

YouQuest Pilot: Evaluation Highlights

YouQuest creates community for Calgarians living with young-onset dementia (diagnosed under 65 years) and their families for active health and well-being.

Participants enjoy recreation and social interaction with their peers; care partners are typically still working and need peace-of-mind to manage their new reality.

If you have a brain, you're at risk of developing dementia!

At age 48, John McCaffery had to leave a career he loved because he “couldn’t figure it out anymore.” Historically well-organized at work, he was finding it hard to keep client information in order. He failed new software testing – a first for this “techie.” He was not thinking straight.

After extensive neuropsychological assessment, the devastating news was that John would never work again due to **frontotemporal dementia (FTD)**. Life turned upside down.



Without a career, John spent long hours at home by himself. Friends and neighbours were busy at work, Cindy was at the office, and their two kids (ages 12 & 17 at the time) were at school. Gregarious and outgoing, he missed the social aspects and challenges of his job, and his community connections as a coach, athlete and Rotarian. John and Cindy looked for **daytime support** but couldn’t find anything active or age-appropriate.

2018 Alberta Health Statistics for young-onset dementia (aged 40-64 years):

- 1419 people in Calgary Health Zone
 - 3890 people in Alberta*
- = 10% of those diagnosed with dementia

**Research suggests these numbers are underreported as the path and duration to diagnosis is part of the challenge.*

While some younger people with dementia already require supportive living or long-term care, many others are both interested and capable of engaging in the community given the right opportunities and resources.

There were 25 adult day programs in the Calgary area in 2018; none were specifically designed to promote active recreation for younger people with dementia.

Dementia isn’t just about the elderly

Tough to diagnose and incurable, young-onset dementia destroys the dreams and aspirations of men and women in the prime of their lives. Careers abruptly end. Income disappears. People become isolated. Loved ones and friends become care partners as families face a life-changing crisis without a safety net.

Filling the Gap

Ineligible for seniors’ benefits, and too young to gain value in programs for the elderly, people with young-onset dementia and their families have very limited access to the unique support they need. YouQuest is **a place to belong** that encourages active recreation and social interaction with peers in the community.

Active recreation with peers and family respite

In September 2018, YouQuest launched as a proof-of-concept pilot, to [narrow this service gap](#), operating one day/week as a daytime service.

Participants enjoy a full, active day in the community with their peers, giving a day of respite for care partners to manage work, family life and their personal health. Being seen as engaged members of society challenges the stigma for people with young-onset dementia, who don't want to be inactive, in care, or treated as elderly patients.

With recreation therapists and a team of volunteers, participants set fitness goals based on their interests, strengths, and abilities. Participants co-plan social, physical, and cognitive activities blending in at the SAIT Wellness Centre, on campus, and around the city. The group enjoys the outdoors, exploring the community, restaurant lunches, and live music with the YouQuest house band!

Participants share feedback about their personal needs and preferences with the team, which provides helpful insights about their cognitive challenges. They all say one of the best things about YouQuest is the camaraderie with others.

Care partners are thankful for finding reliable support not only for their loved one but with each other, and have built new relationships through their shared experiences. They're now asking for more YouQuest days, and more personal support to manage family needs.



*"YouQuest is my haven" –
Bruce, Participant*



*"YouQuest gives my husband purpose and normalcy;
it's the ultimate guilt-free day for me." – Daina, Care Partner*

Evaluation Highlights *(Detailed report with data results and analysis available on request)*

In a society desperately seeking innovation and capacity for dementia support services, YouQuest is [proactive](#), [cost-effective](#) and [inviting to families](#). At a high level, the pilot demonstrated that:

1. The 10 pilot **families unanimously confirmed** YouQuest offers a practical, relevant, and dynamic service, giving much-needed and full-day respite to unpaid care partners who have many roles and responsibilities.
2. Health providers need this **post-diagnosis resource** to help families better manage the years before an inevitable transition to long-term care. Across many disciplines, there are relevant collaborative opportunities to improve the delivery of support services to families.
3. YouQuest **reduces stigma in the community** and the **burden on the health system** by enabling otherwise healthy people to stay at home connected to their families. The therapeutic recreation and volunteer team provide support that preserves dignity and independence for the participant.
4. At the end of the pilot year, the **demand for this service** was reflected in a waitlist of 20+ additional families eager to access this active and appealing YouQuest service as funding and capacity permits.

Four Themes: “Listen to me, I’ll tell you what matters”

Participant families provided critical input for the pilot’s success. Four main themes emerged from the evaluation data analysis across all respondents. For participants in particular, but with direct and positive benefits for care partners and volunteers as well, the results were clear that YouQuest provides:

A sense of belonging and purpose ...
emotional support ... meaningful activity ...
and increased autonomy and confidence

Importantly, families asked for greater understanding that:

- Dementia at a younger age presents different needs than for seniors
- Persons with young-onset dementia can, want to, and need to, speak for themselves
- Supports need to be tailored to an individual’s particular diagnosis, family structure and abilities
- Care partners also need to be heard and supported, with consideration for their own circumstances

Future Focus – Scalable, Replicable

With sustainable funding, the YouQuest model is highly scalable and replicable in any urban or rural community recreation centre and requires three key elements to succeed:

- **Recreation therapists** that understand why young-onset dementia needs a unique approach;
- **Collaborative partnerships** to engage families in the facility and community; and,
- **A strong volunteer network** to facilitate and enrich participant choices and experiences.

Expanding Impact



By engaging **post-secondary students** from relevant medical and social fields in practicum roles, YouQuest increases awareness about young-onset dementia and its implications for families. Combined with more research specific to the young-onset perspective, this knowledge translation will ensure future health providers create services that better match the needs of younger families.



Volunteer engagement research reveals that people are asking for meaningful roles to provide a sense of purpose from investing their time. Flexible assignments and a connection to a community of people who care about helping others are also key factors influencing people to get involved. YouQuest hits the mark for each element, with the added health benefit of engaging volunteers in an active role for their own health.



Recreation therapists are trained to help rehabilitate people back into their community after illness or injury. While a dementia diagnosis is terminal, this non-medical YouQuest approach to normalizing daily life goes a long way toward improving the immediate outlook for families. Research confirms that incorporating music and significant physical activity into each day boosts cognitive benefits – to everyone involved.



YouQuest is unique for many reasons – it is active, full-day, and based on participants making their own decisions. Perhaps the most intriguing feature is the **live band of volunteer musicians** that engage with the group almost every week. From percussion to word-finding skills, the age-appropriate music resonates with participants, families and the entire team to offer cognitive and emotional interactions by sharing the experience.

*“We get as much out of playing at YouQuest as the participants do; it’s about the love of music.”
– Kelly, Band Leader; Recruiter of Volunteer Musicians*