



Not a River in Egypt!

“Denial” is a universal complaint of families when trying to care for a person with dementia. Caregivers often complain that the person with dementia, adult children, neighbors, and health providers “just don’t get it.” Adult children complain about spouses, partners, and siblings being in denial. While people in the early stages of dementia may recognize their memory loss, they commonly refuse to believe that anything is wrong.

Denial is a normal coping response that helps to protect us from terrible news until we are ready to cope. Some common forms of denial related to dementia include:

- Inability to believe that the person has dementia or thinking dementia is either a normal part of aging or that the person is just depressed.
- Thinking the person could perform more capably “if he/she just chose to.”
- Trying to reason with the person or think the person will remember.
- Allowing the person to continue to drive, take their own medications or have guns, despite obvious problems with safety.
- Thinking problem behaviors such as aggression or wandering will never happen.
- Refusing to consult with a physician about the changes seen.
- Avoiding preparation of necessary legal and financial documents.
- Searching to find the perfect doctor, herbal supplement, medication, or expert to cure the disease.

Therefore, when confronted with an illness like dementia, many of us use denial. So what to do about it? First, recognize that denial is a normal, healthy, and often useful emotion. Second, begin to find some neutral ground to explore options to understanding and getting help. Third, think about employing some of these strategies:

1. Ask the person with dementia to help you facilitate specialty care to “see what the real problem is.” Focus on “being the best” mentally and physically.
2. Suggest formulating and completing legal needs as something that is a routine and essential part of healthy aging.
3. Search for information on memory and thinking changes that may allow all parties to learn more about diseases like Alzheimer’s.
4. Make sure all important family members have copies of important records including legal and medical documents.

With a little strategic rethinking, denial can be used to get everyone to work together and moving toward solutions.

Talking about the illness

Recognize that some people with dementia will never believe that they have a problem. Furthermore, others get upset when the word “Alzheimer’s disease” or “dementia” is used. However, these same people are very likely to complain, “My mind isn’t working right” or “I think I am going crazy!”

There is little to be gained in trying to convince the person that they have a problem. But it is important to allow them to talk about it when they offer statements as described. Let the person know that you understand they are having trouble with their memory/ thinking, and that you know they are trying to do their best. Understand that like you, they are often grieving the changes that they are experiencing. It is very helpful to let the person know that you care and that you are there to help them as needed. Research shows that when family refuses to talk with the person about their illness, the person with dementia is likely to become paranoid as family members begin to avoid them. In fact, talking about the illness helps to keep the person on the “same side of the table” as the family.

The Alzheimer’s Association has a very helpful brochure, “If you have Alzheimer’s disease: What you should know, what you should do.” Go to: www.alz.org or call Veronica Ellis (602) 239-6850 for a copy.



“Ask the Expert”

By Geri Hall, PhD, ARNP
Family & Community Services

Dear Geri:

My mother is always complaining about noise. The television is too loud; she can't stand restaurants, the supermarket, or the mall. She yells at my children who are just "being children." If there is music in a public place she demands to leave, yet she doesn't mind the casino. And she is downright rude when we have company for dinner. She refuses to wear her state-of-the-art hearing aids so how can noise bother her? Is it my mother or is it me?
Frustrated

Dear Frustrated:

People with Alzheimer's type dementia routinely develop problems with exposure to noise; probably due to damage to the part of the brain that interprets sound. Many patients stop wearing their hearing aids complaining of insensitivity to noise. In addition they try to avoid noisy crowded places, such as being on the street when traffic is heavy or there is construction or heavy equipment noise. Malls, supermarkets, and restaurants with piped-in music disable the person's ability to cope. In our society these noises have become increasingly loud, pervasive, and are a real problem for the person with dementia.

Patients report that children's voices are shrill and piercing. Trying to follow a social

conversation where there is a lot noise, such as silverware on dishes or an air conditioner can be overwhelming and fatiguing. Carole M, a woman who suffers from dementia wrote the following to help families understand her disability:

Regarding noises: For me, I have developed a serious aversion to noise. I hear things that others hear as normal as extremely loud. Added to that is the fact that it is increasingly difficult to "sort out" a simple conversation from the background noise in a restaurant or a school auditorium. What others would call ambiance or atmosphere, I find utterly incapacitating. Even at home, I can tolerate only the softest sounds from one TV or radio without becoming agitated. While I do not hear a constant buzzing, I do have difficulty sorting out whatever sounds there are in the environment.

The best advice? Be continually aware of ambient noise both in and out of your home. If the person demands to leave an area, go. Make sure your mom has a private TV and lounging space away from the children instead of having them together all of the time. Strive for a balance in meeting your children's needs and the special concerns about your mom. Neither of you is crazy; this a normal part of the disease.

What's New in the Library

The Alzheimer's Healthcare Handbook: How to get the best medical care for your relative with Alzheimer's disease in and out of the hospital (2003) provides specific, practical and sensitive advice on how to meet the challenges of caring for a relative with Alzheimer's disease. This book has very useful steps for caregivers to consider when hospitalization occurs. Tips are provided ranging from riding in the ambulance, how to manage the emergency room and your role as the caregiver in the hospital. Advice is provided on care following hospitalization.

Through the Seasons (2008) is a large-format color picture book that is divided into themes representing the four seasons. Each section provides a variety of activities and discussion ideas for caregivers and people with dementia. This book is useful for those with moderate to advanced dementia.

Did you know that all of the back issues of the BAI Beacon are located on our Web site? Go to www.banneralz.org and click on "Caregiver Resources" that will take you to the link to the Beacon.

Beacon Bits

COMPASS Classes for the Month of August

COMPASS is coming to Tempe, Ariz. at the Changing Hands Bookstore located at 6428 S. McClintock Drive, Tempe, AZ 85283 on Wednesday, Aug. 12, 2009 from 6:30 —8:00 p.m.

COMPASS class at BAI is located at 901 E. Willetta St. the class will be held on Thursday, Aug. 20, 2009 from 10:00 —11:30 a.m. in the 3rd floor conference room.

BAI EXPLORERS is touring the University of Phoenix Stadium on Friday, Aug. 14, 2009 at 11:00 a.m.—12:15 p.m. Registration Fee is \$8 per person. Enjoy a privately guided tour of the home of the Arizona Cardinals.

All these events do require registration, please contact Veronica Ellis at (602) 239-6850 or e-mail her at veronica.ellis@bannerhealth.com.

Do you want to make a gift to the Banner Alzheimer's Institute but are worried about parting with assets you might need in the future? Consider including the Banner Alzheimer's Institute in your will or revocable living trust. These options allow you to make a gift that will have no impact on your financial reserves. Contact Hazel Richards, CFRE at (602)239-3851 for specific bequest language.

Our Mission

To end Alzheimer's disease without losing a generation, to set a new standard of care for patients and their families and to forge a model of collaboration in biomedical research.

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