Diagnosed with young-onset dementia six years ago, Mary Beth Wighton has a powerful message to share.
The greatest breakthrough in senior care? Mom’s cozy cottage.

We help aging parents stay at home, whether they’re dealing with Alzheimer’s, arthritis or anything in between.

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October 7, 2018

Alzheimer Society
CALGARY
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A look at how three dementia experts around the world are helping to build revolutionary, person-centred care models for individuals with dementia.

An exciting collaboration in central Alberta is bringing new support solutions to those living with dementia, and to the health-care professionals caring for them.

Canadian filmmakers and playwrights are finding creative ways to represent life with dementia on the stage and screen.

Living with Dementia
Jeanette Nicholls shares her thoughts on how life with her husband, Ron, has changed since his Alzheimer’s diagnosis.
PEOPLE WITH dementia want to be treated with compassion, dignity and respect, just like everybody else. They also want the right to participate fully in society, just like everybody else. In this issue, we learn how various individuals who are living with dementia, including Mary Beth Wighton, Roger Marple, Jim Mann and Kate Swaffer, are working hard to address stigma and change the way the world views dementia.

This issue also explores how Dementia Re-imagined, a Dementia Network Calgary initiative, challenges us to think differently about how we treat and support our friends, relatives and neighbours who are impacted with dementia.

The development of a Canadian Dementia Strategy and implementation of the Alberta Dementia Strategy & Action Plan are underway. Both will help to create a tangible framework to provide people impacted by dementia with the support they need to live the best life possible.

Changes in the brain may start to occur 20 years before symptoms are evident. Research is helping us to better understand these changes and how to reduce the risks of cognitive decline. Research is also helping us understand the role of technology and the effectiveness of targeted support.

Finally, September is World Alzheimer’s Month, an international campaign to raise dementia awareness and challenge stigma. Each year, Alzheimer associations from around the world unite to organize advocacy events. Consider participating in or sponsoring the Alzheimer Society of Calgary’s annual walk/run on Sunday, Oct. 7, 2018.
Hi Lisa,
I am the new Director of Operations for Health Link and I wanted to reach out and thank you for the Dementia Connections magazines sent to me. It is a wonderful magazine and I appreciate your mentioning the 811 Dementia Advice line in it. Health Link would like to reach as many people as possible who need assistance navigating with their loved ones through the dementia journey. Kind regards,
Tricia Chambers RN, DC, MN
Director of Operations, Health Link, Alberta Health Services

Hi Lisa,
Thank you so much for the information found in the latest edition of Dementia Connections (Summer 2018). The personal stories were very touching and informative. The Resource List will be invaluable in the near future, as I will be needing the services listed there for my wife. In connection with the Resource List, one of the columns is entitled “Care Approach,” with the various choices available. Would it be possible to have a future article (or several) describing the differences and similarities of the approaches? How are each of them different in theory and how does that theory play out in actual practice for the patients with dementia? Are some approaches better for certain types of dementia or Alzheimer’s?
Peter Baljeu

Hello Lisa,
My biggest compliments on your high-quality and relevant publication! I’m so impressed with the publication, especially the personal perspective and focus on quality of life for both people living with dementia and for their loved ones, as well as being a wonderful source of information.
Ms. Annette Meeuwse, RN, BSN, MaOL
Director of Care
Dementia Programs, Extendicare

Hello Lisa,
I have just had the opportunity to peruse the recent edition of Dementia Connections magazine. It is, as with previous editions, astoundingly good!
I trust that you feel a tremendous amount of pride in the quality of the magazine and the impact it is having on supporting individuals and families affected by dementia. It is also, of course, a great resource for providers.

Through this publication, you are having a tremendously positive impact on the awareness, services, supports and peace of mind for many Calgarians and beyond.
Kind regards,
Mike Conroy
President & CEO,
The Brenda Strafford Foundation Ltd.

Hi Lisa,
Just came across your magazine. What a nice production and valuable resource to have!
Thank you.
Jackie Evans

Dear Lisa,
My husband and my story begins with a real challenge at obtaining a diagnosis in the beginning. He and I pursued unsuccessfully for some time with his GP a diagnosis that explained the changes we were seeing. Finally, in September 2015, John was diagnosed with FTD, an early-onset dementia.

We’ve since tried to pull together other families similarly impacted with an aim to establish early-onset programming, training and supports that are virtually non-existent in our community. I’d like John to benefit, while he still can, from programming that is stimulating and challenging for him. He played competitive soccer until August 2017, until he couldn’t remember his position or direction to kick the ball.

We are doing everything humanly possible to delay the progression of this neurological disorder. We’d like the government and service providers to increase their efforts similarly.
We’ve got a report, based on focus groups, and are building an action plan.

Thank you.
Danielle Barrette-Marcuccio
Ottawa, Ontario

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COLLABORATION IS KEY

A groundbreaking event held in Ottawa last May is an exciting step forward in the development of a National Dementia Strategy

BY Geoff Geddes

On June 22, 2017, Bill C-233, the National Strategy for Alzheimer’s Disease and Other Dementias Act, was passed into law, and many see it as an excellent start.

“A national strategy is crucial, as dementia in Canada is not fully recognized or supported by the healthcare system and social service sectors,” says Pauline Tardif, chief executive officer of the Alzheimer Society of Canada. “Canadians are generally aware of dementia, yet it’s not treated the same as other diseases or chronic conditions.”

The new strategy, still in development, aims to change all of that. It will encourage the government to invest in more dementia research, combat stigma, enhance understanding of dementia and provide better support for people with dementia and their families.

Given these ambitious goals, it is vital to involve stakeholders from the public, private and non-profit sectors, including people with dementia and their family care partners.

“Dementia affects not only the person living with it, but those around them,” says Ron Beleno, a family care partner in Ontario whose dad recently passed away after a decade of living with Alzheimer’s. “Many times, the caregiver is forgotten in the dementia journey, but they play a key role in supporting that person, so they must be supported themselves with better programs and services.”

Since collaboration is critical in forming the national strategy, it served as a central theme in the recent National Dementia Conference, held on May 14-15 in Ottawa, and organized by the Public Health Agency of Canada. As the first conference of its kind in Canada, this groundbreaking event aimed to inform and inspire themes and key considerations for the National Dementia Strategy. A broad range of interested parties from across the country, including those living with dementia, care partners, researchers, health care professionals, advocacy groups and representatives from provincial and territorial governments were invited to attend.

“Provinces and territories are all faced with the growing numbers of persons living with dementia and with determining how to best support their quality of life and that of their care partners,” says Corinne Schalm, executive director of continuing care with Alberta Health. “We will only achieve this by working together across all levels of government, and with those living with dementia and their care partners, as well as researchers, community organizations, and health and social service professionals.”

Following opening remarks by the Honourable Ginette Petitpas Taylor, Minister of Health, the national conference offered a variety of keynote speakers, round tables and Q&A sessions on everything from dementia prevention to the use of technology in dementia care.

For Roger Marple of Medicine Hat, a dementia advocate who received an Alzheimer’s diagnosis in 2015, one session in particular struck a nerve. Titled

DID YOU KNOW? Every three seconds, somebody in the world will develop dementia.
“Awareness Raising And Stigma Reduction: Coordination of Efforts,” it explored promising strategies to reduce dementia-related stigma.

“The main thing that stands between me and living well with dementia is stigma, which is a learned behaviour passed on from one generation to the next,” says Marple. “It is perpetuated by ignorance in not recognizing that things like Alzheimer’s jokes can do a lot of damage. If we as a society are to change the stigma culture, we need to challenge the behaviours. We need to speak openly and often, and clearly articulate our expectations for change.”

In the eyes of many participants, the event was integral to ongoing efforts toward a National Dementia Strategy. “The conference succeeded in galvanizing the entire dementia community around taking action now,” says Tardif. “It was also wonderful to see people with dementia and caregivers at the table to ensure that we’re not creating a strategy about them without them.”

In 2011, Alzheimer Scotland was looking for new ways to support its population living with dementia. The charity wanted suggestions that were original and fresh, so they commissioned a service design project to students in the Glasgow School of Art’s Product Design program. The students came back with a great idea: provide trained assistance dogs to individuals with dementia.

The proposal made sense, as the psychological benefits of therapy dogs are well-recorded. According to the American Psychiatric Association, therapy animals help decrease anxiety, increase feelings of safety and comfort, and encourage social interaction. Combining the positive effects of therapy dogs with the day-to-day support provided by a service animal would be very beneficial to an individual with dementia.

The idea soon grew from a student concept into the Dementia Dog Project, a charitable collaboration between Alzheimer Scotland and Dogs For Good. Between 2012 and 2015, the program went through a pilot phase in which four dementia assistance dogs were trained and then provided to four couples (each individual with dementia must live with a caregiver to qualify for a dog).

The pilot was such a success that the program then expanded. The Dementia Dog Project is currently training eight additional dogs who will be paired with eight Scottish couples.

All dementia assistance dogs also offer emotional support. They instill a sense of calm, improve confidence, and, as dogs need to be walked, encourage the individual with dementia to get out of the house, reducing social isolation.

Ken and Glenys Will received a dementia assistance dog during the project’s pilot phase in 2013. Glenys, Ken’s wife and caregiver, says that welcoming Golden Labrador Kaspa into their home was life-changing. Kaspa is trained to wake Ken up, bring him medication and take items between the couple. And, as Kaspa calms Ken, Glenys feels more able to leave the house, knowing Ken isn’t alone.

“Kaspa has given us our lives back,” she says.

**TOP 10 PRIORITIES**

According to Canadians affected by dementia, these are the top research priorities to consider as we move forward in forming a national strategy.

1. Stigma
2. Emotional well-being
3. Impact of early treatment
4. Health system capacity
5. Caregiver support
6. Access to information and services, post-diagnosis
7. Care-provider education
8. Dementia-friendly communities
9. Implementation of best practices for care
10. Non-drug approaches to managing symptoms

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All dogs go through two years of training, first with Dogs For Good and then with HMP Castle Huntly, a prison-based assistance dog training program.

To create a long-lasting bond between animal and human, the Dementia Dog Project team identifies a match based on the dog’s skills and the client’s needs. The dog’s training is then tailored to specifically support the couple it will be placed with. For example, a dog might assist the individual with dementia by fetching a water bottle to remind the individual to hydrate, or by helping remove pieces of clothing when the individual dresses.

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“Kaspa has given us our lives back,” she says.
The Gentle Persuasive Approaches (GPA) program is just a little more than a decade old, but more than 300,000 Canadians have already been trained in this evidence-based dementia education curriculum.

“It’s a comprehensive, practical education program that equips caregivers with the skills, the knowledge and the confidence to deliver person-centred dementia care,” says Patti Boucher, executive director at Advanced Gerontological Education (AGE) Inc. in Hamilton, Ontario.

Volunteer stakeholders (comprising expert clinicians, educators, and researchers specializing in gerontology, nursing and health services) contribute to AGE, a not-for-profit social enterprise dedicated to enhancing the care of older adults. The team at AGE developed the Gentle Persuasive Approaches curriculum to help point-of-care staff “to develop their compassionate and effective techniques in order to assist people with dementia who may become upset or frustrated,” Boucher says. “It really is about safeguarding both the person with dementia, as well as the care provider.”

A 2008 study out of York University in Ontario revealed 90 per cent of front-line workers in Canada claimed to have experienced physical violence from residents and their families, and 43 per cent reported violence daily. Boucher says GPA teaches front-line caregivers, and anyone who regularly interacts with people with dementia.
Three easy tips for implementing Gentle Persuasive Approaches methods from Dr. Patti Boucher:

1. Understand the individual, their unique likes/dislikes and know them as a person — this will equip care providers with diversion ideas that will interest the person with dementia to engage and decrease their agitation.

2. Speak to the individual slowly and provide enough time for them to process the message.

3. Adjust the care around the person; for example, alter bathing and eating times to fit their unique needs.

At the end of a full-day GPA Basics education session, participants earn a certificate of participation. AGE also offers online courses in GPA. The course is broken down into four modules: an overview of the principles of person-centred care and understanding dementia’s impact on the brain; the relationship between the progress of the disease and dementia’s behavioural responses; strategies to safely manage responsive behaviours; and self-protection safeguards for both the care provider and the person with dementia.

Boucher says everything participants learn at these sessions is immediately useful, and this is partly why GPA continues to grow and improve. A fourth edition of the curriculum is being released in late 2019, and AGE also just signed an agreement to bring the GPA curriculum to China.

“We’re continually enhancing and reinvesting into dementia curricula because our mission is to advance learning and make a difference in the lives of people with dementia and care providers,” Boucher says.

To learn more about Gentle Persuasive Approaches, contact the Alzheimer Society at alzheimercalgary.ca, or call 403.290.0110.

Did you know? Cindy Bond at the Alzheimer Society of Calgary has been trained in Gentle Persuasive Approaches and is now offering this training in Calgary and area.
IN focus

BEHIND THE MASK

WP Puppet Theatre brings a mask-making workshop to people living with dementia

BY Jennifer Friesen

When the team from WP Puppet Theatre first walked through the doors of Club 36 — an Adult Day Program operated by the Alzheimer Society of Calgary — last fall, they came bearing a strange gift: a box full of plain white masks. The masks didn’t stay plain for long. They were soon transformed by members of the Club’s day program, who adorned them with vivid colours, family photos, mementos and even a few butterfly stickers.

It was the first time the puppetry-infused workshop, dubbed View from the Inside: Courage Journey, took its mission to people living with dementia. According to Wendy Passmore-Godfrey, founder of the WP Puppet Theatre, the workshop’s goal is to support mental wellness by giving people the chance to create masks that reflect themselves.

“The [masks] are a springboard to conversation,” says Passmore-Godfrey, who explains that each mask communicates on multiple levels by using symbols and metaphors. The front is painted to show the face the individual presents to the world, while the inside collage reflects the inner self with photographs and personal imagery. Attachments also hang by strings off the mask’s sides to show the person’s attachment to their past and community.

“It’s about self-reflection, where you dig deep into colours and the memories associated,” says Passmore-Godfrey. “That self-realization is a big thing for people, because you’re looking back on your life and deciding what are the most important pieces in your history.”

Last fall, the workshop at Club 36 connected nursing students at the University of Calgary with people living with dementia to create art. Third-year nursing student Sydney Flodstedt was there for all six sessions of the program. She spent the semester working one-on-one with a woman who was advanced in her dementia diagnosis, so she couldn’t ask many specific questions about her past. However, on the first day of the View from the Inside workshop, Flodstedt noticed that her partner was drawn to blue and green paints, which allowed the duo to delve into a conversation.

“As she gravitated toward those colours, I asked her questions like, ‘Do you like being outside?’” recalls Flodstedt. “That’s how I started to learn about her past, like how she loved to garden and grew up close to a lake. Honestly, it was the colours that brought everything out in her, and it let her lead me and reflect her life in the mask.”

Flodstedt adds that her experience with the WP Puppet Theatre was her first time interacting with people with dementia, and she found it “invaluable.”

“It’s about seeing that these people can still tell their life stories, and their diagnosis of dementia doesn’t define them,” she says. “They are more than their diagnosis.”

By the end of the six weeks at Club 36, Passmore-Godfrey was so fascinated by the diversities between the masks that she held an experiment by asking staff members to guess which participant made which mask.

“Just by looking at them, they guessed most of the creators’ identities correctly,” Passmore-Godfrey says. “What struck me, and what continues to strike me, was how much the project matched the person. Subconsciously, the [masks] become self-portraits.”

She adds: “It’s about not forcing someone with dementia to remember things, but having them react to a moment and show what they’re thinking. There are prompts, like a family photo, but it lets the person have a choice on whether or not they connect to it. The main thing is to make them feel honoured and respected.”

“Subconsciously, the [masks] become self-portraits.”
—Wendy Passmore-Godfrey

[Photo by Arun Chaturvedi, courtesy WP Puppet Theatre]
DID YOU KNOW? Music can impact all parts of the brain; it evokes emotional and physical responses and can activate stored emotional memories. Both listening to and playing music can have a positive effect.
Joanne Morcom leads laughter yoga sessions at Extendicare Cedars Villa in Calgary.
Laughter is the best medicine may sound like a platitude, but, when it comes to laughter yoga, there’s plenty of truth to the saying.

Conceived by Indian medical doctor Madan Kataria in 1995, laughter yoga is a form of gentle cardiovascular exercise and meditation. It combines the deep breathing that is commonly practiced in yoga with physical movements and simulated laughter. The encouraged playfulness and silliness of these exercises often leads to real — and very contagious — laughter.

Today, laughter yoga is practiced in more than 65 countries. Individuals of all ages and abilities take part — including those with dementia. Joanne Morcom, a trained laughter yoga leader and registered social worker at Extendicare Cedars Villa in Calgary, has led laughter yoga classes for individuals with mild to advanced dementia for five years.

The classes, which are offered on-site to residents of Extendicare Cedars Villa, unfold much the same way each time. Seated in a circle to encourage eye contact and socialization, Morcom warms up her group with jokes, songs and clapping before leading participants through deep breathing and laughter yoga exercises. One of the group’s favourite laughter yoga exercises is Lion Laughter, where everyone holds their hands up like lion paws, sticks out their tongues and tries to laugh from the belly.

“That produces real laughter because of the expression on people’s faces,” says Morcom.

For individuals with dementia, laughter yoga has numerous benefits. Laughter has been found to reduce anxiety and agitation, resulting in improved mood. An additional benefit is that it produces laughter without participants needing to understand a joke or punchline.

According to the Mayo Clinic, laughter can also improve circulation, diminish stress and increase endorphins (the body’s natural painkiller and feel-good hormone), promoting a sense of overall well-being. And, since it encourages togetherness, laughter yoga also offers social benefits to individuals with dementia.

“Sometimes, people who have dementia need a lift — as we all do — and laughter yoga helps them feel good about themselves,” says Morcom. “And the contagious nature of laughter really enhances interpersonal relationships.”

“Sometimes, people who have dementia need a lift, and laughter yoga helps them feel good about themselves.”
—Joanne Morcom

DID YOU KNOW? Table tennis, or Ping-Pong, has the potential to delay the onset and progression of dementia, according to certain studies. Some experts have linked playing Ping-Pong to the enlarging of the hippocampus, the part of the brain that shrinks in people who have Alzheimer’s or other forms of dementia. Besides the enriching social aspect of engaging in a fun game with a partner, other benefits of Ping-Pong include improved hand-eye coordination, the sharpening of motor skills and generally slowing down cognitive decline. —Jennifer Dorazio
9 WAYS TO REDUCE YOUR RISK

1 in 3

CASES OF DEMENTIA COULD BE PREVENTED BY ADDRESSING THESE LIFESTYLE FACTORS:

INCREASE
1. Education
2. Physical Activity
3. Social Contact

DECREASE
4. Hearing Loss
5. Hypertension
6. Obesity
7. Smoking
8. Depression
9. Diabetes

Source: Lancet Commission on Dementia Prevention and Care; Credit: Keck Medicine of USC
FOUR BOOKS TO READ THIS FALL

Neither Married Nor Single by Dr. David Kirkpatrick
In 2007, mental health professional Dr. David Kirkpatrick was sidelined when his wife was diagnosed with young-onset Alzheimer’s disease. Kirkpatrick found himself having to figure out how to maintain the intimacy and partnership of a marriage while also managing his wife’s symptoms and acting as her caregiver. He noticed that there weren’t a lot of relationship-centred resources for partners of people with dementia at the time, spurring him to compile the research that makes up the meat of this honest and informative book. Part personal memoir and part guide for others living with a spouse with dementia, Neither Married Nor Single shares Kirkpatrick’s own experiences to explore issues surrounding sexuality, intimacy and grief within the context of what he calls an “Alzheimer’s marriage.”

MEMORY’S LAST BREATH: Field Notes on My Dementia by Gerda Saunders
Just before she turned 61, Gerda Saunders, now 67, was diagnosed with young-onset microvascular dementia. An academic and lifelong lover of words, Saunders set out to write about both her life and her experience with “dementing” (one of Saunders’ musings is about discovering that “dement” can be used as a verb) before her disease took away her ability to recall her own history. The result is a book that touches on Saunders’ upbringing in South Africa, as well as her philosophies surrounding the progression of her dementia. Memory’s Last Breath provides remarkable insight both to those in the early stages of dementia and to those seeking to understand the journey of individuals who are watching their memories slip away.

DEMENTIA BEYOND DISEASE: Enhancing Well-Being by G. Allen Power, MD
The follow-up to G. Allen Power’s milestone Dementia Beyond Drugs, Dementia Beyond Disease lays out Power’s holistic approach to dementia care. Power explains the importance of looking at the person rather than the disease when caring for a person with dementia, and focusing on individuals’ strengths and maintaining their sense of personhood, even as cognitive function declines. Highly readable, the book is filled with true stories that illustrate how fulfilling life can continue to be for people living with dementia when their overall well-being is truly nurtured.

NO SAD SONGS by Frank Morelli
Seeing a parent or spouse affected by dementia is difficult for grown adults to deal with, so imagine how confusing it can be for a still-developing teenager to understand. This young-adult novel tells the story of an 18-year-old who unexpectedly finds himself caring for his grandfather who has Alzheimer’s disease. Gabe, the book’s protagonist, struggles to navigate his way through his last year of high school while also trying to preserve his grandpa’s dignity and well-being. Morelli creates a story about the pressures of growing up that also may help teenage readers understand what their family members — both those with the disease and their caregivers — may be going through with dementia.
Mary Beth Wighton is frank about why she no longer carries a credit card and doesn’t have ready access to cash.

“People with the type of dementia I have struggle with finances,” says Wighton, 52, who was diagnosed with probable frontotemporal dementia, a type of young-onset dementia, six years ago.

But the conclusion to “close the bank” wasn’t made for her; it’s a decision she and her care partner came to together. Another change they negotiated was switching doctors shortly after her diagnosis. Wighton’s original physician equated dementia with incompetence, while her new doctor shares Wighton’s view that keeping busy and working hard — not giving up — is the best medicine.

“We realized very quickly that we had to do things for ourselves. We had to advocate for ourselves,” says Wighton. “No one else was doing that for us.”

In the years since her diagnosis, Wighton, who lives in Southampton, Ontario, has become an advocate for herself and a voice within Canada’s dementia community, telling others it’s their right to be included in decisions around their health, care, work and life. Her message is so strong that she was recently appointed to the Ministerial Advisory Board on Dementia — she is one of two people living with dementia who sits on the board, and her lived experience will help guide our national strategy.

To be meaningful, Wighton says Canada’s National Dementia Strategy must promote inclusivity, which is a hot
On the path toward equal inclusion, “the biggest hurdle I have seen is the systemic and gross underestimation of the capacity of all people with dementia, even in the later stages of the disease,” says Swaffer. “It is still too much ‘us’ and ‘them.’”

Surrey, B.C.-based Jim Mann agrees there is a lot more work to be done to get over the stigma. Mann, who is also on the Ministerial Advisory Board on Dementia, was diagnosed with Alzheimer’s in 2007 at the age of 58. In the intervening decade, he has worked hard to educate people about the condition.

“So many people think that, as soon as you’re diagnosed, it labels you incapable or incompetent and you immediately go into residential care. And, for most people, it’s a journey,” says Mann. “Most of us are able to live a good life with the diagnosis, and that’s a big message.”

It’s a message that will go a long way toward making inclusion a reality.

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It’s a message that will go a long way toward making inclusion a reality.
For someone who has been diagnosed with dementia, the topic of when to stop driving is a sensitive one. Losing that freedom and independence can often feel devastating for those who are told they are no longer safe behind the wheel.

A dementia diagnosis does not necessarily come with an immediate recommendation to cease driving, but it usually means that, at some point, the person will have to retire from driving. There are signs that we can look for to help tell when it’s time to get off the road.
Q | When should someone diagnosed with dementia stop driving?

A | People with mild dementia can still be safe driving. They should be evaluated on a person-by-person basis. The fairest way to assess driving skills is by a comprehensive on- and off-road evaluation. Typically, a physician or occupational therapist would do the off-road assessment. They would examine the person’s cognitive abilities and aspects of their health that would be important to driving, like vision, grip and leg strength, coordination, and neck movement. On-road testing would preferably happen in a driving centre approved by the provincial ministry of transportation, where they would undergo a road test to show they are as safe as anyone else would be driving. They should be then be re-evaluated every six to 12 months so you can detect any changes that could impair driving ability.

Q | What about drivers who are further along in their dementia journey?

A | For people who have a progressive dementia, for example Alzheimer’s disease, they and their families should know giving up driving will be an inevitable consequence of their disease. At the stage of moderate dementia, when you are unable to perform two or more everyday activities, like dealing with medication or grocery shopping, you should not be driving.

Q | In what ways can having dementia affect someone’s driving skills?

A | Dementia can impact the thinking skills necessary to safely operate a motor vehicle. People with dementia may show poor judgment or get lost in familiar areas, be inattentive while driving, not observe the rules of the road and ignore traffic signs. Other medical conditions they may have and the medications being taken can also affect safety while driving, for example if they have seizures and are not taking the medications prescribed to prevent them.

Q | What are the signs that it’s time for someone with dementia to stop driving?

A | Having close calls, reacting slowly to dangerous situations, veering across the median strip. Multiple fender benders with minor dents may indicate trouble judging distances. If driving makes them anxious, if they start to drive less, or avoid driving at all, that could be a marker that they’re having trouble driving. A useful question to ask a family member is whether they would be comfortable being driven somewhere by the person with dementia.

Q | How can families broach the topic of giving up driving with their loved ones?

A | Begin talking about it sooner, rather than springing it on them two or three years down the road after a diagnosis. If they continue driving, it’s helpful to talk with them about what would be the stage when they feel it would be time to retire from driving, and to identify who they will talk to for advice, like someone in the family who they trust is looking out for their best interests. It is best, but not always possible, for driving to be given up voluntarily, rather than be forced on the person.

Q | What are some tips for helping someone cope with the reduced freedom that comes from no longer driving?

A | Make a transportation plan with the person with dementia that identifies how the individual’s needs can be met once they don’t drive. This means sitting down with them to determine where they drive and why, then researching the available travel options. This would include using family and friends, volunteer programs, taxis and door-to-door services. Generally, public transit is not recommended for people with dementia. In a city like Calgary, you can get pretty isolated if you don’t drive. Think about how you can deal with their need to get around so they don’t feel removed from their community.

7 TIPS FOR SAFE DRIVING WITH DEMENTIA

1. Avoid distractions
2. Watch the road
3. Drive in daylight as much as possible
4. Avoid driving when tired or stressed
5. Refrain from driving if the weather is bad
6. Stay away from busy routes
7. Do not drive during heavy traffic periods, such as rush hour

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

Cynthia Delgado brings comfort — and a sense of purpose — to the residents of St. Teresa Place

BY Jennifer Friesen PHOTOGRAPHY BY Jared Sych

For most of her life, Cynthia Delgado never planned to work in a long-term care facility. But after years in a career as an insurance adjuster, she found herself at a crossroads when she lost her job in 2015. The change spurred her to go back to school at 59 years old, with the aim of becoming a care administrative assistant, and she was hired on at St. Teresa Place in northeast Calgary just last year.

“I never dreamed I would end up working in this kind of facility,” Delgado says. “But I’m so glad I came. The [residents here] are now the reason I get up in the mornings and feel happy to come to work. How could I ever leave?”

As an administrative assistant, Delgado spends the majority of each workday behind a computer or stocking units with supplies. But, soon after taking up her new post, she also began to develop a special rapport with the residents. She found herself spending more and more time with them — playing music, dancing or simply talking.

Delgado was working a shift at St. Teresa Place when Dawn Turcotte moved her mother, Marj, into the facility in August 2017. Delgado felt a connection to Marj right from that very first day.

“I realized Marj was scared, because she didn’t really know where she was,” says Delgado. “I picked up on her fear, so I sat with her. It just came over me that she reminded me of my grandma. And that just put everything into perspective — I wanted to care for her.”

Delgado moved to Canada from Jamaica in 1989 and, as she reflects on her life back home, she realizes that her grandmother likely had dementia, as well.

“I didn’t know what it was back then,” Delgado says. “But I look at Marj, and I think about how I wasn’t there with my grandmother when she was sick.”

Marj grew up outside of Brooks, Alberta, but spent most of her adult years on a farm north of Valleyview, where she enjoyed an active life taking care of her four children and her beloved horses. The family started to notice Marj’s memory difficulties about six years ago, however, which eventually led to Marj and her husband moving to a Calgary condo in 2015 to be closer to their children in the city. Two years later, Marj moved out of the condo and into St. Teresa Place.

According to her daughter, Dawn, it was a big change for such an active woman, and having people care for her wasn’t easy on her mom. Marj was always the caregiver, so, in the early days of care, she didn’t understand why someone was serving her dinner or trying to help set the table.

Delgado noticed this early on, however, and started bringing Marj along with her to stock units with supplies, or they’d go for long walks outside.

“When [Cynthia] came along and gave Mom a cart to push around and some files to hold, it just made her feel useful and important,” says Dawn. “I think that’s something we all need.”

Delgado enjoys the company and says that whenever she thanks Marj for helping her, Marj smiles and says, “Oh, no, you’re helping me!”

“I bring her with me, hold her hand, and give her stuff to carry,” Delgado says. “She feels responsible, and feels like she’s doing something. She loves to walk, so when I get her to help me she’s happy because she doesn’t like to sit still.”

Dawn and her family appreciate the work of all the staff at St. Teresa Place, but they feel especially lucky to have found Delgado, and they know Marj feels the same.

“It’s so nice to know that when we can’t be here, there’s someone looking out for her,” says Dawn. “It brings comfort. We all know that Mom is special, but to have someone else recognize it, and know that she still has so much left to offer, even though she has dementia, it’s really comforting.”

“The [residents here] are now the reason I get up in the mornings and feel happy to come to work.” —Cynthia Delgado
Cynthia Delgado (right) and Marj enjoy spending time together at St. Teresa Place.
Seeing an individual struggle with dementia can be a scary and frustrating experience. These two Calgary programs help care partners navigate their way through their loved one’s dementia, both from a practical and emotional perspective.

**CAREWEST’S LIVING WITH DEMENTIA**

*Living with Dementia* is a program designed both for people with dementia and for those caring for them. It is offered by Carewest, a Calgary-based long-term care and rehabilitation provider. Those participating in the program meet weekly from 9:30 a.m. to 2 p.m. for 12 consecutive weeks. The program admits 12 pairs at a time and is offered on an ongoing basis. Those with dementia take part in recreational and therapy programming, while their care partners meet with staff and offer each other peer support. The care partners spend time learning and discussing topics ranging from dealing with loss to navigating healthcare resources so they can better understand their partner’s dementia.

“When our care partners first start the program, they may not be completely aware of the brain processes that are having an impact on their loved ones,” says program coordinator Sue Jose. “By the end of the 12 weeks, they’re better equipped to understand what is happening and have more coping skills.”

Those interested in the Living with Dementia program can call 403-640-6480 for more information.

**SOUTHWOOD YOUNG ONSET DEMENTIA GROUP**

*Dementia always has* a huge impact on families, but when the person diagnosed is younger than average, the disease can be particularly devastating. The Southwood Young Onset Dementia Group was formed in 2011 to offer support to the families of people with dementia under the age of 65. The group, sponsored by the Alzheimer Society of Alberta and Northwest Territories, meets twice a month at the Southwood United Church in two rooms. One room is for those with dementia, and the other is for family care partners. The people with dementia spend time together, sharing their personal stories, while the care partners meet to discuss the particular challenges of dementia care at a young age.

“It’s a whole different set of challenges for those families,” says Mare Donly, who co-facilitates the group with her partner, Sharon Thurston. “They sometimes still have kids at home, which adds a whole different dimension.”

For more information, prospective participants can call organizer Patricia Dehaeck at 403-283-9537.
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Christine Foran and her mother, Ethel.
BRING ON THAT Loving Feeling

The decline of a loved one’s cognition can often leave family members stumped for conversation topics. Here, Christine Foran writes about how a shift in her own approach has led to happier, more loving interactions with her mom.

PHOTOGRAPHY BY Erin Brooke Burns

My mother has Alzheimer’s disease and has been in a care home now for two years. She is lucky because she has a husband and three children who visit regularly. But it can be hard to come up with things to say. How do you have a meaningful conversation when memory seems to be a factor with every sentence?

It used to make me sad when I’d visit Mom and she’d forget that I’d been there. So I don’t focus on what she remembers anymore, because she, too, feels let down when she can’t tell us our names. Often, she doesn’t even remember that we’re related; instead, she introduces me as her “special friend.” But she smiles whenever she sees me, so I know that she remembers how she feels when we’re together. I take pride in creating moments of joy for her. I pull out my cellphone and play an Elvis song, to which she says, “You’re always so good to me!”

I realize that I have a comfort level that others don’t share. I am a registered nurse and a nursing instructor at the University of Calgary, and I’m used to teaching students how to converse with people with different needs. Simple things that we often forget to emphasize include looking at someone when you are speaking, smiling, and allowing enough time for someone to answer.

When I visit Mom, I greet everyone around her by name. There’s a men’s table in the dining room of her care facility, and, when I get up to refill my mom’s water glass, I ask the men how they’re enjoying their lunches. Mom observes all of this and tells me they should mind their own business! This then develops into a conversation between the two of us in which we both share a few laughs.

I also try to recognize when I’m feeling rushed or impatient, because Mom picks up on this and our visit is less comfortable. Sometimes, if I’m low on energy, I bring my dog, Zipper, in to help take the focus off of me (although you must first ask about the policies at your facility). Zipper brings immediate attention from the residents, and I can hear the conversations develop all around. People tell me about their own previous pets, or how smart my dog appears. I also find it interesting that, while Mom sometimes doesn’t remember who I am, she’ll ask me why I didn’t bring the dog.

Another way I focus on making Mom feel good is to play her music. On my cellphone I have created a playlist with her favourite songs. She used to sing the lyrics, but now she simply closes her eyes and smiles. Even when we walk, I’ll keep the music playing from my phone in my back pocket, and it brings smiles to the faces of others, as well.

Sometimes we’ll do an art walk, critiquing the paintings that hang in the hallways. This creates easy conversation topics: “Mom, do you like this painting? Which colour of butterfly do you like the best, the pink or the blue one?” Questions like these make for safe dialogue, as any answer she gives is correct, and, cognitively, she has to think about her answer and make a choice.

I do other easy activities with my mom, as well. We walk outside, try to sink the billiard balls in the game room with our hands, and partake in the facility’s planned recreational activities — Mom is more engaged in those activities when she knows that someone is there just for her.

Focusing on providing Mom with a loving feeling makes both of us feel good. I think those feelings last. Even if she’s unable to recall our visit, she felt loved when I was there. And that’s my goal.
SAVING ENOUGH MONEY FOR LONG-TERM CARE

BY Sean P. Young

Adjusting to living with dementia brings plenty of challenges for Canadian families, including figuring out the cost of care. Whether you’re leaning toward at-home assistance or a private or public care facility, everything has a cost.

“People sometimes think long-term care is all going to be covered, but it’s not,” says Kathy Mendham, founder of Proactive Seniors, a Calgary-based agency that helps families plan for future aging needs. “You should always be anticipating there will be a cost for long-term care.”

According to Mendham private-facility, long-term care costs an average of $8,000 per month. “That would be a very average cost and it can certainly go up from there,” she says.

Many extras — including things like cable, telephone, personal laundry, personal care products and outings — are typically added on top of the monthly fee, making it possible for private long-term care costs to easily exceed $100,000 per year.

“The higher the nursing needs, the more expensive the care will be,” Mendham says of private facilities, then goes on to point out that there are also “quite a few seniors’ facilities offering public dementia care, and you’d be looking at around $2,000 a month for those.”

But wait lists for the public facilities can be long when there is more demand than supply.

“The private market can often allow for quicker access,” Mendham says.

“Planning for the costs of seniors’ residential care as far in advance as possible is the prudent thing to do.”

But what is the first step in this kind of forward-planning?

Choosing the right insurance

There are insurance options available specifically for long-term care. The problem is, most families don’t consider these policies until a loved one has already been diagnosed with dementia.

“If someone is already diagnosed, there is [little] we can do on the finance side for [long-term care insurance],” says Jennifer Jacobs, owner and senior insurance specialist at LTCI Consulting Inc. “All people should consider insurance of this kind, especially if you know your parents or someone in your family had dementia.”
A life lease is a relatively new housing option that falls somewhere between renting and owning. Life lease housing is a legal agreement that grants a person a unit in a retirement community for life, or for a fixed term. Usually, the occupant pays a one-time entrance fee, which, in Alberta, tends to range anywhere between $25,000 and $100,000. The larger the capital lease payment, generally, the lower the monthly payments. This option is gaining popularity for many seniors in Canada, as it is generally cheaper than owning a home. Plus, having set monthly payments makes it easier financially for retirees on a fixed budget. Some life leases also return a portion of the entrance fee to the occupant or their estate when the agreement expires (for instance, 95 per cent returned after year one, 94 per cent after year two, etc.). Life leasing is intended for seniors who are able to live independently; it typically is not a recommended option for people with dementia.

Jacobs tries to get her clients to start discussing long-term benefit planning around age 40, but she says most people don’t consider it until they are closer to 65. She says someone in their late 60s could certainly qualify for coverage, but the cost-benefit analysis changes quite a bit for older Canadians.

“I wish I could educate more people 25 to 50 to consider long-term care insurance, because, mathematically, it is potentially very beneficial,” she says. “A younger individual would only need to collect on the policy for one year of their life to equal all the payments they could ever pay into that policy. Still, I just can’t convince a lot of young people to [buy in].”

To add to this, the options for long-term care insurance are dwindling. According to Jacobs, as Canadians live longer, insurance companies are abandoning their limited pay policies. These are policies in which the customer only pays premiums for 25 years or to age 65 (whichever is greater) and long-term care coverage is then guaranteed for the rest of their life. Jacobs says major insurance providers Desjardins and Manulife recently discontinued their limited pay policies, leaving Sun Life as the only national provider offering stand-alone income benefit/long-term care insurance.

Jacobs believes within the next five years, Sun Life could stop offering its long-term policy, too. In the meantime, it is selling more of these policies than ever before as customers realize this offering is the last of its kind.

**Care at home**

According to Miles Posner, director of strategic planning and business development at MyDignity (an Ontario-based business providing insurance solutions), getting approved for a long-term care policy can be difficult.

“These policies are great if you can get them, but they have a decline rate of 50 per cent,” says Posner, who helped create an insurance product more than 10 years ago that he says is a more realistic option for many aging Canadians.

“MyDignity is easy to get. We have a 95 per cent approval rate,” he says. MyDignity is endorsed by CARP (formerly the Canadian Association of Retired Persons) and is fixed to pay out $100,000 in total. Because the policy has a set limit, Posner says it is much easier to get than traditional long-term care policies.

The MyDignity plan focuses specifically on home care costs. Customers only require a doctor’s form indicating the individual needs personal assistance to activate the policy, and, according to Posner, they can start expensing home-care costs immediately, unlike most long-term care policies that take 90 days to kick in.

“That’s probably your most vulnerable time, because things are happening and it’s taken you off balance,” Posner says. “The plan we’ve created isn’t Lotto Max, but it goes a long way for most Canadians.”

Many extras — including things like cable, telephone, laundry, personal care products and outings — are typically added on top of the monthly fee, making it possible for private long-term care costs to easily exceed $100,000 per year.
STAYING ACTIVE AND SOCIAL

Two technology companies have created products that boost memory recall, increase social interaction and motivate individuals with dementia to get moving.

By Karin Olafson

MemorySparx One

How It Works:
As the founder and CEO of Emmetros Limited — a tech start-up in Waterloo, Ontario — Mary Pat Hinton is dedicated to finding electronic ways to help people with early dementia symptoms. The company’s MemorySparx One app, which first launched in May 2017, is a memory-recall tool for iPad and iPhone users. The app’s aim is to boost its users’ confidence.

“There is an anxiety when someone is asked a question they can’t answer,” says Hinton, who used to work at Blackberry. “After a time, that anxiety about being put on the spot might result in individuals deciding not to go out anymore — social isolation is a huge problem for individuals with dementia.”

With an easy-to-use interface (which was carefully designed after 1,500 hours of research) MemorySparx One helps individuals remember important details needed for day-to-day social interactions. Doctor’s appointments, shopping lists, the names and faces of friends and family members, important milestones — all of these things, and much more, can be recorded in the app and used as prompts during social interactions. In addition to typing notes and tracking to-do lists, the app also uses visual cues like photographs and audio prompts to aid memory recall.

Hinton is hopeful that MemorySparx One will help users living with early dementia symptoms regain their feelings of independence.

“I hope MemorySparx One helps increase users’ confidence, enabling them to say yes to things, to not be reliant on others to speak for them, and to be more in control,” she says.

Motiview by Motitech AS

How It Works:
Motiview makes it possible for people to cycle down roads all over the world, without ever leaving the safety of their home or care facility. Consisting of a user-adapted stationary bike and
a display screen that shows location videos, Motiview is a motivational tool for seniors and individuals with dementia, encouraging physical activity by tapping into its users’ connection to familiar cities and landscapes.

While pedalling the stationary bike, individuals can virtually cycle down familiar roads or “travel” beyond familiar locations to somewhere brand-new and inspiring. Music or environmental sounds are offered with the videos, further motivating seniors to get moving.

Developed by a Norwegian company called Motitech AS, Motiview first expanded beyond Norway in 2016 and was made available in England and Canada this year.

Today, the Motiview library has almost 2,000 videos from all over Europe and North America, including Alberta locations like Lake Louise, Waterton and Calgary. As Motitech has its own network of camera operators and crews that travel the world to make these videos, the number available will increase each year.

“All people have one thing in common: when we see a familiar place on television, we point at the screen and [share] our memories from that specific place,” says Jon Ingar Kjenes, CEO of Motitech. “Motiview transforms this positive energy from recognition into motivation for physical activity.”

In addition to promoting memory recall and encouraging conversation, Motiview helps users experience the various positive effects of exercise.

**HOW TO BUY IT:**
For more information on purchasing the software, visit motitech.no/en. Licensing ranges from $800 to $4,000.

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Don’t miss 65 of the world’s most illuminating writers, including the award-winning Elizabeth Hay (presenting an exquisite memoir about her aging parents) and the Østby sisters from Norway (with a groundbreaking book on the science of memory).
Meet two researchers who are aiming to make an impact in the ways we deal with dementia — and in the ways we can prevent it

BY Shannon Cleary PHOTOGRAPHY BY Jared Sych and Cooper & O’Hara
What if caregivers could access support, 24/7, with the touch of a button?

Dr. Jayna Holroyd-Leduc is an academic geriatrician at the University of Calgary. She is currently leading a study on CARE, a mobile app designed to help caregivers of persons with dementia. The ongoing study, funded by the Canadian Institutes of Health Research (CIHR) and the University of Calgary, is examining whether the app can decrease caregiver burden and improve self-efficacy. The multi-stakeholder team working on this initiative includes researchers and clinicians from various Canadian universities, along with community stakeholders such as the Alzheimer Society of Alberta and NWT.

CARE combines quick, useful, evidence-informed advice with self-management tools. Initially, Holroyd-Leduc’s study focused on adapting and evaluating online “learning modules” from the World Health Organization, but the study shifted gears when user-feedback suggested that caregivers wanted something more interactive and instantaneous. Holroyd-Leduc learned of Shiftology, a psychology group in Calgary that was developing an app using Cognitive Behavioural Therapy (CBT) tools to support people with mood disorders, and she and her team soon partnered with Shiftology developer Kent Wyrostok to develop CARE.

“We thought it would be interesting if we could provide information that caregivers need at the point of care, for instance if they were dealing with an aggressive episode, and combine it with an application where they could monitor how they were feeling,” Holroyd-Leduc says.

Through the CARE app, users can access real-time strategies for specific caregiving issues, such as sleeping patterns, sexual behaviours or eating. What if someone in your care accuses you of stealing something that is lost? The app provides bulleted suggestions, such as, “Don’t deny stealing. Don’t argue. Consider having multiples of important items.”

The app also tracks a caregiver’s ability to cope. Users rate their “energy” on a scale of one to 10, use word clouds to identify issues such as “aggression” or “wandering,” and then identify the emotions behind those issues, like “I feel afraid” or “I feel happy.” Their input is tracked over time. Consistent low energy or recurring issues might trigger a message: “Here are some resources on respite.”

CARE is currently in a controlled trial, which began last fall and will continue over the next year. Primary and secondary caregivers of people with dementia can submit an application on the CARE website to participate in the evaluation of the mobile app. Users complete confidential online surveys throughout the eight-week trial to determine its effectiveness.

Holroyd-Leduc says supporting this “unofficial health-care system” of caregivers is crucial.

“A lot of caregiver literature and resources tend to focus on their role as a caregiver, and not how caregivers can care for themselves,” she says. “We want to help caregivers care for themselves better, and to cope better with the issues they’re dealing with.”

For more information on CARE, and for useful caregiver advice, visit care.neuromentalhealth.me

“We thought it would be interesting to provide information that caregivers need at the point of care, and combine it with an application where they could monitor how they’re feeling.”

–Dr. Jayna Holroyd-Leduc
Dr. G. Peggy McFall, a postdoctoral researcher at the University of Alberta, are changing their approach. Instead of treatment, McFall is researching prevention — what factors predict dementia-related changes in the brain, and what factors promote stability and delay decline.

“Can we see signs earlier on that identify people who might be at risk for Alzheimer’s disease?” asks McFall. “And, if we can identify those signs, can we develop compensatory interventions?”

McFall is using data from the Victoria Longitudinal Study (VLS), an ongoing, large-scale investigation into human aging. The VLS started in the late 1980s and operates in Edmonton and Victoria. It has collected data on roughly 2,700 dedicated participants since its beginning. Participants are between the ages of 55 and 100 and do not initially display evidence of dementia, as the study seeks to understand the aging brain before clinical diagnosis.

The data from the VLS has provided McFall with a picture of how our memory changes over time. One study is based on memory testing — participants are categorized into three specific classes of agers: “stable” agers, “normal” agers and “declining” agers.

McFall has identified 17 markers, or risk factors, that distinguish these groups. The markers range from non-modifiable factors such as sex and age, to modifiable ones such as exercise, social connectivity and education. This has helped McFall determine differences between the “stable” agers, whose memory function starts high and remains high, and the “declining” agers, whose memory function starts low and exhibits a rapid decline over the course of the study.

Are there reliable, predictive factors that identify those who are eventually converting to dementia? The research still has a long way to go, but important signs are emerging.

“We know that physical activity is a very important part of cognition, for instance,” says McFall. She hopes that, eventually, her research will be used to create a tool kit for general practitioners to identify those at greater risk of dementia, recognize early warning signs, and offer evidence-based preventions that could delay impairment or promote memory stability.

“[Our aim is to] somehow find a way to refine [the research], so it’s inexpensive enough and accurate enough to at least put people on the path of what they need to do to try to prevent [dementia], or keep themselves stable,” she says.

Dr. G. Peggy McFall

The work involved in researching Alzheimer’s disease and other types of dementia is incredibly complex and, over the last 20 years, much of the effort has gone into finding a cure or treatment. But several researchers of late, including
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Upcoming events

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1st & 3rd Wednesday every month, 1:00-3:00 p.m. First Lutheran Church
1st Wednesday every month, 1:00-2:30 p.m. Okotoks Seniors Club

Dementia Awareness Training
Including understanding dementia, risk reduction, resources available and information on volunteer opportunities.

Thursday, Oct 25, 6:30-8:30 p.m. Signal Hill Library
Sunday, Oct 28, 1:00-3:00 p.m. Signal Hill Library

Dementia Talks Library Speaker Series: Young Onset Dementia
Learn about one family’s inspiration to create a wellness community for families and their loved ones impacted by young onset dementia (under age 65).

Thursday, Sep 20, 6:30 p.m. Okotoks Public Library – register at okotokslibrary.ca or 403.938.2220
Friday, Sep 21, 6:30 p.m. Signal Hill Library – register at calgarylibrary.ca or 403.260.2620

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DESIGNING for Compassion

A look at three different approaches to creating effective care facilities and programs

BY Lauren Denhartog

Throughout Alberta and well beyond, health-care professionals, architects, designers and a variety of other experts are exploring new and effective ways of addressing and supporting the needs of individuals living with dementia by creating specific types of environments. Here, we take a closer look at three exciting initiatives.
A Unique Take on Day Programs

In Chula Vista, California, a massive indoor replica townsite for individuals with dementia was designed to provide respite to family caregivers. Operated by George G. Glenner Alzheimer’s Family Centres Inc., Town Square is an indoor, adult day-health care centre where individuals can be dropped off for the day to engage in numerous activities.

What makes Town Square unique is that the model is based on reminiscence therapy. The entire townsite is built to mimic an American town circa 1953–1961, and it encourages individuals with dementia to reminisce about their past by using specific prompts that stimulate memories. The 1950s/1960s were selected because many individuals with dementia are currently in their early 80s, meaning their strongest memories would have been formed during this period.

The town has numerous vintage storefronts — including a diner, pub, library, pet shop, garage and department store — that offer structured activities designed to facilitate reminiscence. For example, individuals can read period-specific books in the library, try on vintage clothing at the department store or tune up the 1959 T-bird in the garage.

“People will come into this town and go about their day doing different activities within each storefront,” says Lisa Tyburski, director of business development at the George G. Glenner Alzheimer’s Family Centers, Inc. “Because the environment is so large and varied, it gives us dozens and dozens more activities to be able to do.”

Visitors rotate throughout the town in small groups and are grouped based on their cognitive ability and personality (what they like and don’t like). All staff employed at Town Square receive comprehensive training in dementia care, and an on-site nurse can administer medications.

Tyburski says other facilities in the U.S. have offered vintage decor, but not quite to this extent. “We’re able to take that reminiscence therapy to a new and more immersive level,” she says.

REMINISCENCE THERAPY incorporates the use of all the senses (sight, taste, touch, smell and sound) to help individuals with dementia recall people, places or events from their past lives. Cherished objects or activities are used to stimulate fond memories and bring comfort to the individual, making them feel less isolated and more connected to the world around them.

Main Street at Schlegel Villages

Creating a sense of community for individuals living with dementia is one of the aims of the “Main Street” design at Schlegel Villages, where various familiar spaces aim to promote planned and informal social interactions between individuals. Based in Ontario, Schlegel Villages operates 12 stand-alone long-term care homes, six...
Individuals living with dementia, says Luth, may find trips into the community stressful and may not be able to access public transportation as freely as they once did, and the Main Street design helps give them a purpose.

“It really helps people express freedom,” Luth says. “They’ve got more spaces to explore, more people to connect with and [more meaningful activities] to choose from.”

Embracing the Butterfly Household Method of Care

When Calgary-based Southwood Care Centre adopted the Butterfly Household Model of Care for its 21-bed Willow Park unit, the dull, beige walls had to go.

“We painted — a ton,” says Cheryl Miles, the clinical program leader at Intercare, which operates the facility. Today, bright and inspiring colours — greens, pinks and yellows — cover the walls of the facility, and the environment has become a representation of the people living there.

The Butterfly Household Model of Care was first introduced in the United Kingdom in 1995 by Dr. David Sheard, founder of Dementia Care Matters, and it has since spread to care facilities around the world. The model is based on the notion that traditional long-term care homes are often devoid of opportunities for meaningful engagement between residents and staff, which can lead to boredom and isolation.

The model aims to improve the lived experience of those with dementia by shifting away from a traditional, task-based approach to care. With this older approach, staff are more focused on completing tasks such as giving medications and feeding instead of forming real connections with residents. The Butterfly Model upholds the belief that “feelings matter most” in dementia care. This is reflected in everything from the environment to interactions between residents and staff.

In February 2017, Southwood Care Centre partnered with Dementia Care Matters for a 12-month pilot project (called a Butterfly Project). The facility received its accreditation in April 2018.

During the transition to the Butterfly Model, Southwood’s two dementia units were renamed Haven Household and Serenity Cottage to reflect a more “home-like” environment.

“Everything you put on the walls, everything you put in the bins, everything you make available to use and to engage with really tells the life story and the life history of the people who live there,” says Miles.

For example, if several residents once counted farming as an occupation, an area with photographs of farmland and objects to engage with might reflect this. Miles says one of the biggest differences since starting the pilot project is that now the facility feels, sounds and...
smells more like a home. Today, everyone sits down together family-style and helps themselves at mealtimes. Residents help set the table and clear away dishes.

With the adoption of the model, housekeepers and therapy assistants now cook breakfast on the unit. “Part of their role of engaging is that they’re doing those things with the residents as well. So it becomes much more of that love and connection being shown on a daily basis,” says Miles.

Another Alberta facility, Legacy Lodge, is also experiencing the benefits of having staff sit and be present with residents. Based in Lethbridge, the lodge started its own Butterfly Project pilot in January 2017 and received accreditation exactly one year later. At the start of the pilot, staff completed eight, eight-hour training sessions through Dementia Care Matters that focused on why feelings matter most in dementia care and how to work with residents who have dementia.

“They learned how to nurture [residents], communicate with them, support them and engage them with different things,” says Chelsey Smith, site director at Legacy Lodge. “There are different ways that we can do the tasks [we need to do] and still make it feel more like a home and feel more relaxed.”

Part of creating a more home-like feel at Legacy Lodge meant scrapping uniforms, name badges and nursing stations. Staff now wear their own clothing, and use their “look” to help connect with residents.

Up in Spruce Grove, Alberta, the Copper Sky Lodge has also embraced the Butterfly approach, but has found one of its pillars particularly challenging. The Butterfly Model supports grouping residents based on their stage of dementia, because the needs that are required from caregivers can differ vastly at each stage.

“It’s exhausting for staff because we look at it as having four different stages of dementia that require four different types of interventions,” says Nicole Gaudet, site director at the facility. “It can be difficult to need to use diverse interventions in the course of a 20-minute period.”

Still, according to Gaudet, Copper Sky’s transition to the Butterfly Model has been positive.

“The cottage with the earlier stage became like a pyjama party; vibrant, a great place to be and work and visit,” says Gaudet.

As dementia progresses, individuals need closeness and relate to others in a whole different way. For residents in later stages of dementia, the Butterfly Model encourages greater access to natural light, fresh air and experiences that stimulate the senses, such as visits with children or animals.

“When you go into [our dementia cottages], you see that it’s about love, and you see that it’s about relationships,” says Gaudet.

“I’m a believer that emotionally intelligent and responsive care is what differentiates the good and the bad in terms of all care,” she adds. “If you’re paying attention to what somebody is feeling, then you relate and connect, and then, as a caregiver, you really start to get something because you are being cared about, as well.”

“There are different ways that [staff] can do the tasks we need to do and still make it feel more like a home and more relaxed.”

–Chelsea Smith, site director at Legacy Lodge
his past June, Dementia Network Calgary, a multi-stakeholder movement dedicated to tackling the complexities of dementia, held a one-day event dubbed Dementia Re-imagined to facilitate discussions on how to foster excellence in person-centred care and ensure that people with dementia are living as fully as possible. The event brought together three dementia experts from different parts of the world to lead a discussion about shifting the ways in which professional caregivers, family members, and the general population look at dementia and dementia care.

The event, which was sponsored by Gordie Howe C.A.R.E.S. and held on June 19, included a working round table during the day, where visiting experts Professor Claire Surr, Daniella Greenwood and Dr. Allen Power met with 50 invited guests, including families of those with dementia, academics, health professionals and other key stakeholders. Later in the evening, the public was invited to see the experts in a panel discussion hosted by local media personality Dave Kelly.

“The intention was to create inspiration and hope for people impacted by dementia,” says Barb Ferguson, Executive Director of the Alzheimer’s Society of Calgary, which partnered with Dementia Network Calgary for the event. “Dementia Network Calgary is really about building a movement around dementia in our community, and this event was part of that movement.”

Surr, Greenwood and Power share similar perspectives when it comes to recognizing and respecting personhood in those with dementia and helping to build care models that do the same. Each has a different area of focus, however, and all contributed different points of view to a productive discussion.
While attending the University of Bradford in the UK, Claire Surr studied under Dr. Tom Kitwood, who pioneered the concept of person-centred dementia care. Now a researcher who has specialized in dementia care for her entire career and currently working out of Leeds Beckett University, Surr focuses on high-quality education of the dementia care workforce so that they can best deliver individualized person-centred care to people with dementia.

While Surr recognizes that the current system of care homes and hospitals isn’t necessarily ideal for people with dementia, her priority is to develop and evaluate evidence-based interventions, methods and approaches that can help to improve care quality.

“There are many different models of care, and I am open to them, but we’ve got to recognize that we have a lot of care homes and we need to improve the quality of care in them now,” Surr says. “The challenge lies in getting staff to have the right skills and to know the right approaches to delivering care to people who are physically frail in addition to living with dementia.”

Surr’s research shows that when professional caregivers are given face-to-face instruction, engaging content, clear educational materials, opportunities for discussion and tailored learning experiences, they are better equipped to deliver quality person-centred dementia care. Surr was part of a consultation process that worked with Health Education England to develop an education framework for dementia care professionals (released in 2015) that covers areas including person-centred care, communication, end-of-life care, working with families of people with dementia and other topics that are key to the well-being of people with dementia.

Unfortunately, Surr’s research also shows that, even with the best training, well-being can’t be improved unless organizations implement a culture and system that’s actually conducive to person-centred care. It’s a tall order, but Surr says the outcomes warrant the effort.

“In terms of outcomes, we would hope through better-thought-out quality of care to see better quality of life for people with dementia, reduced disability and less distress. It could also mean having a better death, and it would mean caregivers feeling less stress,” she says. “There are lots of different outcomes we would see from training, but you have to get all the other pieces in place to put things into practice and realize the benefits.”

“We’ve got to recognize that we have a lot of care homes and we need to improve the quality of care in them right now.”
—Claire Surr
Australia, Greenwood now acts as a consultant, helping care facilities in both Australia and Canada implement staffing models, policies and approaches that best facilitate a more humane vision of care.

“There’s a stigma and a paternalism that we still see toward people with dementia. The minute someone moves into a long-term care setting, it’s just assumed that they won’t speak for themselves anymore,” Greenwood says. “My focus is around rights and how we can promote people’s ability to be self-determining and to actively participate in their lives.”

Greenwood advocates that the first step in achieving that is to implement what she calls the “consistent staff assignment approach.” In the simplest terms, this means ensuring that people living with dementia are supported by a small and consistent care team rather than an endlessly changing parade of caregivers.

Ideally, Greenwood likes to see care facilities broken into smaller sections where the same staff work consistently. As a result, staff get to know the people they’re caring for, and the residents with dementia become comfortable with their caregivers and feel a deeper personal connection. While this model is easier to institute in smaller group home settings, Greenwood says that, with a little imagination, it can work in the largest care home facilities.

The outcomes that Greenwood has observed after implementing a consistent staff assignment model are dramatic — she’s seen the system put into place in more than 40 facilities, and not only do residents appreciate being able to form real relationships with the people supporting them, but staff overwhelmingly also prefer the intimacy of the arrangements, leading to greater job satisfaction and less staff turnover. Most importantly, the consistency and personal nature of this kind of staffing changes the culture of dementia care, making people with dementia feel like they’re valued and looked at as full adult human beings.

“Relationships are everything for these residents, and protecting and nurturing those relationships is important. We’ve got to get rid of these ideas that people need to be taken care of by experts,” Greenwood says. “This model really flattens the hierarchy. It’s about people getting along with each other.”
Dr. Allen Power
Honouring the Seven Pillars of Well-Being

Dr. Allen Power has spent much of his career as an internist and geriatrician, but, as the years have gone by, he’s found that he can make a greater impact as an author, educator and public speaker. A clinical associate professor at the University of Rochester in New York, and the Schlegel Chair in Aging and Dementia Innovation at the Schlegel-U. Waterloo Research Institute for Aging in Waterloo, Ontario, Power uses his platform to advocate for the overall well-being of people who are living with dementia.

Power’s work is centred on the redefinition of dementia so that caregivers see and respect that people with dementia have the same basic emotional needs as everyone else, regardless of their diagnoses. He feels that traditional care models act to manage dementia symptoms, but often fail to look at people with dementia as whole human beings who exist beyond their disease.

“I want to redefine dementia not as a brain disease, but as a shift in the way a person experiences the world around her or him,” Power says. “Our job is to understand that changing experience, and to give every person the accommodations they need to live as fully as possible.”

Power identifies seven different pillars of well-being — identity, connectedness, security, autonomy, meaning, growth and joy — that every human being must tend to in order to be happy and well-functioning. When those pillars aren’t tended to, a person with dementia may exhibit signs of distress that are attributed to their disease, but could easily be alleviated if caregivers address whichever aspects of well-being is lacking. Power gives the example of a care home resident resisting bathing: traditionally, care staff would assume that the resistance is a symptom of dementia, when really the person may simply feel like her autonomy and security are being violated, but isn’t able to articulate it. If that sense of autonomy is nurtured, personal care becomes less stressful and the person’s quality of life is improved.

Instituting this philosophy in a care facility or even through home care can be easier said than done, but Power says that once caregivers start approaching well-being from a holistic point of view rather than seeing someone as being totally ruled by their disease, people with dementia can live more fulfilling lives.

“We can’t cure dementia, but we can improve someone’s well-being today,” he says. “We don’t need to give them a new pill for them to move toward a more meaningful life. To me, it’s an empowering message that anyone can start to support people differently.”
Geriatric nurse Wendy Evans has become a valuable resource for the town of Innisfail, Alberta, since she started working at the Wolf Creek Primary Care Network in September 2017. (The Wolf Creek PCN spans the communities of Innisfail, Sylvan Lake, Lacombe, Ponoka and Rimbey.)

Evans conducts comprehensive geriatric screening in the Innisfail medical clinics to diagnose frailty, both physical and cognitive. Her work means people with dementia, and their care partners, can increase their chances of getting the treatment and services they need before a crisis situation arises. It’s a much-needed service in the town south of Red Deer, where 21.5 per cent of the population is over the age of 65, compared to 12.3 per cent provincially.

“People are very good when it comes to supporting people who have physical needs, but when it comes to those with cognitive needs, it’s a very different challenge that is tough for individuals and their families,” Evans says.

Improved screening and geriatric assessments at the Innisfail medical clinic reflect efforts to improve care for those living in the community with cognitive impair-
ment or a diagnosis of dementia. Action planning around the work being done in Innisfail is also part of a collaboration with the Primary Health Care Integrated Geriatric Services Initiative, or PHC IGSI (a long acronym pronounced fig-see by those involved), which aims to provide ongoing support to those living with dementia and other geriatric syndromes in Alberta’s Central Zone. The work out of Innisfail is just one of many exciting projects in several Central Zone communities that have partnered with PHC IGSI.

Funded by an Alberta Health grant, PHC IGSI began in 2015 as a demonstration project. It is a partnership between the Primary Care Networks (PCNs) of Wolf Creek, Big Country, Provost, Red Deer and Wainwright, and Alberta Health Services’ Seniors Health Strategic Clinical Network, the Primary Health Care Integration Network, and the Alzheimer Society of Alberta and Northwest Territories to better support those living with dementia or other geriatric syndromes.

“There are many stories of people ending up in emergency, or maybe earlier placement than required, because they need community supports and those supports are lacking,” says Charlene Knudsen, a St. Albert-based AHS practice lead for the Seniors Health Strategic Clinical Network who co-leads PHC IGSI with her colleague, Sharon Hamlin, from Provincial Primary Health Care. “We hope to show that this program is supporting people well in their community.”

A large component of the PHC IGSI has been education around the complex topic of dementia care. In 2015, an AHS Seniors Health Strategic Clinical Network survey found that, “38 per cent of family physicians responding … felt that they did not have the necessary training or skills in the area of recognizing and providing care to people living with dementia.”

To address this gap in training and knowledge, the PHC IGSI team has hosted three day-long dementia-care workshops for participating PCNs and their community partners. The workshops were designed to “mirror the journey of the person living with dementia,” says Knudsen. There were between around 90 and 120 primary health-care workers at each workshop, including doctors, nurses, social workers, pharmacists, members of the Alzheimer Society of Alberta and Northwest Territories, home-care case workers, and Family and Community Support Services employees.

During the first workshop, held in Red Deer in June 2017, participants looked at timely recognition of dementia, diagnostic tools and how to put early supports in place. Laurie Grande, regional lead for client services at the Alzheimer Society of Alberta and Northwest Territories,
presented at the event. Her talk centred on how important it is to connect people living with dementia with both the services in their community, as well as more traditional supports offered through the health-care system.

“Historically, community supports have worked independently of the health-care system,” says Grande. “When you’re looking at a more integrated approach, I think you’re more likely to have impactful outcomes if [support] is more coordinated and people are able to access information in the early stages. Being proactive is very important.”

During the second workshop, held in Red Deer in December 2017, participants looked at managing in more difficult times as dementia progresses. This day’s learnings were based on the Geriatric 5Ms model of dementia care, in which care providers create a plan based on: Mind (cognition and mood), Mobility, Medications, Multi-complexity (including other factors such as financial needs and other chronic health conditions), and Matters Most (such as a person’s desire to remain in their own home or remain independent as long as possible).

The final workshop, held in Lacombe in May 2018, looked at late-life support for dementia and frailty, including palliative care and pain management. “It was a great day learning about what other communities are doing to support their clients and families living with dementia in end stage,” says Lori Watts, a registered nurse with the Red Deer PNC who attended the workshop in Lacombe. “We can all learn from each other, having those difficult conversations about end-of-life care and how we need to de-professionalize dying.”

In addition to developing and offering these workshops, Knudsen and her team are also supporting the community teams who are participating in PHC IGSI to achieve their locally defined goals.

“It’s not a top-down approach,” Knudsen says. “We’re not coming in and saying, ‘This is what you have to do!’ And that’s working out really well.”

The Wolf Creek PCN geriatric-screening program in Innisfail, which started last September, is one of the grassroots PHC IGSI projects. Another PHC IGSI-supported project is the new Elder Care Assessment Clinic based out of the Red Deer PCN. In Drumheller, the PCN has developed a partnership with the community mental health nurse to refer people with cognitive changes for further assessment. Results of a community needs assessment of Kneehill County communities (Three Hills, Trochu, Acme, Carbon, Linden, Torrinton, Huxley, Swalwell and Wimborne) identified a need for support for care partners of those living with dementia. This led to the Alzheimer Society of Alberta and Northwest Territories establishing a support group in the village of Linden.

Laurie Grande of the Alzheimer Society sees rural projects, like the one in Linden, as particularly invaluable. “I think it’s critically important to build capacity there,” she says. “Many people who live in those rural areas are not able to come into the city centres to access the support and education they need. Collaboration and integration is essential in order to provide more comprehensive services in all communities. In addition to the medical support in managing dementia, community supports can make a significant impact in helping people to live well in the community.”

While the initial phase of the Central Zone PHC IGSI pilot project will wrap up with a final evaluation report on the project due in December 2018, Knudsen would like to see the initiative expanded across the province in order to improve the journey for people in the community living with dementia and their families.

“The more we can provide knowledge and education, and the more people who are actively involved in trying to make changes, the bigger difference we’ll make.”

You can access the resources offered at the educational workshops online at albertahealthservices.ca/scns/Page13526.aspx.

DID YOU KNOW? A recent report from the Canadian Institute for Health Information (CIHI) notes that only 41 per cent of Canadian doctors feel sufficiently prepared to care for seniors with dementia. For more report findings, visit cihi.ca/en/dementia-in-canada.
Actors on stage during a performance of Cracked, a dementia-focused, research-based play.
n performing arts, the boundary between the stage and the audience is known as “the fourth wall.” Breaking this boundary is typically considered a no-no. There are exceptions, of course — Annie Hall, Fight Club, Ferris Bueller’s Day Off — but conventionally, the audience and the performers exist in two separate realities; only one of which, the audience, knows that the other is there.

Despite this boundary, it’s the performer’s job to engage the audience by telling a story, teaching a lesson, making us laugh, making us cry. That’s the power of good theatre and film: it influences our thoughts, our emotions and, perhaps, our actions.

None of this is lost on Mitzi Murray, executive director of Calgary’s THIRD ACTion Film Festival, an event that celebrates aging and explores the possibilities of life in late adulthood. This year’s inaugural festival (held in June) screened more than 30 films, some of which dealt specifically with stories of dementia.

Even though film is one of society’s most familiar and culturally relevant mediums, says Murray, it reflects so few of our stories. Aging, and especially aging with and caring for someone with dementia, can feel tremendously isolating in our youth-centric culture. Getting more dementia stories on the silver screen helps to educate, evoke empathy and reduce stigma in a way that PSAs and health literature simply can’t.

“Film gives you baby steps to build on your empathy and your connection to others,” says Murray. “Who doesn’t want to see themselves [represented] on film?”

Murray is also a caregiver to her mother, who has dementia. Films that reflect her own experience have allowed Murray to communicate her feelings and experiences in a safe, indirect way.

“You get to that point where you
don’t really want to talk,” says Murray of the day-to-day ups and downs of supporting a loved one with dementia. “You don’t have to educate every one in your circle. Why not say, ‘Go see Still Alice, or go see one of these films, and then you’ll have a good idea of what I’m going through.’”

**CHRONICLING REALITY**

Christopher Wynn is a filmmaker in Montreal and has produced and directed two documentaries on dementia. His first film, *Forgetful Not Forgotten*, is a chronicle of Wynn and his family, including his father who was diagnosed with early-onset Alzheimer’s disease at the age of 57. Meeting younger families while travelling across Canada screening the film inspired Wynn’s second documentary about dementia, *Much Too Young*, co-directed by Russell Gienapp. First screened on TVO last September (and available online at muchtooyoung.com), it gives an intimate picture of teenagers and young adults whose parents are experiencing various stages of early-onset Alzheimer’s. The children range in age from 13 to twentysomething, defying society’s temptation to categorize dementia as an issue for the elderly, or something to be dealt with only when it lands on our doorstep in some distant future.

In one scene, mother Moira, who was diagnosed with early-onset Alzheimer’s in her 50s, is exiting a shop on a busy street in Toronto. She is having trouble trusting her footing, or trusting the height of the steps below, or perhaps trusting whether the steps exist at all. She stands in the doorway as her two young, patient daughters gently encourage her. Their mom extends her foot, only to pull it back. It’s a long process for Moira, and an uncomfortable one for the audience. It’s disconcerting to watch Moira struggle with something so seemingly simple, and to worry that another customer might brush past Moira with the kind of haste and contempt that her daughters see, and fear, almost every time they dare to take up space in public. Someone watching this scene in the film might wonder, “Would I have understood what was happening, or would I have felt terribly inconvenienced?”

Finally, Moira takes the step. With relief and celebration, her daughters guide her out of the shop, lovingly holding hands with their mother as they continue on their day together.

“Why do they do that?” asks Moira, referring to steps. In fairness, the steps were a little steep. The doorframe was a little narrow. Everyone around her is often in a rush. The world does not appear to be built for people like Moira.

“The world isn’t perfect,” offers her youngest daughter.

This scene teaches us how narrow our view of function is, how we have designed a world and upheld a mentality that cognition and physical ability alone deter-

“Film gives you baby steps to build on your empathy and your connection to others.”

–Mitzi Murray
mine whether or not we belong. But it does so with the subtlety of storytelling, not lecture. We don’t learn about dementia, we learn about Moira’s dementia — we learn that steps sometimes stall her. We learn that her daughters love her.

The families in Much Too Young offered their generous consent to be filmed during these private moments, and the result is an astonishing intimacy, one that Wynn felt was important for people to experience.

“At times, [the audience] almost felt like they were intruding,” says Wynn of the reaction to the film. “I think that’s what makes it so much more powerful.”

SHARING EXPERIENCES

Representation matters, not just to validate the experiences of so many who are living with the effects of dementia, but to change the cultural narrative of an illness that is often ignored, simplified or shown in a negative light.

That’s what filmmaker Susie Singer Carter sought to address with her acclaimed short film, My Mom and the Girl. Singer Carter plays daughter to actress Valerie Harper who, in the film, exhibits signs of dementia. The film draws on Singer Carter’s real-life experiences with her own mother, who moved in with Singer Carter and her 16-year-old daughter during the early stages of Alzheimer’s disease. Singer Carter refers to this as the year she helped her mother “cross over the bridge,” a stage where her mother knew she had Alzheimer’s, but was resisting it. Looking back, Singer Carter realizes that she was resisting, too.

“At times, I was going to talk her out of Alzheimer’s,” she jokes from her Los Angeles home. “Our relationship was so strong that I was going to get past the Alzheimer’s and go, ‘Mom, come on. Let’s get real.’”

That difficult process was a gift, says Singer Carter, and one that she wanted to share through her art. My Mom and the Girl (released to the public on Mother’s Day, 2018) is her effort to pull back the curtain and demystify a disease that often has a tragic cultural discourse. Singer Carter’s experience with her mother’s dementia is challenging, yes, but it can also be joyous.

Humour sneaks its way into the film in the very first scene. Harper, playing the mother, is pounding on her adult daughter’s bedroom door in the middle of the night. Perhaps experiencing a memory, Harper’s character is looking for her “baby.” She angrily accuses her daughter of taking it away. Singer Carter denies the accusation at first, but then rolls with it, meeting her mother where she is in the moment, until Harper’s character realizes that her daughter, her baby, is standing right in front of her as an adult. Singer Carter’s
voice narrates, introducing us to her mother: “She’s the love of my life.” Harper’s character then calls her daughter an expletive.

It’s not a cheap laugh. It’s a relief laugh. It’s permission to laugh.

EMBRACING EMOTIONS

That permission — to laugh, or to cry, to be hopeful — is what Calgary puppeteer Michelle Warkentin wants to grant her audience as well. Her puppet show, Family Tear, centres on a mother’s diagnosis of dementia and the family that’s forced to cope. The interactions between family members and the nature of their mother’s dementia were based on research and real-life experiences. Warkentin’s mother-in-law has dementia. She says so many families are going through this very same thing, and that theatre can give people a safe space to emote.

“If you’re crying in the dark, you can just sit there and allow yourself to just let that go,” Warkentin says.

The stage also allows storytellers like Warkentin to use theatrical devices to change the way we think. In the play, a puppet represents the mother’s dementia, distinguishing clearly between the person and the illness. It hovers over her shoulder, visible to the audience but invisible to the characters in the play. As the mother’s cognition declines, the puppet earns more features — eyes, a nose, a mouth. The mother’s worsening condition elicits a visceral reaction from the audience. As the puppet draws more memory by asking the mother to breathe into its mouth, the audience grows angrier and angrier, some even pleading, “Don’t do it!”

At the end of one of the performances, Warkentin noticed a woman who remained in her seat. The room was emptying, but she stayed behind, sitting alone in the row of chairs. She was weeping. Warkentin approached her.

“This is my family,” she told Warkentin, gesturing to the empty stage. She told Warkentin that the play gave her hope, because the family on stage was able to piece things back together. She said to Warkentin, and herself, “Everything’s going to be okay.”

That message, that everything will be okay, is not always the message we receive about dementia. Our cultural assumptions, many of which derive from artistic representation such as films, plays and advertising, often perpetuate a fear around dementia. Living with dementia could only ever be tragedy, we’re often told.

LET THE LIGHT IN

Julia Gray is a Toronto-based playwright and director whose background in social justice theatre led to a partnership with health researchers Dr. Pia Kontos, Dr. Sherry Dupuis, Dr. Gail Mitchell and Dr. Christine Jonas-Simpson. The team created Cracked, a research-informed play (and now a film that can be viewed for a fee at crackedondementia.ca) that follows various people with dementia — and their families — on their unique journeys.

The researchers had approached Gray about developing the play because they recognized the important role art plays in changing our negative public discourse. Not only can this discourse perpetuate stigma, but it affects how policies are made, how long-term
Gray says the scene was based on research from Kontos. People with dementia sometimes enact previous experiences of their lives. These gestures can represent a lived experience, but we don’t always treat it that way. “If it’s seen as this crazy, meaningless thing, you assume it’s tragic, and you’re going to respond to that person very differently,” says Gray. “But if you work from the assumption that this is probably a lived experience that’s happening right in the hallway at three in the morning, then you approach it with more compassion and attention.”

Gray, the researchers, and the performers hold a Q&A with their audiences after the play. Some people thank them for telling a story about dementia that is accurate, validating and hopeful. Some audience members share their own stories. The team points to resources for people to access help. Gray hopes the story can reduce the stigma surrounding dementia by changing how society sees people living with dementia, but also how people living with dementia see themselves.

“Why would you come out and say you are living with dementia if all you ever see around you is that it’s this terrible thing?” says Gray. Following a performance of Cracked at a long-term care facility, Gray recalls a woman who stood up in the audience. Her reaction to the play was one that Gray will never forget. “Having seen this play,” the woman said, “I will no longer hide.”

care facilities are built, and how we interact with people living with dementia in everyday life. Gray says that performances like Cracked invite the audience into conversations that are often difficult and complex, and allows them space to reflect.

With plays, she says, “There’s the potential for people to be far more willing to be reflective on the ways they might be making assumptions about people who live with dementia — more so than just having a didactic lecture.”

The play’s title, Cracked, was inspired by a lyric in Leonard Cohen’s song, “Anthem.” In the song, Cohen sings, “There is a crack in everything / That’s how the light gets in.” Gray was trying to capitalize on some of the negative connotations of the word, as it’s those negative connotations that the play seeks to overturn.

“Something that’s perceived to be negative, or a weakness, is in fact what allows you to be in light in unexpected ways,” says Gray.

One scene in particular often resonates with viewers. The audience hears a foghorn and sounds of the ocean. A family launches a lobster fishing boat into the North Atlantic off the coast of Nova Scotia. The family sings together as they drop lobster traps into the water. Slowly, the main character, a young woman, changes — her singing softens, her surroundings fade. The audience realizes she is actually an elderly woman, living in a long-term care home. She’s singing and gesturing, dropping these imagined traps and drawing the attention of a nurse. It’s three o’clock in the morning. The nurse takes the woman back to bed.

“[With plays], there’s the potential for people to be far more reflective on the ways they might be making assumptions about people who live with dementia.” — Julia Gray
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.

Managing Dementia with Ease (MDE) Program
Use of specialized approaches for individuals with complex behaviours associated with dementia. The goal is to stabilize behaviours and enable residents to move to a less-structured living environment.

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

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

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 $S = $2,500-5,000/month $$$ = More than $5,000/month *Confirm pricing with individual facilities
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<td>4628 Montgomery Boulevard NW</td>
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## RESIDENTIAL

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<td>Evanston Grand Village</td>
<td>evanstongrand.ca</td>
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The BSF = The Brenda Strafford Foundation
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<td>St. Teresa Place</td>
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<td>Scenic Acres Retirement</td>
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<td>themanorvillage.com</td>
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<td>originway.ca</td>
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## Out-of-Town Residential

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*The BSF = The Brenda Strafford Foundation*
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<td>originspringcreek.ca 403-678-2288</td>
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<td>Best Friends Approach™, Teepa Snow’s Positive Approach To Care; Supportive Pathways</td>
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<td>seasonsretirement.com 403-652-1581</td>
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<td>mosquitocreekfoundation.net 403-646-2660</td>
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<td>theBSF.ca 403-995-9540</td>
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<td>classiclifecare.com 403-242-2750</td>
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## HOME CARE

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<td>OT, RN, HCA</td>
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<tr>
<td>All About Seniors</td>
<td>allaboutseniors.ca 403-730-4070</td>
<td>RN, LPN, HCA</td>
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<td>aspencarecalgary.com 403-990-3837</td>
<td>LPN, HCA</td>
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<td>bayshore.ca 403-776-0460</td>
<td>RN, LPN, HCA</td>
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<td>cbi.ca 403-232-8770</td>
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<td>Care to Share Senior Services</td>
<td>caretoshare.ca 403-567-1923</td>
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<td>caringhandscalgary.ca 403-999-3336</td>
<td>RN, LPN, HCA</td>
<td>$29.95/hr</td>
<td>“Treat clients as family would”</td>
</tr>
<tr>
<td>Classic LifeCare Calgary</td>
<td>classiclifecare.com 403-242-2750</td>
<td>RN, LPN, HCA</td>
<td>$31.75/hr</td>
<td>Teepa Snow’s Positive Approach to Care</td>
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<tr>
<td>Company</td>
<td>Website</td>
<td>RN, LPN, HCA</td>
<td>Rate/hr</td>
<td>Minimum Hours</td>
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<tr>
<td>Comfort Keepers</td>
<td>calgary.comfortkeepers.ca 403-228-0072</td>
<td>RN, LPN, HCA</td>
<td>$30.95/hr</td>
<td>2 hour minimum</td>
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<tr>
<td>Enhanced Health Services</td>
<td>enhancedhealthservicesinc.com 403-547-5859</td>
<td>RN, LPN, HCA</td>
<td>$29.99/hr</td>
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<tr>
<td>Focus On Caring</td>
<td>focusoncaring.com 403-264-3839</td>
<td>RN, HCA</td>
<td>$28/hr</td>
<td>4 hour minimum</td>
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<tr>
<td>Global Senior Care</td>
<td>globalseniorcareservices.com 403-452-4555</td>
<td>RN, LPN, HCA</td>
<td>$28/hr</td>
<td>3 hour minimum</td>
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<tr>
<td>Granddaughters Personal Care</td>
<td>granddaughters.ca 403-828-0550</td>
<td>LPN, HCA</td>
<td>$28/hr</td>
<td>2 hour minimum</td>
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<tr>
<td>Home Care Assistance</td>
<td>homecareassistanceofcalgary.ca 403-350-2773</td>
<td>RN, LPN, HCA</td>
<td>$29/hr</td>
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<tr>
<td>Home Instead Senior Care North</td>
<td>homeinstead.com/northcalgary 403-910-5860</td>
<td>Caregivers, HCA</td>
<td>$31.95/hr</td>
<td>3 hours minimum</td>
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<tr>
<td>Home Instead Senior Care South</td>
<td>homeinstead.com/calgary 403-984-9225</td>
<td>Caregivers</td>
<td>$31.95/hr</td>
<td>3 hours, twice a week</td>
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<tr>
<td>The Mad Tasker</td>
<td>themadtasker.com 403-988-2471</td>
<td>RN, LPN, HCA</td>
<td>$30/hr</td>
<td>1 hour minimum</td>
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<tr>
<td>Max Home Care</td>
<td><a href="http://www.maxhomecare.ca">www.maxhomecare.ca</a> 587-352-1010</td>
<td>HCA</td>
<td>$27/hr</td>
<td>2 hour minimum</td>
</tr>
<tr>
<td>Miraculum Homecare</td>
<td>miraculumhomecare.com 403-452-6399</td>
<td>RN, LPN, HCA</td>
<td>$28/hr</td>
<td>3 hour min</td>
</tr>
<tr>
<td>Nurse Next Door</td>
<td>nurseenextdoor.com 403-306-0180</td>
<td>RN, LPN, HCA</td>
<td>$33/hr</td>
<td>3 hour min</td>
</tr>
<tr>
<td>Ohana Care Health Services</td>
<td>ohanacare.ca 403-300-2273</td>
<td>LPN, HCA</td>
<td>$30/hr</td>
<td>2 hour minimum</td>
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<tr>
<td>ParaMed</td>
<td>paramed.com 403-228-3877</td>
<td>RN, LPN, HCA</td>
<td>$35/hr</td>
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<tr>
<td>Qualicare Calgary</td>
<td>homecarecalgary.com 403-209-3210</td>
<td>RN, LPN, HCA</td>
<td>$33/hr</td>
<td>3 hour minimum</td>
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<tr>
<td>Right At Home</td>
<td>rightathomecanada.com/calgary 403-869-8294</td>
<td>RN, LPN, HCA</td>
<td>$30.95/hr</td>
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## HOME CARE

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<th>Website</th>
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<tbody>
<tr>
<td>Senior Homecare by Angels</td>
<td>seniorhomecarecalgary.com</td>
<td>403-862-0129</td>
<td>LPN, HCA</td>
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<tr>
<td>Supportive Outings and Services</td>
<td>soscaregiver.ca</td>
<td>403-816-0428</td>
<td>RN, LPN, HCA</td>
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<tr>
<td>Vinnette Morgan</td>
<td><a href="mailto:vinnettemorgan@yahoo.ca">vinnettemorgan@yahoo.ca</a></td>
<td>403-919-4052</td>
<td>Nursing Attendant</td>
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### OVERNIGHT RESPITE - Assessment Required

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<tbody>
<tr>
<td>AgeCare Glenmore</td>
<td>1729 – 90 Avenue SW</td>
<td>403-253-8806</td>
<td>agecare.ca</td>
<td>●</td>
</tr>
<tr>
<td>Aspen Care Home</td>
<td>3437 6th Street SW</td>
<td>403-990-3837</td>
<td>aspencarecalgary.com</td>
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<tr>
<td>Auburn Heights Retirement Residence</td>
<td>21 Auburn Bay Street SE</td>
<td>403-234-9695</td>
<td>allseniorscare.com</td>
<td>●</td>
</tr>
<tr>
<td>The BSF Clifton Manor</td>
<td>4726 – 8 Avenue SW</td>
<td>403-272-9831</td>
<td>theBSF.ca</td>
<td>●</td>
</tr>
<tr>
<td>The BSF Wentworth Manor</td>
<td>5717 – 14 Avenue SW</td>
<td>403-242-5005</td>
<td>theBSF.ca</td>
<td>●</td>
</tr>
<tr>
<td>Carewest Colonel Belcher</td>
<td>1939 Veteran’s Way NW</td>
<td>403-944-7800</td>
<td>carewest.ca</td>
<td>●</td>
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<tr>
<td>Carewest Sarcee</td>
<td>3504 Sarcee Road SW</td>
<td>403-686-8140</td>
<td>carewest.ca</td>
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<tr>
<td>Carewest Signal Pointe</td>
<td>6363 Simcoe Road SW</td>
<td>403-240-7950</td>
<td>carewest.ca</td>
<td>●</td>
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<tr>
<td>Chartwell Eau Claire Residence</td>
<td>3001 – 7 Street SW</td>
<td>587-287-3943</td>
<td>chartwell.com</td>
<td>●</td>
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<tr>
<td>Evergreen</td>
<td>2220 – 162 Avenue SW</td>
<td>403-201-3555</td>
<td>reveraliving.com</td>
<td>●</td>
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<tr>
<td>McKenzie Towne Retirement Residence</td>
<td>20 Promenade Park SE</td>
<td>403-257-9331</td>
<td>reveraliving.com</td>
<td>●</td>
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The BSF = The Brenda Strafford Foundation

Share your questions and comments with us at feedback@dementiaconnections.com
<table>
<thead>
<tr>
<th>FACILITY</th>
<th>PROGRAM NAME</th>
<th>BUILDING ADDRESS</th>
<th>PHONE NUMBER</th>
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<td>AgeCare Glenmore</td>
<td>AHS Adult Day Program</td>
<td>1729 – 90 Avenue SW</td>
<td>403-253-8806</td>
<td>agecare.ca</td>
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<tr>
<td>AgeCare Midnapore</td>
<td>AHS Adult Day Program</td>
<td>500 Midpark Way SE</td>
<td>403-873-2852</td>
<td>agecare.ca</td>
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<tr>
<td>AgeCare Seton</td>
<td>Club 36 Adult Day Program</td>
<td>4963 Front Street SE</td>
<td>587-349-8444</td>
<td>alzheimercalgary.ca</td>
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<tr>
<td>Auburn Heights Retirement Residence</td>
<td>Young Onset Dementia Day Program</td>
<td>21 Auburn Bay Street SE</td>
<td>403-234-9695</td>
<td>alseniorscare.com</td>
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<tr>
<td>Bethany Harvest Hills</td>
<td>Club 36 Adult Day Program</td>
<td>19 Harvest Gold Manor NE</td>
<td>403-226-8201</td>
<td>alzheimercalgary.ca</td>
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<tr>
<td>The BSF Bow View Manor</td>
<td>AHS Adult Day Program (including Dementia Program)</td>
<td>4628 Montgomery Blvd. NW</td>
<td>403-286-6166</td>
<td>theBSF.ca</td>
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<tr>
<td>The BSF Clifton Manor</td>
<td>AHS Adult Day Program (including Early Onset and Dementia Programs)</td>
<td>4726 – 8 Avenue SE</td>
<td>403-204-9969</td>
<td>theBSF.ca</td>
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<tr>
<td>The BSF Wentworth Manor</td>
<td>AHS Adult Day Program</td>
<td>5709 – 14 Avenue SW</td>
<td>403-686-8602</td>
<td>theBSF.ca</td>
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<tr>
<td>The Calgary Chinese Elderly Citizens’ Association</td>
<td>Adult Program (Special Needs Support Group)</td>
<td>3 Riverfront Avenue SW</td>
<td>403-267-6122</td>
<td>cceca.ca</td>
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<tr>
<td>Carewest Beddington</td>
<td>Comprehensive Community Care (C3)</td>
<td>308 – 8120 Beddington Blvd. NW</td>
<td>403-520-3350</td>
<td>carewest.ca</td>
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<tr>
<td>Carewest Colonel Belcher</td>
<td>Wellness Day Program</td>
<td>1939 Veteran’s Way NW</td>
<td>403-944-7854</td>
<td>carewest.ca</td>
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<td>Carewest Sarcee</td>
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<td>3504 Sarcee Road SW</td>
<td>403-686-8140</td>
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<td>Carewest Signal Pointe</td>
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<td>6363 Simcoe Road SW</td>
<td>403-240-7953</td>
<td>carewest.ca</td>
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<tr>
<td>Peace of Mind</td>
<td>Peace of Mind Adult Day Program</td>
<td>NW Calgary</td>
<td>587-887-4900</td>
<td>peaceofmindcare.ca</td>
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<tr>
<td>Recreation &amp; Wellness locations</td>
<td>YouQuest - A Wellness Community for Young Onset Dementia</td>
<td>Contact YouQuest for current locations</td>
<td>403-255-7018</td>
<td>youquest.ca</td>
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<tr>
<td>St. Andrew’s Presbyterian Church</td>
<td>Side by Side Fellowship</td>
<td>703 Heritage Drive SW</td>
<td>403-255-0001</td>
<td>standrewscalgary.ca</td>
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<tr>
<td>Varsity Acres Presbyterian Church</td>
<td>Side by Side Fellowship</td>
<td>4612 Varsity Drive NW</td>
<td>403-288-0544</td>
<td>vapc.ca</td>
<td>●</td>
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<tr>
<td>Wing Kei Care Centre</td>
<td>Wing Kei Adult Day Program</td>
<td>1212 Centre Street NE</td>
<td>403-277-7433</td>
<td>wingkeicarecentre.org</td>
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*Confirm dates and times with individual programs
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<tr>
<th>PROGRAM</th>
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<tbody>
<tr>
<td>Alzheimer Society of Calgary</td>
<td>NW location</td>
<td>403-290-0110</td>
<td><a href="mailto:findsupport@alzheimercalgary.com">findsupport@alzheimercalgary.com</a></td>
<td>10 a.m.-11:30 a.m.</td>
<td>2nd &amp; 4th Wed Monthly 1st Thurs of Each Month</td>
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<td></td>
<td>SW location</td>
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<td>7 p.m.-8:30 p.m.</td>
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<td>10:30 a.m.-12 p.m.</td>
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<td>3rd Thurs of Each Month</td>
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<td>Calgary N.E. Dementia Support Group</td>
<td>Dementia-specific support</td>
<td>403-273-2371</td>
<td></td>
<td>Times Vary</td>
<td>Dates Vary</td>
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<tr>
<td>Calgary South Dementia Support Group</td>
<td>Dementia-specific support</td>
<td>403-271-9570</td>
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<td>10 a.m.-11:30 a.m.</td>
<td>2nd &amp; 4th Thurs of Each Month</td>
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<tr>
<td>Dementia Support</td>
<td>Dementia-specific support Southwood United Church, 10690 Elbow Dr. SW</td>
<td>403-253-2979</td>
<td>southwoodchurch.ca</td>
<td>1 p.m.</td>
<td>1st Mon of Each Month</td>
</tr>
<tr>
<td>Living with Dementia</td>
<td>12 topics by professional facilitators Carewest Glenmore Park Day Hospital, 6909 – 14 St. SW</td>
<td>403-640-6480</td>
<td></td>
<td>9:30 a.m.-2 p.m.</td>
<td>Wednesdays 12-week Program</td>
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<tr>
<td>Memory P.L.U.S.</td>
<td>Safe, fun, social activities for those with mild dementia and their care partners</td>
<td>403-955-1674</td>
<td><a href="mailto:charlene.retzlaff@ahs.ca">charlene.retzlaff@ahs.ca</a></td>
<td>2 hr Sessions</td>
<td>Fall/Spring Sessions 12-week Program</td>
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<tr>
<td>Movement P.L.U.S.</td>
<td>Fall-prevention, exercise and social program for those with mild dementia and their care partners</td>
<td>403-955-1674</td>
<td><a href="mailto:rene.engel@ahs.ca">rene.engel@ahs.ca</a></td>
<td>75-minute Sessions, Day and Times Vary</td>
<td>12-week Program</td>
</tr>
<tr>
<td>Young Onset Dementia Support Group</td>
<td>For people with dementia (diagnosed under age 65) and their caregivers. Southwood United Church 10690 Elbow Drive. SW</td>
<td>403-975-6685 403-283-9537</td>
<td><a href="mailto:cindy@youquest.ca">cindy@youquest.ca</a></td>
<td>7 p.m.-8:30 p.m.</td>
<td>1st &amp; 3rd Tue of Each Month</td>
</tr>
</tbody>
</table>

*Confirm dates and times with individual programs

Questions? Feedback? Stories to Share?

Write to us: feedback@dementiaconnections.ca
Connect with us online at: dementiaconnections.ca
The good news: There are numerous resources in Calgary for people living with dementia, their care partners and their families.

The not-so-good: It can be daunting to navigate the many services and organizations offering everything from adult day programs to assistance connecting with government resources. Some organizations offer dementia-specific resources, while others have more generalized mandates to assist all seniors.

Understanding what each organization offers can help those looking to access education and resources make the most of what’s available.

Who:
Alzheimer Society of Calgary
What: A go-to point of contact for individuals and families affected by Alzheimer’s and other forms of dementia. This organization offers much-needed help navigating the system, along with workshops and public awareness sessions on topics including pre-diagnosis, caregiver strategies and brain health. Social workers provide emotional and practical support. A program called Club 36, contracted through Alberta Health Services, offers recreational activities such as art and music therapy for people with dementia and respite for caregivers. Many services are offered at no cost. Contact the Alzheimer Society directly at 403-290-0110, or ask your physician to initiate a First Link referral. alzheimercalgary.ca.

Who:
Calgary Chinese Elderly Citizens’ Association
What: Adult day support programs, including one day a week for people with dementia. The association also has an outreach department to help seniors apply for benefits and navigate available supports. A 10-week program called CARERS (Coaching, Advocacy, Respite, Education, Relationship and Simulation), using problem solving therapy, simulated patients and role play, is offered for family caregivers of people with dementia. Cost is $20 for 10 weeks, and snacks and care for loved ones with dementia during the 2.5-hour sessions are supplied.
Contact: 403-269-6122, cceca.ca

Who:
Calgary Seniors’ Resource Society
What: Helps potentially at-risk seniors build and maintain quality of life through programs and services aimed at helping them live independently and without social isolation. Clients tend to be lower-income seniors age 65-plus who lack extensive family or friend support. Programs and services feature volunteers offering escorted transportation, friendly visiting, shopping companionship, support and other help. Community outreach workers are there to help navigate care services, financial benefits, housing, transportation and emergency assistance for crisis situations.
Contact: 403-266-6200; calgaryseniors.org

Who:
carya
What: This non-profit organization provides services and programs for youth, families and older adults. Formerly known as Calgary Family Services, carya offers seniors social connections, counselling, art therapy and group programs focusing on healthy living along with in-home non-medical supports for vulnerable seniors to help them remain in their homes. These supports include community connections, light homemaking, laundry and help with access to information and referrals. Fees for in-home programs are calculated on a sliding-scale basis.
Contact: 403-269-9888; caryacalgary.ca

Who:
Dementia Network Calgary
What: Made up of people from the public, private and non-profit sectors with an interest in dementia, the network aims to make Calgary “a supportive, innovative environment where people impacted by dementia can live life well.” Dementia Network Calgary has a number of initiatives underway targeting education and awareness, ways to support community living and effective educational strategies for those working in dementia care. The goal is a seamless integration of services. The network also connects communities through a calendar of events, a free newsletter and opportunities to participate in research.
Contact: dementianetworkcalgary.ca

Who:
Jewish Family Service Calgary
What: The JFSC Older Adults Outreach team aims to prevent social isolation, alleviate poverty, manage and prevent crises, assist in healthy aging and retain independence for all aging adults across most of the city’s southwest and southeast. Intake is done through The Way In (see next page). Referrals and access to community services, case management and issue resolution, housing assistance, and emotional support are all part of the outreach team’s services.
Contact: 403-SENIORS; thewayincalgary.ca; email css@jfsc.org
Who: Kerby Centre
What: A centre offering services, information and programming for older adults. Kerby Centre offers indirect support for people with dementia and their families, welcoming them and their caregivers into programming where appropriate, but it doesn’t have dementia-specific programming. Offerings include an adult day program, academic and art courses, day trips, travel events, a monthly movie, and workshops related to health, financial planning and issues-based topics.
Contact: 403-265-0661; kerbycentre.com

Who: The Way In
What: The Way In is a collaboration of four agencies (carya, Jewish Family Service Calgary, Calgary Seniors’ Resource Society and Calgary Chinese Elderly Citizens’ Association). It’s a free service for those 65 and up and their families and friends, connecting them with service coordinators. The coordinators help with access to community supports, information and referrals, pension forms, benefits, transportation and housing.
Contact: 403-SENIORS (403-736-4677); thewayincalgary.ca

OTHER ORGANIZATIONS SUPPORTING DEMENTIA CARE & CURE

Alberta Continuing Care Association: A recognized voice in continuing care in Alberta, the ACCA is a member-driven organization that represents a number of home care and support services. ab-cca.ca

Alzheimer Society of Alberta & NWT: With a provincial office and seven regional centres across Alberta and the Northwest Territories, the Society offers support services for those with dementia and their care partners, builds partnerships with health professionals and the community, and advances research. alzheimer.ca/en/ab

Branch Out Foundation: There are more than 600 neurological disorders that affect one in three Canadians. The Branch Out Foundation funds non-pharmalogical research projects to study and cure these disorders. branchoutfoundation.com

Brenda Strafford Foundation (BSF): This charitable organization is involved in a number of projects that promote seniors health and wellness, and supports research at the University of Calgary. thebsf.ca

Canadian Association of Retired Persons (CARP): With more than 300,000 members over the age of 50, CARP is a powerful national advocacy organization. Dementia is an area that affects much of its membership, so CARP is helping channel those voices to affect public policy. carp.ca

Caregivers Alberta: This charity helps those in need of continuing care by supporting the caregivers who care for them with resources to tackle mental health and self-care issues. caregiversalberta.ca

Campus Alberta Neuroscience: Alberta has three university centres for neuroscience: Calgary’s Hotchkiss Brain Institute, Edmonton’s Neuroscience and Mental Health Institute, and Lethbridge’s Canadian Centre for Behavioural Neuroscience. They joined forces in 2009, and now, 250 researchers work together to study dementia with the aim of helping Albertans with brain diseases. albertaneuro.ca

Early Onset Dementia Alberta Foundation (EODAF): Early-onset dementia affects around 16,000 Canadians under the age of 65. EODA works to support and raise awareness, offering programs such as financial awareness clinics, as well as aiding in research. eodaf.com

Gordie Howe C.A.R.E.S.: This nonprofit organization supports the delivery of evidence-based programs that benefit local people with dementia and caregivers, working toward a long-term goal of building a future Centre of Excellence for Dementia Care in Calgary. gordiehowecares.com

Health Quality Council of Alberta (HQCA): HQCA gathers and analyzes information, monitors the health care system, and collaborates with Alberta Health, Alberta Health Services, health professions, academia and other stakeholders to translate that knowledge into practical improvements to health-service quality and patient safety. hqca.ca

Institute for Continuing Care Education and Research (ICCR): This organization consists of post-secondary institutions and continuing-care providers. Its focus lies in encouraging research, and in working to put that research into practice. iccer.ca

Translating Research into Elder Care (TREC): This research program focuses on creating solutions for enhancing the quality of care provided to nursing home residents, supporting the work of front-line care providers and improving overall efficiency in services. trecresearch.ca
Ron has certainly lived a life worth chronicling. He grew up in England where, amid the very tumultuous backdrop of the Second World War, he discovered a love for oil painting and other artistic endeavours. Later, when his family relocated to Canada, Ron — who had no schooling past the age of 16 — got certified as a surveyor, then as a draftsman and, eventually, he and a colleague founded an architectural practice in Calgary.

That firm, known today as GEC Architecture, oversaw the construction of some of the city’s most iconic buildings, including the Saddledome and the Olympic Oval. Add to that an active career in Alberta politics, a strong presence on numerous university boards (where he met Jeanette), and a hobby for completely renovating and flipping homes, and you’ll get a picture of Ron’s work ethic and drive.

Now 87, Ron was diagnosed with early cognitive impairment in 2007 and, in 2011, he was told he had Alzheimer’s Disease. That news was a huge adjustment for Jeanette and Ron, but, as is customary in their relationship, they’ve faced their newest challenge head-on.

Often, during Jeanette’s daily visits to see Ron, they will go over their memory book, discussing bits that trigger a memory in him.

“...I still go every day to visit him. People sometimes ask me, ‘Why do you go every day?’ Well, because I want to. I love Ron. It’s as simple as that.”

Share your story with us at feedback@dementiaconnections.ca.
Kris McElroy: My Dementia Story

Kris McElroy is a 33 year old native of Maryland, United States living in poverty with multiple disabilities including a progressive neuromuscular disorder, autoimmune disorder, and dementia. He holds a Bachelor of Science in Psychology and a Master of Science in Multidisciplinary Human Services. Professionally, Kris has held positions in the education, advocacy, nonprofit, and human services fields. He is also the author of Perspectives: Discovery through Difference, as well as an artist and writer who has been featured in a variety of sources over the past decade.

Kris was diagnosed with young onset dementia while finishing up the second year of his doctoral coursework. The exact dementia diagnosis given on June 21, 2017 was dementia due to other medical condition with behavior disturbance. Similar to his other medical disabilities, the exact etiology is still unknown, while the complexity and overlap of his medical conditions is vast. While Kris has been adapting, adjusting, and fighting through challenges, barriers, stigma, and stereotypes related to his disabilities since childhood; life with dementia has brought its own unique set of challenges, barriers, and stereotypes. Barriers such as access to resources and quality life/health care options; and challenges with areas such as spelling, driving, comprehension, memory, multitasking, confusion, and navigating day-to-day life.

Today, a year later since his dementia diagnosis, Kris has found support through Dementia Alliance International and continues to live independently with the help and support of his sister, a few close friends, and multiple assistive devices. He is an avid volunteer engaging in his community in advocacy, social change and justice work, and finding a way to live out his life purpose; he has good days and bad days but is determined to live life well and each moment to the fullest.

A world where a person with dementia continues to be fully valued and included.

Dementia Alliance International (DAI), provides a unified voice for people with dementia. Established in 2014, it is the first international group of; by, and for people with dementia, where membership is exclusive to people diagnosed with dementia. Members become part of a unified global community that provides support and empowerment to live beyond dementia. Through advocacy, education and awareness, DAI aims to reduce stigma, isolation and discrimination. Join DAI: www.joindai.org

email: info@infodai.org  website: www.infodai.org  www.facebook.com/DementiaAllianceInternational  @DementiaAllianc
**WE CARE!**
CREATING CARING COMMUNITIES

Bethany is a faith-based, not-for-profit provider of seniors’ services and affordable housing in communities in central and southern Alberta. We provide a full spectrum of housing and care options for seniors and adults with disabilities.

### Housing
- **Affordable Housing**
  Independent living for seniors and below-market-rent for adults and small families with reduced incomes.
- **Life-Lease Community**
  Life lease may build equity with buy-back at assessed fair-market value.
- **Rent Geared to Income**
  Five rent geared to income seniors buildings.

### Supportive Living
Bethany offers over 200 Supportive Living suites in a home-like setting to independent seniors.

### Long-Term Care
Bethany’s long-term care residences are home to more than 800 residents. Our programs such as Alternative Level of Care, Young Adult Programs and transitional care provide professional care and services to those who require 24/7 support.

### Unique Complex Dementia Care
Bethany Riverview is our newest care centre and will be home to 210 residents with a focus on complex dementia care. It is part of Riverview Village, which is Bethany’s first Campus of Care for seniors. It is designed to support seniors to age in their community - from those living independently to those requiring long term care.

For more information, please contact us:
**403.210.4600** or **1.888.410.4679**

email: info@bethanyseniors.com

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