

Meeting Notes
Monday November 24, 2014
11:00 a.m.

Present: Delia Sinclair, Maisy, Bea, Nancy (Alzheimer Society of Niagara), Lisa Loiselle, Mary Beth Wighton, Brenda Hounam, Bill Heibein, Phil Caffery, Gina Bendo

Nancy Rushford-Program Director at the Alzheimer Society of Niagara

Maisy- connected with the Alzheimer Society of Niagara

Bea- connected with the Alzheimer Society of Niagara

Gina—Alzheimer Society of Niagara

Delia- Alzheimer Society of Ontario, Public Policy and Advocacy

Phil- Alzheimer Society of Ontario, Public Policy and Programs

Lisa- MAREP, University of Waterloo

Brenda- Paris, Ontario, spokesperson and advocate

Mary Beth Weighton- Southampton, advocate, FTD,

Bill Heibein- advocate and spokesperson,

Elaine- Centre for Education and Research on Aging & Health, Lakehead University

1. Review of meeting notes from November 10, 2014

- Bottom up and top down approaches
- Being proactive rather than reactive
- Understanding more about policy and government (Delia's primer)
- Looked at the Scottish Dementia Working Group as a model; the Dementia Alliance International group

2. Discussion around the structure of the meetings. All agreed that agendas are important to help keep us grounded. It helps keep us in focus and on track. To set the agenda, we will set aside 10 minutes at the end of the meeting to determine the agenda for the next meeting.

Facilitation—there was no preference in particular on the structure of facilitation and who will facilitate. Nancy will continue to facilitate for now. We will have a process person who can help us remember to pause at certain times, to ensure that everyone has had a chance to talk and make sure everyone is on the same page. The process person can also help us to remember to say our names first on teleconference before talking.

Sending out meeting notes and agendas—we will aim to send them out approximately 2-3 days prior to the next meeting (although ideally about a week before the next meeting). Lisa has a student who can help support us in taking meeting notes. The student will send the meeting notes and agenda to Elaine. Anyone that has other documents to distribute can send them to Elaine who will collate everything and send it out in one package. Elaine will send a reminder after the meeting with “action items” prior to the official notes being sent out.

As we sketch out our framework with our mission and vision, we can put some roles and responsibilities around that. The supporters can provide access to new information, promotion and awareness, etc.

3. Delia has exciting news from ASO. In meetings with the Ministry of Health and Long-Term Care and the Ministry of Seniors, they have announced that they will be moving ahead with a comprehensive Ontario Dementia plan. They have agreed to work with ASO to have people living with dementia at the centre of the planning process. The parliamentary assistant to the Minister of Health has in her mandate to work with people living with dementia. This meeting will be planned in January. We want to get in before they start the planning process internally.
4. In preparation for January, Delia will send around a document that they have outlining the other plans internationally. There are different plans across the

world, but only Scotland to our knowledge has actually engaged people living with dementia in their plan. We need to know more about this. Elaine will contact the SDWG to ask about a plan and how they were involved. Mary Beth will contact Kate Swaffer in Australia to find out what is happening there. We need to set a foundation for our meeting in January. We will also look at guiding principles. Elaine will circulate the Scottish Dementia Working Group Charter of Rights for People with Dementia and their Carers.

5. There was great discussion about the name of the group. Two names were proposed: Ontario Dementia Advisory Group and Ontario Dementia Working Group. Advisory Group is used in government circles (eg., patient advisory committees) so it is language that the government knows. However, Working Group connotes getting your hands dirty, doing more than advising, really doing the work. Using “working group” gets it past traditional tokenism and helps to position us as being a part of the planning, not just as “yes” people. Working Group also ties us in with international movements (Scottish Dementia Working Group, European Dementia Working Group) and local movements (North West Dementia Working Group). Brenda commented on how the politicians are very nice and talk to you, but then quickly forget what you spoke about. In the poll, 3 people wanted Ontario Dementia Advisory Group and 2 wanted Ontario Dementia Working Group. We will move ahead with calling ourselves Ontario Dementia Advisory Group unless the group changes their mind before the next meeting.
6. Phil asked for volunteers who would be interested in becoming spokespeople for ASC’s campaign in January. Those who are interested can contact him.

7. Future agenda items: Planning for January by looking at existing dementia plans (Delia will provide a summary) and by looking at the guiding principles of the Scottish Charter of Rights for People with Dementia and Care Partners.

Action Items:

- Elaine will send out the Scottish Dementia Working Group Charter of Rights for People Living with Dementia and Care Partners
- Delia will provide review of existing dementia plans to provide a foundation of knowledge
- Elaine will contact the SDWG to ask about the way that they developed their national plan. Mary Beth will contact Kate Swaffer from Australia about how they are developing their national plan.

Next Meeting:

Monday December 8, 2014
11:00 a.m.-12:30 p.m.

Call-in number:

1-888-892-7292

Passcode: 0190178#

<--- Please remember the # sign, it is very important!

You will be in conference.