

A Telehealth Education Program for
Caregivers of Veterans with
Dementia

Leader Manual



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Tip Sheet for Telephone Support Group Leaders

These tips were extracted from Toseland, R., Naccarato, T., & Wray, L. O. (2007). Telephone groups for older persons and family caregivers. *The Clinical Gerontologist*, 31(1), 59-76.

How does a telephone group differ from an in-person group?

- **Structure**
Telephone groups may need to be more structured than face-to-face groups in order to insure that all participants have a chance to speak.
- **Shorter meetings**
Because of fatigue and other factors such as tying up members' telephone lines, consideration should be given to keeping telephone meetings shorter than in-person meetings.
- **Distractions**
Although distractions within group members' home environments have not proven to be a major problem in groups the authors' have developed, it is a good idea to speak with members from the outset about how they will handle disruptions that might occur. It is a good practice to have members explicitly mention to the group when they have to stop their participation for a brief period and when they have returned and are reengaged in the teleconference.
- **Meeting In-Person**
Group member will likely desire to meet in person, especially after the group ends or between meetings. The cohesion and bonds that are formed among members during telephone group meetings often enhances their desire to meet their fellow group members in person. Therefore, consideration should be given to grouping participants by geographical area to facilitate any desire they may have later to meet in person.

Group dynamics to consider when leading a telephone group . . .

- **Level of self-disclosure and cohesion**
Telephone groups have a greater ability to focus members on common situations and problems without being distracted by non-verbal behavior, appearance, and other visual cues available in in-person groups.
- **Ability of group members to gauge the reactions of others**
While providing a greater ability to focus, the lack of visual cues makes it more difficult for members of telephone groups to gauge the reactions of others during interactions, and their own impact on members of the group. It can also be more difficult for the leader to assess members' needs and the impact of interactions without the benefit of facial expressions and other nonverbal clues.

- **Impact of visual and hearing impairments**
Telephone groups are not able to accommodate members with hearing problems as well as in-person groups, but they are favorably received by visually impaired older persons. Therefore, it is important to screen potential members for hearing impairments and determine if special equipment would allow participation.
- **Limits of confidentiality**
Concerns about confidentiality because of a lack of privacy within callers' households can occur. These can usually be solved by careful thought about the best time to hold the telephone group or by adjusting the environment – for example, moving the telephone conference to another room or ensuring that the care recipient is occupied and cared for during meetings.
- **Potential for the expression of strong emotions**
Some research suggests that the anonymity of telephone can result in increased hostile and aggressive statements. The authors have not experienced this clinical problem in the groups they have developed for older adults and their family caregiver, but more research is needed.

Some interventions to address the lack of visual cues in a telephone group . . .

- **Promoting member self-identification**
To avoid confusion in early group meetings it is important for the leader to remind members to state their name before they begin to talk. Leaders may have to intervene more frequently in telephone groups than in in-person groups to clarify who is speaking, ask members to identify themselves, and ask members if they know who is speaking.
- **Ensuring that all members are engaged in the interaction**
It is important for the leader to ensure that all members are aware of the agenda and feel included in group interaction. Leaders should use go-rounds and other methods to bring each member into the meeting and to keep members involved and active. To foster engagement, telephone group leaders often have to take a more active role in directing questions from one member to another member.
- **Promoting turn taking**
Long descriptions of educational material by the leader should be avoided because these are less well tolerated in telephone groups than in in-person groups. At frequent intervals leaders can ask members to describe their experiences related to the educational content being presented.
- **Facilitating open and clear communication channels and gentle feedback**
Leaders should facilitate open and clear communication channels by reminding members not to make assumptions about how others are reacting, by encouraging members to clarify, restate, or repeat communications that may not be clear, and by verbalizing feelings that may be expressed only by a member's silence or tone of voice.

- **Using the mail to send workbooks, handouts, audio and video tapes and other information and resources**

When conducting time-limited psycho-educational groups leaders cannot use flip charts, films, or other visual media the way they would in in-person groups. Still, they can take full advantage of workbooks, handouts and other materials by mailing them to members before the start of the group.

- **Encouraging socialization between meetings**

Actively encourage members to talk between meetings by asking each person to select a partner within the group who seems to have similar concerns and to call that person between meetings.

TEP Group Session 1: Basic Dementia Education

I. Introduction Section: 15 minutes (Session 1 only) Introductions and Overview of TEP

- A. Introductions of leader:** Group leader explains his or her credentials, refers to Worksheet 1.1 (*Participant Guide pg. 4*) Contact Information, has each group member circle his or her name on sheet, points out that long-distance callers can leave a message at the toll-free number and project staff will return call. Explains roles of various staff members.
- B. Contents:** During the 10 telephone sessions we will be providing you with information about:
- Dementia diseases and progression
 - Changes in communication and strategies for coping with these changes
 - Common and challenging behavioral symptoms and strategies for managing and coping with these behaviors
 - Problem Solving strategies
 - Assistance with the role of caregiver
- C. Goals:** Our goals are to:
- To improve communication between caregivers and patients with dementia
 - To improve or avoid challenging behavioral symptoms of dementia
 - To help caregivers cope with and appreciate their important role in the lives of patients with dementia.
- D. Group Rules:**
- Confidentiality – Will not share information about what others have said about their personal situations. It is okay to talk about the information you are learning
 - Respect for each other – Group members should respect everyone’s opinions and right to speak
 - Consideration for each other – Group members should realize that there is limited time for our meetings so everyone should try to be brief and share the time available to speak.
- E. Group format:** Every week our group meeting will be broken into an education topic, a time to talk about individual action plans (and I’ll explain what I mean by that later today), and problem-solving time. In addition, I will take some time in the beginning of the meeting to remind the group about our previous talk, and some time at the end of the meeting to review and talk about next week’s topic.
- F. Group members introduce themselves by first name; give husbands’ name (note: group members may not be married to the person for whom they are providing care. If this is the case, please substitute an appropriate noun wherever the word “husband” is used, such as “loved one”) and how long patient has had dementia. The facilitator should make sure that each member only gives the required information. Otherwise this part will take too long.**

II. Education: 20 minutes

A. What is Dementia? (Worksheet 1.2 - Participant Guide pg. 5)

1. *Definition of Dementia:* The word dementia refers to any condition where there is a loss of memory AND changes in at least two of the following areas of thinking:
 - Language
 - Perception (understanding visual information)
 - Organization
 - Reasoning
 - Judgment
2. Dementia affects many areas of the brain and so we see changes in many thinking abilities AND behaviors.
3. Some dementias (like Alzheimer's) will get progressively worse. Others may be fairly stable for a time or may even improve in response to medications.
4. Dementia is defined as a progressive decline that causes cognitive (thinking) and functional deterioration leading to changes in the person's ability to continue to work or socialize as they had in the past.
5. Dementia is not the name of a single disease. It is a word to describe the results we see from many different diseases of the brain.
6. Most diseases that cause dementia are progressive, that is, they get gradually worse over time.

B. Dementia is NOT normal aging:

1. The likelihood of dementia increases with age. For example, it is estimated that 10% of people over the age of 65 have some form of Alzheimer's disease. (That means 90% DO NOT have Alzheimer's disease).
2. People used to think that memory loss was simply the result of normal aging. We do experience a mild decline in our new learning abilities. Normal aging DOES NOT bring a decline in general knowledge or the ability to function independently.

C. Causes of Dementia

1. *Alzheimer's Disease:* Most common cause of dementia. Alzheimer's causes changes in the brain cells and affects memory and other thinking.
2. *Vascular Dementia:* Second major cause of dementia. In this case, losses in memory and thinking occur because of damage to circulation in the brain. People who have had strokes, mini-strokes, TIAs, and/or hypertension are at risk for this type of dementia.
3. *Less Common Diseases:* Other diseases that cause dementia can include (but are not limited to) Pick's Disease (also called Frontal Lobe Dementia), Parkinson's disease, and Lewy-Body Dementia.
4. *Multiple Causes:* It is possible for people to have more than one type of disease causing the change in their abilities. For example, a person who has Alzheimer's may also have mini-strokes causing vascular dementia and further lessening their abilities.

D. Group Activity: Have caregivers talk about the diagnosis of the patient if it is known.

III. Introduction of Action Plans – 5 minutes

Each week everyone in the group will have an “Action Plan.” This plan does not have to be complicated. It may be something as simple as going out to lunch with a friend, or trying out a new thing you learned through this group. During each phone call, we will have a brief go-round where everyone can report on how things have been going with their action plan. We won’t be able to talk about everyone’s plan in detail every week, but please let me know if there is something that you are worried about or is particularly troublesome. We can either talk about that during the problem-solving portion of the day’s call, I can help you individually, or we can plan on discussing it as a group in more detail on a future occasion.

After we check-in on everyone’s action plan, we’ll do some group problem solving and help one or two people develop a more detailed action plan. Even if we don’t talk about your particular concern in detail, we hope you will make your own action plan so at the next call, you can tell us what you tried to do during the week that may have been different. Worksheet 1.3 (*Participant Guide pg. 6*) is your Weekly Worksheet for this week. There is a place to write down your Action Plan on that sheet. Each week, you will have a worksheet like this one where you will have space to write down your Action Plan, a reminder about your homework assignment if there is one, and space for jotting down any thoughts that you might have during the week that you might want to talk about at that next session.

IV. Introduction to the Problem Solving Process 15 minutes

Beginning next week we will be talking a lot about the challenging, or problematic behaviors that you might have been experiencing. One of the best things about having a group to talk to is that there are so many different ideas about how to solve a challenge or a problem. The important thing about a problem-solving discussion is to be sure to let everyone discuss ideas BEFORE we evaluate them. That way we won’t jump into working on an idea and miss out on some other suggestion that might have helped even more. This week, we have saved some time for you to talk about your individual situations and what has been happening. How is it going? Who would like to start?

The facilitator should be sure to get at any areas that they feel are problematic. The facilitator should:

1. Try to encourage other group members to share similar experiences.
2. Encourage shared problem solving, i.e., have any of you had that problem before and found a way to handle it?
3. Point out similarities between concerns. For example, one caregiver may be upset by her husband swearing when she tries to help him with grooming and another caregiver may mention that her husband gets agitated and paces when she tries to help with grooming. It is possible that both people with dementia are feeling overwhelmed and may need more help (such as hands on care) or a slower pace. By pointing out that both caregivers are having trouble during grooming, the facilitator can help the group direct problem solving efforts in a direction that could help both caregivers.
4. Have the group generate as many different ideas as possible.
5. Ask the caregiver which things she would like to try during the next week and explain that that will be her “Action Plan” for the week.

6. Encourage the each group member to write down her action plan for the week and be ready to discuss it next time.

During the first few weeks the facilitator should limit pressing problem discussion during group sessions so that the group is learning to develop action plans. During these early sessions, the facilitator may need to assist caregivers with their pressing problems by calling them after the group session or on the next day. When the facilitator has worked with a caregiver over the phone to problem solve and/or develop an action plan, the participant should be asked for permission to share the outcome with the group. The facilitator should bring into group individual work only when it is helpful in teaching or may serve as a model for other members. Therefore, if a caregiver has an individual phone call with the facilitator but the topic is redundant to other group discussions, the individual phone call should not be brought into group for more than brief follow-up of the outcome.

Action plan development should prioritize the management of highly distressing or potentially violent behaviors. For example, a caregiver may report that the patient raises his hand and threatens to strike her when she is attempting to provide personal care. The group facilitator may prioritize that caregiver's action plan development over a caregiver who would like to be more patient with her husband's repetitiveness.

If there is any mention of violence on the part of the patient or caregiver, the caregiver describes severe depression in herself or her husband, or another behavior is creating a dangerous situation (such as uncontrollable wandering placing the patient in danger), the group facilitator should consult with the patient's health care or mental health providers as soon as possible after the group session. Caregivers who express their own serious mental health or physical health symptoms need to be strongly encouraged to discuss such symptoms with their doctor. In the rare event that there is imminent risk for lethal or suicidal behaviors, the group facilitator should follow locally mandated protocols.

V. Wrap-up: 5 minutes

A. If there is still time, ask for any other questions. End the group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.

B. Homework Assignment:

1. Read about the Stages of Dementia. Next week we will be talking about how a person changes when they have dementia. It can be helpful to understand what stage of the disease someone is in so that you will have a better understanding of what to expect from the person. Sometimes caregivers prefer not to know what is coming next in the disease process. If you are worried about talking about patients in more advanced stages than your husband, please let me know and we can discuss that individually before the next session.

2. Think about one thing you'd like to work on while we are in group together. This might be something you have wanted to do, but have procrastinated about or something new that you might want to do by yourself or with your husband that might help to improve your situation. You can write this down on weekly worksheet 1.3.

C. Action Plans: Remind participants to write down and work on their individual action plans.

TEP Group Session 2: Stages of Dementia

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic and homework assignments. For example:

Last week we talked about dementia. Dementia is a term that describes the effects of several different diseases of the brain. This week we will be talking about the stages of dementia so that we can understand more about the ways that dementia affects the person with the disease.

During the week, we hope you've all gotten the chance to read about the stages of dementia on Worksheet 2.1 (*Participant Guide pg. 7*). I'm going to review the stages now and you may want to read along with me. So, before we go on, please have your workbook in front of you. If you don't have it handy, please get it and let me know when you are ready to go on.

II. Education: 10 minutes

Stages of Dementia*

A. Over the last week you read about the stages of dementia. Understanding that stage of dementia can be helpful in many ways.

- It can help us to form reasonable expectations for what a person can do.
- It can help us change the strategies we use to help the person.
- It can help explain some of the unusual behaviors we see in dementia.
- It can help us to anticipate what types of assistance the person will need now and in the future.
- It can help families to make plans for the level of assistance they will need.

B. There are many different ways to break the process of dementia into stages. Often, people will talk about mild, moderate, and severe stages. The worksheet that you read is based on the work of experts at the Alzheimer's Disease Research Center of Washington University in St. Louis, Missouri. This rating scale is often used in studies and by doctors in clinical settings to estimate where the patient is in terms of the progress of their disease. It was developed for use with Alzheimer's disease but can be used with other types of dementia as well. You may feel that your husband shows behaviors in two levels. That is often the case because the symptoms of dementia can vary a lot from one person to the next. For example, your husband may have many of the symptoms described in level 1.0, but still be good at his hobby of playing cards. People often are able to maintain an area of strength, especially if it is one that they practiced a lot during their lifetime. We'll talk about what level each of you think your husband is in, but first, I'll review the levels. It's important to remember that we are always talking about **changes** in a person's abilities. If I describe something that the person was never able to do earlier in life, and still cannot do, then we would not consider that to be a symptom of dementia.

- **Level 0-No Impairment:** The first "stage" or level is Level 6 or normal functioning. This is the same as any person without dementia. We include a normal stage when we think of stages of dementia because we realize that the changes in the brain started happening a long time before we can see changes in the person's behavior.

- **Level 0.5-Questionable Impairment:** Impairment at this stage is "*questionable*" because the changes are so minor that your health care provider could not yet make a definite diagnosis of dementia. Some of these changes happen as part of "normal" aging. In general, when they look back, families of people with dementia can remember a period of time where they were noticing very mild changes, but thought that the person was just "getting old". It was not till the patient's dementia progressed more that they realized it was not normal aging. The person in Level 0.5 has only a mild decline in their ability to do daily activities but there is the beginning of deficits in thinking abilities. Problems may be seen with recent memory, judgment, reasoning and planning ahead. Once in a while, the person may be confused about the time of day or the date, but they are generally able to use a clock, a newspaper, or a calendar to correct themselves. They might even make a mistake and then correct themselves without any help at all. Minor problems may be noticed in conversation. For example, the person may have occasional difficulty finding words. There may be problems with performance of complex tasks like managing finances, driving, and job performance. The person may seem self-centered because he or she is having difficulty considering the needs of others.
- **Level 1.0-Mild Impairment:** By Level 1.0, the person has changed enough that a doctor who is knowledgeable about dementia would definitely make the diagnosis. The person's thinking abilities are impaired. Along with problems in memory and judgment, there are now declines in other areas. These areas may include orientation (knowing the day, time, and one's location), perception (such as correctly understanding what the eyes are seeing), attention, concentration, language, and co-ordination. The person can no longer manage to take care of himself completely independently. Some basic things like dressing or shaving are done fine most of the time, but the person may need prompting from others. The person may need reminders to start an activity or may need help keeping on track to finish the task. When alone, the person in Level 1.0 can lose track of time, may not know what to do and may become anxious. He is may become confused and frustrated by his difficulty in understanding his surroundings. These changes in thinking abilities may cause misunderstandings, suspiciousness, paranoia, and delusional ideas about things that happen. Behavior problems may develop at this stage if the person does not have enough support or help for performing everyday functions. Specific changes depend on the areas of the brain affected and may vary quite a bit from one individual to another. Conversation may become difficult. There may be increasing difficulty finding words. The person may sometimes make up words or facts. Some people with dementia are aware of the changes they are experiencing and may complain of their frustration or become depressed. They may struggle to cover up their problems. Many do not have any awareness and do not intentionally try to cover up. Instead, when asked a question, their brain will fill in the missing information. Because reasoning ability is lost, it is very difficult, if not impossible to convince the person that his mistaken idea is wrong.

- **Level 2.0-Moderate Impairment:** By this level, the person often is confused about time and may be confused about where he is, who he is with, and what is expected of him. For example, our patients in Day Care often believe they are at work or school. They lack awareness of goals and activities and may have limited ability to follow a conversation. However, most enjoy socialization and readily respond to one-to-one attention. Recollections from the past may be fragmented or inaccurate, but the person is generally more comfortable talking about things from the distant past than about current events. Spontaneous speech may be infrequent, fragmented, or make no sense. Yes and no responses to questions may be simply “over-learned responses” rather than real choices. Focusing attention on even a simple task can be difficult and the person may need set-up and step-by-step direction and assistance to complete any activity. The person can be easily overwhelmed by complex tasks or even too much activity around them. When this happens, he may become agitated and upset. He may react with aggression or by trying to leave the situation and “go home” even when he is already home. Because attention span is short and thought processes are concrete, the person can more easily be diverted from problems than at earlier stages. By this stage, the person can no longer effectively participate in activities outside the home, but can still go out with a caregiver.
- **Level 3.0-Severe Impairment:** By Level 3.0, the person may not seem to recognize objects or know what to do with them. Attention may be drawn more toward movement and sounds in the environment. The person at this level needs to be totally cared for by others but may cooperate in simple ways such as holding up an arm or using a spoon or fingers to pick up food. He or she may often be incontinent. Requests to sit or stand may be followed but may require repetition, extra time or modeling (showing the person what to do). The person may resist care because he does not understand what is happening. He may be confused by verbal directions. He may be frightened by being touched. He may be uncomfortable because his movement is being restricted. Moving about often seems purposeless, and the person may have trouble keeping his balance when walking. Spontaneous speech may be infrequent, fragmented or garbled, and may make little sense. At this stage, the person seems too impaired to attend any activities outside the home.

C. Group Activity: Staging the Level of Dementia (10 minutes). The facilitator will now ask each of the participants to discuss what level her husband may be in. The facilitator will ask each caregiver to state what stage she feels her husband is in and describe what caused her to believe that.

Take a minute to write down your husband’s level on the bottom of Worksheet 2.1. (Pause for caregivers to think and write.) Now we’ll go around and have everyone say what level they feel their loved-one is in. Please briefly tell me the level or levels you think apply and briefly give me a few symptoms that make you think he is in that level.

The facilitator should record the level selected for each caregiver. After group, it can be helpful for the facilitator to send out information pertaining to that level.

If there is time, the facilitator should encourage the members to discuss their reactions to talking about the progression of illness. The facilitator can prompt the participants to discuss how their husband's ability to perform a simple task, like making toast or getting dressed, has changed and compare such performance the description of stages. It has been our experience that caregivers may have an emotional reaction when they become aware how far the patient has traveled in the disease process. The group should be encouraged to talk about their reactions and their thoughts about how their husbands have changed over time. The facilitator can begin the discussion this way:

Sometimes caregivers are surprised when we talk about stages how far their loved-one is into the disease process. Did any of you have that kind of reaction to the discussion? (Pause for responses) Did anyone have any other types of reactions to the discussion?

III. Check-in on Individual Action Plans: 10 minutes

In this section, the facilitator will check-in briefly with each participant regarding any action plans that had been developed in the first session. The facilitator will also check-in with the group as a whole regarding homework assignments. The facilitator will remind the group that this time is only to briefly check in.

Remember everyone should be choosing an action plan. If you are having difficulty deciding what to work on, think about your personal goals as a caregiver. What would you like to change in your care giving role? For example, a caregiver might have a personal goal of getting better control of her temper when she feels frustrated with the patient. There are several things she might want to try to help her keep her temper. She might try reminding herself that the patient is repeating himself because he does not remember having just talked about the answer to his question. She might want to avoid mentioning plans ahead of time so that the patient does not worry and repeatedly ask when they are leaving. She might also want to take some time out and leave the room for a few minutes when she feels she is getting close to losing her temper.

You might have a personal goal in mind, but may need some ideas for what type of action plan may help. For example, you might want to find a way to help your husband bathe that doesn't make him upset. That's where the group can be a big help. We can "brainstorm" ideas together. Someone else in the group may have already found something helpful to her that might help you too. So we can all work together to develop action plans for everyone in the group. So you might not have an action plan yet, but be thinking and let us know if you need some help. If you are not ready to talk about it this week, be ready to talk about it next week.

When you think about your action plan, remember to make sure it is something you can change. Unfortunately, you won't be able to change the fact that your husband has dementia and that the disease has changed his abilities. On the other hand, there may be things you can do to improve the situation. For example, you might want to help change your husband's problems with remembering things. You may not be able to change his abilities but you may be able to make a plan with the help of the group to use memory aids that can help him remember things. Likewise you might have a goal of getting your husband to talk with you more. It may not be possible to have as extensive a conversation with your husband as you used to, but you may be able to learn ways to encourage him to

Speak with you more frequently. You may not be able to change the amount of supervision your husband needs, but you may be able to find someone to sit with him so you can go out.

Notes for the Group Facilitator Helping to Develop Action Plans:

Group facilitators should help the participants develop action plans for things they can personally control. For example, a caregiver may want to get her daughter to help out more. She could implement an action plan to discuss her needs with her daughter. After this has been done, however, there would be relatively few other options to control the daughter's behavior. Instead, the caregiver could be asked to reframe the problem as needing more help (not necessarily from her daughter) and then the group can use problem solving to find other strategies to meet her need that are under her control (e.g., paying for someone to watch the patient while she goes out).

In a similar vein, caregivers sometimes try to change behaviors or symptoms of dementia over which they have little or no control. For example, caregivers often wish to reverse the continually developing apathy that is common in Alzheimer's disease. When caregivers select symptoms that are directly attributable to disease process, such as apathy, and there is little hope of change, they should be informed that they may not be able to have much of an impact on the symptom itself. It may be helpful for their action plans to focus on activities such as reading about typical dementia behaviors or attending support groups that will help them to be more accepting of the symptom. They may also benefit from taking time for themselves or performing other self-care activities.

In another example, incontinence is a common problem in dementia care and is often the direct result of the disease process. The caregiver will not be able to change the impact that dementia has made on the patient's bodily functions. On the other hand there are several things that can help the caregiver better manage the incontinence such as use of a toileting schedule, increased assistance when toileting, and use of diapers or incontinence pads to lessen the amount of laundry and cleaning that will need to be done.

Group facilitators will benefit from a solid understanding of the dementia process and symptoms, and some experience in attempting to alter behaviors related to dementia. Such knowledge and experience will be invaluable in helping them determine which types of action plans are likely to result in change. A general rule of thumb, however, is that action plans that seem to be having little impact will need to be re-evaluated. Alternative approaches to the problem should be brainstormed by the group and implemented by the participant. Action plans can certainly include consultation with the medical provider or behavioral health provider. When there is little change on the part of the patient, and all appropriate professionals have been consulted, it is important to first insure that the caregiver understands that the behavior is part of the dementia process. Following any needed education, the facilitator should then try to help the caregiver focus more closely on emotion-focused coping strategies such as taking breaks and participating in pleasant activities.

Finally, it has been our experience that some participants will have difficulty grasping the notion that they can successfully change anything. When group participants continually repeat or rehash the same problem, they should be gently, but firmly, encouraged to develop an action plan that can result in a change. It may be helpful to encourage the caregiver in this situation to select another problem or a smaller, more manageable piece of the problem about which they are complaining. Alternatively, a caregiver in this situation

may be expressing frustration and high distress by repeatedly commenting about her difficulties. It may be helpful to ask such a caregiver to focus on self-care activities that may provide some emotional relief. Use of respite services may also provide some relief for the highly distressed caregiver.

The group facilitator will need to strike a balance between focus on action plan development that may result in long-term improvement, and managing pressing problems as they arise for the group members.

While we will be focusing on developing and trying out your action plans, you may have a pressing problem that comes up during the week. It's okay if the problem is different from your action plan and you want us to help you out. For example, let's say that a caregiver had an action plan to help her be more patient with her husband's repeating himself. Her action plan might be to leave the room for a few minutes when she feels herself getting frustrated. But, let's say that her husband suddenly refused to take a shower. We could use some of our problem solving time to help her with that problem. We don't want to ignore a pressing problem when it comes up! If you have something, please let me know and if we don't have time to talk about it during group, I'll call you so we can talk individually.

The facilitator will lead the discussion by briefly checking in on any action plans she knows about and then checking in with other members. For example, "Mrs. Smith, you were working on reminding your husband to use the bathroom every hour. How did that go this week?" Then, the facilitator will turn to the other group members and prompt as needed. "Has anyone else started working on an action plan this week? (Members respond.) Mrs. Jones, do you have any ideas about an action plan? Maybe the group can help you. Let's use our problem solving time to help you develop your action plan."

IV. Problem Solving and Further Action Plan Development: 15 minutes

This week, the facilitator will focus on one participant's action plan development (unless there is a pressing problem that can not wait). During action plan development, the facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources.

During this section of the meeting we will be working together to solve problems. We'll be using the Problem Solving method depicted on Worksheet 2.2 (*Participant Guide pg. 8*) in your workbook. As I mentioned last week, the most important part of problem solving is the brainstorming step. We need to make sure we get all the ideas out on the table before we get sidetracked by evaluating individual ideas.

Before we get to brainstorming though, we need to be sure we all understand the problem we're working on. We need to be specific about the problem. For example, you may have a general goal of being a better caregiver. That's a great goal but too general for us to come up with an action plan. We will need to pin down how you want to be better. Do you want to show more patience? Do you want to do a better job at helping your loved-one do something, like take a shower? The more specific we are about the problem, the easier it will be to come up with ideas to solve the problem.

As a group, we'll brainstorm as many ideas as we can. You may want to jot down notes so you can keep track of the ideas. I'll try to help with that as well. At this point we

do not want to evaluate or criticize the ideas because that might stop people from making suggestions.

The next step is to evaluate the ideas. Some may not be possible even if they are great ideas. Some may be too hard to try. Some ideas may need a little fine-tuning to fit with your family. By evaluating all the ideas, we'll find the one or ones that are best for you.

V. Wrap-up: 5 minutes

A. If there is still time, ask for any other questions. End group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.

B. Homework Assignment: Think about the stages of dementia and as you are with your spouse this week notice the type of things he needs help with. You may be helping him to function more than you realize! Also, please identify one problematic behavior exhibited by your spouse that you would like to work on during next week's meeting. You can write this down on weekly worksheet 2.3 (*Participant Guide pg. 9*).

C. Action Plans: Remind participants to write down and work on their individual action plans on weekly worksheet 2.3.

TEP Group Session 3: Behavior Management Part I

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic that was focused on stages of dementia and the "homework assignment"

II. Education: 15 minutes

A. Challenging Behaviors - 5 min (Worksheet 3.1, Participant Guide pg.10)

Coping with behavioral symptoms of dementia can be one of the most challenging aspects of being a caregiver. What do we mean by challenging behaviors?

- Behaviors that may endanger the patient, ex, wandering, non-compliance with medication, eating excessive sweets if the patient is diabetic
- Behaviors that may endanger others, ex., aggressiveness, driving
- Behaviors that make life more difficult for the caregivers and family, ex. verbal aggressiveness, swearing, apathy, pacing, agitation, delusional beliefs, hallucinations, depression, inappropriate behaviors such as disrobing, inappropriate comments, unconventional social behaviors (such as making unusual or embarrassing comments in public, "Wow, that woman is really fat!" or hurtful comments to a loved one, "This is all your fault, you never do anything right," or when a caregiver is trying to help, "You are always trying to boss me around!")
- Challenging behaviors may be different over the course of the illness. For example, in the early stages, apathy, difficulty with initiation, and irritability are common. In the middle stages, wandering, agitation (especially when the patient is confused), refusal to cooperate with care, beginning sleep disturbance, and "shadowing" become more common. As the disease progresses into the later stages, agitation may be worse and sleep disturbance may be worse. Of course, each patient differs and your husband may not have any of these symptoms or they may be problematic at different times.

B. Progressively Lowered Stress Threshold – 5 min

Each of us has our own level of stress that we can stand. Some of us are more tolerant of stress than others. When stressors build up, we eventually cross the level, or threshold, that each of us can bare. When that happens, we react by getting angry, crying, getting upset, storming off, or withdrawing into ourselves. We all have our own way of reacting. Dementia causes a person to be less able to withstand the normal everyday stressors. As the disease progresses, the person with dementia has a lower and lower stress threshold. It might take only one or two minor stressors (for example, being a little hungry or cold, having someone ask a question that he or she can't remember the answer to). Because so many things are confusing or frustrating the person with dementia is at risk for stress. For example, the person with dementia may be cold but not realize that he needs to put on a sweater. He is uncomfortable and starts pacing and may be irritable. Then the caregiver says, "We need to get ready to go out." The person with dementia becomes angry and starts yelling. The caregiver feels that the patient has exploded for no reason at all.

C. Becoming a Behavioral Detective - 5 min (Worksheet 3.2, Participant Guide pg. 11)

Caregivers can help their loved ones with dementia by providing a structured environment that has multiple cues for appropriate behaviors. When “behavior problems” arise, we can see them as clues that the person is stressed by something, confused, or upset. By doing some detective work, we can understand and often avoid those upsetting behaviors.

There are three basic areas to examine, the ABCs of Behavior:

Antecedents (the things that come before): signals or cues as to how someone may behave. They may be external: tone of voice, (child knows his mother may give a punishment when she calls him using his middle name), knowledge of a police car. They may be internal: hunger, emotions, and illness.

Behavior: Look at the exact form of the behavior; think about the meaning within the context of what you know about the person.

Examples:

- Following someone – seeking security, or seeking attention, or does not know what else to do.
- Wandering – trying to escape or go to a specific place, or seeking stimulation. Sometimes comments that person is making can give helpful clues.

Consequences (what happens after the behavior): The “paycheck” for the behavior. They may be planned, for example, a promised reward for getting an ‘A’ on a report card or getting paid for working. They may be unplanned, such as kids getting attention from Mom every time they quarrel.

We can only directly change the A or C of the ABCs. For people with dementia, we usually emphasize the A part of the ABCs. Changing the consequences means that the person must learn to expect different results. People with dementia are going to have a hard time learning that consequences have changed. It is much easier to change the antecedents. Here is an example of a case where it was important to change the A, or antecedent:

Three daughters were caring for their mother who had dementia. Mom lived with a different daughter each week. It was a bit difficult for their mother to change houses each week, but it was the best the daughters could do. Mom was flushing pantyhose down the toilet every night, causing great difficulty. The daughters thought Mom was doing this as a way of telling them that their care was not good enough. The psychologist who was helping the family suggested that their mother’s behavior could also be interpreted as just not knowing what to do with her pantyhose and being embarrassed. He had the daughters buy three of the same hampers and put one in Mom’s bedroom in about the same spot in each house. Each daughter prompted her mother at bedtime, “It’s time to change for bed. Put your pantyhose in here.” The problem was solved in the first week. After a few weeks, the daughters came back because the problem had started again. After a little detective work, it turned out that one daughter had moved the

hamper to the bathroom. When the hamper was returned to the bedroom, the problem was solved and did not return again.

There are four important points to this example. **First**, the psychologist had to be a behavioral detective to find a way to help the family. **Second**, it was important for the daughters to avoid making assumptions about their mother's behavior being "on purpose" to intentionally convey a message. **Third**, changing an Antecedent (having a place for dirty clothes and prompting the mother to use it each night) was all that was needed. **Last**, but not least, it was important to be very consistent in implementing the plan.

D. GROUP ACTIVITY: Behavioral Definition -15 min

One of the most important parts of becoming a Behavioral Detective is knowing what behavior you are focusing on. Turn to Worksheet 3.2 in your workbook. Take a minute to jot down a description of a behavior that is challenging for you. It would be a good idea to use the behavior from your action plan if you have chosen to work on a particular behavior of your loved one. For example, last week you might have decided that you wanted to try to avoid getting your husband agitated when he is being bathed. (Or the facilitator uses an example of a patient behavior that was discussed last week. If caregivers have selected action plans to focus on their own emotional coping, "I'll see my friends more often," they will need to choose a behavior of their husband's for this exercise.) If your action plan does not involve a behavior of your husband's please choose a behavior for today to describe. Describe the behavior so that anyone will understand exactly what you mean and know when it has happened.

So a visitor might not be sure if you describe the behavior as "he gets mad at me," but if you say, "he raises his voice and swears" the visitor will be pretty certain about what you mean. Let's go around and read your description. The rest of the group will tell you if they are sure about what you mean. (This tends to be something the caregivers need help with. It's often difficult for the caregivers to understand the importance, but if it's a vague situation, they will have a mixture of data that will make it hard to find a pattern with. Try to push them to be very specific.)

Now turn to worksheet 3.3 (*Participant Guide pg. 13*). Write your behavioral definition at the top of the page. (Pause briefly) Now look at the rest of that page. It has a chart for you to collect information about the behavior that you are focusing on. Each caregiver writes the behavior at the top of sheet. Below this the sheet is divided into four columns.

Example follows on the next page

Here's an example:

When?	A: Antecedents Things That Came Before	B: Behavior	C: Consequences What Happened Next
Tuesday at about 8 am	We were getting ready to go to ADHC. I told John it was time to get dressed. (Encourage them to note who was present, what was happening).	John suddenly became very angry and started swearing at me. (Encourage them to make notes of what patient was saying.)	I tried to stay calm, but ended up yelling back at him that I was only trying to help. (Encourage them to be as specific as possible. I often find when we review that we need to ask for more details about A and C, but that's okay.)

For this week, it is only important that they are clear on what they should be taking notes on. They should be discouraged from making assumptions about the cause of the behavior or planning an intervention until after the next group session. The facilitator should stress that the goal is to get enough information to discuss the behavior without overwhelming the group. We realize that you are very busy and it might be hard to write things down. So please, jot down only what you need to jog your memory when we talk next week. Feel free to use abbreviations and initials instead of writing out every word and name. If the behavior happens more than once in a week, try to take down some notes each time it happens or for at least a few of the times because it will help you to discover patterns. If this is something that happens multiple times in one day, just try to “sample” the behavior a few times during the week. That means, take enough notes so you can see the patterns, but don’t feel you have to write it down every single time. It is also best if you are able to jot down your notes as soon as possible after the behavior happens so it is fresh in your mind. Again, we know that might not be realistic for you. Just do your best to jot down your notes during the same day when you have a quiet moment. Remember, like the daughters in the example, don’t jump to any conclusions about what is causing the behavior or why your loved one is doing it. Try to keep an open mind!

III. Check-in on Individual Action Plans and Action Plan Development - 15 min

The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). How have your action plans been going? If your action plan involves trying to change or avoid a challenging behavior, you can apply this week’s discussion and homework directly to it. Let’s briefly check in on your action plan progress before we help someone with group problem solving.

The facilitator then goes around the group asking each person in turn about their action plan. If the facilitator cannot get to everyone each week, he or she should make sure to check in with at least one or two new group members each week to ensure that all members eventually develop action plans.

IV. Problem Solving and Further Action Plan Development - 10 min

Last week we went over the problem solving model that is presented on Worksheet 2.2 of your workbook. This week and all remaining weeks, we will use the model to work on at least one problem you are experiencing during this time. Who has a problem they would like to work on this week? The facilitator will focus on 1-2 participants' concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources. If no one has a pressing problem, work on action plans can continue.

V. Wrap-up: 5 min

A. If there is still time, the facilitator can ask for any other questions. End the group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.

B. Homework Assignment: Your homework assignment this week is to be a Behavioral Detective by using the Behavioral Observations Sheet to record the behavior that you described today. The facilitator should stress that the caregivers only need to write enough so that they can remember what happened. It would be great if they could write down the events every time these things happen, but we want to be realistic. Caregivers are very busy and so it is okay if they can only write down these things occasionally. They just need to get enough information so we can talk about some of the events during the next group. Also, the facilitator should remind the caregivers to keep an open mind and avoid jumping to conclusions before they are done taking data.

C. Action Plans: Remind participants to write down and work on their individual action plans. Remember, if your action plan is about avoiding a challenging behavior, you are already working on it in your homework assignment! No need to do double duty!

TEP Group Session 4: Behavior Management Part II

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic on becoming a behavior detective and behavior management strategies and the "homework assignment"

II. Education: 30 minutes

A. Applying the ABC's of Behavior Management.

Last week we talked about the ABC's of Behavior Management. This week we will use the information you noted over the week to find ideas about avoiding or managing the challenging behaviors you selected. Please look at the notes you took over the week while I talk about the ABC's. Worksheet 4.1 (*Participant Guide pg. 15*) "Applying the ABCs of Behavior Management" gives you a place to take notes about the things you observed last week.

A = Antecedents: The facilitator reminds the group that antecedents are the things that come BEFORE. He or she asks the caregivers to look for patterns in who, what, when, or where behaviors happened. The facilitator encourages the members to jot down what they noticed about antecedents on Worksheet 4.1.

- **WHO:** Sometimes we see that specific people cause a person with dementia to be upset. We believe that this may happen when a person looks like someone from earlier in the patient's life who the patient did not like. Other times, it may be the tone of voice the person uses or it may be that person speaks too quickly.
- **WHAT:** Think about what was happening when the behavior started. One of the most common difficulties for caregivers of dementia is trying to help with bathing or grooming. Another common "what" is when family is visiting and there is too much activity for the person to tolerate.
- **WHEN:** Look for patterns in the time of day. Often when a person seems agitated at a certain time of day there is a biological reason. He or she may be hungry or need to go to the bathroom. He or she may have arthritis and the pain medication is wearing off. Or maybe, something happens at that time of day. In nursing homes and hospitals, at change of shift time, there is a lot of activity and sometimes that causes patients to become agitated. Or is it that your loved one getting upset when you are trying to help him dress or bathe? So, think about what is happening at that time of day and what can be done differently.

- **WHERE:** Sometimes a certain place can cause difficulty. Some patients become anxious when they need to go to the VA for an appointment. They might think that their family is going to leave them there. Or the place may be too stimulating (have too much activity) for the patient to tolerate it. Imagine that you suddenly found yourself in another country where you could not understand what people were saying to you. That might be frightening and overwhelming! So if there is a place that seems to cause trouble, you can think about what might be causing the person to feel uncomfortable.

B = Behavior: The facilitator notes the importance of keeping focused on only one thing at a time. If we try to take data on ABCs of more than one behavior at a time, we will not see the same patterns. The facilitator again encourages the members to use Worksheet 4.1 as the discussion continues. We defined the behavior last week. Do you notice any difference between the way you described the behavior and what you noticed happening? Sometimes we think we are looking at one behavior but there turns out to be two different behaviors. For example, Dr. Wray was called to a medical unit to help with an elderly lady with dementia who was recovering from a hip fracture. The nursing staff reported that she kept calling out “Help, help, help,” without stopping. When Dr. Wray observed more closely, the patient was calling out “help...help...help” whenever she was left alone in her room. (Facilitator should use calm, but persistent tone of voice.) When the nurses tried to help the patient walk, she cried out, “Help! Help! Help!” (Facilitator should use a frantic tone of voice.) So there were really TWO different behaviors. The first was happening because the patient could not remember where she was when left alone in the room. She was calm and quiet when she was brought to sit in the hall near the nurses’ station where she could see that she was not alone. The second was an expression of her fears about falling and the nursing staff concentrated on reassuring her and telling her in simple sentences what they were doing; “Now we are going to help you move to the bed.” So did you notice any differences between the behavior you described last week and the behavior you observed? Caregivers will note any changes of specifics that differ from their original description.

C = Consequences: The facilitator reminds the group that consequences are what happen after the behavior and they can ask themselves similar questions (who, what, where, when). It is important to try to focus more on antecedents because learning new behaviors through reinforcement after the behavior is very difficult for someone with dementia. However, the facilitator and the caregiver need to be alert to the possibility that the patient is gaining attention by a behavior (not intentionally!) and that he may need to have other behaviors rewarded with attention. Likewise, the behavior may result in escape from a frightening or aversive situation. It is essential to emphasize that the person with dementia does not behave this way intentionally. We will mainly focus on the A’s and B’s of the ABC’s. This is because it would be very difficult for the person with dementia to understand and remember that if he were to do something a certain way that it would “pay off.” So when we think about how to avoid or change a behavior, we will think about changing the antecedents.

But we need to keep in mind that the behavior may be gaining the person attention, or escape from something that is frightening him. We may not focus on changing the consequence, but it may tell us something about what the person is experiencing. For example, if a patient yells and gets angry every time he is in the shower, it may be that the water coming down on his face is frightening to him. It may be time to change to taking baths instead.

B. GROUP ACTIVITY: Application to Specific Situations:

The facilitator has the group members review their data collection sheets. The facilitator prompts the members to look for patterns in antecedents, hints about context of the behavior, and patterns of consequences. The members continue to complete Worksheet 4.1. while the facilitator asks the following questions:

- Does the behavior seem to happen around the same time of day?
- Does the behavior seem to happen in the same place?
- Does the behavior seem to happen during the same activity (ies)?

The facilitator helps group members to look for things they can change to avoid specific antecedents, and encourages group members to help each other come up with ideas. Emphasis should be placed on changing the antecedents. Caregivers may need help in examining their own role in the antecedents of a behavior. For example, is it the tone of voice they are using? Is it that they are pushing the patient to move too rapidly? Are they asking too much of the patient?

The facilitator reminds group members about progressively lowered stress threshold. Is the behavior an example of that? Does the person with dementia need more help in performing a specific activity?

The facilitator and group members develop plans for managing behaviors over the next week. The facilitator can use the Action Plan time and Problem Solving time to accomplish this.

Look at Worksheet 4.2 (*Participant Guide pg. 17*) “Behavior Observation Sheet 2”. This is very similar to the sheet you used last week but there is an important difference. There is a place for you to write in the behavior you are working on just as before, but notice that now there is a place for you to write what you plan to do differently this week. Take a minute to do that now. (The facilitator can assist the caregivers by giving an example. Mrs. Jones, you noticed that your husband has been getting upset when he was trying to get dressed even though you lay out his clothes. This week you are going to try staying in the room while he dresses and giving him one piece of clothing at a time. So you would write that down in your plan.) There is also a new column on your sheet. You may want to write down thoughts or comments about how your plan is going. For example, if you are trying to keep your tone of voice calm, you can note there if you were successful.

III. Check-in on Individual Action Plans - 10 min

The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). How have your action plans been going? If your action plan involves trying to change or avoid a challenging behavior, you can apply this week's discussion and homework directly to it. Let's briefly check in on your action plan progress before we help someone with group problem solving, or work on developing new action plans.

IV. Problem Solving and Further Action Plans Development- 15 min

Does anyone have a problem they would like to work on this week using our problem-solving model? We might want to use this time this week to help each other come up with plans for behavior management (if not completed by all members earlier in this session). The facilitator will focus on 1-2 participants' concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources. If no one has a pressing problem, work on action plans can continue.

V. Wrap-up: 5 minutes

- A.** If there is still time, ask for any other questions. End group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.
- B. Homework Assignment:** Continue behavioral data collection. Focus on antecedents and consequences of behavior. Use new data collection sheet to comment on how you did things differently (Behavioral Observation Sheet 4.2).
- C. Action Plans:** Remind participants to write down and work on their individual action plans using weekly worksheet 4.3 (*Participant Guide pg. 18*)
- D.**). Remind them that their action plans and homework may be the same thing this week.

TEP Group Session 5: Improving Communication Part I

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic about behavioral intervention strategies and the "homework assignments".

II. Education: 15 minutes

A. Communication Changes in Dementia: Overview

Today we will begin to talk about a very important topic, communication. You can follow along on Worksheet 5.1 (*Participant Guide pg. 19*).

Communication becomes more challenging as dementia progresses. Age related sensory changes occur for all people of advanced old age. It is important not to ignore the impact of age-related sensory changes on the ability of persons with dementia to communicate.

In addition to age-related sensory changes there are profound changes in the brain of persons with dementia that impede the processing of information and their ability to communicate. It is important to understand that these changes are not merely cognitive. Profound changes in the brain can lead to mood abnormalities, impaired thought processes, and physical health problems (particularly late in the disease process). For example, there may be hallucinations when dementia is severe. Brain changes also cause progressive deterioration in ability to conduct daily activities such as managing money and driving a car, and in later stages of the disease, the performance of basic self care activities. There is also frequently a negative impact on social skills and social interest, including willingness and interest to engage in activities. There may also be behavioral changes such as wandering and agitated behavior that are challenging to cope with. All of these impairments can interfere with communication.

Communication problems differ depending on the progression of the dementia. In early dementia conversational ability is still largely intact. However, words may become harder to find and naming difficulties may be noticed. There may be more frequent requests for clarification and confirmation. More frequent conversational turns may be needed to hold the person's attention. Vocabulary begins to be limited but this may not become apparent until later stages of the disorder.

As the disease progresses there are breakdowns in proper sentence structure and increased difficulty in finding words. Speech becomes vague with increasing use of indefinite references, and a decrease in topic maintenance. Missing words and phrases become more common with poor noun choices and incorrect verbal tenses. Still, the person with dementia is still able to maintain communication if they have a patient and understanding person with whom to communicate.

In late stages of dementia, people have more difficulty maintaining any conversation. The person still tries to communicate verbally. Gradually, however, there is more difficulty in forming words and the person may become mute. People at this stage may understand more than they are able to convey. Even in the very late stage, people with dementia still send and receive non-verbal messages and they respond to touch.

General Strategies for Communication:

Here are some things that caregivers can do to help older persons with dementia to continue to communicate.

1. Address sensory deficits

Caregivers and all those who interact with older people with moderate and severe dementia should first consider the impact of changes in vision, hearing, taste, smell and touch that are age-related. Vision deficits and hearing difficulties, in particular, can impede communication and cause older persons to withdraw or become confused. The first step in any effort to improve communication with persons with dementia should be a careful assessment of their visual and hearing acuity. A medical evaluation can help to identify deficits and lead to treatment for vision and hearing problems that can be reversed or arrested. It can also inform caregivers about irreversible changes in vision and hearing so that caregivers can take appropriate remedial actions such as helping the person with dementia to use eyeglasses, hearing aids, and other adaptive devices.

2. Ensure that environmental stimulation and physical comfort are not interfering with communication

Environmental and physical stimuli affect communication. Caregivers should consider how the environment is affecting the ability of the person with dementia to communicate. For example are background noises interfering with communication? Is lighting inadequate? Is the person hungry, or uncomfortable in some other way, for example, too warm or too cool? Older persons with dementia may not be able to communicate how environmental and physical stimuli are affecting them so caregivers need to be sensitive to and to anticipate these factors.

Recent studies have indicated that older people with dementia may actually receive less medication to control pain from arthritis or other health problems than persons without dementia. Caregivers should ensure that older persons with dementia are receiving the medications they need to control chronic health problems and reduce any pain or suffering they may be experiencing

3. Be aware of the demands of the environment

With advancing age and dementia progression, information processing slows and becomes impaired. Environmental demands need to be matched to the abilities of the person with dementia. Caregivers should encourage older persons with dementia to use existing skills but at the same time not expect them to do things they can no longer do.

4. Understand communication deterioration as dementia progresses

Some of the changes in communication that are associated with different stages of dementia are shown in Worksheet 5.2 (*Participant Guide pg. 20*) and some of the strengths remaining are shown in Worksheet 5.3 (*Participant Guide pg. 21*). Go over Worksheet 5.2 and 5.3.

As dementia progresses vocabulary is reduced and word finding becomes more difficult. To make up for the deficits a person with dementia uses words that are related to or associated with the intended word. Thus, a caregiver has to listen for the meaning behind a message that may not be readily apparent.

The pragmatics or “rules” of communication that we take for granted are gradually lost. Thus, it becomes more difficult for a person to engage in and maintain a conversation. There is increasing digression, more free association, and more talk that appears not to make sense. Because it becomes more difficult for the person to communicate there is gradual withdrawal from conversation opportunities. The same time the person is having more and more difficulty communicating, caregivers and others around the person often become more frustrated. They tend to give negative verbal and non-verbal feedback to the person about their communication abilities. This helps to make the person with dementia more withdrawn. Therefore, it is important to remain calm. When you feel yourself getting angry or upset try the deep breathing exercise presented in Worksheet 5.4 (*Participant Guide pg. 22*) of your workbook.

In advanced dementia, verbal comprehension becomes very limited. The person’s vocabulary becomes increasingly imprecise and “empty.” Persons with advanced dementia often repeat phrases and respond in an automatic or reflexive fashion with a few words they can still find such as “thank you” or “that’s good.”

It is important for you as a caregiver to understand that these changes are all part of the disease process.

C. Link between Communication and Agitation: 5 minutes

Communication consists of both verbal and nonverbal information. Some say up to 80% of the information we receive when communicating comes over nonverbal channels. As we have been discussing, people with dementia have changes in their ability to understand and produce verbal communication. However, they seem to retain a good understanding of nonverbal communication for a very long time. Can you think of examples of nonverbal communication? The group discusses ways we convey information nonverbally. The facilitator makes sure that facial expression, physical gestures, and tone of voice are mentioned.

The facilitator uses the example of 911 operators. Many people have heard clips of 911 operators on TV. Have you ever noticed the tone of voice the 911 operators use? Why is that important? (Calm, reassuring operator helps person in crisis stay calm and follow directions until help arrives.)

The same is true when person with dementia is upset. In fact, person with dementia is even more likely to respond to tone of voice. Remember that they become more dependent on their environment. The facilitator has the group predict what happens if caregiver sounds anxious or angry when person with dementia is refusing to do something. (Person with dementia is likely to become angry or anxious.)

The facilitator has the group think about the other direction, i.e., how does caregiver feel when person with dementia yells at them? Do they think that their emotions are conveyed when they answer? Are they likely to yell back? The facilitator uses the example of an argument that the couple might have had many years ago. One person sounds annoyed, so the other gets annoyed. This makes the first person angry and the other gets angry. And so the situation escalates and sometimes people end up fighting but neither can say why they started. It’s easy, even natural, to continue that same pattern now with your husband who is suffering from dementia. The person with dementia is more

dependent on their environment, so if the caregiver can control her tone of voice, she is likely to be able to help the patient calm down.

GROUP EXERCISE (5 minutes):

It can be helpful to practice using our voices in different ways so that we can be more aware of the how our voices change. Let's take a minute to practice. I'm going to ask that each member take a turn to say "Put on your shirt." First say it in a frustrated or angry voice like this. The facilitator demonstrates. Then say it in a calm and relaxed voice like this. The facilitator demonstrates again. The group can discuss the exercise. The facilitator should remind the members about the deep breathing exercise on Worksheet 5.4. If there is time, the members can try the exercise during the session.

III. Check-in on Individual Action Plans: 10 minutes

A. The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). The facilitator will also check-in with the group as a whole regarding homework assignments.

B. Examples:

- Education: Did you all read the pages in the manual for group meeting 4?
- Problem Solving: Mrs. Smith, last week you planned to try turning off the TV while you helped your husband dress. How did that go? Mrs. Jones, you were going to work on keeping your voice calm when your husband started to get agitated. Did you see a difference?
- Care of Self: Mrs. White, you were going to go out to lunch with your daughter. Did you go? Did you enjoy yourself?

IV. Problem Solving and Further Action Plan Development: 15 minutes

The facilitator will focus on 1-2 participants' concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources. If no one has a pressing problem, work on action plans can continue.

V. Wrap-up: 5 minutes

A. If there is still time, ask for any other questions. End the group meeting by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week.

B. Homework Assignment: Try the Deep Breathing Exercise on Worksheet 5.4 and practice using a calm tone of voice. Identify barriers to communication in your own home keeping in mind what has been discussed in today's group meeting.

C. Action Plans: Remind participants to write down and work on their individual action plans on Worksheet 5.5 (*Participant Guide pg. 23*).

*Today's Education Material was excerpted in part from: (Toseland and McCallion, 1998)

TEP Group Session 6: Improving Communication Part II

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic about communication and homework assignments

II. Education: 15 minutes

Last week we talked about some ways to maintain communication with your spouse. These included:

- Addressing sensory deficits
- Ensuring that environmental stimulation and physical comfort are not interfering with communication,
- Being aware of the demands of the environment, and
- Understanding communication deterioration as dementia progresses.

You can also change the way you communicate.

There are simple strategies that you can use to maintain communication and make it easier during each stage of dementia. General communication guidelines are presented in Worksheet 6.1 (*Participant Guide pg. 24*).

Go over Worksheet 6.1 – General Communication Guidelines

There are also specific communication strategies you can use during each stage of dementia. These are presented in Worksheets 6.2, 6.3, and 6.4 (*Participant Guide pgs. 25-28*). You will still be frustrated at times by the person's communication deficits so it is important to try and keep in mind the person's deficits are the result of the dementia and that they are trying hard to communicate as best they can using their remaining abilities.

Go over Worksheet 6.2 to 6.4. – Communication Strategies for Early, Moderate, and Late Stage Dementia

You can also use memory albums and memory boards to reminisce.

Memories from the past remain even when there are profound changes in ability to recall recent events. One way to maintain communication is to reminisce with the person with dementia. Using reminiscence can calm a person with dementia who is agitated. The use of prompts such as old photographs can help to engage the person with dementia.

Memory albums can also be prepared. These consist of a photograph, a postcard, or some other type of picture on one side of a page, and simple words describing the photograph above the photo or if necessary on the opposite page. Memory boards are larger displays of familiar photographs with a few words describing each photo such as "Your sister Ann, at the lake house."

Worksheet 6.5 (*Participant Guide pg. 30*) – Making Memory Album Worksheet 6.5 in your workbook shows how to make a memory album.

Encourage them to make a memory album. Discuss what would go into the memory album. The memory album can be used during activities of daily living or other

interactions. In the nursing home, staff use them to help distract a resident if he or she is upset by a misunderstanding.

Worksheet 6.6 (*Participant Guide pg. 31*) – Making a Memory Chart Worksheet 6.6 tells how to make another different tool that can help a person with dementia communicate. It is similar to the memory album, but you use a poster board so that you can keep the pictures in a place that is easily visible to the person with dementia. He may then notice the pictures on his own.

Encourage them to make Memory Chart

III. Check-in on Individual Action Plans: 10 minutes.

A. The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). The facilitator will also check-in with the group as a whole regarding homework assignments.

B. Examples:

- **Education:** Did you all read the worksheets for session 5?
- **Problem Solving:** Check in on recent problem solving activities. Mrs. Smith, last week you planned to try turning off the TV while you helped your husband dress. How did that go? Mrs. Jones, you were going to work on keeping your voice calm when your husband started to get agitated. Did you see a difference?
- **Care of Self:** Mrs. White, you were going to go out to lunch with your daughter. Did you go? Did you enjoy yourself?

IV. Problem Solving and Further Action Plan Development: 25 minutes.

The facilitator will focus on 1-2 participants' concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources.

V. Wrap-up: 5 minutes

A. If there is still time, ask for any other questions. End the group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week.

B. Homework Assignment: Create a memory album and practice using it with your husband

C. Action Plans: Remind participants to write down and work on their individual action plans using weekly workshop worksheet 6.7 (*Participant Guide pg. 32*).

*Today's Education Material was excerpted in part from: (Toseland, R., & McCallion, P. (1998). Maintaining communication with persons with dementia. New York: Springer)

TEP Group Session 7: Caregiver Coping Strategies Part I

I. Review of Prior Week's Session: 5 minutes

The facilitator briefly reviews the last week's topic about communication and homework assignments.

II. Education: 15 minutes

A. Relaxation Exercise: Facilitator begins by asking group about techniques they have been using to help themselves relax. What are their favorite techniques and are they using them frequently? The facilitator uses the following script to practice a relaxation exercise.

Two weeks ago, we talked about using deep breathing to help maintain a calm tone of voice. You may have practiced the deep breathing exercise (Worksheet 5.4, (Participant Guide pg. 22)) during the following week. Today we are going to take a few minutes to practice deep breathing and a technique called visualization. By visualizing yourself in a pleasant place, you can actually help yourself feel more relaxed.

Before we begin this exercise I want you to think of a special or pleasant place. It can be a real place that you have been or it can be imaginary. It can be a place in nature or a place that is manmade. For example, you might choose a favorite beach or a cozy room with a fireplace. It could even be your own bed or bathtub! Whatever place you choose, make it be one where you know you would feel relaxed.

Now, before we start, I want you to be seated as comfortably as you can. If you can put your feet up and rest your head on the back of the chair that would be great. I want you to sit or lie down in a way that every part of you is supported if that is possible. Also, please don't cross your legs or arms. It's better for your blood flow if your limbs are not crossed and that will help your level of relaxation.

Let's begin by taking some deep breaths. Breathe in through your nose (facilitator pauses briefly) and out through your mouth. Again, breathe in through your nose, and out through your mouth. Each time you breathe in, imagine that you are breathing in the relaxation and letting go of the tension. The facilitator spends about two-three minutes repeating variations of these phrases. As he or she is doing so, the voice should be getting gradually slower, softer, and calmer as this helps to ease the group members into a state of relaxation. In addition, the tone of voice should become increasingly monotonous. Once the facilitator's tone of voice has leveled off, he or she should turn to the relaxation exercise while using the same tone of voice and pacing statements to coincide with regular slow breaths.

Now...let's think about that special place...it is a place that is special to you...imagine that you are there...as you continue to breath in the relaxation...and let go of the tension. Imagine yourself in that place...notice the pleasant sensation of being there. Visualize all the details...as you breathe in through your nose...and out through your

mouth. See the colors that are there. See the way the light shines...on the surfaces. Feel the warmth of the sun on your skin. Breathe in the pleasant smells. Notice all the details...as you breathe in the relaxation...and let go of the tension.

As you continue to enjoy your special place...and breathe slowly, I am going to be silent for just a moment... (The facilitator is quiet for 1 to 2 minutes).

The facilitator continues quietly at first. It's time to come back from your special place. You can bring this good feeling of relaxation with you. I'm going to count slowly from 10 to 1 as you become more alert. 10...9...becoming more alert...8...7...beginning to stir ...6...5...moving your arms and legs...4...3...opening your eyes when you are ready...2...1...awake and refreshed. The facilitator asks the group for comments on how they felt during the relaxation exercise and encourages them to practice deep breathing and visualization again in the near future.

B. Caregiver Self-Care: The group will discuss ways they insure their own mental and physical well-being. The facilitator first explains to the group the notion of self-care. Members can follow along using Worksheet 7.1 (*Participant Guide pg. 33*). Self-care is what we do to help ourselves be physically, emotionally, and spiritually healthy. Caregivers are often so busy caring for their loved one that they forget to take care of themselves! Caregivers of people with dementia may be at even greater risk of this because the onset of the disease is so gradual that they do not even notice that bit-by-bit they are giving up more of the activities that help them feel good. They may find themselves giving up their favorite hobbies, get-togethers with their friends, or going to church. It's easy to put aside these activities because you are so busy taking care of someone else. If you give up everything, though, eventually YOUR health will begin to suffer. The person you care for depends on you, but you won't be able to provide him with care if you have exhausted all of your own physical and emotional resources. Have you noticed that you have given up things that used to make life more pleasant? What types of things are you still doing to help take care of yourself? The facilitator elicits responses and discussion.

One form of self-care is taking care of your physical health. We often hear about caregivers who have neglected their own doctor's appointments or medication refills in order to provide care for their loved one. Do any of you fall into this category? What do you do to take care of yourself physically? The facilitator encourages participants to go to the doctor, take medications as prescribed, eat well, get enough sleep (this may be difficult if the patient is up at night), and keep physically safe. The group can use problem-solving strategies if this has been problematic for any of the caregivers.

Another difficult area of self-care for caregivers can be maintaining their own emotional health. Care giving is a stressful undertaking and it can wear away on one's nerves. Caregivers can also become depressed. If the depression is serious, that is, it

interferes with sleep, eating, is limiting your activity, or is causing the person to think about suicide, the caregiver should seek medical help from their doctor as soon as possible. Medications for depression can be helpful. (The facilitator should be prepared to answer questions about when a caregiver might need medication for depression and would that medication cause drowsiness, etc. Caregivers are often concerned that the treatment of depression would limit their ability to provide care or to be alert to supervise the patient with dementia. It should be emphasized if this type of question comes up that there are many options for treatment of depression and with perseverance and a good working relationship with a medical or psychiatric provider, the right one and the right dose can be found.)

Fortunately, although caregiving is difficult at times, most caregivers do not become that seriously depressed. Many of you have already found ways to help yourself cope. What do you do to help yourself stay emotionally healthy? The facilitator leads a discussion and ways to keep one's emotional health. The following may come up. Supportive programs are discussed in the next section. The facilitator can also add to the list generated by the group as appropriate.

- Supportive friends/family
- VA staff/activities/classes/ support groups
- Church/clubs
- Alzheimer's Association or other community groups
- Respite or day programs
- In-home help
- Long-term planning for care (NH, legal, & medical)
- Relaxing/enjoyable activities (elicit)
- Information that reduces anxiety
- Counseling/ medication if appropriate
- Do not isolate yourself
- Time out – time away from dementia

C. Community and Other Resources: Now we will talk about people and programs that can help support your caregiving efforts. Fortunately, most of us have people or groups that can be helpful to us as caregivers too. These people might be someone who will lend a hand, watch your husband while you go out, or just someone that you know you can talk to when you are feeling down. Worksheet 7.2 (*Participant Guide pg. 34*) is a page that you can use to remind yourself of those people.

Let's take a minute now to list those resources and their phone numbers if you know them. If you don't have the phone number handy right now, leave that space blank until after our group session. The facilitator provides time for caregiver to list their "external resources." Examples include: trusted individuals (family or friends), community groups, Alzheimer's Association groups or help lines, VA groups or individuals (such as the local Dementia Care Manager), church groups, etc. The facilitator will need to compile his or her list and appropriate phone numbers prior to the group session so that he or she has the information ready. When the group is ready the facilitator continues as follows: Now let's share our lists. You may have included a resource that others could benefit from hearing about. The group discusses their lists and the facilitator supplies any needed information.

Some of you mentioned agencies or programs that can help. These types of programs include:

- Daycare: In this program the person with dementia goes to a center where he can participate in appropriate activities and socialize. Some programs offer their own transportation. At others, the caregiver must drive the patient to the program. These types of programs can benefit both the patient, by helping him keep active, and the caregiver, by helping her get some “time off” from caregiving.
- Respite: In this type of program, the patient stays in a nursing home for a week or longer. This allows the caregiver to rest while the person is being safely cared for. Respite may be needed to give a break to the caregiver, allow her to travel for a special event like a wedding, or if there is an emergency such as the caregiver needs surgery and there are no other family members to care for the patient. The VA can often help provide respite in its nursing home units, but you may need to plan ahead in order to reserve a space. You may be able to pay for a short-term stay in a community nursing home if needed.
- In-Home Respite: This is a relatively new program being started in some areas. In this type of program, two volunteers visit your home and stay with the patient while you go out for an hour or two. Usually, this arrangement is set up on a regular basis such as every two weeks. Many people find that they can arrange something like this on their own. Sometimes a friend or family member will be willing to come and visit on a regular basis. Some churches will also provide this kind of help. You may be able to hire someone who will visit for a few hours.
- Home Health Aides: The VA will provide a limited number of Home Health Aide (HHA) time for patients who are physically unable to bathe themselves. You may have to wait for a place in the program or even if you are approved, you may need to wait until an aide can be found who can come to your home. (Many aides are dependent on bus service and so it is harder for the agencies to staff homes in suburban and rural areas.)

Many of you may have had experience with programs designed to help caregivers keep going such as respite programs or day care programs. It might be helpful for those who have used those types of programs to share some of their experiences. For example, often people are concerned that the person with dementia will refuse to go to a daycare program. We have found that we can often help the patient and family adjust to day care. When the person is not comfortable in day care, often we only need to wait a few more months. The same person may be much more amenable to day care when we try again at another time. Most programs would be willing to do this for the family.

GROUP EXERCISE: Have caregivers talk about their experiences with respite or day care in their communities. Group facilitators should be prepared with referral information that can be provided to each person based on her community. Facilitators will need to be aware of resources available in each community.

III. Check-in on Individual Action Plans: 10 minutes

The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). The facilitator will also check-in with the group as a whole regarding homework assignments.

Examples:

- **Education:** Did you all read the worksheets for Session 6?
- **Problem Solving:** Mrs. Smith, last week you planned to try turning off the TV while you helped your husband dress. How did that go? Mrs. Jones, you were going to work on keeping your voice calm when your husband started to get agitated. Did you see a difference?
- **Care of Self:** Mrs. White, you were going to go out to lunch with your daughter. Did you go? Did you enjoy yourself?

IV. Problem Solving and Further Action Plan Development: 25 minutes

The facilitator will focus on 1-2 participants' concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participant(s) concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources.

V. Wrap-up-5 min

A. If there is still time, ask for any other questions. End group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.

B. Homework Assignment:

1. This week, do at least one thing to take care of YOU! Take a minute and write down the thing you will do on your weekly worksheet. The facilitator should emphasize making a commitment to do this one thing. It may be possible to encourage specific behaviors after having had the group discussion. (Example: Mrs. Jones, you mentioned that you really miss going to church. Could you find a way to go to church this week? Maybe your son could come and stay with Mr. Jones?)
2. If possible, consider making a visit to a day care or other community agency that would be a support for you.
3. Try practicing relaxation once this week and see if it helps your stress level.

C. Action Plans: Remind participants to write down and work on their individual action plans. Caregivers might want to apply their action plan to doing an enjoyable activity. They can write this down on weekly worksheet 7.3 (*Participant Guide pg. 35*).

TEP Group Session 8: Caregiver Coping Strategies Part II

I. Review of Prior Week's Session - 5 min.

The facilitator briefly reviews the last week's topic and homework assignments

II. Education - 10 min.

A. Internal Cognitive Behavioral Coping Strategies – Triggers, Perspective-Taking, cognitive habits and cognitive restructuring, and taking control of the situation. Members can follow along by turning to Worksheet 8.1 (*Participant Guide pg. 36*) "Coping with Stressful Situations" in their workbook.

We all have different ways that we cope with stressful situations. Sometimes these coping strategies are effective, and sometimes they are not so effective. When coping strategies are not effective it is usually because we do not perceive "triggers" or things that "push our buttons" and instead act automatically and respond out of frustration, anger or some other negative emotion.

For example, suppose that your loved one has a doctor's appointment at 9:00 a.m. You told your loved one the night before and he could not stop asking you questions about the appointment. ("When are we going, why are we going there again?") In fact, he got up about 2 a.m. and got dressed thinking it was time to go. Around 4 a.m. you finally convinced him it was too soon and got him back to bed. Due to lack of sleep, you got up later than you had planned and found your loved one was also difficult to get moving. In fact, he initially refused to get out of bed at all. As the morning hours sped by, you tried your best to keep your loved one moving but every time you left the room to do something, when you returned, he was putting on the wrong piece of clothing or hunting through drawers for something he didn't need. You are becoming more and more stressed as the time to leave approaches. Your loved one is finally ready and sits down calmly at the table to wait for breakfast, but you need him to get in the car. Feeling somewhat angry, you explain that it is time to leave to go to the doctor's appointment and that you have a muffin to eat in the car. He answers by stating that he wants eggs and bacon and doesn't know what you are talking about. He doesn't have any doctor's appointment today. Feeling totally frustrated and angry about his demands, you snap and yell at him. Then you feel even worse for taking out your frustrations on him and storm off to the bathroom in tears. In this hypothetical situation, your automatic response of raising your voice in anger leads to ineffective coping strategies and additional stress and tension.

There are several steps that you can take to improve the way you cope with stressful situations.

- Be more aware of your bodily reactions to stress triggers. When you feel yourself becoming distressed you can do something about it – but when you are not aware of what is triggering your distress you react without thinking. Therefore, make a point of thinking about the most common triggers for your stress and be prepared to change the way you react when these occur. Sometimes simple awareness is all that is necessary to keep you in control.

- Use stress reduction strategies such as deep breathing to calm yourself down. When you perceive stress triggers take a moment out to take some deep breaths before proceeding. Pay attention to your inner dialogue. We all talk to ourselves. Some things that we say to ourselves can increase our stress, while other things we say to ourselves reduce our stress. For example, are you saying things to yourself like, “Why does he do this to me?” or “He does this on purpose to make me mad.”
- Change your inner dialogue. Think of things that you can say to yourself that give you a new, more positive perspective on the situation. For example, you might say to yourself “it’s not him, it’s the disease” or “he is not doing this on purpose.”
- Take his perspective. Consider aspects of the situation that might have caused his reaction that, in turn, heightened your stress. For example could you have approached your spouse too abruptly? Could he be confused or unable to go as quickly as you would like? Could he be uncomfortable or in pain? By taking his perspective you might be better able to understand his reaction, and de-escalate the situation.
- Change the situation. For example, sometimes when people with dementia are physically uncomfortable they pace constantly. They might be in pain, too hot or too cold, or need to go to the bathroom, but they can no longer figure that out or tell you why they are uncomfortable. If you can figure out what might be bothering them, you can change the situation. Are you feeling cool? Maybe you can help him put on a sweater. Has it been a while since he went to the bathroom? You can take him to the bathroom to help cue him to use the facilities. Is there something else about the situation you can change that might make him more comfortable?
- Remove yourself from the situation. If you can’t think of anything right at the moment, try removing yourself temporarily from the situation until you can calm down and approach the situation with a new perspective. For example, you can say you will be right back and go into another room. You could go to the bathroom. You might be able to take a walk within your home or outside.

All of these steps are meant to help you take better control of yourself during stressful situations. Start by recognizing stress triggers. Then interrupt automatic “hot” responses (like raising your voice or snapping at the patient) by using relaxation strategies such as deep breathing, by changing your inner dialogue from negative self-talk to positive self-talk, and by deliberately trying to remain calm and positive. Next “reappraise” the situation by taking his perspective and by viewing his reaction as disease related. Think about how you might approach the situation differently. If this does not work, remove yourself from the situation until you can calm down and re-approach the situation.

Group Exercise: Write down something that your spouse does that triggers stress for you (Worksheet 8.2, *Participant Guide pg. 38*). Now write down one thing that you say to yourself that increases your stress and one thing that you might say to yourself to decrease it. Examples might be (1) thoughts that blame the patient, not the disease, (2) thoughts that assume the patient is intentionally trying to aggravate the caregiver, or (3) thoughts of hopelessness or helplessness. Also, write down one way that you could change or interrupt the situation to gain better control of your stress. Let’s go around and discuss your answers.

B. Relaxation Follow-up: Hopefully you've had some time to practice relaxation in the past few weeks. How has that been going? Remember, even if you can only do a brief deep-breathing exercise, every little bit helps. Worksheet 8.3 (*Participant Guide pg. 39*) gives some ideas about how to maximize your benefit from relaxation exercises. The facilitator reviews Worksheet 8.3. There are lots of tapes and CDs on the market that have music and exercises like the ones we have tried during group. You might want to pick one up as a present to yourself someday soon. You can often find items like that at the library too so that you can try one out before deciding to buy it.

III. Check-in on Individual Action Plans- 15 min.

The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). The facilitator will also check-in with the group as a whole regarding homework assignments.

Examples:

- I. Education: Did you all read the worksheets from the previous sessions?
- II. Problem Solving: Mrs. Smith, last week you planned to try turning off the TV while you helped your husband dress. How did that go? Mrs. Jones, you were going to work on keeping your voice calm when your husband started to get agitated. Did you see a difference?
- III. Care of Self: Mrs. White, you were going to go out to lunch with your daughter. Did you go? Did you enjoy yourself?

IV. Problem Solving and Further Action Plan Development - 10 min.

The facilitator will focus on 1 participant's concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participants. The facilitator will point out similarities between participants' concerns/problems and encourage others to make similar action plans as appropriate. Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources.

V. Wrap-up- 5 min.

- A. If there is still time, ask for any other questions. End group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.
- B. **Homework Assignment:** Practice using new self-talk and perspective taking skills.
- C. **Action Plans:** Remind participants to write down and work on their individual action plans using weekly Worksheet 8.4 (*Participant Guide pg. 40*).

TEP Group Session 9: Planning for the Future—Part I

I. Review of Prior Week's Session- 5 min.

The facilitator briefly reviews the last week's topic and "homework assignment"

II. Education- 15 min.

During this session and the next, we will be talking about planning for the future and tapping into resources that can help you to keep your loved one at home as long as possible. First we will talk about some steps that every caregiver should take to help them care for the person with dementia. You can follow along in your workbook by looking at Worksheet 9.1 "Planning Ahead" (*Participant Guide pg. 41*).

Health Care Proxy and Advanced Directives

It's a good idea for all of us to discuss our health care wishes with those that may someday have to make a decision for us. For example, if you could not speak for yourself, would you want tube feeding, would you want to be kept alive on a machine that breathes for you? When a person is diagnosed with dementia, having taken care of these plans in advance becomes more important because we know there will come a time when he cannot make his own decisions. For some of your loved ones, that time may have already arrived. Others may still be able to participate in medical decision-making.

In the healthcare system, we try to encourage everyone to appoint a Health Care Proxy. The proxy is the person who will make medical decisions for you if you are unable. This only goes into effect when the patient is not capable of making his or her own decision. Often, the person will appoint their spouse, but it is a good idea to have a backup as well. For example, what if the spouse were to die before the patient with dementia? If the patient were in later stages of the disease, he would not be able to appoint a new proxy. Many people chose to appoint a son or daughter as well. This may be particularly important for you if you have some children who have differing opinions.

Some people chose to make specific statements about their wishes for future medical decisions. These statements are called "Advanced Directives" because they tell your healthcare providers ahead of time what you want them to do. For example, people often feel that they do not want to be kept alive by "heroic means" such as ventilators (machines that breathe for you) or by tube feeding (inserting a tube down your nose or directly into your stomach to provide liquid nourishment when you can no longer eat). Others may feel strongly that they want to be fed, no matter what. It is important for you to talk to your healthcare provider and family about these wishes.

Knowing that they have dementia or other chronic illnesses, some people do not want their heart to be resuscitated if it stops. They might feel that when it is "their time to go" that doctors or emergency medical professionals should not interfere. This type of Advanced Directive is called a Do Not Resuscitate Order or DNR order. It means that if a person's heart stops, the doctors and nurses will not do CPR to try to revive them.

It's important to know that making a statement that limits treatment, like DNR or tube feeding, does not mean that you will not be cared for. Your health care providers will continue to do everything possible to provide the right care including keeping you comfortable.

We have included New York State Health Care Proxy and Advanced Directive forms in your workbook. See Worksheets 9.2 and 9.3 (*Participant Guide* pgs. 42 & 43) in your workbook. Let's take a minute to look at these forms and discuss this topic. Do any of you have Healthcare Proxy forms for your loved ones already? Do you have them for yourselves? Do you have questions about the things I've been talking about?

GROUP EXERCISE: The group facilitator checks in with the participants regarding these forms. The facilitator should have checked each participant's record prior to the start of this session to see if there are Advanced Directives in place. Time should be allowed to answer questions, but there may be too many questions to answer during the call. The facilitator may need to direct questions to the appropriate medical providers, dementia care managers, primary team members, or schedule an individual call to cover the questions. The forms provided cannot be completed entirely during the group session, as witnesses are needed. (Facilitators from outside New York should replace the New York State forms with forms from their own state.) Participants should be very strongly encouraged to discuss these topics with their healthcare providers directly so that their PCPs are aware of their wishes.

Power of Attorney – You can follow along by looking at worksheet 9.4 (*Participant Guide* pg. 45) “More Steps to Help You Prepare”

Sometimes people confuse the Health Care Proxy and the Power of Attorney. A Power of Attorney (POA) is for financial and legal matters and does not automatically give you the authority to make health care decisions for a person. The POA form allows you to follow the person's direction and do things like withdraw money from his banking account or sign a paper for him. The POA can be used, for example, if you are in the hospital and you need your son or daughter to do banking for you before you are discharged. It can be very helpful for a caregiver to have a POA as it can help you to more easily take care of accounts or legal items for your husband. You can arrange a POA through your bank, but this would be limited to financial transactions.

You can also have what is called a “Durable Power of Attorney” that covers all types of financial and legal transactions. You can arrange a Durable POA through an attorney. You can also purchase a Durable POA form at office stores (such as Office Max or other similar stores). You do not have to have an attorney to fill out that form but you must get it notarized. **Any POA can be revoked at any point in time if the person who signed it changes his or her mind.**

Understanding Financial Issues

Another thing you can do to plan for the future is to have accurate information about the financial implications of care, whether this means care at home or in an institutional setting. You can get information about current New York State Medicaid limits for income and assets on the internet, from your local State legislators or you county Office for Aging. This information will help you decide if you would benefit from talking to an attorney about your rights under Medicaid law

If you decide to consult with an attorney, it is a good idea to have a consultation with one who is familiar with Medicaid Law, "Elder Law." There may be some decisions that need to be made about your finances or ownership of property that should be thought out ahead of time. For example, if you loved one needs to go to a nursing home at some point in the future, you may need to use Medicaid to help pay for the cost of nursing home care. Medicaid will require documentation of your financial assets. A consultation with an attorney can help you best protect your assets in the future.

GROUP EXERCISE: The facilitator encourages questions and discussion about legal issues. Has anyone consulted an attorney? How did that go?

Crisis Management – You can follow along by looking at Worksheet 9.5 (*Participant Guide pg. 46*) in your workbook.

There may come a time in your role as caregiver when you feel that things are out of control. Hopefully, your participation in this group will help you manage things so that that time never comes, but just in case, it's very helpful to be prepared ahead of time. Many of us have experienced some type of emergency in our lives and you may have noticed that in a crisis it can be hard to think straight. If we have thought out what our "emergency plan" is ahead of time, we won't need to rely so much on our wits in a crisis.

You may be wondering what I mean by the word crisis. For example, if the person you are caring for has been very agitated in the past, you may already know the feeling. Perhaps the person is so upset that they are threatening verbally, or striking out. You know that you have reached that point when you do not feel physically safe or when you feel your loved one is in danger of harming himself, but because of his emotional state, you are unable to stop him. That can be a very frightening situation.

The facilitator can either prompt the group by asking if someone has experienced a situation like that, or, it is possible that a situation has been mentioned during the earlier weeks where the patient's behavior was so far out of control that the situation was dangerous. Or the facilitator can use the following scenario. For example, one caregiver described a situation where her husband was becoming increasingly threatening toward her. He was no longer able to speak much, but each time she tried to interact with him, he made an angry face and would shake his fist at her. (It may be that he was not recognizing her or could not understand what she was trying to do.) At one point, he put his hands around her neck and she was afraid that he would choke her. You can imagine how frightening that would be. Fortunately, these situations do not happen with everyone, and as I said, after being in this group, you have lots of good ideas about how to avoid problems or help calm your husband down if he gets upset. Let's talk about what you might do in this type of situation. The facilitator leads a discussion about things to do in a crisis situation. The facilitator helps the group to develop a list of options to include all the following points:

- Leave the house-Caregivers may feel duty bound to stay with the person with dementia. While supervision is certainly important, if the caregiver is in danger she should always make sure that she maintains her own safety first. The facilitator can use the analogy of oxygen masks on airplanes. The flight steward always instructs passengers to put on their own mask before helping someone else. If a passenger doesn't do so, they would pass out and be unable to help the

child in the seat next to them. The facilitator should impress upon the caregivers that they should leave the situation if they feel they are in danger. They might go to their bedroom or bathroom and shut the door, or they might need to step out of the house for a few minutes until the situation has calmed down again. While they do that, it's a good idea to call someone for help. They can refer to their list of helpful people for ideas and numbers.

- Call 911
- Call Crisis Services (or similar agency)
- Dementia care staff from VA
- Supportive family
- Alzheimer's Association
- The facilitator will be sure that all group members have the phone numbers of the agencies discussed.

Now you can fill in the Worksheet 9.6 “Emergency Numbers” (*Participant Guide pg. 47*) in your workbook with telephone numbers that you may need to call in an urgent situation. For example, you might call 911, your son or daughter, a mobile crisis team if there is one in your area, your Primary Care doctor or other medical providers that are involved in your loved one’s care, the emergency room number at the local hospital, and the local Poison Control number. Two weeks ago during session 7 you made a list of people or agencies you can call when you need some help. Take a look at that list now. (It’s Worksheet 7.2(*Participant Guide pg. 34*)). Are there any numbers you need to add to today’s list from the list you made in session 7? Where should you keep today’s list, by a phone where you can find it easily if you need it? Or, would you want to keep the list in your purse so it is handy if you are out and about?

III. Check-in on Individual Action Plans - 10 min.

The facilitator will check-in briefly with each participant regarding any action plans she had developed in earlier sessions (as appropriate). The facilitator will also check-in with the group as a whole regarding homework assignments.

Examples:

- Education: Have you read the worksheets for session 8?
- Problem Solving: Mrs. Smith, last week you planned to try turning off the TV while you helped your husband dress. How did that go? Mrs. Jones, you were going to work on keeping your voice calm when your husband started to get agitated. Did you see a difference?
- Care of Self: Mrs. White, you were going to go out to lunch with your daughter. Did you go? Did you enjoy yourself?

IV. Problem Solving and Further Action Plan Development - 25 min

The facilitator will focus on 1-2 participants’ concerns in detail. Using problem-solving strategies and multiple references to information that has been presented in prior sessions, the facilitator will lead the group in problem solving and developing an action plan for the participant(s). The facilitator will point out similarities between participants’ concerns/problems and encourage others to make similar action plans as appropriate.

Action plans will focus on behavior management, communication strategies, emotion-focused coping, and problem solving regarding access to needed care or resources.

V. Wrap-up-5 min

A. If there is still time, the facilitator asks for any other questions. End group by encouraging preparedness for next week. Caregivers may want to jot down questions that they think of during the week, etc.

B. Homework Assignment:

1. Fill out the Health Care Proxy forms for yourself and your loved one.

2. Fill in your emergency numbers on Worksheet 9.6 (*Participant Guide pg. 47*) if you haven't already finished this and put it somewhere that it will be easily found when you need it.

C. Action Plans: Remind participants to write down and work on their individual action plans using worksheet 9.7 (*Participant Guide pg. 48*).

TEP Group Session 10: Planning for the Future Part II, Review and Self Evaluation

I. Review of Prior Week's Session - 5 min

The facilitator briefly reviews the last week's topic and "homework assignment".

II. Education: 15 min

Today, in our last session, we will finish our discussion of long range planning and thinking ahead to the future. Then we will quickly review the things we have covered over the ten weeks. We'll end by focusing on our strengths and accomplishments over the past 10 weeks.

Long Term Plans: You can follow along in your workbook by looking at Worksheet 10.1 "Long Term Plans" (Participant Guide pg. 49)

One of the hardest decisions that caregivers make is the decision to place their loved one in a long-term care facility. Many people have the goal of keeping the person with dementia at home throughout the course of the disease. The VA tries to support this goal by offering as much support as they can to caregivers of veterans with dementia. Unfortunately, there may come a time when the person with dementia can no longer stay in his own home. That time may be different for different caregivers. Some patients with dementia are easier to handle than others. Some caregivers have more resources, such as many children living near by who can help out. Whatever the situation, it's a good idea to give some thought to what would cause you to consider placement before you come to a crisis situation.

Some of the challenges that make it impossible for caregivers to manage may be:

- Changing Sleep Cycles: If the person with dementia is up all night long and the caregiver is getting no sleep, she may not be able to manage the patient. Your doctors can try some medications to assist the patient to sleep, and daytime activity may help, but sometimes the patient's sleep cycle is so disrupted (probably due to damage to that area of the brain) that nothing can be done to help and the patient needs to be placed in a protected environment where there are nighttime staff available.
- Incontinence: When the patient's disease progresses to the point where he or she is no longer able to cooperate with bathroom routines diapers can be used. But there are situations where the sheer volume of laundry produced and care needed to clean the patient is more than one person can take on.
- Behavioral Symptoms: In most cases, we are able to either manage symptoms by changing our own reactions, by avoiding stressful situations for the patient, or, if needed, with medications. Unfortunately, there are times, such as in cases of severe wandering where the patient puts himself in danger, or more violent behaviors, when the patient needs the safety of a structured environment or round the clock supervision.
- Caregiver Illness: Most caregiver spouses have their own health problems. Sometimes, these health problems limit their ability to care for their loved ones.

Fortunately, these severe situations are fairly infrequent and many caregivers are able to keep the patient at home long into the illness, or even until death. However, the wear and tear of caregiving, even in less stressful situations, adds up over the years and many caregivers find that the patient needs more help than one person can provide. It's helpful to think ahead of time about what some of your own personal limitations might be. In that way you can use the skills and information that you have learned in this group to be better prepared and can keep your husband at home longer.

We also encourage families to visit nursing homes in your area so that you can see first hand what they look like and what you feel comfortable with. Because there is often a long waiting list, you may want to begin the application process when you begin to feel like you may no longer be able to provide enough care on your own. By visiting nursing homes, you can get a sense of the application process and the waiting times. Being familiar with the process and which people can be most helpful can help you feel less worried. And the less worried you feel, the better able you will be to keep on caregiving!

GROUP EXERCISE: The facilitator encourages the participants to discuss their thoughts and feelings about long term planning. For example: Since last week we have been talking about long term planning and being prepared for the future. Let's take some time now and talk about that. Do you feel ready to meet the challenges of caregiving? Do you know where to access resources when you need them? The facilitator encourages the group to talk about ways they are prepared as well as resources of which they are in need.

Personal Strengths and Accomplishments

I'm going to change topics now as we sum up the progress we've made and the topics we've discussed over the past 10 weeks.

All of us have strengths and weaknesses. An inner strength for one person might be her patience in the face of a situation that would make others frustrated or angry. For another, it might be her sense of humor. Another person might have a very strong faith that helps her get through the rough times in life. Unfortunately, we often focus more on our weaknesses than our strengths. We tend to say, if only I could be less irritable, weigh 10 lbs less, or had fewer bad habits. When we focus only on our weaknesses, we can forget about our positive qualities and feel worse about ourselves. Feeling bad only makes us more likely to focus more on the down side of things, whether it's our situations or ourselves. So today, we're going to spend some time focusing on our strengths and appreciating the parts of ourselves that help keep us going. Turn to Worksheet 10.2 (*Participant Guide pg. 50*) in your workbook. Take a moment to list your inner strengths and assets that help you to keep going in your role as a caregiver. The facilitator gives the group members a few minutes to jot down their internal strengths. When the group is ready, the facilitator continues.

If you feel comfortable, let's go around and talk about what we've listed in the workbook. As each person reads her list, all of us should think about the strengths we have noticed in each other. For example, you may have noticed that one of the group members is very patient, or caring, or has a very positive outlook on life that you have admired. Now would be a good time to share that with her. Mrs. Smith, what did you put on your list of Inner Strengths? The facilitator encourages members to share their lists, members to share strengths they see in others and offers additions. Examples include: sense of humor,

faith, optimism, perspective, intelligence, compassion, persistence, patience, love, and any other positive quality.

TEP Program Summation

Now let's all think about the 10 weeks that this group has been meeting. I'm going to review the things we've talked about. As I do, I'd like you to be thinking about the things you learned and the positive changes you have made over that time. On Worksheet 10.2 of the workbook there is space to jot down your thoughts about the things you have accomplished and the things you want to keep working on now that the group is over.

In **session one**, we learned about how dementia affects your spouse, and what causes dementia. We also focused on how we would develop action plans and engage in problem solving as a group to address the pressing problems you face as caregivers during each session, to help you cope more effectively, and to help you take good care of yourself.

In **session two**, we focused on the different stages of dementia, and how each stage affects your spouse's functioning. Together, we identified what stage of dementia your spouse was currently experiencing. We also began to develop action plans to resolve problems and to help you take better care of yourself.

Session three was the first of two sessions focused on behavior management strategies. We learned about the progressively lowered stress threshold model, which explains why persons with dementia are less able to withstand normal everyday stressors. We then began to learn how to be a behavior detective by observing problem behavior situations to examine the antecedents of the behavior, the behavior itself, and the consequences that follow the behavior. We stressed the importance of really examining the situation, to see what might be causing or sustaining the behavior, and writing down what you find out.

In the **fourth session** we continued to focus on behavior management strategies, continuing to focus on being a behavioral detective, and developing plans to manage problem behaviors using contingency management and other strategies. We also began to focus on the link between communication and agitation, and took time to continue to focus on our individual action plans.

Session five was devoted to communication strategies. At first, we focused on changes in ability to communicate and interact resulting from progressive dementia. We also focused on the communication strengths that remain for your spouse, and simple things that you can be aware of such as sensory deficits, environmental distractions, and so forth that might make it difficult for your spouse to communicate.

In **session six** we continued to focus on communication. We focused on general strategies and tips that you could use to sustain and improve communication with your spouse, strategies that could be used in all stages of dementia. Do you remember some of these strategies? Then, we also talked about some strategies that might be particularly useful for persons with mild, moderate, and severe dementia.

As usual we continued to talk about our individual action plans and engaged in problem solving to resolve difficult caregiving issues.

In **session seven** we focused on you! We talked about the reasons why it was important for you to take time for yourself, to take good care of yourself. We talked about such self-care topics as making sure you are taking good care of your physical health, and what you might do to maintain your emotional health. As you recall, we had you make a list of inner and outer resources that you could use to help you take care of yourself while continuing to

provide care for your spouse. We continued to check in about individual action plans and to problem solve difficult issues.

During **session eight** we continued to focus on helping you to cope with caregiving. We talked about stress triggers, and what you could do to take control of the situation. In addition to using deep breathing and other ways to relax, such as taking a walk or getting away from the situation for a bit, we talked about taking perspective, and how you might change what you say to yourself when you find yourself in a particularly stressful situation. We also talked about being aware of the environment, and seeing if we could identify needs and making yourself and your spouse more comfortable by meeting these needs.

The **ninth session** and today's session focused on the resources that you might use to help you with caregiving, and also planning for the future. We talked about community resources and services as well as drawing on informal supports such as family members or friends. We talked about resources to help you manage crisis situations that you might encounter in the future, and how to try and avoid crises by careful planning for future needs.

So, looking back, what have you accomplished? What do you still want to work on? The facilitator leads a discussion of accomplishments. The facilitator should be prepared to mention to the participants their individual accomplishments that the facilitator has observed. The accomplishments can be behavioral, such as learning how to keep a calmer voice, or they may be related to problem-solving activities, such as finding someone to sit with the patient so that the caregiver can attend a favorite activity. The goal of this discussion is to end the group on a very positive note by praising each caregiver for something and to get other participants to add to each person's accomplishments.

III. Check-in on Individual Action Plans - 10 min

Before ending the session, the facilitator checks-in with the participants to see if there are any final questions about individual action plans. The facilitator mentions the list of accomplishments just discussed, and encourages continued use of problem solving and action plan strategies. The facilitator uses the remaining time to lead a discussion on how the caregivers will use what they have learned in the group.

IV. Farewell

The facilitator should sincerely thank all the participants for participating and sharing with the group. The facilitator tells the participants that they will be receiving a graduation certificate in the mail. The group may decide to share phone numbers so that they can continue to interact in the future. If this happens, the facilitator should state clearly that this is completely optional and no member should feel that they have to share a phone number.

Certificate
Of
Completion

Let it be known that

Caregiver Name

Has successfully completed

*The
Telephone Education Program
For
Caregivers of Veterans with Dementia*

On
Date

Awarded by

Laura Wray, Ph.D.