

BAI BEACON

*The Newsletter from Family and Community Services
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Understanding Moderate Stage Alzheimer's Disease

As a review, in the early stages of Alzheimer's disease (AD), people gradually have increasing difficulty doing tasks and activities that they previously did automatically, efficiently and well. These are centered on those tasks we refer to as *instrumental activities of daily living* (IADLs) and are related to running a household, managing finances and medications, driving, using technology, and performing well at work or in volunteer positions. As memory and understanding of how to do these tasks becomes more problematic, the person with dementia (PWD) is often observed to withdraw from activities, to become more of an observer than a participant, to gradually stop initiating tasks, to become frustrated when offered help; and to do more passive activities such as watching TV. Families often misinterpret this transition as a sign of laziness or willfulness and can themselves become more easily frustrated. Coupled with increasing short term memory loss, to the point that it is apparent to everyone, the stage is set for the transition to *moderate stage Alzheimer's disease*.

In clinical practice and research studies, the results of cognitive testing on the Mini-Mental Status Exam (MMSE) have been used to identify the stages of AD. A score ranging from 10-20 is generally indicative of moderate stage (where lower scores equate to lower functioning). PWD can score higher or lower than expected on this test. However, the better indicator for moderate stage AD is the level of function a person is able to demonstrate. In the moderate stage, we can expect that a person stops doing household tasks, is unable to use technology such as microwaves, computers and/or cell phones. More notably, the person is showing changes in his or her ability to care for self (also known as *activities in daily living* or ADLs). Initially, men may not shave as often or as thoroughly. Women may not comb their hair or apply makeup as well or at all. As time moves on, the person has more trouble with making decisions with choosing clothing. He or she may not dress for the weather, may wear the same clothing for



several days, or take dirty clothing out of the hamper and wear them. Some may not even change clothes, staying in pajamas for the day; or if dressed, not get out of clothing at bedtime. Because of increasing difficulties with *visual/perceptual skills* (which involves interpreting direction, distance, and depth), PWD can have trouble with what sequence to put on clothing, with recognizing front from back, right from left, or top from bottom of clothing. Showering occurs less often, or the need for showering is not appreciated by mid-moderate stage. PWD can forget to shower completely, how to use and/or confuse bath products. Over time, changes can be seen in eating abilities as well. Assistance will be needed to cut food, use utensils appropriately; and some may even forget whether they have just eaten. Food preferences show significant changes during this time as well. Caregivers will note that foods that used to be favorites are no longer. New foods can become favorites; simpler and softer foods are sought; and finger foods become easier to eat. Caregivers will need to prompt eating and drinking as the person quickly forgets. Fluid intake will decrease and water is not the beverage that most will accept. Rather, small cups (4-6 oz.) of juice/sweet beverage are more likely accepted. Drinking or eating may produce coughing or choking as the ability to coordinate swallowing is impaired.

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.

However, this is much later in the moderate stage of the illness and often an indicator of advanced dementia.

As a result of the *functional changes* described above, the need for the care partner changes to becoming a caregiver. It changes from a position of observation to a more interactive one.

Initially verbal prompts or reminders are needed followed by setting up for and supervising personal care tasks. Eventually, the caregiver will assist with completing the tasks as the PWD becomes more dependent. If not noted before this, behavioral issues can arise as more help is needed. However, this is not understood by the PWD, who responds typically to assistance with dressing, bathing or toileting. Assistance is often encountered by the person becoming verbally or physically aggressive, as the person tries to communicate their resistance to help. In reality, this behavior is one of protection of self; a response to being physically vulnerable in a changing intimacy as someone enters “private” space and tries to dress/undress, bathe or help with personal hygiene.

Some degree of mood and behavioral changes are common in up to 80% of those in the moderate stage. Changes can range from mild irritability, sadness or anxiety, to more pronounced agitation and/or anger. Some may become restless, pace or wander, particularly when bored or fatigued. With increased confusion it is not uncommon to see paranoia or suspiciousness, hallucinations or visual misperceptions, obsessiveness, impulsivity, and disinhibition. Aggression occurs infrequently in PWD, however, if the situation causing agitation is not alleviated, it can result in verbal/physical aggression. Many unwanted behaviors signify the inability of the person to filter or temper their thoughts and actions, to show uncharacteristic behaviors such as swearing, being sexually suggestive, or being overly friendly with strangers.

Sleep disturbances also are characterized as part of the spectrum of behavioral changes. It can take the form of difficulty falling and/or staying asleep at night, awakening earlier than usual, and sleeping more during the day, sometimes to the point that night and day become reversed. Over the course of the moderate stage, it is to be expected that the PWD sleeps longer, moving from perhaps 8 hours of sleep at night to 12-14 hours of sleep. In addition, the person may fall asleep intermittently during the day as his or her ability to stay focused and attentive is exceeded. Too much sleep during the day, especially in the earlier moderate stage of the disease process can be a sign of depression. More often, it reflects boredom as the person is unable to create and execute a plan of activity for the day. This should not be interpreted that the person cannot or would not still enjoy an activity. Rather, activities need to be planned and facilitated for them by another person. In some instances, the PWD can experience severe apathy, or the complete lack of interest, enthusiasm, or concern. Some may show indifference to their surroundings and people around them and others may appear extremely lethargic. This may represent depression and needs to be evaluated by the doctor.

Behaviors in moderate dementia become an important form of communication and are often referred to as *behavioral expressions*. Therefore, understanding what triggers behaviors is important in helping reduce them and potentially avoiding the need for medications. Behaviors typically represent an unmet need: **discomfort** (hot, cold, hungry, pain, fatigue, need to toilet, illness), **boredom** (loss of meaningful activities), **overload** (excessive activity, too much demand placed on person, communication at a level that exceeds the person’s ability to follow or to interpret, overwhelming or misleading stimuli).

Creating a daily, predictable routine is critical. The routine balances activities requiring more focus and concentration with those that are quieter and more restful. Having activities that the person can look forward to creates a sense of hopefulness and engagement. Learning effective communication techniques such as not reasoning or arguing with the person, distracting and redirecting them, and/or apologizing can also reduce stress and prevent a need for medications.

Throughout the moderate stage, *short term memory* continues to decline, and *long term memory* also becomes involved. Time orientation is lost. Language becomes affected in the ability to express self, to understand, to read and to write. Motor abilities also show changes, with slower and more shuffling walking, difficulty rising to stand from sitting position, unsteadiness at times, and a more stooped posture.

Treatments for the moderate stage of Alzheimer’s disease are symptom specific. Namenda (memantine) is added to donepezil (Aricept), rivastigmine (Exelon) or galantamine (Razadyne) which is started in early stage for cognitive symptoms. Mood and behavioral features are treated, if not responding to strategies outlined above, with anti-depressants/anxiety medications or in more severe cases, anti-psychotics. Medications may be used to assist with sleep if needed. Recommendations may be made for pain management to improve wellbeing, help to maintain mobility, and reduce potential behaviors.

One of the key concerns in the moderate stage is vulnerability due to the need for 24/7 supervision. As short term memory is more impaired, and reasoning and judgment are affected, the person with dementia is unable to decipher a situation as appropriate or inappropriate, safe or not safe, good or bad. The person lacks the ability or capacity to make decisions for themselves with regards to finances or medical issues. The person can be prone to exploitation from those around him or her, or to telephone or front door solicitation. More importantly, the person cannot interpret and respond appropriately to emergency situations. They may not remember emergency numbers, or even how to use a phone. This is not unlike the issue of leaving a younger child alone, knowing that emotional and physical safety and wellbeing are necessary assurances from parents.

Clearly as one views the progression of cognitive and functional changes, the demands on the primary caregiver grow exponentially. Not only does the caregiver assume all household tasks, but also the direct care of the person with dementia as well. This becomes more emotionally and physically demanding. In addition, there is grief associated with witnessing ongoing changes in the relationship, and specifically in the person with dementia. The cumulative effects of stress make the risk of depression, anxiety, and health issues in the primary caregiver significant. This is why professionals in the dementia field stress the need for self-care, to do pro-active planning for “what if” scenarios, and encourage finding ways to share care. This can include asking family or friends for routine help, utilizing home care agencies, adult day health programs; or even transitioning to living in residential settings.

While challenging, navigating the moderate stage of AD or other dementias can be successfully done if one understands the changes that are occurring while learning to accept a new reality in order to work with a loved one at his or her level. It also requires accepting help from others, all of which can allow for moments of joyfulness, of laughter, and of great reward.



Ask The Expert

Helle Brand, PA
Physician Assistant, Stead Family Memory Center

Dear Helle,

I notice lately that my husband gets upset if I am in a different room in the house as he comes searching for me. He also interrupts me each time I am on the phone. When my daughter comes over to stay with my husband to give me a break, he repeatedly asks for me and then is angry when I return, demanding to know where I have been. He also refuses to go to bed without me. Needless to say, I am worn out and feel like I am caring for a toddler NOT a husband. What can I do?

Signed,
Barbara

Dear Barbara,

What you describe is very common in those with moderate stage Alzheimer's disease/dementia as you have become your husband's "working" memory. Without you, he can no longer carry out his day. He does not know what to do next and is looking for you to remind or direct him. A very real fear of those with dementia is that they are being deserted. He is having more trouble remembering where you have gone. Just because you are out of sight doesn't mean you are out of his mind. This is not unlike what a young child might do as the parent leaves. This is creating a lot of anxiety for him and these actions are communicating his discomfort. Remember that this is confusion talking, not a demanding husband. This requires reassurance, comfort and patience. However, you need a break and it must become routine or your anger will show through and your health will suffer.

I'd suggest you try the following for this separation anxiety behavioral expression:

- Put in place a routine that includes either in home care or adult day care to provide him pleasant events/activities and gets him used to either being away from you or having someone else in the home.
- Knowing he becomes anxious, excuse yourself to go to the bathroom and leave quietly. Leave a pleasant distractor at home such as watching a favorite recorded TV show/sports event, special treat, etc.
- Remember not to preannounce upcoming events that lead to unnecessary worry.
- Let you daughter know strategies that you use with him that provide distraction and comfort.
- Take advantage of times when your husband is napping or engaged in activities to make/return calls. Use your cell phone allowing you to be mobile in the house and let your caller know that you may need to end your call quickly.
- Create pleasant bedtime rituals that include reading to him, have a bedtime snack, hold hands, give him a back rub to relax, play pleasant music.

Try these suggestions for at least 2-3 weeks as this is the time it takes to create new habits. If you find that he is not responding to the strategies provided, it may be time to check in with your medical provider to see if medications are necessary. I know this is demanding on you. Be sure to take care of yourself during these difficult periods. Thanks for all you do to keep your husband comfortable. I know it is easier said than done.

Did you know that many of Banner Alzheimer's Institute's programs and services rely on the generosity of others?

To join our community of friends, call 602-747-

GIVE (4483) or visit www.banneralz.org.

[org/support-our-mission](http://www.banneralz.org/support-our-mission).

Have a Question?

To submit your question for future consideration email us at: baiinfo@bannerhealth.com

For more information on "Understanding Moderate Alzheimer's disease," we invite you to join the Dementia Dialogue webinar/teleconference on July 20, 2016 from 12N - 1p.m. (AZ time) with Banner Alzheimer's Institute dementia expert Helle Brand, PA. Register online at www.banneralz.org. Click on 'Events and Education' then 'Online Education' or call 623-832-3248.



Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Care TIPS to promote sleep:

Daytime Strategies:

Keep a routine

- Try to be consistent with wake-time
- Provide structured activities, including exercise
- Get outside and exposed to sunlight
- Encourage rest periods/naps twice a day (30 - 60 minutes is ideal)
- Avoid more than one alcoholic beverage

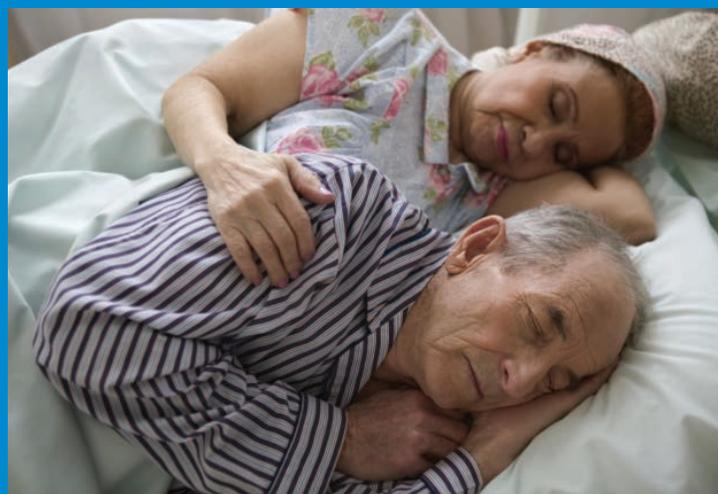
Cue the senses- It's time to get up!

- Auditory: Try singing or playing energizing music
- Visual: Open shades to let light in
- Olfactory: Brew coffee or tea, fry bacon or toast bread

Nighttime Strategies

Keep a routine

- Try to be consistent with bedtime
- Develop evening rituals: read a comforting passage, give a massage, or have a cup of decaffeinated tea
- Give a bedtime snack and consider a warm glass of milk
- Snuggle with the person if appropriate



Cue the senses- Time for rest.

- Auditory: Turn off the TV and try soft soothing music instead
- Visual: Close shades, darken the room, but provide night lights for safety
- Olfactory: The scent of lavender can be very soothing and promote sleep



CAREGIVER EDUCATION PROGRAM SCHEDULE

July/August 2016

JULY

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.

Friday, July 8; 10:00 a.m. - Noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

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.

Tuesday, July 12; 4:00 - 6:00 p.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix AND
Tuesday, July 19; 10:00 a.m. - Noon
Mesa Red Mountain Library
635 N. Power Road, Mesa
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.

Wednesday, July 13; 10:00 a.m. - Noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

Banner Brain Health Program

Learn how lifestyle choices can minimize the risk of Alzheimer's disease and then "flex" your cognitive muscles as you determine how to exercise your brain! This class teaches and provides tips for healthy adults how to use certain activities to help improve cognition, memory and recall.

**Cognitively Normal Adults.
Friday, July 15; 9:00 - 11:30 a.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 230-CARE (2273)

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.

Thursday, July 21; 10:00 - 11:30 a.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

Free Memory Screenings

Free monthly memory screening allowing community participants to screen for potential memory concerns and provide direction to prevention studies, clinical trials and memory clinics.

Friday, July 22; 9:00 a.m. - Noon
Banner Alzheimer's Institute
901 E. Willetta Street, 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.

Tuesday, July 12; 1:00 - 2:30 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248

Understanding Options to Pay for Care: ALTCS

Understanding Options to Pay for Care: VA Benefits

There are options to assist patients and families in offsetting the cost of long term care for those who qualify. Attend one or both of these sessions to dispel common myths, learn eligibility criteria, and steps needed to apply.

Wednesday July 13; ALTCS (10:00 - 11:00 a.m.) & VA Benefits (11:30 - 12:30 p.m.)
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248

Dementia Dialogue Webinar Series: Moderate Alzheimer's disease:

What is it?

As the person progresses to moderate stage disease, changes are more notable as the person now relies on assistance for most aspects of daily life. In addition, changes in mood, personality and behavior often feel perplexing to the caregiver. This Dialogue will review common changes associated with moderate AD, treatment options, and important considerations in managing behaviors, sleep, pain and more.

July 20, Wednesday; Noon - 1:00 p.m. (AZ Time). Register online at www.bannershri.org under events/education and then online education. All webinars are recorded and put on our website 24-48 hours after the "live session".

Please turn over for more classes →



AUGUST

Problem Behaviors: Solutions That Work

This two-hour class will address the most common types of behavior problems and pose a variety of solutions that caregivers can easily utilize.

*Thursday, August 11; 10:00 a.m. – Noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850*

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.

*Tuesday, August 16; 10:00 – 11:30 a.m.
Mesa Red Mountain Library
635 N. Power Road, Mesa
To register, call (602) 839-6850*

Banner Brain Health Program

Learn how lifestyle choices can minimize the risk of Alzheimer's disease and then "flex" your cognitive muscles as you determine how to exercise your brain! This class teaches and provides tips for healthy adults how to use certain activities to help improve cognition, memory and recall. ****Cognitively Normal Adults.**

*Thursday, August 18; 9:00 – 11:30 a.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 230-CARE (2273)*

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.

*Tuesday, August 23; 10:00 – 11:30 a.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850*

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.

*Wednesday, August 24; 10:00 a.m. – Noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850*

Communication Tips for Avoiding Arguments

This 2 hour 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.

*Monday, August 1, 2016; 9:30 – 11:30 a.m.
The Colonnade
19116 N. Colonnade Way, Surprise
To register, call (623)207-1703*

Planning Ahead

This 2 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.

*Wednesday, August 3; 10:00 a.m. – Noon
Banner Sun Health Research Institute*

*10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248*

Dementia Dialogue Webinar Series: Moderate Alzheimer's disease: Facilitating Care Needs

You will find your role as caregiver changing as that of a partner from early stages to more hands on in moderate stage. Join this dialogue to learn how to help your person manage day to day tasks. Keep them safe, and options for outside help.

Wednesday, August 17; Noon – 1:00 p.m. (AZ Time). Register online at www.bannershri.org under events/education and then online education. All webinars are recorded and put on our website 24-48 hours after the "live session"

Free Memory Screening Event

Banner Sun Health Research Institute is offering free memory screenings allowing community participants to screen for potential memory concerns and provide direction to prevention studies and research opportunities. The event will also include information on brain health and information. The memory screening takes up to 30 minutes to complete and an appointment is required.

*Friday, August 19; 9:00 a.m. – Noon
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Building C, Sun City
To register, call (623) 832-3248*

All classes are free, but registration is required.

To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit 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 and click on "Events and Education" or call Veronica Flores, Events Coordinator at 623-832-3248

These programs are made possible by the generous support of the Banner Alzheimer's Foundation.



Banner Alzheimer's Institute
Banner Sun Health Research Institute

