BEREAVEMENT GUIDELINES

The following guidelines and procedures are used when a CR dies during the six month intervention period. The goal is to keep the caregiver active in the intervention and provide relevant, useful aspects of the intervention.

Initial Reporting of Placement

The death of a care recipient may take place at any point in the study. The interventionist is the most likely individual to be notified of the care recipient's death. The following procedure should be followed:

- Complete Care Recipient Tracking Form (RT)
- Complete Acute Baseline Alert/Adverse Event Form (AR)
- Place note on Personal Information Form (PI) or site specific form to inform other staff of the bereavement. This information will be useful especially in preparing for the follow-up interview.

Contact Caregiver to Express Condolences

The interventionist should first and foremost express condolences either when contacted or by calling the caregiver after learning of the CR's death. During this conversation, the interventionist will provide support and understanding to the caregiver. This first contact may not be the most appropriate time to discuss the study further. A follow-up call may be necessary. Either during the first call or a subsequent call, the interventionist must ascertain the caregiver's readiness to discuss study continuation and/or whether to refer the caregiver to other formal services, such as support groups or counseling.

Caregiver's Options for Continuing with Study

Caregivers may not be aware of their eligibility to continue with the study after bereavement. The interventionist needs to discuss the caregiver's options with him or her. The interventionist should encourage the caregiver to remain involved in the study (see script below). Emphasize the benefits of continued participation in the study for the caregiver, as well as the caregiver's value to the study. The caregiver has the following options for continuing with the study:

1. Continue with home visits and schedule as originally determined
2. Initially reduce interaction with the study and then resume the original schedule
3. Withdraw from the active intervention but participate in the 6-month interview
4. Withdraw from the study, including the 6-month interview

The first three should be presented to the caregiver as options. Each of these options will indicate a separate procedure to be followed by the interventionist. These procedures are described here.

Continue with Intervention

Some aspects of the protocol remain in place when the care recipient dies. Use of the Caregiver Network and participation in support groups may still be helpful to the caregiver. The Caregiver Network section on bereavement will be especially useful, and caregivers should be specifically referred to it. Support groups can be useful, but the caregiver may choose not to participate or may need some encouragement to continue. For the more individualized aspects of the intervention, the interventionist should help the caregiver reprioritize his or her needs using the Risk Priority Worksheet (RPW). From this reprioritization, the interventionist and caregiver will determine which well-being modules, social support issues, self-care issues and communication issues may be appropriate to address and in what order.

Reduce Study Involvement Initially, then Resume

In this option, the caregiver feels unable to immediately continue with the intervention. However, the caregiver understands the potential benefits of continuing to receive the intervention and would like to resume the schedule at a later point in time. In this situation, the interventionist will maintain contact with the caregiver through periodic phone calls to check in and support the caregiver. These contacts will be captured on the Delivery Assessment (DA) form, thus not impacting the protocol for the intervention when it resumes. The interventionist will attempt to resume the intervention with the caregiver as soon as possible.

Withdraw from Active Intervention

In this option, the caregiver is unwilling to continue participating in the intervention. The Delivery Assessment (DA) form and Off Protocol (OP) form will be filled out appropriately. The caregiver is contacted for the 6-month follow-up interview on schedule and the Bereavement Interview is administered.

Withdraw from Study

In this option, the caregiver is unwilling both to continue participating in the intervention and to be interviewed at follow-up. The Delivery Assessment (DA) form and Off Protocol (OP) form will be filled out appropriately.

Materials to Use with Caregivers after Bereavement

The attached "Grieving" document should be read by the interventionist. It can be provided to the caregiver if requested.

Guiding Script for Continuing in Study

The following guiding script can be used to lead a discussion with the caregiver about continuing on in the study and determining which procedure the interventionist will follow with the caregiver.

Let me tell you a little bit about your options for our study. We would very much like you to continue to participate as we believe our program has much to offer you even now that your (CR) has passed away. We still have suggestions about ways to help you cope with your new situation. We also know that your participation will help us to help other caregivers who may find themselves in a similar situation to yours. This project is flexible and we are able to make it work for you with a number of different options.

1. **First, we could continue as we had planned in terms of scheduling and adjust the program to fit your needs now.** *(see how caregiver responds. If they are amenable, continue to discuss your schedule)*

2. **Alternatively, we could take a break right now and resume our visits in a few weeks. That could give you some time to yourself. I would be happy to check in with you over the phone and then we can decide when to resume.**

3. **Even if you prefer not to continue with our visits, we would still want to interview you at the 6-month follow-up point. The interview would be different and somewhat shorter. It would be of great value to the study to have you participate in the 6-month interview.**

Grieving

Overview

Understanding the Problem

Normal feelings to expect after the death of a loved one

Each person’s reaction to the loss of a loved one is different, and each person must work through grief in his or her own way

There is no “right” or “wrong” way to feel after someone dies

Most people who are very upset over someone’s death take months to get beyond the most severe emotional stress. Grief beyond a year is common but may require help

When To Get Help

Start with your family doctor

Symptoms indicating the need for professional help

Information to have ready when you call for help

What to say when you call

What You Can Do To Help Yourself

Allow yourself to experience the pain of grief

Select a person to share your grief with

Find what works for you in returning to normal routines

Read books or poetry on the subject

Keep a diary or journal

Encourage others to talk about the deceased

Talk out loud to the person who has died

Find out about a bereavement support group

Consider Obstacles

“People say I should be over this.”

“People give me advice that I don’t want to take.

“Nobody wants to talk about Dad when they’re around me.”

Carrying Out and Adjusting Your Plan

Checking on results

If your plan does not work

Topics with an arrow in front of them are actions you can take or symptoms you can look for.

The information in this home care plan fits most situations, but yours may be different. If a doctor, nurse, or counselor tells you to do something other than what is recommended here, consider all of the information and apply what is meaningful to your own needs.

Understanding the Problem

People who lose a friend or family member to cancer face the same issues as anyone who experiences the death of a loved one, whether by accident or illness. Your feelings and emotions after someone's death can profoundly affect how you relate to others and get through your daily routine. Depending on your personality, you may find it helpful to confide your feelings to another person-sometimes a friend is best, sometimes a family member, and sometimes a professional such as a nurse, a counselor, or a member of the clergy. You may find consolation through sharing or listening at a group-sharing session involving others who have had a recent loss; such groups usually are led by a counseling professional. On the other hand, if you have never been open about your feelings, it is unlikely that you will suddenly change now. Well-meaning people may insist that you must talk it out, but they may not understand you, your past, or your methods of dealing with life's difficult moments.

Each person must work through grief in his or her own way-and it is work (even if not always of the physical kind). Despite the existence of widely published "stages" of grief, each survivor deals with loss as an individual, and the ways in which people handle their loss vary widely. When you are struggling to deal with your own loss, it is useless to worry about whether you are following somebody else's timetable.

The range of reactions to someone else's death is broad. Some people are devastated when it occurs, and others feel very little emotion. Sometimes, people feel their grief only later, and some people never have strong feelings. Different people also may experience different emotions. They may feel guilt, remorse, sadness, or resentment toward others, such as doctors, nurses, hospice workers, or even God. Some people who lose a family member or close friend feel anger and ask questions such as "Why did this happen to him (the one who died)?" and "Why did this happen to me?" Anger also may reach back to events that occurred during diagnosis and care, and you may ask, "Why didn't the doctors find the cancer soon enough?" or, "Why did mother suffer so?"

You may think that you hear the deceased person's voice calling to you, or you may want to have a conversation with that person. You may experience flashbacks, such as remembering the funeral or even the moment of death itself, for no apparent reason. In addition, you may feel as if you are making progress but then suddenly feel worse, and without knowing what triggered it. Although upsetting, these are normal experiences for people who grieve.

Even if the illness was prolonged and you anticipated the death of your loved one, you still may encounter both shock and numbness in the same way as if the death had occurred unexpectedly. During this time, which may last from only a few up to 6 weeks, you may experience a sense of “just going through the motions,” as if you were in shock.

When this feeling of numbness and shock begins to subside, you may feel as if you might be overcoming it-thinking “I’m getting back to normal.” Just then, however, you unexpectedly may encounter a deeper sense of grief or sadness as reality sets in. When this occurs, you may experience symptoms of grief like those of acute depression-being unable to sleep soundly, losing your appetite, not wanting to get up in the morning, or not wanting to be around other people.

Whatever happens, understand that there is no “right” or “wrong” way to feel after someone’s death. Most people’s feelings, even if they seem extreme at the time, fall within a range of normal reactions.

Most people who lose someone close to them take months to get over the most severe part of their emotional stress, and for most, it will take at least a year to work through the grieving process. Counselors often consider how a person is doing at the 1-year anniversary of the death as an indicator of how well he or she has adjusted to the loss. Grief that lasts beyond a year is common but may require help.

Remember that life will never again be exactly the way it was before your loved one died. If you are expecting things to “get back to normal” after awhile, you may be disappointed or frustrated to find that the new “normal” is not like the old “normal.” Your life will go on, but-precisely *because* the person was important to you-it will not be the same without him or her.

Your goals

Know when to get professional help with grief.

Understand that people handle loss with a wide range of emotions, none of which is “right” or “wrong.”

Grieve for your loss in your own way rather than feeling that you should be the same as other people you have known or read about.

Understand that most people who grieve return to their daily routines in 2 to 4 months, but healing often takes a year or longer. Each person’s reactions are unique, so be wary of timetables that others may try to force on you.

When to Get Help

The first question you should ask is whether you need help from other people. If you do, an excellent place to start is with your family doctor. He or she may help you directly or aid you in finding the right group session, counselor, or clinic. You should seek help if any of the following is true:

⇒ **Continued difficulty in sleeping.**

> If you are losing sleep or feel tired all the time, the first place to go for help is your family doctor. A physician who knows you and your medical history can make an informed decision whether to prescribe medication and, if so, what kind.

⇒ **Substantial weight gain or loss.**

> Any substantial change in eating, such as loss of all appetite or a sudden increase in appetite, may be the result of emotional distress. Again, consult your family doctor first, because he or she already knows you and can make an informed judgment about treatment.

⇒ **Prolonged emotional distress.**

> If, after 6 months, you do not see a marked improvement of your ability to function in daily life, you should consider seeking help. It is natural to want to withdraw from others after losing a loved one, but if you still cannot enjoy a reasonable quality of life after 6 months, this is a signal that you may need help working through your grief.

⇒ **If you are overcome by suicidal thoughts.**

> If suicidal thoughts become central to your thinking and you are encountering them every day, seek help from your family doctor, a counselor, member of the clergy, or a mental health clinic.

Have the answers to the following questions ready when you call your family doctor, counselor, or clinic:

1. How much does grief interfere with my ability to do my job or normal daily activities?

2. Am I having difficulty sleeping?

3. Is my appetite gone, or do I eat significantly more than before the person died?

4. Is suicide an option I would consider?

Here is an example of what someone might say when calling for help:

"I'm David Winters, son of Katherine Winters, who died of cancer 6 months ago. Ever since my mother's death, I've been very upset. I've also been having trouble sleeping through the night since about 2 weeks after she died, and I never had trouble before. I think I may need some help."

What You Can Do To Help Yourself

You can do many things on your own to handle the emotional stress of grief, and you can get help from others as well. You may need one or both forms of help to successfully restore your sense of well-being.

⇒ **Allow yourself to experience the pain of grief.**

What this means is to work through your emotions in the best way you can. If this means crying, screaming, talking to the person who has died, or doing physical activity such as punching a pillow or lifting weights, do that. To heal emotionally, many people need to express their feelings. If you are embarrassed about crying in front of other family members such as your children (whether younger or adult), you may need to tell them: "It may be upsetting to you, but I need to cry and express my feelings. I need to work through this grief."

⇒ **Select a person to share your grief with.**

Find a good listener who has experienced a similar loss, although it probably is best to choose someone who is not grieving over the same person as you are. Someone outside of your immediate family often is a good choice. You want someone who will let you express yourself, not someone who will try to reason you out of your feelings. Candidates might be a member of the clergy or a sympathetic friend or coworker. Although you may expect family members to be supportive, they most likely are burdened with that very same loss as well. For example, if your spouse dies and you want to share with your adult children, remember that they are grieving the loss of their parent. As a result, they may be unable to give you the compassion you need. In addition, it often is painful for an adult child to see a parent grieving, and they may want you to “get over it” so that their lives can return to some form of “normal.”

Be aware that some people, even professionals such as clergy, may not be personally prepared to deal with death-perhaps because of their own grief over someone they have lost or feelings about their own mortality. If you are unable to relate to one person, find another. Many hospice programs offer a one-on-one assignment of a bereavement volunteer to aid families after a death, one of many programs typically extended by hospice to help with grief. Others might include newsletters, a library of books about grieving, or information about bereavement support groups.

⇒ **Find what works for you in returning to normal routines.**

If certain activities such as reading or swimming were relaxing for you before, try to pursue them now. See if that will help you to get back to a normal cycle of living. For some people, losing a loved one is so upsetting that they cannot resume these activities until their grief subsides to some extent.

⇒ **Read books or poetry on the subject.**

Many books, including those with first-person accounts, about working through and overcoming grief are available at your local public library. As with other techniques, however, this will not help everyone. Some people will react by saying, “I have enough to worry about without reading someone else’s grief,” while others will find direction, a sense of what is normal to experience, and a feeling of connection with others who have had this experience. Similarly, reading poetry, whether alone or aloud in a group, can help by giving artful expression to feelings that often are hard to express or even identify.

⇒ **Keep a diary or journal.**

Some people find it helpful and therapeutic to write their thoughts and feelings in a diary as they proceed through the process of grieving. The British author, critic, and novelist C.S. Lewis (1898Ð1963), after losing his wife, kept a journal (*A Grief Observed*) of how he was feeling. A private person for whom neither a support group nor reading a book is helpful may find comfort in keeping such a journal. Some people also find it helpful to write their feelings in a letter to the person who has died, which can help to resolve unfinished business or feelings.

⇒ **Encourage others to talk about the deceased.**

Friends and family frequently avoid discussing the deceased to avoid upsetting the person who is grieving. If you want to talk about the person who has died, you should reassure others that it is okay. All you have to do is say, “I’d like to talk about Dad.” Reassure your visitors that while you may cry or become upset, you would rather do that than awkwardly skirt the subject, because he or she was very important to you. Most people can accept your crying or being upset if you are the one who brought up the subject.

⇒ **Talk out loud to the person who has died.**

In much the same manner as the letter noted earlier, it is not unreasonable to want to resolve issues with a person who has died by holding a one-sided conversation, aloud, with the deceased. Do this if it makes you feel better.

⇒ **Find out about a bereavement support group.**

Bereavement support groups can help to make the process of dealing with loss easier. Signing up for a bereavement support group may be a difficult decision, however, because many people think of their grief as something that is private. You may feel uneasy talking with strangers about your feelings or your loved one. Keep in mind, however, that such groups have helped many people get through their grief and, therefore, may help you.

In a bereavement group, participants learn from each other about normal reactions to grief. Because of their shared experiences, group members often come to care about and to support each other emotionally, and they often share practical ideas for working through their grief as well. In addition, a support group also can help you to get through difficult times like holidays or anniversaries.

Most support groups meet for a limited time, such as six weekly sessions. Others run continuously, and people come in and out as their emotional needs dictate. Most are free; some require a fee. Call a hospice, counseling clinic, member of the clergy, your local Area Agency on Aging, or a hospital to find out about bereavement groups. If that does not work, check your newspaper or the human-services listings of a phone book. It often is good to talk with the leader of a group in advance to learn what is expected and how the group is conducted. Some people attend with a family member or a friend.

If you decide to attend a support group, understand that you may feel worse when you go home after the first session. The reason is that you are dealing with your feelings openly (as well as hearing about everyone else's). In the long run, however, this can be helpful. It also is important to realize that a support group will not restore you to the way you were before the person's death, but it will help you to cope with your new life without the deceased.

Possible Obstacles

Here are some obstacles that other caregivers have faced:

1. "People say I should be over this."

Response: Everyone deals with grief at his or her own pace. You may need to say, "We each go at our own pace. I guess my pace is slower than you expected."

2. "People give me advice that I don't want to take."

Response: Well-meaning advice is not always helpful advice. One example might be if you regularly walked with your deceased spouse and now can no longer bear the thought of walking alone. When people offer advice to take walks, do your best to be gracious and thank them, but then do what *you* feel is best.

3. "People avoid the subject of Dad when they're around me."

Response: Take charge of the conversation, and reassure them: "I want to talk about Dad, and it makes me feel better to talk about him." Your family and friends may not know that you feel this way, so it is important to tell them.

Think of other obstacles that could interfere with carrying out your plan

What additional roadblocks could get in the way of the recommendations in this plan? For example, will other people help? How will you explain your need for help to other people? Do you have the time and energy to carry out the plan?

You need to develop plans for getting around these roadblocks. Use the COPE ideas (creativity, optimism, planning, and expert information), and see Solving Problems Using This Guide for a discussion of how to use these ideas in overcoming your obstacles.

Carrying Out and Adjusting Your Plan

Carrying out your plan

The process of grieving is unique for each person, so you need to find your own, special way of dealing with it. Experiment, and let your feelings tell you which are helping.

Checking on results

The important thing to remember is that people respond to grief in widely varying ways, and that you will have both ups and downs, good days and bad. Healing takes time. You will know that you are successfully working through grief when your stronger emotions begin to dissipate, such as when you no longer feel anger or deep sadness, and when your interest and involvement in outside activities return to their normal level.

If your plan does not work

Grieving is a difficult but natural process. If you cannot resume some of your normal activities or do not seem to feel better after 6 months, you may want to review When to Get Help.

PLACEMENT GUIDELINES

The following guidelines and procedures are used when a caregiver in the intervention group places his or her care recipient in a residential facility during the six month intervention period. The goal is to keep the caregiver active in the intervention and provide him or her with relevant, useful aspects of the intervention.

Initial Reporting of Placement

The placement of a care recipient may take place at any point in the study. The interventionist is the most likely individual to be notified of the care recipient's placement. The following procedure should be followed:

- Complete Care Recipient Tracking Form (RT)
- Complete Acute Baseline Alert/Adverse Event Form (AR)
- Place note on Personal Information Form (PI) or site specific form to inform other staff of participant's status. This information will be useful especially in preparing for the follow-up interview.

Caregiver's Options for Continuing with Study

The caregiver may not be aware of their eligibility to continue with the study after the placement of the care recipient. The interventionist needs to discuss the caregiver's options with him or her and encourage the caregiver to remain involved in the study. The caregiver has four options:

1. Continue with home visits and schedule as originally determined
2. Initially reduce interaction with the study and then resume the original schedule
3. Withdraw from the active intervention but participate in the follow-up interview.
4. Withdraw from the intervention and refuse the follow-up interview.

Each of these options will indicate a separate procedure to be followed by the interventionist. These procedures are described here.

Continue with Intervention

Most aspects of the protocol remain in place when the care recipient is placed. The most obvious exception is discussion of home safety issues. Use of the Caregiver Network and participation in support groups are still of great benefit for the caregiver and can continue as planned without modification. For the more individualized aspects of the intervention, the interventionist should help the caregiver reprioritize his or her needs using the Risk Priority Worksheet (RPW). From this reprioritization, the interventionist and caregiver will determine which well-being modules and behavioral and communication issues will be addressed and in what order. All of the well being modules remain pertinent to the caregiver whose family member has been placed in a residential facility. Within the problem solving area, issues may focus on CR's problems relating to agitation, depression or other adjustment problems; or if the caregiver continues to help with ADL's in the residential facility, ADL issues may also remain. Lastly, it may be important to focus on residential facility issues such as communication with staff, laundry getting lost, meals, CR cleanliness, or other aspects of CR's care. Sessions can be held in an alternate location, such as at the residential facility, if that is more convenient for the caregiver

Reduce Study Involvement Initially, then Resume

In this option, the caregiver feels unable to continue with the home visit schedule as planned prior to the placement of the care recipient. The caregiver understands the benefits to receiving the intervention and would like to resume the schedule, but feels unable to do that during the period immediately following the care recipient's placement. In this situation, the interventionist will maintain contact with the caregiver through periodic phone calls to check in and support the caregiver. These contacts will be captured on the Delivery Assessment (DA) form, thus not impacting the protocol for the intervention when it resumes. The interventionist will attempt to resume the intervention with the caregiver as soon as possible. As with the previous option, when sessions are resumed, they can be held in an alternate location, such as at the residential facility, if that is more convenient for the caregiver

Withdraw from Active Intervention but Participate in Follow-up Interview

In this option, the caregiver is unwilling to continue participating in the intervention but willing to be interviewed at follow-up. The Delivery Assessment (DA) form and Off Protocol (OP) form will be filled out appropriately. The caregiver is contacted for the 6-month follow-up interview on schedule and the Placement Interview is administered.

Withdraw from Intervention and Refuse Interview

In this option, the caregiver is unwilling both to continue participating in the intervention and to be interviewed at follow-up. The Delivery Assessment (DA) form and Off Protocol (OP) form will be filled out appropriately.

Guiding Script for Continuing in Study

The following guiding script can be used to lead a discussion with the caregiver about continuing on in the study and determining which procedure the interventionist will follow with the caregiver.

Let me tell you a little bit about your options for our study. We would very much like you to continue to participate as we believe our program has much to offer you even now that your (CR) is living in a nursing home. We still have suggestions about ways to help you cope with your new situation. We also know that your participation will help us to help other caregivers who may find themselves in a similar situation to yours. This project is flexible and we are able to make it work for you with a number of different options.

1. **We could continue as we had planned in terms of scheduling and adjust the program to fit your needs now. If you wish, we could meet for our sessions at the nursing home.** *(See how caregiver responds. If they are amenable, continue to discuss your schedule)*

2. **We could take some time off from the program, and then resume it later.**

3. **You could continue as a study participant without our intervention sessions. This would mean having the 6-month interview when the time comes. It would be extremely valuable for the study to have you participate in the 6-month interview.**

REACH II

Resources for Enhancing Alzheimer’s Caregiver Health

Training Program - REACH II Intervention

Funded by the National Institute on Aging and the National Institute on Nursing Research

Training Program for REACH II INTERVENTIONISTS

- Intervention MOP
- Readings
- CTIS Training Notebook
- Video of ABC process
- Didactic training (power point presentations)
- Certification Procedures
    - Role plays
    - Learning Process Worksheet
    - Observation of 2 sessions
    - Audiotape of part of 1st session

Part I: Introduction

(Intervention MOP Section I)

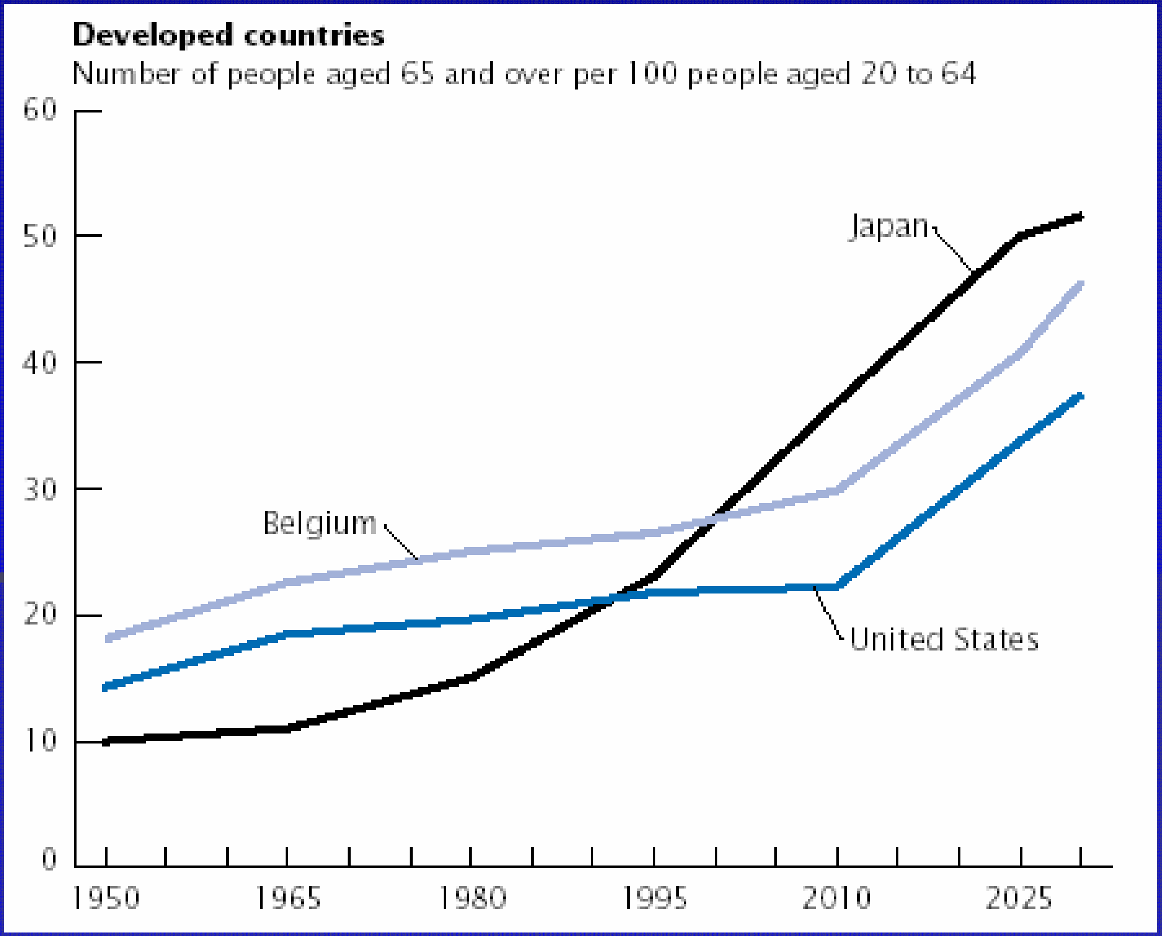
- Quick Facts about Dementia and Caregiving
- Background
  - REACH I goals and outcomes
- REACH II
  - Goals
  - Study Design
  - Outcome measures
  - Intervention objectives
  - Control Group

Quick Facts about Dementia and Caregiving

Some Caregiving Facts

- More than 54 million people provided care for a chronically ill, disabled or aged family member or friend in past year; 59 % of adult population is or expects to be family caregiver
- People over 85 years of age are fastest growing segment of population; half need help with personal care
- Value of “free” services provided by family members is $196 billion annually
- American business lose between $11 and $29 billion each year due to employees’ need to care for loved ones 50 and over

Elderly Support Ratios: 1950-2030



Quick Facts About Dementia and Caregiving

- 4 million diagnosed with Alzheimer's disease or related disorder (ADRD) in USA
- Most persons with ADRD cared for at home
- Caregiving occurs over extended time
    - Average course of disease is 8 years
    - Range from 4 to 20 years
- High personal and societal health care costs

Effects of Dementia and Nondementia Caregiving on Physical, Emotional, Financial, and Role Stress

Item	Dementia	Nondementia
Less Time for Other Family Members (percent) *	52.0	40.9
Emotional Strain of Caregiving (mean)*	2.99	2.22
Physical Strain of Caregiving (mean)*	2.40	1.80
Mental or Physical Problems as a Result of Caregiving (percent)*	22.3	12.6
Financial Hardship of Caregiving (mean)*	1.87	1.50

* p< .001.

Ory, Yee, Tennstedt, & Schulz (1998), Gerontologist

Who are Caregivers of Persons with ADRD?

- Most caregivers are:
  - Women (spouses and daughters)
  - Spouses
  - Aging
- Caregiving occurs across all racial, ethnic and socioeconomic groups
- Caregiving does not stop with nursing home placement

Caregivers - The Hidden Patient

CG AT RISK FOR:

- Depression (>50% caregivers are depressed)
- Morbidity
- Financial loss
- Social isolation
- Extreme fatigue, stress
- Anxiety, upset, feeling overwhelmed
- Mortality

Schulz, et al, 1995. *The Gerontologist, 35*, 771-791; Ory et al., 1999, *The Geronntologist, 37*, 804-815 Schulz & Beach, 1999, *JAMA, 282*, 2215-2219

- Background:
    - REACH I goals and outcome

- REACH II
  - Goals
  - Study Design
  - Outcome measures
  - Intervention objectives
  - Control Group

Major Goals of REACH I

Primary Goal

Examine the effectiveness of social, behavioral and technological interventions to strengthen family members' capacities to care for individuals with ADRD

Secondary Goal

Develop standardized outcome measures and methodologies to assess the effectiveness of specific intervention components on caregivers and care-recipients.

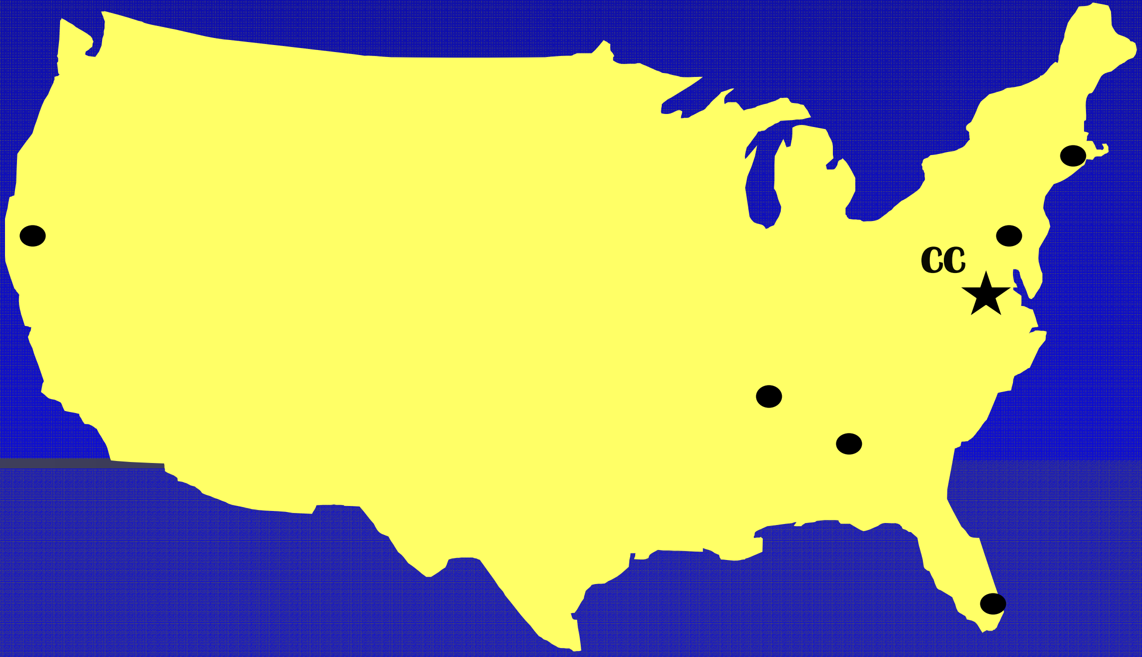
REACH I

Cooperative Agreement Among:

NIH (NIA and NINR)

6 Intervention Sites
- Birmingham
- Boston
- Memphis
- Miami
- Palo Alto
- Philadelphia

Coordinating Center
- Pittsburgh



Special Characteristics of REACH I

Large numbers of AD caregivers (N = 1222)

Multi-site (six sites)

Randomized interventions

Common measurements and assessments

Unique interventions at each site

Inclusion of multiple racial/ethnic groups

Types of Interventions in REACH I

- <u>Active Treatments</u>
  - Skill training
  - Information and referral
  - Voice mail / support / advice / behavioral distraction
  - Environmental skills building
  - Behavioral management
  - Stress management
  - Psychoeducational / coping
  - Technology enhanced communication and support

- <u>Control Conditions</u>
  - Usual care
  - Minimal support (empathic listening)

REACH I:
Outcomes - Pooled Data

- Active interventions superior to control conditions in reducing CG burden
- Interventions that emphasize active engagement of caregivers had greatest impact in reducing CG depression
- Women and those with high school or lower education in active interventions reported reduced burden compared to similar individuals in control conditions
- CGs in active interventions who were Hispanic, non-spouses, and had less than high school education reported lower depression scores than similar persons in control conditions

REACH I:
Site Specific Outcomes

Site	Active Intervention & Control Conditions	Site-Specific Outcomes
Birmingham	Problem Solving Skill Training & Minimal Support Condition	Behavioral skills training greater benefits for African American and nonspouse caregivers
Boston	REACH for TLC telephone based intervention & Usual Care	Wives with low mastery & high anxiety benefited the most from automated telecare
Memphis	Behavior Care; Enhanced Care & Usual Care (Information and Referral)	Education delivered in primary care setting effectively reduced caregiver stress and burden
Miami	Family-based Structural Multi-system In-home Intervention (FSMII); FSMII + CTIS & Minimal Support Condition	Technology based information and support alleviated distress & depression
Palo Alto	Coping with Caregiving Class; Enhanced Support Group & Minimal Support Condition	Improved coping in female caregivers provided with enhanced skills for managing distress
Philadelphia	Environmental Skill-building Program & Usual Care	Less upset & better affect in intervention caregivers; Enhanced mastery in females & decreased vigilance in males in intervention

REACH II

- Systematically builds on REACH I and caregiver research
- First multi-site clinical trial designed to enhance caregiver well-being
- First RCT multi-component caregiver intervention
- Trans-disciplinary
- Multi-component
- Multi-treatment modalities and behavioral techniques
- Reproducible/standardized/portable protocols

REACH II:
Addresses Challenges of Caregiving

- Caregiving characterized by multiple diverse challenges
- Caregivers are at moderate risk for adverse outcomes in multiple domains but not at extreme risk for any one outcome: safety, lack of support, burden and distress, demoralization, compromised self-care
- In combination, multiple risk factors erode quality of life and place caregiver at risk for psychiatric and physical morbidity

Goals of REACH II

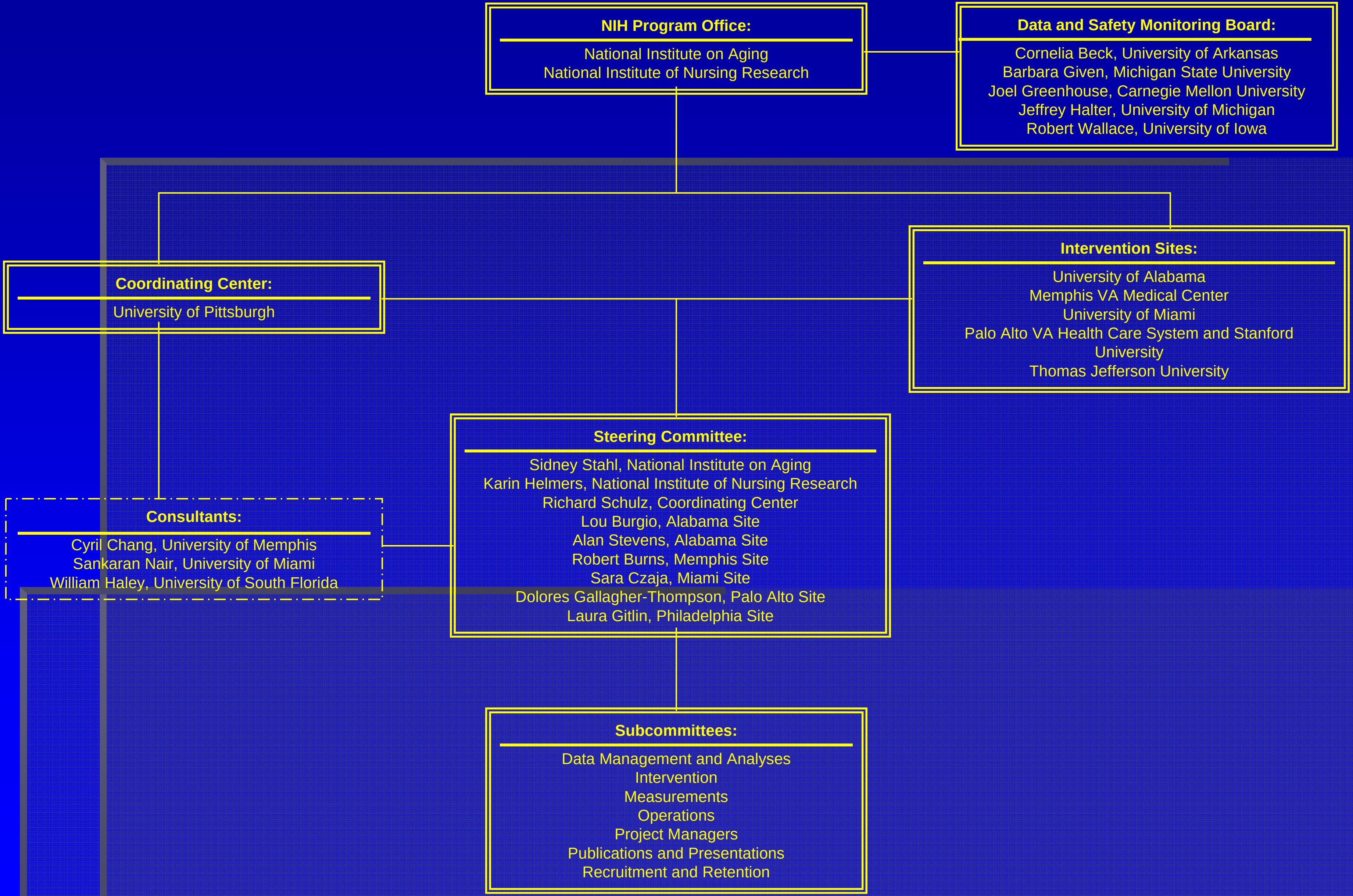
REACH II is a multi-site, two group randomized clinical trial to:

- Test a multi-component intervention designed to increase caregiver knowledge, skills, well-being, self-care and support
- Assess the impact of the intervention on racial/ethnically diverse populations
- Provide new measures for assessing quality of care and caregiver risk
- Evaluate the cost effectiveness and public health significance of the intervention

Principal Investigators of REACH II

- Louis Burgio, Ph.D. Applied Gerontology Program
  University of Alabama
- Robert Burns, M.D. University of Tennessee
- Sara Czaja, Ph.D. Center on Adult Development and Aging
  University of Miami
- Dolores Gallagher-Thompson, Ph.D. Stanford University and VA Palo Alto Health Care System
- Laura N. Gitlin, Ph.D. Community and Homecare Research Division, Thomas Jefferson University
- Richard Schulz, Ph.D
  (Coordinating Center) University of Pittsburgh

REACH II Project Organization Chart



NIH Program Office:

National Institute on Aging
National Institute of Nursing Research

Data and Safety Monitoring Board:

Cornelia Beck, University of Arkansas
Barbara Given, Michigan State University
Joel Greenhouse, Carnegie Mellon University
Jeffrey Halter, University of Michigan
Robert Wallace, University of Iowa

Coordinating Center:

University of Pittsburgh

Intervention Sites:

University of Alabama
Memphis VA Medical Center
University of Miami
Palo Alto VA Health Care System and Stanford University
Thomas Jefferson University

Consultants:

Cyril Chang, University of Memphis
Sankaran Nair, University of Miami
William Haley, University of South Florida

Steering Committee:

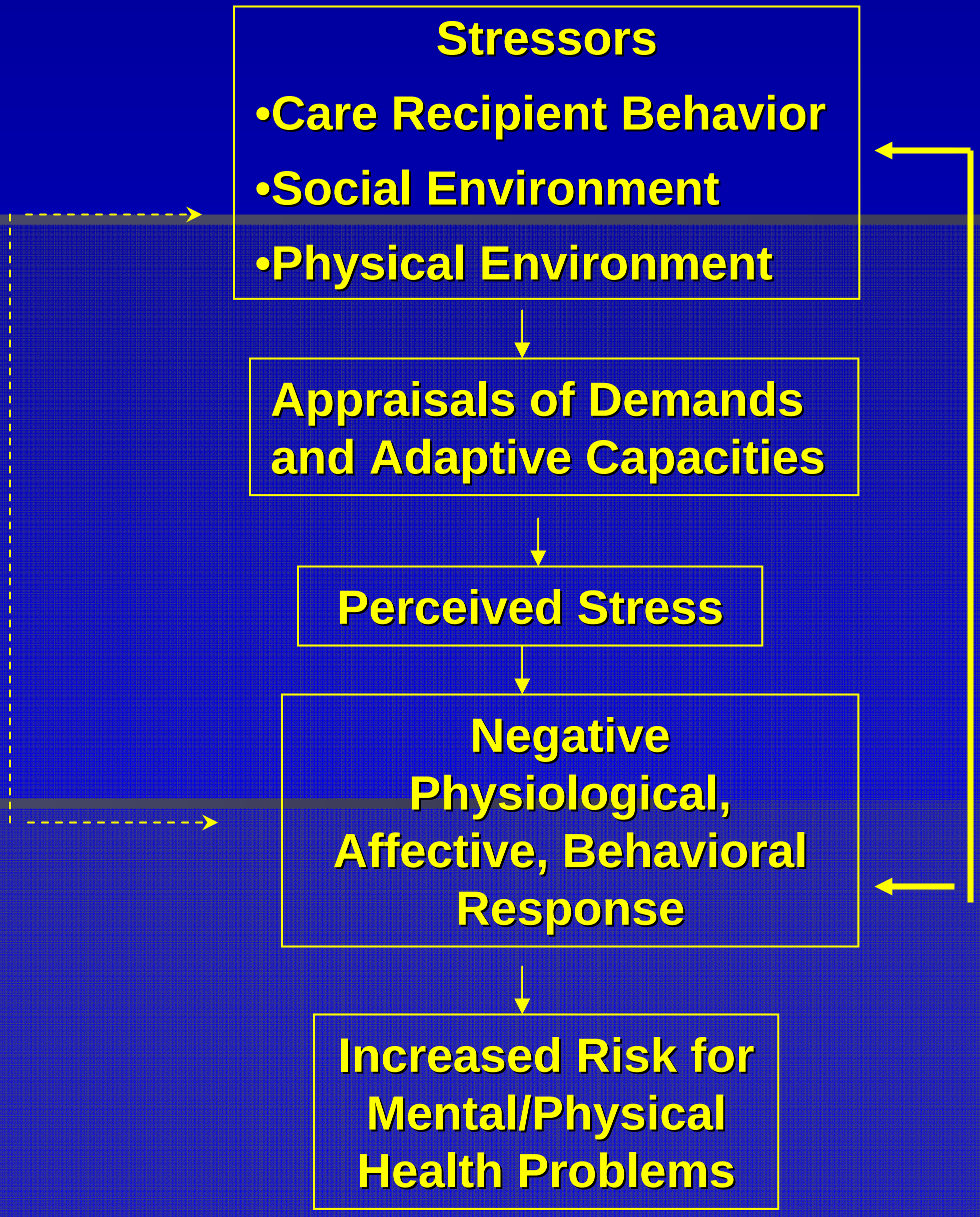
Sidney Stahl, National Institute on Aging
Karin Helmers, National Institute of Nursing Research
Richard Schulz, Coordinating Center
Lou Burgio, Alabama Site
Alan Stevens, Alabama Site
Robert Burns, Memphis Site
Sara Czaja, Miami Site
Dolores Gallagher-Thompson, Palo Alto Site
Laura Gitlin, Philadelphia Site

Subcommittees:

Data Management and Analyses
Intervention
Measurements
Operations
Project Managers
Publications and Presentations
Recruitment and Retention

REACH Stress-health Process Model

(Schulz et al., Handbook on Dementia Caregiving)



Stressors

- Care Recipient Behavior
- Social Environment
- Physical Environment

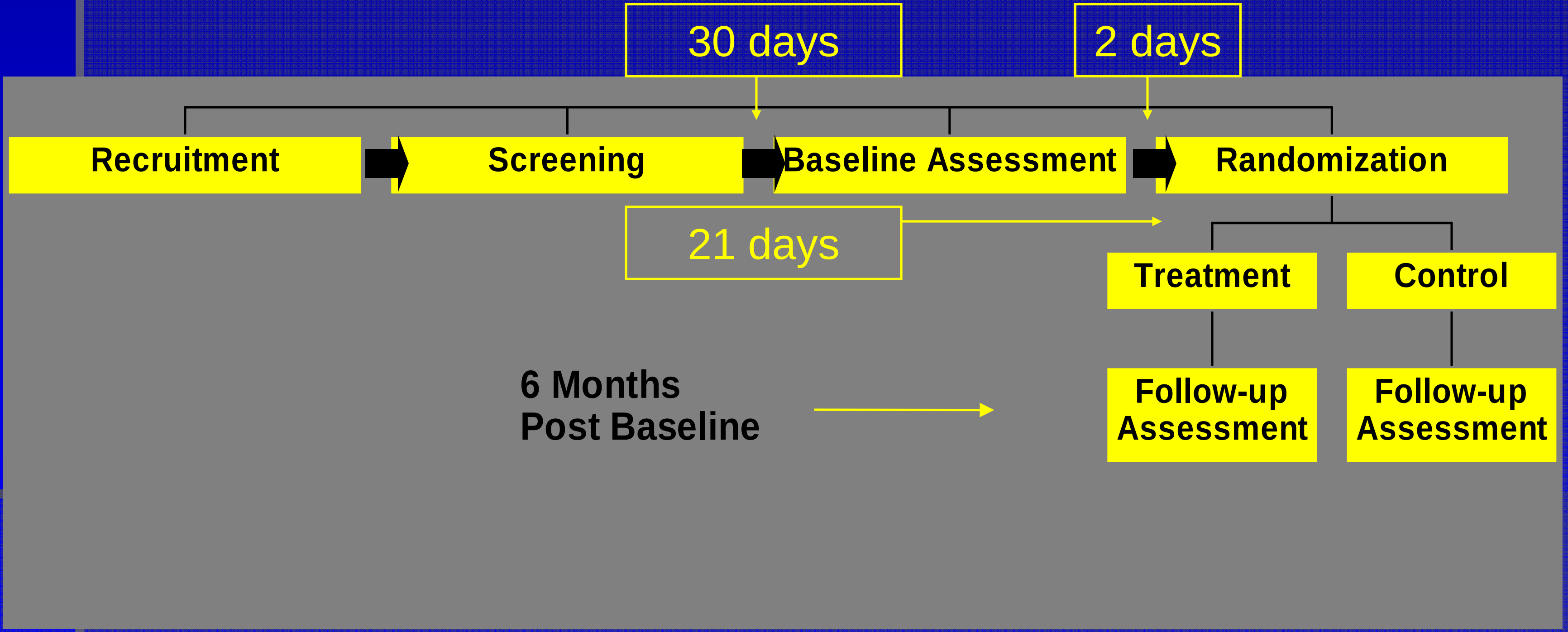
Appraisals of Demands and Adaptive Capacities

Perceived Stress

Negative Physiological, Affective, Behavioral Response

Increased Risk for Mental/Physical Health Problems

Study Design and Assessment Intervals



30 days

2 days

Recruitment

Screening

Baseline Assessment

Randomization

21 days

Treatment

Control

6 Months
Post Baseline

Follow-up Assessment

Follow-up Assessment

Sample Sizes by Ethnicity for Treatment and Control Conditions at Each Site

	Active Treatment	Control
African American	20	20
Hispanic	20	20
White	20	20

X 5 sites = 600 dyads

REACH Inclusion/Exclusion Criteria

Caregiver		Care Recipient	
Inclusion	**Exclusion**	**Inclusion**	**Exclusion**
Age: 21 yrs or older	Active treatment (chemotherapy, radiation therapy) for cancer	NINCDS (MD diagnosis) or cognitive impairment (raw score on MMSE of 23 or less)	Active treatment (chemotherapy, radiation therapy) for cancer
Family member of the care recipient	Imminent placement of care recipient into a nursing home or with another caregiver (within 6 months)		More than three acute medical hospitalizations in past year (other than psychiatric or Alzheimer's disease related admission)
Must live with the care recipient or share cooking facilities	Involvement in another clinical trial for caregivers		Schizophrenia (onset of delusions before age 45) or other sever mental illness
Must have a telephone	Participant in REACH I study		Dementia secondary to head trauma (probably)
Must plan to remain in the recruitment area for the duration of the intervention and follow-up			Blindness or deafness if either disability prohibits them from completion of data collection or participation in the interventions
Caregiver role for more than 6 months			MMSE = 0 and Bedbound (confined to a bed or char for ≥ 22 hours per day, for at least 4 of the past 7 days)
Must provide on average 4 hrs of supervision or direct assistance per day for the care of recipient			Planned nursing home admission in 6 months
Risk Screen Tool: must have a total score of at least 1 for question 1 – 3, and a total of at least 2 for questions 4 - 9			Participant in REACH I study

REACH II:
Intervention Characteristics

- Systematically builds on REACH I and existing caregiver literature
- Multi-component
- Involves a range of treatment modalities and behavioral techniques
- Reproducible/standardized protocols
- Customized to areas of risk for caregiver
- Systematic and standardized approach for identifying risk areas
- Intervention content standardized across sites

REACH II:
Intervention Approach

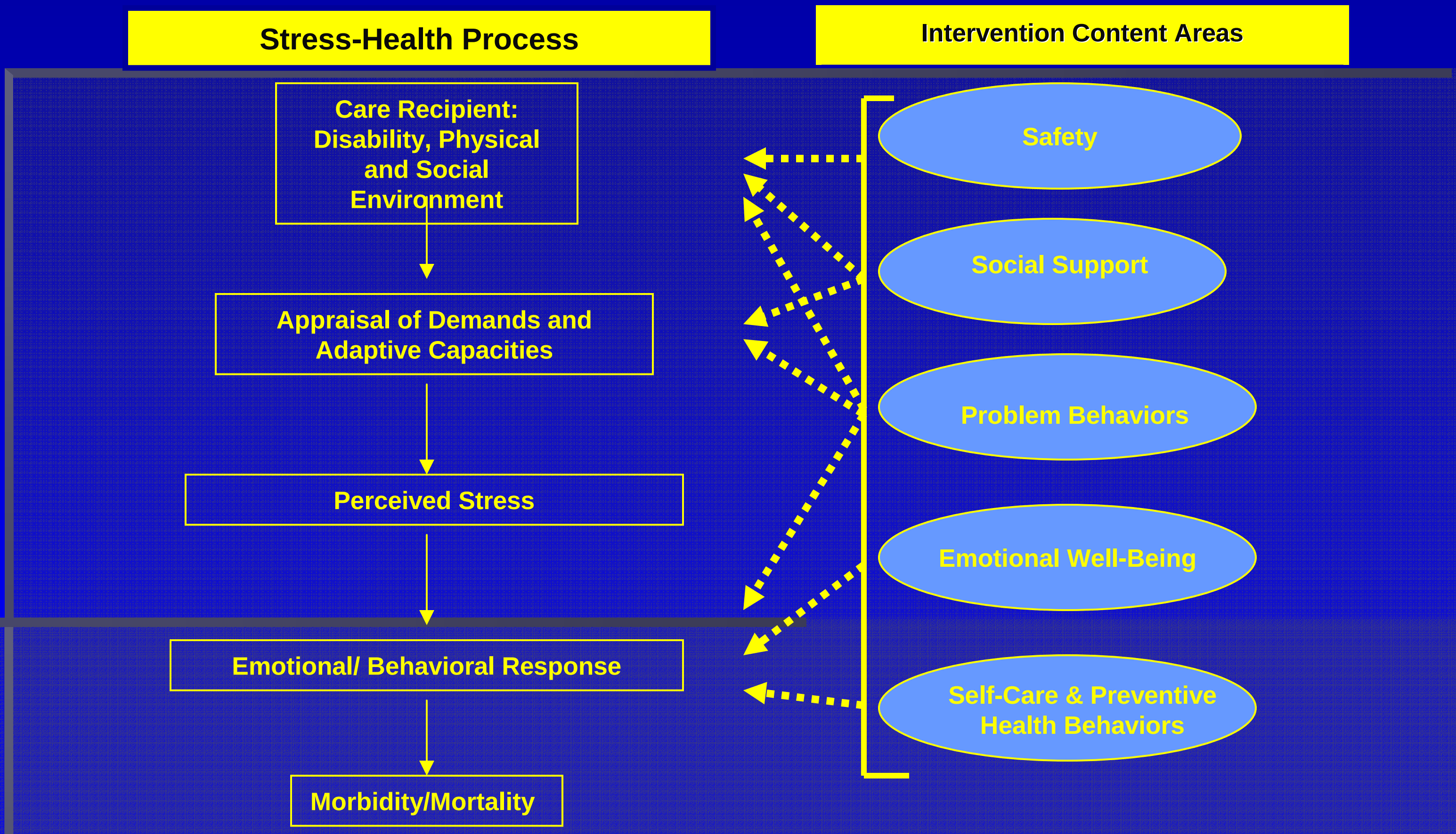
- Determine risk profile of caregiver via risk assessment
- Deliver Standard Multi-component Intervention with dose adjusted to risk profile
- Use technology to support one-on-one contact to enhance dosing

REACH II:
Intervention Approach

The REACH II intervention is a multi-component intervention designed to address five areas linked to caregiver risk profile:

- Safety
- Social Support
- CR Problem Behaviors/Burden
- Emotional well-being
- Self-care and Health Behaviors

Hypothesized impact of various intervention components on the stress-health process applied to caregivers.



Stress-Health Process

Intervention Content Areas

Care Recipient: Disability, Physical and Social Environment

Appraisal of Demands and Adaptive Capacities

Perceived Stress

Emotional/ Behavioral Response

Morbidity/Mortality

Safety

Social Support

Problem Behaviors

Emotional Well-Being

Self-Care & Preventive Health Behaviors

Control Group Activities

- Provision of standardized educational materials
  - Alzheimer’s disease facts
  - Fact sheet: Dementia
  - Fact sheet: Caregiving
  - Stress and the caregiver
  - Home safety for the Alzheimer’s patient
- Two “check-in” telephone contacts
- Invitation to a workshop

Battery of Measures

- CG & CR socio-demographic information
- CR functioning
  - MMSE
  - ADL/IADL
- CR behavior
  - Revised memory and behavior checklist (RMBPC)
- CG burden
  - Revised memory and behavior checklist (RMBPC)
  - Burden inventory
  - Positive aspects of caregiving
  - Vigilance

Battery of Measures (cont)

- Desire to institutionalize
- CG health and health behaviors
- Quality of care
  - Quality of care
  - Personal appearance
- CESD
- Social support
- Social activities
- Religious/spiritual coping
- Caregiver risk appraisal
- Caregiver/care recipient medication
- Formal care and services

Outcome Measures

Risk Area	Measure	Description
Emotional Well-Being	CES-D	10 items assessing depressive symptoms (range 0-30)
Social Support	Social Support - Received Support - Lubben Social Network Index - Negative Interaction Subscale - Satisfaction with Support	Measures social networks, received support, satisfaction with support and negative interactions (16 items, range 0-40)
Self Care	Caregiver Health and Health Behaviors	Measures ability to care for oneself (11 items, range 0-11)
Burden	Short form Zarit Burden Inventory	Items assess caregiver burden (11 items, total score 0-44)
Problem Behaviors	RMBPC- changes in memory, depression and disruptive behaviors	Perceived change in 3 categories (3 items, range 3-15)
*Safety	Quality of Care Risk Appraisal	Items address care recipient living environment, access to a gun or other weapon, driving, and threats to hurt self or others

* Because prevalence of safety problems is unknown, this area not included as part of multivariate outcome

Project Timeline

	Year 1	Year 2	Year 3
Development (months 1 - 8) ▪Refinement of Intervention ▪Development/Translation of Intervention Materials and New/Modified Measures ▪Training and Certification of Interventionists ▪Training and Certification of Interviewers	********		
Rolling Recruitment and Baseline Assessment (months 9 – 27)	****	************	***
Intervention/Assessment (months 9 – 33)	****	************	*********
Analyses and Final Report (months 34 – 36)			***

* = 1 Month

Part II: Principles for Working with Caregivers

- Considerations in working with caregivers at home
- Active listening and effective communication
- Cultural diversity

Considerations in Working with Caregivers at Home

-The Home Setting

-Establishing roles

-Building a relationship

The Home Setting

- Be prepared for uncomfortable temperature conditions.
- Expect multiple generations within some homes. This is particularly true of African American homes.
- Suggest sitting at a table; however, be flexible regarding location in which interview occurs (e.g., outside, porches).
- Expect distractions and attempt to minimize (e.g., ask caregiver to turn off TV).
- Expect offers of food and drink. Accepting a glass of water is a good alternative.
- Remember, you are a guest in a person's home.

Consideration of the Caregiver

- Some caregivers may appear less dynamic, engaged, or interested, but do not make judgments regarding their level of interest, caring or motivation based on these observations.
- Always use Mr., Mrs., Ms., Ma’am, and Sir. when interacting with caregivers until told otherwise.
- Expect caregivers to be tired and distracted. Schedule appointments accordingly.

Overall Demeanor of Interventionist

- Keep prejudices and biases in check.
- Call the day before and/or immediately before appointment.
- Be on time or early for appointments.
- Be informed about the overall caregiving situation.
- Portray yourself as a self-assured professional. Tone of voice is key. Speak clearly and confidently.
- Maintain as much eye contact as possible.
- Monitor body language (i.e., sit up straight in the chair and lean slightly forward, respect the other person’s space).
- Keep control of the response cards.

Establishing Roles

- Interventionist and caregiver develop a collaborative relationship:
  - CG has important knowledge of CR and everyday care
  - Interventionist possesses unique knowledge and skill
- Interventionists need to balance knowledge and authority with empathy and caring:
  - Allow time for exchange and story telling, but react professionally
  - Acknowledge complexity/severity of caregiving situation
  - Link CG stories/situations to the intervention
  - Portray confidence in the upcoming intervention – offer hope
- Be prepared for questions regarding upcoming contacts
  - CG are looking to you for answers
  - Exercise judgment to effectively guide the intervention agenda

Building a Relationship

- Listen to the caregiver
- Recognize the caregiver’s individual needs
- Be aware of your own feelings about the caregiver
- Look for shared interests, commonalities
- Be knowledgeable of what you have to offer and the limits to what you can offer (shared understanding)

Building a Relationship

- Understand that caregiver needs to feel understood and supported
- Realize that intervention components can represent heavy physical and emotional demands
- Be aware of and respond to the caregiver's reaction to intervention
- Accept advice from other team members

Barriers to Building a Relationship

- Lack of motivation (readiness) by caregiver
- Clinical depression of caregiver
- Pessimism on part of caregiver and/or interventionist
- Perceived lack of empathy from interventionist
- Lack of professionalism from interventionist
- “Mismatch” between interventionist and caregiver

Active Listening & Communication Skills

-Empathy

-Active listening skills

-Communication

-Assertiveness

Empathy
(Genuine and non-judgmental responding)

- Empathy requires knowledge of dementia and dementia caregiving, awareness of feelings and frustrations associated with caregiving, respect for caregiver, and a genuine desire to understand caregiver’s unique situation/problem.
- Empathy gives interventionist credibility, facilitating the transfer of knowledge and skill from interventionist to caregiver.
- Empathy requires interventionist to be aware of what the caregiver is “saying” as well as what caregiver is “feeling”.
- Empathy is essential as interventionist guides and coaches caregiver through the intervention.

Active Listening

- **Learned communication skill.**
- **Understand speaker's intention or meaning.**
- **Lets speakers know they're "heard".**
- **Creates atmosphere of trust.**
- **Facilitates adherence.**
- **Useful for interviews & intervention.**

Considerations

- Sociocultural differences.
- Based on mutual respect.
- Use more Open than Closed responses.
- “Don’ts.” (refer to MOP)
- Useful phrases (and not – refer to MOP).

Active Listening Techniques

- Body language & eye contact.
- Repeat. Use of CG language.
- Rephrase, Reflect, Summarize.
- Identify the emotion.
- Go for intent.
- In all cases, *CHECK IT OUT.*

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Communication Skills

- **Three Basic Styles:**
  - **Passive: "You win, I lose."**
  - **Aggressive: "I win, you lose."**
  - **Assertive: "We both win."**
- **Respect for CG's needs, feelings, rights.**
- **Respect for yourself & your boundaries.**
- **Appropriately expressing expectations, thoughts, and feelings to participants.**

Assertiveness and Intervention

- Good assertive communication will:
  - Identify/clarify issues and obstacles.
  - Problem solve the situation.
  - Describe what/who might help.
  - Encourage and support.
  - Review outcome and repeat as needed.
- Caregivers the right to say “No.”
- Interventionists do too.
- Importance of practice; enactment.

Cultural Diversity: Increasing Cultural Competence

Before Entering the Field

- Acknowledge that you will be entering homes that are different from your own.
- Be aware of your own prejudices.
- Need to be non-judgmental when working in caregiver homes.
- Know the caregiver’s situation prior to entering the home.

Considering the
Sociocultural Context

- **Sociocultural influences can shape:**
  - **signs and symptoms of caregiver distress**
  - **caregivers' understanding of their feelings, thoughts, behavior views of others and environment**
  - **help-seeking behavior, treatment practices**
- **Sociocultural context can create barriers:**
  - **language barriers, culturally insensitive services, financial constraints**
- **Interventionists bring their own sociocultural history**

- Studies show recognizable differences across cultural groups as to disease incidence and beliefs about dementia.

- Also, there is significant within group heterogeneity.

- Need to pay attention to differences in beliefs about nature of human life, role of religious beliefs and traditions, to family decision-making structures, inter-generational differences, and value placed on affective versus cognitive capabilities within a household.

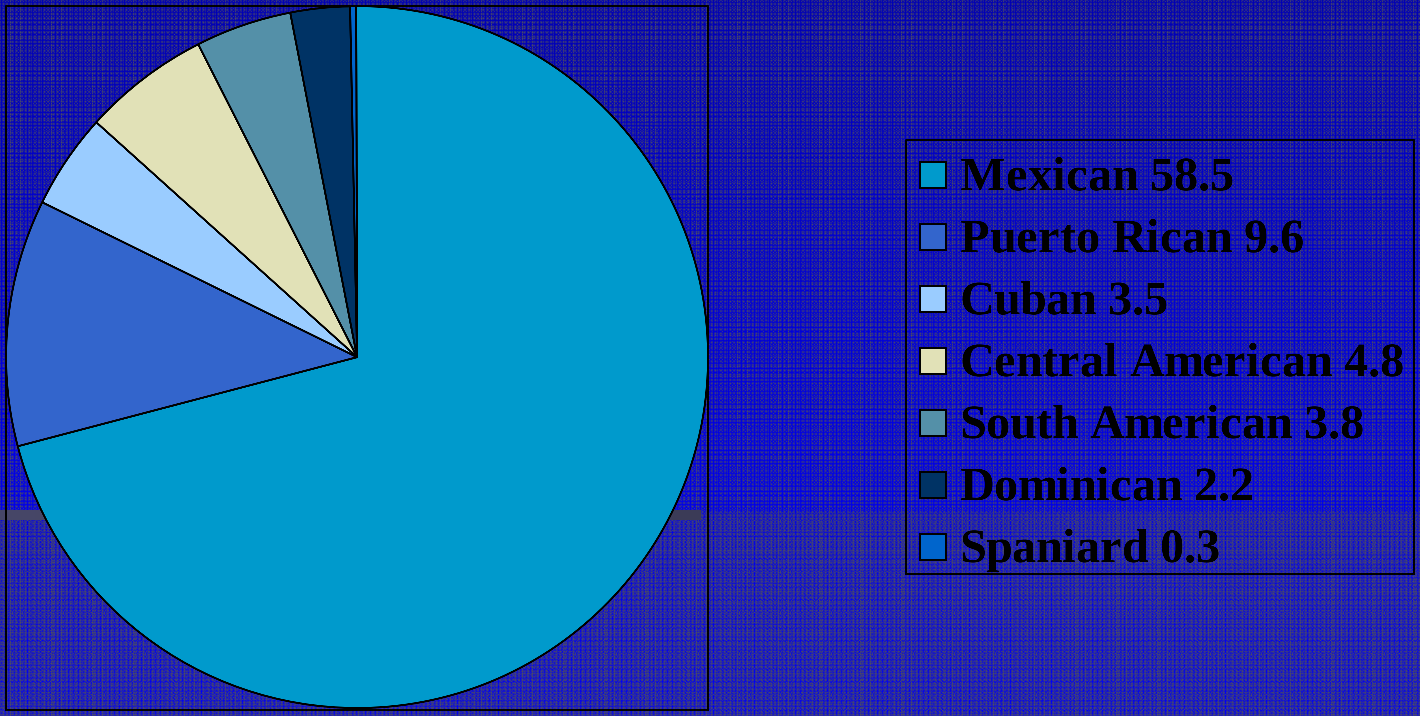
Factors to consider

- **Familiarity/Comfort/ Experience with:**
    - **Dementia/AD/Memory problems**
    - **Caregiver**
    - **Stress**
    - **Burden**
    - **Intervention/treatment**
    - **Disclosure**
    - **Professionals**

Special Considerations in Working with Latino Caregivers

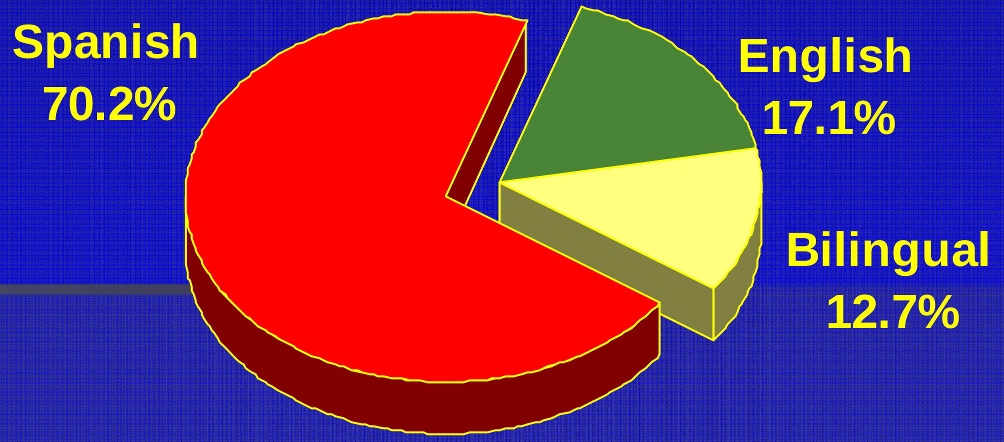
Percent Distribution of the Hispanic Population by Type: 2000

Source: U.S. Census Bureau, 2000 Summary File



One Common Language

**82.9% of Latinos
prefer to speak Spanish at home**



Source: Strategy Research Corp.2000 U.S. Hispanic Market

Latino Cultural values

- **Turn to family first for assistance.**
- **Emphasis on getting to know others, sharing life experiences.**
- **Attend to family, not punctuality.**

Intervention Considerations

- **What is preferred language?**
- **Cultural graces**
  - **Food/Coffee**
  - **Distance/closeness between you and CG**
- **Time flexibility**
  - **Platicar**
  - **Allocate more time for good-bye**

Intervention Considerations (cont)

- “Usted” instead of “Tú”
- Privacy during sessions
  - Family members may be present and want to participate
  - Frequent visitors/phone calls

Potential influential factors

- **Education**
- **Acculturation Status**
  - **Years in the US**
  - **Contact with other ethnic groups**
  - **Education**
- **Health Beliefs**

Summary

- Avoid Stereotypes
- Take time to gain CG trust
- Communicate openly

Part III: The Intervention

- Goal, objectives and delivery characteristics of intervention
- Session Structure
- CTIS
- Education Component
    - -Safety
    - -Health promotion
- Social Support Component
- Behavioral Skills Training Component
- Well-being Component

Goals, Objectives and Delivery Characteristics of Intervention

3 Goals of Intervention

- Identify and reduce modifiable risk factors
- Enhance quality of care of care recipient
- Enhance emotional and physical well-being of caregivers

Components of the Intervention

Intervention targets areas linked to caregiver stress and health outcomes:

- Lack of knowledge about disease, caregiving
- Social support
- CR problem behaviors
- Emotional well-being
- Self-care and Health Behaviors

EDUCATION OBJECTIVES OF INTERVENTION

- **<u>Increase caregiver knowledge about</u>**:
  - Disease and treatment options
  - Caregiving: duties, demands, and consequences
  - Available resources
  - Safety
  - Self-care and health-related behaviors

SOCIAL SUPPORT OBJECTIVES OF INTERVENTION

- **Enhance Social/Emotional Support:**
  - Enhance communication
  - Making decisions
  - Help handling difficult situations
  - Ability to express feeling concerns
  - Reduce social isolation
- **Enhance support with instrumental activities**
  - Managing caregiving tasks
  - Help with non-caregiving activities (e.g., transportation, shopping)

PROBLEM SOLVING OBJECTIVES OF INTERVENTION

- Increase caregivers ability to solve problems related to:
  - Managing ADL/IADL problems
  - Managing behavior problems
  - Communication
  - Safety/emergency situations

PHYSICAL AND EMOTIONAL WELL-BEING OBJECTIVES OF INTERVENTION

- Enhance caregivers emotional and physical well-being through skill development and education related to:
  - Stress reduction and relaxation
  - Increase pleasant events
  - Mood regulation
  - Health information
  - Preventive health services

DELIVERY CHARACTERISTICS

- 6 months
- 9 home sessions (1½ hours in length)
- 3 phone sessions (up to 30 minutes)
- Substitution Rule:
  - replace up to two phone for home sessions for total of 11 home & 1 phone sessions;
  - or replace up to two home for 2 phone sessions for a total of 7 home & 5 phone sessions

Delivery Characteristics (Cont)

- Each session designed to be completed in one contact
- However, some caregivers may need more time to complete one session
- An additional 3 contacts are available to interventionists to complete all 12 sessions (e.g., for a total of 15 contacts)

Delivery Characteristics (cont)

- Systematic approach to risk identification
- Level of intensity in delivery of each component varies based on caregiver need
- Intervention components are customized to caregiver identified risk areas

SESSION STRUCTURE

-Overall session structure

-Session by Session description

-Risk Appraisal and Prioritization

Refer to Intervention MOP Sections 3 & 4

Training Materials Necessary for this Section

- Session by Session Checklist
- Risk Prioritization Worksheet
- Relevant Baseline Information
- CG Notebook

Overview of Primary Focus of Each Session

Session 1	Introduction/CTIS Training
Session 2	Safety and taking care of self
Session 3	1st Targeted behavior & stress management (1st component)
Session 4	Behavioral prescription & 2nd component of stress management module
Session 5	2nd Target behavior & 3rd component of stress management module
Session 6-12	Reinforcement/review & introduce new target behaviors & well-being issues

Session Structure

Each session includes:

- Introduction to session purpose
- Reinforcement of CTIS, Support Group participation and strategies introduced
- Specific topic/focus
- Closure (identification of what to practice, next steps)

SESSION STRUCTURE

- ☐ **Provide brief explanation of session focus**
- ☐ **Review use of CTIS and troubleshoot if difficulty**
- ☐ **Reinforce CTIS use**
- ☐ **Review social support group enrollment and encourage participation**

SESSION STRUCTURE (cont'd)

- ❑ **Review strategies/educational materials offered in previous session:**
  - **evaluate if CG has specific questions & concerns about material/strategies**
  - **determine if CG uses strategies**
  - **evaluate if target problem is resolved or continues**

SESSION STRUCTURE (Cont'd.)

☐ **Engage in active training (behavioral prescriptions and/or well-being module)**

☐ **Obtain closure:**

- **establish date/time of next session**
- **briefly review problem area(s) addressed and primary strategies offered in session**
- **briefly review strategies caregiver agrees to try prior to next intervention contact**
- **help caregiver problem solve when and how to practice/implement selected strategies**
- **review home practice and help CG identify time to carry it out**

BEFORE CONDUCTING A SESSION

- Review baseline information
- Review Risk Prioritization Worksheet (RPW)
- Review treatment implementation (TI) documentation from previous session
- Use Session by Session Checklist to identify structure of next session & necessary materials/forms to bring to session (e.g., prescriptions)

BASELINE INFORMATION PROVIDED TO INTERVENTIONISTS

- Participant Information Form (Caregiver and care recipient demographics)
- Risk appraisal form
- Revised Memory and Problem Behavior Checklist (behavioral occurrence and upset)
- CR Personal Appearance Index and Home Environmental Assessment
- CES-D score

Risk Prioritization Worksheet (RPW)

- RPW is used to guide conduct of intervention (it is not for data entry purposes)

- RPW is used throughout intervention to:
  - assist in identification of Adverse event alert items;
  - identify safety and health areas to emphasize when reviewing CG Notebook (2nd session)
  - assist in negotiation of target behaviors and well-being modules (beginning in 3rd session)

Use of RPW

- Transfer relevant baseline information to RPW using guidelines in the MOP (Section 4)
- Items transferred represent areas of risk or behaviors identified as upsetting to CG
- Double check that all relevant areas of risk are transferred to form
- Keep in mind that items that are recorded as low risk may actually become the target focus of the intervention and that all items/behaviors listed need to be reviewed and considered with caregiver

SESSION BY SESSION DESCRIPTION

(REFER TO SECTION 3 OF MOP)

SESSION #1: HOME VISIT

- Introduce self and intervention goals
- Provide CG Notebook; briefly review contents; explain its use throughout intervention and where to keep intervention handouts/materials
- Set up CTIS and practice use with CG
- Introduce social support group purpose, language preference, time slots and complete group enrollment
- Use open-ended probes to obtain CG story
- Refer/Review risk areas referring to RPW
- If Acute Screening Criteria Alert items, address in this session (refer to CG Notebook and review materials)
- Obtain closure

USE OF RPW IN SESSION #1

- ☐ Use open-ended probes to engage CG to build rapport and learn about CG story
  - -When was CR first diagnosed?
  - -How did you know there was a problem?
  - -What is your day like?
  - -How are things going now?
- ☐ As CG tells story and discloses problem areas, refer to RPW. Check those areas identified by CG.
- ☐ For behavioral upset and emotional well-being items on RPW not identified during this discussion, ask CG if still problematic
- ☐ Explain that the intervention will address these areas.

Guidelines for Session #1

- Need to develop rapport while following outline of session structure
- The structure of session should be viewed as a guideline:
  - Some caregivers may need to tell their story first prior to setting up CTIS or introducing CG Network
  - You may have to introduce the elements of the session in a different order than shown on the session by session checklist
- If ALERT items, must address them first

Materials Needed for Session #1

(Refer to Session by Session
Checklist for detailed list)

- Personal Information Form
- CG Notebook
- Interventionist Badge
- Highlighter
- Forms (DA, TI, RPW)
- CTIS materials and forms

Caregiver Notebook

- 3-ring binder of key information
- Give to caregiver in first session
- Review sections with caregiver in first session

CAREGIVER NOTEBOOK

- About Dementia
  - Alzheimer’s Disease Facts
  - Fact sheet: Dementia
- About Caregiving
  - Fact sheet: Caregiving
  - Stress and the Caregiver
- Safety for the Alzheimer’s Patient
  - Safe Return Brochure
  - Driving
  - Home safety
- Health Passport

Session #2: Home Visit

- Introduce goals of session
- Review CTIS and practice its use
- Encourage social support group participation
- Review in detail Safety and Health Passport in CG Notebook
    - Use RPW to identify specific safety and personal health areas to emphasize
    - Identify and highlight specific strategies for CG to try
- Obtain closure

USE OF RPW IN SESSION #2

- Prior to session #2 review RPW to identify specific safety and CG health issues
- Prior to session read CG Notebook safety and health passport sections to identify what you will emphasize with CG
- In session, review safety/health passport with CG

  -Refer to RPW items as specific risk areas

  -Highlight relevant strategies for risk areas

Materials Needed for Session #2

(Refer to Session by Session Checklist for detailed list)

- Forms
  - RPW
  - DA
  - TI
- Extra CG Notebook if CG lost or misplaced original

Guidelines for Session #2

- If caregiver has few safety and health risk areas, you may start to identify first target behavior
- Use RPW to identify priority area
- If time, you may introduce first component of Stress Management Module

Session #3: Home

- Review use of CTIS, CG Notebook
- Review use of specific safety and health passport information/tips and encourage their use
- Identify Target Behavior #1
- Use ABC approach to identify and name problem, antecedents, behaviors and consequences
- Introduce 1st component of Stress Management Module (need 30 minutes)
- Set up appointment for next home session

Materials for Session #3

- Forms
  - DA, TI, RPW
  - ABC problem identification and brainstorming
  - Stress Diary
- Handout - Effects of Stress

Guidelines for Session #3

- Engage in dialogue with CG to identify target behavior
  - Use RPW to guide discussion
  - Help CG focus on most problematic area and indicate other issues will be addressed in subsequent sessions
- Following ABC approach, introduce signal breadth (1st component of Stress management module) as a way of addressing target behavior
- Refer CG to CTIS for tips that may be relevant to identified target area

Session #4: Home

- Check in about CTIS and support group participation
- Review use of safety and health strategies
- Introduce behavioral prescription for Target Behavior #1 following guidelines
  - Describe each strategy and why selected
  - Practice strategies using demonstration, role play
  - Identify which strategies CG will practice
- Review use of signal breadth
- Introduce 2nd session of stress management module (use of music)
- Obtain closure

Materials Needed for Session #4

- Forms (DA, TI, RPW)
- Behavioral Prescription
- Behavioral Worksheet Handout
- Stress management handout
- Tape recorder and tape

Session # 5: Home Visit

- Check in about use of CTIS and support group participation
- Review use of prescription for 1st target behavior
  - Modify strategies if necessary
  - Validate CG's efforts
  - Reinforce continued use
  - Determine if new target behavior can be addressed (rate resolution of problem on TI)
- Review use of stress management modules and introduce 3rd component (exercise)

Session #5 – cont.

- If appropriate, identify and define next behavior problem (target behavior #2)
    - Review RPW
    - Decide priority behavior
    - Use ABC method to define goals, determine how success will be measured

Materials Needed for Session #5

- Forms (DA, TI, RPW)
- Relevant prescriptions
- ABC forms to identify Target behavior #2 if relevant
- Stress diary and exercise forms

Session #6: Home

- Encourage use of CTIS and support group
- Review/encourage use of prescription strategies
- Review/encourage use of stress management modules
- Refer to decision rules and RPW to determine if appropriate to negotiate 2nd target problem
  - If 2nd well-being module is appropriate, introduce 1st component of mood or pleasant event module
  - If 2nd skill area, probe to identify ABCs of problem
  - Refer CG to Notebook tips
  - Indicate next session will have prescription
- Set up next appointment

Session # 7: Phone

- Check in with CG about use of CTIS
- Reinforce participation in social support groups
- Review relevant prescriptions
- Determine what was attempted, what worked, what did not
- Evaluate usefulness and success of solutions
- Validate/praise CG efforts
- Reinforce continued use of strategies and stress management techniques
- Obtain closure

Session # 8: Home Visit

- Same as session #6
- Determine if appropriate to introduce 2nd component of a well-being module

Session #9: Phone

- Same as Session #7

Session #10 and 11

- Session 10 – Home visit, same as previous home session
- Session 11 – Phone, same as previous phone session

Session #12: Home Visit

- Instruct in final segment of well-being module if relevant
- Review problem areas and strategies that have worked
- Validate CGs techniques
- Encourage use of resources
- Obtain closure
    - Encourage use of CG notebook
    - Encourage use of referral numbers

FOLLOWING EACH SESSION

- Complete treatment documentation

  - ☐ Delivery Assessment Form
  - ☐ Treatment Implementation Form

- Review Summary Table of Resources available per risk appraisal item (Appendix A of MOP) to develop treatment plan

- Present caregiver case at on-site weekly review meetings

FOLLOWING EACH SESSION: (Cont'd.)

- Use resource material to develop prescriptions

  - ☐ Education materials
  - ☐ Prescriptions in MOP Appendix
  - ☐ Prescriptions posted on REACH II web from other sites

- Post prescription on REACH II web page

RESOURCES AVAILABLE TO INTERVENTIONIST

- ☐ **Weekly on-site supervisory sessions:**

  Interventionists meet weekly with on-site research team. At meetings, each caregiver case is discussed and guidelines reinforced for developing prescriptions.

- ☐ **Summary of Resources: (see Appendix A) Serves as quick and easy reference for interventionists of materials available for each risk and RMBPC item.**

RESOURCES AVAILABLE TO INTERVENTIONIST

- ☐ **Bi-Monthly tele-conference sessions**: These sessions will involve interventionists from each research site, the purpose of which will be to troubleshoot and review basic procedures and to insure consistent application of intervention procedures across sites

- ☐ **Web-based prescriptions**: Each new prescription developed by an interventionist will be posted on a secured password protected section of the REACH II web site. Interventionists will be able to access and use prescriptions developed at other sites for an identified target behavior.

Intervention Guidelines and Scripts

- Introduction to study and intervention goals
- Negotiation guidelines
- Guidelines for ABC and introducing prescriptions
- Closure

Use of Scripts

- Use as guidelines for interaction
- Reflect bulleted talking points
- Provides key vocabulary
- Should not be read

PRIMARY FORMS USED BY INTERVENTIONIST

(Refer to Chart of Forms)

- Risk Priority Worksheet (RPW)
  - Transfer baseline information
  - Refer to throughout intervention
- CTIS enrollment form
  - Enroll caregiver in first session
- Social support enrollment form
  - Enroll caregiver in first or second session
- Social support log
  - Facilitator completes after each on-line support group

FORMS USED (CONT'D)

- ABC behavioral process forms
  - Intervention uses for target behaviors
- Stress management module materials
  - Intervention uses to instruct in module

FORMS USED (CONT'D)

- Delivery Assessment
  - Interventionist must complete within 24 hrs following each contact
  - For data entry
- Treatment implementation
  - Interventionist must complete following each session
  - Interventionist refers to each session
  - For data entry at end of 6 months

Handouts to Caregiver

- Prescription developed by Interventionist
- Weekly recording of target behavior
- Overview of stress management
- Stress readings
- Mood and pleasant event handouts

REACH Caregiver Network Computer Telephone Integrated System (CTIS)

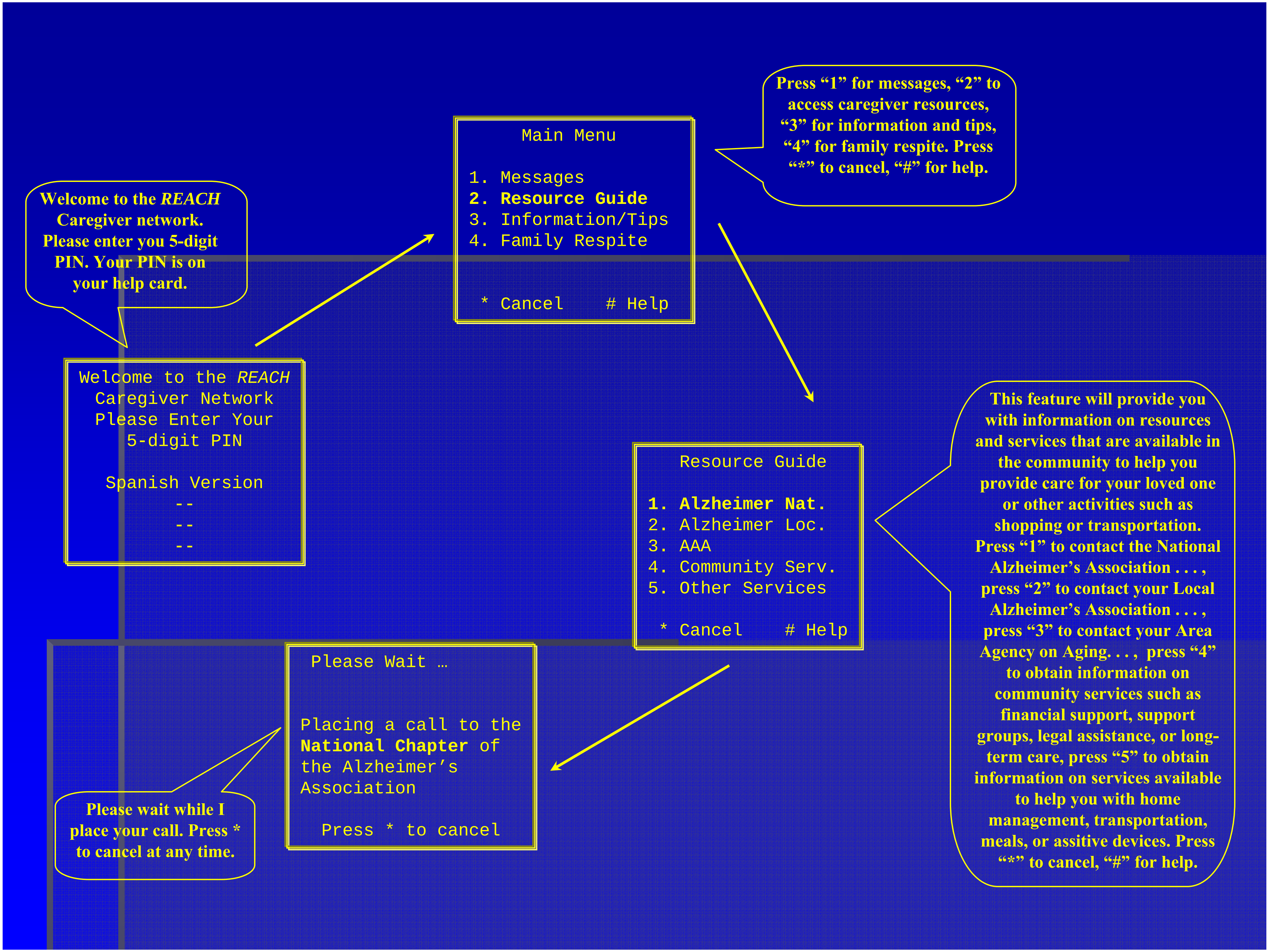
The CTIS system is a computer-integrated telephone system designed to:

- Facilitate caregiver access to information and resources
- Enhance communication
- Reinforce the content and strategies of the intervention
- Enhance social support

Computer Integrated Telephone System (CTIS)

Computer Telephone Integrated System Description of the CTIS

- Simple to use and “works” like a regular telephone
- Menu driven
- User is guided through the menus by visual and voice prompts
- Menus customized for the language preference of the caregiver (English vs. Spanish)
- System collects real-time usage data on a per call basis



Welcome to the *REACH* Caregiver network. Please enter you 5-digit PIN. Your PIN is on your help card.

Welcome to the *REACH*
Caregiver Network
Please Enter Your
5-digit PIN

Spanish Version
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Main Menu

1. Messages
2. Resource Guide
3. Information/Tips
4. Family Respite

* Cancel # Help

Press “1” for messages, “2” to access caregiver resources, “3” for information and tips, “4” for family respite. Press “*” to cancel, “#” for help.

Resource Guide

1. Alzheimer Nat.
2. Alzheimer Loc.
3. AAA
4. Community Serv.
5. Other Services

* Cancel # Help

This feature will provide you with information on resources and services that are available in the community to help you provide care for your loved one or other activities such as shopping or transportation. Press “1” to contact the National Alzheimer’s Association . . . , press “2” to contact your Local Alzheimer’s Association . . . , press “3” to contact your Area Agency on Aging. . . , press “4” to obtain information on community services such as financial support, support groups, legal assistance, or long-term care, press “5” to obtain information on services available to help you with home management, transportation, meals, or assitive devices. Press “*” to cancel, “#” for help.

Please Wait …

Placing a call to the **National Chapter** of the Alzheimer’s Association

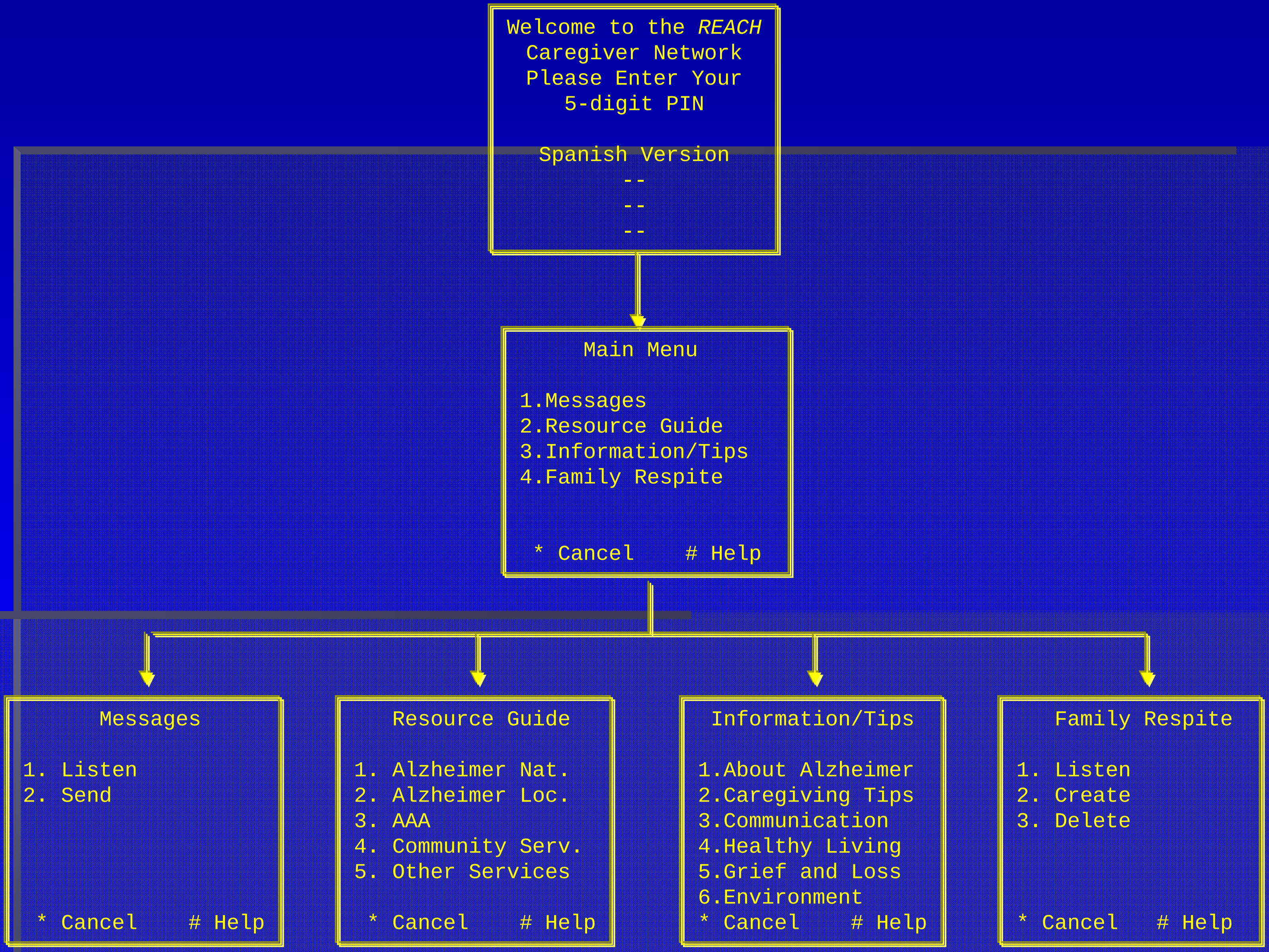
Press * to cancel

Please wait while I place your call. Press * to cancel at any time.

Caregiver Component

- *Messages:* This feature will allow caregivers to send and receive messages
- *Resource Guide:* This feature provides information on various resources, community agencies, and services
- *Information/Tips:* This feature consists of short educational dialogs (5 – 10 minutes on various topics)
- *Family Respite:* Family members or friends or the caregiver can develop messages/ vignettes for the care recipient
- *Support Groups:* Each caregiver will participant in five on-line support group sessions

Caregiver Component



Welcome to the *REACH*
Caregiver Network
Please Enter Your
5-digit PIN

Spanish Version
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Main Menu

1.Messages
2.Resource Guide
3.Information/Tips
4.Family Respite

* Cancel # Help

Messages

1. Listen
2. Send

* Cancel # Help

Resource Guide

1. Alzheimer Nat.
2. Alzheimer Loc.
3. AAA
4. Community Serv.
5. Other Services

* Cancel # Help

Information/Tips

1.About Alzheimer
2.Caregiving Tips
3.Communication
4.Healthy Living
5.Grief and Loss
6.Environment
* Cancel # Help

Family Respite

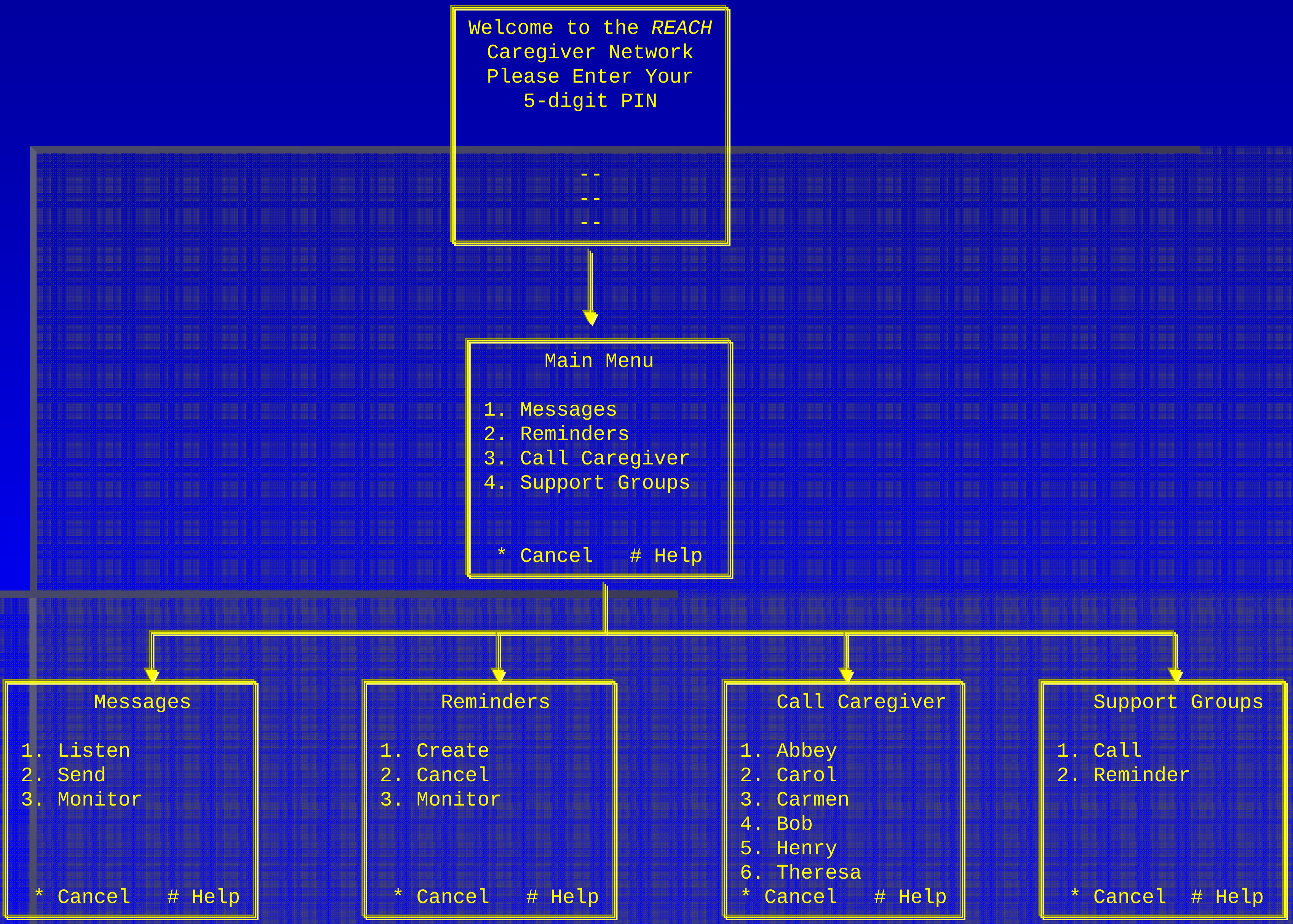
1. Listen
2. Create
3. Delete

* Cancel # Help

Interventionist Component

- *Messages:* This feature will allow interventionists to send, receive, and monitor messages
- *Reminders:* This feature will allow interventionists to send reminders to a caregiver at a pre-appointed time and date
- *Intervention Delivery:* This feature is used by the interventionist for delivery of the intervention

Interventionist Component



Welcome to the *REACH*
Caregiver Network
Please Enter Your
5-digit PIN

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Main Menu

1. Messages
2. Reminders
3. Call Caregiver
4. Support Groups

* Cancel # Help

Messages

1. Listen
2. Send
3. Monitor

* Cancel # Help

Reminders

1. Create
2. Cancel
3. Monitor

* Cancel # Help

Call Caregiver

1. Abbey
2. Carol
3. Carmen
4. Bob
5. Henry
6. Theresa

* Cancel # Help

Support Groups

1. Call
2. Reminder

* Cancel # Help

System Data

Per Contact:

- Initiator of the call
- Individual vs. group contact
- Call participants
- Feature(s) accessed
- Duration of contact per feature
- Time and date of contact

Implementation Protocol

Prior to initial home visit

- Enroll yourself and caregiver into network
- Prepare caregiver help card
- Create a message for the caregiver
- Assemble screen phone and set time and date

Initial Home Visit

- Provide a brief overview of caregiver network
- Install screen phone
- Demonstrate basic operation of screen phone
- Practice
- Complete training observation checklist
- Administer the training questionnaire
- Review help card
- Encourage caregiver to use the system
- Complete support group preference form

Second Home Visit

- Review the basic features/ operation of the network
- Practice
- Reinforce use of the network

Installation Checklist

- Screen Phone ____
- User Help Card ____
- 12 - 14 foot telephone cable ____
- Small coin (dime) ____
- Caregiver Training Manual ____
- Observation Checklist ____
- Training Questionnaire ____
- 1 to 2 jack adapter ____

Social Support Groups

Goals of Social Support Component

- Enhance social/emotional support
  - Help making decisions
  - Enhance communication
  - Help handling difficult situations
  - Ability to express feeling concerns
  - Reduce social isolation
- Enhance support with instrumental activities
  - Managing caregiving tasks
  - Help with non-caregiving activities (e.g., transportation, shopping)

Social Support Component Intervention Strategies/Activities

- Educational materials
  - Community resources and programs
  - Communication
  - Well-being
- Caregiver Network features
  - Resource guide
  - Information/tips
  - Family respite
- On-line support groups
- Communication and well-being modules

Setting up a Support Group

- Introduce support group during initial home visit
- Complete support group preference form and fax to Miami
- Inform caregiver of initial group meeting
- Encourage meeting attendance
- Use network to remind caregiver of meeting – create a reminder message for the day prior to the meeting
- Review talking points and background material
- Complete support group schedule form for next meeting and fax to Miami

REACH On-Line Groups

- Are Educational Family Caregiver Groups
  - The Goal is to help family members learn to function better in their caregiver roles
  - The Leader is a Facilitator that provides structure, education and support
  - The Group focuses on activities and learning that address the needs of caregiver/care recipient and the demands of caregiving
  - The Members are diverse in terms of Age, Gender, Ethnicity, Relationship to Care Recipient, etc.
  - The Communication is member to member and leader to member

Characteristics of On-line Support Groups

- 5 monthly support group sessions
- 5 – 6 caregivers and trained facilitator
- Closed, national groups
- English and Spanish groups
- Standardized structured format

Structure of On-line Support Groups

- 10 minute “Check-In”
- 15 minute Educational Component
  - Accessing community resources
  - Communicating with health care providers and service agencies
  - Communicating with family and friends
  - Communicating with your loved one
  - Taking care of yourself
- 35 minute free form discussion
  - Encourage caregivers to share issues, problems, concerns, solutions

Talking Points:
Initial Group Meeting

- General introduction
  - Name?
  - Who are you providing care for?
  - Goals for group attendance?
- Define purpose and structure of groups
- Review “Group Rules”
  - Commitment to attend all of the meetings
  - Notify facilitator if unable to make meeting
  - Be on time
  - Don’t interrupt others
  - Be a good listener
  - Be positive and constructive

Talking Points: Accessing Community Resources

- Multiple roles of caregiving
- Review of available community resources and programs
    - e.g., respite care, legal and financial services
- Tips for accessing community resources
    - Preparation
    - Making the calls
    - Future planning
- Reinforce use of resource guide and information tips features of REACH Caregiver Network

Talking points:
Communicating with Health Care Providers and Service Providers

- How to make the most of physician appointments
- Effective communication skills
- Working with other service providers
- Financial concerns
- Reinforce use of "Communication" feature of REACH Caregiver Network

Talking points: Communication with Family and Friends

- Reasons for communication difficulties
- Strategies for communicating with family and friends
- Visiting with family and friends
- Reinforce use of “Communication” feature of REACH Caregiver Network

Talking points: Improving Your Interaction with Your Loved One

- Barriers to communication
- Strategies for improving your ability to communicate with your loved one
- Helping your loved one to communicate
- Making use of nonverbal cues and information
- Managing vision and hearing problems
- Reinforce use of “Communication” feature of REACH Caregiver Network

Talking points:
Taking Care of Yourself

- Education
- Exercise
- Nutrition
- Sleep
- Asking for help and support
- Engaging in pleasant activities
- Reinforce use of “Healthy Living” feature in the REACH Caregiver Network

Facilitator Skills

- Be an effective listener
  - Refer to people by name
  - Do not interrupt
  - Do not make judgments
  - Ask for clarification
  - Briefly summarize what has been said

Facilitator Skills

- Provide effective feedback
  - Timely
  - Non-judgmental
  - Make sure your message is understood
  - Do not force your thoughts or opinions

Facilitator Skills

- Be an effective leader
  - Be knowledgeable about: dementia, caregiving issues; community resources; and educational topic
  - Inform but don't lecture
  - Be flexible
  - Speak loudly and clearly
  - Stay in control of the meeting

Facilitator Skills

- Be an effective leader
    - Create a safe atmosphere
    - Give everyone an opportunity to participate
    - Encourage interaction and expression of feelings
    - Encourage humor

Facilitator Skills

- Display ethnic competence
  - Be sensitive to ethnic differences
  - Be aware of ethnic phrases and vocabulary
  - Try and create similarity among experiences

Support Group Facilitator Training

- Background reading material
  - Group Work with the Elderly
  - Support Group Facilitator Manual
  - Caregiver Notebook
  - Caregiver Network User Manual
  - Talking points and scripts
- Participate in 2 audio group training sessions with Miami site
  - Procedural and operational issues
  - Facilitator skills
- Attend at least 2 community support groups
- Role play session as a facilitator with Miami site

Problem Solving Module to Develop Caregiver Skills in Managing Target Behaviors

-

Problem Solving with the Caregiver

- The interventionist and caregiver engage in joint problem solving.
- An overview of the problem solving model being used is presented in the chapter, “A Prescriptive Model of Social Problem Solving”.

Behavioral Prescriptions

- Define the problem and gather information.
- List possible solutions.
- Decision making and prescribing solutions to be used.
- Solution implementation and tracking progress towards stated goal.

Define the Problem and Gather Information

- Identify and name the target problem.
- Define how success will be measured (goal setting).
- Gather information; identify antecedents and consequences (the ABC process).

Defining the Problem

- Important step. Don’t rush it.
- Re-state out loud what the caregiver is reporting.
- Active listening is essential.

Setting Goals

- Concrete, realistic expression of the caregiver's expectations.
- Problem-focused goals focus on actual changes in the targeted problem behavior.
- Emotion-focused goals are aimed at managing the emotions or feelings of the caregiver that are linked to the target problem behavior (appraisal).

Gathering Information via the ABC Process

- "ABCs of Problem Behaviors" Form structures this process.
- Interventionists must be very familiar with this document before working with caregivers.

ABCs of Problem Behaviors
Probes for the 'ABC Process'

1	**What is the behavior?** ☐ "Take a minute and describe what CR does." ☐ Listen for irrational thoughts, misunderstandings about AD (dementia), unrealistic expectations of the CR	**Notes**

2	**Why is this behavior a problem?**
	☐ People react differently to behaviors. What about this behavior really gets to you?
	  ☐ What bothers you?
	  ☐ Why does this get on your nerves?
	☐ Can you list the reason(s)?
	☐ What effect does this behavior have on you?
	☐ How does it make you feel?
		Notes

3	**How would you like this behavior to change?** ☐ When would you consider the problem "solved"? ☐ What would make it seem to you that it was better? ("tolerable") ☐ What would make you feel better about this problem?	**Notes**
4	**Why do you think this behavior happens?** ☐ Do you see any causes or triggers?	**Notes**
5	**When does the behavior happen?** ☐ Time of day? ☐ Days of the week? ☐ When does the behavior begin? ☐ Can you recognize any cycles or patterns? ☐ What happened right before the problem behavior occurs? ☐ Does behavior happen constantly? ☐ How often does the behavior happen?	**Notes**

ABCs of Problem Behaviors
Probes for the 'ABC Process'

5	**Where does the behavior happen?** ☐ Is there a unique place in the house? ☐ Does it only happen in certain places? ☐ Are there places where it does not happen? ☐ Have you changed the surroundings of your family member? If yes, did it get worse or better when this happened?	Notes
6	**Who is around when the behavior occurred?** ☐ Do other people help care for your family member? ☐ Do you care for other people? children? ☐ Is the behavior influenced by other family members/friends? ☐ How do other people react to your family member's problem behavior? ☐ Any special sleeping arrangements?	Notes
7	**What have you tried?** ☐ What do you do when she/he does this? ☐ Have you tried anything that hasn't worked? ☐ Have you tried anything that seems to help? ☐ How often have you tried doing that?	Notes
8	**Additional information** ☐ Has your doctor been told of this behavior? ☐ If yes, what has your doctor recommended? ☐ Does care recipient have problems? ☐ Does care recipient have vision problems?	Notes

List Possible Solutions (Brainstorming)

- Interventionist and caregiver work together to generate a list of possible solutions or strategies.
- Postpone criticizing or negating of possible solutions until brainstorming is complete.
- Establish “ground rules” that define the parameters of the brainstorming activity.
- After the brainstorming activity is completed, the caregiver (and the interventionist) rule out unacceptable solutions.

Problem Solving Module

Brainstorming Sheet

Target Behavior Problem:

Possible Solutions:

*Note all solutions that are unacceptable to caregiver

Decision Making and Prescribing Solutions to be Used

- Review solutions in order to select the most appropriate strategies.
- Use core prescriptions and resource materials to generate an individualized behavioral prescription (Appendix A of MOP).
- Use the expertise of the entire REACH II team.
- Present behavioral prescription to the caregiver on the following home visit.

Template for Behavioral Prescription Module

Behavioral Prescription

Target Behavior Problem:
Strategies for Changing Triggers or Antecedents:
Strategies for Changing Consequences:
General Information:

Sample Behavioral Prescription

Behavioral Prescription

Target Behavior Problem:
Difficulty getting Vera to understand you while dressing to leave the house

Strategies for Changing Triggers or Antecedents:

1. Have Vera's hearing checked. Be sure to see a hearing doctor that has experience in treating older adults with memory problems. Be sure to ask the doctor about hearing devices to help with hearing, like hearing aids, and the best way to convince her to wear them.

2. Use one step instructions.
    - Break each task into the simplest steps and give instructions one step at a time.
    - For Example: *Instead of saying, "Stand up and get dressed",* try breaking it up into simpler steps by saying, "Stand up", "Remove your pants", "Remove your underwear", "put on these underwear", "sit down", "put your leg in the pant leg", etc.

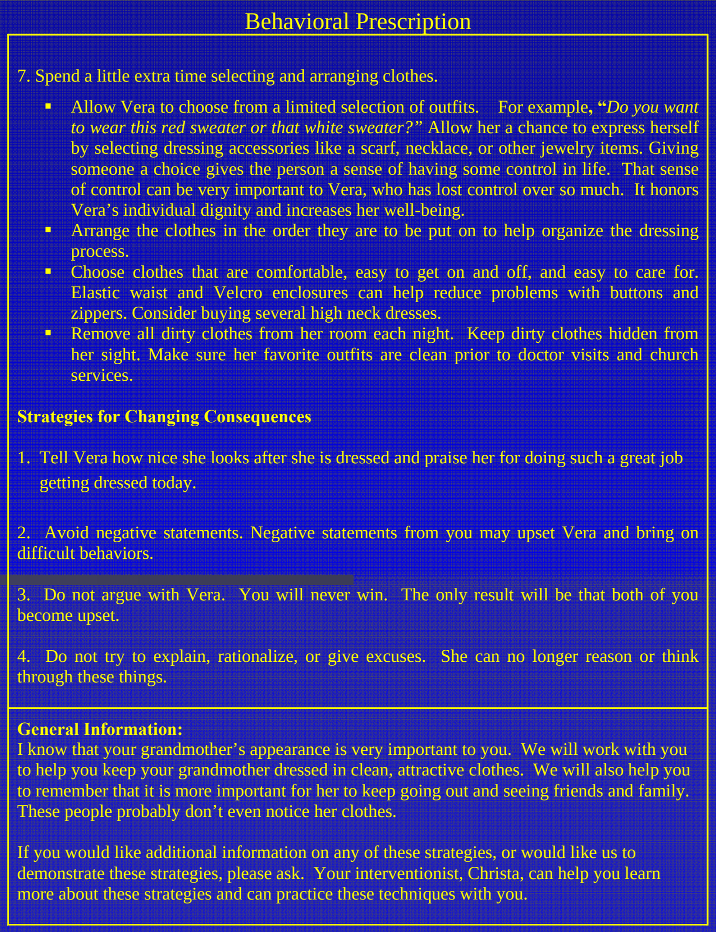
3. Speak slowly and say individual words clearly.
    - Vera needs extra time for her brain to understand what you are saying. It will help you make this technique a habit if you count to 5 after each question or statement you make to Vera.

4. Call Vera by the name that she prefers.

5. Eliminate distractions from the area or room in which you are helping with Vera's daily care.
    - When dressing Vera, make sure that the den TV and the bathroom radio are turned off.

6. Use gestures to help communicate your point.
    - Gestures provide another "clue" besides words and tone of voice. Vera needs as many clues as possible to understand you.
    - Using hand gestures like pointing will help direct Vera's attention during an activity. Using a flat hand raised will help you to communicate stop or motion to come towards you. Patting your hand on a chair can help signal to sit down in the chair.
    - Use head gestures like nodding or shaking your head.

Sample Behavioral Prescription Module



Behavioral Prescription

7. Spend a little extra time selecting and arranging clothes.

- Allow Vera to choose from a limited selection of outfits. For example, **"***Do you want to wear this red sweater or that white sweater?"* Allow her a chance to express herself by selecting dressing accessories like a scarf, necklace, or other jewelry items. Giving someone a choice gives the person a sense of having some control in life. That sense of control can be very important to Vera, who has lost control over so much. It honors Vera's individual dignity and increases her well-being.
- Arrange the clothes in the order they are to be put on to help organize the dressing process.
- Choose clothes that are comfortable, easy to get on and off, and easy to care for. Elastic waist and Velcro enclosures can help reduce problems with buttons and zippers. Consider buying several high neck dresses.
- Remove all dirty clothes from her room each night. Keep dirty clothes hidden from her sight. Make sure her favorite outfits are clean prior to doctor visits and church services.

Strategies for Changing Consequences

1. Tell Vera how nice she looks after she is dressed and praise her for doing such a great job getting dressed today.

2. Avoid negative statements. Negative statements from you may upset Vera and bring on difficult behaviors.

3. Do not argue with Vera. You will never win. The only result will be that both of you become upset.

4. Do not try to explain, rationalize, or give excuses. She can no longer reason or think through these things.

General Information:
I know that your grandmother's appearance is very important to you. We will work with you to help you keep your grandmother dressed in clean, attractive clothes. We will also help you to remember that it is more important for her to keep going out and seeing friends and family. These people probably don't even notice her clothes.

If you would like additional information on any of these strategies, or would like us to demonstrate these strategies, please ask. Your interventionist, Christa, can help you learn more about these strategies and can practice these techniques with you.

SIMPLIFICATION – a principle to use in development of prescriptions

Physical and Task Environment

- Simplification of physical environment and tasks can contribute to:
  - Safety for CG and CR
  - Orientation and awareness of CR
  - Physical function of CR
  - Comfort of CR
  - Reduction of problem behaviors

What to simplify?

OBJECTS

Physical items

- fixed attributes of home (layout, doors, windows, floors, stairs)
- portable items
- furniture
- visual and auditory attributes

TASKS

Actions performed

- home chores (IADL)
- self-care (ADL)
- leisure
- communication (verbal and non-verbal)

Object Simplification

Complexity
- How difficult is it to use this object?

Availability
- Are needed items available and accessible?

Flexibility
- Can an item be used for more than one purpose?

Age and Gender Appropriateness
- Does the item fit the user’s self-image?

How to simplify physical environment

DOMAIN	EXAMPLES
Complexity	• Labels (orienting, instructions) • Level of visual & auditory impact • Low technology
Availability	• Necessary items available • Unnecessary items put away • Limited clutter (background noise, camouflage)
Flexibility	• Clear, unambiguous use (spork, combination bedroom/living room)
Age/Gender Appropriateness	• Use of infant or children's items • Use of items in typical gender roles

Specific Examples of Simplifying Objects

- Remove unnecessary/dangerous objects
- Place needed objects in full view
- Place items in order of use (eg., for dressing, bathing, eating)
- Place objects of comfort in full view (stuffed animals, photos)
- Set up control center (e.g.,needed objects for CG or CR in one area (e.g., use tray) for use throughout day
- Label objects (e.g, written, pictorial labels)

Task Simplification

- Complexity
  - What is the number and sequence of activities?
- Rules
  - What are the consequences of mistakes?
- Relationship to time
  - Is the task ongoing, seasonal, or periodic?
- Symbolic Meaning
  - How is the task associated with self-image?

How to simplify tasks

DOMAIN	EXAMPLES
Complexity	• Adjust number and order of steps • Use repetitive motions • Reduce difficulty of instructions • Aim for familiarity • Gross motor>fine motor>cognitive
Link to Time	• Routines are GOOD • Periodic rests are GREAT • Pacing is FANTASTIC
Symbolic Meaning	• Adult roles usually involve productivity • Link to former roles
Rules	• Make tasks "error-proof" • Ignore harmless mistakes • Aim for non-competitive "play"

Simplification of Communication

-Non-verbal

-Verbal

Order of Difficulty (most to least)

- Verbal instructions
  - Full instructions
  - Single instruction as needed
- Pictorial instructions
  - Drawing or photo of unidentified person
  - Photograph of impaired person
- Demonstration
  - Show me
  - Watch me
- Hand Over Hand Guiding

Demonstration with Caregivers

Recommended order:

- Demonstration *Watch me try TASK with you/your ELDER*
- Simulation *You be the caregiver and try TASK with me*
- Observation *Let me watch you try TASK with your ELDER*
    - accompany with hand-over-hand, if necessary

Transitioning and behavioral prescriptions: Deciding when to start, stop and move on

Solution Implementation and Tracking Progress Towards Stated Goal

- Review the behavioral prescription with the caregiver.
- Use modeling, role playing, and demonstration techniques when appropriate (as much as possible).
- Provide multiple examples of how the behavior might be manifested, and how the caregiver should respond.

Follow-Up Visits

- Assessment of the caregiver’s use of the solutions and strategies
- Review tracking forms
- Evaluate the usefulness/success of the solutions
- Praise caregiver

Tracking Progress

- How good was the caregiver's <u>effort</u> in the implementation of the prescribed strategies?
- How good was the <u>result</u>?
- Evaluate the usefulness/success of the solutions

Weekly Recording Form

- Introduced to caregivers as a way of monitoring progress.
- Caregivers are encouraged but not required to complete forms.
- Tracking the target behavior is an “intervention process” technique.

Weekly Recording Form for CG Use

BOOCA Date: ____________ WEEKLY RECORDING FORM

DAY OF THE WEEK	**PROBLEM BEHAVIOR #1** **Difficulty getting Vera to understand you while dressing to leave the house.**			**BEHAVIOR PROGRAM #1 USED** 1. Use one step instructions. 2. Speak slowly. 3. Eliminate distractions. 4. **Use gestures.** 5. **Spend a little extra time selecting and arranging clothes.** 6. Tell Vera how nice she looks. 7. Avoid negative statements. 8. Do not argue with Vera. 9. Do not try to explain, rationalize, or give excuses.		
	Midnight to 8:00 AM	**8:00 AM to 4:00 PM**	**4:00 PM to Midnight**	**Midnight to 8:00 AM**	**8:00 AM to 4:00 PM**	**4:00 PM to Midnight**
SUNDAY						
MONDAY						
TUESDAY						
WEDNESDAY						
THURSDAY						
FRIDAY						
SATURDAY						

Start with list of areas identified on Risk Priority Worksheet and areas negotiated between caregiver and interventionist.

Start with most burdensome problem that is “changeable” in 6-month period.

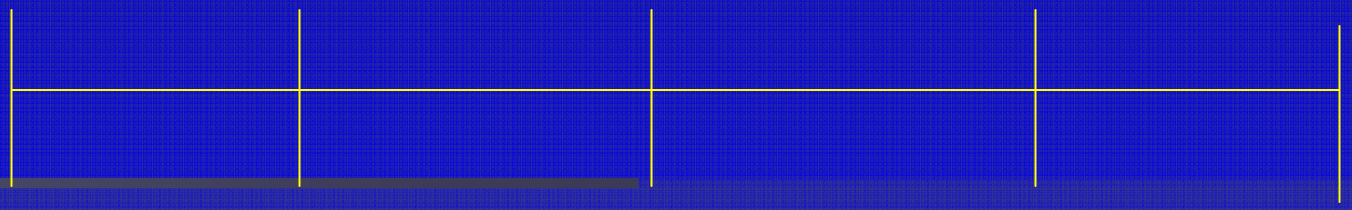
General Rule:
Keep a behavioral prescription active and in place for at least three weeks

- Takes time to work
- Requires consistent application
- Can alter behavioral prescription from week-to-week (i.e., adding/subtracting strategies on prescription)

Unless:

- Marked increase in CR agitation
- Marked resistance to prescription as a whole

At each subsequent session, ask: "Compared to when we started, is the problem…" (record on TI form)



A lot Worse

A little Worse

The Same

A little Better

A lot Better

[Use Response Card]

When to Stop a Behavioral Prescription?

- In general, don’t stop. Modify throughout life of project.
- Unless: Rating of “a lot worse” for 2 sessions.

When to start second behavioral prescription?

- Two (2) sessions after start of first prescription, and
- Caregiver expresses interest in working on another problem, and
- The interventionist believes other intervention efforts are not too burdensome

Team Meetings

- Use weekly interdisciplinary team meeting to help make transition decisions
- Use weekly (?) inter-site telephone conference for particularly difficult decisions

Inter-site Coordination

- Need to track:
  - Types of behavioral prescriptions
  - Number of problems targeted
  - Number of well-being modules
  - Number of home visits/phone sessions
- Track statistically using DA form

Enhance Caregiver Emotional Well-being

Empirical Support & Background

- **Stress Management**

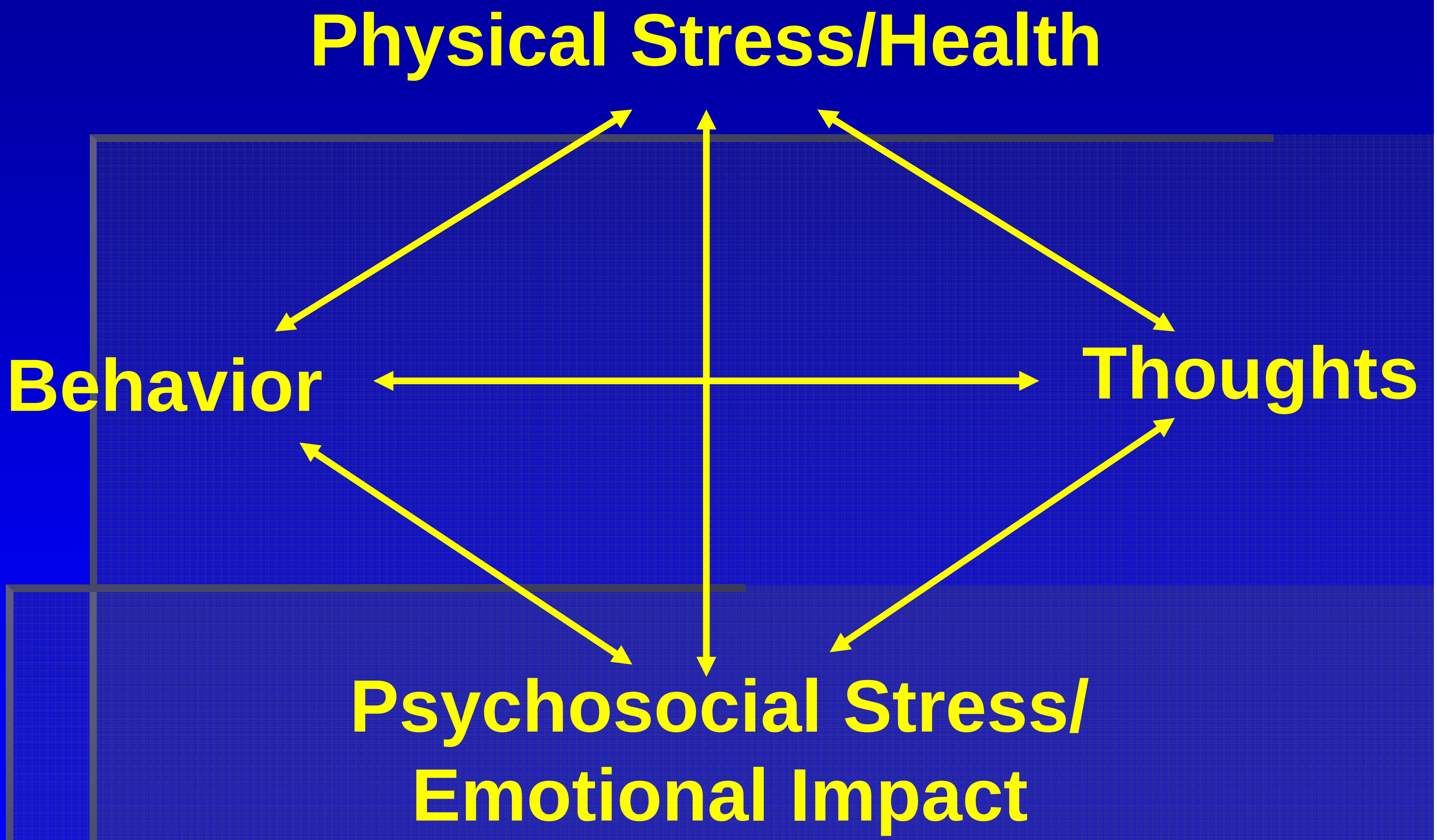
  (Fisher & Laschinger, 2001).

- **Pleasant Events**

  (Lewinsohn, Muñoz, Youngren, & Zeiss, 1986; Gallagher-Thompson et al., 2000; Rivera et al., 1991; Thompson et, 1993).

- **Mood Management**

  (Beck et al., 1979; Coon et al., 1999; Gallagher-Thompson & DeVries 1994; Gallagher-Thompson & Steffen, 1994; Gallagher-Thompson et al., under review).



Physical Stress/Health

Behavior

Thoughts

Psychosocial Stress/
Emotional Impact

Module Format

- **Brief Education on Skill**
- **Demonstration/Discussion/Practice**
- **Home Practice**
- **Home Practice Review**

Stress Management:
Session 1 - Stress Effects & Signal Breath

Effects of Stress

- **Physical**
  - **Blood pressure, immune system.**
- **Psychological**
  - **Irritability, frustration, depression, anxiety.**
- **Social**
  - **Relationship strain, social isolation.**

Stress Management: Session 1
Stress Effects & Signal Breath

General Steps to Take

- **Taking care of themselves.**
  - **Exercise, time with friends, spiritual practices.**
- **Problem-solving.**
  - **Prioritize & organize time.**
- **Physical health.**
  - **Keep appointments, sleep & rest, medications.**

Stress Management: Session 1

Stress Effects & Signal Breath

- **Signal Breath**
  - **Tension Rating.**
  - **Practice.**
  - **Stress Diary.**

- **Home Practice & Preparation for Music Session.**

Stress Management: Session 2
The Power of Music

- **Home Practice Review.**
- **Tension Rating.**
- **Introduction to Music.**
- **In session Music Exercise.**
- **Tension Rating.**
- **Home Practice.**

Stress Management: Session 3
Stretching

- **Home Practice Review.**
- **Tension Rating.**
- **Introduction to stretching.**
- **In session stretching exercise.**
- **Tension Rating.**
- **Home Practice.**

Pleasant Events:
Session 1 - Identifying PE’s

- **Discuss the benefits.**
- **What counts as a Pleasant Event?**
- **Start Small *and* Keep it Simple.**
- **Daily engagement is key.**
- **Provide examples.**

Pleasant Events: Session 1
Identifying PE's

- Develop CG's list.

My list of Pleasant Events

☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺

1. Yoga Video.
2. Take a walk in the park.
3. Call Sally about DOL's.
4. Wednesday night church supper.

Pleasant Events: Session 1
Identifying PE's

- Identify & Schedule.
  - Material.
  - Time/Location.
  - Steps needed for success.

- Home Practice & Potential Barriers.

Pleasant Events: Session 2
Events for CR & CG

- **Review Home Practice.**
- **Identify potential barriers.**
- **Problem-solve solutions.**
- **Identify CR/CG list.**

Pleasant Events: Session 2
Events for CR & CG

- Develop list.

Our list of Pleasant Events

☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺ ☺

1. Look at family photo album.
2. Take a walk in the park.
3. Listen to music.
4. Garden.

Pleasant Events: Session 2
Events for CR & CG

- Identify & Schedule.
  - Material.
  - Time/Location.
  - Steps needed for success.
- Home Practice & Potential Barriers.

Pleasant Events: Session 3
Fine Tuning

- **Review Home Practice.**
- **Identify potential barriers.**
- **Problem-solve solutions.**
- **Finalize CG and CG/CR lists.**
- **Reinforce and encourage ongoing home practice.**

Mood Module: Session 1

- Relationship between thoughts and feelings.

- Three steps to managing your feelings:

1. Stop and identify current thoughts.
2. Challenge & replace unhelpful thoughts.
3. Pay attention to how you feel.

Mood Module: Session 1

- Introduction to Thought Record.

Situation	Current Thoughts	Feelings
My best friend asks me to a party.	I can't leave Bill with anyone. It's not fair if I go and he doesn't. He's done so much for me. I'm selfish.	Trapped. Guilty. Sad.

Mood Module: Session 1

- **Model how to fill out Thought Record.**
- **Caregiver In-Session Practice.**
- **Reinforce and Home practice.**

Mood Module: Session 2

Changing & Replacing Unhelpful Thoughts

- **Review home practice.**
- **Identify potential barriers.**
- **Problem-solve solutions.**
- **Strategies to challenge thoughts.**

Introduce 5 Column Thought Record

Situations	Current Thoughts	Feelings	Challenge & Replace	New Feelings
My best friend asks me to a party.	I can't leave Bill with anyone. It's not fair if I go and he doesn't. He's done so much for me. I'm selfish.	Trapped. Stressed. Guilty. Sad.	I can ask Rob, his best friend to stay for a couple of hours. He has good times with Rob. I have done for him too. He would want me to go.	Less trapped and less guilty. Happier. More relaxed.

Mood Module: Session 2

Changing & Replacing Unhelpful Thoughts

- **Model how to fill out 5 Column Thought Record.**
- **Caregiver In-Session Practice.**
- **Reinforce and Home practice.**

Mood Module: Session 3

- Review home practice.
- Identify potential barriers.
- Problem-solve solutions.
- Practice 5 column Thought Record.
- Summarize techniques.

Mood Module Basics

- Thought. New Thought. How do you feel now?
- Ask how do I know XYZ is TRUE?
- Remember you are human. What's a kinder way of looking at the situation?
- Stop running negative thoughts through your mind. It seems to bring you down.
- One option is not a choice; two is often a dilemma. Look for another alternative.
- Power of positive thinking/positive self-talk.

Barriers to Home Practice

Home Practice Barriers

Barrier	Solution
Did not have time.	Schedule 5-10 minutes each day to complete home practice.
Forgot.	Identify a place in their home (e.g., mirror, nightstand, refrigerator) that they see or go to frequently. Keep the home practice sheet in that spot
It won't help. It did not work.	Try doing the home practice at least once. What evidence does s/he have that it will not work? It will take time to see results. Keep practicing.

In Session Barriers

Barrier	Solution
Phone rings, they answer it.	Remind CG that you only have XX amount of time together and have lots of material to cover. Role play acceptable alternatives.
CR interrupts meeting.	Help CG develop activities that s/he can use to occupy CR's time. Refer to appropriate behavioral prescription.
Visitors.	Ask CG if s/he could ask the visitor to come back after the meeting. Role play acceptable alternatives

In Session Barriers

Barrier	Solution
CG repeatedly brings up non-agenda topics.	Refocus caregiver. Set an agenda. Spend 5-10 minutes catching up on weeks events and then redirect to goal of session.
Not interested in the module.	Encourage CG to try the module for short period as an experiment to test it out. Identify barriers.
"I am not making progress."	Remind CG that progress is often slow and comes in small steps.

Caregiver Characteristics

Barrier	Solution
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. Rely on printed material. Ask CG to repeat material frequently.
Reading/literacy level is low.	Revise material to 3 key points a session. Use familiar/simple words. Consider taping key points and having CG tape record home practice where appropriate.

Personal Safety

The Community Setting and Safety

- Know the neighborhood you will be entering.
- Be realistic – enact safety precautions.
  - Consider time of appointments.
  - Document location and time of appointments.
  - Carry a cell phone.
  - If feel unsafe, go with escort.
  - If approach home and feel unsafe, leave area, call caregiver on phone to cancel and reschedule appointment, contact project director and arrange for escort

Crisis Communication

- **Stay Safe. Safety helps insure action.**
  - **Remain calm.**
  - **Identify exits; obstacles to exits.**
  - **Basic escape plan.**
  - **Avoid placing agitated individual between you and the exit.**
  - **Recognize there are times to remove oneself from situation.**
  - **Call for "back-up"; 911 as warranted.**

Crisis Communication

- **Follow Alert/Crisis protocol.**
- **Signal Breath with CG to reduce distress and deescalate the situation.**
- **Active listen, but more directive (more probes; more closed questions as warranted).**
- **Try to return CG to previous level of functioning before precipitating factor.**

Crisis Communication

- Use direct questions to obtain specifics to determine action steps.
- Communicate and reiterate action steps to CG. Write them down.
- Reassure CG that you are there to help.