

Ontario Dementia Advisory Group

Meeting Minutes

Monday December 8th, 2014

11:00 a.m. – 12:30 p.m.

Present: Lisa Loiselle, Nancy Rushford, Gina Bendo, Bea, Maisy, Mary Beth Wighton, Brenda Hounam, Elaine Wiersma, Delia Sinclair, Bill Heibein, Phil Caffery

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| 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 Bendo | Alzheimer Society of Niagara |
| Delia Sinclair | Alzheimer Society of Ontario, Public Policy and Advocacy |
| Phil Caffery | Alzheimer Society of Ontario, Public Policy and Programs |
| Lisa Loiselle | MAREP, University of Waterloo |
| Brenda Hounam | Paris, Ontario, spokesperson and advocate |
| Mary Beth Wighton | Southampton, advocate, FTD |
| Bill Heibein | Advocate and spokesperson |
| Elaine Wiersma | CERAH, Lakehead University |

1) Reviewed meeting minutes from November 24th, 2014

- There were no questions about the notes from the previous meeting.

2) Confirmed name of the group

- Two names were proposed: Ontario Dementia Advisory Group and Ontario Dementia Working Group. Since “advisory group” is the language used in government circles, we will move ahead with calling ourselves the Ontario Dementia Advisory Group.

3) Reviewed components of existing dementia plans

- Discussed Table 1 of the document “Dementia and Big Data”, which highlights common policy elements from worldwide Alzheimer’s disease and dementia plans.
- To our knowledge, only Scotland has actually engaged people living with dementia in their plan. More recently, Australia has been engaging people with dementia but we are unsure if this is reflected in their plan. Mary Beth e-mailed Kate Swaffer to find out more about Australia’s plan; she is awaiting a response.
- The 12 common policy elements are not clearly defined. It would be helpful to have a description of what is included under each definition.
- Apart from *Raising Awareness*, the topics are focused primarily on the health-care system. It would be important to take a step back and think about people with dementia who are actively contributing to their communities. Perhaps a focus on the community and reducing stigma could be a key area where the Ontario Dementia Plan differs.
- Input from people with dementia should be a component of each policy element.
- There should be a topic #13 that requires the consultation of people with dementia. This would identify supports that need to be in place to help address the needs of people with dementia, particularly those who are living alone. Emotional support should also be included.

4) Discussed the upcoming meeting in January 2015

- The Ministry of Health and Long-Term Care and the Ministry of Seniors have agreed to work with ASO to have people with dementia at the centre of the planning process for the Ontario Dementia Plan. ASO will be hosting two initial meetings with the parliamentary assistant to the Minister of Health and four other staff.
- There will be two meetings to kick-start the engagement process: one with persons with dementia and another with partners in care. It is important that these two meetings are held separately and that people with dementia and partners in care are not related to each other.
- It is important for us to be at these initial meetings. The more members of the group who are able to attend, the better.

- We need to ensure that the process of consultation involves more than one meeting, and that it engages people in different ways to ensure that everyone's voice is heard.
- Delia will send more information about the dates for the meetings.

5) Agreed to draft a letter of support

- The group agreed to draft a "letter of support" which will explain the value of having people with dementia at the centre of the planning process. It will also support the group's vision by adding weight to the proposal and outlining our expectations.
- It would be ideal to have the letter of support completed by the first week of January so we can provide it in advance of the meeting.

6) Identified supports for the involvement of people with dementia

- Transportation should be provided for people with dementia who are without a mode of transportation, in order to assist them in physically participating in a meeting.
- Peer support should be available to people with dementia who may need assistance when attending a meeting in person (e.g. taking notes, providing guidance, if needed).

7) Discussed mechanisms to ensure everyone's voice is heard

- If a group member will be unable to physically participate in a meeting, it would be important to have a collective voice to make sure they are still being heard.
- The group will discuss everything ahead of time and provide notes for those who are representing the group as a whole.
- Conference calls can be made in advance of meetings to provide everyone with an opportunity to discuss important points and voice their concerns.

Summary of Key Discussion Points:

- Our approach will be different than the traditional approach of developing plans without the input of people with dementia; it will be based on lived experience.
- People with dementia need to be central to the entire planning process. Their engagement in all aspects of policy development will be an overarching principle.
- The focus of the plan needs to be broader than the health care model. It should reflect people with dementia living and contributing to their communities. It should also consider the perspectives of people with dementia living alone.
- People with dementia should be included in the definition of “stakeholders”.
- Language and terminology should be familiar and already in use by the government. Terms such as “self-management” and “dementia-friendly communities” could help to get our point across, as “self-management” is often used in chronic diseases, and “dementia-friendly communities” has already been adopted in Australia and the UK.
- Transportation and peer support should be provided for people with dementia who may need assistance when participating in meetings.
- If a person is unable to physically participate in a meeting, there needs to be mechanisms in place to ensure that their voice will still be heard.
- The approach needs to be bottom-up, rather than top-down. The approach should start with people with dementia and force things back up the chain. Having one spokesperson is not enough; we need a collective voice.
- Input from people with dementia should be a component of each policy element. There should also be a topic #13 that requires the consultation of people with dementia and identifies additional supports that need to be in place.
- There must be equal representation from all communities, regardless of their geographic location or cultural background. The perspectives of rural and remote communities and those of diverse backgrounds must be equally considered.

At our next meeting, we will review these points and the guiding principles of the *Scottish Charter of Rights for People with Dementia and Care Partners*. Their strategy is foundationally different than other strategies internationally. A person’s rights is a good place to start as we sketch a framework for our vision.

Action Items:

- Delia will provide dates for the January meetings
- Elaine will send out the minutes and agenda

Next meeting:

Monday, December 15th, 2014

1:30 p.m. – 3:00 p.m.

Call-in number: 1-888-892-7292

Passcode: 0190178# <--- Please remember the # sign, it is very important!

You will be in conference.