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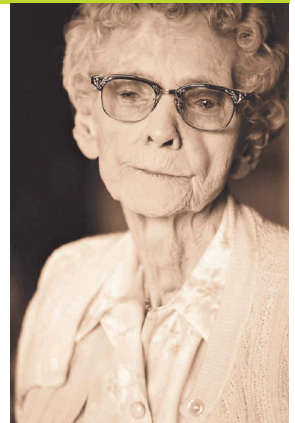
## DEMENTIA & DEVELOPMENTAL DISABILITIES

Dementia in persons with developmental disabilities (DD) is a topic of increasing interest over the past few years due to the aging of this demographic group. Our consumers are living well into their elder-years these days and along with this come all the diseases of old age that we are all subject to. Providers are realizing that the medical care and support needs of an aging person with dementia who is also diagnosed with one or more developmental disabilities are greatly increased. How do we support more needs with less resources? Education and training of staff, families, nurses, and physicians will help. Identifying those individuals early who need more support so intervention can take place is key.

The most common type of dementia in the DD and non-DD populations is Alzheimer's disease (AD). The other 2 types of dementia are dementia with Lewy bodies (DLB), and frontotemporal dementia (FTD).<sup>\*</sup> Other sources for dementia-like behaviors should be ruled out before a diagnosis of any dementia is made. In our DD population, this should include a thorough medication review as many of the meds our consumers take alter cognition and therefore, also may alter the person's ability to perform daily living skills adequately at times. Diagnostic tests such as brain MRI or CT scan may identify vascular changes in the brain, a brain injury, or tumors that may be the culprit for the altered behavior that sent the consumer to the doctor. A thorough workup eliminating what it "can't be" will be the path to lead to the dementia diagnosis, along with a full history and assessment. A person's usual level of functioning will be used as the basis for evaluation. Make sure you can define this.

In the general population, dementia is suspected when a person becomes forgetful, shows obvious signs of memory loss, has problems finding words when they speak, and may get lost in familiar surroundings, or have difficulty performing usual

activities of daily living.<sup>\*</sup> With our consumers who have DD along with a variety of other medical diagnoses, the presentation of 'cues' that may tell you they have dementia can be quite different. It could be that the consumer you support:



- ⇒ Becomes apathetic about doing the things they used to enjoy doing
- ⇒ Has problems doing simple tasks able to perform before
- ⇒ Has changes in behavior (may become aggressive when was not before, may be irritable, may isolate more or be more impulsive)
- ⇒ May become incontinent
- ⇒ Has memory problems—hard to assess usually, especially if nonverbal or lower functioning<sup>\*</sup>

As you can see, evaluating these could be tricky with many of our consumers. The answers are not clear-cut.

It's important to know that dementia is not just loss of memory. It's a pattern of signs and symptoms that you can recognize that includes the memory loss and ALSO loss of cognitive abilities affecting other areas of functioning. You'll have to be a keen observer with your consumers to pick up on these signs. Please report to the physician anytime you see this pattern of behaviors/signs.

<sup>\*</sup> Haller, K., Dementia Evaluations in Persons with Mental Retardation: They Don't All Have Alzheimer Disease, NADD Bulletin Vol. III, 3, Article 1.



# ALZHEIMER'S TREATMENT TODAY

There is currently no cure for Alzheimer's dementia, however, there are interventions that can improve the quality of life for the person with this disease that include non-medical interventions as well as medication therapy. The FDA has approved 5 medications for the treatment of Alzheimer's dementia and these may slow the progress of the disease and allow for a person to maintain a more independent life for a longer period of time. These medications are:

1. Aricept (donepezil)—All stages of Alzheimer's
2. Cognex (tacrine)—Mild to Moderate stages
3. Exelon (rivastigmine)—Mild to Moderate stages
4. Razadyne (galantamine)—Mild to Moderate stages
5. Namenda (memantine)—Moderate to Severe stages

## So, how do these medications work in the brain?

The brain's communication network is like a fine web of connections that communicate by electrical and chemical pathways. Neurons (the nerve fibers) carry the electrical message impulse from one end of the neuron to the other end of the neuron. At this point, there is a gap between the neurons called a synapse. And it's at this synapse that a lot can happen. Tiny molecules of chemical messengers, called neurotransmitters, hang out in these synapses. These neurotransmitters can enhance an electrical message, delay a message, or completely block a message from getting across that gap between neurons. If the neurotransmitters are out of whack for some reason (too much or too little of them), the message can get messed up. This is the area where most psychiatric medications work...on or at the synapses or on the neurotransmitters.

The first 4 drugs on the above list are called cholinesterase inhibitors. Choline is an important, needed chemical in the brain. Cholinesterase breaks it down. So, a cholinesterase inhibitor will INHIBIT, or slow down the breakdown of this needed chemical so more of it is available for use by the brain to enhance messages being carried across the synapse. That is how these first 4 drugs work.

Namenda, the 5th option listed, works differently than the others. It is involved with the neurotransmitter called glutamate, which is a chemical messenger involved in learning and memory. Too much

glutamate contact with brain cells can speed up cell damage and dementia (it is believed). So, Namenda works by regulating the amount of glutamate that reaches the cells.

But, often, with the individual with Alzheimer's dementia, other symptoms can develop over time that may require a different treatment. It is not uncommon for someone with Alzheimer's to become depressed, anxious, irritable, or even to strike out at those who care for them. In the moderate to severe later stages of Alzheimer's, symptoms such as aggressiveness, crying, emotional outbursts, restlessness, wandering, hallucinations, and sleep problems can also be a part of the picture. These symptoms may be managed with non-medical approaches for some (see below). Medications such as anti-depressants, anti-psychotics, or mood stabilizers are not uncommon at this time. Physicians need to weigh the risk vs. benefit picture with a given consumer before using some of these medications in the elderly.

Non-medical approaches should always be tried first before moving to medications...unless it is a serious situation or safety risk to the consumer. Behavioral problems can be provoked by staff or from seemingly simple situations with little apparent causation. These might include such things as:

- ⇒ Being admitted to the hospital and the consumer being away from people and the environment they know, confusion ensues, fear develops, striking out happens
- ⇒ Being asked to do something such as take a bath, change clothes, get ready for bed, take medicine
- ⇒ New staff they don't know
- ⇒ Moving to a new home, new bedroom, or getting a new roommate

If new behaviors or symptoms develop, always review everything going on in that person's world before adding medications. And start with a review of medications. What is the anticholinergic load of all the meds they take? How many meds do they take?

Make sure any potential pain or discomfort issues are dealt with. Dental appointments regularly. Shoes fit appropriately...no red marks on feet. Allergies? Sinus congestion? Constipation? UTI or respiratory infection? Ongoing discomfort can cause behavior to be out of the norm and even aggressive. Redirect negative behaviors. Avoid confrontation with consumers or arguing. They are allowed to say "NO".

If non-medical approaches are unsuccessful, the physician needs to identify the next step with team input.

## New Drug News:

### NUEDEXTA™ : What's PBA?

NUEDEXTA™ is a new medication, the first and only treatment for Pseudobulbar Affect (PBA). So now, you might ask, 'What is PBA?'

Pseudobulbar affect, or PBA, is a neurologic condition that happens because of a disease or injury to the area of the brain that controls a person's expression of emotion. This damaged part of the brain causes disruption to the normal messages being sent and sets off these episodes of involuntary emotion, characterized by outbursts of crying or laughing or emotional lability. There is a disconnect between what is being expressed on the outside (the outburst of crying or laughing) and what the person may be actually feeling on the inside. So, the display of emotion is incongruent to the actual feeling, with periods of exaggerated expression of the person's inner emotional state that seem to occur without any clear trigger prior to the episode. This can be very disturbing to the person with PBA, can create anxiety or embarrassment and even cause them to avoid social situations. It can also be upsetting to those around them when outbursts occur.

NUEDEXTA™ is approved by the FDA for the treatment of PBA in people diagnosed with ALS (amyotrophic lateral sclerosis, also known as Lou Gehrig's disease), MS (multiple sclerosis), stroke, TBI (traumatic brain injury), or people with underlying neurologic conditions such as with Alzheimer's Disease and other dementias.

NUEDEXTA™ is a unique formulation of 2 ingredients:

1. Dextromethorphan hydrobromide (20 mg) which works in the central nervous system
2. Quinidine sulfate (10 mg) which increases the effectiveness of the dextromethorphan and allows it to cross the blood-brain

barrier. It also extends the availability of the medication in the system which allows for the every 12 hour dosing schedule.

NUEDEXTA™ is available in capsules containing the combination of 20 mg dextromethorphan hydrobromide + 10 mg quinidine sulfate. Dosing should be initiated by taking 1 capsule a day for 7 days, then beginning to take 1 capsule every 12 hours.

Patients taking NUEDEXTA™ in studies had a significant reduction in the frequency and severity of these emotional outbursts and a greater likelihood of episode remission from their PBA. The most common adverse drug reactions were diarrhea & dizziness.

NUEDEXTA™ would be contraindicated for patients with certain serious cardiac conditions. Extensive information about NUEDEXTA™, including prescribing information, safety information, side effects, and interactions can be found at [www.NUEDEXTA.com](http://www.NUEDEXTA.com).

NUEDEXTA™ is an interesting option for those consumers with PBA. If you think you, a family member, or a consumer may have this condition, please discuss your options with a neurologist or psychiatrist, who can identify if PBA is the diagnosis.

There is support in the literature for evidence of PBA in Parkinson's Disease and in other conditions characterized by Movement Disorders. Angelman Syndrome, or "happy puppet" syndrome, as it was once called, was also identified as a possible condition where PBA was a component.

Check out this medication online. I think we'll be seeing more about it in the future. Learn more about Pseudobulbar Affect by going to [www.PBAinfo.org](http://www.PBAinfo.org)

## Alzheimer's Disease: The Future

Several new treatments for Alzheimer's Disease are being studied currently to slow down the progress of the disease or to prevent its development. It takes many years to identify potential effective treatments and get them through the rigorous research clinical trials required to meet FDA approval. The 5 current medications approved to treat Alzheimer's Disease only treat the symptoms of the disease, but new medications being studied have the goal of actually modifying the disease process itself to slow down or stop the disease altogether. Researchers are looking at drug "cocktails", focused on attacking the disease from several directions at once. One of the obstacles in Alzheimer's research at this point, is the limited supply of volunteers for the clinical trials they are planning. Many people don't know that you can be a part of a Clinical Trial for just about any research being done out there, as long as you meet the Trial Admission Criteria that they are searching for. If you are interested in being involved in a clinical trial for Alzheimer's Disease, go to Alzheimer's Association Trialmatch at [http://www.alz.org/research/clinical\\_trials/find\\_clinical\\_trials\\_trialmatch.asp](http://www.alz.org/research/clinical_trials/find_clinical_trials_trialmatch.asp)

Future targets of research in Alzheimer's Disease are focusing on several aspects of the disease, like the beta-amyloid plaques found in the brains of patients with Alzheimer's. Neurofibrillary tangles are

another feature of Alzheimer's Disease and researchers have identified a Tau protein component of these that they are investigating how they can alter its current abnormal function in the disease.

Researchers now know that inflammation is key to Alzheimer's brain abnormality and they are identifying ways to decrease overall body inflammation pathways to alleviate this problem in the brain.

Aside from these potential future treatments, diagnostics for the disease are advancing at a rapid rate also. Various brain imaging studies and custom diagnostics for blood and spinal fluid are providing early cues to the disease that may help us in earlier detection of the onset of Alzheimer's, making treatment an option sooner, even before symptoms of the disease show up.

Studies are being done on genetic components of Alzheimer's disease as well as on the rare genetic mutations that cause increased beta-amyloid production...pretty much guaranteeing a future with Alzheimer's Disease.

Need more information? Videos, education, research, and more can be accessed on Alzheimer's Disease by going to [www.alz.org](http://www.alz.org)



## THE POST SCRIPT

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All articles to be considered for submission to this newsletter should go to Georgia Swank at the above email address. We welcome your comments and ideas!

**[www.palrx.com](http://www.palrx.com)**

### RESOURCES ON DEMENTIA & DEVELOPMENTAL DISABILITIES

1. American Association of Developmental Medicine & Dentistry National Task Group on Dementia in DD ([www.aadmd.org.NTG](http://www.aadmd.org.NTG))
2. The ARC ([www.thearc.org](http://www.thearc.org))
3. University of Albany, Intellectual Disabilities, Aging, & Dementia (<http://www.albany.edu/aging/IDD/r-id.htm>)
4. National Institute of Neurological Disorders & Stroke ([www.ninds.nih.gov/](http://www.ninds.nih.gov/))
5. Alzheimer's Association, 2011 Alzheimer's Disease Facts & Figures, ([http://www.alz.org/downloads/Facts\\_Figures\\_2011.pdf](http://www.alz.org/downloads/Facts_Figures_2011.pdf))
6. Southeast PA Dementia Screening Tool for Individuals with Developmental Disabilities ([http://pchc.org/Documents/Forms/Dementia-Screening-Tool\\_2011Revised.pdf](http://pchc.org/Documents/Forms/Dementia-Screening-Tool_2011Revised.pdf))

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