

PROCEDURAL ASPECTS - SCHEDULING CONTACTS

1. Protocol for Scheduling Contacts

Once a telephone screen has been completed and it has been determined that a caregiver is eligible for participation, he or she will receive a home interview by a member of the research team. Following the baseline home interview, the caregiver will be assigned on a random basis to the control group or the treatment group. The Interventionist will be given the names of the caregivers in the treatment group. The Interventionist will telephone each caregiver in the treatment group within two days from the date of the baseline interview. In this call, the Interventionist will inform the caregiver that s/he is assigned to the intervention group and make an appointment for the first home visit.

When initially contacting a caregiver to request an appointment, the interventionist must adhere to the following guidelines:

- The Interventionist will speak only with the caregiver. If the caregiver is not available, then the interventionist leaves his/her name and number. A message may be left on the answering machine of a caregiver.
- The Interventionist will introduce him/herself as working with _____ University's REACH program. The caregiver will be reminded that s/he recently, within the past several days, was interviewed in their home by an interviewer from the project.
- The Interventionist will briefly review the purpose of the study, its procedures and overview of the intervention group.
- The first home visit will be arranged to occur within 21 days post-baseline (goal is 1-10 days) on a day and time convenient to the caregiver and Interventionist.
- The Interventionist is prepared to answer basic questions about the study. If there are questions that cannot be answered by the Interventionist, they will be documented and the caregiver will be informed that the Project Manager will call him/her back within two days.
- To minimize the chance of refusals, the Interventionist must have confidence in his/her role in such a way as to communicate that the study is important, and that information shared by the caregiver is important and will be considered strictly confidential.

Interventionist must confirm all appointments either the day before or that day prior to* actually traveling to a caregiver's home. Confirmation will minimize "no-shows" or the possibility of the caregiver forgetting an appointment. Interventionist must recognize that some caregivers will be fragile and of poor health so that their ability to adhere to established meeting times may be difficult. Interventionist should be sensitive to unforeseen difficulties that the caregiver faces and the likelihood that missed visits may occur.

2. Protocol for Rescheduling Failed Contacts

Home Interventions

- If caregiver is not home at the time of scheduled visit, wait 30 minutes past scheduled home visit, then leave. Leave a message stating the time of arrival and indicate that you will be contacting them later in the day or the next day to reschedule another visit.
- After failed home visit, the caregiver will be contacted to reschedule another visit.
- Notify Project Manger if you are unable to reschedule the visit within 48 hours of the original visit.
- The caregiver will be contacted the day before the rescheduled visit to confirm visit and time.
- If a second failed home visit occurs, notify Project Manager and the caregiver will be reviewed and reevaluated for participation at the weekly team meeting.

Phone Interventions

- If the caregiver is unable to speak at the scheduled time, the call is rescheduled for a time that same day or if this is not possible, the caregiver is called the next day. If the caregiver is still not available within 48 hours of the original phone call, he/she will be referred to the Project Manager.
- If caregiver is not home at the time of scheduled visit, wait 15 minutes past scheduled time and phone the caregiver again. If the caregiver does not answer, leave a message stating the time of phone call and indicate that you will be contacting them later in the day or the next day to reschedule another visit.
- After failed phone intervention, the caregiver will be contacted to reschedule another visit.
- Notify Project Manger if you are unable to reschedule the call within 48 hours of the original call.
- The caregiver will be contacted the day before the rescheduled visit to confirm visit and time.
- If a second failed phone visit occurs, notify Project Manager and the caregiver will be reviewed and reevaluated for participation at the weekly team meeting.

3. Confidentiality

Confidentiality in research takes a different form than the guidelines followed in a clinic or home health care setting. In research, each Caregiver signs a formal consent form. The consent form informs the individual of the study procedures, indicating the voluntary nature of their participation, and assures that the information s/he provides remains strictly confidential.

We have both a legal and ethical responsibility to assure that information provided by caregivers is shared only with designated research staff, which include the Principal Investigator, Co-Investigators and Project Director. Any breach of CG confidentiality is sufficient reason for a breach of contract or dismissal.

Confidential means that all information that pertains to the caregivers and their affairs is kept private. Written and audiotaped information is stored securely at the project site (for example, within a locked filing cabinet within our office), the Caregiver's name is removed from any documentation that is used for analytic purposes and there is no reference to any individual by name; rather, analyses and presentation of the data occur in aggregate. The participation in a study is a personal, confidential experience and the information shared is guaranteed not to be identified directly with the person providing it.

YOUR OBLIGATION AS A MEMBER OF THE RESEARCH TEAM IS TO ASSURE CONFIDENTIALITY. Here are guidelines you need to use to assure the confidentiality of Caregivers participating in this study.

Verbal Communication

- When making an appointment with a Caregiver or otherwise talking on the telephone in the presence of others who are not members of the research team, care should be taken to keep your voice low and not to use last names excessively (e.g., one may start out the conversation with "Hello, may I speak to Mrs. Smith?" and thereafter find no need to refer to the caregiver as "Mrs. Smith" again). This is important when calling from home if others are around or in an office with individuals who are not directly involved in the study.
- Refer to caregiver by his/her initials in discussing cases with individual colleagues, in our informational meetings or in a group debriefing meeting.
- Do not discuss a particular caregiver with another interventionist unless this is under the direction of a member of the investigatory team.

Written Communication

- When carrying treatment documentation or any other materials pertinent to or referring to a caregiver, use a sealed envelope marked "Confidential" and the message, "Return to Your Office Address Here." The only "identifying" information (containing the caregiver's name, address, directions to the home, and telephone number) should be on the over sheet; all other documentation should have the subject identification number only.
- Caregiver names, treatment documentation and phone numbers, and other materials must be kept secure (for example, within a locked filing cabinet within your office).
- Information, verbal or in writing, about a particular caregiver cannot be shared under any circumstances with any individual, physician, or agency except for the immediate, designated study staff. In other words, no one outside the project can have access to a Caregiver's data or identifying information.

Troubleshooting

Home Practice Barriers

Problem	Barrier	Possible Solution
<p>CG did not do homework <i>Interventionist:</i> Probe for the Barriers that prevented CG from completing home practice.</p>	Did not have time	Remind the CG the importance of home practice. If you do not do the home practice, there is no way for me to know if the material is helpful or needs to be modified. Help caregiver schedule 5-10 minutes each day to complete home practice.
	Forgot	Help caregiver identify a place in their home (e.g., mirror, nightstand, and refrigerator) that they see or go to frequently. Encourage CG to keep the home practice sheet in that spot.
	It won't help/ It did not work	Encourage CG to try doing the home practice at least once. Ask CG how s/he knows it will not work. What evidence does s/he have that it will not work? If the CG does not try, he/she will never know if it helps or not. If the CG has been stressed for a long time, it will take time to see results. Keep practicing. Remind CG they are worth it.
	CG is embarrassed of his/her spelling or grammar; neatness	Remind the CG that the home practice is for him/her to practice the skills discussed during your meetings. Remind the CG the important thing is that they do the home practice and that they understand their own writing and can verbally share what they did with you. There may be situations where audiotaping and assignment could be useful.

In Session Barriers

<p>Frequent interruptions</p>	<p>Phone rings, they answer it, and wind up talking while you wait.</p>	<p>Remind CG that you only have X amount of time together and have lots of material to cover; and that you are there to help them. Encourage CG to ask the person to call back or find a time to call them back. Role play/refer to assertiveness information for CG if appropriate/ if necessary.</p> <p>If this occurs consistently, role play acceptable alternatives (turn off ringer, screen, answering machine). Identify if other intervention times would be better.</p>
	<p>Care receiver comes in and wants to know what is happening</p>	<p>Help CG develop activities that s/he can use to occupy CR's time during the meeting. Refer to appropriate behavioral prescription.</p>
	<p>Someone comes over to visit</p>	<p>Ask CG if s/he could ask the visitor to come back after the meeting.</p> <p>If this occurs consistently, role play acceptable alternatives (note on front door, identify if other intervention times would be better). Role play/refer to assertiveness information if appropriate/if necessary.</p>

In Session Barriers

Problem	Possible Solution
CG offers interventionist food.	Accept it if appropriate and have a taste or a sip of the beverage/food so as not to be rude to the person or ask for a glass of water as a simple alternative.
CG wants to show interventionist pictures or mementos from the past.	Spend a few minutes on this then gently re-direct. Do not “cut them off” – this can negatively impact rapport.
CG repeatedly brings up problems that have nothing to do with the agenda.	Refocus caregiver. Remind CG that you only have X amount of time to meet and that you want to make the most of your time together. If problem continues, consider setting an agenda with CG. For example, spend the first 10 minutes of the meeting catching up on the week’s events, and the remaining time on the goal of the session. Inform CG of this agenda.
The CG reports that a crisis occurred during the week.	Assess and evaluate the CG’s crisis. Follow REACH 2 alerts/crisis protocol as applicable. If not a “crisis”, refocus caregiver. Remind CG that you only have X amount of time to meet and that you want to make the most of your time together, If problem continues, consider setting an agenda with CG. For example, spend the first 10 minutes of the meeting catching up on the week’s events/crisis, and the remaining time on the goal of the session. Inform CG of this agenda.
CG wants to drop out of project.	Assess the CG’s concerns. Refer to/adhere to REACH 2 protocol.
Not interested in the module or does not want to continue module.	Encourage CG to try the module for a short period as an experiment to test it out; remind CG it has been helpful for many CG’s. Help CG express concerns about the module and identify barriers. Use problem-solving model to obtain a solution.
CG reports “I am not making Progress”	Remind CG that progress is often slow and comes in small steps. The more they practice the more progress they will see.

Caregiver Characteristics

CG visual/hearing impairment requires changes to protocol	Visual impairments: Increase font size of essential material/homework and discuss tape recording of essential material if appropriate. Hearing impairment: Minimize noise/discuss amplification options if available. Rely on printed material/highlight printed material. Ask CG to repeat their understanding of material frequently.
CG reading/literacy level is low	Revise material to 3 key point session. Use familiar/simple words. Consider taping key points and having CG tape record home practice where appropriate.