



Support Group Facilitator **MANUAL**



DEMENTIA
ALLIANCE

of North Carolina

A STATE OF CARING

MANUAL FOR

Alzheimer's & Related Dementias Support Group Facilitators

With thanks to our contributors

Our Support Group Manual is dedicated to the thousands of North Carolinians who have lost their lives to Alzheimer's disease and other dementias; the many more thousands of caregivers who have given or lost their lives caring for a loved one; and to our Support Group Facilitators who have given and continue to give so freely and unselfishly of their time, talents and energy to others in need of support – emotional, educational and physical.

We extend a special thank you to *Melanie Bunn, RN, MS, GPN, Virginia Meiburg, RN, and Teresa Johnson, MSW*, for creating our first Support Group Manual. We would also like to thank everyone else who has had a hand in creating this wonderful tool.

Information, education, medication and attitudes about Alzheimer's disease and other dementias are changing rapidly. This Support Group Manual is a collection of many thoughts, ideas and works – gleaned from many resources – and we have made every effort to give credit to all involved in its production. Should you, the Support Group Leader, or reader of our manual find something for which you should have received recognition, please know that it was not our intention to omit credits. We ask you to accept our thanks and appreciation for the many ways you will help through your contributions.

Our deepest appreciation to all who have assisted in making this manual possible.



**DEMENTIA
ALLIANCE**

of North Carolina
(Revised 2020)

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Updated 08/20

MAKING A DIFFERENCE – ONE AT A TIME

*One child came upon another
child on the beach one day.
The second child was walking
alone, looking down, then every
few feet would bend down, pick
something up out of the sand,
and toss it into the ocean.*

*The first child asked what kind
of game it was. The second child
replied, “I’m saving starfish.”
The first child was incredulous.
“Are you kidding? There are too
many! What are you going to do?
Spend all day and night out here,
tossing starfish back into the
ocean? You’ll never save them
all. And anyway, in the grand
scheme of life, they’re just
starfish. It doesn’t matter if
they live or die.”*

*The second child scooped up
another starfish from the sand,
considered it briefly, then hurled
it into the ocean. “It mattered
to that one.”*

Author Unknown



Photo by Adam Cavanagh on Unsplash

INTRODUCTION

Facilitating a dementia support group is a challenging, yet rewarding, experience. Accommodating the needs of individuals, while addressing the interests of the group can be an overwhelming endeavor. While the diversity of members makes the facilitator’s task complex, it also deepens the opportunity to develop coping skills, support networks and cherished friendships.

Education and support, common experience and friendship give people the strength to cope with the tragedy of Alzheimer’s disease or related dementias. People learn from each other and most importantly learn they are not alone.

*While we can’t take care of every
caregiver of loved ones with
Alzheimer’s disease or
related dementias,
we make a tremendous
difference to those we serve.*



MISSION

Improving lives of caregivers and others impacted by Dementia in North Carolina, engaging and empowering them through support, education and research.

Dementia Alliance of N.C. programs are built around a foundation of **CARE** - providing *Comfort, Assistance, Resources and Education* for individuals and families living with Dementia. Through our CARE approach, we seek to help N.C. become a state of caring for caregivers and individuals living with Dementia with:

- Educational Outreach – Regional conferences and workshops for family and professional caregivers, community awareness programs, professional training for long term care providers, law enforcement, clergy and other groups
- Support – Dementia navigation services, support groups for caregivers and those living with Alzheimer's and other dementias, individual and family counseling and emergency respite
- Services - Referrals, free information packets and advocacy for research funding

FINANCIAL INFORMATION

Contributions received through grants, memorials, honoraria, combined federal, state, county and city campaigns, corporate donations, employee payroll deductions and fundraising events provide programs and services — 100% of funds received for research are allocated to research. All funds raised remain in North Carolina to assist with family services and educational programs.

HISTORY

Established and incorporated as a 501 (c) 3 nonprofit at Duke University in 1982 by family members and professionals, the organization has provided information, education, conferences, training, programs, services, advocacy, research funding and counseling for families and professionals throughout North Carolina. In 2009, this organization known as the *Eastern North Carolina Chapter of the Alzheimer's Association* disaffiliated and became *Alzheimer's North Carolina* to focus time and funding on meeting the needs of North Carolinians in local communities. The name changed again in 2018, to *Dementia Alliance of North Carolina (DA-NC)*, to better reflect the commitment and mission to support families and professionals living with all types of dementia across North Carolina.

We are honored to have the opportunity to help individuals and families during their time of need. We are extremely grateful of your time, talent and commitment to serve others as a DA-NC Support Group Facilitator. We welcome you to visit our web site (below) for additional information or call us at (919) 832-3732 to inquire further about resources available to facilitators.



**DEMENTIA
ALLIANCE**
of North Carolina

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www.DementiaNC.org



Support Groups for

ALZHEIMER'S DISEASE & RELATED DEMENTIAS

DEFINITION & PURPOSE:

Dementia Alliance of North Carolina Support Groups consist of families, caregivers, friends and other interested individuals meeting to share feelings, thoughts, experiences and information; to give and receive mutual support; and to exchange coping skills with one another in matters relating to people with dementia and their care. In short, *"someone to stand by you."*

GOALS:

- To develop and promote a mutual support system
- To share information on care and community resources
- To accept and express feelings, thoughts and common experiences
- To exchange coping skills with one another

- To help maintain the health and well-being of the members and group
- To seek balance between education and support for optimal benefit!

BENEFITS:

- Establish a new set of **norms**
- Accurate updates and interpretation of **research, resources, and caregiving strategies**
- Expression of **feelings**: guilt, embarrassment, grief, sadness, loss and joy; emotional support
- Provide opportunities for different types of people to **communicate and learn**
- Easier to hear from a non-relative
- Laughter with loving understanding

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GROUP MEETING FORMATS

Closed Groups

Primary goal: A closed group meets to address the specific needs of individuals who are associated with an organization. The general public is not invited to attend.

Positives: Participants have a common experience. They can develop relationships with other members that may provide opportunities for informal support during visits. Often these relationships extend to the person with dementia and may result in additional support to him or her as well.

Negatives: There is a tendency for these groups to begin to address organizational issues rather than issues of dealing with dementia. For example, in care facilities, discussions about staffing ratios, laundry and food services, while important, are more appropriately addressed in family or resident council. Confidentiality can also become an issue with participants thoughtlessly sharing information and feelings expressed during the meeting with other family members and staff.

Suggestions: The goals of the group need to be carefully identified. The group needs to be carefully differentiated from other meetings. The facilitator should acknowledge participants' non-support group related concerns as important and provide information on using the chain of command to resolve the issue. Strong and responsive family and resident councils and other similar groups will do much to limit these discussions. If a staff person is the group facilitator, these roles need to be distinguished and the boundaries respected by both the staff member and the participants. Reviewing the rules of confidentiality, addressing any situations when confidentiality is breached quickly and asking up front for permission to share information with others outside the group can reduce the potential for problems.

Open Groups

Primary goal: Open groups meet to provide support to individuals associated with an organization and to members of the community at large.

Positives: Open groups may be more dynamic and meet the needs of a larger group. Specifically, participants who do not have a loved one in the facility may benefit from relationships with others who have a family member living in the facility. Interacting with facility staff members can reduce anxiety about the potential for placement. Within other organizations, awareness of additional resources may be increased.

Negatives: The organization that sponsors an open group risks having their "dirty laundry" aired in public; some participants may bring up issues that the organization would prefer not to be discussed with individuals not associated with the group.

Suggestions: Be consistent in defining the purpose of the group as support in dealing with the issues associated with dementia.

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COMMON GROUP TYPES

Education/Program Groups

Primary goal: Information sharing.

Positives: Can be an effective way to start a new group. Often participants are uncomfortable sharing personal information with strangers. An education or program group can provide a mode for people to establish a bond before beginning to provide support.

Negatives: Limits support. Both education and support are critical to the health of caregivers. A group that spends a large portion of time in education will have difficulty meeting the emotional needs of the participants.

Suggestions: Occasionally have meetings with sharing as the agenda. Limit speakers and videos to less than one-half of planned meeting time. Schedule a meeting topic around an emotional issue (grief management, dealing with the holidays, etc.)

Support Groups

Primary goal: Provide emotional support.

Positives: Caregivers often find that others in their lives do not understand Alzheimer's disease or the difficulties of living with someone with Alzheimer's disease. Through the support group, they can express feelings and needs to people who can understand.

Negatives: People may need opportunities to problem solve and gather information/education.

Suggestions: Poll the participants or keep a list of common issues. Consider asking a professional in a healthcare or social service area (a nurse or social worker for example) to be available as a volunteer or co-facilitator.

Note: A balanced group will meet group members' needs through education AND support. They do not have to be split 50/50, just offer opportunity for both education and support in each meeting.

OTHER GROUPS

General Caregiver Groups

General Caregiver Groups are not specific to dementia, but offer caregiving support for a broad range of health issues. They offer information, resources and support

Early Stage Support Groups

Groups for people recently diagnosed with dementia lead by experts to help process feelings, assist with coping strategies and maintain the highest level of function possible.

There are a variety of configurations: meetings dedicated to the person with dementia, meetings that include care partners, meetings starting with the dyads together then separating into separate groups.

Young Onset Groups

Young-Onset Support Groups are designed for individuals and/or their care partners 65 and under that have been diagnosed with dementia. These groups provide support to each other by sharing their experience with their peers who are dealing with some of the same situations.

Men's Groups

Men's Support groups are designed for males caring for a loved one with dementia. The group provides a safe place for them to share personal experiences and to develop mutual support and resources from one another.

Private Groups

Groups that meet under the umbrella of other organizations (for example, care facilities, faith communities, civic organizations, etc.) have the opportunity to provide much needed support to families and loved ones. Having an additional shared experience, whether placement or faith or other, can strengthen the ties between participants.

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SUPPORT GROUPS ARE NOT

Group Therapy

Group therapy can be tremendously beneficial to participants because of the ability to process and resolve emotional issues. Most DA-NC facilitators are not clinical psychotherapists. Group therapy should only be facilitated by credentialed professionals. Contact the DA-NC office for assistance.

Sale Generators

Support groups should never be used as a marketing strategy or platform to sell goods or services.

CONFIDENTIALITY

The facilitator of a support group must not only personally respect the confidentiality of the group members, but he or she must also instruct the members in the group of the importance of protecting the privacy of others. Rarely do group members maliciously or intentionally break confidentiality. A more common problem is the thoughtless sharing of personal information that is found to be embarrassing or hurtful outside the group.

One tactful way of instructing new members and reminding old members of the importance of confidentiality is to stress that personal issues discussed in the group are not to be discussed outside the group setting. The exception to confidentiality is information concerning the abuse of a dependent person. Knowledge of abuse must always be reported to the appropriate agency. Assistance in making those decisions can be obtained through our office. Confidentiality must be reinforced at every meeting.

GROUP FINANCES

Groups are discouraged from collecting or dealing with large sums of money. A small amount to be used for postage and mailings, flowers or memorials is optional (less than \$50). While groups are encouraged to

participate in fundraisers to support Dementia Alliance of North Carolina, the funds raised should be turned in to the office. Please call the office for additional details.

DEALING WITH VENDORS

Often, support group facilitators are approached by vendors or marketing representatives of products, facilities and services. The decision to allow these individuals access to participate should be made carefully. While they may be able to contribute helpful information, the confidentiality of support group members must be maintained. Vendors should never be given mailing lists or lists of support group participants. Be very careful of allowing individuals with agendas of personal gain to solicit group members. Any vendor who attends the group should be expected to provide some service to the participants, for example, information. The support group meeting is not the appropriate setting for a marketing demonstration. If a vendor would like to make contact with, but has nothing to contribute to the group, it may be appropriate to ask for marketing information that can be made available to the participants at the next meeting. If there are questions about allowing vendor access to the group or participants, please contact the office.

Any product, service, research, website and/or drugs that are shared in the support group meeting are not an endorsement by Dementia Alliance of North Carolina

THE GROWTH OF A SUPPORT GROUP

Groups are like people in that they grow, develop and mature. You've probably noticed how your group members, who were strangers at first, have grown to know and care about each other.

Though no two groups are alike, support groups have common stages of development.

It's hard to say how fast a group will grow or how long each stage lasts, but it's helpful to know the general path a group will travel on its way to maturity.

Below are the stages of support group development. In reading them, think about how they compare to the growth of your support group.

Stage One: Information Gathering

When a caregiver first enters a group, she may be timid and unsure of what the group has to offer. She is unsure of how comfortable the group will be for her. She may wonder, "Do I fit in?" By talking about her personal caregiving situation and hearing others, she sees she is not alone in her problems. A common bond is formed among strangers and the seeds for the group cohesion are planted.

Many of the group members have just begun to grapple openly with dementia and are still numbed by the diagnosis. Hungry for information, but having difficulty accepting or using it all, new members respond best to topics about diagnosis, treatment and common symptoms of Alzheimer's disease without pressure to expose their feelings.

Stage Two: Emotional Sharing

In this stage, group members open up to share their frustrations and fears in coping with dementia. They look to the group leader for more detailed information on the disease, coping and what to expect in the future. Members swap ideas on how to deal with specific problems. Resistance may surface during this stage. Some caregivers, having difficulty accepting the diagnosis, are often "doctor hopping," looking for the magic cure. It is common to hear a caregiver at this stage say "My husband doesn't have that problem, so he must not have Alzheimer's disease." Others may resist any new caregiving technique or refuse to consider using a

support service. Sometimes this resistance is expressed in a judgmental attitude toward another member's style of coping, i.e., "I'd never put my mother in a nursing home."

Stage Three: Mutual Support

Group members gradually turn to each other rather than the leader, for support and opinions. They feel safe and are sharing more with the group. Dominant members spontaneously reach out to support others and orient new members.

Groups at this stage usually agree on a definition of Alzheimer's disease and caregiving. Members practice new skills related to caregiving and serve as role models for each other. The mutual support that has grown among members seems important to motivate them to rearrange their lives to include the new roles of caregiving.

Stage Four: Self Determination

In this stage, members have adjusted to being caregivers and look beyond their personal roles as caregivers. Some help others in the support group. Some leave the group because it has fulfilled its usefulness.

The group often re-evaluates its purpose at this point and expands beyond the need of its immediate members to pursue broader goals such as recruitment, program planning and advocacy.

In reality, groups rarely move smoothly from one stage to the next. Instead, groups may bounce back and forth between stages or get stuck in one stage during their development.



WHAT DO YOU NEED TO FACILITATE A SUPPORT GROUP?

CARING HEART | OPEN MIND | WILLING HANDS | PREPARATION

CARING HEART:

- Respect for people with dementia
- Compassion for caregivers
- Comfort dealing with the range of emotions

OPEN MIND:

- Learn about dementia and Alzheimer's disease

New ways:

- Positive physical approach, empathetic communication, progression of gems

New research

Different ways:

- Different from how you did it
- Different from your value system
- Ability to problem solve

WILLING HANDS:

- The commitment to start...and follow through

So you pass the test...now what?

PREPARE:

- Learn about Alzheimer's disease and other dementias
- Explore resources in your community
- Other support groups—Alzheimer's, aging etc.
- Possible meeting sites
- Potential speakers
- Sources of assistance

The Facilitator's Role:

- A helper rather than an expert
- Listener more than talker
- An encourager rather than a leader
- A sharer of mutual concerns rather than a problem solver

The facilitator is not expected to be a psychologist, nurse, lawyer, social worker or therapist. Rather, the principal role of the facilitator is to encourage participants to share feelings, concerns and information in a safe, nonjudgmental setting. Ideally, the facilitator will have prior personal or professional experience working with people with dementia and their families.

Specifically, a successful support group facilitator is empathetic, warm and sensitive, knowledgeable, and current in issues about dementia, knows how to access community, state and national resources and manages both the logistics and the group processes of the support group.

The varied, combined experiences of the participants of the group will provide the information for most problems identified in a meeting. The facilitator should first ask participants how they solved or handled certain problems, feelings and situations – rather than offer his/her own answers.

Not only does this kind of attitude or approach encourage discussion and sharing, it improves participants' self-esteem. It also removes the facilitator from being considered an expert, and demonstrates the various ways that situations can be handled. Participants will feel free to choose strategies/options that best fit their situations, or reject all of them if they choose, without feeling pressured to do the "right" thing.

Good facilitators are perceived as understanding and compassionate, patient and willing to listen to all emotions: sadness, guilt, grief, anger, resentment, love, etc. They must be able to understand and accept individual's

beliefs and value systems, decisions and cultural variations.

Key Roles of a Successful Support Group Facilitator:

Offers Emotional Support

- Being a good listener.
- Encouraging an atmosphere of acceptance and respect for group participants
- Understanding the cultural values and beliefs of the group participants
- Having an open mind about other's personalities, views and experiences
- Being nonjudgmental and understanding of the person's experience from his/her point of view
- Creating a safe atmosphere and reinforcing confidentiality
- Remaining emotionally present and really listening to what others are saying through words, body language and feelings, showing through words and deeds the understanding and acceptance of thoughts and feelings
- Communicating, facilitating and articulating ideas, feelings and thoughts, and encouraging others to do the same
- Being genuine and authentic and not afraid to show true feelings and thoughts, including sharing personal feelings, reactions and experiences when appropriate and if needed
- Maintaining a sense of humor and ability to lighten tension
- Giving encouragement and recognizing accomplishments
- Remaining open to feedback and willing to grow and learn new ways of doing things
- Being available to support group members as needed

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More skilled facilitators will develop the ability to listen and then help the participant to move to the next step in emotional development or decision. This takes the ability to first support and encourage ventilation, then rephrase what you've heard and lead individuals into problem solving to develop their own answers.

Sometimes experienced facilitators may know the next appropriate step or decision and feel led to direct rather than facilitate. While this is tempting, each person needs to work through the steps one by one to successfully move on.

Provides Accurate Information and Resources

- Being knowledgeable about dementia and current research developments
- Informing – but resisting the urge to lecture. Helping members learn from each other rather than teaching the “right” way of doing things)
- Gently correcting misleading or inaccurate beliefs
- Being aware of community resources that could be helpful to persons with the disease and their families
- Communicating with the office about resources

Facilitators must be committed to the concept of providing helpful information and resources to the support group members. The best

way to stay up to date about AD and related dementias, from diagnosis and drug therapy to strategies for managing risk behaviors, is to stay in touch with the DA-NC office and attend community education conferences and workshops.

While the media can be helpful in identifying the newest findings in the field, the information is often presented in a manner designed to get quick attention, sometimes making research appear to be more promising or closer to being available than it really is. A good support group facilitator will use the DA-NC office to help in understanding and disseminating research in an accurate and realistic way.

First-hand knowledge and personal experience providing service to people living with dementia and their families/ caregivers is very helpful to the facilitator and promotes credibility. If one facilitator doesn't have this type of skill, try to recruit a co-facilitator who does.

Manages Group Discussion

Leadership is tricky business. To be a leader, you don't have to be a “super organizer”, a “wonder woman” or “Mr. Muscle.” To be a facilitator, you do need to have a healthy respect for your own limitations and an appreciation for the talents of others.

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Perhaps you don't feel comfortable speaking in front of large groups. You don't need to be, as long as you are willing to ask Mrs. Jones to be "program moderator" for the August meeting, or to invite that dynamic nurse you met at the nursing home to be guest speaker for the evening.

Leadership is best "group owned" and "community based." If one person does it all, burnout is fast and fatal, and the entire group folds. As leader of the group, your willingness and ability to listen is very important to the participants. Measure your success by how you feel at what you are accomplishing! You will pick up on this from the pulse of the group.

1. How can you get people relaxed about talking in a group? At the first meeting especially, it is natural for people to feel a little ill at ease and reluctant to speak. As facilitator, take this bull by the horns at the onset. You can open by asking people to introduce themselves and express why they came.
2. Don't insist on immediate disclosure of an individual's situation. Many new members find the range and variety of symptoms and experiences overwhelming. They just want to sit and listen at first.
3. Present concrete information on a specific topic to trigger discussion. Try to present the topic fully, although briefly, before discussion. Discussion may drift off the chosen topic, but at least group participants will feel that they come away with more information and a better understanding of a particular area of interest or concern.
4. Allow silences. Encourage members to ask open-ended questions of each other, such as "What do you do when...?" or "Has anyone else had this experience?" This isn't just the responsibility of the facilitator.
5. Encourage members to use each other for peer consultation. For example, one group member requested to speak to others with adolescents living in the same home with a

demented grandparent. She was eager to compare experiences and to figure out for herself if her adolescent's reaction to the grandparent was "normal" or "expected."

6. Avoid "leading." Encourage the group to share the leadership. Don't always feel you have to give the answers. Sometimes there are no answers.
7. If you don't know the answer, admit it and follow up.
8. Thank group participants for taking the time to attend. Let them know that what they do is important and appreciated. Sometimes a meeting is the only occasion at which they will hear words of appreciation. A "thank you" means a lot!

Dr. Albert Heyman, an early researcher and medical advisor, once told a group, "There are no stupid questions." Don't be afraid to ask about what you have read or heard. Facilitators don't have to know all the answers, but they should be committed to helping others locate answers from the office, medical advisors and other resources.

(Adapted from "Mobilizing Networks or Mutual Support. How to Develop Alzheimer's Caregivers' Support Groups" – Gwyther and Brooks)

Availability to Support Group Members

The group leader is expected to be available to group members for support outside of group time. Appropriate interventions could include emphatic listening, information and referral and comforting. However, the group leader is not expected to provide therapy or counseling to a group member. Individuals requesting or requiring these services should be directed to the appropriate mental health

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professional or clergy. It is appropriate for the facilitator to set limits with individuals or the group concerning availability.

Be clear with the members of the group on how and under what circumstances they can contact the facilitator and other resources that are available when the facilitator is not. Also, encourage members to develop supportive relationships outside of the group. Remind them that confidentiality of sharing within the group continues even when members of the group meet informally outside of the group.



Maintain Contact with Dementia Alliance of North Carolina

It is important for the facilitator to maintain contact with the office in the following ways:

- Forward any group facilitator changes and/or meeting times and location to Dementia Alliance of North Carolina. See form "Support Group Facilitator Form" (Appendix A:1)
- Rely on the staff for support, support group materials and educational training
- Seek guidance on interpreting the ever-expanding body of lay and professional literature on Alzheimer's disease and related dementias

- Use Dementia Alliance of North Carolina branded literature and materials available at regular meetings
- Forward names, addresses and any information on new support group attendees to the Dementia Alliance of North Carolina office for mailings, i.e. newsletters, research updates. See form "Support Group Member Mailing List & Interest Form" (Appendix A:4)
- Direct donations to sponsoring Dementia Alliance of North Carolina
- Support Dementia Alliance of North Carolina sponsored events. See website for events: www.DementiaNC.org

Do you have a co-facilitator?

- It is recommended that you identify a co-facilitator
 - May assist you with group management
 - Provides help with logistics
 - Identify someone who compliments your skills but perhaps is in a "different place in the caregiving journey" or profession
 - Someone that can run the meeting in your absence
 - It is helpful in case a member gets upset, or a caregiver unexpectedly brings their loved-one with dementia
 - Safety in numbers

GETTING STARTED: Specifics & Logistics of Effective Group Meetings

Do your research before you decide where and when to hold your meetings. Find out when other support groups meet, what other events may compete with your group and the preferences of the potential participants.

WHO: Participants of support groups come from many sources; word of mouth, and referrals by doctors, hospitals, churches, nursing homes and agencies, media (press releases, newspaper, radio & TV stories, and social media.

LOCATION: Meetings can be in-person or virtual via Zoom or other online platforms (See Appendix A:12; 13-18). If meeting in-person, locate a safe environment that is central to participants and accessible for those with physical or sensory disabilities. Make sure well lit, ample parking is available. Meeting room should be large enough to allow for increased attendance or newcomers. Consider the type of setting—are there positive or negative associations. Finally, get permission to post signs indicating the location of the meeting in or near the building entrance.

TIME: The time of the meeting will depend upon the potential audience or participants. Evening meetings will work best for caregivers who are employed and for those who rely on other working family members to stay with the person with dementia. An afternoon meeting

may be preferable for caregivers who are elderly, who wish to avoid night driving or who use day respite services. It is important to schedule the new support group at time that compliments, and doesn't compete with, existing support groups.

FORMAT: Educational topic/speaker or support group. Or both?

CO-FACILITATOR: Identify a co-facilitator to assist you with the group.

MAKE ARRANGEMENTS: After you've made decisions about specifics, start to make arrangements. Negotiate time, place and speaker. Follow up conversations with confirmation letter or email. Contact the DA-NC office to notify of meeting time and place, and to request arrangements for supplies and materials. Plan refreshments.

PUBLICITY: In order for people to attend support groups, they need to know they exist. Publicity is an inexpensive way to make people aware of the existence and function of support groups. Consider personal contact to invite people to the group. Host a Community Education Meeting (see section: "Hosting a Community Education Meeting-CEM") and inform them of the follow up meeting/support group. Visit groups where potential participants may be recruited.

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Ideas for promoting the program include:

- Media
 - Social Media
 - Local newspapers
 - Television and radio stations
- Faith communities
 - Newsletters and bulletins
 - Post flyers
 - Visit appropriate classes or meetings to extend a personal invitation
- Health Care Systems
 - Long term care facilities
 - Adult Day Centers/Senior Centers/ Assisted Living Facilities
 - Home health agencies
 - Health department
 - Hospital discharge planning, social work or education departments
 - Medical practices: family, internal medicine, neurology, psychiatry
- Government agencies
 - Family and mental health agencies
 - Area Agencies on Aging
- Dementia Alliance of North Carolina office
- Community groups/organizations
- Attorney's offices
- Community resources
 - Libraries
 - Public bulletin boards in stores or shops

Samples are included in the Appendix B: Media & Public Relations Information

The Meeting

Before the meeting:

- Set up refreshments, educational materials, sign in sheets, name tags, DA-NC contact forms
- Arrange the room for the comfort of the participants. While chairs in a circle may promote group participation, new groups may feel more comfortable with

a more formal arrangement with tables and chairs

- A support group meeting needs to follow an outline but should not be rigid. A friendly, informal atmosphere helps participants feel comfortable. Set up an agenda that allows time to greet people as they arrive and also enough time for people to sign in, look over displayed materials and select a seat
- Many groups have found positive responses to sending out meeting reminders. Examples of meeting reminders include emails, notices in newsletter, flyers and postcards. Other groups use phone calls, either by the facilitator, a volunteer or a phone tree

As people arrive:

- Greet participants and introduce self. Greet new members when they arrive and introduce them to old group members
- Provide name tags
- Offer refreshments, educational materials, New Member Group packets
- Invite early arrivals to participate by handling administrative tasks (name tags, information tables, refreshments, arrange chairs)

Start the meeting:

- Begin the meeting with the Guidelines or "rules". For example: confidentiality, respecting choices and talking one at a time. See suggestions in Appendix A:3
- Offer participants an opportunity to introduce themselves and express why they came to the meeting (new members) or how things have been since the last meeting

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- Sometimes the connections made before and after the meeting may be as meaningful as what happens in the group
- Have co-facilitator available to assist late arrivals
- Welcome and introductions
- Orient participants to space, bathrooms, schedule, etc
- Make announcements
- Depending on size of group, ask participants to introduce themselves
- Define purpose of meeting: education and support and why both are important

Program:

- Introduce speaker
- Program typically lasts 30-45 minutes with time for Q&A
- After program is completed, thank speaker and have co-facilitator walk out or invite to stay as appropriate

Support:

- Ask participants to introduce themselves. They may want to describe why they came to the meeting
- Facilitate discuss of program and how it impacts on various participants

If a speaker or program is planned, it is often a good idea to start with the program and plan for sharing time to follow

Closing:

- Thank everyone for attending
- Encourage participants to form outside of group relationships
- End on time. Some participants may have made care arrangements and feel uncomfortable leaving before the formal part of the meeting is over. Also, considering providing respite
- Allow time to debrief: what was

helpful and what would they like to be done differently

- Reinforce the ownership of group—for and about participants' needs
- Solicit feedback on types of programs desired and format of support group
- Ask for contact information
- Request specifically how to contact: email, mail, phone
- Reinforce confidentiality
- Provide contact information
- Talk about next meeting date
- Thank participants and encourage them to stay and talk informally
- Encourage refreshments and education materials

After the Meeting

Debrief with your co-facilitator:

- Spend some time discussing and considering how the group went and participants responded
- What went well and what should be changed
- Each participant arrives at the meeting with individual needs. At the end of the initial meeting, it is important to have learned the needs of the individuals and the group and to make preliminary plans to meet those needs
- Follow up with the new member with a phone call or a note
- Plan for the next meeting
- Clean up meeting site

Follow up:

- Forward contact information to Dementia Alliance of North Carolina
- Contact participants and invite to share reactions, responses and additional needs
- Invite attendees to the next meeting

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HELPFUL TIPS FOR CONDUCTING A MEETING:

- Follow a support group meeting format. Include introductions, make announcements and provide the group with an overview of the meeting
- Begin the discussion by picking up on things mentioned in introductions or by asking if anyone has something they wish to discuss first
- Elicit responses from other participants with comments like “Has anyone else had a similar experience?” or “How would you handle this situation?”
- Listen. Try to understand. Ask for clarification. Reflect back on what was said if appropriate. Accept participants as they are
- Keep the group on track by helping them stay with the topic
- Do not make a diagnosis or give medical or legal advice
- Do not give advice or present information as your experience, unless appropriate
- Show concern and respect for people in the group, working towards establishing rapport
- Assist people in recognizing and understanding their feelings
- At the end of each meeting, summarize the discussion and leave the group on a positive note. Point out progress made. Recognize special events. Socialize. Serve refreshments
- Being flexible, yet organized
- Speaking audibly and clearly
- Monitoring group process
- Identifying issues within the group and assisting the group and members in moving towards resolution
- Providing the group opportunity to problem solve together is an important part of the group process
- Offer participants an opportunity to introduce themselves and express why they came to the meeting (new members) or how things have been since the last meeting
- To summarize the meeting, try to find themes and commonalities among discussions

We recommend sharing some of these responsibilities with a co-facilitator or group of assistants.

For additional information, see the section [Additional Resources for Facilitating a Support Group](#):

- Think About & Evaluate the Support Group
- Notes from Support Group Leader Facilitator Meetings

It is also recommended to set up a RESOURCE TABLE with the following materials:

- Dementia Alliance of North Carolina contact information
- Fact sheets about Alzheimer’s disease and related dementias
- Calendar of Educational events
- Other newsletters and brochures
- Schedule of support group meetings
- Name and phone number of group facilitator
- Handouts for caregiving tips, etc.

In addition, a “New Member Group Packet” may be provided for each attendee. (See Appendix A:2)

THE 5 ABSOLUTES OF SUPPORT GROUP

one

TALK OPENLY

Remember all conversations are to remain confidential within the group- And Listen Openly, try not to interrupt others in the group

two

BE RESPECTFUL

Leave judgment at the door, use kind words and remember other's loved ones are in different places/stages and everyone is doing the best they can

three

GIVE ADVICE/
OFFER SUGGESTIONS

Instead of "Telling" others what to do-
Avoid statements starting with:

- You should . . .
- You need to . . .
- You have to . . .
- Don't do . . .
- You can't do . . .

Instead use words such as:

- I recommend . . .
- Maybe you could try . . .
- This worked for me . . .
- I'm sorry that didn't work for you, maybe this could help . . .

four

SHARE WITH
THE GROUP

Not just your neighbor, save sidebar conversations for later

five

BE MINDFUL TIME

Give others time to share and offer feedback- all groups are limited in time so we want to try to ensure everyone has an opportunity to share and to respond to others



**DEMENTIA
ALLIANCE**

of North Carolina

www.DementiaNC.org

Maintaining an Effective Support Group

Maintaining a support group can be as or more challenging than starting a new group.

Keeping a focus on basic principles can help a group stay healthy and growing.

Evaluate the Group's Needs

In a survey of existing groups, some common denominators have been observed. Attendance at regularly scheduled meetings may vary greatly from meeting to meeting. It is important to review attendance records and assess the reasons for non-attendance. Please refer to the Support Group Evaluation Form to assist in identifying which particular factors may be affecting attendance of a specific group. (See Appendix A: 7- Think About & Evaluate Support Group).

On an on-going basis, monitor the number attending and patterns for attendance. For example, on average, how many people attend each month and how often do people attend only one meeting? When the facilitator notices attendance beginning to dwindle or other signs of problems, step back and evaluate the group's situation. While the success of a group is not based simply on numbers, a waning group attendance may be reflective of unmet needs.

Periodically offer opportunity during the group to discuss individual and group needs; how the group feels about the group, feedback on facilitator skills, ideas to update or change format, logistics and recommendations for change, possible programs or topics, etc. Use these sessions as a resource as you plan future sessions. Consider handing out lists of possible programs and ask for preferences or providing the group with a formal feedback survey.

Other Suggestions

1. Give participants jobs – Have available opportunities for participants to get more involved with the group. For example, ask for volunteers to bring refreshments, arrive early to help set up the room, stay late to help clean up, manage the mailing list or be

available for phone calls between meetings. Having a "job" often helps participants feel more connected to the group and provides a sense of giving back

2. Vary the routine; sometimes have a meeting purely for socializing or a meeting including the person with dementia
3. Consider hosting a community awareness meeting to reach out to the general community. See section "**Hosting a Community Education Meeting (CEM)**"
4. Maintain close connections with the DA-NC office. Receiving mailings from the office will often trigger a return to the group. Ask the staff for assistance in problem solving solutions to a declining attendee
5. Don't be too hard on yourself – support groups seem to have a natural ebb and flow of participants. If group attendance is dropping, do an assessment of possible problems, review the basics of meeting and maintaining groups, consider additional outreach efforts – then relax. If you offer good programs and support in an accessible manner, they will come ... eventually
6. Be sensitive to a new group member's response to issues expressed by members who are caring for a person in the middle or last stages (particularly those attending soon after diagnosis is made). Stories of violence, incontinence and difficulties sometimes experienced in long term care can be overwhelming to a new member
7. After the meeting, introduce the person to another member who shares a common situation, has successfully managed something similar in the past or has an interest in developing ongoing rapport

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8. Debrief the new person—especially if difficult issues are discussed (end of life, hospitalization, behaviors)
 - Validate their feelings
 - Don't mislead the person, but do provide support as appropriate
 - Everyone is different
 - Behaviors in later stages of the disease



Outreach and Public Relations -- Spreading the Word

When a group is going well, sometimes the tendency is to back off of outreach to new members. Have a system in place so this is managed automatically. Routinely post meeting notices in publications that provide monthly calendars or in locations where people who might benefit from your group might gather.

Make a conscious effort to send out monthly reminders. Ask each new attendee if they would like to be included on the email list and how they would like to be contacted.

There are a number of vehicles that can be used to inform the public of support group meetings and upcoming events or activities.

You first want to call your local newspaper(s), TV and radio stations and ask who handles calendar items and/or community affairs issues and get the contact information.

These days, the media prefer to receive their news via e-mail, but fax and regular mail still work. Just ask for their individual preferences. Once you have sent the release, it's important to follow up about a week later to make sure they received the information.

An important thing to keep in mind is how far in advance you need to send the release or calendar item to the media. Again, check with the local newspaper, TV or radio station—some want items two weeks in advance, others four.

Also, check when the deadline is. For instance, a weekly newspaper that comes out on Thursdays may have a deadline of Monday at the close of business to get an item published that week.

Be sure to consider non-traditional media, such as church (or synagogue, mosque, or temple) bulletins, newsletters from other non-profits, or professional and specialty journals.

The following are the types of media releases you are likely to use (*Appendix B:2-3*)

1. A **General News Release** is a short, concise factual description of an event or program that is prepared for all media. It answers the basic five W's (who, what, when, where, why) and should be double-spaced. It should also include the name and contact information of a contact person
 - a. A **Broadcast Release** is the same as a general news release but is written as a manuscript that an on-air announcer could read. It could also be created as a pre-recorded audio tape (also known as a public service announcement)
2. **Calendar Items** are a brief, one-paragraph news release that describes an upcoming program or event and includes the time, location and cost, as well as the contact information of someone to call with questions
3. **News Advisories** are a very simple listing of the basic facts of an upcoming program, answering the 5 W's written in a memo style
4. **Public Service Announcements (PSAs)** are commercials for future meetings or events that radio and television stations will run without charging, if they are from non-profit organizations. The station's public

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service director can provide formatting requirements. PSAs usually are only between 10 and 30 seconds. Some stations prefer receiving just the copy and writing their own PSAs. Check with the station(s) to find out their preference

5. **Flyers** are a great way to spread the word about an upcoming workshop, special speakers, or even just your regularly scheduled support group meeting. They can be distributed at public gatherings such as health fairs, community events, etc., or posted at locations such as libraries, coffee shops, grocery stores, etc. (see Appendix B:4-6). The Dementia Alliance Communications Specialist can provide you with branded flyer templates and social media graphics for your event. Simply email your request to: dshark@DementiaNC.org

Monitor the Balance between Education and Support

Providing opportunity for both education and support is the optimal way to meet participants' needs. Realize that the balance may change as the support group changes; for example, new groups or groups with many new people may temporarily have a stronger focus on education while groups that have been together longer may have a stronger focus on support. If a group needs some variety, having a series of educational programs may reenergize the participants.

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DEMENTIA ALLIANCE

of North Carolina

A STATE OF CARING

Create more interest in your events by using branded templates and social media graphics and informational brochures.






Dementia Alliance Communications Specialist can provide you with branded flyer templates and social media graphics for your event. Simply email your request to: dshark@DementiaNC.org.

Meeting Agenda

1. Welcome and Introduction (15 minutes)

- Welcome attendees, introduce self and other key persons and deal with housekeeping issues, such as the location of bathrooms, length of meeting, etc
- Make any announcements of upcoming events or research updates, etc
- Review the support group guidelines about confidentiality and treating other members with respect and other pertinent issues (talking one at a time, etc.)
- Have participants introduce themselves and briefly share their reason for attending the meeting. Be especially attentive to the needs of first time attendees who may be overwhelmed with their own or other attendees' situations

2. Formal Program (30-45 minutes)

- Speaker: Introduce speaker and describe the approach to questions (address during or after formal program)
- Allow time for Q&A
- Other program: Introduce and present the topic or video

3. The Support Group (30-45 minutes)

- Allow each attendee who is interested express his or her response to the program
- Help individuals interact with each other and share common experiences and solutions
- Try to find themes and commonalities among the different issues and concerns expressed

4. Closing Remarks (15 minutes)

- End the meeting on time. If at a difficult point to stop, wind up the formal meeting, excuse those with commitments or who would prefer to leave, and follow through with the crisis work
- Summarize the process of the meeting and try to offer general words of support
- Encourage those who have had an emotional experience to follow up with another member or facilitator if needed
- Ask for volunteers to perform certain roles for the next meeting – providing refreshments, setting up or cleaning up
- Thank attendees for coming and invite them to attend the next meeting. Ask for any suggestions to make the next meeting more successful
- Encourage attendees to review and take available information
- Provide a warm and accepting opportunity for participants to talk casually and begin to establish/continue relationships

5. After the Meeting:

- Debrief with co-facilitator
- Send mailing list to Dementia Alliance of North Carolina office
- Make arrangements for the next meeting

QUESTIONS TO FACILITATE DISCUSSION

Questions designed to open up discussion:

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

Questions designed to broaden discussion:

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

Questions designed to limit participation:

- You have made several good statements, and I am wondering if someone else might like to comment or share?
- Since all the group participants have not yet had the opportunity to speak, I wonder if you would hold your comments till a little 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 expressed?

Questions designed to focus discussion:

- Where are we now in relation to the topic of 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?
- Your comment is interesting. However, I wonder if it really centers on the main issue which we are now discussing?

Questions designed to help the group move along:

- I wonder if we have spent enough time on this aspect of the issue. Should we move to another aspect of it?
- Have we explored this part of the issue far enough so that we might now shift our attention and consider another area?
- Given the time, should we look at another person's concern?

Questions to help the group evaluate itself:

- I wonder if any of you have the feeling that we are stuck on this particular question. Why are we tending to slow down?
- Originally we were discussing _____. Where are we in relation to that issue?
- Now that we are nearing the conclusion of our meeting, would anyone like to offer suggestions on how we might proceed at our next meeting?

Questions to help the group reach a decision:

- Am I right in sensing agreement on these points? (Facilitator then gives a brief summary.)
- What have we clarified in our discussion up to this point?

Questions designed to lend continuity to the discussion:

- Since we talked about this issue briefly at the last meeting, would someone care to summarize what we said then?
- Has your situation changed or has anything new happened since you shared with us last time? More information needed?

NOTE: Sometimes the best thing to say is nothing. Silence can be powerful and healthy.

VALUABLE TOPICS FOR GROUP SESSIONS

Choosing a Topic:

- Find a balance between education/information sessions and coping/caregiver support sessions
- Discuss different stages of dementia
- Planning for future caregiving needs
- Ask Dementia Alliance of North Carolina representatives/other facilitators for ideas
- Ask speaker what topic they might enjoy talking about or find helpful for the participants

BUILDING RESOURCES & SPEAKERS' BUREAUS

Choosing a Speaker and Working With Speakers:

- Recruit speakers with care. Just because a speaker is a health care, social services, legal or investment professional doesn't mean he or she understands the needs of people with Alzheimer's disease and their caregivers (or is a good public speaker)
- Ask office representatives, other facilitators and local experts if they know of someone who might be knowledgeable and a good presenter on a particular topic
- Be cautious about accepting requests from providers to present programs. Many of these are very helpful to participants but, on occasion, a presenter may have an agenda that does not serve the group. If you don't think the person is appropriate, offer to have materials available at the support group
- Be specific about what will happen during the time the speaker is at the meeting, including the available time frame
- Depending on the topic and type of speaker, you may not wish to invite the person to stay for the support segment of the group. If you do not wish the person to stay, thank him or her and stand up
- If appropriate, ask speakers if you can add their names to your resource list and if they would be willing to receive occasional calls from group members.
- If the speaker is good and willing, pass their contact information on to the office
- After the meeting, send the speakers a personal note thanking them for their time and mentioning a specific point of information that will be helpful to group members. With permission, include positive comments made by group members
- Consider adding speakers with a particular interest in working with people with dementia to your mailing list
- Potential speakers might include:
 - Health care providers: physicians, nurses, occupation therapists, physical therapists, social workers, registered dieticians, recreation therapists, etc
 - Ask support group members for their input
 - Social services providers: DSS, SS, Family specialists
 - Other: clergy, financial planners, insurance providers and attorneys



Words of WARNING—REMEMBER

- Make certain the speaker's goal is to provide information not sell a product or service
- Good credentials do not necessarily make good speakers

CHECKLIST

POSSIBLE TOPICS FOR LEARNING & DISCUSSION

This is a partial list of topics that have been identified by caregivers as being of interest. You may want to look through these and see if you can identify some topics that you would be interested in as a topic for your support group meeting. Seek additional input from your support group members.

- ☐ Using a Positive Physical Approach to Give Care
- ☐ Wandering and Elopement - Understand the Behavior, Reduce the Risk, & Improve Recovery
- ☐ Planning and Delivering Activities that Match Abilities and Interests
- ☐ Meeting the Needs of the Whole Person - Spiritual Well-Being is a Critical part of Care
- ☐ Changing Resistance to Care to Participation in Care
- ☐ Resistance to Care & Challenging Behaviors
- ☐ How to Communicate with Someone Who Has Dementia
- ☐ Medications - The Good, the Bad and the Ugly
- ☐ Differential Diagnosis - Does It Make a Difference in Care?
- ☐ Issues of Depression and Pain in Dementia
- ☐ Building Hands-On Caregiving Skills for Middle Stages of the Disease
- ☐ Matching Your Help to the Needs and Abilities of the Person with Dementia
- ☐ Typical Progression of Dementia - What Can You Do to Help?
- ☐ Looking at the Environment - How Does it Affect the Person with Dementia?
- ☐ Alternative Therapies in the Treatment of Dementia - music, animals, plants, aroma therapy, massage therapy
- ☐ Early signs and symptoms - Recognizing the beginning signs so something can be done
- ☐ Changes that Signal the End of the Journey - What Happens & How to Help
- ☐ What You Need to Know About the Person to Provide Care
- ☐ Promoting Wellness and Well-Being after the Diagnosis
- ☐ Understanding the Condition - "What is Dementia? - Why Do They Do That? How Can I Help?
- ☐ Understanding Medications and Dementia
- ☐ Stress Management for the Caregiver
- ☐ Changing Roles and Relationships in Dementia
- ☐ Wandering & Elopement - How to Prevent It and How to Cope If It Does
- ☐ Programs and Supports for Caregivers
- ☐ The Unique Challenges of Being a Male Caregiver
- ☐ Grief and Loss: Coping with the Long Good-bye
- ☐ Dealing with Guilt - Making Hard Choices and Living with Them
- ☐ Coping with Challenging Behaviors
- ☐ Living with Early Onset Alzheimer's Disease
- ☐ Comparing Different Dementias What If It's Not Alzheimer's...
- ☐ Issues for Law Enforcement
- ☐ What Should a Family Member Do? Dealing with Hospitalizations When Dementia Exists
- ☐ Hospital Care Issues - How Can Staff Cope & Help?
- ☐ Planning for End of Life Care with Dementia
- ☐ Dealing with Distress: Using Empathy & Support
- ☐ Making Visits Valuable and Positive
- ☐ Developing Activities that Have Meaning & Work
- ☐ Person-Centered Care Planning
- ☐ What Do I Do When I Suspect Neglect, Abuse, or Bad Care?
- ☐ HELP! - Specific Behavioral Issues
- ☐ Technology and Caregiving
- ☐ Use of Reminiscence
- ☐ Storytelling as an Activity
- ☐ Art as an Activity
- ☐ Learning to 'Sing' the Old Songs
- ☐ Practicing Your Communication Skills
- ☐ Using Photos and Pictures to Have a Conversation
- ☐ Using Props to Have a Conversation
- ☐ Getting the Person 'Clean' – Bathing, Showering, or Washing Up
- ☐ Caring and Giving Care When there is a BAD History between the Caregiver and the Person with Dementia
- ☐ How to Set Limits for Yourself as a Caregiver
- ☐ Maintain Your Brain – Reduce Your Risk - Strategies to Help Yourself!
- ☐ The Use of Touch and Simple Massage in Dementia Caregiving

CHALLENGES of a SUPPORT GROUP-

A problem-solving approach

Many support groups will periodically go through spells when attendance and enthusiasm decline. However, when participation and group energy is consistently low, reevaluate!

STEP 1: Is it really a problem?

Numbers don't tell the whole story about your group! Common problems include poor attendance, inconsistent attendance, first time attendees never return, absence of new attendees, and lack of group growth or stagnation.

- Expect attendance to fluctuate
- Expect some one time attendees
- Expect some people to drop out

Groups have a natural ebb and flow (time of year, group process)

Some people aren't ready for support groups, get their questions answered, just don't like groups, care unavailable or scheduling problems

Needs/situation changes

STEP 2: If really a problem... THINK it THROUGH!

Really think about what's going on. Ask yourself:

1. What exactly is the problem?
2. When did the problem start?
3. What seems to make a difference?

Consider possible causes

- Logistics
- Meeting issues
- Publicity/outreach
- Group issues

Examples

Location

Time of meeting

New conflicts

Availability of respite

Starting and ending on time

Size of group

Inconsistent meeting times/cancelled meetings

Meeting notices

Promoting meeting

Challenging members (confrontational, judgmental, dominating, frozen)

Facilitator skills (managing challenging members, disease knowledge, group management)

Balance between education and support

Lack of trust

Overwhelming first time attendees

Poor group commitment

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STEP 3: BRAINSTORM with others and come up with a PLAN of ACTION

Brainstorm with...

- Co-facilitator
- Participants...what's their perspective?
Are their needs being met?
- Other facilitators
- Dementia Alliance of North Carolina resources

Develop a PLAN of ACTION

- What to do?
- Who will do what?
- How to do it
- When to start and when to look again
- Set a goal
- DO IT!!!



STEP 4: Evaluate

Are things better?

Yes *CELEBRATE*

No *Rethink and Problem Solve again*

REMEMBER to KEEP the FAITH

NOTE: This is similar to the process we use for addressing risky/challenging behaviors of people with dementia

Problem Focused Suggestions for the Challenges

LOGISTICS

Start by...think through the arrangements

- Location:
- Time of meeting:
- New conflicts:
- Availability of respite:

Is it safe? Convenient?

Emotionally acceptable?

Meet the need of current and potential participants?

Daytime/night time—driving issues

New groups competing: new support groups or other events at the location

School and other scheduling issues

is respite available?

Then consider adapting:

- Notify participants well in advance
- Update publicity
- Research available respite
- Recruit volunteers to help with respite

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Meeting Issues

People who attend support groups often experience unpredictability in their lives and care situations; they don't need their support groups to be unpredictable as well!

- Starting and ending on time: some participants may have limits on time they can stay/care arrangements and may feel uncomfortable walking out in the middle of a discussion
 - Try to be consistent with starting and ending on time
 - Do some orientation and cuing for the new behavior
 - Consider a visual cue
- Size of group
 - Expect the size to vary in different settings and from week to week
 - Expect fluctuations in size
 - Try to maintain size between. Very large groups may be overwhelming and intimidating and logistically limit the amount of individual attention each member can receive. If the group is very large, consider breaking up into smaller groups for part of the meeting or holding 2 meetings
 - Very small groups may be overwhelming and intimidating and participants may feel put on the spot. Try reaching out to previous attendees or a community education program to re-energize the group
- Inconsistent meeting times/cancelled meetings
 - Avoid changing or canceling meetings. Have a backup facilitator or volunteer (previous attendee?) available to fill in if needed
 - Cancellations: Some system is needed to notify participants of cancellation or change of meeting: telephone tree or email notification

- Lack of trust:
 - Go over guidelines for the group at every meeting
 - Reinforce the issue of confidentiality
 - Discuss respecting other's choices and not judging others decisions

Publicity

- Regularly review your mailing lists and update contact information as needed
- Verify the best way to contact individuals (email versus phone etc.)
- Send out monthly reminders—email, post card or phone call
- Go back to the basics and make contact with potential referral sources
- Encourage group members to sign up for Dementia Alliance of NC newsletters
- Maintain close connections with the DA-NC office. Receiving email newsletters from the office will often trigger a member to return to the group. Ask the staff for assistance in problem solving solutions to a declining attendance
- Consider personal contact to invite people to the group. Contact interested participants identified through the CEM and inform them of the follow up meeting. Visit groups where potential participants may be recruited
- Consider hosting a community education meeting to reach out to the general community

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Some ideas for promoting the support group include:

- Media
- Faith communities
- Visit appropriate classes, groups to invite
- Health care systems
- Government agencies
- Dementia Alliance of North Carolina office
- Community groups/organizations
- Attorney's offices
- Community resources

Local newspapers, Television and radio stations
Newsletters and bulletins,
Post in facilities
Long term care facilities
Adult Day Centers/Senior Centers
Assisted Living Facilities
Home health agencies
Health Department
Hospital discharge planning, social work or or education departments
Medical practices: family, internal medicine, neurology, psychiatry
Family and mental health agencies
Area Agencies on Aging

Libraries
Public bulletin boards and listservs

Making the media work for you

- Know the rules:
- Know a person:
- Know how to say thank you:

Consistent branding reduces confusion
Word limits for print media
Time frames—when to submit etc.
How to submit—hard or e- copy

Directing your ad to a specific kind of individual will increase the chance of catching their attention

Follow up with a personal note when you get a helpful response





Strategies for Managing Challenging Group Members

General approaches

- Clearly identify the group norms before the group starts
- Treat all members—even challenging ones with respect
- Keep group issues within the group—don't encourage talking about challenging members outside of the group
- Consider addressing individual issues with the person outside group
- Encourage group members to address issues with each other
- Focus on meeting the goals of the group and the individual
- Utilize co-facilitator
- Use verbal AND non-verbal skills to interact with the group
- Explain what the participants can expect from the group or describe the format in a general way. For example, "This is a place where we can share our feelings, hear from others in a similar situation and get help with problem solving"
- Point out similarities between situations

Non-verbal strategies

- Sit close to the challenging person

- Make eye contact then clearly change focus to another participant
- Provide physical contact - offering hand to a person in distress
- Stand up, pack up materials etc. to signal the end of the meeting or need to move on

Verbal strategies

- Validate feelings, summarize situation and then move on
- Teach group about the important of silence
- Refocus gently and respectfully

What do I do if...

Nobody talks? How to deal with a quiet group:

- Use icebreakers – go around the room, have each person introduce themselves, telling what he/she wants to get from the session
- Prearrange to call on specific people
- Break into smaller groups, having each member tell the others something about themselves; exchange goals, etc
- Refer to the group member's earlier comments using his/her previous example. ("I'd like to follow up on what we talked about last time")
- Wait for a response after you ask a question. Sometimes, it takes people time to formulate an answer. Don't be too quick to respond yourself
- Rephrase the question and/or create a hypothetical situation that would elicit a response
- Prepare additional questions in advance of the meeting. Use open-ended and ice breaker type questions
- Temporarily focus more on education than support

(continued on page 33)

Dealing with a quiet person

- Give positive feedback for any comments.
- Arrange the seating so that you sit directly across from that person. You will often encourage a response
- Sometimes it is helpful to sit next to the person to offer reassurance or a physical touch to encourage participation
- Speak to the person before and after the meeting, ask to share an insight or suggestion with the group at large
- Remember that some people benefit from being in the group even if they don't talk and may not come back if they feel pressured

General principles

- Use both verbal and nonverbal communication to encourage participation
- Provide positive reinforcement for sharing

One person talks all the time:

- Allow the person to ventilate briefly
- Explain that you don't have time to deal with their issue fully, but will write it down to deal with later
- Redirect their comments by making a link back to the original topic
- Try, "We're hearing a lot of good comments from Mary, but we need to hear from others," then direct your next comment to someone else
- Gently interrupt the person and say, "What you're saying is something we need to talk about more – maybe you could see me after the meeting"
- Say, "At this point, why don't we summarize what we've just discussed."
- Speak to them privately to discuss the issue of group participation. Encourage them to allow others to speak first, giving others a chance to respond

- Ask for their help in drawing out other members

A member is argumentative, negative or hostile:

- Allow some ventilation
- Be interested, empathetic and reflect back their thoughts
- Avoid trying to problem solve
- After time to ventilate, attempt to refocus their attention
- Then move into problem solving
- If they can't let go, offer an alternative time for them to ventilate
- Monitor your own verbal and non-verbal communication. Avoid seeming angry, scared, defensive or insulting
- If continues and not able to mediate emotions, offer opportunity to step out with co-facilitator

A member is in crisis.

Initially:

- Allow the person to ventilate and express emotions and issues
- Use empathy and reflect back
- Model calm behavior and speak slowly
- Suggest deep breathing and make a concrete suggestion to relax
- Use touch when appropriate

When the person begins to calm:

- Continue to provide support and move towards problem solving
- Try to break the problem down, "What is the most difficult part?" "What can you do to work on that?"
- Focus the discussion on one main issue
- Help mobilize the person's resources and problem solve
- Don't minimize or discount the problem

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If the person remains distressed:

- Use your co-facilitator. One of you may need to take the person to a more private place and spend time one-on-one

Finally: Validate then:

- Refocus the group
- Try "I'm so sorry you and your family are going through this. It's hard to remember every person's situation and every person with AD is different." Or, "What do the rest of you do you feel as if one more comment about AD will make you explode?"
- Make sure you follow up with new or other vulnerable people

One person knows the answer to EVERYTHING:

- Start every group with the guidelines to treat other and their decisions with respect. Firmly emphasize the uniqueness of each participant's situation, resources and abilities
- Listen to and value their opinions. Then include the point of view of others. Acknowledge their experiences and expertise but maintain commitment to individualized problem solving

- Try: "I realize that this technique may have worked for you, but it may not work for someone else," or "We often find that there are two equally valuable solutions to the same challenging situation. Can anyone give another example of a solution?"

Poor group commitment

- Give participants jobs: Having a "job" helps participants feel more connected to the group and provides a sense of giving back. The job should reflect an individual's interests, skills, personality and available energy:
 - Refreshments
 - Set up the room or help clean up
 - Manage the mailing list
 - Phone calls between meetings
- Vary the meeting:
 - Holiday theme—ice cream for July
 - Invite person with dementia
 - Social meeting
- Emphasize the contributions long-term group members offer to the group process. Acknowledge gifts each bring to the group
- Provide opportunity for socializing before and after the meeting. Talking over coffee and cookies one-on-one may be easier for some group members

FINAL POINT:

Don't be too hard on yourself – support groups seem to have a natural ebb and flow of participants. If group attendance is dropping, do an assessment of possible problems, review the basics of meeting and maintaining groups, consider additional outreach efforts – then relax. If you offer good programs and support in an accessible manner, they will come... eventually.

See APPENDIX A: 7-9 for EVALUATION OF SUPPORT GROUP

(Adapted from: Detroit Alzheimer's Association Support Group Leader Training Manual)



Working With Group Members With Mental Health Needs

Sometimes participants in a support group have needs that are beyond the abilities of the facilitator or outside of the mission of the support group. This may be due to an overwhelming care situation, impaired situational coping or chronic individual/family coping that escalates in a time of crisis. Some members may have new or ongoing mental health issues such as depression or anxiety disorders. Watch for the following signs. If you see some of these signs and are concerned, don't hesitate to call the office for guidance.

Signs a group member may need additional help:

- Prolonged emotional distress, for example, continued or increasing intensity of feelings of sadness, anxiety or despair, or episodes of crying without any improvement in mood despite participation in the group
- ANY suggestion of feelings of uncontrollable anger or any episode of violence to or from the person being cared for (potential risk for abuse) (Evaluate for emergency referral)
- ANY statements that could be construed as expressing potential for murder/suicide (ending our suffering...no reason to go on...) (Evaluate for emergency referral)
- Changes in appearance or behavior or personality
- Suspicions of drug or alcohol abuse
- Chronic fatigue or sleep deprivation
- Changes in appetite
- Expressions of helplessness or hopelessness
- Constant complaints of physical problems
- Inability to accept the reality of the impact of dementia on the life of the person with dementia and the caregiver
 - denial or continued unrealistic expectations of the person with dementia or avoidance of real issues about care and planning for future needs

Remember that distress may be expressed verbally and non-verbally. Pay special attention to non-verbal cues such as crying, wringing hands, avoiding eye contact, etc.

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Addressing the participant's needs:

In these situations, the facilitator has a responsibility to address these concerns with the participant. This must be done gently and respectfully. Several approaches may work depending on the particular situation. The facilitator may try speaking with the participant before or after the group meeting or by phone outside the group setting. One co-facilitator may address the issue privately with the individual while another continues the group meeting. Occasionally, a group member may bring the topic to the table and the issue may be addressed in the group setting. With this approach, the facilitator must monitor the participant's response to provide support and to avoid the sense of being "picked on" or embarrassed.

Important points:

1. Treat the person with dignity and respect.
There remains an unfortunate stigma about needing mental health services and some individuals may feel embarrassed, insulted or angry that you have identified a need for such services
2. Reassure them that your wish for them is to get the additional help needed and not to remove the group's support
3. Empathetic phrases such as "you are in a difficult situation and I think it's reasonable for you to need some extra support getting through this" may help the person feel less threatened by your recommendation
4. Offer options and suggestions for treatment including clergy or mental health professionals (clinical nurse specialists in psych/mental health, clinical social workers, counselors, psychologists and psychiatrists)
5. Follow up with the person's response to your recommendation

Guidelines for making an emergency referral:

Trust your instincts. If you have a sense or reason to believe a person with dementia is at risk of being hurt or hurting a caregiver, you must make an emergency referral to the mental health/health care system. Don't hesitate to contact the DA-NC office for support and guidance but if the person is in imminent danger, begin a referral as soon as possible. In most situations, you can make a confidential referral to mental health, Adult Protective Services/Department of Social Services (APS/DSS).



Hosting a Community Education Meeting (CEM)

Description

A CEM is an opportunity for people caring for someone with dementia to learn helpful tools and techniques. The meeting is usually held in a public place that is convenient to the population expected to attend. A sample agenda and list of possible topics follow. Often a speaker may be available from the DA-NC office and assistance with planning and publicity is always available.

A CEM is a great way to start new support groups or re-energize and increase attendance of an existing group.

Purpose

Many caregivers of people with dementia desperately need support but are unwilling or unable to make the commitment to meet their own needs without feeling guilty. These same individuals will often find the time and energy to attend a one time, educational seminar that is advertised as a Community Education Meeting (CEM). After attending

the CEM, caregivers may come to a new understanding of the importance of support groups and become loyal participants.

Sponsoring a community awareness meeting will provide information and insight into the specific needs of caregivers of people with dementia in a particular community. Caregivers express different needs based on their relationship with the person with dementia. For example, older caregivers may not want to drive at night and caregivers with jobs may need meetings that they can attend after work. A CEM gives the facilitators the opportunity to identify the characteristics of potential group members and arrange the support group to best meet their needs.

Benefits of a CEM

- Broad appeal (will come for education)
- Less stigma
- Helps identify interested individuals

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How to hold a CEM

Try to establish a comfortable environment for the CEM. Pay special attention to the location and physical spaces. Having refreshments available and educational materials displayed before and after the meeting will help people feel more welcome and comfortable and give opportunity for casual interaction. Welcome people as they arrive and encourage them to complete nametags, register and sign up for the DA-NC mailing list (form available in the Appendix A: 4).

Try to find the balance between information and support. Allow and encourage participants to talk about their reasons for attending and situations and needs. Try to begin and end on time; some attendees may have arranged for care for the person with dementia or have other time commitments. The formal part of the meeting typically lasts about 1-1.5 hours with time for socializing and casual questions and answers following.

Choose a speaker who is knowledgeable and personable. Remember, simply because an individual has impressive credentials does not necessarily mean he or she is competent to speak on the needs of people with dementia and their families. If possible, verify the person's expertise with DA-NC or another source. Encourage the speaker to leave time for questions and answers after the formal talk is concluded.

After the presentation, it is important to offer attendees an opportunity to ask questions and identify individual needs. Mention the possibility of future times together and ask for feedback about possible topics and arrangements. It is also a good idea to have available a survey to be completed to help facilitators focus on the specific needs of the group (form available in the Appendix A: 10).

Only include as options requests that can actually be met. For example, if both facilitators work and cannot commit to a daytime meeting, offer choices of which night to hold the meeting – not what time of day. If

needs are expressed that cannot be met by facilitators, please pass this information on to the Dementia Alliance of North Carolina office for consideration and follow up.

A few days after the meeting try to follow up with the attendees with the results of the survey and information about additional classes/support group.

Final notes: *It's not all about numbers—starting small is fine. Many successful groups start small and grow slowly.*

Planning Guide for CEM

Preparation

Step 1. Choose your audience, topic, speaker, time and location.

- **Choose your audience—potential participants:**
 - BROAD; open to anyone or
 - SPECIFIC; open to members of a group (family member of residents, church), OR relationship based (adult children, spouses, paid caregivers)
- **Carefully choose a topic that appeals to the audience you have chosen:**
 - Topics such as *Is it Aging or Alzheimer's*, *Alzheimer's Update*, and *Living with Alzheimer's*, would appeal to those seeking information or who are aware of the problem
 - Prevention topics such as *The Aging Brain* and *Maintain your Brain*, appeals to those seeking to reduce own risk
- **Choose a knowledgeable speaker who is interesting, fun, and approachable:**
 - Provide specific expectations such as 30 minute program with 15 minutes for Q&A; Signals being used for 5 minute warning, etc.
 - Possible speakers include DA-NC representatives, health care providers, or a panel of professional and family caregivers

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- **Choose a time that is convenient for both you and your audience:**
 - Older adults, daytime or early evening
 - Working adults, evenings and weekends
 - Your commitments to mealtime, weekends and work time
- **Choose a location that best suits your audience:**
 - Larger space for BROAD, smaller venues ok for SPECIFIC audience:
 - Logistics; safety (time of day); parking; centrally located to target group
 - Associations (Positive and negative); Long term care facilities, medical facilities, and religious spaces

Step 2. Let People Know

- **Start early...really early:**
 - Generally, allow at least 1 month
 - Consider "Save the date" promotions even earlier
- **Develop a flyer & press release:**
 - See Media & Public Relations Information (*Appendix B:1-6*)
- **Spread the word:**
 - Community calendars on Network/Cable TV channels
 - Public service announcements on radio
 - Distribute flyers focused on target audience. Remember to ask permission first!
 - Retired people: Senior centers/AAA
 - Working people: Businesses
 - Church bulletins
 - Libraries/community bulletin boards
 - Service/community groups
 - Attorney's offices
 - Malls, shopping centers, local merchants
 - Hospitals
 - Office practices: family, medicine, neurology, psychiatry
 - Care facilities
 - Health department
 - Adult day programs
 - Contact DA-NC office for assistance with materials for display: brochures, books etc.

Step 3. The Final Push

- **Verify all arrangements: location, speaker & materials**
- **Organize food: healthy options**
- **Arrange for equipment: speaker's needs**
- **Plan for educational materials/table**
- **Decide about registration: sign in sheets, name tags**
- **Assign roles to helpers: welcome, register, manage food, introduce**
- **Follow up with potential participants**
- **Last minute media opportunities**
- **Consider respite options for participants**

Conducting the Meeting

Before the Meeting

- **Give yourself enough time**
- **Set up ahead of time so you can respond to early arrivals:**
 - Food (Having food available before and after the meeting can help people feel more comfortable and encourage casual interaction.)
 - Educational materials: brochures and books (Identify clearly materials that are free and those that can be purchased)
 - Registration table with sign in sheets and name tags
 - Arrange room so everyone can see and hear the speaker easily. Provide enough chairs and position for "personal space" and have extra chairs available to add if needed
- **Expect something to go wrong**
- **Greet people as they arrive:**
 - Introduce yourself and others as appropriate
 - Ask to sign in and complete nametag
 - Invite them to choose refreshments
 - Encourage them to look over educational materials
 - Ask early arrivals to help if appropriate

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The Meeting

- **Begin and end on time: (Some attendees may have made care arrangements)**
 - Have one helper available to help late arrivers
- **Start the program:**
 - Welcome of the group and introduce leader
 - Orient participants to the room, bathrooms etc
 - Give an overview of the program
- **Introduce speaker:**
 - Use prearranged cues to stay on time
- **Call for final question**
- **Close the program on time:**
 - Thank speaker
 - Thank participants
 - Offer opportunity to participate in ongoing education/support group
 - Pass out and encourage completion of survey
 - Invite participate to linger for refreshments, questions

Debriefing

- **Talk about attendance (numbers and type of people)**
- **Review survey responses**
- **Plan a follow up meeting to discuss starting support group**

Typical Agenda

Opening remarks	10-15 minutes
Program	30-45 minutes
Q&A	10-15 minutes
Closing remarks	15 minutes
Total program	1½-2 hours

Facilitators: Please see Appendix A; 10 "Support Group & Education Survey". Use for distribution at the Community Education Meeting. Please keep for your records and follow-up with attendees.

Become a Better Listener:

ACTIVE LISTENING

By JOHN M. GROHOL, PSY.D.

Most people go through their daily lives engaging in many conversations with friends, co-workers, and our family members. But most of the time, we don't listen as well as we could or sometimes should. We're often distracted by other things in the environment, such as the television, the Internet, our cell phones, or something else. We think we're listening to the other person, but we're really not giving them our full attention.



Enter a skill called "active listening." Active listening is all about building rapport, understanding, and trust. By learning the skills below, you will become a better listener and actually hear what the other person is saying, not just what you think they are saying or what you want to hear. While therapists are often made fun of for engaging in active listening, it is a proven technique that helps people talk and feel free to continue talking even if the person they are talking to doesn't have a lot to offer the other person (other than their ear).

Are you as good a listener as you think you are?

13 STEPS TO BETTER ACTIVE LISTENING SKILLS

Below you will find 13 different skills that help people be better active listeners. You do not have to become adept at each of these skills to be a good active listener, but the more you do, the better you'll be. If you even just use 3 or 4 of these skills, you will find yourself listening and hearing more of what another person is saying to you.

1. Restating

To show you are listening, repeat every so often what you think the person said — not by parroting, but by paraphrasing what you heard in your own words. For example, "Let's see if I'm clear about this. . ."

2. Summarizing

Bring together the facts and pieces of the problem to check understanding — for example, "So it sounds to me as if . . ." Or, "Is that it?"

3. Minimal encouragers

Use brief, positive prompts to keep the conversation going and show you are listening — for example, "umm-hmmm," "Oh?" "I understand," "Then?" "And?"

4. Reflecting

Instead of just repeating, reflect the speaker's words in terms of feelings — for example, "This seems really important to you. . ."

5. Giving feedback

Let the person know what your initial thoughts are on the situation. Share pertinent information, observations, insights, and experiences. Then listen carefully to confirm.

6. Emotion labeling

Putting feelings into words will often help a person to see things more objectively. To help the person begin, use "door openers" — for example, "I'm sensing that you're feeling frustrated. . . worried. . . anxious. . ."

7. Probing

Ask questions to draw the person out and get more meaningful information — "What do you think would happen if you. . .?"

8. Validation

Acknowledge the individual's problems, issues, and feelings. Listen openly and with empathy, and respond in an interested way — for example, "I appreciate your willingness to talk about such a difficult issue. . ."

9. Effective pause

Deliberately pause at key points for emphasis. This will tell the person you are saying something that is very important to them.

10. Silence

Allow for comfortable silences to slow down the exchange. Give a person time to think as well as talk. Silence can also be very helpful in diffusing an unproductive interaction.

11. "I" messages

By using "I" in your statements, you focus on the problem not the person. An I-message lets the person know what you feel and why — for example, "I know you have a lot to say, but I need to. . ."

12. Redirecting

If someone is showing signs of being overly aggressive, agitated, or angry, this is the time to shift the discussion to another topic.

13. Consequences

Part of the feedback may involve talking about the possible consequences of inaction. Take your cues from what the person is saying — for example, "What happened the last time you stopped taking the medicine your doctor prescribed?"



7 COMMUNICATION BLOCKERS

These roadblocks to communication can stop communication dead in its tracks:

1. "Why" questions. They tend to make people defensive.
2. Quick reassurance, saying things like, "Don't worry about that."
3. Advising — "I think the best thing for you is to move to assisted living."
4. Digging for information and forcing someone to talk about something they would rather not talk about.
5. Patronizing — "You poor thing, I know just how you feel."
6. Preaching — "You should. . ." Or, "You shouldn't. . ."
7. Interrupting — Shows you aren't interested in what someone is saying.



5 SIMPLE CONVERSATION COURTESIES

1. "Excuse me..."
2. "Pardon me...."
3. "One moment please..."
4. "Let's talk about solutions."
5. "May I suggest something?"

THE ART OF QUESTIONING

The four main types of questions are:

1. Leading Questions

For example, "Would you like to talk about it?" "What happened then?" "Could you tell me more?"

2. Open-ended Questions

Use open-ended questions to expand the discussion — for example, lead with: "How? What? Where? Who? Which?"

3. Closed-ended Questions

Use closed ended questions to prompt for specifics — for example, lead with: "Is? Are? Do? Did? Can? Could? Would?"

4. Reflective Questions

Can help people understand more about what they said — for example, someone tells you, "I'm worried I won't remember. . ." Reflective Q: "It sounds like you would like some help remembering?"

Source: Grohol, J. (2007). Become a Better Listener: Active Listening. <http://psychcentral.com/lib/2007/become-a-better-listener-active-listening/>

*National Aging Information
& Referral Support Center*

Self-Review of Active Listening Techniques

- | | | |
|---|------------------------------|-----------------------------|
| 1. Do you maintain eye contact? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 2. Do you try to paraphrase what has been said before you respond? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 3. Do you ask questions at the end of the speaker's statement in order to completely understand what has been said? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 4. Do you make an effort to understand the speaker's point of view? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 5. Do you give members the opportunity to finish what they are saying before you speak? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 6. Do you consciously watch the group member's body language for additional clues as to how they feel about the topic under discussion? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 7. Do you maintain eye contact with group members at least 90% of the time? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 8. Does your facial expression, posture, and body language indicate your interest in what the speaker is saying? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 9. Do you put aside preconceived opinions to really listen with an open non-judgmental mind? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 10. Do you refrain from offering advice? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 11. Do you periodically assess your listening skills by reflecting on your listening strengths and weaknesses? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 12. Does the group reflect a "warm", confidential, and safe environment for members to openly share their emotions? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |
| 13. Has trust been developed between you and the group members? | <input type="checkbox"/> YES | <input type="checkbox"/> NO |

Source: www.clas.ufl.edu/users/pkricos/activelistingchecklist.pdf



DEMENTIA ALLIANCE

of North Carolina

A STATE OF CARING

Communication Styles: A Self-Assessment Exercise

Instructions: Please select from each pair of attributes the one which is most typical of your personality. No pair is an either-or proposal. Make your choice as spontaneously as possible.

THERE IS NO WRONG ANSWER.

- | | |
|---|---|
| 1. I like action. | 21. I extrapolate and project all the time. |
| 2. I deal with problems in a systematic way. | 22. I am sensitive to others' needs. |
| 3. I believe that teams are more effective than individuals. | 23. Planning is the key to success. |
| 4. I enjoy innovation very much. | 24. I become impatient with long deliberations. |
| 5. I am more interested in the future than in the past. | 25. I am cool under pressure. |
| 6. I enjoy working with people. | 26. I value experience very much. |
| 7. I like to attend well-organized group meetings. | 27. I listen to people. |
| 8. Deadlines are important for me. | 28. People say that I am a fast thinker. |
| 9. I cannot stand procrastination. | 29. Cooperation is a key word for me. |
| 10. I believe that new ideas have to be tested before being used. | 30. I use logical methods to test alternatives. |
| 11. I enjoy the stimulation of interaction with others. | 31. I like to handle several projects at the same time. |
| 12. I am always looking for new possibilities. | 32. I always question myself. |
| 13. I want to set up my own objectives. | 33. I learn by doing. |
| 14. When I start something, I go through until the end. | 34. I believe that my head rules my heart. |
| 15. I basically try to understand other people's emotions. | 35. I can predict how others may react to a certain action. |
| 16. I do challenge people around me. | 36. I do not like details. |
| 17. I look forward to receiving feedback on my performance. | 37. Analysis should always precede action. |
| 18. I find the step-by-step approach very effective. | 38. I am able to assess the climate of a group. |
| 19. I think I am good at reading people. | 39. I have a tendency to start things and not finish them up. |
| 20. I like creative problem solving. | 40. I perceive myself as decisive. |
| | 41. I search for challenging tasks. |
| | 42. I rely on observation and data. |
| | 43. I can express my feelings openly. |
| | 44. I like to design new projects. |

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45. I enjoy reading very much.
46. I perceive myself as a facilitator.
47. I like to focus on one issue at a time.
48. I like to achieve.
49. I enjoy learning about others.
50. I like variety.
51. Facts speak for themselves.
52. I use my imagination as much as possible.
53. I am impatient with long, slow assignments.
54. My mind never stops working.
55. Key decisions have to be made in a cautious way.
56. I strongly believe that people need each other to get work done.
57. I usually make decisions without thinking too much.
58. Emotions create problems.
59. I like to be liked by others.
60. I put two and two together very quickly.
61. I try out my new ideas on people.
62. I believe in the scientific approach.
63. I like to get things done.
64. Good relationships are essential.
65. I am impulsive.
66. I accept differences in people.
67. Communicating with people is an end in itself.
68. I like to be intellectually stimulated.
69. I like to organize.
70. I usually jump from one task to another.
71. Talking and working with people is a creative art.
72. Self-actualization is a key word for me.
73. I enjoy playing with ideas.
74. I dislike wasting my time.
75. I enjoy doing what I am good at.
76. I learn by interacting with others.
77. I find abstractions interesting and enjoyable.
78. I am patient with details.
79. I like brief, to the point statements.
80. I feel confident in myself.

Scoring Sheet for the Communication Styles Assessment

Instructions: Circle the items you have selected and add up the totals for each style (one point per answer). The maximum is 20 per style and your total for the four styles should be 40.

Style	Circle your answer here	Total Score (max. 20)
Style 1	1 - 8 - 9 - 13 - 17 - 24 - 26 - 31 - 33 - 40 - 41 - 48 - 50 - 53 - 57 - 63 - 65 - 70 - 74 - 79	_____
Style 2	2 - 7 - 10 - 14 - 18 - 23 - 25 - 30 - 34 - 37 - 42 - 47 - 51 - 55 - 58 - 62 - 66 - 69 - 75 - 78	_____
Style 3	3 - 6 - 11 - 15 - 19 - 22 - 27 - 29 - 35 - 38 - 43 - 46 - 49 - 56 - 59 - 64 - 67 - 71 - 76 - 80	_____
Style 4	4 - 5 - 12 - 16 - 20 - 21 - 28 - 32 - 36 - 39 - 44 - 45 - 52 - 54 - 60 - 61 - 68 - 72 - 73 - 77	_____

THE FOUR COMMUNICATION STYLES

Style 1: WHAT

ACTION (A)
Results
Objectives
Achieving
Doing

Style 3: WHO

PEOPLE (PE)
Communication
Relationships
Teamwork

Style 2: HOW

PROCESS (PR)
Strategies
Organization
Facts

Style 4: WHY

IDEA (I)
Concepts
Theories
Innovation

The Main Characteristics of Communication Styles

Style	Content – people with this style talk about	Process – people with this style are
ACTION (A)	Results Objectives Performance Productivity Efficiency Moving ahead Decisions	Responsibility Feedback Experience Challenges Achievements Change Pragmatic (down to earth) Direct (to the point) Impatient Decisive Quick (jump from idea to idea) Energetic (challenge others)
Process (PR)	Facts Procedures Planning Organizing Controlling Testing	Trying out Analysis Observations Proof Details Cautious Systematic (step-by-step) Logical (cause and effect) Factual Verbose Unemotional Patient
People (PE)	People Needs Motivation Teamwork Communications Feelings Team spirit Understanding	Self-development Sensitivity Awareness Cooperation Beliefs Values Expectations Relations Spontaneous Empathetic Warm Subjective Emotional Perceptive Sensitive
Idea (I)	Concepts Innovation Interdependence New ways New methods Improving Problems	What's new ... Creativity Opportunities Possibilities Grand designs Issues Potential Alternatives Imaginative Charismatic Difficult to understand Ego-centered Unrealistic Creative Full of ideas Provocative



**Communicating with an Action (A)
oriented person:**

- ☐ Focus on the result first; state the conclusion at the outset
- ☐ State your best recommendation; do not offer many alternatives
- ☐ Be as brief as possible
- ☐ Emphasize the practicality of your ideas
- ☐ Use visual aids

**Communicating with a Process (PR)
oriented person:**

- ☐ Be precise; state the facts
- ☐ Organize your discussion in a logical order:
 - Background
 - Present situation
 - Outcome
- ☐ Break down your recommendations
- ☐ Include options and alternatives with pros and cons
- ☐ Do not rush a process-oriented person
- ☐ Outline your proposal

**Communicating with a People (PE)
oriented person:**

- ☐ Allow for small talk; do not start the discussion right away
- ☐ Stress the relationship between your proposal and the people concerned
- ☐ Show how the idea worked well in the past
- ☐ Indicate support from well-respected people
- ☐ Use an informal writing style

**Communicating with an Idea (I)
oriented person:**

- ☐ Allow enough time for discussion
- ☐ Do not get impatient when he or she goes off on tangents
- ☐ Try to relate the discussed topic to a broader concept or idea
- ☐ Stress the uniqueness of the idea or topic at hand
- ☐ Emphasize future value or relate the impact of the idea to the future
- ☐ If writing, try to stress the key concepts that underlie your recommendation at the outset. Start with an overall statement and work toward the particulars

(Based on the work of P Case "Teaching for the Cross-Cultural Mind", Washington, DC, SIETAR, 1981)

Words of Wisdom & Experience

Notes and ideas from Support Group Leader Facilitator Meetings

PROGRAM IDEAS FOR SUPPORT GROUPS (please see your manual for additional ideas)

- Pieces of “Powerful Tools” – i.e., the Communication piece; AARP
- Care Plan Notebook making
- Holiday specific programming
- Compassion fatigue/burnout
- Organization with health/medical records and forms
- Hospitalizations – hospital discharge speaker, hospital social worker
- Pharmacist – medication management
- Videos (driving/bathing/dental)
- Advocacy – Family Decisions and Conversations
- Dealing with other diseases along with AD/dementia
- Laughter yoga
- Financial advisors
- VA certified counselor for benefits
- Elder Care Attorney

CHALLENGES IN SUPPORT GROUP

These are answers provided by support group leaders in attendance at the meetings.
If you have any questions, please feel free to call our office.

How do I end the meeting on time?

- If meeting is going long, revisit ground rules from manual and mention at beginning of meeting, or put in place an official meeting end time
- Remind the group when there is 15 minutes left in case there is someone who hasn’t shared and would like to before it ends

How do I handle disruptive group members?

- When a member talks about the same thing each month, or dominates the conversation, try: **“Put it in the parking lot”** – Have a big easel with paper, and draw a rectangle. When that person starts talking excessively or repetitively, say, “okay we are going to put that in the parking lot for now, and revisit a little later.” Draw something or write something in the rectangle that validates the conversation for the person,

but also moves the conversation along to someone else

- Come up with an action plan for that person. Discuss a goal that they need to accomplish before the next meeting
- Start of the meeting – tell the group that you want 2 or 3 sentences about how they are doing today. This will focus the group and allow everyone to speak
- Have everyone write down on a piece of paper what is bothering them the most – put the paper in a hat and pull each out to start discussions
- Only talk about updates for the past month to avoid long winded stories
- Catch the group up yourself if you know one member tends to go back to the beginning each meeting

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How do I address separate conversations going on between the group members?

- Reply “I know you’re interested and want to help, but we need to focus on this person right now”
- Reply “It sounds like what you are talking about is important please share this with the group”
- Announce this as a ground rule at the beginning of the group and it may help to eliminate the problem. If consistently a problem, you may have to talk to the family member outside of the group time

How do I keep flow of conversation from being dominated by one caregiver, or family member?

- Go around and check-in with new situations, gives everyone a chance to speak. Also, put in the ground rules as a reminder
- Politely reinforce that everyone needs to have a time to speak. If a member dominates the time tell them you’ll be glad to spend time with them after the meeting, so that we can allow others time to share. Assert your role as facilitator
- Physically sit next to the person and tap them gently
- Redirect the conversation to another group member that you know might be willing to share their similar experience
- May need to ask that person to not return to group, and to seek counseling/therapy

How do I handle very probing questions that are almost to the point of being intrusive?

- Reply “whew, that is personal”
- Attempt to lighten the mood
- Ask the person to whom the question was directed “are you comfortable answering that?”
- Ask them more about their situation and themselves to redirect the question off of that family member

- Remind group in guidelines about asking questions as we all come from different perspectives and to be respectful of background, language, cultural differences. What might be offensive to someone may not be to another

How do I open the group for sharing in the event a large number of people show up one month and the assumption is everyone wants to share something?

- Ask new person if they want to go first and then proceed around the room
- Allow members to leave when they need to; establish this in ground rules
- Sometimes you may have to cut them off midstream to keep the group moving
- Ask those that will need to leave early to share first
- Ask members to share what has recently happened since last meeting; ask this in the ground rules
- Sometimes there are members that do not want to share and that is ok too

How do I address professionals that attend my support group that are not group family members?

- If the professional is not pushing their services and positively contributes to the group, I don’t see that it would be a problem. I would ask that they remove any of their company identification if possible
- Should the professional be pushing services, or if group members become uncomfortable, then the group leader should discuss this with the professional in private
- If your location of the group has a problem with professionals and/or their services, the group might need to consider relocating or discussing that the groups are self-directed and they “belong” to the family members and if they want the professional there that is their decision

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- If a situation arises and you are not comfortable handling, please call the DA-NC office as I have had to do this in the past
- I consult the manual for tips on this subject
- It is a good idea to always have several local referral sources so as to avoid a conflict of interest, i.e. lawyers, doctors, facilities

How do I get the word out about my support group?

- There are some tips in the manual about publicizing groups
- Start with an educational meeting or series and then go to support group format
- Flyers to doctor's offices
- Church bulletins
- Local newsletters, flyers at health fairs
- Keep the DA-NC office up-to-date of new groups/changes

What if I have a group member that wants to bring their loved-one with dementia to the meetings?

- The caregiver groups are designed for the caregiver to come alone so they may freely speak about their concerns. I would try to assist them with finding someone/someplace that the person could be during the meetings. DA-NC may also have some ideas
- Perhaps respite could be provided on-site, or at home with a friend/family member
- This would be a good example of having a co-facilitator always so that one of you could be with the person during group if they came unexpectedly

What do I do if I suspect a caregiver may not be practicing the safest caregiving with respect to the person they are caring for?

- Talk to the caregiver outside of group to get more information on the situation
- Refer to the DA-NC manual: "Guidelines for making an emergency referral: Trust your instincts. If you have a sense or reason to believe a person with dementia is at risk of

being hurt or hurting a caregiver, you must make an emergency referral to the mental health/health care system. Don't hesitate to contact the DA-NC office for support and guidance but if the person is in imminent danger, begin a referral as soon as possible. In most situations, you can make a confidential referral to mental health, Adult Protective Services/Department of Social Services (APS/DSS)"

Some additional notes:

- It is the responsibility of the group leaders to protect the group members while allowing them ownership of the group in regards to speakers, meeting times/frequency, etc
- DA-NC nor any of the support groups endorse any individuals, products, services, research and/or drugs. Ideas and suggestions offered in support group are not an endorsement by DA-NC. The support group is for exchanging ideas and offering support to each other. As leaders we do not offer advice, but provide support and encouragement to group members
- Many group leaders have education materials on-hand at the meetings, as well as books and DVDs for family members to use. Please refer to the support group manual for handouts