

Ontario Dementia Advisory Group

Engagement and Involvement in Public Policy

Developed January 21, 2015

Updated February 25, 2015

Forward

As a group of Ontarians living with dementia who are interested in being involved in public policy that will affect people living with dementia across Ontario, we have developed this document to provide an outline of what we feel it means to be engaged in public policy activities. We believe this will help with understanding the best manner of moving forward in any new partnerships, and will assist all stakeholders involved in this process.

It is also important to note, that our care partners have their own perspectives which should be listened to. This can be done separately from our own involvement. By having distinct meetings, we ensure our views are heard and not overwhelmed by our care partners.

Furthermore, collective engagement is a powerful alternative to meetings with individuals. Being in a group setting provides opportunities for each member of the group to contribute and help others in their contributions if needed. This makes us stronger and more unified in our quest for “nothing about us without us.”

The information presented in this document is a summary of discussions our group has had and informed by the work conducted by:

- Dementia North, UK - Listen to Us: Involving people with dementia in planning and developing services
- Meaningful Engagement Framework developed Wiersma et al., (2014) (see <http://www.rethinkingdementia.ca/self-management-of-dementia.html>)
- The Authentic Partnership Approach developed by the Murray Alzheimer Research and Education Program at the University of Waterloo
- National Older Person’s Mental Health Program, UK – Strengthening the Involvement of People with Dementia: a Resource for Implementation

As people living with dementia we have personal perspectives about dementia that no one else has. We recognize that the involvement of people living with dementia has lagged behind other groups because there are often assumptions that people living with dementia are unable to communicate their needs, wants, and perspectives with others. This has led to social exclusion, and this is something we find unacceptable.

We are still the same people we were prior to our diagnosis. We have a lifetime of knowledge and experience to share. Life does not end when you receive that diagnosis, and we want to reinforce that each person living with dementia is still a whole person with much to contribute.

Nothing About Us Without Us

When provided the opportunity to have our voices heard, we are able to communicate how dementia affects us and how services should meet our health and social needs.

Involvement versus Consultation

We believe there is an important distinction between involvement of people living with dementia and consulting people living with dementia.

Consultation tends to be a one-off event, which includes focus groups or questionnaires to receive feedback from stakeholders. This type of approach is helpful in specific circumstances, but it lacks the commitment of meaningful continued involvement in the process of decision-making.

Involvement is a process and not a one-off event. In order to really engage and involve people living with dementia, a commitment to greater involvement needs to be explicit and planned.

What is Engagement?

Engagement refers to the manner in which you involve people living with dementia throughout the process of developing, implementing and evaluating policy.

This process should be conducted in a culturally sensitive manner.

The following points should be kept in mind when engaging with people living with dementia:

- Recognize the expertise that people living with dementia bring to decision-making and that we should be considered key stakeholders, not an afterthought.
- Recognize that power imbalances exist between people living with dementia, care partners, service providers and other stakeholders, and work to provide equal footing.
- Look to develop a partnership rather than one-off consultations, and provide consistent updates as the project moves forward.
- Be open to adapting your practices based on feedback received from people with dementia during the process of engagement.
- Value personhood based on a holistic appreciation of the emotional, social, spiritual and artistic dimensions of individuals.

Methods of Engagement

Each person's experience of dementia is unique, but there are certain realities that need to be remembered as you move to involve people with dementia in public policy work.

- Engagement is an exhausting process for all involved. There needs to be recognition that on some days, people will be better at contributing than other days, just like with anyone.
- The appropriateness of particular approaches, activities, and methods needs to be considered in relation to the abilities and characteristics of the people living with dementia being engaged.
- Recognize the value of the collective engagement experience: Engaging with others as a group allows us to support each other to overcome some common challenges, such as:
 - Difficulty concentrating
 - Memory lapses
 - Difficulty retrieving information
 - Time to absorb information
- Translate into action the views and experiences gathered through involvement.

In order to overcome the imbalances in power between people living with dementia, care partners and service providers, it's important to ask "what degree of control and influence do people living with dementia really have? How does it compare to care partners? How does this compare to other stakeholders?"

Below is a list of **practical considerations** that need to be made when facilitating the engagement process (Borrowed from "Listen to Us: Involving people with dementia in planning and developing services" developed by Dementia North in the UK).

Facilitating the process:

- Do not assume that the issues identified for consultation are important issues for the people with dementia. Ask them for their agendas.
- At each meeting, spend some time prompting and reminding the people with dementia who you are and what you discussed at the previous meeting.
- Take time to talk – don't be hurried.
- Allow for periods of silence to assist with absorbing information.
- Do not try to move people on at a faster pace than they are able to cope with.
- Recognise that the views of the person with dementia may change in the course of a meeting or from day to day, as well as over longer periods.
- Ensure that options and the implications of any choices made by an individual or the group are understood.
- Check that the participants agree with any views or suggestions recorded.

- When people with dementia are participating in formal meetings, ensure that minutes and other documents are delivered to them well before the meeting to allow them time to consider the content and to prepare to present their views. Ask them when they would prefer to receive these documents. Provide assistance with this if required.
- Arrange for people with dementia who are participating in formal meetings to be supported, as required, to present their views.

Summary

- Focus on what we can do, not on what we can't do.
- Acknowledge the power of collective engagement in enhancing our ability to overcome challenges.
- Life doesn't stop when you receive a diagnosis. Our ability to access this information may change, but our personal histories and experiences are still there.
- We are more than our diagnosis.

Members

Bea Kraayenhof, Welland
 Bill Heibein, Thunder Bay
 Brenda Hounam, Paris
 Maisie Jackson, Niagara Falls
 Mary Beth Wighton, Southampton, Bruce County

Partners

Alzheimer Society of Niagara Region
 Gina Bendo
 Alzheimer Society of Ontario
 Delia Sinclair Frigault, Phil Caffery, Nancy Rushford
 Centre for Education and Research on Aging & Health (CERAH) at Lakehead University
 Elaine Wiersma
 Murray Alzheimer Research and Education Program (MAREP) at the University of Waterloo
 Lisa Loiselle