



Young Onset Dementia Information Gap Analysis: Executive Summary

“In Canada today, it is estimated that there are 16,000 Canadians under the age of 65 years living with dementia.” (Prevalence and Monetary Costs of Dementia in Canada, Alzheimer Society of Canada (2016)). With advances in knowledge and diagnostics, this number is expected to rise. We do know that there are problems with recognition of the signs of dementia in younger persons and difficulty in obtaining a diagnosis can cause considerable stress on individuals and families. We also know that the personal and social consequences of young onset dementia can be much different than those experienced by persons with dementia which has been diagnosed later in life. Emotional issues, family environment, and financial issues can all play a role in contributing to added stress. The Alzheimer Society is committed to help improve the quality of life of those affected by dementia.



In February 2016, A Young Onset Gap Analysis Project was initiated through the National Information Support and Education Committee (NISE) and the Alzheimer Society of Canada (ASC), in order to explore the gaps of available learning and support resources for this population, ask for advice and feedback from those with lived experience, and use this information to inform the development of a Resource List of learning and support resources for those with Young onset dementia their caregivers.

Young onset dementia was defined as dementia that was diagnosed before the age of 65 years. The project began with a literature review including scanned citations and articles from 2009-2016 to ensure they were relevant and a total of 19 articles were listed in the final search results. The literature revealed that very few learning and support resources have been evaluated through research. Instead the literature summarized the evidence on the learning and support needs of persons with young onset dementia (YOD) and the needs of their caregivers. The evidence confirmed that those affected by YOD need:

- Advocacy on: Delayed diagnoses; professional's lack of knowledge about YOD; limited availability of services; community services that are not appropriate for under 65 years; lack of clinical tools to ensure that patients under age 65 were diagnosed and received follow-up care; difficulty with placement needs; lack of employment and resulting financial issues; lack of programs and activities that normalize life; stigma,
- Information on: the course, treatment and management of the dementia; heredity; changing family relationships; communication strategies, behavioural challenges,
- Support: professional counselling, support groups specifically for YOD and YOD caregivers; family oriented support approach; specifically for children/teens; activities that provide meaning for their lives; flexible forms of respite.

More than 350 persons with YOD experience were consulted as part of this project through on-line surveys or focus groups. Those needs identified in the literature review were clearly supported by those with lived experience.

Persons with YOD want to know, “they are not alone”. Information about dementia, available community supports and where they can go to access activities and programs with others who have YOD was a consistent theme.

Caregivers also reiterated the need for information on a variety of topics, and obtaining support for themselves, and their children/teens. They want to obtain this information and support at times convenient to them and in different ways such as in person and/or through the web.

Health care professionals confirmed what the literature and persons with YOD and their caregivers said. Health care professionals want more available information specifically on YOD to help them with their clients. They recognize the need for professional counselling and specific support groups for YOD. However, this is not always easy to arrange when organizational finances are an issue. More creative ways need to be identified including: sharing of resources; working with Alzheimer Societies across Canada and internationally; and working with community partners on programming needs.

The project included a scan of national and international learning and support resources that are currently available. There are a number of International Alzheimer Societies that have developed YOD information materials and programs as well as other organizations and they offer these resources in written and web-based formats. Some of the information offered is generic which can be adapted for use by ASC while other information is specific to a country or organization. There is a need to provide Canadian content on some of the learning needs identified. This can be done by re-vamping existing materials. There are social groups and activity programs available for YOD persons in some parts of Canada and internationally. Information about these groups and programs need to be made available to all Alzheimer Societies across Canada.

Recommendations

1. There is a need to investigate web based learning and support resources for persons with YOD, their caregivers and their children. There are opportunities across Canada within Alzheimer Societies to collaborate with those who have already developed a web-based platform.
2. Develop a Resource List on available learning and support resources for YOD and make this available on the Alzheimer Society website.
3. Develop a Checklist on Planning Ahead aimed specifically at those affected by YOD. It could be divided into early, middle, and late stages identifying steps and learning and support resources that are useful to know.
4. More information needs to be made available to serve the needs of this population. Some existing information could be re-vamped to reflect Canadian content. Content such as financial assistance, legal issues, housing etc. will need to be developed provincially.
5. Support interventions: Separate support groups for YOD and also their caregivers need to be available. Web based interventions need to be explored so individuals can join from a distance. There needs to be separate support groups for YOD; one-on-one counselling available; investigation of family based counselling as a technique or provide information as to how to access.
6. Promote the development of and provide a listing of activity/social programs that are suitable for YOD and their caregivers. Programs that give meaning and fulfilment to their lives are important as well as providing normalization to life.
7. Resources need to be made available to children/youth living with persons with YOD. They need separate support groups, chat lines, one-on-one counselling and follow up. A Checklist for parents on available resources needs to be developed to include: what to look for in their children/youth that would be cause for concern, and resources and strategies in helping children/youth.