

Meaningful Engagement of People with Dementia

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What do members of our Advisory Group have to say about meaningful engagement of people with dementia...



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Engagement work is important as it gives one the opportunity to be actively involved in one's future. It also helps to dispel the stigma associated with the "diagnosis of dementia" and the common belief that those diagnosed with dementia are no longer capable of advocating on their own behalf.

"NOTHING ABOUT US WITHOUT US!"

~ Bill Heibin





Getting doctors better trained to deal with this disease is key! Early diagnosis allows people with dementia to have a voice as well as work towards removing the stigma involved in such a diagnosis.

~Gord Grant



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*It's about purpose. It's the Alzheimer Society: it's **our** Society, so we – people living with dementia - should be involved at all levels and having our voices heard. It's more than stuffing envelopes or doing odd jobs. It is regularly and systematically inviting and involving us throughout the organization because we truly are #stillhere.*

~Jim Mann



Take away messages: the Alzheimer Society of Canada...

1. addressed the **uneven experience** of people with dementia with our organization nationwide
2. developed an **ethical framework, staff training plan and Resource Guide** to help with this issue
3. formed an **Advisory Group** of people with dementia to guide our work
4. outcomes included a **positive and humbling learning experience** for us all
5. next steps will include a **multi-year engagement plan** with a more robust process of implementation and **new Advisory Group recruitment**



What issues were we trying to address?

Uneven...

- **Involvement** of people with dementia across Canada
- **Experience** of people with dementia with our organization
- **Staff** knowledge & commitment



What did we decide to do?

- Develop an **ethical framework** to guide all of our work
- Develop and pilot a **Staff Training Plan** with 6 Alzheimer Societies nationwide to help staff reflect on and plan for better engagement of people with dementia
- Create a **Resource Guide** based on tips and strategies from people with dementia



What strategies did we use?

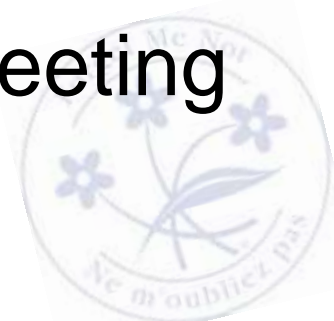
- Create an **Advisory Group** of people with dementia with representatives from across the country (invited by our colleagues nationwide)
- Co-chairs of Advisory Group: one person with dementia and one ASC staff person
- Teleconference meetings every 8 weeks with updates by email if no meeting necessary



What were the outcomes?

For the members of the Advisory Group

- A positive experience contributing to the development of tangible resources that would be shared nationwide
- A sense of “team” and satisfaction with the person centred approach and tools we trialed in our communications and meeting format



For the Alzheimer Society

Staff learning:

- Always **amazed** and **humbled** by the commitment, insights, energy and abilities of the Advisory Group members
- We had no dedicated staff resources so the group was usually waiting for us – not the other way around!



What's Next?

- A thoughtful and structured recruitment process for an **expanded Advisory Group** with grandfathered members
- The hiring of a **consultant** to help us get a few **quick wins** (e.g. policies drafted; ongoing staff training modules and check in processes created)



Creating a new Culture :

We aspire that...

- the **meaningful engagement** of people with dementia in the work of the Alzheimer Society is our **new norm**
- the way we engage people with dementia in our work reflects the values embedded in a **person centred approach**
- the way we support our staff does the same!



Wish us well!

- If you have tools, resources, experiences to share to help us on our way, we'd love to hear from you! mschulz@alzheimer.ca
- If you would like to take a look at the resources we have developed, please visit our website at:
EN: www.alzheimer.ca/meaningfulengagement
FR: www.alzheimer.ca/participationactive

