

The Importance of Social Programs for People Living with Young Onset Dementia



Romina Oliverio
Alzheimer Society of Toronto
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“The limited Alzheimer's programs available are for seniors. I think it's probably the most lonely disease on earth,” she says. “I used to be very social. Now, I spend my days in the house. I feel very trapped here.”



Andrea Bridge, 50 years of age
The Hamilton Spectator, Feb 14 2019

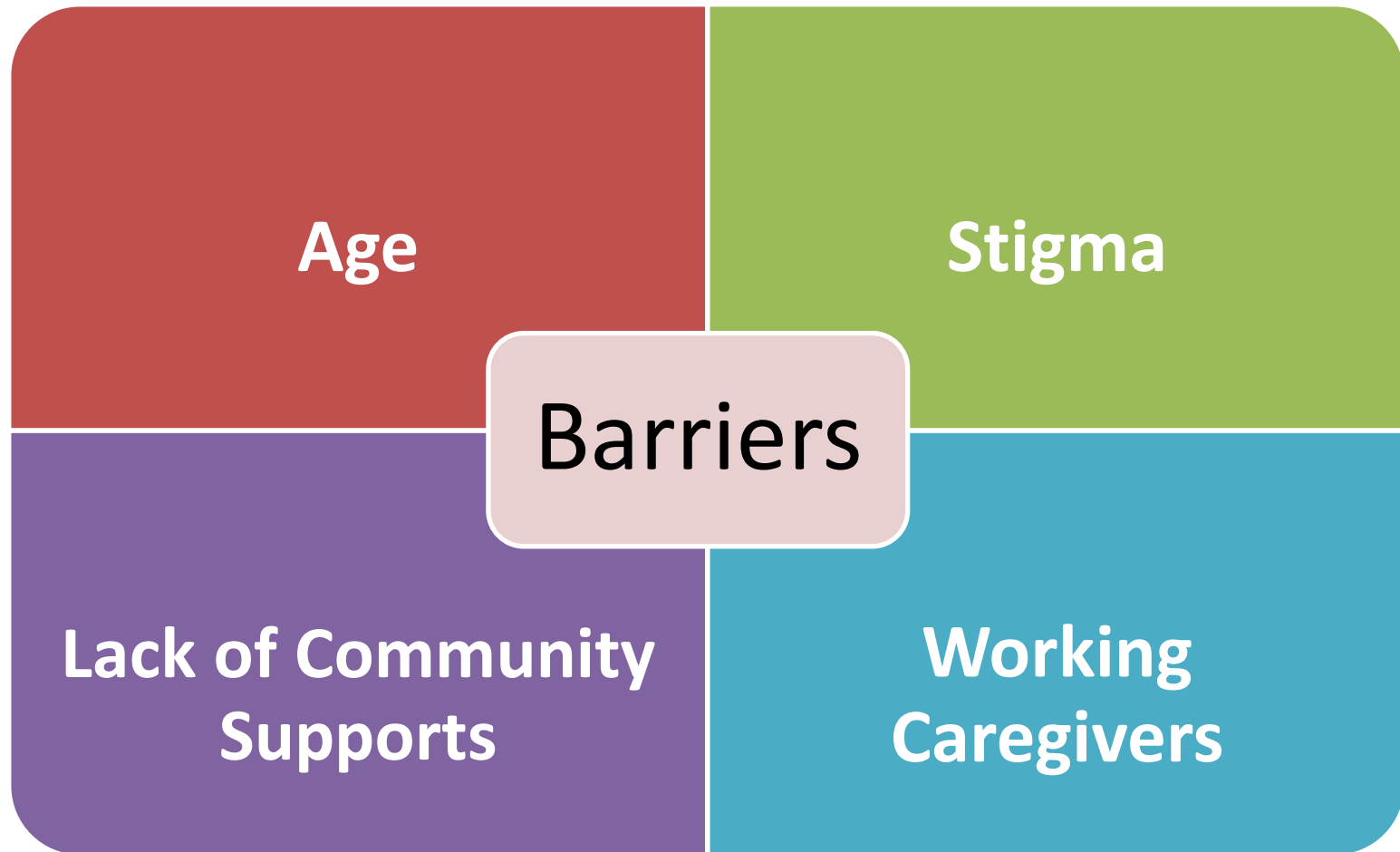
A Case for Support

YOD comprises 2 – 8 % of all dementias

Services typically geared towards elderly

Estimated 16,000 Canadians under the age of 65 are living with dementia

Barriers to Accessing Services



Impact on the Person with YOD

- Fight for Diagnosis
- Issues of Selfhood
- Feelings of Isolation
- Change in Roles
- Financial Issues

Unique Needs

Seek Normalcy

Maintained Status Quo

Honour Identity

Meet Colleen

- 60 years old
- Dx: Alzheimer's disease
- Former baker
- 'Alone'



Meet Eric

- 39 years old
- Dx: FTD
- Background in IT
- Lives with wife (carer) and twin boys



Introducing The Boomers Club

Free weekly program

Physical activities, cognitive stimulation,
creative therapies

Tailored programming based on abilities,
needs and interests

The Boomers Club

Client Driven Programming

Post-program check-ins and ongoing support

**Facilitated by Community Partnerships
Manager and 4 volunteers**

First Year Outcomes

Facilitated three 8-week sessions in one year; program is now offered year-round

Numbers grew by 55% in a year with referrals coming in from other agencies

Incorporated intergenerational component

Program Eligibility

Diagnosed with YOD

Client would benefit from socialization, community engagement and recreation

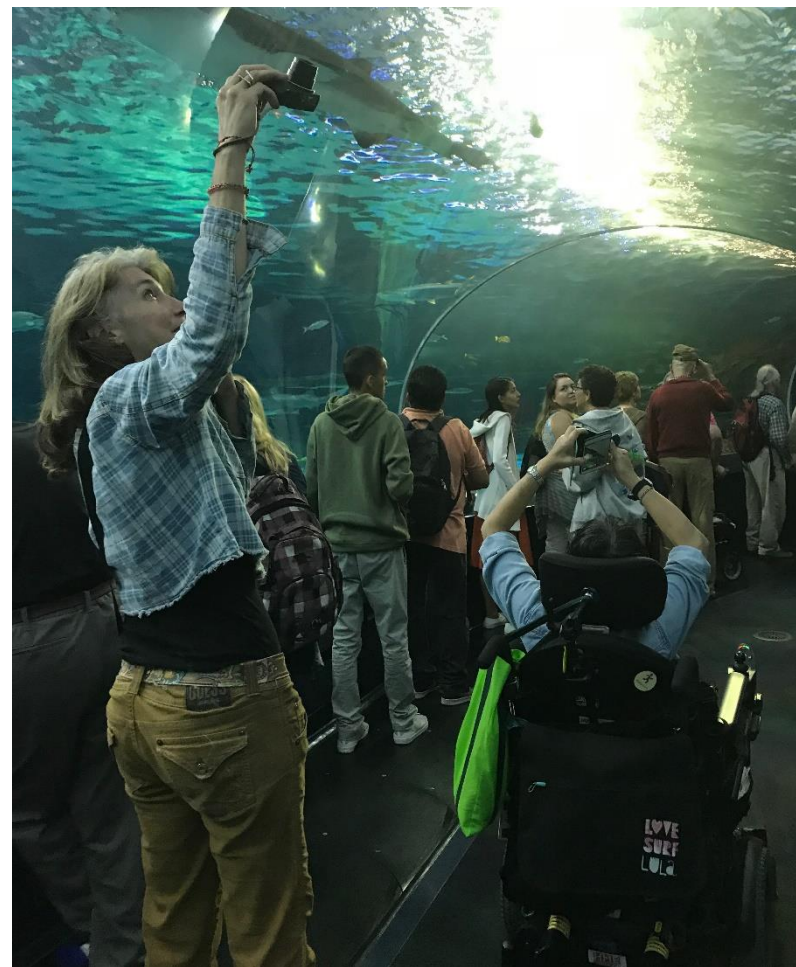
Client is independent with ADLs

Meet Boomers

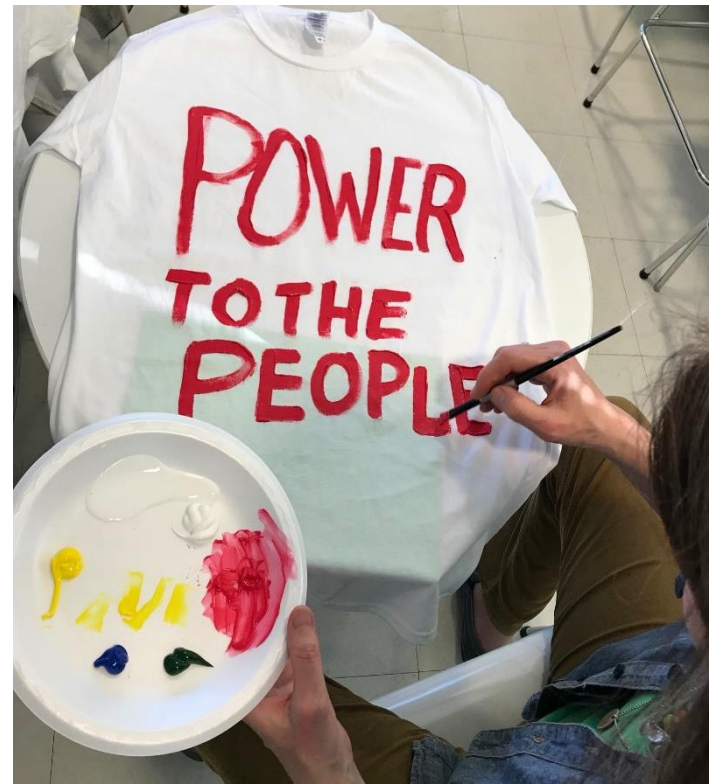


New Experiences





Creative Expression





Culinary Experiences





Celebrating Traditions



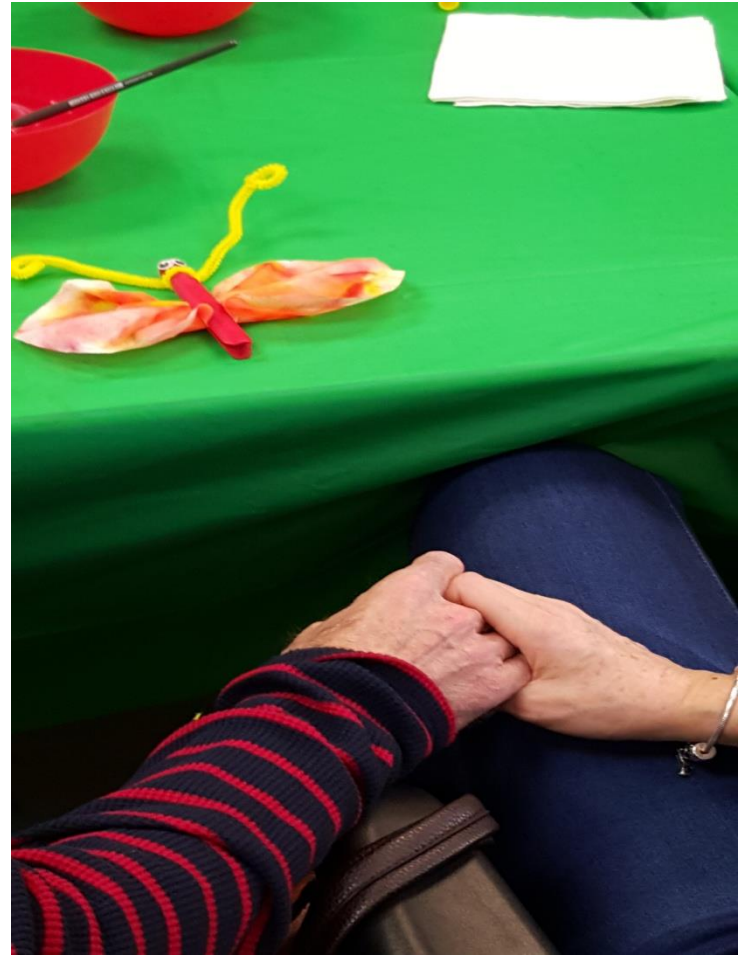
Physical Activity



Cognitive Stimulation



Promoting Family Intimacy



Community



All Ages



Family



Benefits for PLWD



Consistency and Routine



Cognitive and Physical Stimulation



New Experiences



Socialization & Community

Benefits for Caregiver

- Community
- Respite
- Peer Support
- Option to Attend Concurrent Training or Support Sessions

A Sense of Purpose

- Volunteering Roles
- Task Distribution
- Inform the Programming
- Ambassadors for the YOD Community

Lessons Learned



Be Flexible



Engage clients in programming ideas



Seek regular feedback



Normalize the environment

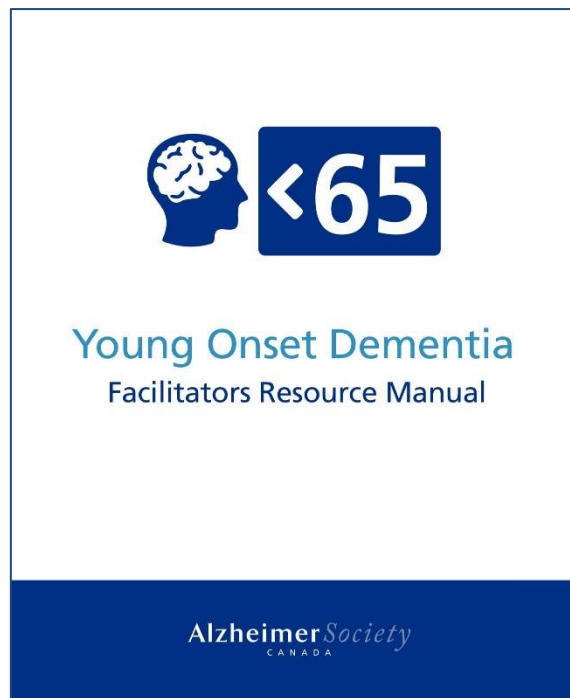
Pilot: YOD Adult Day Program

- Partnership with Alzheimer Society of Durham Region and Alzheimer Society of Peterborough, City of Kawartha Lakes, Northumberland & Haliburton Counties
- Program offered twice a week; funded for 10 spots
- Pilot runs January 2019 to March 31, 2019

Across The Country

- Paul's Club, Vancouver BC
- Young/Early Onset Club (YODA), Waterloo ON
- Alzheimer Society of Kingston, Frontenac, Lennox and Addington YOLD Group, Kingston ON
- Alzheimer Society of York Region Adult Day Program, York ON

ASC YOD Facilitator Resource Manual



<https://alzheimer.ca/en/Home/About-dementia/Dementias/young-onset-dementia>

www.alz.to

What Clients Say

“This group has a great benefit for me. I feel more grounded and happy.” – Lynda, PLWD

“I come here to make friends – I’m lonely outside.” Rose, PLWD

“It never felt like 2 hours of volunteer work - more like 2 hours for me to play and dance with some of the most vibrant, resilient people in the city!” Lauren, volunteer

“I can take time by myself and have a coffee or run errands. This is such a lifeline for me.” Marie, caregiver

THANK YOU

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