

# BAI BEACON

*The Newsletter from Family and Community Services  
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## When it's Not Alzheimer's Disease

While Alzheimer's disease (AD) accounts for 60 – 80% of all dementias, this means that 20-40% of those with cognitive, mood or behavioral symptoms will have another form of dementia. There are dozens of conditions that cause dementia. The differences in symptoms are caused by several things:

- The disease affects a different part of the brain than AD; and/or
- The underlying *pathology* (cause) is different than AD; and
- Lifelong personality traits differ from person to person and affect how the person responds to the symptoms.

So why bother with a rigorous diagnostic evaluation when we can't treat most of these diseases? First, recognize that non-AD dementias often require different medical and care management strategies. Second, the person may have an unfavorable response to medications commonly used in AD. And finally, issues affecting the family differ from AD. For this article we will look at three relatively common non-AD dementias: Vascular dementia (VaD, formerly called multi-infarct dementia); Lewy body dementia (LBD); and Frontotemporal dementia (FTD).

### Vascular dementia

It used to be thought that all dementia was caused by "hardening of the arteries" resulting from decreased blood flow to the brain. This has been disproved, however dementia can occur when there are recurring large and/or small strokes. People with strokes can exhibit slowed cognitive decline usually with preserved awareness. *Motor* (movement) problems include one-sided weakness, often

with spasticity; changes in *gait* (the ability to walk); or small areas of weakness such as one-sided facial droop or weakness in a hand. Language problems, and even Parkinson-like movement disorders can occur depending on the locations of the strokes. Often the strokes are so small they go undetected until motor changes appear.

People with vascular dementia often have a history of *hypertension* (high blood pressure), diabetes, and smoking which cause thickening and damage to the very small arteries. This can result in *mini strokes* that leads to slowing and impaired recall of recent information. But, the ability to recognize things and people may stay intact (1). For people with vascular dementia, careful control of medical conditions, especially blood sugar, cholesterol, and blood pressure, is essential to stabilize the condition. Depression is common in vascular dementia and should be treated in order to maximize quality of life. In addition, physical and occupational therapy may produce modest gains in day to day function.

### Lewy body disease

LBD, also known as dementia with Lewy bodies (DLB), is an important cause of dementia affecting about 1.4 million people in the US over age 65. Lewy bodies are cells that usually occur in Parkinson's disease (PD). In LBD, the Lewy bodies form in the areas of the brain usually affected by AD, producing a unique set of symptoms (2).

- A *REM sleep disorder* characterized by continuous restless movement of extremities while asleep. It can also appear to be acting out dreams. This can happen years before other symptoms.
- Impaired thinking, attention, and alertness that can fluctuate. The person can have long periods or relatively normal cognition.

## 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.

- Sensitivity to medications, especially those given for behavior. Tiny doses of medications may produce profound side-effects. People with LBD may respond quite well to the *cholinesterase inhibitors* (e.g. Aricept) usually given for AD. These drugs can often help with behavioral symptoms when the usual mood controlling medicines are not tolerated.
- *Autonomic dysfunction* means the person has difficulty maintaining blood pressure, body temperature, bowel, and bladder function. With sudden drops in blood pressure upon standing, the person may suffer sudden unexplained falls or blackouts.
- Development of a *Parkinsonism* with difficulty walking and functioning due to tremors and stiffness. As a general rule the medications for these Parkinson's symptoms are ineffective in LBD and can cause or worsen hallucinations and other psychotic symptoms.
- *Hallucinations*, usually visual images of people or animals.
- Behavior and mood symptoms including depression, apathy, anxiety, agitation, delusions, or paranoia. (2).

LBD is a complex multi-system disorder requiring careful knowledgeable medical management from a primary care provider and, at minimum, a behavioral neurologist or movement disorder specialist. Physical, occupational, and speech therapies can be helpful from time to time; especially with programs designed for use in PD such as "Big and Loud" programs.

### Frontotemporal dementia

Frontotemporal dementia (FTD) is by far one of the more challenging dementias. It is also commonly referred to as fronto-temporal lobar degeneration (FTLD), or Picks disease. FTD is caused by conditions that cause degeneration/progressive damage to the *frontal* and *temporal* lobes. It causes a group of brain disorders that share many clinical features including marked personality change, language disorders, and motor symptoms which may include ALS. In early disease, FTD tends to present in one area of the brain initially producing either personality symptoms or changes in language function. As the disease progresses to the moderate stage it spreads to both areas of the brain leaving the people with both language and personality losses (3). There are several distinct forms of FTD as described below.

*Behavioral variant FTD (bvFTD)* was formerly known as "Pick's disease", and is characterized by a loss of the ability to interact socially in a meaningful manner. The person loses empathy towards others, becomes socially inappropriate and self-centered. The ability to reason and plan an activity to reach a goal is impaired. It is also coupled with the loss of insight (*Anosognosia*). The inability to inhibit actions may produce behaviors such as hypersexuality, excessive spending, or compulsive eating. Since memory is largely intact, the family cannot rely on the person forgetting to eat or spend money as a strategy to manage the behavior. Instead, the family tries to gain the person's cooperation and provide

structure. However efforts to gain some control and reason often result in paranoid ideas and acting out. This can place care partners and others at extreme risk of personal injury.

*Language variants* occur in several forms and affect both expression and understanding of written and spoken language. Early in the disease people with *primary progressive non-fluent aphasia* lose the ability to coordinate the tongue, teeth, palate and muscles to produce speech; yet many have good insight and can continue to live alone. In moderate disease these people become mute, and develop behavioral issues. Many people with FTD develop obsessive behaviors to relieve their stress. Stopping the obsessive behaviors can result in spontaneous vocalizations or aggression.

There are several *motor disorders* that can develop as part of FTD, the most common being *motor neuron disease* (FTD-MND or ALS). Others include *corticobasal degeneration* (CBD), *progressive supranuclear palsy* (PSP), or a Parkinsonism. After several years of either language or bvFTD the person begins to develop *fasciculation's* or fibrillations (twitching). The person will then lose strength and have a relatively brief survival time.

A major hurdle in care of people with FTD is age. Onset of FTD often occurs in a person's 50s and 60s, but has been seen as early as 21 and as late as 85 years. Roughly 60% of cases occur in people 45-64 years old, thus FTD can affect work and family in a way dementia in older people does not. People with bvFTD are often working and may have school-aged children. Because of the person's young age and behavioral disorders they are often misdiagnosed with psychiatric conditions such as bipolar disorder with mania. Treatment rarely succeeds and, because of the diagnostic error, the person does not qualify for Social Security and disability benefits.

Referring the family of a person with FTD to an attorney specializing in elder law is a critical first step in providing care. The attorney can help with obtaining benefits (such as Social Security Disability) and obtaining decision-making authority. Because of the person's lack of insight they often refuse to sign durable powers of attorney. Moreover, the person with FTD scores well on tests of memory normally used in determining capacity. The attorney can also be helpful with driving cessation and protecting family assets from reckless spending.

In summary, non-Alzheimer's dementias are relatively common. Because they involve different parts of the brain than AD, they have different symptoms and disease progression. Care of people with non-AD dementias differs from care of AD in several ways:

- Their responses to medications can differ either because of heightened drug sensitivity or the drugs being administered for AD are ineffective for non-AD dementias. This can include causing psychotic symptoms, aggression, and other life-altering effects.
- People with non-AD dementias need quieter and more structured environments with caregivers who understand the changes in the person's behavioral

responses. For example, while one might try to distract a person with AD from repetitive behaviors; in FTD we try to facilitate them as it helps manage the person's stress.

- Family needs differ with diseases like FTD where the person is often younger, employed, and may have a young family. People with FTD are three times as likely to get into legal trouble and commit crimes (4).

In summary, it is imperative for families to keep seeking a thorough diagnosis and answers to the question "Why doesn't my person act like others who have AD?" Seeking education and support to manage many of the differences outlined will be essential for good care. For more on this topic, we invite you to join in the March 16, 2016 Dementia

Dialogue from 12 Noon – 1 p.m. (AZ time) as Dr. Geri Hall discusses "Non-Alzheimer's Dementias." Registration is required and must be done online at [www.bannershri.org](http://www.bannershri.org) under events and education and online education OR you can call 623-832-3248.

#### References

1. Rosser, M. (2013) The ABCs of neurodegenerative dementias. In Gary Radib and Lisa Radin (eds) What if it's not Alzheimer's?, third edition. Amhurst New York: Prometheus Books, pp. 35-6.
2. Lewy Body Dementia Association (2015). <http://www.lbda.org/category/3437/what-is-lbd.htm> retrieved January 3, 2016.
3. Association for Frontotemporal Degeneration (2015). FTD Overview. <http://www.theaftd.org/understandingftd/ftd-overview>, retrieved January 5, 2016.
4. Liljegren, M., Naasan, G., Temlett, J., Perry, D.C., Rankin, K.P., Merrilees, J., Grinberg, L.T., Seeley, W.W., Englund, E., & Miller, B.L. (2015). Criminal behavior in frontotemporal dementia and Alzheimer's disease. *JAMA Neurol.* 72(3), 295-300.



## Ask The Expert

Geri Hall, PhD, RN  
Stead Family Memory Center

Dear Geri,

*My wife and I been married for over 55 years. She was a bright and dynamic mom to our four sons. Two years ago she developed restless legs at night. She flails and kicks half the night but can't tolerate medication to stop the movements. Her walking has slowed way down and she is falling about once a week. She has some mild memory problems some of the time. Last week she started to see an imaginary duck in the living room. Her primary doctor says she has Alzheimer's disease but she sure doesn't seem like other people with that disease. Her doctor says nothing can be done and to put her in a nursing home. I want to care for her always and need to know what to do.*

Signed,  
Don

Dear Don,

There are many different conditions that cause dementia. My first advice to you is to ask for a referral to a "Behavioral Neurologist," or "Geriatric Psychiatrist" to provide a second opinion. This will involve a careful history, mental status testing, a neurological evaluation, and probably a brain scan to rule out tumor, a bleed, or stroke (see January 2016 Beacon). Hopefully this will define a specific type of dementia or reconfirm the presence of Alzheimer's disease.

Your second task is to find people who can help you figure out the best strategies to care for your wife. No two people with dementia have exactly the same needs and there are systems in place to help you understand and solve problems as they arise. Seek out other health care team members such as Geriatric Nurse Practitioners and/or Licensed Clinical Social Workers to help you, particularly if they work for a dementia-specific program.

Finally, there may be a support group in your area for non-AD dementias. You would be interested in groups for "Lewy Body Disease" or for patients with movement disorders. Either contact the Alzheimer's Association ([www.alz.org](http://www.alz.org)), or the Lewy Body Disease Association ([www.lbda.org](http://www.lbda.org)) for information on support in your area. Meeting with others facing similar conditions can be a great source of education and comfort about your wife's condition.

To join us in preserving memories, call 602-747-GIVE (4483) or visit [www.banneralz.org/waystogive](http://www.banneralz.org/waystogive). The memories we save could be your own.

## Have a Question?

To submit your question for future consideration email us at: [baiinfo@bannerhealth.com](mailto:baiinfo@bannerhealth.com)



Banner Alzheimer's Institute  
Banner Sun Health Research Institute

Banner Health  
901 East Willetta Street  
Phoenix, AZ 85006

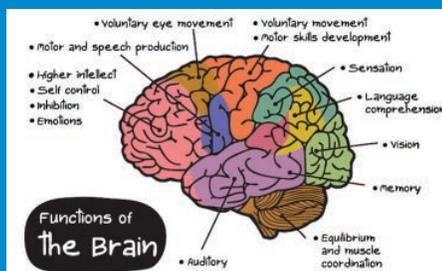
## *Resources for non-Alzheimer's dementias*

### NATIONAL ORGANIZATIONS:

**Lewy Body Dementia Association**  
[www.lbda.org](http://www.lbda.org)  
Caregiver Link: 800-539-9767

**The Association of  
Frontotemporal Degeneration**  
[www.theaftd.org](http://www.theaftd.org)  
Helpline: 866-507-7222

**The National Stroke Association**  
[www.stroke.org](http://www.stroke.org)  
Helpline: 800-STROKES



### LOCAL SUPPORT GROUPS:

**FTD Support Group**  
2nd Tuesday of each month.  
12:30 p.m. – 2 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta St., Phoenix, AZ

**Lewy Body Dementia  
Support Group**  
1st Friday of each month.  
12:30 p.m. – 2 p.m.  
Banner Alzheimer's Institute  
901 E. Willetta St., Phoenix, AZ

**New Lewy Body  
Dementia Support Group**   
(beginning April 26)  
4th Tuesday of each month.  
10:30 a.m. – 12 Noon  
Banner Sun Health Research Institute  
Building C Conference Room  
10515 W. Santa Fe Dr., Sun City, AZ

**Parkinson's Disease Coffee Talk**  
Every Friday.  
10 a.m. – 11 a.m.  
Banner Sun Health Research Institute  
Building B Morin Auditorium  
10515 W. Santa Fe Dr., Sun City, AZ

**FTD Support Group**   
(beginning April 26)  
4th Tuesday of each month.  
12:30 p.m. – 2 p.m.  
Banner Sun Health Research Institute  
Building C Conference Room  
10515 W. Santa Fe Dr., Sun City, AZ

## March 2016 Program Schedule CAREGIVER EDUCATION PROGRAMS

### PHOENIX

#### 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, March 8; 4:00 p.m. – 6:00 p.m.*

*Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

#### Transitioning Care from Home to a Residential Setting

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

*Monday, March 14; 12:30 p.m. – 2:30 p.m.*

*Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
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.

*Friday, March 18; 10:00 a.m. – 11:30 a.m.*

*Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

**These programs are made possible  
by the generous support of the  
Banner Alzheimer's Foundation.**

### PHOENIX (CON'T)

#### 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, March 22; 10:00 a.m. – 11:30 a.m.*

*Banner Alzheimer's Institute  
901 E. Willetta Street, Phoenix  
Free but registration is required.  
To register, call (602) 839-6850*

### MESA

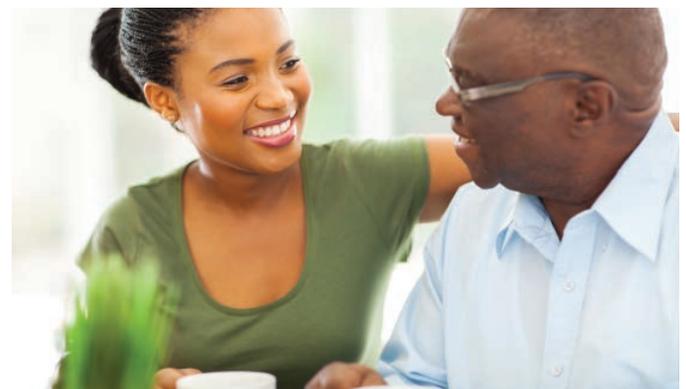
#### Communication Tips to Avoid Arguments

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.

*Tuesday, March 15; 10:00 a.m. - Noon*

*Mesa Red Mountain Library, 635 N. Power Road, Mesa  
Free but registration is required.  
To register, call (602) 839-6850*

*Please turn over for more classes →*



## March 2016 Program Schedule

# CAREGIVER EDUCATION PROGRAMS

### SUN CITY

#### Clinical Trials 101

Clinical Trials allow patients to receive tomorrow's treatments today and assist researchers in the fight against diseases like Alzheimer's and Parkinson's. Attendees will learn the basics of clinical trials including what a clinical trial is, what it entails how long they last and how to participate.

*Wednesday, March 2; 10:00 a.m. - 11:30 a.m.*  
*Banner Sun Health Research Institute*  
*10515 West Santa Fe Drive, Sun City*  
*Free but registration is required.*  
*To register, call (623) 832-3248*

#### 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, March 9; 10:00 a.m. - 11:30 a.m.*  
*Sun City Library, 16828 N 99th Ave, Sun City*  
*Free but registration is required.*  
*To register, call (623) 832-3248.*  
*This location can only hold 25 people*

#### 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.

*Saturday, March 12, 10:00 a.m. - 12:00 p.m.*  
*Banner Sun Health Research Institute*  
*10515 West Santa Fe Drive, Sun City*  
*Free but registration is required.*  
*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!

*Tuesday, March 15; 1:00 p.m. - 3:30 p.m.*  
*Banner Sun Health Research Institute*  
*10515 W. Santa Fe Drive, Sun City*  
*Free but registration is required.*  
*To register, call (602) 230-CARE (2273)*

### SUN CITY (CON'T)

#### BSHRI Community Lecture Series

##### Understanding Options to Pay for Care: ALTCS (Medicaid)

##### Understanding Options to Pay for Care: 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.

*1st Session: Wednesday, March 16; ALTCS Lecture: 1:00 p.m. - 2:00 p.m. 2nd Session: Wednesday, March 16; VA Benefits: 2:30 p.m. -3:30 p.m.*

*Banner Sun Health Research Institute*  
*10515 West Santa Fe Drive, Sun City*

*Free but registration is required for each session.*  
*To register call (623) 832-3248*

### WEBINAR/TELECONFERENCE

#### Dementia Dialogue Series: Connecting Caregivers to Experts in Dementia Care

##### Webinar Topic: Non-Alzheimer's dementia

Although there are some common features in all dementias, non-Alzheimer's dementias have noticeable differences in symptoms, diagnosis, treatment and care. This Dialogue will review the most prevalent types of non-AD dementias (FTD, LBD, and VaD) and outline treatment and care needs for each.

*Wednesday, March 16; 12:00 p.m. - 1:00 p.m. (Arizona Time)*  
*Free but registration is online at [www.banneralz.org](http://www.banneralz.org) or [www.bannershri.org](http://www.bannershri.org) under events/education and online education. If you have any additional questions, please call the Events Coordinator at (623) 832-3248.*

*\*\*All webinars are recorded and available on the website 24 hours after the event date.*

#### To learn about upcoming education and support programs dates at:

- Banner Alzheimer's Institute, visit [www.banneralz.org](http://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](http://www.bannershri.org) and click on "Events and Education" or call Veronica Flores, Events Coordinator at 623-832-3248