

Understanding the Needs of People with Young Onset Dementia: Process, Products and Partnerships



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What is young onset dementia?

- When symptoms of dementia start before the age of 65
- Young onset dementia accounts for 2-8% of all dementia cases



Challenges faced by younger people with dementia

- Still working at the time of diagnosis
- Having dependent children or parents living at home
- Financial commitments such as a mortgage
- Difficulties getting an accurate diagnosis
- Lack of information and appropriate services
- Lack of financial support



The diagnostic process



The Diagnostic Process

Living with Young Onset Dementia
Let's have a conversation!

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Source: www.alzheimer.ca/youngonset

YouTube: <https://youtu.be/Q-tG8PPG6Ew>



What has ASC done to understand the needs of people with young onset dementia?

- In 2016, ASC conducted a gap analysis
 - 98 people with young onset dementia
 - 188 caregivers
 - 128 health care providers
- A literature review of resources was compiled
- Five individuals with young onset dementia were engaged to plan and deliver a national webinar for health care providers available at www.alzheimer.ca/youngonset



What have we learned?

The gap analysis and literature review revealed that there is a need for:



- Specific information about YOD
- Programs specifically for people with YOD and their caregivers.



- Practical tools on planning ahead



- Web-based learning and support



- Resources for youth



Shared leadership: lessons learned

As a result of persons with young onset dementia planning and delivering a webinar, ASC learned valuable lessons:

- **Planning will take time!** It took us 16 months to plan and deliver the webinar
- When holding a meeting, try to keep it **under 90 min**
- **People like to see each other!** If you can't meet in person, consider using video tools (such as "Zoom") for meetings
- If you are considering involving a facilitator, it is recommended to involve someone with **clinical and facilitation expertise**



What is next?

- Young Onset Dementia Facilitator's Resource Manual
- Web-based resources and resource list
- Meaningful engagement of people with young onset dementia
www.alzheimer.ca/meaningfuleengagement



Young Onset Dementia
Facilitators Resource Manual

Alzheimer Society
CANADA

Alzheimer Society

Meaningful Engagement
of People with Dementia
A Resource Guide



Thank you!

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For more information about young onset dementia, please visit

alzheimer.ca/youngonset || alzheimer.ca/debutprecoce

