

Confused about Dementias

Independent Study

ONF-11-05-I

The Spectrum of Cognition to Confusion and Dementia

We will begin this module with a definition of terms related to confusion and dementia. It is important to recognize the differences between delirium and dementia so as to avoid unnecessary medications or missed opportunities to help the affected individual. Next we will discuss a variety of diseases in which dementia may manifest itself. Finally, to conclude we will discuss treatment modalities, nursing care, and caregiver support.

DEFINITIONS

Cognition is the act or process of thinking, perceiving and learning. Cognitive functions that may be affected by dementia include decision making, judgment, memory, spatial orientation, thinking, reasoning, and verbal communication.

Confusion is defined as being a mental state in which reactions to environmental stimuli are inappropriate. The person may also be described as being bewildered, unable to orient himself or is perplexed, when otherwise he or she would not be. Confused states can occur with either delirium or dementia.

Delirium is a *reversible* condition of extreme mental confusion and motor excitement marked by defective perception, impaired memory and a rapid succession of confused and unconnected ideas. Speech may be rambling and/or incoherent. Often the patient may experience illusions and hallucinations. Delirium is a transient acute mental disturbance that manifests as disorganized thinking and a decreased ability to pay attention to the external world. In an elderly individual delirium can be brought on by a urinary tract infection, constipation, colds, under-managed pain, illness, or stressful situations. Patients receiving narcotic analgesics or anesthetic agents may also present with delirium. Drug interactions and side effects are also causes of delirium in the elderly.

Delirium is generally caused by some underlying condition. When the cause is eliminated or resolved, the person returns to his or her baseline of cognitive function. Delirium is generally characterized by a sudden onset of confusion; however bear in mind in an elderly person the confusion may actually become chronic due to a neglected or under-managed chronic illness.

Pseudodementia is a type of severe depression that occurs mostly in the elderly. Cognitive changes resemble dementia to include slow motor movements and thinking and short-term memory loss. They may be apathetic and answer questions without attempting to provide the correct response. Often they may exhibit poor eye contact and little spontaneous movement.

A person in a state of pseudodementia may exhibit poor hygiene and inappropriate dress, as he may be so depressed, he takes no interest in appearance. Because it is often difficult to determine whether the individual has pseudodementia versus a true dementia, often the individual will be treated with an antidepressant. If there is improvement in mood, one can come to the conclusion the individual was suffering from pseudodementia. If there is no improvement, the individual may then be diagnosed with a dementia.

Dementia is defined as a gradual *irreversible* mental deterioration with loss of cognitive function due to organic or psychological factors. Alzheimer's Disease is a classic example that comprises 50% of the dementia cases. Other diseases associated with dementia include multi-infarct dementia (vascular),

Huntington's disease (inherited), infectious disease (HIV, syphilis), Lewy body dementia, Pick's disease (atrophy of the frontal & temporal lobes), progressive supranuclear palsy, ALS, Creutzfeldt-Jakob disease, and Parkinson's disease.

Table 1 (compares delirium to dementia)

Characteristics	Delirium	Dementia
Onset	Acute or slow	Insidious
Duration	Days to weeks, almost always worse at night	Permanent, commonly worse at night
Associated Conditions	Drug abuse or withdrawal or systemic illness is always present, UTI's , stressful events, narcotic analgesics	No systemic conditions necessary
Attention Span	Poor	Usually unaffected
Appearance	Slovenly	Often neat until much later stages
Arousal Level	Fluctuates from lethargy to agitation	Normal
Orientation to person, place & time	Variably impaired for person & place, almost always impaired for time	Impaired if disease results in social isolation
Cognition	Disorganized thoughts, hallucinations and <i>illusions</i> * are common	<i>Delusions</i> ** or hallucinations are common
Speech and language	Dysarthric, slow, often not coherent, and inappropriate	Aphasia is possible
Memory	Impaired	Loss of recent memory with impaired remote memory.

Delirium versus Dementia

* **Illusions** occur when a person has a false perception. He mistakes something for what it is not. For example, one may ask a patient, "What color is the apple?" He responds it is blue. The delirium resolves and again you ask, "What color is the apple?" The patient responds red.

****Delusions** are false beliefs or wrong judgments held with conviction despite evidence to the contrary. The individual persists in stating the apple is blue, even when a bag of red apples is shown to the patient. Another example of a delusion is when a person with dementia persists in thinking she has to go to work, when she has been retired for 25 years. Even when shown a retirement certificate, she persists in stating she still has to go to work.

Types of Dementia

There are many types of and contributing factors to dementia. In this section we will discuss the more commonly encountered conditions that can cause dementia. These include the following:

- Lewy Body Dementia
- Pick's Disease
- Progressive Supranuclear Palsy
- ALS
- Creutzfeldt-Jakob Disease
- Parkinson's Disease
- Multi-infarct Dementia
- Binswanger's Disease
- Alzheimer's Disease

Lewy Body Dementia is the second most frequent cause of dementia in the elderly. Lewy Body Dementia is suspected when a patient presents with progressive cognitive decline in combination with

three additional defining features. The additional features are: 1) pronounced fluctuations in alertness and attention with frequent periods of drowsiness, lengthy periods of staring into space, or disorganized speech; 2) recurrent visual hallucinations; and 3) parkinsonian motor symptoms to include rigidity and loss of spontaneous movement.

Abnormal structures containing deposits of a protein called alpha synuclein (Lewy Bodies) are found in areas of the brain. Lewy bodies are found in both Alzheimer's and Parkinson's patients, but it is unclear whether Lewy Body Dementia is a distinct entity itself, or a variant of Alzheimer's or Parkinson's disease. Symptoms of Lewy Body Dementia range from traditional parkinsonian effects (bradykinesia, rigidity, tremor and shuffling gait) to those of Alzheimer's Disease (acute confusion, loss of memory, loss of or fluctuating cognition). Visual hallucinations may be one of the first symptoms noted, followed by delusions and depression. Currently most patients are treated with the medications used for Parkinson's disease and Alzheimer's Disease as well as antidepressants and antipsychotic medications. Antipsychotic medications are used with caution, if at all, as these medications may increase the severity of hallucinations and worsen motor symptoms (increase rigidity problems). Average survival time after diagnosis is approximately eight years, similar to Alzheimer's Disease.

Pick's Disease, also known as *Frontotemporal Dementia*, is a rare form of dementia, but accounts for 5% of all dementia types. It generally occurs between the ages of forty and sixty years old and slightly more often in women than men. The patient with Pick's Disease presents very much like a patient with Alzheimer's Disease, with the difference being detected on autopsy. In Pick's Disease, the patient develops Pick's bodies in localized areas of the brain, predominantly in the frontal and temporal lobes. With Alzheimer's Disease, the neurofibrillary tangles develop over more generalized areas.

Pick's bodies are very different in appearance than the neurofibrillary tangles seen in Alzheimer's Disease. Pick's bodies are straight versus paired and helical. While early symptoms of Alzheimer's Disease tend to be memory impairment, early symptoms of Pick's Disease tend to be frontal lobe symptoms. Remember the frontal lobe houses our cognitive functions, our sense of humor, personality traits and social functioning. Thus it is often a change in mood such as euphoria, disinhibition and deterioration of social skills that are first noticeable. An individual with Pick's Disease may become an extrovert or withdrawn. They can be rude, impatient, aggressive, and/or make inappropriate remarks in public. They may exhibit a change in sexual behavior that can be linked to the loss of inhibitions.

Like Alzheimer's Disease, when early stages reveal subtle loss of memory, early stages of Pick's Disease may reveal subtle changes in behaviors. Early changes may include difficulty in maintaining a line of thought, easily becoming distracted, and/or have difficulty maintaining a conversation for any length of time. It isn't until the behaviors become more bizarre that Pick's Disease may be suspected. Later stages of Pick's Disease may include gluttony, gross over eating, and/or increased alcohol consumption. Individuals with Pick's Disease may compulsively put things in their mouths. Pick's Disease is treated with the same modalities as Alzheimer's Disease. The progression for Pick's Disease may last anywhere from 2 to 10 years.

Progressive Supranuclear Palsy is a movement disorder occurring more often in men and in individuals aged 60 years or more. The patient with Progressive Supranuclear Palsy will decline with death resulting in 5 to 7 years.

Typically the patient with Progressive Supranuclear Palsy presents with Parkinsonian type symptoms. These symptoms include bradykinesias (slow movement), rigidity, shuffling or uncoordinated, unsteady gait, repeated falls, slow speech patterns, poor ability to enunciate words, and low voice volume. They suffer a *mild dementia* and the same widespread neurofibrillary tangles seen in Alzheimer's Disease. In this mild dementia, the patient tends to have difficulty using knowledge, is forgetful, may be apathetic and in general has slowed thought processes. Vision difficulties further complicate this disease. The

patient experiences uncontrollable and uncoordinated eye movements as well as the inability to look up or down without bending his or her neck. The condition may be diagnosed via a MRI (magnetic resonance imaging) that may show shrinkage of the brainstem.

Treatment for Progressive Supranuclear Palsy includes medications used for Parkinson's disease to treat movement disorders and the Alzheimer's Disease medications for dementia symptoms.

Amyotrophic Lateral Sclerosis is often called Lou Gehrig's disease, named for the famous baseball player who died of this disease. This is a motor neuron disease in which there is damage to and loss of motor neurons. Motor neurons are located in the brain, brainstem and spinal cord and control our voluntary movements. Amyotrophic Lateral Sclerosis causes weakness, twitching, cramping, stiffness of muscles, slurred speech, difficulty swallowing and/or chewing. Patients may experience stumbling and falling. Eventually, the individual may succumb to respiratory failure as the diaphragm fails to function. These patients will not survive without mechanical ventilation at that point. While not all patients with Amyotrophic Lateral Sclerosis experience dementia, studies have shown some patients do experience problems with depression, decision-making and memory loss. There is one medication called riluzole (Rilutek™) that is believed to reduce the damage to the motor neurons. Riluzole seems to extend survival time by a few months and delays the need for mechanical ventilation.

Creutzfeldt-Jakob Disease is a rare, degenerative and fatal brain disorder that affects about 200 new cases per year in the U.S. The disease has a rapid course, with death occurring in 90% of patients within one year. Early stages of the disease reveal a failing memory which rapidly progresses to dementia, behavioral changes, a lack of coordination, falls, and visual disturbances.

As the disease progresses, mental deterioration becomes very pronounced resulting in severe dementia, involuntary movements, blindness, weakness of extremities and coma may occur. Creutzfeldt-Jakob Disease is part of the family of diseases known as the transmissible spongiform encephalopathies (TSE). Spongiform refers to the spongy appearance the brain tissues develop as this disease progresses.

It is thought the cause of Creutzfeldt-Jakob Disease is a virus with an unusually long incubation time. although no such virus has been isolated to date. Another theory maintains that a type of protein called a prion causes Creutzfeldt-Jakob Disease. Household members of Creutzfeldt-Jakob Disease patients have no higher risk of contracting the disease than the general population. Iatrogenic causes of the disease include grafts of the dura (the outer covering of the brain), corneal transplants, inadequately sterilized implanted brain electrodes, and injections of contaminated pituitary growth hormone derived from cadavers.

A variant of the disease has been identified in Great Britain and France. It is speculated that perhaps the consumption of contaminated beef has been the cause, but this has not been proved as of yet. Currently there is no treatment for Creutzfeldt-Jakob Disease, thus measures are undertaken to ease the patient's symptoms and promote comfort.

Parkinson's Disease is a movement disorder that results in the loss of dopamine producing brain cells. Patients experience tremor, rigidity, bradykinesia and postural instability. Other symptoms of Parkinson's disease include depression, mood changes, and sleep disruption. Some individuals experience dementia along with Parkinson's disease. Most often this dementia is a Lewy Body Dementia. We have already discussed Lewy Body Dementia in this module.

Multi-infarct Dementia is a very common cause of memory loss in the elderly. It is caused by multiple strokes that lead to damaged brain tissue. Often these strokes occur without any noticeable clinical symptoms, in other words, the patient doesn't even know it occurred. These are often referred to as

"silent strokes." Over time when more of the brain is damaged, symptoms of Multi-infarct Dementia are seen.

Symptoms include confusion, loss of short-term memory, wandering, getting lost in familiar places; walking with a rapid, shuffling gait; losing bladder and/or bowel control; laughing or crying inappropriately; having difficulty following instructions; and having problems with counting money and making monetary transactions. Multi-infarct

Dementia affects more men than women and typically begins between the ages of 60 to 75. Because Alzheimer's Disease and Multi-infarct Dementia may occur simultaneously, it is often difficult to make a diagnosis. An MRI or CT Scan of the brain may reveal areas of stroke confirming Multi-infarct Dementia.

There is no treatment for Multi-infarct Dementia. Once it has occurred, the damage to the brain is irreversible. Most emphasis is placed on prevention via promoting sound cardio- and cerebrovascular health. A healthy diet, exercising, not smoking, moderately using alcohol and maintaining a healthy weight are all part of a healthy lifestyle that promote cardio- and cerebrovascular health. Controlling hypertension, dyslipidemias, and diabetes also factor in to minimizing the risk for Multi-infarct Dementia.

Binswanger's Disease, also known as *Subcortical Vascular Dementia*, is caused by widespread microscopic areas of damage to the deep layers of white matter in the brain. (Recall myelin has a white color, thus white matter are tissues protected by a myelin sheath.) The damage that occurs is due to atherosclerosis of the subcortical areas of the brain. The subcortical area of the brain refers to the structures below the cerebral cortex. As the atherosclerotic process continues, blood flow becomes impaired and eventually brain tissue dies. When enough loss of brain tissue occurs, it can be visualized on an MRI or CT scan. Binswanger's Disease affects the patient's executive cognitive functioning that includes short-term memory, organizational skills, mood, and attention, the ability to make decisions and act, and appropriate behavior. Similarly to Parkinson's disease, Binswanger's Disease produces a psychomotor slowness. (e.g., it takes a longer period of time to form a letter when writing). Other symptoms of Binswanger's Disease include forgetfulness (not as severe as seen in Alzheimer's Disease), changes in speech, an unsteady gait, clumsiness, frequent falls, and changes in personality or mood. These patients may also experience urinary symptoms, such as incontinence, which are not attributable to urological diseases.

There is no specific treatment for Binswanger's Disease. Medications used to treat Alzheimer's Disease are employed to assist with memory loss, and antipsychotics may be used to treat mood and behavior problems. Like Multi-infarct Dementia, prevention is the best treatment. Thus adopting a healthy lifestyle, curbing alcohol consumption, smoking cessation, and controlling problems such as hypertension and diabetes are key elements.

Alzheimer's Disease is the most common cause of dementia in people age 65 and older. Just as in the previously discussed dementias, Alzheimer's Disease is irreversible, progresses over a period of 5 to 20 years and culminates in the patient's death. Initially the individual experiences memory loss and confusion, which is often attributed to "normal aging". However as symptoms worsen, it becomes evident the individual is experiencing more than normal aging. Alzheimer's Disease leads to behavior and personality changes and a decline in cognitive abilities that affect decision-making and language skills. The Alzheimer's Disease patient develops difficulty in recognizing familiar objects and familiar faces. They often lose the ability to name friends and family members. Alzheimer's Disease primarily affects the cerebral cortex and hippocampus, ultimately causing three *hallmarks*.

Amyloid plaques are made up of fragments of a protein called beta-amyloid peptide. The beta amyloid peptide becomes mixed with other proteins, remnants of neurons and other brain cells to form a clump known as amyloid plaque. Beta amyloid peptide has been shown to be associated with genes ApoE4 (chromosome 19) and chromosome 21 (trisomy 21 or Down Syndrome). These genetic mutations generally cause Alzheimer's Disease at an earlier age, such as in the person's 30's or 40's. While there are some genetic components to Alzheimer's Disease, it is *not* necessary to have one of these genetic defects to develop Alzheimer's Disease.

Neurofibrillary Tangles are found inside neurons and are abnormal accumulations of a protein called tau. The tau protein is necessary for the development of healthy neurons, but in the individual with Alzheimer's Disease, the tau protein clumps together. The clumps of tau protein cause the neurons to fail to function and eventually die. The now dead neurons contribute to formation of more amyloid plaques.

Loss of connections between neurons occurs first with the hippocampal neurons. The hippocampus is where short-term memory resides, thus when these neurons are lost, loss of short-term memory ensues. As neurons die, connections are lost with surrounding neurons. Neurons do not survive when they lose their connections with other neurons. Thus the death of neurons due to neurofibrillary tangles and amyloid plaque only perpetuates even more neuron loss. As there is more and more neuron loss, the affected areas of the brain will begin to atrophy and shrink. When the disease is widespread, there is widespread and significant atrophy of the brain, which can be easily seen on a CT scan.

In the next section, we will discuss the diagnosing, stages and treatment for Alzheimer's Disease. As one reads this section, bear in mind many of the treatment options and nursing care implications are pertinent to *any patient with a dementia*. Many of the medications used to treat Alzheimer's Disease are also used to treat Lewy Body Dementia, Pick's Disease, or any of the other dementias we have discussed.

Nursing Care and Implications for Dementia

Risk Factors for Dementia: There are many types and causes of dementia. Besides the causes and risk factors we have already discussed, other risk factors include:

- Advanced age
- Cardiovascular disease
- Cerebrovascular disease
- Head trauma
- Alcohol and/or drug abuse
- Malnutrition
- Brain Tumors
- Hydrocephalus
- Kidney disease
- Diabetes
- Liver diseases
- Thyroid diseases
- Infections (HIV, syphilis)
- Vitamin B deficiencies
- Sex (women have a higher rate, adjusted for age)

Diagnosis, Signs and Symptoms:

Besides the tests such as CT scans and Magnetic Resonance Imaging, there are a number of tools used to establish a diagnosis of dementia. Other routine tests are performed to rule out other causes of dementia, such as laboratory studies (vitamin levels, electrolytes, thyroid, glucose, CBC, drug levels, liver and kidney function,

VDRL); urine tests and electrocardiograms (ECG) are also valuable. A careful patient history, often with the family providing much of the information, is essential. An electroencephalogram (EEG) may reveal "slowing" of waves or other patterns indicating dementia. PET scans are being used more and more in diagnosing cerebral diseases, especially as the PET scan technology becomes more readily available to healthcare centers.

The *American Psychiatric Association* has established criteria for the diagnosis of dementia to include:

- 1) Erosion of recent and remote memory **and**
- 2) Impairment of one or more of the following area (See Chart 1):

Chart 1

Language	Aphasia: Misuse of words or inability to remember and use words correctly
Motor activity	Apraxia: Unable to perform motor activities even though the physical ability remains intact.
Recognition	Agnosia: Unable to recognize objects, even though sensory function is intact.
Executive function	Unable to plan, organize activities and/or think abstractly.

Patients may have unusual difficulty learning names, or may lose events, like forgetting a brunch date from the previous morning. Early signs of dementia may include the misuse of common words or use of odd locations; for example, the individual may put laundry soap in the freezer. Some may show compulsive or impulsive behaviors and cannot be left alone. The individual may repeat the same task over and over, such as check and recheck a locked door multiple times. Often subtle symptoms attributed to "old age" or stress, are exhibited over a period of years and delay the diagnosis of dementia.

Let's talk about loss of memory for a moment. How many times have you thought to yourself that you have developed Alzheimer's Disease because you could not find something or remember a name? *We all forget things from time to time and that is normal.* For example you returned home from work after a busy day and as you were entering your home, the phone was ringing. In your hurry to answer the phone, still distracted by the busy day, you absent mindedly put your car keys in your coat pocket instead of in your purse or on the kitchen counter where you normally store your keys. You answer the phone call and proceed with the rest of your day.

The next morning as you head out the door to go to work again, you can't find your keys. You look in your purse or on the kitchen counter and you can't find them. You look everywhere and no keys! You begin to panic because you don't want to be late for work. You even ask the kids and the dog where your keys are. The entire time you are wearing your coat as you are looking for your keys. In exasperation, you stop to think and in putting your hands in your coat pocket-there they are! And you don't even remember how they got there. *This is normal memory loss*, due to being distracted and or tired. (Makes you kind of worry about all the distractions you experience every day at work, doesn't it? It makes you wonder what else you've forgotten to do at work.) For the person who has dementia, she has the car keys in her possession and/or knows where the keys are, however she doesn't remember what she is supposed to do with the keys, or doesn't remember for what the keys are used. When asked what the keys are for, the person with dementia may state the keys are actually small knives used to cut things versus start the car or open the door to the house.

Another tool used to diagnose dementia is the **MiniMental State Exam (MMSE)**. This consists of tasks including memory, naming items, drawing, and counting skills and has a maximum score of 30 points. As a caution, it should be noted that performance might be affected by education. It is possible for a highly educated patient to score a perfect 30, yet have moderate impairment of cognitive function. The MiniMental State Exam is also used to identify which stage of Alzheimer's Disease the patient is exhibiting.

Stages of Alzheimer's Disease or Dementia

Stage of Dementia/ MMSE Score	Characteristics
Stage 1 MMSE 22 - 26 out of 30	Moderate impairment of short-term memory; impaired visuospatial skills ¹ ; word finding difficulty; possibly impaired smell; reduced glucose metabolism and blood flow to parieto-temporal areas of the brain. The individual functions well at baseline, but easily decompensates with stressful events.
Stage 2 MMSE: 18-20 out of 30	More severe loss of short term and long term memory affecting ADL's i.e., forgets how to tie shoes; fluent aphasia ² , dyscalculia ³ , ideomotor apraxia, ⁴ and apathy; EEG slowing; mild to moderate cerebral ventricular dilatation.
Stage 3 MMSE: 0-10 out of 30	Severe loss of intellectual function; frontal lobe impairment may be the last to occur; motor limb rigidity; incontinence; abnormal MRI; return of grasp and snout reflexes seen in infancy.

1. **Visuospatial Skills** pertain to hand eye coordination and the placement of objects. For example with impairment of visuospatial skills the individual may set a glass on the edge of a table, thus resulting in the glass falling on the floor. They may also misjudge steps and risk falling.
2. **Fluent aphasia** occurs when the individual begins to exhibit more and more aphasia in their speech versus normal speech patterns. Just as someone becomes fluent in a foreign language such as French or German, this individual becomes fluent in aphasia.
3. **Dyscalculia** is the inability to perform simple calculations one would expect the individual to know how to do. The individual may no longer be able to answer "4" when asked what 2 + 2 is. Often this individual will begin to experience overdrafts at the bank, as they are no longer to maintain a bank ledger.
4. **Ideomotor apraxia** pertains to the inability or difficulty in translating thought into motion. For example, the patient is asked to move a pen so it is next to a pad of paper and while the person has the physical ability to do so, they are unable to undertake the task.

Another tool used to stage dementia is the **Functional Assessment Stages Tool (FAST)**. The Functional Assessment Stages Tool gives 8 stages of Alzheimer's Disease versus the 3 stages defined by the MiniMental Status Exam. Using the Fast Assessment Stages Tool, it allows one to classify patients in stages 6 through 8, after they score 0 on the MiniMental Status Exam. One advantage of the Functional Assessment Stages Tool over the MiniMental Status Exam is that family members or caregivers can easily assess the individual based on what assistance they are providing for the individual.

Where the average family member caregiver does not have the tool used in the MiniMental Status Exam, the caregiver can use the Functional Assessment Stages Tool independently. The Functional Assessment Stages Tool tends not to be influenced by educational level as experienced with the MiniMental Status Exam. Another advantage of The Functional Assessment Stages Tool is that it assists caregivers in planning for the future by anticipating what needs the individual may expect to develop as he or she progresses.

Functional Assessment Stages Tool

Stage	Functional Assessment	Classification
1	No decrement	Normal Adult
2	Mild word finding or difficulty in finding location. Able to live and function independently.	Normal Aging
3	Deficits present in a demanding setting, returns to baseline when stress is removed.	Incipient Alzheimer's

	Requires minimal assistance and monitoring. If the individual has not done so previously, he or she should designate a financial and medical power of attorney (advocate).	Disease possible
4	Requires assistance e.g. finances: planning a dinner party; abandons hobbies; unable to perform household tasks. Requires minimal to moderate assistance with activities of daily living. Usually needs a financial and/or medical power of attorney (advocate) to assist at this level.	Mild Alzheimer's Disease
5	Needs assistance choosing proper attire, requires reminders and assistance with hygiene, inappropriate emotional responses may be present at times. Requires moderate assistance with activities of daily living, financial and medical power of attorney should be in place.	Moderate Alzheimer's Disease
6	Assistance with dressing/bathing; urinary/fecal incontinence present. Requires moderate to total care, requires total monitoring of behaviors and actions.	Moderately severe Alzheimer's Disease
7	Progression and worsening of all of the above, speech becomes limited to a half dozen words. Usually requires total care.	Severe Alzheimer's Disease
8	Cannot sit up, smile or hold head up, fetal position, becomes immobile, seizure activity may be present. Will require total care.	Severe, terminal Alzheimer's Disease

Comparing the Stages of the MiniMental Status Exam to the Functional Assessment Stages Tool

MiniMental Status Exam Scores	Functional Assessment Stages Tool
Stage 1 MMSE 22 to 26 out of 30	Stage 2 moving into Stage 3
Stage 2 MMSE: 18-20 out of 30	Stage 4 moving into Stage 5
Stage 3 MMSE: 0-10 out of 30	Stage 5 moving into Stage 6
	Stages 6 through Stage 8

Regardless of the tool that is used to diagnose and classify dementia, it should be noted we still do not know how long an individual will stay in one stage or another. Some individuals may spend months to even years in one stage, then may rapidly progress through the remaining stages of the disease. The tools are helpful in giving family members an idea as to what to expect as the dementia progresses. Unfortunately the tools do not offer a time frame.

Medications and Nursing Implications for Dementia

It wasn't until recent years that any medications have even been available for the treatment of memory deficits. It should be noted that none of these medications offer a cure for Alzheimer's Disease and generally less than half of all patients taking these medications show any improvement. Some patients experience no improvement while others realize an improvement in memory and cognitive functioning. It is believed these medications prolong the current stage of dementia for the individual before progressing into the next stage. Therefore, while there may be no apparent improvement in memory or functioning, the medications may slow the progression of the dementia.

Acetylcholinesterase Inhibitors: The first group of medications all function to preserve the brain's supply of acetylcholine by inhibiting acetylcholinesterase. If one recalls the function of the neurons, after an action potential travels the length of the axon, there is a release of neurochemical transmitters. Acetylcholine is one of our main neurochemical transmitters in the brain. Acetylcholine travels across the synapse and makes contact with the dendrites of other neurons, thus communicating thoughts, evoking memories and creating cognition. Once acetylcholine is released into the synapse, an enzyme called acetylcholinesterase is released.

The acetylcholinesterase dissolves or removes the acetylcholine from the synapse and thereby ends the neurochemical transmission. By giving medications that inhibit the actions of acetylcholinesterase, the acetylcholine is able to stay in the synapse for a longer period of time and thus make more connections with surrounding neurons and hopefully improve cognitive function for the patient.

Side effects for the acetylcholinesterase inhibitors include nausea, vomiting, diarrhea, dyspepsia, anorexia, abdominal pain and dizziness. To avoid side effects, it is helpful to take these medications with meals (except Cognex) and drink 6 to 8 glasses of water every day. It is also important to initiate these medications at a lower dose and then slowly increase to the desired dose.

Reducing the dose may be effective in eliminating side effects should they become apparent. Insomnia may also occur as a side effect and may subside as the patient continues on the medication. Be sure to administer these medications with food, as that will help curb the development of gastric side effects. Patients taking these medications may experience anxiety, tremor, agitation, aggressiveness, and personality changes. Should these side effects occur, lowering the dose or discontinuing the medication altogether may be warranted. Surgeons and anesthesiologists should be aware the patient is taking these medications, as they may experience exaggerated muscle relaxation if a succinylcholine type medication is used during an operative procedure.

Donepezil (Aricept) was the first medication approved for use in treating the symptoms of dementia. It is available in 5 and 10 mg tablets. Dosing is initiated at 5 mg and may be increased to 10 mg after 4 to 6 weeks. Aricept is taken only once per day and is best taken at bedtime. Also note the name Aricept has been confused with Aciphex (rabeprazole), so caution patients and their caregivers to be sure they have received the correct medication.

Galantamine (Razadyne, formerly known as Reminyl): This is the newest of the acetylcholinesterase inhibitors. Razadyne, besides inhibiting acetylcholinesterase, also has the added benefits of increasing the production of acetylcholine and makes the brain cells more receptive to the acetylcholine it does have. Effects may not be fully appreciated for 6 to 12 months after beginning therapy with this medication. Razadyne is available in either a liquid or tablet form. Most patients begin with a 4 mg dose, twice per day, then increase *slowly* (over a 4 week period of time) to an 8 mg dose twice a day, then 4 weeks later progress to a 12 mg dose, twice per day. The usual dosage range is 16 to 32 mg per day in two divided doses. The liquid preparation does not have a very appealing taste, thus should be mixed with juices or sodas to improve compliance if given orally. If this medication is stopped for a number of days, it should be restarted at a lower dose, then increased in 4-week intervals to the pre-existing dosage. Besides being used to treat Alzheimer's Disease, Razadyne may be used to treat vascular dementias.

Rivastigmine (Exelon) is used to treat mild to moderate Alzheimer's Disease and Lewy Body Dementia. It is available as a capsule, a liquid or a patch. With the oral form, patients usually start off with a small dose of 1.5 mg, two times per day. Over the next 4 weeks, the dosage is increased to 6 to 12 mg daily, in divided doses. Gradually increasing the dose and administering with food helps lower the risk of developing side effects.

The Exelon patch is available in two doses. Usually the patient begins with the 4.6 mg per 24 hour patch. After a minimum of 4 weeks, the dose is increased to the 9.5 mg per 24 hour patch. The patch is a nice convenience as it eliminates the twice per day capsules, which can be a big advantage if one has encountered an individual who is uncooperative with taking oral medications. However, the patch may cause reddening and itching. It is important to rotate the site of application everyday and be sure to inspect the skin where previous patches were applied. The skin should be clean, dry and devoid of any lotions or creams in the area it is to be applied. Some patients will remove the patch; thus using the upper or lower back may prevent removal.

Tacrine HCl (Cognex) is supplied in 10, 20, 30 and 40 mg capsules. The medication is initiated at 10 mg, four times daily (around the clock), and then increased by 10 mg every 4 weeks for a total of 120 to 160 mg per day in four divided doses. One of the major side effects of tacrine is *hepatotoxicity*. Thus patients taking this medication should have liver function studies monitored on a routine basis.

Unlike the other acetylcholinesterase inhibitor medications that are taken with a meal, tacrine is best taken on an empty stomach, either 1 hour before or 2 hours after a meal. This allows for ready absorption to maintain therapeutic drug levels. It is also important that this medication be taken around the clock for best results. Besides the liver toxicity problems, one can see this is not the easiest medication to use. Having to take it around the clock in four doses makes for a complicated medication regimen for an already forgetful patient and his or her caregivers. For these reasons, Cognex is not used as much as it once was.

Memantine (Namenda) is the only medication approved for use in *moderate to severe* Alzheimer's Disease. It is *not* an acetylcholinesterase inhibitor, but an N-methyl D aspartate receptor antagonist. Memantine helps protect nerve cells in the brain from excess glutamate. It is thought that glutamate (an excitatory amino acid) may contribute to the symptomatology of Alzheimer's Disease. By blocking these receptor sites, glutamate is not able to excite the brain.

Memantine has been shown to improve memory and cognitive function and prolong the ability of Alzheimer's Disease patients to perform some tasks independently. Again, as seen with the other medications we have discussed, Memantine is not a cure, but it tends to slow the progression of Alzheimer's Disease. Memantine is commonly combined with Aricept (an acetylcholinesterase inhibitor). With this combination of medications, patients seem to benefit since the two drugs work differently. Memantine is supplied in 5 and 10 mg tablets. Again the dosing is initiated with a 5 mg daily dose. The dosing is then increased at weekly intervals to 5 mg twice per day; 15 mg per day (5 mg and 10 mg doses); and finally to the target dose of 20 mg per day (10 mg taken twice per day). Side effects include headache, constipation, confusion and dizziness. Usually side effects subside with continued use of the medication. If side effects do not subside, a lower dose with a slower progression to the target dose may be necessary.

New Medications on the Horizon

When considering the aging Baby Boom population, it makes us realize there will be an "epidemic" of Alzheimer's Disease in the future. Looking ahead to that future, new medications are being developed. Some medications that are showing some promise include:

Dimebolin (Dimebon) is a "retired" antihistamine originally used in Russia. It has been shown to improve cognitive functioning in mice and humans; however it was found to actually increase the levels of beta amyloid. It has long been thought that beta amyloid is one of the culprits in Alzheimer's Disease. And while most pharmaceutical companies are looking for ways of decreasing beta amyloid levels, here is a medication that not only improves cognition, but also elevates the beta amyloid levels. Dimebolin may shed additional light on how beta amyloid is metabolized and its role in the development of Alzheimer's Disease.

Tau Vaccination. Using shortened versions of the tau protein vaccines has been shown to reduce the neurofibrillary tangles, but do nothing to reduce beta amyloid levels. However, tau vaccines have caused inflammation of the brains of mice. So while this looks promising, clearly more research is needed.

Vitamin D and Curcumin Curcumin is found in the spice Tumeric, which is often used in curry powders. When combined with Vitamin D, it is found to stimulate the immune system and clear the brain of beta amyloid. We already know Vitamin D plays a role in the immune system and it also helps preserve the myelin sheath in multiple sclerosis patients. So it will be interesting to watch this combination for future use.

Insulin and Anti-diabetes Medications It has been suggested that Alzheimer's Disease is perhaps a third form of diabetes. Beta amyloid attaches to neurons, causing amyloid plaques to form and damage the neurons. It has been discovered that insulin blocks the receptor sites for beta amyloid on the neurons, thus preventing the formation of amyloid plaques. In other research, it has been found that beta amyloid plaques remove insulin receptors from the neuron, thus rendering the neuron insulin resistant. Early studies took hippocampal cells and exposed them to low doses of insulin and rosiglitazone (Avandia). The results revealed that beta amyloid proteins were not able to attach to the neurons and insulin sensitivity was enhanced with the rosiglitazone. As research continues, it will be interesting to see what the future brings.

Antidepressants and Anti Psychotic

Neurobehavioral symptoms Depression often accompanies Alzheimer's Disease especially during the early stages or the patient may be experiencing a pseudo dementia. Thus an antidepressant may prove to be beneficial for that individual. Using selective serotonin reuptake inhibitors (SSRI's) such as Prozac or tricyclic antidepressants may be of benefit.

Benadryl may be helpful in treating insomnia, but can cause a "hang over" type sensation the following morning. Side effects of these medications include drowsiness, dry mouth and constipation. Antipsychotic agents (haloperidol, risperidone and the benzodiazepines) may be used to treat agitation and belligerence. Side effects of these medications include sedation, confusion and increased muscle tone (Parkinsonianism). Discuss the need for additional medications with the primary healthcare provider as well as the patient and his caregivers. It is imperative the patient and his caregivers understand all medications, what effects they should expect to see as a result of that medication and side effects for which to monitor.

Other medications and nutritional supplements are being considered for the treatment of dementias. It is thought that antioxidants (vitamins C and E) may slow the process. Calcium channel blockers may help preserve cells by combating glutamate destruction.

Melatonin may be helpful to induce sleep and promote better sleep/wake cycles. Omega 3 Fatty Acids and/or Fish Oil Capsules are believed to have anti-inflammatory properties as well as support the health of neurons.

Staving off Alzheimer's Disease. A recent study suggests that those individuals who have purpose in their lives are less likely to develop Alzheimer's Disease or cognitive impairment. Again in thinking about the increasing population of dementia diagnoses, there is a need to look at how to stave off or to prevent the problem. People who scored higher on a purpose in life and happiness measures were *2.5 times less likely* to develop cognitive problems, however it is not known if there is a biological reason for these findings. While the biological link remains elusive, this study does have significant implications. Providing opportunities for social activity, physical activity, higher cognitive activities and high purpose in life activities may all contribute to a longer life, decreased mortality, decreased disability and enhanced

independence in the elderly population. Of course, keeping people healthy and functioning independently in their own homes is the goal.

We can encourage the elderly to maintain and create new friendships, and remain socially active. Perhaps joining a seniors group for travel, crafts, or a simple noon meal is all it takes to maintain some social contact. Many senior citizen groups offer exercise programs, as well as there are an abundance of exercise facilities up to and including personal trainers that are available as well. Of course, just going for a walk or bike ride every day or gardening can be done to maintain physical health.

Learning a foreign language, learning to play the piano or other musical instrument, learning a new craft or hobby, reading a book, working those Sudoku™ or cross word puzzles in the newspapers are all forms of higher cognitive activities. Purpose in life activities can include such things as babysitting for someone, taking care of another person or a pet, having a part time job, and of course there are many volunteer opportunities for seniors. Volunteering can range from working with the young to the elderly.

Volunteering gives the individual a social outlet as well as purpose, and the recipient of the volunteer's efforts gain benefits. While we may never identify the biological link between purpose in life, happiness and cognitive functioning, we know anyone can benefit from undertaking such activities. The added benefit is that these activities can be very inexpensive and may prove to be the most cost effective methods of dealing with dementias, by preventing or at least delaying the onset.

Nursing Care of the Memory Impaired Patient

- Safety is a major nursing concern with Alzheimer's Disease patients. There are, no doubt, many other safety precautions the reader can add to this chart. Review the table below.

Safety Checklist for Patients with Alzheimer's Disease, Delirium and/or Dementia

Factors for Home Safety
Clear, written instructions about safety measures
Effective teaching of safety measures
Effective home supervision
Inclusion of caregiver in teaching sessions
Willingness of family members to recognize the patient's declining
Proper drug use, monitoring and teaching
Adequate lighting
Water heater set to never exceed 120° F
Removal of dangerous objects or potential poisons from patient's reach
Smoking cessation (patient and family members)
No low or broken furniture, unpadded sharp edges on furniture, or changes in furniture arrangements
Clean, spare traffic patterns, no throw rugs, and no steps without barricades
Safe use of stove and other appliances
Durable, nonbreakable fixtures, decorations and kitchenware
Minimization of decorations to reduce visual stimulation
Sturdy door and window locks
Moderate stimulation: visual, auditory
Identification bracelet
Low bed
Sufficient effective memory aids
Stair markings, Safety rails in bathroom, stairways and halls.
Factors for Hospital & Nursing Facility Safety
Clear policy regarding use of physical restraints or sedatives
Adherence to established safety policies

Identification of the patient's high risk for injury
Effective communication of the patient's high risk status to staff members
Properly functioning equipment
Staff members well educated in safety measures, such as transfer techniques
Use of wheelchairs for no other purpose than transportation
Absence of clutter
Raised toilet seats
Bed at proper height
Adequate staffing and effective use of staff members. Consistent staff assigned to patient's care.
Seating with high backs and armrests on chairs
Adequate lighting in rooms and hallways
Absence of dangerous item such as scissors or disinfectant in patient's room
No wheels on over bed tables. If patient uses it for support, table can slide.
Appropriate use of side rails
Adequate paging system
Familiar environment
Moderate stimulation: visual, auditory
Make use of caregivers/family members in caring for the patient
Floors dried and clean

Trying to reorient an Alzheimer's Disease patient may only serve to agitate him or her; instead "step into their reality". If he thinks it's Christmas time, sing a Christmas carol versus arguing with him that it is Easter. In the grand scheme of things, for the dementia patient, does it really matter if it's Easter or Christmas?

- Remain flexible, everyday is a new adventure. What worked today, may not work tomorrow, but may work again next week. Caregivers often have to have a "bag of tricks" as to what works for a given dementia patient.
- Reduce stress for the dementia patient, follow a routine, decrease stimulation, and simplify decor. Every day we take in all kinds of stimuli. Simultaneously we listen to music as we work, we are aware of the person working beside us, we recognize the origins of various smells, and we are aware of the fact that it is getting close to our lunchtime. As we take in all this stimulation, we are able to filter out non-meaningful stimulation from meaningful stimulation. In other words, while we are cognizant of our surroundings, we are still able to concentrate on our work.

The dementia patient often loses the ability to filter out non-meaningful from meaningful stimulation. It is all stimulation whether it is visual, auditory, olfactory or tactile. Consider Sue, the nurse, as she visited Mr. W.

During a home visit, Sue encountered Mr. W., who was very agitated, rocking back and forth in his chair. He was very upset about "those people in the hallway". Upon entering the home, Sue noted the volume on the television was very loud, the rooms were full of décor and clutter, and in the hallway were family photos that Mr. W. could see from his chair. To make matters worse, the carpeting in the living room was a very large plaid pattern, the wallpaper pattern was an all over large medallion pattern, and the upholstery was a floral pattern. There was so much stimulation going on in this room, even Sue began to feel agitated! How did she handle this?

The first thing she did was turn off the television so she could speak with Mr. and Mrs. W. Next she suggested they move the family photos to the opposite side of the hallway, thus removing them from Mr. W.'s line of vision. In other words, "those people in the hallway" left and thus were not bothering him

anymore. Just these two interventions had a calming effect on Mr. W.

Over the next few weeks, with the support of educational materials from the Alzheimer's Disease Association, Sue convinced Mrs. W. the patterns in the carpeting, wallpaper and furniture could also be over stimulating Mr. W. Mrs. W. had the rooms redone, removing the wallpaper and painted the walls and had new carpeting installed, but she retained the furniture. This created a much more subdued environment and Mr. W.'s agitation almost totally resolved.

- Provide cues, i.e., post pictures such as a toilet on the bathroom door or socks on the sock drawer. Cues can give them an orientation of where they are. They may recognize that the green hallway leads to their room or to the bathroom. The blue room is the room where they eat.
- Identification bracelet, necklace or anklet are available and are helpful in the event the patient becomes lost. The ankle bracelet may be covered by a sock or stocking, thus deterring removal by the patient. Safe Return Program: 888-572-8566, has identification products available.
- Use a one to one approach. Dementia patients can become fearful if approached by a number of people. Fear often elicits agitated or aggressive behaviors. Think about how you present yourself. Are you frowning or angry in your appearance? Dementia patients often rely on non-verbal signals, as they do not always understand other forms of communication. Be calm, matter of fact, gentle and smile as you approach them and talk with them. Often your ease will put them at ease. Try using humor or cajoling to get them to complete a task versus demanding they do it.
- Give simple instructions, one step at a time. Again bear in mind stimulation and how much the individual can take in at one time. Some patients may be able to handle 2 to 3 steps of instructions, while another patient will need cueing to complete one step of instructions.
- Initiate conversations by using the patient's name, make eye contact and touch as appropriate and tolerated. We all like to be called by our names and it is respectful to the patient. An individual is more likely to respond appropriately to his or her name versus being called "sweetie" or "honey". Touching them shows you care and it focuses them on you versus other stimulation going on in the environment. A simple touch on the forearm can be very calming. Initiate conversations with social chit chat as that will gain trust and cause the dementia patient to relax. Once he has relaxed and trusts you, you might then try to get him to take a bath or take a medication.
- Make sure the individual is wearing their glasses (if he does indeed wear glasses), and that the glasses are clean. Is the individual wearing the glasses that belong to him? Are they wearing a pair of glasses, when they do not normally wear glasses? Individuals with cognitive disorders may pick up any pair of glasses and wear them. The glasses may not belong to them or perhaps they do not normally wear glasses. Is there adequate lighting available for them to be able to see? Is there a lot of glare on highly polished floors that is impeding visual acuity? These can create quite a lot of visual distortion for the individual, adding to their confusion.
- They may not necessarily be deaf or hard of hearing, so don't shout at them. Use normal conversation tones, speak slowly and enunciate clearly. Include them in the conversation, and use their name. If the dementia patient is hard of hearing, be sure he or she is wearing their hearing aids.
- Instead of asking open-ended questions to which they don't know how to respond, ask leading (Yes-No) questions. Give them time to formulate their answer. Do not answer the question for them. Try repeating your question or visually demonstrating what you are asking. Sometimes, in spite of all this, the dementia patient is still not able to respond to you. Give them a hug and change the subject. To further persevere will only frustrate him as well as you. One can also try rephrasing questions in the form of a statement.

For example, instead of asking "Who is this in this picture?" try saying, "This must be your son." It gives the patient an opportunity to reply in a noncommittal manner if he is not sure.

- Make the most of the last word of a sentence. The dementia patient will latch onto the last word, i.e.; Do you want to wear the green shirt or the one that's blue? Most likely, he will respond "blue", thus giving him the illusion of having made the choice.
- **Music therapy:** Music is so familiar to us. Have you ever heard a song and it evoked a memory for you? Do you remember where you were or remember what you were doing or a certain person when you hear a certain song? Music can evoke memories for the memory impaired. Music can transform a mute memory impaired individual into a singer! While the music is playing, it may be possible to engage the individual in brief conversations. It is important to play music from the time the patient came of age. "Coming of age" generally is when we are late teenagers into our early 20's, or the time we become adults.
For someone who is currently in his or her 80's, music from the 30's and 40's is appropriate. So consider the likes of Glenn Miller, Rudy Vallee, and Big Band Music for this generation. Also be sure to ask the family what types of music the individual enjoyed. For a person who is in his or her 50's or 60's, music from the 60's or 70's is appropriate. So in thinking about the aging Baby Boom population, there may be a lot of Beach Boys, Beatles, Rolling Stones and Bob Seeger being played in nursing homes in the future!
- **Pet therapy** is proving to be beneficial for people with cognitive decline. Often the individual will respond to an animal when he or she will not respond to other people. One does have to be a little cautious in introducing an animal to the dementia patient. Be sure you introduce the animal, by name and type of animal, to the patient. Observe how the patient responds to the animal. Be sure they are not fearful of the animal. Not all people are dog lovers or cat lovers. Also, for the safety of the animal, monitor how the patient treats the animal.
- Give them something to do, ask them for their assistance in completing simple projects, i.e., folding washcloths, set the table, and help with singing a song. Be sure the task is something they would have been familiar with and had done numerous times in the past. Remember we all benefit from having a purpose in our lives, even those with dementia.
- In dealing with behaviors such as wandering, agitation, screaming, paranoia, belligerence or combativeness, consider the following and take action to remedy the situation:
 - Are they in pain or fatigued or stressed?
 - Have their vision and/or hearing become impaired?
 - Are they ill? Do they have something as simple as a urinary tract infection?
 - Is there an exacerbation of a chronic illness?
 - Are they dehydrated? Constipated?
 - Are they eating enough food or becoming malnourished?
 - Are they depressed?
 - Is the behavior a result of medications?
 - Are they too warm? Too cold?
 - Is their clothing comfortable? Do their shoes fit?
 - Is there too much stimulation in the environment?
- Introducing the individual to an unfamiliar environment is likely to create stress and elicit behaviors from the person with dementia. Allowing them to have familiar objects around, having family members assist whenever possible and maintaining a consistency of nursing staff from day to day may all lessen the stress on the individual. Think about the dementia patient who has to be admitted to the hospital, and then on each shift on each day, new nursing staff is introduced to them. No wonder some of these patients become stressed and act out.

- Distraction often works well to divert attention to another activity. Distraction activities may include suggesting a walk, a snack, turning on some music, singing a song, or simply changing the subject.
- Agitation can be a sign of anger as the person is feeling a loss of control in regard to his life. Calmly acknowledging this feeling, even if you do not think the person will necessarily understand, may be helpful in minimizing the agitation. To calm an agitated person, try soft music, soft conversation, holding his hand, or reading to him. Remove the person from a stressful environment. Try engaging them in another activity such as a walk or dance. Physical activity is helpful in reducing stress for the dementia patient, just as it is for a non-dementia person. Massage may have a calming effect. See if you can identify stressful times of the day for the individual and schedule care such as baths or dressing at other times.
- Dementia patients may experience paranoia, accusing individuals of stealing from them. Be sure to take their claims seriously until the situation can be solved. Learn the patient's favorite hiding places, as he may have just put an item away for safe keeping, only now he can't remember where he put the item. Have extra items that can be substituted until the original is found. For example, have an extra pair of slippers, so if the originals are misplaced, another pair can be used until the originals are found.
- Some dementia patients wander. **Wandering** is sometimes thought of as being a stress reducing activity undertaken by the dementia patient, and that it is actually helpful. Wandering can indicate a need to exercise, a need to use the bathroom, pain, or a way of expressing anger. If there is no acute reason for the wandering, allow the person to wander, as long as it can be done safely without interfering with others. Wandering/walking will provide the dementia patient with exercise; something to do; reduces agitation and may help the patient sleep better.
- Wanting to go home is another behavior that can be very challenging to handle. Often this occurs when the person is now a resident of a nursing care facility. Or the individual may be in her home, but is thinking about her childhood home and wants to return there. "Home" often means a time when the person felt loved, comfortable and safe. So wanting to go home may mean the person is feeling sad, lonely, or scared. Recognizing this, attempt to comfort the patient. Offer reassurance that you will take care of him. Ask if he or she is feeling scared or lonely. Take the individual for a walk or a ride in the car. Upon returning home after the walk or ride, he or she will recognize home as home again.
- Dementia patients are at risk of becoming a victim of theft or fraud. There are many scam artists out there who can easily befriend a person with dementia all the while stealing and/or transferring assets from him or her. This is why it is so important to have a trusted financial and medical power of attorney established before dementia develops. Consider this scenario. Judy, who has some mild cognitive impairment, but is still able to live independently, was recently widowed. An insurance salesman, who regularly scanned the obituaries, trolling for possible clients, had seen her husband's obituary.

A couple of months after her husband's death the insurance salesman arrived at Judy's home offering her his condolence and led Judy to believe her husband had established a relationship with the insurance salesman. Judy, not knowing any differently and being a little lonely since the death of her husband, invited him into the house. He inquired about items in the house, making social chit-chat with her, further befriending her. He told her that her husband had initiated some "paperwork" with him and it hadn't been finished before his death. All that was needed, he told her was her signature and a check. Judy wrote the check and signed the paper, not knowing what she was signing, but thinking it was something her husband had desired.

Unbeknownst to her, she had just purchased an expensive life insurance policy which she did not need. A neighbor noticed the strange car in Judy's driveway and went over to Judy's home just as the

insurance salesman was leaving. Upon inquiring if he was a friend of Judy's, the neighbor got some vague answers and became suspicious. The neighbor obtained the insurance salesman's business card, returned home and phoned Judy's son. The son was able to contact the unscrupulous insurance salesman, cancel the policy and retrieve Judy's money. Had it not been for the neighbor, who knows where this situation could have ended, possibly with Judy having nothing left!

There are many interventions that can be undertaken when caring for a dementia patient. We have discussed a few here and hopefully one can add these to one's bag of tricks in caring for these challenging patients. Now let's turn our attention to caring for the caregivers.

Providing Support for the Caregiver

Because the dementia patient will need assistance and eventually full care, we often rely on family member caregivers and others. Taking care of a dementia patient can be physically draining, but is probably more psychologically and emotionally draining for caregivers. As nurses we must stop and consider the caregivers, as it is these individuals that make it possible for many of these dementia patients to remain in their homes for as long as they do. Below is a list of ideas to assist with the care of caregivers.

- Provide support for the family and caregivers. See the listing of support services available for caregivers and family members. There are a lot of educational materials available (often free of charge), that are very informative and helpful. While there is no cure of these dementias and we spend a lot of time taking care of the patient, we need to remind ourselves to take care of the caregivers as well.

The September 2008 supplement to the American Journal of Nursing was solely devoted to supporting family member caregivers. Contained in this supplement is a tool for measuring the stress the caregiver is feeling. It is a helpful tool for assessing the caregiver and recognizing needs the caregiver may have. The nurse can either complete this tool by discussing the various aspects with the caregiver or have the caregiver complete the tool independently. By having the caregiver complete the tool, it can also serve as a teaching tool and point of discussion in encouraging the caregiver to take care of him or herself.

Modified Strain Index Components

- My sleep is disturbed.
(Patient is in and out of bed at night, requires care at night, wanders at night.)
- Care giving is inconvenient.
(Helping takes a lot of time, have to drive distances, have to attend a lot of appointments, have to deal with many team members.)
- Care giving is a physical strain.
(Caregiver lifts, transfers, bathes, toilets patient.)
- Care giving is confining.
(Helping restricts time, cannot participate in desired activities, visit friends, have lost friendships.)
- There have been family adjustments.
(Helping has disrupted routine, lack of privacy, have more people around all the time, has impacted children in the family.)
- There have been changes in personal plans.
(Caregiver had to turn down a job, put off going to school, come out of retirement.)
- There have been other demands on my time.
(Other family members need caregiver, commitments to other groups, i.e., church committees, school committees.)
- There have been emotional adjustments.
(Severe arguments about care giving, taking on roles caregiver did not necessarily want to do,

- feeling isolated and alone.)
- Some behavior is upsetting.
(There are inappropriate behaviors, wandering behaviors, memory problems, paranoid, and/or delusional behaviors.)
- It is upsetting to find the patient has changed so much from his/her former self.
(Patient is a different person than he/she used to be, loss of life partner, loss of intimacy.)
- There have been work adjustments.
(Caregiver has to take time off work, readjust work schedule, take a different job to accommodate helping.)
- Care giving is a financial strain.
(Extra costs, loss of income)
- I feel completely overwhelmed.
(I worry about the patient; I have concerns as to how we will manage or how we will survive this.)

Scoring: Each component is scored 0, 1 or 2. The scores are totaled and can range from 0 {no strain} to 26 {extreme} caregiver strain.

- Help the caregiver and/or family member deal with **ambiguous loss**. As part of the author's role as a case manager for individuals who have sustained traumatic brain injuries, I see a multitude of dementia problems. In an effort to support the family caregiver, I adapted a paper from the Family Caregiver Alliance on ambiguous loss that I give to caregivers. Included below are some of the tips for coping with ambiguous loss.

Teach and discuss with the caregivers that caring for a person once known dearly to them, who is now different, can bring on feelings of loss that are difficult to categorize. Hence, these losses are called "**ambiguous losses**". The patient may not only be different physically, but emotionally and mentally. The dementia patient may exhibit uncharacteristic emotional outbursts, become withdrawn and/or experience memory lapses. At times the caregiver may see glimpses of the "old person" in the individual only to have them slip away again. Some caregivers describe this as if the person is gone, but still here. Unlike death, there is no closure. Adding to ambiguous loss is the uncertainty of what the future holds for the patient and caregiver. Caregivers may experience isolation, depression, anxiety and a feeling they are left to cope on their own.

Tips for Coping with Ambiguous Loss: (taken from a client information sheet prepared by NurseNotes, Inc.)

1. **Name the problem.** Know the cause of your stress is the ambiguity of a loved one being here, but not here. Ambiguous losses are caused by the illness or injury; not you or your loved one.
2. **Practice "both/and" thinking.** "Both/and" thinking is less stressful than "either/or" thinking. "Both/and" thinking means balancing two different ideas at the same time and is less stressful than trying to seek out a perfect answer. Some examples of "both/and" thinking are:
 - "I am *both* sad about my loss of hopes and dreams, *and* happy about some new plans."
 - "I am *both* a caregiver, *and* a person with my own needs and interests."
 - "I am *both* sad for the loss of companionship *and* glad to be able to care for my partner."
3. **Know your "family" and community support systems.** The ambiguity of care giving will be ever present; thus it's important to identify some predictability. To whom can you talk and count on for help? These resource people may not necessarily be family members, but outside individuals who

may become like "family" to you. Who do you have for spiritual support? What do you do for recreation and respite? Do you have a friend you can call for a lunch date? Who do you seek out for informational support?

4. **Continue family holidays, celebrations, rituals and traditions.** Do not cancel these important family times. However simplify them. Perhaps you won't be able to have the big dinner at your home, but could the event be hosted by someone else? Could it be a potluck? We remain connected through celebrations and get caught up in the spirit of the celebration. The celebrations give us a respite from our everyday lives and can be rejuvenating. Maintaining these human connections can help lower your stress, especially during times of sadness.
5. **Revise family roles and rules.** Injury or illness often results in role revision. Things you never did are now your responsibility. Plans you had may now be gone or changed. Perhaps you are now the major breadwinner for the family. Remember though, one person cannot and does not need to do it all. Have discussions with family about who should or could be doing what to assist you in your role as caregiver. Is there a "family rule" that only women are caregivers and do laundry? Are the men the only ones to handle financial matters? Have discussions with your family about these "unwritten rules" and needed revisions.
6. **Understand that anger and guilt are normal, but avoid harmful actions.** Care giving can be incredibly frustrating and it is not uncommon to experience mixed emotions, especially when dealing with ambiguous losses. Caregiver stress may be displayed as anger, or worse yet abuse, that is not acceptable. Talk with another caregiver, professional or understanding friend or family member about your negative feelings. By talking about these feelings, the caregiver can identify them and prevent him/herself from acting out on the anger.
7. **Imagine something new to hope for.** This may seem contradictory in times of sadness and loss, but having something to look forward to gives us hope. As long as we have hope, we stay healthy. Talk with other caregivers, professionals or trusted friends. They may be able to help you identify new things to look forward to such as a new hobby, new connections to others, a renewal of spiritual faith, or developing new skills.
8. **Check on your own health.** You have a duty and a right to care for yourself. If you become ill, who will care for your loved one? Take your own pulse regarding feelings of depression, anger, self-abuse, dependence on alcohol or recreational drugs. Are you more argumentative or irritable than usual? Are you no longer taking care of your own hygiene and clothes? When is the last time you had a haircut or sat down to a hot meal? How much sleep are you getting every night? Seek professional help in caring for yourself. Be aware of the fact you can lose sight of yourself in the face of care giving. Maintain your own identity and interests.

Tips to manage the stress of care giving.

- Connect with other people
- Respite care
- Join a support group-local or internet-based
- Tap into informational resources & educate yourself about your loved one's condition
- Attend a book club, social event, or faith based group
- Make time for your hobbies & interests
- Learn a new hobby
- Call a friend for a lunch date
- Enjoy a television show or radio station
- Listen to or play music
- Read a book or magazine
- Delegate to others-you don't have to do it all alone

- Hire/contract for services such as lawn care, snow removal, housekeeping
- Take time for yourself everyday even if it is only 10 to 15 minutes
- Try a new recipe
- Spend time with the family pet

Agencies that provide both professional and patient information:

Lewy Body Dementia Association
 PO Box 451429
 Atlanta, GA 31148
 lbda@lbda.org
 www.lewybodydementia.org
 404-935-6444/800-LEWYSOS
 480-422-5435 (fax)

Alzheimer's Disease Education & Referral Center
 PO Box 8250
 Silver Springs MD 20907-8250
 adear@nia.nih.gov
 www.alzheimers.nia.nih.gov
 301-495-3311/800-438-4380
 301-495-3334 (fax)

Alzheimer's Association
 225 North Michigan Ave
 Floor 17
 Chicago, IL 60601-7633
 info@alz.org
 www.alz.org
 312-335-8700/800-272-3900
 866-699-1246 (fax)

Family Caregiver Alliance
 National Center on Caregiving
 180 Montgomery St. Suite 1100
 San Francisco, CA 94101
 info@caregiver.org
 www.caregiver.org
 415-434-3388/800-445-8106
 415-434-3508 (fax)

Amyotrophic Lateral Sclerosis Association
 27001 Agoura Road, Suite 250
 Calabasas Hills, CA 91301-5104
 www.alsa.org
 818-880-9007/800-782-4747
 818-880-9006 (fax)

Creutzfeldt-Jakob Disease Foundation, Inc.
 PO Box 5312
 Akron, OH 44334
 www.cjdfoundation.org
 800-659-1991
 330-668-2474 (fax)

National Hospice Foundation
 National Palliative Care Foundation
 1731 King St
 Alexandria, VA 22314
 www.nhpco.org
 703-837-1500/800-658-8898
 703-837-1233 (fax)

National Family Caregiver Association
 10400 Connecticut Ave. Suite 500
 Kensington, MD 20895-3944
 infor@familycaregiver.org
 www.thefamilycaregiver.org
 800-896-3650
 301-942-2302 (fax)

National Institute on Aging
 National Institutes of Health
 31 Center Drive, Room 5C27 MSC 2292
 Bethesda, MD 20892-2292
 www.nia.nih.gov
 301-496-1752/800-222-2225

National Institute of Mental Health
 National Institutes of Health
 6001 Executive Blvd. Room 8184, MSC 9663
 Bethesda, MD 20892-9663
 www.nimh.nih.gov
 301-443-4516/866-415-8051
 301-443-4279 (fax)

National Stroke Association
 9707 East Easter Lane
 Suite B
 Centennial, CO 80112/3747
 www.stroke.org

National Organization for Rare Disorders
 PO Box 1968
 55 Kenosia Ave.
 Danbury, CT 06813-1968
 www.rarediseases.org

303-649-9299/800-STROKE
303-649-1328 (fax)

American Heart Association
7272 Greenville Ave
Dallas, TX 75231-4596
www.americanheart.org
214-373-6300/800-AHA-USA1

WeMove Worldwide Education & Awareness
for Movement Disorders
204 W.84th St.
New York, New York 10024
www.wemove.org
212-875-8312
212-875-8389 (fax)

National Respite Care Network
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
www.thefamilycaregiver.org
800-896-2650
301-942-2302 (fax)

C-Mac Informational Services
Caregiver News (Dementia)
120 Clinton Lane
Cookeville, TN 38501-8946
www.caregivernews.org

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www.ninds.nih.gov/disorders/fact sheets

203-744-0100/800-999-NORD
203-798-2291 (fax)

Foundation for Progressive Supranuclear Palsy
Executive Plaza III
11350 McCormick Road Suite 906
Hunt Valley, MD 21031
www.curepsp.org
410-785-7004/800-457-4777
410-785-7009 (fax)

Association for Frontotemporal Dementias
Radnor Station Building #2 Suite 200
290 King of Prussia Road
Radnor, PA 19087
www.FTD-Picks.org
267-514-7221/866-507-7222

Well Spouse Association
63 West Main St., Suite H
Freehold, NJ 07728
www.wellspouse.org
732-577-8899/800-838-0879
734-577-8644 (fax)