

CAREGIVER MANUAL

The Dementia Caregiving Skills Program:

Reducing Stress And Enjoying Time with Your Family Member

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Goals of the Program

(Read pages 1-6 when you get this workbook, as soon as you can.)

This program is for you, because you are caring for a relative with dementia at home. Dementia is hard for both the person with memory loss and for you. Caregiving can be stressful.

The Caregiving Skills Program uses videotapes, this workbook, and weekly phone calls with your “coach.” These different parts of the program will help you develop and use new ways to make life better for you and your family member.

Using the video, this workbook, and time with your telephone coach, you are going to learn skills to:

- 1). Make life more pleasant for you and your family member.
- 2). Change ways of handling caregiving problems.
- 3). Give yourself credit for your efforts as a caregiver.

Can I share this information with my family? Absolutely!

You are welcome to share these videos, information, and materials with other family members, if you want.

- This notebook and the videos are yours to keep.
- Review the workbook and videos as often as you like.
- Underline parts you want to remember.
- Write in notes to yourself. This helps you learn more easily.

What will be asked of you?

You will take an active part over the time of participating in the program.

This involves:

- (1) watching a ½ hour video each week,
- (2) finding the time to talk with your telephone coach each week,
- (3) setting aside time each day for your “To Do” assignments.

This program is much more than information and suggestions. We will work with you in a step-by-step way to improve your situation. However, watching the videos and reading the workbook will not be helpful by themselves. You will have to be actively involved. We will help.

We know how stressed and overwhelmed many caregivers are. You may feel as if this program is asking too much of you. On the other hand, we know that this program can be very helpful for you. Any effort you put in now will really pay off in the long run, and may decrease your level of stress in the future.

What is this program not going to provide?

This program is not meant to be therapy or the type of support you would get from a support group.

This program focuses completely on caregiving skills, and helps you practice new ways of handling caregiving situations. If you begin to think that you need more help than you can get in this program, please talk to a member of our project staff. They will give you information about where you can find such services.

Caregiving Examples

We understand that every situation is different.
You may have problems and challenges that other caregivers don't have.

On the other hand, there are experiences that dementia caregivers share.
When a new skill is taught, we show how the skill can be used by caregivers.
The situations of two caregivers, Diane and Karen, are used as examples.

Let's look at our example caregivers: Diane and Karen.

Diane is 76 years old and cares for her husband, *Leon*, who is 78. They have lived in the same house in a Midwestern city for the past 50 years, and had both retired before Leon was diagnosed with Alzheimer's Disease.

Leon has had memory problems for 7 years, but only started needing a lot of help in the past 2 years. The doctor has told Diane that Leon is in the "middle stage" of Alzheimer's. Leon can do many things (like dressing, bathing, and eating) only if Diane tells him what to do one step at a time. Diane joined the program saying, *"I might as well try something different. I'm getting more and more stressed, and that's hard on both me and Leon."*

Karen is 60 years old and cares for her mother, *Mary*, who is 85 and has vascular or "multi-infarct" dementia. Karen has lived her whole life in the small community where she grew up. She moved in with her mother after Karen's father died 5 years ago. None of the family realized that Mary had so many memory problems until he passed away.

Karen still runs her beauty shop, but has had to cut back on her hours as her mother has needed more and more help. At this point, Karen still brings her mother in to the shop where she can watch T.V. in a back room while Karen is with her clients. Karen volunteered for the program, telling us, *"I love my mother and would do anything for her, but I'm close to my wit's end. I don't like it when I get so overwhelmed and frustrated that I yell at her."*

How the Program Works

Watch one video lesson per week. Then read that session in your workbook. Each lesson is based on the one before. Skipping ahead to a topic that seems interesting is not a good idea. You will miss the important information that leads up to it. Watch each video in order, with a week between watching the next one. This gives you time to practice the new skills you learn.

Choose a specific time during the week to view each video, read the workbook, talk with your coach, and do the brief assignments. You can rewatch a video anytime.

Try to find times when you will be able to focus your attention without distractions.

Give Yourself Time!

Take the time you need each week to do the exercises and answer questions. Stop the video when prompted, and do the suggested activity. Give yourself time to learn and practice new skills!

Overcoming Challenges

Here is how one caregiver handled things. Karen was excited about the program. At the end of the second week, she had only done one exercise and had not finished the reading for Lesson 2. She decided to make a list of things that got in her way.

Karen's list of what got in the way:

- 1. I kept forgetting.*
- 2. Mom was following me around.*
- 3. I was too busy with more urgent things yesterday.*
- 4. When I started reading, my friend called me. When we finished talking, I had to start dinner.*
- 5. I was so frustrated when a stressful time came that I didn't use the skills I learned.*

Karen then figured out a plan that would handle these problems. She chose the following strategies:

-I will use each evening from 7:00 to 7:30 to watch the video, read, and work on exercises. Mom is happy listening to the radio then.

- Since this video can help me, I need to make it a priority. A little effort now is really going to help in the long run. I'll remind myself that I deserve this.

-I'll ignore the phone and let the answering machine take messages.

- I can write down helpful thoughts to carry with me, like "I deserve credit for trying something new with Mom, even if it didn't work all that well." I can also reward myself with a cup of my favorite tea whenever I practice the things I learned in the video.

Before I Begin! My Plan for Overcoming the Challenges of Watching the Video and Fully Participating in the Program

(Do this before the next call from my telephone coach.)

I need to write down what might get in the way of my watching the video and doing the suggested activities. Then I list some ways (“solutions”) for taking care of these problems. (The next page has some examples from Karen).

Things that might get in my way:

Possible solutions:

A.

A.

B.

B.

C.

C.

D.

D.

I need to think about a few things that could help motivate me when I feel stuck. Write down ideas for each of these 3 questions:

1. What would I like to get out of the program?
2. Of my friends and family, who can offer the best support as I learn about these new skills?
3. How can I make the most of this program?

Session 1

This Session covers

1. Information about dementia and Alzheimer's Disease
2. How providing care can affect you as a caregiver
3. Some "Basic Rights" of caregivers
4. An exercise that looks at what you and your family member are doing that is still enjoyable or fun

Friendly Reminder

For this first week of the program:

1. Watch the Session 1 video
2. Read Session 1 in this workbook
3. Complete Exercise 1

Do these three things in this order, before your scheduled talk with your telephone coach.

Date to watch video 1: _____ Time: _____

Date for next call: _____ Time: _____

It is important to try to keep this scheduled date and time.

What is Alzheimer's Disease?

Alzheimer's Disease is the most common form of disorders referred to as *dementia*. *Dementia* is caused by damage to nerve cells in the brain.

What is Dementia?

Dementia is not a specific diagnosis. Instead, it is a term used to describe a group of symptoms. Those symptoms have to do with one's *intellectual ability*, or the ability to think, remember, and reason. You will also hear these abilities called cognitive abilities. There are many conditions that can cause the symptoms of *dementia*, and *Alzheimer's Disease* is one of those conditions. Throughout this notebook, when we refer to "Alzheimer's Disease," you can feel confident that the information applies to most other memory disorders as well. This notebook will be helpful to anyone caring for a person with severe memory loss.

What Does Alzheimer's Disease Do to a Person?

No two people experience the disease exactly alike. Problems happen sooner for some than others, but for every *Alzheimer's* patient, many of these symptoms will eventually happen because of the damage the disease does to the person's brain. In many types of dementia, including Alzheimer's Disease, nerve cells in the brain die. This cell death causes memory problems and changes in how patients think. The cerebral cortex and the hippocampus are two areas of the brain that experience the greatest loss of nerve cells in Alzheimer's Disease patients. These areas affect memory, speech, and reasoning among other skills.

Dementia will affect memory of:

- Recent events: what they had for breakfast (*recent memory*)
- Remote events: whether they went to school (*remote memory*)
- How to do activities like dress themselves (*ADLs, IADLs*)

Your relative will lose the ability to do things. These are called *deficit behaviors*. They may become unable to:

- Perform the activities of daily life (called *ADLs*) like bathing, dressing, preparing, and eating a meal
- Follow instructions
- Complete simple tasks
- Walk in a steady manner

Dementia affects *communication* ability, both their ability to say what they want to say (*expressive language*) and their ability to understand what others say to them (*receptive language*).

As nerve cells in the brain continue to die, a person with dementia begins to show changes in behavior. This means they will do things they didn't do before or do things in an exaggerated way. These are called *behavioral excesses*. They may have problems with:

- what they say (repeating words or questions, screaming)
- how they treat others (aggressively hitting, pinching)
- how they behave (restlessness, *wandering*, resisting care)

It is important to remember that these behaviors are the result of changes in your relative's brain and are not done on purpose.

Dementia affects mood, experience of what is real, and the way your family member expresses how they feel. This means they may have:

- *Depression*
- *Hallucinations*
- *Delusions*
- *Agitation* and nervousness
- Little or no expression (*affect*)

Note: Several of these effects may be helped by the use of proper medicine.

Stages and Symptoms of Alzheimer's Disease

Thinking of *Alzheimer's Disease* in terms of stages can be helpful, especially when you need to talk to others about your family member. On the other hand, no two people respond to the disease in the same way or at the same pace. These stages can only serve as a crude road map or a way to look at the big picture. You may hear of the disease as having three or five stages. We give you a rough description of the three stage model.

In the early stages of Alzheimer's Disease, a person may:

- become more forgetful (*recent memory*)
- be confused about decisions, handling money, and directions (*IADLs*)
- seem tired and lacking in enthusiasm (*affect*)
- seem somehow “different” from usual, and make odd judgments and social mistakes
- repeat things: say and do things over and over again
- be confused about times and places

In the middle stages of the disease, the person may:

- *wander* or pace
- have difficulty recognizing even family and friends (*remote memory*)
- become impatient, restless, irritable or emotional
- be unable to learn new things and be unable to use math skills
- have trouble organizing and expressing thoughts (*expressive language*)
- become suspicious of others or see and hear things which are not there (*delusions, hallucinations*)
- have trouble dressing appropriately (*ADLs*)
- resist being helped and be more aggressive toward others

In the late stages of the disease, a person may:

- be unable to perform any activity of daily living (*ADLs* and *IADLs*)
- lose control over bladder and bowel functions (*incontinence*)
- be unable to communicate or follow direction (*receptive and expressive language*)
- seem to live an unreal “fantasy world,” talking to people and about things which are not real (*delusions, hallucinations*)
- be unable to walk or sit alone
- sleep more and more

Can Alzheimer's Disease Improve or be Cured?

Alzheimer's Disease and most other dementias are progressive. This means that brain cells continue to die, and the patient gets worse over time.

Vascular (also called multi-infarct) dementia can sometimes be stabilized with medication, but the patient does not usually return to normal. At this time, there is no cure or way to reverse brain damage done by these diseases.

You may notice that your family member has some days that are better than others.

These “good” and “bad” days can be very confusing. Is your relative just trying harder on the “good” days? Or are they just being stubborn on “bad” days? Not at all. We don't have all the answers to this confusing picture, but we know that abilities can really be different on a day-to-day basis.

Daily changes in patients' abilities can be due to several things:

-We all have “good days” and “bad days”; these are just more obvious in people with dementia because of their limitations in functioning.

-There could be small, but important changes in the situation or environment that make it easier or harder for the person with dementia to do things. This could be something like the television being on while you are talking to them. This makes it more difficult for them to concentrate.

-There could be daily changes in your relative's mood, including depression. This can influence concentration and activity level (and is one reason why we focus on improving mood for you and your family member).

This program is meant to help you and your family member have as many good days as possible!!

How Caregiving Affects You

Sadness, confusion, anger, and frustration are some common feelings that family members have when caring for their relative. These feelings are very normal, but can make the caregiving job more stressful.

You do not stop being who you are because your family member is sick. You may still be a spouse, parent, friend, or relative to other people who have expectations of you and you of them, in spite of the demands of caregiving. This fact means there are lots of places for misunderstanding, miscommunication, conflict, and hurt feelings.

What kinds of things lead to stress and frustration in caregivers?

- A. Knowledge.** *“I don’t know what to expect.” “Why is she doing that?”*
- B. Thoughts and Attitudes.** *“I have no one to help me.”
“There’s no use.” “I’m not going to be able to handle it.”
“Nobody really understands.”*
- C. Past relationship.** *“No matter what I do she won’t like it.” “He’s always been stubborn.”*
- D. Skills.** *“I can’t change his/her behavior.” “I don’t know what to do to feel less overwhelmed.”*
- E. People or Situations.** *“I’ve had a long day. My spouse soiled the sofa. And now, more than one person needs my attention at the same time.”*

But...

There are ways to take care of yourself as you are taking care of your family member. We will help you learn those things.

The intention of our program is to teach you, the primary caregiver, a set of skills or “tools” for coping with caregiving problems. This will help you to feel more “in control” of your everyday life.

To get started, remind yourself to close your eyes and take three slow, deep breaths whenever you are feeling stressed or overwhelmed.

A CAREGIVER'S BILL OF RIGHTS

Please read aloud and think about this list of basic rights for caregivers.

I have the right

- To keep up with parts of my own life that do not include the person I care for, just as I would if he or she were healthy.
- To make mistakes, and to try something out, even if it doesn't work right away.
- To take care of myself. This is not an act of selfishness. It will give me the energy to take care of my relative.
- To get help from others even if my relative doesn't want me to. I recognize the limits of my own endurance and strength.
- I have the right to do some things just for myself. I know that I do everything that I reasonably can for this person.
- To get angry, be depressed, and express other difficult feelings occasionally.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.

Add your own statements of right to this list. Read the list yourself from time to time, to review these rights. Hopefully, you will become more comfortable with them as time goes on.

- To: _____

- To: _____

Question 1.1.

Look over the Caregiver Bill of Rights. Which of these is the most important for you to really accept and believe? (write it down here).

Questions 1.2.

Why is this important for you? (write your ideas down here).

Use a piece of paper or a little card and write down the right you think is most important for you. Put this someplace where you will see it (refrigerator door, taped to the bathroom mirror, in your shirt or pants pocket, etc.). Read it from time to time when you start to feel discouraged or too overwhelmed to try anything.

Do you remember Diane and Leon from the beginning section of this workbook? You may recall that Diane is caring for Leon, her husband with Alzheimer’s Disease. Part of Diane’s stress is that she feels all alone in her caregiving. Two of Diane and Leon’s children live nearby, but they all work and are busy raising their own family. Diane feels like she spends all of her time caring for Leon, and doesn’t have much in her days to look forward to.

Here is what Diane wrote down for these first questions....

Question 1.1. Diane’s Example

Which of these rights is the most important for you to really accept and believe?

Questions 1.2. Diane’s Example

Why is this important for you?

Points to Remember from Session 1

- The information in this workbook can be helpful to you if you use it.
- *Dementia* affects intellectual (*cognitive*) functioning. Your relative may have changes in mood, behavior, personality, and the ability to remember, to reason, and to do things. Your family member is not responsible for these changes. The disease is responsible for these changes because of how the brain is changing.
- Dementia affects not only that person, but also all who care about the person. That means that dementia affects you. You can learn to do some things that will improve your situation. We will help you learn some of these things.
- We reviewed a list of “Basic Rights for Caregivers.” Many caregivers expect too much of themselves. Some caregivers don’t give themselves credit for all that they do on a daily basis. This list of basic rights is meant to help you look at your situation in a new light.
- Remind yourself to close your eyes and take three slow, deep breaths whenever you are feeling stressed or overwhelmed.

What you need to do before Session #2:

- **Read Session 1 in this workbook (pages 8-14).** Sometimes reading something over will remind you of questions that you have. Did this happen to you? Write down here any questions that you want to ask your telephone coach:
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- **Be sure that you have written** down answers for Questions 1.1 and 1.2 in this reading. Your telephone coach will ask you about these answers.
- **Fill out Exercise 1 on page 17.** You will be talking about this exercise with your telephone coach in the next week. You will also use this information in Session 2 as we work on improving your caregiving situation.

Exercise 1: Pleasant Events for Me and My Relative

I should circle a number that describes how often I have done each of the following activities in the past month. Then I should do the same rating for my family member - how often have they done these in the past month?

0 = not at all in past month

1 = 1-6 times in past month

2 = 7 or more times in past month

	Me			My Relative		
	0	1	2	0	1	2
1 Spending time outside	0	1	2	0	1	2
2 Shopping or buying things	0	1	2	0	1	2
3 Reading or listening to stories	0	1	2	0	1	2
4 Listening to music	0	1	2	0	1	2
5 Watching T.V.	0	1	2	0	1	2
6 Laughing	0	1	2	0	1	2
7 Having meals with friends or family	0	1	2	0	1	2
8 Making or eating snacks	0	1	2	0	1	2
9 Helping around the house	0	1	2	0	1	2
10 Being with family	0	1	2	0	1	2
11 Wearing favorite clothes	0	1	2	0	1	2
12 Listening to the sounds of nature	0	1	2	0	1	2
13 Getting or sending letters, cards	0	1	2	0	1	2
14 Going on outings	0	1	2	0	1	2
15 Having coffee, tea, etc. with friends	0	1	2	0	1	2
16 Being complimented	0	1	2	0	1	2
17 Exercising (walking, dancing)	0	1	2	0	1	2
18 Going for a ride in the car	0	1	2	0	1	2
19 Grooming (wearing make up, shaving)	0	1	2	0	1	2
20 Recalling and discussing past events	0	1	2	0	1	2