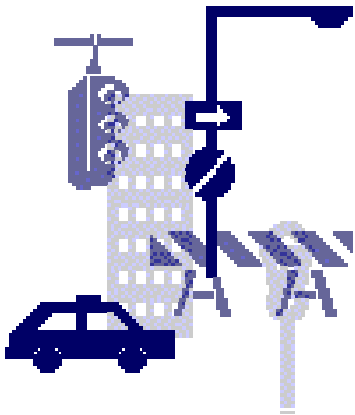


# Independence with Safety

Knowing when to take a stand: feeling okay about it

How to find balance on  
this tight-rope



## **Independence with Safety: When to Be Concerned & What to Do**

The focus of this section is safety with independence – not an easy task!

Memory loss affects judgment. This usually happens early on in the disease process. How adept someone is in making their point does not reflect their ability to get the big picture.

Persons living with memory loss want their independence judged on their good days. Family members fear for safety based on a person's not so good days.

To better assess safety needs, please see the brochure in your handouts entitled, *Safety at Home*. It has a wonderful checklist at the end.

Waiting until they agree with you usually doesn't work!

## **Driving Issues: Tips for Family Members**

The freedom to slide behind the wheel of a vehicle, turn the key and drive away symbolizes many things: independence, convenience, and competence...It often symbolizes the end of the road when one has to give it up.

Caring for Someone with Alzheimer's Disease, MayoClinic.com

The issue of driving and memory loss is not any easy topic to confront. Those with a diagnosis of memory loss should have a life as full and meaningful as possible, but without the threat of harm or injury.

A diagnosis of Alzheimer's disease or of other related disorders does not necessarily mean that a person should stop driving immediately. It greatly depends on the rate of progression of the disease.

However, driving a motor vehicle requires many abilities such as:

- ✓ quick reaction
- ✓ fast judgments and recall
- ✓ an understanding and memory of the rules of the road
- ✓ orientation to time and place.

These are abilities that may be affected by the disease process and important to assess when discussing how long an individual should continue driving.

### **Warning Signs To Look For:**

- ✓ Disorientation with usually familiar areas
- ✓ Damage to the vehicle
- ✓ Tickets or violations from the police
- ✓ Increased agitation or anxiety about driving
- ✓ Difficulty with signaling or lane changing
- ✓ Driver not remembering where he or she went
- ✓ Driving either too fast or too slow
- ✓ Problems with parking the car
- ✓ Fear of safety for driver or others places
- ✓ Accidents
- ✓ Near misses
- ✓ Failure to abide by rules of the road

There are no definite standards to make the decision of when someone with Alzheimer's disease or other memory related disorders should stop driving; it is a process that involves many people, which if possible should **include** the individual with memory loss. While it is important to assess the priority of independence, there is also a need to assess the risk of harm to self or others. This may create feelings of **guilt and anxiety in a caregiver or family member**, but safety should be the ultimate priority. Family, friends and professionals need to be both supportive, but strong and firm in addressing this issue.

### **Startling Statistics:**

- ✓ It has been reported that people with Alzheimer's Disease are 19 times more likely to have a car accident than other older adults without the disease. (mayoclinic.com)
- ✓ 40% of individuals with dementia have been in an accident
- ✓ 44% have become lost while driving
- ✓ 75% drove well below the speed limit

## **Coping Strategies**

- **Involve the person with dementia;** including the individual experiencing memory loss in this decision and discuss it in an open environment, may help to decrease anxiety over this loss.
- **Begin discussions early;** anticipate that driving may become an issue and talk about the feelings that might occur when it comes time to give up driving completely.
- **Be honest and share observations;** be up front about what you, as the caregiver, friend, or family member, are feeling or are concerned about. Let the person know that you respect them, but are also concerned about their safety, as well as the safety of others.
- **Realize that the loss of driving represents a loss of independence and control;** put yourself in the place of having to give up **your** license and think about the feelings you might have about losing this piece of your life. This may increase your understanding of what the person might be going through.

*We all mold  
one another's dreams.  
We all hold each other's  
Fragile hopes in our hands.  
We all touch each others' hearts.*

*Shared by Kathy Doberstyn*

- **Acknowledge the loss and offer reassurance;** support the person and reaffirm that they are still a person that has worth.
- **Consider the social networks that will be lost;** driving allows individuals to meet several social needs such as visiting friends, shopping or other social activities. Think of ways to help maintain these networks.
- **Anticipate the individual's negative reactions to the loss of driving and independence;** giving up driving will generally not be easy and it is important to be prepared for negative reactions such as denial, anger or grief.
- **Remember that there is no right answer or way to handle this issue;** try different methods, taking into account your knowledge of your loved one and what might work for him or her.
- **Base decisions about the individual's ability to drive from observations taken over a period of time;** assess the driving abilities of the individual on different occasions, everyone has both good and bad days.
- **Look to others for support;** one family member or caregiver does not have to make the decision alone, it is all right to ask for help and support from others.
- **Allow all people interested and involved, the opportunity to assess the individual's driving;** this helps to alleviate the stress of guilt or blame from falling onto one person.
- **Be prepared for excuses;** the individual will probably think of excuses to continue driving after it is safe to do so. Be prepared and anticipate what your answers or plan of actions will be.
- **Caregivers often times HAVE to take responsibility;** people with memory loss might not recognize their inability to drive safely, having lost judgment due to the disease. Caregivers may have to step in, be assertive and make the decision, all in the best interest of the individual.
- **Follow patterns of how family decisions have been made in the past;** try to maintain consistency in discussing issues such as this and plans of action.
- **If there is not an imminent safety risk, try decreasing driving over time, having the person:**
  - ✓ Drive only short distances
  - ✓ Only with someone else in the car
  - ✓ Only drive on familiar roads

- ✓ Avoid difficult intersections
- ✓ Avoid driving during busy hours
- ✓ Drive only during good weather
- ✓ Avoid driving at nighttime, dusk or dawn

- **Introduce the idea of public transportation;** if it is safe for the person to use buses, taxi's etc., have them start utilizing these services
- **Anticipate the needs of the individual before they arise;** alleviate possible needs they may have that would cause them to get into the car (anticipate medication needs, grocery needs), bring goods and services to them if possible...create a schedule
- **Talk to others in similar positions;** other families are going through the same thing, talking about it may help in gaining support and knowledge

### Helpful Hints

- Trade in license for state picture ID
- Get a prescription in writing from the doctor stating that individual is not to drive; often times the individual will have respect and authority for a medical professional and will abide by their directives
- Ask the individual to go for a driving test
- Say that car insurance will not be renewed
- Say the car needs repair
- Exchange working car keys for unusable keys; some individuals associate caring keys with independence and just having keys will satisfy them
- Disconnect battery in car
- Install a kill switch in car to prevent it from starting
- Parking the car around the corner or out of sight
- Alert neighbors to the issue
- Place sign under the hood in a location where a mechanic could see it, asking that the caregiver be called before any work is to be done

**TALK, LISTEN, OBSERVE AND ANTICIPATE!**  
**Do not wait for an accident to happen!**

## **Information was compiled from the following references:**

Alzheimer's Association, Northern Virginia Chapter. Last updated march 1, 1999. <http://www.alz-nova.org/caretips/driving.asp>

Alzheimer's Association, Oklahoma Chapter. VIDEO. Issues and Answers- Driving with Dementia.

Alzheimer's Society. Care-Ethical Issues: Driving. Last updated September, 2000. [Http://www.alzheimer.ca/alz/content/html/care\\_en/care-ethics-driving-eng.htm](Http://www.alzheimer.ca/alz/content/html/care_en/care-ethics-driving-eng.htm)

Mayo Clinic. Caring for Someone with Alzheimer's; Alzheimer's- When driving becomes an issue. Last updated September 25, 2000. <http://www.mayoclinic.com/home?id=HO00046>

The Hartford. At the Crossroads. A Guide to Alzheimer's Disease, Dementia and Driving. Last updated, 2000. <http://www.thehartford.com/alzheimer's/faq.html> 2000.

Vann, K., (2000). Driving Safely with Alzheimer's. The Chronicle-Telegram.

## **Community Resources**

### **Bureau of Motor Vehicles**

P.O. Box 16784

Attn: MVODIC

Columbus, OH 43266-0084

614-752-7600 (general information) \* \* \*

614-752-7500 (medical department)

To revoke a license, you can request a #MVB 2310 form- Request for Statement of Physician. The person with memory loss would sign section on release of medical information; take the form to their doctor who sends out form and sends it to the BVM in Columbus. The BMV would then contact the individual stating that his or her license has been suspended.

### **Cleveland Clinic Rehabilitation Department Walker Building**

East 107<sup>th</sup> and Euclid Ave.

Cleveland, OH

Appointments: (216) 445-2273

Information: (216) 445-8472

Fax: (216) 445-2161

Must have a doctor's prescription, which needs to say "Occupational Therapy Driving Evaluation and Rehabilitation".

### **Euclid Hospital Campus/ Outpatient Rehabilitation Therapies**

Health Center Building

18901 Lake Shore Blvd.

Euclid, OH 44119

(216) 692-8780

Must have a doctor's prescription

### **Heights Driving School (19 locations)**

Eastside Office: 440-449-3300

An evaluation costs \$110 and includes a vision and hearing test, \$ 70 for an in-care test. Center is certified to test people with dementia.

Information on additional transportation/driving resources can be found by looking in the yellow pages under **Taxi-cabs, Transportation Services for the Disabled**. Also many non medical Home Health Care Agencies will provide limited transportation.

## **Safe Return Identification Program**

A national program to identify, locate and return individuals with memory loss. Almost 60% of persons living with memory loss will wander at some point in their illness. Ensure safety early on by registering in the Safe Return program. Benefits include identification materials, registration in a national database, a 24-hour toll-free number to contact, and coordinated outreach to police, emergency rooms, etc. There is a one-time \$40 registration fee and \$20 annual program administration fee.

PLEASE NOTE: Assistance is provided in wandering situations even if the person is not yet registered in the Safe Return program. Call the Alzheimer's Association at 1-800-272-3900. **A Safe Return Registration Form is included in your packet.**

### **Ideas for Encouraging Someone to Wear a Safe Return Bracelet or Necklace:**

- **Wrap the bracelet or necklace in a box and present it as a gift.** Birthday, Hanukkah, Fourth of July.
- **Have a grandchild or other loved one present the bracelet.** The individual may appreciate the gesture, cherish the bracelet, and wear the bracelet even if not initially taken with the style.
- **Ask the physician to give the jewelry.** If the individual has a medical appointment soon after receiving the products, ask the physician to place the bracelet on the affected person during the appointment. It may be better received from a physician.
- **Place the bracelet on the individual's dominant hand.** This will make it more difficult for the individual to release the clasp.
- **Make sure that it is not too big for the individual.** A bracelet that is too loose may be easy to remove!
- **Place the bracelet next to the individual's current bracelet or wristwatch.** If the individual is comfortable wearing a watch or other jewelry on a particular wrist, place the bracelet on the same wrist to avoid any new adjustments.
- **Try the necklace!** If the individual is not comfortable wearing the bracelet perhaps they would prefer the necklace.
- **Order matching caregiver jewelry.** Consider ordering a matching caregiver bracelet or necklace. This may signal the memory-impaired person that it is acceptable to wear the jewelry.

- **Encourage the individual to wear the jewelry in alternate places.** If the individual does not want to wear jewelry around the wrist or neck, find a more creative place. Try attaching the bracelet to a belt loop, purse handles, on the ankle, or, lace it with their shoelaces. Remember however, the more visible the jewelry, the more likely it will be noticed when the individual is in need of assistance.
- **Use “dog tags” for former military personnel.** If the individual served in any branch of the armed forces, then the Safe Return bracelet or necklace may be accepted as a new form of “ dog tags.”
- **Attach it to a wristwatch band.** If the individual will not wear the identification jewelry, it may be helpful to attach it to something such as a watch. (One caregiver took the back panel of the bracelet and had this attached to the individual’s watch band!)
- **Engrave the Safe Return information onto an existing piece of jewelry.** Consider engraving all of the Safe Return information onto the individual’s existing jewelry.
- **Use the additional Safe Return identification products!** The clothing labels, wallet card and key chain will also help identify a person who is lost.

### **What to Do If the Person Says No?**

- Ask 1-2 others to join you in explaining the situation.
- Keep it simple: a clear, short statement, e.g. it isn’t safe for you to drive anymore.
- Add a physical reason, e.g. your eyesight isn’t good anymore.
- Enlist help from an authority figure, e.g. doctor, attorney.
- Note risk financially if the person is involved in an accident.

**Loving decisions don’t always feel good.**

- Acknowledge thoughts and feelings by validating and rephrasing the words, e.g. you seem very angry.
- Reassure person that you understand and will be there to help, e.g. I'm so sorry this has happened, but we'll get through this.
- Redirect, e.g. let's take a break now, have some tea, go for a walk.
- Use the same short explanation in each future discussion.
- Hold your ground!

## Staying Alone Safely: When to Be Concerned

### **Does the person:**

- ✓ Become confused or unpredictable under stress?
- ✓ Recognize a dangerous situation: for example, fire?
- ✓ Know how to use the phone in an emergency?
- ✓ Stay content within the home or become confused and may wander?
- ✓ Show signs of agitation, depression, or withdrawal when left alone for any period of time?

Commonsense is the wick of the candle.  
Ralph Waldo Emerson

- ✓ Seem vulnerable to financial exploitation by friends or strangers? Would they open the door to a stranger?
- ✓ Attempt to pursue former interests or hobbies that might now warrant supervision such as cooking, appliance repair, woodworking?

Taken from *Home Safety for People with Alzheimer's Disease*, US Department of Health and Human Services, Public Health Service. NIH Publication No. 02-5173.

## Frauds and Scams: Protecting Vulnerable Adults

- Remove person's name from telemarketer's lists and junk mailings. To stop telemarketing: call National Do Not Call Registry at 1-888-382-1222 or write to Telephone Preference Service, Direct Marketing Association, P.O. Box 9014, Farmingdale, NY 11735-9014. To stop

junk mail: write to Mail Preference Service, Direct Marketing Association, P.O. Box 9008, Farmingdale, NY 11735-9008.

- Set-up a P.O. Box for mail delivery.
- Screen mail and phone calls.
- Arrange for automatic direct deposit of monthly income checks.
- Limit credit card access.
- Look for unpaid bills.
- Look for unusual activity in bank accounts, bounced checks, “maxed out” credit.
- Arrange with the bank to allow access only to predetermined amounts of money and ask to be contacted if a request for a large withdrawal is made.
- Look for checks or documents with signatures that appear forged.
- Be sure the person’s social security number is not on checks.
- Check the person’s credit report once a year.
- Be aware if someone isolates the person or talks excessively about finances.
- Notice if a new acquaintance expresses inordinate affection/loyalty.
- Look for changes in documents, e.g. will, deeds, Powers of Attorney.

Revised from Rocky Mountain Chapter Alzheimer’s Association

Questions around safety will need to be reassessed as a person’s competency will decline over time.

**For assistance in assessing safety, call the Alzheimer’s Association Helpline at 1-800-272-3900.**

## **Managing Emotions You’d Rather Not Have**

As much as we would like our lives to be filled only with pleasant experiences, eventually circumstances will generate a mixture of emotions—some good, some difficult to face. What is important is how we choose to deal with our own negative feelings.

Because of the stress such a situation generates, it is inevitable that at some point we will feel we can never do enough, that we are isolated, unappreciated, and angry.

Guilt and anger are normal and familiar emotions for caregivers and others close to a person who has been diagnosed with Alzheimer's disease. Because of the stress such a situation generates, it is inevitable that at some point we will feel we can never do enough, that we are isolated, unappreciated, and angry.

At the end of the day, it is easy to feel exhausted, as if there is nothing left of the self. All of the little annoyances that occur during a day can add up, creating situations of high tension. While it is important to realize there is nothing wrong with experiencing such feelings, we need to take steps to find ways to work through the stressful periods.

### **Releasing Anger**

According to professional counselors, we must recognize that it is never acceptable to strike another person, even if we feel that we have reached our breaking point. This includes striking out verbally as well as physically. Harsh words such as, "I hate you," and, "You are a burden to the family," can hurt just as much as physical abuse. Rather than reaching a breaking point, as caregivers we must learn to find alternative outlets for our anger. Linda Teri, Ph.D., Professor of Psychiatry and Behavioral Sciences at the University of Washington, Seattle, offers the following practical suggestions:

- Share your concerns with others. If you are feeling isolated and alone, take advantage of those in your life who would be willing to help if they knew what to do. *Be clear and specific about your needs.* Tell another family member, "I'm feeling overwhelmed. It would help if you could take Mom for one day a week so that I can get my needs met." Talk to anyone who will listen. Many times, all we need is a chance to verbalize our feelings. Cry in the shower to release pent-up frustration.

- If you do not have a family who can help you, seek out and access other resources. Join support groups or professional societies. Assign other people to do routine tasks. If someone else will clean your house, you can have more time with Dad. This will save your energy and help you to be more patient and kind.
- Even feeling very angry is not wrong. Deal with this situation by removing yourself immediately for a short period of time. Go outside for a moment to get away. Go into a separate room, close the door and yell and scream until you feel in control again. If possible, take a short walk. Release your anger in any safe way that makes you comfortable.

Recognize your limits and release your anger before you reach the breaking point.

- If you feel you are in danger of inflicting physical harm, remove yourself from the situation completely. You do not need to react by striking out. Rather, walk away; take some deep breaths; remind yourself that you are a loving and caring individual. Recognize your limits and release your anger before you reach the breaking point.

### **Dealing with Guilt**

- When you feel guilty, it is helpful to admit it, to yourself and to others who will listen. Chances are you will discover you are not alone; others experience the same emotions that you do. Many times there is not an answer to "why" you feel guilty, and you will find that you need not blame yourself.

Take time to care for yourself. No one will benefit if you are worn out and exhausted.

- There will also be times when you feel that you can never do enough, or that no matter how good a job you do, your Mom will say or do things to make you feel inadequate. For this reason, it is helpful to take the time to learn about Alzheimer's disease and its

various manifestations. Recognize that you are doing your best. Be honest with yourself; know that your feelings are going to get hurt and that this, too, is OK. Don't take the diagnosed person's actions personally.

- Take time to care for yourself. No one will benefit if you are worn out and exhausted. Find a few moments of every day to give yourself time. Wake up a few minutes early and make a cup of coffee or tea before your day begins. Organize your thoughts while you are taking a shower. Don't feel guilty for addressing your own needs.
- Be patient with yourself and remember that you are doing the best you can. Try not to blame yourself for things that you did not know you were mishandling. You are human and therefore not perfect.

## **Seek Balance**

Cleveland Heights social worker Mary Ann Wetzler, ACSW, LISW, a specialist in mid- and later-life counseling, stresses the importance of remembering that living is a balance of both good and bad. This means accepting our imperfections and learning from past mistakes. She adds that there may not always be an answer to every problem we encounter. Ms. Wetzler suggests that caregivers try writing about their thoughts and feelings. "Putting things in writing helps to identify emotions and helps you work through them. Alternatively, sit facing an empty chair. Pretend that the person about whom you feel guilty is sitting across from you. Talk to that person. Express your concerns and feelings. It's OK to say, 'I resent this. I know it's not your fault, but I feel as if this is never going to end.' Perhaps you could voice your feelings of inadequacy by saying, 'It seems as if nothing I do is enough for you.' Continue to talk with this person until you feel better about yourself.

Do your best for your current circumstances. Just remember that your best will vary from day to day, depending on life's other pressures and involvements.

“Remind yourself that your loved one would not want you to feel guilty. Talk with a trusted friend or professional, or talk over your guilt with God. Forgive yourself. Learn from your guilt by trying to adopt a new lifestyle for the future.” However, Ms. Wetzler notes that guilt should not be pushed away. Instead, she advises talking about it until you can let it go.

“Do your best for your current circumstances. Just remember that your best will vary from day to day, depending on life’s other pressures and involvements. Don’t get caught up in, ‘last week I did all this, and this week I can barely get out of bed.’ Learn by trial and error,” says Ms. Wetzler.

“Perfect caregiving is a role beyond realistic capability. There is no magic bullet. Just remember to act toward others as you would want them to act toward you.”

*By Rachael Yuni, Alzheimer’s Association Cleveland Area Chapter, Issues in Focus, 7/98.*

## **Brilliant Insights on Driving From Persons Living with Memory Loss**

1. It will be a sad day when I give up driving.
2. I'm going for the driving test tomorrow. My son thinks it's necessary. We'll see.
3. I named my daughter after my mother. That was a mistake! Now she thinks she is my mother. She wants to take my car keys away.
4. I am going to give up driving because I'm tired of hearing my kids talk about it!
5. When there is friction between us and our families over issues like driving, it takes the pleasure out of the whole day.
6. One day I can drive and the next day they tell me I can't, but I'm the same person.
7. I don't like losing privileges – like driving. Believe me, it hurts.
8. I can't drive anymore. I used to be able to get the keys, get in the car, and go. Now I have to wait until they are ready.
9. Having to rely on someone else to take you somewhere is hard! They don't always go where you want to go.
10. I'm lost without my steering wheel.
11. The doctor said I couldn't drive any more. That was the one thing that made me cry.
12. When you decide for yourself to give up driving, you still have the control.

13. I think I could drive, but I don't need to.
14. The only safe place for me to drive is Wyoming!
15. Sometimes it's not easy being a passenger.
16. I say to my wife, "Who is driving this car, you or me?"
17. My husband drives me everywhere. He is driving me nuts!
18. We have to be honest with ourselves about our limitations.
19. It's a relief not to drive. I feel safe being a passenger.
20. I stopped driving because I was afraid of hurting someone.
21. I have such freedom. I can get dressed and eat as slowly as I want. I don't even have to worry about driving anymore; about finding my way or getting there on time.
22. I don't drive anymore, now I just sit back and relax.
23. I understand more about my problems when I listen to others in the group.
24. I don't want to get into trouble that somebody else has to straighten out.
25. I know it is inevitable that I will have to stop driving.
26. You learn to live with it.
27. Don't take 'the moment' for granted, remember the beauty of things. We have a lot to be grateful for.

# Stress Reduction Tips

- Add something beautiful to your life on a daily basis, e.g. fresh flowers.
- Do some enjoyable activities whenever possible.
- Walk, work and eat at a relaxed pace.
- Take a short break after meals to relax.
- If possible, go outside at least once per day and notice the simple things such as the weather, the scenery, etc.
- During the day whenever possible, notice the tension in your body (jaw, neck, diaphragm, shoulders, etc.) Breathe deeply and gently stretch and relax any tense areas.
- If you notice your mind racing or worrying about the past or future, take a minute to breathe deeply and gently focus on something in the moment, such as your breath, scenery, birds.
- Take breaks during the day to relax.
- Wear comfortable and loose clothing when possible. Take off your shoes when you can.
- Avoid holding in feelings day after day, but instead, find a safe place to feel, express and embrace them.

# Learning Together II Leaders Manual: Family Members

## February Focus: Independence with Safety

### Supplies:

Flip chart

Marker

Safe Return sample packet and application forms

Handouts for workbooks (3-hole-punched, paper clipped to take home)

1. Welcome individuals. If there are new people, ask each person to introduce themselves (without giving a snapshot view) and mention confidentiality.
2. Last month we talked about activities. Did anyone have any luck arranging a new activity with someone else? What was it? How did you do this? What did you do during this time?
3. Note the focus for this session is safety with independence.

Memory loss affects judgment, which is in the front part of the brain. This usually happens early on in the disease process. How adept someone is in making their point does not reflect their ability to get the big picture. Waiting until they agree with you usually doesn't work!

Persons living with memory loss want their independence judged on their good days. Family members fear for safety based on a person's not so good days.

To better assess safety needs, please see the brochure in your handouts entitled, *Safety at Home* - wonderful checklist at the end.

4. Focus discussion on driving, noting that several families in this group have already had to make the decision to take the keys away.

- Open to these families. How did they know it was time? How did they do it? Did their person agree? If they didn't agree, what did they do?
  - Note: there is further information in their workbooks on assessing driving and getting the keys away.
  - Suggest families call our Helpline for individual help in doing this. Helpline number is on card clipped to front pocket of their workbook.
5. What do you think are some of the common feelings families have around this issue of independence versus safety (may list on flip chart, e.g. guilt, anger, fear)? Focus on one feeling at a time, opening to group for input and suggestions on how to deal with this feeling. What has been helpful?
  6. Highlight *Safe Return* program, noting brochure with application form in their handouts, pass around sample kit. Ask if anyone in the group has ordered this, suggestions for doing this, benefit of ordering one for family member also.

**Let families know that if their person becomes lost, they can call the Alzheimer's Association EVEN if their person is not already registered in the Safe Return program. We can help! 216-721-8457 or 800-272-3900**

7. Focus on safety considerations when leaving their person alone. Open to families who are using help in the home or a day center. How did they do this? Did their person agree to do this? What did they do?

Note Family Care Planning Meetings offered through the Alzheimer's Association for when your family isn't on the same page.  
(Listed on *Services for Families* handout)

8. End with summary of key points, particularly helpful comments made during the group, or inspirational piece.