

# BAI BEACON

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## ***Moderate Alzheimer's disease: Maintaining Connections***

As someone enters the moderate stages of Alzheimer's disease/related dementia, a new set of situations begin to emerge as outlined in the July and August 2016 Beacon newsletters. There is continued need to keep the person with dementia (PWD) engaged and connected but family caregivers recognize the increasing difficulty of doing so. This dual challenge, in turn, adds to the growing list of responsibilities for the caregiver- who, more than ever, needs time to disengage from their role as caregiver. It is vital that caregivers stay socially connected and participate in activities that bring joy to themselves. This constant increase of demands placed on the caregiver during the moderate stage can become overwhelming and result in social isolation. The good news is, there are strategies that can help and supports that can be put into place to help both the PWD and their caregiver stay engaged and connected – both together and separately.

For the PWD, engaging with activities can improve both their mood and self-esteem. With any activity, the focus needs to be on the *pleasure* of the event rather than the outcome. For example, when playing an easy card game, who wins is less important than the fun of the game and connecting with others. Building on a person's strengths and interests can help to identify familiar activities the PWD may enjoy and more readily engage in. Activities must be adapted, simplified, or shortened in the moderate stage. Participating in one activity for 30 to 60 minutes is usually long enough.

Adaptation can happen for nearly every activity when considered creatively. If the PWD has always been part of a bridge club and it starts to become a challenge, do not eliminate the activity altogether. Instead adapt it to their current abilities. If the size of the group has become upsetting or overwhelming,, invite a few of the members over to the house to play with a smaller group. If bridge has



become too complicated, try a simpler card game. Instead of meeting the group beforehand for lunch, join up just for the game or just for lunch. Be sure to involve the person at their best time of day and provide a rest period after an activity to manage fatigue. If you are not present to observe how the PWD responds to an activity, ask for feedback from friends or others you trust to be honest with you. Remember that engaging the PWD in an activity rather than asking if they want to participate ensures more success.

Staying socially connected is also vital in the moderate stage. Be aware that crowds and groups of people can be more disturbing, so limit time spent at large gatherings. Try to have one on one time to help the person with dementia not feel overwhelmed or withdraw. For example, if you go to lunch with family or friends, ask a member of the group to engage your person in discussion. Conversations will need to be simplified and fewer questions asked that the PWD

## ***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.

may not know how to answer. It may be more beneficial to share stories about your day or family events while remaining attentive and respectful. It will be helpful if you share techniques you have learned with family and friends to keep the PWD engaged in conversations.

The importance of the primary caregiver staying connected and engaged cannot be stressed enough. Often, caregivers lose these connections in such small increments that they don't even perceive the change. Their vision shifts from 'I' prior to dementia, to 'we' in the early stages, to 'they' in the moderate stage. Recognizing this is the first step. However, by the moderate stage caregivers are so focused on their person, they do not feel their own self-care is a priority, or feel guilty taking even a little time for themselves.

A common analogy can be used to illustrate the importance of the caregiver taking personal time: You are seated on an airplane, and the flight attendant is going through the pre-flight instructions. "... And should the cabin lose pressure, oxygen masks will drop from the ceiling. If you are traveling with someone who needs assistance, put your mask on first." This is an essential part of the instructions. If you do not get oxygen to yourself, you are no good to the person who needs your help. Personal time is oxygen. It is not selfish. It is not neglectful. It is when the caregiver can breathe. When they can reconnect with who they are beyond the role of caregiver. When they can rejuvenate themselves, and return to their person at their best.

Beyond making it a priority, caregivers report that time, or an inability to get away, as one of the main reasons they do not take time for themselves. However, there is a variety of assistance from both informal and formal resources. Informal resources can include family, friends, and neighbors. Look into support that may be available with groups the person is currently involved in. For example, does the church have a volunteer program that would send a visitor?

Frequently, people in the social circle or family will offer to spend time with the PWD so the primary caregiver can get a break (e.g. respite). Many caregivers listen, but do not accept these offers. The concern of being a burden on others may prevent accepting offers of help. However, it is important to realize that people want to spend time with your person and/or you because they care. Think twice before declining a gift of time.

Friends and neighbors may still enjoy common interests or socializing with your person. Having a successful activity for all involved should be the goal. Caregivers will need to consider what they should share about their person. For example, if long-time friends take a person with moderate dementia to lunch, they may need to assist with paying the bill and helping the PWD order from the menu. Sharing best-learned strategies can help ensure everyone is successful.

Another way informal supports can be invaluable is assistance with tasks, such as shopping or running errands, which can lessen some of the responsibilities of the primary caregiver. Even though caregivers are not getting time for themselves, they are getting to check off the extensive 'to-do' list. Additionally, even friends or family members that

live out of state can assist with finances online, managing insurance benefits or doing research into options.

Sometimes people do not know how best to help a family with dementia. Prepare a list of activities that others could help with. Think about what could be handed off to someone else, or even what someone else could do better. Hate weeding the yard, or shoveling snow? Put that on the list! Informal assistance allows the caregiver to have a break with the added advantage of not paying for services. Be specific as you outline your needs and then when someone asks how they can help, you can go to your list and ask which one they might help you with!

Formal resources for respite involve structured community resources, including non-medical in-home care or an adult day health center. These services are typically on a fee for service basis unless there is long term care insurance or other benefits available. It is beneficial to begin services as early as possible so they are familiar and become part of the person's routine. Think about how you are going to introduce the formal resource. Asking "Do you want to?" will probably elicit a negative response. Instead, try to rephrase to positively engage, "We're heading to a new social club I'm sure you're going to love!" Remember decision making in the moderate stage of dementia is more difficult and change in routines will take time to adapt to.

In-home care can be a friendly visitor, companion or attendant who can assist with hands on care. There are agencies that specialize in this type of service. It is most important to find the right match for the PWD as this will allow for more success. Be aware that this may not be the first person interviewed and it is best to be specific about your person's likes, dislikes, and preferences. For example, the PWD may be very active and like to take walks or exercise. The paid caregiver would need to be someone that can engage in these types of physical activities. Having a list of activities to engage your person in is essential to reflect what they enjoy and will participate in. It is advisable that a paid caregiver have some dementia training so they know how to best interact with your person. It is helpful to be present for the first few visits to observe their caregiving skills and personality.

An adult day health center is an option that can benefit both the PWD and their caregiver. This is an ideal setting for the person to engage in socialization and structured activities and the caregiver receives the added bonus of some respite time. Centers usually have a nurse on site and attendants who help the participants engage in activities that are modified to ensure successful participation. As there is a schedule of activities, choose days that have things your person would enjoy. Some centers have gender specific activities, such as wood working for the male participants while some will have outings to various community events. It is helpful to pick consistent days to attend as this aids in establishing a routine. Many adult day health centers even provide transportation to and from the location.

*(cont'd on back panel)*



## Ask The Expert

Heather Mulder  
Outreach Program Manager

Dear Heather,

*My mother lives with me and has moderate stage Alzheimer's disease. I would love to have her attend the adult day health center near our home. I have little time to go out for errands, appointments, or meet my friends without her. When I mention this, she does not want to attend. What can I do to change her mind?*

*Signed,  
Rosie*

Dear Rosie,

An adult day health center would be an ideal option for your mother to attend. I would suggest that you visit this program to be aware of the activities that are offered and take your mother on days that they have events she would enjoy. Do not ask if she wants to attend. Rather, be very encouraging about the fun activities she can participate in. Call it a "social club" as this sounds more positive than a day health or day care center. If you think she will be resistant, you can state that this is part of her memory treatment or that her doctor ordered this as therapy. Some people think they are volunteers and they are there to help others.

Be aware that it may take several visits for her to feel comfortable with a new setting and routine. Encourage her to return if she initially seems reluctant. Ask the staff how she engages with activities and interacts with other participants. She may not remember what she did, so do not feel bad if she is unable to report on her activities there. Pick consistent days to establish a routine. I recommend that she attends 2 - 3 times/week for a minimum of three weeks before you decide it is not a fit.

Be sure to inform the center of your mother's likes and dislikes so they can best meet her needs and interests. If she needs assistance with toileting or personal care, they likely can assist. Make them aware of any mood or behaviors that could arise so they can be prepared to manage or minimize them. The more they know about your mom, the better they can meet her needs. And if she is happy with this setting, you will have much deserved respite time so you can continue as her caregiver. Give it time. In my experience, most PWD love attending these programs.

## Have a Question?

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

Did you know you can honor physicians and staff at Banner Alzheimer's Institute through a gift of support? For more information, please contact us at 602-747-GIVE (4483) or visit [www.banneralz.org/support-our-mission](http://www.banneralz.org/support-our-mission).



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## *Moderate Alzheimer's disease: Maintaining Connections*

*(cont'd from inside)*

Sometimes families can be a bigger barrier to participation than the PWD. If you find yourself saying, "My person would never enjoy this" you may be that barrier. Allow your person to try this option as they may unexpectedly enjoy the setting or activity. Be aware that it may take several attempts for them to become used to a new addition to their routine. Remember that the approach taken when introducing a new activity or service can make all the difference. Some caregivers have reported that their PWD thinks they are going to work or assisting other participants at the adult day center which helps them to look forward to attending. Therefore, just because the first couple of days may be difficult, don't quit. Get a report from the day program or in home care provider on what the person enjoyed as he/she will forget any fun that happened while you were away due to their own memory loss. However, this will assure you that they were fine and even had fun.



Staying engaged and involved in activities that bring joy is crucial for PWD and their caregivers. It is still possible for the PWD to find success and stay connected to you and others. By adapting activities, assessing your resources and involving informal and formal supports, you can ensure your person is able to stay involved. As importantly, you are able to have peace of mind and some much needed and much deserved respite time to care for self.

**For more information on this topic, we invite you to join in the Dementia Dialogue Webinar/ Teleconference on September 21, 2016 from 12N – 1pm (AZ time) with Banner Alzheimer's Institute dementia expert, Heather Mulder. See the calendar for more details.**





# CAREGIVER EDUCATION PROGRAM SCHEDULE

September/October 2016

## SEPTEMBER

### Clinical Trials 101

Clinical Trials allow patients to receive tomorrow's treatments today and assist researchers in the fight against diseases like Alzheimer's and Parkinson's. Attendees will learn the basics of clinical trials including what a clinical trial is, what it entails, how long they last and how to participate.

*Wed., September 7; 10:00 – 11:30 a.m.*  
BSHRI, 10515 W. Santa Fe Drive, Sun City  
To register, call (623) 832-3248

### Mindfulness Matters

The art of mindfulness can help you. Scientific studies show the practice can relieve anxiety and depression, pain and other medical conditions-actually changing the way you feel, think, work and play – by opening new pathways in the brain. Learn how to focus on the present and live in the moment.

*Wed., September 7; 1:00 – 2:30 p.m.*  
BSHRI, 10515 W. Santa Fe Drive, Sun City  
To register, call (623) 832-3248

### Free Parkinson's Screening Event

Banner Research invites community participants to a free 30-45 minute screening for Parkinson's disease (PD), a common neurodegenerative disorder in older adults. Early detection and management can improve quality of life. Participants will complete a brief questionnaire and be observed by a board certified movement disorders neurologist.

*Fri., September 9; 1:00 – 4:00 p.m.*  
BSHRI, 10515 W. Santa Fe Drive, Sun City  
To make an appointment, call (623) 832-3248

### Keeping the Person with Dementia Occupied

Keeping people with dementia engaged and mentally stimulated is often challenging for caregivers. This class will discuss how to adapt activities as the disease progresses, how to find a variety of stimulating and engaging activities that work in order for the person to have fun or feel success.

*Wed., September 14; 10:00 – 11:30 a.m.*  
BAI, 901 E. Willetta Street, Phoenix  
To register, call (602) 839-6850

### Transitioning Care

Transitioning from home to a residential care setting can be challenging for caregivers and the person with dementia. This class will discuss the importance of planning and considerations when making the transition from one level of care to another.

*Thurs., September 15; 10:00 a.m. – Noon*  
BAI, 901 E. Willetta Street, Phoenix  
To register, call (602) 839-6850

### Lack of Awareness v. Denial in Dementia

Families often think their person is in denial about their dementia diagnosis. However, some people with the disease are unable to see changes in themselves. This 60 minute class will assist participants to learn the difference between denial and lack of insight providing strategies to avoid confrontation.

*Fri., September 16; 1:00 – 2:00 p.m.*  
La Loma Village, 14260 Denny Blvd., Litchfield  
To register, call (623) 207-1703

### 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.

*Mon., September 19; 2:00 – 4:00 p.m.*  
BSHRI, 10515 W. Santa Fe Dr., Sun City  
To register, call (623) 832-3248

*Tues., September 27; 10:00 a.m. – Noon*  
BAI, 901 E. Willetta St., Phoenix  
To register, call (602) 839-6850

### Alzheimer's Medications

This class will review medications used, how to set reasonable expectations for use, potential side effects and tips for common issues.

*Tues., September 20; 10:00 – 11:00 a.m.*  
Mesa Red Mountain Library  
635 N. Power Road, Mesa  
To register, call (602) 839-6850

### Dementia Dialogue Webinar: Moderate Alzheimer's disease: Maintaining Connections

Now is the time when 24/7 care is required and both you and your person need to stay connected to family, friends, and meaningful activities. But how can you do this when there

is so much to do? This dialogue will outline methods of finding respite care to meet the needs of the caregiver and options to keep the person engaged with activities and others.

*Wed., September 21; Noon – 1:00 p.m.*  
(AZ Time). Free online, register at [www.banneralz.org](http://www.banneralz.org) under Education & Events and online education. If you have any questions, please call (623) 832-3248

### Good News in Alzheimer's Disease Research

Now is a new era of Alzheimer's disease (AD) treatment and care. As leaders in AD prevention and treatment research, some of the most exciting advances are happening in Arizona. Join one of our researchers to learn how you can participate and make a difference.

*Thurs., September 22; 10:00 – 11:30 a.m.*  
Tempe Public Library, 3500 S. Rural Rd., Tempe  
To register, call (602) 839-6850

### GeneMatch Informational Session

This informational session will discuss GeneMatch, a program that has been developed by the Alzheimer's Prevention Initiative for individuals aged 55-75 years with normal memory and thinking abilities who may be interested in participating in Alzheimer's research studies. We will also discuss the latest in prevention research and clinical trial opportunities that are available at our institute.

*Fri., September 23; 10:00 a.m. – 1:00 p.m.*  
BAI, 901 E. Willetta St., Phoenix  
To register, call (602) 839-6500

*Fri., September 30; 1:00 – 4:00 p.m.*  
BSHRI, 10515 W. Santa Fe Dr., Sun City  
To register, call (623) 832-5328

### When Hands on Care is Needed

This 2 ½ hour skills lab will allow caregivers to learn how to provide personal care (grooming, oral care, bathing, dressing), manage incontinence, adapt to changes in eating, move the person in/out of a chair and bed, and identify medical equipment for home use.

*Fri., September 30; 10:00 a.m. – 12:30 p.m.*  
Foundation for Senior Living  
1201 E. Thomas Rd., Phoenix  
To register, call (602) 839-6850

## OCTOBER

### Communication Tips to Avoid Arguments

This two-hour class reviews changes in communication as dementia progresses and the common mistakes that caregivers make leading to arguments. A variety of alternative strategies are introduced and practiced during class so that caregivers can walk away with new techniques to immediately put into place!

**Tues., October 4; 10:00 a.m. – Noon**  
BAI, 901 E. Willetta Street, Phoenix  
To register, call (602) 839-6850

### ABC's of Finding of Dementia Care

There are many options available when additional care is needed. However, it is often overwhelming to know where to begin and how to find the right fit for you and your person. This 90-minute session will review possible options for care in and out of home; how to make an informed decision and ensure success.

**Wed., October 5; 10:00 – 11:30 a.m.**  
BSHRI, 10515 W. Santa Fe Dr., Sun City  
To register, call (623) 832-3248

**Tues., October 18; 10:00 – 11:30 a.m.**  
Mesa Red Mountain Library  
635 N. Power Rd., Mesa  
To register, call 602-839-6850

**Wed., October 19; 4:00 – 5:30 p.m.**  
BAI, 901 E. Willetta St., Phoenix  
To register, call (602) 839-6850

### Duet Caregiver Symposium: “How to Find Hope While Coping with Stress and Grief”

Researcher, educator and psychologist Dr. Pauline Boss will offer techniques to help caregivers deal with loss and grief.

**Thurs., October 6**  
Family caregivers' session: 9 a.m. – 1:30 p.m.  
(includes lunch)  
Professionals & students' session:  
1:30 – 3:30 p.m.  
Duet at Church of the Beatitudes  
555 W. Glendale Ave., Phoenix  
Cost: \$20 per session  
Registration: [www.duetaz.org](http://www.duetaz.org)  
Information: (602)274-5022

### Dementia Dialogue Webinar: Advanced Dementia: What is it?

Advanced dementia presents many challenges to both the person and caregiver as there is now complete dependency for all daily living activities. Behavior now becomes the method of communication and caregivers are called upon to make important decisions to promote comfort until death. Join the dialogue to learn the nuances of advanced dementia and what powerful tools you can use to ensure comfort.

**Wed., October 19; Noon – 1:00 p.m. (AZ Time).** Registration is required online at [www.banneralz.org](http://www.banneralz.org) under events/education and online education. \*All webinars are recorded and available on the website 24-48 hours after the live session has taken place.

### Problem Behaviors: Solutions that work

Dementia affects the ability to manage emotions, carry out daily living tasks, navigate the environment and communicate in a logical way. Therefore “behaviors” communicate a real sense of discomfort for both the person and caregiver. This 2 hour class will address the most common types of behavior problems and pose a variety of solutions that caregivers can easily utilize.

**Wed., October 26; 2:00 – 4:00 p.m.**  
The Colonnade  
19116 Colonnade Way, Surprise  
To register, call (623) 207-1703

### Free Parkinson's Screening Event

Banner Research invites community participants to a free 30-45 minute screening for Parkinson's disease (PD), a common neurodegenerative disorder in older adults. Early detection and management can improve quality of life. Participants will complete a brief questionnaire and be observed by a board certified movement disorders neurologist.

**Fri., October 28; 1:00 – 4:00 p.m.**  
BSHRI, 10515 W. Santa Fe Drive, Sun City  
Free but an appointment time is required.  
To make an appointment, call  
(623) 832-3248

## MULTIPLE MONTH CLASSES

### Planning Ahead Class for Caregivers

This two-hour class reviews necessary planning for legal, financial and medical decisions for someone with Alzheimer's disease/related dementia or a movement disorder. Included is an overview of community resources and agencies, how to find help and pay for care in the home, community, and residential care.

**Tues., September 13; 4:00 – 6:00 p.m. AND  
Tues., October 11; 10:00 a.m. – Noon**  
BAI, 901 E. Willetta St., Phoenix  
To register, call (602) 839-6850

### COMPASS: Directions for Caregivers After the Dementia Diagnosis

Over 90-minutes caregivers are introduced to the basics of disease progression, treatment and care. In addition, caregivers will learn to implement 8 practical strategies to avoid many of the common problems that arise when caring for the person with dementia.

**Mon., September 19; 4:00 – 5:30 p.m. AND  
Mon., October 10; 4:00 – 5:30 p.m.**  
BAI, 901 E. Willetta St., Phoenix  
To register, call (602) 839-6850

**Wed., October 19; 10:00 – 11:30 a.m.**  
BSHRI, 10515 W. Santa Fe Dr., Sun City  
To register, call (623) 832-3248

### Mindfulness Matters 6 Week Session

This six-week series is open to the community. Participants will learn mindfulness practice and learn how mindfulness can positively influence the mental and physical health of caregivers of persons with dementia. Caregivers will learn to incorporate these into daily life to promote personal wellness. \$25 fee for the series.

**Mondays, September 26 – October 31;  
10:00 a.m. – Noon**  
BSHRI, 10515 W. Santa Fe Dr., Sun City  
To register, call (602) 636-5393 or email  
[events1@huv.org](mailto:events1@huv.org)

All classes are  
free,\* but registration  
is required.  
(\*unless noted)

### 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

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Banner Alzheimer's Institute  
Banner Sun Health Research Institute

