



# Young Onset Dementia

## Facilitators Resource Manual

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## Chapter 1: Introduction

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### **Purpose of the manual:**

This Resource Manual is a practical, user-friendly guide for Alzheimer Societies and other community organizations to help them develop and implement social/support groups for persons with young onset dementia and their families. The Manual provides strategies and resources on how to plan, implement, and evaluate groups based on best practices and available research.

This manual is a work in progress and as new processes are developed, it will be updated. Electronic copies of this manual will be made available and reviewed every two years or more frequently as new information becomes available.

In the Resources Section, you will find a Young Onset Dementia Strengths and Strategies Interview Form.

This form was adapted from the Meaningful Engagement of People with Dementia Resource Guide, Alzheimer Society of Canada (ASC) 2015 ([www.alzheimer.ca/meaningfulengagement](http://www.alzheimer.ca/meaningfulengagement)). It focuses on the strengths and abilities of the person with dementia as well as supportive strategies that will help the person achieve success.

### **Background:**

In 2016, ASC presented a report that analyzed the gaps of available learning and support resources for people with young onset dementia living in Canada. The report incorporated feedback from people with young onset dementia, caregivers and health care professionals. The full report is available on ASC's website at [www.alzheimer.ca/youngonset](http://www.alzheimer.ca/youngonset).

Following the dissemination of that report, Alzheimer Societies across Canada were asked to identify programs that were currently being offered for people with young onset dementia. Using the knowledge and expertise of those currently providing social/support groups, a Working Group was formed to guide the development of a Resource Manual so that Alzheimer Societies and other organizations across the country will have tools and information to create groups in their own communities.

### **What is Young Onset Dementia?**

Young onset dementia is defined as dementia that is diagnosed before the age of 65 years. "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). This number represents an estimated 2 – 8% of all dementias. While young onset dementia is rare, we know that the personal and social consequences can be much different than those experienced by persons with dementia who have been diagnosed later in life.

“In our middle years, our lives are full; we have many roles and responsibilities at work and home. Other people rely on us, and we have plans for the future, including a retirement to enjoy the fruits of our labours and focus on the things we value in life. Imagine being told you have a disease which everyone around you associates with old age.” (*Approaching an Unthinkable Future: Understanding the Support Needs of people living with young onset dementia. Dementia Pathfinders Community Interest Company 2015*)

### Family Impact:

A diagnosis of young onset dementia can have a major impact on employment, finances and family relationships. Many younger people with dementia report that the diagnosis was harder to accept because it was completely unexpected and had come “at the wrong time” in their lives. As well as fear about the future, the diagnosis can cause feelings of loss, guilt or anger. The whole family finds it has to adjust to a wide range of changes. In general, younger people with dementia are more likely to:

- be employed at the time of diagnosis.
- have a partner who still works.
- have dependent children.
- have older parents to care for.
- have heavy financial commitments, such as a mortgage.
- be more physically fit and active.
- have a rarer and genetic form of dementia.

## Chapter One: Key Points

- Personal and social consequences of persons with young onset dementia can be much different than those with later onset dementia.
- A diagnosis of young onset dementia can have a major impact on employment, finances and family relationships.
- Persons with young onset dementia usually have many responsibilities and plans for the future.

## Chapter 2: Issues living with young onset dementia

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### Defining the issues

A diagnosis of young onset dementia comes with unique challenges for the person with dementia, and their family members. The following challenges have been derived from research studies as well as the ASC Young Onset Gap Analysis survey (See Reference section):

- **Social isolation:** friends and family and the broader community may find it difficult to accept or understand that dementia can occur at a young age. Because of this, people with young onset dementia may lack social support in their communities, resulting in feelings of social isolation.
- **Disengagement from activities:** the person may have poor self-esteem, reduced sense of competency and sense of purpose. Caregivers may feel overwhelmed and socially isolated.
- **Family relationships:** such as changing roles, supporting children, sexuality and intimacy, caring for aged parents.
- **Managing symptoms:** such as behaviours and communication difficulties.
- **Workplace/employment issues:** may need to retire early or ask for accommodation for changing abilities.
- **Financial commitments and challenges:** mortgages, tuition fees, future planning, where to access assistance, reduced or no employment income.
- Caregivers who are still working with younger children possibly still living at home.
- Support for children/youth.

In the 2016 ASC Young Onset Dementia Gap Analysis survey, persons with dementia and their caregivers said they needed:

- Support, such as separate support groups for people with young onset dementia and their caregivers.
- Web based interventions so individuals can join from a distance.
- One-on-one counselling.
- Family based counselling and how to access.
- A listing of activity/social programs that are suitable for persons with young onset dementia and their caregivers. These types of programs provide meaning and fulfilment and help to normalize their lives.

“In 2009 we eventually got a diagnosis of Pick’s disease. I became a full-time carer. I have to watch out for her 24 hours a day. For me it’s very lonely. Your life shrinks. Our families live quite far away and Elaine has difficulty holding a conversation. The worst time is in the evening, especially in winter. We rarely socialise now because she gets agitated in new places or with other people in the house.”  
(*Approaching an Unthinkable Future: Understanding the Support Needs of people living with young onset dementia. Dementia Pathfinders Community Interest Company 2015*)

## Case studies

When reading the following case study think about how Ron and Sandy's needs differ from someone who was diagnosed later in life. What type of support can your organization offer to help them manage their unique challenges?

Ron Walker was diagnosed with dementia at the age of 54 years.

"When Ron was first diagnosed, he was angry and frustrated. He was a successful executive with a local importing firm. He knew something was wrong, but he couldn't see why. His doctor said it was low testosterone, which he treated, but it didn't help. After 18 months, he finally saw a neurologist who made the diagnosis. For Ron it was a relief. "I knew I was not going mad, that I had instead an illness."

Ron became a voracious reader and seeker of information. He wanted to know what young onset Alzheimer's disease was and what to expect. He also wanted to know how he could cope better with the disease. He would read the newspapers, talk to staff at the local Alzheimer Society, and attend workshops. There were times at night when he could not sleep. He would be up pacing the floor and would become more agitated. Barry's wife felt he would have benefitted from someone to "chat" with at those times."

Sandy Walker has personal experience as a caregiver and support for her husband Ron who was diagnosed with young onset Alzheimer's disease six years ago. They have two teenage children.

"Before Ron was diagnosed, he would come home from work feeling frustrated and angry with himself. Those times were a nightmare. We never knew from one day to the next what to expect. When you have a successful man at the peak of his career who is suddenly unable to be the breadwinner, it is distressing but understandable that he is most likely going to take out his frustration on those nearest and dearest to him. He finally had to resign and it was very traumatic. I have been a housewife and homemaker for our married life. Taking care of two teenage children can be challenging at times. We have had to come to grips with reduced income, creating concerns about things like mortgages and the costs of everyday living. The children are finding it difficult to see the changes in their father and its effect on their everyday life. We are learning to live one day at a time."

## Chapter Two: Key Points

- Unique challenges arise for both the person with young onset dementia and their caregivers. Financial planning and where to access resources are very important.
- Caregivers and family members need support, information, access to programs and services, and opportunities for respite.
- It is important for everyone's self-esteem to offer programs that 'normalize' life.

## Chapter 3: Why young onset dementia groups can be helpful

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The diagnosis and symptoms of young onset dementia with associated losses in abilities may lead to changes in self-identity and feelings of powerlessness. As well, changes in abilities and the stigma of dementia may lead to losses and changes in social relationships and avoidance of others. These social challenges go beyond those of older people living with dementia and often result in an even greater negative impact on their lives. The loss of meaningful activity, often the result of losing their job, is particularly challenging for people with young onset dementia. Regaining control by reconnecting and being with others in similar situations can be a very important means of support.

### Value of groups:

Peer support helps to reduce social isolation, and helps the person feel that they are not alone. Groups which provide meaningful activities help to increase a sense of control and independence, which again helps to reduce social isolation. Maintaining autonomy is very important for people with young onset dementia. Although some abilities are reduced or lost, quality of life can be maintained by “normalizing activities” as much as possible. Research shows that there is a strong sense that people with young onset dementia do not believe that a dementia diagnosis means their lives are over. Many want to stay engaged with others, to take part in meaningful activity and to be included in society. In short, they want to be treated as ‘normal human beings’.

Just because your life has taken a different fork in the road does not mean that it is a dead end; go off the path and enjoy whatever adventure you can find and seek what it can bring to your lives. It's a big world out there and there are others on the paths to help you, or head you in another direction. You are not lost, you are just on a different path. *(Caregiver and member of Alzheimer Society of Kingston, Frontenac, Lennox and Addington's Young Onset Living with Dementia Group group (YOLD)).*

Research has shown that groups help people cope better with their illness. In these groups, feelings are often validated, social isolation is reduced and experiences are normalized. But to feel this connection, it is critical that people see the others in the group as similar to themselves. A group that is specifically for people with young onset dementia enables its members to support each other and possibly find new ways of dealing with a particular problem. Peer groups can provide participants with a sense of satisfaction from helping others.

### Types of groups

**Support groups** for those with young onset dementia as well as support groups for caregivers

- Provide information and support where participants raise issues that they are experiencing. Through sharing with peers, they discover solutions and feel less isolated, experiences are normalized, gain a sense of empowerment and control, and improve their coping skills.



### Online/web-based support groups

- Online/web-based support groups are one way to ensure that people living with dementia who have trouble travelling or who live in small communities are able to connect with others who have a similar diagnosis. In many provinces in Canada, people have to drive several hours to a city centre.
- Online/web-based support is different than web-based Forums in that support groups have facilitators or leaders whereas Forums provide peer to peer support.

### Social groups

- Facilitate peer support while focusing on social and recreational activities selected by the participants.
- The goal is to keep the focus off dementia, while creating a place of belonging, and a sense of community. Being in social groups for hobbies and interests helps those with young onset dementia feel that they are still included within their communities.

“The most important part of Paul’s Club is the “community” it offers to my husband – a place where he feels he belongs”. (*Spouse of a member of Paul’s Club, Vancouver*)

### Adult Day Programs

Adult Day Programs can be very beneficial for caregivers and those living with young onset dementia. Persons with young onset dementia may be integrated into existing day programs, or join a separate day program just for them. In either case, individualized care planning based on the needs of the person is provided.

Support for the caregiver and children are very important, whether it is provided through a separate support group or within a social club where both the person with young onset dementia and the caregiver are included. These groups may be available through the Alzheimer Society or other community organizations.

**Chapter Three:  
Key Points**

- Groups for people with young onset dementia help participants cope better with their illness; feelings are validated, social isolation is reduced and experiences are normalized.
- Social/support groups may be available through the Alzheimer Society or community organizations.
- Descriptions of a successful group for people with young onset dementia and/or their caregiver include: client-driven; strengths based; flexible; relationship centered; inclusive and non-judgemental; and promotes self-esteem and confidence.
- Online/web-based groups are needed so people can join from a distance and/or at a time that is right for them.

**Philosophy of successful groups**

Successful groups are ones that are person and family centred, knowing who the participant is and where they are in their “journey”. The following descriptions of a successful group for young onset dementia and/or their caregiver are based on research as well as evaluations from participants of existing groups:

	Description
<b>Participant driven</b>	Participants own the program; people are empowered to plan and lead the program, if they wish to do so. Facilitators ask for feedback, noting what works or doesn’t and incorporating or modifying the program accordingly.
<b>Strengths-based</b>	Participants are asked what they can still do, what their interests were before, and identify their current interests. Activities may be different than those of an older population. For example, music choices may be different. Physical abilities may be different. If an online/web-based group is offered, participants need to have the capacity to utilize the technology.
<b>Flexible</b>	Programming may need to be adjusted based on the strengths and needs of the group. Use of dementia specific programming allows participants to be “failure free” and focuses on the process and not on the outcome.
<b>Relationship-centred</b>	Activities are planned which allow people to get to know each other. Facilitators participate as much as the people in the group. If there are volunteers, they are encouraged to do the same.
<b>Inclusive and non-judgemental</b>	Varying abilities, cultures, genders, and sexual orientation are accommodated. The group is welcoming of needs of those with young onset dementia and all persons are respected and treated with dignity. It is a safe place to voice opinions.
<b>Promotes self-esteem, confidence</b>	Process-oriented activities are included that focus on spending time together, where participants enjoy meaningful activities and feel wanted and alive (E.g. use of music, arts, story-telling, etc.) Opportunities for advocacy are included.

## Chapter 4: Assessing needs and what to offer

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There are different ways that you can assess whether your organization should offer a social /support group for young onset dementia.

- Your own observations: Do you have persons under the age of 65 years in existing groups who don't seem to "fit into" the discussions and activities currently being offered?
- Reviewing your database: Are you seeing an increasing number of persons with young onset dementia and caregivers who are not accessing your programs?
- Connecting with community agencies such as Memory Clinics, diagnostic centres, community clinics, senior centres to determine whether there is a need for programming for those under 65 years.
- Conducting needs assessments through focus groups, simple surveys, personal interviews, or connecting with community agencies will help to determine needs and interest in forming a group. It will also help to determine the critical mass for offering a particular type of group.
- What groups are currently available for young onset dementia in your community? Could you collaborate with an existing program to enhance what is being offered?
- The next step is to determine what type of group to offer and whether the group will be for persons with young onset dementia or for both persons with young onset dementia and their caregivers.

What is it that potential participants are wanting? Is it:

- Information
- Support
- Social activities
- Community outings
- All of the above?

Who is the group for? Is your target population a person with young onset dementia or both the person with dementia and caregiver?

- Will they attend in person or through an online/web-based group?

If responses indicate that there is a need for information and peer support, then a support group may be the best option. If responses indicate that there is a need for more social and recreational type activities and doing things together, then a social group may be a consideration. If responses indicate that geography is an issue and that people can't attend because of distance, then an on-line/ web-based group could be a consideration.

I approached the Alzheimer Society to see what programs they had for my husband. They had lots of groups but none that cater to the younger person. My husband likes hard rock music and loves a sip of fine whiskey, not sing a longs and tea. So I suggested that we start a group geared towards those young and/or young at heart. I had to return 4 months later and make the suggestion again, I was persistent as we needed to learn and adapt to our new way of life. *(Caregiver and member of Alzheimer Society of Kingston, Frontenac, Lennox and Addington's YOLD group)*

### Determining eligibility requirements

This is an important step as it will set the stage for forming your group. Here are a few questions for consideration:

- Will you allow someone who is in their 70s to join this group? Or will you be strict about participants being under age 65? Will you accept persons who are 'young at heart'?
- Will you accept clients who are at the middle stage of their dementia? [www.alzheimer.ca/stages](http://www.alzheimer.ca/stages)
- Will you accept clients who experience incontinence and need toileting support?
- What behaviours are acceptable?
- Will you accept people with only Alzheimer's disease or will you consider other dementias? (Note: many people with young onset dementia have a form of dementia other than Alzheimer's disease. To read more, visit "Other dementias" at [www.alzheimer.ca/brochures](http://www.alzheimer.ca/brochures))
- Will you accept someone who has an unclear or unconfirmed diagnosis? For example, would you accept a 37-year old man who has stroke-related cognitive issues and where this is the only group which serves young people and is able to meet the needs of his family? Is a diagnosis required?
- What if the person with young onset dementia wants to bring their children to the group?
- What criteria will you use to decide if a member is no longer appropriate for the group? How will you communicate this and when? Do you have other support opportunities to offer the person?

### Some examples of eligibility requirement statements:

- Diagnosed with a dementia before the age of 65 years.
- Have a valid health card where required.
- Willing and able to participate safely in group programming.
- Medically stable.
- Behaviours that are manageable in a group setting.
- Independent with activities of daily living (and able to self- manage medications with reminders).
- Not actively exit-seeking.
- Smokers must agree to refrain from smoking for the duration of the program.
- Program eligibility is determined by the Health Authority (adult day program setting).
- Able to discuss their diagnosis and the impact it has on their life (support group setting).

### Is the type of dementia an issue?

In general, people with different types of young onset dementia can be welcomed into young onset dementia groups. The issue is whether the changes in cognitive and functional abilities can be supported within the group setting. Some dementias, such as frontotemporal dementia, present specific challenges. For example, frontotemporal dementia can create issues for programming as communication challenges are common. It is important to obtain information during the Intake Interview as to the strengths and abilities of potential participants so that programming can be adapted to their needs.

Remember that dementia affects each person differently. Common challenges that people with dementia may face will vary from individual to individual and will also vary on different days of the week as well as times of the day. On some days, people will be better at participating than other days, just like anyone else.

For the person with dementia, research tells us that:

- Persons with memory loss may feel uncertain about themselves and their behaviour as symptoms fluctuate (Phinney, 1998).
- The world can seem overwhelming as rhythms slow down (Mitchell et al., 2006) so they may be hesitant to ask. Be receptive.
- Conversation slows down and persons with dementia may feel scared when they cannot remember things (Phinney & Chesla, 2003).
- Doing simple tasks can be tiring, and when fatigue sets in, thinking and speech slow down even further (Truscott, 2003).

These changes can impact not only enjoyment of activities, but also self-esteem and self-concept. With support and encouragement, you can help persons with young onset dementia to feel more confident about themselves and their participation.

*"My husband has had many different labels of diagnosis by several doctors in the neurological field. The broader term Young Onset Dementia and the latest being Alzheimer's with Primary Progressive Aphasia. What attracted us to the group initially was that it was specifically for people who were under the age of 65 years and their care partners. My husband and I participate in Boomers Club together. We have learned through time that this specific group for young onset dementia has given us connectivity to others our age that are facing similar challenges and age related issues.." (Caregiver and member of Alzheimer Society of Toronto's Boomer's Club)*

## Goals of the program

The overall goal of young onset dementia groups is to reduce social isolation and improve quality of life. Generally, it is important to:

- Provide a group where all are included which is accessible, safe, comfortable, and welcoming.
- Create a circle of support and comradery where all experience a sense of belonging.
- Learn and explore new talents.
- Develop friendships and enhance quality of life.

The type of group offered will influence the specific program goals and how they will be achieved. For example, a support group may focus more on learning and peer support, whereas a social group may focus more on group activities such as physical activity, arts, eating, etc. Remember that people with dementia should always be involved in the planning of the program and be the ones who set program goals whenever possible.

There's a routine there, like when I was working. It reminds me that I have some strengths to offer, qualities I can share, experiences that others find interesting. It reminds me that I am still me. It's a welcomed break from my struggles with my brain. *(Member of Alzheimer Society of Kingston, Frontenac, Lennox and Addington's YOLD group)*

## Transitioning out of young onset dementia groups

As their condition progresses, the person with young onset dementia will lose more of their cognitive and functional abilities and will not be able to fully participate in a social/support group. It is good practice to let the person with young onset dementia and their caregiver know during the Intake process that you will engage them in an open dialogue about this, as changes arise. Sometimes the changes will be related to behaviours that seem to escalate in a group setting. Or the person with dementia may not want to come to the group but the family insists that they should. You should encourage the person with young onset dementia to talk with you if they notice that it is becoming more difficult for them to participate.

It would be helpful if the eligibility requirements as well as criteria for transitioning out of the group were in writing and signed by the person with young onset dementia and/or caregiver during the intake process. These requirements will be a guideline for your conversation. When this conversation takes place, it would be helpful if you have some suggestions and contact information regarding other programs in the community that may be available for the person, such as Adult Day Programs.

### Example of criteria for transitioning out of on-line/web based support group in Saskatchewan:

A discharge occurs when the facilitators feel that the participant is no longer able to benefit from attending the group. This may occur if the dementia has progressed significantly, or if the client chooses to step away from the group.

Example of transitioning out of a young onset dementia group in an adult day program:

- If behaviours are not manageable.
- 2-person physical transfer required.
- Bowel incontinence (regular).

### Meeting the needs of children/youth

Children/youth need to be able to talk about their feelings and fears. They too are experiencing ambiguous losses and changing roles within their family. Some suggestions for providing support are:

- If a children's support group is not available, then provide information about chat lines. For example: Alzheimer Society of Toronto Young Carers Meet Up: [www.alz.to](http://www.alz.to) AlzConnected: [www.alzconnected.org](http://www.alzconnected.org)
- Investigate other children/youth programs in the area such as Big Brothers and Big Sisters programs or programs like the Young Carers Program in Niagara: [www.powerhouseproject.ca](http://www.powerhouseproject.ca)
- One-on-one counselling and follow up could be offered by your organization or through another community organization.
- Provide a checklist for parents on available print and non-print resources, what behaviours to look for in their children/youth that would be cause for concern, and resources and strategies that can be helpful in managing these.

### Chapter Four: Key Points

- Assess needs of potential participants and determine type of group.
- Determine eligibility requirements and criteria for transitioning out.
- Set goals for the group.
- Develop a plan for transitioning someone out of the group.
- Identify resources and provide a list with contact information that could be offered to children/youth.

## Chapter 5: Special considerations for planning and implementing an on-line/web based group

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### **Determining the “hub” site or platform for an online group:**

When deciding which “hub” site or platform to use, remember that online/web-based support groups require facilitation and technical support. It is important to consider who will manage the web-based supports, who will pay for ongoing platform costs, and who will facilitate.

Telehealth, a government platform, provides free video conferencing and they have dedicated staff that provides technical support. There are a number of Telehealth sites throughout each province, allowing participants in rural areas with no Alzheimer Society services to participate. If your own staff do not have the technical ability to support participants, or if participants do not have their own computers or internet access, this may be a viable option. Participants need to travel to the video-conferencing location.

If you have participants who have the required technology capabilities, and you have staff that can support an on-line group, there are home-based platforms available such as Adobe Connect, Zoom Online video conferencing, Freebridge, and Skype. Contact an expert in your area to obtain their advice on which platform meets your needs. You will need to find out whether there is a cost for setting up and using a home-based platform and, if there is a cost, if it can be incorporated into your operating budget.

### **Training needs of facilitators**

The training needs of facilitators will depend upon whether the platform you are using is operated by an outside organization or whether you are setting up your own. If you are using an outside organization such as Telehealth, they have dedicated staff that provides technology support. Your role would be to make sure participants are able to travel to the on-site location and then facilitate the group meeting. If you are using a home-based meeting platform, the training needs of facilitators will change. Facilitators will need to know how the technology works and be able to problem-solve connection issues from a distance. The company that is providing the home-based platform will have training aids to assist facilitators.

### **Assessing the technology level of potential participants**

Before considering setting up a home-based meeting platform, it is important to consider the:

- Types of technology used by the target audience
- Speed of Internet services
- Skill level of the target audience



This information could be obtained through a survey which is distributed by email to potential participants. Possible survey questions to use include:

- Which methods do you use to access the Internet? Cell phone? Other mobile device such as an iPad or tablet? Computer?
- Does your device (cell phone, iPad or tablet, computer) have internal speakers? A microphone?
- What type of Internet access do you have? Dial-up? High-speed? Is your intranet service fast enough to watch streaming videos such as news broadcasts and movies?
- How would you describe your computer or technology skills? (Poor, Fair, Good, Excellent)
- Does your device/computer have a webcam? (Camera to capture video of you). Are you comfortable using the webcam feature on your device?
- Are you comfortable changing your device's settings, such as enabling pop-ups and adjusting audio sources?
- Are you comfortable uploading files? Are you comfortable downloading files?
- What do you do when you have difficulty with your device or computer?
- Did you complete the survey independently, with a little help, or did a family member/friend complete the survey on your behalf?

### **Facilitation and follow-up with group members**

There are a number of things to consider when implementing a home-based meeting platform:

- Once you have decided on the platform for your online meeting, it is important that participants are provided with clear instructions on how to operate the technology, the steps to take in order to join the meeting, and whom to call if they need assistance. Ensure that these instructions are both mailed and emailed to the participant, using bullet points and consider using # 14 Courier font.
- Once the group has started, some participants may still experience difficulty connecting. Contact them and try to identify any technology issues so that connection can be facilitated.
- Monitoring group process: Online support groups lack the body language and verbal cues of participants that help determine how a support group is progressing. Other ways need to be used to monitor the group process. Here are a few suggestions:
  - Ask participants how they think the meeting is progressing. Use phone, email or a check-in topic.
  - Provide a means for participants to ask you questions and broadcast the responses.
  - Establish regular check points to discuss how things are going.
- When the on-line support group first begins, you may find that you will need to facilitate the conversation more until participants become comfortable with each other, and conversation flows much more organically. For the first meeting, you may wish to have a topic ready to discuss and let the participants know beforehand.

## Chapter Five: Key Points

- For an online/web-based support group, consider who will provide technology support, who will pay for ongoing platform costs, and who will facilitate.
- There are platforms available that provide free video conferencing and dedicated staff for technical support.
- For a home-based meeting platform, assess the technology capabilities of participants and provide participants and staff with training.
- Body language and verbal cues that help assess group process are not available with online/web-based support groups. Other assessment measures are needed.
- Collaboration with community organizations is beneficial for raising awareness of your needs and the needs of persons with young onset dementia and their caregivers.

## Collaboration with community

Creating awareness of your online support group with community organizations is important. They will be able to refer clients to your group, may be able to provide assistance in setting up a platform or provide a site for video conferencing, and may help to create awareness of your group with other networks. By creating awareness of your support group with community organizations, you not only help to raise awareness of the needs of persons with young onset dementia and their caregivers, but you will also raise interest among community organizations on how they can provide support.

## Chapter 6: Program Planning

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### Identifying the participants

Will the young onset dementia group be for the person with dementia or will it include the caregiver? Again, there are different models to consider. Young onset dementia groups in adult day program settings are for persons with dementia. Caregivers attend a caregiver support group usually offered by the Alzheimer Society. Some young onset dementia groups include both the person with young onset dementia and their caregiver such as The Alzheimer Society of Toronto Boomer's club. If the group focuses on learning and support, then usually separate groups are held for the person with dementia and their caregiver.

### Recruitment:

The size of your group will depend on the type of group being planned. A support group can be effective with four or more persons. A social group will require more participants. You may not have enough persons with young onset dementia in your data base and are wondering if it is even possible to form a group. That is when you should consider recruiting potential members from the community, those who have not come to your organization for services. Start recruitment strategies a few months before your program starts. Suggestions on recruitment strategies include:

- Creating a flyer that describes your program and includes contact details.
- Promoting your program either by flyer or personal letter to memory clinics, diagnostic centres, seniors' centres, and community agencies.
- Using social media, and website, to promote your program.
- Talking personally about the program with providers in your professional database.

"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." (ASC YOD Gap Analysis Report, 2016)

### Intake Interview:

Individualized assessment of the person with young onset dementia that focuses on abilities is critical to forming a successful group. This will require screening in order to better understand how the person's skills, interests and availability fit with the proposed type of group. The discussion should be a conversation that includes identifying:

- Individual strengths, abilities, and background experiences.
- Relationships and interests.
- Current situation and how dementia has affected the person.
- Supportive strategies that may help. Family members can play an important role in facilitating the

participation of people with dementia. They will have information that can help staff understand the support that is needed and available.

- When changing abilities affect level of participation in the group.

The Intake Interview also provides an opportunity to discuss the proposed program design. During the intake interview you can:

- Obtain participants' suggestions on proposed activities.
- Discuss logistical questions such as transportation needs that will help you determine the location of the group. Transportation can be an issue. Alzheimer Society York & Region adult day program requires "hand to hand" transit as does their mobility service which will do a grouped ride door to door. Someone must be home to help participants on and off transit. This process ensures safety and lowers risk. For other young onset dementia groups, persons will need to be able to travel to the meeting site of the group.
- Assess technology capacity of persons joining an online/web-based group. Participants who access the group at home need to have confidence in using the technology.
- Obtain preference as to time of day and how frequently the group should meet. Often time is an issue and this is one of the reasons for people preferring an online/web-based program. Some groups, such as Paul's club and those groups offered as part of adult day programs will schedule their groups several days per week. Try to determine what the needs are of the person with young onset dementia.

In the Resources Section, you will find a Young Onset Dementia Strengths and Strategies Interview Form. This form was adapted from the Meaningful Engagement of People with Dementia Resource Guide, ASC 2015 ([www.alzheimer.ca/meaningfulengagement](http://www.alzheimer.ca/meaningfulengagement)). It focuses on the strengths and abilities of the person with dementia as well as supportive strategies that will help the person achieve success.

### **Location of meetings:**

A number of factors need to be considered when choosing a location for your support/social group.

- Type of group being offered. If a support group is offered, then a meeting room would be ideal. If a social group is offered, depending on the program, being near other services such as a restaurant or fitness organization might be a consideration.
- Unfortunately, people can be hesitant to go into the Alzheimer Society office due to shame or embarrassment. Is there another location that could be considered?
- Accessibility is important. Consider things such as: the members' functioning abilities, accessible transit, and availability of parking, access to power outlets, audio-visual equipment and washrooms, signage and help with wayfinding.
- Try to think creatively when choosing a location. Look at community spaces which will 'normalize' life such as a recreation centre, library, meeting room in a restaurant or hotel. For example: Paul's club in Vancouver meets in a hotel beside a restaurant; YOLD group in Kingston meets in a restaurant/pub.
- On-line/web-based virtual setting, if outside the home, needs to be accessible.

## Frequency of meetings

During the Intake Interview, determine the person with dementia's preferences as to:

- How often the group will meet: several times a week, weekly, monthly, bi-monthly?
- Time of day and length of meeting. If you're choosing to have caregivers and persons with young onset dementia attend together, you may need to consider a weekend or an evening time slot to allow people who are still working to participate.

## Examples of how frequently young onset dementia groups meet:

- Alzheimer Society of Toronto Boomer's club: meets once a week from 5:30 – 7:30 pm.
- Vancouver's Paul's club: can choose to attend 1, 2, or 3 days a week for 6 hours a day.
- Alzheimer Society of Kingston, Frontenac, Lennox and Addington YOLD group: 2 hours from 7:00 to 9:00 pm once/month.
- Waterloo's YODA: 5 hours from 11:00 to 4:00 pm, weekly.
- Alzheimer Society of York Region groups: 7 am to 6 pm Monday through Friday and 8 am to 5 pm Saturday.
- Alzheimer Society of Saskatchewan's on-line/web based group: monthly for two hours/day.

Budgetary considerations such as staff time, rental of space and/or transportation costs could be a deciding factor for determining timing and frequency of meetings.

The other decision to make is whether the group will be on-going or time limited. If on-going, you will need to decide how often to evaluate the program and obtain participant feedback. If time-limited, new members will need an intake interview prior to starting the group.

## Chapter Six: Key Points

- When planning a young onset group, first decide whether the group will be for the person with dementia or if it will include the caregiver.
- Recruitment starts with going through your own data base, and then reaching out to community organizations to increase participant numbers.
- An intake interview of potential participants will help to identify individual strengths, abilities, background experiences, current situation, relationships and interests, and if the person with dementia may need support in order to participate.
- Location of the support group will be determined by the type of support group offered.
- Budgetary considerations could be a deciding factor for both participants and your organization when determining timing and frequency of meetings.

## Chapter 7: Program implementation

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### Choosing activities

Planning your program activities will depend upon what type of group you are offering.

**Support groups** meet primarily for discussion about the effects of dementia and through sharing, gain peer support. In these groups, feelings are often validated, social isolation is reduced and experiences are normalized. Group members support each other and possibly find new ways of dealing with a particular issue. There are different models for setting up young onset dementia support groups:

- For the person with young onset dementia: Topics for discussion are determined by the group.
- For both the person with young onset dementia and caregiver: In this model both people with young onset dementia and caregivers meet together at the beginning of the program and discuss a particular topic. Then persons with young onset dementia and caregivers meet separately. Those with dementia may enjoy activities together, while caregivers would talk about issues, share strategies and gain support.
- Members of the young onset dementia and caregiver groups may come together for a social time at a local restaurant for coffee and dessert. Usually, the only rule at this social time is that dementia is not discussed!

"I find the Alzheimer's Society Young Onset Support Group so beneficial. You are talking to other people that just get it. No stigma, no problems. I live one step at a time, one day at a time. I do trips from time to time. I try to laugh at my merry go round life. I work very hard at being positive." I.R. (On-line/web based support group Alzheimer Society of Saskatchewan)

### Social groups

Research shows that when choosing activities for social groups, it is best to focus on physical strengths, aspects of activities of daily living, the arts, and the person. It is important to draw on the experiences of the person with dementia and their family members about the kinds of activities they would like and find engaging. Living in the moment is important. Here are a few suggestions:

- Physical activity: exercises, yoga, walking, visit to a day spa or a museum, gardening.
- Activities of daily living: cooking or baking, eating at a restaurant, a picnic
- Arts: music programs: everything from the "classic" seniors songs to a bar singer who sings country or a Beatles fan who only performs Beatles repertoire; art activities; storytelling; photography excursions; visit a museum.
- The person: share pictures of personal importance.

### Examples of groups and their activities:

- Alzheimer Society of York Region Adult Day Program: The participants are a mixed group including those with young onset dementia. The program workers plan the activities based on the strengths and abilities of the participants. Those attending the group are encouraged to suggest activities that they would like to have incorporated. All activities are scheduled inside the day program.

- **Waterloo's YODA:** The program activities are chosen by the participants, those with young onset dementia, and group members bring forward suggestions for activities to try, places to go, etc. The Recreation Therapist plans the days and books the outings as appropriate. Lunch is provided as part of the day – sometimes lunch is held at a restaurant as part of an outing, sometimes it is provided by the facility where the program is housed, and sometimes it is prepared in the program space with the assistance of the participants.
- **Vancouver Paul's club:** A Recreational Therapist leads the program along with 25 volunteers. Participants are persons with young onset dementia, and they are called members. Members arrive in the morning and have coffee together. They then decide what they would like to do, reading newspapers, exercise in the hotel's exercise room, yoga, or if they should listen to music or watch a movie. Lunch is held in a restaurant followed by afternoon walking and ending up at the ice cream parlour.
- **Alzheimer Society of Kingston, Frontenac, Lennox and Addington YOLD group:** The participants are persons with young onset dementia and their caregivers. They focus on having dinner and a social time together in a local restaurant.
- **Alzheimer Society of Toronto Boomers Club:** The participants are both persons with young onset dementia and their caregivers. The program encourages exercise and personal connection in a fun social setting. The program is flexible and can be modified based on the needs and interests of the group participants. Boomers Club encourages bonding between people who are on the same journey.

*"At Boomers Club he enjoys socializing with people, drumming, dancing, theme nights, eating, or preparing a food item(e.g. we have made jam, energy balls, smoothies), light exercises, chair yoga, storytelling, art activities as long as they are simple and instructions are step by step." (Caregiver and member of Boomer's Club)*

### **Facilitation/leadership style:**

There are different styles of leadership that you can consider for young onset dementia social/support groups.

- Staff led
- Staff and participant co-led

Support groups are usually facilitated by staff. Participants are encouraged to suggest topics for discussion.

### **Examples of activity/social groups' leadership models:**

- **Staff led groups:** Alzheimer Society of York Region's group, YODA group, Alzheimer Society of Toronto Boomer's Club, Paul's Club, Alzheimer Society of Saskatchewan support group
- **Staff and participant co-led:** Alzheimer Society of Kingston, Frontenac, Lennox and Addington YOLD group

It could be a consideration to engage volunteers to assist with the facilitation of your social/activity group. Depending on their skills and abilities, volunteers could provide expertise in leadership for the whole session or for a specific activity.

## Staff and volunteers

In order to implement your program, you need to determine what resources are required in order to be successful.

- Do you need to hire staff or are you able to use existing resources?
- Will you need volunteers to help in implementing the program? If so, how many?
- Can you partner with other community agencies and other Alzheimer Societies for resources?
- What education and training will staff and volunteers need to work in the program?

It is important that staff and volunteers want to work with young onset dementia groups. They must have the “knack” of working with those who are living with dementia (Bell, V. and D. Troxel. Best Friends Approach to Dementia Care). “Knack” refers to having knowledge; nurturing and making care relevant to each person, using effective communication, encouraging community through facilitating successful activities, and kinship by including family and friends. Staff and volunteers need to be flexible when working with persons with young onset dementia, be able to “go with the flow” and focus on the process not the outcomes. They need to be able to “risk” themselves by getting attached/making a connection with the people they are working with, be able to think creatively, have a good sense of humour, and believe that all persons deserve respect and dignity.

In some cases, you may include college and university students who are taking a practicum course with you. These students may come from programs such as: Personal Support Worker, Social Service Worker, Recreational Therapy, and Social Work. While this experience will require supervisory time, it can be a benefit to you as well as to the student.

### Leadership training:

All staff and volunteers need to have had education on dementia and specifically education on young onset dementia and its effects on the person and their family. The Alzheimer Society provides general education on dementia that all program staff can take. In addition, the education program needs to:

- Include specific information on young onset dementia.
- The effects of young onset dementia on them and their family members as well as issues that affect their daily lives.
- How to meaningfully engage persons with young onset dementia.
- Types of meaningful engagement.
- What using a person-centred approach means, with examples and strategies to try.
- The importance of identifying strengths and abilities of participants.
- Evaluation processes to measure success.

### Setting the budget:

Depending on your organization and how it is funded, the costs of implementing your group may be covered through existing operating costs or separate funding may be required. Itemizing the expenses for starting and implementing a support/social group will help you identify costs for potential funders. It will also provide information on program costs in your operating budget. It may be that participants will be required to pay a fee to offset the expenses.



**Expenses to consider:**

- Staffing and benefits
- Education and training for staff and volunteers
- Space rental including utilities
- Cleaning costs
- Programming costs including:
  - Program supplies such as puzzles, papers etc.
  - Admission fees in the community etc.
- Emergency supplies (E.g. incontinence supplies)
- Safety features, such as insurance costs
- Refreshments, and meals if required
- Nutrition supplements
- Transportation if included
- Advertising
- Printing and photocopying
- Volunteer appreciation

**Examples of costs to participants:**

- Waterloo's YODA funding comes from the Waterloo Wellington Local Health Integration Network and is funded as part of their adult day program. A fee is charged for the day (currently \$16.00 per day) which is the same charge as their other day programs. Additional fees are charged for transportation to and from the program (currently \$6.50 per day) if family is not able to provide the transportation. YODA is generously supported through the Sunnyside Home Foundation.
- Paul's club charges \$50/day but no-one is turned away due to cost. Paul's club holds fundraising activities to help with expenses.
- Alzheimer Society of Kingston, Frontenac, Lennox and Addington YOLD: meet in a restaurant/pub, clients pay for their drink/meal, and staff costs of \$30 per month for group insurance coverage is paid by the Alzheimer Society.
- Alzheimer Society of York Region Adult Day Program: funded by the Ontario Ministry of Health and Long-Term Care. A daily fee of \$22 is charged for participants but with a sliding scale. About 55% of clients are receiving a subsidy. Some pay \$1 per day and attend 5 or 6 days per week. Most use full hours of operation. When designing programs this must be considered.
- Alzheimer Society of Toronto Boomer's club: no charge to participants. Financial assistance for transportation is provided through their Caregiver Project.

**Chapter Seven:  
Key Points**

- In choosing program activities, consider how meetings will be facilitated and by whom, need for volunteers, staff/volunteer training, and the operating budget.
- It is important that staff and volunteers have the "knack" of working with those who are living with dementia.
- Staff and volunteer training programs need to include: how to engage persons with young onset dementia, types of meaningful engagement, using a person-centred approach, examples and strategies to try, the importance of identifying strengths and abilities of participants, and evaluation processes to measure success.
- Determine how expenses will be covered.

## Chapter 8: Strategies for success

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### Marketing/outreach:

Marketing/outreach will help to promote your group by raising awareness of the needs of persons with young onset dementia and their caregivers as well as raise interest among community organizations on how they can provide support.

**Step #1:** The first step is to identify your key messages about young onset dementia and how the support/social group can be helpful. Some key messages for consideration are:

- The personal and social consequences of persons with young onset dementia can be much different than those experienced by persons with later onset dementia.
- Many persons with young onset dementia want to stay engaged with others, take part in meaningful activity and be included in society. In short, they want to be treated as 'normal human beings'.
- Groups for young onset dementia help participants cope better with their illness. Feelings are often validated, social isolation is reduced and quality of life is enhanced.

**Step #2:** Once you have identified your key messages, decide on the promotional material that will best convey the message. There are a number of resources that could be developed:

- Print material such as one-page information sheets, brochures, an article in a community newspaper, sharing relevant articles and research.
- Awareness event focusing on young onset dementia, including needs of persons with young onset dementia and family.
- Attending and presenting at community network meetings.
- Use of social media: website, Facebook, blogs.

Outreach will be more successful if you identify "champions" who will promote the benefits of young onset dementia groups and share their personal stories. Ask persons with young onset dementia and their caregivers to assist with messaging.

### Branding:

Elements of a brand such as the logo, fonts, colour and wording choices matter because they are the first visual message that people receive about the organization and the specific program you are promoting. The brand communicates the organization's "personality," such as the perception of quality, relationships, value and trustworthiness.

Remember: All materials from the Alzheimer Society need to use the official Wordmark. Please refer to the Alzheimer Society Branding Guidelines for complete instructions regarding the use of the Wordmark and copyright rules.

## Funding:

Determine what funding you may receive and/or what monies you have to spend toward your program. Your financial needs will be guided by the tangible resources you have already, what will be donated, and what you will need to purchase.

Government and other potential funders are always interested in statistics and evaluations that demonstrate “the value” of a program. Keep statistics on the numbers of people that attend your group, the number of family members affected, and ask participants to share quotes on the value they receive by attending the group. This information is valuable when writing a funding application.

There are a number of potential sources for funding:

- Provincial government (community health and social services).
- Community foundations.
- Charitable organizations.
- Community service organizations such as rotary clubs etc.
- Local fundraising events.
- In-kind donations such as donation of space.

## Community Partnerships

Community partnerships or collaboration can expand your program’s capacity and help to support program sustainability. By reaching out and engaging other community organizations in developing and implementing your program, it could also result in: recruitment of volunteers; shared program space, increased awareness of programs and issues for those affected by young onset dementia, and preventing duplication of services.

Some types of collaborations/partnerships that you may wish to investigate are:

- **Businesses:** Sponsorship for service projects, in-kind donations of goods or services, meeting space, volunteers, promotion. Be creative. Look for businesses like restaurants and other for-profit organizations.
- **Colleges and Universities:** Community research, speakers about community needs/issues, interns, volunteers, meeting space, promotion.
- **Faith-based Groups:** Community research, speakers about community needs/issues, in-kind donations, volunteers, meeting space, recruitment of clients and promotion.
- **Neighbourhood Associations and Civic Groups:** Community outreach and recruitment of volunteers, recruitment of clients, and speakers about community needs/issues, in-kind donations and promotion.
- **Non-profit Organizations:** Community research, speakers about community needs/issues community outreach and volunteer recruitment, recruitment of clients, meeting space, in-kind donations, and promotion.

Engage in networking by contributing to various community health care committees that allow people to get to know you such as: a community health organization, senior's centers, Aboriginal community connections, End of Life and Elder Abuse Committee, Palliative Care Network, Falls Coalition Network, Geriatric Assessment team meetings. Choose committees carefully as committee work can become a time management issue.

Through your Dementia Friendly Communities program, create awareness of the needs of persons with young onset dementia in your community. Collaborate with community partners with activities such as: delivery of learning, providing locations for events, promotion of outreach for young onset dementia groups. "Minds in Motion®" is an example of a successful collaborative program between the Alzheimer Society and community organizations.

**Example of collaboration:** YODA has a community partnership with the Alzheimer Society of Waterloo Wellington to host a joint Young Onset Dementia Caregiver Support Group on a monthly basis. Caregivers of YODA, participants and other community members are invited to attend. They also have a community partnership with the Joseph Schneider Haus Museum. On a yearly basis, participants of YODA volunteer as a group filling shoe boxes for Operation Christmas Child.

### Program Evaluation

Evaluation is a key component of the continuous quality improvement process. By committing to evaluating young onset dementia groups, you are saying to participants and all stakeholders that you are being accountable to try and deliver the best service possible and will keep trying to improve your program as much as you are able to do so.

Participant satisfaction surveys may be completed once per year. They can be administered by a paper or electronic survey or through face-to-face discussion with a neutral person. They provide valuable information about whether the goals of the group program have been met. Some examples of general questions are:

- Did you feel welcomed, comfortable in participating, and included in the program?
- Please comment on the timing and location of the group program.
- Has participating in this group been a positive experience for you?
- Do you feel that the group has met your needs for socialization with peers of a similar age range?
- How would you describe the experience of being a part of the group?
- Do you have any suggestions on how this group program could be improved? Be sure to give members the opportunity to give you specific examples!

Specific questions regarding features of your program should be asked. For example for social groups:

Which activities did you like the best? Which activities did you like the least?

Staff/volunteer evaluations provide a different perspective on whether the group program has met its goals. They have the ability to see the group process as a whole and how participants interact with each other. Some examples of evaluation questions are:

- Have you learned anything new about young onset dementia during your participation in this group program?
- Have you observed any changes in the participants of your group over the past year?
- Do you have any suggestions on how this group could be improved?
- Please comment on the timing and location of the group program.

## Chapter Eight: Key Points

- Raising awareness of the needs of persons with young onset dementia and their caregivers will help community organizations identify how they can provide support.
- Identifying “champions” to promote the benefits of young onset dementia groups and sharing their personal stories provides a powerful message.
- Branding communicates the program and the organization’s “personality,” such as the perception of quality, relationships, value and trustworthiness.
- Potential funders are always interested in statistics and evaluations that demonstrate “the value” of a program.
- Community partnerships or collaboration can expand your program’s capacity and help to support program sustainability.
- Evaluation is a key component of the continuous quality improvement process.

## Chapter 9: Self-care for Facilitators

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### **Why is self-care so important when facilitating a young onset dementia group?**

Self-care refers to activities and practices that we can engage in on a regular basis to reduce stress and maintain and enhance our short- and longer-term health and well-being. Working with persons with young onset dementia and their families can, over a period of time, result in “compassion fatigue” as you try to process unresolved grief from clients and other sensitive issues that arise. It is important to recognize the need for self-care and acknowledge that, when you are feeling stressed, addressing your needs deserves to be a priority. Make sure you are developing healthy habits, creating clear boundaries, asking for and accepting help, debriefing in a safe place, and managing “perfectionist tendencies”, being aware of what you are humanly capable of doing.

### **Individual self-care**

There are several aspects involved in providing self-care:

- You need to be able to meet your basic physical, mental and emotional needs. Getting enough sleep, eating nutritious food and adequate exercise is important, but it is more than that. You need to be able to lean on others for support and to pay attention to your body when it says “slow down” so that you do not push yourself to the point of a breakdown.
- You need to know when to say ‘no’. If you are constantly giving from your heart there will be nothing left for you. Saying ‘no’ is very powerful. Self-care means saying ‘yes’ when you mean ‘yes’ and ‘no’ when you mean ‘no’. Being a people pleaser is not healthy and learning to set healthy boundaries to be better able to serve the greater good is what self-care allows you to do.
- You need to discover what brings you happiness, joy and meaning in your life and then prioritize them daily. This will provide you with protection from burnout.

### Setting up regular peer support between co-facilitators

One of the ways you can receive emotional and practical support is from other facilitators of young onset dementia groups. Your peers can provide you with information, advice, guidance, and also tangible support such as assistance in times of uncertainty. You will be able to talk to others who are having similar issues and concerns, you won't feel alone, you will have a safe place to vent and you will feel comforted and more secure.

Peer support can be provided between co-facilitators of a particular young onset dementia group, or within an organization where there are a number of young onset dementia groups being offered. One-on-one peer support or group support could be arranged. Whatever you decide to do, remember that peer support is a safe place for you to manage your stress and recognize how you can use your strengths in new ways.

One of the ways that organizational support could be facilitated is through the creation of an online support group for facilitators. This could be set-up through the organization's website on the Intranet. Providing organizational support sends a message to staff and volunteers that they are valued and are important to the service delivery of their organization.

### Chapter Nine: Key Points

- Self-care includes:
  - Activities and practices that reduce stress and maintain and enhance short- and longer-term health and well-being.
  - Being able to lean on others for support and paying attention to your body when it says "slow down" so that you do not push yourself to the point of a breakdown.
- Learn to set healthy boundaries in your role as facilitator.
- Peer support provides a safe place where you can talk to others with similar issues and concerns and gain recognition on how you can use your strengths in new ways.

## Appendices

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### Resources

- Checklist for start-up and implementation of a group
- Sample recruitment flyer
- Sample Interview Process form
- Sample participant interview questions
- Sample Introductory Letter for online/web-based group
- Referral form for adult day program setting
- Sample evaluation forms
- Examples of types of groups with contact information

### References



## Draft Checklist for starting and implementing a group

	Yes	No	N/A	Comments
<b>Determining philosophy</b>				
Have you identified your philosophy which will guide all aspects of your program planning and implementation?				
Are all staff and volunteers involved in program aware of the program's philosophy?				
<b>Assessing needs and what to offer</b>				
Do you have persons in your organization wanting a young onset dementia group?				
Have you consulted with community organizations to determine if there is a need?				
Are you planning on conducting a needs assessment? Focus group? Survey? Other?				
Have you decided on whether you will offer a social or support group? Who will be the participants?				
<b>Determining eligibility requirements</b>				
What criteria will you use to determine eligibility? Have these been set out in writing?				
Will eligibility be determined by a Health Authority or your organization or both?				
Will transportation be an issue?				
<b>Setting goals for the program</b>				
Have you identified specific goals for the group?				
Will the group help to reduce social isolation and encourage a sense of belonging?				
<b>Transitioning out of the group</b>				
What criteria will you use to decide when the group is not appropriate?				
Will you let participants know what the discharge criteria are ahead of time? Have these been set out in writing?				
Do you have suggestions on which community programs, at this point, would be of benefit?				
<b>Meeting the needs of children/youth</b>				
Have you developed a plan on how you can support children/youth?				
Do you have print and non-print resources to share with parents?				
Did you connect with community organizations that may be able to assist?				
<b>Recruitment</b>				
Are you networking and building relationships with community organizations?				
Have you developed marketing material to advertise your group to the broader community?				
Are you using your social media effectively for outreach?				
Have you conducted an intake interview with each participant?				

	Yes	No	N/A	Comments
<b>Location and frequency of group meetings</b>				
Do you need to look for a location that is off-site?				
Is the location you have selected accessible?				
Is there a rental charge for the location and how will this be paid?				
Have you determined the length of time and frequency of the group meetings?				
Is the group going to be time-limited or on-going?				
<b>Program planning</b>				
Have you drafted a general plan for your group meeting?				
Have you researched similar groups to get ideas on activities/programming?				
Did you consult with participants?				
Who will lead/facilitate the group?				
Have you set up a budget and determined how/who will pay expenses?				
<b>Staff and volunteers</b>				
Do you need to hire staff? Do you need to recruit volunteers? If so, how many?				
What qualities will you look for in your leadership team?				
Have you a training plan in place for staff/volunteers?				
<b>Evaluation</b>				
Who will evaluate the group? Participants? Leadership team? When will this occur?				
How will the results be used to enhance program delivery?				

Sample recruitment flyer

*Alzheimer Society*  
**Family Support Group**  
Young Onset Dementia

Alzheimer Society of York Region's caregiver support groups are **FREE** and designed to provide a forum to learn and understand how to cope with and care for a family member diagnosed with dementia who is younger than 65.

THE D.A.Y. CENTRE  
BOARDROOM  
240 EDWARD STREET, UNIT 2  
AURORA ON, L4G 3S9

2nd Tuesday of each month • 1:00 pm – 2:30pm

Group Runs Monthly

April 11, 2017

May 9, 2017

June 13, 2017

July 11, 2017

August 8, 2017

September 12, 2017

October 10, 2017

November 14, 2017

December 12, 2017

January 9, 2018

February 13, 2018

March 13, 2018

For more information, please contact Hemal Joshi:  
hjoshi@alzheimer-york.com  
905-731-6611 Ext. 50

## Sample Young Onset Dementia Social/Support Groups Interview Process Form

Name of person being interviewed: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Interview was held:  by telephone  in person  Other: \_\_\_\_\_

Names of interviewers: \_\_\_\_\_

- I. Welcome; introductions. Brief overview of the purpose of the conversation; check time allocated, etc.
- II. Orientation to young onset dementia programming available through the Alzheimer Society.  
Check for questions from the person about the above. Is there anything that needs to be clarified? Do they have suggestions regarding programming ideas for the social/support group?
- III. **Complete Strengths profile for answers to the following questions:**
  1. Can you tell us about your past history and skills that you have acquired?
  2. What are your interests now?
  3. a) How has the diagnosis of dementia affected you, physically and emotionally?  
b) How do you see your life now that you have dementia?
  4. What is your availability during the week?
  5. In order to attend the young onset dementia group program, will you require any assistance? If so, what do you think will help you be successful? (note: ensure that it is clear that the need for support is not viewed negatively. We want to be sure we can provide the support needed).
  6. Issues of changing abilities: our plan for having open dialogue about this with each participant and commitment to try to offer other program opportunities when necessary. Discuss.
  7. What questions do you have for us?
  8. Next steps in the process.
- IV. Thank you and goodbye (If the interview is in person, enquire if the person would appreciate any assistance leaving the building).

Interviewer makes sure Strengths Profile is completed and filed.

**Tips on Interviewing:**

- Treat the person with dementia like any other interviewee. Act naturally, greet them with a handshake, and avoid patronising or over-praising.
- Interviewing a person with dementia may require patience. If necessary, allow more time for answers and repeat questions if required.
- Be clear and precise when seeking information on the person's experiences and ask only one concisely phrased question at a time.
- Often the person with dementia will reply to questions with short, concise answers rather than longer comprehensive ones, so be prepared to move on to the next point or topic.
- If you do not understand the answer you receive, ask for clarification, or repeat what you have understood for confirmation.

## Sample Young Onset Dementia Social/Support groups Strengths Profile of Participant

Name of person being interviewed: \_\_\_\_\_

Date of interview: \_\_\_\_\_

Strengths, gifts, interests	Supportive strategies for success
<ul style="list-style-type: none"> <li>• Previous employment</li> <li>• Skills</li> <li>• Lives in ...</li> <li>• Family and friends</li> <li>• Interests</li> <li>• Challenges</li> <li>• Comfort using computer including email and teleconference calls. (for online/web-based group)</li> <li>• Other</li> </ul>	<ul style="list-style-type: none"> <li>• For group meetings</li> <li>• Is transportation required? (companion; assistance with arrangements, etc.)</li> <li>• Other assistance needed?</li> </ul>

For further assistance, please consult Meaningful Engagement of People with Dementia: A Resource Guide ASC July 2015 available at [www.alzheimer.ca/meaningfulengagement](http://www.alzheimer.ca/meaningfulengagement)

## Sample Participant Interview Questions

1. How long have you / your family member been living with the disease? Is there a specific type of dementia that has been diagnosed?
2. What are the most common difficulties that you / your family member experiences currently?
3. Will you/your family member be attending by yourself or with someone?
4. How will you / your family member get to the venue?
5. Are you/your family member currently part of any social programs anywhere else? (Gives a glimpse into the person's current activation level)
6. Are you/your family member experiencing issues with getting lost (to be asked only if coming alone)?
7. Has your family member demonstrated issues with hitting, getting angry? If so, what are the triggers?
8. What other responsive behaviours does your family member demonstrate?
9. Are there issues with incontinence?
10. Are there dietary restrictions (Ask if you are providing food)?
11. Is there any other information about yourself / the person that would help us to welcome them into our group?
12. Are there any mobility issues?
13. Are there any allergies?
14. Please provide emergency contact information.

## Sample Introductory Letter for online/web-based group

September 2015

Name  
Address  
Address  
Address

Dear

Re: Young Onset Telehealth Support Group

We are so pleased that the Young Onset Group is off and running, and we are very happy that you have chosen to participate.

This Group is unique in a couple of ways. There are very few Support Groups for people with Young Onset Dementia reported in the literature, and the concept of meeting face to face over vast distances is also very new. We feel you are breaking new ground for so many individuals who are on a path similar to yours.

This letter is sent to provide confirmation about some of the details of the Group.

Meeting Dates: Group will meet on the third Monday of every month at 3:30 pm. Any changes in the dates will be agreed upon by Group Members.

Next Six Meetings:

October 19, 2015	November 16, 2015
December 21, 2015	January 18, 2016
February 15, 2016	March 21, 2016

Equipment Set Up: Telehealth Equipment will be set up by health Region Staff. There will be a number available if there are technical problems.

Confidentiality: All members agree that Group meetings may only be attended by persons with Dementia, Alzheimer Society facilitators and invited guests. Details of conversations and interactions during Group meetings are confidential.

We are looking forward to being with you again in October. If you have any comments or questions about the Young Onset Telehealth Support Group, please contact either one of us.



## Sample Younger Onset Dementia Association Referral Form (Adult Day Program)

FAX TO 1-519-904-0920	
YOUNG ONSET DEMENTIA ASSOCIATION CRITERIA	
<p>The Young Onset Dementia Association (YODA) program brings together people who are living with young onset dementia to learn, socialize and explore new talents. Eligibility criteria for the program is as follows:</p> <ul style="list-style-type: none"> <li>• Applicant was diagnosed before the age of 65 with a dementia</li> <li>• Applicant would benefit from recreational programming and community engagement</li> <li>• Applicant is willing and able to participate safely in group programming</li> <li>• Applicant is not exit seeking</li> <li>• Applicant is medically stable</li> <li>• Applicant is independent with Activities of Daily Living and is able to self manage medications with reminders</li> <li>• Have emergency contact available (able to take client home if required)</li> </ul>	
REFERRAL	
<p>Applicant wishes to also be placed on the waitlist for the Community Alzheimer Day Program  <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>Applicant attends a Day Program (or is on waitlist) <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If Yes Name of Program:</p>	
Applicant's Last Name:	Applicant's First Name: <input type="checkbox"/> Male <input type="checkbox"/> Female
Address:	HCN:
	Date of Birth (dd/mm/year):
REFERRAL SOURCE	
<p>Referral Source: <input type="checkbox"/> CCAC <input type="checkbox"/> Memory Clinic <input type="checkbox"/> Alzheimer Society <input type="checkbox"/> Hospital  <input type="checkbox"/> Day Program <input type="checkbox"/> Other:</p>	
Primary Contact Person (Referral Source):	Alternate Phone Number:
Phone Number:	
Secondary Contact person (Referral Source):	Alternate Phone Number:
Phone Number:	
RESPONSIBLE PHYSICIAN	
Most Responsible Physician:	Phone Number: Fax Number:
Family Health Team:	After Hours Contact Information:

**Sample Younger Onset Dementia Association Referral Form  
(Adult Day Program) *continued***

Allergies:  Environment     Food     Medication     Details:

**COMMUNICATION**

Client is aware of the daily charge of \$15.50:  Yes     No

\*Please note other charges might apply for special outings

**COMMUNITY SUPPORT SERVICES client is currently receiving e.g. Mobility Plus,  
PLEASE PROVIDE DETAILS**

- Transportation:
- CCAC services:
- Respite:
- Specialized Geriatrics Services:
- Other:

For CCAC Referrals: Please submit all other documentation including RAI and notes via HPG.

## Sample Evaluation Forms

### Evaluation YOLD (Young Onset Living with Dementia)

1. Do you feel that the YOLD group has met your needs for socialization with peers of a similar age range?  

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2. Do you feel that the YOLD group has provided a recreational outlet for you/and or your spouse?  

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3. How would you describe the experience of being a part of YOLD?  

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4. Has the YOLD group provided you with a circle of support among younger care partners and individuals living with dementia?  

---

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---
5. On a scale of 1 to 10, with 10 being the highest how would you rate the YOLD group in helping to reduce stigma for living with dementia and their care partners?  

1-----2-----3-----4-----5-----6-----7-----8-----9-----10
6. What has this group meant to you?  

---

---

---
7. Would you like to see the YOLD group continue monthly?  

---

---

---
8. Any other suggestions for improving the group?  

---

---

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## Sample Support Group Survey 2016-2017

1. Please indicate which support group you have attended?

- Aurora (Thursday Evening)
- Aurora (Spouses group – Monday afternoon)
- Thornhill
- Stouffville
- Markham
- Keswick
- Maple
- Young Onset – Richmond Hill

2. How would you rate your overall experience participating in the support group?

- Excellent
- Good
- Average
- Poor

3. Has participation in the support group:

	Yes	No
Increased your knowledge of the disease and the disease process?		
Helped you to manage your stress level and cope more effectively?		
Provided you with emotional support?		
Provided you with practical suggestions on how to deal with your family member?		
Provided you with information about new resources?		
Made you realize you are not alone?		
Connected you with other caregivers?		
Made you feel better about yourself?		

4. Has the group facilitator:

	Always	Sometimes	Yes	No
Explained things to you in a way you could understand?				
Delivered service to you with a caring attitude?				
Treated you respectfully?				
Ensured you had an opportunity to share and ask questions?				
Taken your cultural values/preferences into account?				

5. Did you get the help you needed from the support group program?  
 Yes    No
6. Were you involved as much as you wanted to be in decisions about your care and/or services?  
 Yes    No
7. How often have you attended the support group in the past year?  
 1-3 times    4-5 times    More than 5 times
8. Does the location of the support group meet your needs?  
 Yes    No
9. Does the day/time of the support group meet your needs?  
 Yes    No
10. Have you experienced any barriers to accessing the support group program? If yes explain?  
 Yes    No
- 
- 
11. Were hand hygiene procedures encouraged (use of hand sanitizer)?  
 Yes    No
12. Were you asked to sign in and complete an infectious disease screening when you arrived?  
 Yes    No
13. Would you recommend the Alzheimer Society of York Region Support Group program to other people dealing with Alzheimer's disease and related dementias?  
 Yes    No
14. What can the Alzheimer Society of York Region do to improve the support group program?
- 
- 
- 
15. Would you like to share your experience with the support group program at the Alzheimer Society of York Region?
- 
- 
- 

Thank you for your time in completing this questionnaire!

## Examples of types of groups with contact information

### Online/web-based support group:

**Alzheimer Society of Saskatchewan Online Support Group:** An online/web-based support group for persons with young onset dementia that is set up through Telehealth Saskatchewan.

For more information visit [www.alzheimer.ca/en/sk](http://www.alzheimer.ca/en/sk)

### Social Groups:

**Alzheimer Society of Toronto Boomer's Club:** An ongoing program that connects people living with young onset dementia and their caregivers through exercise, music, dancing, art and games.

For more information visit [www.alz.to](http://www.alz.to)

**Alzheimer Society of Kingston Frontenac Lennox & Addington: Young Onset Living with Dementia Group (YOLD):** An ongoing group for persons with young onset dementia and their caregivers that provides a social and recreational outlet.

For more information visit [www.alzheimer.ca/en/kfla](http://www.alzheimer.ca/en/kfla)

**Paul's Club, Vancouver (community based group):** An ongoing program for persons with young onset dementia whose goals are to keep the individual socially integrated, socially activated, and to have fun.

Contact: Nita Levy at <https://paulsclub.weebly.com/contact.html>

### Adult Day Program Groups:

**Alzheimer Society of York Region Adult Day Program:** An on-going adult day program where persons with young onset dementia are integrated into existing adult day programs. Individual programming needs of participants are met.

For more information visit [www.alzheimer.ca/en/york](http://www.alzheimer.ca/en/york)

**The Community Alzheimer Program Seniors' Services, Region of Waterloo Waterloo's Young Onset Dementia Association Program (YODA):** A community based adult day program for persons with young onset dementia which includes a combination of day outings as well as activities on site.

Contact: Janice Paul at: [japaul@regionofwaterloo.ca](mailto:japaul@regionofwaterloo.ca)

[www.regionofwaterloo.ca/en/health-and-wellness/dementia-services.aspx](http://www.regionofwaterloo.ca/en/health-and-wellness/dementia-services.aspx)

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# Alzheimer *Society*



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