

REACH II INTERVENTION SOCIAL SUPPORT COMPONENT: INTERVENTION ACTIVITIES

Overview

One of the objectives of the REACH II intervention is to provide caregivers with enhanced emotional/social support and support with instrumental activities. With respect to emotional/social support the goal is to help caregivers receive support making decisions, managing caregiving tasks, and handling difficult situations. An additional goal is to reduce problems with social isolation and help caregivers maintain contact with their social network. It is envisioned that the primary source of emotional/social support will be provided by family members, friends, and other caregivers. In terms of instrumental support, the goal is to help caregivers receive the assistance they need with both caregiving and non-caregiving tasks (e.g. shopping, transportation). Support from these activities will come from both informal sources such as family/friends and other caregivers and formal sources such as health care providers and community services/agencies.

The social support component of the intervention will involve the following strategies: 1) information and referral, 2) education and didactic instruction, and 3) provision of support. The primary intervention activities will involve the on-line support groups, the caregiver information network, and active behavioral training (e.g., communication and assertiveness). The strategies and content of the various activities associated with this component of the intervention will be standardized across sites however, the emphasis on particular topics will vary according to the needs of the caregiver. For example, if communicating with family members is identified as a risk/problem, one of the areas of emphasis within the behavioral skills training will be communication skills. Similarly, if a caregiver has problems interacting with the care recipient an area of emphasis within the well-being component of the intervention will be caregiver assertiveness. Use of the Caregiver Information Network will be integrated throughout the intervention sessions. The specific intervention activities associated with this component of the intervention are outlined below.

Intervention Protocol

Sub-goal 1: Enhance Social/Emotional Support

- Help making decisions
- Help handling difficult situations
- Expressing feelings/concerns
- Reducing social isolation

Intervention Strategies

1. Education/Didactic Instruction

The intent is to reinforce strategies/skills training related to social support and communication that are presented in the educational materials and the intervention sessions. This will be accomplished through the education/didactic instruction portion of the “on-line support” groups and the “information/tips” feature of the Caregiver network.

2. Support

Caregivers will be able to interact with other caregivers and express their feelings and concerns during the “free form” portion of the groups.

3. Behavioral Skills Training

If problems with social support are identified on the risk appraisal caregivers will receive active behavioral skills training on communication skills (see Caregiver Skills Component).

Sub-goal 2: Enhance Support for Instrumental Activities

- Managing caregiving tasks
- Help with non-caregiving activities (e.g., shopping, transportation)

Intervention Strategies

1. Information/Referral

Caregivers will be provided enhanced access to community resources through the “resource guide feature” of the Caregiver network. The caregiver resource guide will provide information about various resources, community agencies, and services.

2. Education/Didactic Instruction

The intent is to reinforce strategies/skills training related to social support and communication that are presented in the educational materials and the intervention sessions. This will be accomplished through the education/didactic instruction portion of the on-line support groups and the “information/tips” feature of the Caregiver network.

3. Support

Caregivers will be able to interact with other caregivers and express their feelings and concerns during the “free form” portion of the support groups.

4. Behavioral Skills Training

If problems with accessing resources or help are identified on the risk appraisal caregivers will receive active behavioral training on assertiveness skills (see Sections 8 and 9 of MOP).

Overview of Caregiver Network Features

On-Line Support Groups

The on-line support groups will meet on a monthly basis and will begin in month two (4 – 6 weeks following baseline assessment) of the intervention. The intent is to have each caregiver participate in five group sessions. The groups will be closed and national (across site) and will be in English or Spanish. The group will consist of a professionally trained facilitator and up to six caregivers. The groups will interact using a conference call format and will meet for 60 minutes. The general structure of each meeting will be: 1) an initial 10 minute check-in; 2) a 15 minute educational component that will include a presentation and discussion of specific topics related to social and instrumental support and communication; and 3) a 30- 35 minute support component that will be free form and will consist of a loosely structured, interactional format that encourages CGs to share issues, problems, concerns, and potential solutions. The groups will be formed using a rolling basis and each site will facilitate 12 groups across the intervention period. We anticipate that there will be 3 new groups per month. There will be both English and Spanish speaking groups. The Miami and Palo Alto sites will facilitate the Spanish speaking groups.

The specific topics that will be addressed in the support groups are: 1) taking care of yourself; 2) how to access community resources; 3) how to communicate with health care providers and service agencies; 4) how to communicate with family members/friends; and 5) communicating with your loved one. The content of the educational component will be consistent across groups. The scripts for each sessions are provided in Section 4 of the Reach II Caregiver Network User Manual.

Information/Tips

The caregiver information/tips feature of the Caregiver network will consist of short (~ 15 minute) educational dialogues on various topics such as communication skills, strategies for relaxation and socialization, etc. It will be used to provide information and reinforce the education/skills training activities of the intervention. (See Section 4 of Caregiver Network User Manual for details).

Resource Guide

The resource guide feature of the Caregiver network will provide information on, and easy access to various resources, community agencies, and services. (See Sections 1 and 3 of the Caregiver Network User Manual for details).

Specific Intervention Activities

Intervention Session #1

In the first intervention session, the interventionist will demonstrate and review the features of the Caregiver Network (see caregiver training section of the REACH II Caregiver Network User Manual for detailed training information). In this session, caregivers will also be asked to join an on-line support group. They will be informed about the nature and format of the groups and that group participation is voluntary. However, the importance of the groups will be stressed and they will be encouraged to participate. They will be introduced to the support groups during the initial home session using scripts (see Script - Appendix B-3; Section 4 Caregiver Network User Manual). They will also be asked if they prefer morning or afternoon/evening group meetings and their language preference (English vs. Spanish). Use of the Caregiver network will be integrated in and reinforced throughout the intervention sessions. Caregivers will also be provided with a “user help card” (see Caregiver Network User Manual).

Subsequent Intervention Sessions

There are specific items on the baseline risk appraisal form that identify risk in the area of support. Outlined here are the specific intervention activities related to either the on-line support groups or in-home sessions as linked to items on the risk appraisal baseline form.

Risk Item # 23: Do you have someone (other than CR) you can talk to about important decisions or difficult caregiving situations?

Intervention activities:

Refer to the “Communication” feature on the information/tips feature on the Caregiver network and the menu items specifically related to “family/friends” and “socializing”.

Refer to the “Family Respite” feature of the Caregiver network.

Inform the caregiver that strategies for communicating with family and friends and for enhancing social interactions will be discussed in their support group.

Risk Item # 24: If you were unable to care for CR or yourself, do you have someone who would take over?

Intervention activities:

Refer to the “Legal Issues and Financial Support ” features on the community services feature on the Caregiver network.

Refer to the “Resource Guide” feature of the Caregiver network and the menu items related to the Alzheimer’s Association, Area Agency on Aging and “Community Services”.

Risk Item # 25: Do you have someone, like a family member, friend, or neighbor (other than CR) who can take your places if you needed help?

Intervention activities:

Refer to the “Communication” feature on the information/tips feature on the Caregiver network and the menu item related to “Accessing Resources”.

Refer to the “Resource Guide” feature of the Caregiver network and the menu item related to “Other Services”.

Inform the caregiver that strategies to help them communicate with family and friends and how to access community resources will be discussed in their support groups.

Risk Item # 26: *Is it hard for you to find services like adult day care, sitters, or respite care?*

Intervention activities:

Refer to the “Communication” feature on the information/tips feature on the Caregiver network and the menu item related to “Accessing Resources”.

Refer to the “Resource Guide” feature of the Caregiver network and the menu items related to the Alzheimer’s Association, Area Agency on Aging, and “Community Services”.

Inform the caregiver that strategies to help them access community resources and communicate with health care professionals and service agencies will be discussed in their support groups.

Risk Item # 27: *Is it hard for you to find a friend or family who can stay with CR to give you a break from caregiving?*

Intervention activities:

Refer to the “Communication” and “Healthy Lifestyle” items on the information/tips feature of the Caregiver network and the menu items related to “Accessing Resources” and “Relaxation”.

Refer to the “Resource Guide” feature of the Caregiver network and the menu items related to the Alzheimer’s Association, Area Agency on Aging, and “Community Services” (respite care).
Refer to the “ Family Respite” Feature of the Caregiver network.

Inform the caregiver that strategies to help them access community resources and communicate with family and friends and the importance of taking care of themselves will be discussed in their support groups.

Risk Item # 28: *Do you have someone to comfort, listen to your feelings, or express concern for you?*

Intervention activities:

Refer to the “Communication” and “Healthy Living” items on the information/tips feature of the Caregiver network and the menu items related to “Accessing Resources” and “Pleasant Events” and “Socializing”.

Refer to the “Resource Guide” feature of the Caregiver network and the menu items related to the Alzheimer’s Association, Area Agency on Aging, and “Community Services” (support groups).

Reinforce the importance of participating in the on-line support groups.

Inform the caregiver that strategies to help them communicate with family and friends and the importance of taking care of themselves will be discussed in their support groups.

Risk Item # 29: Do you feel isolated from your family/friends?

Intervention activities:

Refer to the “Communication” and “Healthy Living ” items on the information/tips feature of the Caregiver network and the menu items related to “Pleasant Events” and “Socializing”.

Reinforce the importance of participating in the on-line support groups.

Inform the caregiver that strategies to help communicate with family and friends and for enhancing social interactions will be discussed in their support groups.

Problem Solving Approach for Specific Support Items

If problems with communication or accessing resources are identified on the risk appraisal and negotiated with the caregiver as a target area, the caregiver will receive active behavioral training on strategies (see Section 8 of MOP).

Detailed Description of “On-Line” Support Groups

The on-line discussion groups will meet on a monthly basis and will begin in month two (4 – 6 weeks following baseline assessment). The intent is to have each caregiver participate in five group sessions. The groups will be closed and national (across site) and will be in English or Spanish. The group will consist of a facilitator and up to six caregivers. The groups will interact using a conference call format and will meet for 60 minutes. The general structure of each meeting will be: 1) an initial 10 minute check-in; 2) a 15 minute educational component that will include a presentation and discussion of specific topics related to social and instrumental support and communication; and 3) a 30- 35 minute support component that will be free form and will consist of a loosely structured, interactional format that encourages CGs to share issues, problems, concerns, and potential solutions. There will be both English and Spanish speaking groups.

The specific topics that will be addressed in the support groups are: 1) taking care of yourself; 2) how to access community resources; 3) how to communicate with health care providers and service agencies; 4) how to communicate with family members/friends; and 5) communicating with your loved. The content of the educational component will be consistent across groups. The scripts for each of sessions are provided in the Appendix.

A member of the Miami team will coordinate the enrollment and scheduling of the support groups. The interventionist will introduce the support groups during the initial home session (see script for Support group introduction) and obtain information from the caregiver on language preference and meeting time preference (morning vs. evening). They will transmit this information to the group coordinator using the support group preference form (Section 5 - Caregiver Network User Manual). The coordinator will form and schedule the groups on a rolling- as needed basis and the optimal group size will be 5 caregivers (range 4-6). However, if a caregiver is enrolled and there is no group available within 6 weeks of their initial home visit a smaller group may be formed. On the basis of recruitment projections we anticipate adding 3 new groups per month (2 English and 1 Spanish) with an average number of 15 groups active simultaneously. Each site will be responsible for running 12 groups across the intervention period (see attached schedule). There will be a total of 60 groups across the intervention period. The Miami site will assume responsibility for the first three groups and the Spanish groups will be distributed across the Miami and Palo Alto sites.

The facilitator will initiate the call using the support group menu option of the interventionist component of the Caregiver network. They will be provided with information on the name and location of the group members. The name of the group members will also appear on the menus. Caregivers will receive a reminder from the system the day prior to the call and be asked to contact the group facilitator if they will be unavailable to participate in the group or will be at a different telephone number. The facilitator will be asked to complete a support group log (Section 5 – Caregiver Network User Manual) for each session. The log includes information on attendees, time and length of the call, and general content of the interaction. They will also keep a record of reasons for nonattendance among group members. As described below the facilitator will be trained and certified in: 1) the use of the system; 2) conducting telephone support groups; 3) dementia and caregiving; and 4) the education/intervention materials.

Facilitator Training

The facilitator will have at least a bachelor’s degree in psychology, counseling or a related discipline. They will be trained and certified in the: 1) the use of the system; 2) conducting telephone support groups; 3) dementia and caregiving; and 4) the education/intervention materials. They will learn about dementia and the difficulties encountered by caregivers of persons with dementia, and resources that can assist caregivers in managing the care recipient in the home and performing non-caregiving tasks (e.g., transportation). They will also receive training in conducting effective support groups, establishing group rules, and maintaining session notes/completion of the support group contact form. Training materials will be adapted from the materials currently being used by the Miami site for the Telecare project. Training will include guidelines that address potential problems with telephone

interactions such as decreased cues, technical difficulties, and group process issues. They will also be trained in the use of the intervention materials. Specific certification criteria are outlined in Section 4 of the REACH II Caregiver Network User Manual. They include reading of background and REACH II Intervention materials, review of the REACH II Intervention Training Packet; participation in 2 audio group training sessions with the Miami site; and attendance at least 2 community support groups.

Monitoring Plan for Support Group Facilitators

A total of four sessions will be monitored for each facilitator including: the initial, third, and fifth sessions from the facilitator's first support group and the second session from the facilitator's fourth group. These sessions were chosen as they will provide us with an opportunity to evaluate the facilitator's understanding and presentation of the support group protocol (session 1); the facilitator's ability to actually "conduct" a support group and their knowledge/presentation of educational materials (sessions 1, 2, 3, and 5); the facilitator's skills in terms of terminating/ending the formal group (session 5); and "drift" from the protocol (session 2 – 4th group). The monitoring will take place by M. Rubert, a member of the Support Group Intervention workgroup (L. Nichols, S. Czaja, D. Coon) or a support group facilitator who has achieved a high level of competence as determined based on the monitoring of his or her own 4 sessions. Monitoring will involve listening to the session and completing the "monitoring checklist". The checklist will then be submitted to the CC and feedback via e-mail will be sent to the site P.I. and copied to the CC.

REACH: On-line Support Group Schedule

Project Month	Group #	Birmingham	Memphis	Miami	Palo Alto	Philadelphia
8	1			English		
	2			English		
	3			Spanish		
9	4	English				
	5		English			
	6				Spanish	
10	7					English
	8	English				
	9				Spanish	
11	10		English			
	11					English
	12			Spanish		
12	13	English				
	14		English			
	15				Spanish	
13	16					English
	17	English				
	18			Spanish		
14	19				English	
	20		English			
	21			Spanish		
15	22					English
	23	English				
	24				Spanish	
16	25		English			
	26					English
	27			Spanish		
17	28	English				
	29					English
	30				Spanish	
18	31					English
	32	English				
	33			English		
19	34				Spanish	
	35					English
	36		English			
20	37				English	
	38			Spanish		
	39					English
21	40	English				
	41		English			
	42				Spanish	
22	43					English
	44	English				
	45		English			
23	46			Spanish		
	47				English	
	48	English				
24	49		English			
	50				Spanish	
	51					English
25	52	English				
	53		English			
	54			Spanish		
26	55					English
	56	English				
	57		English			
27	58				Spanish	
	59					English
	60			Spanish		

Assumes: Five participants per group and a ratio of 2:1 English to Spanish Groups
 Recruitment Rate for the Intervention Condition of 15 per month (3 per site)
 Support Groups begin in Month 2 of the Intervention Period

SUPPORT GROUP PROCEDURES

FORMING SUPPORT GROUPS

The forming of support groups begins after the interventionist completes the support group enrollment form with a new caregiver, usually during the first home visit. The support group enrollment form is faxed by the interventionist to the Miami site (fax number 305-355-9207). In addition, the Miami site generates a list of new caregivers in the intervention based on CTIS usage. The following steps are taken to form a new support group:

- a. The Coordinating Center (CC) receives an updated master list of caregivers (CGs) and new enrollment forms from Miami on a weekly basis.
- b. The CC forms a potential group based on information provided on enrollment forms, specifically: preferred language; days of the week; and time of day.
- c. The CC contacts the interventionist of the caregivers considered for the new group once it has identified a potential group (4-6 caregivers are needed to form a group).
 - CC staff decides on a time and date based on caregivers' preferences. The start date for the group is targeted for 2 - 3 weeks from the date the process begins.
 - Interventionists contact their caregivers to inform them about the selected time and date for the support group and confirm the caregiver's availability. Each interventionist explains to his/her caregiver that the date and time will still need to be confirmed once all the caregivers have responded.
 - The interventionist lets caregiver know when the date and time for the first support group session has been finalized.
 - If the caregiver accepts the offered time and date, the interventionist contacts the CC to confirm.
 - If the caregiver does not accept the offered time and date, the interventionist asks for alternative times the caregiver is available and provides these to the CC. The CC and interventionists continue to negotiate time and date until an agreement is reached.
- d. The CC selects a facilitator/leader for the newly formed group and determines times he or she is available for the identified group.
- e. Once the beginning date for a support group has been confirmed, interventionists contact the caregivers to inform them about the finalized starting date/time of the support group.
- f. The CC provides the facilitator with the following information about the members of the support group he/she will be facilitating:
 - First (and last?) name of the caregivers
 - Each caregiver's interventionist's name

PREPARING FOR FIRST SUPPORT GROUP SESSION

1. Responsibilities of the Support Group Facilitator

- a. The support group facilitator calls each caregiver in his/her support group using the CG Network system, at least 24 hours prior to the first session. This call serves a number of purposes:
 - It gives the support group leader an opportunity to introduce her/himself;
 - It gives the CG an opportunity to ask questions about the format of the support group;
 - It gives the facilitator an opportunity to check that all the caregivers are able to be contacted through the CG Network.
- b. The following are talking points to use as a guide for this initial contact with each caregiver in the group.
 - i. Introduce yourself as the support group facilitator.
 - ii. Review the date and time of the first group call
 - iii. Ask them some general questions about their caregiving situation such as
 - Who they are caring for?

- How long have they been caring for the care recipient?
 - Do they have expectations or something they would like to get from the support group?
- iv. Explain the format of the telephone support group including:
- It is a hour call
 - There will be 3 to 5 other caregivers on the call
 - There will be a total of 5 calls, one/month for 5 months
 - The format of the calls: check-in, topic presentation, open discussion
 - Each month will have a different topic presented
- v. Introduce basic ground rules of telephone group
- Try to set-up the call time as a quiet time when you won't be interrupted
 - It is important to be on time for the call; if you aren't going to be available at the time the call starts, but you would still like to join the call, send a message to me using the Caregiver Network and I will make arrangements for you to join the group when you are available.
 - If you are interrupted during the session and have to leave the call for a short period of time, **don't hang-up**—let the group know you are putting the phone down and you will return
 - Turn down any sources of background noise—tv/radios
 - Take turns speaking with the other group members; wait for each person to finish speaking.
 - Identify yourself before speaking so others know who is speaking. This is especially true in the first couple of calls before we get to know each other's voices
 - We ask that personal information shared in the group remain confidential, which means that what is discussed in the group should not be shared outside of the group.
- vi. Discuss some of the procedures you will follow for use of the Caregiver Network
- What caregivers should do in case they are cut off during a support group session.
 - i. The caregiver who is cut off during a support group session should call the 1-866-559-1971 Caregiver Network number. After entering his/her PIN, the Caregiver should be automatically reconnected to the session.
 - ii. If the attempt to dial into the call fails, the caregiver should hang up and wait for the facilitator to contact him or her to reconnect.
- vii. Remind them again about the date & time of the call and make sure any questions are answered.

FIRST SUPPORT GROUP SESSION

The first support group session is an important session to establish group rules, expectations, and procedures. The support group facilitator will use the *Support Group Introduction* to begin the first session. Time should be left at the end of the first session to discuss specific logistical issues related to using the CG Network and participating in the group.

- a. Set the date and time for the next group with the caregivers.
 - Using the same day and week of each month (e.g. 2nd Wednesday of the Month) seems to be easier to remember than setting dates four weeks apart.
 - Suggest that you will stick with that time for the group for the remaining sessions.

- b. Discuss how caregivers would like to be reminded of upcoming sessions.
 - Try to find an acceptable time of the day to leave reminders, hopefully catching most of your group members at home regularly at that time of day.
 - All caregivers will receive reminders at the determined time according to local time. Time zones will not affect this function.
- c. Review how the reminder function works and how caregivers can pick up their messages.
 - A reminder will ring your phone automatically at an agreed upon time.
 - If the phone is not answered the system will try you twice more during the next hour.
 - If none of the reminders are answered, the reminder will become a message and can be picked up by the caregiver by accessing the Caregiver Network.
 - Caregivers must press “1” after listening to a reminder to let the system know the reminder has been received, otherwise it will continue to try and reach you.

REMINDING CAREGIVERS OF AN UPCOMING SUPPORT GROUP CALL

- a. To remind CGs of a session that is coming up, facilitator should:
 - Leave a message a day or two before the session (NOT DAY OF SESSION). Please make sure that the message is clear. For example, avoid leaving messages like “there will be a call **tomorrow**”. You need to be clear about the day/time. Instead of tomorrow, state the day e.g. **Monday**.
 - Use the following script as a guide for developing reminders.
 - "Hello. This is a prerecorded message from xxx from the REACH II project calling to remind my support group members of our upcoming session Monday, March 10th, at 4pm EST, 3pm CST, and 1pm PST. As always, I will be calling you in your home for that group. If you are unable to make it to the group, please leave me a message on the Caregiver Network system, or ask your interventionist to contact me and let me know. Otherwise, I'll talk to you Monday. Press one now to let the system know that you got this message. Thank you."
 - Group reminders will be delivered to caregivers at the designated time, locally. Therefore, if you set the reminder for 8:00 pm, each caregiver will receive the reminder call at 8:00 pm locally.
 - Check if reminders and/or messages have been picked up by the caregivers. Reminders and messages that have NOT been picked up will be displayed under option 5 & 6 respectively.

WHAT TO DO WHEN A CAREGIVER MISSES A SUPPORT GROUP CALL

- a. If a caregiver misses a support group call, the facilitator should contact the caregiver as well as the caregiver's interventionist:
 - If the first session was missed by a caregiver, try contacting the interventionist first to obtain information before contacting the caregiver.
 - When caregiver is contacted, share information about what was missed (get permission from the group to fill the CG in on the make up of the group), confirm next session date and time and inform caregiver you will use the Caregiver Network to leave a reminder for the next support group call closer to the date.
 - If facilitator cannot reach caregiver through the system, the caregiver's direct number can be used.

Script for Support Group # 1

Taking Care of Yourself

Talking Points (Short Version)

Taking Care of Yourself

Priority Talking Points

1. **Asking for Help and Support**-Sometimes getting help from someone else is as easy as asking.
 - a. Give yourself permission to ask for help.
 - b. Rely on family, friends, social services, and support groups for information, emotional support and understanding as well as tangible assistance (e.g. sitting with the care recipient) where appropriate.
 - c. Accept that sometimes people will turn down your request.

Reinforce use of Caregiver Network

Family Respite

[or]

Resource Guide→ National Alzheimer's Assoc. [or] Local Alzheimer's Assoc. [or] AAA

[or]

Resource Guide→ Community Services

2. **Health Lifestyle**

- a. Exercise
 - i. Reducing tension is one of the biggest benefits of exercise
 - ii. Try to choose a practical exercise program that will fit in to your busy life
 - iii. Consider walking as an exercise option as it may fit best into your routine as a caregiver
 - iv. Schedule someone to sit with care recipient while you exercise
- b. Sleep
 - i. Remember that getting enough sleep is one of the keys to managing a busy, stressful day.
- c. Nutrition
 - i. Try to eat balanced meals by eating foods that are high in vitamins and nutrients.
 - ii. Be good to yourself-make sure your get enough to eat. Drink plenty of fluids
 - iii. If you can afford to pick up or go out for a good balanced meal, do so to treat yourself.
- d. Pleasant Activities-Arrange for at least 4 pleasant activities a day.
 - i. Change the scene
 - ii. Arrange for time to talk or see family and friends
 - iii. Be good to yourself-you are worth it. Treat yourself to a dinner, concert or a movie.
 - iv. Listen to music or a relaxation tape
 - v. Reading is a wonderful way to leave stress behind
 - vi. Indulge yourself in a warm bath, Jacuzzi tub or get a massage

- vii. Escape by watching a good TV program or a movie
 - viii. Spend time on a hobby
- e. Avoid drugs, smoking and alcohol abuse

Reinforce use of Caregiver Network

Information/Tips → Healthy Living → Your Health [or] Eating/Exercise [or] Pleasant Events [or] Sleeping Better [or] Stress Management

3. Other Important Issues

- a. Change Negative Ways of Thinking-the challenges and stresses of care giving and seeing a loved one change dramatically can lead to negative thinking and feeling of worry, frustration, sadness and guilt.
 - i. Try to reframe the problem
 - ii. Remember you are human. No one is perfect. None of us can always say or do exactly the “right thing”
 - iii. It is o.k. to take time for yourself
 - iv. Remember it is a disease. The changes aren’t someone’s fault

- b. Education
 - i. Become an educated caregiver
 - ii. Learn to accept that people wit dementia change and so do their needs
 - iii. Educate your family, friends and neighbors

Reinforce use of Caregiver Network

Information/Tips → About Alzheimer’s

Script for Support Group # 1

Taking Care of Yourself

(Long Version)

Taking Care of Yourself

Stress is a natural by-product of caring for a person with memory problems. Your days are long and you have many caregiving responsibilities that are physically and emotionally tiring. You may find yourself feeling very tired at the end of the day and yet unable to relax. You may also feel blue, anxious, frustrated or irritable.

Taking care of yourself and maintaining a healthy lifestyle can help you manage stress, aid in relaxation and help chase blue moods, irritability or worry away. Certain activities may allow you to take time out from your demanding schedule. Taking time for you can often help you relax and enjoy life more. It takes planning to find time for yourself as a caregiver but the following suggestions can help guide you toward that goal:

Simple Activities Are a Key to Reclaiming Your Life

Taking care of yourself involves some simple steps— simple, but not always easy to accomplish. The first step in taking care of yourself is to learn the things you need to do:

- **E**ducation
- **E**xercise
- **E**at balanced meals
- **G**et enough rest
- **C**hange negative ways of thinking
- **E**ngage in Pleasant Activities Daily

Things you can do

While it may seem difficult to change your lifestyle during caregiving, it can be done one step at a time. Sometimes you have to take very small steps to begin a change in behavior or habit. The most important step is to begin. The following activities are the foundations of good self-care:

Education

1. Become an educated caregiver. Use the resource material our project has provided you as well as material available through the CTIS and other reliable community sources like the Alzheimer's Association.
2. Learn to accept that people with dementia change and so do their needs. As dementia progresses, different knowledge and skills are necessary to help caregivers cope with changes in your loved one.
3. Educate your family, friends and neighbors. They often don't offer to help because they lack information on how to "be" with people with dementia. However, avoid overwhelming them with too much information.

Exercise

Beginning an exercise program may sound harder than it is. Exercise can be as simple as taking a walk or may involve a routine of exercise patterns such as aerobics. The most successful exercise programs usually involve performing a physical activity that you enjoy.

The following information shows how important exercise can be for the caregiver of a patient with memory problems:

1. **Reducing tension is one of the biggest benefits of exercise. It produces many positive effects on the body and improves overall physical health.**
2. **Choose a practical exercise program that will fit into your busy schedule. Finding time for exercise may be challenging for you as a caregiver. Make sure to talk to your doctor before you start a new exercise program.**
3. **Consider walking as an exercise option as it may fit best into your routine as a caregiver. Walking does not require buying any major equipment other than good walking shoes. It can be done at any time and near your home. Some caregivers find walking at the mall enjoyable. If the patient is able, he can walk with you or be pushed in a wheel chair.**
4. **Schedule someone to sit with the patient while you exercise if the patient is not able to go with you or if exercising alone works better for you.**

Nutrition

It is worth the time to prepare yourself a nutritious meal. The payoff is one you'll want – a feeling of well-being.

A good meal does not need to be a “fancy” meal:

1. **Try to eat balanced meals by eating foods that are high in vitamins and nutrients. Avoid caffeine, sugary snacks and foods that are high in saturated fat and cholesterol. Limit your salt intake. Make sure your diet contains plenty of fiber by eating fresh fruits and vegetables.**
2. **Be good to yourself—make sure you get enough to eat. Drink plenty of fluids: 6 to 8 glasses of water daily is recommended.**
3. **If you can afford to pick up or go out for a good balanced meal, occasionally do so treat yourself.**

Sleep

Remember that getting enough sleep is one of the keys to managing a busy, stressful day. Never underestimate the importance of a good night's sleep. Proper rest helps you think more clearly, handle challenges better, and function better. Consult your physician if you are having trouble with sleeping.

Ask for Help & Support

Sometimes getting help from someone else is as easy as asking. Other people do not always know what you do as a caregiver and what you are feeling. They may hesitate to offer help to you as they may feel they are intruding or lack understanding about dementia—they need for you to ask and provide some information.

Pay attention to the following suggestions:

1. **Give yourself permission to ask for help** -- before you find yourself with “burnout.” If you don’t, you may not have anything left over for the care recipient.
2. Rely on family, friends, social services, and support groups for information, emotional support and understanding as well as tangible assistance (e.g., sitting with the care recipient) where appropriate. Learn about respite opportunities in your area that could work for you and your caregiving situation.
3. Accept that people can turn down your request. Ask them what they would be willing to do or when they would be willing to help instead and go from there.

Change Negative Ways of Thinking

The challenges and stresses of caregiving and seeing a loved one change dramatically can lead to negative thinking and feelings of worry, frustration, sadness and guilt.

1. Try to reframe the problem or challenge. Look for other helpful alternatives to the issue. Review educational material for ideas and ask for help.
2. Remember you are human. No one is perfect. None of us can always say or do exactly the “right thing”.
3. It’s ok to take time for yourself.
4. Remember it is a disease. The changes aren’t someone’s “fault”.

Engage in Pleasant Activities Daily

Arrange for at least 4 pleasant activities a day. These do not have to be major activities, rather they can be relatively short and simple.. Still it is important to arrange for about four a day to take care of YOU. Make list of quick activities you would like to do and keep it on the refrigerator or mirror. Develop a schedule to regularly check the list and do an activity. Activities may or may not involve your loved one, depending upon your situation.

Here are some examples:

- **Change the scene.** Get out of your house as often as possible (as long as your loved one is safe) – even if it’s for a few minutes. It is surprising how a walk to the mailbox, a quick tour of the flowers in your garden or a brief glimpse of the stars can give you a relaxing sense of “being away.”
- **Arrange for time to talk with or see family and friends.** If you can’t manage to get away, use the phone and call a friend. A short phone call to a friend or family member can go a long way toward lifting your spirits. Attend functions meetings important to you (church, senior centers, etc) whenever you can.
- **Be good to yourself – you’re worth it.** Treat yourself to a dinner, concert or movie.
- **Listen to music or a relaxation tape.** You can even make a tape of your favorite recordings to help relax or lift your spirits. Music may also help your care recipient.
- **Reading is a wonderful way to leave stress behind.** The material is up to you - novels, newspapers, scriptures- as long as it is enjoyable for you.
- **Indulge yourself in a warm bath or Jacuzzi tub or get a massage.** Some people find the jets of a Jacuzzi tub help to reduce tension. Heating pads and hot packs also help to relax muscles much as a bath does.
- **Escape by watching a good TV program or movie.**
- **Spend time on a hobby.** Hobbies can range form bird watching, gardening or biking to sewing, and knitting. A hobby can be both relaxing and stimulating.

Think of activities you like, make up the list and then add to it as you do more and more activities!

Things to avoid

Drug and alcohol abuse

- Remember that alcohol is a depressant and if you are feeling “down or blue,” alcohol can make you feel more that way. Drinking too much alcohol, using illegal drugs, or overusing prescription drugs are unhealthy habits. Talk with your physician about other treatment options.

Smoking

- Smoking is unhealthy. If you need help with stopping, talk with your doctor and/or the American Heart and Lung Association about stop-smoking programs in your area.

Finally, caregivers sometimes think they just can't find time to take care of themselves because of their caregiving responsibilities. However, we must keep in mind that taking care of ourselves is essential in order for us to take care of our loved ones.

References

1. Caring for the Caregiver. (1994). New Jersey: Warner-Lambert Company. (Parke-Davis PD-102-BK-8845-A2(044)404309.
2. Simpson, C. (1996). At the Heart of Alzheimer's. Gaithersburg, MD: Manor Healthcare Corporation.

Script for Support Group # 2

How to Access Community Resources

Talking Points (Short Version)

Community Resources

Priority Talking Points

How to access community resources:

Before we talk about specific community resources, let me go over some tips to guide you through the calling process:

- (1) Get yourself ready prior to making your calls.
- (2) Make sure you take good notes on the information you are given.
- (3) Make your calls whenever you have time to concentrate on what you are doing.
- (4) Be assertive and don't hesitate to ask for help.
- (5) Don't wait until the last minute to call for help.

Reinforce use of Caregiver Network

Resource Guide → Community Services

Resources that are available to help

- **Respite Care Options**
Respite Care services give caregivers an opportunity to take a break from their caregiving responsibilities. There are usually three respite care options
 - (1) **in-home care provider**
 - (2) **adult day care center**
 - (3) **residential facility that offers overnight stays**

Reinforce use of Caregiver Network

Resource Guide → Community Services → Respite Care

- ***Residential Options***
 - (1) ***Assisted Living Facilities (ALF)***: These are apartment-style residential facilities for older adults, who are generally independent, or in the case of couples one is mildly impaired but the other is not
 - (2) ***Residential Care Facilities (RCF)***: These facilities are also known as boarding or care homes. They are usually smaller in size, specialize in older adult care and disabilities, such as Alzheimer's disease, and provide assistance with personal hygiene and grooming, and bedside care to moderately impaired individuals.

- (3) **Skilled Nursing Facilities (SNF):** They are also referred to as nursing homes, convalescent hospitals and rest homes. Skilled Nursing Facilities provide continuous nursing services under a registered nurse or licensed vocational nurse.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Residential Care
[or]

Information/Tips→ Communication→ Access Resources

There are many other community resources available to help you. Your **REACH Caregiver Network** has excellent descriptions of these resources. It can also connect you to your local Area Agency on Aging or Alzheimer's Association. These two agencies can tell you how to contact any of these services. Another place to check for information on different types of services is your REACH Caregiver Notebook.

Some of the services you may find helpful include:

- **Legal and Financial Services**
- **Care Manager Services**
- **Transportation Services**
- **Nutrition Services**
- **Shopping Services**
- **Assistive Devices**
- **Support Groups**
- **Hospice Care Services**

We can now open the floor for questions and comments on today's topic.

Other Helpful Information and More Detail If Needed on Services

- **Legal and Financial Services**

There may be a time when you need the help of an attorney or financial consultant to assist you in making long-term care plans for yourself or your loved one. There are some Legal and Financial Services that specialize in elder law and financial services. You may also need legal or financial advice if you plan to place your loved one in a skilled nursing facility and want to protect your life savings.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Legal Issues [or] Financial Support

- **Care Manager Services**

A person that can be instrumental in locating and managing a range of services for your loved one's ongoing needs is a **Care Manager**. They also can help you determine your eligibility for entitlement programs, such as Medicaid programs and intervene in crisis situations.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Care Management

- **Transportation Services**

Transportation service programs usually provide low cost transportation to incapacitated individuals and his/her companion to and from a variety of destinations, such as medical appointments, day programs, grocery store, friend's home, etc. You can also make arrangements for regular pick-up appointments.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Transportation

- **Nutrition Services**

Nutrition services can either be community based or in-home programs. The community based meal programs are generally those found in senior centers or specific congregate meal sites. In-home programs such as "Meals-on-Wheels" deliver in-home meal services to individuals who are unable to shop for or prepare their own meals.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Meals

- **Shopping Services**

Shopping services are resources that may be available in your community. Caregivers who are unable to leave their homes or do not have another person that can stay with their loved ones can make arrangements with their local grocery store or community program to have a list of groceries delivered to their home.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Shopping

- **Assistive Devices**

There may be a time when you or your loved one needs the help of an assistive device. These devices can be anything from items that help you maintain stability in the shower, for example a shower bar, to emergency monitoring systems, such as an emergency electronic pendant. If you are interested in obtaining more information about assistive devices, speak the treating physician or your local Area Agency on Aging or Alzheimer's Association.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Assistive Devices

- **Community Support Groups**

Support Groups are also a valuable resource for caregivers. Most caregiver support groups are facilitated by a volunteer or mental health professional, and meet on a regular basis. You will meet other people who share the same concerns as you, exchange information, discuss practical solutions to common problems, and give and receive encouragement. You will be able to speak freely about ways of dealing your loved one's illness and discover you are not alone in sometimes feeling frustrated, angry, or guilt.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Support Groups

- **Hospice Care Services**

The Hospice program is a way of providing terminally ill persons with a variety of care services that focus on proving comfort and pain relief to those who are no longer actively seeking a medical cure. This program is designed to make the ill person and his/her family members feel more in control of your loved one's end-of-life needs.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Hospice Service

Multiple Roles and Demands of Caregiving (This section is going to be moved to the introduction?)

- Personal care
- Health care
- Emotional care
- Household duties
- Long term planning
- Other responsibilities (e.g., work, family, friends)

Script for Support Group # 2

How to Access Community Resources

(Long Version)

• Community Resources

1. Respite Options
2. Residential Options
3. Hospice Services
4. Support Groups
5. Legal and Financial Services
6. Care Manager Services
7. Transportation Services
8. Meals Services
9. Shopping Services
10. Assistive Devices

How to Access Community Resources

Today we will be discussing how to access different community resources available to caregivers. During the first part of today's group meeting we will provide you with a **brief description of various community resources**, the **types of services they offer** and **how to access them**. The second part of our meeting will be devoted to an open discussion of today's topic.

Community Resources

*Taking care of an ill person can be overwhelming if one tries to do it alone. Caregivers are often responsible for performing a broad range of care services in order to meet their loved one's needs. Most caregivers provide **personal care** (bathing, dressing, feeding, toileting, etc.), **health care** (managing medication, keeping and taking their loved one to multiple medical appointments, etc.), **emotional care** (providing companionship, emotional support, recreational activities, etc.), and **household care** (cooking, cleaning, shopping, doing laundry, etc.). Some of you are even forced to take on new roles, such as financial and legal experts, and long-term planners. The majority of caregivers reach a point when they can't do it alone anymore and need the help of different health services providers. Finding information about the different community resources, however, can be confusing and frustrating if you are not aware of their role, services being offered and how to contact them. The following information can help you gain a better understanding of the different community services available and how to reach them. **Keep in mind that each community differs in the types of services available and their eligibility requirements, therefore, you may need to do a further inquiry regarding their current services.***

Reinforce use of Caregiver Network

Resource Guide → Community Services

Let's talk about what are some of these community services, what do they offer, and how can you access them.

We will first start with:

- **Respite Care Options**

Respite Care services give caregivers an opportunity to take a break from their caregiving responsibilities. There are usually three respite care options - (1) an **in-home care provider**, (2) an **adult day care center**, (3) or a **residential facility that offers overnight stays**. Any of these options will temporarily take care of your loved one while you attend to other things or just take that well deserved break. *In-home care providers* generally offer custodial care for a few hours at a time during the week or on the weekends. *Adult day care centers* monitor your loved one for longer periods of time and have a variety of recreational activities, such as crafts, reading, exercise, and music sessions. Most day care centers provide lunch and snacks, and some form of transportation services. You may want to consider a few things before sending your loved one to a day care center – **for example:**

- (1) Is the day care center culturally appropriate for your loved one – primarily do staff members and other participants speak the same language as your loved one?
- (2) Does the adult day care center have the necessary staff, and other health care personnel to meet the needs of your loved one?
- (3) Are they licensed, and approved by the necessary review agencies?
- (4) What type of security system do they have - are they a locked facility?
- (5) Do they provide transportation services if you are unable to take your loved one yourself?

The last respite option available to you is placing your loved one in a residential facility for extended periods at a time, such as a weekend or several days. Respite care services are usually paid privately or sponsored by non-profit organizations. These respite care options can be arranged through your local Area Agency on Aging or Alzheimer's Association. Each agency may provide you with up to 80 hours of respite a year; however, it is best if you contact them directly and ask them about their current respite programs.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Respite Care [or] Hospice Services

Other resources available to you and your loved one are residential facilities.

- **Residential Options**

Many caregivers continue to provide care services far beyond their physical and emotional capacity before they even consider finding an alternative residential facility for their loved one. A thoughtful comparison of the available residential options in your community can help you gain a better understanding about the right facility to meet your loved one's needs. We will review three types of residential options that differ in their level of care.

(1) **Assisted Living Facilities (ALF):** These are apartment-style residential facilities for older adults, who are generally independent, or in the case of couples one is mildly impaired but the other is not. Each facility varies on the type of available services to their residents; however, most offer 24-hour security, transportation, and emergency call system inside their apartment units. Recreation and social activities may also be available. The units include an individual kitchen area, private bathroom and sleeping quarters. Some facilities offer personal care, housekeeping and laundry services, medication reminders and, care management services for a fee. Assisted living facilities rarely offer skilled nursing care; therefore, if the adult person becomes incapacitated, their family will need to look for another facility that can provide a higher level of care. Assisted Living Facilities are privately owned and are not covered by any government program or private insurance.

(2) **Residential Care Facilities (RCF):** These facilities are also known as boarding or care homes. They are usually smaller in size, specialize in older adult care and disabilities, such as Alzheimer's disease, and provide assistance with personal hygiene and grooming, and bedside care to moderately impaired individuals. Each facility may differ on the type of services they offer; however, most residents are provided with three meals a day in a common dining area, and some recreational or social activities. Residents can rent private sleeping quarters or share a room with residents of the same gender. In general residential care facilities are open facilities; however, there are some that provide secured areas. These facilities have also lower monthly costs than ACLFs or Skilled Nursing Facilities and in some cases arrangements can be made to use monthly SSI payments as reimbursement to the facility.

(3) **Skilled Nursing Facilities (SNF):** They are also referred to as nursing homes, convalescent hospitals and rest homes. Skilled Nursing Facilities provide continuous nursing services under a registered nurse or licensed vocational nurse. These facilities are equipped to provide a variety of services to individuals who are severely impaired. These services range from custodial care services, such as bathing, feeding, getting the person in and out of bed, using the toilet, etc., to more extensive health care services, such as administering injections, monitoring blood pressure, ventilator care, etc. Skilled Nursing Facilities also offer rehabilitation services like physical, occupational, or speech therapies. Because Skilled Nursing Facilities are federally regulated, they must meet a certain level of care standard and provide their residents with a variety of social and recreational activities. Unfortunately, Medicare does not cover skilled nursing facilities beyond 20

days of medically necessary skilled nursing care. Most skilled nursing facilities are privately paid or covered by Medicaid, a social welfare program.

Regardless of the residential option you select, we recommend that you make the needed arrangements to carefully evaluate the facility. Your local Area Agency on Aging and Alzheimer's Association can provide you with several checklists to help you evaluate the environment, staffing patterns, activities, and services of the various types of residential facilities. These checklists include inspection of safety procedures, visiting policies, cleanliness, attentiveness of nursing staff, quality of food, availability of pharmaceuticals, laundry services, and more.

Reinforce use of Caregiver Network

Resource Guide→ Local Alzheimer's Assoc. [or] AAA
[or]

Resource Guide→ Community Services→ Residential Care
[or]

Information/Tips→ Communication→ Access Resources

Another community resource you may need is:

- **Hospice Care Services**

The Hospice program is a way of providing terminally ill persons with a variety of care services that focus on providing comfort and pain relief to those who are no longer actively seeking a medical cure. This program is designed to make the ill person and his/her family members feel more in control of your loved one's end-of-life needs. People in the last phase of an incurable illness receive help from a team of health care providers, such as physicians, nurses, social workers, religious leaders, and volunteers around the clock, seven days a week. All you have to do is call one of their hospice team provider and they will come to the home. Some services offered by the Hospice program are (1) nursing care; (2) physician care; (3) specialized therapies; (4) in-home care aide services; (5) medical supplies and appliances; (6) respite care; (7) medical social services; (8) outpatient drugs for pain relief and symptom management; (9) counseling services; etc. Support for surviving loved ones usually continues through the bereavement phase. Hospice services are often covered by either Medicare, Medicaid, and some private insurance plans. In order for your loved one to receive Hospice services under Medicare he/she must meet the following criteria: (1) Your loved one's treating physician and Hospice medical director certify that he or she is terminally ill – in other words the ill person's life expectancy does not exceed more than 6 months, (2) Your loved one, or family member in charge, agrees to receive care from a Hospice provider, and (3) the Hospice provider is a Medicare participating provider. If you are interested in obtaining more information about Hospice you should speak to your physician, care manager, and your local Area Agency on Aging, and Alzheimer's Association.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Hospice Services

Another great resource that can help you make new friends and expand your knowledge of other resources is a support group.

- **Support Groups**

Support Groups are also a valuable resource for caregivers. Most caregiver support groups are facilitated by a volunteer or mental health professional, and meet on a regular basis; for example every third Tuesday of the month. When you attend a support group you will meet other people who share the same concerns as you, exchange information, discuss practical solutions to common problems, and give and receive encouragement. You will be able to speak freely about ways of dealing your loved one's illness and discover you are not alone in sometimes feeling frustrated, angry, or guilt. Support groups are a wonderful venue to make new friends, network, and learn from each other. You can find

information on support groups at your local hospitals, Area Agency on Aging, Alzheimer's Association, and mental health programs.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Support Groups

- **Legal and Financial Services**

There may be a time when you need the help of an attorney or financial consultant to assist you in making long-term care plans for yourself or your loved one. There are some Legal and Financial Services that specialize in elder law and financial services. For example, an elder law attorney can help you formulate a living will or a durable power of attorney. These legal documents allow the ill person to give directions about their future medical care. You may also need legal or financial advice if you plan to place your loved one in a skilled nursing facility and want to protect your life savings. Your local Area Agency on Aging and Alzheimer's Association can help you obtain information about different legal and financial services in your community that specialize in older adult practice.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Legal Issues [or] Financial Support

- **Care Manager Services**

A person that can be instrumental in locating and managing a range of services for your loved one's ongoing needs is a **Care Manager**. Professional Care Managers usually have a background in social work, counseling, or a related health care field, and are trained to assess your individual situation, and to implement and monitor a care plan to meet your needs. They also can help you determine your eligibility for entitlement programs, such as Medicaid programs and intervene in crisis situations. You may find case managers at your local hospitals, Area Agency on Aging, home-health agencies, social service agencies, (such as adult protective services), and in the private sector.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Care Management

Other community resources available to you and your loved one are Transportation Services.

- **Transportation Services**

Transportation service programs usually provide low cost transportation to incapacitated individuals and his/her companion to and from a variety of destinations, such as medical appointments, day programs, grocery store, friend's home, etc. These programs may be offered through your local Transportation Department or a private non-profit organizations, such as your local Area Agency on Aging. Transportation services usually require for you to give them advance notice of the pick-up date and type of transportation vehicle needed – **for example**, *wheel chair transport vehicle*. You can also make arrangements for regular pick-up appointments, **for example** *if your loved one goes three times a week to a day care center*. Most of these programs involve an application process, where the incapacitated individual needs to meet certain criteria. You may want to check with your local Area Agency on Aging or Transportation Department for availability and limitations.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Transportation

Another community resource you may benefit from is a Nutrition program.

- **Nutrition Services**

Nutrition services can either be community based or in-home programs. The community based meal programs are generally those found in senior centers or specific congregate meal sites. In-home programs such as “Meals-on-Wheels” deliver in-home meal services to individuals who are unable to shop for or prepare their own meals. Most Nutrition programs offer a “hot meal” Monday through Friday for a minimal fee, depending on the individual’s ability to pay. You may want to check with your local Area Agency on Aging, and senior centers for more information on nutrition services.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Meals

- **Shopping Services**

Shopping services are resources that may be available in your community. Caregivers who are unable to leave their homes or do not have another person that can stay with their loved ones can make arrangements with their local grocery store or community program to have a list of groceries delivered to their home. Some community programs offer this service free of charge through a network of volunteers who help older adults with their weekly groceries. To obtain more information about Shopping Services in your community you can call your local Area Agency on Aging or Alzheimer’s Association, and neighborhood grocery store.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Shopping

- **Assistive Devices**

There may be a time when you or your loved one needs the help of an assistive device. These devices can be anything from items that help you maintain stability in the shower, for example a shower bar, to emergency monitoring systems, such as an emergency electronic pendant. Assistive devices can also make activities of daily living such as bathing, dressing, and eating meals easier to perform. They allow your loved one to maintain their independence and provide you, the caregiver, with peace of mind. If you are interested in obtaining more information about assistive devices, speak the treating physician or your local Area Agency on Aging or Alzheimer’s Association. Sometimes they have a list of assistive devices that are recommended in the care of someone with dementia.

Reinforce use of Caregiver Network

Resource Guide→ Other Services→ Assistive Devices

Now that all of you know more about different community resources let me go over some tips to guide you through the calling process:

- (1) Get yourself ready prior to making your calls. That is, knowing exactly what your needs are, having current information on your loved one’s condition and something you can take notes with.
- (2) Make sure you take good notes on the information you are given – for example the name of the person you spoke to, date, and a brief summary of the conversation.
- (3) Make your calls whenever you have time to concentrate on what you are doing. Calling is best early in the morning.
- (4) Be assertive and don’t hesitate to ask for help.
- (5) Don’t wait until the last minute to call for help. Some agencies may have a waiting list; therefore, it is best if you get on them before your situation reaches a crisis level.

Today we covered a lot of information on different community resources available to you and your loved one. I would like to encourage you to use your Caregiver Network to help you learn more about these services. The Caregiver Network will also help you obtain information on how to contact the different organizations that offer these services. I would also like to remind you that each community differs in the types of services available and their eligibility criteria; therefore, you may need to call and ask about their current services.

We can now open the floor for questions and comments on today's topic.

Script for Support Group # 3

How to Communicate with Health Care Providers and Service Providers

Talking points (Short Version)

Closure Notes

***Remember to mention that there are only two sessions left after this one.

How to communicate with Health Care Providers and other Care Service Providers

Priority Talking Points

Effective Communication

Effective communication and information sharing between the physician(s) and you, the caregiver, is crucial to sound decision-making.

(1) Come to the Doctor's Visit Prepared

- **Understand the problem**

It is important that the person caring for the patient becomes familiarized with all aspects of the "presenting problem".

- **Prioritize your concerns**

Your list of questions needs to be short and to the point.

- **Write down your issues and concerns**

Writing things down will help you remember what you wanted to discuss.

- **Make the proper arrangements to speak to the doctor(s)**

You need to think about what would be the best arrangements for you to be able speak to the doctor without interruptions.

- **Take notes**

Take a note pad and pen to write down all of the things you need to remember or don't understand. You may want to ask the doctor to sum up the information in order for you to take notes on the most important points of the visit. If the doctor doesn't object, you can even bring a tape recorder to tape the doctor's recommendations.

- **Arrive a few minutes before the appointment**

Sometimes you need to fill out paperwork or meet with another office staff member before meeting with the doctor. You may also need the time to make your loved one comfortable and settled to the office or hospital environment.

- **If you need to, bring someone to help you**

A family member or friend can help you with your loved one and give you a chance to speak to the doctor alone or can help you listen to what the doctor is saying.

(2) Using Good Communication Skills

- **Good listening skills**

The ability to receive information without being distracted or interrupted. Make sure you listen to what the doctor is saying and understand it. Sometimes we don't hear because we are thinking about our next question or what was said before. Ask the doctor to repeat if you don't hear or understand.

- **Direct communication**

Expressing your thoughts or concerns in simple and clear terms.

- **Clarification of unclear information**

If you do not understand something in your conversation with the doctor, don't hesitate to ask him/her to be patient and clarify the information.

Reinforce use of Caregiver Network

Information/Tips → Communication → Health Care Professionals

We can now open the floor for questions and comments on today's topic.

Other Important Points

Working with Other Service Providers

Most family caregivers reach a point when they need the help of other service providers. Although you may come in contact with many community service providers in the course of your loved one's care, today we will only focus on those related to health care services.

(1) Medical Specialist

Obtaining an accurate diagnosis often involves visiting several specialists and undergoing a series of tests.

- Ask your treating physician about these specialists.
- Contact the National and Local Alzheimer's Associations for more information.
- Contact different diagnostic centers in your area that specialize in cognitive disorders.

(2) Care Managers

A person that can be instrumental in locating and managing a range of services for your loved one's ongoing needs is a *Case Manager*.

Reinforce use of Caregiver Network

Resource Guide → Other Services → Care Management

(3) In-Home Care Service Provider

In-home care help can range from housekeepers to certified nurse assistants.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Respite Care

How do I pay for services?

- (1) If your loved one has been discharged from a hospital and his/her treating physician recommends post-hospital care, in-home health care services may be covered by Medicare.*
- (2) If your loved one has a limited income, he/she may be eligible for services provided through their local Area Agency on Aging.*
- (3) You can also contact your local Alzheimer's Association for information on home care services.*

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Financial Support

Script for Support Group # 3

How to communicate with Health Care Providers and Service Providers

(Long Version)

- **Effective Communication: Strategies to improve the caregiver-physician communication.**
- **Working with other Care Service Providers: Medical Specialists, Care Managers, and In-Home Aids.**

How to communicate with Health Care Providers And other Care Service Providers

Today we will be discussing how to communicate with Health Care Providers and other service providers that may be part of the overall care of the person you are caring for. During the first half of today's group meeting we will talk specifically about strategies to improve the caregiver-physician communication, and work with other service providers. The second part of our meeting will be devoted to an open discussion of today's topic.

The caregiver-physician relation:

An essential component in your loved one's care is the relationship between the caregiver and their loved one's doctor(s). Several studies have already established the importance of the physician-patient relationship on a patient's health status, treatment adherence, and satisfaction (Cecil, 1997; Green, 1994; Kaplan, 1989; Rost, 1987). Unfortunately, inadequate or limited communication between the person who is seriously ill, or his/her caregiver, and health care providers ultimately influence the quality of the relation. A recent editorial in the Age and Ageing Journal points to communication problems as the principal reason for complaints against doctors (Black, 2000). Caregivers report walking out of the doctor's office feeling dissatisfied, neglected, and confused regarding their loved one's condition. These feelings are usually the signs of an ineffective communication interaction between the caregiver and the doctor(s). Although it is best if everyone works to make sure that his/her thoughts are clear and understood by others, it is more often up to you, the caregiver, and your family members to make sure the communication is effective. That is, for the physician to understand what information is needed from him/her, and that they understand the information you are providing them.

Let's talk about what effective communication means and how we can improve it.

Effective Communication

Effective communication and information sharing between the physician(s) and you, the caregiver, is crucial to sound decision-making, but communicating with physician(s) and other service providers can be an extremely challenging task for many caregivers. Family members in the crisis of a life-threatening illness are generally not assertive consumers and are often misunderstood. Effective communication occurs when two or more people exchange information in a manner in which both parties are able to understand the message being sent and received. In order for you to increase the probabilities of having an effective communication interaction with your loved one's physician(s) you need to: (1) Come prepared to the doctor's appointment; and (2) Use good communication skills.

The following are suggestions that can help you develop a more productive and efficient way of communicating with the doctors involved in your loved one's care:

1. Come to the Doctor's Visit Prepared: A well-prepared individual who visits a physician, with a prioritized list of complaints or questions, relevant medical history, and current medical information, is more likely to make the best use of the doctor's visit and feel more satisfied. Coming prepared to a doctor's visit involves: (1) **Understanding the problem;**(2) **Prioritizing your concerns;** (3) **Making the proper arrangements to speak to the doctor(s);** (4) **Taking notes;** and (5) **Arriving a few minutes before the appointment.**

- **Understand the problem**

It is important that the person caring for the patient becomes familiarized with all aspects of the “presenting problem” – *for example, what, when, and how long*. This may take a little investigation and active observation from the individual’s part, but it will provide the doctor with a contextual picture of what may be happening. Write notes about the things that are occurring and develop a list of complaints and questions to be discussed on your next visit to the doctor.

For example: My loved one sees people that are not there when it begins to get dark ever since his medication was changed.

*In this case the problem is?
When does the problem occur?
and How long has it been occurring?*

- **Prioritize your concerns**

Planning a visit to the doctor involves taking the time to prioritize your questions. Keep in mind that doctors have their own style and time constraints; therefore, your list of questions needs to be short and to the point - *for example 2-3 main questions*. You may want to advise the doctor early on in the appointment that you have some questions that you would like to address. It is also a good idea to make a copy of the questions, current medications, changes in treatment, and latest tests results, for the doctor to review and keep inside your loved one’s record. Caregivers are most of the times, the link that keeps the team of doctors updated as to the current status of the person being treated. If you are unable to obtain a copy of the test results, you can request for the results to be sent to the doctor’s office. There may be a cost involved in obtaining copies of some tests results, or actual films - *for example, MRI, CAT Scans, etc*, but the cost is well worth it if you can facilitate the continuity of your loved one’s medical care.

- **Make the proper arrangements to speak to the doctor(s)**

Once you have the list ready, you need to think about what would be the best arrangements for you to be able speak to the doctor without interruptions. If you plan to take your loved one to the doctor for an appointment and have questions that need to be addressed in private, try to bring someone with you that can stay with your loved one while you meet with the doctor. If you are unable to have someone with you, call the doctor’s secretary and let her know that you would like to have a few minutes alone with the doctor and would appreciate if someone could monitor him/her during that time. Take something with you that can distract your loved one – *for example, food, pictures, magazine, etc*. If your loved one has a behavioral problem and finds it difficult to stay in one place, it may be a good idea to tell the doctor that you will be calling him at a later time to ask him some questions.

For example: *My husband had an MRI done two weeks ago and I requested for a copy of the results to be sent to your office. Did you receive them? I also would like for us to set some time aside for me to ask you a few questions – here is a copy of the questions.*

- 1) *What is (new medication) used for?*
- 2) *What are some of the side effects?*
- 3) *When is the best time to give this medication to my loved one?*

- **Take notes**

Take a note pad and pen to write down all of the things you need to remember or don’t understand. You may want to ask the doctor to sum up the information in order for you to take notes on the most important points of the visit. This will give you the opportunity to later on research it on your own, consult with other caregivers or family members.

The last suggestion for you to consider is to,

- **Arrive a few minutes before the appointment**

Sometimes you need to fill out paperwork or meet with another office staff member before meeting with the doctor. You may also need the time to make your loved one comfortable and settled to the office or hospital environment.

Now that you are prepared let's talk about how to use good communication skills.

2. Using Good Communication skills: Communicating effectively with another person requires: (1) **Good listening skills**, (2) **Direct communication**, and (3) **Clarification of unclear information**.

- **Good listening skills**

When we refer to having good listening skills, we are talking about the ability to receive information without being distracted or interrupted. Sometimes the communication between two people gets affected because the listening party may be distracted by what they want to say or respond.

For example: *The doctor may be asking you about your loved one's hallucinations (the people that he sees) and you are thinking about not forgetting to ask him about the new medication that just came out for Alzheimer's Disease.*

Another common error in communication is interrupting the person who is conveying the information. While this may seem like a good way of saving time you may run the risk of misinterpreting or losing part of the message. In both of these situations the information that is being received may seem confusing or incomplete.

- **Direct Communication**

A second important part of communicating effectively is sending messages in a clear and direct manner. That is, expressing your thoughts or concerns in simple and clear terms. This may take a little effort from the senders' part because it implies organizing your thoughts, but in the end the result is a better understanding of the information being sent. A common problem in this situation is minimizing symptoms or situations. This may lead the doctor to make wrong conclusions and recommendations.

For example: *"he/she is only a little confused", or "my mother's incontinence does not really bother me".*

- **Clarification of Unclear Information**

The last ingredient to a better communication between you and the doctor(s) is clarifying unclear information. If you do not understand something in your conversation with the doctor, don't hesitate to ask him/her to be patient and clarify the information – *for example, what does hallucination mean?* Ask him/her to give you something to read or to refer you to a member of his/her staff (assistant, social worker, education specialist, etc.) to learn more about the topic in question. *Be assertive* – doctors' recommendations are only valuable if you understand them and have the ability to put them into practice

Reinforce use of Caregiver Network

Information/Tips → Communication → Health Care Professionals

We have covered a lot of information on how to increase the probabilities of communicating more effectively with your loved one's physician(s). He or she is one of many health care providers that are

involved in your loved one's care. We are now going to talk about other service providers that may be part of your loved one's health care team.

Working with Other Service Providers

Most family caregivers reach a point when they need the help of other service providers. Although you may come in contact with many community service providers in the course of your loved one's care, today we will only focus on those related to health care services. These include: (1) Medical Specialist, (2) Care Managers, and (3) In-Home Care Service Providers.

- **Medical Specialist**

Obtaining an accurate diagnosis often involves visiting several specialists and undergoing a series of tests (i.e. physical and cognitive tests). The treating physician – *for example, primary care physician or family doctor*, may need to refer the case to a specialist, such as a *Geriatrician, Neurologist, Geriatric Psychiatrist, etc.* to determine the appropriate diagnosis and course of treatment. Some caregivers may not be aware of the role these specialists play in the overall care of their loved one's symptoms. For example, just as a Pediatrician specializes in the area of pediatric care, a Geriatrician specializes in older adult care. Another example is a Geriatric Psychiatrist. This specialist will focus on treating psychological symptoms – *for example, hallucinations, paranoid behavior, aggressive behavior, depression, etc.* associated with a diagnosis of dementia. A team of doctors may ultimately be involved in order to achieve the most comprehensive treatment plan.

The following are some ways for you to obtain more information and become familiarized with the different specializations:

1. **Ask your treating physician about these specialists.** He/she may already work with some of them and can explain their role in your loved one's care.
2. **Contact the National and Local Alzheimer's Associations for more information.** These service agencies may have a current list of doctors that specialize in elder medicine.

Reinforce use of Caregiver Network

Resource Guide → *National Alzheimer's Association [or] Local Alzheimer's Association*

3. **Contact different diagnostic centers in your area that specialize in cognitive disorders.** These centers usually have a team of specialists in the area of cognitive functions and area able to perform different cognitive tests to determine the possible causes for the individual's dementia or presenting problem. If you want to know if there is a diagnostic center in your area you may want to contact your local Alzheimer's Association or Area Agency on Aging.

Reinforce use of Caregiver Network

Resource Guide → *AAA*

- **Care Managers**

A person that can be instrumental in locating and managing a range of services for your loved one's ongoing needs is a *Case Manager*. Professional Care Managers usually have a background in social work, counseling, or a related health care field and are trained to assess your individual situation, and to implement and monitor a care plan to meet your needs. They also can help you determine your eligibility for entitlement programs, such as Medicaid programs and intervene in crisis situations. You may find case managers at hospitals, Area Agencies on Aging, home-health agencies, social service agencies, and in the private sector.

Most of the time caregivers come in contact with a case manager at the hospital when they or their loved one is admitted or discharged. The hospital care manager or social workers are there to explain hospital procedures and policies, serve as a link between you and the health-care team, provide referrals and assistance, help with financial arrangements, and other discharge planning - *for example, post-hospital care, such as home care services or transfer to another facility; transportation, meal programs, etc.* You can request to speak to the hospital care manager at the hospital's nurses' station, social service department, or admissions department.

Another place where you may find the help of a care manager is through your local Area Agency on Aging. Care Managers review an individual's psychosocial and physical health challenges and design a plan of care for services or treatment.

Reinforce use of Caregiver Network

Resource Guide → AAA

You may also come in contact with a care manager when your loved one is provided with home health-care services. Upon your loved one's discharge from the hospital his/her treating physician may recommend home health-care services. These can include part-time skilled nursing care, a variety of specialized therapies, help with personal care, and medical social services. The Medicare participating agency providing the home health-care services initially sends a care manager or social worker to evaluate the individual's needs and develop a comprehensive treatment plan.

Care manager are also used by social services agencies, such as Adult protective services to insure that older adults are not abuse or neglected. Anyone suspecting that an older adult is being abused or neglected needs to call the 1-800-ABUSE hotline. This national abuse hotline refers the report to the local social services agency and a caseworker or care manager is immediately sent to the reported home.

Lastly, you can contract a private care manager to work with you in developing care arrangements for your loved one – for example, they can help you find a residential care facility to meet the needs of your loved one or link you with local services. Fees for a private case manager usually run between \$60 and \$150 per hour. If you are interested in a private care manager you can contact your local Alzheimer's Association, Area Agency on Aging, or look through the telephone pages.

I would like to encourage you to use the CTIS system to learn more about Care Managers – for example what questions to ask the hospital care manager before leaving the hospital.

Reinforce use of Caregiver Network

Resource Guide → Other Services → Care Management

The last care service provider covered under today's topic session is the In-Home Care Service Provider.

- **In-Home Care Service Provider**

In-home care help can range from housekeepers to certified nurse assistants. Before you consider hiring an in-home care services provider, you may want to ask yourself a few questions in order to assess your needs and the needs of your loved one.

For example;

(1) What are the needs of the person I am taking care of – does he/she need help with medication, bathing, dressing, transportation, or other daily activities?

(2) What are some of my own needs? – Do I need the most help with his/her personal care or do I need for someone to stay with him/her while I run errands?

(3) How long do I need the services? – Do I need help round the clock, half a day, two or three day in the week, or only on weekends?

Once you have a better idea of the type of help you need, you can either go through a home health care agency or hire someone yourself. Both of these choices have their pros and cons. If you select the services from a home care agency they take care of the employment process - screening, hiring, firing, paying and filing the taxes. If the worker gets sick, they will send a substitute. Also a home health care agency can provide you with a range of services, skill nursing, specialized therapies, personal care, housekeepers, etc. Some of these services may also be covered under Medicare. The downside may be fewer choices of workers, rotating workers, and higher fees than if privately hired.

If you decide to privately hire a home care worker you have the advantage of choosing the person you think has the strongest qualifications, having a one-to-one relationship between the care worker and your loved one (although you can have the same experience with a care worker from an agency if he/she is the only one providing the services), and paying less for the services. A downside may be incurring the responsibilities of developing a job contract, interviewing, hiring, firing, paying and processing the paperwork to pay his/her taxes, not having a backup in case the person gets sick or has an emergency, limits as to the services that the person is able to do, and not covered by Medicare.

Reinforce use of Caregiver Network

Resource Guide→ Community Services→ Respite Care

The last piece of information I like to share with all of you is perhaps what most caregivers seem to struggle with – not being able to pay for health care services. Unless your loved one needs the care on a temporary bases, the cost of long term home care services are usually beyond the means of middle income families. The following are ways to obtain in-home care services through government or community programs:

(1) If your loved one has been discharged from a hospital and his/her treating physician recommends post-hospital care, in-home health care services may be covered by Medicare. Keep in mind that in order for Medicare to cover in-home care services the physician needs to determine that the person needs it, he/she is confined to his/her home, he/she needs certain types of care, and the services are provided by a Medicare participating agency.

(2) If your loved one has a limited income, he/she may be eligible for services provided through their local Area Agency on Aging. Some of the services provided by AAA are homemaker, home health aide services, transportation, home-delivered meals, chore and home repair, legal assistance and more.

(3) You can also contact your local Alzheimer's Association for information on home care services. Each chapter may have a program to assist caregivers.

Reinforce use of Caregiver Network

Resource Guide→ Local Alzheimer's Association [or] AAA

[or]

Resource Guide→ Community Services→ Financial Support

Today we covered a lot of information: (1) the importance of the caregiver-physician relation, (2) effective communication strategies (coming prepared to the doctor's visit and using good

communication skills), and (3) working with other care service providers (Medical Specialist, Care Managers and In-home care service providers). We learned that the relationship between the family/caregiver, the person requiring the assistance, and the different health care service providers is perhaps one of the most important aspect of your loved one's care, and that good communication is essential to preserve the quality of these relationships. I hope this information was of help to all of you. We can now open the floor for questions and comments on today's topic.

Script for Support Group # 4

Communication with Family and Friends

Talking points (Short Version)

Closure Notes

At the beginning of session or at the beginning of the content section, remind members of the group that this is the fourth of five planned meetings.

At the end of the session remind group members that we will be meeting in one month for our last (with subtle emphasis) group meeting.

A remark on how good they have been as a group is often helpful. They may wish to exchange phone numbers at this point. At this time we do not have an official policy on this. You may want to allow it (it would be hard to forbid them), but not to initiate it.

Communication with Family and Friends

- Reasons for Communication Difficulties with Others
 - Afraid of how others will react
 - Too upset to tell others
 - Embarrassed about the disease and how it has changed your loved one
 - Not sure others will want to help you
- How to Communicate with Family and Friends
 - (1) Be honest about your loved one's diagnosis and condition.
 - (2) Educate your family and friends about Alzheimer's symptoms and its effect on the your loved one.
 - (3) Make it clear to others that Alzheimer's disease is not catching; it's a medical disease.
 - (4) Explain to family and friends how this disease affects you as the caregiver.
 - (5) Ask for help. If you need help and others offer it, accept it.
 - (6) Encourage family and friends to visit you and your loved one. Plan simple activities to help the visit go well. Ask people to call before they come.
 - (7) Consider writing neighbors a letter to tell them about your loved one's condition.
 - (8) Remember that some people may avoid you or lose touch with you for a time once they know your loved one has Alzheimer's disease.

Reinforce use of Caregiver Network

Information/Tips → Communication → Family/Friends

Script for Support Group # 4

Communication with Family and Friends

(Long Version)

Communication with Family and Friends

A diagnosis of Alzheimer's disease affects both the patient who gets the diagnosis and the patient's family. The caregiver and the patient feel confused, lonely, and frightened. Often caregivers are ashamed of the diagnosis and are afraid to tell family, friends and neighbors about the disease. They are afraid of how others will react when they hear about the diagnosis.

This is the time when communication with family and friends is critical. However, many caregivers may not know **how** to communicate with their families and express their pain and ask for support.

In this section we will learn good techniques for communication about the disease that will help you, the caregiver, the patient, and the family cope with this difficult disease. These strategies will help you feel that you have more control during this uncertain time.

Reasons for Communication Difficulties with Others

It is important for caregivers to realize that the problems you experience with communication with others are often the same ones that other caregivers have. The following are some of the reasons that communication with family and friends is difficult for everyone:

- **Afraid of how others will react**
- **Too upset to tell others**
- **Embarrassed about the disease and how it has changed your loved one**
- **Not sure others will want to help you**

How to Communicate with Family and Friends

In many ways, telling someone about Alzheimer's disease is much like telling someone about anything else. The stigma of the disease lessens the more you talk about the disease to others. As other people become familiar with the symptoms of the disease, they become more comfortable with the changes they see in the person with Alzheimer's. They began to realize that the person with Alzheimer's is still the person they've known and loved.

The following suggestions will help you feel more comfortable in talking about Alzheimer's disease to others:

- (1) Be honest about the patient's diagnosis and condition.**
- (2) Educate your family and friends about Alzheimer's symptoms and its effect on the patient.**
- (3) Make it clear to others that Alzheimer's disease is not catching; it's a medical disease. Emphasize to them that this is not a mental illness.**

- (4) Explain to family and friends how this disease affects you as the caregiver. Don't be afraid to ask for help and support. If people ask you what they can do – give them suggestions on how they can help.

*For example, you can ask friends and family members if they can sit with the patient while you run errands, go to a support group, a movie or an exercise class. **You deserve time for yourself!** You might try saying, "I would like to go to the caregiver support group. I need someone to sit with my wife. Would you be available to sit with her for three hours on Friday?" Have you thought also that your patient may welcome the change of being with another person for a change of pace?*

- (5) Ask for help. If you need help and others offer it, accept it. Often when others offer to help, many caregivers do not accept. They may be afraid others may not really want to help.

Most caregivers need help with errands. Friends and family could help you with this chore. Most people are willing to help, but they may be waiting for you to ask them. You can say, "Would you mind picking up some milk for me when you go to the store?"

- (6) Encourage family and friends to visit the patient and you. Plan simple activities to help the visit go well. Ask people to call before they come.

- (7) Consider writing neighbors a letter to tell them about the patient's condition. This courtesy will educate them about the disease and make them feel more comfortable around both you and the patient.

Explain to them the best way to approach and talk to the patient. By sharing your situation with your neighbors, you increase chances they'll be more likely to call you if the patient were to wander or need help in an emergency.

- (8) Remember that *some* people may avoid you or lose touch with you for a time once they know the patient has Alzheimer's disease. Please don't take this personally as they may be afraid of Alzheimer's or of being asked to care for the patient.

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4. Simpson, C. (1996). At the Heart of Alzheimer's. Gaithersburg, MD: Manor Healthcare Corporation.

Script for Support Group # 5

The Importance of Communication: Improving your Interactions with Your Loved Ones

The Content of Good Communication

Talking Points (Short Version)

Closure Notes

Begin with recognition that this is the final meeting of the group.

Thank them for their participation in the group and in REACH.

The exchange of phone numbers and/or contact information may occur at this point, if not already completed.

At the beginning or end of the session, leave time to recap the topics that you have presented in the sessions that have been completed.

At the end of the group, again thank them for their participation. Any small comment about some special moment shared with the group may be appropriate at this time.

Encourage them to attend a support group in the community, if they don't already attend one.

Remind them of session two where we discussed the Alzheimer's association and the Area Agencies on Aging as places to find out where these groups are located.

Remind them that they will still be seeing the other REACH personnel and they can discuss any problems or concerns with their interventionist.

Make sure that you begin the ending script a few minutes early to give them time after you are done to say goodbye to each other.

The Importance of Communication: Improving Your Interactions with Your Loved Ones

Priority Talking Points

Barriers to Communication

Communicating with a person with memory loss can be difficult. You may find that your family member has trouble finding the right word or staying on track with a conversation. The first step in improving communication is to make sure your family member can see and hear you clearly – you may need to have his/her vision and hearing checked.

How to Improve Your Communication

- **Reduce Distractions**

Removing distractions may be as **simple** as making a few changes in your home environment. Making changes may involve:

- (1) *Try turning the television or radio down or off before you trying to talk to your family member. Sometimes reducing or getting rid of noise and visual distractions is helpful.*
- (2) *If you have difficulty keeping your loved one's attention, on the conversation or task at hand, stop, walk away for a little while, use the signal breath, and try to talk to your family member again after a few minutes.*

- **Make Your Messages Positive and Easy to Understand.**

- (3) *Keep words and sentences short.*
- (4) *Give your family member simple instructions one step at a time. For example, instead of saying, "Go brush your teeth," you might say, "Go into the bathroom." Then, "Pick up your toothbrush." Then, "Put toothpaste on the brush."*
- (5) *Ask questions one at a time.*
- (6) *Repeat the question or statement more than once if needed.*
- (7) *Speak in positive terms. Tell your family member what you would like him to do instead of what you want him to stop doing. For example, instead of saying, "Stop trying to get up.", you might say "Please stay in your chair. Let me help you."*
- (8) *Use signs, labels, and written reminders in the early stages of the disease to help get the message across.*

Make Use of Nonverbal Cues and Information.

- (1) *Speak calmly in a gentle tone and in a low-pitched voice. This is reassuring and the lower pitch of your voice is easier to hear.*
- (2) *Maintain eye contact and stay near the person.*

- (3) *Touching your family member on the arm can help let her know you are interested in what she is saying.*
- (4) *Show your family member what you want them to do (e.g., eating, brushing teeth).*
- (5) *Draw, point at, or touch the thing(s) you are talking about.*
- (6) *Smile, touch, or hug. It is often reassuring. However, if your family member doesn't recognize you, you may need to remind them of who you are before hugging or communicating.*
- (7) *Remain as calm as possible as your loved one may pick up on your frustration.*

Help Your Family Member Communicate With You.

Your loved one **wants** to communicate with you but needs your help. It can be very frustrating for him or her to be unable to find the right words to express feelings. Different things may work for different caregivers. These are some problems your family member may have and some suggestions you could try.

- **Trouble Finding the Right Word or Words**

- (1) *Offer a guess or supply the correct word. Remember that the words that your family member says may not reflect exactly what she wants.*
- (2) *Give your family member time if he is feeling upset and is having trouble explaining his frustration or anger in words. If this happens, don't push for words.*

- **Saying Words That Don't Make Sense**

- (3) *Be aware that your family member may repeat words or phrases because those are the only words he can remember. The words your family member repeats may not have anything to do with what is going on at that time.*
- (4) *Be tolerant of your family member if she uses swear words that she has never used before. This is part of the disease and your family member is not doing this on purpose.*

Reinforce use of Caregiver Network.

Information/Tips → Communication → Your loved one

Other Helpful Information and More Detail if Needed on Communication

Detect and manage vision problems that make communication more difficult.

- (1) *Reduce or get rid of visual distractions in your home.*
- (2) *Arrange things in your house so it is easier for family member to see.*
- (3) *Try putting bright picture labels or signs on drawers and room doors.*
- (4) *Vary the level of light in the room to see what makes your family member the most comfortable.*

- (5) Allow time for your family member's eyes to adjust when there is a sudden change in the level of lighting.*
- (6) Make sure your family member can see your face when you speak.*
- (7) Take into account that some vision problems may be caused by the disease and not by impaired vision.*
- (8) Keep in mind that patients with vision problems may have trouble seeing nonverbal signals.*
- (9) Pay attention to vision problems.*
- (10) Remember that poor vision (near-sightedness or far-sightedness) can be treated or corrected with glasses.*
- (11) Take your patient to the eye doctor if he wears glasses to see if he needs his prescription adjusted.*
- (12) Bring your family member's glasses or contact lenses to the eye doctor when you go for his check-up.*
- (13) Report any new problems in vision to your family member's doctor.*
- (14) Keep in mind that your family member may still have vision problems that cannot be corrected even after the doctor's visit. Arrange your routine and environment so you and your family member can cope with vision problems.*

Detect and manage hearing problems.

- (1) Look for signs of hearing loss such as your patient seeming removed from you or what is going on around her.*
- (2) Consider that your family member may not have a hearing problem at all.*
- (3) Make sure your family member can see you when you talk.*
- (4) Keep eye contact with your family member when you are speaking.*
- (5) Speak slowly and pronounce each word clearly.*
- (6) Try to speak up when you talk to your patient but avoid shouting or sounding too shrill.*
- (7) Use short, simple words and sentences when you talk to your family member.*
- (8) Monitor signs of hearing loss in your patient, and describe them to the doctor if you notice them.*
- (9) Remember that hearing aids make **all** sounds louder even the sound of voices or noises like the hum of the refrigerator.*
- (10) If your family member already wears a hearing aid, check to make sure it works, is turned on, and is loud enough.*
- (11) Determine if your family member has only one good ear and speak on that side.*

Script for Support Group # 5

The Importance of Communication: Improving your Interactions with Your Loved Ones

The Content of Good Communication

(Long Version)

The Importance of Communication: Improving Your Interactions with Your Loved Ones

Our topic today will focus on the importance of communication. Communication involves the process of sending a message from one person to another person who receives the message and understands the concept. Communication is often difficult with an Alzheimer's patient because Alzheimer's disease causes problems with remembering things, paying attention, focusing, and making decisions. All of these skills are important for good communication. The patient may have a hard time understanding and remembering what others say. The patient may also have difficulty turning his own thoughts into words. Often the patient may feel lonely and cut off from the world.

Barriers to Communication

Patients may have other reasons that cause barriers to their ability to communicate and keep them from understanding what has been said to them. For instance, here are some valid reasons for the patient having trouble with communication:

- **Trouble with eyesight**
- **Hearing Problems**
- **Fear**
- **Memory Problems**
- **Too much going on with the task at hand**
- **Difficulty paying attention**

How to Improve Communication

Even though your loved one has Alzheimer's disease, there are still effective strategies that can be used to improve communication.

The following are suggestions that are easy to do and can improve communication with your loved one with Alzheimer's disease:

Reduce Distractions

*Removing distractions may be as **simple** as making a few changes in your home environment. Making changes may involve:*

- (1) Setting aside a quiet place in your home that is just for talking.**
- (2) Reducing or getting rid of visual distractions.** For example, cover light bulbs with a shade or turn them off.
- (3) Keeping background noise as low as possible.** For example, turn off or turn down the radio or television when you talk.
- (4) Trying to keep your words and the way you say them agreeing with how you feel and what you want.** "Mixed" messages can be confusing to the patient.

- (5) Making an effort to keep your distance from the patient so you are not too close to him and make him feel uncomfortable. If this is the case, talk to the patient from an arm's length away.
- (6) Trying to keep the patient's attention on the conversation or task at hand. If you're having trouble with the patient's attention span, **stop** and try to talk to the patient again after a few minutes.

Make your messages positive and easy to understand

This is not as hard as it may sound and practice will help. Try these methods:

- (1) Keep words and sentences short. Stick with words that the patient knows.
- (2) Give the patient instructions one step at a time --when asking the patient to do a task. Break up the task into small steps that the patient can understand.

For example, instead of asking the patient to do a whole task like getting dressed, ask him only to put on his shirt. When he's put on his shirt, then move on to his trousers. As the illness worsens, you will need to make the steps even smaller. For instance, "put your arm in here," as you help the patient guide one arm into the sleeve of a shirt.

- (3) Ask questions one at a time. The patient needs more time to answer questions. She may become more confused if rushed to give an answer.
- (4) Repeat the question or statement more than once if needed. Try to use the same words as you do the first time you asked the question.
- (5) Speak in positive terms. Tell the patient what you would like him to do instead of what you want him to do.

For example, say "Put the toothpaste on the toothbrush," instead of, "Don't put the toothpaste in the sink."

- (6) Try not to say things in front of the patient you do not want her to hear. In the earlier stages, she may be able to understand more of what you say than she can tell you.
- (7) Use signs, labels, and written reminders in the early stages of the disease to help get the message across to the patient.
- (8) Make every effort not to challenge or argue with the patient about hallucinations or delusions. These are a natural and common effect of the disease. If the patient is frightened by a hallucination, reassure him and redirect his attention.
- (9) Identify yourself at the start of all communication with the patient. Address the patient by name frequently and maintain good eye contact.

Help the patient communicate with you

*The patient **wants** to communicate with you but needs your help. Keep these suggestions in mind:*

- (1) Offer a guess or supply the correct word if the patient is having "word finding" difficulties. If this upsets the patient, do not offer a guess.
- (2) Repeat back to the patient what you think she is saying to be sure you understand.

For example, say “Are you thirsty now?” or “Do you want to rest for a while?”

- (3) Repeat the last word the patient said, if the patient forgets what she is saying in mid-sentence. If she can't continue, re-cue her by asking a question that pertains to what she has been saying.
- (4) Remember that the words that the patient says may not reflect exactly what she wants.

For example, “Go home” could mean, “I feel nervous here and I need to be comforted.” Ask her if that is what she wants.

- (5) Be aware that the patient may repeat words or phrases because those are the only words he can remember. The words the patient repeats may not have anything to do with what is going on at that time.
- (6) Offer support to the patient when he cries or becomes angry because he cannot find the right words to tell you something. It can be very frustrating for the patient to be unable to find the right words to express feelings.
- (7) Be tolerant of the patient if she uses swear words that she has never used before. Keep in mind that this is part of the disease and the patient is not doing this on purpose.
- (8) Show patience with the patient if it takes him longer now to understand and/or respond to your questions and statements. You may have to wait for a few minutes.
- (9) Give the patient time if he is feeling upset and is having trouble explaining his frustration or anger in words. If this happens, don't push for words.

Make use of nonverbal cues and information

Communication consists of more than words. There are ways of communicating that can be meaningful and personal. Try these suggestions:

- (1) Speak calmly in a gentle tone and in a low-pitched voice. This is reassuring to the patient and lower pitches are easier to hear.
- (2) Maintain eye contact and stay near the person. Eye contact and facial expression show the patient you are listening.
- (3) Touching the person on the arm can help let the patient know you are interested in what he is saying.
- (4) Watch what the patient does for your cue before making statements or giving instructions. Never assume the patient understands what you are saying or doing, even if he says, “I understand.” Actions may show more clearly than words what the patient understood.
- (5) Act out any activity you want the patient to perform (e.g., eating, brushing teeth). This is sometimes easier to show and may be a better form of communication with the patient.
- (6) Draw, point at, or touch the thing(s) you are talking about.
- (7) Smile, touch, or hug the patient. She may understand gestures more than words. Non-verbal communication can be very useful when you are expressing emotion to a patient.
- (8) Understand what he is trying to say. As the disease goes on, the patient will have more trouble with spoken communication. Eventually, she may lose the ability to speak.
- (9) Remain as calm as possible as the patient may pick up on your frustration. Express your feelings later (e.g., in a diary or letter, or while talking with a family member or friend).

Detect and manage vision problems that make communication more difficult

Vision is an all-important sense for the Alzheimer's patient as he is no longer able to rely on his words to convey meaning. He relies on seeing you and the world around him to explain things to him. If the time arrives when the patient is no longer able to speak, the patient's ability to see you become even more important. Follow these simple suggestions to make it easier for you and the patient:

- (1) Reduce or get rid of visual distractions in your home. Remove unnecessary clutter and decorations.
- (2) Arrange things in your house so it is easier for the patient to see. For example, contrasts between light walls and a dark door may help her to see the doorway better.
- (3) Try putting bright picture labels or signs on drawers and room doors. Do this for rooms that are used often, such as the bathroom. Check and make sure that labels are large enough to be seen easily. Signs should be at the height of the patient's normal line of vision. For signs with words, use light letters on dark background.
- (4) Vary the level of light in the room to see what makes the patient the most comfortable. Older persons may need brighter lights as they have trouble seeing in dim light.
- (5) Allow time for the patient's eyes to adjust when there is a sudden change in the level of lighting.
- (6) Make sure the patient can see your face when you speak. Try not to sit or stand to one side. Do not place a glaring light or bright window behind you.
- (7) Take into account that some vision problems may be caused by the disease and not by impaired vision. The disease may make the patient unable to understand or remember what he has seen.
- (8) Keep in mind that patients with vision problems may have trouble seeing nonverbal signals. For example, a shoulder shrug or a nod of the head may not be enough to communicate with a patient with vision problems.
- (9) Pay attention to vision problems. One sign of vision problems could be increased clumsiness, such as falling or bumping into things.
- (10) Remember that poor vision (near-sightedness or far-sightedness) can be treated or corrected with glasses.
- (11) Take your patient to the eye doctor if he wears glasses to see if he needs his prescription adjusted.
- (12) Bring the patient's glasses or contact lenses to the eye doctor when you go for his check-up.
- (15) Report any new problems in vision to the patient's doctor. Do this even if the doctor does not find any correctable eye problems.
- (16) Keep in mind that the patient may still have vision problems that cannot be corrected even after the doctor's visit. Arrange your routine and environment so you and the patient can cope with vision problems.

Detect and manage hearing problems

Hearing problems can also hinder communication. It is difficult to determine if an Alzheimer's patient has a hearing problem or if they cannot understand what you are saying. Pay attention to these suggestions that may answer hearing questions you have about your Alzheimer's patient:

- (1) Look for signs of hearing loss such as your patient seeming removed from you or what is going on around her. She may seem distracted or ask constantly for you to repeat what you say.
- (2) Consider that the patient may not have a hearing problem at all. He may be able to hear you, but have trouble responding to you because of the disease.
- (3) Make sure the patient can see you when you talk. Always approach the patient from the front and face her directly, and sit close enough for the patient to see your face and mouth. Try to keep your hands away from your mouth when you are talking. Check to make sure that no bright lights are shining in the patient's face.

- (4) **Keep eye contact** with the patient when you are speaking. Often a gentle touch on the arm or hand, if the patient allows it, will help you make eye contact. Begin talking only after the patient is focused on you.
- (5) **Speak slowly and pronounce each word clearly.** If your words run together, the patient will have trouble understanding you.
- (6) Try to speak up when you talk to your patient but avoid shouting or sounding too shrill. This will make you sound upset or angry and will confuse the patient.
- (7) **Use short, simple words and sentences** when you talk to the patient.
- (8) **Monitor signs of hearing loss** in your patient, and describe them to the doctor if you notice them. The hearing loss may be partly due to a hearing loss that can be treated or corrected with a hearing aid.
- (9) **Remember that hearing aids make **all** sounds louder** even the sound of voices or noises like the hum of the refrigerator. This increased volume caused by the hearing aid may be confusing and irritating to the patient. Often people who get a hearing aid want to stop using them at first because noises seem so loud. Allow the patient time to get used to the hearing aid. Doctors will often advise patients to wear the hearing aid part of the day at first and gradually wear it more.
- (10) If the patient already wears a hearing aid, check to make sure it works, is turned on, and is loud enough.
- (11) **Determine if the patient has only one good ear and speak on that side.**

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