

Session 1: Introduction to the Intervention

I. Background

Introduction: I want to tell you a little bit about what REACH II is and how it was developed. Some of this you heard about when you signed the consent form before the interview, so I'll just go over it briefly.

- A. REACH II is a national, multi-site research project. This means that the REACH II project is going on in five different cities at one time with caregivers just like you. These cities include: Birmingham, Memphis, Miami, Palo Alto, and Philadelphia (name your own city first).
- B. REACH II is based on several years of research with hundreds of caregivers like yourself. These caregivers tried a number of different approaches for caring for loved ones and worked with us to figure out which were the most helpful. We took the most helpful approaches and put them into a single package for the REACH II project. We think that this combination of approaches can be useful to caregivers like you; that's why we developed the REACH II research project. We want you to feel confident that you are providing the highest quality of care possible for (CR) while maintaining your physical health and a positive mood.
- C. Because this is a research project, we need to follow this plan exactly how it was designed. Therefore, sometimes we may seem a little inflexible, or may ask you to follow specific instructions. Following the program as it was designed is the only way that we will know if the program is helpful to caregivers.
- D. One of the really great things about this project is our team work approach to solving problems. I work with a whole team of people right here in (your city) who will provide ideas, support, and guidance as you and I work on problems that you face in your daily caregiving. Furthermore, our team is in contact with the teams in the other cities, so we have even that much more support to help you solve your caregiving problems.

II. General Overview of Timeline and Contacts

Introduction: We have a great deal of information to share with you. However, we know you already have a very busy schedule. For this reason, we designed this program so that we can bring it to you. The entire project will be made available for you to access from your home. Here is a copy of the timeline that we would like to follow over the next six months. We can change this schedule if necessary since situations may come up. This gives you an idea of how we'd like to spend the next six months together. *Give CG an outline of the timeline for the study.*

- A. **Individual Contacts.** During the next six months, you and I will have a total of 12 sessions. Nine of these sessions will be face-to-face meetings in your home. Three of these meetings will be over the telephone. Face-to-face meetings usually last between 1 ½ to 2 hours; phone meetings are about ½ hour long. We can change a home meeting to a phone meeting or vice versa if we think it is necessary.
- B. **Support Group Contacts.** You will also be involved in 5 support group meetings during the next six months. Support group meetings occur over the telephone, so you will not have to leave your home to attend. Each support group meeting lasts about an hour.

- C. Follow-up.** At the end of the six months, someone will come to your home again to do an interview that is similar to the one you had a few days (weeks) ago.

III. Overview of Areas Addressed in the REACH II Intervention

Introduction: There are five major areas that we have found to be important to cover when working with caregivers. Because so many caregivers have responded positively to these topics in the past, we included all of them in this research project.

- A. Safety.** Safety issues were one of the first things we considered when designing REACH II. As a person with Alzheimer's moves to more advanced stages of the disease, safety becomes increasingly important. Each person with Alzheimer's is different, though, so it's hard to predict what kind of safety problems you will be up against as your (CR's) disease progresses. Because safety is such an important issue, we provide many different educational materials and we spend a significant part of the next session discussing possible safety situations that might impact you and your (CR).
- B. Health.** Health issues are the second area we address; this includes both your health and that of your (CR). Often, as a loved-one progresses through this disease, he/she has increasing healthcare needs. It can be hard to keep track. At the same time, caregivers tend to neglect their own healthcare needs because they are so busy taking care of their loved-ones. We want to help you find ways to make it easier to stay on top of what both you and (CR) need for staying healthy.
- C. Social and Emotional Support.** The third area we cover in REACH II is that of social and emotional support. Most caregivers report that, at least sometimes, they feel emotionally exhausted and somewhat isolated from others. An important element of the REACH II project is to link caregivers to each other for ideas and emotional support. Furthermore, we provide resource information to help you explore services that might be available to you.
- D. Caregiver Well-Being.** Just like we want to help you take care of your health, we also want to help you find ways to manage your mood and emotions. This is the fourth area we address in this project. Starting in the third session, we spend time in several of the meetings discussing and trying different methods to help you manage tension, moods, emotions, etc. We have lots of different ideas that have been helpful to other caregivers, and what's even better is that we can individualize many of them to really fit for you. You'll get to try each method, and by the end of the project you will have several tools to draw upon for managing your moods and emotions.
- E. Problem Solving.** Finally, we know that there are many challenges to caregiving, and that these challenges are different for each person's situation. For this reason, we start in Session 3 to look at your individual concerns surrounding caregiving. For example, some caregivers become distressed when their relative asks the same question over and over. Some caregivers have to care for a loved one who tries to leave the home and gets lost in familiar surroundings. Using the information from your interview to help guide us, you and I will talk about the most difficult or distressing situations that you are facing. We'll work on these one at a time, and we'll get ideas and guidance from the REACH II team as we build plans for addressing each concerns. By working this way, we can design a program to address the unique issues that you face in your situation.

IV. Components of the Intervention

Introduction: So, the question is, how are we going to bring all of this information to you? Rather than me describing it to you, let's just get started!

A. Caregiver Notebook (15 minutes)

1. **Introduction:** The first thing I have for you is the CG Notebook. Every part of our program is presented in the Notebook. We are excited about the Notebook component of this project, because it not only contains lots of great information, but it also serves as a "central location" where you can organize all of your REACH II materials. It's yours to keep even after you complete the project, and by that time it will be full of the personal materials that you and I will develop for you during our time together.
2. **Review of Notebook:** *Go through each section of the Notebook. Point out that the "REACH II Caregiver Network" section will be discussed in detail next, and that the "Safety Issues" and "Taking Care of Health Issues" sections will be discussed further in the next session.*
3. **Identify a place for the CG to keep the Notebook:** Where is a good place in your home that you can keep the Notebook so we can refer to it in future sessions and any other time you might need it?

B. REACH II Caregiver Network and Screenphone Installation (30 minutes)

1. **Introduction:** You might recall someone from the project talking about a special telephone network and screen phone (during the screening call and when signing the consent form). The phone will cost you nothing and it works like a regular telephone. Let's install the CG Network and go over how we will use it in the coming months. Once we get the phone set up, I will demonstrate each feature of the CG Network and then we can practice together. Here is a help card to guide you. At the end, I'll watch you go through the steps and ask you to complete a questionnaire. The questionnaire may seem like a test, but it's actually a good way for me to know if I did my job in covering all of the feature and uses of the CG Network with you.
2. **Details of the network:** *Use the REACH II Caregiver Network Caregiver Training Manual (in the REACH II Caregiver Network User Manual, Section 3) to introduce and teach the features of the network. Complete the "REACH II Caregiver Network Training Observation Checklist for Caregivers" and have CG complete the "REACH II Caregiver Network Training Questionnaire" ("Now I'd like to watch you use all the features of the system and complete the training questionnaire").*
3. **Respite Function:** I'd like you to begin thinking about how you might use the respite feature of the CG Network. Do you have any thoughts about what friends/family members you may like to ask to create respite messages?

C. Online Support Group (10 minutes)

1. An important part of the REACH II program is the "on-line" monthly support groups. Support groups are a valuable resource for caregivers. They allow you to meet and interact with other caregivers who share your concerns and responsibilities. They will also enable you will to exchange information, discuss potential solutions to problems, and offer encouragement and support to others.
2. Support groups usually meet in the community and are sponsored by different organizations, local hospital or community organizations. For this project the support

groups will occur using the REACH II Caregiver Network so you will not have to leave your home to “attend” the meeting.

3. The groups will begin in the next 4 or 5 weeks and will meet on a monthly basis for one hour in the morning or afternoon. We will try to schedule your group meeting at a time that is convenient for you.
4. In addition to yourself the groups will involve a group leader and 4 or 5 other caregivers from other parts of the country who are also participating in the REACH program. This will give you a chance to interact with other people who live in different cities.
5. Once the groups are formed and the meeting times are established, the network will automatically call you to remind you of the meeting time and date. In addition, you will be automatically contacted at the time of the meeting so it will be very easy for you to attend.
6. During the first group session, your group leader will discuss the structure of the group and guidelines for how the group will work.
 - a. In general, the group is structured with about 5-10 minutes in the beginning to just sort of “check in” with everybody. During the 20 minutes following the check-in, the group leader will present informational material that caregivers have found to be useful in the past. The last 30 minutes or so are set aside for an open group discussion of the topic and/or other issues that the members would like to discuss.
 - b. The information shared in the group is confidential, which means that what is discussed in the group is not shared outside of the group. There are, however, two exceptions to this rule. The first is if the group leader can't reach a group member during the support group time. In this case, the group leader would contact the people on staff who could help figure out what happened. This staff person might be a technical support person or the group member's interventionist. The second exception is if the group leader has a specific concern about a caregiver in the group. For example, if a caregiver seems to be in a crisis situation. In this instance, the group leader might contact the person's interventionist or the project coordinator. Even in these instances, however, information about caregivers is never shared outside the staff at the REACH II project.
7. I just want to emphasize again that it is really important for you to participate in the groups. Can you think of any problems that you might have with attending? What questions do you have about the Support Group?

D. Well-Being and Problem Solving Components (20- 30 minutes)

1. **Introduction:** Now, there are two other very important parts to this intervention, the one that targets your mood and emotions, and the one that targets specific problems you are having with your (CR). We won't talk about these in detail today, because I don't want to overwhelm you with information. However, we will start laying the groundwork today, and by the time we start these components in the third session, we will really be ready! The way for us to get started is to take a few minutes for you to tell me your story. Even though we gathered a lot of information from you at the interview, I would like to hear about your story in your own words.

2. Caregiver Story (5-10 min) – *Use gentle probes to elicit caregiver story. For example:*
 - When was your (family member) first diagnosed with dementia?
 - How did you know?
 - How are things going?
 - What is your day like?

3. Review RPW (15-20 min) - Now I'd like to review the areas of caregiving concerns that were identified from the first home interview with you. I'd like for you to be thinking about particular concerns you would like to target during the course of the project. We'll start talking about the first concern in our third session together. *Review the RPW, tying it back to the CG story whenever appropriate. You could say something like: At the initial interview, you indicated that (NAME PROBLEM) is upsetting. Is this an area of concern for you now?*

V. Closure to Session I (10 min)

- Let's briefly go over what we discussed during today's session.

- *Confirm date and time for next session.*

- I'd like for you to review the Caregiver Notebook and when I come back, we can discuss any questions that you might have or discuss what was helpful to you.

- Remember that the Caregiver Network user card is provided to help you become familiar with the CG Network. Before we meet again, I would like for you to begin using the Caregiver Network so we can discuss what you found helpful or may have questions about.

- I know that you are very busy in caring for your loved one and we appreciate you taking the time to work with us. Some of the topics we discussed today will take time to learn. But with a little practice, we hope that you will become comfortable using the program we will develop together over the coming months and that it will be helpful to you in your day-to-day life as a caregiver to your loved one.

- Do you have any questions about anything we covered today?

REACH II Support Group Introduction

1. Welcome statement: *Welcome everyone to the REACH II support group. I am very pleased to have all you in this group and I look forward to having many good discussions on issues related to being a caregiver.*

2. Introduce yourself and other REACH II facilitators on the call.

My name is _____ and will be working with you over the next five months.

{Today we are also joined by (one or several) group facilitator(s) from our other sites (Birmingham, Memphis, Miami, Palo Alto and/or Philadelphia) who are in training and will be listening in to our group.}

3. What is a support group? *Let me begin by talking about what is a support group.*

Support groups are a wonderful way to meet and interact with other caregivers who share your same situation and concerns. They provide caregivers with an opportunity to exchange, discuss potential solutions to problems, and offer encouragement and support to others.

4. What is a REACH II support group? *The REACH II support group is different from a regular community support group in that:*

- You don't have to leave your home! We will call you.
- You'll get to meet other caregivers who live in different cities.
- If you need to step away for a few minutes just put the phone down and return to the group when you're ready.

5. Timeline of the REACH support group. In addition:

- There will be 5 meetings, one each month for the next 5 months
- The meeting dates and time will be standard
- Meetings are usually for an hour.

6. Format of the REACH II support group. *All of the REACH II support groups will begin:*

- Firstly with a 5-10 minute check-in period
- Then, during the following 20 minutes or so of each group, I will be presenting information on a specific topic.
- There are a total of 5 Topics:
 1. Taking Care of Yourself
 2. How to Access Community Resources
 3. How to Communicate with Health Care Providers and Service Providers
 4. Communicate with Family and Friends
 5. Good Communication with your Loved One

- We will begin with Taking Care of Yourself today.
- The final 35 minutes or so are reserved for open discussion – CGs can share their thoughts, feelings and experiences (related to the monthly topic).

7. Rules of the group. *I would also like to take this opportunity to go over some basic group rules:*

- 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. Please do not share the names of your fellow caregivers with anyone. There are, however, two exceptions regarding confidentiality:
 - The first is if I can't reach a group member during the support group time. In this case, I would contact the people on staff who could help figure out what happened. This staff person might be a technical support person or your interventionist.
 - The second exception is if I have a specific concern about a caregiver in the group. For example, if a caregiver seems to be in a crisis situation. In this instance, I might contact your interventionist or the project coordinator. Even in these instances, however, information about caregivers is never shared outside the staff at the REACH II project.
- Be on time to the group. If you are not able to start on time send me a message by using the Caregiver Network and let me know when to try to include you in the group.
- Show respect and courtesy to each other. That is, wait for the other person to finish speaking before sharing, express your thought without hurting or imposing on others, and value everyone's opinions, etc.

8. Introduction of group members: *Let's get to know each other – Please briefly:*

Introduce yourself – Give your name, where you are from, who you are caring for, how long have you been a caregiver, and one thing you would like to learn in this group.

9. Today's topic: Let's begin with today's topic: "Taking Care of Yourself".

Notes for the facilitator:

- *After you go over the material (didactic for 15-20 minutes) encourage the group to participate in an open discussion of the topic.*
- *Secure the next meeting day and time.*
- *Encourage them to use the Caregiver Network*

Good luck!

**3 Month Phone Call
Script for Telephone Contacts**

Script to be read to caregiver is in bold. Script in italics are notes to TCC, not to be read to caregiver.

A. Script for 3 month Phone Call

“Hello, Mr./Mrs. _____ . This is _____ calling from the REACH II Project. “Is this a convenient time for us to talk for a few minutes?”

If the answer is yes, then proceed with script.

If this is not a convenient time, reschedule call. Date _____ Time _____

Great, how are you doing today? I am calling to check in with you and to thank you once again for your participation in this national study. As you know, this project is evaluating different ways of helping families care for individuals with memory problems. We are trying to get a better understanding of the experiences of caregivers so that we will be able to develop new improved ways of helping caregivers. At this point there are over 100 (*check recruitment number*) caregivers who are participating in this study throughout the country. As you may recall from our previous call/letter, you will be receiving two telephone calls from us, just to check-in and see how you’re doing and to make sure we have your correct phone number and address. This is the first of these two calls.

Let me confirm/verify that your address is: _____

Also, remember that you will be able to participate in a workshop that will provide you with more information about caregiving and resources available in your community to help you and your (CR). You can choose to have the workshop in your home or can join other caregivers at (location). Either way the workshop will take place in about _____ months from now. I’d also like to thank-you for completing the baseline assessment interview and remind you that we will be asking you to do this again in about 3 months from now.

Do you have any questions about the project?

*(If the caregiver requests information or help with a particular problem or issue such as wandering refer them to the Educational Materials that they received in the mail and provide them with the telephone numbers of the Alzheimer's Association and the Area Agency on Aging. Use the caregiver request scenario as a guide. Remember that the intent of this call is to briefly "check-in" with the CG, and to provide minimal nonspecific support. If the caregiver presents a situation or provides information which implies or indicates that the caregiver or care recipient is in emotional or physical distress and/or possible danger (e.g. physical abuse or depression) follow the protocol for caregiver/care recipient adverse events. State to the caregiver, **You seem very upset/ or You must be very upset by this. I am going to have my supervisor, who is a member of the research team call you back to speak about this more. She/he will call you today/tomorrow.**)*

Thank-you so much for your time. I want to remind you that we will be calling you to check-in again in about 8 weeks.

**5 Month Phone Call
Script for Telephone Contacts**

Script to be read to caregiver is in bold. Script in italics are notes to TCC, not to be read to caregiver.

B. Script for 5 month Phone Call

“Hello, Mr./Mrs. _____ . This is _____ calling from the REACH II Project to see how you are doing. Is this a convenient time for us to talk for a few minutes?

If the answer is yes, proceed with script.

If this is not a convenient time, reschedule call. Date _____ Time _____

Great, how are you doing today? Just to remind you this is the second of two check-in calls we are making to you. Currently, we are finalizing our plans for the workshop that you will receive from us. The workshop will be occurring about _____ month from now. To help make sure that the workshop is helpful to you I’d like to ask you some questions.

- 1. The workshop will take about 2 hours of your time. What day and time would be most convenient for you?**
- 2. Would you prefer to have the workshop in your home or at (NAME LOCATION)?**
- 3. I am going to read you a list of topics we might cover. Which ones are of most interest to you:**

- _____making your home safe**
- _____managing problem behaviors**
- _____strategies to manage your own stress**
- _____how to communicate effectively**

I can’t guarantee that we will be able to cover everything that you are interested in but we will try to cover the main topics and issues.

I’d also like to remind you that someone from the study will be contacting you again in the next few weeks to schedule your follow-up interview.

Thank-you for your time.

*(If the caregiver requests information or help with a particular problem or issue such as wandering refer them to the Educational Materials that they received in the mail and provide them with the telephone numbers of the Alzheimer's Association and the Area Agency on Aging. Use the caregiver request scenario as a guide. Remember that the intent of this call is to briefly "check-in" with the CG, and to provide minimal nonspecific support. If the caregiver presents a situation or provides information which implies or indicates that the caregiver or care recipient is in emotional or physical distress and/or possible danger (e.g. physical abuse or depression) follow the protocol for caregiver/care recipient adverse events. State to the caregiver, **You seem very upset/ or You must be very upset by this. I am going to have my supervisor, who is a member of the research team call you back to speak about this more. She/he will call you today/tomorrow.**)*