

USING MY BRAIN AGAIN

TEXT BY ASHLEY NAUD // PHOTOS BY LEAH HENNEL

DEMENTIA DOESN'T JUST AFFECT THE ELDERLY — IT IMPACTS THOUSANDS IN THEIR 40S, 50S AND EARLY 60S. A CHARITY CALLED YOUQUEST MEETS THE UNIQUE NEEDS OF CALGARIANS WITH YOUNG-ONSET DEMENTIA BY OFFERING FAMILIES A PLACE TO BELONG.



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SINCE THE COVID-19 PANDEMIC WAS DECLARED IN MARCH 2020, STAY-AT-HOME ORDERS WORLDWIDE HAVE GIVEN MILLIONS OF PEOPLE FIRST-HAND EXPERIENCE IN SOCIAL ISOLATION — SOMETHING PEOPLE WITH YOUNG-ONSET DEMENTIA OFTEN FACE ON A DAILY BASIS. ALTHOUGH YOUQUEST IS STAYING IN TOUCH WITH ITS COMMUNITY ONLINE, ITS IN-PERSON SERVICES WERE SUSPENDED DUE TO THE PANDEMIC. THIS STORY, WRITTEN AND PHOTOGRAPHED ON THE EVE OF PUBLIC HEALTH ORDERS LIMITING GROUP GATHERINGS, IS A PRE-COVID SNAPSHOT — AND A REFLECTION OF THE IMPORTANCE OF HUMAN CONNECTION.

“YOU HAVE FRONTOTEMPORAL DEMENTIA.”

Stephen Clarke (EDT '95) was just 50 years old when he received this life-altering diagnosis six years ago.

“There were things on the computer that started to get really confusing for me ... I started to miss deadlines, which I never did — I had a reputation for never missing a deadline.

“Then it was driving. About a year later, I think, I was driving home on either South 14th Street or Elbow Drive — I can't remember which. And I couldn't remember how to get to my place in Willow Park. I remember thinking, ‘What the hell is happening to me?’”

Initially Clarke was misdiagnosed with anxiety. He went on long-term disability and started working with a psychiatrist to manage his symptoms. Finally he was sent for a PET scan, which checks brain function.

“It was a bittersweet moment when I finally got the diagnosis after so long looking for an answer,” Clarke says. “All right, an answer — boom, here it is. Now I can get it fixed, right?’ But the answer is, there is no fix. And it's just going to get worse, right?

There goes everything I've worked for. There goes the career I was really good at.”

Clarke is one of about 16,000 Canadians under the age of 65 living with young-onset dementia, according to the Alzheimer Society of Canada.

His long search for answers isn't rare — young-onset dementia is often difficult to diagnose. Even after diagnosis, resources and practical support specifically geared to people under the age of 65 are hard to come by.

That's something Cindy McCaffery discovered when her husband, John, was diagnosed at the age of 48. It was the impetus for McCaffery and her friend, Myrle Bulman, to establish YouQuest, a Calgary charity that provides recreation therapy and community for those living with young-onset dementia and for their families.

“Only the family or person living with someone who has young-onset dementia would understand how it limits their lives,” says Bulman. “Dementia changes every relationship and it can be very isolating.”

Bulman oversees the logistics of YouQuest's weekly service, where recreation therapists, volunteers and participants meet in SAIT's Campus Centre. I visit the group one Thursday morning in January. It's a frigid -28 degrees Celsius, but the weather serves as no deterrent for participants. As volunteers help them find their way to the Odyssey Café, everyone is eager to connect with one another after the Christmas break.

Because young-onset dementia symptoms differ widely from person to person, YouQuest recreation therapists,

volunteers and participants co-plan each week to incorporate individual interests and needs. YouQuest also works with SAIT Recreation and other groups to create a safe and welcoming atmosphere where the group can enjoy a full day of active independence and social connections — a basic human need.

“The most important thing we do is offer choice,” says Bulman. One example is lunch, when the group heads to the 4 Nines Dining Centre. They join the short order

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STEPHEN CLARKE



A) In non-pandemic times, Stephen Clarke spends Thursdays working out at Campus Centre with YouQuest, a community of people with young-onset dementia. **B-D)** When LINK visited YouQuest for this photo shoot on March 12, the day began as usual: buying coffee at the Odyssey, then chatting and reconnecting.



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lunch line and choose from four options — all visible on the counter.

“An entire lunch menu may be overwhelming for someone with young-onset dementia, but four options makes it easier for them to make a selection for themselves,” Bulman says.

“We’re creating a culture where participants tell us what they need. There is a certain amount of routine but there is freedom within that routine.”

Among the group of 12 participants, I meet an anesthesiologist, an immigration lawyer, a competitive lifeguard and a librarian. Some share updates from their holiday breaks, while some have more difficulty finding words. Still, each shows respect and offers encouragement to one another.

Then, as participants finish up their fitness activities

— this morning, the choices include rowing, squash and cycling — they gather together in front of the SAIT Recreation window.

“We try not to rush these moments,” Bulman explains. “The simplicity of it is stunning. It may seem like they’re just standing around after their workout, but they are enjoying having a conversation — even if they don’t remember one another’s names. This kind of ordinary interaction can make Thursdays one of the best days of their week.”

Retired telecommunications professional Dave Grose (TXT ’81) has seen the benefits of the service first-hand since he began volunteering with YouQuest when it was launched as a pilot project in September 2018.

“We used to wear name tags but now we don’t. People wonder, ‘Well, who is the participant and who is the volunteer?’ But does it matter?” Grose says. “Many of the participants know they have dementia and it’s frustrating for them, so why bring it up?”

“I guess a big key is knowing we are all the same — we all just want to belong.”

And for participants like John Wood — a graduate of SAIT’s Industrial Instrumentation Technology program — YouQuest also means a chance to keep playing a favourite sport.

“John loves to play a hard game of squash — his wife says he’s always asking if it’s a SAIT day,” Bulman says. “Although his memory loss is extensive, playing squash draws on John’s muscle memory and gives him both independence and enjoyment.”

A 2009 article published in *Geriatrics & Aging* by Ann Kolanowski, Donna M. Fick and Linda Buettner outlines how recreation therapy is also more effective than medication in helping to reduce behavioural symptoms caused by the isolation and boredom that often accompany dementia. Recreational programs help “promote quality of life by providing an appropriate level of stimulation using meaningful activities,” the article continues, and help ease symptoms such as agitation, aggression and apathy that can be difficult for an individual’s caregiver — often a family member or friend — to navigate.

WHAT IS DEMENTIA?

Dementia is the overall term for a combination of symptoms that include a decline in the ability to remember, think, reason, and relate to others. The symptoms can worsen over time until the person can no longer take care of themselves and live independently.

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MYRLA BULMAN // CO-FOUNDER, YOUQUEST

“While we offer a lot of support that is good for the participant, it’s also incredibly valuable to the caregiver — that can’t be understated,” says YouQuest board member Roc Spence (DET ’74).

Spence, who joined the board in 2019, says YouQuest hopes to expand to a multi-day service, as requested by participants and families.

The group is also working to secure funding to further develop a web application prototype that will allow participants to track and, working with their therapists, reflect back on their individual progress and preferences. It’s a project that began as a SAIT student capstone and is now overseen by SAIT’s Applied Research and Innovation Services (ARIS) department.

Clarke, who continues to live independently with the daily help of his two childhood best friends and their families, says the experiences and relationships he’s gained through YouQuest are invaluable. He’s looking forward to the day when its services are offered twice a week.

“I have an exercise bike at home, but at YouQuest, I’m in a gym with other people,” he says.

“Just now, I was playing pool with a bunch of peers who have whatever dementia they’re dealing with, right? But what were we doing? We’re shooting a game of pool and everybody’s familiar with pool. Are we all really great at it anymore? No, but that doesn’t matter.



REBECCA KIMBER ILLUSTRATION

H)

E) Stephen and YouQuest volunteer Dave Grose (left) work out side-by-side. **F & G)** Badminton, bowling, lunch and music often round out a typical Thursday with YouQuest. During the pandemic, YouQuest expanded its weekly email to include ideas for fitness at home, birthday messages and links featuring volunteer musicians playing everything from Dylan to The Stones. **H)** Artist Rebecca Kimber led a storytelling project for YouQuest while simultaneously illustrating comments from the group. “She also created this team caricature — we were amazed to see ourselves sketched out at top speed,” says YouQuest co-founder Myrla Bulman (front row, left). “We look forward to future stories with Rebecca!”

“YouQuest lets me use my brain again, like I used to use it before. One day per week, I get that back. My opinion matters to YouQuest. I could say it frees me, I guess, from the confines of an otherwise dementia existence.” **1**

WHAT CAUSES DEMENTIA?

Many diseases can cause dementia, including Alzheimer’s disease. Frontotemporal dementia is an umbrella term for a group of disorders that impact the parts of the brain usually associated with personality and behaviour.

Source: Alzheimer Society of Canada