

BAI BEACON

*The Newsletter from Family and Community Services
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Understanding Advanced Alzheimer's disease/Dementia

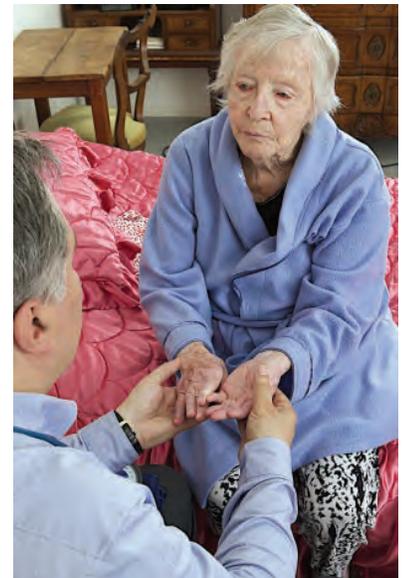
Throughout 2016, we have described in detail the early to moderate stages of Alzheimer's disease. Practical tips have been outlined for our readers to provide assistance with care while also assisting both the person with dementia and caregiver to stay engaged and connected. Now we discuss a more difficult phase of Alzheimer's disease and related dementias – the advanced stage. This stage can take both a physical and emotional toll on the affected person and the family due to the progression of the illness. And while much of the focus is on the accumulative losses experienced by the person and family, there are still opportunities to find meaningful connections.

Advanced dementia is also referred to as late stage Alzheimer's disease or severe dementia. It can include the terminal or final stage of the illness. Because the underlying illness spreads throughout the brain, the person with advanced dementia now loses all independence in daily life. Communication is quite limited and often the person's behavior signifies an unmet need. Memory is severely impaired, so the ability of the person to call someone by their name or role is lost (e.g. "Ed is my husband"). However, this should not imply that the person with advanced dementia is not aware that they are in the presence of someone who loves and cares for them. While usual language is lost, the ability to understand non-verbal communication, such as facial expressions and verbal tone, stays strong until the end. And, there can often be windows of lucidity as the person communicates words of importance!

There will be changes in motor function as the disease progresses. Walking becomes more difficult and eventually leads to immobility. However, keeping the person moving as long as possible is essential, even if it only means

moving from a sitting to standing position and taking a few steps. Movement is freedom and most people with advanced dementia will not readily welcome a wheelchair! Finding comfortable seating and positioning (including in bed) is critical as the ability to reposition is very limited. For those living at home, families will find that lift chairs provide comfortable seating and can assist the person to rise in order for the family

to walk or transfer them. Likewise a hospital bed may be helpful for families to provide care as mobility changes. Ideally, an electric bed is best that adjusts height, head and feet to minimize the strain of caregivers as they transfer or lift the person. Finally, family caregivers should purchase a gait belt that can be secured around the person's waist and used for support during lifting or transferring. A home health care physical therapist can teach family caregivers how to use the gait belt along with other safety measures to transfer/move the person in order to prevent a back injury. Working with the medical team to obtain physician orders for home medical equipment, home health care and insurance authorization is crucial.



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.

Changes in eating and drinking will need additional accommodation. Food continues to be one of the most pleasurable events during the day for most. As noted well before this time, people with dementia develop a clear preference for soft textured, sweet foods. Some individuals will still be able to hold a cup or a spoon but will get easily fatigued or distracted during meal time requiring the caregiver to prompt eating/drinking. Most will forget to chew and/or swallow food so it is important that the texture allow for easy swallowing. Many people will accept pureed food while others will prefer whole foods such as applesauce, yogurt, protein shakes, peanut butter and jelly sandwiches. The most important thing to note is the person's pleasure when eating food. Now is not the time to worry about the food pyramid – it is time for the comfort and joy of food; focusing on those foods the person enjoys and consistently accepts! Where a meal could once be consumed in 30 minutes, now it can take up to an hour to feed the person. Small more frequent meals should be considered and should be timed when the person is awake.

Providing adequate fluids can also seem like a daunting task. Using a small 4 ounce glass with a straw can be ideal as large beverage containers can be overwhelming. Provide whatever fluid the person is willing to accept. It does not need to be water. Room temperature fluids are often best and include apple and cranberry juices. If the person starts to choke on thin liquids, it will be essential to provide a thicker consistency. There are a variety of “thickening agents” that can be purchased commercially to add to fluids that help to prevent choking. Getting the person to eat and drink requires time and patience as the goal is to prevent aspiration of food and fluids into the lungs that can lead to pneumonia.

Support will also be required for toileting and managing incontinence which results as the person can no longer respond to the body's cue to independently urinate or have a bowel movement (BM). A good adult brief is necessary to collect and pull the urine away from the person's bottom. But even with the best of adult briefs, it is important that the person not sit in a soiled brief for long as it can lead to urinary tract infections and skin breakdown. Ideally, if the caregiver can learn the person's habit for a BM (which is generally in the morning following breakfast with some coffee), sitting on a toilet is much more comfortable than having a BM in an adult brief. Likewise, if the caregiver is able to put the person on the toilet for urination a few times throughout the day, it will decrease the amount of wet briefs. Underpads, either washable or disposable, are useful in protecting both chairs and beds. Not all products are alike so it can be helpful to shop around. Sometimes paying more for a product will be more cost effective in the long run.

Family caregivers will note that as dementia progresses, the sleep-wake cycle continues to change. The person can often sleep up to 16-20 hours/day. During the wakeful hours, important activities include eating, bathing, moving, and participating in brief but meaningful activities. While many think the person with advanced dementia

cannot or will not participate in activities, nothing could be farther from the truth. However, connecting with modified activities that reflect lifelong preferences and pleasure is the best. **Please note the November 2016 Beacon will discuss specific strategies for families to stay connected during advanced dementia.

Due to the physical demands of caring for a person with advanced dementia, many families will transition care to a residential facility. Caregiving does not stop when the person no longer resides at home. But, the role can shift from providing care to overseeing care – an equally important role. If care is transitioned out of the home or if care is brought into the home, it is imperative that these paid caregivers know who the person with advanced dementia is! A short biography or life story that introduces staff to your person will allow them to be more successful when providing care. (See Tips to Creating the Life Story).

A final important task for family caregivers is to understand and carry out health care decisions that will likely play out during this final phase of the illness. Since Alzheimer's disease/related dementias are now a leading cause of death, it should come as no surprise that decisions regarding end of life care must be addressed. Most people with advanced dementia will die from infection, usually due to aspiration pneumonia or urinary tract infection. Ideally, discussions about end of life care should have happened well before this point. If not, your medical provider should understand what your person's preferences (or yours as Medical Power of Attorney) are around use of: cardiopulmonary resuscitation (CPR), feeding tubes, hospitalization, intravenous hydration, and/or use of antibiotics to treat infection. If you are unclear about what is to come, we recommend that you schedule an appointment with your primary care physician or dementia specialist and clarify these decisions before a crisis strikes. Ask about the hospice care benefit for dementia that can provide care for your person and support for you wherever your person resides. Hospice is an insurance (Medicare) covered benefit that brings a team of professionals to ensure a comfortable death. It is never too soon to begin discussing these final care decisions.

In summary, advanced dementia is the final phase in this chronic condition and can last from 1-3 years. It requires constant assistance by caregivers to meet daily needs. Families continue to learn new skills to not only provide care, but monitor care and continue to seek to connect to their person. For more detailed information on this topic, we invite you to join the Dementia Dialogue Webinar/ Teleconference on October 19, 2016 from 12N – 1pm Arizona time. BAI dementia expert Jan Dougherty, MS, RN, FAAN will facilitate the discussion. To register, visit www.banneralz.org (education and events) online education or call 623-832-3248.



Ask The Expert

Dr. William Burke, MD

Director, Stead Family Memory Center at Banner Alzheimer's Institute

Dear Dr. Burke,

My father has been a fantastic caregiver for my mom who now is in the late stage of her Alzheimer's disease. He moved her to a wonderful care facility near his home so he can go in every morning and help feed her breakfast. He expressed some concerns to me recently about all the medications she continues to receive because she has started having some difficulty with swallowing. At this point both of us are wondering if there is any benefit to her continuing any of her medications, including those she takes for her Alzheimer's?

Sincerely,
Mark

Dear Mark,

Routinely reviewing medications is an important task that all medical providers should complete at least annually or when a patient's condition has changed. In this case, it seems your mom's condition has changed now that she has advanced Alzheimer's disease. Now is the time when the focus of her care is on comfort versus cure. Each medication should be reviewed with that perspective in mind. Is the medication aiding in her overall comfort v. adding years to her life? For example, if she is taking medication for high cholesterol, at this point there is probably no added benefit and therefore it could be stopped. The same might apply for over the counter vitamins or supplements. The physician overseeing her care should carefully evaluate each medication using that principle. For medications that are continued, some of them may come in liquid form or be crushed and put in applesauce.

In regards to added benefits from her medications for her Alzheimer's disease, I would suggest you speak with her dementia specialist. If the decision is made to discontinue any/all of these medications, I would suggest slowing taking her off one medication at a time. If you see no change in her overall function, mood or behavior, then it is probably safe to discontinue the medication. However, if you do see a decline in function, mood or behavior, it could be that medication was adding to her comfort. As one example, I have cared for a person where taking one of these medications was the difference between being mute vs. being able to communicate with their spouse. When one of these medications is stopped a period of careful observation before and afterwards is essential.

Since you and your dad know your mom well, keep an eye on anything that represents discomfort such as facial grimacing, clenched fists, moaning, striking out, and restlessness, just to name a few. These "behavioral expressions" often represent unmet needs from hunger, thirst, a soiled brief, and even pain. Report these to the caregiving staff. Often non-drug strategies can minimize discomfort including light massage, music, favorite treats, and engagement in a brief but pleasurable activity. Let the staff know of comfort measures you have used for your mom at home so they can try them too. If you suspect pain that is usually due to lack of movement, you may ask the staff about the routine use of liquid acetaminophen (Tylenol) which can add to her overall comfort.

Your mom is lucky to have two advocates who will ensure that her comfort needs are met to the end. I wish you and your dad the best as you continue to care for her.

Have a Question?

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

A charitable bequest is a wonderful way for you to help further the work of Banner Alzheimer's Foundation and its mission of delivering care and hope to families while advancing research. To learn more, please contact us at (602) 747-GIVE (4483) or plannedgiving@bannerhealth.com.



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Tips to Creating the Life Story

Each of us has an important life story to share. Now is the time to share the story of your person with others so each can find a more meaningful way to care and support him/her. Be sure to include in the story:

- Name/preferred name
- Place of birth or favorite place lived
- Favorite people (including relationship)
- Favorite memories including life work
- Hobbies and interests
- Things that bring peace/relaxation
- Favorite movies, TV shows, sports
- Favorite music, songs, sound preferences
- Forms of touch (or no touch!)
- Favorite food and beverages
- Sleeping habits
- Rituals (eating, bedtime, quiet time, prayers)
- Things that are disliked

On a piece of paper, you can use each of the categories as a header and then fill in the blank with the pertinent information. Once this is complete, think about placing it in a location that those who support your person can see it.

The Life Story

My name is: _____ I prefer to be called: _____

I was born in (city and state): _____

Important people in my life are (include relationship): _____

I like to be remembered for: _____

I like to reminisce about: _____

My work in life includes: _____

My interests, hobbies and talents: _____

Things that bring me peace or solace (prayers, readings, rituals, music, nature): _____

Favorite movies, TV shows, and videos: _____

Music, song or sound preferences: _____

Massage or other forms of touch preferences (neck, hands, feet): _____

Favorite foods and beverages: _____

I like the smell of: _____

My sleeping habits are (waking, napping, things that help me sleep): _____

Things I dislike include (food, situations): _____

Other things I would like you to know about me (routines, quiet time, bath or shower): _____



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CAREGIVER EDUCATION PROGRAM SCHEDULE

October/November 2016

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
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 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.

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 Dr., Sun City
Free but an appointment time is required. To make an appointment, call (623) 832-3248

NOVEMBER

Helping Caregivers Find Meaning while Living With Loss

This 90-minute presentation will focus on strategies to infuse hope and meaning into one's life while providing care in order to cope with continual changes.

Fri., November 4; 10:00 – 11:30 a.m.
Tempe Library
3500 S. Rural Road, Tempe
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 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., November 9; 10:00 a.m. – Noon
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

Please turn over for more classes →

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

Preparing for the Holidays

Learn how to navigate through the holiday season and a variety of ways to help minimize stress and maximize success for the person with dementia and family alike.

Tues., November 15; 10:00 a.m. – Noon
Mesa Red Mountain Library
635 N. Power Road, Mesa
To register, call (602) 839-6850

Free Memory Screening Event

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

Fri., November 18; 9:00 a.m. – Noon
Pyle Adult Recreation Center
655 E. Southern Road, Tempe
To register, call (602) 839-6850

Dementia Dialogue Series: Honoring the Spirit of the Person with Advanced Dementia

Alzheimer's disease/dementia is a disease of the brain – not of the spirit. And, despite the losses caused by dementia, there are still many opportunities to connect with your person. Join this Dialogue and learn a variety of practical strategies to stay engaged with your person and to continue to create memories for you.

Wed., November 16; Noon – 1:00 p.m.
(AZ Time). Register online at www.banneralz.org under events/education and then online education. All webinars are recorded and put on our website 24-48 hours after the "live session."

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., October 11; 10:00 a.m. – Noon
Tues., November 8; 4:00 – 6:00 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850
AND
Mon., November 7; 2:00 – 4:00 p.m.
BSHRI, 10515 W. Santa Fe Dr., 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.

Wed., October 12; 9:00 – 11:30 a.m.
Grandview Terrace
14515 W. Granite Valley Dr.
Sun City West
To register, call (623) 207-1703
AND
Wed., October 26; 9:30 a.m. – Noon
Wed., November 9; 1:00 – 3:30 p.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (602) 230-CARE (2273)
AND

Thurs., November 17; 9:00 – 11:30 a.m.
BAI, 901 E. Willetta St., 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.

Mon., October 10; 4:00 – 5:30 p.m.
Tues., November 22; 10:00 – 11:30 a.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850
AND
Wed., October 19; 10:00 – 11:30 a.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

Parkinson's Screenings: Why It's So Important to Learn the Early Signs

Parkinson's disease (PD) is one of the most common neurodegenerative disorders in the elderly. Parkinson's disease is defined as a progressive neurologic condition that causes motor and non-motor symptoms, including tremor, rigidity, swallowing problems and constipation. This one hour lecture will provide you with vital information to help you understand the disease and the early signs of Parkinson's disease.

Wed., October 19; 3:30 – 4:30 p.m.
Wed., November 30; 10:00 – 11:00 a.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

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

