



November 9th, 2016

The Ontario Dementia Advisory Group (ODAG) is a group of Ontarians living with dementia. Our mandate is to influence policies, practices and people to ensure that we, people living with dementia, are included in making decisions that affect our lives.

ODAG Overview

Forming in the Fall of 2014, we have created a unique independent structure that places our Members at the center with supporting organizations around us. We work in partnership and have adopted a collaborative approach. This has been shown to be highly successful in promoting the voice of people living with dementia – not just in Ontario, but on a national and international scale. Our opinion is regularly sought out by a variety of different types of organizations who are seeking the "lived experience" perspective.

Membership

Currently, free membership is open to all people living within Ontario with dementia. We have approximately 30 members including five Board Members. Our growth strategy plan anticipates our membership growing by 500 members over the course of the next 18 months. Through the use of some of our partners programs, projects, committees, etc., we believe we will have the mechanisms in place for February 2017 to begin this important and strategic growth phase.

Operating Area

ODAG uses video conferencing technology which allows us to connect with members all over Ontario, regardless of geography.

Finance

Our Group has its own budget. Alzheimer Society of Haldimand Norfolk is responsible for book-keeping and auditing. There is no financial liability for ODAG board members. Board or a delegated finance/fund-raising subgroup will be fully involved with making funding applications on behalf of the Group.

Technologies

ODAG prides itself on our innovative usage of technologies to help in enabling the inclusion of people living anywhere in Ontario. Using Zoom Technologies we host meetings for our members, partners and guests. The ability to not only hear but also to see people makes an incredible difference for people with dementia to actively participate. It is easier for us to follow the conversation, stay focused, provide feedback, enjoy socialization, etc. Although, ODAG provides a free Zoom license for our members, they are required to have the equipment and internet connection to participate.

UN CRPD Framework for Advocacy

ODAG fully endorses the concept of disability rights principles. We have been actively lobbying to ensure that Ontario and national dementia policies reflect the international treaty of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Canada has accepted by its signing and ratifying the CRPD that it applies to all levels of governments: federal, provincial and municipal. All are bound by the CRPD. We firmly believe that all persons with dementia, regardless of age, stage, or place of residence, have a fundamental right to help define and feel included in their communities. Recently, ODAG included access to the CRPD as one of our recommendations in testimony before a committee of the Canadian Senate.

Regards,



Mary Beth Wighton
Chair
www.odag.ca

Appendix A

ODAG Committee Memberships

- Committee Member, Canadian Dementia Working Group - Task Force, Consortium of non-governmental disability organizations in Canada
- Committee Member, AGE-WELL SIP Advisory Group, University of Waterloo, Emmetros Ltd
- Co-Chair, Dementia Friendly Communities Ontario, Alzheimer Society of Ontario
- Board Member, Dementia Alliance International
- Committee Member, Ontario Retirement Community Association (ORCA) Dementia Program Development
- Co-Chair, Eli Lilly Canada – Alzheimer Support Services Advisory Meeting
- Committee Member, LHIN4 Dementia Network Committee - Client Experience Adviser, Alzheimer Society of Brant, Haldimand Norfolk, Hamilton and Halton
- Committee Member, Canadian Dementia Priority Setting Steering Group, Toronto Rehab and James Lind Alliance
- Committee Member, Ontario Dementia Capacity Planning Clinical Advisory Committee
- Committee Member, Dementia Program Development Advisory Committee, Schlegel Villages Long-Term Care and Retirement
- Ontario Brain Institute (OBI) Patient Advisory Committee
- Committee Member, Ontario Dementia Strategy Healthy Brain Working Group, Ontario Ministry of Health & Long-Term Care
- Committee Member, Ontario Dementia Strategy Advanced Stage Working Group, Ontario Ministry of Health & Long-Term Care
- Committee Member, Ontario Dementia Strategy Early Stage Working Group, Ontario Ministry of Health & Long-Term Care
- Committee Member, Ontario Dementia Strategy Moderate Stage Working Group, Ontario Ministry of Health & Long-Term Care
- Committee Member, Ontario Dementia Strategy Moderate Stage Working Group, Ontario

Ministry of Health & Long-Term Care

- Committee Member, Dementia Strategy Research and Innovation Working Group, Ontario Ministry of Health & Long-Term Care
- Committee Member, Ontario Dementia Strategy Advisory Group, Ministry of Health and Long Term Care
- Committee Member, Inclusion Task Force, Alzheimer Society of Ontario

Appendix B

Presentations

(2016). Dementia: Together on the Journey. Trinity Village Well-Being Series 2016, Waterloo, Canada

(2016). Patient Perspective. Senate of Canada, Ottawa, Canada

(2016) Panel. Person Living with Dementia. 2nd Annual Canadian Conference on Dementia Care, Toronto, Canada

(2016). Creating Space at the Table: Recognizing the Rights of People with Dementia. Care at Home at Home for Individuals Living with Dementia, Canada. BrainXchange.

(2016) Living with Young Onset Dementia – Let's have a conversation! Alzheimer Society of Canada & BrainXchange

(2016) Dementia: From Global Attitudes to Retirement Communities. ORCA Summer Conference, Blue Mountain

(2016) Consent and Capacity in Dementia. North Simcoe Muskoka Dementia Network Conference

(2016). Patient Perspective. Canadian Consortium on Neurodegeneration and Aging, Ottawa, Canada

(2016). Patient Perspective. Symposium on Research Involving Persons with Dementia, Toronto, Canada

(2016). "Nothing about them without them". First Link Conference, Toronto, Canada