

AS MEMORY FADES.....

THE CAREGIVERS CHALLENGE BEGINS

UNDERSTANDING AND COPING WITH PROBLEM BEHAVIORS RELATED TO MEMORY LOSS: A LEARNING GUIDE

Supported by: *Iowa Scottish Rite Masonic Foundation,
National Caregiving Training Project,
University of Iowa College of Nursing,
Gerontology Nursing Intervention Center
Research Development and intervention Core*

Developed by: *Geri R. Hall, Ph.D., ARNP, CS, FAAN
Clinical Professor, Behavioral Neurology,
and, Faculty Associate, Center on Aging
Director, Master's Program
University of Iowa College of Nursing
Iowa City, Iowa 52242
Phone: 319-335-8709
E-Mail: geri-hall@uiowa.edu*

Revised June 2004

This booklet has been designed to help you understand the care of your loved one with chronic a neurological degenerative condition. We encourage you to make copies of this booklet.

Introduction

Diseases causing memory loss and neurologic degeneration are common, affecting more than 3 million Americans. Although Alzheimer's disease is the most common disease causing memory loss, many neurologic conditions have similar symptoms and are managed in approximately the same way.

The average family spends about \$200,000 on care for a loved one after they have been diagnosed, yet the costs of the illness far exceed the money spent. Families selflessly devote their love, time, energy, and creativity to care for their loved ones while watching the slow agonizing progression of the disease

Diseases that cause memory loss --- including Alzheimer's disease, Parkinson's disease, and strokes --- have a variety of symptoms that can baffle and overwhelm family members. Some of the most challenging and frightening problems rarely occur early in the disease but may "pop up" when it is least expected as the disease progresses. Examples might include the following:

- Demanding to leave during an activity or event they had been looking forward to
- Waking up in the middle of the night to get dressed and start the day
- Not recognizing familiar settings, home, or family late in the afternoon
- Accusing family members of stealing items the patient has hidden -- or blaming "outsiders" for taking things
- Threatening family members with physical violence

- Becoming irritated or belligerent late in the day
- Refusing to bathe, go to the doctor, or out socially for no apparent reason
- Walking away from home or getting lost
- Telling stories you know aren't true
- Thinking there are extra people or children in your home
- Seeming selfish

These behaviors may seem mean-spirited and purposeful, but they are simply symptoms of the patient's brain disease. **These behaviors are normal and expected in mid-disease.** It is important to realize that **the patient can not control these sudden behavior changes, but you can help to prevent or minimize them.** While not everything works all the time, we can eliminate much of the "acting out," behavior by making simple changes in our behavior and the environment. The changes help the patient to succeed. Unexpected changes in behavior are often triggered by things you can control -- once you know how. The purpose of this pamphlet is to teach you what triggers those unexpected problem behaviors and how to change the patient's routine to prevent them.

Staging Dementia:

Dementing illnesses average 7-10 years in length with many patients living as long as 20 years. Families always want to know what stage of the illness their loved one is in, what comes next, and how long the person will live. While no one can answer the last question, the first two are a bit easier.

Most experts agree there are up to seven stages of dementing illnesses. We can define each stage using tests, such as counting backwards by 7's or 5's, it is easier to look at the person's usual day to day function and make an estimate.

THE SEVEN STAGES ARE:

- 1. No cognitive decline**
- 2. Very mild cognitive decline - Forgetful**
- 3. Mild cognitive decline - Early confusional**
- 4. Moderate cognitive decline - Late confusional**
- 5. Moderately severe cognitive decline - Early dementia**
- 6. Severe cognitive decline - Middle dementia**
- 7. Very severe cognitive decline - Late dementia**

2. Very mild cognitive decline (occasionally referred to as mild cognitive impairment)

- Changes in short-term memory
- Depression – may refuse treatment
- Conflict with others (marital conflict)
- Increasing frustration, increased anger
- Symptoms seen as willful or purposeful
- Problems with employers
- Refuses treatment for depression

3. Mild cognitive decline (Early confused stage)

- Losses or changes in the ability to:
 - Manage employment
 - Manage money
 - Drive safely (gets lost, makes mistakes, fender benders)
 - Shop and make change
 - Plan vacations and trips

- Comprehend complex written materials
- Understand phone scams, ordering from catalogues, or subscribing to appropriate magazines may become a problem.
- Chores, especially those with power implements (snow blowers, saws, gas tanks) become unsafe.
- Social participation may change

4. Moderate cognitive decline (Late confusional stage)

- Decreased time sense
 - Cleaning
 - Cooking
 - Thermostat
 - Withdrawal from complex tasks
 - Loss of sense of “risk”
 - Withdrawal from high stimulus activities and social activities
 - Increased irritability and self-absorption
 - Difficulty with planning
 - High degree of awareness, yet may be denial
 - Anger with lost activities
- Loss of sense of humor

5. Moderately severe cognitive decline (Early dementia phase)

- Bathing – starts with resistance
- Catastrophic behaviors become more regular
- Grooming
- Selecting clothing
 - Wears same clothing all the time
 - Changes clothing frequently
 - Odd combinations
 - Occasional problems with recognition of family
- Dressing
 - Regular recognition of family
 - Non-recognition of TV, mirrors, pictures, objects
- Personal withdrawal from activities and people
- Decreasing awareness
- Increased visual-perceptual deficits and recognition, complaints that glasses need changed
- Sensitivity to noise, avoidance of groups
- Clings to caregiver
- Repetitive behaviors
- Decline in language ability
- Resistance to intimacy
- Child-like affect (Piaget in reverse)

- Pacing, Wandering
6. Severe cognitive decline (Dementia)
- Toileting
 - Ambulation (walking)
 - Getting “glued” to floor
 - Falling
 - Shuffling
 - Coasting from object to object
 - Difficulty rising from chair
 - Toddler-like affect
 - Eating with fingers
7. Very Severe cognitive decline (Late dementia or end stage)
- Loss of ability to move about purposefully, i.e. pushing a wheelchair
 - Loss of regular verbal communication
 - Dependence in all activities of daily living
 - Loss of recognition of family members except during moments of clarity
 - Spontaneous behaviors, such as yelling
 - Contractures, pathologic fractures, & joint immobility
 - Complications of immobility & medical complications
 - Weight loss
 - Skin breakdown
 - Repeated infections
 - Aspiration
 - Falls from bed (rollouts or climb-outs)
 - Return of primitive reflexes
 - Seizures, additional neurological problems
 - Needs to be fed

Unfortunately these stages are not clearly identifiable. Most health providers use an average of what the person can do over a period of a week or so. Patients may improve slightly with medications or worsen temporarily due to fatigue, the wrong environment, or too much change. The rest of the booklet explains common pitfalls and problems encountered by patients and families with tips for preventing some of the more common problems. There is also a section on where to find additional help.

Fatigue:

The biggest enemy of the person with memory loss is fatigue. People with brain diseases tire very easily -- because they have to concentrate so hard all the time. Try the following suggestions to prevent fatigue:

- Give the person a rest both in the morning and the afternoon. This may be just a quiet period or an actual nap. If the person naps, have him/her sleep in an easy chair or the

sofa so they know when they wake up that the rest period was a nap -- that it is not morning all over again!

- **If the person is waking at night DO NOT keep them up all day.** Forcing them to stay up all day can make the night waking worse!
- Avoid foods and beverages with caffeine. Try decaffeinated coffees, teas, colas, and pops containing no caffeine
- If you are planning a social activity or trip, make sure the patient is well-rested both before and after the trip. Many families make the mistake of trying to accomplish too much during a day. Travel for a while, then stop and rest.
- Get to know the patient's "best time of day." Use that time to visit friends, go to the doctor or dentist, or travel
- Plan activities that are of a shorter duration. Instead of cleaning the house in a single day, spread the chores across several days to prevent the person from becoming overtired.
- During holiday gatherings or special occasions such as weddings or reunions -- when the person is away from home -- plan in advance a place and times when he/she can get away to rest during the activity.
- Many patients go through a period where they sleep a great deal. If this happens, check for depression or boredom. If neither is present and the person is still sleeping at night, understand it is normal for the illness. This is a good time for you, the caregiver, to get things done, catch up on your rest, or indulge your own interests.

Change:

People with memory loss have problems with planning. The more they think about an activity, the less they are able to do it -- even though they could do it yesterday or can tell you how to do it! Help the patient and decrease their frustration by doing the following:

- Have a routine you follow during the day. While the timing of the routine is not important, the sequence of activities is very important. For example, if the patient gets out of bed, has breakfast, and then bathes and dresses -- it is not a good idea to have them get out of bed, bathe and dress, and then eat breakfast. This produces frustration and anxiety that can accumulate throughout the day and produce increasing problems in late afternoon or at night
- When well-meaning family and friends suggest the patient needs a change of pace, gently reassure them that this may not be in the patient's best interest.
- Redecorating the house, decorating for the holidays, moving, or even rearranging the furniture can produce problems. Before moving, redecorating or remodeling consult with a memory loss specialist such as the Alzheimer's Association office nearest you. Seeking advice in the beginning can save many problems later.
- Keep holiday decorations simple. Avoid having many long holiday gatherings and parties with large numbers of guests. Simple, quiet festivities are enjoyed more by the patient and do not result in behavior problems
- If the patient demands to be taken home during a party or becomes rude to friends or children, understand this behavior is not aimed at the person. It is simply the patient's way of telling you he/she is tired or overwhelmed by the activity level and/or changes
- Travel can be especially difficult. Plan trips with the help of a knowledgeable professional who regularly helps families manage problems associated with Alzheimer's disease and related disorders and travel. Ask for a copy of the Mayo Clinic Travel Brochure, designed to help families who must travel with people with memory impairment.
- Occasionally you will plan trips or events that you know will trigger increased confusion. Expect the confusion. Plan to have extra help or medications on hand to see you through this period.

Overwhelming or misleading stimuli:

People with memory problems suffer the loss of ability to interpret what they see and hear properly. Noises and things they see may become distorted -- like a fun house on the midway at the state fair. This causes the patient to become uncomfortable in crowds or in noisy settings. Groups as small as ten people can result in an angry outburst, a demand to leave, or rude statements -- especially if the patient is tired.

- If the person wants to leave, it is a good idea to honor their wishes and leave the setting, or have them retire to rest for a while
- Encouraging the patient to continue to attend or stay at a social gathering may produce severe agitation or waking up confused that night
- Use the patient's requests to leave as an indication of how much activity, noise, and how large a group the patient is able to tolerate.
- If the patient begins to complain of people at home who aren't there--for example seeing little people or children-- turn off the TV, take down family pictures, and cover windows at night. Mirrors may have to be covered with roller shades especially in the bathroom. The patient may not recognize their reflection and leave thinking a stranger is in the room.. It is best to call the Mayo Clinic Neurology Clinic and talk this over with a professional.
- If the patient begins to develop ideas that people are in the house, becomes suspicious that people are doing things behind his/her back, or tell stories you know aren't true, **Don't argue or correct them.** Recognize that the person's brain is "playing tricks," and the illusions and beliefs are very real to them. The patient believes these statements. Correcting the person will simply convince them that you don't know or care about what they are experiencing. It is best to reassure the person of the following:
 1. They are safe
 2. You have taken care of the problem or your intention to take care of it. (This is a statement, you do not necessarily act on it)
 3. You understand the patient is concerned and upset by what they are seeing or hearing.

Loss of meaningful activities:

Activities define who we are. When the patient loses the ability to drive, work, mow the grass, cook, or perform other meaningful tasks, depression or anxiety may result. It is important to substitute old cherished activities with similar simpler activities.

- If there is an occupational therapist in your area, talk with either occupational therapist or activity therapist to help design replacement activities. If no therapists are available in the hospital in your area, contact a nursing home and ask for the activity director.
- If you have adult day programming available, use it. It can provide social contact and meaningful activities for the patient as well as respite for you..
- Allow the patient time to talk about their losses. Grieving is normal -- even desirable. If the grieving lasts for more than 3 weeks, affects sleep or appetite, see your doctor about treating the patient's depression.
- Discuss the disease process with the patient so he/she can understand why activities are being lost and they do not think, "they are going crazy." If the patient is losing driving privileges either you or a health professional should tell them the reason. If no one discusses the problem with the patient, they are likely to develop paranoid or suspicious ideas. While you may not choose to use the term "Alzheimer's disease" most patients can understand the idea of "brain disease," or "memory loss problem."
- The patient may become angry or deny their memory loss. If this happens, drop the subject for a time. The goal is not to get the person to admit the memory loss, but to help them to understand why these things are happening. Denial and anger are a normal part of the grieving process.
- Do not assume that ignorance of the disease process will lead to a happier patient. Also, do not think that telling the person about the memory loss will "kill them," or cause them to "give up." This is very rarely the case. Trying to hide the illness from the patient becomes increasingly difficult and strains your relationship with the patient.

- Have the patient help around the house. Many people can manage simple activities such as dusting, sweeping, table setting, sorting, and helping with simple cooking tasks late into the disease. Think of the activities as therapy. Do not evaluate the results. If the person's performance is incomplete or sloppy accept it is part of the disease process and recognize that the activity remains valuable for your loved one.
- Look at activities that may be too dangerous such as using power tools, hunting, feeding livestock, working with flammable tools, and try to replace them with safer activities. Many men who have not had hobbies are able to learn simple repetitive tasks with supervision such as painting, latch hook rug making, cooking, and simple woodworking.
- Pets, gardening, and musical activities often produce a high degree of satisfaction and offer good exercise.
- Exercise three times each week will help to maintain a positive mood and functional abilities. Exercise may include walking, gardening, dancing, or use of a stationary bicycle.
- Reading aloud to your loved one is often a satisfying and reassuring activity even late in the disease.
- Use videotapes to your advantage. Obtain videos of old television comedies, tape favorite sporting events, and have videos of family members. Avoid stories that include violence, murders, or cartoons.

Creating too much demand:

Many caregivers feel they need to exercise the patient's brain, testing every day and pushing them to achieve. In addition, it is unnerving for family members to hear the patient make mistakes and not correct them, but it is essential.

- Think about how you feel when someone tells you you've made a mistake. Being corrected feels pretty bad. The patient with memory loss is constantly confronted with their mistakes, which is pretty uncomfortable. What we try to do is make the patient feel comfortable with the knowledge they have -- as long as they are safe
- First, don't try to exercise the brain. The brain is not a muscle. People with memory loss are not lazy, they have a disability that is, in many ways, like an amputation. We have to assume they are working as hard as they can at any given moment with the abilities they have left at that time. People with memory loss have good days and bad days. Accept the patient's changing abilities each day -- or hour-- as the best the person can do right now.
- Avoid quizzing the person: "Do you remember me?" "What is her name?" "Remember what we did yesterday?" Life becomes like a constant test for people with memory loss and we don't want them to feel as if they have failed that test again and again.
- If the person becomes upset, try to distract them rather than confronting. If that does not work and the person is safe, walk away and let them forget
- Do not announce things in advance. People with memory loss have problems figuring out time. They become upset and fearful about schedules -- especially doctor visits. Announce activities at the last possible moment.
- Let the patient forget. If you lose your temper, the patient refuses to bathe, or there is a behavioral outburst, leave the patient alone and approach them again later. The outburst will probably have been forgotten
- If the patient has forgotten how to do an activity, help them with it. Don't try to "talk them through it," or have them "think about it." Thinking about it only worsens the problem. Use distraction instead. Distraction is simply changing the subject. Examples include: moving on to another task; giving the person a glass of juice or water; making a phone call to a friend; looking at family pictures in an album; or reading a letter aloud. Let the memory loss work for you. If a letter, joke, or other distracter is helpful once, don't be afraid to use it again and again.
- Sometimes your loved one's forgetting can actually be useful. If they become upset about something, reassure them and don't bring it up again.

- Whenever possible give the person a choice. “Do you want a bath or a shower?” “Would you like a person to stay with you in the home or to enroll in an adult day program?” Realize that we avoid the term “Do you want to.....?” The person with memory loss will tend to answer “No!”

Illness:

If the patient is not feeling well, has pain, is coming down with a cold, has a medication reaction, or an infection, you will probably see a sudden onset of problem behaviors and confusion that do not go away with rest. If this happens and the patient does not improve in an hour, complains of pain, shortness of breath, is bleeding, or vomiting you need to see the doctor as soon as possible. Think about the following common problems:

- Has the person been drinking at least one and a half quarts of liquid each day? Are they urinating frequently? Does their urine smell strong? Urinary tract infections are very common causes of agitation.
- Does the person have arthritis or another painful condition? Is the patient on his/her feet all day? Does the patient “hold” or protect a part of his body? Even though the patient may not complain of pain, we need to think about it. Ask the doctor for a medication you can use to relieve pain and use it regularly for **mild** pain. If the pain is allowed to become severe, the pain medication will be ineffective. If the person begins to moan, yell, or scream, suspect he might be in pain.
- Worry about constipation. Make sure the patient receives adequate fiber in their diet, but avoid laxatives and enemas
- Have the person’s prescriptions, over-the-counter medications, vitamins, and herbal preparations checked regularly by your doctor or pharmacist.
- Avoid alcohol intake as it can worsen memory permanently. Many people with memory loss over-react to alcohol. Try alcohol-free beers, wines, and mixed drinks as a substitute. If the patient becomes upset, try mixing more and more dilute drinks. Some caregivers add water to liquor bottles after their loved one goes to bed. Ask your physician to tell your patient not to drink alcohol.
- Talk with your physician about health and preventing illness. You may want to ask about flu shots or the vaccination for pneumonia.
- Diet and nutrition may become a problem. Have your patient take a simple multiple vitamin daily -- especially if they are not eating a balanced diet. Become concerned if the patient begins to lose more weight than 6 pounds in 6 months. Unless the person is on a weight reduction diet, weight loss greater than 6 pounds in 6 months is cause for alarm -- no matter how heavy they were before. See your doctor. Consult with a dietitian. If the person refuses to eat, try different foods that are high in calories, and contact a helping professional. Instant breakfast drink in whole milk can be used as an inexpensive, tasty, and fully effective nutritional supplement.

When a Problem Behavior Occurs:

You have used these recommendations, but despite your best efforts, one day your loved one begins to scream at you, doesn’t recognize your home, or wanders away. There are some tips for managing these stressful events:

1. Recognize the problem is temporary and will pass
2. Give the person something to do
3. Don’t argue with or confront the person. Treat the person as if he/she is frightened. Tell them you understand and intend to help.
4. Get the person to a quiet place where he/she can rest briefly.
5. If it is the middle of the night, try to give them a snack and get them to an easy chair
6. If the person does not recognize his/her home, try driving them around the block, or reassuring them that this is the place where you will spend the night (implying it is a hotel). Reassure them you will go home tomorrow.

7. Try calling one of the person's children to reassure the patient. Sometimes a call to a family member can be reassuring when all else fails.
8. If the episode does not resolve within an hour or so, contact your physician or take the person to the nearest urgent care center or emergency room. Do not try to get an agitated confused person into your car. Call the paramedics.
9. Do not blame yourself for this episode. These agitated and confused episodes are a normal aspect of the disease. They will occur to even the best of caregivers.
10. Do not become upset if you get angry. Anger is a natural response to stressful and unpleasant situations. Learning to manage these behaviors is a matter of trial and error. With practice and understanding you will become more skilled.

Worrying About Safety:

People with memory loss lose their sense of "danger" quite early in the disease. They become unsafe with power tools, lawnmowers, snowblowers, cars, medications, propane tanks, and vulnerable to unscrupulous individuals and scams very early in the disease. While you can not protect the patient from all possible harm, you can decrease the potential for harm by recognizing and preventing the possibilities.

- Try to remove the car when the patient begins to ask directions, follows too close, causes accidents by stopping too soon, or misses common traffic signals.
- Hire someone to mow the grass and shovel or blow the snow. Contact your nearest Area Office on Aging in the blue government pages of your phone book to locate chore services. Chore services can help with these services.
- Turn the water heater to about 110 degrees.
- Remove power tools
- Recognize that telephone solicitors target people with mild memory loss and plan to stop "junk" mail. This may mean renting a post-office box without the patient's knowledge.
- Supervise or administer all medications early in the disease -- particularly insulin, Coumadin (blood thinner), Cognex, and other potentially toxic medications.
- Avoid having the patient change the propane tank -- especially if he/she smokes.
- No guns, ammunition, or hunting knives in the house, please
- Pull the knobs off of the stove when it is not in use. Put away knives, the blender, mixer, toaster, food processor, and hot appliances when not in use. Store medications and liquor in either a locked cupboard or a place where the patient will not find them.
- Have the patient smoke in a single area, preferably the kitchen. Avoid having cigarettes near upholstery. **If you see upholstery smoking, do not try to extinguish it. If possible, move the piece outside. Call the fire department.** If the piece of furniture can not be moved, leave the house immediately.
- "Safety-Proof the house as if you had a visiting toddler, evaluating every possible thing that pose safety hazards.
- Recognize that the patient loses their sense of danger very early in the disease. Simply telling them to be careful will not be effective, as the patient is unable to use reasoning.

Special Problems:

The following section deal with approaches to problems that are commonly encountered when caring for people with memory loss. While there are no definitive answers to these problems, the approaches suggested may help.

1. Bathing

Many patients go through a phase where they either refuse to bathe or tell you they have already finished their bath. This can be frustrating, especially if the patient develops body odor. The first (and most important thing to remember is that no one ever died from not bathing. Many older adults are modest about disrobing, or become afraid of bathwater or the shower. Some of the following suggestions have been helpful:

- Let the patient choose the time of day to bathe
- Remind him/her of a special occasion they must be clean for (e.g., “we can’t go out for lunch until you bathe”)
- Associate a pleasant experience with the bath (such as a chocolate treat or music)
- Make sure you check the temperature of the bathwater or shower to prevent freezing or scalding.
- Color the bathwater or use bubble bath
- Try a hand-held shower head so water does not hit the person’s head
- Allow the person to bathe with underwear on
- Sing during bath-time to relieve the tension or have some soft music in the background.
- Compliment the patient after the bath
- Don’t take refusals to bathe personally

2. Wearing the same clothing day after day

This is an indication that the patient can not handle change and is normal for people with memory loss. Purchase several identical outfits when shopping. Then, when the person takes one set of dirty clothing off, remove it and replace with an identical set of clean clothing. Make sure you have a picture of your loved one in this clothing in case they wander. You will be able to tell the police exactly what the person is wearing.

3. Hiding things

Hiding and losing things are the most frustrating aspect of the disease for many caregivers. Understand that hiding things often represents a concern about theft. Things will be hidden. It is important to minimize the loss of money and valuables.

- Remove valuables from the house whenever possible. Remember, these possessions still belong to the patient and can not legally be dispersed using the patient’s will. Take larger valuables such as the family crystal, silverware, and china, and pack them away. Label the carton “books,” or something that does not attract attention and place them in a safe area, such as a little-used closet or basement.
- Place jewelry not used daily in a safety deposit box.
- Take jewelry worn daily and have it appraised. Have the jeweler remove the most valuable stones and place them in a safety deposit box. Replace the valuable stones with cubic zirconium and return to the patient.
- Never ever send jewelry you would mind losing with the patient to a nursing home or assisted living facility.
- Put “clappers” on house and car keys so they beep when lost
- Get to know where some of the more common hiding places are. Families report hiding money, keys, jewelry, medications, and many other things in the following locations:
 - under the mattress
 - in the pages of books
 - in the hems of curtains
 - under the paper in back of pictures or mirrors
 - under pillows
 - in food containers
 - in the freezer
 - behind bricks in the basement
 - in breakfront cabinets
 - wadded in tissues in toilet paper cardboard cylinders

- in the trash

It is important to remember that things will be lost. Make sure that there are duplicates of keys and other items. Also, losing the car keys is an excellent way to have your loved one stop driving. This is one example where you may decide to let the keys “stay lost,” and not volunteer another set.

4. Fear of abandonment/refusing help

Many patients refuse to go to adult day programs or to allow in-home respite services. Patients become dependent on their caregivers to remember when they can't and become nervous and upset when their caregiver is not around. This can become so severe that the caregiver is unable to have even a moment alone, including to go to the bathroom.

The best defense against this is a good offense. Have your loved one go to day programming. Have extra help in the home as early as possible, usually a cleaning person, so the patient is used to having others around. Make sure that family members participate in care on a regular basis and, if possible, friends take the patient out whenever possible.

If the patient becomes enraged when a service provider or family member is used for respite, understand that this is not uncommon. Insist that you need your time and space. Gently reinforce that staying alone or going with you is not an option. Insist that you will try to find respite workers that the patient likes.

The first time or two the patient attends day care or has a new respite worker, stay with him/her during the event. As your loved one becomes accustomed to the day program or respite worker, anger will subside. Successful adaptation to respite will keep your loved one at home longer and will help to keep you from feeling trapped.

5. Aphasia

Loss of language abilities are a usual part of memory loss. Loss of reading comprehension generally occurs first. One of the ways to determine this is if mail starts to pile up or the person begins to pay anything that even resembles a bill. Another clue is when the person either stops reading the paper or can't tell you what they have read.

When the person starts to stumble over words, it is important to understand that they also have trouble understanding what is being said. Talk more slowly using simple phrases. Give the person extra time to respond. Use gestures and point to objects whenever possible.

If the person begins to use word that don't make sense, often called “jargon” or “word salad,” try to find bits and pieces that relate to the patient's world. The patient may have good understanding of the world around them, but may simply not be able to express himself or herself.

It is acceptable to explore potential meanings with the patient unless frustration begins to rise. If he/she becomes frustrated, distract them to another task and try later. A single consultation with a speech pathologist may be helpful to develop communication strategies.

If the person develops slurred speech or problems swallowing, speak to your physician immediately. The patient may run the risk of aspirating (breathing it into their lungs) food or saliva.

6. Made-up stories

One of the more frustrating effects of memory loss is called “confabulation.” People with brain diseases, especially those that cause memory loss, tend to have their brains “fill in the blanks” when they can't remember what happens. So, the patients come up with stories that they believe are true.

Confabulation is not a lie. It is a story the brain makes up. Trying to correct the patient leads to anger and frustration for you both. A good rule is that anything the patient says is fine – as long as safety is not compromised.

7. Repeated Questions

Patients ask repeated questions for several reasons: they can't remember asking the question; they have no sense of time; and the question they are asking is not really what they want to know. When your loved one asks a question over and over, most often it has to do with when or where something will happen. These questions can become obsessive. There are two rules for these questions:

- A. Never announce anything more than 24 hours in advance because it precipitates obsessive questions.
- B. When a question is asked more than once or twice, ask "why are you asking?" Then address the underlying concern. Example:

The patient asks "What day is it?"

You ask "Why do you want to know?"

The patient says "I don't want to miss church."

You answer "I will make sure you get to church on Sunday."

Another strategy is to write the answer on a file card and have the patient carry it in his/her pocket. When the question is asked you direct the patient to read the card.

Coping with Violence: If Your Loved One Changes

A caregiver under siege reported:

"It is like a switch got thrown yesterday and all h- -l broke loose. He even seemed to have the urge to hit me when I was helping him get dressed today."

Aggression can be a normal part of dementing illnesses. It can occur for many reasons, including extra demand, psychosis, a non-Alzheimer presentation, and/or premorbid personality traits. While real physical aggression is relatively rare, verbal aggression or belligerence is relatively common. People with dementia become depressed from time to time, get frustrated, or may not see their deficits as clearly as their caregiver. And the person with the disease is also going through the grieving process, which also involves anger.

Verbal Aggression

People with dementia who are angry don't always become violent or aggressive, however, care should be taken to diffuse verbal aggression before the situation escalates. Some of the more common techniques for diffusing verbal aggression include the following. Remember, the goal is to get on the same side of the table as the patient and regain emotional support. You have to suspend your previous notions about right and wrong, and just go with making peace:

1. Agreeing – It is impossible to argue with someone who agrees with you. You can agree by seeing someone's point. For example:

Patient: "I want to drive and you won't let me. The doctor says I can't drive. What does he know? Give me the car keys NOW!"

Caregiver: "We can't have you drive with your memory loss, but that is so awful. I can see why you are angry. It is unfair this should happen to you"

You don't have to give in, but you can acknowledge their feelings and put yourself in the same position. You can see the patient's point of view. It isn't fair.

2. Apologizing – Now I know you haven't done anything wrong and you shouldn't have to apologize, but again, we are diffusing an argument here. You can not argue when a person is being contrite:

Patient: "You have having an affair. You snuck out while I was napping and slept with the neighbor!"

Caregiver: "Oh (name), I am so sorry you think that! How hard this must be for you. Know that I would never do anything to hurt you. I love you . I am so sorry you feel this way. How can I make it better?"

Of course you didn't have an affair, but one of the person with dementia's biggest fears is abandonment. They know what is happening – even if they can't say it and fear having to leave their home and family. Thus the charges of infidelity are common. When you are apologizing, notice you are not admitting guilt. You are saying you apologize for the way the person feels.

3. Playing dumb – "I don't know anything about this. Tell me more? How could this have happened? I don't understand?" These buy a lot of calmness
4. Avoid trying to reason and explain. The person's "reasoner" is broken.
5. Back off and let time heal the wound.

Physical Aggression

While certainly not a normal part of a dementing illness, violence occasionally becomes a problem. When it occurs caregivers often report mixed feelings of disbelief, embarrassment, guilt, shame, and more than just a bit of denial.

When you have a loved one who is aggressive towards you, this is a crisis. Suspend everything until the episode passes. This is not the time to get someone dressed for bed or in the morning. This is not the time to insist on a shower. When a crisis presents, you want to back off and stay back until help arrives -- whether it be medication, a hospitalization, an ER visit or whatever.

It is sort of the idea that when the house is on fire, you don't want to finish breakfast and get dressed before you call the fire department. In a behavioral crisis there are several essential steps:

1. Step back. Suspend cares until the crisis is over. Do only what absolutely HAS to be done, such as food and getting in any mood controlling medications. If you try to intervene with normal activities you are increasing the risk to you and your loved one.
2. Use care in body language. Make sure you always approach from the front. Do not turn your back. And make sure you give the person plenty of space. Turn OFF TV, radio, and stop any extraneous stimuli. Just for now take down family pictures and cover mirrors. This is a crisis and needs special care. Talk in a measured low soft voice. If you have to give directions, make sure they are simple declarative sentences. ("Give me the knife" or "Put the knife down.")
3. Do not think because the person calms after a while that it won't happen again. Two basic principles of violence:
 - A. Violence episodes are time-limited because of the energy expended.
 - B. As soon as the person regroups their injury and there is a trigger (in the case above it was hallucinations), the violence WILL reoccur.

C. Untreated violence goes from bad to worse. It does not get better on its own. In every episode of an injured or murdered caregiver, there were warnings...but the caregiver chose not to heed them, often out of disbelief that their loved one would never do anything to hurt them. This is not your loved one acting here. This is disease and it needs quick and effective treatment.

4. This is not a time to let family "vote" on a solution. Much of the serious injury I've seen happened after the family told the caregiver that "it wasn't that serious, " "dad/mom will get over it," "Dad would NEVER try to hurt you Mom," or "Gee Mom, you are just overreacting."

5. Get help immediately. Do not stay alone in the house with a violent person. The patient is in a panic mode and can not be counted on to inhibit any impulses. Recognize the danger and call the doctor.

- A. If you can't get the doctor within an hour, call 911 and head for the nearest ER where the person will be sedated. Once at the ER, DO NOT MINIMIZE THE EPISODE!!!! "Gee, I think it only happened once, and I probably caused it because I tried to give him applesauce for breakfast."
- B. Make sure you have a prescription for a mood controlling medication and a psychiatry appointment for follow-up in the next day or two before you agree to take the person home.
- C. Many times the police coming is reassuring to the patient as he/she is terribly frightened. The uniform can work wonders. Do not be embarrassed to call BUT if the police think the episode is over because the person calms for a few minutes, forget that thinking. As soon as they leave there is a good chance, an excellent chance, the fear will start again. Insist on an ER visit.

6. If you live alone with the person, make sure you have a Lifeline (panic button) so you can call for help. Patients who are violent rarely hand you the phone or act out in close proximity to the phone. Moreover, most could not dial for help in an emergency

7. Act defensively. Plan an escape route. Lock yourself away from a violent patient and take the cordless phone. Never be without your cordless phone.

- A. The caregiver in the closet phenomenon may seem absurd, but I'd rather have my caregiver in a closet with a cordless phone than out trying to fend off a person who is out of control.
- B. If the person is violent it is far more likely to start at night. Move to another bedroom and make sure you can lock it in case the person comes after you. Two of my caregivers woke to find their loved one standing over them and beating them.
- C. Make sure that you are at least standing up if the loved one wakes you. Get out of the bedroom you share. This alone could save you serious injury. A patient in this situation is not thinking about the warm snuggle of a spouse or even abandonment by a spouse. They are fearing for their lives and you are part of the problem.

8. Remember, anything can be used as a weapon. There should be no guns in the house at all, not even in a locked cabinet. Fireplace pokers and knives should be stored out of sight. Your loved one is panicked at this point and may use a book, alarm clock, letter opener, or even a small table to injure you. Minimize potential weapons in the house and make sure you watch for anything that might be used. Never turn your back on someone who is violent.

9. DO NOT REFUSE MOOD CONTROLLING MEDICATION! There is this myth that if we are only good enough, only kind enough, the patient will respond. While there are few patients who become violent, you need to treat it medically. Worry about tapering the medications after a few weeks of good behavioral control.

10. DO NOT BLAME YOURSELF. This just happens some time. No one is going to think it is you that caused this. Do not try to avoid treatment because it might be socially stigmatizing. It is better to seek help in a timely manner than to have your loved one become remembered as ___, who injured his/her family!

11. Realize that if it happened once, it WILL happen again.

12. Never never let an angry or violent person drive as the car can/will become a weapon. If the person takes the car to go out looking for a real or imaginary enemy. Call the police to stop them if you have to.

13. Do not rule out a psychiatric admission. Go for the best center you can find and let them treat the person, which may mean a brief period of zombification. make sure you play an active role in treatment, not by refusing medications but by asking "What now?" If your loved one is zombified, you can't take them home like that, but also recognize that there are some people who cannot be let up from medications. Know that if you have someone with Lewy Body Disease, you cannot stop and start the medications or even try to taper a dose that is effective. With Lewy Body disease, once you taper and the symptoms start again, there is an excellent chance the higher dose will no longer work.

Last print this out. If you have any inkling of aggression, give a copy of this to your family and doctor. That way they know you are not being crazy or overreacting.

Taking Care of Yourself

Caregivers experience a terrible time planning for their own needs. As the symptoms of their loved ones' illness become more pronounced and more demands made on their time, caregivers often neglect social relationships, physical and emotional health. This experience can produce depression, anger, guilt, isolation, and physical illness. Moreover friends and families may expect this degree of self-sacrifice as a part of the marriage vows or their perception of familial obligations.

You must be your own advocate in meeting your needs. This is not selfish. Taking care of yourself is the most important thing you can do to take care of your loved one. Some suggestions:

- A. Eat right – make sure you get a balanced diet
- B. Get adequate rest
- C. Drink plenty of fluids
- D. Exercise at least 3 times a week
- E. Make sure you get annual health screenings
- F. Get flu and pneumonia vaccinations
- G. Get out with friends and by yourself regularly
- H. Make sure you have some time alone each day
- I. Attend support groups and keep in touch with professionals

Expect family conflict during this time. Most families argue to create enough energy to cope. Each member will go through stages of grief – at their own pace. Try to keep the arguments fair and seek help from a family therapist if needed.

Support groups

Many people find support groups very helpful, while others feel embarrassed. Look in the telephone book under "Alzheimer's Association" to find the groups nearest to you. It may take a few tries before you find a group you like, but it is well worth the effort. Sometimes talking with other people who are experiencing similar problems and understand your concerns is invaluable. No one fully understands what it is like to live with someone with memory loss until they have done it.

Many support groups offer services for the patient: respite while the caregiver attends the meeting; support groups for patients; and/or allow patients to attend with their caregiver.

Watch your local newspaper for announcements of special speakers and events. A support group can be an invaluable new resource for making friends and social contacts. Events such as Memory Walks can involve you and your loved one in positive social events that will reduce your sense of isolation and help you to continue to feel engaged in your community..

On-Line Support

For those who have access to a computer, there are numerous home pages and information sites for neurological diseases. One valuable resource for people with memory loss is the Alzheimer Net. Run by the Alzheimer's Disease Research Center at Washington University in St. Louis, this free site is accessed by sending e-mail to the following address:

Address: mj2@lists.biostat.wustl.edu

Title: (none)

Message: subscribe ALZHEIMER

You will receive a confirmation notice with a phrase that must be copied and returned. Once that is done you belong to a support group staffed by laypersons and professionals. You can simply read the messages or participate by sending or replying to messages.

While you may not have a computer, or may be uncomfortable participating, others in your family might benefit from this free service. Many adult children copy postings from the support group for caregiving parents who are intimidated by computers.

Legal/Financial Affairs:

Legal and financial issues are critical during this disease. At a certain point the patient can no longer be counted on to make informed decisions. Someone will need to be empowered to do this when the time comes. Many couples assume they will be able to step in for their loved one, write checks, sell property, obtain medical records, etc.. This is not the case in most states.

Early planning is needed to prepare for when this type of care is needed. An attorney who specializes in elder law, family law, or probate law should be consulted. Standby durable powers of attorney for health care and finances should be developed for when the person is not able to make informed decisions. Such documents require careful thought and planning. There may be additional decision-makers that need to be appointed for the patient in complex family of financial situations. These vary widely from state to state. Seek legal counsel at your earliest convenience to assure that your wishes are recorded and your estate preserved.

Recognize that caring for a loved one with memory loss is often frustrating. Not everything works all the time. Copy the learning guide and try a few things each week. Some will work. Some won't. Those that don't work, may work tomorrow...and those that work today might be ineffective tomorrow. Use the professionals available to you at the Mayo Clinic, Scottsdale and at the Alzheimer's Association nearest you for help and support. Remember we are here for you and want to help however we can to lighten your burden. There are many books to help you during this illness. Most are available from the Alzheimer's Association or can be ordered from your favorite bookstore.

ADDITIONAL RESOURCES

On-line Support:

The Alzheimer's Disease Research Center from Washington University in St. Louis facilitates an on-line support group. An invaluable source of almost instant on-going information from other families and health care professionals, participation in the AD NET is free. It can be accessed by sending the following e-mail:

Address: mj2@lists.biostat.wustl.edu

Title: None

Message: subscribe ALZHEIMER

Once the message is sent a verification message will be sent to you. Copy the verification sentence only and return it in a reply. This subscribes you to the list.

Surfing the World Wide Web:

There are numerous sites for information on Alzheimer's disease and related disorders. Some helpful ones include the following sites:

The Alzheimer's Association: <http://www.alz.org>

To help you locate chapters of the Alzheimer's Association and resources nearest you. Also provides research update, has a library of reference materials, and caregiver information.

Alzheimer's.com

This is a comprehensive website that has tips on managing specific problems and information for caregivers.

Candid sites

This English site has information on non-Alzheimer's dementias and chat groups.

Please copy this booklet so you can use it as a constant reference, and share it with your family and fellow caregivers.