

## Ontario Dementia Advisory Group

### Meeting Minutes

Monday January 19<sup>th</sup>, 2015

11:00 a.m. – 12:30 p.m.

---

Present: Nancy, Maisie, Bea, Gina, Delia, Lisa, Brenda, Mary Beth, Bill

Regrets: Phil Caffery, Elaine Wiersma

---

Nancy Rushford	Program Director at the Alzheimer Society of Niagara
Maisie Jackson	Connected with the Alzheimer Society of Niagara
Bea Kraavenhof	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 January 12<sup>th</sup>, 2015

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

### 2. Updates and information regarding the meeting with the Ontario government

- Delia submitted our proposed date and time for the meeting, but has not heard back so she will follow up with Indira's executive assistant this afternoon.
- Delia also inquired about support for travel costs and options for accessing the meeting remotely.
- The offer to have the meeting at Niagara still stands. The Niagara group has also offered to prepare a luncheon before the meeting so that we can all become acquainted with one another.

- Other options for the location of the meeting includes the Oakville office (which is in Indira's riding) or Peel office of the Alzheimer Society.
- We will hear by email from Delia if meeting at Niagara will be possible for everyone.

### **3. Reviewing the executive summary (Meaningful Engagement and Involvement in Public Policy document)**

- At the start of the document, it was suggested that we need to add a summary stating the purpose of the document.
  - The purpose of the document is to outline what we want to discuss in the meeting. It provides information on how to engage people with dementia and how this group wants to be involved in public policy.
  - The statement "Focus on what we CAN do – not on what we can't" should be included in the summary.
- We want to make sure that the government understands that this meeting will not be any different from any of their other meetings.
- Within the document, we want to highlight that along with having expertise on living with dementia, people with dementia also have past history and personal experiences to draw upon. This information may not be accessible to them all the time, but it is important to recognize that they have expertise beyond living with dementia.
- We really need to get the message across about how people with dementia have history and experience before their diagnosis. They are knowledgeable in other areas along with being knowledgeable on living with dementia.
- Bea suggested that in order for the government to get a better understanding on why people living with dementia need certain supports and strategies, we should list some issues that they might be facing. However, we want to frame our messages in a positive way.
- Delia suggested that instead we could explain the advantages of having a group like ours working together. We could write about examples of how our team has overcome the challenges faced by people living with dementia. This also reinforces the idea that multiple people with dementia needs to be consulted, not just one.
- We need to make sure that the following key messages are summarized at the beginning and the end of the document:
  - Focus on what we CAN do – not on what we can't
  - Collective engagement – Involvement of multiple people living with dementia

- People with dementia have expertise on living with dementia as well as other areas since they all have past history and personal experiences, but they may not be able to recall this information all the time
- Nothing about us without us
- Within the “Facilitating the process” section, we need to add that they need to allow for periods of silence as people with dementia may need time to absorb the information being shared.
- Since we want to prove that this meeting is no different than any other meetings that they’ve had, we should be using the same language as the government. Therefore, it was decided to drop the word, “meaningful” from “meaningful engagement”.
- The grammatical and formatting edits include:
  - Adding page numbers and the date
  - In the “What is Meaningful Engagement?” section:
    - Meaningful engagement refers to the manner in **which** you...
  - In the “Involvement versus Consultation” section:
    - Consultation tends to be a one-off **event** which includes...
    - This type of approach is helpful **in** specific circumstances...
  - In the “Methods of Engagement” section:
    - Change “service providers” to “other stakeholders”
  - In the “Facilitating the process” section:
    - **When** people with dementia are participating in formal meetings...
  - Throughout the entire document, use “people living with dementia” instead of “persons with dementia” since it seems more collective
- We plan to send the executive summary along with the four documents (Engagement Framework, Listen to Us, Strengthening the Involvement of People with Dementia, 10 recommendations for Dementia Plans) used for information so that Indira’s staff could use them as resources.
- Delia and Mary Beth will add all the key messages, apply all the grammatical and formatting edits, make any other needed changes, and circulate the revised document before our next meeting.

#### **4. Announcement from Delia**

- David Harvey was asked to speak about the provincial and national dementia strategy for an event on Feb 10<sup>th</sup>. He would like to have someone from our group to speak about the work that we have been doing. If you are interested, please reach out to Delia.

#### **Action Items:**

- Giselli will send out the meeting minutes and agenda.

- Delia will follow up with Indira's executive assistant regarding our proposed date and time to meet, and transportation costs.
- Delia and Mary Beth will revise the executive summary and will circulate it to the group before the next meeting for review.
- Delia will create a document with information about the people who will be attending the meeting and the Ministers involved.
- All members should send their profile to Delia and Mary Beth.

**Next meeting:**

**Monday, January 26<sup>th</sup>, 2015**

**11:00 am – 12:30 pm**