CONTROL GROUP

Following baseline interview, caregivers will be assigned to the intervention or control group. The Project Manager or Telephone Contact Control (TCC) staff will contact caregivers assigned to the control group to inform them of their group placement. The following script is used for this telephone call. If the caregiver can not be reached after five attempts have been made, the control group letter with the educational material is sent out without first making phone contact. No additional attempts at phone contact are made then, until the 3 month call.

Script to inform Caregiver of Control Group Assignment following Randomization

The following call should be made by a member of the project staff in such a way as to assure that the Interviewer remains blind to treatment condition

Hello, this is ________________________ from ______________________ regarding the REACH II project. Is this a convenient time to talk? This will only take a few minutes.

If no: When would be a more convenient time to call you back?

If yes: I am calling to inform you that you have been assigned, by chance, to Group B. This is the group in which you will receive 2 phone calls to check in on you during the next six months. At the end of the six months, you will be invited to participate in a workshop that will take place in your home or at (NAME LOCATION). At this workshop, you will be told about community programs, helpful information about caregiving and memory loss, and new ways of managing behavior problems, your own stress and other areas of caregiving difficulty. I’m going to put a package of educational materials in the mail for you this week, and we will be calling you back within the next several months to see how you are doing. Do you have any questions? Thanks again for your involvement with this important project.

Control Group Activities

Caregivers in the control group will a) receive education materials; b) receive two telephone contacts, the protocol of which follows, and 3) be invited to participate in a workshop in their home or at a central location following completion of the 6-month follow-up (each site will design its own workshop that will include materials and activities provided to intervention group).

Educational Materials

Education materials are mailed to the caregiver following baseline and randomization to the control group. Materials include the following:

1. Alzheimer’s Disease Facts*  
   - Published by Alzheimer’s Association: 1-800-272-3900  
     - Order form enclosed  
     - English version: item # PR617Z  
     - Spanish version: item # ED227ZS  
     - $10/100

2. ‘Fact Sheet: Dementia’*  
   - Published by Family Caregiving Alliance: 1-415-434-3388  
     - Order form enclosed  
     - Specify language on order form  
     - $1/each
3. Fact Sheet: Caregiving’*
   - Published by Family Caregiver Alliance: 1-415-434-3388
     - Order form enclosed
     - Specify language on order form
     - $1/each

4. ‘Stress and the Caregiver’*
   - Published by Journeyworks Publishing: 1-800-775-1998
     - Order form enclosed
     - English version Title #: 5071
     - Spanish version Title #: 5238
     - Prices:
       - $16/50
       - $54/200
       - $125/500
       - $225/1000

5. Home Safety for the Alzheimer’s Patient’*
   - Published by ADEAR: 1-800-438-4380
     - Order form enclosed OR mail order information and check or money order to:
       - The ADEAR Center
       - PO Box 8250
       - Silver Spring, MD 20907-8250
     - English version catalog #: A-11
     - Spanish version catalog #: A-21
     - $2.50/each, postage and handling included in price

*represents materials available in both English and Spanish
Control Group Telephone Contact Protocol

The two telephone contacts made to the caregivers assigned to the control group are intended as an opportunity to briefly “check-in” with the CG, to remind the CG that a skills workshop is forthcoming and to provide minimal nonspecific support if elicited as a way to maintain CG in the study. The support provided by the TCC staff who conducts the call consists only of active listening and empathic comments when appropriate. TCC staff neither provides additional information on dementia, nor provides recommendations or strategies. If the caregiver raises a specific concern, the TCC staff reminds the CG of the educational material sent to them after they entered the study and encourages the CG to contact the Alzheimer’s Association or Area Agency on Aging for more information or assistance. The TCC staff can give the CG the telephone numbers to these agencies.

I. Control Group Telephone Contact Time Point Windows

The control group telephone contacts occur at 3 months and 5 months following randomization of a participant to the control group. The 3 month and 5 month due dates are generated by the Coordinating Center following randomization and shared with the sites each month in the form of a data report. The phone calls must be completed within a 4 week window—two weeks prior to the due date through two weeks after the due date.

II. General Guidelines for Telephone Contact

1. Allow telephone to ring 9 times to give caregiver an opportunity to answer.

2. TCC identifies himself/herself and states the reason for the call.

3. Discuss with caregiver if this is a convenient time for a 10 minute conversation. If caregiver states this is not a convenient time, schedule a more convenient time for the call.

4. Use the Delivery Assessment Form to Record “Beginning Time”. The target duration of the call is 10 minutes. The telephone conversation is timed with watch or stop clock. If the caregiver leaves the telephone conversation for any reasons, stop the watch/clock. Once caregiver returns, start watch/clock again where it was stopped.

5. Use the Delivery Assessment Form to Record “Ending Time” of conversation and duration time of the call.

III. Protocol for Caregiver/Care Recipient Adverse Events

As noted, the purpose of the TCC call is to briefly “check-in” with the caregiver, to remind the CG that a skills workshop is forthcoming and to provide minimal nonspecific support if elicited as a way to maintain CG in the study. The TCC staff uses the scripts to engage the CG and receive input from the CG on the skills workshop. The TCC staff responds with empathy and active listening but does not provide information or any other type of intervention. However, caregivers may present crisis situations that ethically require more follow-up than is within the parameters of the TCC call (caregiver presents a situation or provides information which implies or indicates that the caregiver or care recipient is in extreme emotional or physical distress and/or possible danger). In these situations, the TCC staff first must recognize an adverse event situation and then follow the adverse events protocol for the CG/CR described in the Manual of Operations (MOP). The protocol requires the PI or PI designee to contact the CG to follow up on the adverse events and complete the adverse event forms. These forms must be submitted to the Coordination Center within 24 hours of learning of an adverse event.
The TCC staff’s first response to the CG expressing a desire for information or help immediately is to remind the CG of the educational material sent to them after they entered the study and encourage the CG to contact the Alzheimer’s Association or Area Agency on Aging for more information or assistance. If the CG tries to engage the TCC staff further in the specifics of a problem in an agitated, distressed or hopeless way, and is unable to end the call or provide answers to the questions in the script, then the TCC staff should consider this to be an adverse event. At this point, the TCC staff should inform the CG that (phrasing/script for TCC – “it seems you are quite upset and I’d like to have my supervisor call you back to speak about this more”). The TCC staff needs to be sure the CG understands that another member of the REACH II team will call them back today (or tomorrow) to discuss this issue further. The TCC staff will then inform the PI or PI designee who responds to Acute Baseline Alerts/Adverse Events of the situation and turn the CG over to that person.

IV. Protocol for Caregiver Request for Specific Information

Sometimes a caregiver may request specific information related to a CG behavior problem or the need for some type of assistance. The TCC staff reminds the CG of the educational material sent to them after they entered the study and the skills workshop that they will receive in the next few months. The TCC staff should also encourage the CG to contact the Alzheimer’s Association or Area Agency on Aging for more information or assistance. The TCC staff can give the CG the telephone numbers to these agencies.

V. Protocol for Failed Telephone Call at 3 Month and 5 Month Time Points

1. Allow telephone to ring 9 times or until an answering machine picks up. If an answering machine picks up, leave a message identifying yourself, reason for the call, and that you will call back.

2. If a caregiver wishes to discontinue the telephone call but does want to be contacted next time, thank caregiver and schedule a convenient time.

3. If a caregiver refuses to participate, thank caregiver and notify supervisor.

4. Complete the Failed Call Log form.
CERTIFICATION CHECKLIST FOR THOSE COMPLETING REACH II CONTROL GROUP TELEPHONE CONTACTS

The following criteria must be met by every individual before he/she is eligible to conduct a control group telephone contact for the REACH II study.

1. Read the following REACH II Intervention Manual of Operations (MOP) materials. _____
   a. Section 1. _____
   b. Section 2. _____
   c. Section 5. Pages 1-6 _____
   d. Section 8. Pages 1-4 _____
   e. Section 9. Pages 4-20 _____
   f. Section 13. _____
   g. Section 14. _____

2. Review DA, OP, RT, AG, AR, AF forms and QxQs in REACH II MOP Section 2 & 11. _____

3. Review the standardized educational materials provided to control group caregivers (Alzheimer’s Disease Facts; Fact Sheet: Dementia; Fact Sheet: Caregiving; Stress and the Caregiver; Home Safety for the Alzheimer’s Patient) _____

4. Complete Learning Process Worksheets for control group telephone contacts._____ 

5. Review scenarios of adverse events and procedures that are followed on site.

6. Complete two role play training calls. The two calls must be conducted in the following way: The PI/Project Coordinator, acting as a caregiver, will stage the telephone calls. The first role play phone call will be of the 3-month telephone contact, using the script provided. The second role play phone call will consist of the caregiver presenting an adverse events situation during the 5-month telephone contact. The role plays are evaluated by the PI/Project Coordinator using the Observational Checklist. ______

7. The TCC staff’s first real control phone call must be audio taped. The audiotape is evaluated by the Intervention Certification Committee (ICC) using the role play checklist. _____

The prospective TCC staff should complete the items in the above checklist in the order given. With the successful completion of each item, the prospective TCC staff should check the item completed. The PI or the trainer should review the Learning Process Worksheets and discuss them with the TCC staff. The certification checklist, observational checklist for the two role plays of control group calls, and LPWs should be signed and sent to the Coordinating Center (CC). The CC reviews the certification checklists and LPWs for completeness and quality. At this point, with completion of steps 1-6, the TCC staff is qualified to begin control group telephone calls. The first TCC call will be audio taped and sent to the Intervention Certification Committee (ICC) who will use the certification checklist to certify the TCC staff. The ICC will then notify the CC and site PI of passing status. The CC will provide the certification number to the site within 2 days of certification. The certified person also receives feedback on the materials submitted for review and a certificate for control group certification.

TCC staff’s signature _______________________________ Date___________

Site PI’s signature _______________________________ Date___________
Failed Call Log

If caregiver is not available for telephone contact, please provide the following information:

<table>
<thead>
<tr>
<th>TC-C Call Attempt #</th>
<th>Date</th>
<th>Reasons for Failed Call</th>
<th>Check One</th>
<th>Interventionist Response</th>
<th>Check One</th>
<th>TCC Initials and Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>1</td>
<td>No Answer</td>
<td></td>
<td>Attempt control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>call another day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>No Answer</td>
<td></td>
<td>Attempt control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>call another day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>No Answer</td>
<td></td>
<td>Attempt control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>call another day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>No Answer</td>
<td></td>
<td>Attempt control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>call another day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>No Answer</td>
<td></td>
<td>Attempt control</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>call another day.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver</td>
<td></td>
<td>Establish a</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Unable to Speak</td>
<td></td>
<td>suitable time to</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>at Present Time</td>
<td></td>
<td>complete call.</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Caregiver</td>
<td></td>
<td>Thank caregiver,</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>Refused to Participate</td>
<td></td>
<td>report information</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>to supervisor.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Allow telephone to ring 9 times or answering machine pick-up before deciding to hang-up.
Scripts 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.
B. 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.**
**Telephone Contact Control**

**Caregiver Request Scenarios**

Proposed Responses to Caregiver Requests for assistance with specific issues/problems.

Discussion of these topics must be initiated by the caregiver. Staff should attempt to follow the Staff Responses as closely as possible; however, some flexibility is allowed based on clinical needs of the situation. If staff classifies the call as an Adverse Event please adhere to the adverse event protocol. In this case the 10-15 minute target time is waived. In all cases, the interventionist must record how they responded to the caregiver’s request/crisis and the length of the call.

<table>
<thead>
<tr>
<th>Topics Initiated by Caregiver</th>
<th>Staff Responses</th>
<th>Caregiver Response</th>
</tr>
</thead>
</table>
| Caregiver requests support services - support group, respite, adult day care, etc. | 1. Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging.  
2. Remind caregiver that they will receive additional information on these topics if they attend the workshop. | |
| Caregiver requests financial services - SSI, help with medical bills, etc. | 1. Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging. | |
| Caregiver requests medical assistance. | 1. If a medical emergency is suspected, staff should instruct the caregiver to terminate the call, and call 911. Staff should immediately notify their supervisor and attempt to call the caregiver back in approximately 15 minutes.  
2. If not a medical emergency, direct the caregiver to contact a physician. If caregiver reports not having a physician, provide telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging. | |
| Caregiver requests help with family issues. | 1. Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging.  
2. Remind caregiver that they will receive additional information on these topics if they attend the workshop. |
| Caregiver requests help with patient problem behaviors. | 1. Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging.  
2. Remind caregiver that they will receive additional information on these topics if they attend the workshop. |
| Caregiver requests help with home modification. | 1. Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging.  
2. Remind caregiver that they will receive additional information on these topics if they attend the workshop. |
**Adverse Event Scenarios**

**Physical Abuse of Care Recipient by Caregiver**

**Scenario # 1:** Distressed caregiver reports increased behavior problems that have resulted in her feeling angry and desperately helpless in managing her mother. Caregiver is very upset and acknowledges having urges to hit her mother. Further probing reveals that the caregiver has, indeed, struck her mother several times.

**Response # 1:** It is determined that this is an adverse event and 10-15 minute time limit is waived.

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Follow the adverse event protocol in the MOP.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience.</td>
<td></td>
</tr>
<tr>
<td>3) If indicated, direct the caregiver in deep breathing with the goal of reducing the caregiver's immediate distress.</td>
<td></td>
</tr>
<tr>
<td>4) Ask direct questions with the goal of obtaining specific information about the abuse incident.</td>
<td></td>
</tr>
<tr>
<td>5) Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer's Association and the Area Agency on Aging.</td>
<td></td>
</tr>
<tr>
<td>6) Schedule follow-up phone call.</td>
<td></td>
</tr>
</tbody>
</table>

Day
Date
Time
Severe Depression

**Scenario #2:** Caregiver appears unresponsive to staff and evidences flat affect. Sensitive probing results in tearfulness and caregiver’s description of hopelessness and grief over the condition of the patient. Caregiver acknowledges insomnia and reports not eating in two days.

**Response #2:** Staff determines that this is a crisis call and 10-15 minute time limit is waived. Staff will respond...

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) If indicated, direct the caregiver in deep breathing with the goal of reducing the caregiver’s immediate distress.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience if desired.</td>
<td></td>
</tr>
<tr>
<td>3) Ask direct questions with the goal of obtaining specific information about suicidal/homicidal intent (method, time, date, location, etc.).</td>
<td></td>
</tr>
</tbody>
</table>
| 4) a) If caregiver is imminently suicidal/homicidal, inform the caregiver that the law requires that the information about suicidal/homicidal intent be reported to authorities and that authorities have been contacted. Stay on phone and have a colleague call 911.  
  b) If caregiver is NOT immediately suicidal/homicidal but has acknowledged specific plans, inform the caregiver that the law requires that the information about suicidal/homicidal intent be reported to authorities and that authorities have been contacted (911).  
  c) If caregiver is NOT suicidal/homicidal, provide caregiver with hotline numbers as a resource, discourage social isolation, encourage use of formal and informal supports. | |
| 5) a) If caregiver is immediately suicidal/homicidal, stay on the telephone and DO NOT HANG UP until authorities have arrived.  
  b) If caregiver is NOT immediately suicidal/homicidal but has acknowledged specific plans, provide caregiver with hotline numbers as a resource and inform caregiver that authorities will be contacting her/him. | |
| 6) Schedule follow-up phone call.  
  **Day**  
  **Date**  
  **Time** | |

**Immediate Need for Formal Services**
**Scenario #3:** Distraught caregiver reports having quit her job in order to care for her husband and no longer has income. She has no money to buy food or pay rent, and is scared that she and her husband will be evicted at the end of the month.

**Response #3:** It is determined that this is an adverse event and 10-15 minute time limit is waived.

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Follow the adverse event protocol in the MOP.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience.</td>
<td></td>
</tr>
<tr>
<td>3) If indicated, direct the caregiver in deep breathing with the goal of reducing the caregiver’s immediate distress.</td>
<td></td>
</tr>
<tr>
<td>4) Ask direct questions with the goal of obtaining specific information about the abuse incident.</td>
<td></td>
</tr>
<tr>
<td>5) Provide caregiver with telephone numbers of the National and Local (if available) Alzheimer’s Association and the Area Agency on Aging.</td>
<td></td>
</tr>
<tr>
<td>6) Schedule follow-up phone call.</td>
<td></td>
</tr>
<tr>
<td>Day</td>
<td></td>
</tr>
<tr>
<td>Date</td>
<td></td>
</tr>
<tr>
<td>Time</td>
<td></td>
</tr>
</tbody>
</table>
### Physical Abuse of Care Recipient and Caregiver

**Scenario # 4:** Caregiver’s responses are evasive. With some encouragement, caregiver reveals that her alcoholic son has recently moved back to the area and has been coming to the house asking for money. Caregiver describes how he assaulted her and the patient, his father. She indicates that she does not want the authorities involved.

**Response # 4:** Staff determines that this is a crisis call and 10-15 minute time limit is waived. Staff will respond ...

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) If indicated, direct the caregiver in deep breathing with the goal of reducing the caregiver’s immediate distress.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience.</td>
<td></td>
</tr>
<tr>
<td>3) Ask direct questions with the goal of obtaining specific information about the assault.</td>
<td></td>
</tr>
<tr>
<td>4) Inform the caregiver that the law requires that the information about the abuse incident be reported to Adult Protective Services and that an APS caseworker will be contacting the caregiver and/or making a home visit. (APS # ______________________)</td>
<td></td>
</tr>
<tr>
<td>5) Provide caregiver with hotline numbers as a resource and inform caregiver that some informative materials will be sent. (Hotline #'s ______________________)</td>
<td></td>
</tr>
<tr>
<td>6) Schedule follow-up phone call.</td>
<td></td>
</tr>
<tr>
<td><strong>Day</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Date</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Time</strong></td>
<td></td>
</tr>
</tbody>
</table>
**Dramatic Decline in Care Recipient’s Abilities**

**Scenario # 5:** A caregiver reports a dramatic decline in her husband’s abilities. In the past week, the patient has lost the ability to feed himself and is now incontinent of urine. The caregiver appears to understand that AD is a progressive dementia and that a loss of abilities is to be expected, but is surprised and concerned by the sudden decline.

**Response # 5:** Staff determines that this is a crisis call and 10-15 minute time limit is waived. Staff will respond...

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) If indicated, direct the caregiver in deep breathing with the goal of reducing the caregiver’s immediate distress.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience.</td>
<td></td>
</tr>
<tr>
<td>3) Ask direct questions with the goal of obtaining specific information on the decline.</td>
<td></td>
</tr>
<tr>
<td>4) Direct the caregiver to contact the patient’s physician. If the patient does not have a physician, provide local phone numbers for physician finders. Local #’s</td>
<td></td>
</tr>
<tr>
<td>5) Schedule follow-up phone call. Day Date Time</td>
<td></td>
</tr>
</tbody>
</table>

Local #’s: ________________ ________________ ________________
Dramatic Increase in Problem Behaviors

Scenario # 6: A caregiver reports a dramatic increase in problem behaviors. Since our last conversation with the caregiver a week ago, the patient has begun to wander away from home. The patient becomes very agitated if her daughter attempts to bring her back into the house. The caregiver reports that her mother is confused about her surroundings and is resisting all ADL care.

Response # 6: Staff determines that this is a crisis call and 10-15 minute time limit is waived. Staff will respond ...

<table>
<thead>
<tr>
<th>Staff Responses</th>
<th>Caregiver Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) If indicated, direct the caregiver in deep breathing with goal of reducing the caregiver’s immediate distress.</td>
<td></td>
</tr>
<tr>
<td>2) Engage in empathic, active listening with the goal of allowing the caregiver an opportunity to talk about the experience.</td>
<td></td>
</tr>
<tr>
<td>3) Ask direct questions with the goal of obtaining specific information on the problem behaviors.</td>
<td></td>
</tr>
<tr>
<td>4) Direct the caregiver to contact the patient’s physician. If the patient does not have a physician, provide local phone numbers for physician finders.</td>
<td></td>
</tr>
<tr>
<td>Local #'s</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Identify appropriate problem behavior fact sheets to be sent to caregiver. Tell caregiver that you will mail her/him helpful information. ‘Safe Return’ information a MUST.</td>
<td></td>
</tr>
<tr>
<td>6) Schedule follow-up phone call. Day Date Time</td>
<td></td>
</tr>
</tbody>
</table>
Active Listening

Active listening is a communication style and a skill which is often used in the interview or counseling setting. The goal of using active listening is two fold; to insure the interventionist or helper that s/he is accurately hearing and understanding the client, and to help the client know that s/he is being heard and understood. The theory supporting the use of active listening is that it is when the client feels heard and understood that s/he will trust enough to be open to help and change. There are several skills that can be learned to enhance one’s ability to be an active listener.

In the current study, researchers will learn and use the skills of active listening. Although not all the techniques discussed below will be applicable to the Telephone Contact Control (TCC) condition, it is to be expected that caregivers in that condition as well as in the experimental condition will be more likely to continue in the project if they feel that they are being listened to and understood at a deep level. In the experimental condition, caregivers may well be more likely to be compliant when they feel that the researchers have listened and understood their caregiving experiences and needs.

Techniques used in active listening

1. Empathic Responses

   When an empathic response is given, it is implied that the hearer can view the situation from the point of view of the speaker. Such responses greatly enhance the feeling of being understood and heard at a deep level. To respond with empathy appropriately, one must listen not only to the words, but also to the feelings of the other. An empathic response often gives voice to feelings of which the speaker is unaware at the time.

   In an interview setting which has a time limit, the interventionist should be aware that empathic responses, as well as other techniques of active listening, may well increase the openness of the other to the extent that s/he will want to spend more time talking that is available or appropriate. Some therapists see this sort of interaction with clients as a total treatment modality in and of itself. For this reason, caution must be exercised that such listening not itself become an intervention beyond that which is intended.

2. Rephrasing and reflection

   To rephrase a statement is to say back to the speaker what you have heard in a different way. Rephrasing allows you to check the accuracy of your understanding and gives the speaker confidence that s/he is being understood. Furthermore, it is important that the speaker have the opportunity to correct miscommunication or misinformation to protect the quality of data being recorded. Rephrasing can also be used as an empathic response to communicate a deep level of understanding of both fact and point of view.

   Reflection is a technique differing only slightly from rephrasing, but carries a still deeper intent. A reflection is a response made in order to allow the speaker to more clearly see or hear him/herself. This technique is an important therapeutic tool, but it is one which will rarely be called for in the current project.

3. Probing

   Probing is a technique used to get the speaker to elaborate, explore more deeply, or respond in more detail. Empathic responses, rephrasing, and reflection may all be used as probes, as can open ended questions. Probing carries with it the implication that a deeper understanding or different perspective is called for in addition to more information. For this reason, “closed” questions, or those which can be answered with “yes” or “no” are not good probes. The interventionist is not seeking...
clarification, but rather calling for the client to go deeper or further into the subject at hand. Probing might be a very useful technique to use in helping the caregiver define a problem to be worked on in the project.

4. Summing Up

Summing up can serve several purposes in interviews. It can indicate that a portion of the interview has come to an end. It can provide a checkpoint or reiteration of mutual understanding of what has been said or decided. It can include not only what has transpired recently, but also what will happen next. Summing up at the end of an interview may provide closure and a comfortable ending for the person sharing information. Because the interventionist should listen far more than s/he should talk, summing up should be brief and clear and should always be checked out with the other person for consensus.