



Canadian National and Ontario Dementia Plans Input from those living with Dementia

Background

In November 2013, in partnership with Murray Alzheimer Research and Education (MAREP), a group of individuals living with dementia and their care partners, came together to discuss the lack of both an Ontario and national dementia strategy plans. Conversations were guided using the philosophy “Nothing about Us without Us.” The primary goals of the meeting was to educate, create, and document recommendations which will significantly enhance the lives of those living with dementia and their care partners. The second phase of this project is to advocate to policy influencers and developers these 10 recommendations.

When creating and modifying Canadian policies about dementia, organizations must work in partnership and include representation from the population of those living with dementia. The following 10 recommendations were developed with the intention of underlying what is most important to those living with dementia.

Policy Priorities - Recommendations

1. Improve the diagnosis experience. This can be accomplished through/by:
 - Testing experiences
 - Shorten length of time between assessments / testing
 - Timely follow-up after diagnosis from professionals
 - Acknowledge remaining skills/ strengths / capabilities
 - Driving license removal progress – needs to be re-evaluated
 - Improved sensitivity during communication of diagnosis to persons living with dementia and family partner in care.
2. Information about local community supports be provided to person living with dementia and family partners in care by physicians / specialists at time of diagnosis.
3. Improved and simplified process to access community supports and advocacy after diagnosis.
4. Access to meaningful activities/programs regardless of age and diagnosis and sustainable funding for programs.



5. Financial assistance - to persons living with dementia and family partners in care
 - With medication and medical treatments/testing
 - Home renovations
 - Travel
 - For family partners in care to provide care at home, and
 - Readily Information about available financial assistance and subsidy.
6. Expand staff training and education - at all levels (e.g., physicians/specialists to personal support workers, CCAC case managers, etc.)
7. Increased support to live and self-manage at home as long as possible
 - Accessible community supports - finances, access to paid care partners, increased hours of paid support
 - Financial adviser to help with remaining at home longer, and
 - Monies for home modification.
8. Services and supports for people with early onset dementia and their families
 - Different employment opportunities/options - for person living with dementia and family partners in care, and
 - Young carer supports.
9. Long-term care - access, enhanced services by trained staff.
10. Fight stigma and enhance public education and awareness.



PALWWD Project Team Members

The following names comprise the project team Policy Advocates for Living Well with Dementia (PALWWD). They are individuals living with dementia and/or their partners in care.

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