

BAI BEACON

*The Newsletter from Family and Community Services
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Dementia Jargon Surrounding Diagnosis

You or someone you know just received a diagnosis of dementia. Hopefully you got a more specific diagnosis, such as Alzheimer's disease (AD), vascular dementia, etc. But you likely heard many other new terms thrown out during the meeting with the doctor. Perhaps you attended a new support group and they were talking about "ALTCs", "stages of dementia" or "memory care" and you began to feel overwhelmed. This article will define some of the most common terms you are likely to hear. Let's begin from the first visit with the medical provider.

Generally when a diagnosis is made, the person with memory and thinking problems (*also called cognitive changes or impairment*) will see a specialist. A *neurologist* (specializing in problems of the nervous system), *geriatric psychiatrist* (specializing in problems with mood, memory and/or behavior) or *geriatrician* (specializing in care of older adults) are the main medical specialists for dementia. However, primary care physicians can also make the diagnosis. A family member or friend (often called an "*informant*") should be present for this appointment as people with memory and thinking problems may not be able to fully report or even appreciate the cognitive changes that are occurring. In addition to a thorough social history, a medical and neurological examination will take place. Cognitive testing is done to identify possible changes in brain function. Common cognitive tests include the *Mini Mental State Examination (MMSE)* and/or *Montreal Cognitive Assessment (MoCA)*. Each of these tests have a total score of 30 points. Scores above 27 on the MMSE or above 25

of the MoCA are generally considered normal. However, there are many other assessments that can be used as well. All of these tests look at cognitive domains; i.e. different parts of brain function. They usually include measures of:

- ***Executive Function*** (thinking, problem-solving, sequencing)
- ***Short term memory*** (recall of recent information provided during testing)
- ***Language*** (naming items, interpretation of information)
- ***Visuospatial*** (ability of the brain to interpret the spatial relationships of what the eyes see)
- ***Attention*** (ability to pay attention and on task)
- ***Orientation*** (ability to track time, date, location)

Sometimes these tests are not conclusive in making a diagnosis so the physician will order *neuropsychological testing*. This detailed testing takes another 2 - 4 hours to look more carefully at the various cognitive domains, adjusting for the person's age, gender, and years of education. A *neuropsychologist* who specializes in testing and interpretation will generally administer the tests in a quiet location allowing for breaks. Neuropsychological testing is used most often in those with unusual presentations or *mild cognitive impairment (MCI)*. People with MCI have complaints of memory and thinking issues but are still functioning at a normal level, therefore are not considered to have dementia. However, many are at risk for developing AD in future years.

The physician is also likely to inquire about the person's *functional status* which is their ability to independently take care of work, household chores and personal care. *Instrumental activities of daily living (IADL)* is a term used to measure ability to manage chores in and around

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.

the home such as shopping, cooking, cleaning, managing money, etc. *Activities of daily living (ADL)* is a term used to describe the ability to groom, bathe, dress, toilet, and feed self. These are important tasks to measure as they often relate to changes in the brain due to cognitive impairment.

Brain imaging is another part of the dementia evaluation. Most individuals will get a *magnetic resonance image (MRI)* or a *computerized tomography (CT)* scan. The MRI uses magnets to gather a sharper image of the brain and is usually preferred over a CT scan. On occasion, the physician may order a *positron emission tomography (PET)* scan which uses a radioactive or glucose (sugar) tracer to measure brain activity. PET scans are not typically covered by insurance so they are utilized primarily to differentiate specific types of dementia. However, PET scans are being used quite frequently in AD clinical trials as they can measure the amount of *beta amyloid* (an abnormal protein that occurs in AD) and is considered a common *biomarker* (a measure of AD in the brain).

Laboratory studies are done to make sure that there are no other medical reasons that are contributing to cognitive changes. On occasion, genetic testing for AD or Frontotemporal Dementia (FTD) may be recommended. Ideally, these individuals will meet with a genetic counselor to understand what the tests mean. In AD, a gene called *APOE 4* is associated with late onset (after age 65) Alzheimer's disease. Those carrying *2 copies of the APOE 4* (one gene inherited from mother; one gene inherited from father) have the highest risk for developing late onset AD. New studies in AD are beginning to focus on individuals who carry 2 copies of the APOE 4 genes also referred to as *homozygotes*.

After a thorough social, medical, and neurological exam, the physician will look at the results of cognitive testing, brain imaging and lab results and put the pieces together to determine that a dementia is present. Dementia means that there are substantiated changes in memory and thinking abilities that are interfering with a person's independence in everyday life activities. The next step in the process is determining what type of dementia is present. Here are the most common types of dementia that you are likely to hear about (but understand that there are many other less common types).

- **Alzheimer's disease (AD)** is the most common form of dementia accounting for about 60% of all dementias. It is typically characterized by gradual onset of memory loss followed by a continued decline in other areas of mental, and eventually physical functioning.
- **Lewy body dementia (LBD)** is a form of dementia that shares symptoms of both AD and Parkinson's disease (PD). LBD is characterized by gradual onset and fluctuating mental alertness/abilities, along with physical symptoms of Parkinson's and vivid and reoccurring visual hallucinations occurring at times.

Brief periods of unexplained loss of consciousness, repeated falls, sleep disturbance and sensitivity to some anti-psychotic medications also frequently occur.

- **Vascular dementia (VaD)** often in combination with Alzheimer's, is a deterioration of mental function caused by multiple strokes (infarcts) in the brain. The onset may appear suddenly, depending on the size and location of the stroke. Although vascular dementia is not reversible, treatment of risk factors, particularly high blood pressure, may modify or slow the progression. Losses in function, memory and language may appear much like Alzheimer's, although due to continued strokes, sudden changes may be more evident.
- **Frontotemporal dementia (FTD)** is a condition that affects the front (frontal lobes) and the sides (temporal lobes) of the brain. The first symptoms often involve changes in personality, judgment, planning and social functioning. Individuals may make rude or inappropriate remarks to family or strangers. They may make unwise decisions about finances or personal matters and are prone to excessive eating and/or sexual disinhibition. Some individuals may demonstrate difficulty with language that includes the inability to produce a sentence while others may not be able to understand what is being said.

Generally after the diagnosis is made, you are likely to hear what stage of illness the person is in. While there are a number of different ways to stage AD, keeping it simple is usually best. That is:

- **Mild stage** – person is needing assistance with Instrumental Activities of Daily Life (money management, driving, meal preparation, shopping, cooking, cleaning)
- **Moderate stage** – person is needing assistance with Activities of Daily Life (grooming, bathing, dressing, toileting, eating)
- **Advanced stage** – person is dependent for all daily needs

We refer to those living with dementia as a *person with dementia (PWD)* rather than a "patient." We want to recognize the individual, along with their unique abilities, interests and self v. focusing solely on the illness. PWD need partners in care to work around the obstacles created by the illness, thus we often refer to *care partners* as those who will assist the PWD in the mild stages. By the moderate stage, care partners transition to *caregivers* as more assistance and hands on care is needed by the PWD. We recommend that the PWD get enrolled in the *Medic Alert/Safe Return* program through the Alzheimer's Association. This medical ID is very helpful should the PWD ever become lost or separated from the caregiver. An ID is also encouraged for the caregiver, should an emergent situation arise, this would alert emergency personnel that a PWD may be alone at home.

We highly recommend that caregivers get connected to others. *Support groups* provide a group setting for caregivers to come together, share concerns, get educated and find valuable resources. In the mild stage, many couples will benefit from “Partner Support Groups.” Those caring for someone with FTD or LBD may profit from a specialty group due to the many different issues that arise. Likewise, spousal caregivers, men and adult children all have unique needs and may seek out such a group. While BAI and BSHRI provide many specialty groups, the Alzheimer’s Association provides an even greater network of support groups. We recommend that caregivers take

time to find the group that suits their unique needs. It may take some time but it will be well worth it.

In summary, there is a lot of “dementia jargon” used when a diagnosis is made and as the disease progresses. If you don’t understand something being said, ask your provider to clarify. We invite you to join the Webinar/teleconference “Dementia Dialogue” on January 20, 2016 from 12N – 1pm Arizona time when Jan Dougherty, MS, RN, FAAN explores more “Dementia Jargon.” Registration is required and must be done online at www.bannershri.org under events and education and online education OR you can call 623-832-3248.



Ask The Expert

Jan Dougherty, MS, RN, FAAN
Family & Community Services Director

Dear Jan:

My husband has been showing changes in his memory for well over two years but he refuses to listen to me and won't let me go with him to the doctor. He denies that anything is wrong. My kids and I want him to see a dementia specialist but if he won't cooperate, what else can I do?

*Signed,
Shirley*

Dear Shirley,

It is not uncommon for people experiencing changes in memory and thinking to have little to no insight into their situation; and pointing it out will most likely end in an argument. Here are a couple of things to consider. Write your husband's primary care doctor a letter detailing the changes that you are seeing and request that he either complete an evaluation (in which you attend) at an upcoming appointment or refer him to a specialist. However, knowing that he doesn't have insight into his situation, your husband will probably refuse (or forget) to see a specialist. You can make an appointment for him with a dementia specialist but pose the appointment to him by saying, "I am having us visit a doctor who specializes in caring for older adults. I want to make sure that we are both our best as we continue to age." Note, I am not even mentioning memory issues – this is what you want to avoid. Be sure not to announce the appointment too far in advance. We recommend telling him just a few days prior to the visit and again stress this is preventive as you are trying to age successfully. Then change the subject.

Play an active role with the primary care doctor or dementia specialist by giving good information and asking for time alone with the medical provider when reporting cognitive losses or behaviors that may cause him to get upset. When the diagnosis is given – and if he gets angry – just provide reassurance that you love him and this is another medical condition you will work through together.

If none of these strategies work and he still refuses to see a doctor, get educated anyways. You can learn strategies to help him be his best (attend COMPASS class), learn options to find help (Planning Ahead) and a variety of other techniques to support you and others to understand his behaviors, avoid arguments, and keep him safe and occupied. Be sure you hang onto the 2016 caregiver course descriptions. We have a lot we can offer you as his caregiver – with or without a diagnosis.

Did you know you can honor physicians and staff at Banner Alzheimer's Institute through a gift of support? For more information, call 602-747-GIVE (4483).

Have a Question?

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



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Be prepared for your medical visit as most patients and families feel anxious during visits and often forget the questions they wanted to ask. Write down a list of questions ahead of time and bring some paper and a pen along. Be sure you get these questions answered when a diagnosis is made.

- If dementia, what type?
- How will the dementia be treated?
How long will these medications work?
- Are there any research studies that may help?
- What are non-medication options for treatment?
- Where can the family get needed education, support and information to find help?
- What should I expect in the coming 6 months to a year?
- Do we need to see an attorney to sort our affairs and sign legal documents?
- When is it no longer safe to drive? Live alone? Self-administer medications?



January 2016 Program Schedule CAREGIVER EDUCATION PROGRAMS

PHOENIX

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.

Monday, January 11; 12:30 p.m. – 2:00 p.m.

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

Free but registration is required.

To register, call (602) 839-6850

Planning Ahead Class for Caregivers

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.

Tuesday, January 12; 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

Communication Tips to Avoid Arguments

This 2-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!

Thursday, January 21; 10:00 a.m. - noon

Banner Alzheimer's Institute

901 E. Willetta Street, Phoenix

Free but registration is required.

To register, call (602) 839-6850

MESA

Everything You Always Wanted to Know About Dementia

This 60-minute class will differentiate the different types of dementia along with disease progression. Participants will learn about care needs and concerns during each stage of the illness while identifying resources to help with care for the affected person.

Tuesday, January 19; 10:00 a.m. – 11:00 a.m.

Mesa Red Mountain Library, 635 N. Power Road, Mesa

Free but registration is required.

To register, call (602) 839-6850

SUN CITY

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 participate and make a difference.

Wednesday, January 6; 10:00 a.m. - 11:30 a.m.

Banner Sun Health Research Institute, 10515 W. Santa

Fe Drive, Bldg B Morin Auditorium, Sun City

Free but registration is required.

To register, call (623) 832-3248

Please turn over for more classes →

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

January 2016 Program Schedule CAREGIVER EDUCATION PROGRAMS

SUN CITY (CON'T)

Communication Tips to Avoid Arguments

This 2-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, January 12; 1:00 p.m. – 3:00 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Drive, Bldg B Morin Auditorium, Sun City
Free but registration is required.
To register, call (623) 832-3248*

Transitioning Care

Transitioning from home to a residential care setting can be challenging for caregivers and the person with Alzheimer's or Parkinson's disease. This 2-hour class will discuss the importance of planning and considerations to make in a transitioning into long term care.

*Wednesday, January 20; 10:00 a.m. – 12:00 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Drive, Bldg B Morin Auditorium, Sun City
Free but registration is required.
To register, call (623) 832-3248*



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

SUN CITY (CON'T)

Emotional Impact of Parkinson's Disease Lecture

This one hour lecture focuses on helping you better grasp the common emotional changes that occur in a person with Parkinson's disease. Learn how increasing empathy for both caregivers and their person can reduce frustration. Explore the significant emotional impact of PD on care partners and discover strategies to help create better balance.

*Friday, January 22; 2:00 p.m. – 3:00 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Drive, Bldg B Morin Auditorium, 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.

*Friday, January 29; 1:00 p.m. – 2:30 p.m.
Banner Sun Health Research Institute, 10515 W. Santa Fe Drive, Bldg B Morin Auditorium, Sun City
Free but registration is required.
To register, call (623) 832-3248*

WEBINAR/TELECONFERENCE

Dementia Dialogue Webinars

Topic: Decoding Dementia Jargon Surrounding Diagnosis

*Wednesday, January 20; 12:00 p.m.-1:00 p.m. AZ Time
Please register for this webinar at www.bannershri.org under events/education and online education. If you have any additional questions, call (623) 832-3248.*