This newsletter is produced quarterly by the Mayo Clinic Alzheimer’s Disease Research Center in cooperation with the Minnesota-Dakotas Chapter of the Alzheimer’s Association. For information about our services in Rochester, Minn., call 507-284-4059. In Jacksonville, Fla., call 904-953-7103. To access the Alzheimer’s Association helpline call 1-800-232-0851.

The purpose of this newsletter is to share stories, ideas, thoughts, and poems that may be helpful to those caring for a loved one with dementia. Not only is the newsletter intended for caregivers, but much of it is written by caregivers. We welcome your words, your thoughts and your stories. Please send to:

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You may have heard the saying, *when you have met one person with Alzheimer’s disease, you’ve met one person with Alzheimer’s disease.* In other words, no two persons are similar in how the disease impacts them. This holds true for caregivers as well. If you have seen how Alzheimer’s disease impacts one caregiver, you have seen how it impacts one caregiver. There are significant differences in the way families, and ultimately caregivers cope when life presents difficult and devastating situations like Alzheimer’s disease. Although never easy, over time many caregiving husbands, wives, sons, and daughters manage in amazing ways. They begin to incorporate a set of beliefs and expectations about their situation that helps them cope. Somehow, many can find meaning, joy, and contentment in their lives as they travel down the path of caring for a loved one with Alzheimer’s disease. Here are some of the beliefs “coping caregivers” have come to accept on their undeserved journey.

**Coping Caregivers learn to separate what they can and cannot control.**

Once the diagnosis of AD is made, caregivers find that modern medicine is limited in its ability to treat or prevent the progression of the disease. Caregivers soon realize which aspects of the disease they can control and where they have no control. While the disease process will not change, coping caregivers know one thing they can control is their own attitude and their own expectations about the disease.

For example, caregivers generally understand that Alzheimer’s disease includes changes in the person’s personality and behaviors. However, when disruptive behaviors are present, or their loved one speaks hurtful words, the caregiver will often take this personally. Coping caregivers are able to keep an objective attitude about these behaviors or words; they can better separate the disease from the person, and therefore the person from the behaviors.

...the attitude we choose ultimately determines how we approach problems and how we solve them. It sets the tone and influences the quality of our interactions with the AD person. Attitude determines the quality of our care. — Lela Knox Shanks

**Coping Caregivers know that it is critical to care for themselves.**

A more difficult lesson to learn is that in order to continue effectively providing care for their loved one, caregivers must take care of themselves. For example, caregivers often indicate that they want to care for their loved one in his or her own home as long as possible, but then caregivers fail to create a lifestyle to support that goal. If caregivers ignore their own health and well-being, they cannot be as helpful to their loved one. Coping caregivers will do such things as learn relaxation techniques, join support groups, meet regularly with friends, and exercise daily.

No matter what your situation, start now and get involved with your own life once again... Just as we need to relieve stress for a person with dementia, you need to relieve stress in your own life. — Jolene Brackey

**Coping Caregivers**

By Angela Lunde
Coping Caregivers have a sense of humor, or learn to acquire one!
Coping caregivers have a sense of humor that helps them through difficult situations. They have learned that Alzheimer’s disease brings with it many embarrassing or otherwise painful situations. Coping caregivers have learned to allow themselves to view many situations in a lighthearted way.

As caregivers we have a choice. We can let the continuous drone of our loved one overwhelm us, or we can find the humor and release our stress. Lela Knox Shanks (Your Name is Hughes Hannibal Shanks)

Coping Caregivers know how to focus on and enjoy what their loved one can still do.
It is natural to focus on what your loved one can no longer do. Coping caregivers allow their loved one to perform whatever activities they can still do, even if it is not done as well or as quickly as it could be. They realize the importance of allowing their loved one with dementia the ability to feel useful and maintain a sense of purpose. If the dishes are not cleaned as well or the lawn-mowing job misses a few spots, coping caregivers have learned to graciously adjust their expectations.

I’ve learned to be more elastic. If she burns the hamburgers who really cares. I just add more ketchup. Husband and Caregiver

Courage is not the absence of fear, but rather the judgment that something else is more important than fear. Ambrose Redmoon
Ask a Specialist

By Glenn Smith, PhD

Dr. Glenn Smith is a board-certified clinical neuropsychologist who specializes in Alzheimer’s disease.

Is there a link between flu shots and an increased risk of Alzheimer’s disease? I’ve heard that it’s because the shots contain mercury. My friend skipped her flu shot last year based on this rumor.

Sue /Indiana

There’s no evidence that influenza vaccine increases the risk of Alzheimer’s disease. Inactivated influenza vaccine used in the United States may contain thimerosal, a preservative that contains a very small amount of mercury. There’s no evidence that the mercury in thimerosal is harmful at these low levels.

Alzheimer’s is a complex illness involving damage to and degeneration of the neurons within the brain. Its cause isn’t fully understood. But it may be due to abnormal protein (amyloid) deposits and inflammation in the brain. It was once thought that aluminum contributed to this process. But most experts believe that there’s no clear evidence to support this theory. Influenza vaccine doesn’t contain aluminum.

Flu shots save many lives every year. The Centers for Disease Control and Prevention recommends flu shots for:
- Children ages 6 months to 2 years
- Adults age 50 and older
- Anyone with an impaired immune system or a serious illness such as chronic heart or lung disease, kidney disease, diabetes, or sickle cell anemia

Original Article:
http://www.mayoclinic
My name is Gail. One day at my job, I went to add up a charge for a customer, and I discovered that numbers no longer meant anything to me. Simple mathematics was now beyond my capability. It was very scary. I discovered that I could still use a calculator, although I did not know how to interpret the numbers.

There were other tasks that were difficult as well. Using the new computer system was very stressful. It was more difficult for me to keep up with my co-workers, and it was harder to use the VCR and DVD machines.

In late December of 1999, I was diagnosed with probable Alzheimer’s Dementia. The following month, I resigned my position.

How have I coped with the disease? I have a wonderful husband who is a constant pillar of strength. He loved and cares for me. My family support includes my sons, their wives, and my grandchildren. Most of my family lives near by.

There are many activities that help me cope with my illness. Nature rejuvenates me, especially the water, the lakes, rivers and streams of our state. My husband and I enjoy walking in many of the area parks, and I enjoy horseback riding when I can convince my husband to take me. I have an interest in Native American culture, of which I have many books and artifacts. From a very early age, I have enjoyed dancing and it is still one of my favorite activities.

I spend some of my time with our grandchildren. We play dress up, go to the parks and zoos, play hide and seek and go to the movies. I have a lifelong interest in film and the magic of theater. I enjoy many kinds of music from opera to folk music, to Rock ‘n Roll (no rap or heavy metal please!).

As you can see, I have many activities to fill up my time. I have friends and relatives who support me. I have a husband who loves me.
With the holidays upon us, caregivers and families often wonder how they should plan for the various events of the season. They may believe that they should “live up” to the expectations of family traditions, and have thoughts of how things “ought” to be. Memories may surface and create reminders of what they’ve lost or maybe what they are losing. In the face of these emotions, caregivers (like all of us) believe it is a time when we should be happy. Unfortunately, increased stress, disappointment, and sadness may occur.

Persons with dementia function best in a calm, structured environment with activities that are familiar to them. Naturally, the holidays can disrupt the sanctuary of this comfort. The person with dementia may feel pressure to engage in activities beyond their ability, they may feel the anxiety of being in a gathering where they do not recognize anyone, or they may feel the discomfort of people who do not understand how to interact with them. These situations can have them feeling scared, insecure, angry or frustrated.

Below are a few ideas, adopted from the book *Mayo Clinic on Alzheimer’s Disease*, that can get you thinking about ways to create a meaningful and enjoyable season.

**Adjust Expectations.** As a caregiver, it is not realistic to think that you will have the time or the energy to participate in all of the holiday activities you once did. At the same time, the person with dementia may not be able to handle a disruption in routine and the extra stimulation. Consider participating only in what you feel comfortable doing. Pick and choose which traditions are most important to you and which you can live without. This may mean less traveling, less entertaining, or it may mean making plans to enjoy some events without your loved one. By limiting the activities your loved one is involved in, you are often looking out for his or her best interest.

**Simplify the Season.** There are many ways to simplify and make things easier for you, the caregiver. You may want to consider less baking. Instead of dozens of different holiday baked goodies you could limit it to 2 or 3 different varieties. If hosting the holidays at your home makes sense, consider a potluck, or have some of the items catered. Other ideas include photocopying your holiday letter rather than
sending individually handwritten cards. Minimize holiday decorating, which is not only time consuming, but can be confusing (i.e. blinking lights) and sometimes unsafe (i.e. wires, cords, candles) for the person with dementia. Plan to avoid holiday shopping with your loved one during evenings and weekends. Consider respite care for your loved one while you shop, or avoid stores all together and pick out items from a catalog, or delegate shopping to another family member. Try to keep the days and the routine unchanged for your loved one as much as possible.

**Modify Traditions.** Think about ways you can modify traditions that will still provide meaning to you and your family. During the holiday season, religious church services can be very stimulating, possibly overwhelming for the person with dementia. Consider attending services around the holiday that may not be as crowded, or have some family stay at home with your loved one and attend an alternate service. At home, families can read traditional passages and/or sing favorite hymns familiar to the person with dementia. Include your loved one in holiday activities that are modified to meet their abilities. These activities might include reading seasonal stories or holiday cards together, attending short concerts, taking a ride to look at Christmas lights and decorations, shopping through the catalogs, helping with baking or gift wrapping. Remember it’s the process of generating pleasant emotions that you want the activities to accomplish, not what the final product looks or tastes like!

Finally, consider hosting a smaller gathering. If possible, have a few smaller gatherings spread out over several days or a week, verses one large family get together. If you do have a large gathering, locate a quiet room, away from the noise and activity to which your loved one can “retreat” as often as needed. It may be better to have a meal earlier in the day rather then later, as person’s with Alzheimer’s can get worn out easily as the day progresses. Once again, try to keep the routine of your loved as intact as possible.

Celebrate the season by focusing on the simple ways we can connect with those we love.
Coping Resources

The Alzheimer’s Association provides help and hope to those experiencing Alzheimer’s disease. Their services include Helpline (1-800-232-0851) which provides 24 hour a day telephone support and information. They offer an identification search and return program called Safe Return for persons who might wander. Other services include educational trainings, conferences and written materials. They also offer support groups, work for action on Alzheimer’s issues, and provide funding for research. You can access their web-site at www.alz.org

Men’s Caregiving Support Group meets the 2nd and 4th Wednesday of every month from 1:15-2:30 p.m. at the Mayo Clinic Alzheimer’s Disease Research Center. This group is appropriate for husbands, sons and any other men caring for a loved one with dementia. Simply contact Angela Lunde at 507-284-4059 to join us!

Women’s Caregiving Support Group meets the 1st and 3rd Thursday of every month from 4:45-6:00 p.m. at the Mayo Clinic Alzheimer’s Disease Research Center. This group is appropriate for wives, daughters and any other women caring for a loved one with dementia. Simply contact Angela Lunde at 507-284-4059 to join us!

A support group for persons in the early stages of Alzheimer’s disease or a related dementia will be offered beginning in April 2004. This group provides a caring and confidential place for gathering information, sharing thoughts, and discussing topics important to the person who has been diagnosed with Alzheimer’s disease or a related dementia. For more information contact Angela Lunde at 507-284-4059 or Jamie Pennington at 507-289-3950. If you are not from the Rochester, Minnesota area call the Alzheimer’s Association Helpline at 1-800-232-0851 to locate a program near you.

An 8-Week Dementia Education Series will be offered this Spring. More information in the next edition of Coping

Would you like to receive this Coping newsletter quarterly?
Call 507-284-4059 or e-mail: lunde.angela @ mayo.edu to have your name added to the mailing list.