

An exciting year of firsts, including this newsletter!

Just over a year ago we launched Calgary's first daytime support service designed for people living with young-onset dementia.

At YouQuest, we set out to give our participants a place to belong with peers and an active day filled with choices, while providing much-needed respite and support to care partners. The feedback from our families categorically tells us we've reached our goal, but we continue to listen and fine tune our service.



With recreation therapists Bev Hillman and Melissa Olin in the lead, we've covered a lot of ground this last year and have had the privilege of making deep friendships. Many of our experiences are showcased in this first newsletter. We hope you enjoy reading about our progress and look forward to your feedback.

Thank you for helping us give a valuable day of wellness to those with young-onset dementia.

Cindy McCaffery and Myrle Bulman
Co-founders

Oh, the places we've been!

Congratulations on YouQuest's 1st Anniversary - By John McCaffery

I was diagnosed with young-onset dementia at age 48. Dementia stole my career, my workplace friendships, and the ability to prepare for retirement.

Until my diagnosis I had been engaged in my community and active in many sports. Suddenly, I was home alone, bored and becoming more isolated as time dragged on. There was little for me to enjoy day after day while my wife Cindy was at work and the kids were at school.

Cindy and I looked into day programs for me, but since they are intended for seniors, they weren't suitable for my interests or activity level. Thankfully Cindy and her friend Myrle Bulman were determined to fill this service gap with the first active community for Calgarians under age 65 living with young-onset dementia. (continued next page)

All the preparation paid off on September 27, 2018, when YouQuest celebrated its first service day in partnership with SAIT Recreation. One year later, I – and others with a diagnosis similar to mine – look forward to getting out of the house to do the things we enjoyed before we ever heard of young-onset dementia.

It seems there's something for everyone at YouQuest. Caring volunteers and skilled recreation therapists support and encourage us in all we do, and value our opinions and suggestions.

Days full of choices

Our morning begins with ordering a coffee or tea at the Odyssey and joining in great discussions from current events to sharing tips on how to navigate the world of dementia. Then we lace up and choose a morning wellness activity: court sports, working out on the fitness equipment, or practicing yoga and meditation. Having worked up an appetite, we gather for lunch where we might laugh about our performance on the badminton court that morning or discuss what's going on with our families and friends.

Fortunately Calgary is filled with many interesting places to visit so we're often out exploring the city and beyond. Via public transit we have gone to the Zoo, the new Calgary library, and even the Dior exhibit at the Glenbow Museum. As one volunteer said recently, "I've seen more of Calgary with YouQuest in the last year than in all my years in the city!"

Thanks to donations and the [DREAMS Bus](#), we've ventured to the Hangar Flight Museum to soak up some history, and to Fish Creek Park and Kananaskis for barbeques and day hikes. Our days always end with music, usually courtesy of our own house band, the YouQuest All Stars.

Celebrating our community

Days at YouQuest are positive and we make a point of celebrating birthdays as well as each other's achievements. In this photo, a group of friends congratulated me on my streak of playing disc golf for 900 days in a row! My streak ended at 918 days for a very exciting reason, but that's a story for another day ...

I'd like to turn the tables and wish a very Happy Birthday to YouQuest – and many happy returns of the day!



We're on a roll ...

While designing YouQuest, our focus was to find out directly from families what kind of support really mattered. What actually help when dementia exerts its grip in this earlier than expected stage of life? Coming soon, the pilot year evaluation report will feature stories about how our service is having a positive impact on family life.

Our intent has always been to help both those diagnosed and their support system, whoever that might be – a spouse, a sibling, a son or daughter, or a friend – as the young-onset care partner has many different faces.



Care Partner Respite



Volunteer Contribution



Physical Activity Hours

As a weekly service from September 2018 to mid-November 2019, we are proud to report on these key metrics to illustrate the 'boots-on-the-ground' assistance to families:

- **Care partners** have received over 4500 total hours in respite time to help manage life around this diagnosis – they way they need to, for their family. (Equivalent to \$157,795 in private care, based on \$35/hour rate).
- **On-site volunteers** have contributed over 2100 hours to ensure our service delivery model was feasible, always with a smile on their faces and ready to lend a hand.
- **Participants** have gathered for 53 service days and an average of 3.5 hours/day of actual physical activity – that's over 1800 hours of wellness with their peers

We are so grateful for the countless hours invested by our dedicated volunteer board and committee members, and the many valued external advisors that have helped us on our way.

Rock and roll magic!

In the New Year, we will profile Kelly Morstad as the catalyst for weaving live music into our days for so many unforgettable moments with his circle of musician friends. We frequently turn heads at SAIT as the memorable tunes reach the hallways!



Respect & Remembering

Recently, Remembrance Day had us reflecting on family members connected to the wars and everyone was keen to show respect for those who gave us our freedoms.

There were many memories, and a few tears, because even the passing of the years doesn't dull our connection to these people in our lives. Our visit to the Military Museums was a very sensory experience to absorb all the information and the trip back to SAIT included a tour of the Field of Crosses on Memorial Drive.

The conversation flowed into the next week as the group explored the topic of conscientious objectors and we heard from one volunteer how a family member went to prison over the issue.

We listened to some of that man's poetry to understand his perspective and were able to read actual medical reports (gunshot wound to the head!) and letters to a family when their son was reported missing in action. Such thoughtful conversations always bring us closer together.



On the road again ...

Who doesn't love communing with nature and getting out of the city into the fresh air? Everyone had the choice of taking a 30-minute or 1.5-hour hike at Forget-me-not Pond in August. What a perfect day, and one of our many trips!

Our participants tell us that they want interesting and active choices for their recreational pursuits, and we have had fun obliging. We've racked up many kilometres on 24 trips around the city and on the highway – and some destinations have been repeated we've enjoyed them so much!

Some family members join us on our walks as we visit many city parks in our travels. Everyone enjoys gathering to connect over food and conversation at our family social events.



"YouQuest creates an environment where everyone feels welcome."

Profile: Susie Dooley, Volunteer Coordinator *(with Myrla at 2019 Calgary Volunteer Fair)*

I joined YouQuest in January 2019 after hearing about the charity at a speaker series on dementia at the Calgary Public Library. People are intrigued by my volunteer work at YouQuest; they are also surprised that we have participants that are well under 60 years of age. They want to know more about what we do and to understand the challenges and struggles families face.

I value my involvement with YouQuest because it is an interesting learning experience. We have a welcoming team of volunteers and recreation therapists that are committed to improving the lives of everyone within the YouQuest family. There is great understanding and compassion for the participants and their families, and deep appreciation for the efforts of our dedicated volunteers.



Why volunteer with YouQuest?

We are growing and welcoming new volunteers to help us improve the quality of life for younger people with dementia. YouQuest volunteers come from all walks of life and help us both onsite and/or behind the scenes supporting our participant families. Training is provided; on-site shifts are 3+ hours and flexible to individual schedules. Off-site committees working to sustain and expand YouQuest services will benefit from your insights and expertise.

Wondering how you can make a difference?

Here's a snapshot of our on-site volunteers who help in many ways:

- making an immediate and lasting impact on younger people with dementia
- helping reduce isolation and improve the health of care partners
- reducing the stigma of dementia in the community
- actively participating in fitness options and community trips around Calgary and area
- enjoying a hot lunch, healthy snacks, and live music with participants
- learning and sharing with our team how to help support each individual

Whether you are a post-secondary student, a community member or an interested professional, we invite you to volunteer. Please [apply here](#) and we will be in touch.

Special Thanks for charitable status



2019 was a big year in many respects, but none moreso than sailing through our charitable status application after a Rotarian's suggestion to enlist help from Pro Bono Law Alberta. Full marks to **Alicia McKinley** who volunteered her expert guidance on the requirements and documentation. Thanks as well to **Margaret Dickson**, an advisor whose tax law and charitable administration talents ensured success in this important step for our organization.



Partners & Funders Spotlight: It's all about COLLABORATION

Rotary Club of Calgary Centennial

It all started with a first gesture by **Russell Kane** who was keen to recognize our cause in honour of former club member John McCaffery.



Rotary Club of
Calgary Centennial

Rotary is well-known for its mantra of 'service above self' and we have since presented to many other Calgary clubs to spread awareness about young-onset dementia and report on our successful pilot. We thank Rotary Centennial for their ongoing interest in how our community-based organization provides practical support to families.

SAIT Athletics & Recreation Partnership

Our heartfelt thanks to **Budd Brazier** at SAIT Athletics & Recreation for access to the Wellness Centre and exceptional staff who are always ready to make our day go smoothly. Campus life suits us just fine as we blend in with students and take advantage of LRT access to easily explore the city.

We enjoy a convenient home-base space and have discovered interesting campus features such as the Radio Broadcast station and the Green Building Technologies lab. We always delight in the tasty hot lunches created by the culinary students who welcome us at the 4Nines restaurant and, of course, in occasional treats from the Market Café.



The campus setting also brings back memories for two of our participants and some volunteers who are all SAIT graduates. Thank you to the SAIT community for helping us to reduce the stigma of dementia!

Centre for Aging and Brain Health Innovation (CABHI)

The [Centre for Aging + Brain Health Innovation](#) (CABHI) was our first major funder that facilitated the September 2018 YouQuest launch through their Spark Program for early-stage innovations.



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+ BRAIN HEALTH
INNOVATION
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Recognizing that services from the young-onset perspective were lacking, they got behind us to help demonstrate how and why the needs of families are different with this diagnosis at an earlier stage of life. CABHI helped foster our unique culture of participant self-determination and community-based support for families by funding our team, activities and nutrition plan.

Thank you to **Jonathan Suckling**, **Simon Cheesman**, **Rebecca Ihilchik**, and **Stacey Guy** at CABHI for your guidance and support. Read more about us in the [CABHI 2018-19 Annual Report](#).



Our individual donors are truly extraordinary ...

Whether it is a personal connection to dementia within one's circle or just a genuine caring for our YouQuest mission, there is nothing quite like individual donors who give a gift to sustain our unique services. These donor funds afford us much freedom to apply resources where and when they are needed most.

On behalf of our YouQuest families and our wonderful team, we thank each and every one of you for contributing to the resounding success of our first year in operation.

In 2020, we are gearing up to meet the demand for more service days from current and waitlisted families. We invite you to come along for the ride!

