

Alzheimer Society of Alberta and Northwest Territories - Young Onset Dementia Project - Final Report

Executive Summary

The 2016 Alzheimer Society of Canada gaps analysis identified a need for information on a variety of topics specific to the unique circumstances of people living with young onset dementia and their care partners/families. Due to the different life stage of this client group, there are many topics and concerns relevant to these clients that are different than those for individuals over the age of 65.

To meet the needs of the growing young onset dementia population, Alzheimer Society of Alberta and Northwest Territories (ASAB/NT) staff undertook a literature review, identified regional, national, and international learning and support resources, provided practical and emotional support for the person diagnosed with young onset dementia and family members, offered continuity of support, coordinated services, facilitated support groups, and built capacity for Alzheimer Society staff from all regional offices to respond to those living with young onset dementia and their families through knowledge translation, coaching, mentoring, and the development of resources specific to this client group.

Objectives/Implementation

The Young Onset Dementia (YOD) Project was a knowledge- and capacity- building project for ASAB/NT. The initiative provided services, supports and resources for persons diagnosed with young onset dementia and their care partners. The objective of the project was the development of a service framework which would lead to the provision of individualized services and support for people living with young onset dementia and their care partners/families that met their needs and connected them to appropriate community resources. This occurred through identifying regional, national, and international resources that are currently available for young onset dementia and obtaining feedback from those with lived experiences of young onset dementia and their care partners through specific young onset dementia assessment tools, surveys, and interviews. The project then provided information on a variety of topics related to living with young onset dementia and provided support for people living with young onset dementia, care partners, and family members at times convenient to them and in different ways. To provide information and support, the project identified appropriate services and supports for young onset dementia in the Edmonton region and linked individuals with appropriate services and supports in their community. Through the project, the Alzheimer Society of Alberta increased its capacity to respond to persons living with young onset dementia and their care partners across the province and increased the awareness of the Alzheimer Society as an organization that provides information and support to all persons affected by Alzheimer's disease and other dementias.

Impact

The focus of the final evaluation of the YOD Project was to facilitate a collaborative process to articulate the impact, sustainability and spread of the project goals and objectives. The YOD Project Evaluation successfully generated the knowledge for ASAB/NT to make decisions and recommendations necessary to address the needs of YOD clients and their care partners. ASAB/NT gained a better



understanding of the capacity necessary to develop and implement YOD resources, engage stakeholders and the community and adapt YOD service delivery during a pandemic. Throughout the evaluation process, ASAB/NT staff and stakeholders consistently spoke about the positive impact and benefits they observed for people living with young onset dementia and their care partners because of the YOD Project. Stakeholders described the important role the Alzheimer Society plays in navigating the resources, services and supports for people living with young onset dementia.

Upon completion of the formative evaluation of the YOD Project, it is evident that access to YOD resources and participation in YOD support groups resulted in significant expansion of information and dissemination of knowledge necessary to promote positive community engagement. Through continued partnerships with Alberta Health Services, universities, local organizations and community groups, ASAB/NT plans to resume the provision of high quality YOD programs and expand their services to meet the needs of all Albertans diagnosed with young onset dementia. In conclusion, the YOD Project has proven to be a promising program committed to improving the lives of people living with dementia and their care partners.