



Mary Beth Wighton  
ODAG Board Member  
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February 10<sup>th</sup> 2016

Re: People with Down Syndrome & dementia - involvement in the Ontario Dementia Strategy

Canadian Down Syndrome Society  
Address: Suite 103 - 2003 14 Street NW, Calgary  
AB, Canada, T2M 3N4  
(sent via email : <http://www.cdss.ca/>)

Hello:

My name is Mary Beth Wighton. I am 49 years old and have a medical diagnosis of probable Frontotemporal Dementia. I am a Board Member of the Ontario Dementia Advisory Group (ODAG) <http://www.odag.ca/>

ODAG is busy working with the Ontario Government on the creation of a provincial dementia strategy. This strategy will impact over 200,000 people who currently have this disease. The numbers are still climbing. It is also worth noting that Canada is the only G7 country not to have a national dementia plan.

You may be well aware that overall the incidence of Alzheimer's disease in the Down syndrome population is estimated to be three to five times greater than the general population (NDSS, 2009).

I am contacting you as I believe it is imperative that the Down Syndrome community in Ontario has the opportunity to play a role in the shaping and implementation of an Ontario dementia strategy plan. People with dementia, regardless of any additional type of disability they may have need to stand up and make our voices heard. This means we need to work together and reach out to anyone who may have dementia and help educate them about this disease. In addition, we need to provide a safe forum for us to participate in providing direct feedback into the development of the Ontario dementia plan.

Our work crosses many different types of companies and government agencies. For instance, we are partners with: Alzheimer Society of Canada; Alzheimer Society of Ontario, Ministry of Health and Long-Term Care; Facebook Canada; University of Waterloo (MAREP), Mindset Centre for Living with Dementia, Center for Education and Research on Aging and Health (CERAH – Lakehead University), Zoom Canada, etc. These relationships are key in helping us stand up and have a voice. We are grateful for them.

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# **ODAG**

The reason I am contacting you is to ask for your help in reaching out to people in Ontario with Down Syndrome who also have dementia. ODAG has exclusive membership for those with dementia and I am hoping to add members to its group. We help in providing opportunities for people with dementia to be involved in different projects, initiatives, media events, and of course – feedback on the development of the Ontario Dementia Strategy.

ODAG looks forward to your thoughts on this important topic and appreciates feedback you may have for us. We welcome the opportunity to discuss this on the telephone at your convenience.

Best Regards,

Mary Beth Wighton  
ODAG Board Member

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