

Dear Professional,

Alzheimer's and Dementia... more prominent now than ever. Patients and their families must deal with not only the medical aspects of a diagnosis, but also the emotional and practical issues they now face.

*We can help.*

TheRibbon.com is a website dedicated to providing information and support for caregivers who have loved ones with Alzheimer's and Dementia. Simply put, we offer "care for caregivers".

Our site is centered around The Ribbon Newsletter\*. Written by fellow caregivers and professionals, the newsletter provides a wealth of information. Practical care tips, the latest medical news and articles covering hundreds of topics can all be found. We feature an extensive archive, with easy access to over 5 years of articles in our back issues.

We are enclosing a sample of our newsletter as well as a few of our most requested articles. There is also a reproducible flyer, which we hope you will copy and share with your patients.

Another main feature of TheRibbon.com is The Gathering Place, an online support group for caregivers. This is a chatroom where people dealing with Alzheimer's can "Gather" at any time just to relax and talk to folks who care and understand. There are hosted chats five nights a week, but stop in anytime to share thoughts and find support.

We invite you to visit TheRibbon.com and we hope you find it to be a valuable resource for families facing this terrible disease.

Please know that all of our services are offered free of charge; there will never be a fee for any service we provide.

Please contact the following people for further information or answers to any questions you may have.

Jamie Aguilar  
Co-Editor, The Ribbon  
1104A Murfreesboro Pike  
PMB 114  
Nashville, TN 37217-1918  
615-360-8709  
[Jamie@theribbon.com](mailto:Jamie@theribbon.com)

Linda Tucker  
Administrator,  
The Gathering Place  
[Linda@theribbon.com](mailto:Linda@theribbon.com)  
  
Karen Menges  
Co-Editor, The Ribbon  
[Karen@theribbon.com](mailto:Karen@theribbon.com)

Kevin Fisher  
Site Manager, TheRibbon.com  
1210 Kenwood Road  
Glen Burnie, MD 21060  
410-768-9519  
[Kevin@theribbon.com](mailto:Kevin@theribbon.com)

*\* Delivery of The Ribbon newsletter via postal mail is available to those without access to a computer. Contact Jamie Aguilar for more details.*



Volume 6, Issue 21  
October 20, 2002

[www.TheRibbon.com](http://www.TheRibbon.com)  
1104A Murfreesboro Pike  
PMB 114  
Nashville, TN 37217-1918

Things are finally getting a bit "normal" here at home now. Yesterday I finally bit the bullet and started cleaning Nanny's room. This was to be my "Coca-Cola" guest room and then we needed to move Nanny here to our house. I am very hesitant to start with the decorating again because I may be moving Mama over here sooner rather than later.

It seems that both my husband and Mama are dealing with depression. With my husband, it is making his dementia worsen. Mama is sleeping a lot. This week will have me making more doctor visits with them. I am in the process of writing notes to give to the receptionists so that the doctors will read them and I won't have to "tell things about them" in their presence. I found that this approach is so very helpful.

Halloween is fast approaching. I'm actually getting a bit excited about it for the first time in several years. I won't decorate again this year but I have high hopes for next year!! I do love Halloween and Christmas!

Jamie

---

## *A Kitchen Window to the World*

by Mary Emma Allen

My mom enjoyed gazing out a window while washing dishes and recalled the window of her childhood above the pantry sink. For years she bemoaned the fact that, in our farmhouse kitchen, she only had a wall to stare at.

So one day my dad hauled saw and other tools into the kitchen, bought a window with four panes, and installed it above our kitchen sink. It did brighten the large kitchen and helped make washing the dishes for six family members and hired man an easier task...for Mother, and for Sister and me.

### *Window to the World*

That became Mother's "window to the world". It looked out to the brook that ran between the house and barn. Beyond the barn were a corn field, pasture, and woodland. The scenery was ever changing, depending on the time of day and year.

Glimpsing deer at late afternoon grazing in that pasture adjacent to the woodland was a time of excitement for us children. This almost became a daily ritual looking for the white tailed deer moving slowly across the pasture as they grazed.

### *Windows in Later Years*

Even after she developed Alzheimer's, Mother looked out the window of the house where she then lived and went back in time to the scene from her farmhouse kitchen, even though she was no longer there.

It took me awhile to figure out what she was talking about when Mother told me she saw the cows coming to the barn or the

deer near the woods when neither were outside this kitchen window. Then I realized she was talking about the window of my childhood and we both reminisced over a cup of tea, providing us a happy occasion.

## *My Kitchen Window*

Wherever my husband live, even though we have a dishwasher and I don't spend so much time at the kitchen sink, I still want a window. I like to gaze at the woods around my home, see my grandchildren playing in the yard, watch the birds flitting around, or look at trees budding in spring and changing color in autumn.

A window above the sink becomes the heritage of women who spend time in their kitchen. Mine encompasses memories of my childhood and of my mother who wanted her window to the world.

---

Mary Emma Allen, (c)2002  
[me.allen@juno.com](mailto:me.allen@juno.com)

*Mary Emma Allen is a columnist, children's writer, book author, travel writer, and writing teacher. She often writes family nostalgia and inspirational pieces. After recovering from a broken back and spending time in a body cast, she has tried to use her writing talent to encourage others.*

Visit her web site: <http://homepage.fcgnetworks.net/jetent/mea;>

E-mail: [me.allen@juno.com](mailto:me.allen@juno.com)

---

## *Telling Tales*

by Mary C. Fridley RN, C

One of the most dreaded tasks for caregivers is the trip to the doctor. The scenario goes something like this: Appointment made; Mom forgets appointment; Mom refuses to go; it's all down hill from there. For weeks she has had various complaints, but on the day of the appointment, she denies any discomfort and wonders where you got that idea. After much cajoling you finally get her into the car and you're off. The office wait is long and Mom becomes restless frequently asking why she's there. Finally you get to see the doctor and feel like your mission's been accomplished. WRONG! The doctor greets Mom with "How are you?" and she replies, "Just fine". Every time you try to interject with a comment, Mom glares at you and denies what you're saying. You hesitate to say more for fear of being a tattletale and causing a scene. After a quick physical exam and renewal of prescriptions you're out the door in 12 minutes. Stressed and tired, you realize you left without having your questions answered and feel like it was all a waste of time. So how can you prevent this from happening again? Plan ahead. Here are some tips that are helpful:

- Keep your loved one's routine in mind. If he/she is a late riser, don't make the appointment for early morning.
- Avoid a long office wait by scheduling the visit for the first or last appointment of the day. If this isn't possible because of your loved one's daily routine, explain the circumstances and ask the receptionist to suggest an appropriate time. Some offices close for lunch and may be able to schedule you for the first appointment in the afternoon.
- Keep your loved one involved in the visit. Help him/her write down concerns or problems that the doctor should address. An ongoing list is a good idea. Every time a discomfort is voiced or observed, add it to the list. Keep the list visible as a reminder for the upcoming appointment.
- If there are problems you don't want to discuss in front of your loved one, write a separate list and hand it to the receptionist explaining that the doctor needs to read it in advance. Or, request a private consultation either in person or by phone before the visit.
- Bring paper and pen to take notes. Don't rely on your memory to recall all that was said.

- Sometimes a loved one doesn't want you in the exam room. Offer to go as the secretary to take notes. Keep a low profile until he/she becomes more comfortable with you in the room. It could take a few visits before this happens.

Healthcare visits are very important but tend to be rushed. With good planning and organization they'll go smoothly and be less stressful for both you and your loved one.

---

*Mary C. Fridley RN, C is a Registered Nurse board certified in gerontology with more than twenty years experience in the geriatric health field. She provides community workshops and motivational seminars on caregiver, eldercare, and aging issues as well as writes articles and caregiver advice columns for websites and publications. Mary will be glad to answer any questions you have and can be reached at P.O. Box 573 Riva, MD 21140, or by email: [geroresources@hotmail.com](mailto:geroresources@hotmail.com).*

---

## *Communicating with the person with dementia*

Alzheimer Scotland - Action on Dementia

Communication is a very complex process and it is not surprising that many communication skills are lost when someone has dementia. Expression and understanding are both affected. Some skills of expression are well preserved whilst other aspects are considerably impaired. Although individual people who have dementia will differ in how their language and communication skills are affected, there are often similarities in their losses.

### *How communication is affected*

- The ability to think of the right word may be noticeably worse in the early stages. Later, only everyday words may be used and other words lost completely.
- Pronouncing letters and words is not affected until the very late stages.
- Putting sentences together is not much affected in the early and middle stages, but may get worse later.

Knowing when to reply is not affected at first, but the person will tend to say things which relate to him or herself rather than respond to what has been said. This makes the person appear uninterested in what others are saying. He or she may fail to pick up humour or sarcasm or subtle messages. What the person has to say is most affected. In the early stage topics are fewer and the person does not try to explain original thoughts or insights. He or she may speak less and conversation is dull. Later he or she cannot keep to the topic and becomes vague and rambling. He or she may speak more but begins to make less sense. Messages are repeated. Less and less is communicated.

In the late stages the person may say almost nothing, or keep repeating only one or two phrases or sounds which make no sense.

Generally it is the automatic language skills, for example responses such as 'hello', which are said without thinking which are retained for the longest time. Aspects of communication which require careful thought are soon lost.

### *How you can help*

When we speak to someone with dementia we must try to send messages which he or she will understand. This can be difficult because problems with understanding are harder to spot than problems with expression. The response of the person to what you say can indicate if he or she have understood. The person's ability to communicate should give you a good idea of the level at which to pitch a conversation. It can help if you are guided by a few rules.

1. Make sure that the person is paying attention to you. Eye contact is important. Gently touching and calling the person's

name can draw his or her attention.

2. Keep sentences short and simple. Make one point at a time. Stick to simple, familiar ideas rather than complicated new concepts. Make statements and not logical arguments.
3. Say exactly what you mean. Avoid suggested or implied messages. Don't say (with a sigh) "Monday, and its raining again!". Say, "It's raining, I can't put the washing out to dry."
4. Use real names, not pronouns (he, she). This reminds the person of who you are talking about.
5. Do not ask questions which need a complicated answer. Questions which can be answered with a word or two are best.
6. Information is not easily taken in. It helps to repeat the important parts of a message.
7. Gestures, body language (how we use our hands, eyes and posture), touch and tone of voice are often understood right through to the late stages of the illness. Sit in a position where the person can easily see you.
8. Conversation is enjoyable, but the topic needs to be one which both parties can grasp. For people with dementia this tends to be the old and familiar things in life.

It is possible, of course, that a problem with communication is caused by a hearing problem. If you suspect this, arrange for the person to see their GP. A speech therapist can give professional help with communication. Ask your GP or hospital consultant about this.

Sometimes people think that if the person with dementia does not understand then it is all right to talk about him or her in his or her presence, or believe that even if the person does grasp something of what is being said, he or she will forget about it in five minutes. Both ideas are wrong. Body language and gesture is likely to be understood and so the person with dementia will be aware of being talked about even if he or she cannot grasp the meaning. This can be upsetting. It is also possible that he or she will continue to feel angry or upset long after forgetting the original reason.

In company, conversation becomes much more difficult to follow. People talk quickly or talk at the same time, and the person with dementia is soon lost and feeling isolated. Generally, it is best to avoid large groups but encourage visits from old friends and members of the family.

Contact the 24 hour [Dementia Helpline](#) if there is a communication problem you want to talk about. Our trained volunteers may be able to help, or if the problem is complex, can get advice from our speech therapy advisor.

*Thanks to Sandra Walker, Speech Therapist, for commenting on this information sheet.*

[Alzheimer Scotland - Action on Dementia](#)  
[www.alzscot.org](http://www.alzscot.org)

---

## *Links*

[Helpguide: Your Web Gateway to the Issues and Options for Mental Health and Aging Well](#)

Helpguide provides user-friendly mental health resources and information, including sources of help for mental and emotional problems, substance abuse, Alzheimer's / Dementia, caring for the elderly and healthy aging. Helpguide assists you in finding the best non-profit non-commercial links on the web focusing on mental health and aging well. Our editors continually search the web for the best sites on each of our topics and present these sites along with overviews and options.

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

---

[Helpguide-Resources: Your Web Gateway to Southern California Resources for Mental Health and Aging Well](#)

Helpguide-Resources provides user-friendly information about Southern California resources for mental and emotional problems, substance abuse, Alzheimer's and Dementia, caring for the elderly, and healthy aging  
[www.helpguide-resources.org](http://www.helpguide-resources.org)

---

I was just channel surfing this morning, and I found a story CNN was running on Leeza Gibbons and her mom, who has Alzheimer's. Here's the news story that goes along with the TV appearance:

[CNN.com - Leeza Gibbons takes on new, difficult role - Oct. 17, 2002](http://www.cnn.com/2002/HEALTH/10/17/hln.bio.leeza.gibbons/index.html)

<http://www.cnn.com/2002/HEALTH/10/17/hln.bio.leeza.gibbons/index.html>

The 'health correspondent' said a couple interesting things:

- There appears to be no link between aluminum cans/cookware and Alzheimer's, no matter what you hear on the Internet. She talked with the people doing the 'research' you'll find out there, and there's nothing to support the claims.
- There are only 120 diagnosed cases of EOAD worldwide. **This seemed odd to me, given how many people we talk to through The Ribbon who have the disease.**

According to the site, they're going to run the spot at the following times:

*WATCH BIOFEEDBACK ON HEADLINE NEWS*

*Friday - 5 p.m. and 9 p.m.*

*Saturday - 7 a.m., 9 a.m. and 11 a.m.*

*Sunday - 6 p.m., 7 p.m., 8 p.m., 9 p.m., 10 p.m. and 11 p.m.*

*\*all times Eastern*

From [kevin@theribbon.com](mailto:kevin@theribbon.com)

---

If you go to the Cigna web site and click on the pink ribbon, Cigna will donate \$1.00 to fight breast cancer.

Only good the month of October, pass it on to everyone!

Click on the pink ribbon at: <http://www.cignafoundation.org>

---

## *Email Bag*

From [AZUREE1650@aol.com](mailto:AZUREE1650@aol.com)

**Thank you for a very informative newsletter! The topic on incontinence was excellent. Although I have been at that stage for approximately six months now, it was most helpful in understanding the issues caretakers and, those our loved ones face.**

**Congratulations Karen, in your upcoming wedding!**

**Charlene  
Clearwater, FL.**

---

From [BigtreeMur@aol.com](mailto:BigtreeMur@aol.com)

I see you used one of my articles. I appreciate the reference to my page and as always, your web site does a real service. I have been going through one of those years with family members spread all over the country and being the only one with the time to do duties. In any event. Hope all is well in your life and thanks again for the mention.

Best wishes, Beverly Bigtree Murphy

---

From [CGlaughter@aol.com](mailto:CGlaughter@aol.com)

Thanks so much for including me in "Before I Forget." I loved it. I have so much I want to say to other's about early onset Alzheimer's Disease. We need to be heard and we can be of help by sharing with others. Thanks for making this possible. I look forward to receiving The Ribbon. God bless you as you serve caregivers and those affected with the disease. So many of us are in pain and you bring us some sunshine.

Chip Gerber

---

From [me.allen@juno.com](mailto:me.allen@juno.com)

I'm one of those former caregivers (of a mom and aunt with Alzheimer's) who is more involved than ever with Alzheimer's since Mother and Auntie are gone. I'm doing more writing and more speaking about this disease.

I hope that what I learned in caring for them will help others as they care for a family member.

Mary Emma Allen  
Author/Illustrator/Speaker  
Author -When We Become the Parent to Our Parents  
Contributor - Finding the Joy in Alzheimer's  
<http://homepage.fcgnetworks.net/jetent/mea>  
[me.allen@juno.com](mailto:me.allen@juno.com)

---

Hugs and Peace,  
Karen and Jamie





## *Stages of Alzheimer's Disease: 7 Stage Model*

Global Deterioration Scale for Assessment of Primary Degenerative Dementia

### *1) No Cognitive Decline*

- No subjective complaints of memory loss.
- No memory deficit evident on clinical interview.

### *2) Very Mild Cognitive Decline (Forgetfulness)*

- Subjective complaints of memory deficit, most frequently in the following areas:
  - Forgetting where one has placed familiar objects
  - Forgetting names one formerly knew well.
- No objective evidence of memory deficit on clinical interview.
- No objective deficits in employment of social situations.
- Appropriate concern with respect to symptomatology.

### *3) Mild Cognitive Decline (Early Confusional)*

- Earliest clear-cut deficits. Manifestations in more than one of the following areas:
  - Patient may have gotten lost when traveling to an unfamiliar location
  - Co-workers become aware of patient's relatively poor performance
  - Word and name finding deficit becomes evident to intimates
  - Patient may read a passage or book and retain relatively little material
  - Patient may demonstrate decreased facility in remembering names upon introduction to new people
  - Patient may have lost or misplaced an object of value
  - Concentration deficit may be evident on clinical testing
- Objective evidence of memory deficit obtained only with an intensive interview.
- Decreased performance in demanding employment and social settings.
- Denial begins to become manifest in patient.
- Mild to moderate anxiety accompanies symptoms.

### *4) Moderate Cognitive Decline (Late Confusional)*

- Clear-cut deficit on careful clinical interview. Deficit manifest in the following areas:
  - Decreased knowledge of current and recent events
  - May exhibit some deficit in memory of one's personal history
  - Concentration deficit elicited on serial subtractions
  - Decreased ability to travel, handle finances, etc.
- Frequently no deficit in following areas:
  - Orientation to time and person
  - Recognition of familiar persons and faces



- Ability to travel to familiar locations Inability to perform complex tasks.
- Denial is dominant defense mechanism.
- Flattening of affect and withdrawal from challenging situations occur.

## 5) *Moderately Severe Cognitive Decline (Early Dementia)*

- Patient can no longer survive without some assistance.
- Patient is unsure during interview to recall a major relevant of their current lives, e.g., an address or telephone number of many years, the names of close family members such as grandchildren, the names of the high school or college from which they graduated.
- Frequently some disorientation to time (day of the week, season, etc.) or place.
- An educated person may have difficulty counting back from 40 by 4's or from 20 by 2's.
- Persons at this stage retain knowledge of many facts regarding themselves and others. They invariably know their own names and generally know their spouse's and children's names.
- They require no assistance with toileting and eating, but may have some difficulty choosing the proper clothing to wear.

## 6) *Severe Cognitive Decline (Middle Dementia)*

- May occasionally forget the name of the spouse upon whom they are entirely dependent for survival.
- Will be largely unaware of all recent events and experiences in their lives. Retain some knowledge of their past lives but this is sketchy.
- Generally unaware of their surroundings, the year, the season, etc.
- May have difficulty counting from 10 both backwards and, sometimes forward.
- Will require some assistance with activities of daily living, e.g., may become incontinent, will require travel assistance but occasionally will display ability to familiar locations.
- Diurnal rhythm frequently disturbed.
- Almost always recall their own name.
- Frequently continue to be able to distinguish familiar from unfamiliar persons in their environment.
- Personality and emotional changes occur. These are widely variable and include:
  - Figures in the environment, or talk to their own reflection in the mirror
  - Obsessive symptoms, e.g., person may continually repeat simple cleaning activities
  - Anxiety symptoms, agitation, and even previously nonexistent violent behavior may occur
  - Cognitive abulia i.e., loss of will power because an individual cannot carry through long enough to determine a purposeful course of activity.

## 7) *Very Severe Cognitive Decline (Late Dementia)*

- All verbal abilities are lost. Frequently there is no speech at all - only grunting.
- Incontinent of urine, requires assistance toileting and feeding.
- Lose basic psychomotor skills, e.g. ability to walk. The brain appears to be no longer able to tell the body what to do.
- Generalized and cortical neurological signs and symptoms are frequently present.

**TheRibbon.com**

URL: <http://www.theribbon.com/articles/7stages.asp>

© 1998-2003 TheRibbon.com



## Caregiver's Checklist

What you should do and know at the different stages:

### *Stages II and III*

- Decide who will be the primary caregiver.
- The primary caregiver needs to realize that the job ahead will be hard and help will be needed.
- Decide which of the family members will help the caregiver and decide how much help they will be able to give.
- Talk to other family members (brothers, sisters, etc.) and ask if they will be able to help with the patient in some way. Maybe they can help one day a week or one weekend a month.
- Obtain an identification bracelet for the patient.
- Remove important identification, hospital, and credit cards from the patient's purse or wallet so that those items will not get misplaced.
- Establish a good relationship with the patient's medical doctor.
- Talk to the doctor about the patient's ability to drive.
- Meet with a lawyer to get legal advice on decisions that need to be made about health care and finances.
- Learn all you possibly can about the illness so you can deal with it in the best possible way.
- Try to teach family and relatives about the illness so they will understand what is happening to the patient and be of some help to the primary caregiver.
- Find a good support group in your area and attend the meetings.

### *Stage IV*

- Reassure and comfort the patient, repeatedly, with words or hugs.
- Give the patient time alone if he or she needs it.
- Keep your sense of humor.
- Don't take what the patient might say or do personally.

### *Stage V*

- Be patient and make an effort to guess what the person is telling you.
- Read the patient's body language.
- Ask questions that offer choices (For example: ask "Do you want orange juice or coffee?" not "What do you want?").
- Help the patient save face or avoid being embarrassed.
- Ignore wrong answers. Don't argue.

- Keep the anxiety level down to prevent catastrophic reaction.
- Stay with the patient during an activity.
- Expect to have to reengage the patient in the activity frequently.
- Don't try to get a restless patient to sit still or lie down.
- Seek respite for your own health and well-being.
- Do not use logic or try to reason with the patient.
- Never assume the patient does not understand what is being said or done.

## *Stage VI*

- Be prepared to help the patient judge distances, find chairs when sitting down, and keep his/her balance.
- Keep a watchful eye and step in gracefully when the patient needs assistance with feeding, dressing, and day-to-day activities.
- Ask questions that include answers.
- Replace worn-out items in the patient's wardrobe with clothes that are easy to put on and take off -- such as pullover shirts, pants with elastic waistbands, shoes with Velcro straps.
- Make sure shoes are a good fit.
- Patients sometimes cannot tell when the water temperature is too hot. Therefore, check the temperature setting on your home's hot water heater to prevent scalding.
- Make a safe sleeping area because patients may get up confused during the night. Keep objects out of pathways to the bathroom and other rooms.
- Let the patient eat with his or her fingers and cut food into pieces he or she can easily eat.
- Be sure tea or coffee is not too hot.
- Learn the Heimlich maneuver and also CPR.
- Include exercise in the patient's daily routine.
- Choose outings that do not require concentration and that don't last too long.
- If you are unable to have a live pet, fill the vacancy with a stuffed animal.
- Do crafts, one step at a time with the patient. The easier the craft, the better.
- Make sure anything you leave lying about is harmless.
- Remove or cover mirrors and other reflecting objects.
- Allow rocking and repetitive behavior. It helps to relieve stress in the patient. If it distresses others, distract the patient with an activity or remove him or her to another room.
- Recognize the good that comes from even the simplest things you do.

## *Stage VII*

- Do not attempt full care without assistance.
- Exercise the patient by moving each part of the body gently.
- Allow children and pets to play with the patient.
- Take the patient outdoors several times a day.
- Give the patient pleasure with music.
- Dance with him or her or move his or her arms gently to the music.
- Be alert for signs of developing physical problems.
- Provide the patient with a twin bed or hospital bed.

- Bathe the patient daily and give a bed bath if necessary.
- Keep the patient's hair short for easy care.
- Lubricate and massage the skin to prevent bed sores.
- Cushion sensitive areas of the body with pillows.
- Move a chair or bed-bound patient every hour or two.
- Talk with the patient's doctor about whether the patient should be kept in bed and about problems with toileting.
- Always have assistance when trying to lift the patient.
- Establish a routine to avoid bowel and bladder problems.
- Wear rubber gloves if you must come in contact with body fluids.
- Provide partial adult diapers or full diapers as needed.
- Always accompany the patient when he goes to the bathroom.
- Keep patient's fingernails and toenails clean and trimmed.
- Watch for dental problems, clean the patient's dentures, and/or assist the patient in brushing after meals.
- Check glasses and hearing aids to make sure they are clean, they fit, and they work.
- Provide food that can be eaten with little effort.
- Be careful about choking. Give the patient food a little at a time to prevent him from eating too quickly.
- Watch for signs of dehydration (not enough fluids in body).
- Provide frequent snacks to make sure that the patient is getting enough food and drink.

*The above lists are adapted from the book Alzheimer's: A Handbook for the Caretaker by Eileen Driscoll.*

**TheRibbon.com**

URL: <http://www.theribbon.com/articles/carechecklist.asp>

© 1998-2003 TheRibbon.com



## **Dementia Information For Children and Teens**

### **What is dementia?**

Dementia is a name given to a group of symptoms. There are several diseases which cause dementia. People with dementia have memory loss and difficulties with speaking and understanding others. They will have problems with thinking, recognising people (even family members) and will forget what simple objects are used for (like a knife or fork).

For a long time the person may look healthy on the outside, but on the inside their brain is not working properly.

### **What's the difference between Alzheimer's disease and dementia?**

There are several diseases which cause dementia. We hear more about Alzheimer's disease because it is the most common cause of dementia.

### **Is dementia a mental illness?**

No. It is a disease of the brain. Our brain is our control centre and everything we do and say and think is controlled by our brain. When the brain is sick, we have problems with all our actions (remembering, speaking, understanding, learning new skills, walking, etc).

### **Is dementia something all older people get?**

No. We all forget things from time to time, especially if we are stressed, and maybe a little more if we are older. An example of something an older person without dementia might forget is where he or she put their car keys. A person with dementia might forget what the keys are even used for.

Only about 2 or 3 people out of 100 people who are between 60 and 65 years old have dementia. However, as people get older, their chances of getting dementia are higher. For people 85 and over, 20 out of 100 have dementia.

### **Can younger people get dementia too?**

In rare cases, people in their 30s, 40s and 50s can get dementia.

### **What problems do people with dementia have?**

Not all people with dementia will have all these problems. But here are a few things that can happen:

- Increased forgetfulness
- Not able to learn new information or follow directions
- Repeating the same story over and over and asking the same questions many times
- Difficulty finding the right words or completing a sentence
- jumbling words or phrases (not making sense)
- losing things, hiding them or blaming others for stealing
- confusion about the time of day, where they are or who others are
- fear, nervousness, sadness, anger and depression
- crying a lot or becoming silly
- forgetting how to do every day tasks such as cook a meal, feed themselves, drive a car or take a bath.

## Can you die from dementia?

Yes. Unfortunately there is no cure for Alzheimer's disease and other dementias. Over time, the disease only gets worse. It is the fourth biggest cause of death in older people.

## How long does it last?

Some people can live up to 20 years after they show signs of Alzheimer's disease. But the average number of years they live for is eight.

## How do doctors know someone has dementia?

There is no one test. Several medical tests must be done as well as information given by the person's wife, husband, daughter, son or someone who has known them for a very long time. There are some illnesses which might seem like dementia but are treatable. If these are ruled out, the doctor may then be able to say that the person has a particular type of dementia, such as Alzheimer's disease.

## What causes Alzheimer's disease?

There is much research happening throughout the world, but still we do not know the cause of Alzheimer's disease. However, we do know that many small strokes cause the second most common form of dementia, which is vascular dementia.

## How does dementia affect children and grandchildren?

If someone in your family has dementia, the disease affects you and other family members, even if you don't live in the same house as the person with dementia. It can be very upsetting and stressful. You may experience some confusing feelings and not want to believe that this is happening. This is very normal.

You may feel upset that your grandparent or parent whom you love very much has become like a stranger to you.

If the family member with dementia lives in your house, it may mean you miss out on some care and attention, or that you are asked to take on other jobs and responsibilities. You may no longer feel like a "normal" family. You may feel angry or resentful that your parents are too busy and no longer have as much time for you.

Caring for a relative with dementia can make your parent or grandparent feel stressed, tired and worried. Sometimes this may make them cranky or short-tempered with you. Try to be understanding of what they are feeling too.

You may not want to have your friends over to your house any more because you are embarrassed by the person with dementia's behaviour. If you are able to learn more about the disease, you can then explain it to your friends. Then, it might still be upsetting in many ways, but might not be so frightening.

## **Are there activities kids can do with people who have dementia?**

Yes. Safe, simple and quiet activities that involve repetition are best, such as folding the washing, brushing the person's hair, rolling a ball of wool, walking, gardening or looking after a pet. Often people with dementia can remember things from long ago, but not things from just a few minutes ago. You might look at a family photo album with them, or play old songs and music they might remember.

The person may only be able to concentrate for 20 or 30 minutes, or even less. Stop or change the activity if they become anxious or distracted. Even though they may not recognise you, your love and understanding can be a great comfort. Give them a cuddle, a kiss, stroke their arm. The best help you can give is reassurance and to let them know that you care about them.

## **What can kids do to make life easier for the person with dementia?**

Learn all you can about the disease. Be calm and patient. Be loving. Be involved. Be understanding. Help around the house. Take care of yourself. Explain the situation to your friends so they know what to expect.

## **What if the person gets angry?**

Don't argue with them because they don't understand when they are wrong. Their anger is the result of the disease and not something you did. The best thing may be to leave the room and return later when their mood has changed.

## **Handling your own feelings:**

You must understand that all the feelings you have are normal. It is a great loss to watch a grandparent, parent or other relative with whom you used to be very close, forget who you are and become helpless. You must remember that even if the person becomes angry, cries a lot, does strange things like putting a jumper in the oven, they have a brain disease and cannot help what they are doing. These things are beyond their control. You must not blame yourself for having upset them.

**TheRibbon.com**

URL: <http://www.theribbon.com/articles/teeninfo.asp>

© 1998-2002 TheRibbon.com





## *Coping with Alzheimer's*

When driving becomes an issue

The freedom to slide behind the wheel of a vehicle, turn the key and drive away symbolizes many things: independence, convenience and competence. So its understandable that most of us want to be able to drive as long as possible. Although advancing age may bring a decrease in vision and hearing and a slowing of reflexes, most people learn to compensate for such diminishing abilities. For example, an older person may decide to drive fewer miles, more slowly and not at night. Even though its never an easy choice, most people determine for themselves when its time to limit or stop driving.

### *When to stop*

For a person with Alzheimer's disease, the decision to stop driving is often not voluntary. Just how long someone with Alzheimer's should be permitted to drive (if at all) is an issue that stirs the emotions of those with the disease, their caregivers and the general public. Although some states, such as California, require that people with Alzheimer's disease be reported by their physicians to the state health department and the department of motor vehicles, most states don't have such requirements.

### *Increased risk*

The risk of being involved in a traffic accident increases with a drivers age. Even older adult drivers without Alzheimer's disease are more than twice as likely to be involved in fatal traffic accidents as are middle-age drivers. According to a study published in the December 1988 issue of the Annals of Neurology, per mile, people with Alzheimer's disease are 19 times more likely to have an accident than an older adult without the disease. Despite this increased risk, people with Alzheimer's on average drive 2.5 years after their diagnosis &em; even though they may have significant cognitive impairment and have been advised by a caregiver to stop.

Surveys indicate the general public prefers that physicians help keep unfit drivers off the road. However, health care professionals have conflicting opinions on the subject of when to take away the keys from people with Alzheimer's. Because the disease progresses differently in each person, its nearly impossible to generalize about when people with Alzheimer's lose their ability to safely handle a motor vehicle. What makes it even more imprecise is that some people in the early stages of the disease are still able to pass a driving test.

Psychological tests can help determine whether someone with Alzheimer's has the memory, perception and coordination needed to drive safely. But there are no definitive, quantifiable, standardized tests to pinpoint when driving should be discouraged or stopped. As a result, caregivers remain responsible for continually reassessing the driving abilities of a person with Alzheimer's. As the person becomes more impaired, the caregiver must balance loss of independence and dignity against the risk to self and others in making the decision.

## *When safety becomes an issue*

Knowledge of the rules of the road, good judgment and adequate eyesight, hearing and coordination are all needed for safe driving. Some experts say that over the years, the ability to drive is so ingrained that it becomes somewhat "automatic." Driving skills seem to be well-preserved into old age in most people.

Most experts agree that even if a person has good coordination and reasonably sharp senses, when judgment is compromised, driving becomes unsafe. "Most people with Alzheimer's disease think they're safe and skillful drivers," says Dr. Jonathan M. Evans, a specialist in internal medicine and geriatrics at Mayo Clinic, Rochester, Minn. "What's interesting is that people with the disease forget that they can't remember how to make good judgments," Dr. Evans says. "They lack the insight to voluntarily stop driving."

## *Warning signs of unsafe driving*

If you're the caregiver of someone with Alzheimer's, it's up to you to assess that person's ability to drive. When any one of these signs is apparent, it's time for the person to give up driving:

- Inability to locate familiar places
- Failure to observe and obey traffic signs and speed limits
- Poor or slow decision-making in traffic
- Anger, confusion or frustration while driving

"My concern is that real-life driving situations, even in familiar areas, are not predictable," says Dr. Evans. "People with Alzheimer's disease are unlikely to be able to judge or respond quickly. That means they may have difficulty reacting properly to a situation like a child crossing in front of them or a car stalled in traffic, even when it happens on a familiar stretch of road."

Dr. Evans adds that there may be no warning signs of deteriorating driving skills. He says the unpredictable course of the disease, with an inevitable decline in cognitive skills and judgment, are reason enough to advise all people with a diagnosis of Alzheimer's disease not to drive.

"My opinion is that you can either drive a day longer than you should and risk a tragedy, or you can stop a day early and avoid serious injury or death," Dr. Evans says. "As a physician, it's my responsibility to bring up this issue with the patient and family. This relieves the caregiver of that pressure."

One thing is certain. Eventually the physical limitations of the disease stop everyone with it from driving.

© 1995-1999, Mayo Foundation for Medical Education and Research.

**TheRibbon.com**

URL: <http://www.theribbon.com/articles/driving.asp>

© 1998-2002 TheRibbon.com



## Nursing Home Checklist

This checklist is designed to help you evaluate and compare the nursing homes that you visit. It would be a good idea to make several copies of this checklist, so that you will have a new checklist for each home you visit. After you have completed checklists on all the nursing homes you plan on visiting, compare your checklists. Comparisons will be helpful in selecting the nursing homes that might be the best choice for you.

### Part 1 - Basic Information

Name of Nursing Home:	.
Address:	.
Phone:	.
Cultural/Religious Affiliation (if any):	.

Medicaid Certified?	Yes	No
Medicare Certified?	Yes	No
Admitting New Residents?	Yes	No
Convenient Location?	Yes	No
Home capable of meeting your special care needs?	Yes	No

*For parts two through five, rate the nursing home on a scale from one to ten, with ten being a perfect score.*

### Part 2 - Quality of Life

1. Are residents treated respectfully by staff at all times?	1	2	3	4	5	6	7	8	9	10
2. Are residents dressed appropriately and well-groomed?	1	2	3	4	5	6	7	8	9	10
3. Does staff make an effort to meet the needs of each resident?	1	2	3	4	5	6	7	8	9	10
4. Is there a variety of activities to meet the needs of individual residents?	1	2	3	4	5	6	7	8	9	10
5. Is the food attractive and tasty? (sample a meal if possible)	1	2	3	4	5	6	7	8	9	10
6. Are resident rooms decorated with personal articles?	1	2	3	4	5	6	7	8	9	10
7. Is the home's environment homelike?	1	2	3	4	5	6	7	8	9	10
8. Do common areas and resident rooms contain comfortable furniture?	1	2	3	4	5	6	7	8	9	10
9. Does the facility have a family and residents' council?	1	2	3	4	5	6	7	8	9	10
10. Does the facility have contact with outside groups of volunteers?	1	2	3	4	5	6	7	8	9	10

**Part 3 - Quality of Care**

11. Does staff encourage residents to act independently?	1	2	3	4	5	6	7	8	9	10
12. Does facility staff respond quickly to calls for assistance?	1	2	3	4	5	6	7	8	9	10
13. Are residents and family involved in resident care planning?	1	2	3	4	5	6	7	8	9	10
14. Does the home offer appropriate therapies (physical, speech, etc.)?	1	2	3	4	5	6	7	8	9	10
15. Does the nursing home have an arrangement with a nearby hospital?	1	2	3	4	5	6	7	8	9	10

**Part 4 - Safety**

16. Are there enough staff to appropriately provide care to residents?	1	2	3	4	5	6	7	8	9	10
17. Are there handrails in the hallways and grab bars in bathrooms?	1	2	3	4	5	6	7	8	9	10
18. Is the inside of the home in good repair and exits clearly marked?	1	2	3	4	5	6	7	8	9	10
19. Are spills and other accidents cleaned up quickly?	1	2	3	4	5	6	7	8	9	10
20. Are the hallways free of clutter and well-lighted?	1	2	3	4	5	6	7	8	9	10

**Part 5 - Other Concerns**

21. Does the home have outdoor areas (patios, etc.) for resident use?	1	2	3	4	5	6	7	8	9	10
22. Does the home provide an updated list of references?	1	2	3	4	5	6	7	8	9	10
23. Are the latest survey reports and lists or resident rights posted?	1	2	3	4	5	6	7	8	9	10
24. (Your Concern)	1	2	3	4	5	6	7	8	9	10
25. (Your Concern)	1	2	3	4	5	6	7	8	9	10

**Additional Comments:**

*This checklist may be reproduced and circulated. It is designed to be used in concert with the Health Care Financing Administrations booklet, The Guide to Choosing a Nursing Home. This booklet can be obtained by calling (800) 638-6833.*

**TheRibbon.com**

URL: <http://www.theribbon.com/articles/nhchecklist.asp>

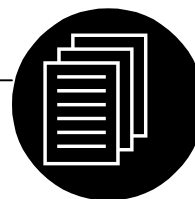
© 1998-2002 TheRibbon.com

# “How can *TheRibbon.com* help me?”

**TheRibbon.com** provides Care for Caregivers of loved ones dealing with Alzheimer’s disease.

## **The Ribbon Newsletter**

The Ribbon Newsletter delivers information and support to your e-mailbox.\* Search our archives for information on hundreds of topics.

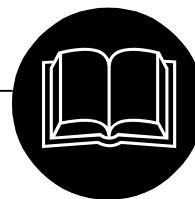


## **The Gathering Place**

Chat with caregivers across the country at The Gathering Place. It’s your own online support group available five nights a week.

## **Reading Room**

Read all our most popular articles from The Ribbon newsletter. Print them out, or email them to your friends. Locate hard to find books at The Ribbon Bookstore.



## **Dedication Garden**

Place a lasting online dedication to your loved one in our special garden.

**TheRibbon**  
**.com**   
*Care for Caregivers*

Find us at [www.TheRibbon.com](http://www.TheRibbon.com)

\*The Ribbon is also available via postal mail for those without access to a computer. Write to:  
1104A Murfreesboro Pike PMB 114 Nashville, TN 37217-1918