

## Which Comes First the Dementia or the Neuropsychiatric Symptoms?

The title of this article reminds us of the age-old adage of “Which comes first the chicken or the egg?” That question has been discussed for a very long time without resolution. In order to find an answer to “Which Comes First the Dementia or the Neuropsychiatric Symptoms?” question, we need to explore the world of dementia and find out the answer to another question: “Why does it matter?”

Dementia is a degeneration of the brain that causes a progressive decline in people’s ability to think, reason, communicate and remember. Their personality, behavior and mood can also be affected.<sup>1</sup>

Dementia is a common diagnosis in the older adult. Approximately 7.9 million people have dementia in the United States. Of those approximately 3.95 million have a diagnosis with neuropathologies. The prevalence of dementia increases with age and with the population growing older the number is expected to grow. Younger age onset (30-65) is experienced but not at the rate of those aged 65 and older.<sup>2</sup> It is anticipated that the number of people affected by dementia will double every 20 years, so by 2040 the number of affected persons world wide will be 81.8 million and 71% are located in developing countries.<sup>3</sup>

Simply because someone has some memory problems does not necessarily mean they have dementia. A guideline of experiencing at least 2 symptoms would lead one to look into the possibility of that diagnosis.

There are different kinds of dementia. They include Alzheimer’s, Vascular dementia, Dementia with Lewy bodies (sticky clumps of protein found in nerve cells of people with Parkinson’s) diagnosis is made before or at the time of Parkinson’s diagnosis, Parkinson’s disease dementia (symptoms appear a year or more after the Parkinson’s diagnosis) and Frontotemporal dementia.

Some early symptoms of dementia include subtle short term memory loss, difficulty in selecting the right words, mood changes, difficulty concentrating, listlessness or apathy, inability to complete normal daily tasks, confusion, unable to follow a story line, lack of sense of direction, repetitive, and difficulty adapting to change.<sup>4</sup>

Each individual will experience the disease of dementia differently. Dr. Barry Reisberg of New York University developed a progression of Alzheimer’s Disease (AD) into 7 stages<sup>5</sup> that creates a framework of understanding for how the disease may advance. Here are those stages:

**Stage 1: No Impairment** – disease not detectable and no symptoms are present.

**Stage 2: Very Mild Decline**- Minor memory problems may be noticed but is hard to distinguish between normal age-related memory loss. Unlikely to be identified by physician or loved ones.

**Stage 3: Mild Decline** – Cognitive problems are likely to be noticed. Memory tests will reflect poor performance and the physician will be able to identify impaired cognitive function.

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<sup>1</sup> <https://www.youngdementiauk.org/young-onset-dementia-facts-figures> Young onset dementia facts & figures

<sup>2</sup> [https://morethancognition.neurologyreviews.com/newsletter/prevalence-neuropsychiatric-symptoms-dementia-related-psychosis/?gclid=Cj0KCQiA88X-BRDUARIsACVMYD9NVpxHO4Oo5nqQjiUXBbzA8zbnBvabDLANBCxGu6POz4SBSyUpaKgaAnD6EALw\\_wcB](https://morethancognition.neurologyreviews.com/newsletter/prevalence-neuropsychiatric-symptoms-dementia-related-psychosis/?gclid=Cj0KCQiA88X-BRDUARIsACVMYD9NVpxHO4Oo5nqQjiUXBbzA8zbnBvabDLANBCxGu6POz4SBSyUpaKgaAnD6EALw_wcB) More Than Cognition: The Prevalence of Neuropsychiatric Symptoms in Dementia-Related Psychosis

<sup>3</sup> <https://nursinghomehelp.org/wp-content/uploads/formidable/17/Behavioral-Health-MDS-N-O-QIPMO-webinar.pdf> Behavioral Health MDS N&O CMS Changes 2017

<sup>4</sup> <https://www.healthline.com/health/dementia/early-warning-signs> 10 Early Symptoms of Dementia

<sup>5</sup> <https://jnnp.bmj.com/content/76/10/1337> Neuropsychiatric profiles in patients with Alzheimer’s disease and vascular dementia

**Stage 4: Moderate Decline** – Symptoms are very apparent such as difficulty with very short-term memory (food eaten at breakfast), unable to perform simple arithmetic, and unable to pay bills.

**Stage 5: Moderately Severe Decline** – Experience need for help with normal day-to-day activities such as dressing remembering their phone number, wandering or confusion.

**Stage 6: Severe Decline** – Need constant supervision and may require professional care. They experience confusion with the environment or surroundings. Loss of bowel and bladder control is common.

**Stage 7: Very Severe Decline** – Since AD is a terminal disease those in this stage are nearing death. They lose the ability to communicate or respond to the environment. They need total care.

As the dementia advances the symptoms increase and worsen. These include

**Memory loss** – where the individual does not recognize family and friends,

**Communication issues** – may lose the ability to talk at all,

**Mobility problems** – become less mobile and may become confined to wheelchair or bed

**Behavior issues (neuropsychological symptoms)** – These include increased agitation, depression, aggression, anxiety or hallucinations and delusions

**Incontinence problems** (bowel and bladder)

**Weight loss and lack of appetite** – some experience difficulty chewing and swallowing which can lead to other issues such as choking, aspirations etc.

Dementia affects all components of cognition. With the persistent progression of this disease, it has a 98% incidence of neuropsychiatric symptoms (NPS) during some point in the disease including

**Apathy**, absence or suppression of passion, emotion, or excitement; lack of interest in or concern for things that others find moving or exciting

**Aggression**, the action or an act of attacking without provocation.

**Psychosis**: a severe mental disorder in which thought and emotions are so impaired that contact is lost with external reality. (hallucinations/delusions),

**Sleep disturbances**, involve problems with the quality, timing, and amount of sleep, which result in daytime distress and impairment in functioning

**Agitation** - Excessive motor activity (examples include: pacing, rocking, gesturing, pointing fingers, restlessness, performing repetitious mannerisms, wandering); Verbal aggression (e.g., yelling, speaking in an excessively loud voice, using profanity, screaming, shouting); Physical aggression (e.g., grabbing, shoving, pushing, resisting, hitting others, kicking objects or people, scratching, biting, throwing objects, hitting self, slamming doors, tearing things or destroying property)

**Vocalizations** - nonaggressive behaviors such as continuous talking and complaining and aggressive behaviors such as screaming and abusive language

**Disinhibition**<sup>6</sup> a loss of inhibition, a lack of restraint, disregard for social convention, impulsiveness, poor safety awareness, an inability to stop strong responses, desires, or emotions.

**Pseudobulbar Affect (PBA)**: Can be found in any underlying neurologic disorder such as Alzheimer's Disease (AD), Parkinson's Disease, Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Traumatic Brain Injury (TBI) etc. It consists of inappropriate, uncontrollable, exaggerated laughing or crying outbursts, with or without reason or trigger.

Approximately 2.4 million people in the United States have dementia related psychosis (Delusions & Hallucinations). Agitation, being one of the most commonly observed neuropsychiatric symptoms, is

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<sup>6</sup> <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6544588/> Neuropsychiatric Symptoms in Dementia: Considerations for Pharmacotherapy in the USA

reported to be found in up to 70% of dementia patients.<sup>7</sup> Neuropsychiatric symptoms in Alzheimer disease and other types of dementia are extremely common and often much more troubling than cognitive symptoms.

Symptoms can persist or recur over time and are associated with patient and caregiver distress, increased rates of institutionalization, and increased mortality and cost.<sup>8,9</sup>

As a Nurse Leader we recognize our responsibility to provide our staff with the knowledge and tools that can provide our residents, with a diagnosis of dementia, the best care possible.

One way to do that is provide training on what dementia is and what the symptoms are. We must also provide them with the tools to deal with these symptoms to ensure that the resident is kept safe and as comfortable as possible when they occur. Failure to prepare for and intervene appropriately can produce distress for both the resident and the care giver as mentioned above.

More than just the direct care staff need this training. In a study by J. Appl Gerontol it was found that behaviorally based dementia -skills Internet training designed for NAs may have positive effects on non-direct care workers in an LTC. Trainees scores improved and showed positive results with NAs and decreased number of assaults by residents.<sup>10</sup>

Dementia training is the first step in helping the staff to recognize the neuropsychiatric symptoms. Currently 23 states require dementia training for its nursing home staff.<sup>11</sup> Recommended basic topics for this training include:

- An overview of dementia/Alzheimer's disease; (Including symptomology)
- Basic skills in communicating with persons with dementia;
- Managing difficult behaviors;
- Understanding and working with families and caregivers;
- Promoting independence with activities of daily living (ADLs); and
- Identifying and alleviating safety risks to the resident

In the article "Training to Serve People with Dementia: Is our Health Care System Ready?"

("([https://act.alz.org/site/DocServer/2\\_-\\_Training\\_Standards\\_by\\_Health\\_Settings.pdf;jsessionid=00000000.app20018b?docID=49069%EF%BB%BF&NONCE\\_TOKEN=87CFC59D863D62F8F569B71FB6FE6775](https://act.alz.org/site/DocServer/2_-_Training_Standards_by_Health_Settings.pdf;jsessionid=00000000.app20018b?docID=49069%EF%BB%BF&NONCE_TOKEN=87CFC59D863D62F8F569B71FB6FE6775)) tables can be found outlining the state requirements for those that have legislation regarding Dementia training for health care settings. Hand-In Hand, a familiar training program was recently updated and can be found on the CMS website ([https://ahca.myflorida.com/MCHQ/Field\\_Ops/Training/Other\\_Training/CMS\\_Hand\\_in\\_Hand\\_Toolkit.pdf](https://ahca.myflorida.com/MCHQ/Field_Ops/Training/Other_Training/CMS_Hand_in_Hand_Toolkit.pdf)).

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<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5682601/#:~:text=Agitation%2C%20being%20one%20of%20the,to%2070%25%20of%20dementia%20patients>. Dementia-related agitation: a review of non-pharmacological interventions and analysis of risks and benefits of pharmacotherapy

<sup>8</sup> <https://alzres.biomedcentral.com/articles/10.1186/s13195-020-00604-7> Neuropsychiatric symptoms in cognitively normal older persons, and the association with Alzheimer's and non-Alzheimer's dementia

<sup>9</sup> <https://www.atrainceu.com/content/5-neuropsychiatric-symptoms-dementia> Alzheimer's Disease and Related Dementias, 6 units 5.

**Neuropsychiatric Symptoms of Dementia**

<sup>10</sup> <https://doi.org/10.1007/s11920-019-1058-4> Current Psychiatry Reports (2019) 21:79 Advances in Management of Neuropsychiatric Syndromes in Neurodegenerative Diseases

<sup>11</sup> [https://act.alz.org/site/DocServer/2\\_-\\_Training\\_Standards\\_by\\_Health\\_Settings.pdf;jsessionid=00000000.app20018b?docID=49069%EF%BB%BF&NONCE\\_TOKEN=87CFC59D863D62F8F569B71FB6FE6775](https://act.alz.org/site/DocServer/2_-_Training_Standards_by_Health_Settings.pdf;jsessionid=00000000.app20018b?docID=49069%EF%BB%BF&NONCE_TOKEN=87CFC59D863D62F8F569B71FB6FE6775)

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The Alzheimer's website is another excellent resource for training opportunities (<https://www.alz.org/professionals/professional-providers/dementia-care-training-certification/recognized-dementia-care-training-programs>).

Often the resident and family fail to mention the neuropsychiatric symptoms on admission. These can be discovered through a nursing assessment and interviews with the resident and family/caregivers.

A thorough assessment of the resident is indicated next. This can be completed on admission and at least quarterly during the MDS (Minimum Data Set) cycles. Interviews with the resident and family/caregivers are encouraged as well. A sample assessment and interview tool can be found at: <https://www.nadona.org/assessment-and-interview-tools/> and included with the Director.

Documentation of the occurrence of neuropsychiatric symptoms is important for many reasons. First a good description of what occurred and the circumstances surrounding the occurrence can help identify any triggers that might have caused the event. Secondly the documentation should reflect what interventions were initiated and if they were successful. This assists the care givers and care planners to determine if the interventions are appropriate or if they need to be changed. Finally, it documents the history and frequency of the symptoms for the physician and the pharmacist, which when reviewed, gives insight into medication management if necessary. See an example of a documentation tool at <https://www.nadona.org/documentation-of-neuropsychiatric-symptoms-related-to-dementia-tooldocx/> and included with the Director.

Utilizing the assessment, interviews, and documentation, the care plan needs to be created and updated. When interventions are found to be unsuccessful, we need to update the care plan to ensure that the resident has the best care possible and to prevent the staff from becoming frustrated over interventions that don't work.

This sounds easy but has some difficulties attached to it. Who is going to update the care plan during the night? How do we communicate the changes to the staff on a timely basis? Where do we get new interventions from, when we have used everything we can think of? I don't have the answers to all of these questions but I have found that using the Interdisciplinary Team (IDT) to review these occurrences quickly does help. It shows that this issue isn't owned by nursing only and also gives some outside perspective to the situation. See samples of IDT tools at <https://www.nadona.org/behavior-assessment-idt-tools-docx> and included with this issue. Also see a care plan intervention tool at <https://www.nadona.org/behavior-interventions-4/> and included with the Director.

#### Summary:

Cognitive declines in elder adults have a variety of potential causes such as side effects of medications. Metabolic and endocrine imbalances, delirium due to an illness or infection, depression and dementia. Some of the reasons for the decline could be reversed with treatment while others might be treated for a while and thus prepare families for potential changes and provide the resident some relief from the symptoms.

So, the question "Why does it matter?" has this as the answer –the earlier the root cause of the symptomology is determined the earlier interventions to remove or decrease them can be implemented. Anything that we can do to relieve the resident's stress level as well as keeping them safe and comfortable matters. We may find it is a dementia or we may find it is an underlying condition that is triggering the

symptom. Either way discovering it and intervening will provide the resident with a better outcome and quality of life.

The answer to the other question “Which Comes First the Dementia or the Neuropsychiatric Symptoms?” is it depends. The neuropsychiatric symptoms may appear before a diagnosis has been made. Hopefully we used the symptoms to find the cause. Or they may come after the diagnosis and we were equipped to handle them. Either way because we were prepared the resident got the benefit of our training and assessment skills and has a plan of care that will provide him or her with the best possible outcome.

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## Resources

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9. <https://www.atranceu.com/content/5-neuropsychiatric-symptoms-dementia> Alzheimer’s Disease and Related Dementias, 6 units **5. Neuropsychiatric Symptoms of Dementia**
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33. <https://www.alz.org/documents/national/CCN-AD03.pdf> Tools for Early Identification, Assessment, and Treatment for People with Alzheimer's Disease and Dementia
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