

BAI BEACON

*The Newsletter from Family and Community Services
Banner Alzheimer's Institute
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Banner Alzheimer's Institute

December: The gift that keeps on giving

December is when many families reconnect, celebrate traditions, and make resolutions for care in the coming year. Alzheimer's disease rarely makes the connections between family members easier. From the beginning of the disease each family member begins to grieve; progressing through several stages including shock, anger, denial, over-involvement, sadness, and acceptance. The problem is that each family member progresses through the stages at their own pace. While one member may be actively involved, another may be denying the problem. One way of coping with different stages is simply to recognize that these are normal stages and that everyone's feelings are valid.

The issue of distance is one that must be negotiated. People who live more than an hour away can still participate in care by spending a weekend thus relieving the caregiver. Distance people can send cards and flowers, call frequently, and listen to the caregiver's issues without offering solutions. They can also periodically send money, gifts of food, mailed movie services, and occasional respite to help caregivers to feel less isolated and lonely.

Siblings must remember that while you may have grown up in the same household, each child's experiences and relationship with their parents are unique. While one child may have felt nurtured and protected, other siblings may have experienced something entirely different. It is important to acknowledge these differences when considering who makes what commitments to provide care.

One researcher found that families cope in three ways to providing care: 1) Strong families all pitched in and became closer; 2) Weaker families fell apart; but 3) Most families did not have enough strength to manage the entire disease so the members began to bicker and fight. Interestingly, the fighting gave the families enough energy to cope. When family therapists were used to resolve these conflicts, the families fell apart as they did not have enough energy to continue without the arguments.

The bottom line? Arguments and bickering are normal and desirable for families caring for people with dementia. Fought fairly, these battles are the key to holding family together during this most difficult period. And even family who live at a distance can participate in the person's care. Most families can work together to support both the person with dementia and the primary caregiver. Open discussion among family members and sharing unique talents of time, money, listening, etc. provides for the gift of caring! As Rosalyn Carter writes, there are four types of people in this world:

- Those who have been caregivers,
- Those who currently are caregivers,
- Those who will be caregivers and,
- Those who will need caregivers.

Respite Care Choices

While there are many choices for respite care, finding what's right for you might seem overwhelming. Here are some ideas to begin:

If you are more comfortable keeping your loved one at home while you go out, either find a friend or volunteer or utilize a home care agency to find a companion/caregiver. You will need to plan ahead so the friend/volunteer or paid caregiver knows how to interact, plan for the day, and assist in making this a positive experience for all. Adult Day Health Care is very helpful when you want your loved one to get out of the house and socialize. These programs provide socialization, activities, medication administration and more in a structured and safe setting. There are numerous programs throughout the valley and transportation is generally provided. You can also call the Family and Community Services staff at BAI. These are some community agencies that can be very helpful in finding help:

- Area Agency on Aging Region One Helpline 602-264-HELP
- Alzheimer's Association Desert Southwest Region 800-272-3900
- Foundation for Senior Living 602-285-1800
- Interfaith Community Care 623-584-4999



“Ask the Expert”

by Geri Hall, PhD, ARNP

Dear Geri:

I am caring for my mother in my home who has moderate dementia. It is pretty much a 24/7 job. I have 3 brothers and a sister who live in other states. When I tell them I need help, they tell me to let them know what mother needs. Mother needs care but I NEED A BREAK!!!! My husband and I have not been alone together for months and we bicker all the time. How can I get my siblings to help out?
Signed: Exhausted

Dear Exhausted:

It is time to turn you from a direct worker into an executive who delegates. First, make a list of everything you do and how often you do it. Record what jobs you can give away, dividing what can be done by family and what can be done by agencies. Second, (and here is the hard part) ASK each sibling to do at least one of the jobs. An annual family meeting is a good way to “make assignments” and helps everyone to remember that caregiving is a “team sport.” You might be surprised at some of the things family suggest to help. Just don’t let them redelegate to you.

You want to be kind, but firm about needing their help to continue. You might ask one to pay

Mom’s bills, while another might trade houses one weekend every quarter. A third might send food baskets or come to take Mom to the beauty shop. All out-of-town children should be sending Mom cards routinely.

If no family member can be available for occasional respite, it is reasonable to ask them to help finance professional services. If no one in the family agrees to help, then it is time to consider community services, especially adult day programming, in home care, or even placement in a nearby residential facility.

Providing care to aging parents is one way we have of “paying dues” to belong in a family. In addition it is the only way your children will see how you wish to be cared for when you are old. When reminded of this family often finds ways of “pitching in.”

Finally, one thing that is often overlooked is expressing gratitude. While it is certainly an expectation that if a family member will help with care, all too often the “thank you” is forgotten. If a family member pitches in — even if it is just a little — reward him/her with praise. Saying a heartfelt “thank you” is one way of ensuring that family will continue to help throughout the illness.

Banner Alzheimer’s Foundation

If you could help find a way to prevent Alzheimer’s disease before another generation is lost...if you could ensure that people with the disease can get the most comprehensive and compassionate treatment available...if you could give families the support they need, but so often don’t receive...if you could protect the future of your loved ones and protect your own tomorrows...if you could, of course you would.

Now you can.

By making a gift to Banner Alzheimer’s Foundation to benefit the efforts of the Banner Alzheimer’s Institute, you can turn help us turn hope into healing and be part of medical history in the making.

As an alternative to making a current gift with cash or a stock transfer, an enduring way to support the Banner Alzheimer’s Institute is through a bequest – a gift in your will. There are a variety of ways to make this simple and flexible gift. Following is sample language to show your attorney:

“I give (insert dollar amount, or percentage of estate) to the Banner Alzheimer’s Foundation, located in Phoenix, Arizona, to be used by it for the benefit of Banner Alzheimer’s Institute.”

Beacon Bits

Join the BAI Explorers as we venture out on Friday, January 16th from 9:30 – 11am to enjoy the Chihuly Nature of Glass tour at Desert Botanical Garden. This private walking tour will allow us to view many of the Chihuly spectacular creations that are found in more than 200 museums worldwide including the Metropolitan Museum of Art, London’s Victoria and Albert Museum and the Smithsonian American Art Museum. For more information or registration, call Veronica at 602-239-6850

In 2009, any BAI caregiver can attend a *90-minute introduction* to “Memory Assistance and Planning.” This program is free of charge and will provide survival skills for caregivers. The program will be held the **3rd Thursday of each month** in the BAI 3rd Floor Conference Room. Call Veronica at 602-239-6850 to register.

The full 2-day workshop Memory Assistance and Planning Series (MAPS) provides in-depth caregiving skills for enhanced daily living. We will be holding the next MAPS on Feb 7 and 21, 2009. The cost is \$50 and includes all materials, light breakfast and lunch.

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.