



## Am I Going Crazy?

All caregivers complain at some point that they feel like they are "going crazy." Much of this has to do with the loss of control. This feeling is often accompanied by a sense of being alone in their situation. A large group of caregivers were once asked what drives them crazy. Dozens of responses were received with two underlying themes: loss of control and disappointment in others. See if you can find yourself in these responses (permission was obtained to use these responses):

- "The destruction my husband has caused because of his Alzheimer's disease (AD). I know he's not intentionally sabotaging, but that's what it feels like. He can't remember not to use something, he won't read a note that says to not use something, or he can't recognize a problem."
- "Hearing family and friends tell me that they couldn't visit Mom any longer because it just hurt too much to see her that way and they wanted to remember her as she used to be. Therefore, any help or support they might have been to me went right out the window."
- "People who question whether your loved one really has dementia since s/he seems just fine to them."
- "People who would ask me why I bothered to visit my father so often since he "wouldn't remember my visits."
- "Not only the trying to inform myself to stay one step ahead of my mom's stages and symptoms, but that I also have to be the schoolmarm to my siblings, my mother's siblings and to the caregivers in the residences where my mom has lived. Can others not read and learn some techniques and background for themselves?"
- "The silence in our home without conversations."
- "Having to do everything myself."
- "Repeating the same question every two minutes!"
- "When people talk about her, in front of her."
- "Why do I have to go stay with her, why can't she come and stay with me?"
- "Why does everything have to be my mother's way?"

So what to do about this? First, there is help in knowing others in the same situation and having helpful professionals. Support groups are great ways to find people with whom you can share frustrations. If you aren't a support group type or unable to attend one, make sure you have a friend who will listen to you without passing judgment. Second, be more assertive with family and friends. Tell them what drives you crazy and request they *visit for your sake*. It is okay to ask for help because it is what families do to help one another. Finally, find nurses, social workers and other professionals who understand the disease who can help to guide you through this maze called Alzheimer's disease/dementia.

## Taking Care of Yourself

Research shows us that caregiving is a very complex activity: draining yet rewarding; demanding yet fulfilling; boring yet challenging and intimate yet lonely. Caregivers often suffer from guilt, fatigue and depression as their responsibilities may span decades. Taking care of yourself is the most important thing you can do to take care of your loved one. Here are some ideas for you to consider. Give yourself permission to try at least two of these in the coming week.

1. Eat right – make sure you get a balanced diet
2. Get adequate rest
3. Drink plenty of fluids (1 ½ - 2 quarts per day are suggested for good health, but notice we do not advocate just water.)
4. Exercise at least 3 times a week (5 is preferable) for a minimum of 20 minutes
5. If you find you are feeling sad, overwhelmed, irritable, crying more, and/or having changes in your sleep, call your doctor and ask about treatment with an antidepressant. Make sure you get annual health screenings
6. Get flu and pneumonia vaccinations
7. Get out with friends and by yourself regularly
8. Make sure you have some time alone each day
9. Pursue a hobby, especially with family or friends
10. Find something that makes you laugh and do it regularly
11. Rent movies you enjoy
12. Attend your spiritual or religious center regularly
13. Use respite services, especially adult day programming as often as possible. With adult day programs 3 days per week is recommended
14. Attend support groups and keep in touch with professionals
15. Do something challenging (crosswords or puzzles)
16. Splurge on yourself on a regular basis, whether clothing, a food treat, a long distance phone call or whatever makes you happy



## “Ask the Expert”

By Geri Hall, PhD, RN

### Family & Community Services

Dear Geri,  
 The one thing that really drives me crazy is trying to respond to Mom’s request to “go home.” She begs to be allowed to go home, usually late in the afternoon. I spent hours trying to explain that she *is* at her home, not in the hospital, and that I will take care of her. When I stop to get her a glass of water and after one drink she starts anew asking to be allowed to go home. No amount of explaining helps. Now she knows she is not in the hospital, but not at home. I have taken her to houses we lived in before and the location of her childhood home, but she doesn’t know them. Now I just drive her around the neighborhood but that doesn’t stop it either. Last week I lost my temper. How can I get her to understand?  
 Signed “Out of Gas.”

Dear “Out of...”  
 This is a very complicated problem that commonly occurs about the same time when the person has difficulty with selecting their own clothing and dressing. There are several reasons that help to explain the behavior. First, people with AD have changes in their visual perception that limit their ability to recognize objects and places, making familiar places seem unfamiliar. Second, the fact that the behavior occurs later in the day means fatigue is compounding the problem. If her home does not look familiar it can be frightening. Third, you need to expand your definition of the word “home” to include more than a house. Our friend Carole M. who has AD describes needing to go home:

“Home” is a state of mind. ....  
 Home may have been any of a number of different places

physically, but emotionally and intellectually it was always the one place in which I felt most comfortable.”  
 No matter where your relative with dementia refers to when he or she asks to go home, the chances are that it is somewhere neither of you will ever visit again. In some respects, I am still “home,” but in others I will never get home again. Living in this twilight zone is frightening, and I wish I were not there. However, I understand that none of my living relatives could help me to get somewhere that no longer exists.” (printed with permission).

How to handle requests to go home:

1. Acknowledge your Mom is feeling lost and frightened. Tell her you know she doesn’t recognize the house and don’t try to convince her she is wrong. Ask her to tell you about the home she longs for: who lives there; what she would be doing; and why it feels safe.
2. Reassure her that you will keep her safe.
3. Try to involve her with a familiar activity such as helping you prepare supper.
4. Increase her rest periods during the day so she is not so fatigued in the late afternoon.
5. If the behavior includes agitation, crying, or trying to elope, speak with her health care provider to check for urinary tract infection, and/or determine the need for medications for anxiety.
6. Enrolling the person in adult day programming provides additional structure and the reinforcement that she is now “home” in the afternoon.

## BAI Family & Community Service wants to hear from you!

BAI is committed to *setting a new standard of care for patients and families*. As such, your input is essential as we plan for 2010. We want to know:

- What topics would you like to read about in the monthly Beacon?
  - Do you like the monthly updates provided in this newsletter?
  - What additional information would be helpful to you as care partners?
  - Would you like to attend a monthly one-hour seminar on various topics of Alzheimer’s disease, such as current treatment, living alone, managing behaviors, cognitive exercise, genetics, etc?
  - What lecture topics would you most like to hear?
  - What would be the best time of day for you to attend a seminar?
  - What else can BAI do to better meet your needs?
- Please e-mail [veronica.ellis@bannerhealth.com](mailto:veronica.ellis@bannerhealth.com) or send your comments to:

Banner Alzheimer’s Institute  
 901 E. Willetta St., 3rd Floor  
 Phoenix, AZ 85006  
 Attn: Veronica Ellis

### Beacon Bits

#### NEW DATE & TIME FOR SEPT COMPASS CLASS

Date: September 24, 2009 (Thursday)

Time: 11 a.m.—12:30 p.m.

Location: 901 E. Willetta St., 3rd floor conf. rm.

Registration is required for this class. Please notify Veronica Ellis.

*Circle of Friends*, will be meeting in the BAI Library on Thursday, Sept. 10, in conjunction with our new *R.I.S.E. (Refresh-Inhale-Sit-down-Exhale) for Yoga program* this class is in conjunction with the Circle of Friends. There is a \$10 fee per person, per class for the Yoga program. No registration required, just walk in and pay at the door. R.I.S.E for Yoga is from 12:30 p.m.—2 p.m., the class is conducted by instructors from Yoga Phoenix.

*NEW Frontotemporal Dementia Support Group*, will meet Tuesday, Sept. 8, from 12:30 p.m. -2 p.m. BAI Library . R.I.S.E will be offered in conjunction to this support group as well.

If your concerned about your memory or know someone that is, there is a **FREE Memory Screening** at the Via Linda Senior Center at 10440 E. Via Linda, Scottsdale, AZ, Friday, Sept. 25, from 8 a.m.—noon. Registrations are being taken at (480) 312-5810.

For more information contact Veronica Ellis, Events Specialist, (602) 239-6850 or [veronica.ellis@bannerhealth.com](mailto:veronica.ellis@bannerhealth.com).

## 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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