

Meeting Agenda
Monday November 10, 2014
11:00 a.m.

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

1. Review of meeting notes from October 24, 2014

Skype might not work. We need to have some options to integrate the phone and video. Lisa and Elaine will look into some options. Look into what platform the Dementia Alliance International uses.

Nancy Rushford-Program Director at the Alzheimer Society

Maisy- connected with the Alzheimer Society of Niagara

Bea- connected with the 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

2. Delia—ASO has been focusing on pushing the Dementia plan with the provincial government. There is some investment in long-term care under Behavioural Supports Ontario initiative. Delia is identifying the different work that the government is doing that is aligned with a possible dementia plan. In the midst of a series of meeting with the Minister Responsible for Seniors and the Ministry of Health. Both of those ministries have been

tasked by the premier with enhancing dementia support. ASO wants to frame that work rather than doing what they want, to push for an Ontario Dementia plan. We need to externally push the government and identify who is in charge of what and who should be targeted. CCAC is cutting services, focusing on high needs populations at the expense of lower needs populations. Part of this reason is because of cost. We need to go to that person who made that decision to tell them that this is unacceptable.

3. Scottish Dementia Working Group—influencing public policy that impacts the lives of people living with dementia and their care partners. We need to have a plan that is not reactive, but one that is proactive. We need a framework and strategy that can coherently influence public policy. We have to be unified. One of the purposes of this group would be for people to know where to go to identify these things that are happening so that we can become the collector of all of these things, and take steps to have a plan to put in place to address them. There's lots of work on prejudice and stigma that we're all working on. But the gap is the understanding of the public policy that is happening right now. If we can be a base of information, that would be good. We have to pull all that information in because all of us are not knowledgeable about what is happening with our health care system. We can become that go-to group when people are aware of something. Delia can put together a public policy primer for the group to get a standing of where we are in Ontario. You can only spread yourself so thin and it's all important. The Alzheimer Societies hear about things, but people living with dementia don't know. There are so many layers of communication. We need to look at what the communication channels are so that we don't have to react. What part of the process engages dialogue in some of these answers?

4. I don't think that if we are going to be a political body, there has to be a good mix of areas to focus on. The political area is one area. The vision of communication, information and money can be part of the public policy discussion. We can get a handle on the public policy and then influence some of those different areas. The public policy is quite important. But we shouldn't overlook the grassroots either. There should be a meeting in the middle. We can't wait to get public policies changed, but we can get some changes at the grassroots. Waiting for political change takes a long time. For example, age-friendly communities are important because it impacts our day-to-day lives.
5. Mary Beth mentioned the Scottish Dementia Working Group and their Constitution. Below is their constitution:

“Our Constitution commits the Working Group to:

- **Being the voice of and for people with dementia nationally and locally**
- **Influencing public policies that impact on the lives of people with dementia and their families**
- **Promoting improved provision of services in Scotland**
- **Developing information, education, awareness and training in the field of dementia**
- **Reducing the prejudice and stigma attached to dementia”**

6. How do we find the energy for both the bottom-up and the top-down initiatives? The grassroots initiatives benefits are being able to get more peers involved, and understanding what advocacy is all about. Encourage the people living with dementia in advocacy. We are not going to make change until we have a large voice. It means opening up to sharing what it means to live with dementia. We have to encourage people at a comfort level where they're willing to start out.

7. The Bobcaygeon Dementia Friendly Communities initiative was really great.

Elaine can send around the Global News link.

[\[http://globalnews.ca/video/1596011/living-with-dementia-pt-4-making-communities-dementia-friendly/\]](http://globalnews.ca/video/1596011/living-with-dementia-pt-4-making-communities-dementia-friendly/) Is this a focus that we need to concentrate

on? Messaging, education, energy, etc. People living with dementia are willing to participate in these kinds of initiatives. The Alzheimer Society of Niagara advisory group started with the Alzheimer Society fundraiser but branched into the community sector. There is a passion for this. It is very impactful. Brenda's experience: by declaring that we have dementia and announcing it when we went into the stores, we found it made our lives easier. We were recognized and our lives were easier doing banking and everything else. Maisy is going to contact one of our councillors to see if we could do the sticker and information like Bobcaygeon with the umbrella. Elaine will send the link for the summary of the Dementia Friendly Communities report as well as the presentation slides.

http://www.rethinkingdementia.ca/uploads/2/5/8/3/25838663/dfc_report.final.pdf [Dementia Friendly Communities Report]

8. We will design a framework for this group looking at the model of the SDWG and the Dementia Alliance International. Mary Beth will give information to Elaine. Elaine will send this link and pull together the information.

9. Schedule a meeting with Bobcaygeon once we have more a base and framework once this group knows where they want to go.

10. Roles—Elaine will be the information role—gathering things together, meeting notes, etc. Lisa and Nancy will help facilitate. Delia will be the conduit to the ministry and policy related discussions as well as ASO.

Action Items:

- Mary Beth will send information on the mission/vision/aims/objectives of the Scottish Dementia Working Group and the Dementia Action Alliance to Elaine
- Elaine will circulate the link to the report by Moira Haggarty on Dementia Friendly Communities along with the Powerpoint slides from her presentation on Dementia Friendly Communities for the North West Dementia Network presentation in October.
- Elaine will send the link to the Bobcaygeon Global News segment.

Next Meeting:

Monday November 24, 2014

11:00 a.m.

Call-in number:

1-888-892-7292

Passcode: 0190178#

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

You will be in conference.