

# BAI BEACON

*The Newsletter from Family and Community Services  
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## ***Maintaining Realistic Expectations***

When someone we care about has been diagnosed with Alzheimer's disease, the world around us takes on a different hue. It creates repercussions within one's circle of family and friends, who all come to be "living with dementia." Even the word "dementia" takes on a life of its own, defining an absolute change in life as it once was. As with every unexpected change in our lives, attitude makes all the difference.

When dealing with dementia, *a new normal* must be defined and one of the key components to this normal is maintaining realistic expectations. By examining where our expectations (or lack thereof) lie, we can begin to formulate a plan for the future. 'Maintaining realistic expectations' is a phrase that is thrown around a lot, especially for those caring for someone with dementia. We need to be sure we have a good understanding of what this phrase means before we can begin to adopt it into our lives. By definition, **Maintaining** is "keeping in good condition by making repairs, correcting problems." **Realistic** refers to "having a sensible, practical idea of what can be achieved, and representing ideas that are true to life." **Expectations** are things we "look forward to or anticipate will happen." Embracing what needs to happen as dementia progresses is vital to quality of life for all. This is not an easy task, but a very critical one.

Dementia causes changes in personality, mood and behavior. When persons develop dementia, their world—both cognitively and emotionally—has begun to change, long before anyone else is aware of any deficits. For this reason, it is often difficult to know what they are still capable of doing and when they need extra help. Think about your own situation. What changes have you seen in your family member with dementia? What changes do you think s/he would say have occurred? What changes have friends, family, or professionals who know you both observed?

You may find, when you think about it, that each person would give a different answer. Perhaps your loved one would say, "I'm a little more forgetful than before, but it doesn't interfere in my life at all"—even though YOU may see examples of how it interferes. Or perhaps, a distant relative who hasn't seen your loved one in a long time notices many areas of decline that you haven't observed in your continual daily interactions. Who is correct? Who is seeing most accurately?

The answer may be that you probably all are correct, at least in part. Although AD is progressive, its day-to-day effects can be very inconsistent. A person with dementia may have trouble performing an activity today that was performed yesterday with ease. S/he may remember one appointment and forget the next. As caregivers, we may come to believe that these inconsistent gaps in ability are because the person "just isn't trying," or "isn't motivated." I have heard it expressed by caregivers that their person is "just doing things to annoy me." This is particularly the case when our demented loved one still has some personality traits that have always been bothersome to us in some way.



## ***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.

Nevertheless, it is important to understand that no matter how similar the actions of a person with dementia are to how he or she acted in the past, their behaviors do not have the same meanings or causes now. The person with dementia is increasingly incapable of fully understanding the consequences of their actions. Their disease may make them unable to remember mistakes they have made or to see how much they need help from other people now. Motivation and insight become skewed, causing a person to no longer initiate activities, or finish activities that they have begun.



Changes in mood are common symptoms. Even though your person looks the same as always, and uses some of the same words and actions to express feelings and desires, changes in the brain interfere with their ability to fully understand what they are doing.

If you find yourself feeling disbelief that many of your loved one's actions are unintentional, you are not alone. This is a normal reaction. However, try to remember that this person has less and less control over his/her actions. Although remembering this may not stop you from getting angry sometimes or becoming resentful or embarrassed, you will get through your feeling more quickly.

Finding new ways to interpret your loved one's actions can be a lifesaver for everyone. Empathy is a most important concept at this junction. Fear is always easier to grasp for some; hope is a much better option! And baby steps are the only safe steps to take from the point of diagnosis forward...

So, let's begin-

It is important to look around and gather what will become your support team, your lifeline. The Alzheimer's Association has a helpline that is available 24 hours a day (800.272.3900), in addition to local chapters that will provide opportunities to meet others and share very vital information. (BAI has incredible support groups!). I have witnessed support group members become close friends, who are available to each other for continual support and guidance. These groups provide a secure, normal environment, where caregivers can safely share stories, laugh, cry, and realize they are not alone on this journey. Reaching out to friends, family, church associates, home health agencies and volunteer members can provide a foundation of encouragement and assistance on which to grow. When families develop the resources they need to succeed, their worlds can change from "help!" to "hope."

Post-diagnosis education equals empowerment. There is such a wealth of information available to assist your understanding

of your person's day-to-day struggles. Imagine waking up from a disturbing dream, i.e. you can't get to your destination in time, your teeth fall out during a speech, someone scary is chasing you. Now, remember that moment when you awaken and feel immediate relief when you realize, "It was all just a dream, I am safe and sound in my own warm bed." Please realize, your loved one with dementia is unable to awaken from that confusing or frightening dream. They must wake up each day and assemble their world again, piece by piece. How valuable is a hug, kiss and warm smile to this person, to reassure and validate their worth?

The internet, Alzheimer's Association, local bookstores and libraries all have valuable resources to facilitate your empowerment. A spouse shared with me that he has devoured countless books on Alzheimer's since his wife was diagnosed a few years ago. Each time he reads another article, he learns another piece of his game plan; a new skill emerges that validates his successful journey as a caregiver. It may be as simple as learning a new bathing technique which calms your loved one, and makes the task more enjoyable. If you've always enjoyed singing in the shower, this is no time to stop! Practice skills that work for you. Sincerity is mandatory; people with dementia are very tuned in to intention.

Nothing is a small victory in this war against a brain-robbing invader. Providing safety and security is huge; what a gift you can deliver! Another way to look at empathy is to equate it with decreased agitation and confusion. When you can anticipate what your loved one is trying to communicate, you've opened the door to trust and acceptance. Facial expressions, gestures and history all tell us what words cannot. Hunger, thirst, pain, confusion, fear- how would you communicate these sensations to others? All human behavior is motivated. So, if you are paying attention to your mood and attitude towards your loved one's conduct, you can become an expert at changing the outcome of any situation!

There is no shame in a diagnosis of dementia. Each individual can still maintain a sense of purpose, and in doing so, command respect from others. Look at your person with new eyes by putting yourself in their shoes; react to their actions with compassion and consideration. Your loved one will rise to meet your expectations if you present a safe and therapeutic atmosphere in which they can thrive.

You must cross over to their side of the street; they can no longer meet you in the middle. If your person could remember, reason, calculate and understand, s/he would! Simplify, agree, be flexible, and most of all, express love and recognition. You just might be pleasantly surprised by the outcome.

Finally, allow yourself to be still. I have never encountered a person with dementia who could not understand intention. Listen to and learn to appreciate feelings and emotions rather than words. Being genuine is being realistic.

Being realistic can provide a safe place to land and regroup.

Connecting with your person on this voyage might just validate a talent that you never realized you possessed, but one that your loved one has always known.

## Ask The Expert

Connie Sands, RN

Registered Nurse, Stead Family Memory Center, Banner Alzheimer's Institute

Dear Connie:

*My husband and I are making a trip back east for a family reunion in the coming months. While we are both excited to see old family and friends, I am a bit nervous for my husband as his memory has faded since our last visit about three years ago. I don't want to be over protective, but I want to make sure he has a good time and people continue to talk with him. What suggestions do you have so that I can try to make this reunion fun and memorable for both of us?*

Signed:  
Teresa

Dear Teresa:

I am so happy you are thinking ahead about how to make this trip pleasurable. I am going to draw from the wisdom of many caregivers who have been successful in this same venture. Here are their suggestions:

- Write a letter/email and send to important people that you are likely to meet up with during your trip. (Not everyone will need this – just the folks that matter)
- Update them on your husband's condition but focus on what he can do—not what he is no longer able to do. Let them know about his favorite daily activities so perhaps they can discuss these activities with him.
- Let them know a bit more about his illness if it makes sense. For example, one of our spousal caregivers wrote to her family telling them a bit about her husband's vascular dementia.
- Most importantly, outline specific ways that each of them can help you to have a great visit. Such ideas include:
  - We are looking older since our last visit so I imagine you are too! Don't be afraid to introduce yourself to him (and me!). He will appreciate the cue you provide.
  - Talk more slowly and give him time to respond – it might take a bit longer but he will love talking with you.
  - Be patient if he repeats himself.
  - If you see his glass getting empty, please feel free to get him another beverage but please avoid alcohol as it makes his memory worse.
  - He loves to talk about (you fill in the blanks)
  - Reminisce with some of your favorite memories as his long term memory is quite good. And, even if he doesn't remember the story, he loves to laugh with others.

Now that you have provided necessary information to them, thank them for their continued love and support. As you travel, be sure he is well rested before attending the reunion. If you see him getting fatigued, irritable, withdrawing, or doing something out of character, remember this is your cue to get him away from the crowd for a rest.

Creating realistic expectations for everyone goes a long way. We wish you a safe trip and many happy moments reconnecting with family and friends.

*To learn more about this topic, we invite you to join us in the Dementia Dialogue Webinar/Teleconference on August 19 from 12N – 1:00pm as Connie Sands, RN discusses more tips on "Maintaining Realistic Expectations." 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)



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## ***CLINICAL TRIALS ANNOUNCEMENT***

### **The AMARANTH Study**

A new clinical research study in early Alzheimer's disease – known as the AMARANTH Study – is underway and we are looking for people who would like to participate. The study will examine an investigational drug that may have some effect on the brain changes associated with Alzheimer's disease. The purpose of the study is to find out whether this investigational drug can influence the decline in memory and mental functioning. "Investigational" means that the drug has not been approved for clinical use, and is still being evaluated in clinical studies.

The AMARANTH Study involves more than 1500 participants from around 175 study centers like ours, in 15 countries worldwide.

The study will last for approximately two years (about 8 weeks to see if you qualify, plus 2 years of treatment, then 4-6 weeks of follow-up). The study treatment will be a tablet to be taken once a day. The tablet will contain either lower-dose investigational drug, higher-dose investigational drug

or a placebo, depending on which group you are assigned to. A placebo tablet is one that contains no active medication.

If you join the study you and your study partner will be asked to attend clinic visits and telephone calls during which we will assess your health with some standard medical tests and questionnaires. We will also ask you about any side effects you may experience. These visits will be every 1 – 3 weeks for the first two months, and then every 6-7 weeks throughout the course of the study (or throughout the treatment period).

To learn more about the AMARANTH Study, call 602-839-6500 and talk with a BAI/BSHRI Clinical Trials Representative.

*Did you know you could help us make the breakthrough that will change lives for generations to come? To support the work of Banner Alzheimer's Foundation, call 602-747-GIVE (4483) or visit [www.banneralz.org/waystogive](http://www.banneralz.org/waystogive).*

## August 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.

*Monday, August 10; 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*

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

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

*Tuesday, August 11; 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*

#### **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, August 25; 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)

#### **Brain G.Y.M. (Grow Your Mind)**

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.

*Tuesday, August 25; 9:00 a.m. – 11:30 a.m.*

*Foundation for Senior Living, Caregiver House*

*1201 E. Thomas Road, Phoenix*

*Free but registration is required.*

*To register, call (602) 230-CARE (2273)*

### MESA

#### **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, August 18; 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

## August 2015 Program Schedule

### CAREGIVER EDUCATION PROGRAMS

#### SUN CITY

##### **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.

*Monday, August 3; 1:00 p.m. – 2:30 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*

##### **BSHRI Lecture Series: Myths and Truths: ALTCS (Arizona Long Term Care System)**

Learn the services, eligibility requirements, and options to pay for care using a Myths and Truths process.

*Wednesday, August 12; 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*

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

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

*Tuesday, August 18; 3:00 p.m. – 5:00 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*

#### SUN CITY (CON'T)

##### **BSHRI Lecture Series: The Good News; The Latest in Alzheimer's Research**

Join Dr. Marwan Sabbagh as he updates us on the latest findings in Alzheimer's research.

*Wednesday, August 28; 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*

#### WEBINAR/TELECONFERENCE

##### **Dementia Dialogues: Maintaining Realistic Expectations as Dementia Progresses**

With the continual changes you see in the person you care for, it can seem absolutely unrealistic and be difficult to maintain perspective on the stage of dementia, the help you need as a caregiver and future care needs. However, as dementia progresses, it becomes even more important to possess realistic expectations. Learn what is realistic, and what can be expected in an unexpected disease.

*Wednesday, August 19; Noon – 1:00 p.m. MST (AZ Time)*

*Free webinar but registration is required online at [www.bannershri.org](http://www.bannershri.org) under event/education and online education. Any questions in regards to this program, call (623) 832-3248*