RATIONALE FOR SELECTION OF BASIC EDUCATIONAL MATERIALS

Providing education about different aspects of caregiving is an important component of the REACH II intervention. Basic information about the disease process is provided to caregivers in both the experimental and control groups following the completion of the baseline interview. Participants in the intervention group will receive additional materials that are essential to providing a knowledge base for the other components of the intervention that will be introduced.

Materials that are provided to the caregivers in intervention have been selected from a vast pool of educational resources from each of the participating REACH sites, ADEAR, as well as materials located based on a comprehensive search of publishing companies and websites offering educational/training materials for caregivers. All materials were systematically reviewed by a subcommittee and material available in both Spanish and English were selected for distribution to caregivers.

These materials are used in the intervention in the following ways:

- ☐ Each site will have the education materials and interventionists will refer to them in developing strategies tailored to the particular target behaviors
- ☐ Caregivers will receive a subset of these materials, which are organized in a three ring binder, referred to as the Caregiver Notebook. An outline of the notebook is provided in this section. The Notebook is provided to the caregiver in the first session of the intervention. The interventionist will briefly orient the caregiver to each section of the notebook and indicate that these materials will be referred to throughout the intervention. The Table of Contents and key sections of the Caregiver Notebook can be found in Section 5, Page 7.

Below is a list of some of the key materials that caregivers will receive. Also, the following pages summarize the key educational points of these materials. These summaries can be used by the interventionist to guide the introduction of these materials to caregivers and identify the key points to make.

List of Materials

'Alzheimer's Disease Facts'

- Published by Alzheimer's Association: 1-800-272-3900
  -Order form enclosed
  -English version: item # PR617Z
  -Spanish version: item # ED227ZS
  -$10/100
- Free web download in **ENGLISH ONLY**:
  http://www.alz.org/media/understanding/fact/general.htm

'Fact Sheet: Dementia'

- Published by Family Caregiving Alliance: 1-415-434-3388
  -Order form enclosed
  -Specify language on order form
  -$1/each
- Free web download in **English**: http://www.caregiver.org/factsheets/dementia.html
- Free web download in **Spanish**: http://caregiver.org/factsheets/S_dementia.html

‘Fact Sheet: Caregiving’

- Published by Family Caregiver Alliance: 1-415-434-3388
  -Order form enclosed
  -Specify language on order form
  -$1/each
- Free web download in **English**: http://www.caregiver.org/factsheets/caregiving.html
- Free web download in **Spanish**: http://www.caregiver.org/factsheets/S_caregive.html

‘Stress and the Caregiver’

- Published by Journeyworks Publishing: 1-800-775-1998
  -Order form enclosed and can also be downloaded at http://www.journeyworks.com
  -English version Title #: 5071
  -Spanish version Title #: 5238
  -Prices: $16/50
  $54/200
  $125/500
  $225/1000

‘Home Safety for the Alzheimer’s Patient’

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

OVERVIEW OF ALZHEIMER’S DISEASE FACT SHEET

Alzheimer’s disease is a progressive disease of the brain. It causes problems with memory, behavior, and thinking or judgment. It is the most common form of dementia and was first described in 1906.

Four million Americans have Alzheimer’s disease.
It affects men and women at the same rate.
It can occur when people are much younger, but is usually diagnosed after age 65. After symptoms begin, it can last from 3-20 years, but the average is 8 years.
It progresses at different rates for different people.
Symptoms include:
  Gradual memory loss
  Loss of ability to perform routine tasks
  Disorientation
  Difficulty in learning
  Loss of language skills
  Impairment of judgment
  Personality changes
  Behavior changes

There is not one single test, which can determine that a person has Alzheimer’s disease. Among the evaluations a doctor can use are:

Physical exam
Neurological assessment
Blood and urine analyses
Brain scans
Complete health history
Mental status assessment
X rays

Using these tools, the doctor can make a decision as to whether or not someone probably has Alzheimer’s disease. He will not be positive unless an autopsy is performed after the person dies.

There is currently no known cure for Alzheimer’s disease, but researchers have learned ways to help.

☐ Caregivers can learn skills to help the person continue functioning.
☐ Caregivers can learn skills in handling problem behaviors.
☐ Physical exercise, social activity and nutrition are important.
☐ Medications may decrease agitation and anxiety, improve sleep, and
☐ enhance participation in activities.
☐ New drugs may delay or temporarily relieve some symptoms.

The causes of Alzheimer’s disease are being investigated by researchers in many fields of science. Suspected causes are:

☐ Diseased genes or a genetic predisposition
☐ Environmental toxins
☐ Abnormal protein buildup in the brain

DEMENTIA FACT SHEET

Dementia is an “umbrella term” **used to refer to the condition of people who have thinking and memory problems. Dementia is not a normal part of the aging process. There are other labels given to those who have dementia, but they all refer to problems with memory and thinking.** Many people in the country have dementia. **Nearly half of all people age 85 and older are thought to have some form of dementia.**

Some of the symptoms or signs of dementia are:

- Short-term memory loss.
- Inability to think problems through
- Needing step-by-step instructions to complete a complex task
- Confusion
- Difficulty concentrating
- Paranoid, inappropriate or bizarre behavior

Some causes of dementia can be treated and some cannot.
Some of the causes that can be treated to reverse symptoms are listed below:

Reaction to medication
Metabolic disturbances
Endocrine abnormalities
Infections
Emotional Distress
Problems with vision or hearing
Nutritional deficiencies
Brain tumor
Blood clot on the surface of the brain
Pressure inside the brain from fluid build up
Hardening of the arteries or “atherosclerosis”

Some causes of dementia cannot be reversed.

Some cases of injury to the brain from a fall or accident.
Diseases which cause the brain to degenerate.
Lewy bodies disease
Huntington’s chorea disease
Stroke
AIDS
Multiple sclerosis
Parkinson’s disease
Pick’s disease
Loss of oxygen to the brain
Creutzfeld-Jakob’s disease
Binswanger disease
Alzheimer’s disease; the most common.

For diagnosis, a doctor can use medical and neuropsychological evaluations, as well as brain scans. The cause of some dementias can be established. In other cases, diagnosis involves ruling out causes and looking closely at symptoms. Sometimes an autopsy is required to absolutely establish diagnosis.

Caring for someone who has dementia is a very demanding role. Caregivers need support for themselves, new skills to handle problematic behaviors, strategies for safety, and knowledge about how to take care of themselves while caring for someone else. Our project is designed to help you in your caregiving role.

GENERAL CAREGIVING

It’s important to acknowledge that your role as a caregiver is a stressful one, and that many caregivers like yourself feel overwhelmed, burdened, and sometimes burned out. However you should not feel guilty for asking for help.

One of the first issues to think about is **safety**, for you and for your [cr].

- Potential dangers and ways to prevent them are listed in this material.
- You may have many safety precautions already in your home, but when someone has dementia, they present new safety problems that you normally wouldn’t think about.

As you already know, when someone has dementia they may present certain **behavioral problems**, such as repeating questions or stories.

- Everyone with dementia is different, so the way you approach [his or her] behavioral problems will be different. However, this material presents some general tips to use when dealing with problem behaviors, such as using better communication.
- It also suggests getting help from other people, including formal support, such as police, fire, and medical personnel, and informal support, such as friends, family, and church members.

Getting help from others also helps to take care of you.

- Many caregivers neglect their health, their interests, and their emotions when taking care of their [cr].
- It is important that you are willing to ask for help and to take that help when it is offered to you.
- Your friends, family, and community should know what they could do to help.
- This material gives ideas about how to make it easy for you and your friends to get that help for you, for example writing everything on paper to get organized.

Many caregivers feel like they are completely **alone**.

- It often helps to talk to other caregivers, alone or in support groups, to be reassured that you are not the only one going through this.
- Other caregivers can often give good ideas for solving caregiving problems because they’ve experienced them too.

Make sure that you do not ignore your own **health**.

- Continue to take your medications and go to doctors’ appointments.
- Caregiving places a strain on your mind and body, even if you don’t think or feel like it is.

Although the day-to-day issues that happen with caregiving are obviously always on your mind, it is important to think about **long-term issues** as well.

- This material gives tips on issues that may happen in the future, such as long-term care, financial, and legal information.

CAREGIVER STRESS

Caregivers and research literature have both stated how difficult and stressful the job of caregiving is. The book, 36-Hour Day, was named that because to a caregiver, that is how long every day feels like. Therefore it is very important that every caregiver find his or her own way of dealing with stress and any negative feelings they experience. This education material gives some general tips for dealing with that stress. You may have already read about stress or discovered some of these things yourself, but I just want to review some of the important points from this information.

Talking with other caregivers, one on one or in support groups can help you to understand that you are not alone. Some caregivers are mistaken that support groups are only for caregivers who want to gather together and complain about how bad life is. Support groups reassure caregivers that they are not the only ones experiencing difficult times, and they also provide time for caregivers to share ideas about how to deal with difficult issues like problem behaviors. Sometimes it may be just as comforting to take the time to talk to someone close to you.

Although you feel like you should be available for your [cr] 24 hours a day, seven days a week, **you are allowed to and should take time away from your caregiving duties**. Even though you are the person that spends the most time with [him or her] and probably knows what is best for [him or her], your friends and relatives can help you by keeping your [cr] safe while you go out to eat with a friend or go to a show.

Do not be afraid to **ask for help**, even when you do not feel like you need it. There is no reason to feel guilty for taking time to enjoy yourself and give yourself a break, and most of the time your friends and relatives want to help. However they may not know exactly what to do. Writing your needs on paper can help you organize and help your friends know what they are able to help you with. There are other ways to get help outside of your community, such as adult day cares and the Alzheimer’s Association.

Choose your battles wisely. Many things that were important to you and your [cr] in the past may need to take a lower priority now to reduce your stress and simply make things easier for you, such as the housework. It is probably not as important that your house remain consistently spotless, especially now that you don’t have the time or the money to do it. It is not important that your [cr] take a bath every day, just like [he or she] used to. Focus on the things in your life that are most important to you, even if that means thinking about what those truly important things are.

Take care of yourself. Don’t focus so much on your [cr] that you neglect your own mind and body. Make sure you get enough rest. You certainly need it for the requirements of being a caregiver. Eat enough, and eat well. Sometimes caregivers skip meals because they are too busy or they eat foods that are bad for them because they are the quickest things to fix or buy. Avoid substances like alcohol or drugs to help you cope with your situation. They may seem to dull the pain at the moment, but in the long run they cause more problems. Try to exercise at least 3 times a week or even a few minutes a day. Many caregivers cannot leave their house for various reasons, but even walking up and down the driveway can keep you from losing endurance and feeling “stiff”.

Try to keep your sense of humor. Surround yourself with supportive, positive people who make you laugh, and try to always enjoy the times that you have with your [cr].

Reach II

Resources For Enhancing Alzheimer's Caregiver Health

CAREGIVER NOTEBOOK

USING YOUR CAREGIVER NOTEBOOK

Your caregiver notebook will serve a very important purpose while you are in the **REACH II** program and even after you have completed the program. Your interventionist will refer to many of the items found in your notebook during your home-visits, and will also encourage you to read through the notebook on your own. You can think of your caregiver notebook as a "central location" to place all materials brought to you by your interventionist. You may want to place your notebook in an easy to find spot so that you and other family members will always know where it is when you need to refer to it. **In addition**, if someone else should need to take care of your family member, your caregiver notebook could become an invaluable tool in guiding that person to the best resources and care for your family member.

TABLE OF CONTENTS

REACH II CAREGIVER NETWORK

In this section, you will find informative materials about the REACH II Caregiver Network, including how to use your special phone called a “Screenphone”. The REACH II Caregiver Network is an important part of the REACH II project. The network can be used to communicate with members of the REACH II project, access community resources and services, obtain information on caregiving, and provide you with tips on taking care of yourself and your loved one. It will also allow you to communicate with other caregivers like yourself who are participating in REACH II. You will use the screenphone to participate in monthly support groups, which will allow you to attend the group meetings without leaving your home. In addition to you, the group will involve a leader and 4 to 5 caregivers from other study sites in the country who are also participating in REACH II. Please remember, if you have any questions about the phone, just ask your interventionist or use the screenphone to contact the REACH II help staff.

Materials included in this section are:

- Screenphone Help Card
- Social Support Group Enrollment Form

GENERAL INFORMATION

ALZHEIMER'S DISEASE (OR OTHER MEMORY LOSS) AND LEGAL ISSUES

Most people with a spouse, other family member or close friend who has been diagnosed with Alzheimer's disease have many questions about the disease. In this section, you will find informative materials about memory loss, Alzheimer's disease and dementia. In addition to general materials on dementia and memory loss, you will also find information regarding legal issues, such as wills and trusts, which will help you plan now for the future of your family member. Early attention to these issues can prevent problems later as the disease worsens and your family member is no longer mentally capable of making decisions. Making decisions regarding these issues now will assure you that your family member's wishes are being respected and will ease your mind as the disease progresses.

Materials included in this section are:

- Alzheimer's Disease Facts
- Fact Sheet: Dementia
- What You Should Know about Wills
- Estate Planning with a Living Trust

SAFETY INFORMATION

Some symptoms of Alzheimer’s disease such as wandering, confusion and forgetfulness will make it necessary for you to take a new look around your home and surrounding areas. You will want to make sure your loved one is safe and secure in and around your home. In this section, you will find informative materials about the following: the importance of smoke detectors; securing all potentially dangerous substances and objects; the importance of identification bracelets or other forms of identification; monitoring all smoking by your relative; kitchen safety; basic supervision guidelines; wandering risks and the dangers of allowing your relative to drive.

Materials included in this section are:

- Home Safety for the Alzheimer’s Patient
- At the Crossroads-A Guide to Alzheimer’s Disease, Dementia and Driving
- Smoking Fact Sheet
- Safe Return Brochure
- Safe Return Fact Sheet

TAKING CARE OF HEALTH ISSUES

As a Caregiver, it is very important for you to take care of your health, as well as your relative's health. Many people find if they keep track of health care issues by documenting them, it is easier to stay organized with preventive health needs. This could help you better manage your health and the health of your loved one. In this section you will find informative materials that will assist you in keeping track of your health and the health of your loved one.

Materials included in this section are:

- America's Senior Healthcare Guide: Health Begins With You for Your Health
- America's Senior Healthcare Guide: Health Begins With You for Your Relative's Health
- Healthy Lifestyle

CAREGIVER WELL-BEING

Caring for a loved one with Alzheimer's disease twenty-four hours a day can be an exhausting job physically and emotionally. Many caregivers put aside their own needs to care for their relative, leaving himself or herself at high risk for stress. As a caregiver, clearly you have a duty to your relative. But your needs are also important and you have a duty to take care of yourself. The most loving and responsible thing you can do for your relative is to stay as emotionally and physically healthy as you can while caring for them. In this section, you will find informative materials that will assist you in better managing your daily stress.

Materials included in this section are:

- Fact Sheet: Caregiving
- Stress and the Caregiver
- Target Plans - Developed with your Interventionist

CAREGIVER CHALLENGES

One of the most difficult challenges you may face as a caregiver is dealing with the difficult behaviors of your relative. Many of the daily tasks that you will assist your relative with (bathing, dressing, grooming, eating) can become a struggle as the disease progresses. Finding a way to better manage these difficult behaviors can make the day go more smoothly for both you and your relative. In this section, you will find informative materials that will assist you in dealing with these behavior problems that can be challenging at times.

Materials included in this section are:

- Caregiver Guide: Tips for Caregivers of People with Alzheimer's Disease
- Target Plans - Developed with your Interventionist

NOTES

In this section, you will find helpful tools to assist you in taking care of your family member. Included are several forms to help you better document important issues such as your family member's insurance information, emergency contacts and a system for organizing important legal documents that you may have in the home or elsewhere. We also have included a packet of "Note" sheets, for your convenience, for taking notes during your intervention sessions or jotting down any questions you may have for your interventionist. This section would be very helpful, for example, if someone else were to provide care for your loved one while you are out of town, in the hospital or unable to provide care for any reason. Again, your caregiver notebook is meant to be shared with your family and any other part-time caregivers so they will be familiar with important matters should you be unable to provide care for your family member.

Materials included in this section are:

- Person Receiving Care Information and Emergency Contacts
- Insurance Information and Important Paper Locater
- Note Sheets

Person Receiving Care Information:

Name____

Address______________________________________

City____

State____________________**Zip**__________________

Phone #______________________________________

Date of Birth___________________________________

☐ **Male** ☐ **Female** **Blood Type**____________________

Race____

Identifying Features______________________________

____

Social Security #________________________________

Allergies/Sensitivities____________________________

____

Emergency Contact:

Name____

Phone #______________________________________

If someone besides you assists with daily care please list:

Name____

Phone #______________________________________

Yes, He/She Has Advance Directives

- ☐ **Living Will**
- ☐ **Declaration to Physician**
- ☐ **Durable Power of Attorney for Health Care**

Kept at _____________________________________

Insurance Information:

Medicare #____

HMO____

Supplemental Ins.____________________________________

Supp. Insurance #____________________________________

Other Health Care Insurance______________________________

Insurance #____

Important Paper Locater:

Write the code letter in the box, recording the location of important papers.

Safe Deposit Box = S
Home = H
Office = O
Lawyer = L
Elsewhere (specify) = E
Unknown = UK
Do not have = NA

Birth and Marriage Certificate	____________
Cemetery/Mausoleum Papers	____________
Certificates of Deposit	____________
Checkbooks	____________
Deed to Home	____________
Funeral/Burial Trust Papers	____________
Insurance Policies	____________
Military Papers	____________
Promissory Notes, Mortgages	____________
Social Security Cards	____________
Stocks and Bonds	____________
Tax Returns	____________
Titles, Bill of Sale – auto, boats, ect	____________
Wills and Trusts	____________

Notes: