Young Onset Dementia

Information Gap Analysis Report

Alzheimer Society
CANADA

Contents

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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.

Project Overview:

In order to more effectively serve persons with young onset dementia and their caregivers through information, education and support, the Alzheimer Society embarked on a Young Onset Gap Analysis project in February 2016 with the following goals:

- Identify national and international learning and support resources that are currently available.
- Obtain advice and feedback those with lived experience of young onset dementia, their caregivers and health care professionals.
- Inform the development of a Resource List of learning and support resources which will include: recommendations of inclusion of resources from other sources; revamping current resources; development of new resources.
- Increase 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.

Literature Review

Literature review
- 19 articles
- 2009-2016

Surveys

On-line surveys
Person with YOD
Caregiver
Health care prof.
Focus groups

Scan

National and international scan of available resources

Final Report

Recommendations

Literature Review:

Background:

The intent of the literature review was to identify learning and support resources that have been evaluated as being effective in supporting those affected by young onset dementia (YOD). Key search words used were: young onset, selfhood and dementia, working with dementia, parents with dementia, children of parents with dementia, unmet needs/ dementia/ young onset, learning and support needs, services for YOD, family challenges/ YOD, risk factors and YOD, and programs for YOD.

Searches were conducted in the following databases: PubMed Medline (National Library of Medicine index); Google Scholar (not Google); SageLink (Puxty and LeClair website); Cochrane Database of Systematic Reviews. In addition searches were conducted in the following sources: National Institute on Aging a subgroup of the US Department of Health and Human Services; University of British Columbia Library EurekAlert Science News; Waterloo Wellington LHIN publications. Manual searches were also conducted in relevant health related journals. The results were limited to English language materials with a publication date between 2009 and 2016.

Citations and articles from the searches were scanned to ensure they were relevant and a total of 19 articles were listed in the final search results. (See Appendix 1 and 3)

The literature revealed very few learning and support resources that 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.

Two activity programs, “Walking in the Neighbourhood” and a “Structured Gardening Program” were evaluated as being effective. One research article focused on the use of technology and the importance of using simple technology with auto correction functionality. The rest of the literature focused on the needs of those affected by YOD and their families.

A quality of life study by Baptiste (2016) found that greater awareness of the disease among people with YOD is associated with better quality of life in caregivers. This supports the need for learning resources for those affected. In the NeedYD study (Bakker 2010), an exploration of the experiences of a caregiver of a patient with early onset dementia (EOD) and the needs of patient and caregiver, they found that services designed for the over 65 age group have more difficulty recognizing the specific needs of these younger people and have less resources to meet those needs and they identified four issues that need to be addressed for the YOD population: (a) prolonged time to diagnosis, (b) a lack of fit between needs and services, (c) the strain of dedication to care versus the caregiver’s own future perspective, (d) the need for response of health care services to changing individual. These findings were supported in the Ducharme 2014 mixed design study which focused on the unmet support needs of early onset family caregivers.

A number of articles focused on the needs of children. In Johannessen 2015, they found that, “The children may experience guilt and shame, and feel embar¬rassed when their friends meet their parent who is forgetful (AD) or exhibits a change in personality. The main task of youth is to develop a robust sense of self, identity, self-respect, and self-confidence – to become a vital actor in one’s own life. In this process, the parents are mirrors for their children, being affirmative and directing, and serving as models for their children. Having a parent with dementia during youth in many ways deviates from what is considered a normal parent–child relationship”. This view was supported in Gelman 2011, which went further to say that children need to be supported with chat rooms, bulletin board for teens, groups for parent and child, and counselling with professional support.

The literature review revealed four themes of needs that should be addressed in supporting persons, caregivers and family members dealing with YOD. A summary of these needs according to the four themes is listed below.

Summary of Literature Review: Needs Identified

Advocacy	Support	Information	Children
• increase professional expertise re: recognition and diagnosis; • Better services available for emotional support; • Placement issues that need to be appropriate for younger age; Respite services appropriate for age; • Follow up provided to children when the parent receives a dementia diagnosis; Use of technology needs to be simple with auto correction functionality.	• FTD support group; • One-on-one counselling; • Case management; • Professional support; • Psychosocial intervention offered at home: telephone, on-line intervention; • Family approach; • Peer support; • Normalizing life; • Meaningful activities.	• Education for health care professionals; • Behavioural strategies; • Communication strategies; • Info on financial assistance; Stigma; Diagnosis disclosure to others; Info about heredity; • Family relationships; • Maintaining employment; • Driving issues.	• Needs based emotional support from point of diagnosis; • Children's/teen support group; • Chat room and bulletin board for teens; • Monitoring at school.

Surveys:

In order to obtain advice and feedback from those with lived experience of young onset dementia, their caregivers and health care professionals, an online survey in both English and French was conducted. In addition, a face-to-face facilitated discussion group package was developed and used with persons with YOD and caregivers.

On-line surveys:

The on-line surveys were pilot tested at a Local Alzheimer Society in Ontario with persons with YOD, caregivers, and health care workers respectively. The survey was then posted on the Alzheimer Society website in May 2016 with a closing date of June 30, 2016. Provincial societies were asked to promote awareness of the survey. The francophone respondents were low in number and consequently, the survey deadline was extended to the middle of September. The number of persons who completed the on-line survey is listed below:

Group	Number of Responses	Number of respondents who completed the full survey	Partial (they started the survey but did not complete it)	Number disqualified
People with dementia	75	36	17	22
Caregiver	164	120	31	13
Healthcare Professionals	106	63	30	13
FR – People with dementia	23	0	5	18
FR – Caregiver	24	3	3	18
FR – Healthcare Professionals	22	16	6	0

People with Young Onset Dementia results:

In the Anglophone population, 48% of respondents completed the survey. 29% were disqualified as they were not diagnosed with dementia before the age of 65 years. 22% started the survey but did not finish. Their answers to the questions that they did complete were included in the survey analysis. The results for the francophone population were different in that 0% fully completed the survey, 21% partially completed and 78% were disqualified.

In analyzing the Anglophone results, 48% is a good response rate for an on-line survey. This view is supported through a survey of the internet comparing paper-based and on line surveys. It is noted that paper-based surveys yield higher results with 30% response rate deemed average for on-line surveys and 50% response rate for paper-based surveys. In general, online surveys are much less likely to achieve response rates as high as surveys administered on paper. There could be different reasons for the low response rate for francophone survey, which will need to be analyzed should future on-line surveys through the Alzheimer Society be administered.

78.7% indicated that when they received the diagnosis, they looked for information about the disease, what to expect and how to live with it. 72% said they found the information they were looking for in:

Doctor's office	34.8%
Alzheimer Society	78.3%
Internet	73.9%
Through a community agency	8.7%
Other (please specify) friends, Mayo Clinic, Medical Case management resources	26.1%

There was a richness of responses to the survey with specific advice for the Alzheimer Society on the type of learning and support needed. There was a great deal of support for YOD support groups, one-on-one counselling and knowledge of and access to community services. A sampling of quotes is provided below:

> "If I could only drive but my family doesn't want me to because they say I keep forgetting things when I drive. I often am bored during the day, I get tired of watching TV by myself and eating by myself I wish there was places I could go where there would be people who understood me, who were in my age group to have some mental stimulation and fun doing things together."
>
> "I think it would help if my support group met twice a month rather than once a month and maybe during the summer too."
>
> "There is a huge gap in rural areas. The support group I went to was dominated by one individual and so wasn't helpful. While I was in SK they were doing through Tele-health or Health-links a conference video for individuals with young on-set. I found this helpful but then when I moved to AB there was no such program. I think the funding the society does should not be as focused on research or a cure as that could be years away but more helping individuals to function and live now with a better quality life. In the Alzheimer Society in SK, I did receive when necessary wonderful one to one support."

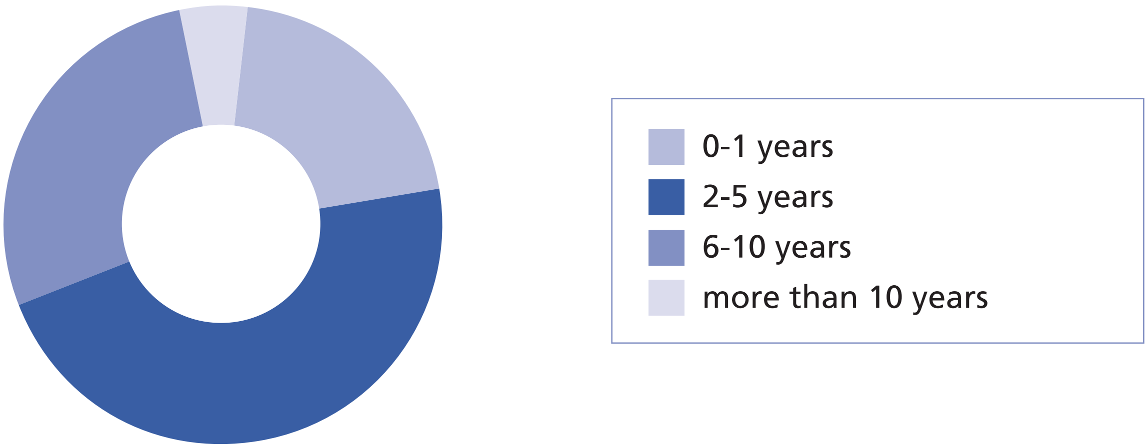
Summary of Responses for Person with Dementia: Needs Identified

At diagnosis	Needs now	Advice for AS
Support: • Emotional support; Daily contact with a knowledgeable person; YOD support group and group for caregiver; • Knowing that you are not alone; • Peer and group support; one on one counselling. **Information:** • cause, effect, drug trials, medications, financial planning, community supports, what to expect; • educate family and friends about the disease.	**Support:** • Community supports: Family dynamics. **Information:** • New trials and treatments; • Financial counselling; • Nutritional information; • Role of sleep apnea; Importance of exercise; Music therapy; Dementia friendly places.	• Don't generalize. There are different types of dementia with different symptoms; Hold support group twice a month and in the summer; House visits; Support group through Telehealth for rural areas; Telephone support; Support groups for YOD; help keeping up with mail and paying the bills; Education sessions; Better training for facilitators in support groups; • Info on Medical Aid/Dying Legislation.

Caregivers of People with Young Onset Dementia results:

In the Anglophone population, of the 73% of respondents who completed the survey, 78% were current caregivers of a person with young onset dementia. 7.9% were disqualified. Again, the results for the francophone population were different in that only 12.5% fully completed the survey, and 75% of respondents were disqualified.

Of the Anglophone caregivers that responded, the majority of respondents, 46.8%, have been supporting a person with young onset dementia for 2-5 years.



Whereas, in the francophone results, 33.3% have been providing support for between 2 – 5 years.

When Anglophones were asked if they had accessed any of the Alzheimer Society programs, they responded:

Education sessions	53.2%
Support groups	54.6%
One-on-one counselling	26.2%
None	26.2%
Other (please specify)memory clinic, Minds in Motion, Minds in Song, Boomer’s club	

The francophone results were different in that caregivers accessed education sessions and support groups but had not accessed one-on-one counselling.

When Anglophones were asked whether at diagnosis they found the information they were looking for, 55% responded yes, and 45% responded no. For those that did search for information, they went to:

Doctor's office	42.9%
Alzheimer Society	72.9%
Internet	55.7%
Through a community agency	12.9%
Other (please specify)friends, Mayo Clinic, AFTD, government	24.3%

100% of Francophones went to the Alzheimer Society for information.

In response to the question as to whether they reached out for emotional support at diagnosis, 59.4% and 33% of Francophones answered yes. They found support in the following places:

One on one professional support	52.0%
Support Group	62.7%
Web Based discussions	14.7%
Family and friends	73.3%
Other: Health care facilities, psychiatrist	

Again, there was a richness of responses to the survey with specific advice for the Alzheimer Society on the type of learning and support needed. There was a great deal of support for education, peer support, appropriate community services, YOD support groups, one-on-one counselling and community services. A sampling of quotes is provided below:

"Information on early onset, there is not that much available. People who listen and sympathize. More help on how to manage everything, it's just tough when your partner changes through AD and you have to take care of kids, to everything around the house that two people used to do and work."

"Because of the timing of the diagnosis - just before Christmas - We tried to keep everything calm and normal this past year. The classes provided good information. Now I am ready to start looking into the support groups more. The staff I spoke to at the Alzheimer's office we exceptional and I will start reaching out there again soon. The First Steps were a little difficult as most of the participants were elderly and already set up with pensions and both spouses or caregivers home. With Early onset I am still not sure how long I will be able to work and leave my spouse on his own. When I answered No to if all my questions were answered this is kind of where I still am unsure of the future?"

Summary of all Responses for Caregiver: Needs Identified

At diagnosis	Needs now	Advice for AS
Support: • Need of a mentor; Peer support; Counselling; That you are not alone; House visits for support; Support group, **Information:** • Community supports: Legal and financial issues; Communication strategies; How to educate your children about the disease; Mental stress and how to deal with it; Greater public awareness; that there are different forms of YOD; Self-education; Know the progression; Someone to call for small repairs and simple things; Education sessions; Activity programs.	**Support:** • Child support group; • Meeting other caregivers, activity programming for pwd; Family relationships **Information:** • Challenging behaviours; • Community resources; • Long Term Care/ Nursing Home issues; Financial assistance info; • Workplace/employment issues; Life expectancy; Moving to other provinces; access to appropriate services.	• In-person intake interview; • Support for kids; Train support group leaders; Self-advocacy; Need to talk about feelings; Educate GPs; Providing educational seminars on the web; A place where YOD can drop in for coffee and a chat; More day programs; Experienced knowledgeable navigator; Practical advice on-line; Educate insurance companies.

Face-to-face Facilitated Group Discussion:

A guided facilitation group discussion package was developed which was first piloted with a group of persons with YOD and caregivers. The final package was then used by six Alzheimer Societies with six persons having dementia and 31 caregivers participating. The groups were held between June and September.

There was a low uptake for persons with dementia and the reasons that were given for this were the time of year, as groups normally did not meet in the summertime, and persons saying they would participate but not showing up. The breakdown of participants is listed below:

Summary of Participants in Face-to-Face Facilitated Group Discussion

Site	PWD	Caregivers	Length of time supporting pwd
Alberta (Red Deer)	0	5	2 (2-5yr); 1 (6-10yr); 2 (more than 10)
York		6	2 (2-5); 4 (6-10yr)
Hamilton Halton (2 separate groups)	3	8	3 (2-5); 2 (6-10); 3 (more than 10)
Niagara	3	5	1 (Under 2 yr); 1 (6-10) 3 not reported
Toronto		7	Not reported
TOTAL	**6**	**31**	

The groups were asked two questions each:

1. Please take a moment to think about when the diagnosis of young onset dementia was first known to you and your experience with finding out information regarding the disease and what to do. Consider the information you gained, how you obtained it, what worked well, what didn't work well and share with us what advice you would give someone who is trying find out information that would meet your needs.
2. Please take a moment to think about what information (and supports) would be useful for you to know now. Consider the information (and support) you would like to receive, how you would like to receive it, how you learn best, and share with us your advice on content and method of information distribution and methods of support that would meet your needs.

In analyzing the responses, they are very similar to the ones obtained from the on-line survey. However, caregivers in the facilitated group discussions were much more specific in their responses as to what they would like to know now. One caregiver, who had a father with later onset dementia, compared her experiences to those she has with her husband who is diagnosed with early onset dementia. The main differences that this respondent points out are related to diagnosis and difficulty obtaining one; employment and finances; person looks young and physically active which public do not understand; support needed for children; activity programs not age specific; support groups and discussion groups not available for YOD caregivers; transportation issues because of age and not using assistive devices; and lack of understanding from health care workers.

Summary of all Responses for Caregiver: Needs Identified

	Person with dementia	Caregiver
What I needed when diagnosed	**Support:** • Need to be referred directly to the AS; Lots of information given; Having a family member present helps; Grieving; Need emotional support; **Information:** • Causes, symptoms, treatments, life expectancy, what I could do to help myself, how do I tell my family, resources available.	**Support:** • Need support from the beginning **Information:** • What to expect, how to provide care and support; • Health professionals need to know more about what is happening; Capacity assessment; Reading materials about the disease; Community services; Financial planning; Behaviour strategies
What I need now	**Support:** • A "web based discussion line" so people can use it any time of the day and night; Staying connected on social media; Activity and social programs; Support groups **Information:** • New trials and treatments; Financial counselling information; Role of sleep apnea; Importance of exercise; Music therapy; Dementia friendly places; • Family dynamics; Community supports.	**Support:** • One-on-one counselling; Support group; On-line chat forum; Help with caregiver stress **Information:** • Life expectancy; Symptoms that may developed; More on why meds are given, purpose etc.; Content such as POAs, LTC, Day Program, Disability Credit, funeral planning; Respite care options; Navigation of services; Communication strategies; • Provincially: How to navigate government programs for LTC and financial assistance; In Ontario: CCAC, Day Care, LTC. • Federally: CPP, Tax Credit; Registered Disability Savings Plan.

Health Care Professionals Survey

In the Anglophone population 106 persons started the survey with 59.4% of respondents finishing and in the francophone survey 72.7% of the 22 persons who started the survey completed it.

We asked health care professional what challenges they had faced in trying to support persons with YOD or their caregivers. The responses for both the Anglophone and francophone respondents were similar:

	English	French
Financial assistance	63.6%	72.7%
Challenging behaviours	77.3%	72.7%
Workplace/employment issues	65.2%	72.7%
Community resources	78.8% 55.6%	55.6%
Long term care/Nursing Home	60.6%	55.6%
Family relationships (e.g., changing roles, supporting children, sexuality and intimacy)	92.4%	94.4%
Other (please specify)	39.4%	

One respondent summarized it well:

> "Based on observations, media, informal support provided to friends experiencing this type of situation and other sources of information, it seems that many challenges relate to: (1) Financial assistance (i.e., finding information about financial assistance programs, form completion and navigating various systems to access such assistance); (2) Responsive behaviors; (3) Workplace/employment issues (e.g., lack of understanding by employers, lack of work accommodations by employers - for the person with dementia AND caregivers and lack of alternate, suitable employment options for people with young onset dementia who are capable of working in some roles); (4) Community resources (e.g., clinical counseling services for people with young onset dementia and their caregivers, system navigators, access to formal health services, volunteers/companions and qualified, private home services and/or health service providers); (5) Long term care/Nursing Home (e.g., staff in facilities knowledgeable and experienced in providing care to people with young onset dementia and meeting some of their unique needs); (6) Family relationships - All of the examples mentioned in this survey in addition to challenges families may experience when there are children/teens still living in the home, a person with young onset dementia, a spouse who is employed, and an aging parent or parents also requiring support; (7) Volunteer opportunities specific to this population - People in the early stages of young onset dementia may want to volunteer, and experience difficulty finding an agency willing to include them.; (8) Meaningful activities; and (8) Materials specific to young carers of persons with young onset dementia as well as support and community resources."

Summary of Health Care Professionals and Alzheimer Staff Response

At Diagnosis for pwd and caregiver	What is needed now for pwd and caregiver
Support: • You are not alone; Support groups; Peer support for children; One-on-one counselling; How to build a circle of support; Dealing with grief **Information:** • Basic info package; Workplace issues; Insurance info; POAs; Progression of disease; Family dynamics; How to communicate the diagnosis to others; Disability tax credit info; Dementia education; Maintaining a quality of life; Community services for those under 65 years; Heredity; Holistic/herbal medicine; Respite, Cognitive stimulation techniques.	**Support:**: • Social media; On-line chat; Group support, Counselling; Ambiguous grief support **Information:** • Community resources; Recreation support; Day programs that are appropriate; Preparing for LTC; Financial assistance information; Transportation strategies; System navigation help; Self -care for the caregiver; Challenging behaviours.

In response to the question, “What further learning and support resources do you need?” here are their responses:

- Literature specific to this population; Information Sheets
- Easy access for on-line opportunities for this population to connect with each other
- More training for staff on how to support the children of pwd
- Community resources specific to this population
- Recreation resources specific to this population
- Webinars: e.g. specific challenges faced by YOD
- Tool checklist for planning ahead, list of resources and websites that would help
- Advocacy for appropriate programs, care facilities etc.
- Information about financial and legal aspects that can affect YOD
- Specific support groups for YOD and their caregivers.

Survey of available National and International Learning and Support Resources:

A scan of available national and international learning and support resources was completed and divided into: Booklets; Fact Sheets or Information Sheets; Support Programs; and Web based programs. The Resource List includes the resources that Health Care Professionals said they used when supporting persons with YOD or their caregivers. The list does not include the core service programs of the Alzheimer Society for support (groups, one-on-one support). However, it is noted that in the analysis of the needs and what is currently available, specific support groups for YOD, their caregivers, their children are not readily available within the Federation. It is interesting to note that the following Alzheimer Societies are ones that have resources for YOD: Canada, Australia, United States, Scotland, and United Kingdom. This is not an exhaustive list and will need to be added to as information becomes available. Beside each resource are comments as to whether the content could be adapted into Federation wide resources. (See Appendix 2)

Recommendations - Young Onset Learning and Support Resources:

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 written 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.

Appendix 1: References

1. Bakker et al (Netherlands).Needs in Early Onset Dementia: A Qualitative Case from the NeedYD Study* American Journal of Alzheimer's Disease and Other Dementias 2010.
2. Baptista et al. Quality of life in young onset dementia: an updated systematic review. Trends Psychiatry Psychother. 2016:38(1) – 6-13.
3. Ducharme et al.The Unique Experiences of Spouses in Early Onset Dementia American Journal of Alzheimer's Disease and Other Dementias 2013.
4. Ducharme et al (Quebec).Unmet support needs of early-onset dementia family caregivers: a mixed-design study** BioMed Central 2014.
5. Gelman et al (US).Young Children in Early Onset AD Families: Gaps and Emerging Service Needs. American Journal of Alzheimer's Disease and Other Dementias 2011.
6. Hewitt et al. Does A Structured Gardening Programme Improve Well-Being In Young-Onset Dementia? Thrive 2011 www.thrive.org.uk
7. Hutchinson et al. The emotional well- being of young people having a parent with younger onset dementia. University of Sydney, Email: karen.hutchinson@sydney.edu.au
8. Johannessen et al, (Norway).A shifting sense of being: A secondary analysis and comparison of two qualitative studies on young-onset dementia. International Journal of Qualitative Studies. 2014.
9. Johannessen et al (Norway). Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors. Journal of Multidisciplinary Healthcare 2015.
10. Johannessen et al. Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: a qualitative follow-up study. International Journal of Qualitative Studies on Health and Well-being, 2016, 11: 30535.
11. Kendell et al (UK).With Semantic Dementia: A Case Study of One Family's Experience. Qualitative Health Research 2014, Vol. 24(3) 401–411
12. Massimo et al (U.S.). Caring for loved ones with frontotemporal degeneration: The lived experiences of spouses Geriatr Nurs. 2013 ; 34(4): 2013
13. Massimo et al (U.S.).Caring for Individuals with Early-Onset Dementia and Their Family Caregivers: The Perspective of Health Care Professionals. Geriatric Nurs. 2013; 34(4): 2013.
14. Merrilees et al (U.S.). Advanced Practice Nursing: Meeting the Caregiving Challenges for Families of Persons with Frontotemporal Dementia. Clin. Nurse Spec. 2010; 24(5): 245–251.
15. Phinney et al. Walking in the neighbourhood: Performing Social Citizenship in Dementia The International Journal of Social Research and Practice, Feb 2016.
16. Rosenberg et al. Readiness for Technology Use with People with Dementia: The Perspectives of Significant Others. Journal of Applied Gerontology 2011.
17. Shinagawa et al. Non-Pharmacological Management for Patients with Frontotemporal Dementia: A Systematic Review. Journal of Alzheimer's Disease 45 (2015) 283–293.
18. van Vliet et al (Netherlands).Impact of early onset dementia on caregivers: a review. International Journal of Geriatric Psychiatry 2010.
19. Wylie et al (Canada and U.S.).Management of Frontotemporal Dementia in Mental Health and Multidisciplinary Settings. Int. Rev Psychiatry2013 April; 25(2): 230–236.

Appendix 2: Young Onset Dementia: Resources available

Booklets	Comments
The Doctor thinks its FTD. Now what? A Guide for Managing a new Diagnosis (FTD). AFTD 2013 *https://www.theaftd.org/wp-content/.../AFTD-40-pg-booklet*	US content which contains legal and financial information
Approaching an unthinkable future: Understanding the support needs of people living with young onset dementia. Dementia Pathfinders 2014 *https://www.youngdementiauk.org/sites*	Alzheimer's Australia: includes driving, some services info, legal, payments for home help, which is specific to AU
The Milk's in the Oven. A booklet about dementia for children and young people. Mental Health Foundation UK. (2003) *https://www.mentalhealth.org.uk/publications/milks-oven*	UK: Content is about dementia in general not specifically about YOD. Good resource.
Supporting employees who are caring for someone with dementia. Carers UK 2014 *http://www.dementiaaction.org.uk/assets/0000/9168/Supporting_employees_who_are_caring_for_someone_with_dementia.pdf*	UK resource. For any form of dementia, not YOD specifically.
Understanding the Genetics of FTD: A Guide for Patients and their Families. AFTD 2012 *www.theaftd.org/wp.../03/Final-FTD-Genetics-Brochure-with-Cover-8.2.2012.pdf*	US booklet. Only deals with FTD
Younger People with Dementia Living well with your diagnosis. Alzheimer Scotland 2013 *www.alzscot.org/assets/0001/0841/YoungerOnsetDementia_FINAL.pdf*	Scotland, good booklet, some specific info for Scotland but generally good useful info. Could be re-vamped
What about the Kids Information for Parents with young children and teens. AFTD 2012 *www.theaftd.org/wp-content/uploads/2009/.../What-About-the-Kids-web-version.pdf*	US. Info. FTD specific but good info and nicely presented.
What is Young Onset dementia? Alzheimer's Society UK 2016 *https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=164*	UK booklet. Generic info. Could be used.
The Long and Lonely Road Insights into living with younger onset dementia Alzheimer Australia 2012 *https://fightdementia.org.au/files/20121016_The_Long_and_Lonely_Road.pdf*	Australia: good resource. Could be used
Family Ties: Dementia Early Onset Diagnosis Shatters Calgary Family's Dreams. Troy Media Vol 1 *Issue 2 www.troymedia.com/wp-content/uploads/2013/07/FT-Dementia.pdf*	Canadian, well done.
Self care for caregivers *http://www.phac-aspc.gc.ca/publicat/oes-bsu-02/pdf/self-care-caregivers_e.pdf*	Canadian Public Health Agency of Canada. generic
By Us For Us Guides: Booklets on various topics written by persons with dementia. Support Matters is the first guide in the Young Carer series of guides, written by and for young carers. *https://uwaterloo.ca/murray-alzheimer-research-and-education-program/*	MAREP, generic

Fact Sheets	Comments
Tips and strategies for people living with early onset. ASC *www.alzheimer.ca/en/...dementia/Dementias/early-onset-dementia/eod-tips-strategies*	Canadian
If you have younger- onset Alzheimer's disease. Alzheimer's Association *http://www.alz.org/i-have-alz/if-you-have-younger-onset-alzheimers.asp*	US: includes types of insurance and benefits that can help people with the disease. Need to re-vamp
Early onset dementia: Advice for Caregivers, NICE *www.nicenet.ca/tools-early-onset-dementia-advice-for-caregivers*	Canadian and generic
When Dementia is in the House, NICE *http://www.nicenet.ca/tools-when-dementia-is-in-the-house-advice-for-parents*	Canadian and generic
Early Planning and Younger Onset Dementia. Alzheimer Society Australia *https://fightdementia.org.au/...dementia/what-is-younger-onset-dementia/early-planning*	Australian and generic
NIA: Early-Onset Alzheimer's Disease: A Resource List *https://www.nia.nih.gov/alzheimers/early-onset-alzheimers-disease-resource-list*	Resources are listed and include different countries
Young Onset Dementia *http://www.alzheimer.ca/en/About-dementia/Dementias/young-onset-dementia*	Canadian
I have Younger Onset Dementia Fact Sheets *https://fightdementia.org.au/national/support-and-services/i-have-younger-onset-dementia*	Australian with different topics and fact sheets.
Younger People with dementia *https://www.alzheimers.org.uk/Younger_People_with_Dementia*	UK: video clip as well as Fact Sheets on different topics
Younger People with dementia *https://www.alzheimers.org.uk/Younger_People_with_Dementia*	Ontario: good info

Programs	Comments
Social clubs fill gap in dementia support, UBC News, May 2016 Paul's Club provides YOD members a friendly environment without medical or hospital associations. The focus is on having fun, so dementia is rarely mentioned or discussed. Social time, lunch at a restaurant, plus walking in the neighborhood. *news.ubc.ca/2016/05/03/social-clubs-fill-gap-in-dementia-support*	UBC
Adult Day Programs for YOD Innovative Adult-Day Programs Giving a Voice to Individuals with Early Onset Dementia. Waterloo-Wellington LHIN *www.waterloowellingtonlhin.on.ca/newsandstories/.../fall2014_newsletter.aspx*	Waterloo-Wellington
National YOD Key Worker Program The younger onset dementia key worker acts as a primary point of contact for people with younger onset dementia, their families and carers. The key worker provides information, support, counselling, advice and helps consumers effectively engage with services appropriate to their individual needs. *https://fightdementia.org.au/.../national-younger-onset-dementia-key-worker-program*	Australia
Minds in Motion Program A community based social program for early onset dementia *http://www.alzheimer.ca/en/on/We-can-help/Minds-In-Motion*	Canadian
The Boomers Club is a weekly, 8-session wellness program blending physical exercise, music, and brain stimulation activities, offered free of charge to people with Young Onset Dementia (YOD) and their care partners. Ekta Hattangady *(ehattangady@alzheimertoronto.org)*	AST
Structured Gardening Program for YOD *www.thrive.org.uk*	UK
Reitman's Carer Centre Therapeutic skills training intervention program for caregivers of pwd and health Professional Guide *http://www.mountsinai.on.ca/static/carers/*	Toronto
Minds in Song A program for persons with early to mid-stage dementia and their caregivers living in the community. No training or music background needed. *http://alzheimerottawa.ca/?s=Minds+in+Song*	Ottawa

Web based Programs	Comments
Chat room and bulletin board for teens AlzConnected is a free online community for everyone affected by Alzheimer's or another dementia. *https://www.alzconnected.org/*	USA
Dementia Advocacy and Support Service (DASN International: Message Board, email list, and Chat Room *www.alzinfo.org/alztalk/flashchat.php*	International
When Dementia is in the House: Early-onset dementia and its impact on families. Has Website for Teens with information for Parents created by Dr. Tiffany Chow and Katherine Nichols *http://lifeandminds.ca/whendementiaisinthehouse/*	Canadian
ASANT Café: discussion board for pwd and caregivers. Has a message board for Early Onset caregivers *https://www.asantcafe.ca/*	Canadian

Appendix 3: Young Onset Dementia: Analysis of Articles

Article	Key messages	Learning & Support	Needs
Bakker et al (Netherlands). Needs in Early Onset Dementia: A Qualitative Case From the NeedYD Study American Journal of Alzheimer's Disease and Other Dementias 2010.	Explores the experiences of a caregiver of a patient with early onset dementia (EOD) and the needs of patient and caregiver. (1) prolonged time to diagnosis, (2) a lack of fit between needs and services, (3) the strain of dedication to care versus the caregiver's own future perspective, (4) the need for response of health care services to changing individual preferences. Caregiver was forced to make all of the decisions concerning work, finances, the household, and the care of her husband.	Behavioural problems are distressing for the caregiver. Issues concerning work, financial difficulties, and the household, as spouse became increasingly unable to fulfill his roles as husband and financial provider. Services designed for the elderly people, did not adequately address the needs of the YOD patient. It is likely that services designed for the elderly people have more difficulty recognizing the specific needs of these younger people and have fewer resources to meet those needs.	Behavioural strategies Advocacy role: More appropriate services
Baptista, Maria Alice Tourinho et al. Quality of life in young onset dementia: an updated systematic review. Trends Psychiatry Psychother. 2016;38(1) – 6-13	Systematic review conducted using Cochrane, PubMed, SciELO, PsycINFO, Scopus and Thomson Reuters Web of Science electronic databases. Nine papers were reviewed. People with YOD rated their own QoL significantly hi¬gher than their caregivers. Greater awareness of disease among people with YOD is associated with better QoL in caregivers. A relationship was found between unmet needs and daytime activi¬ties, lack of companionship and difficulties with memory. Issues associated with unmet needs were prolonged time to diagnosis, available health services and lack of caregiver's own future pers¬pective.	Unmet needs were a recurring theme. Delayed diagnoses and the use of support services in these families, professional's lack of knowledge about YOD and limited availability of services are closely related to higher levels of unmet psychological needs in caregivers.	Educate health professionals Advocacy role: More appropriate services
Ducharme et al. The Unique Experiences of Spouses in Early Onset Dementia American Journal of Alzheimer's Disease and Other Dementias 2013	6 Themes: Managing behaviours; diagnosis; non-disclosure and denial; grief; changing roles; planning for future.	Information on caregiving role and preparation for changing family life and marital relationship; disruption of the intergenerational dynamic; disruptions on finances; loss of self-esteem; professional support tailored to specific needs; caregivers need to mobilize support of family and friends, case manager approach, professional interventions.	Information and education

Article	Key messages	Learning & Support	Needs
Ducharme et al (Quebec) Unmet support needs of early-onset dementia family caregivers: a mixed-design study BioMed Central 2014,	What often sets these types of dementia apart from late-onset types is the saliency of behavioural, praxic, executive and language problems over memory loss [1,6]. Moreover, the delay of diagnosis has been found to be longer for early-onset forms, daily reality of spouse family caregivers was marked primarily by the following: long quest for diagnosis; denial of diagnosis and non-disclosure to others; difficulty managing behavioural and psychological symptoms; grief over loss of spouse, married life and midlife projects; difficulties associated with assuming caregiver role prematurely and juggling this with other roles; and difficulties, planning for the future.	Receive more information on the type of help and financial assistance available and how to get it; information to help the family understand this disease that occurred at such an early age and to know how to disclose the diagnosis and its consequences to the immediate and extended family. The question of heredity, in particular, was often raised; innovative forms of support designed specifically for young-onset dementia caregivers are needed; assigning a nurse case manager to assess specific caregiver support needs at time of diagnostic disclosure and to ensure follow-up of the caregiver-care-recipient dyad, Moreover, various modalities (i.e., at home, by telephone, or online) of psycho-educational interventions to reduce stress. New forms of respite, too, have been suggested to meet the needs of caregivers in the workforce. Young people could take part in support groups specifically designed for them in the early stages of the illness. Support groups could also be organized for caregivers of like age going through similar situations.	Info on financial assistance Stigma: Diagnosis disclosure to others, stigma Info about heredity Case management Advocacy for Appropriate respite Teen support groups Caregiver support groups
Gelman et al (US) Young Children in Early Onset AD Families: Gaps and Emerging Service Needs. American Journal of Alzheimer's Disease and Other Dementias 2011	Feelings of shame, stress, fear and grief, loneliness, frustration, confusion, worry about getting AD. Are positive effects as well: strengthened relationship to caregiving parent, increased spiritual growth, increased coping skills.	Chat room and bulletin board for teens Group for parent and child Counselling Professional support	Chat room and bulletin board for teens (USA) Group for parent and child, Counselling Professional support
Peter Hewitt et al Does A Structured Gardening Programme Improve Well-Being In Young-Onset Dementia? Thrive 2011 www.thrive.org.uk	12 caregivers with YOD were recruited. This project set out to identify the benefits of a brief (2 hours/week) structured activity programme for people with YOD. Over a one year period the carers of the people with YOD found that the project had given participants a renewed sense of purpose and increased well-being while cognitive functioning declined. This study suggests that a meaningful guided activity programme can maintain or improve well-being in the presence of cognitive deterioration.	Horticulture therapy: community gardens Meaningful activity Enjoyable	Activity program

Article	Key messages	Learning & Support	Needs
Karen Hutchinson et al The emotional well- being of young people having a parent with younger onset dementia. University of Sydney, karen.hutchinson@sydney.edu.au	Semi-structured interviews with 12 young people who had a parent with YOD looking at their lived experiences between 10 – 24 years. Under four main themes: the emotional toll of caring, keeping the family together, grief and loss and psychological distress.	Stigma, lack of services, behavioural issues, potential genetic component, need for physical escape and resulting feelings of guilt, unfairness of diagnosis as cancer diagnosis is understood better by others, abandonment, anger, depression.	Family approach needed
Johannessen et al, (Norway). A shifting sense of being: A secondary analysis and comparison of two qualitative studies on young-onset dementia International Journal of Qualitative Studies. 2014	Coping with stigma; Finding meaning in their lives; Feeling of being alone: contributes to the reality that people with YOD may lose contact with society and may lose their ability to give meaning to life. Loss of social roles, such as being the financial provider or being a spouse or a parent, resulting in a loss of personal identity. The diagnostic process is longer than it is among the elderly, and causes more negative experiences and a greater burden for families	Increase awareness among experts, so that they listen more carefully to people with depression, anxiety, and cognitive impairment who have not reached the age of 65 and organize hospital departments and municipality services so that the period before receiving a diagnosis can be compressed in order to reduce or prevent stress-related health problems. Services must be offered to help persons with YOD to cope with their feelings of being alone and of isolation and to help them find other solutions to build meaning into their lives through relationship.	Advocacy role: Increase professional expertise re: recognition and diagnosis Advocacy role: Better services available for emotional support
Johannessen et al (Norway) Adult children of parents with young-onset dementia narrate the experiences of their youth through metaphors Journal of Multidisciplinary Healthcare 2015	Aim: to gain knowledge of how children experience the situation of growing up with a parent with dementia. The children may experience guilt and shame, and feel embar¬rassed when their friends meet their parent who is forgetful (AD) or exhibits a change in personality. The main task of youth is to develop a robust sense of self, identity, self-respect, and self-confidence – to become a vital actor in one's own life.16,17 In this process, the parents are mirrors for their children,18–20 being affirmative and directing, and serving as models for their children. Having a parent with dementia during youth in many ways deviates from what is considered a normal parent–child relationship.	Children can get into contact with service providers to receive tailored information and indi¬vidual follow-up needs to be established. Need special social and emotional support tailored to their situation – caring for a middle-aged person – during the development and course of the dementia disorder. Most children need a follow-up when the parent receives a dementia diagnosis Importance of peer support	Children need info and support Children need needs based emotional support from point of diagnosis Children's/teen support group

Article	Key messages	Learning & Support	Needs
Johannessen et al (Norway) Coping efforts and resilience among adult children who grew up with a parent with young-onset dementia: a qualitative follow-up study. International Journal of Qualitative Studies on Health and Well-being, 2016, 11: 30535	14 interviews with adult children of families with YOD. The goal of this study was to explore how adult children experienced the influence of their parents' dementia on their own development during adolescence; what coping efforts, strategies, and resources they employed; and how they evaluated the most recent changes in their life situation. They used different instrumental, cognitive, and emotional coping strategies, under the concept detachment which includes: moving apart, greater personal distance, and calmer emotional reactions. They developed resilience, when social support was offered by people they saw who listened to them and responded to their needs	The support systems for families of persons with YOD should be family-oriented (Gelman & Greer, 2011; Support systems are vital to help them establish themselves as individuals outside the family, gain recognition, maintain friendships, discover new arenas, and get on with their own lives. Knowledge, counselling etc.	Counselling One-on-one support Support groups Activities
Kendell et al (UK) With Semantic Dementia: A Case Study of One Family's Experience. Qualitative Health Research.2014, Vol. 24(3) 401–411	The themes within the care partner experience for one family living with semantic dementia, namely: (a) living with routines, (b) policing and protecting, (c) making connections, and (d) being adaptive and flexible.	Routines Safety concerns Communication strategies Flexibility	Info and support
Massimo et al (U.S.). Caring for loved ones with frontotemporal degeneration: The lived experiences of spouses Geriatr Nurs. 2013 ; 34(4): 2013	The emotional loss confounded by anger in response to embarrassing and socially inappropriate behaviors. Feelings of isolation and anger as caregivers assume new roles and reimagine their future. Identity and role change, isolation. Anger at behaviour and lack of emotional responsiveness.	Greater understanding of behavioral interpretations and associated emotional responses could contribute to a more complete picture of the caregiving experience for these couples, especially when anger and disruption of emotional attachment and connection are each significant sources of burden. Special attention and support should be offered to FTD caregivers early in the disease process to identify coping strategies, provide alternate interpretations and facilitate articulation of the loss of shared. meanings and emotional capacities between caregivers and persons living with FTD.	Info and support needed

Article	Key messages	Learning & Support	Needs
Massimo et al (U.S.) Caring for Individuals with Early-Onset Dementia and Their Family Caregivers: The Perspective of Health Care Professionals. Geriatric Nurs. 2013 ; 34(4): 2013	Aim of this qualitative study was to document the experiences and service needs of patients and their family caregivers for optimal clinical management of early-onset dementia from the perspective of health care professionals.	1) identification with the difficult experiences of caregivers and powerlessness in view of the lack of services; 2) gaps in the care and services offered, including the lack of clinical tools to ensure that patients under age 65 were diagnosed and received follow-up care, and 3) solutions for care and services that were tailored to the needs of the caregiver-patient dyads and health care professionals, the most important being that the residual abilities of younger patients be taken into account, that flexible forms of respite be offered to family caregivers and that training be provided to health care professionals.	Family –centered approach Psychosocial intervention offered at home: telephone, on-line intervention Education for health care professionals
Merrilees et al (U.S.). Advanced Practice Nursing: Meeting the Caregiving Challenges for Families of Persons with Frontotemporal Dementia. Clin Nurse Spec. 2010 ; 24(5): 245–251	Issues faced by caregivers are organized into 6 categories: diagnosis, behavioral symptoms, function, communication, long term management and care, and maintenance of the caregiver's emotional and physical health. Financial hardships. Existing services not suitable to meet needs of YOD Relationships with spouses and children may suffer profound disruption. Families may be embarrassed by inappropriate behaviors and relationships in the family often suffer as a result of odd and upsetting behaviors.	Diagnosis: A referral to a specialty clinic or center helps future planning and decision-making. Placement needs: Behavioral: Disinhibition, lack of judgement, need coping strategies LTC: Caregivers have described the difficulties in finding placement in long term care (LTC) facilities that are reluctant to accept younger patients exhibiting social and personal misconduct.	Advocacy role: Better diagnosis Placement issues. Need to be appropriate for younger age
Phinney et al.Walking in the Neighbourhood: Performing Social Citizenship in Dementia The International Journal of Social Research and Practice, Feb 2016	Paul's Club is an independent social recreation group for people who have young onset dementia. Meets one to three days a week from 10 am-4 pm. The day includes meeting for coffee and snacks, casual conversation, a group activity such as yoga, lunch at a restaurant and then a walk around the neighburhood.	Normalizing life, maintaining social dignity especially when out walking, raises awareness that it is possible to live well with dementia which builds social capital and contributes to the development of dementia friendly communities.	Activity program
Rosenberg et al Readiness for Technology Use With People With Dementia: The Perspectives of Significant Others. Journal of Applied Gerontology 2011	Explores how significant others relate to technology and to their relatives with dementia as technology users. The focus is on both their own use of technology as significant others and the use of technology by their relatives with dementia. To develop appropriate means of support for people with dementia through technology, involving significant others	Technology should be familiar technology also needed to be simple to use if a person with dementia were to be able to use it. Needs to be equipped with intelligent functions that prevented the user from making mistakes and preferably also could correct possible errors	Use of technology needs to be simple and auto correction functionality

Article	Key messages	Learning & Support	Needs
Shinagawa et al Non-Pharmacological Management for Patients with Frontotemporal Dementia:A Systematic Review. Journal of Alzheimer's Disease 45 (2015) 283–293	Review the literature on non-pharmacological management for FTD and to propose directions for future research, with reference to findings; to examine effects of non-pharmacological interventions on behavioral symptoms of FTD.	Behavioral management; behavioural therapy, redirection, retraining, Environmental strategies, Safety issues; physical, structured schedule, Hyperorality and swallowing Financial issues: neglecting bills, impulsive spending, compulsions, and poor judgment, as well as costs associated with providing care Driving issues: poor judgments and antisocial behavioral problems, including speeding, impulsive acts, and disregard for traffic rules Caregiver support: delay to proper diagnosis; limited advocacy within professions; lack of knowledge and training by health care; insufficient funding; depression and stress	Challenging behaviours Info: financial issues Education health care professionals
van Vliet et al (Netherlands) Impact of early onset dementia on caregivers: a review. International Journal of Geriatric Psychiatry 2010	Review of 17 articles The majority of EOD caregivers experienced depression, ranging from mild to severe. Spousal caregivers were more at risk of experiencing loneliness compared with other EOD caregivers. Caregivers experienced trouble with responding to their spouse in the right way, they experienced feelings of sexual frustration, or difficulties with forming new relationships, with accompanying feelings of guilt, or with issues of selfhood and self-esteem. Fifty one per cent of the caregivers even reported that their children had been in conflict with their ill parent. This occurred more often with an affected father than with a mother, and was more common in the case of a relatively young parent. A patient's young age was also associated with children experiencing difficulties at school In the majority of caregivers, the illness had an effect on their employment, resulting in retirement or reduced working hours. Problems at work were recurrently found to lead to financial difficulties and could also lead to a lack of meaningful occupation in caregivers. Female EOD caregivers and younger caregivers appeared to be at higher risk for adverse psychological effects.	Caregivers of institutionalized patients had a low morale at baseline and that time-limited group counseling had a positive effect on morale. Relationship issue: marital Support for children: in home and monitoring at school Financial issues/reduced employment of caregiver	Counselling and group therapy Support Information about financial assistance

Article	Key messages	Learning & Support	Needs
Wylie et al (Canada and U.S.). Management of Frontotemporal Dementia in Mental Health and Multidisciplinary Settings. Int Rev Psychiatry2013 April ; 25(2): 230–236	Describes practical issues in the management of FTD, specifically the issues that clinicians, patients and their families face in managing this disease. Barriers to specialist care exist, including the afflicted individual's resistance, family disagreement about a course of action, dearth of specialists, lack of proximity, and type of insurance coverage. However even for those who do not attend a specialist clinic, print materials about FTD and information about support groups and advocacy organizations (particularly the Association for Frontotemporal Degeneration, AFTD).offered. The family and carers must learn about the disease they are confronting. The deterioration in social functioning, personality and behavior seen in FTD has deleterious effects on relationships Thus dementia in FTD can bring about an abrupt loss or reduction in family income, which in turn causes abrupt financial distress	Diagnosis is an issue and needs to be done early in the disease for treatment/management Opportunities for education occur throughout the illness and can be offered incrementally and through various sources and formats (e.g., reading materials, websites, support groups and referral to advocacy organizations). Issues: in the sense of personal loss, being regularly confronted with asocial and offensive behaviors, raising dependent children, managing financial pressures, and maintaining employment. Support groups comprised of FTD caregivers can be helpful to carers to discuss issues related to the illness and to feel less isolated and integrated into a community of carers	Advocacy role Getting a diagnosis Education in various formats Coping with emotional issues of caregivers FTD Support groups