

## **CREATING AN EFFECTIVE SUPPORT GROUP**

Getting a support group started requires patience, fortitude and creativity. Caregivers don't automatically understand the value of attending a support group. Some actually are frightened by the idea. However, with proper preparation you will have a higher success rate when establishing such a group. A support group has a job to do. Some individuals are only looking for socialization more than support. It is best to have them initiate their own socialization or to set up a socialization meeting not connected with the support group meeting. Keeping boundaries clear is essential. Group process is a combination of communication (speaking and listening) and interpersonal interaction. Keeping both flowing smoothly is essential. As a facilitator you will ask appropriate questions to keep the discussion focused and moving along. Effective groups promote emotional and physical health, sound caregiving strategies, awareness of resources, problem solving, stress reduction and personal growth.

### **SETTING IT UP:**

Think about:

- who will be invited
- time of day
- frequency
- length of meeting
- size of the group
- location/ambiance
- marketing your group
- facilitating
- what to bring
- meeting format

1. **WHO WILL BE INVITED** - Determine the type of caregiver you want to provide support to—who might participate. Common caregiver groups may include those caring for someone with chronic illness, those dealing only with dementia or young onset dementia, men only or adult children, relatives raising relative children, socio-economic or ethnic specific members. If you are concerned about getting enough attendees, a non-specific, general caregivers group might be best. As the group expands you can diversify if needed. A third option is a 1:1 or peer to peer match.
2. **TIME OF DAY** - Identify a time of day you will hold the group and that will depend on who the group members are. For instance, adult children generally work or are caring for family so they would only attend in the evening. Elderly caregivers prefer daylight hours and not too early in the morning. When there is a concern about recruiting enough members, it is helpful to identify a few caregivers who are interested in being in a support group and ask them when a good time/day is. Work with this core group - reminding them and involving them in your planning to ensure there are attendees. Don't guess what a good time/day is; ask.
3. **FREQUENCY** - Generally speaking, holding the group on a monthly basis is best. However, if you have a group for newly diagnosed or young onset dementia you may wish to offer it twice a month.

4. LENGTH OF MEETING - Determine how long the meeting will last. Support groups should never last more than 90 minutes. The size of the group can affect this. A very small group of 4 or 5 people may be able to complete the work of supporting one another in one hour. A group of 10 to 12 will likely require 90 minutes. Two hours is too long. It is important to start and stop the meeting on time. Encourage anyone who wants to remain and visit (if possible at the facility you meet at) to do so. Otherwise they can continue their discussion outside.
5. SIZE - The size of the group will affect how successful it is. An ideal group is between five and ten people. If your group consistently exceeds the number 12 you will want to consider starting a second group by encouraging some members to transfer to the new group. When a group is too large there is not enough time for everyone to be heard or to wrestle with some of the difficult issues that come up. When just starting out, your group may be very small. Do not become discouraged by this. It may take several months to build a good sized group.
6. LOCATION/AMBIANCE - Based on those who might participate, explore sites at which the group can meet. Think about accessibility, privacy, parking, and how someone might perceive the building he is entering. For instance, caregivers may not want to attend in a nursing home or assisted living because the public might think they are planning to place their loved one. Or, the caregiver may feel the group meets there so they will be approached about admitting a loved one. This can happen even if the group is facilitated by an independent group. Examples of great sites include:
  - conference rooms in community building
  - hospitals
  - senior centers
  - senior apartment complexes
  - city halls, libraries, churches
  - independent living facilities

If the caregivers are elderly or disabled you will want a place where parking is close to the door and the entrances are handicapped accessible with buttons that open the doors. If an evening support group make certain the parking lot has good lighting.

Ambiance of the room includes lighting, size of room, comfort of furniture, room temperature and layout. The room should match the size of the group, i.e. don't put a group of five in an auditorium. Lighting should be soft--avoid harsh lighting. Chairs should be sturdy, comfortable and are safer without wheels. Arrange chairs around a table or at least in an open circle to promote sharing. The goal is to make a comfortable, intimate setting that puts the participants at ease to share. Do not underestimate the importance of the atmosphere of the meeting room and location.

Do not meet in places where there is no private place to talk (i.e. restaurants, activity areas in facilities, etc).

7. MARKETING YOUR GROUP - Promoting the meeting is an important step. Remember that it may take three to four meetings to establish a core of members and to function as a support group ought to. Media notices, flyers, letters will help promote attendance. Media notices are brief descriptions to give someone a basic idea of the purpose of your group.

Examples of where to place notices:

- community calendar of the local newspaper
- local public access channel
- church newsletters
- ADRC newsletters

Flyers are eye-catching, at-a-glance ways to communicate the purpose of your support group. Post flyers in a variety of locations:

- beauty and barber shops
- laundromats
- restaurants
- grocery stores
- exercise centers
- libraries
- pharmacies
- clinics and hospitals (if they approve)
- adult day and home health agencies.

Draft a letter for health care social workers to include in their welcome packets to caregivers. This is an invitation letter to the caregiver that details information about your support group. (see sample letter)

Create a brochure. Send brochures to health providers to hand to their consumers. Share brochures and other marketing materials with caregiver coalition members to give to their consumers as well.

Important things to include in marketing materials:

- group name
- place
- time
- “for more information contact (facilitators name and number)”
- “free and open to the public”

8. FACILITATING - Facilitating a support group works best with two people. At least one of those should be a caregiver (past or present) and one could be a professional such as a nurse, social worker, psychologist, etc. Having two people facilitate often provides variety in the personalities of the individuals and the way they relate to people and can strengthen the group. Remind caregivers, too, that each group has its own feel so try different groups until you feel you have found a good fit. Maintain a formal agenda except perhaps celebrating caregiving once a year by lunching together, having a potluck, or holiday party. Utilize the group as a source for planning topics, speakers, and other resources. It is important that you are comfortable with silence. Because it may take someone time to compose their thoughts to ask a question or give a response, please refrain from jumping in to keep the conversation going. Silences can be a result of someone being shy, a need to reflect, or is a way the group expresses empathy for the one who has just revealed something very personal.

Decide whether to have speakers or informal discussion. At the start of the group it is a good idea to invite speakers. It is less intimidating coming to a meeting to listen than to share. Once established, ask the group for input on whether to have speakers or open discussion. A combination of the two usually works best; either have part of the meeting for a speaker and the other part for discussion or have speakers come every other month with alternating months reserved for discussion.

9. WHAT TO BRING - Supplies to bring to each meeting include:

- contact information for the facilitators
- name tags (request first names only)
- a sign-in sheet
- printed caregiver resources
- handouts appropriate to the monthly topic
- extra pens
- refreshments – While having refreshments is not essential, it does add to the ambiance of the meeting. Make sure the host facility approves of refreshments being brought in or ask if they wish to provide them.

10. MEETING FORMAT

- Pre-Opening / Get Acquainted
- Introductions of facilitators
- Announcements
- Review ground rules
- Member introductions
- Information topic
- Exchanging support and problem solving
- Q&A
- Closing/next meeting

**MEETING FORMAT**

1. Pre-Opening/Getting Acquainted

The time before the actual meeting starts is important as it sets the tone for your meeting.

Having refreshments out and welcoming folks at the door encourages them want to stay and even return for the next meeting.

2. Introduction of Facilitators

At the start of the meeting identify the type of group it is and who sponsors it. The facilitators should introduce themselves and tell the group what experience or background they have related to the type of caregiver group it is. This establishes credibility from the outset.

3. Announcements

Inform members of any caregiver related education sessions, conferences, or services that will be open to them in the next couple months. Provide print information when possible.

4. Review Ground Rules

Hand out copies of the ground rules to all new members and read them over every meeting.

Emphasize the value of confidentiality and that group is a safe place to be open about feelings

and problem solve. (“We know that caregiving can bring on strong emotions, some that non-caregivers may not understand. This group is intended to be a safe place for you to express these feelings without the need to explain yourself and without the fear of being judged. Everything that is said here is confidential – it stays here.”). Stress the fact that sharing is voluntary—participants can share as much or as little as they choose to. Mention that you will start and stop each meeting on time out of respect for everyone.

5. Member Introductions

Ask members to introduce themselves by first name and a brief description of their caregiving situation (how they are related to the person, what the diagnosis is and if they live with the person or not). They should also say if they have something they want the group to discuss (get them to name it).

6. Information Topic

This is when you introduce the topic and how it will be presented; either a speaker, video or you can center your discussion on a tip sheet or other handout. This portion of the meeting should not last over 30 to 45 minutes (30 minutes if the group lasts one hour, 45 if the group last 90 minutes). Inform a speaker in advance that time is limited and you will stop them on time. During the meeting you must stop the speaker or discussion on time unless your group has not indicated they want problem solving time.

7. Exchanging Support and Problem Solving

During this time facilitators balance the number of requests from caregivers to discuss specific topics with the time left for the meeting. Be sure to encourage all members to help problem solve telling what did or did not work for them.

8. QUESTIONS TO FACILITATE DISCUSSION:

a. To open up discussion

- ✓ What do you think about this situation?
- ✓ What has your experience been in dealing with this issue?
- ✓ Would anyone care to offer suggestions or facts to help us better understand this issue?

b. To broaden the discussion

- ✓ Now that we have heard from some of you, would others who have not spoken like to share any ideas?
- ✓ How do the ideas that have been presented so far sound to those of you who have been thinking about them?
- ✓ What other aspects of this issue should we explore?

c. To limit participation

- ✓ You have made some good statements, and I am wondering if someone else might like to share a comment?
- ✓ Since all the members have not yet had the opportunity to speak, I wonder if you would hold your comments until later.

- ✓ We appreciate your contributions. However, it might be useful to hear from some of the others. Would some of you who have not spoken care to add any ideas to those already discussed?

d. To focus discussion

- ✓ Where are we now in relation to the topic of our discussion?
- ✓ Would you like me to review my understanding of the things we have said and the ideas we have come up with in this discussion?

9. Closing

Some facilitators find creating a ritual for the end of the meeting such as a short relaxation or meditation exercise is a good way to wrap things up. Here are some examples:

*As we close today, take a few minutes to remember that we can help ourselves better manage by slowing down and taking a few deep breaths. In this way we are able to respond to the needs of the person for whom we are caring rather than react to situational stress. We are also better able to help ourselves manage.*

*Close or partially close your eyes and sit with both feet flat on the floor. Let your hands rest comfortably in your lap. Take a slow, deep breath and hold it for 3-4 seconds. Slowly exhale. Continue to take deep, slow breaths, exhaling slowly as you repeat a calming word or short phrase to yourself. Try something like “I’m doing my best” or “I’m grateful” or “relax.” During the exercise relax each part of your body starting with your head, neck, torso, arms, hands, legs and feet. End the ritual and give the group a minute or so of silence.*

Another option is to just use a simple phrase to set a clear boundary for everyone. For example: *“I am honoring the time commitment for this session to insure that those who must leave can and those who wish to stay and visit may do so.”*

Remind everyone of the next meeting, stating topic and/or speaker. It is a good idea to send reminder postcards a few days before each meeting with the topic, short description and speaker if there is one. (See sample) Collect attendees’ addresses for this purpose and gather names/addresses of other potential caregivers throughout the month and from the ADRC/Aging Office and other collaborative agencies.

## **IDEAS FOR INCREASING ATTENDANCE**

- Start with a short, educational series. Calling the meetings educational might bring in caregivers who are leery of “support groups.” Have speakers do a presentation and then open up for discussion. This will allow people to get to know each other in a non-threatening way. If the turnout for these meetings is good you will have a base to continue meeting as a more traditional support group. Good speakers to attract caregivers include lawyers, doctors and pharmacists.
- Personally contact caregivers and invite them to attend the group. They may be uneasy or have questions as to what the meetings will be like. Make follow-up phone calls or send cards to attendees after the meetings. The personal touch will bring people back.

- Offer free transportation and respite during the meeting. NFCSP funds can be used for this purpose.

## **FACILITATORS NEED SUPPORT**

Remember that you will need to renew and relax as well as find your own support system. Model this behavior for your caregivers who also need to find ways to recharge. We give caregivers permission not to provide care 24/7 and as a facilitator, if you feel drained and empty; model the way by taking some time off. Find a substitute facilitator or replacement and do something that fulfills and renews you.

## **CHALLENGING SITUATIONS AND PERSONALITIES**

### Griping

Determine the difference between someone letting off steam and griping (even getting other participants to get on the “griping” bandwagon). Identify the specific problem and address it immediately to ask if any of the participants has a suggestion about how to turn the situation around. Try to stop it at the outset by getting the caregiver to also talk about what they have tried. Try to stop it at the outset by getting the caregiver to also talk about what they have tried. In these cases, the session turns into a complaint session without intent to resolve the issue. When this happens, your job as a facilitator is to change the direction of the negativity. If it is a complaint about a facility, suggest you speak with them outside the meeting and problem solved with them at that time. Tell the group that situation specific complaints are best dealt with the facility directly.

Emergencies can occur. If someone abruptly leaves the group, one facilitator stays and the other goes to assist. In the absence of two facilitators, place a participant with experience in charge and follow the caregiver who is leaving to talk with him/her. It is never a good idea to let someone go who is emotionally upset without additional support given.

- A. The withdrawn, quiet or passive member: Reluctance to speak is common at times. Try giving him permission not to work for a session or two. However, you can test the waters by asking a simple ‘yes’ or ‘no’ question such as “have you experienced this situation?”

If you suspect this ahead of time ask an experienced and open caregiver to sit next to this individual to engage in conversation before the meeting in an attempt to increase his comfort level.

Phrases to use include:

- You are shaking your head. Would you like to say something?
- For those who we haven’t heard from, please share your thoughts and feelings about this whenever you are ready.
- This reminds me of something you have told me. Would you like to share it with the group?

- B. The dominator: This individual always turns the conversation back to self, does not listen well and interrupts others. She may also deviate from the topic of discussion. You will redirect discussion back to the topic at hand and may wish to call on a member who you

know will be able to talk about his experience with the topic. If redirection does not work you may need to talk with the “dominator” after the meeting.

Phrases you can use include:

- We are running short on time so let’s write this down and address it at next meeting.
- We are hearing good comments. Does anyone else have a similar experience?
- You have brought up an interesting point. Let’s go back to this later after others have spoken. Or perhaps we can talk after group today.

- C. An argumentative, negative or hostile member: Some participants will only discuss the negative aspects of their experience and this impedes group process. Excessive negativity may create reluctance by others to attend or may even cause them to leave early. Acknowledge the situation and arrange a meeting outside of the group to address the anger and negativity. This could be a sign of depression or other life issues the individual is dealing with.

Use phrases such as:

- “Remember that while this is your experience, not everyone has the same situation. If Alzheimer’s disease is the diagnosis, it works differently for everyone.
- Does anyone else feel that don’t want to think about caregiving or this disease anymore?
- Why don’t some of you comment on how you handled things when you were angry and feeling the situation is hopeless.

- D. The Know It All: There are those participants who believe they have the answer or comment for everything. They will interject their opinions as fact and interrupt conversations. As a facilitator you will explain that each caregiver situation is unique to them. Listen and reflect back what you are hearing. Translate what is coming through at anger to hurt, disappointment, depression etc.

Use phrases such as:

- There are many solutions to these experiences. What worked for you may not be work for other caregivers.
- Who else would like to provide a solution to this situation?

- E. A member in crisis or crying: It is easy to become overwhelmed or feel hopeless during the caregiving. When someone cries very easily and becomes upset be empathic not sympathetic. Remain calm and speak slowly. Being relaxed may help the caregiver mimic relaxation. Let the person know they are not alone, that many caregivers become overwhelmed and teary. At this point avoid giving lots of advice but encourage that individual to talk about his/her feelings.

Use phrases such as:

- Take your time...many of us have felt the same way.
- We will be ready to listen when you feel ready to talk.
- Would you like a minute to collect yourself and we can come back to you?
- Who would like to share how they handled the situation when they felt overwhelmed and sad?



- F. Someone who is not appropriate for the group: Occasionally you may have an individual come to group who is not appropriate. For instance, sometimes lonely people come to meet someone who they hope to pair with. Or, someone with dementia may come to a dementia caregiver group. In these cases let your co-facilitator take over and call this individual out of the group to explain this group is not a good fit for the individual. Sometimes business owners serving caregiver will come just to do some marketing. Explain that is not the purpose of the group and they are not welcome to market there.

**Excerpted and revised from material developed by the Wisconsin Alzheimer's Association to train support group facilitators.**

## VOICES OF EXPERIENCE:

### The Seven Deadly Pitfalls

Discovered Through Personal Experience

THE PITFALL	WARNING SIGNS	WHAT TO DO
You are too close to your own Alzheimer story	It's hard to listen to someone else's story. What they are describing "doesn't sound like Alzheimer's" to you. You want to "set the person straight."	Educate yourself about the many symptoms and manifestations of Alzheimer's disease and other forms of dementia. Remember, your role is to facilitate education, sharing, and problem-solving.
The issues are emotionally charged.	You come to meetings with a message or "hidden agenda." It bothers you when someone else expresses different values or priorities.	Practice limiting what you say to questions, invitations to share and facts.
You have unresolved guilt or ambivalent feelings.	You are envious when someone is in the midst of a hard decision but has not made a commitment – yet. You want approval for a past choice you made or a situation you handled. You feel threatened by the possibility that a group member might make a choice different from yours.	Find someone outside the group to help you make peace regarding your past decisions. List everything about your choices that makes you uneasy now, and remind yourself why you did what you did. Remember that your past experience gives you the ability to empathize with others.
You are seduced by the role of a facilitator	You like having everyone listen to you. It makes you feel wise, witty and appreciated. You are starting to feel a little possessive of "your" group.	Come to the meetings prepared with the 24/7 Helpline phone number, Chapter brochures and handouts, book and video lists, and other local resources to offer you members.
You are thrown by the role of a facilitator	You are unnerved by being the point person. How can you remember everything? What if something comes up you can't handle?	Remember how to darn a sock: your job is to crisscross the hole in the middle of the group with the threads of encouragement and experience from one person to another.
The support group is no longer your support	When the meeting ends, everyone tells you what a great meeting it was but you feel depressed.	You may need to find a source of personal or professional support. Perhaps you need to step away from your facilitator role for now and give yourself additional time to grieve.
You are trying harder to be a nice person than effective facilitator.	Side conversations. Long-winded participants. People checking their watches.	Make a collection of friendly but effective phrases to interrupt and redirect unnecessary discussion. Remember, the meeting will be most beneficial to all if you keep it on course.

Material for challenging situations or individuals and this Voices of Experience section were developed by the Alzheimer's Association.