

Provincial Advocacy Group—First Meeting!
Meeting Notes
October 24, 2014 1:00-2:00 p.m.

- Nancy Rushford, Bea, Maisy, Bill Heibein, Elaine Wiersma, Lisa Loiselle, Delia Sinclair

Introductions:

- Nancy Rushford, Program Director @ Alzheimer Niagara; happy to get the discussions going, need for advocacy group; OT by background
- Elaine Wiersma, professor at Lakehead University's Centre for Education and Research on Aging & Health;
- Bill Heibein—retired accountant, diagnosed in January 2000; met Elaine and became involved
- Maisy—diagnosed last year; put on some medication and feel better; enjoys her group sessions; looking forward to being on our group
- Bea—diagnosed around 2000; originally with Alzheimer's but they're not sure now—dementia of some sort; nursing as an RPN

This would be the first advocacy group in Canada of only people living with dementia. What do we do from here? What is our vision and what would we like to see? Related to dementia? Health services? Public perceptions?

Changing perceptions:

- Wouldn't it be great to have people have a change in their perception of what dementia is?
- When people who have a diagnosis are involved in panels, discussions, before the public and medical people, where they can see that we are still doing well, it can change perceptions
- I think it would be wonderful to get something going to get our voices out there to hear what we can contribute, what we can do for other people.

Political Advocacy:

- It would be awesome if we could get politicians to respond to legislation that we would like. Somebody has to try.

Delia—Alzheimer Society of Ontario has conducted a series of meetings with Ministry of Health and Long-Term Care, staff, Minister responsible for seniors. They are very open to hear what people living with dementia need. At the Society they've started with Dementia Champions meeting with MPs, one by one. This group would be different than Dementia Champions. There is an opportunity for people living with dementia to be Dementia Champions and connect with their local politicians. But this group would be different.

The Ministry has talked about the idea of an engagement period, a consultation group that would advise the plan. Who would be involved? They have political staff, and then have bureaucratic staff who would be involved. We meet with them. Now are meeting with Minister of Health and Associate Minister of Health. Bea pointed out that we need to find out the people who do the policy making to talk to. They can't make policies without us. We need to tell them.

Bea suggested that the first step for us is to get as many of us that we can to still speak for ourselves to go to our MPP and get an appointment. Ask him who his workers are and time with his workers if there's any upcoming legislation.

Lisa suggested that it might be a beneficial for the group to have a real handle about what ASO (Alzheimer Society of Ontario) and ASC (Alzheimer Society of Canada) are doing so we aren't working at cross purposes.

The distances in this country can be frustrating. Starting small would be important—getting the conversation going consistently and seeing where it goes. The more we can be seen active in public by participating in panels, public, etc., the better. It helps to put a whole different view on the stigma that's associated with this. It's important to know what events are going on to know what's going on and get invited to them. Do we have a sense of everything going on that we should have a voice at the table?

For example, the "Finding our Way" program—people living with dementia weren't on the list. Why didn't this come down the pipes? Societies are not giving the right amount of time, space, and thought to involving people with lived experience. Being a part of these things and being a part of them earlier is important.

Lisa suggested that once we start recruiting more people to be involved, we can decide on some areas where we want to focus, we have subcommittees. We can have local groups who can help. Examples could include connecting with recreation and leisure programs in the cities—how do you engage people in the community? We can offer advice to recreation programmers to be thoughtful in that way. There's lots of places we can go. Spread the word that we're here and willing to help. We want to be involved and share our experiences. Town councils. Recreation and leisure. Political. Universities and education institutions.

Another suggestion is to start a speaker's program that would include profiles, bios, and people who are willing to speak with groups, media, etc. We would need to be proactive and seek out those opportunities. These groups are available. There's experience.

The provincial group can provide support and resources more broadly so we can each do work in our own communities. We can have a standard way to move forward.

This group would like to try to advertise and be ready for January Alzheimer Awareness month. Every area that we represent should have a representative of the press talk to them.

Elaine will email Scottish Dementia Group if we can use “nothing about us without us.”

Identity and name of the group to be considered at the next meeting.

Frequency of meetings? Maizy is flexible. Bea is flexible.

Mondays are good. 11:00 on Mondays. Every two weeks until January. Teleconference will work, but we will try skype.

Next meeting:

Monday November 10 at 11:00 a.m. Teleconference # will follow, and we will try Skype.