

Ontario Dementia Advisory Group

Meeting Minutes

Wednesday, February 4th, 2015

1:00 p.m. – 3:00 p.m.

Present:

ODAG members – Brenda Hounam, Bill Heibein, Bea Kraavenhof, Maisie Jackson, Mary Beth Wighton, Elaine Wiersma, Nancy Rushford, Gina Bendo, Delia Sinclair Frigault, Lisa Loiselle

Guests - Parliamentary Assistant Indira Naidoo-Harris, Samantha Latch

1. Thank you to AS Niagara	CEO of Alzheimer Society of Niagara welcomes guests on behalf of the chapter.
2. Welcome and outline of Agenda and Process for the meeting	Delia welcomes guests on behalf of the ODAG members.
a. Roles of persons during the meeting b. Overview of materials	Delia will facilitate meeting. Nancy will keep an eye on the process. Lisa will take minutes.
3. Introductions	<p>Went around the table and introduced each other:</p> <p>Brenda – advocate and spokesperson; found true passion after diagnosis Bill – diagnosed in Jan 2000; taking good medication and is still able to self-manage Bea – diagnosed in 2000; mother of 4 children and a nurse, so has multiple perspectives; personality has changes; passion is for speaking for those who can't speak for themselves Maisie – diagnosed 3 years ago; been hard; mother, grandmother and sister also had Alzheimer's disease Mary Beth – 48 years old and living well with dementia; the ODAG group can conquer everything; mom is in end stage dementia; young family; everyone has a different perspective</p> <p>Support people introduced themselves – Elaine, Nancy, Gina, Delia and Lisa</p> <p>Indira – spent her time as a journalist, news anchor and producer; motivation was to improve society; was easy to point out problems but not work on solutions. Ran in 2011 election and lost. Was encouraged to run again and won June 2014. She is very passionate about her new portfolio to help create the structure for a dementia strategy.</p> <p>Samantha – event and outreach in the Milton office.</p>
4. Why the Ontario Dementia Advisory Group came together (Brenda)	Brenda - Passionate group and wanting to make a difference and want to speak for those who can't. For many years persons with dementia were not

	<p>heard. Today is the start of seeing the light. Excited about where the journey will go.</p> <p>Bea – ODAG members are meeting each other for the first time. ODAG members thought long and hard about the points being presented. There is no self-pity in this room. Our time is so precious and we have to use it for the good – the moment has got to be now, not 50 years from now. Don't walk away from us.</p> <p>Bill – information is an accumulation from across the province.</p>
<p>5. Overview of mandate regarding dementia strategy – Indira</p>	<p>Do not need to convince her about how difficult and challenging - she is already in the door. She feels it is the right direction for the government. Thanks for sharing stories.</p> <p>She is here to listen and find out how she can assist everyone. It is her job and is very committed to be the voice in government. Dr. Hoskins and the Premier will work and develop comprehensive strategy for PWD and PIC.</p> <p>Indira's father in law was diagnosed with dementia - watched him as he progressed through the disease.</p> <p>It is time for everyone to work together and raise awareness about how devastating the disease is.</p> <p>There is an immeasurable toll – the cost on family and friends is devastating. The government understands the magnitude. She works with a minister and premiere that understand the dynamics.</p> <p>There is a plan to support persons with dementia and their families. Will provide support for those living in their home</p> <p>Government has improved but are willing to move forward.</p> <p>We will work across government to expand support to caregivers and families:</p> <ul style="list-style-type: none"> - Look at research and bring it under one umbrella to develop a strategy that will be forward thinking and bring it into a strategy that will work - how can we better design long term care for those with specific needs - Support the roll of 25 memory clinics across Ontario <p>She is committed and wants ODAG commitment to help – we need to work together.</p> <p>How are we going to plan and work together for the storm that is coming We need to come up with results and not just words.</p> <p>Indira wants to be the voice of those with dementia.</p>
<p>6. Engagement process</p>	<p>Brenda – time is of the essence. The process needs total inclusion of people with dementia in every step of the way. Anything that is being developed, programs or strategies, can only be developed if people with dementia are included – cannot be a token person at the table.</p> <p>Indira – Agreed. Need to engage those who are living with dementia and their families.</p> <p>Wants to engage as many people as possible so that we move forward as efficiently as possible.</p>

	<p>Indira does not want to delay this strategy, but wants to get it out quickly so that people are living better.</p>
<p>a. Why people with dementia should be involved:</p>	<p>(MB) We want Indira to take away the 3 things in why people should be involved.</p> <ul style="list-style-type: none"> i. We are the experts ii. Doing WITH, not FOR iii. Nothing about us without us: we need to be central <p>Brenda – Partners in care do not always work with, but for people with dementia – even though it is with the best intentions. Want and should be independent for as long as possible. Partners in care don’t always know what is best.</p> <p>Bill – the stigma does not have to be as it appears. Many have the capacity to participate. Don’t count us out.</p> <p>Bea – with better medication and care, we can do things for ourselves for as long as we can. When making legislation make sure there is good representation by people with dementia and let them have a say. We can still live meaningfully, and can help produce the actual legislation.</p> <p>Indira – we are all a part of this. There will be more people diagnosed and it could be me living with a dementia – we are all in this together.</p> <p>MB – ask yourself: where does a person with dementia sit. Are they equal to other stakeholders? Where are you putting us on the list? Ensure people with dementia are on the list, and on the top of the list of stakeholders.</p> <p>Brenda – encourage a change of language “suffering” – it can be demeaning. We don’t change as a person from one day to the next after diagnosis. Need to be positive in our approach so it is not depressing and people are not depressed. People fall in to the stigma of the disease.</p> <p>Indira – society only thinks about end stages. Society needs to be educated about the disease. Her experiences go back to the time she was a teenager.</p> <p>Maisie – When diagnosed she thought it was the end. Closed herself in. Need more funding to help people. Alzheimer Societies need more funding to help more people with dementia.</p> <p>Bea – There is a 5 year waiting list for an apartment. When it comes up, the Alzheimer society of Oshawa does not have programs to support her. So she is going from a chapter that is the top notch to a chapter that has no support for people with dementia. No funding support available from the chapter. Need funding to help people to live on their own. Funding is only for care partners and not for people with dementia.</p> <p>Nancy – Alzheimer societies are not equal in the amount of funding they offer or the programs they offer.</p>

<p>b. How to engage people with dementia in this process:</p> <p>i. Existing groups across the province ready to be engaged</p> <p>ii. Practical Considerations moving forward (how to facilitate ongoing involvement)</p> <p>c.</p>	<p>These are things to keep in mind practically when Indira has consultation meetings around the province with people with dementia:</p> <p>Brenda – People with dementia draw strength from each other. Better as a unit rather than individually. People with dementia become yes people because if you disagree, people will walk away thinking you are being difficult.</p> <p>MB – was interviewed for an article and was not given the opportunity to read the article before it went national. She contacted the writer and was shut down probably because she told the writer that she was not happy with the negative tone of the story. Everyone has a different diagnosis and are in different phases – not just Alzheimer’s disease, there are other types of dementia as well.</p> <p>Indira – need to make it clear that the time is now and she needs to convince people that it is very urgent and a serious matter.</p> <p>Brenda – stating the reality is a necessity, but it is what other labels that everyone else is putting on us. Those other labels are what is damaging to people with dementia.</p> <p>Indira – that is why education is important. One piece of the strategy is also to provide education for partners in care to give them tool and be educated about how to care and support people with dementia.</p> <p>Brenda – people with dementia are excluded from the medical process. It is the only disease like this. Some people think they are doing things right, but they are not – some of these are the Alzheimer society chapters. They are the last ones to come to people with dementia and ask their opinion.</p> <p>Maisie – People have changed as a result of their experience in the support groups at the Alzheimer society.</p>
<p>7. 10 Recommendations for an Ontario Dementia Plan</p>	<p>Mary Beth - Philosophy – nothing about us without us.</p> <p>People with dementia and partners in care were asked what is important to them. This is an example of a group of people and does not represent the voice of those throughout Ontario.</p> <p>Other regional dementia advisory groups exist in thunder Bay, Hamilton, K-W, Peterborough, Sudbury and Niagara – not all connected through the Alzheimer societies.</p> <p>How is ODAG going to work with regional advisory groups? Anyone that wants to can contribute and channel info from regional groups through to the provincial group. Can access information from all regional groups through the provincial group. That way we can engage many different groups (aboriginal community) and cultures. People will feel more comfortable working in their own communities and sending information to the provincial group.</p>

	<p>Elaine – there is a gap in the plan – there needs to be an emphasis on education for people with dementia, not just partners in care.</p> <p>Nancy- Need to be efficient in the engagement strategies.</p> <p>Indira - Consultation process has not started yet but there needs to be consultation across the province. Cultural differences are very important.</p> <p>Brenda – people need to feel comfortable to relaying information.</p> <p>Indira – maybe a handbook for PWD for resources.</p> <p>Mary Beth – there are a lot of resources out there and we should try to pull everything together rather than reinventing the wheels.</p>
<p>a. Review existing work (MB)</p>	<p>BUFU guides are a resource – but they need to be translated so they are more accessible – Currently there are 12 guides published.</p>
<p>8. Moving forward together: Net Steps</p>	<p>Indira - Still early stages in the development of a strategy.</p> <p>Work plan is being formulated that includes a timetable on who, when Indira will talk with.</p> <p>We need to keep having these conversations.</p> <p>Indira will give us her contact information – Her executive assistant Samantha will be our contact.</p> <p>Sam will figure out next steps for our team.</p> <p>We will share the minutes of this meeting with Indira.</p> <p>Peers mentors – need to create those connections for people with dementia.</p>