

MEANINGFUL ENGAGEMENT OF PEOPLE LIVING WITH DEMENTIA

Position statement

Background

The Alzheimer Society of Canada is the leading nation-wide health charity that works to improve the quality of life for Canadians impacted by Alzheimer's disease and other dementias. Historically, people with dementia were often diagnosed late in the disease, making it more likely for the Alzheimer Society to connect directly with family caregivers, rather than with people with dementia.

With improvements in early diagnosis and the availability of medications, individuals with dementia themselves now reach out to the Society. These individuals are often strong advocates who want to contribute to the work of the Alzheimer Society to make it even more relevant and impactful for all Canadians affected by dementia.

People with dementia remind us, “**nothing about us without us.**” Knowledge of the disease and resources are needed to ensure that people with dementia are meaningfully engaged in the work of the Society so that their contributions are empowering and provide them with a sense of purpose, while building organizational capacity.

Issue

The mission of the Alzheimer Society is to “improve the quality of life for Canadians affected by Alzheimer's disease and other dementias.” To do this effectively, it is important to partner with people with dementia and learn from their input and “lived experience.” However, people with dementia often tell us that their experience in working with the Alzheimer Society, regardless of where they live in Canada, is sometimes “uneven.” They are not always included in ways that benefit the Society or that are satisfying to them. Involving people with dementia is an ongoing and evolving process that must be embedded in the Society's culture and day-to-day practice.

Our position

The Alzheimer Society of Canada believes that people with dementia want to inform the work that directly impacts their quality of life and well-being. The Society recognizes the right of people with dementia to be actively involved in the work of organizations that represent their interests and value their involvement. With this in mind, the Society is committed to building and fostering a culture of learning, shared responsibility and partnerships with people with dementia.

Alzheimer Society

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In so doing, their unique insights will contribute to the planning and implementation of all aspects of our work.

The Alzheimer Society will ensure that the voices of people with dementia are actively sought and heard. In this way, we can together grow organizational and individual capacity towards a supportive environment for meaningful engagement opportunities within Alzheimer Societies across Canada. We will also ensure that our relationships with people who have dementia are based on equality, understanding, sharing, participation, collaboration, dignity, trust and respect.

References

- Alzheimer Society of Canada and Knowledge Development Centre. Imagine 2006. Engaging People with Early Stage Alzheimer's Disease in the Work of the Alzheimer Society: A Research Report.
- Alzheimer Society of Canada. (2011) Prioritizing the involvement of people with dementia in the work of the Alzheimer Society.
- Alzheimer Society of Canada. (2015) Meaningful Engagement of People with Dementia: A Resource Guide.
- Cantley C., Woodhouse J. Smith M. (2005) Listen to Us: Involving people with dementia in planning and developing services. Dementia North, Northumbria University.
- Dupuis, S., Gillies, J., Carson, J., Whyte, C., Genoe, R., Loiselle, L. & Sadler, L. (2010). « Moving Beyond Patient and Client Approaches: Mobilising “Authentic Partnerships” in Dementia Care, Support and Services.” International Journal of Social Research and Practice. p. 1-40.

Definitions

- *Meaningful engagement:* This is a person-centred approach which encourages and invites people with dementia to purposefully participate in the work of an organization that represents their interests. Participation includes actively contributing ideas, skills and abilities, while recognizing that individual participation will vary, depending on abilities, personal histories and available opportunities.

