

BAI BEACON

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

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Understanding Early Stage Alzheimer's Disease

Alzheimer's disease, by definition, has as its main early symptom, that of *forgetfulness*. It is *insidious* (gradual) in onset, literally sneaking up on one like a snake in the grass. One of the challenges of Alzheimer's disease lies in recognizing the early signs or symptoms. In fact, the symptoms are subtle, intermittent, easily missed and/or often attributed to "old age". The person who is developing memory loss can also compensate or cover up for his or her gradually increasing difficulties. We often see the person using humor, talking around a word not remembered at a moment, or by relying on notes and/or a day planner. A spouse may gradually accommodate to the changes in a loved one with changing memory. Often the family only becomes aware of the extent of decline in memory and function upon the death of or serious illness in the spousal caregiver. Other barriers to recognizing and addressing the early symptoms of Alzheimer's disease include denial on the part of the family, and the lack of insight or awareness on the part of some people with memory loss. In the latter case, the person who is experiencing the memory loss can also have *personality changes*. It is not uncommon for the person to develop anger and irritability which can make it difficult for families to get their loved one into a physician for evaluation of their symptoms. Those people who experience a decline in memory and function, without awareness of their problems, also present unique challenges in addressing their changing abilities to handle their affairs and to live alone or to be left alone.

If we look at the early changes in memory, thinking and function, we see difficulty with *short-term or more recent memory*. Newly obtained information is quickly lost even



though the person was engaged in hearing the content. There is trouble remembering a word or name and the person is much more prone to misplacing and losing items. Accusations of theft may occur by the person who cannot retrieve lost things. At the same time, there is more difficulty with *awareness of time* thus appointments or important dates are forgotten or met with repetitive questioning.

Changes in function become quite obvious over time. Once efficient in the home, the person now has difficulty organizing and managing household affairs which used to be done both well and automatically. Over time, this translates as having trouble with shopping, cooking, cleaning and other house or yard work. The person will struggle with managing medications; including taking medications per instructions and reordering medications as needed. It is not uncommon for the person with memory loss to resist efforts of the spouse to assist with medication reminders. Driving will create new challenges as the person may be prone to getting lost, need more cues from passengers, drive too close or too far away from other cars, just to name a few issues. Finally, managing finances can become problematic as the person may forget

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.

to pay bills, struggle to balance accounts, or make important financial decisions. Use of tools, electronics, phones and household appliances becomes more problematic. And, ability to learn new information becomes very challenging, if not impossible.

A person's *ability to initiate activities* or chores gradually becomes impaired, and he or she begins to spend more time sitting, often in front of the television. Also changing are the person's ability to focus or to concentrate, to follow more complex plots in TV shows, movies or books; or to engage as fully in a social setting as they might have in the past. The person is now becoming more of an observer than participant. The person's *mood* may become more socially withdrawn, depressed or anxious. Some may become more resistant to leaving the house. Where the person would have been fully autonomous, or able to live and to function fully independently, he or she shows *changing judgment and reasoning*. The ability to understand more complex discussions and to reach well informed decisions or to interpret a situation appropriately and safely has now been compromised. The person may spend money inappropriately, leave stove burners on, and be prone to exploitation from scams, outsiders or even some family members. However, he or she does retain long term memory and the ability to manage personal care stays intact during the early stage.

Over the course of 1 to 3 years, a person with evolving changes in memory, thinking, mood and function gradually needs supervision or assistance to accomplish chores or tasks. And more specifically, extra support is needed for his or her physical and emotional wellbeing and safety.

Seeking a medical evaluation is important for establishing the diagnosis, initiating treatment with medications which might slow, but not prevent disease progression. Obtaining the diagnosis is also essential for gaining understanding of Alzheimer's disease and its associated issues. The evaluation will consist of a detailed interview with the family and patient, reviewing the medical and social history, identifying observed changes in daily living and function, cognitive testing, physical and neurological examination, lab and imaging studies. The evaluation essentially rules out other identifiable causes of memory loss, and identifies a pattern of changes consistent with Alzheimer's disease (see January 2016 Beacon for more detail on diagnosis). Learning

about research options can also be helpful at the time of diagnosis as new treatment options continue to develop and be studied. Being a part of a clinical research study can add benefit for many. It is important to ask the physician about this as another option for care.

Once diagnosed, identifying the critical issues and developing a plan to address them needs to be initiated. Planning ahead for things like giving up driving, assuming financial management, knowing when someone can no longer be alone is of utmost importance. Financial and legal counseling, estate planning, and completing advanced care directives are all critical in the early stage, if not already done. Accessing educational and support opportunities will be of benefit to both the patient and the family. Establishing daily predictable routines, creating opportunities for social, mental and physical engagement or activities; and managing mood or personality changes in the person with dementia will be essential in allowing for successful day to day living for all.

While getting a diagnosis of Alzheimer's disease can be difficult to hear, and living with the disease can be challenging, the course can be less overwhelming when planning for change is done ahead of time. Crisis situations can be avoided when people are well informed. Likewise, finding support early in the disease allows a person with Alzheimer's disease to do better in the long run. As the condition is disclosed to family and friends, they too can better support the affected person and assist with continued engagement in activities which are pleasurable and meaningful. It is equally important for family and friends to become partners in care and this will require learning new skills. Support now and for the future is essential to ensure the caregiver's health is not compromised. Learning to ask for and accept help will be a new skill that many will need to learn. However, these lessons will take time, patience, practice and persistence.

In the upcoming editions of the Beacon, we will discuss specific details on improving day to day function in early stage Alzheimer's disease and how to stay socially connected to improve mood, function, and well-being for both the affected person and care partner. For more information on early stage Alzheimer's disease and necessary planning during this stage, we invite you to join the Dementia Dialogue webinar/ teleconference on April 20, 2016 from 12N - 1p.m. (AZ time) with BAI dementia experts Helle Brand, PA and Mary Lou Hernandez, LCSW. Registration is required and must be done online at www.bannershri.org under events and education and online education OR you can call 623-832-3248.

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 or call 602-747-GIVE (4483).



Ask The Expert

William Burke, MD
Director, Stead Family Memory Center
Banner Alzheimer's Institute

Dear Dr. Burke,

My husband was recently diagnosed with Alzheimer's disease and started on Aricept. However, I have not seen any improvement in his condition. I've read that the medications for Alzheimer's disease don't seem to make much of a difference. What is reasonable for me to expect with his treatment?

Signed,
Pam

Dear Pam,

This is a very important question that I often receive from family members. The overall goals of treatment of Alzheimer's disease include improving memory, minimizing or improving problematic behaviors and slowing the disease progression to optimize daily life. A treatment regime will generally include use of current Alzheimer's medications, managing other health issues, treating any changes in mood, maximizing diet, exercise and social engagement; and exploring clinical research/study options.

Currently, there are four FDA approved treatments for Alzheimer's disease. Three of the medications are in the same category and are known as cholinesterase inhibitors. These drugs, donepezil (Aricept), rivastigmine (Exelon) and galantamine (Razadyne) act by slowing the action of the enzyme that breaks down acetylcholine, an important chemical in the brain for memory. This allows for higher levels of acetylcholine in the brain. This can result in people with Alzheimer's disease maintaining thinking, memory, speaking, activities of daily living, and hopefully slowing the progression of these symptoms. The second type of medication used acts by regulating the activity of the chemical glutamate. This medication is called memantine (Namenda) and can result in improvement in attention, language, and the ability to perform simple tasks (such as grooming and dressing to name a few) in the moderate to severe stage of the illness. Because these drugs work in different target areas, memantine is frequently used in combination with one of the cholinesterase inhibitors. As dementia progresses to the moderate and severe stages, there is evidence that use of memantine with donepezil or rivastigmine has a positive effect on the person's function and activities of daily living or personal care abilities. However, none of these medications are curative – they will simply slow the progression of the disease. The goal is to help people maintain independence in daily function for a longer period of time.

If your husband has other health issues, it is important to provide careful attention to managing these chronic conditions. Poor control of these conditions can also contribute to decline in memory, thinking and function. Depression and anxiety are also common in many people with Alzheimer's disease. Medications to manage mood, such as antidepressants can be very helpful as well. In addition, routine exercise, eating a heart healthy diet and staying socially active will benefit your husband (and you!).

You may also want to talk with your medical provider about any new research studies that may benefit your husband. While most studies are "double-blinded, placebo-controlled," (which means that neither the research participant nor the study team know if the person is receiving the study medication/treatment or control), in my experience most participants and their study partners benefit greatly. Not only do each receive extra attention from the study team, most feel a real sense of accomplishment by participating in studies that may have benefit now or in the future.

As your husband's partner in care, your input moving forward will be essential. I encourage you to come prepared as you meet with your husband's medical team. Report changes you are seeing – both positive and negative. Ask questions about his condition, medications, suspected side effects and any concerns you may have. Don't be afraid to call his medical team as the condition changes – you don't need to wait until the next visit. You are the "eyes and ears" to what is happening to your husband. Thank you for being an engaged and caring wife!

Have a Question?

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



Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Steps to Take Following Diagnosis

Get Educated about the condition

- Attend a class at BAI/BSHRI (visit www.banneralz.org/education-events)
- Tune into an online education program or webinar (www.banneralz.org/education-events/online)
- Look into a local Alzheimer's Association class (www.alz.org)
- Read books and online sites (www.alzheimersreadingroom.org)

Get Connected!

- Attend a support group
— Look for Early Stage/Partner groups
- Stay socially engaged with friends/family
- Get involved in a life enrichment program (www.banneralz.org/education-events/life-enrichment-programs)

Plan for the Future

- Think about how and to whom you will disclose the dementia diagnosis
- Complete any necessary financial/legal planning
- Have important discussions about end of life care, complete advance directives and appoint someone to serve as your decision maker
- Have discussions about what type of care will be needed in the future and what preferences would be; e.g. “When you can no longer live alone in your home, would you prefer to have help in your home or move to a residential setting?” “When you can no longer stay alone and need supervision, would you prefer a home care companion or attend a Day club?”
- Begin to think about who you can ask for help now and in the future
- Care partners must think about factoring in time away for their own self-care
- Explore what is in your local community by connecting with your local area agency on aging (www.n4a.org)
- Attend a “Planning Ahead” class at BAI or watch it online (www.banneralz.org/education-events)



CAREGIVER EDUCATION PROGRAM SCHEDULE

April/May 2016

APRIL

Keeping the Person with Dementia Occupied

Keeping people with dementia engaged and mentally stimulated is often challenging for caregivers. This 90-minute 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.

Tuesday, April 19; 10:00 - 11:30 a.m.
Mesa Red Mountain Library
635 N. Power Road, Mesa
To register, call (602) 839-6850

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.

Thursday, April 7; 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, April 12; 10:00 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.

Thursday, April 14; 4:00 - 5:30 p.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

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.

Friday, April 22; 10:00 a.m. - 12:30 p.m.
Foundation for Senior Living
1201 E. Thomas Road, Phoenix
To register, call (602) 839-6850

Free Memory Screening

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, April 29; 9:00 a.m. - Noon
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

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.

Friday, April 15; 10:00 - 11:30 a.m.
Granite Reef Senior Center
1700 N. Granite Reef Road, Scottsdale
To register, call (602) 839-6850

Understanding Options to Pay for Care: ALTCS (Medicaid) and 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.

Friday, April 8; ALTCS (10:30 - 11:30 a.m.) & VA Benefits (Noon - 1:00 p.m.)
Pyle Adult Recreation Center
655 East Southern Avenue, Tempe
To register, call (602) 839-6850

BSHRI Community Lecture Series: Is it Essential Tremor or Parkinson's? What's the difference?

In Honor of Parkinson's disease Awareness Month, Dr. Shprecher will be speaking on distinguishing the difference between Essential

Tremor and Parkinson's as both of these disease are always mistaken as the same.

Wednesday, April 6; 10:00 - 11:30 a.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248

COMPASS: Directions for Caregivers after the Dementia Diagnosis in ESPANOL

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. This class will be conducted in Spanish as well as the materials provided will be in Spanish.

Tuesday, April 12; 1:00 - 2:30 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (602) 839-6918

BSHRI Community Lecture: Non-pharmacological and complimentary therapies for Parkinson's

This 90 minute lecture will discuss Parkinson disease as a chronic disorder that requires broad-based management. Join us as we discuss viable treatment interventions outside of traditional pharmacotherapy and surgery.

April 20, Wednesday 2:00 - 3:30 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: Early Stage Alzheimer's disease: What is it?

There are a number of subtle changes that occur in memory, thinking, emotion and function in the person with early stage AD. This dialogue will review common changes associated with early AD, treatment options, and important health care, legal, and financial decisions that should be addressed.

Wednesday, April 20; 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".
To register, call (623) 832-3248

Please turn over for more classes →

MAY

Planning Successful Travel

Travel can still be enjoyable for someone with dementia but extra time, effort and planning will be needed. This 60-minute class will provide methods on how to make trips as successful as possible.

Tuesday, May 17; 10:00 – 11:00 a.m.
Mesa Red Mountain Library
635 N. Power Road, Mesa
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, May 10; 4:00 – 6:00 p.m.
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.

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

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 the both the person with dementia and caregiver. This class will address the most common types of behavior problems and pose a variety of solutions that caregivers can easily utilize.

Thursday, May 19; 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.**

Wednesday, May 25; 1:00 – 3:30 p.m.
Banner Alzheimer's Institute
901 E. Willetta Street, Phoenix
To register, call (602) 230-CARE (2273)

Free Memory Screening

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, May 13; 9:00 a.m. - Noon
Granite Reef Senior Center
1700 N. Granite Reef Road, Scottsdale
To register, call (602) 839-6850

BSHRI Community Lecture Series: Helping Caregivers Find Meaning While Living with Loss

Caring for someone with dementia creates ongoing awareness of loss as the person with dementia is physically present but psychologically different from who they once were. This can be confusing and overwhelming for family and others who care about them. This presentation will focus on strategies to infuse hope and meaning into one's life while providing care in order to cope with continual changes.

Wednesday, May 4; 10:00 – 11:30 a.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248

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.**

Tuesday, May 10; 1:00 – 3:30 p.m.

Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call 602-230-CARE (2273)

BSHRI Community Lecture Series: 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 make a difference.

Wednesday, May 18; 2:00 – 3:30 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Drive
Morin Auditorium, Sun City
To register, call (623) 832-3248

Planning Successful Travel

Travel can still be enjoyable for someone with dementia but extra time, effort and planning will be needed. This 60 minutes class will provide methods on how to make trips as successful as possible.

Tuesday, May 24; 1:00 – 2:00 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: Early Alzheimer's disease: Living Day to Day

Fatigue, change, and overwhelm become enemies of the person living with early stage AD. Now is the time when caregivers will benefit from using a daily routine and negotiating how to partner in tasks like medication management. Join the Dialogue and learn these and other useful strategies for living day to day.

Wednesday, May 18; 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".

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