

BAI BEACON

*The Newsletter from Family and Community Services
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Early Alzheimer's disease: Living Day to Day

You've noticed for months or even years that your person is faltering a bit mentally. Their memory is inconsistent; worse for recent events. They have a diminished sense of time. Their judgment may be less sharp than in the past, and they make mistakes on complicated activities such as driving, managing money, preparing meals, or taking medications. The person may be more emotional: depressed, argumentative, or distant at times. You've been to the doctor who has diagnosed your worst fear: early Alzheimer's disease (sometimes referred to as mild dementia).



Despite having suspected this, you are in shock. A million questions flood your mind. How long will this last? Will the person become violent? Will our children get this? What do we need to do and how will we ever know enough to cope with this? How can I make sure he/she is cared for in the home and not a nursing home? Will this bankrupt us? What do I need to do first? What help will I need and where do I turn to find it? And, am I strong enough to do this?

The answers to these questions are similar to the old joke: "How do you eat an elephant?" The simplest answer is "One bite at a time!" Most dementias progress relatively slowly

allowing the care partners time to try new strategies, gain new skills from experience, and find the many available resources. In this month's Beacon we are going to focus on some of the basics of planning care on a day to day basis. Implementing these techniques one bit at a time has been shown to decrease problem behaviors and enhance quality of life.

Fatigue

Fatigue is the leading cause of behavioral issues in dementing illness. Having an illness like Alzheimer's disease is stressful and exhausting. The person needs to work hard to follow conversations, perform tasks, and simply try to remember what they should be doing. Having Alzheimer's is like studying for a final examination every minute of every day. The person experiences significant fatigue even when they appear to be doing little. One of the most important habits people with dementia need to develop is the ability to take regular breaks. In early disease we encourage people to sit and read or put their feet up and relax in mid-to-late morning and again after lunch. This helps the person to have a stable mood and avoid "sundown syndrome" (a.k.a. late day confusion). Additional ideas:

- Provide two rest periods per day, morning and afternoon. These can be simply sitting, but you do NOT want TV on during a rest period.
- If your person is not sleeping well at night, increase the number or duration of rest periods during the day.
- If the person wants to "sleep in" let them. Adjust rest periods accordingly.

Functional Loss, Avoiding Change

Functional loss is the inability to accomplish tasks. It is the result of decreased "executive function" in the brain. What this means is that when trying to reach a goal, such as laundering clothes, a normal brain automatically breaks the task into steps that must be done in order to accomplish the

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.

task. In a healthy individual the more we do those tasks, the less thought it takes to do them. For people with dementia the ability to determine the order of steps needed to be done is lost – especially when the person has to think about the activity. The more the person has to think about how to do the activity, the more anxious and confused they become. If you try to coach the person through the activity, the confusion about steps will become worse and people with dementia become frustrated and frightened. They know they should be able to accomplish the activity. There are several ways to help your person with this.

- First, do not try to point out that they could do the activity yesterday or ask them to try and think about how to do the task. Do not think the person is pretending not to be able to do the activity in order to manipulate or punish you. Simply offer to help.
- Limit the person's access to potentially hazardous activities such as driving or managing finances.
- Instead of focusing on the task, offer a distraction such as a cookie or another task.
- You can try to cue the person by telling them the next step.
- Develop a relatively predictable sequence of daily activities so that the person can use the repetition of activities to be on "automatic pilot." While you can have changes in activities your person will probably do best when the basic activities are consistent.
- Think twice about changing location, such as travel or having guests in your home. Think twice about modifying your home such as remodeling, updating, or redecorating as these often produce negative responses that may last weeks.
- Accept that the person is trying as hard as they can at any given moment, despite statements that they don't care or want to do the activity. Dementia does not make a person lazy or manipulative; it produces disability that is inconsistent.

Controlling Environmental Stimuli

Some dementias affect the parts of the brain that interpret what our senses learn from the environment. This means that vision, hearing, taste, touch, and smell are affected. The person still sees, hears, etc. but is progressively unable to interpret the sensory input. It is somewhat easier to understand if you imagine your eyes as a camera. They still take the picture but the brain doesn't necessarily develop the film correctly. This results in decreased depth perception, ability to see moving objects, or not identifying common things. This is especially true of what is seen on television.

- In early Alzheimer's the person may think the interactions seen on TV are real and misinterpret what is in the environment. These are not hallucinations. Before asking for medication, turn off the TV for 24-48 hours.
- Avoid violent programs on TV; shows with dysfunctional people, overt sexuality, or continuous news channels. These can cause illusions or delusions (fixed false beliefs) that are very difficult to stop.
- If you plan an activity with a lot of people, make sure your person stays for 30-60 minutes and has a place to

go and rest.

- Loud noises and large groups of people, such as a supermarket, mall, or restaurant can produce enormous fatigue. If you notice your person beginning to fidget, withdraw, or asking to leave, end the activity and return home.
- If your person asks to leave a restaurant or activity, do so. Do not ask your person to wait a while as overstimulation can produce significant emotional distress.
- Take care to limit long visits to places with boisterous children.

The Importance of Activities

Activities are the most important aspect of dementia care as they provide for personal growth and positive self-esteem. People with early Alzheimer's continue to need activities, outings, socialization, and stimulation.

- In mild dementia many can participate in a wide variety of senior center activities including exercise, games, cards, arts and crafts, music, and discussion groups. Many senior centers have transportation available to allow the care partner to have time and respite.
- Caregiver training classes can offer ideas.
- Speak with friends about having outings or coming to visit.
- An occupational therapy evaluation can often help with designing new activities.

Too much demand

All too often well-meaning family and friends try to "exercise the person's brain," asking repeated questions about the date, names of people, and current events. This can be very upsetting as the person with early dementia is usually aware of their deficits. Continuously testing a person does not help their memory and can produce anxiety and depression.

- The best way to evaluate disease progression is to evaluate what the person is able to do, such as driving, managing money, cooking or cleaning.
- Rapid changes in these abilities often indicate depression, infections, or other problems.
- Research shows the single best activity to help with cognition is regular aerobic exercise a minimum of 20 minutes, three times a week. That also helps with preventing falls.

In summary, the best way to plan for care for someone with early Alzheimer's is to organize a consistent routine, with generous activities in an environment with moderate noise and people and at least two rest periods per day. As your person's dementia advances the above recommendations can be tweaked or intensified to continue providing care in the moderate stages.

For more in depth discussion of this topic, we invite you to join the May 18, 2016 Dementia Dialogue from 12 Noon-1p.m. (AZ time). Register online at www.banneralz.org. Click 'Events and Education' then 'Online Education' OR call 623.832.3248.



Ask The Expert

Gerri Hall, PhD, GCNS, RN
Advanced Practice Nurse

Dear Geri,

My Mom was diagnosed with early Alzheimer's disease two months ago. The doctor says her mental status score is 24/30. She lives alone in the same town I do and has been managing to do her housework, shopping, and cleaning until now. Over the past month she seems to be progressing really quickly. Her grooming and her house are becoming untidy and her house smells stuffy. The mail hasn't been opened. Her medications were mixed up on the kitchen table. She has never lived alone before but managed well while my dad was alive.

I found a dent in her new car and told her I was thinking of selling it and moving her to a memory care community. She didn't like that idea much!

Last night I found her sitting with her cat in the dark eating ice cream from the carton. She said she misses dad who has been dead for 6 months. Shouldn't she be over that by now? Mom seems depressed to me but how can that be if she has dementia?

Signed,
Debbie

Dear Debbie,

Your letter is heartbreaking! Both you and your mom have undergone significant losses in the last 6+ months and are probably grieving both the loss of your dad and your mom's condition. A few insights:

- Judging by your mom's recent history of being independent and having lost her husband, it is perfectly normal for her to be grieving the loss of your dad. Widowed people often report grieving for several years.
- This grief can produce depression. Most people who have early Alzheimer's disease/mild dementia are quite aware of their losses and many are frightened of them. Fears of disability, losing contact with friends and family, fears of long term care placement, not living to see grandchildren grow, and fearing potential suffering at the end of life can all produce depression which is characterized by sudden functional decline.
- There may also be a component of physical illness from mismanaged medications.

Before you move your mom I would suggest the following:

1. She needs to see her primary care provider or her dementia specialist (neurologist, geriatric psychiatrist, or geriatrician) to make sure she hasn't become ill, she is taking only essential medications, and to assess for depression and treat it.
2. You need to speak with your mom and ask her what she wants. Does she want to live in her own home with hired help? A retirement assisted living apartment? The two of you need to set some goals after meeting with a social worker.
3. While the details of her living arrangement are worked out, have a friend come by (or her other daughter) to assist with medications.
4. For the time being have housekeeping help in her home.
5. There needs to be emphasis on activities including exercise. Is it possible she could attend a senior center with friends?
6. She needs a driving assessment before you force her to stop driving. Ask your mom's doctor for a referral.
7. You need to make sure your mom has advanced directives including durable powers of attorney for health care and mental health so you can help her without violating her privacy rights.

As you can see, this is a time when many decisions will need to be made. One decision at a time choosing the most important issue will be best. Thanks to your watchful eye and involvement, you will help your mom make the necessary transitions.

Have a Question?

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



Banner Health®

Banner Alzheimer's Institute
Banner Sun Health Research Institute

Banner Health
901 East Willetta Street
Phoenix, AZ 85006

Further Education on Early Stage Alzheimer's

Newly added!

NEW

Online education opportunities!

The information you need at a time and location convenient for you! Check out all our online education has to offer!

Three Easy Steps:

- Visit www.banneralz.org
- Click on **Education and Events**
- Then **Online Education**

Did you know that you can help make a difference in the lives of those touched by Alzheimer's and other memory disorders? To join us in preserving memories, call 602-747-GIVE (4483) or visit www.banneralz.org/waystogive. The memories we save could be your own.

COMPASS:

Strive for success as a partner in care when you learn about dementia as a chronic condition, what to expect over time and acquire new strategies for daily living. Rich in content, COMPASS provides essential information for new and seasoned caregivers alike.



Planning Ahead:

Learn the necessary planning for legal, financial and medical decisions for someone with Alzheimer's disease/related dementia or a movement disorder. Planning Ahead provides you information on community resources and agencies as well as how to find help and pay for care in the home, community or residential setting, and more.

** DVD format of both COMPASS and Planning Ahead also available for purchase. Call 602.839.6850 for a copy today!*



Banner Health®

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Banner Sun Health Research Institute



CAREGIVER EDUCATION PROGRAM SCHEDULE

May/June 2016

MAY

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

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

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

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)

Planning Ahead

This 2 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.

Monday; May 2; 1:00 p.m. – 3 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Dr., Morin Auditorium, Sun City
To register, call (623) 832-3248

Emotional Impact of AD

It is well recognized that Alzheimer's disease causes memory loss. This program focuses on helping you better grasp the common emotional changes that may occur in the person with AD. Learning to better understand emotional changes can help you to increase your level of empathy and reduce caregiver frustration.

Wednesday; May 4; 2:00 – 3 p.m.
Banner Sun Health Research Institute
10515 W. Santa Fe Dr., Morin Auditorium, Sun City
To register, call (623) 832-3248

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 Dr., 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 Dr., 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 Dr., 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."

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 Dr., Morin Auditorium, Sun City
To register, call (623) 832-3248

Please turn over for more classes →

JUNE

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 session will review possible options for care in and out of home; how to make an informed decision and ensure success.

Wednesday, June 1; 12:30 - 2:00 p.m.

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix AND

Monday, June 27; 9:30 a.m. - 11:00 a.m.

Pecos Community Center

17010 S. 48th 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, June 8; 9:00 - 11:30 a.m.

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

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

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, June 14; 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, June 16; 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.

Tuesday, June 21; 10:00 a.m. - Noon

Mesa Red Mountain Library

635 N. Power Road, Mesa

To register, call (602) 839-6850

Keeping the Person with Dementia Occupied

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

Thursday, June 23; 10:00 - 11:30 a.m.

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 Arizona. Join one of our researchers to learn how you can make a difference.

Wednesday, June 1; 10:00 - 11:30 a.m.

The Colonnade, 19116 Colonnade Way, Surprise

To register, call (623) 207-1703

BSHRI Community Lecture Series: ABC's of Finding Dementia Care

Caring for someone with dementia creates 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 session will review possible options for care in and out of the home; how to make an informed decision and ensure success.

Wednesday, June 15, 2016; 2:00 - 3:30 p.m.

Del Webb BDWMC Auditorium A and B

14502 W. Meeker Blvd, Sun City West

To register, call (623) 832-3248

Dementia Dialogue Webinar: Early Alzheimer's disease: Staying involved and connected

Successful participation in activities is more than possible when living with early AD. Making mindful accommodations while seeking old and new opportunities for engagement can promote meaning. This Dialogue will review how to tweak familiar activities and seek new options to stay involved.

Wednesday, June 15; 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".

As Dementia Progresses: Next Steps for Caregivers

This 2 hour class outlines the moderate to advanced stages of dementia, how common symptoms can be managed, and how to cope with changing function while assisting caregivers to find success in their daily efforts.

Monday, June 20, 1:00 - 3:00 p.m.

Banner Sun Health Research Institute

10515 W. Santa Fe Dr., Morin Auditorium, Sun City

To register, call (623) 832-3248

BSHRI Free Community Memory Screening

Banner Sun Health Research Institute is offering free monthly memory screenings allowing community participants to screen for potential memory concerns and provide direction to prevention studies, and research opportunities. The memory screening takes up to 30 minutes to complete and is scheduled by appointment.

Friday, June 24; 9:00 a.m. - 12:00 p.m.

Banner Sun Health Research Institute

10515 W. Santa Fe Drive, Building C, Sun City

To register, call (623) 832-3248

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.

Wednesday, June 29; 10:00 a.m. - 12:00 p.m.

Banner Sun Health Research Institute

10515 W. Santa Fe Dr., Morin Auditorium, Sun City

To register, call

(623) 832-3248

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

