The Alzheimer Society of PEI

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Introduction

Alzheimer’s disease and other forms of dementia can leave those with the disease and their caregivers feeling isolated. However, they are not alone. There are other people to share the journey with them.

One of the ways that people experiencing difficult situations can find help and relief is through meeting with others in the same situation as themselves. These groups rely on the experience and support of members more than on the knowledge of experts.

The Alzheimer Society of PEI currently supports several Family Caregiver Support Groups Islandwide. These groups are there for people who want to educate themselves with current information that will help improve the quality of life for both themselves and their loved one. It’s a safe environment where they can learn, laugh, and help each other through mutual understanding and support.

The Alzheimer Society of PEI provides Support Groups with reliable information that can be used to supplement and affirm the information discussed among members.
Support Group- What's the purpose?

The purpose of a Family Caregiver Support Group is to provide a safe environment where people affected by Alzheimer's disease or a related dementia can mutually support one another by sharing their thoughts, ideas, concerns, questions, and coping strategies in a non-judgmental and caring atmosphere.

A Family Caregiver Support Group will provide many benefits:

- A place to exchange information, support, and friendship with others whose lives are affected by dementia.
- A forum for sharing practical tips and strategies for coping with the many changes connected with the disease.
- A place to express feelings and be reassured that these feelings are normal and expected.
- An opportunity to decrease feelings of isolation and loneliness.
- A place to find a positive outlook on things without being misunderstood.
- The chance to regain some control in the face of a disease that cannot be controlled.
- A place to find a sense of hope.
- A place to access the most current information provided by the Alzheimer Society of PEI.
Why do people join a Support Group?

1. A sense of belonging:

Caregivers often feel like they are alone. Therefore a Support Group can act like a family, where members feel supported, cared for, and accepted for who they are.

2. Empathy:

People outside a Support Group may not understand the experiences of people who have dementia, or their caregivers. They may even dismiss their feelings. In a Support Group people are heard and understood.

3. Feeling Safe:

Inside a Support Group, people often feel protected and safe to express their feelings, whether positive or negative. A Support Group offers a place to be vulnerable and one's self.

4. Reducing Isolation:

Support Groups develop a sense of community through shared feelings and experiences. People feel connected with one another which can assist them in addressing their personal concerns and their need to ask questions.

5. Humour:

People feel comfortable to have a good laugh and rejuvenate through inspiring, and often comical stories that are shared between members.
What does a Support Group meeting look like?

Agenda

1. Welcome & Introductions:

The Support Group facilitator would begin by welcoming all members in attendance, and recognizing any new members who may be joining the group for the first time. Brief introductions could also take place when a new member is present.

A sign in sheet will be completed at the beginning of each meeting, with each member's name and contact information recorded for further references. This will be important for reminder calls, event planning, etc.

2. News from the Alzheimer Society of PEI:

Support Group members will be kept up-to-date with important and accurate information about up-coming events at the Alzheimer Society of PEI. It is important to direct the members' attention to the Alzheimer Society website and online calendar. Follow us on Facebook and Twitter too.

http://www.alzheimer.ca/pei

3. Address Unanswered Questions/Concerns from Prior Meetings:

As a facilitator of the group meeting, be prepared to deliver updates or comments on questions and/or concerns that were left unanswered or unaddressed from prior meetings. If you are not able to answer a question or give a response to the concerns shared in a meeting, make note of the question/concern and contact the Education Coordinator at the Alzheimer Society of PEI for assistance.
4. Regular Group Discussion and/or Guest Speaker:

This aspect of a Support Group meeting can take various forms:

**Discussion:**

To prompt discussion, select one or more related discussion questions and invite the members to express their thoughts, opinions, and ideas. This can be planned ahead of time, from meeting to meeting, to ensure that the facilitator has gathered accurate and up-to-date information from the Alzheimer Society of PEI.

As the facilitator, you may also invite members to begin the discussion with any concerns that they may have on their mind.

The best way to avoid the quiet members of the group to be left out of the discussion is to adopt the round-robin approach and a policy where only one person speaks at a time. Some groups use a variation on a First Nations custom of passing the "talking stick". Only the person in possession of the talking stick is allowed to speak.

**Guest Speakers:**

If you decide to have a guest speaker at one of your meetings, consider having time for group discussion and questions and answers. See *Appendix 1* for a list of potential guest speakers.

5. Goal Setting:

Some groups set aside some time after discussion for personal goal setting. Each member who is willing to participate, sets a personal goal that they hope to achieve by the next meeting. At the next meeting, members may wish to report back on how they did.

6. Wrap-Up:

This time is set aside for any information the group wishes to share, such as fundraising, advocacy efforts, arrangements for future meetings such as choosing discussion topics or guest speakers, or reporting on special projects.
This is also the time for the facilitator to remind members of the next meeting time and details. The meeting sign-in sheet should be provided to the member who has offered to make reminder calls and send reminder emails to the rest of the group members.

7. Refreshments:

Refreshments can be served at each Support Group meeting, at a time that is agreed upon by the members. Be mindful of any special dietary requirements and food allergies.

8. Dignity & Respect for Those Living the Dementia Journey:

Some members of the Support Group may be living the journey of Alzheimer's disease or a related dementia. Be mindful of how the conversations in the room may effect that individual. A side conversation before the meeting could take place to indicate that in no way are members trying to discuss their journey as if they are not present.
Support Group Facilitator(s) Roles & Responsibilities

As a Support Group facilitator you will have a significant effect on the other group members. Facilitators use communication, vision, esteem, and personal enthusiasm to motivate and encourage members to feel excited and passionate about their role as a caregiver.

Key roles and responsibilities include:

* maintain a safe, friendly, and warm environment that encourages mutual support and an opportunity to participate.

* facilitate balanced discussion. (lead the discussion, but do not dominate it)

* be an active listener.

* implement the ground rules and mediate any conflicts that arise.

* maintain confidentiality.

* begin meetings on time and facilitate items on the monthly meeting agenda.

* make use of up-to-date and accurate information obtained from the Alzheimer Society of PEI.

* maintain group attendance records.

* be honest- if you don't know an answer to a question, say so, but commit to finding out.

* recognize when a member's concerns are beyond the group's ability to help and be willing to suggest alternative resources such as the Alzheimer Society of PEI.

* have fun.

The Alzheimer Society of PEI will support the facilitators of the Support Group by providing accurate and up-to-date information and access to educational resources, training opportunities, and educational presentations when required as a guest speaker.
Ways of Participating- Support Group Members

One of the primary purposes of a Support Group is to provide an environment where people with similar life situations can meet with one another and help one another address their questions and concerns in a supportive, caring, and non-judgmental atmosphere.

You can actively participate in a Support Group in the following ways:

* invite new members to attend the Support Group meetings.
* help members feel comfortable and get to know one another.
* participate in the discussions.
* promote positive comments and new viewpoints.
* listen attentively.
* notice shy people in the room and encourage them to contribute their thoughts.
* offer to make reminder calls or send reminder emails to each member on a monthly basis.
* provide some refreshments for the group members to share.
* etc.
The Ground Rules For Discussion

1. Everyone will have a chance to talk; no one should dominate the discussion.

2. Only one person will talk at a time, uninterrupted, while others listen and refrain from side conversations.

3. At times of sharing, everyone will have the right to pass. Silence is okay.

4. Feeling upset or sad is allowed; tears are acceptable.

6. Respect one another's differences.

7. Follow the seven step Solution Focused Approach.

8. Keep other members' identities and issues confidential; refrain from discussing other members situations outside the group environment.

9. The facilitator may discuss what happens during the group with someone at the Alzheimer Society when imminent danger, abuse, or neglect are suspected.
Tips for Making Your Support Group the Most Effective

Solution Focused Approach:

Advice giving is a common occurrence among Support Group members. Although most advice is given with good intentions, it sometimes can be ineffective, and perhaps even aggravate the problem. When addressing concerns related to dementia, it is important to remember, that each individual's journey is unique and what works for one caregiver, may not work for another.

Rather than giving advice, group members may assist one another by using a seven step solution focused process that invites the individual to explore various options. The steps are as follows:

Step 1- Define the situation

This may be the most difficult part. Often times a group member may think their problem is one thing, when it actually isn't. It is very important to explore the "pieces" that may be contributing to the problem, before clearly defining the situation. (See Appendix - P.I.E.C.E.S.)

Step 2- Brainstorm solutions

Invite Support Group members to come up with a list of things that might work to overcome the challenge. A generic suggestion should always be to seek professional advice from a family physician and/or the Alzheimer Society of PEI.

Step 3- Test the solutions

Suggest that each group member who shares the challenge, or a similar problem, select one of the solutions to test for a couple of weeks.
Step 4 - Assess the results

At the next meeting assess the results. If a problem is solved completely, great. Be sensitive to the fact that what might work this week, may not next. If a challenge still exists for some...

Step 5 - Try another solution

Select another solution to test and assess.

Step 6 - Start over

If nothing seems to work, ask the group to re-examine the problem identified. Perhaps the real problem has not yet been identified.

Step 7 - Be honest

If nothing seems to work, be honest. What may not be solved today, may be solved at a later date. A certain behavior may be constant for a while, but generally behaviors change as the individual’s condition progresses.
**Overcoming The Challenges:**

Reality is that as a Support Group facilitator you will face challenges. This section will address some of the common challenging situations and provide suggestions on how to respond.

**Disease Progression:**

Support Groups typically have a mix of people at various stages of dementia. The needs of a person caring for a loved one who has been recently diagnosed are often very different from a person whose loved one's disease has advanced.

Acknowledge that each person in the group has different needs and that all needs are valid and can be addressed. Also encourage those who are reluctant to speak up in the meeting, to talk with you, the facilitator, after the meeting has concluded.

**Attendance:**

A group is defined as two or more individual. Ups and downs in attendance are normal. Group members' lives are very busy. If numbers are low, you may wish to discuss the scheduled time and location. Phone calls and emails may need to be made or sent out each month, as a friendly reminder of the up-coming Support Group meeting. Encourage group members to recruit others who may benefit from the mutual support of a Support Group meeting.

(See "What to do if your Support Group meetings are Losing Steam")

**Death:**

Due to the nature of the relationships built between Support Group members, the loss of a loved one, or a member themselves, can be incredibly emotional. Acknowledging the loss at the time of death via email or a phone call to group members, will prevent any surprises at the next meeting. Invite the participants to offer their support- send flowers, cards, etc.
What to do if your Support Group Meetings are Losing Steam

- Invite a guest to speak about Alzheimer Disease and answer questions.

- Arrange to have the group preview a video and discuss it afterward. The Alzheimer Society of PEI can provide information regarding up-coming webinars, online presentations, and educational videos related to Alzheimer disease and related dementias.

- Arrange for a special demonstration of a particular skill or coping strategy. Arrange it so that group members can practice these skills during the meeting.

- Coordinate a tour of a nursing home or hospital unit that cares for people with Alzheimer Disease and related dementias.

- Change of pace of the meeting. Have at least one “Social Only” meeting per year where having fun is the only goal- Christmas party, Dinner plans, Potluck, Coffee Breaks, etc.

- Participate in a fund-raising event with the Alzheimer Society of PEI as a team. Visit our website for a list of up-coming events. (www.alzheimer.ca/pei)

- Always ask the members of the group what they would like to do for a change of pace, and include their participation as much as possible when planning the structure for a particular meeting.
Group Meeting Topics

Activities to do with an individual living the Dementia journey
Advocacy for caregiver recognition
Banking
Bathing
Communication with the Person with Dementia
Current Events / News related to Alzheimer’s and Dementia
Dealing with the Diagnosis
Delusions
Dementia - what is it?
Depression
Disease Progression
Dispelling the myths of Dementia
Division of Caregiving Responsibilities among family members
Driving
Grief
Guilt
Healthcare System
Healthy Brains
Holidays
Home Safety Checklist
Important information to document for your family physician
Isolation / Withdrawing from social activities
Legal Planning- Will, Power of Attorney, Health Care Directives
Long-Distance Caregiving
Meal Time
Person Centred Care
Personal Care
Programs & Services
Quality of Life- End of Life Care
Repetitive Behaviours
Research
Responsive Behaviours
Safely Home Registry
Self-care for Caregivers & Caregiver Stress
Sexuality
Sleep Patterns & Sundowning
Taxes
The Power of Music
Tips when hiring outside help (private respite care)
Toileting
Transitioning from home to long-term care
Travelling
Treatment Options
Wandering
Confidentiality Agreement

Name:  
Address:  
Phone:  
Email:  

During my membership in the Support Group I may learn personal and confidential information about individuals who participate or are involved with this Group.

Whether information is available to me through the Group or accidentally, I agree to maintain confidentiality and not reveal information to any person in the Group or outside the Group while a member of the group or at any time in the future when I may no longer be a member.

I understand that medicine is an ever-changing science. In view of the possibility of human error or changes in medical sciences, the Support Group facilitator, nor any other party who has been involved in the preparation or on-going functioning of the Support Group, warrant that the information communicated is accurate or complete, and are not responsible for any errors or omissions or for the results obtained from the use of such information. Any information pertaining to my health, or the health of my loved one, should be reviewed by a health care professional.

Good faith efforts will been taken to preserve participant confidentiality.

Signature of Member:  
Date:  

Signature of Witness:  
Date:  

Société Alzheimer Society
PRINCE EDWARD ISLAND
ALZHEIMER SUPPORT GROUP

LOCATION: ____________________________________________

DATE: _______________________________________________

FACILITATOR(S): _______________________________________

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COMMENTS:
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Please mail, email or fax each month to:

Alzheimer Society of PEI

166 Fitzroy St, Charlottetown PE C1A 1S1

Tel: (902) 370-3135  Fax: (902) 368-2715  Email education@alzpei.ca
P.I.E.C.E.S. provides a framework for understanding why we behave the way we do and what resources we have to build on. Exploring the “PIECES” that may contribute to the responsive behaviors that caregivers frequently view as challenging can often result in solutions that are life giving for both the individual living the journey of dementia, as well as the caregiver.

Consider the following:

**Physical**- Is my loved one... hungry, thirsty, depressed, fatigue, constipation, pain, etc?

**Intellectual**- Do they understand the task and the process of completing it?

**Emotional**- Has my loved one experienced a loss or emotional event recently?

**Capabilities**- Are my expectations too high? Are there too many steps to a task? Can my loved one express their fears or needs? Am I maximizing my loved one's capabilities?

**Environment**- Is my loved one's surroundings unfamiliar? Is the room too noisy? Are there too many items in the room? Does your loved one have a new roommate?

**Social**- Is my loved one willing to participate in physical, cultural, spiritual activities?