

BAI BEACON

The Newsletter from Family and Community Services
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It Depends: Answers to Uncertain Questions in Dementia

Families receive information about Alzheimer's disease/related dementias from a wide variety of sources including newspapers, magazines, fictional novels, the internet, social media, Alzheimer's Association, support groups, public forums, friends and family. Often times, the information obtained conflicts with other sources or may not apply to your personal situation. For example, families with a person who has Lewy body dementia may gather information on Alzheimer's disease assuming the diseases are essentially the same when in fact, there are striking differences.

At Banner Alzheimer's Institute (BAI), answering your questions is an important part of our mission and care. Families need a wide variety of information and education which is why, depending on your needs, you see a variety of professionals including your physician, social worker, advanced practice nurse, physician assistant, neuropsychologist, and/or researchers. Each professional will answer your questions related to the scope of their practice. However, there are certain questions we cannot answer with total certainty. Following are some of the most common questions we receive in which we begin our discussion with, "Well, it depends...."

"How long will the disease last?" or "How long will my person live?"

People with Alzheimer's disease/related dementias are often older and have multiple medical problems. While some can live as many as 20-30 years with the illness, the average life expectancy is generally 8 - 10 years following the diagnosis. Even in the advanced stage, a person can live another 1 - 3 years. We often ask families to think about how much change they have seen in the person over a given year and then apply that same rate of change to the coming year.

"When won't my person know me?"

As dementia progresses it worsens memory for facts, names, and images; and putting names to faces is particularly difficult. It is not uncommon for the person to use the incorrect name for a family member but know who the person is to them. We typically see individuals lose memory for more distant friends and relatives (e.g. grandchildren) long before forgetting a spouse or adult children. In advanced dementia, it is unlikely that the person will connect the name or face to the family member; however, they will always know when they are in the presence of someone who loves them.

"When does the violent stage start?"

The vast majority of people with dementia do not become violent. In moderate to advanced dementia, some will become resistant to personal care, especially when placed in a shower or bath. Many people feel vulnerable being naked and cold; some will panic as the water hits their face and want it to stop. Assisting with toileting is also difficult and can lead the person to slap a caregiver's hand, kick, or bite. This "resistance to care" should be viewed as self-protective behavior and will require the caregiver to learn distracting and non-confrontational techniques.

NEW PROGRAMS IN 2015



"Dementia Dialogue Series: Connecting Caregivers to Experts in Dementia Care" — *This new monthly Webinar/Teleconference series will parallel the Beacon newsletter and expand upon important topics that our readers have requested. For a full listing of topics, see the "2015 Caregiver Program" insert.*

Caregiver Focus (Finding Optimal Conditions Under Stress) Series — *This monthly caregiver program on the 3rd Thursday of each month, will provide a variety of self-care strategies for improved health and well-being (see Beacon Bits).*

“When should I stop the medications as I hear they only work for 6 – 9 months?”

There is a lot of conflicting information about the use of medications to treat Alzheimer’s disease/related dementias. There is no “one- size- fits all” treatment for these illnesses and it should be understood that the current medications (Aricept/donepezil; Exelon/ rivastigmine; Razadyne/galantamine; and Namenda/ memantine) are not curative. Rather, these medications may help people with dementia to maintain daily living skills longer in the illness. They may also help to prevent the emergence of behavioral and psychiatric symptoms such as depression, paranoia and delusions. Generally well tolerated, these medications will be used into the advanced stages of the illness. If patients or families want to stop these medications during the course of the illness, we strongly suggest that they work directly with the physician to do so as sudden withdrawal for some will lead to dramatic loss of function and even agitation.

“When is it time for the person to stop driving?”

Sometimes taking the car keys is an obvious decision and must be done immediately such as when the family observes unsafe driving, getting lost, missing traffic signals, etc. However, since driving represents independence, families are reluctant to take the privilege away too soon. It is important to recognize that driving is impacted even early in the illness as there are vision/perception changes in dementia. Slowed processing of incoming information for decision making combined with memory changes render the person at greater risk for an accident. We recommend that a designated family or friend routinely ride with the person to assess driving or have the person’s driving evaluated by a professional (contact BAI for a list of driving programs).

“When is the ‘right time’ to move the person to a residential facility?”

There is no “right time” for placement in assisted living, memory care, or a group home. Placement depends entirely on the caregiver and/or family. As the person’s dementia worsens, care becomes more physically demanding. Family caregivers vary enormously in how much care they can give and how providing that care will affect their physical and emotional health. As a general rule families find the following to be tough to manage at home: urinary and bowel incontinence; aggression that does not respond well to treatment; wandering away from home; not sleeping at night; and resistance to care. For the person who lives alone, movement into a structured setting will often occur earlier and ensure both safety and opportunity to be connected to others. In our experience, while transition is difficult for the person and the family, most people with dementia will adapt well into the new setting and the renewed energy from the well-rested family will improve the quality time with their person.

“How can I get Medicare (or other insurance) to pay for care?”

Medicare does not pay for long-term care unless the person has rehabilitation needs or a specific time-limited skilled service (which usually follows a hospitalization). While the care of someone with moderate to advanced dementia takes tremendous skill, it is categorized as “custodial care.” If the person with dementia has a long term care insurance policy they will likely have some or all of their care covered. Unfortunately you cannot purchase long term care insurance following the dementia diagnosis. For those who qualify for Medicaid, known as Arizona Long Term Care Services (ALTCs), this will assist families to pay for care at home or in a residential setting.

These are just a few of the questions for which we have “it depends” responses, but we encourage you to keep asking. Many questions that had no answers years ago now have answers. So, use the Baby Boomer mantra: “Question everything!” To continue this conversation, we encourage readers to join in our Webinar/Teleconference on Wednesday, January 21, 12N – 1:00p.m. (Registration information in Beacon bits) Helle Brand, PA and Mary Lou Hernandez, LCSW will lead a discussion on “Everything you ever wanted to know about dementia but were afraid to ask.” Come prepared with your questions!



Ask The Expert

Mary Lou Hernandez, LCSW
Social Worker, Stead Family Memory Center

Dear Mary Lou:

I have been caring for my wife with Alzheimer's disease for the last six years. Unfortunately my health is failing and I am finding it more difficult to take care of her needs. I have found a wonderful group home about two miles from my home and I think they will take good care of her and will be close enough for me to visit her every day. I love her so much and don't want her to think that I am abandoning her. How do I explain to her that I must move her from our home into this new place?

*Signed,
Ted*

Dear Ted:

What a devoted husband you are and will continue to be as you oversee your wife's care in this new setting. Because your wife's memory and thinking has been impacted by her illness, explaining a move to her will only serve to frustrate her and increase her anxiety, especially if she sees you getting emotional. I suggest that you have a family member or friend come to your home and stay with her while you go to the new home and prepare your wife's room with her favorite things. Sensory objects such as a favorite pillow and blanket will feel welcoming to her. Bring pictures of favorite people in her life and help the staff to know who these people are. I also recommend that you write up a brief life story about your wife and share it with the staff so they know about your wife and her preferences. Also share any routines/rituals that she finds particularly comforting so that they can use these as well.

Once the room is settled, go home and pick up your wife, and bring her to the new home. Stay with her for a meal and then let the staff take it from there. You have helped the staff to know her a bit better and now will come a period of her adapting to this new setting. Go home and get a good night sleep and then plan to come in for your daily visits. Over the course of the coming weeks, you will both adjust to this new living situation. Focus on your own health and well-being which will help you enjoy quality time with her. With no explanations needed, you will both succeed with this change. I wish you all the best.

Have a Question?

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

Clinical Trials Announcement

Healthy seniors: help us shed light on Alzheimer's disease. Despite progress being made in our understanding of Alzheimer's disease (AD), there's still a lot we don't know. Currently, there is no cure for Alzheimer's...and no way to delay its symptoms. The TOMMORROW study seeks to learn more about the early phase of Alzheimer's—a phase referred to as mild cognitive impairment due to Alzheimer's disease (or MCI due to AD). This important clinical research study is now seeking healthy senior participants between the ages of 65 and 83. To learn more: Call 602-839-6500 or visit www.TOMMORROWStudy.com

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.

Did you know, Banner Alzheimer's Institute is a not-for-profit and relies on financial contributions of the community to support programs and services offered to our patients and families? Make a gift and join our community of friends, call 602-747-GIVE (4483) or visit www.banneralz.org/waystogive.



Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

BEACON BITS

COMPASS: Directions for Caregivers after the Dementia Diagnosis

Thursday, January 8, 10:00 - 11:30 a.m. *OR*
Monday, January 19; 4:00 - 5:30 p.m.
Banner Alzheimer's Institute, 901 E. Willetta St., Phoenix
Free but registration is required. To register, call (602) 839-6850

GPS Lecture for Caregiving: Try this, Not that: Solutions for Common Behaviors in Dementia

Dementia experts Lori Nisson, LCSW and Helle Brand, PA will address a variety of behaviors with strategies that are likely to minimize, if not eliminate, common behavior problems.

Friday, January 9, 10:30 a.m. - noon
Banner Sun Health Research Institute, 10515 W. Santa Fe Dr., Sun City
Free but registration is required. To register, call (602) 230-CARE

COMPASS: Directions for Caregivers after the Dementia Diagnosis

Monday, January 12, 4:00 - 5:30 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Dr., Sun City
Free but registration is required. To register, call Veronica (623)-832-3248

Planning Ahead Class for Caregivers

Tuesday, January 13; 4:00 - 6:00 p.m.
Banner Alzheimer's Institute, 901 E. Willetta St., Phoenix
Free but registration is required. To register, call (602) 839-6850

Caregiver FOCUS: A Mindful Approach to Self-Care

Caregiving expert, Debbie Harbinson, RN, MHI, will help caregivers to increase attention and awareness in the daily caregiving experience to reduce stress and strive for balance.

Thursday, January 15, 12:30 - 1:45p.m.
Banner Alzheimer's Institute, 901 E. Willetta St., Phoenix
Registration is required. To register, call (602) 839-6850

COMPASS: Directions for Caregivers after the Dementia Diagnosis

Tuesday, January 20, 10:00 - 11:30 a.m.
Banner Heart Hospital, 6750 E. Baywood Ave., Mesa
Free but registration is required. To register, call (602) 839-6850

Dementia Dialogue: Everything You Wanted to Know about Dementia and were Afraid to Ask

BAI experts, Helle Brand, PA and Mary Lou Hernandez, LCSW, will review the basics of Alzheimer's disease and open the session to your unanswered questions.

Wednesday, January 21, 12N - 1:00p.m.
Webinar or Teleconference . Free but registration required.
For Webinar, register at: <https://attendee.gotowebinar.com/register/439275049554995201>; Webinar ID: 147-646-643
For Teleconference registration, call Veronica at 623-832-3248

As Dementia Progresses

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

Planning Ahead Class for Caregivers

Monday, January 26; 3:30 - 5:30 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Dr., Sun City
Free but registration is required. To register, call Veronica (623)-832-3248

Memory Screening Event

Friday, January 30, 9:00 a.m. - 1:00 p.m.
Via Linda Senior Center, 10440 E. Via Linda, Scottsdale
Free but registration is required. To register, call (602) 230-CARE