

BAI BEACON

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

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Meaningful Connections with the Person with Advanced Dementia

Alzheimer's disease or a related dementia is a disease of the brain – not of the spirit. We are all created with a mind, body and spirit; and there is no greater time or ability to test our openness to honor the person's spirit and maintain connections than during the advanced stage. Despite changes in the person's memory, thinking, and language that occur during advanced dementia, the ability to provide meaningful connections exist if we remain open to the possibilities. However, like other stages of the disease process, we continue to adapt our approach and the amount of time we need to connect during the person's wakeful hours. This Beacon will explore different ideas to engage the person with advanced dementia.

We use the person's comfort as our guide as we learn to anticipate and meet the needs of those affected. We want to alleviate anything that may cause suffering or distraction when trying to connect in a more meaningful way. This may include relieving pain, physical or verbal agitation, anxiety, loneliness and boredom. If you hear "there is nothing more we can do," recognize there are many things that can be done to create comfort and you can do them! So, before we begin to engage the person in a more meaningful activity, we remember to make sure the person's comfort needs have been met. This includes toileting or changing a brief, hunger and thirst needs are met, pain/discomfort have been attended to through medication and positioning, fatigue and overstimulation are considered.

As we noted earlier, people with advanced dementia will struggle to understand language. But the good news is that over 90% of what we understand is non-verbal language. This means the tone of our voice and facial expressions are well understood by the person. We recommend taking



a "soft approach." This means that we use both verbal and non-verbal ways to promote communication, minimize frustration and increase a sense of trust and safety. So, instead of asking your person, "Who am I?," you are better off with the greeting, "Hi Mom, it's Jane, I'm so glad to see you today!." This will minimize your mom's confusion and let her know that she is with someone who loves her! We know that this is difficult for family members. But, think back to when your infants could not speak your name. They always knew they were in the presence of those who loved them. So it goes with your person now! Don't worry if language is garbled. These are only words. Pay attention to their non-verbal "behavioral expressions." Anything they do or say that looks uncomfortable needs further evaluation. When we lose the ability to talk, we rely on expressions and behaviors to communicate. When you hear tones that seem uncomfortable, see facial grimacing, witness repetitive behaviors such as scratching, picking, tapping, recognize these represent an unmet need for the person. The person may be wet, hungry,

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.

thirsty, overwhelmed, bored, in pain or fatigued. As you address each of the possible unmet needs, you are likely to understand what your person is communicating.

“Sensory memory,” that is the memory of sights, smell, taste, touch, and sound can stay intact and spark meaningful connections. Drawing upon the senses provides a unique opportunity to connect with the spirit. Sensory awareness does not require higher cognitive processing. The sensory and visual parts of the brain are some of the least damaged in dementia. By stimulating the senses, there is an opportunity to tap into remaining abilities in order to create an increased awareness of self and the surroundings. Stimulating the senses that draw upon lifelong preferences, interests and habits of the person are likely to spark those connections. This in turn can enhance communication and quality of life. Listed below are ideas for 5 unique sensory experiences.

Vision: Pictures, flowers, bird feeders

Visual cues of past treasured experiences can help the person with dementia recall the feeling of joy and even humor. Recall how many of us enjoy simple pleasures, such as watching children and puppies play. Taking a walk together outdoors to enjoy beautiful flowers or birds gathered by a bird bath or feeder. Together with your person, you can look at old family pictures while telling the stories behind each photo. You can look at picture books that reflect favorite places, food, hobbies. With each picture, you will provide most of the conversation with the goal of creating a shared sense of warmth, love and memory! The tone of your voice, laughter and accompanying facial expressions will communicate the most important aspect of all – your love.

Don't forget about the use of humor especially in those who used humor throughout life. Hearing a funny joke or watching a funny video can bring a smile to the face. For example, most of us remember the “I Love Lucy” show when Lucy and her friend Ethel worked in the chocolate factory. This visual imagine combined with laughter is sure to produce a smile, if not laughter!

Smell: Aromatherapy, scented lotions and flowers

Smell cues include the use of essential oils (aromatherapy), strong spices, scented lotion or a favorite perfume. Flowers may also provide a familiar aroma in which the person can connect. Responses to aromas vary from person to person. When using essential oils (i.e. aromatherapy) most perceive lemon oil and lavender oil as pleasant. Generally speaking, lemon essential oil is reported to be refreshing and stimulating so this should be used during awake hours. Lavender essential oil is reported to be calming and can aid with sleep and relaxation. Watch your person's facial and verbal response(s) as you introduce different types of aromas. If you discover the person loves the smell of vanilla, cinnamon, rosemary, basil, etc., continue to use these aromas.

Taste: Chocolate Kisses, lollipops and ice cream

Food continues to be enjoyed until the last days of life. When we stimulate taste, the goal is to always create pleasure. Taste and texture are the most important considerations in

choosing food – not the nutritional value of the food. The person with dementia will usually accept food that is soft in texture and sweet in taste. We often refer to these as “comfort foods.” Think about what soft and sweet treats the person has enjoyed in life and then offer those foods. Common treats that are enjoyed include ice cream, shakes, yogurt, applesauce, bananas, peanut butter and jelly sandwiches, mashed potatoes (and gravy). Of interest, chocolate connects with most and is a non-verbal way of showing love. Think about when we give chocolate as a gift – Valentine's Day or a special occasion to celebrate and show love. By placing a piece of chocolate into the person's mouth, not only will they enjoy the sweet but they will experience your love!

Touch: Hand massage, soft objects

Human touch is a basic need. While we touch persons with advanced dementia, most of the touch is related to attending to bodily needs. Holding the hand of a person with dementia can communicate love, warmth and safety. Using lotion and giving a gentle hand or foot massage can create a unique connection. We often find in giving a hand massage, the person with dementia will attempt to massage the caregiver's hand in return. This can be done in conjunction with conversation, music or simply by itself.

Additional touch/tactile cues can include textures that are interesting or pleasant to feel. Suggestions include objects that are pleasant to the touch such as pets or soft stuffed animals and objects that invoke memories such as fabrics, baseballs, footballs, etc. You can also try to use touch cues along with movement cues. This could include tossing a balloon or beach ball or blowing bubbles. Each can help raise the person's awareness to the surrounding environment.

Hearing: Music, soothing sounds

Sound cues can include favorite songs or sounds, such as musical instruments, nature, children's voices, bells, etc. A pleasurable connection with music remains intact for most persons with dementia.

Music from the time the person was between 18 – 25 years old tends to be best as those songs are steeped with lasting memories of graduation, career, falling in love, having children, etc. Try to put those favorite songs on a playlist or CD so they can be played while the person is awake. Also, try singing aloud favorite songs to your person. Try to slow the tempo a bit and focus on the chorus instead of the verse(s). Repeat the song a few times and before you know it, your person will be singing along with you!

Remember that music can also help stimulate eating and create a nice background ambience. Use music in a purposeful way, that is, playing music or singing for 15 – 30 minutes and then turning the music off. Continual music just becomes white noise to the person with dementia. When playing a CD or tape, hold the person's hand, tap to the rhythm or sing along to draw the person into the experience. Don't worry about the quality of your voice – your love and intention will be understood.

There is a continued need to allow the soul of the person with dementia to express itself – and it does not require an official clergy to make it happen. Being connected

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Ask The Expert

Jan Dougherty, MS, RN, FAAN
Family and Community Services Team

Dear Jan,

My mom has advanced Alzheimer's disease and now lives in a memory care community. I still visit her almost every day of the week for a few hours. My sister says it is too much and I need to focus on getting a life beyond my mom. But, I know my visits make a difference. Is this unhealthy?

Signed,
Bonnie

Dear Bonnie,

Many people have opinions about visiting people with dementia in care facilities. However, there is no correct or single answer about visitation. It sounds like you have a wonderful relationship with your mom and that both you and your mom find benefit during your visits. Clearly your role of caregiver has not ended – nor should it as you continue to provide oversight in her care. I know many caregivers who enjoy spending time with their loved one in a care facility – some even assisting in providing care such as helping with meal time or even personal care. I've seen other family members get involved in assisting with activities in care settings. All of those are more than acceptable.

I know of other family members that find it difficult to visit. Some are overcome with a sense of grief and loss that is worse following a visit. Others have not found a way to feel connected to their loved one. For those, we need to provide understanding and even education on how to better cope with loss and/or how to connect in a different but meaningful way with their person. But in both cases, the family must be open to the possibilities. We are each different as we confront our role as caregivers of a person with dementia.

Be sure that you are taking care of your own needs. It is essential to maintain relationships with other immediate family members (i.e. your husband and children) and friends. Find things outside of your caregiver role that bring joy and satisfaction. And begin to look ahead to new hopes and dreams when your mom is no longer living. I know that this can be a difficult one but is essential in maintaining your own resiliency.

Enjoy your mom. Keep creating moments of joy for her and memories for you. You will not look back with regrets!

Have a Question?

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

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/support-our-mission or call 602-747-GIVE (4483).



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Meaningful Connections with the Person with Advanced Dementia

continued from inside

to nature through the sight and smell of fresh flowers or a walk outside can touch the soul. Reading favorite passages aloud from a book of faith that are short, positive and easy to understand can bring comfort and awareness of the Divine. Singing a favorite sacred song or hymn can provide a meaningful connection. Using a particular religious item or symbol can assist the person to sense the presence of God. Such symbols may include incense, holy pictures, a rosary, prayer shawl or candles.

Some general guidelines to keep in mind when providing meaningful connections include:

- Carry out activities during the best time of the day for the person (usually when the person is well rested).
- Call the person by their preferred name and let the person know who you are and what you intend to do.
- Observe for any signs that indicate the activity is causing a negative reaction or discomfort (such as distressing facial expressions, tense muscles or restlessness). If this occurs, stop the activity and provide comfort.

- Provide the activity over a 10-15 minute period. Adjust as needed so that it is easily experienced and tolerated by the person.
- At the end of the activity, determine how pleasant it was for your person. Did you notice any positive changes in the way the person appears to feel or behave?
- Share what works with other family members, friends or even members of the health care team so they too know what to do to create a meaningful visit.

In summary, while advanced dementia does take its toll on the affected person, the ability to continue to connect to that person is more than possible. As we simplify our methods and adjust our expectations that focus on comfortable and meaningful connections, both the person and family will greatly benefit. For more detailed information on this topic, we invite you to join the Dementia Dialogue Webinar/Teleconference on November 16, 2016 from 12N - 1pm Arizona time. BAI dementia experts Helle Brand, PA and 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.



CAREGIVER EDUCATION PROGRAM SCHEDULE

November/December 2016

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

Dementia Friendly Tempe Presents: Surviving the Holidays

The holiday season brings additional stress for most, but the added demands on the caregiver and the person with dementia can overwhelm. This class will provide practical strategies to modify shopping, food preparations and traditions so that this time of year can be successful.

Wed., November 9; 1:00 – 2:30 p.m.
Tempe Library
3500 S. Rural Road, Tempe
Free, registration not required

As Dementia Progresses: Next Steps for Caregivers

This 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.

Mon., November 14; 1:00 – 3:00 p.m.
BAI, 901 E. Willetta St., Phoenix
To register, call (602) 839-6850

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 opportunity 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”.

DECEMBER

Transitioning Care

Transitioning from home to a residential care setting can be challenging for caregivers and the person with dementia. This class will discuss the importance of planning and considerations when making the transition from one level of care to another.

Tues., December 6; 4:00 – 6:00 p.m.
BAI, 901 E. Willetta Street, Phoenix
To register, call (602) 839-6850

BSHRI Community Lectures: Holidays and Grief

The Holiday Season is quickly approaching and for many people that signifies joy. For others who may be caregiving for someone with Alzheimer's disease or Parkinson's disease or struggling with the recent loss of a loved one the holiday season may feel stressful. Lori Nisson, LCSW will explore the emotions that may surface, how to better manage them and offer strategies to enhance self-care during this time.

Wed., December 7; 10:00 – 11:30 a.m.
BSHRI, 10515 W. Santa Fe Dr., Sun City
To register, call (623) 832-3248

Please turn over for more classes →

Dementia Friendly Presents: Emotional Impact of Living with Memory Loss

This class will focus on helping you better grasp the common emotional changes that may occur in the person with dementia. Learning to better understand emotional changes can help you to increase your level of empathy and reduce caregiver frustration.

Wed., December 14; 1:00 – 2:30 p.m.

Tempe Library

3500 S. Rural Road, Tempe

Free, registration not required

Good News in AD 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.

Tues., December 20; 10:00 – 11:30 a.m.

Mesa Red Mountain Library

635 N. Power Rd., Mesa

To register, call (602) 839-6850

Dementia Dialogue Series: Finding Myself Beyond My Role as Care Partner

Caregiving can be an incredibly rewarding role while also creating feelings of overwhelm. This dialogue will focus on strategies to infuse hope and meaning into your life while, balancing necessary care for you and your person.

Wed., December 21; 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.

Mon., November 7; 2:00 – 4:00 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

To register, call (623) 832-3248

AND

Tues., November 8; 4:00 – 6:00 p.m.

Tues., December 13; 10:00 a.m. – Noon

BAI, 901 E. Willetta St., 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.

Wed., November 9; 1:00 – 3:30 p.m.

Wed., December 7; 1:00 – 3:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

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

AND

Thurs., November 3; 9:30 a.m. – Noon

Wed., December 14; 1:00 – 3:30 p.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.

Tues., November 22; 10:00 – 11:30 a.m.

Tues., December 15; 4:00 – 5:30 p.m.

BAI, 901 E. Willetta St., Phoenix

To register, call (602) 839-6850

AND

Wed., December 14; 1:00 – 2:30 p.m.

BSHRI, 10515 W. Santa Fe Dr., Sun City

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

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., November 30; 10:00 – 11:00 a.m.

Free Lecture on Understanding PD.

Fri., December 16; 1:00 – 4:00 p.m.

Free PD Screening Event and requires an appointment. Call (623) 832-3248.

BSHRI, 10515 W. Santa Fe Dr., Sun City

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

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

