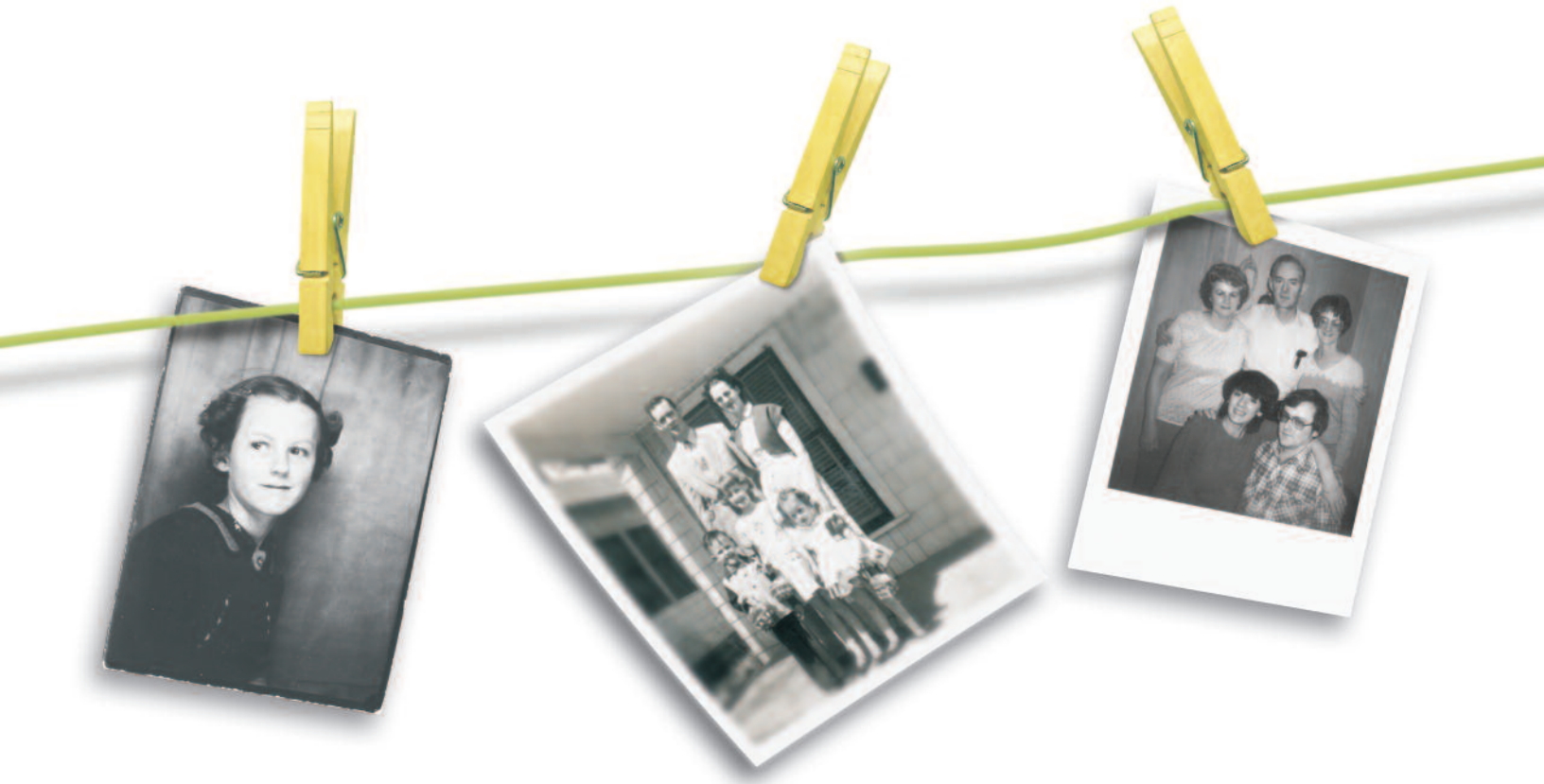


# Alzheimer's Disease: Helping Yourself Help A Loved One





**Advancing Science. Enhancing Lives.**

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[www.agingresearch.org](http://www.agingresearch.org)

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# Alzheimer's Disease: Helping Yourself Help A Loved One



## Introduction

### **Purpose**

The purpose of this workshop is to educate family caregivers on how to best care for a loved one with Alzheimer's disease while effectively taking care of their own needs. This Leader's Guide will provide guidance to leaders (healthcare leaders, community outreach coordinators, etc.) for conducting the workshop.

### **Audience**

The primary target audience for this workshop is family or friends who are caring for a loved one recently diagnosed with Alzheimer's disease. The number of participants in a given workshop will vary by site. Suggestions are made throughout this guide on how to adapt the curriculum for large or small groups.

### **Workshop Goals**

To help family/friend caregivers to (1) recognize when they need help and (2) know where to turn to get help.

### **Objectives**

Each section of this guide contains learning objectives. The objectives state specifically what those who attend should know or be able to do at the conclusion of that section.



# Planning and Promoting The Workshop

## Preparing for the Workshop

Before you conduct the workshop, you will need to do the following:

- **Choose a date and time.** Consider coordinating with other events that your audience may attend.
- **Secure a location.** See below for space requirements.
- **Promote the workshop.** See below for tips on letting people know about the workshop.
- **Make copies of worksheets and evaluation forms.** You may want to wait until you have a head-count for the workshop.
- **Prepare a list of local resources.** This can include support groups for Alzheimer's caregivers, options for respite care, sources of information about the disease, etc. You should post this on the flipchart or blackboard for participants to copy into the appropriate place on their brochures. Alternatively, consider creating a handout with this information.

## Getting the Word Out

Consider how you will let your intended audience know about the workshop. Different promotion techniques will work in different communities, so use your own experience or the experience of others in your community to determine the best ways to bring people to the workshop. Below are some ideas to get you started:

- **Prepare a flyer.** Announce the workshop location, date and time, and registration information.
- **Distribute the flyer.** Bring or send to different organizations that have regular contact with family caregivers, such as:
  - Caregiver support groups
  - Local Alzheimer's Association chapter
  - Respite programs
  - State agency for elders and aging
  - Alzheimer's resource centers
- **Advertise.** Many newspapers have a section that lists local support groups and seminars. Contact your local newspaper to submit your workshop information. Local radio public service announcements provide another way to promote the workshop.
- **Tell people.** *There is no substitute for personal contact.* Whenever possible, make a personal contact with those who are most likely to refer participants to the workshop.

## Registering Participants

Decide whether or not you will require registration in advance. Advance registration may help you to better plan for the workshop, but be sure to accommodate individuals who may not be able to register in advance. Make sure you provide a registration contact name, telephone number, and email address in all advertisements.



## Workshop Logistics

### Timing

This workshop will last approximately one hour and ten minutes.

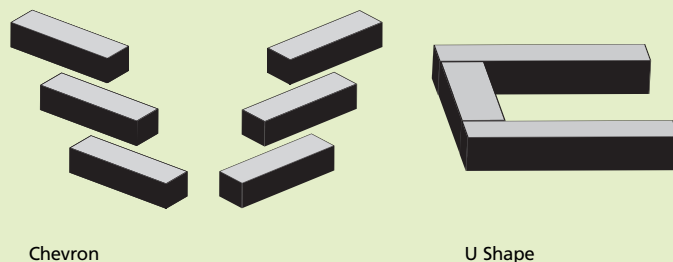
**Leader Note:** *This workshop is full of information and resources. To get through all of the material you will need to manage the time well, overcoming the natural tendency to make this a support group. Reassure participants that there will be time to share stories and network at the end of the workshop.*

### Space Requirements and Room Set-Up

The space requirements vary depending on group size. Ideally, each participant will have a seat at a table to best enable them to take notes and participate in the writing components of the workshop.

### Set-Up with Tables

If round tables are used, simply place the tables so that no table is immediately in front of another. If rectangular tables are used, set them up chevron style for a larger group, or in a “U” shape for a group smaller than 15. These two set-ups are illustrated below:



## Materials List

- Leader's Guide
- DVD with video
- Family Caregiver brochure
- Caregiver Workbook
- Caregiver Self-Assessment and Action Plan form—provided in back of guide
- Workshop Evaluation form—provided in back of guide
- LCD projector
- Laptop and DVD player
- Screen
- Table or podium (for leaders)
- Flipcharts and markers OR blackboard and chalk OR whiteboard and markers
- List of local resources that you have prepared in advance of the workshop
- Pens or pencils

**Leader Note:** *To order additional copies of the caregiver resources go to [www.agingresearch.org](http://www.agingresearch.org) or call 202-293-2856.*

## After the Workshop

When the workshop is over, please take a few moments to complete and mail the leader survey form. Your feedback will help us to better support you and other workshop leaders in the future. The survey is already addressed and stamped for easy mailing.

# Workshop Outline

		Learning Objectives	Activities and Notes
:00	<b>Welcome and Introduction</b> (10 minutes)	<ul style="list-style-type: none"> <li>• Meet one other.</li> <li>• Understand what will be covered during the workshop.</li> </ul>	<ul style="list-style-type: none"> <li>• Leader introduces the course, describes what will be covered, and points out necessary logistical information such as the location of restrooms.</li> <li>• If the group is smaller than 15 people, participants introduce themselves.</li> </ul>
:10	<b>Caregiving at the Time of Diagnosis</b> (10 minutes)	<ul style="list-style-type: none"> <li>• Learn about treatment options and current research.</li> <li>• Know how to talk to and work with your loved one's physician.</li> <li>• Identify steps you can take to become an effective advocate for yourself and your loved one in the health care system.</li> </ul>	<ul style="list-style-type: none"> <li>• Leader presents information/talking points.</li> </ul>
:20	<b>Caregiving as the Disease Progresses</b> (15 minutes)	<ul style="list-style-type: none"> <li>• Understand how the progression of the disease affects families and their loved ones.</li> <li>• Describe how the needs of your loved one will change over time.</li> <li>• Identify options for creating a community of support.</li> <li>• Develop strategies for coping with the changing needs of your loved one.</li> <li>• Develop strategies for helping family members understand and adjust to the changes in your loved one.</li> </ul>	<ul style="list-style-type: none"> <li>• Leader presents information/talking points.</li> <li>• Possible discussion question: "What enables you to have the flexibility to respond to the changing needs of your relative/friend with Alzheimer's disease?"</li> </ul>
:35	<b>Integrating Caregiving Into Your Life</b> (15 minutes)	<ul style="list-style-type: none"> <li>• Understand the causes of family caregiver stress.</li> <li>• Understand the health implications of family caregiver stress.</li> <li>• Recognize the warning signs of family caregiver stress.</li> <li>• Describe ways to be a healthy family caregiver.</li> <li>• Identify sources of information and support.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants watch the DVD.</li> <li>• Possible discussion question: "What struck you most about this film?"</li> </ul>
:50	<b>Caregiver Self-Assessment and Action Plan</b> (15 minutes)	<ul style="list-style-type: none"> <li>• Identify local sources of support.</li> <li>• Determine which areas of your wellness (e.g., sleep, recreation, anxiety) currently need attention.</li> <li>• Create a self-care action plan for those areas that need attention.</li> </ul>	<ul style="list-style-type: none"> <li>• Participants complete the caregiver wellness assessment.</li> <li>• Participants create action plan for addressing specific areas of wellness.</li> <li>• In small groups, participants discuss action plans—if there is time.</li> </ul>
1:05	<b>Wrap-Up and Evaluation</b> (5 minutes)		<ul style="list-style-type: none"> <li>• Participants and workshop leaders complete evaluations.</li> </ul>
1:10	<b>Adjourn</b>		



# Workshop Script

## **Welcome and Introduction (10 minutes)**

- Objectives:**
- Meet one another.
  - Understand what will be covered during the workshop.

**Leader Note:** *Arrive at least 30 minutes before the start time to familiarize yourself with the room and facilities, specifically:*

- *Lighting and light switches/adjustment*
- *Temperature controls*
- *Arrangement of participant tables & chairs*
- *Location of leader table or podium*
- *Audio-visual equipment*
- *Location of fire exits and restrooms*

**WELCOME** participants to the workshop. If there are fewer than 15 people, you may want to have them introduce themselves to the group. Be mindful of the time and limit this to about 7 or 8 minutes.

**POINT OUT** logistical information such as the agenda, location of the restrooms and fire exits, etc.

## **Caregiving at the Time of Diagnosis (10 minutes)**

- Objectives:**
- Learn about treatment options and current research.
  - Know how to talk to and work with your loved one's physician.
  - Identify steps you can take to become an effective advocate for yourself and your loved one in the health care system.

*Sources: Alzheimer's Association website: [www.alz.org](http://www.alz.org)*

*National Family Caregiver's Association website: [www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)*

- SAY:**
- When your loved one was first diagnosed, you probably needed to draw upon your support network right away.
  - When the diagnosis is first made, friends and family can be particularly responsive. Take advantage of their offers to help you with some of your immediate concerns such as:
    - Researching treatment options and learning about current research.
    - Having a buddy during healthcare encounters.

## **Learning About Treatment Options and Current Research**

### **Treatment Options**

- There is currently no cure for Alzheimer's disease but there are a number of treatments for symptoms. These drugs can help delay or prevent symptoms from getting worse, but do not stop the disease.
- Alzheimer's symptoms are often put into two categories:
  - Cognitive—affecting memory, reasoning, and other thought processes, and
  - Behavioral or psychiatric—affecting feelings and actions.






- We will mainly focus on drugs that treat cognitive symptoms, but you may also need to consider behavioral or psychiatric medications such as anti-depressants or anti-anxiety medications.
- There are two types of drugs approved by the Food and Drug Administration (FDA) to treat cognitive symptoms.
- One type is cholinesterase inhibitors (KOH-luh-NES-ter-ays) inhibitors, which prevent the breakdown of acetylcholine, a chemical messenger that affects learning and memory. Donepezil, Rivastigmine, and Galantamine are commonly prescribed to treat various stages of the disease.
- Note that cholinesterase inhibitors can increase risk of stomach ulcers. Prolonged use of non-steroidal anti-inflammatory drugs (NSAIDs), such as ibuprofen and aspirin, can also increase risk so the two should be used together only with caution.
- The other type of drug that treats symptoms—Memantine—regulates another chemical involved in learning and memory called glutamate, and treats moderate and severe stage Alzheimer's.
- As with all medications, these drugs should be taken as prescribed and you should take steps to reduce drug interactions and watch for side effects.
- About 50% of people who use these drugs find them modestly effective at temporarily delaying the worsening of symptoms. The effectiveness and side effects vary from person to person.
- There are also a number of alternative therapies such as vitamins, herbs, and supplements that are promoted as treatments for Alzheimer's. Keep in mind that they are not regulated by the FDA and most have not been tested for safety and effectiveness in clinical trials. Discuss any alternative therapies with your loved one's physicians, especially since they may interact with prescriptions.


### Current Research

- There is a lot of research being done on diagnosis and treatment options for Alzheimer's that may slow, or even stop, the progress of the disease. These types of treatments are called disease-modifying because instead of just easing symptoms, they stop or slow the disease.
- Some of the research on diagnosis is exploring technologies that produce images of the brain, substances in the body that help measure the progress of the disease (biomarkers), mental evaluation tools, and ways to look for risk based on genes. These tools could allow earlier diagnosis and as a result, earlier treatment before the disease becomes severe.
- Research on new treatments targets major paths of the disease and includes:
  - A potential vaccine that would attack protein build-up (plaques) in the brain;
  - Ways to reduce plaques which are thought to be a potential cause of cognitive decline;
  - Ways to block or reverse the build-up of tau protein which can form tangles (called neurofibrillary tangles);
  - Ways to fight inflammation in the brain which is caused by proteins; and
  - Exploration of antioxidants and other supplements which may restore some brain function.



- 
- These are just some of the many research studies taking place. Many are clinical trials which may be accepting patients into the study. You may want to explore having your loved one participate and the *Caregiver Workbook* in this kit provides more information on how to do this.
  - At some point you'll need to make some changes to minimize or prevent behavior problems. Although this may not be the case early on, it is good to prepare by:
    - Simplifying the environment as well as tasks and routines.
    - Allowing adequate rest between stimulating events.
    - Using labels to cue or remind the person.
    - Equipping doors and gates with safety locks.
    - Removing dangerous items, such as matches and knives.
    - Using lighting to reduce confusion and restlessness at night.
    - Limiting driving and taking away car keys.

### ***Working with Your Loved One's Physician***

- SAY:**
- You will need to rely on the doctor to help you sort through questions about treatment and management of the disease. That's why it's important for you and the physician to work as a team.
  - Prepare for doctor visits by:
    - Gathering background information on issues you want to discuss.
    - Making a list of questions and concerns.
    - Making a list of developments and observations you want to share with the doctor.
    - Use the caregiver workbook for tips on keeping a journal and preparing for appointments.
  - This will help you make the most of your limited time with the doctor. It will also communicate respect for the doctor's time, which will help you to build a relationship of mutual respect.
  - As you make your list of questions for the doctor, here are some to consider:
    - How will you determine if the drug you are prescribing is effective?
    - How much time will pass before you will be able to assess the drug's effectiveness?
    - How will you monitor for possible side effects?
    - What effects should we watch for at home?
    - When should we call you?
    - Is one treatment option more likely than another to interfere with medications for other conditions?
    - What are the concerns with stopping one drug treatment and beginning another?
    - At what stage of the disease would you consider it appropriate to stop using the drug?
- 

- Don't be afraid to ask the doctor questions, or to question a decision the doctor has made if you don't understand it.
- The doctor has expertise in the disease, but you have expertise and the greatest interest in your loved one.

### ***Becoming a Healthcare Advocate***

- SAY:**
- To be a true advocate for your loved one in the healthcare system, you must not only work well with the physician, but you must also:
    - Know your loved one's health history and maintain a copy of his or her record.
    - Facilitate communication among all involved care providers.
    - Understand your health plan(s) and what they cover. When you know what the plan covers, you are in a better position to make sure your loved one receives the proper coverage. Remember that you need to take care of yourself too, so be sure you also know your own coverage.
    - Document all communication with the health plan organization, and always get the name of the health plan representative you speak with.

### ***Caregiving as the Disease Progresses (15 minutes)***

- Objectives:**
- Understand how the progression of the disease affects families and their loved ones.
  - Describe how the needs of your loved one will change over time.
  - Identify options for creating a community of support.
  - Develop strategies for coping with the changing needs of your loved one.
  - Develop strategies for helping family members understand and adjust to the changes in your loved one.

*Source: Alzheimer's Association website: [www.alz.org](http://www.alz.org)*

- SAY:**
- As the disease progresses, you will have some additional issues to consider:
    - How will the disease change over time, and how can I flexibly respond to it?
    - How will this affect our family and friends and how can I help them? How can they help me?

### ***How Does the Disease Change Over Time?***

- SAY:**
- There are three general stages in Alzheimer's disease, based on the severity of the symptoms.
    - Early-stage
    - Mid-stage
    - Late-stage



## Early-Stage

- SAY:**
- Friends, family and co-workers notice lapses in memory or concentration. Your loved one may forget names, misplace items, and have difficulty with planning.
  - During this stage you will need to help your loved one plan and organize, manage finances, and remember things.
  - This is also the time to plan for legal and financial matters in preparation for later stages of the disease, and to decide on how you will get help with caregiving as the disease progresses.
  - This is the right time to make an appointment with an eldercare attorney.

## Mid-Stage

- SAY:**
- At this stage your loved one will need assistance with some daily personal care activities, such as choosing appropriate clothing, dressing oneself, and remembering the details of a personal care routine. They may also wander during this stage.
  - It's clear that the demands on the primary family caregiver increase dramatically during this stage. You will need to have some assistance with caregiving because your loved one will need care all of the time. When people offer to help you, say "yes" and give them something specific to do.
  - You must take steps to ensure your loved one's safety, especially regarding wandering.
  - Unfortunately, the extra physical caregiving coincides with behaviors that will be emotionally hard on you. Your loved one may not recognize close family members, friends, or even himself in a mirror. Your loved one may also be delusional and suspicious and may believe that you will harm them.
  - It's absolutely necessary for you to have emotional and social support during this time. We will talk more about this in a few minutes.

- SAY:**
- One way you can plan for this stage of the illness is by having a plan for creating a network of support.
  - Because the person with Alzheimer's will need 24 hour care, and you also need to take care of yourself, you cannot do this alone.
  - Some people you can include in your network of support are:
    - Other family members or friends
    - Hired companions
    - Home health aides
    - Nurses
    - Respite care centers (adult day care)
    - Support groups
    - Online discussion groups
    - Clergy

## Late-Stage

- SAY:**
- In this stage, your loved one may need assistance with eating. He or she may experience progressively worse incontinence.
  - Eventually, your loved one may lose a lot of muscle control and have trouble walking, sitting up, holding up his head, smiling, or swallowing.
  - It may be necessary to have some nursing care during this time, either at home or in a nursing home.

### ***How Will this Affect Friends and Family, and How Can I Help Them?***

- SAY:**
- Friends and family will look to you to help them understand what is happening to their loved one.
  - Those who know your loved one, including you, will continue grieving. The grieving process often begins at diagnosis and lasts for the duration of the illness.
  - It's important to talk with friends and family to let them know what to expect.
  - Friends and family, including you, will feel a wide range of feelings at different times: embarrassment, anger, frustration, sadness, and guilt.
  - If you have children or teens, it's important to tell them that you have additional responsibilities now. It might be helpful to work together on a plan for communicating and making time to be with each other.
  - Also, children and teens may not understand the disease. They may not know why their relative is different. They may think it's contagious.
  - Everyone, including you, must be prepared for every day to be different, and for your loved one to become a different person at any time.
- ASK:**
- What strategies could you use to keep yourself and your family flexible during this time?

### ***Integrating Caregiving Into Your Life (15 minutes)***

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- Objectives:**
- Understand the causes of family caregiver stress.
  - Understand the health implications of family caregiver stress.
  - Recognize the warning signs of family caregiver stress.
  - Describe ways to be a healthy family caregiver.
  - Identify sources of information and support.

- SAY:**
- You will not be able to care for your loved one if you are not well. For this and other reasons, it is critically important to take care of yourself.
  - You have probably spent a lot of time recently in "crisis" or "coping" mode. We don't care for ourselves well when we are in that mode.
  - That's why it's going to be important to move from coping to caring—both for yourself and for your care recipient.
  - Moving out of crisis mode means accepting that this disease will be a part of your life for a while, and learning how to effectively make it a part of your life.
  - We will now watch a video that looks at the signs of family caregiver stress, and suggests some ways to care for yourself while caregiving is a part of your life.

**VIEW** video.

If there is time when the video is over, **ASK:**

- What surprised or struck you as you were watching the video?

## ***Caregiver Self-Assessment and Action Plan (15 minutes)***

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- Objectives:**
- Identify local sources of support.
  - Determine which areas of your wellness (e.g., sleep, recreation, anxiety) currently need attention.
  - Create a self-care action plan for those areas that need attention.

**DISTRIBUTE** Caregiver Self-Assessment and Action Plan

- SAY:**
- Right now we're going to take some time to allow you to assess your current level of caregiver stress.
  - You will also have some time to brainstorm some ideas for addressing the areas that need attention.
  - The self-assessment lists a number of areas, and asks you to rate each as a 1, 2, or 3, with 1 being "Very True" and 3 being "Not at all true." For any area given a 1 or 2 rating, write down one step you can take towards caring for yourself in that area.
  - Don't try to solve the whole problem. Just write down one step you can take right now. Try to consider all of your options, and use the local resources listed on the flipchart/board. There is a place in the brochure to copy down these resources so you can take the information home with you.
  - You have 15 minutes to work on this. If you finish before the time is up and would like to share ideas with the person next to you, please do so.

## ***Wrap-Up and Evaluation (5 minutes)***

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**DISTRIBUTE** Evaluation Form, Caregiver Resources, and Caregiver Workbook.

**Leader Note:** *For additional copies go to [www.agingresearch.org](http://www.agingresearch.org) or call 202-293-2856.*

- SAY:**
- Please take a few minutes to fill out a brief evaluation form.
  - Your feedback will help ensure that this workshop is helpful to other family caregivers.
  - You can leave the completed evaluation on your chair (or the table).
  - Thank you for your participation.



## Workshop Evaluation

Please rate each of today's activities in terms of how likely you are to use what you learned. Please use the following 1-5 scale:

1 = not at all      2 = somewhat      3 = moderately      4 = very      5 = extremely

- |  |   |   |   |   |   |
|--|---|---|---|---|---|
| 1. Caregiving at the Time of Diagnosis           | 1 | 2 | 3 | 4 | 5 |
| 2. Caregiving as the Disease Progresses          | 1 | 2 | 3 | 4 | 5 |
| 3. Integrating Caregiving Into Your Life (video) | 1 | 2 | 3 | 4 | 5 |
| 4. Caregiver Self-Assessment and Action Plan     | 1 | 2 | 3 | 4 | 5 |
| 5. Local resources                               | 1 | 2 | 3 | 4 | 5 |
| 6. How effective was today's workshop overall?   | 1 | 2 | 3 | 4 | 5 |
| 7. What suggestions do you have for improvement? |   |   |   |   |   |

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8. What comments or suggestions do you have for the workshop leader?

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*Thank you for your feedback*



## Caregiver Self-Assessment and Action Plan

**Directions:** Answer each of the questions below with "Always," "Sometimes," or "Never." For each question you answered with "Always" or "Sometimes," write down one step you can take to better care for yourself in this area. These should be small, doable steps. For example, "Accept my neighbor's offer of bringing over dinner once a week for the next month."

Question	Response	Action Step
Do you feel that because of the time you spend with your relative/friend, you do not have enough time for yourself?		
Do you feel stressed between caring for your relative/friend and trying to meet other responsibilities for your family or work?		
Do you feel that your relative/friend currently affects your relationship with other family members or friends in a negative way?		
Are you afraid about what the future holds for yourself?		
Are you afraid about what the future holds for your relative/friend?		
Do you feel strained when you are around your relative/friend?		
Do you feel your health has suffered because of your involvement with your relative/friend?		
Do you feel that your relative/friend seems to expect you to take care of him or her, as if you were the only one he or she could depend on?		
Do you feel that you do not have enough money to care for your relative/friend, in addition to the rest of your expenses?		
Do you feel you have lost control of your life since your relative's/friend's illness?		
Do you feel uncertain about what to do about your relative/friend?		



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