

# BAI BEACON

*The Newsletter from Family and Community Services  
Made possible by generous donations to Banner Alzheimer's Foundation*

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## BEACON BITS

### Clinical Trials Announcement:

Are you feeling more forgetful? Having a hard time recalling recent events? It could be more than simply forgetting. More than 35 million people worldwide have Alzheimer's disease. You may even know someone who has it and are worried that you could get it too. Prodromal Alzheimer's disease is the very early stage of the disease when minor symptoms first appear. A person in this early stage may have more memory problems than normal for their age, but are still able to carry out most daily activities. If you have noticed changes in you or your loved one's memory over the last year and are wondering if it is a normal part of aging or if it is something more serious, you or your loved one may be interested in the APECS study. The APECS Study is evaluating an oral investigational medication that may help slow down the progression of what could be very early Alzheimer's disease.

Why participate? You may find out if your forgetfulness is due to very early Alzheimer's disease. All study-related medication and medical tests will be provided at no cost. Your health will be monitored through the study by a team

of medical experts. You may be compensated for time and travel. You will help advance medical research for Alzheimer's disease.

To participate, you must be between 50 and 85 years of age; have had memory problems for at least one year; have someone in your life that can attend study visits with you and help you follow study requirements. To learn more call 602-839-6500 and talk with a clinical trials representative.

*Did you know that Banner Alzheimer's Foundation secures charitable contributions to support our model of care and research aimed at treating and preventing the disease? To learn more about the ways you can help us win the fight against Alzheimer's, visit [www.banneralz.org/waystogive](http://www.banneralz.org/waystogive) or call 602-747-GIVE (4483).*



## Caregiver Wisdom

Becoming a caregiver for someone with dementia demands learning a new way to be with that person. At some point most caregivers encounter challenges resulting from the disease. This can be a difficult time in the caregiving experience. Many caregivers learn effective strategies and techniques to address these obstacles. The knowledge and expertise of implementing successful strategies and adaptations result in **CAREGIVER WISDOM**.

The iconic late night television host, David Letterman, developed a top ten list, highlighting specific topics followed by suggestions and responses to the subject. With that model in mind and with the permission of real life caregivers attending various support groups at Banner Alzheimer's Institute, we proudly present **CAREGIVER WISDOM: THE TOP FOUR CAREGIVER CHALLENGES AND HELPFUL SOLUTIONS**.

These suggestions and ideas are from the REAL experts: the family member, friend, partner, adult child, or spouse who are caring for and loving the person with dementia every day. Before we begin, a disclaimer: There is never one single solution to any caregiving challenge. The hope is that the following ideas and options will be helpful in allowing you to tailor a plan by providing strategies to address the challenges you face.

### **CAREGIVER CHALLENGE #4: Lack of knowledge and understanding of the dementia process and its progression.**

Dementia affects more than just memory. It affects how the brain sees the world and how the person perceives reality. This can result in challenging behaviors, changes in the person's personality and emotions, and an inability for the person with dementia to recognize and appreciate how much you, the caregiver is doing for them.

**CAREGIVER WISDOM SAYS:** The more you understand the cause of the problem the easier it is to identify a solution.

1. Get a cognitive evaluation early on to accurately identify the diagnosis.



2. Work with your medical provider to keep updated as to the newest treatments in medications and research studies, as well as non-medication treatments.
3. Learn about the stages of the disease and special considerations throughout the disease process through educational classes, workshops, trainings, written materials, and attendance at conferences.
4. Attend caregiver support groups to learn from others who are doing the same thing. We all need a place where we feel understood. In addition to support, many groups provide ongoing education, practical assistance and ideas for successful caregiving.
5. Ask a lot of questions. If you don't understand something a medical provider has told you, or someone in a support group has said, ask for clarity. Eliminate as many question marks as you can.

### **CAREGIVER CHALLENGE #3: Managing Challenging Behaviors**

Dementia places extra strain on the person as (s)he loses the ability to tolerate stress, plan and carry out many usual activities and correctly interpret their world. This leads to excess demand on the person and results in behavior becoming

## 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.

a more prominent form of communication. Think of these as “behavioral expressions.”

**CAREGIVER WISDOM SAYS:** As caregivers, we play an important role in anticipating the needs of our person which can help us minimize or prevent upset.

1. Identifying the triggers that lead to excess demand can help us change our own behavior, our approach, and modify the environment or activity as needed.
2. The biggest enemy of the person with dementia is fatigue. The brain is working harder than it did previously and it gets tired sooner. As caregivers we can encourage/engage the person in rest periods throughout the day.
3. Be aware and take advantage of the person’s “best time of day” to engage in the most important activities.
4. Routine, habits, and predictability bring comfort to all of us. These are especially important for someone with memory loss who has difficulty planning and tracking time. Implement a routine that stays relatively similar day to day whether you are at home or traveling. Include social, physical, cognitive stimulating activities and pleasant events.
5. Share your routine with family and friends and help them understand how they can support it.
6. Avoid major changes in the home- such as redecoration, or renovations.
7. Too much noise, too many people, too much chaos equals too much demand. In dementia “less is more”.
8. Avoid quizzing, reasoning, giving long explanations or too many details.
9. At times of upset, distraction can be helpful. Some caregivers have found music to be a helpful distractor. Others give the person a big hug or some chocolate; and never underestimate the power of humor.
10. Plan activities in shorter duration- most people do best with activities less than two hours.
11. Work with the person to adapt, modify and eventually substitute activities with a focus on remaining strengths and abilities toward enhancing self-esteem. Find chores around the house that the person can successfully do: folding laundry, sweeping, setting the table. Engage the person in physical activity that can be done together: walking, gardening, moving to music. Provide social interaction with peers through visits in the home, adult day programming, or support groups.

### **CAREGIVER CHALLENGE #2: Lack of caregiver support**

It is not uncommon for caregivers to feel alone as they care for someone with dementia. Caregiving is a complex activity that is demanding. It is best done when there is back up support from friends and family to fill in, provide needed breaks for the caregiver and varied fun interaction with the person with dementia. What can be done if one’s family or friends cannot, or will not, help as hoped for?

**CAREGIVER WISDOM SAYS:**

1. **ASK FOR AND ACCEPT HELP.** Amazingly, family and friends may not know what would be helpful. They may even believe that because you appear to be handling your role as a caregiver so successfully you don’t need any help. It is important to embrace the idea of caregiving as “a team sport”. Identify team members and if necessary identify the specific tasks and activities that would be most helpful. For example, perhaps your sister could initiate a Saturday

outing with your mom twice a month. Regularly scheduled events add fun, enhance her weekly routine, AND provide regularly scheduled breaks for you as the caregiver. In addition this provides an opportunity for family and friends to demonstrate how much they love and care about her.

2. Find a support group where you feel comfortable to share your frustrations, challenges and your successes. It is powerful to be with others that understand and “get it”, especially if there are few people in your life that are able to. The relationships that develop within these groups often become friendships outside the group setting that can provide ongoing support and social engagement in the future.
3. Don’t waste time and energy agonizing or trying to understand why family members won’t help. Certainly ask for help, but if it is not forthcoming, use your energy instead to create a “family of choice”. We all need people who can be there for us. If our biological family is unable to fill that role, we create a new one that will. These people may be good friends, neighbors, other caregivers, or work colleagues who are ready and willing to help and connect as needed.

### **CAREGIVER CHALLENGE #1: Managing Grief and Loss**

When the question was posed at a caregiver support group, “What is your most difficult challenge as a caregiver?” a man with very sad eyes answered, “Living with the grief”. Caregiving is a continual experience of dealing with loss as the person’s cognition and function continues to change and decline. Caregivers often hear about caregiver stress or burden. However the underlying culprit may well be caregiver loss. Pauline Boss, Ph.D, author of the book *Loving Someone Who Has Dementia* calls it ambiguous loss. It is a loss that is unclear, has no resolution, and no closure. Dementia creates ambiguous loss when the person is physically present but psychologically absent in the way they were prior to the diagnosis.

**CAREGIVER WISDOM SAYS:** Feel the sadness and be open to new ideas of how to cope with this unique loss.

1. It is normal to feel sad when the person we love is no longer able to be the same and do the things they once did. It changes their life and the relationship we had with them. It is important to honor our feelings of sadness, to express them and not fear them.
2. Decide to live with what Dr. Boss calls “a less than perfect relationship”. Accept the reality of the disease. One caregiver shared that once she was able to get into her mother’s world, she was freed up to enjoy time spent with her mom. She decided to love her mom just the way she was now and stop comparing her to her past self.
3. Accept their changing abilities knowing they are doing the best they can. Focus on what they CAN do and celebrate by doing it with them.
4. Try to change rigid perceptions, to allow you to find meaning and hope. Consider alternative ways of thinking toward this end. Your previous relationship is lost, but it still exists.
5. Stay connected with friends, family, professionals and/or family of choice- share your story with people and learn from their wisdom as well.

Caregiver wisdom serves great purpose as we each continue to grow and adapt to situations we thought would not be possible. However, the shared wisdom produces abundance to the recipients of such wisdom! Don’t be afraid to share your wisdom along the way.



## **Ask The Expert**

Susy Favaro, LCSW  
Social Worker, Banner Alzheimer’s Institute

Dear Susy:

*My mom has had Alzheimer’s disease for about five years. She continues to live in her home but requires paid help. I live near her and visit often, but the visits are becoming more and more difficult. Regardless of what I do, it is never enough and she is never happy. I have read about the disease, I have taken classes to learn more, and I attend a support group, but I have not been able to find the answer of how to make her happy. All I want to do is to make her smile. I cry daily about this. I feel guilty and so desperate. Please help!!!*

Signed,  
Peggy

Dear Peggy,

My heart breaks for you as I hear your anguish of doing everything you know, learning new strategies, and still feeling that it is not successful. In dementia, sometimes things don’t go well or work out as we hope they would. Some caregivers have found comfort in looking at their experience in a different way. Pauline Boss Ph.D offers a new “theoretical lens” called ambiguous loss. Ambiguous loss is a loss that is unclear, has no resolution, and has no closure. Dementia creates ambiguous loss because your mom is physically here but she is psychologically absent in the way she was prior to her diagnosis. When there is no cure for an illness, when you can no longer have the same relationship with her as you once did, it can feel confusing and excruciatingly painful. However, having a name for this type of loss can sometimes help us find new ways to cope. The following guidelines from Dr. Boss may be helpful:

1. **Find Meaning**  
Finding meaning or making sense of dementia may sound somewhat absurd because of its ambiguous nature. However by doing so, we can feel less hopeless. To find meaning in such a confusing situation you must accept two ideas at the same time: your relationship is NOT lost, it is different, but it still exists. One caregiver reported that she no longer compares what and how her husband was prior to his diagnosis. Instead she enjoys that he is now less demanding of himself and he enjoys being in the moment in ways that he was unable to prior to the diagnosis. She states “I just love him the way he is.”
2. **Hold On and Let Go**  
With the dementia your relationship is more one sided than it once was. If you can change your perception of the relationship to “both-and”, meaning my mom is both here and gone, you may be able to reframe your attachment. We can choose to settle for a less than perfect relationship. You continue to visit and care for your mom and understand the cause of the changed relationship is the dementia, not anything that you are doing or not doing.
3. **Become More Comfortable with Ambiguity**  
Some situations can’t be fixed. Allowing ourselves to accept ambiguity can help us let go of trying to find a perfect solution. Instead we must try to be happy with doing the best we can and recognize that sometimes we can do no more. Finding this middle ground of being comfortable with uncertainty can strengthen our resilience.

Wishing you good luck and peace in your caregiving role.

To learn more about this topic, we invite you to join us in the Dementia Dialogue Webinar/Teleconference on September 16 from 12N – 1:00pm as Susy Favaro, LCSW discusses more “Caregiver Wisdom.” To register, call 623-832-3248 or visit [www.banneralz/dementiadialogues](http://www.banneralz/dementiadialogues).



## **Have a Question?**

To submit your question for future consideration email us at:  
[baiinfo@bannerhealth.com](mailto:baiinfo@bannerhealth.com)

## September 2015 Program Schedule

# CAREGIVER EDUCATION PROGRAMS

### PHOENIX

#### **COMPASS: Directions for Caregivers after the Dementia Diagnosis**

Learn the basics of Alzheimer's disease/related dementia and how to implement 8 practical strategies to avoid many of the common problems that arise.

*Tuesday, September 1; 10:00 a.m. – 11:30 a.m. AND  
Monday, September 21; 4:00 p.m. – 5:30 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

#### **Keeping the Person with Dementia Occupied**

Learn how to adapt activities as the disease progresses and how to find a variety of stimulating and engaging activities that work in order for the person to have fun and feel success.

*Wednesday, September 2; 12:30 p.m. – 2:00 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

#### **Planning Ahead Class for Caregivers**

Learn how to plan for legal, financial and medical decisions for someone with Alzheimer's disease/related dementia.

*Tuesday, September 8; 4:00 p.m. – 6:00 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call 602-839-6850*

#### **As Dementia Progresses: Next Steps for Caregivers**

This two-hour class outlines the moderate to advanced stages of dementia, how common symptoms can be managed, how to cope with changing function while assisting caregivers to find success in their daily efforts.

*Tuesday, September 15; 10:00 a.m. - Noon  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

### PHOENIX (CON'T)

#### **Problem Behaviors: Solutions that Work**

Learn about the most common types of behavior problems in dementia and a variety of solutions to minimize them.

*Wednesday, September 22; 12:30 p.m. – 2:30 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

#### **Transitioning Care from Home to a Residential Setting**

Learn the importance of planning and considerations when making the transition from one level of care to another.

*Thursday, September 24; 12:30 p.m. – 2:00 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

### MESA

#### **Communication Tips to Avoid Arguments**

This two-hour class will review changes in communication as dementia progresses along with the common mistakes that caregivers make that lead to arguments. A variety of alternative strategies will be introduced and practiced during class.

*Tuesday, September 15; 10:00 a.m. - Noon  
Mesa Library Red Mountain Branch  
635 N. Power Road, Mesa  
Free but registration is required.  
To register, call (602) 839-6850*

*Please turn over for more classes →*

#### **To learn about upcoming education and support programs dates at:**

- Banner Alzheimer's Institute, visit [www.banneralz.org](http://www.banneralz.org) and click on "Events Calendar" icon or call Deidra Colvin, Events Coordinator at 602-839-6850
- Banner Sun Health Research Institute, visit [www.bannershri.org](http://www.bannershri.org) and click on "Events and Education" or call Veronica Flores, Events Coordinator at 623-832-3248

## September 2015 Program Schedule CAREGIVER EDUCATION PROGRAMS

### SUN CITY

#### **BSHRI Lecture Series: Legal Consideration for Long Term Care**

Learn the tool that you will need to help plan for long term care and avoid any possible loop holes.

*Wednesday, September 9; 2:00 p.m. - 3:30 p.m.  
Banner Sun Health Research Institute  
10515 W. Santa Fe Drive, Sun City  
Free but registration is required.  
To register, call (623) 832-3248*

#### **GPS Lecture for Caregiving: Staying Me**

Caregiving can result in loss of health, relationships and interests. This lecture will provide a variety of ideas and solutions to restore balance while maintaining a self during caregiving.

*Friday, September 11; 10:30 a.m. - Noon  
Banner Sun Health Research Institute  
10515 W. Santa Fe Drive, Sun City  
Free but registration is required.  
To register, call (602) 230-CARE (2273)*

#### **Transitioning Care from Home to a Residential Setting**

Learn the importance of planning and considerations when making the transition from one level of care to another.

*Friday, September 18; 1:00 p.m. - 3:00 p.m.  
Banner Sun Health Research Institute  
10515 W. Santa Fe Drive, Sun City  
Free but registration is required.  
To register, call (623) 832-3248*

#### **BSHRI Lecture Series: The ABC's of Palliative Care and Hospice Care**

Learn what Hospice and Palliative Care is and when it's time to use those services.

*Friday, September 25; 2:00 p.m. - 3:30 p.m.  
Banner Sun Health Research Institute  
10515 W. Santa Fe Drive, Sun City  
Free but registration is required.  
To register, call (623)832-3248*

### SURPRISE

#### **COMPASS : Directions for Caregivers after the Dementia Diagnosis**

Learn the basics of Alzheimer's disease/related dementia and how to implement 8 practical strategies to avoid many of the common problems that arise.

*Wednesday, September 16, 9:30 a.m. - 11:00 a.m.  
The Colonnade Recreational Village  
19116 Colonnade Way, Surprise, AZ  
Free but registration is required.  
To register, call (623) 207-1703*

### TEMPE

#### **Tempe Making Music — Making Memories**

This weekly music therapy group session provides an opportunity for music lovers to come together to sing, play rhythms, and move to music. This program is designed not only to improve memory but also to enhance quality of life through music and social support.

*Pyle Adult Recreation Center  
655 E. Southern Ave., Tempe  
9:30 a.m. - 10:30 a.m. Fridays beginning August 28  
Registration and Information: Sun Joo Lee  
ssoli96@hotmail.com*

### WEBINAR/TELECONFERENCE

#### **Dementia Dialogues Webinar: Caregiver Wisdom**

This session will share what the real experts, caregivers themselves, identify as the biggest challenges they face in their caregiving role and their tried and true strategies to address them.

*Wednesday, September 16; 12:00-1:00p.m. AZ Time  
Registration is required online at either [banneralz.org](http://banneralz.org) or [bannershri.org](http://bannershri.org)*