. It is often too much to comprehend and they don't want to get involved in my life of caregiving.

Self-managed home care was an option, but one we couldn't use, as family members, friends and informal caregivers are not allowed to be hired as paid care providers. This is very difficult since family members are so often the ones supplying daily care. I had to get support from Alberta Works to find health insurance and funds for myself.

My mom was placed on the waiting

a reverse mortgage on my mom's house that we thought we could get more money from but discovered we were at the max limit. The terms of the reverse mortgage are that the full amount must be repaid in 180 days of my mom being moved to a facility. We would have to get the house ready to sell and make sure it sold in less than six months or we would lose more than \$200,000.

We met with my mom's doctor at the Cognitive Clinic in September. We explained our situation, problems and concerns. He agreed that placement was the best option for my mom and that her quick decline would mean that long-term care was an option now instead of

assisted living. He contacted our Dementia Care Team caseworker to advocate for my mom. Thanks to our doctor, my mom was placed into long-term care in November 2018.

Alzheimer's is seen as a disease that affects only the old, but that is not true. If a parent doesn't have a spouse, then it is up to the children to take care of them. I see others my age buying houses, getting married and having children but I have had to put my energy and focus on making sure that my mom is taken care of. Young caregivers are putting their lives on pause and putting their parent's needs ahead of their own. They need support to get through caregiving, which is a full-time job.

Caregiving is often a thankless job. Being the one closest to my mom, I was often her punching bag. She would take out her frustrations and anger on me and could be verbally abusive. I know it's the disease and I tried not to take anything she said personally.

Caregivers need as much support as people living with Alzheimer's, which isn't always understood. Support is key. I wouldn't be able to make it through without my family and friends. They reassure me and help me at my lowest points. I have to be aware of my own mental health, and when I feel like I am struggling, I have accessed my own community resources and mental health clinic to help me.

My mom is still physically here, but she is not the same person due to changes in personality, mood and behaviour. She is no longer my support system and I cannot confide in her. It is a strange feeling to miss and grieve for someone who I can still sit next to. When I visit her, she recognizes me and starts to cry. My greatest fear is for her to not recognize me and know that I am her daughter. It is hard for me to think about what the future holds. The loss of my mom and the loss of who she is as a person has been devastating. ■



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# A *Sympathetic* EAR

Sharing experiences is vital to care partner well-being

BY Victoria Lessard PHOTO BY Bryce Meyer Photography

**H**ashing out a conundrum over coffee or giving a friend a call can help the stickiest of problems, simply by sharing and feeling heard. The power of connecting is being recognized in the mental health community through formal peer support programs.

Meghan Reid, the recovery college

and peer support lead at the Canadian Mental Health Association (CMHA) Calgary, notes that peer support works well in conjunction with other forms of mental health support. “[Peer support] establishes equality in the caring relationship where the individual can learn and benefit from the similar experiences that others have gone through,” says Reid.

In 2008, Alberta Health Services

established a program focused on peer support for people living with dementia and their care partners. Created by Silver Threads in Victoria, B.C., Memory P.L.U.S. (Practice, Laughter, Useful Strategies) is a 12-week program designed to both inform and create a social space — care partners especially are given the opportunity to connect and share their experiences with one another.





“It didn’t take me long to realize that I needed that support group. It was so important to me.”

—Norma Whitney

“Our caregivers refer to the other people in the group as family,” says Charlene Retzlaff, a social worker and caregiver support with the program. “There’s [a] sense of connectedness. When someone’s going through a crisis, they rally behind them.”

For Norma Whitney, the peer support she found in Memory P.L.U.S. became an integral part of her support system while

she was caring for Donald Cranston, her late husband. Cranston was a busy petroleum engineer who worked overseas, but whenever he was off work, the couple would head out to Vancouver Island to spend time together on their sailboat. When Cranston noticed that he could no longer do tasks that used to come easily, the couple began a whirlwind of doctor’s appointments and visits with

The Memory Plus Alumni Group. From left: Sue Singleton, Marilee Jasper, Diane Poole, Meta Wieser, Bev Will, Norma Whitney and Annette Koelwyn.


specialists — Cranston received a formal diagnosis of Alzheimer’s in early 2013.

“We were both kind of shocked at the diagnosis. We had no idea what we were up against,” says Whitney.

After receiving a visit from occupational therapist Beverly Hillman, who runs the Memory P.L.U.S. program, an initially sceptical Whitney agreed to do the program with Cranston. “It didn’t take me long to realize that I needed that support group. It was so important to me,” says Whitney. “It probably was the one thing that helped me get through every new chapter where something else changed.”

Care partners often put their own self-care at the bottom of an extensive to-do list. In Reid’s experience, isolation is something experienced by a lot of them. “[Peer support] really provides an opportunity for carers to connect and to feel validated,” says Reid. “It reduces burnout [and] they become more aware of resources. Whether that be social networks or support groups online that are informal or different coping and wellness strategies.”

Whitney says that she and the other care partners she met at Memory P.L.U.S. try to get together once a month to give each other comfort, support and a shoulder to lean on. “Our own lives had [been] put on hold for such a long time that even just trying to get together with a bunch of other ladies who all understood what was going on and how you felt was a necessary move for us,” says Whitney.

For other care partners of people living with dementia, Whitney stresses the importance of self-care and participating in a support group. “There’s nothing more important than knowing you’re not alone out there.” 

Email [family.caregivercentre@ahs.ca](mailto:family.caregivercentre@ahs.ca) to register for Memory P.L.U.S.



## A HEAD START

BY Colleen Biondi

*Between our head and shoulders, knees and toes, reducing our dementia risk may be in taking care of our eyes, ears, mouth and nose*







## The Eyes

“Everything we do revolves around good functioning vision,” explains Dr. Regan Nowlan, an optometrist in Calgary. When people age and become less physically able due to decreased mobility, they become more reliant on visual activities like reading and seeing loved ones. When their vision is compromised, they are less able to participate in these activities. This can result in isolation and depression, which may increase the odds of developing dementia.

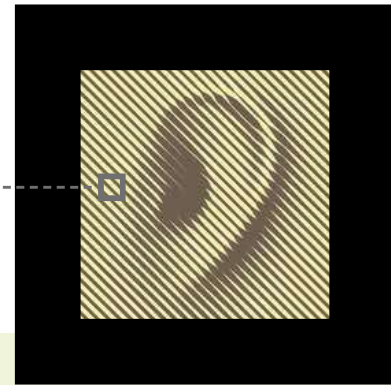
One eye condition that is particularly impactful is age-related macular degeneration (AMD). When the tiny, oval-shaped macula in the retina begins to deteriorate, central vision disappears, leaving only sight in the margins. “If you lose your central vision — what you use to read, to drive, to function — the loss is significant,” says Nowlan.

AMD accounts for 90 per cent of new cases of legal blindness in Canada. Risk factors include age, a genetic predisposition, a history of smoking and sun damage to the eye. Although there is no cure for the condition, the following strategies could reduce your chances of getting it or slow progression if you do.

- 1 Use UV protection with sunglasses and hats
- 2 Eat dark, leafy veggies like kale and spinach, which contain lutein, an antioxidant that has been nicknamed “the eye vitamin” and helps protect the eye by filtering out damaging sunlight
- 3 Be active, which keeps blood flowing to the macula
- 4 Get annual eye exams



**LOOKING DEEPER** With the help of powerful imaging techniques, such as spectral domain optical coherence tomography and hyperspectral imaging, researchers are investigating a link between specific ocular and visual changes in the eye related to the onset of Alzheimer’s disease. With these techniques, optometrists may be able to offer early detection of the disease.



## The Ears

Untreated hearing loss is a big issue, explains Calgary-based audiologist Carrie Scarff, PhD. A 2012-2015 Canada Health Measures Survey reported that 78 per cent of adults 60 to 79 years old have at least slight hearing loss in one or both ears.

This increases the risk of social withdrawal, depression and even cognitive decline.

Think of the ears as a muscle; if you are not getting enough aural stimulation, electrical activity from the auditory nerve to the brain

**78%**  
of adults 60 to 79  
years old have at least  
slight hearing loss in  
one or both ears.

starts to diminish. Hair cells within the ear contribute to the ability to hear, but can become damaged as you age, which means that your brain may not

be able to make sense of what you are hearing. In fact, recent research out of Johns Hopkins Medical Center has noted that after only 4.5 years of hearing loss, functional MRIs have picked up “significant atrophy” of the brain.

If you do not hear as well as you used to, or if you are 60 years old or older, get a thorough quality hearing assessment, suggests Scarff. Use assistive devices if they are recommended. For example, Scarff uses aids for a mild hearing loss and can go for a run and comfortably listen to podcasts on her phone. Preserve the hearing you have by using protective ear muffs or earplugs to muffle loud sounds. Keep the brain active by listening to music and having casual conversations.

Treat the ears well, she says. “They are the doorway to our communication.”



## → The Mouth

"Issues that affect the mouth can have systemic effects on the rest of the body," says Dr. Bruce Yaholnitsky, a Calgary periodontist. Take periodontal gum disease (PGD), for example.

"PGD is a chronic infection that results in low-grade inflammation in the soft tissues around the teeth," he explains. It is a more aggressive condition than garden-variety gingivitis, which affects 32 per cent of the population aged 20 and over. Warning signs for PGD include bleeding gums, but this condition may not be diagnosed until advanced

stages when teeth become loose or abscesses develop.

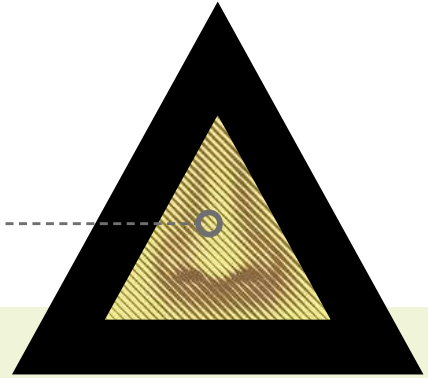
Recently, PGD has been linked with an increased risk of developing dementia. A first-of-its-kind study from the University of Illinois discovered that mice with gram-negative anaerobic bacteria — a dangerous component of PGD — developed more amyloid structures (toxic protein clumps that interfere with cell function) in the brain than mice without the bacteria. "You were able to see the neuropathology," says Yaholnitsky.

The good news is that PGD is preventable. With quality brushing twice a day, flossing at least once a day and regular gum tissue exams and maintenance from your dentist or periodontist, you should be fine.

"Good oral care with regular professional evaluation is important," Yaholnitsky says. "And the sooner you do this, the better. When you are 20, you don't worry about dementia, but that is when gum disease begins."

**32%**

of the population, aged 20 and older, are affected by garden-variety gingivitis

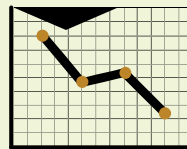


## The Nose

"Smell is connected to food, memory and emotion. It adds colour to our lives," says Jamie Knight, a PhD student with the faculty of psychology at the University of Victoria (UVic). "But historically, olfaction has been an understudied area."

That is changing.

Once standardized, empirical tests were developed in the mid-1980s, "research exploded." We now know that losing our sense of smell can happen as a result of colds (temporary), repeated sinus infections, viruses, certain medications or from head injuries. We also know that cognitive and memory test scores worsen as you lose your sense of smell. Knight is digging deeper into this connection, looking into a variety of factors including how recovering smell may reduce the rate of any cognitive decline.



Cognitive and memory test scores worsen as you lose your sense of smell.

As far as the smell recovery process is concerned, there is good news on the horizon: neurons in the olfactory pathway regenerate. Knight is working on seeing if something called "smell training" helps speed up the process.

This involves a daily process of stimulating the sense of smell with potent aromas (rose, eucalyptus,

lemon and clove oils are popular) to re-awaken olfactory function. "It is like nasal physiotherapy," Knight says. This year, she will conduct a smell training intervention study at UVic, which will be the first of its kind in Canada.

In the meantime, nose care is important to keep that smell function intact. Knight recommends exercising to keep the blood flowing to the nose and paying attention to scents (literally, stopping to smell the roses). Keeping your nose warm, by covering it with a scarf in cold weather, for example, will also ensure your immune system remains strong to keep toxic viruses at bay. [7]

**DID YOU KNOW?** According to a 2017 Ipsos poll conducted for Global News in Toronto, 85 per cent of respondents understood the sooner dementia is diagnosed, the faster it can be treated. But, 30 per cent of respondents also said they would rather not know if they had dementia at all.



# Q + A

Dr. Adrian Wagg  
reflects on the issue  
of incontinence



BY Elizabeth Chorney-Booth PHOTO BY Cooper & O'Hara

**INCONTINENCE** or the inability to control one's bladder is a big fear for many as they age, but it's especially concerning for people living with dementia. Toileting issues are often what determines a person's ability to stay in their home. Accidents related to incontinence are almost always out of the person's

control, but dealing with incontinence is often more than care partners can handle. Dr. Adrian Wagg, professor in the University of Alberta's faculty of medicine's division of geriatric medicine, specializes in the topic of incontinence. He wants people to better understand this condition.







**Q |** Why is incontinence such a pressing issue for people with dementia?

**A |** It's a big concern for patients, but also their care partners. It's such a huge change in roles when partners are having to deliver quite intimate care. It can sometimes be the straw that breaks the camel's back and facilitates the decision to institutionalize an older person. Obviously, it's still very much a taboo kind of condition that people don't talk about.

**Q |** What causes incontinence?

**A |** In later life the most common underlying cause is something we call urgency incontinence, which is an inability to suppress the sensations of bladder emptying, [and] can occur suddenly at any time even when the bladder's not full. There can be a combination of underlying bladder disorders but also a failure of the brain to be able to suppress that sensation.

**Q |** How is this issue compounded for people with dementia?

**A |** A person with dementia may have underlying urgency incontinence, but with the impairment of cognition, perhaps they don't have the ability to recognize the need to toilet normally, to precipitate the right action to find the toilet or to recognize the toilet.

**Q |** Are there specialist services in Edmonton, where you are located, that would be helpful?

**A |** Yes, there are specialist continence services available throughout the city. The main clinics are located either at the Glenrose Hospital, which provides a multi-professional specialist conference clinic and a women's health continence clinic based at the Misericordia Hospital and at the Royal Alexandra Hospital. Other clinics tend to be run by single medical specialists and are maybe less appropriate for those with either dementia or their care partners.

**Q |** Is there anything care partners should know before visiting a specialist?

**A |** Most clinics need a general practitioner referral.

**Q |** What can care partners do to manage incontinence issues?

**A |** It's often about maintaining successful toileting. So that might mean a combination of making sure that the environment is conducive to the individual being able to recognize and to get to the lavatory and that there are no obstacles or things that look like they might be urinals in the house. Things like prompted voiding, suggesting that people go to the lavatory, giving clear instructions and taking people to the toilet regularly can help.

**Q |** Are store-bought pads an effective option?

**A |** Yes, but people do tend to overuse them and change them too often. Most of them have got more capacity to absorb than people think. Often people are concerned about smell, but actually that's seldom a problem. They are more expensive than menstrual products, which many women use for light to moderate incontinence and that's largely because they're so very absorbent. But for dependent individuals, the largest incontinence pads can hold up to a litre of urine without making your skin wet.

**Q |** Are there any new technological advances to help people with dementia deal with incontinence?

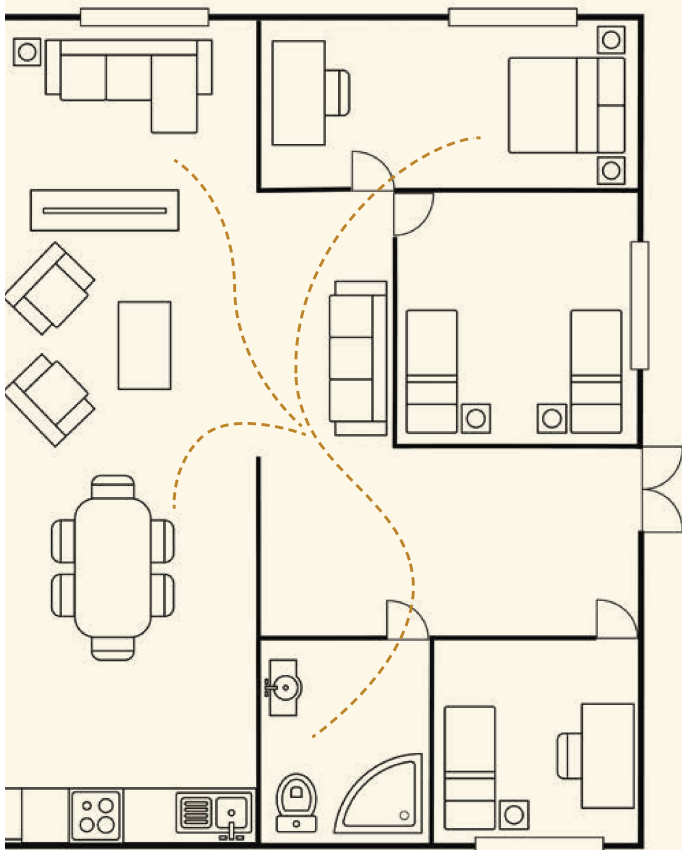
**A |** There are a couple of products that can be used in different situations. [That includes] a pad with a sensor to help people construct a voiding habits calendar, which allows you to institute a prompted voiding program. We're [Wagg's research group] currently testing those and there's one on the market from Australia. There are also pads that signal when they're full to a caregiver by SMS messaging. ■

[ "[Incontinence] is a big concern for patients, but also their care partners. It's such a huge change in roles when partners are having to deliver quite intimate care." —Dr. Adrian Wagg ]



# UNDERSTANDING INCONTINENCE

## 3 ADDITIONAL TOOLS FOR CARE PARTNERS



1

### Clear a Path

Help the person living with dementia easily find the toilet by marking walls or floors with a direct path to it. Ensure there are no obstacles in the way of that path. Try labelling the bathroom door with words or a picture of a toilet.



iStock / Getty Images Plus

2



### Use Colour

Make the toilet easier to find with the use of colour. Use a different coloured toilet seat, coloured tape around the toilet or coloured water in the toilet bowl. Using colour may help people living with dementia more easily locate the toilet, especially if they are struggling with perception issues or loss of vision. Learn more about coloured toilet seats on page 45.

3



### Establish a Routine

Take note if the person living with dementia is drinking large amounts of liquid or taking medication that may be contributing to the issue and adjust accordingly. Offer reminders to use the toilet on a schedule, such as every two hours. Note if there are issues during those two hours and adjust the schedule to best fit with the person's personal rhythm.

## WHERE TO GET MORE INFORMATION

Need more help managing your own incontinence or that of someone you're caring for? Dr. Wagg recommends these online resources to help people manage incontinence with dignity:

### The Canadian Continence Foundation

The CCF's website is full of resources, helping those with incontinence to devise a voiding plan, keep track of symptoms and destigmatize the condition. [canadiancontinence.ca](http://canadiancontinence.ca)

### Continence Product Advisor

This informative site breaks down the differences between various pads and other incontinence products to help those with incontinence decide what works best for their specific needs. [continenceproductadvisor.org](http://continenceproductadvisor.org)

## SELECT INCONTINENCE SPECIALISTS IN CALGARY

### The Alberta Bladder Centre (VESIA)

(403) 943-8900, [vesia.ca](http://vesia.ca)

### Claire Harris-Intrinsi Physiotherapy

(403) 229-9214, [intrinsi.ca](http://intrinsi.ca)

### Dr Leanne Kroeker - The Pelvic Floor Clinic

(403) 944-4000, [ahs.ca](http://ahs.ca)

Share your questions with us at [feedback@dementiaconnections.ca](mailto:feedback@dementiaconnections.ca).



# 4 INNOVATIONS IMPROVING DAY-TO-DAY LIFE

BY Jennifer Dorozio

*From adaptive clothing to interactive home care, these new technologies make a difference for people living with dementia*



## Marlena Books

After watching her grandmother, who is living with dementia, successfully read a wordy newspaper headline out loud, Rachel Thompson, a then-University of Waterloo student, had an “aha” moment.

“[My grandmother] was always an avid reader but as her dementia progressed, we noticed her struggling with

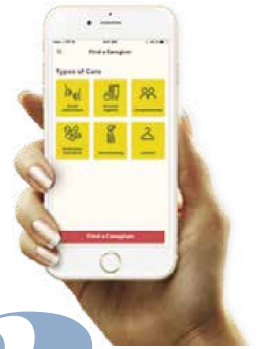
traditional books,” says Thompson. But she realized, “It wasn’t that Grandma couldn’t read, just that her needs had changed with reading.”

Thompson began to hunt for books catered to people living with dementia, with large clear words, laid out simply. When she couldn’t find anything on the market, she decided to publish her own.

In the fall of 2016, Ontario-based Marlena Books (Marlena being a combination of Thompson’s grandmothers’ names) was launched. Offering dementia friendly writing, layout and content — at a grade five level of reading — Marlena Books work to engage the minds of those with dementia with age-appropriate themes and easy-to-read content. The books also feature wider margins and prompt for when to turn the page.

“Reading is something that is so based in our childhood, something that is so comforting and familiar to everyone and we wanted to preserve that,” says Thompson.

**DID YOU KNOW?** Marlena Books has developed an app version of the books, which won first prize in the inaugural AGE-WELL National Impact Challenge, a contest for new technology-based solutions for healthy aging. The app, currently available for download on iTunes, offers customizable font size, automatic page turning and more. Learn more at [agewell-nce.ca](http://agewell-nce.ca) and [marlenabooks.com](http://marlenabooks.com)



## 2

### Vytality At Home

Vytality At Home, a home care company that launched in Calgary in September 2018, connects home care workers with people living with dementia and has created an app that offers insight into those visits. Through its app, which can be used on a smartphone, tablet or laptop, loved ones are alerted to valuable information like when a Vytality At Home care worker arrives, leaves and what they did that day. They can also video conference or call family members during the visit.

“This gives the family that ability to know and be hands-on without having to physically be there with their loved one while they’re receiving the care,” says Nicole Dyer, co-founder of Vytality At Home.

For more information, visit [vytality.ca](http://vytality.ca).

Photos courtesy Marlena Books; Vytality At Home; Monarch Adaptive Clothes; Ambient Activity Technology





### 3 **Monarch Adaptive Clothes**

Kristine Goulet was visiting her mother, who was living with dementia in long-term care, when she noticed the back of her mom's shirt was open. Goulet's mother, François Blanchette, was wearing "adaptive" clothing but she was still left exposed.

"It's an incredible struggle for the person doing the dressing, but also the person getting dressed can be robbed of their self-esteem and self-worth," says Goulet.

Inspired by her mother's experience, and together with her friend-turned-Monarch co-founder, Pat Quinn, Goulet began designing clothing that

was easy to put on and secure but was also beautiful.

Monarch Clothes come in a variety of styles such as an "Easy-On T-Shirt" with snaps along the side and trousers with side snaps on the top.

The clothes are available in a retail location in Sherbrooke, Quebec, and on Monarch's e-commerce site, and shoppers can watch tutorials on how the clothing works with helpful photos and videos — some feature co-founder Quinn's mother, who is living with early-stage dementia.

Visit [monarchclothes.com](http://monarchclothes.com) to learn more.



### 4 **Ambient Activity Technology**

Ambient Activity Technology's flagship product ABBY provides stimulating, self-directed recreational activity for people living with dementia in long-term care facilities.

Designed by the minds that have created a number of play areas, including in the Alberta Children's Hospital, ABBY is a wall-mounted multi-activity stimulus centre. Thanks to wearable Bluetooth devices programmed with personalized information and preferences, ABBY can create customized experiences tailored to individual residents. It can include wheels, buttons, an old-school radio — that plays familiar songs — textured images of animals, a touchscreen that displays personal photos, and more.

"People living with dementia will retain, to some degree, their implicit memory — they can still pet a cat, or turn a wheel or flip a switch," says Marc Kanik, managing director at Ambient Activity Technology. "Play is therapeutic."

Currently, ABBY is being trialled in a care facility in Didsbury, Alta., with plans for Western Canada expansion, says Kanik. 📺

Learn more at [ambientactivity.com](http://ambientactivity.com).



# WHY YOU SHOULD MAKE AN ADVANCE CARE PLAN TODAY

BY Sean P. Young

**F**or families impacted by dementia, creating an advance care plan is one of the most important things you can do now for when the later stages of dementia occur.

“Dementia [can] cause a series of losses to the individual but also their family, and one of the ways that people can have some control over this really difficult series of events is to take part in advance care planning,” says Dr. Jessica Simon, physician consultant to Advance Care Planning: Goals of Care, Calgary Zone, Alberta Health Services.

Simon is also division head of palliative medicine for the University of Calgary. She has seen first-hand, in her years of experience as a palliative care physician, the distress families are put through when their loved one can no longer make important medical decisions. She says having an advance care plan is critical in this situation.

“If they have to make medical decisions on your behalf, they will feel less distressed and more comfortable because they know they are honouring what’s important to you,” she says.

Developing an advance care plan involves five important elements: think, learn, choose, communicate and document.

## 1 Think

First, think about your wishes and values. For example, do you want health care providers to do everything they can to prolong your life? Or is quality of life more important to you than length?

## 2 Learn

Next, learn about your medical condition and the common choices a loved one may have to make on your behalf related to this condition. If you or a loved one has been diagnosed with dementia, you’ll want to consider creating an advance care plan as soon as possible.

## 3 Choose

For the third step, choose an agent, a person who can make medical decisions on your behalf (only if you are no longer able to).

## 4 Communicate

Next, communicate this decision. Getting everyone on board and aware of your choice, including family, friends and your health care team, is key to garnering the best outcomes.

## 5 Document

Finally, document your plan and agent in a personal directive (PD) document. This document names your agent and allows you to leave written instructions they can follow when you are no longer able to make key medical decisions.

A complete advance care plan also includes two legal documents: a power of attorney, which designates who can make financial decisions on your behalf, and a will, which tells your family what to do with your estate when you’ve died.

There is no time like the present to create your advance care plan, and everyone over the age of 18 should make it a priority, says Simon.

“It really is a gift to those around you in a very distressing time.”


April 16th is National Advance Care Planning Day in Canada. Visit [goals.conversationsmatter.ca](http://goals.conversationsmatter.ca) to learn more.



## THE GREEN SLEEVE PROGRAM

The Green Sleeve program is specific to Alberta Health Services. It is like a medical passport that holds your advance care planning forms: your personal directive (outlined in main article), goals of care designation (a medical order written by your doctor or nurse practitioner that helps the health care team quickly know your desires and values in an emergency), and your tracking record of previous advance care planning discussions.

Any AHS medical provider can give you a Green Sleeve, or you can have up to four mailed to you by visiting [my-health.alberta.ca/Alberta/Pages/advance-care-planning-green-sleeve.aspx](http://my-health.alberta.ca/Alberta/Pages/advance-care-planning-green-sleeve.aspx).

An up-to-date Green Sleeve should be kept near the fridge at home, as first responders are trained to look for it there. You should also share copies with your agent, family and health care provider. 



**Imagine.** A world free from  
neurological disorders.



From idea to clinical impact, Branch Out is paving the way towards a world free from neurological disorders.



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*Proactive*





# MEASURES

These two Albertans are taking vastly different approaches to dementia research, both with the ultimate goal of improving people's lives

BY Elizabeth Chorney-Booth

PHOTOGRAPHY BY ◀ Cooper & O'Hara and Paul Bamford ▶







## DR. MATTHEW MACAULEY



**M**atthew Macauley isn't an expert in neurology or dementia, but he may just be on track to finding a cure to Alzheimer's disease. The researcher at the University of Alberta (U of A) specializes in glycomics (the study of sugars) and more specifically, the protein receptors that recognize those

sugars. To most, it's a fairly abstract area of study, but Macauley is currently doing work that may shed some light on why some people develop Alzheimer's and others do not.

Originally from British Columbia, after seven years studying and researching in San Diego, Macauley moved back to Canada in 2017 to take a position as an assistant professor at the U of A in the faculty of science. With funding from GlycoNet, a body that supports glycomic research in Canada, Macauley and his lab have been trying to figure out how a genetic variation in certain receptors present in patients' microglia (a type of white blood cell found in the brain) provides protection against Alzheimer's.

Macauley, who works closely with John Klassen, another researcher at the U of A, was set on this path after several studies revealed about one in 10 people carry specific DNA variances related to microglia receptors that seemingly protect them from developing Alzheimer's. (A 2008 study foreshadowed the link and two 2011 studies took a closer look at the findings.) The studies caught Macauley's attention because the DNA variances weren't a predictor of who would develop Alzheimer's, but of who wouldn't. He knew that if the lab could figure

out exactly what that DNA variant was doing to prevent Alzheimer's, he'd be on his way to potentially discovering a cure.

"We thought that if we could understand why that DNA sequence protects someone from getting Alzheimer's disease, we could then leverage that to try to develop a drug that creates the same effect," Macauley says.

Macauley isn't the only scientist working on developing a cure via the information revealed in the studies, but as someone whose expertise lies in glycomics rather than neurobiology, he's able to bring a different perspective to his research. Currently, he's researching these receptors at a molecular, cellular and physiological level.

"We are doing work at all three levels, which increases our chances of figuring out the mechanism, which is a prerequisite to create a drug," Macauley says.

Macauley says if he and his team can find a way to mimic these protective variants that one in ten lucky people have, then a medical cure that does the same thing is not far off.

"It's potentially a fairly straight shot to develop a drug," he says.

## DR. THERESA GREEN

**F**ew things can shake a family like a diagnosis of young onset dementia. Most of us certainly don't expect to experience a dementia diagnosis when we're only in our 50s, and the impact of illness at such an early age can complicate the lives of younger patients and their caregivers who are still in the workforce or have children

[ "If we could understand why that DNA sequence protects someone from getting Alzheimer's disease, we could then leverage that to try to develop a drug that creates the same effect." —Matthew Macauley ]



at home in ways that go beyond what older people with dementia may experience.

Theresa Green is a researcher and a professor in the faculty of nursing at Queensland University of Technology in Brisbane, Australia. Originally from Calgary, Green was previously based out of the University of Calgary and, before that, worked clinically in neurosciences at the Foothills Medical Centre for many years, then completed her PhD and moved into the U of C academic environment. After studying questions of care surrounding stroke patients she shifted towards working on projects focused on early onset dementia with the U of C's Dr. Eric Smith, an area of study she's continued since moving to Australia in 2015.

As a nursing academic, Green focuses on patient and family-centred care. While her scope is broad, she's particularly interested in the ways that doctors deliver diagnoses to young onset patients, which can be an emotionally fraught process that can leave families blindsided.

"I'll never forget the story of a couple who had just received a dementia diagnosis," Green says. "They left the doctor's office and went to the river and just walked very fast for a very long time, holding hands and without saying a word to each other because it was hard for either of them to breathe. It rocked the very foundation of their lives and sense of self as part of a couple and as individuals."

Green's research is primarily based on interviews with people with young onset dementia and their care partners, usually a spouse. While every family's story is different, there are com-

"The very bottom line for me is that we can never forget that we're talking about people and their lives. Guidelines are just a guide." –Theresa Green



mon themes: frustration with the diagnosis process, worry about financial and physical burdens since both partners are often still in the workforce, concerns about childcare and other familial relationships and trying to ensure that those with dementia are still able to enjoy the activities that make them happy. Having done interviews both in Calgary and Australia, Green says these priorities are consistent in both countries.

Green's goal is to use the material gathered from her qualitative research to help inform clinical guidelines, both for inpatient and outpatient care, which will address the specific needs of families dealing with early onset diagno-

ses. She also hopes that it will encourage health care providers to think beyond guidelines and think carefully about each family's individual needs.

"The very bottom line for me is that we can never forget that we're talking about people and their lives," Green says. "Guidelines are just a guide. More importantly, it's about how care fits with the individual you're working with." ■

**DID YOU KNOW?** 59% of care partners of individuals with young onset dementia had to reduce their hours at work or stop working due to their caregiving role.



## Brain In Motion Study II

### Interested in participating in dementia prevention research?

We are looking for volunteers to participate in a study looking at the **relationship between exercise and brain health** in individuals who are at increased risk of dementia.

The study includes a 6-month **aerobic** exercise program or a **stretch and strength** program.

For more information, contact our **Study Coordinator**:  
[bimstudy@ucalgary.ca](mailto:bimstudy@ucalgary.ca) or 403-210-7315



# THIRD ACTION

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# DESIGNING for *dementia*

*When plans were hatched for Calgary's new Bethany Riverview care centre, the team knew they weren't just designing a building — they were designing a home*

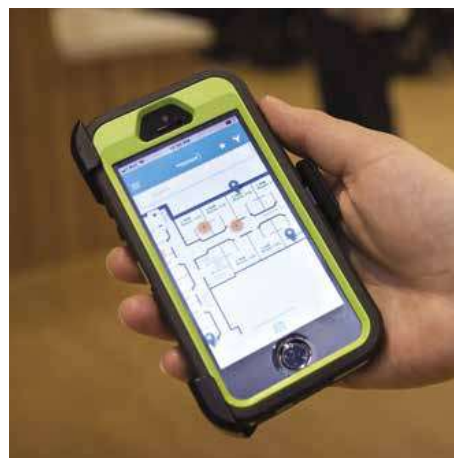
STORY AND PHOTOGRAPHY BY Jennifer Friesen







Clockwise from left: The Atrium has interactive gardening stations; residents, guests and staff dine together; final food preparation is done in the neighbourhood kitchen; a small grocery offers items for sale; the Momentum technology system allows residents to wander freely and safely; bathrooms are designed with a spa-like feel, complete with a fireplace and heated towels.



**M**assive windows cascade light through each of Bethany Riverview's seven unique "neighbourhoods" inside, where residents are free to roam at their will, just like they would at home. Designed for people with complex dementia, the care centre utilizes colour, light,

shapes and textures to help residents navigate the space easily and safely. Both residents and care providers are monitored by the Momentum resident safety system, a safety initiative that allows occupants to move freely but be located when needed.

Bethany Riverview care centre is a part of the Riverview Village, Bethany's

first "Campus of Care" for seniors that includes multiple housing buildings, including some for independent seniors.

Jennifer McCue, president and CEO of the Bethany Care Society, says Bethany Riverview's design is about providing residents a sense of independence and encouraging a sense of place through intentionally designed cues.





Above: Private, 400-square-foot bedrooms include ensuites with blue toilet seats, which help residents recognize the toilet more easily and note if it is open or closed.

Left: Every bedroom door is designed differently — colours and panels differ and door handles are unique. This helps residents identify which door is theirs.








The Rotary Atrium offers 3,000 square feet of space for safe and purposeful wandering. Large windows and plants bring the outdoors in.



“Our whole concept here is to have multiple cues,” she says. “If you don’t recognize the light, then maybe you recognize the colour. If you don’t recognize those, maybe you recognize the feel. It’s about trying multiple ways to have the resident be as comfortable as they can in the space.”

Since opening last September, the 210-bed long-term care centre has focused on fostering community. Staff members dress in street clothes as opposed to scrubs, meal preparation is done in the dining rooms to bring in the sights and smells of home cooking, and its 3,000-square-foot second-floor atrium offers a light-filled

space where everyone can mingle freely with each other and with family.

“As more residents are moving in, we’re very aware that this moves from being a building to being their home,” said Gail Urquhart, acting executive director of Bethany Care Foundation. “You feel it.” 



## Christine Thelker: My Dementia Story

Christine Thelker is a 59 year old Canadian. While working as a nurse for dementia patients, Christine had a stroke. Now, she is living with younger-onset vascular dementia after being diagnosed at the age of 56. She shares the following with us:



"I've realized that while I am no longer who I was before the diagnosis, I can still make new, healthy connections by working to help others with dementia.

I began asking questions like: Who am I now? What do I do now?

After being told I was no longer able to work, I spent a lot of time just 'being,' but one day, I decided, "I am going to keep living." I started writing in a journal to empower myself. In addition, I started a Facebook page called Chrissy's Journey. People from all over the world have reached out to me and told me that my writing and advice have helped them and their families. I have had the privilege of meeting some of these people face to face. I like who I am now. I love being able to provide hope to others and because of that, my diagnosis has become a huge gift.

Nevertheless, dementia has not been easy and I try to be honest about the internal struggles I go through every day so that I have a purpose and can raise awareness about dementia. I am a Board member of Dementia Alliance International and

talk to people from around the globe through this work. We offer online support groups and once a month, we meet with our counterparts in Japan, Canada, Australia and the USA. I am very involved with the support groups. We also speak at a lot of different conferences and provide one-on-one support if needed. We put together events and host fundraisers to help our members attend conferences and provide free services for members.

I presented last July at the ADI Conference in Chicago. There was a large contingent of us travelling from various parts of the world to speak at this conference in our efforts to improve quality of life and raise awareness. Fundraising efforts had to be done, as we do not receive sufficient funding to speak and travel to these conferences (something I will never understand). It felt like a daunting task for me, because although in the past it would have been something I took on eagerly it was overwhelming and frightening. With the help of some special friends, donations were given, a garage sale held, then a hot dog sale outside at the local mall; I sold some of my own artwork, and then I made succulent planters and sold them. Amazingly between all those efforts I was able to self fund my trip to Chicago.

I still believe we should be funded by the Alzheimer's Organizations who collect under the auspice of it being for people with dementia and our families, especially when they fund many of their staff to attend."



# 24 hours a day, 365 days a year, DAI works hard to help people like Christine. But, we need your help.

Every 3 seconds, that's 20 times every minute, 1200 times an hour or 28,800 times a day, a person somewhere in the world is diagnosed with dementia. There is no cure and our members are commonly told to get their end of life affairs in order and get acquainted with aged care. They are given no hope.

Their future and pre-diagnosis life is taken away from them. Stigma and discrimination is still endemic

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

Donate or partner with us today: <https://www.dementiaallianceinternational.org/donate-or-partner/>



email: [info@infodai.org](mailto:info@infodai.org)



website: [www.infodai.org](http://www.infodai.org)



[www.facebook.com/DementiaAllianceInternational](https://www.facebook.com/DementiaAllianceInternational)



@DementiaAlliance





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# *Death* and *Decisions*

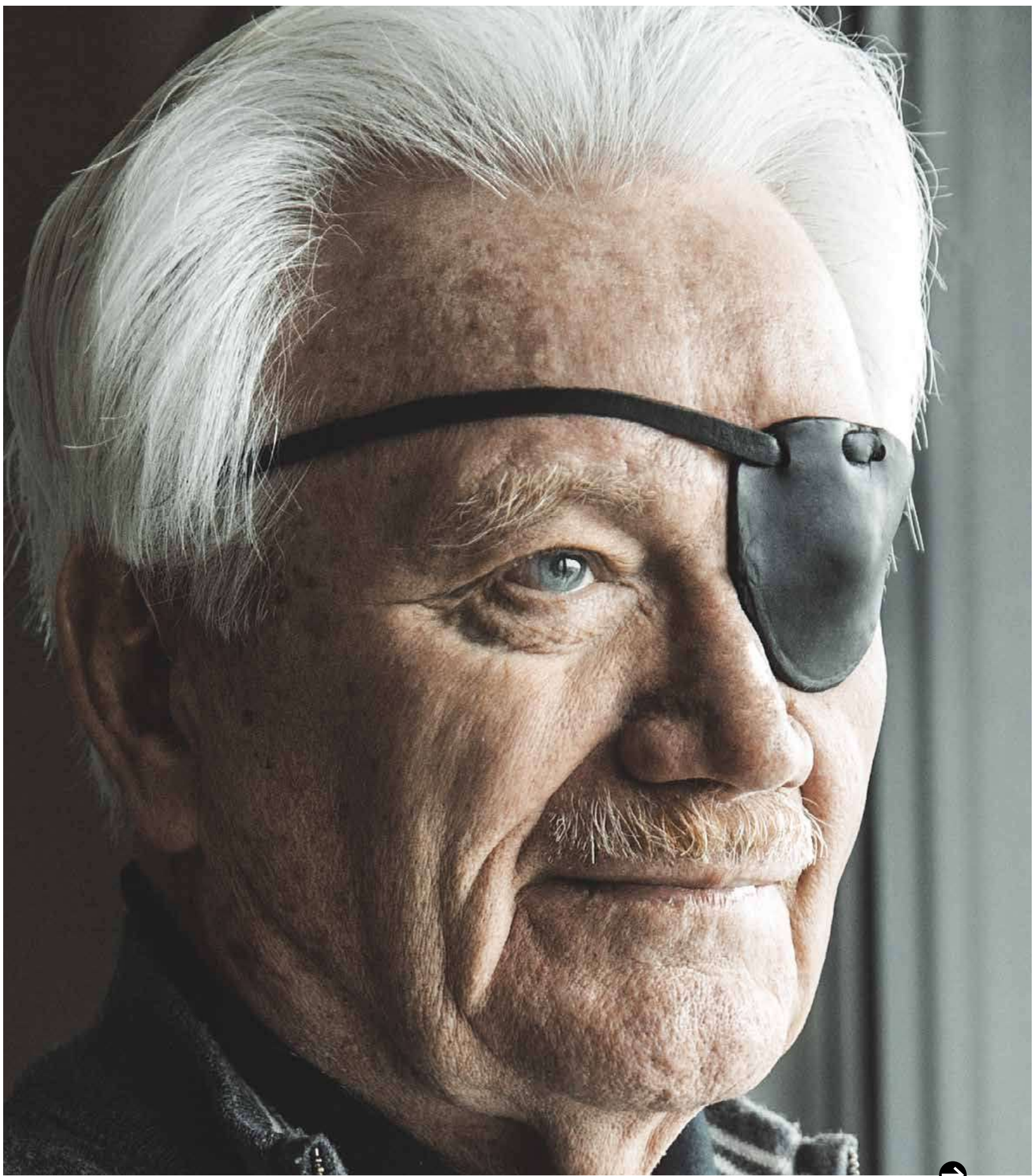
BY Julia Williams

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*For the last three years, Ron Posno has been defending his right to die. This isn't how the 79-year-old expected to spend his retirement, but when he was diagnosed with mild cognitive impairment in August of 2016, his life changed — and so did the way he thought about his death.*

*A lifelong planner, Posno, who lives in London, Ont., did everything possible to manage the terms of his own exit. He worked with his lawyer to change his living will and assigned power of attorney to his wife, who supports his wishes. He laid out eight clear conditions, in writing, under which he no longer wishes to live, all of which have to do with losing mental capacity. But here, Posno knows he is caught in a paradox: Once any of the conditions under which he wishes to die becomes reality, he will no longer be able to consent legally to an assisted death. For this reason, Posno believes Canada's Medical Assistance in Dying law is a "failure by design," and he's on a mission to change it.*







Dr. Samir Sinha is the director of geriatrics at Sinai Health System and the University Health Network in Toronto.



## ➔ The question of advance requests

The law, usually referred to as MAID, was passed by Parliament in June 2016, two months before Posno's diagnosis. It grants incurably ill Canadians the right

to choose an assisted death, but under the condition that they are mentally competent and capable of providing consent at the time of the procedure. The law does not allow for advance requests or directives, which means a person who becomes cognitively incapacitated (as a person with dementia certainly would) can't access an assisted death.

To Posno, MAID's rejection of advance requests discriminates against people with conditions that cause cognitive decline. According to Health Canada's most recent report on assisted dying, 1,086 people received assisted deaths between July 1 and Dec. 31, 2017. In another study reflected in the Health Canada report, when requests were denied, the most frequently cited reason was loss of competency and that death was not reasonably foreseeable.

Dr. Samir Sinha is the director of geriatrics at Sinai Health System and the University Health Network in Toronto. Where Posno sees a clear violation of his Charter rights, Sinha sees a complex ethical issue. Recently, Sinha sat on a Council of Canadian Academies expert panel that examined three kinds of complex types of requests for MAID, including advance

requests. On December 12, 2018, the panel delivered The State of Knowledge on Advance Requests for Medical Assistance in Dying report to the federal government, presenting issues with the current law, identifying risks to changing it and listing potential safeguards to mitigate these risks.

For one thing, lawmakers must consider the risk advance requests could pose to people who are incapacitated by cognitive decline, and who could become vulnerable to the self-interest of family members and other substitute decision-makers. In such cases, advance requests could be used as tools of coercion against the very people whose interests they're meant to protect. The report states: "Removing a requirement for express consent immediately prior to the MAID procedure raises the possibility that a person might receive MAID against their wishes."

Only four jurisdictions (the Netherlands, Belgium, Colombia and Luxembourg) allow advance requests for assisted dying, and only under certain conditions. In the Netherlands, where assisted dying has been legal since 2002, only six publicly available case reports indicate incapacitated people have received assisted deaths based on an advance directive. Each of the six patients had advanced dementia, and some of the cases stirred up controversy. In one of the cases in particular, an oversight body found that the physicians had not acted in accordance with the law. "Even in the Netherlands, [the question of advance requests] hasn't been figured out in a way where everyone is comfortable," Sinha says.

"If people felt there could be a high level of care provided and had a better understanding of what dementia is and isn't, then I think there would be less distress about MAID." —Dr. Samir Sinha



“Vulnerable people don’t need bad law. What makes people vulnerable is avoidance, silence and ignorance.” —Ron Posno

## Defining vulnerability

Posno thinks the argument that MAID’s final consent requirement protects dementia patients is laughable. “Vulnerable people don’t need bad law,” he says. “What makes people vulnerable is avoidance, silence and ignorance.”

Dana Livingstone shares Posno’s scepticism that MAID protects vulnerable people. Livingstone’s mother, Irma, who died in 2018, was told by doctors she likely had both vascular dementia and Alzheimer’s. Irma had hoped for an assisted death, but because of

the final consent and sound mind requirements, she could not access one. To Livingstone, it was Irma’s loss of the right to die according to her own wishes and values — as well as her dementia —that made her vulnerable.

In 2014, Livingstone says her mother confirmed with her doctor that she was of sound enough mind to make health care representational changes. At that time, Livingstone says Irma requested three things in writing (although the document was not officially notarized): she wanted to live with

Livingstone if her home became unavailable, that Livingstone be on her health care representational papers and her right to MAID. When Irma could no longer make her own decisions, Livingstone and other members of her family found themselves in fundamental disagreement over Irma’s care plan. The family disagreed about who should have the legal right to make Irma’s decisions once her disease incapacitated her. It was difficult to find appropriate facilities and in-home help for a woman with advanced dementia on Vancouver Island. They disagreed over whether institutionalizing and medicating Irma was inappropriate or merciful, and over whether flying her to another jurisdiction for an assisted death (as Livingstone wished to do) was honouring Irma’s wishes or consenting to her murder. Livingstone says there was a disconnect in her family’s principles and Irma was caught in the middle. Livingstone says that unfortunately Irma’s three wishes were never honoured.

If MAID had honoured her mother’s stated wishes, Livingstone believes it would have eased her mother’s suffering and the family’s conflict. “The law needs to change so that you can decide with your doctor what stages of the disease become intolerable for you, and you can make an advance request,” Livingstone says. “How do we determine what suffering means for another person?”

## Exiting early

On November 1, 2018, 57-year-old Haligonian Audrey Parker died of an assisted death. It was



Dana Livingstone, on Vancouver Island, believes the MAID law needs to change.



→ a peaceful event carried out with her full consent, but there was one significant issue: Parker had hoped to live until Christmas and New Year's Eve. Parker, whose stage-4 breast cancer had spread into her brain, expected to be too incapacitated to provide final consent by then and because of the current state of the MAID law, had to make the decision to end her life earlier, while she was still able. Her case attracted considerable media attention, which was Parker's intention; she wanted to shine a spotlight on the final consent requirement in Canada's MAID law, which she called "unfair and extreme." Parker's death has fuelled the national conversation about the assisted dying law and end-of-life care.

Weeks after Parker's death, when the Council of Canadian Academies reports were released, Dying with Dignity Canada issued a strong statement to the federal government. The human rights charity, which defends end-of-life rights, is a staunch advocate for MAID reform. "Even before these studies were conducted, the government was aware that Canada's assisted dying rules discriminated against suffering people on the basis of their medical condition," said Dying With Dignity Canada CEO Shanaaz Gokool in an official statement.

Posno is equally appalled that Parker was compelled to die early to retain her right to choose. Preserving life, even against the wishes of the patient, should not be the

goal of medicine. "What is life? Is it as long as your heart is beating?" Posno says. "The centre of my life is my brain. When that's gone, my life is gone." He believes assisted dying should be part of palliative care, and any Canadian should have the right to declare what they do and don't want regarding medical interventions. "Caring can be interpreted in terms of support in dying," Posno says.

## Morals and medicine

The Canadian Society of Palliative Care Physicians doesn't share Posno's opinion; it officially opposed Bill C-14 before it became law. In October 2017, the society conducted a member survey on MAID, which found that 57 per cent of respondents would support allowing advance requests for assisted dying, but not unless strict safeguards to reduce harm are put in place. These safeguards include national criteria for certifying substitute decision-makers, robust best practices for determining competence in patients and legal protections for medical personnel. These measures are intended to protect patients, but just as significantly, they protect medical professionals from situations that can be confusing and morally fraught.

Sinha says there have been cases in the Netherlands where advance requests aren't carried out because there is just too much uncertainty about the patient's wishes. "It's hard to interpret in certain circum-

stances whether [an assisted death] is what that individual still really would have wanted at that point in time," he says. This persistent uncertainty motivated 350 Dutch physicians to sign a petition in February 2017 denouncing assisted death for people with advanced dementia. Their reason? "Moral reluctance."

People with advanced dementia can seem content and responsive, placing their decision-makers and care team in a position of unbearable responsibility: Am I honouring this person's wishes, or am I forcing their hand? As a physician, what should I do if a patient seems to be resisting the procedure? "Should we push through and force the act to occur because this is what the patient said they wanted 10 or 15 years ago?" Sinha says. Sinha adds that what we expect to make us suffer isn't necessarily what will make us suffer. In some cases, mental decline can change a person's perception of their situation.

## Legal system vs. health care system

It's impossible to talk about Canada's MAID law without a conversation about Canada's health care system, which is currently unprepared to handle rising numbers of dementia cases. Today, half a million Canadians are living with dementia; by 2031, that number is expected to increase by 66 per cent. Costs are rising, both for the health care system and overburdened care partners. Canada still has no official national dementia strategy, although legislation is in place to create one this year.

Posno, who has spoken widely on living with dementia, says the

[ "How do we determine what suffering means for another person?" —Dana Livingstone ]



disease is rarely the subject of open, frank discussion. Instead, it's treated like a "social disease," to the point where he's heard of people refusing to share their dementia diagnosis with their spouses. While dementia remains so poorly understood, quality care will be difficult to access.

Livingstone worked in dementia care for 12 years before her mother's diagnosis. "It's not a good death," she says. Thousands of patients with dementia are cared for in hospitals, which are ill-equipped to meet their needs. Most family members and friends struggle to care for someone with advanced dementia, and most families don't have the means to access high-quality private care. Livingstone describes the rising numbers of dementia cases as "a coming epidemic." Compared to overhauling Canada's health care system, amending MAID seems comparatively easy, which may be why advocates for legal reform are so determined. "If we can't have quality care, then I would pick the right to die," Livingstone says.

The Canadian Society for Palliative Care Physicians hopes to avoid the situation Livingstone describes. In a 2016 brief to the Standing Committee on Justice and Human Rights, the society recommended amendments to draft Bill C-14, specifically, a clear and substantial commitment to palliative and end-of-life care. The brief states, "We want to ensure that patients do not choose hastened death [used here to mean 'assisted death'] due to lack of access to high-quality palliative care services."

This is Sinha's worst-case scenario — that some people will look to MAID as a solution

"The law has provided me with my choice. No one has the right to limit my choices." —Ron Posno



because they can't access good health care and palliative care. "That would be a travesty," he says. In his opinion, improving our health care system could calm the heated conversations around Canada's assisted dying law. "If people felt there could be a high level of care provided and had a better understanding of what dementia is and isn't, then I think there would be less distress about MAID as an option," he says.

## Life and death

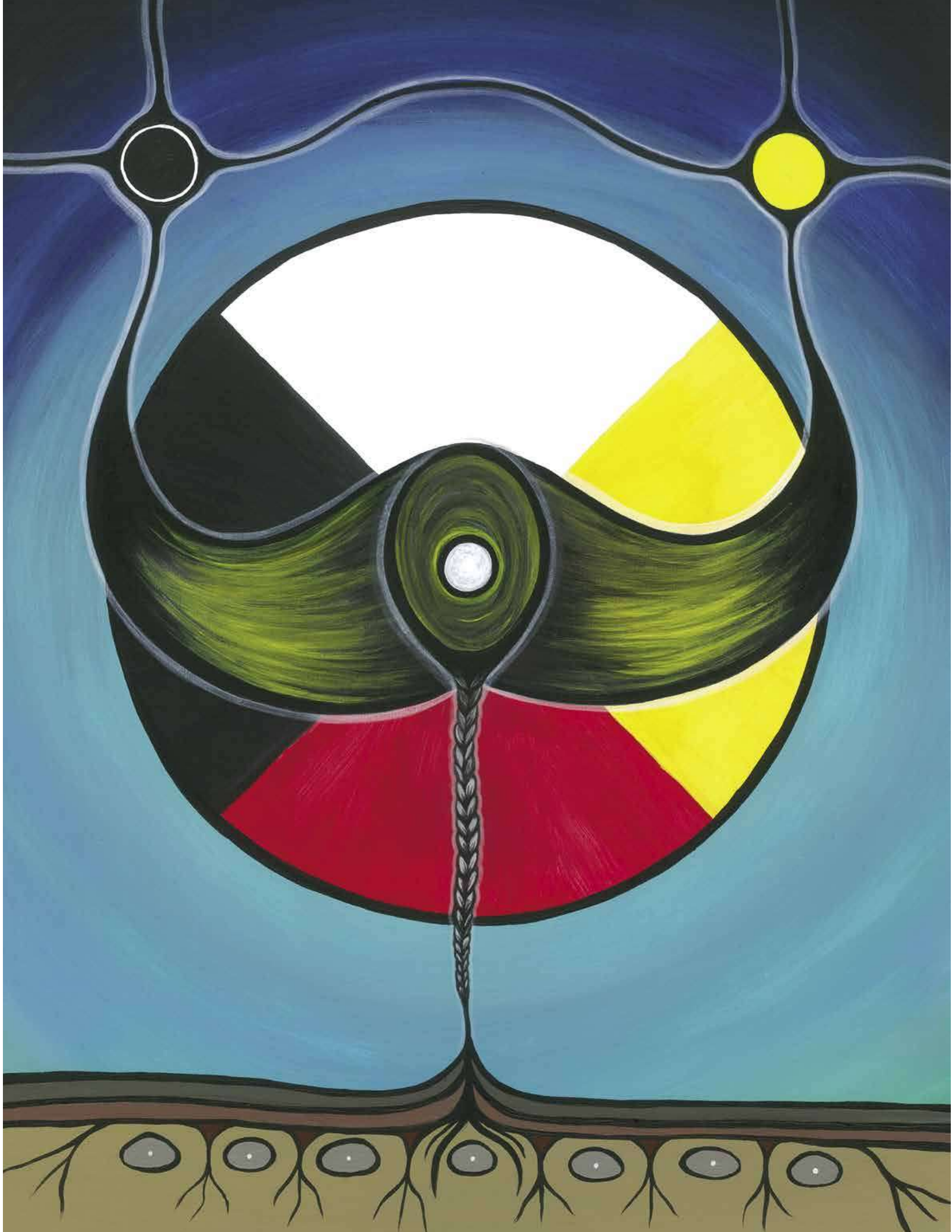
At its heart, a conversation about assisted dying is a conversation about living well. Sinha says a growing body of statistics from jurisdictions where MAID is legal show that many people who request an assisted death don't actually choose to go through with

it, but they may gain a therapeutic benefit from knowing they have the option. A dementia diagnosis can be terrifying. "Knowing you have control over your future can alleviate a lot of distress," Sinha says.

Posno, who lives with a version of this distress each day, is hopeful that MAID will change; he just doesn't think it will change in time for him. The Council of Canadian Academies report bears this out: It calls not for speedy legal reform, but for further research on end-of-life practices in Canada and worldwide.

As research slowly progresses, Posno continues to write letters to policy-makers, to give talks about dementia and to advocate for his rights. "The law has provided me with my choice," Posno says. "No one has the right to limit my choices." ■







# A NEW WAY OF *seeing*

*A team of researchers and clinicians is working with Indigenous Canadians to create culturally appropriate dementia care*

BY Shannon Cleary ILLUSTRATIONS BY Katheryn Wabegijig

**d**ementia can affect anyone. But how we're diagnosed, how we seek treatment and even how we view memory loss can vary by culture, geography, experience with the health care system and experience with Canadian institutions in general. That's why Canadian clinicians and researchers are investigating culturally appropriate strategies to provide Indigenous communities with equitable access to dementia care.

## The Value of Truth

Karen Pitawanakwat is a registered nurse and community researcher for the Canadian Consortium on Neurodegeneration in Aging (CCNA) Team 20: Indigenous projects – Ontario. She describes a scenario where assessing

memory loss in an Indigenous client using common screening tools can lead to confusion. A visiting geriatrician asks an older Indigenous person to complete a simple task. First point to the sky, he says, and then point to the ground. The client doesn't respond.

"An Indigenous client would not respond to this task because in our language our values are intertwined. The value of truth is experienced when an Indigenous client pauses before answering, gathering or processing what is truly being asked and will not respond unless it is the truth," Pitawanakwat explains. "In our way of knowing, it's rude to point. There are spirits everywhere. It's inappropriate."

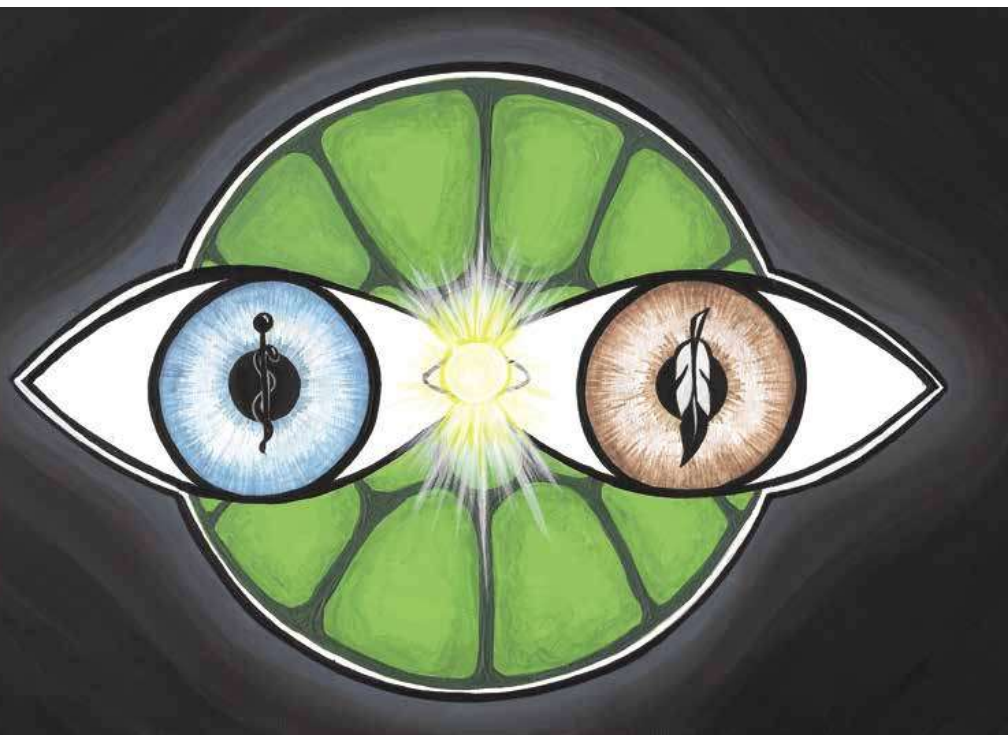
Indigenous languages are very detailed and particular, says Pitawanakwat, and speaking the truth is one of the sacred prin-

ciples of the Seven Grandfather Teachings. If you are sitting inside an examination room, how can you accurately and "truthfully" point to the sky? Does the examiner mean the ceiling? Patients may take a long time to process their response, or, within the limited timeframe of a brisk examination, may not respond at all.

Pitawanakwat, who is Anishinaabe Kwe from the Wiikwemkoong Unceded Territory in Ontario, says health authorities have long identified gaps in appropriate and effective dementia care for Indigenous populations. Indigenous people are not accessing dementia care services, and the tools used to diagnose dementia are not culturally relevant. Pitawanakwat's research has focused on the Manitoulin Islands, but much of her work can be adapted to fit other communities across Canada.







Previous page: The medicine wheel represents the life force of a person entering through the Eastern doorway at birth and leaving through the Western doorway at death.

Left: “Two-eyed seeing” incorporates the strengths of Indigenous knowledge and Western knowledge.

## → Words as a Tool

The CCNA is a consortium of Canadian clinicians and researchers studying the development of age-related neurodegenerative diseases, their impact, and how to slow their progression. Team 20: Indigenous is the only team within the CCNA focused on strengthening these understandings within Indigenous communities. Since 2007, they have worked closely with traditional knowledge keepers, language experts, and local health care providers in Ontario and, from 2014, in Saskatchewan, to examine how Indigenous culture affects the experience of dementia.

In 2015, Team 20: Indigenous projects – Ontario researchers and

community advisors partnered with Australian researchers to adapt the Kimberly Indigenous Cognitive Assessment Tool (KICA). They translated KICA screening questions into the Anishinaabemwin language, then into English and then back again. The result was the Canadian Indigenous Cognitive Assessment (CICA), a culturally appropriate assessment tool for screening memory loss. Instead of asking a patient to point to the sky, an examiner using the CICA tool will ask a client to, “Pick up this piece of paper, fold it once, and give it back to me.”

“Now you’re now doing this activity together,” says Pitawanakwat. The language is reciprocal,

less commanding and more reflective of Indigenous communication and relationships.

CICA has now been validated (an academic term meaning it has demonstrated effectiveness) in Ontario, and a version of it is being piloted in Saskatchewan with research currently underway to adapt it to urban Indigenous people in Calgary. The project is just one of the team’s examples of how Indigenous culture can be built into existing health structures to improve client care.

## Raising Awareness

Drs. Kristen Jacklin and Carrie Bourassa co-lead Team 20: Indigenous, and Jacklin also founded the International Indigenous Dementia Research Network (IIDRN) and the Indigenous Cognition & Aging Awareness Research Exchange (i-caare). The goal of the i-caare website is to explore and promote healthy aging among Indigenous communities and to raise awareness about cognitive health. Jacklin’s research shows that the prevalence of dementia in Canada’s Indigenous communities is 34 per cent higher than the rest of the population — a rate that is steadily rising — and the average age of onset is 10 years younger.

According to the Alzheimer Society of Canada, some of the risk factors of age-related dementias include increasing age, genetics, diabetes, head trauma, social and economic status, and

The Anishinaabe word, “keewayabinoocheeaway” describes age-related memory loss as a return to childhood



“...a person may feel like they have to tell their story over and over again to actually be heard.” –Dr. Melissa Blind

cerebrovascular disease and its associated factors such as hypertension, stroke, smoking, and obesity. Many of these risk factors disproportionately affect Indigenous people.

“Indigenous people have higher rates of diabetes and heart disease, and even head injuries are much higher than in the non-Indigenous populations,” says Dr. Melissa Blind, a research coordinator for Team 20 Indigenous and a member of Gordon’s First Nation Band in Saskatchewan. “Then you start looking at the impact of historical trauma, of unresolved grief.”

### Meaningful Change

Blind has been a part of the research team since 2014 and is currently a senior research associate with the Memory Keepers Medical Discovery Team at the University of Minnesota Medical School Duluth. She says that for meaningful change to occur within the health system, we need to understand not just the biomedical context, but the lived experience of Indigenous people.

“If a person has had a very negative experience within the health care system, they’re probably not likely to go back or want to go back,” says Blind. “And if you’re in a more rural or remote area

where there are rotating physicians, a person may feel like they have to tell their story over and over again to actually be heard.”

Furthermore, Indigenous communities have cultural perceptions of memory loss that contradict the idea of dementia as a diagnosis of impairment. There is no directly translatable word for dementia in the Indigenous languages spoken on the Manitoulin Islands, but an Anishinaabe word, “keewayabinoocheeaway,” describes age-related memory loss as a return to childhood.

Karen Pitawanakwat says this reflects the traditional teachings of the medicine wheel. At birth, she says, we enter the physical world through the Eastern doorway. When we leave the physical world and return to our spiritual form, we travel through the western doorway. At that time, the eastern and western doorways are close together. An elder who is experiencing symptoms of dementia is seen as “coming full circle” in their journey back to the spiritual world. Pitawanakwat says children and elders are considered to be closest to the Creator.

“Towards the end of life, you become like a child again. You go through that doorway to meet your Creator, to that ever after place of happiness,” she says.

### Two-Eyed Seeing

Developing an ethical relationship with Indigenous communities has become part of the critical discourse on health and health care in Canada. Many research groups, including Team 20: Indigenous, have embraced the methodology of “two-eyed seeing,” which incorporates the strengths of both Indigenous knowledge and Western knowledge to determine and deliver the benefits of both.

Dementia is on the rise in both Indigenous and non-Indigenous communities throughout the country and can be confusing, isolating and overwhelming. Adapting health care protocols that are culturally safe and therefore more effective, building relationships with clients based on their unique lived experience, and educating communities on dementia without diminishing their beliefs — these are practices that Blind says can benefit everyone.

“Just anecdotally,” she says, “when I share these tools with not just my Indigenous family but my non-Indigenous family, they say, ‘This makes sense. This isn’t as scary. This helps me understand.’”

**DID YOU KNOW?** According to the Alzheimer Society of Canada, the cost of dementia in Canada was estimated at \$10.4 billion a year in 2016. This amount is projected to double by 2031.





# Have Dementia, Will Still Travel

*With proper planning — including knowing the kinds of resources available — individuals with dementia and their care partners can still enjoy a holiday away*

BY Karin Mantyka

**A**LAN RAE AND HIS WIFE JOAN CONNOR were bitten by the travel bug decades ago. They spent weeks at a time away from their Calgary home, hiking through mountains in Europe, road tripping through the U.S. and doing humanitarian work with the non-profit organization Kids Around the World.

Then in 2012, Connor was diagnosed with Alzheimer's disease. But Rae made sure that wouldn't put a halt to their travel plans.

Today, Connor is living with advanced Alzheimer's, yet in 2018, the couple spent 23 weeks travelling. They hiked on the rugged Spanish island of Mallorca, snowmobiled in Utah and explored the lush Prosecco Hills in Italy. And

those are only some of the adventures they embarked on last year.

Connor and Rae are proof that a dementia diagnosis doesn't have to mean giving up on your dream trips. Whether planning your first trip away or hunting for ways to make travelling a little easier, these tips will help ensure travelling with dementia is safe, enjoyable and memorable.





Facing page: A selection of images from Alan Rae and Joan Connor's adventures.

## Is Travel Right For You?

While routine and familiarity are beneficial for individuals with dementia, Padmaja Genesh, a Learning Specialist at the Alzheimer Society of Calgary, says travel can be invigorating for both the person with dementia and their care partner.

"Travel can offer new experiences and memories," says Genesh. "Years later, the caregiver can look back on those happy times and cherish those memories."

However, before planning out a big trip, Genesh recommends that care partners have a clear idea of the individual with dementia's capabilities and limitations, as well as their own. (See sidebar for questions to ask before planning a trip.)

"Some dementia symptoms would indicate that travelling is not a good option. For example, if the person gets confused and agitated even in familiar surroundings, if the person gets extremely anxious and upset in loud or crowded environments... or if the person has delusions, anger issues, or a tendency to wander away, then travelling can be too overwhelming," says Genesh. "A high risk of falling, incontinence and multiple unstable health conditions can also make travelling very challenging."

Simply, taking a trip shouldn't be done on a whim, and Genesh

recommends consulting with a physician before making any definite plans.

## What If I Want Help Planning a Trip?

If planning a trip as a care partner feels overwhelming, consider employing the help of an accessible travel agent. Tarita Davenock is the CEO of Travel For All, a global company she started in 2008. Travel For All arranges trips for clients living around the world who would like to travel. But unlike other travel agencies, Travel For All specializes in accessible travel, meaning the company plans and customizes trips for clients with a range of health challenges, including dementia.

"We find out what exactly our clients' travel requirements are and what their health challenges are. We investigate to find out exactly what their needs are and then ask where they'd like to go, just like any other travel agent," explains Davenock.

Davenock adds that the company works with more than 250 suppliers around the world, including hotels, vehicle rental companies and cruise lines, that are known to have accessible offerings that can cater to their clients' health challenges.

The Travel For All team also understands intimately what's involved in putting together an

accessible vacation. Davenock lives with multiple sclerosis, and hires people with disabilities and health challenges to work for Travel For All.

"We get it. I think it's easier to speak with someone who completely understands any and all limitations. We don't limit clients by their challenge," says Davenock. "You can still do whatever you originally had on your bucket list!"

## What If I'd Like To Travel With a Group?

Consider searching for dementia-specific travel packages and tour groups, such as those offered by Elite Cruises and Vacations. Kathy Shoaf RN worked as a geriatric and neurology nurse for 20 years before launching Elite Cruises and Vacations, a Chicago-based travel company catering specifically to caregivers and clients with health challenges, including dementia.

Part of its appeal is that cruise ships offer individuals with dementia continuity and familiarity.

"I use a cruise ship because clients don't have to unpack and pack all the time, which is very much a challenge for people with dementia. We can still see the world, but we're going to do it from the same bed every night," says Shoaf.

The company offers group cruises that, on average, last seven days and leave from destinations

**TIP 1** Keep it simple "All our travel is broken up into one-week allotments. One of our secrets is to keep things from constantly changing — this will cause someone with dementia to be confused, frustrated and upset. Make bases and make them comfortable." —Alan Rae





**TIP 2 Be flexible** “Have an itinerary laid out but build flexibility into your planning, too. By having yourself settled in one spot, you have more options. Don’t try to over-plan or do too much.” —Alan Rae



Elite Cruises and Vacations offers dementia inclusive cruises to Alaska, the Mexican Riviera, the Caribbean and more.

restaurants and exploring the surrounding neighbourhood can still feel like a holiday. According to Genesh of the Alzheimer Society of Calgary, staycations can offer care partners an idea of how their loved one might react to changes in their routine, in an environment where the outing can easily be ended if symptoms worsen.

Short day trips also offer new experiences and a chance to engage with new surroundings. In 2018, the Kerby Centre in Calgary, a not-for-profit organization dedicated to supporting and enhancing the lives of older adults including programs specific to those living with dementia, planned a variety of short excursions for clients. There were trips to Jubilations Dinner Theatre in Calgary, to the Museum of the Highwood in High River, to the Spruce Meadows International Christmas Market, and, its most popular, to the Arrowwood Hutterite Colony near Blackie. Each trip accommodates an average of 25 guests, and the excursions often sell out months in advance.

According to John Vaillancourt, the Kerby Centre’s senior manager of knowledge and recreation, it’s the experience, not the destination, that’s most important to the guests.

“When you talk to the people that go on these trips, they will tell you they enjoy the different places we go,” says Vaillancourt. “But the part they really enjoy is socializing with other people and just having a good time.”

all over the U.S. and Canada. The company welcomes clients living with all stages of dementia. Whether clients book a group cruise to Alaska or the Caribbean, each trip provides trained medical and support staff, and offers care partner assistance and respite care. There are daily activities, such as Zumba and crafts, as well as the occasional shore excursion.

Since Elite Cruises and Vacations launched 10 years ago, Shoaf has seen numerous repeat clients. And to her, that’s proof that the company is doing its job.

“This is all about giving our clients the perfect moment,” says Shoaf. “I see how our clients with dementia are happy and enjoying their life — and those are memories that will last a lifetime for their caregivers.”

## What If We’re Not Sure About a Long Trip Away?

A shorter trip can still offer a break in routine for both the care partner and the individual with dementia. Booking an overnight stay at a favourite hotel nearby, eating at



**TIP 3** *Speak up* “We do group hiking trips, and I make a point of saying, ‘Joan has dementia, so some days she might seem distant.’ It’s amazing because it’s a conversation starter and I also find the group is more likely to talk with Joan and engage with her.” –Alan Rae

## Savour the Moment

Alan Rae isn’t sure how much longer he and his wife will be able to travel internationally. But even as Connor’s dementia progresses, their travelling will continue. Rae knows their trips will need to be altered in the future: he suspects they’ll stick closer to home, with road trips to Palm Desert and Florida, using a trailer so the familiarity travels with them.

But for Rae, this change doesn’t matter. For him, travelling is about spending quality time with his wife, doing an activity that they’ve both loved for decades.

“Wherever you’re travelling, take the time to savour the small things.

Enjoy that smile from the individual, stop to take a picture, look at the fun side of travel. Recognize what’s important, because things are going to change. Every little moment is precious,” says Rae.

“Regardless of whether you do international trips or decide to go out to the farm for the day, travel is about taking the time to savour the moment.”

Learn more at [travel-for-all.com](http://travel-for-all.com) and [elitecruisesandvacationstravel.com](http://elitecruisesandvacationstravel.com).



## 3 SAFETY TIPS CARE PARTNERS SHOULD KNOW

**Tip #1** Encourage the person with dementia to wear a bright piece of clothing so they’re easy to spot in crowds and in case of separation.

**Tip #2** Ensure the person with dementia carries an identification card at all times with their name, and also the name and contact information for the care partner, should you get separated.

**Tip #3** Be watchful and diligent. The care partner should always consider the safety and well-being of the person with dementia, as well as their own.



## TRAVEL PLANNING:

*Alzheimer Society of Calgary's Padmaja Genesh on care partner considerations and important details*

**1** Can the person with dementia complete their daily living activities?

**2** How does the person respond to changes in routine and environment?

**3** Are you able to take on the challenges of providing complete care without assistance?

**4** Are you dealing with any health issues?

**5** Would you be able to adapt to the person with dementia if their needs change?

**6** Would you be able to adapt to changes in your original travel plans?



**Genesh also recommends discussing the idea of travel with the person's doctor.**

## THE DETAILS

- “Inform the airlines and the flight crew that the person travelling with you has dementia and request seating assistance if possible.
- “Carry small business-size cards that say, ‘the person with me has dementia’ (downloadable & printable from [dementianetworkcalgary.ca](http://dementianetworkcalgary.ca)). This makes it easier for others to accept your family member’s behaviour and help avoid unnecessary explanations and frustration.
- “Travel insurance is highly recommended, when travelling with a person with dementia, to cover unexpected costs that may be incurred during travel. Take time to find the best travel insurance for your needs,” Genesh says.





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to help give you the  
support, guidance and  
information you need.

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# 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**

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 therapy program that brings animals into long-term care facilities.

#### **P.I.E.C.E.S.**

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

#### **Positive Approach to Care (PAC)**

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

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

#### **Supportive Pathways**

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

#### **United Minds**

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

#### **WanderGuard**

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

#### **For more information**

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







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

**Private Pay:** Please contact facility for pricing and availability

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



## RESIDENTIAL

FACILITY NAME 	CONTACT INFO 	PRIVATE 	SUBSIDIZED 	PRICE 	CARE APPROACH 	NOTEWORTHY 
<b>AgeCare Glenmore</b> 1729 – 90 Avenue SW	agecare.ca 403-253-8806	●	●	\$	Best Friends Approach™; Company specific; Eden Alternative; P.I.E.C.E.S.; Supportive Pathways	
<b>AgeCare Midnapore</b> 500 Midpark Way SE	agecare.ca 403-873-2600		●	\$	Best Friends Approach™; Company specific; Supportive Pathways	Intergenerational childcare program
<b>AgeCare Seton</b> 4963 Front Street SE	agecare.ca 587-349-8444		●	\$	Best Friends Approach™; Company specific; Gentle Persuasive Approach	Intergenerational childcare program
<b>AgeCare SkyPointe</b> 179 Skyview Circle NE	agecare.ca 587-619-1900		●	\$	Best Friends Approach™; Company specific; Specialty Mental Health; Non-Violent Crisis Intervention	Intergenerational childcare program
<b>AgeCare Walden Heights</b> 250 Walden Drive SE	agecare.ca 403-873-4700	●	●	\$\$	Best Friends Approach™; Company specific; PAC; P.I.E.C.E.S.	Intergenerational childcare program
<b>All Seniors Care at Auburn Heights</b> 21 Auburn Bay Street SE	allseniorscare.com 403-234-9695	●		\$\$\$	Company specific	Couples may live together; secure memory care unit and assisted living
<b>Amica Britannia</b> 750 – 49 Avenue SW	amica.ca 403-476-8992	●		\$\$\$	Best Friends Approach™	
<b>Beaverdam</b> 2012 – 66 Avenue SE	silvera.ca 403-279-4623		●	\$	Best Friends Approach™	One story building
<b>Bethany Harvest Hills</b> 19 Harvest Gold Manor NE	bethanyseniors.com 403-226-8200		●	\$	Supportive Pathways; Gentle Persuasive Approach; P.I.E.C.E.S.; Complex Dementia Care	Secure outdoor area; purpose-built for people with moderate to severe dementia
<b>Bethany Riverview</b> 200, 2915 – 26 Avenue SE	bethanyseniors.com 587-392-3999		●	\$	Supportive Pathways; Gentle Persuasive Approach; P.I.E.C.E.S.; Complex Dementia Care	Purpose-built for people with complex dementia care needs
<b>Bow Crest Care Centre</b> 5927 Bowness Road NW	reveraliving.com 403-288-2373		●	\$	Dementiability Methods	
<b>The BSF Bow View Manor</b> 4628 Montgomery Boulevard NW	theBSF.ca 403-288-4446	●	●	\$-\$\$\$	Supportive Pathways	WanderGuard; long-term care
<b>The BSF Clifton Manor</b> 4726 – 8 Avenue SE	theBSF.ca 403-272-9831		●	\$	Supportive Pathways	Long-term care; secure outdoor area; smoking permitted
<b>The BSF Wentworth Manor</b> 5717 – 14 Avenue SW, Calgary	theBSF.ca 403-242-5005	●	●	\$-\$\$	Supportive Pathways	Age-in-place (multi-levels of care); secure outdoor area
<b>Carewest Colonel Belcher</b> 1939 Veteran's Way NW	carewest.ca 403-944-7800		●	\$	Supportive Pathways	Priority to veterans; secure outdoor area; smoking permitted

The BSF = The Brenda Strafford Foundation



## RESIDENTIAL

<b>Carewest Garrison Green</b> 3108 Don Ethell Boulevard SW	carewest.ca 403-944-0100		●	\$	Supportive Pathways	
<b>Carewest George Boyack</b> 1203 Centre Avenue NE	carewest.ca 403-267-2750		●	\$	Supportive Pathways	
<b>Carewest Rouleau Manor</b> 2206 – 2 Street SW	carewest.ca 403-943-9850		●	\$	Supportive Pathways; P.I.E.C.E.S.	Smoking permitted
<b>Carewest Signal Pointe</b> 6363 Simcoe Road SW	carewest.ca 403-240-7950		●	\$	Supportive Pathways; Complex Mental Health Care	Dementia-specific design; smoking permitted
<b>Chartwell Eau Claire Care Residence</b> 301 – 7 Street SW	chartwell.com 587-287-3943	●	●	\$-\$		WanderGuard
<b>The Edgemont</b> 80 Edenwold Drive NW	reveraliving.com 403-241-8990		●	\$-\$	PAC	
<b>Evanston Grand Village</b> 40 Evanston Way NW	evanstongrand.ca 403-274-6416		●	\$-\$	Supportive Pathways	Secure outdoor area; music and arts programs
<b>Evergreen</b> 2220 – 162 Avenue SW	reveraliving.com 403-201-3555	●		\$-\$		Pets welcome
<b>Extendicare Cedars Villa</b> 3330 – 8th Avenue SW	extendicarecedarsvilla.com 403-249-8915		●	\$	Best Friends Approach™	Couples may live together; outdoor courtyard; PALS; WanderGuard
<b>Extendicare Hillcrest</b> 1512 – 8 Avenue NW	extendicarehillcrest.com 403-289-0236		●	\$	Supportive Pathways; Best Friends Approach™; PAC	Couples may live together; intergenerational programming; PALS; Roam Alert
<b>Father Lacombe Care Society</b> 270 Providence Boulevard SE	fatherlacombe.ca 403-256-4641		●	\$		
<b>Holy Cross Manor</b> 70 Evanspark Manor NW	covenantcare.ca 587-230-7070		●	\$	Supportive Pathways	
<b>Intercare Brentwood Care Centre</b> 2727 – 16 Avenue NW	intercarealberta.com 403-289-2576		●	\$		
<b>Intercare Chinook Care Centre</b> 1261 Glenmore Trail SW	intercarealberta.com 403-252-0141		●	\$		
<b>Intercare Southwood Care Centre</b> 211 Heritage Drive SE	intercarealberta.com 403-252-1194		●	\$	Butterfly Approach	
<b>Manor Village at Varsity</b> 40 Varsity Estates Circle NW	themanorvillage.com 587-393-9999	●		\$-\$		
<b>Manor Village at Fish Creek Park</b> 22 Shawnee Hill SW	themanorvillage.com 403-918-2127	●		\$-\$		Secure outdoor area
<b>Mayfair Care Centre</b> 8240 Collicutt Street SW	mayfaircarecentre.com 403-252-4445	●		\$		



## RESIDENTIAL








<b>McKenzie Towne Care Centre</b> 80 Promenade Way SE	reveraliving.com 403-508-9808		●	\$	Dementiability Methods	
<b>McKenzie Towne Retirement Residence</b> 20 Promenade Park SE	reveraliving.com 403-257-9331	●	●	\$-\$		Secure outdoor area
<b>Millrise Seniors Village</b> 14911 – 5 Street SW	retirementconcepts.com 403-410-9155	●	●	\$		
<b>Monterey Seniors Village</b> 4288 Catalina Boulevard NE	retirementconcepts.com 403-207-2929		●	\$		
<b>Mount Royal Care Centre</b> 1813 – 9 Street SW	reveraliving.com 403-244-8994		●	\$	Dementiability Methods	
<b>Newport Harbour Care Centre</b> 10 Country Village Cove NE	parkplaceseniorsliving.com 403-567-5100	●	●	\$-\$	Supportive Pathways; Best Friends Approach™	Multi-sensory robotics; lakefront location
<b>Origin at Whitehorn Village</b> 5200 – 44 Avenue NE	originway.ca 403-271-2277		●	\$	Butterfly Model; Best Friends Approach™	
<b>Prince of Peace Retirement Community</b> 285030 Luther Rose Boulevard NE	verveseniorliving.com 403-285-5080		●	\$-\$	Supportive Pathways; Best Friends Approach™	Secure outdoor area
<b>Providence Care Centre</b> 149 Providence Boulevard SE	flccfoundation.ca 587-393-1350		●	\$	Complex Dementia Care; Person-Centred; Supportive Pathways	Secure outdoor area; intergenerational programming; age-in- place; purpose built for people with complex dementia care needs; WanderGuard
<b>Rocky Ridge Retirement Community</b> 10715 Rocky Ridge Boulevard NW	rockyridgeretirement.com 403-930-4848		●	\$	Gentle Persuasive; Person-Centred; Supportive Pathways	Secure outdoor area; momentum tracking
<b>Sage Hill Retirement Residence</b> 6 Sage Hill Gardens NW	allseniorscare.com 403-455-2273		●	\$-\$		Age-in-place; pets welcome
<b>St. Marguerite Manor</b> 110 Evanspark Manor NW	covenantcare.ca 587-955-9788		●	\$		Couples may live together
<b>St. Teresa Place</b> 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; intergener- ational programming
<b>Scenic Acres Retirement</b> 150 Scotia Landing NW	reveraliving.com 403-208-0338	●	●	\$-\$	PAC	Secure outdoor area; pets welcome
<b>StayWell Manor Village at Garrison Woods</b> 174 Ypres Green SW	themanorvillage.com 403-242-4688	●		\$-\$	Best Friends Approach™	
<b>Swan Evergreen Village</b> 2635 Eversyde Avenue SW	originway.ca 587-481-6638	●	●	\$\$\$	Best Friends Approach™	Intergenerational pro- gramming; age-in-place; secure outdoor area; couples may live together



## RESIDENTIAL

<b>United Active Living at Fish Creek</b> 51 Providence Boulevard SE	unitedactiveliving.com 587-481-7907	●		\$\$\$	United Minds	Secure outdoor area
<b>United Active Living at Garrison Green</b> 3028 Don Ethell Boulevard SW	unitedactiveliving.com 403-685-7200	●		\$\$\$	United Minds	
<b>Westman Village Journey Club</b> 100, 3132 – 118 Avenue SE	westmanvillage.com 403-723-8411				Butterfly Model	Secure outdoor area
<b>Wing Kei Crescent Heights</b> 1212 Centre Street NE	wingkeicarecentre.org 403-277-7433		●	\$		Chinese language & culture; age-in-place
<b>Wing Kei Greenview</b> 307 – 35 Avenue NE	wingkeicarecentre.org 403-520-0400		●	\$		Chinese language & culture; age-in-place

## OUT-OF-TOWN RESIDENTIAL

FACILITY NAME 	CONTACT INFO 	PRIVATE 	SUBSIDIZED 	PRICE 	CARE APPROACH 	NOTEWORTHY 
<b>AgeCare Sagewood</b> 140 Cambridge Glen Drive, Strathmore	agecare.ca 403-361-8000		●	\$	Best Friends Approach™; Gentle Persuasive; Supportive Pathways	Intergenerational childcare program
<b>Aspen Ridge Lodge</b> 1100 – 20 Avenue, Didsbury	mvsh.ca 403-335-9848		●	\$		Couples may live together
<b>Bethany Didsbury</b> 1201 – 15 Avenue, Didsbury	bethany seniors.com 403-335-4775		●	\$		Secure outdoor area; age-in-place
<b>Meadowlark Senior Care Home</b> 203 Hillcrest Boulevard, Strathmore	meadowlarkcare.com 403-934-5294	●		\$-\$		Secure outdoor area; age-in-place
<b>Origin at Spring Creek</b> 808 Spring Creek Drive, Canmore	originway.ca 403-678-2288	●		\$\$\$	Best Friends Approach™; PAC; Supportive Pathways	Secure outdoor area
<b>Seasons High River</b> 660 – 7 Street, High River NW	seasonsretirement.com 403-652-1581		●	\$-\$	Company specific	Secure outdoor area; pets welcome
<b>Silver Willow Lodge</b> 2007 – 22 Avenue, Nanton	mosquitocreekfoundation.net 403-646-2660		●	\$	Person-Centred; PAC; Supportive Pathways	
<b>The BSF Tudor Manor</b> 200 Sandstone Drive, Okotoks	theBSF.ca 403-995-9540		●	\$	Person-Centred; Supportive Pathways	Intergenerational programming; secure unit and outdoor area; supportive living

The BSF = The Brenda Strafford Foundation



## HOME CARE

AGENCY 	CONTACT INFO 	STAFFING Qualifications 	STARTING RATE 	CARE APPROACH 
<b>Alberta Health Services</b>	albertahealthservices.ca 403-943-1920	OT, RN, HCA, LPN, PT	Free	Client-dependent
<b>All About Seniors</b>	allaboutseneiors.ca 403-730-4070	RN, LPN, HCA, Companion	\$30/hr 2 hour minimum	Best Friends Approach™
<b>Bayshore Home Health</b>	bayshore.ca 403-776-0460	RN, LPN, HCA, Companion	\$28.75/hr 2 hour minimum	Supportive Pathways
<b>CBI Home Health</b>	cbi.ca 403-232-8770	RN, LPN, HCA	\$33.76/hr 1 hour minimum	
<b>Calgary Elder Care</b>	calgaryeldercare.com 403-464-2455	RN, LPN, HCA	\$32/hr 3 hour minimum	Best Friends Approach™; Supportive Pathways
<b>Caring Hands Home Health Calgary</b>	caringhandscalgary.ca 403-999-3336	RN, LPN, HCA, Companion	\$25/hr 3 hour minimum	Treat Clients as Family Would
<b>Classic LifeCare Calgary</b>	classiclifecare.com 403-242-2750	RN, LPN, HCA, Companion	\$32.75/hr 2 hour minimum	PAC
<b>Comfort Keepers</b>	calgary.comfortkeepers.ca 403-228-0072	RN, LPN, HCA	\$30.50/hr 2 hour minimum	Best Friends Approach™
<b>Enhanced Health Services</b>	enhancedhealthservicesinc.com 403-547-5859	RN, LPN, HCA	\$29.99/hr 2 hour minimum	
<b>Focus On Caring</b>	focusoncaring.com 403-264-3839	RN, HCA	\$28/hr 4 hour minimum	Dementia Care Curriculum
<b>Global Senior Care</b>	globalseniorcareservices.com 403-452-4555	RN, LPN, HCA	\$28/hr 3 hour minimum	Best Friends Approach™
<b>Granddaughters Personal Care</b>	granddaughters.ca 403-828-0550	LPN, HCA	\$29-\$35/hr 2 hour minimum	Best Friends Approach™; Gentle Persuasive Approach; PAC; Gentlecare; Supportive Pathways
<b>Home Care Assistance Calgary</b>	homecareassistancecalgary.ca 403-301-3777	RN, LPN, HCA	\$30/hr 2 hour minimum	Cognitive Therapeutic Method; Best Friend Approach™; Client-Centred Approach
<b>Home Instead Senior Care North</b>	homeinstead.com/northcalgary 403-910-5860	Companion, HCA, LPN	\$33.95/hr 3 hours minimum	Dementia CARE Curriculum
<b>Home Instead Senior Care South</b>	homeinstead.com/calgary 403-984-9225	Companion, HCA, LPN	\$33.95/hr 3 hours, twice a week	Dementia CARE Curriculum
<b>The Mad Tasker</b>	thematdasker.com 403-988-2471	RN, LPN, HCA	\$30/hr 1 hour minimum	Best Friends Approach™; Person-Centred Approach
<b>Max Home Care</b>	maxhomecare.ca 587-352-1010	HCA	\$27/hr 2 hour minimum	
<b>Miraculum Homecare</b>	miraculumhomecare.com 403-452-6399	RN, LPN, HCA	\$28/hr 3 hour minimum	Family Care Focus
<b>Nurse Next Door</b>	nursenextdoor.com 403-454-1399	RN, LPN, HCA	\$35/hr 3 hour minimum	Senior Home Care Services; Making Lives Better
<b>Ohana Care Health Services</b>	ohanacare.ca 403-300-2273	LPN, HCA	\$30/hr 2 hour minimum	Best Friends Approach™



## HOME CARE

<b>ParaMed</b>	paramed.com 403-228-3877	RN, LPN, HCA, Companion	\$55/hr	Client-Centred
<b>Qualicare Family Homecare Calgary</b>	homecarecalgary.com 403-209-2210	RN, LPN, HCA, Companion	\$33/hr 3 hour minimum	Nurse Managed Care; Best Friends Approach™; Gentle Persuasive Approach
<b>Right At Home</b>	rightathomecanada.com/calgary 403-869-8294	RN, LPN, HCA	\$30.95/hr 3 hour minimum	Supportive Pathways; Best Friends Approach™
<b>Senior Homecare by Angels</b>	seniorhomecarecalgary.com 403-862-0129	LPN, HCA	\$29.95/hr 2 hour minimum	Client-dependent
<b>Supportive Outings and Services</b>	soscaregiver.ca 403-816-0428	HCA, Companion	\$28/hr 1.5 hour minimum	Client-dependent
<b>Vinnette Morgan</b>	vinnettemorgan@yahoo.ca 403-919-4052	Nursing Attendant	\$25/hour	Client Dignity; Help Clients Stay at Home
<b>Vytality at Home</b>	vytality.ca 403-488-7991	RN, LPN, OT, HCA, Rec Therapist, Physio, Companion	\$33/hr 2 hour minimum	Supportive Pathways; Person-Centred Approach

## OVERNIGHT RESPITE - Assessment Required

FACILITY 	BUILDING ADDRESS 	PHONE NUMBER 	WEBSITE 	SUBSIDIZED	PRIVATE
<b>AgeCare Glenmore</b>	1729 – 90 Avenue SW	403-253-8806	agecare.ca	●	
<b>Auburn Heights Retirement Residence</b>	21 Auburn Bay Street SE	403-234-9695	allseniorscare.com		●
<b>The BSF Clifton Manor</b>	4726 – 8 Avenue SW	403-272-9831	theBSF.ca	●	
<b>The BSF Wentworth Manor</b>	5717 – 14 Avenue SW	403-242-5005	theBSF.ca	●	
<b>Carewest Colonel Belcher</b>	1939 Veteran's Way NW	403-944-7800	carewest.ca	●	
<b>Carewest Sarcee</b>	3504 Sarcee Road SW	403-686-8140	carewest.ca	●	
<b>Chartwell Eau Claire Care Residence</b>	301 – 7 Street SW	587-287-3943	chartwell.com		●
<b>Evergreen</b>	2220 – 162 Avenue SW	403-201-3555	reveraliving.com		●
<b>McKenzie Towne Retirement Residence</b>	20 Promenade Park SE	403-257-9331	reveraliving.com		●



## ADULT DAY PROGRAMS

FACILITY 	PROGRAM NAME 	BUILDING ADDRESS 	PHONE NUMBER 	WEBSITE 	SUBSIDIZED 	PRIVATE 
<b>AgeCare Glenmore</b>	AHS Adult Day Program	1729 – 90 Avenue SW	403-253-8806	agecare.ca	●	
<b>AgeCare Midnapore</b>	AHS Adult Day Program	500 Midpark Way SE	403-873-2852	agecare.ca	●	
<b>AgeCare Seton</b>	Club 36 Adult Day Program	4963 Front Street SE	403-255-0700	alzheimercalgary.ca	●	
<b>Auburn Heights Retirement Residence</b>	Young Onset Dementia Day Program	21 Auburn Bay Street SE	403-234-9695	allseniorscare.com		●
<b>Bethany Harvest Hills</b>	Club 36 Adult Day Program	19 Harvest Gold Manor NE	403-226-8201	alzheimercalgary.ca	●	
<b>The BSF Bow View Manor</b>	AHS Adult Day Program (including Dementia Program)	4628 Montgomery Blvd. NW	403-286-6166	theBSF.ca	●	
<b>The BSF Clifton Manor</b>	AHS Adult Day Program (including Early Onset and Dementia Programs)	4726 – 8 Avenue SE	403-204-9969	theBSF.ca	●	
<b>The BSF Wentworth Manor</b>	Adult Day Program	5717 – 14 Avenue SW	403-686-8602	theBSF.ca	●	
<b>The Calgary Chinese Elderly Citizens' Association</b>	Wellness Day Program, Dementia Day Program *Intended for clients who speak Chinese	111 Riverfront Avenue SW	403-269-6122	cceca.ca	●	●
<b>Carewest Beddington</b>	Comprehensive Community Care (C3)	308 – 8120 Beddington Blvd. NW	403-520-3350	carewest.ca	●	
<b>Carewest Colonel Belcher</b>	Wellness Day Program	1939 Veteran's Way NW	403-944-7854	carewest.ca	●	
<b>Carewest Sarcee</b>	Comprehensive Community Care (C3)	3504 Sarcee Road SW	403-686-8140	carewest.ca	●	
<b>Carewest Signal Pointe</b>	Carewest Signal Pointe Adult Day Program	6363 Simcoe Road SW	403-240-7953	carewest.ca	●	
<b>Ohana Care Health Services</b>	Ohana Care Day Program	156 – 8888 Country Hills Blvd.	403-300-2273	ohanacare.ca		●
<b>Peace of Mind</b>	Peace of Mind Adult Day Program	#26, 5440 4 Street NW	587-887-4900	peaceofmindcare.ca		●
<b>SAIT</b>	YouQuest - A Wellness Community for Young Onset Dementia	13016 Avenue NW	403-255-7018	youquest.ca		●
<b>St. Andrew's Presbyterian Church</b>	Side by Side Fellowship	703 Heritage Drive SW	403-255-0001	standrewscalgary.ca		●
<b>Varsity Acres Presbyterian Church</b>	Side by Side Fellowship	4612 Varsity Drive NW	403-288-0544	vapc.ca		●
<b>Wing Kei Care Centre</b>	Wellness Day Program, Dementia Day Program *Intended for clients who speak Chinese	1212 Centre Street NE	403-277-7433	wingkeicarecentre.org	●	●

\*Confirm dates and times with individual programs





**Book a Tour and Learn More About Our Private Choice Seniors Care and Specialized Dementia Care Services at Wentworth Manor**

### **Private Choice Seniors Care Services Carefully Designed for Peace of Mind.**

Located in beautiful Christie Park, Wentworth Manor offers spacious and enhanced private rooms in a safe and caring home-like setting.

Our compassionate staff provide exceptional nursing and clinical care, plus a full range of health and wellness services and amenities designed for convenience and peace of mind.

### **Specialized Dementia Care with Innovative Therapies to Enrich Lives**

We offer innovative therapies to optimize well-being and enrich lives including Virtual Reality, Individualized Music Therapy, and Intergenerational Art Therapy.



**The Brenda  
Strafford** Wentworth  
Foundation Manor

5715 14<sup>th</sup> Ave SW  
Calgary, AB T3H 3M2  
403.242.5005

**theBSF.ca**

# Help us make dementia matter in 2019

## Join us!

Get involved at  
[www.dementianetworkcalgary.ca](http://www.dementianetworkcalgary.ca)



*Creating a Dementia-Friendly Community*

**Alzheimer Society**  
CALGARY 30<sup>years</sup>







**GORDIE**  
HOWE C.A.R.E.S.

CENTER FOR ALZHEIMER'S RESEARCH  
AND EDUCATION SOCIETY

**#dementiamatters**



## CARE PARTNER SUPPORT

PROGRAM 	PROGRAM DETAILS 	PHONE NUMBER 	E-MAIL 	HOURS 	DATES 
<b>Alzheimer Society of Calgary</b>	Contact the Society for program details	403-290-0110			
<b>Calgary N.E. Dementia Support Group</b>	Dementia-specific support	403-273-2371	Call Jean, at number listed	7 p.m.	4th Thurs of Each Month
<b>Calgary South Dementia Support Group</b>	Dementia-specific support	403-271-9570	Call Claire, at number listed	10 a.m.-11:30 a.m.	2nd & 4th Thurs of Each Month
<b>Conversation Café</b>	Monthly meet-up for people with dementia and their care partners	403-290-0110 x 237	kim@dementianetworkcalgary.ca, dementianetworkcalgary.ca	2 p.m. - 4 p.m.	2nd Tues of Each Month
<b>Dementia Caregiver Support</b>	Dementia-specific support Southwood United Church, 10690 Elbow Dr. SW	403-253-2979	southwoodchurch.ca	1 p.m.	1st Mon of Each Month
<b>Living with Dementia</b>	12 topics by professional facilitators Carewest Glenmore Park Day Hospital, 6909 – 14 St. SW	403-640-6480		Call to confirm	Call to confirm
<b>Memory P.L.U.S.</b>	Safe, fun, social activities for those with mild dementia and their care partners	403-955-1674	family.caregivercentre@ahs.ca	2 hr Sessions	Fall/Spring Sessions 12-week Program
<b>Young Onset Dementia Support Group</b>	For people with dementia (diagnosed under age 65) and their caregivers. Southwood United Church 10690 Elbow Drive. SW	403-975-6685 403-283-9537	cindy@youquest.ca, call for first time participants	7 p.m.-8:30 p.m.	1st & 3rd Tue of Each Month

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

## Questions? Feedback? Stories to Share?

Write to us: [feedback@dementiaconnections.ca](mailto:feedback@dementiaconnections.ca)  
Connect with us online at: [dementiaconnections.ca](http://dementiaconnections.ca)





## Are you or a loved one interested in **research** on the **aging brain**?

We are seeking volunteers over the age of 60 to participate in studies relating to **memory**, **thinking** and **behaviour** in the aging brain. We are looking for those with no memory issues, mild memory issues, and those with dementia with distress and changes in behaviour.



Options for participation may involve:

1. Answering questions related to memory, thinking, mood, and behaviour
2. Giving a blood sample
3. MRI scan
4. We have medication trials as well

For more information about currently enrolling studies, or to assess eligibility, please contact:

[brainresearch@ucalgary.ca](mailto:brainresearch@ucalgary.ca)

[403-210-7737](tel:403-210-7737)

The University of Calgary Conjoint Health Research Ethics Board has approved these research studies.

*Ethics ID#s REB15-0601, REB16-0338, REB18-0052, REB17-1930, REB18-1463*



Dementia  
Advocacy  
Canada

*Voices of Lived Experience*

**We are speaking up.**

We want to change policy,  
influence program development,  
and improve access to services  
across the country.

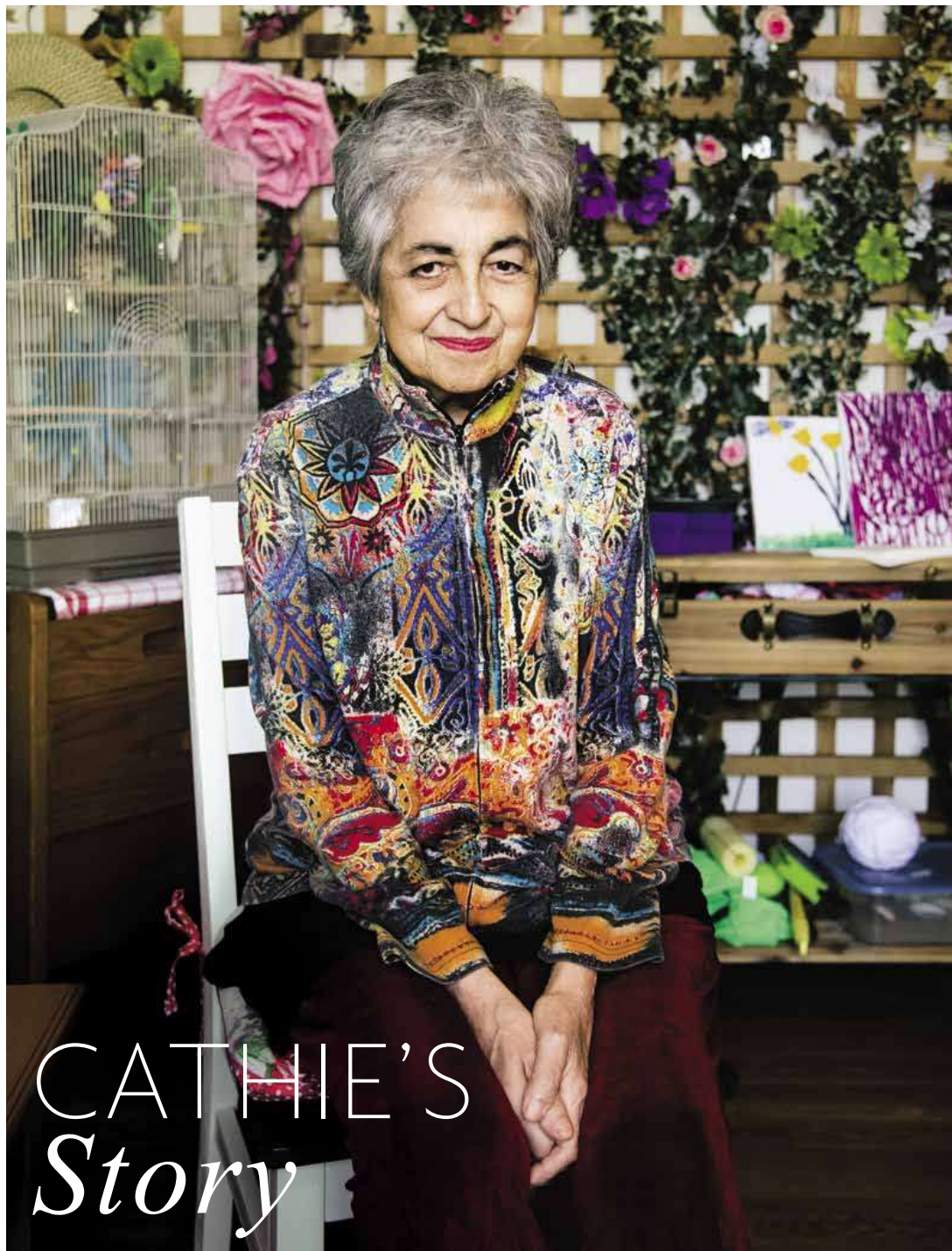
Register at:

[www.dementiacanada.com](http://www.dementiacanada.com)

Introducing  
a grassroots  
group of  
care partners  
and people  
living with  
dementia.

Join us  
and be  
heard.





## CATHIE'S *Story*

AS TOLD TO Jennifer Dorozio and Erin Thrall, Cathie's daughter PHOTO BY Jared Sych

*Cathie Thrall was born in 1936 to Greek parents, Chris and Anastasia Christou, in Lethbridge, Alta. She enjoys a full, colourful life and finds pleasure in family, her community and in the arts.*

**T**hrall had an early career as an English and home economics teacher in Calgary, before moving back to her hometown of Lethbridge. It was there, in 1962, that she married her husband, Ralph.


As a couple, Cathie and Ralph were passionate about supporting close-to-home music and art initiatives including the Lethbridge Symphony and local

visual art institutions. She was able to feed her creative fire throughout her life by studying textile design in Red Deer, Banff and California. Thrall was also a devoted mother to her four children and their household was full of laughter and activity.

In 2011, after 49 years of marriage, Ralph passed away. Around the same time, Thrall began to display early signs of dementia. She says having Alzheimer's "is a strange new experience. Some days I remember things more than other days. You do the best you can each day.

"[I have learned] I have to accept help. [The advice I would give to others with dementia is to] become familiar with your own home — that's a big plus— and jot down some of your experiences."

Thrall currently resides at the Legacy Lodge in Lethbridge, Alta., which integrates vivid colours in its design and offers playful art programs. Up until recently, Thrall relished in playing classical piano pieces she retained from childhood. Charming and gregarious, she enjoys socializing with other residents and spending time with her family.

"[Life now] looks bright and sunny. I like to hear good music, I like spending time with my children, I love them. I feel lucky." 

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