



BAI Beacon

The Newsletter from Family and Community Services

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“Just Let Me Know What I can Do!” Giving Care from a Distance



Providing ongoing care for people with dementia is a challenging, exhilarating, and often exhausting long-term job for families. With dementia's progressive nature, caregiving can last 10 years or longer. Past generations of families were able to divide the tasks and responsibilities, as families were larger and often lived in the same town. Today's families are often smaller and may be spread across the country or even the world, communicating by telephone, email, Facebook, or Skype.

Family members providing direct care are often isolated, and distant family members may not understand the effects or severity of the dementing illness. This can lead to conflict, frustration, and long term dysfunction despite the best intentions of all family members. This month we are addressing ways to help distance caregivers to understand the disease and provide meaningful help with care.

Here are some ways for distance caregivers to stay involved:

With the direct caregiver:

- Set a schedule and call the caregiver directly. You don't have to say much, just be a good listener. There will be times when the caregiver is angry or frustrated. Don't try to correct the problem or change the caregiver's perception. Instead, listen carefully and quietly. Use phrases like "Help me to understand," "This must be difficult for you," "You must be tired (frustrated, etc)," "What do you want to do about that?" and "It sounds like you are doing such a good job, (Insert person with dementia's name) would be so proud!"
- Ask for copies of the medical reports so you can understand the person's condition.
- Read up on Alzheimer's disease and methods of care so that you can offer meaningful suggestions that do not add to the caregiver's burden. Attend an Alzheimer's disease support group to become aware of the problems.
- Inquire about the caregiver's health and whether they are able to get out at times.
- Offer to contact the Area Agency on Aging to help find respite services and day programs. If you can visit, try to make it at significant times, such as for a physician visit, a hospitalization or surgery, starting day care, or placement in a facility.
- Offer to trade places for a weekend every few months so the caregiver gets a "free vacation" and you get to provide the necessary care, or offer to pay for a house cleaning service or respite.
- Always remember the caregiver's birthday, anniversary, Mother's or Father's day, and holidays with a card, gift, or gift card to a favorite store. Special days are the most difficult for caregivers.

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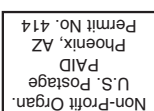
Tip on Brain Health:

Keeping your blood pressure, cholesterol, blood sugar and weight within recommended ranges are important in maintaining your brain fitness. Work with your doctor to keep all of these numbers in check!

Beacon Bits:

GPS for Memory on September 9th from 11 a.m. – 12 Noon will feature "Enhancing Oral and Dental Care in People with Dementia." Join Dental Hygienist Ann Benson from Mobile Dentistry of Arizona, as she provides some practical tips and strategies to maintain oral health.

Advanced Care Planning will help you complete your advanced directives such as a living will,



With the person with dementia:

- Send cards and/or letters weekly. Purchase a scrap book for the caregiver to store the cards, letter, and pictures.
- Speak directly to the person with dementia on the phone or Skype. Have anecdotes of the person's life you can share during the call – even if you said the same thing last week.
- Always, always, remember birthdays, anniversaries or other special occasions.
- Another way to say hello is to send photos with labels on the back that identifies everyone in the picture. In addition to pictures of family members, send images of your home, your new dog, a re-covered sofa, a vacation, and other experiences that tell about your life.
- When visiting, don't forget to build in leisure time to spend with the person. Join him/her in relaxing activities such as looking through photo albums or other activities the person enjoys. Try to stick with the person's regular routine to avoid agitation or confusion.
- Depending on the person's condition, dinner at home may be less stressful than going out to a fancy restaurant and a movie. Listen to what the caregiver reports about limitations. Try to keep activities to no more than 90 minutes.
- If the person doesn't communicate as well as in the past, listen anyway and keep talking. Often in a jumble of words there are one or two words that make sense.
- Don't expect the person to remember the activity. You are doing this for moments of enjoyment, not creating memories.

It is important to remember that your job as a distance caregiver is to ease the caregiver's burden. If you are visiting, plan to stay in a hotel as extra people in the house can worsen confusion. Offer to help with cooking, cleaning, or a chore. Stay with the person while the caregiver takes some time to run personal chores. Finally, don't suggest that the caregiver is getting it wrong. Offer suggestions occasionally, but communicate to them in a respectful way that preserves the caregiver's dignity. Ask caregivers "How can I help?" and "How do you manage" Your continued presence and concern will be appreciated.



Ask The Expert

Jan Dougherty, RN, MS
Director, Family and Community Services

Dear Jan:

Two years ago I gave up my career to move in with my parents. My dad is frail and is unable to care for my mom who has advanced Alzheimer's disease. Together we struggle to care for Mom's personal needs but her personality has changed. She is so mean to Dad and me – even the dog suffers. And, she is up at night every night.



When I moved in the family agreed to support me while I cared for my parents on the condition that I promised never to put them in a home. Now they treat me like a servant. My brother in another state refuses to let me take her to the doctor for medications to calm her. When I ask for help or respite they remind me that they are paying for my services and offer no help.

I don't think I can do this much longer; the care is difficult and mom resists by slapping and biting. I have no life of my own, I feel trapped. Any suggestions would be appreciated.

"Youngest Daughter"

Dear Youngest Daughter:

This is certainly a difficult situation, however you are not powerless. A few suggestions:

Let your brother know that people who are agitated are not comfortable or happy. A person with this high level of agitation needs to see a physician who can determine what might be happening in order to begin to make her more comfortable. Schedule a physician visit and take her. Make sure you write her problems on a single file card and ask the assistant to give it to the doctor immediately prior to the appointment.

You may need to hire a certified nursing assistant or bath aid to assist with bathing. Sometimes this "stranger" is more accepted by the person with dementia and has additional methods to make bathing more comfortable. It will be the best money you ever spent if it works!

Remind your siblings that successful dementia care is a team effort. Let them know that without their help (give a list of what you want and need); you will reconsider your agreement and leave. Reiterate that Dad needs their attention and care too. It is reasonable to insist that they visit on a regular basis, provide respite, agree to medical care, adult day programming, and pay you a wage that you can use as savings for the time when your caregiving days are over. And finally don't back down. Providing this level of care and support to your parents is far more than a one person job.

Finally, as a family, you may need to rethink the decision about keeping mom at home until the end of her life. This does not make you, your dad or your siblings failures. You are only human and facing a very difficult disease.

Have a question?
To submit your question for future consideration email us at
baiinfo@bannerhealth.com

Medical Power of Attorney, Mental Health Power of Attorney, etc. Join us for this class on Thursday, September 22nd from 10:00 a.m. – 11:30 a.m. and you will be able to complete your directives and have them notarized at the same time. \$10 covers the cost of materials and instruction. Registration is required.

Memory Screening will take place on September 30th from 9 a.m. – 1 p.m. at the Via Linda Senior Center, 10440 E. Via Linda Road, Scottsdale. Schedule a FREE 15-minute appointment and receive an assessment from a professional, get advice on how to improve your brain health, and/or learn how to get additional evaluation for memory concerns.

National Memory Screening Day is Tuesday, November 15th. Watch for details as BAI will be hosting free memory screenings at 10 city of Phoenix Senior Centers.

COMPASS comes to Sun Lakes United Methodist Church on October 26th from 1:00 p.m.-2:30 p.m. Join us for this free 90-minute lecture to help you begin your caregiver journey with Alzheimer's disease/dementia.

For more information or to register, call the Events Line at 602-839-6850 or email Deidra.Colvin@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.