

# The Itty Bitty Dementia Book

**An Untangling Dementia Workbook**

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*Wilma Jean Smith Sargent*

**1921-2020**

**My other Mother. She kept me  
safe. She taught me faith. A wise  
and truly funny lady.  
Godspeed my dear friend.**

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# **One: Dementia is a Brain Disease**

Dementia caregivers are often challenged to understand the disease and its total impact on themselves and their loved one. Information about these brain diseases is confusing. Medical professionals are often uninformed about the many types of dementia, the disease process, and the extent of the damage to the brain. Rather than addressing dementias with a medical approach, the lack of research, understanding and education means that care for your loved one is not always coherent, consistent, or rooted in causation. Some caregivers seem innately be aware of the mental and physical decline that Persons With Dementia (PWD) experience, while others have difficulty separating the disease from the person.

This lack of general knowledge about the progression of dementias is also hampered because of how People with Dementia look throughout most of the disease process. People with Dementia typically do not appear physically ill until the final stages of the disease. It is only after significant brain tissue loss, that the illness is apparent on the outside of the person, in their posture, facial features, and amid sudden moments of appearing confused.

The loss of weight, the loss of facial emotion, vocal emotion or a monotone speaking sound, a shuffling gait, the loss of language, a decline in executive function, and the inability to perform coordinated movements like chewing food and swallowing, are some of the outward physical changes caregivers will witness. But only after the significant brain loss of one pound or more of cells and tissue will the Person With Dementia begin to look sick to outsiders and professionals.

Dementia is one of the most confusing medical words we encounter. Its original translation from French means “incapacitation of the medical facilities.” But that translation never made it to today’s interpretation. Instead families and many professionals think dementia is the name of an illness affecting memory. It is not.

## **Five Questions All Families Need To Know**

Dementia is the umbrella term for a group of brain diseases. It is not the name of a particular form although it may be the term the doctor uses until a definitive diagnosis is made. Diagnosing the type of dementia or dementias your loved one has required more than two dozen medical tests, including blood work, spinal tap, EEG, EKG, MRI, and cognitive measurements. The testing requires a specialist such as a neurologist who focuses on dementias to review these materials and also includes observation of the person and input from the family.

Think of dementias the way you have been taught to think about cancer. Cancer is also an umbrella term. Cancer means cells of the body are attacking the body. There are more than 400 identified cancers and cancers have domains or subsets. It is common to ask which breast cancer form? Which skin cancer form? Which bone cancer form?

It is critical that the form of dementia be diagnosed, just as we expect the type of cancer to be diagnosed. The diagnosis is part of a family’s health history, the type determines progression, behaviors, medications, and how to plan care.

## **Question 1: Which Dementia Does Your Loved One Have?**

Dementia is not the name of a brain disease. It is the umbrella term for a group of diseases affecting the brain. The disease is impacting at least two of the seven lobes of the brain. It is progressive, so the person cannot recover or regain abilities. It interferes with the ability to function or complete the Activities of Daily Living (ADLs). The activities of daily living include the ability to transfer, walk, toilet, bathe, groom, dress, and eat. Dementia interferes with memory. Memory includes the activities of daily living, language, unassisted movement, balance, and the recognition of self and others. Memory is everything you and I are able to do.

The type of dementia also determines behaviors the person with dementia might display. Some dementias include sexual behaviors such as a heightened interest in sex or inappropriate comments about sexual activity. Others might display scatological (feces) behaviors. Some dementias include sudden outbursts of crying or laughing without any apparent cause. Other dementias cause people to overeat, while still other dementias mean the person is prone to anorexia.

Some of the dementias are very aggressive in attacking the brain. Generally, the younger a person is, the more aggressive the dementia is in the brain. Other dementias are thought to be present for decades in the brain with no noticeable ill effect, awaiting some silent signal to begin the destruction caused by the failure of proteins in the brain tissue.

The type of dementia dictates medication usage. There are medications used to slow the disease progression by allowing a chemical connection between brain cells to work a bit longer. Other medications stop the buildup

of glutamate in the cells. Dementia is defined by seven progressive stages. The first group of medications is intended to be given in the early part of the disease in Stages Two (also called Mild Cognitive Impairment or MCI) or to persons in Stages Three or Four. Unfortunately, most persons are not diagnosed until the late or terminal stages. The dementia diagnosis is most commonly made in Stage Five. In this stage there is significant brain tissue damage although the person will not yet appear physically ill with dementia.

The medications may actually slow the progression of the disease during the worst part of the disease, when the person is suffering significant brain damage, and is no longer herself. For families, the risks and benefits of medication during later stages of the disease is something that their physician may have neglected to discuss with them.

Most medical professionals neglect to discuss these important issues with the family caregiver. Would the person with dementia want medication that extends the disease during these difficult final stages of significant brain tissue loss? Would she want her caregiver to literally kill himself providing care or spending their life savings for the final part of care, leaving the caregiver penniless? Or would she simply want to be kept comfortable during the final stages of a terminal illness?

The type of dementia also indicates heredity or sporadic genetic assignment. Huntington's Dementias are hereditary. Early Onset Familial Alzheimer's Dementia is hereditary. And since forms of vascular disease are hereditary, so the forms of dementia caused by Vascular Disease would also follow. The type of dementia tells the caregiver how much time is left. From very aggressive to very slow, different forms of dementia advance in their

own way. Staging the person with dementia every two to three months allows caregivers to track the decline, the behaviors, and prepare for the next stages of the disease.

The type of dementia will begin to answer the questions about what kind of care your loved one needs. Some communities are simply not large enough or skilled enough to provide care for some types of behavioral dementias.

## **Question 2: Do You Understand the Brain is Dying?**

In basic brain function, one cell gathers an electrical charge and the neurotransmitters (chemicals in the brain) fire a signal down a dendrite (root), across a space to the next cell. When the neurotransmitter is received, the new cell releases a chemical, signaling enzymes to move into the space and eat or clear the pathway of used up neurotransmitter parts and pieces.

As proteins begin to break apart in the brain fluid between the cells, the resulting plaque is thought to trigger a reaction of the tau proteins in the dendrites (roots) of the cells. The tau protein begins to break apart, to curl and tangle, causing the dendrites to tangle as well. The space between cells is slowly becoming a little farther apart as the roots shrivel.

Normally, the first cell fires its electrical charge sending neurotransmitters across the cell, through the dendrites, firing across the synapse (space) to the next cell. This second cell receives the neurotransmitters into docking spaces and the connection repeats to the next cell. Then enzymes sweep across the synapse to clear the debris for the cell's next function.

But as the cell is beginning to shrivel, the cell continues to attempt to function. But the neurotransmitter can't get through to the next cell because the synapse is now a bit farther away. As the first cell fires its charge, the enzymes are waiting and attacking as though the cells are functioning normally and are still close to each other.

Some dementia medications cause a reaction in the cell function that allows the connection between the cells to work longer, until there is too much space between the cells, or the cell has finally starved. Once dead, the cell is removed and the space refilled with cerebral spinal fluid. In most forms of dementia, the brain cells starve, die, and are removed from the brain as waste.

At night, when we reach deep sleep, our brains cells draw up to allow the brain to wash itself clean of broken bits and pieces of cells and proteins. That's why you wake up refreshed and clear for the next day.

Another way brain cells are dying is due to a lack of oxygen caused by some form or forms of vascular events. Strokes for example interrupt blood flow in an area of the brain. The specific lobe affected by the suddenly dead or damaged brain cells will cause the person with dementia to behave differently. Where those cells once existed, the space is now filled with cerebral spinal fluid. And so bit by bit, cell by cell, the brain is destroyed.

Oddly enough, even as the brain is dying, it is only when a pound of tissue is compromised that your loved one will begin to appear physically different.

Eventually, the cranium containing a three-pound brain will have more spinal fluid weight than brain cell weight. In the beginning, this person's brain was like yours or mine, an amazing collection of 100 billion neurons doing

trillions of activities per second. The brain retrieves and stores information, allowing growth, learning, and life. Using electrical charges and a variety of neurotransmitters (chemicals in the brain), the brain continues to try to function even when it has only a pound or so of remaining tissue. It is the most complex and impressive organ in the human body.

The sheer number of brain cells and connections helps to explain sudden moments of cognition and conversation, when there may have been no language from the Person with Dementia in months. The brain continues seeking pathways, even when heavily damaged. A sudden rush or release of these neurotransmitter chemicals may occur from excitement, sudden noise, movement, or even socialization. That sudden rush can even leave you believing your loved one's brain is better or even recovering.

As the form of dementia progresses and more and more brain cells are in the process of slowing dying, the operation and interpretation of electrical signals is interrupted or lost. As more and more cells die, the person with dementia is less able to use her body and her mind, which is also running her body. Slowly over time, the person with dementia loses the brain cells holding the information and instructions for the Instrumental Activities of Daily Living (IADLS), including independent living, managing money, shopping for and preparing food, operating a television, telephone, or computer, performing housework and laundry, taking medications, and managing transportation.

Somewhere during this time of changes, the decline of a person's ability to perform the Activities of Daily Living (ADLs), including transferring, walking, toileting, bathing, dressing, grooming, and eating, begins in a steady

and relentless manner. There are fewer brain cells operating correctly with each passing day. In Vascular Dementias, the vascular causes are addressed medically, but even with medical intervention, events continue to occur. With each new event, this person suffers continuing damage and decline. Eventually, as with all dementias, there won't be enough brain cells to continue life.

Providing care in the beginning of symptoms of dementia typically happens for 10 years or more at home, before the person is moved into professional care. Early care means verbal reminders, notes, calendars, and more and more explanation for each of the steps related to the activities of daily living and instrumental activities of daily living. As dementia progresses, the family caregiver may be performing all the instrumental activities and assisting the person with other activities.

### **Question 3: Has Your Loved One Started Falling Yet?**

Most human behavior involves using the motor and movement areas of the brain. Whether its talking, eating, gesturing, driving, texting, bathing, dressing, etc., movement is constantly with us. If the motor cortex becomes damaged, any person would be challenged or even unable to successfully begin and complete movement.

This includes the coordinated movement and motor function, as well as memory of each step required to perform the activities of daily living.

And this includes falls. The falls experienced by People with Dementia are directly related to a change in both coordination and perception due to brain damage. The slow and gradual destruction of four areas located on the

top of the brain, means eventually the person with dementia won't be capable of movement. The damage and loss of the Primary Motor Cortex, the Premotor Cortex, the Supplementary Motor Cortex, and the Posterior Parietal Cortex means eventually the person with dementia won't be able to move parts of their body. Walking, eating, holding the head erect, will all be affected as the dementia progresses.

In most dementias, these areas of the brain are the first to display signs of the dementia. In the beginning, these cortexes are only slightly damaged. Enough healthy brain structure allows the person to continue to function. But eventually these motor areas are destroyed. People with Dementia in Stage Seven of the disease become bedbound and totally reliant upon others for care because of extensive brain damage. It's not that your loved one isn't trying, it's brain damage.

Alzheimer's Dementias begin in these four cortexes, leading to early stumbles or missteps. A slight change in coordination, a subtle variance in lifting the foot properly, and there is a fall. All other movement is being affected as well, but we are less likely to notice subtle changes in chewing, eye and hand coordination, driving, dressing, or bringing food or drink to the mouth, etc.

Brain damage from each form of dementia makes falls an expected event. Falls are a symptom, a sign of the disease. Falls are not a sign of poor care; they are a sign of specific brain damage caused by dementia. Unfortunately, regulatory agencies and medical providers are not always aware that brain damage equals functional impairment in People with Dementia. Medical

professionals and families must plan for and anticipate falls, and prepare for the coming decline.

Adding to the increase of falls in People with Dementia, additional areas of the brain also being damaged by the dementia. Normal aging changes in vision, such as the gradual loss of the peripheral vision which allows you to see to the side while looking straight ahead, are now exacerbated by dementia-caused damage in the Occipital Lobes. People who can't translate the environment around them are likely to trip, stumble, or fall over items dropped on the floor or in a cluttered environment. They are likely to trip when trying to step onto a carpet or a rug. It's not uncommon to see a person with dementia backing up and bending to sit in a nonexistent chair because of damage in the Occipital Lobes.

A condition called Occipital Blindness may occur in some People with Dementia. In Stage Six of the disease, the right Occipital Lobe appears to turn off information from the left eye. The PWD has only a small tunnel of sight in the right eye. This vision change makes approaching the person with dementia from the front critical for all caregivers.

As research has progressed, much more has been learned about the way in which People with Dementia fall. In Alzheimer's, the person has a tendency to attempt to rise out of a chair, lose her balance, but fall back into the chair. Obviously, these "falls" don't get recorded and are usually not even noticed by staff because there is no injury. Otherwise, she will fall when attempting to stand or walk because the brain can no longer provide the needed instruction to the body.

People with Vascular Dementias have a different experience when attempting to stand from a seated position. Vascular dementias frequently damage areas throughout the brain, causing even greater difficulty with movement. A person with Vascular Dementia may also lose her balance as she stands, but she has a higher risk of falling face forward out of the chair, rather than backwards. She continues the fall to the floor, landing on her face, her elbows, and knees.

Because of the physiological response of the body to bruising, the facial bruise is particularly painful to view. In other areas of the body, bruises normally occur in areas with muscle cell structure. A bruise indicates a strike or insult to the body that resulted in a blood vessel rupturing or tearing, causing blood cells to spill into the muscle tissue. The abundance of cells in muscle tissue means the body is able to respond. Over the course of several days, the dead blood cells are removed from the tissue and the bruise lightens, changes color, and is finally gone.

But there is very little musculature around the face. There is no place for the blood cells to absorb or be hidden in tissue. Instead, gravity pulls the dead blood cells down to the bottom of the face. Healing is much slower due to the lack of muscle tissue and blood vessels, though the dead blood cells are eventually removed. A blow or fall strike to the forehead easily turns into a slow, red, yellow, green, massive insult, then slowly moves down the face, finally disappearing at the jaw or neck.

People with Vascular Dementia are also prone to falls towards the weak side of the body when walking. Remember, the right side of the brain controls the left side of the body, and the left side of the brain controls the right side.

While she is up and walking, anticipate she will fall towards the weaker side of her body, the side compromised by the stroke or vascular activity.

Lewy Bodies Dementias (LBD) or the Parkinson's Disease Dementias (PDD) also have unique falls related to where the brain damage has occurred. Unlike Alzheimer's and Vascular Dementias, these falls aren't related to sudden changes in blood pressure or motor damage, but to an area of the brain responsible for being awake and alert.

Persons with Lewy Bodies Dementias and Parkinson's Disease Dementias fall stiffly, almost like a board, standing up and suddenly falling forward, landing on their faces. If you witness this fall, It might surprise you that she doesn't put her hands out to catch herself. Likewise, while standing still, she will fall stiffly backwards, cracking the crown of her head, with no flailing of the arms as the fall occurs. Both of these very unique falls happen because of where her brain is damaged. She falls because she suddenly loses consciousness, not because of a change in her blood pressure.

Those people with behavioral or communication FrontoTemporal Dementias (FTDs) may still be walking late in the disease, but may walk in a very awkward fashion. It is not unusual to see a person with FrontoTemporal Dementia bent forward from the waist while walking. This person is especially out of balance as the weight of the head, shoulders, and arms tip her headfirst into objects or the floor. She may have dozens of falls a day, with each fall possibly causing more damage to her brain due to ruptured vessels and bruising.

And she will remove any headgear or helmets designed to protect her.

People with Wernicke-Korsakoff's Syndrome, the dementia most commonly caused by alcohol abuse, may fall in any direction. It will depend on how long alcohol was abused and how damaged the brain has become.

People with Huntington's Disease or Huntington's Chorea may fall in any direction. For people with the limb-jerking motions of Huntington's, falls can be especially dangerous due to the force of the jerking limbs. So as the body falls, the thrashing movement of the limbs adds to the force of the fall.

People with Chronic Traumatic Encephalopathy (CTE) may have falls in any direction. Distinct forms of CTE are classified as Movement Forms, meaning the areas of the brain responsible for coordinated and purposeful movement are especially damaged.

Everybody with dementia falls. It's a part of the disease, directly linked to brain damage. Some dementias cause falls to happen earlier in the disease process, some dementias are even partially identified by the person's type of fall. Some people will fall only a few times, while others will suffer daily impacts. It's another cruelty of a terrible disease.

#### **Question 4: Has Your Loved One Had A Urinary Tract Infection (UTI) Yet?**

Urinary Tract Infections (UTIs) are not only an ongoing scourge in dementia care, but they are potentially deadly to the person with dementia. UTIs are often greatly misunderstood by caregivers and medical professionals. One of the biggest medical myths I run into is families and even medical staff insisting UTIs are caused by the person with dementia having a soiled or wet brief. That scenario is unpleasant, but very real in elder

care. But for People with Dementia, that is not how the infection begins in the urinary tract. Rather, the UTIs are directly linked to brain damage. The UTIs are even considered a symptom of late stage dementia.

People with Dementia begin to develop and continue to experience UTIs because of brain damage. By the end of the disease in Stage Seven, the UTIs may be detected, treated for 10 days, and the person with dementia will begin a new UTI within a few days.

As caregivers, knowing how many UTIs the person with dementia has had in the past two years is crucial. It is believed the third UTI occurring in a short time period indicates the probability the body has now created a super-drug resistant UTI form. The physician needs to know this is happening so the antibiotic can be changed with each new infection.

The causation of the UTIs is quite apparent, but often completely overlooked. The brain runs the body. As the brain becomes more damaged, the body works less and less efficiently. You and I have a three-pound brain. This means we can fight infections, even infections you don't realize you have.

Our brain recognizes infection and begins a reaction in the body to destroy the infection. The brain alerts white blood cells and T cells to seek out, attack, and destroy the infection. The brain raises the body's core temperature to increase the effectiveness of the assault on the infection. And the result is we aren't even aware there had been an assault on our body's systems.

But the person with dementia has a damaged brain. A damaged brain cannot run the body effectively. A damaged brain is less and less capable of telling the body how to function.

As the disease of dementia progresses, the body temperature in a person with dementia also begins to fall. The damage in the Parietal Lobes makes it hard to raise the core temperature to the normal temperature of 98.6 degrees. Somewhere in Stage Five of the disease, the person with dementia will begin to have a lower body temperature, usually between 97 and 95 degrees. Death occurs at 93 degrees, so a person with dementia would be in Stage Seven and near the end of life with a temperature of 95.

And as there is less and less healthy brain tissue, there is a correlating drop in the brain's ability to respond and protect the body. The infections experienced by People with Dementia are especially concerning due to the brain's inability to respond. UTIs quickly overwhelm the body's systems, leading to sepsis (the blood is overwhelmed with infection), and the sepsis leads to kidney failure (renal failure), which leads to death. Sepsis is commonly called "blood poisoning" because the blood is overrun with infection. Kidney Failure is referred to as Renal Failure.

Caregivers alert to sudden changes in their loved one's behavior should immediately notify the physician, and using the hat method (a plastic cup that fits on the toilet bowl to catch urine), attempt to collect a urine sample when the Person with Dementia toilets. Hospitalization may be needed in some People with Dementia, depending to how much healthy brain tissue can respond to each new infection.

Some research theorizes the person with dementia is unable to effectively destroy the infection, in spite of the antibiotics. This would create the possibility that the person with dementia is carrying a low grade infection that can suddenly take over the body's functioning.

Communities, especially memory care communities, train caregivers to be alert to the signs of infection and UTIs. Operating under a medical model, People with Dementia are encouraged to drink fluids at all mealtimes. Then additional hydration stations or carts are utilized in between meals to continue to offer drinks. Fluids are offered during activities, following exercise, and even up to bedtime. Note that urinary tract infections for People with Dementia are usually not related to the fluid intake; they are related to brain damage and the brain's resulting inability to produce a normal immune response.

### **Question 5: How Guilty do You Feel?**

One of the most stressful things family caregivers face is the decision to seek outside placement for their loved one. There are a number of reasons for feeling this stress.

Typically, care has been going on for a decade or more and the family caregiver is physically and emotionally exhausted. The caregiver may be afraid of what others will think of them, there may be no funds available, or the behaviors of their loved one may be embarrassing or challenging. Spouses and relatives may see placement as the breaking of wedding vows.

Cultural issues for African American, Hispanic American, Asian American, and other families may mean facing severe backlash for placement of a loved one into dementia care. Members of the family, church members, neighbors, and other friends may view the move as abandonment rather than an attempt to get your loved one the specialized medical care they need.

Addressing guilt, the giant elephant in the room, is critical for an ongoing partnership of care. Many people have made a promise to loved ones to never place them in a nursing home. Chances are people made this promise never realizing there were diseases like the dementias that eventually require specialized, round-the-clock medical care.

By Stage Five, People with Dementia require a great deal of reminders, hands on assistance, socialization, exercise, care, and patience. In Stage Six, two caregivers may be required for transfers, bathing, and toileting. Stage Seven means two or more caregivers may be required to do full care for the person with dementia. The care is physically challenging and is mentally and emotionally exhausting as well.

Other families may be dealing with the social expectations of caring for a loved one at home. African-Americans and Hispanic Americans have the highest risks for Vascular Dementias and the least support for care. They may even face a loss in social standing or family backlash. Other groups also face shame at home, places of worship, or in their neighborhoods, all for seeking outside care that their loved ones need.

It is important to support all families in their decision to turn over care of a loved one to medical professionals, to encourage them to join support groups, and to praise them for their loyalty to their loved one.

People who shame caregivers about seeking outside assistance are showing a lack of education about the disease, a lack of awareness of its impact on the person with dementia, and a lack of understanding about the physical, mental, and emotional impacts on caregivers. The stress the caregiver faces is dangerous, with research in 2018 determining that an

estimated two in 10 family caregivers are dying before their loved ones, due directly to the stress of care.

Once a person with dementia needs placement with professional caregivers, will the family come back for breakfast or lunch or dinner? Will they come to holidays, birthdays, parties, and education nights? Will this family continue to visit and treat this person with dementia as an honored family member? If the answers are “yes” then the family and the caregiver need to let the guilt go. No one expected dementias to appear, no one knew this would happen, and no one understands what the family caregiver faces, except for other family caregivers and perhaps the professional caregiver.

The move into the community should allow the family caregiver to return to being a spouse or a son or daughter. Time together can be spent sharing a slice of pie or watching an old movie, not changing a brief, or arguing about a dirty shirt.

Don't discount the level of stress suffered by the family caregiver. That crabby, short-tempered, exhausted person may be doing dementia care and working at a fulltime job and providing for a family still at home. There is significant stress suffered by the caregiver and a heightened risk of death. Being open and honest about the care the person with dementia needs gives families the information they need to seek out professional care.

## **SUPPORT GROUPS**

**Seeking out the professional care that a person with dementia needs is a very challenging and emotional process. Feeling guilt is common and caregivers may or may not receive the support of their families**

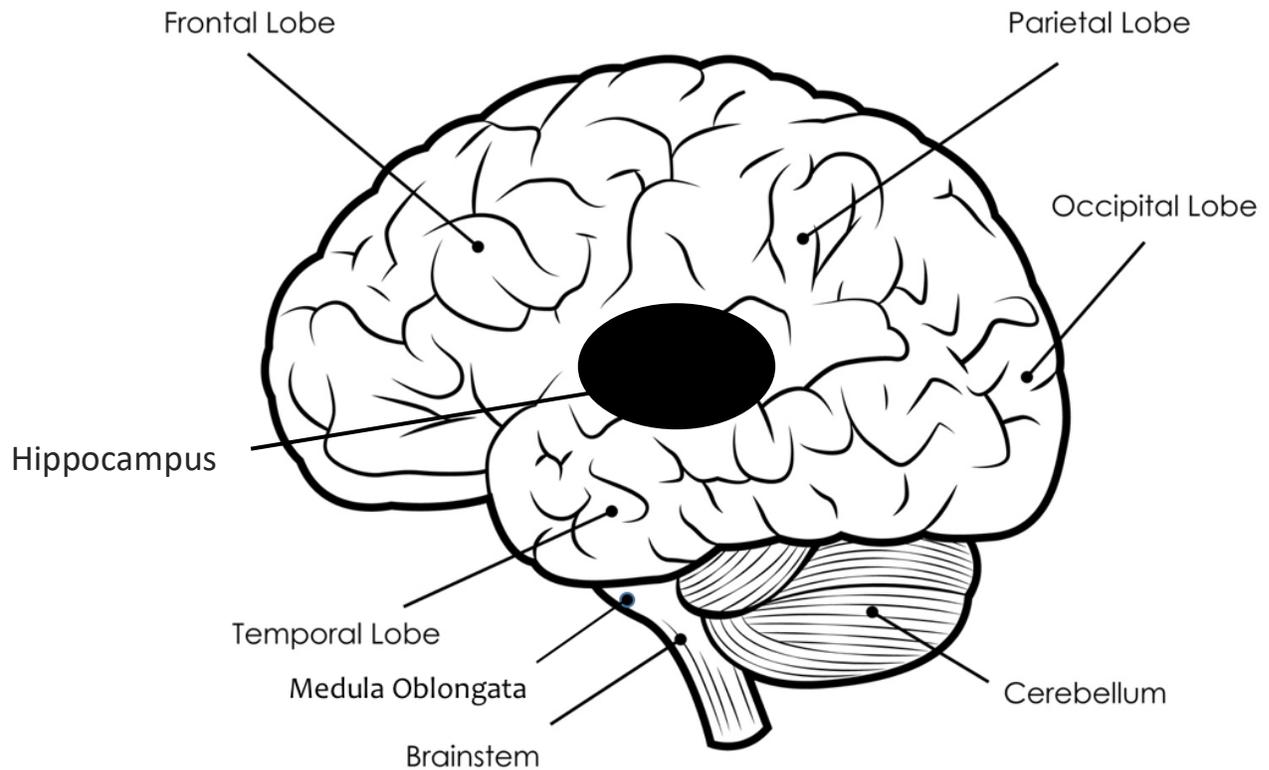
**and communities throughout this difficult time, which makes support groups for the family caregiver critical. The family caregiver's own health is at risk during this disease and a support group can save the caregiver's life.**

### **Five Things to Remember**

1. The brain runs the body. As the brain becomes more and more damaged, the body works less effectively.
2. Most falls are likely to happen because of brain damage to the motor cortex, premotor cortex and the limbic system. Other falls are related to the sudden loss of consciousness.
3. Urinary Tract Infections (UTIs) are caused by damage to the brain. When UTIs become chronic, it indicates the brain has become too damaged to monitor and fight infection.
4. Each lobe of the brain has certain duties and when that lobe becomes damaged, the person with dementia will display different behaviors.
5. When a person with dementia begins to have difficulty chewing and swallowing food, the disease is now in the brainstem.

# Two: The Brain's Lobes

## Lobes of the Brain



The brain contains seven sets of lobes and weighs about three pounds. The brain runs the body and also contains the personality that makes you who you are. There are chemicals being produced and used by the brain and body, electrical impulses firing within the cell structures, white matter, gray matter, neurons, proteins and pathways connecting the different lobes to each other.

The lobes of the brain contain a matched set or identical lobes on each side of the brain. The left side controls the right side of the body. The right

lobes control the left side of the body. Generally, both sides perform similar actions, although some lobes appear to have different functions based upon which side of the brain the lobe is on.

Understanding what each lobe is responsible for, how it affects the person's normal function, and how the People with Dementia's behaviors will change as each lobe is damaged, allows us to determine where brain damage is occurring and causing changes.

### **Hippocampus and Limbic System**

The Hippocampus and Limbic System of the brain are where memory begins. Without these areas functioning correctly, a person cannot learn new information. It's that simple. If the hippocampus and limbic systems are damaged, the person cannot learn or retain new information. It doesn't mean a person doesn't love her new great grandchild; she is simply missing a piece of her brain that makes memory work.

And she typically doesn't look physically ill. She probably won't appear physically ill until Stage Six of the disease, so it's common for family caregivers to believe she is behaving in a bothersome manner to be purposefully annoying.

Once the Hippocampus becomes damaged, the person with dementia will likely ask the same questions or repeat behavior again and again without realizing she is doing so.

No matter how many times you repeat the information, she will not be able to learn or retain it. The area of her brain that makes memory no longer

functions, and the ability to remember information will eventually go away entirely.

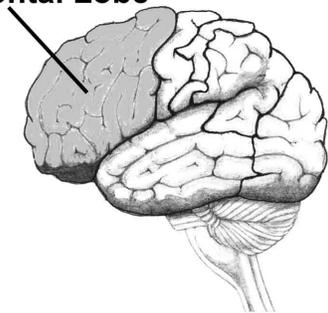
## **Which of the A's of the Dementia do you usually see here?**

### **Amnesia**

Amnesia is the inability to use or retain memory, including short term and long term memory. The person may constantly repeat questions such as “Where am I?” and “Who are you?” and “When are we going to eat?” or accuse the caregiver of stealing or being an imposter. This type of behavior can continue for hours at a time. This process occurs due to damage to the Frontal lobes and the Hippocampus.

### **Frontal Lobe System**

**Frontal Lobe**



The Frontal Lobes store memory, personality, cognition, impulse control, speech, attention, rational thought, imagination, and judgment. The Hippocampus allows us to learn new information, such as being able to answer the question “Where are we going?”

This is usually the first area of change noticed by families and the “A” which has most likely caused verbal or physical abuse within the family

structure. In this beginning of Amnesia, the person with dementia does not look ill, so the confusion and inability to remember can appear purposeful. The person with dementia's behaviors are often interpreted as just "annoying" behavior, rather than signs of the disease and its progression in the brain.

**Normal Function of the Frontal Lobe includes:** abstract thought, personality, attention, behavior, sexual behavior, emotional expression, initiation, concentration, organization, motor planning, self-monitoring, awareness of ability, coordination of movement, creative thought, imagination, impulse control, inhibition, initiative, intellect, judgment, memory, problem solving, the ability to produce and understand language, rational thought, reflection, speech, and some emotion.

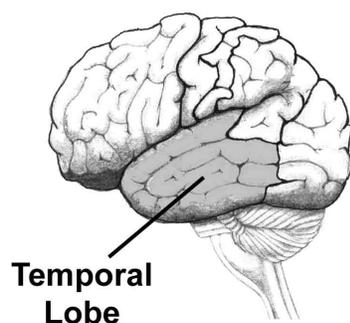
**Symptoms of Frontal Lobe Impairment:**

- Changes in personality & social behavior
- Loss of spontaneity in interactions
- Loss of flexibility in thinking
- Sequencing – inability to complete tasks in the right order
- Easily distracted
- Mood swings
- Diminished abstract reasoning
- Difficulty with problem solving
- Language difficulties – word usage and word finding
- Loss of simple movement in various parts of the body
- Perseveration – repeating actions or comments without awareness

## Which of the A's of the Dementia do you usually see when the Frontal Lobe is damaged?

**Anger, apathy, attention, anxiety** – these are often witnessed as the person with dementia begins to react to her brain's failure to function normally. Anxiety and anger may come in short outbursts with no recall of the behavior. Frustrated by the brain's failure to secure needed information, a typical reaction is agitated behavior, with no recognition of brain failure. Pointing out this inability to produce the correct thought or action typically results in the person with dementia becoming annoyed with the caregiver. She may direct her anger towards you if you insist on pointing out the deficits in her thinking. Since she is not aware that her thought processes are incorrect, she will naturally believe you are trying to trick or fool her.

## Temporal Lobe System



The Temporal Lobes controls hearing, language, and sense of smell. The left lobe is believed to control formal language and the right lobe is thought to control automatic speech (yes and no), singing, and forbidden or hateful words including cursing. The left lobe is generally destroyed first, leaving the person with dementia only the ability to communicate with swearing and singing.

**Normal Function of the Temporal Lobe includes** auditory memories, cursing, fear, hearing, understanding, language, music, awareness, sense of identity, singing, some behavior and emotion, feelings, organization and sequencing, sense of smell, some visual pathways, speech and visual memories (faces, places, foods, objects), memory, learning, and information retrieval.

**Symptoms of Temporal Lobe Impairment:**

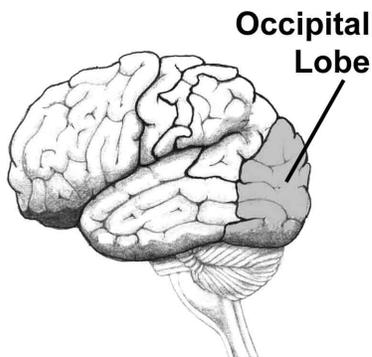
- Difficulty remembering names and faces
- Difficulty with Identification and verbalization of objects
- Difficulty understanding the spoken word
- Concentration difficulties
- Aggressive behavior
- Short-term memory loss
- Long-term memory loss
- Change in sexual interest
- Persistent talking
- Difficulty locating objects in the environment

- Inability to categorize objects
- Religiosity
- Seizure disorders, auras, and strange reveries

### **Which of the A's of the Dementia do you usually see when the Temporal Lobe is damaged?**

**Aphasia** – the inability to use or understand language. The person will use the wrong word, or complete a story with phrases from another story, or provide a lengthy description of an item because she cannot find the right word. She may call family members by the wrong name, which increases the family's anxiety and concern. This word finding difficulty will increase until all language use is lost. This is associated with damage to the Temporal Lobes and the Frontal Lobes.

### **Occipital Lobe System**



The Occipital Lobes are responsible for translating the visual imagery sent from the eye. These two lobes translate the information from each eye into a three dimensional image and connect that image to the appropriate

memory. Eyeglasses are not part of the visual translation. Rather they function to force a muscle in the eye to constrict causing the signal to be in focus for the Occipital Lobes. Vision loss is not due to a bad eyeglass prescription, but to progressive damage to the brain.

**Normal Occipital Lobe Function includes** depth perception, facial recognition, visual reception area, reading, visual acuity, and visual interpretation.

### **Symptoms of Occipital Lobe Impairment:**

- Impaired vision
- Front visual fields impacted
- Loss of 3D to 1D
- Possible loss of vision in left eye
- Peripheral vision field is reduced
- Misinterpretation of persons, objects, and environment

### **Which of the A's of the Dementia do you usually see when the Occipital Lobe is damaged?**

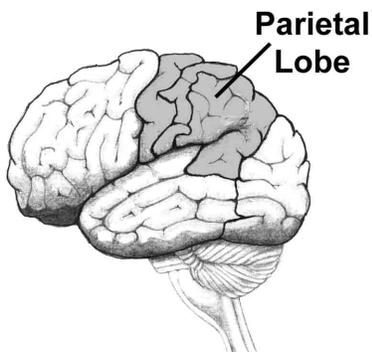
**Agnosia** -- the inability to recognize people or use common objects. The person may become lost in a familiar place because she doesn't recognize the items that alert us to our surroundings. She may confuse a fork with a spoon, a toothbrush with a hairbrush, or toothpaste with denture cream. Eventually, the ability to recognize objects is lost completely. The person may also confuse memories of a son with a husband or a father or an uncle. She may confuse her daughter with a mother or an aunt or a

grandmother. This process is associated with increased damage to the Frontal lobes, the Occipital lobes (visual association, distance and depth perception) and the Temporal lobes. Memory is lost in a reverse order of being learned. A person with dementia may think she is 40 even though she is 80.

Since her memories only go to the age of 40, she will attempt to identify family by assigning them the identity of a family member who most closely meets their expected appearance and age. In other words, great grandchildren may be confused with her children because the ages of the great grandchildren match her current memories.

The process of dementia reverses the order of learning in most people. Maslow and Eriksen's scales of development go from infancy to adulthood. The Alzheimer's RetroGenesis Scale (retro – back to, and genesis – the beginning) means the person with dementia will slowly lose memories from adulthood back to her infancy. Old memory or long term memory or lifetime memory, the building blocks of our files of knowledge, become our last memories. Basically, a person with dementia may know where she was raised, but not where she is in the present time.

## **Parietal Lobe**



The Parietal Lobes control pain, touch, taste and body temperature. Recognizing infection and responding with an increase in the body's core temperature is controlled and monitored here. As the disease progresses, damage to this lobe will cause the person with dementia to have a much lower body temperature.

**Normal Function of the Parietal Lobe includes** monitoring the body's temperature perception, sensory combination, and comprehension. Normal function also includes writing and reading, some visual functions, taste and touch, math calculations, academic skills, visual perception, spatial perception, differentiation of shape, size, and color, and sense of touch, taste, smell.

**Symptoms of Parietal Lobe Impairment:**

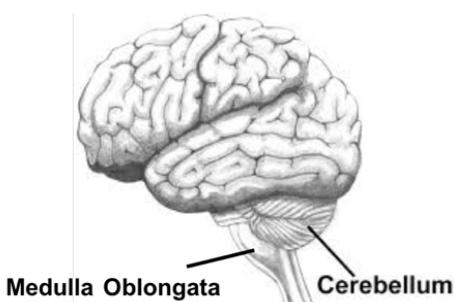
- Difficulty naming objects
- Difficulty writing words
- Difficulty multitasking
- Problems with reading
- Poor hand-eye coordination
- Confusion with left-right orientation
- Difficulty with math and drawing
- Poor visual perception – the inability to focus visual attention
- Lack of awareness of body and space
- Lower body temperature

- The person may be left with only the ability to taste sweets and frequently begins to crave sweets because it's what she can taste.

### **Which of the A's of the Dementia do you usually see when the Parietal Lobe is damaged?**

**Apraxia** – the inability to use or coordinate purposeful muscle movement. In the early stages, the person may reach for an item and miss it. She may have difficulty catching a ball or clapping her hands. The floor may appear to be moving to this person and balance becomes affected, increasing the risk for falls and injury. In time, this loss of ability to move affects the Activities of Daily Living (transferring, sleeping, walking, toileting, bathing, grooming, dressing, and eating). In the end stage, the person is not able to properly chew or swallow food, increasing the risk of choking or aspiration. This is linked to damage to Parietal lobes (pain, touch, temperature and pressure, sensory perception), the Cortex (skilled movement), and the Occipital lobes.

### **Cerebellum and Medulla Oblongata Systems**



These minor lobes have a hand in coordination and control of coordinated movement, balance and muscle tone, equilibrium, and some memory of reflex motor acts.

### **Symptoms of Cerebellum and Medulla Oblongata Impairment:**

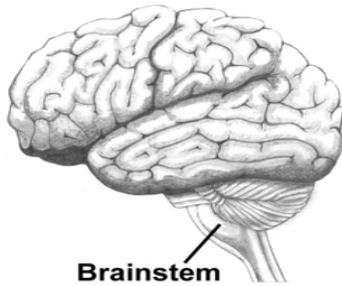
- Tremors
- Involuntary eye movements
- Ataxia – the lack of coordination
- Weak muscles
- Inability to judge distance and when to stop
- Inability to perform rapid altering movement
- Slurred speech

**Normal Medulla Oblongata functions:** helps regulate breathing, heart and blood vessel function, digestion, sneezing, swallowing, respiration and circulation.

### **Symptoms of Cerebellum and Medulla Oblongata Impairment:**

- Communication between the brain and the spinal cord is disrupted.
- In chronic alcohol use, significant synapse loss and axonal impairment makes the brain susceptible to injury.
- Swallowing food and liquids
- Swallowing plays a role in heart rate, reflexes to sight and sound, sweating, blood pressure, digestion, temperature, levels of alertness, ability to sleep, and balance.

## Brain Stem System



### Brain Stem Symptoms of Impairment:

- Difficulty swallowing food and liquids
- Dizziness and nausea
- Sleeping difficulties
- Decreased breathing capacity
- Problems with balance and movement
- Difficulty with organization and/or perception of the environment

# Three: The Nine Common Dementias

## Dementia

So let's review now that you understand the functions of the brain lobes. Dementia is the umbrella term for a group of terminal brain diseases. To be a dementia, the disease must be in two of the 7 lobes of the brain. There are four major and three minor lobes on each side of the brain. The disease must interfere with a person's ability to function, meaning to perform and complete the Activities of Daily Living (ADLs) and the Instrumental Activities of Daily Living (IADLs).

The disease must cause the loss of memory, which is all the accumulated information that makes you who you are. How you walk, how you chew food, how you greet others, how you appear, how you see yourself, your life, personality, family, education, skills, hobbies, experiences, loves, losses, births, and deaths are all parts of memory.

Dementia is a progressive and terminal disease. The brain runs the body. A damaged brain cannot correctly operate or protect the body systems. People with Dementia fall down and suffer from urinary tract infections (UTIs) because of the brain damage.

At the end of dementia, the person with dementia doesn't recognize herself. She doesn't know her family. She is totally reliant upon the care of others. She cannot use or respond to language; she cannot chew or swallow food properly. If her death doesn't come from stroke or heart attack, her end will come from aspirating food into her lungs, developing pneumonia, widespread infection, and kidney failure (renal failure).

Forty-eight dementias have been identified, although a different set of classifications lists 108 dementias. These dementias have subsets and mutations and mixtures of different types. The largest of the dementia groups is Mixed Dementias, the second group is Dementias of the Alzheimer's Type.

### **Challenges for Caregivers and the Identification and Treatment of Dementias**

- Early death of the caregiver as a result of stress and exhaustion
- Isolation of the caregiver
- No standardized or required testing to declare the diagnosis
- No clear path to care
- Lack of federal or state involvement to support care at home
- The cost of care may be frightening.
- Fear of losing home or savings
- No medications for stopping the progression of the disease

### **Classifications of Dementias**

One of the reasons people are confused about dementias is simply the variation and the complexity of what doctors are discussing. The word "disease" has now been replaced by the word "dementia." Alzheimer's Disease is now referred to as Alzheimer's Dementia. But the medical name/term is Dementias of the Alzheimer's Type or DAT. Vascular Dementia is now referred to as Dementias of the Vascular Type.

And now all dementias are classified as Major NeuroCognitive Diseases, which more clearly addresses and describes what the diseases do.

Dementias cause significant damage to and eventually destroy the brain. Translated, the name means Neuro (brain) Cognitive (ability to think, use memory, movement, language, etc.) Disease.

Dementias are also classified as either Dementias of the Alzheimer's Type and Non-Alzheimer's Dementias. Other descriptions used to distinguish dementias or to give details about the diseases follow. Variations within types of dementias are called Domains.

### **Secondary Dementia**

This is a dementia that develops as a peripheral or secondary condition to a pre-existing mental condition or illness. Progressive Supranuclear Palsy, a FrontoTemporal movement Dementia, is an example of a secondary dementia.

### **Multiple Dementias**

It is now thought it may be much more common for a person with dementia to have more than one form of dementia attacking the. The most common form of Mixed Dementia is the combination of Alzheimer's and Vascular Dementias.

Now through new testing and information from longitudinal research, it appears there are multiple mixtures of Alzheimer's and any other dementia, for example Lewy Bodies and Alzheimer's, Vascular and FrontoTemporal Dementia and Alzheimer's, etc. Some people may have as many as four or five different forms of dementia.

Many times it is the professional caregiver's direct observation of behaviors that begins to point doctors towards the realization that this person with dementia is struggling with multiple forms of dementia at once.

## **Cortical Dementias**

The brain damage begins primarily on the brain's cortex, or outer layer. The folds and turns of the outer layer function in part for language and memory. The gray matter of the brain is impacted. These dementias cause problems with memory, language, the inability to find the right word, thinking, and social behavior. Alzheimer's, Binswanger's Disease (Vascular Dementia form), Frontotemporal Dementia (FTD), and Creutzfeldt-Jakob are cortical dementias.

## **Subcortical Dementia**

The initial damage in these dementias occurs in the parts of the brain below the cortex and include more function damage to the white matter of the brain. Huntington's, Parkinson's Disease Dementias, and AIDS Dementia Complex are subcortical dementias.

The ability to start activities and the speed of thinking are usually impaired, while forgetfulness and language are unchanged. Changes in personality, emotions and movements are noted and in time there are memory problems.

## **Dementias Related to Sports**

Chronic Traumatic Encephalopathy – Football Dementia and Soccer Dementia, Pugilistic Encephalopathy – Boxer's Dementia.

## **Inflammatory Disorder Dementias**

- Multiple Sclerosis
- Vasculitis with or without Systemic Involvement
- Systemic Lupus Erythematosus
- Sjogren's Syndrome
- Sarcoidosis

- Bechet's Disease
- Non-Vasculitic Autoimmune Encephalomyelitis (NAIM)

### **Toxin Dementias**

- Alcohol, Chemicals, Cigarette Smoke

### **Structural Pathology Dementias**

- Malignant Tumors
- Benign Tumors
- Abscesses

### **Infection-Related Dementias**

- Creutzfeldt-Jacob Disease
- HIV-Related Dementia
- Syphilis
- Whipple's Disease
- Herpes Encephalitis and other Viral Encephalitides
- Chronic Meningitis
- Progressive Multifocal Leukoencephalopathy
- Subacute Sclerosing Panencephalitis

### **Metabolic-Related Dementias**

- B12 Deficiency
- Thyroid Disease
- Parathyroid Disease

### **Hereditary Dementias**

- Early Onset Alzheimer's (EOA), Familial Alzheimer's Dementia (FAD)
- Huntington's Disease, Juvenile Huntington's Disease, and/or

## Huntington's Chorea

- CADASIL, and other forms of Vascular Dementias are known to be inherited.

## Unusual Progressions in Dementia

For each form of dementia there can be severe and most often unexplained or sudden declines in the person with dementia's health and cognition. There are a number of factors to keep in mind as these events begin to occur. Any person with a dementia may suffer unnoticed seizures or mild stroke activity. These events are thought to be more commonly occurring during night sleep and therefore often go undetected because the change is subtle.

Keep in mind that in dementia care it's not the second or third or even the tenth stroke that may change the person's behavior. It's the stroke that tipped the balance in the brain's ability to function. Strokes change the brain's overall structure and now there is a noticeable change. A person with dementia may have accumulated dozens of strokes over time with no one noticing a difference in behavior. Eventually enough damage occurs so that the overall effect catches up and others can observe the changes in the person's behavior and abilities.

There may have been an unwitnessed fall with a head strike. Remember, the brain is shrinking due to the loss of tissue. The dying cells are being removed from the brain as the body rids itself of dead or broken cells and proteins. The brain structure will eventually have a large amount of

cerebrospinal fluid in the central ventricles and the brain may even be floating in cerebrospinal fluid.

Falls with strikes to the head can cause significant damage in just one fall because of the loss of tissue. The force of the fall and the force of the impact from the fall have serious effects. This combined energy of a fall with a head strike causes the brain to shift back and forth inside the cranium.

Striking the front or rear of the head is medically referred to as a contra-coup strike. This is a significant blow to the front or rear of the head, and the energy or force from the fall causes a bouncing effect in which the brain strikes the front and back of the cranium. These falls cause additional damage to the brain tissue as the brain moves and bounces within the space of the cranium. Sudden and dramatic changes that significantly progress the disease in the person with dementia can certainly be linked to falls with strikes or impact to the head.

Dementias are described medically as inflammatory diseases. Changes in the function of the brain-blood barrier, responsible for removing dead cells and broken proteins from the brain, may cause unusual changes to occur in the person with dementia as the ability to clean the brain diminishes.

Another inflammatory effect is seen suddenly and usually disappears within a few days. The person with dementia begins walking bent at the waist to the right side of her body, or her body is at an odd angle and out-of-balance. She moves and walks with her body leaning sideways. She may not show an infection in blood or urine tests, and scans for stroke activity may be equally unproductive. Then in a few days she will straighten back up and walk the way she had previously. It is theorized that this is due to a

sudden inflammation of the brain; however she should be seen by the physician to determine next steps for care.

The inflammation occurs because the disease process eventually damages the blood-brain barrier. Normally this barrier protects the brain by preventing harmful bacteria, viruses, or other infections from entering the brain structure. The brain-blood barrier allows oxygen to pass through to supply the brain. The barrier also allows glucose to pass through to provide nutrition to the brain.

Likewise, the barrier provides the way for the brain to safely clear away and dispose of toxic debris, such as broken beta-amyloid and twisted tau proteins, and assorted dead cell pieces. The buildup of these bits and pieces of cellular structure causes inflammation to occur due to their toxicity. The continued stress to the brain-blood barrier begins to cause vascular problems in the brain structure as well.

## **The Nine Most Common Dementias**

These are the most common forms of dementia by their order of occurrence as determined by the National Institutes of Health (NIH).

Each of the dementia forms has variations, additional domains, and can join each other forming a Mixed Dementia. These nine dementias are estimated to be 98 percent of all the dementias, given the rarity of most other forms.

Once you understand these nine dementias, remove the ones your loved one cannot have, and return to the physician with the dementias remaining on the list.

1. Mixed Dementia
2. Dementias of the Alzheimer's Type
3. Dementias of the Vascular Type
4. Lewy Bodies Dementia
5. FrontoTemporal Dementia
6. Parkinson's Disease Dementia
7. Wernicke-Korsakoff Syndrome
8. Huntington's Dementia
9. Chronic Traumatic Encephalopathy

## **Mixed Dementia**

**The name Mixed Dementia indicates presence of more than one form of dementia**

Historically, Mixed Dementia is when a person has forms of both Alzheimer's Dementia and Vascular Dementia. The disease presentation of behaviors varies based on the location and severity of the stroke damage and the stage of Alzheimer's.

Recent research indicates more forms and variations of Mixed Dementias exist than was previously thought. Dementias of the Alzheimer's Type may join with any other form of dementia and Dementias of the Vascular Type can do the same, meaning a great variation in behaviors and presentation of the disease.

Additional research also indicates some dementias may mutate or form variations of specific dementias. Dementias of the Lewy Bodies have shown dramatic shifts in presentations, leading to new questions about the progression and formation of dementias.

### **Order of Progression**

- Where the stroke activity has occurred and the stage of Alzheimer's progression helps determine the progression of the Mixed Dementia progression. Identifying the features of additional dementias also helps determine the progression of the disease.

### **Anticipated Behaviors**

- Behaviors of Alzheimer's and Vascular Dementias or any other forms of dementia.

### **Challenges**

- Spotty areas in memory means doctors and family may not notice cognitive changes.

## **Dementias of the Alzheimer's Type**

### **Named for Dr. Alois Alzheimer**

#### **Domains:**

- Early Onset Alzheimer's—Familial Alzheimer's Dementia (EOA-FAD) or Sporadic (estimated 90 percent plus of cases)
- Down's Syndrome Alzheimer's
- Regular Onset Alzheimer's, variations with delusions, hallucinations, and/or persecutory beliefs, which may include aggressive, agitated, or

anxious behaviors

- Late Onset Alzheimer's, variations with delusions, hallucinations, and/or persecutory beliefs, which may include aggressive, agitated, or anxious behaviors

This dementia, with the exception of EOA, begins as a cortical dementia on the surface of the brain. The entire brain is eventually impacted by the disease. Characteristic features of Alzheimer's Dementias are beta-amyloid plaques clumping between the nerve cells, impairing cellular function and neurofibrillary tangles of damaged tau proteins causing the cells to starve to death. It is not yet known if these two proteins start Alzheimer's or are a result of some other as yet unidentified trigger.

## **Falls**

- The most common fall is a fall backwards into the chair she was trying to get out of, with little damage to her body.

## **Early Onset Alzheimer's (EOA)**

### **Sporadic and Familial Alzheimer's Disease (FAD)**

There are an estimated 500,000 persons in this country affected by EOA. The familial form strikes multiple persons within the family. This is not the 90-year-old great grandmother form of Alzheimer's. This form attacks the young adult and mature adult, it attacks multiple family members, cousins, aunts, uncles, siblings, and one parent is also affected.

Most will display features between their 40s and 60s. There is typically a rapid and aggressive progression through the stages of the disease. Research suggests these families originated from a valley region of Germany and this is a genetic mutation shared through marriage.

The Sporadic form of Early Onset Alzheimer's accounts for 90 percent of the cases. This may be a family with no history of dementia and suddenly a 35-year-old sister develops the disease.

In both forms, there is rapid and widespread atrophy in all four lobes, then decline in the medial temporal and parietal regions, followed by the cortical region. Research indicates there is a significant loss early in the disease of the brain's ability to metabolize glucose. The brain runs on glucose, so this is significant and possibly related to the rapid progression of the early dementias. Myoclonus, a form of muscle twitching and muscle spasms are not uncommon in EOA. Death occurs typically within weeks of becoming bedbound.

This dementia's name is frequently misinterpreted by families. After visiting the doctor, the caregiver was told their loved one is in the early "stages" of dementia, meaning the disease is only beginning to show an impact visible to others.

Human nature and mistakes turn the word "stages" into the word "onset" and suddenly the diagnosis becomes "Early Onset Alzheimer's" and the information families find about that disease doesn't make sense. Early Onset is the name of a disease and Early Stage is telling you how advanced (early, middle, late) the disease is.

## **Down's Syndrome Alzheimer's**

As early as the middle to late 40s, Persons with Downs' Syndrome begin to experience a significant buildup of plaques and neurofibrillary tangles in their brains. Spinal fluid testing shows enough plaque and tangles for a diagnosis of Alzheimer's Dementia, although symptoms may not show for ten more years. The increase in Alzheimer's neuropathology research appears to indicate an acceleration of the disease between the ages of 40 and 50.

Cortical damage and white matter degeneration appear more profound in Downs' Syndrome. White matter in the brain are the bundles of neurons and microscopic blood vessels that feed the brain tissue. The accelerated aging found in Persons with Downs' Syndrome affects organs, structural and muscle systems. The impaired immune system is also a concern as the dementia progresses because a damaged brain cannot protect the body adequately from infection.

The onset of seizures and a distinctive and usually quite sudden refusal to perform the Activities of Daily Living (ADLs) are common behaviors. There is marked decreased in the person's activity with things of interest (hobbies, etc.) or the usual enthusiasm for previously enjoyed activities. The person will present with a depressed state and a loss of affect on the face and in the voice. She may experience sleep disturbances, and exhibit increased sadness, fearfulness, or anxiety. Caregivers may witness irritability, uncooperative behavior, and even aggression from the person with dementia. Changes in coordinated movement are marked by a loss of balance and increased falls.

Nurses and physicians should be aware of depression, thyroid changes, chronic ear and sinus infections, vision loss, and sleep apnea. Staff should be alerted that persons with untreated sleep apnea experience multiple nightly events of oxygen loss to the brain. With each stoppage of breath, the person's heart comes close to collapse or an attack as it struggles to take in oxygen from the lungs, which have stopped working for that second when breathing stopped. The continual stress can lead to clots in the vessels leading to strokes in the person. Note that this is any person with sleep apnea.

### **Regular Onset Alzheimer's Dementia**

This dementia is generally thought of as persons showing symptoms in their 60s and 70s. Typically this person is unaware she is having memory problems, something called anosognosia. She therefore may become quickly frustrated and annoyed when she is corrected, or errors are pointed out to her.

Or she may become momentarily frightened that people are talking about her or that she is in trouble. There are multiple forms of this dementia and individual mutations that can be expected.

This is an especially stressful dementia for the caregiver. As dementia progresses, the loss of the planning for retirement, the loss of a person who will not know her grandchildren, the death of a person who is categorized as young-old. For every person with dementia at this age group, it is estimated seven other people are aging normally.

There are multiple variations of Regular Onset Alzheimer's, including Atypical Frontal Variant Alzheimer's (fvAD) and Posterior Cortical Atrophy.

### **Late Onset Alzheimer's Dementia**

This is the dementia found in people in their 80s and 90s who begin to show symptoms of cognitive changes. Again, they are typically unaware of their disease. This is a much slower progressing disease than other forms of dementia. Due to the person's great age, death typically comes via a heart attack or stroke.

In gerontology, persons older than 85 are called the "Oldest-Old." In the eighties, she is in her ninth decade of life and she has outlived her peer group by a dozen or more years. Her peer group are other women born in her birth year. People with Dementia in their nineties have entered their tenth decade of life and are considered extremely old, frail, and fragile. Even at this great age, they may be very strong but you should recognize they are frail and fragile. They continue along with the disease rather stable until the fall, or the illness, or the infection, or the hospitalization. Then they fade quickly towards death.

People in this age group are believed to have outlived all dementias except Late Onset Alzheimer's, Vascular Dementia or the combination called Mixed Dementia.

### **Progression of the disease**

Typically, the disease begins on the outer area or cortex of the brain in the Parietal Lobe and eventually impacts the function of the Hippocampus

and Limbic Systems. These are the areas of the brain associated with being able to learn new information. Once these lobes become damaged, the person can no longer take new information in and lay down memory because the pieces of the brain that perform that function are damaged and eventually no longer exist in the brain's structure. Now the Person With Dementia will rely and react upon old information or memory that still exists in the brain.

While the spouse typically notices something is different in Stage Three of the disease, others such as family, neighbors, co-workers, friends, physicians and other professionals often do not notice anything amiss until Stage Five of the disease. At this point, the Hippocampus and Limbic System are impacted and the loss of Short Term Memory (STM) is displayed by the person with dementia late in Stage Five.

Signs the disease is in the Hippocampus will be indicated by repetitive questioning, sudden frustration or angry outbursts without recognition of the behavior, and increased anxiety when away from familiar areas. Some families notice dementia for the first time in their loved one once she is taken on a trip. Removed from her regular landmarks and the familiarity of her bedroom and home, she will become increasingly agitated as the world around her makes no sense.

The reason her environment makes no sense is because her Hippocampus is already damaged, and her brain can't figure out what is happening around it.

The disease will typically progress from the Hippocampus and Limbic system to the temporal lobes, then to the frontal and occipital lobes, and

finally the parietal lobes are again impacted. The cerebellum and brain stem are finally damaged at the end of the disease.

The spouse will typically notice a change in behavior in Stage Three, but may be chastised for pointing out cognition changes, behavior changes, or odd and unusual bursts of anger or anxiety. In Stage Four of the dementia, the adult children and friends and neighbors begin to suspect she has dementia.

For caregivers in urban areas, Stage Four can be when they suddenly find themselves isolated as caregivers. This is a process called Urban Isolationism. Friends stop calling or dropping by. Invitations to dinners, parties, golf, bridge, poker, coffee, etc., dry up as others react to the stigma or fear of dementia.

It is not unusual to meet a family caregiver completely cutoff from society as the amount of time care required slowly exhausts him. It is critical for caregivers to find and attend a caregiver support group as one way to deal with the stress of care.

**Stages Five, Six and Seven** are also called the Terminal Stages or the Late Stages because death will occur in one of these stages for most people. Most persons aren't diagnosed until Stage Five of the disease, which leads to the statistic that people die within three to five years of the diagnosis.

The loss of Short Term Memory (STM) is noticed first, followed slowly, eventually, years later, by the loss of Long Term Memory (LTM). These two forms of memory may be separated by a decline that may last as long at 15 years following the diagnosis. However, most persons are not diagnosed with any dementia until Stage Five of the disease.

This is typically the stage when a family caregiver can convince the person to see a specialist, or it is when the family practitioner is alerted to memory problems. But by Stage Five, there is global damage occurring in the brain and a significant loss of brain volume or brain tissue is to be expected. It is estimated that at the Stage Five diagnosis, most people have already lost a half-pound or so of brain tissue and can still function and possibly fool an unskilled professional.

Behaviors will vary based on the progression of the disease and the presence of other medical conditions or other dementias.

Visually, persons may experience illusions, misperceptions, misidentifications, rather than hallucinations.

## **Challenges**

- Death of the caregiver as a result of stress and exhaustion.
- Isolation of the caregiver.

## **Dementias of the Vascular Type**

### **Named for the Vascular System**

#### **Domains:**

- Multi-Infarct Dementia, cortical or subcortical
- Binswanger
- Subcortical Vascular Dementia
- Amyloid Angiopathy
- Strategic Infarct-related Dementia (SID)

- CADASIL – Inherited
- Mixed Dementia and variations
- White Matter Disease
- Gray Matter Disease

**Vascular Dementia** may be caused by strokes, atherosclerosis, endocarditis, or amyloidosis. Structural damage to brain tissue can also be caused by blocked arteries, blood clots, or internal hemorrhaging.

### **Falls**

- Common falls occur when trying to stand and move. This PWD frequently falls forward, landing on her face, elbows and knees.

### **Strokes**

Strokes can occur anywhere in the brain. The sneaky one is the silent stroke, often written off as “normal aging ischemic damage” by radiologists in MRI reports, but considered by neurologists and gerontologists to be anything but “normal aging.”

All strokes vary based on the type, size, causation, and location of the attack in the brain. Recovery from strokes is also based on the area of the brain and the size, type and frequency of the stroke.

Migraine headaches are not uncommon as a symptom along with transient ischemic attacks or TIA strokes, but migraines do not mean a person is having a stroke.

## **Transient Ischemic Attacks (TIA)**

Commonly called mini-strokes, baby strokes, tiny strokes, pen point strokes, these are strokes that typically last only a few moments. The clot is tiny and typically the brain recovers quickly. But the cumulative effect of years or decades of TIAs is Multi-Infarct Dementia or Multiple Stroke Dementia.

## **Ischemic Stroke**

Ischemic strokes are caused by embolic clots that reduce blood flow as the clots move through the blood vessels. These clots originate elsewhere in the body and travel to the brain with the flow of blood, eventually reaching a blood vessel too small to allow the clot to pass and the Ischemic Stroke occurs. Thrombotic clots are clumps of blood cells that form within the small brain arteries. Eventually the clot blocks blood flow and causes the stroke to occur.

## **Large Vessel Strokes**

Large Vessel Strokes affect greater areas of the brain. Features include substantial swelling or bleeding in the brain, which may require surgery to open the cranium to relieve pressure. This would typically be a Hemorrhagic Stroke.

## **Silent Strokes**

Silent Strokes occur in the Internal Capsule of the brain. Activity on the left side of the brain affects the right side of the body and activity on the right

side of the brain affects the left side of the body. The common causation of these strokes is the blockage of small blood vessels.

The Internal Capsule allows the cerebral cortex and areas of the brainstem to communicate. These connections allow physical movement and perception of sensory information (the five senses). Damage in this area means the arms, legs, trunk, and facial movements become impaired.

### **Binswanger's Disease**

This dementia, Binswanger's Disease, begins in the early 40s and death typically occurs within five years. Cerebrovascular lesions in the deep white matter of the brain cause a loss of memory, mood changes, abnormal blood pressure readings, and an unsteady gait. Falls are anticipated early on in the disease. This is a very aggressive dementia due to the young age of the person.

### **CADASIL**

CADASIL is one of the hereditary dementias that also begins to show features in the late forties. Again, because of the age of the person, the disease process is quite aggressive. Death is usually within five years of diagnosis. Cerebral Autosomal Dominant Arteriopathy with Subcortical Infarct and Leukoencephalopathy (CADASIL) is a stroke dementia.

### **White Matter Disease**

White Matter Disease is the tissue in the brain composed of microscopic blood vessels and bundles of nerves fibers. These bundles of nerves connect

the brain to the spinal cord. The millions of fibers are covered by a fatty tissue called Myelin sheath. This sheath provides insulation and protection for the nerves. The color of the myelin is what gives this area of the brain its name. Myelin speeds up signals between cells, allowing the brain to quickly assess a situation and respond.

**White Matter Hyperintensities** means the MRI scan is showing bright white areas, indicative of some type of brain injury. Decreased blood flow would indicate **White Matter Leukoaraiosis**. There might also be a diagnosis or conclusion of **Nonspecific White Matter Changes**, indicating no causation can be identified completely. Other causes of white spots could be TIAs (transient ischemic attack), Multiple Sclerosis, Lupus, B12 Deficiency, brain tumor, HIV, or Lyme Disease.

## **Gray Matter**

Gray Matter is the area of the brain comprised of the neuronal cell bodies, glial cells, dendrites, myelinated and unmyelinated axons, synapses, capillaries. This is where the bulk of memory is contained. Again, the name comes from the color of the cells.

## **Anticipated Behaviors**

- Problems with short-term memory
- Wandering or getting lost
- Laughing or crying at inappropriate times (PseudoBulbar Effect)
- Trouble concentrating

- Trouble managing money
- Aggressive behavior
- Inability to follow instructions
- Loss of bladder or bowel control
- Hallucinations
- Nighttime wandering
- Depression
- Incontinence
- One-sided body weakness
- Falls to the face, knees and elbows or to the weak side of the body.

## **Challenges**

- Death of the family caregiver due to stress.
- Increased chance of aggressive or highly agitated behaviors.
- Typically the person has a history of high blood pressure or other cardiovascular disease.
- Risk factors are smoking, high cholesterol, diabetes, heart disease, inactivity, obesity, and inherited factors. African Americans and Hispanic Americans also have a higher risk factor for Vascular Dementia.
- Vascular Dementia's risk increases with the presence of atrial fibrillation, previous strokes, heart failure, cognitive decline prior to stroke, high blood pressure, diabetes and atherosclerosis, excess alcohol consumption, poor diet, and little to no physical activity.

- Catching Vascular Disease early, and diet and exercise make for a better prognosis.
- Family may have gone from having a normally aging person to a completely demented person from one stroke.

## **Dementias with Lewy Bodies (LBD)**

### **Named for Dr. Frederic Lewy**

#### **Domains:**

- Diffuse Lewy Bodies
- Cortical Lewy Bodies
- Parkinson's and Lewy Bodies
- Lewy Bodies and Parkinson's
- Dementia with Lewy Bodies
- Mixed Alzheimer's and Lewy Bodies
- Mixed Vascular and Lewy Bodies
- Mixed Lewy Bodies and FrontoTemporal Dementia

#### **Area(s) of the Brain**

Lewy Bodies proteins begin to form inside the brain's nerve cells. These abnormal deposits of the protein alpha-synuclein prevent the cell from functioning properly. Eventually, the disease may impact the hippocampus and limbic system. Symptoms may begin between the ages of 60 and 80. It is currently believed more males than females develop this dementia.

## **Falls**

- Common falls are distinct and due to a sudden loss of consciousness. This person will stiffen like a plank and fall forward landing on her face. Or she may stiffen and fall backwards cracking the crown of her head. Parkinson's Disease Dementia falls are very similar to Lewy Bodies falls.

## **Progression**

In a variation from the normal behavioral progress on the Dementia Behavioral Assessment Tool (DBAT), persons with LBD may accuse caregivers or family members or theft or sexual infidelity in Stage Three rather than Stage Five. Mild mannered husbands may begin to fixate on sexual activity and pressure the wife for intercourse, even scheduling dates and times. He may also ask for medication for erectile dysfunction, which adds to the challenge of care and the wife's stress.

Persons with LBD also may experience sudden and severe depression in Stage Three rather than late Stage Five. He may have moments or days of great confusion and frustration as his brain struggles with the change in the protein Alphasynuclein.

As this protein begins to alter its function, and it begins to stay in the brain and its levels begin to build. This stops the brain from making the correct amounts of the chemicals Acetylcholine and Dopamine.

Acetylcholine affects memory and learning in brain function. Dopamine is a chemical that affects movement, moods, and sleep.

The visual hallucinations may appear in Stage Three, along with sudden changes in alertness, attention, and cognition. A slowness in movement is noted and gait changes include difficulty walking and rigidity.

This group is very sensitive to medications and should not receive antipsychotics.

### **Anticipated Behavior**

- Some symptoms of LBD can be similar to Alzheimer's Dementia.
- These include impaired memory, poor judgement, confusion, and depression. Anxiety and delusions may also be present, especially when cognition shifts intermittently. (Delusions are beliefs that are not real.)
- Delusions may include a sexual component and current news events. "My wife is having sex with the president on his plane but tomorrow when she goes to meet him on his plane, the plane will fall out of the sky."
- Or the delusion may stay closer to home with the wife accused to infidelity with everyone connected with this person, including the mailman, the doctor, the trash guy, the lawn man, the handyman, etc. REM sleep behavior begins (kicking or punching in sleep).
- Trouble falling asleep, restless leg syndrome, sleeping through the night then napping for hours the next day are also possible symptoms.
- Constipation not related to diet or medication, a shuffling gait, an inability to stand up straight, shaking, and increasingly dangerous falls are also noted. Perhaps best recognized by professional staff are the

presence of hallucination behaviors.

- Hallucinations are things a person may see, hear, smell, taste or feel that are not real. Common examples include
  - Seeing children
  - Seeing and knowing bad people are trying to kill you and one of those bad people may be the son or daughter or another family member
  - Visual and tactile sensation of spiders, rats, snakes and bugs crawling on you and biting you
  - Seeing the spouse or caregiver having sex with multiple people.

## **Challenges**

- Death of the family caregiver due to the stress of care
- Death occurs five to eight years after diagnosis and usually involves complications from immobility
- Swallowing difficulties, chokes, leads to pneumonia, sepsis, renal failure
- Falls
- Poor nutrition
- Pneumonia
- The person is aware at times of what is happening
- The person may decline from being unsafe but ambulatory to bedbound within days.
- Death typically follow within a few weeks or days.

# FrontoTemporal Dementias

## Named for Frontal and Temporal Lobes

### Domains

- Behavioral Variant FTD (bvFTD)
- Pick's Dementia
- Corticobasal Degeneration (CBD)
- Progressive Supranuclear Palsy (PSP)
- FTD with Motor Neuron Disease or FTD with ALS
- Nonfluent/Agrammatic Variant Primary Progressive Aphasia
- Semantic Variant Primary Progressive Aphasia
- Logopenic Variant Primary Progressive Dementia
- FTD with HIV/AIDS
- FTD in any form with Dementia of the Alzheimer's Type (DAT)

### Area(s) of the Brain

The behaviors specific to areas of the frontal and temporal lobes determine which of these dementias a person has. The degeneration of nerve cells in these two sets of lobes and the accumulation of the tau protein and the protein TDP-43 cause the damage to the brain. Some people have shown abnormal tau-filled on the lobes as well.

The average age of onset is the 50s and 60s. The duration of the FTDs is between two and eight years. In these dementias, memory is functioning for a long time because the disease is not impacting the hippocampus and limbic

systems yet. But the areas of the brain that are affected mean we expect to see significant changes in the person.

## **Falls**

- This population has unique falls. The movement disorder FTDs are usually wheelchair bound early in the disease and may fall attempting to get up.
- The communication and behavioral FTDs become bent at the waist in the final stages of the disease. They suffer repeated falls with head strikes, which cause additional damage to the brain, due to the way the body can no longer stand and move normally. They will not keep helmets on, and the falls can occur throughout the day.

## **Behavioral FrontoTemporal Dementias**

### **Behavioral Variant FTD (bvFTD)**

These persons display everything from apathy to a change in personality, loss of social boundaries and conduct, sexual inhibition, impulsive behavior, and craving sweets or certain foods or alcohol. It is not unusual to find that this person is only correctly diagnosed after being arrested for shoplifting.

Damage in the frontal lobes means there is a disconnect between the action and the consequence, so this person walks out of a store with no thought of hiding his actions, because he is not aware he has done anything wrong.

It is not unusual that this person has become estranged from his family as he will not appear ill, but seems rather uncaring and unloving towards

them. It is not unusual for this person to be recently divorced as the wife and children have left due to the unemotional responses from the husband/father.

More than half of the families of persons with FTD have no family history of these dementias. This person typically has a rapid decline towards the end of life.

**Pick's Dementia** (named for Dr. Arnold Pick) has an average onset of symptoms in the person's mid-fifties. The Pick's Bodies are abnormal collections or the buildup of Tau protein. Slow, steady and progressive deterioration in behavior, personality or language can occur.

Behaviors include impulsivity, obsessive compulsive behaviors, abrupt mood changes, unusual loss of social boundaries (may take off her clothing or masturbate in public) and demonstrate a lack of empathy.

Failure to understand financial outcomes can mean this person gives away her money without comprehending the consequences of being broke. When walking through the community, she may appear to "run over" other residents.

This is related to her impaired vision and care should be taken to protect her from residents angry about being knocked down and to protect residents from being walked into or being knocked down. From the loss of ambulation to becoming bedbound, death can occur in just a few weeks or months.

## **Movement FrontoTemporal Dementias**

### **Corticobasal Degeneration (CBD)**

The presentation of this dementia may appear suddenly with an unexpected and detrimental onset. The disease causes a loss of nerve cells

in the cerebral cortex and basal ganglia areas of the brain. The first symptoms may involve the motor system of the body or issues with cognition (difficulty with math is common) or both.

Symptoms also include parkinsonian features such as poor coordination, muscle rigidity, and shaking. It also has features of all late stage dementias such as difficulty with speech, trouble swallowing, and memory loss.

This dementia is frequently misdiagnosed as Alzheimer's, Parkinson's Disease Dementia, Progressive Supranuclear Palsy (PSP, another of the FTDs), or Lewy Bodies Dementia. Due to the same areas of the brain being affected and similar behaviors and movements, physicians may confuse the diseases. The varied symptoms often lead to the correct diagnosis.

An estimated 40 to 60 percent of this group will develop alien hand syndrome, a condition in which one hand is not seen as controlled by the person. In other words, the person does not seem to be aware that the hand is there and is a part of their body. They are not able to identify the hand or rings on the hand. The brain is not able to find the hand. The brain is not aware the hand is there. The hand may react to stimuli or it may not. Ideomotor apraxia (the inability to have coordinated muscle movement) may be seen in the hands and arms, or in the lower limbs causing walking challenges.

One foot may appear to be stuck to the floor, causing stumbling and falls. The fingers and hands may be unable to perform fine motor movements. This person may decline rapidly from Stage Six to Stage Seven and death may occur from choking which then leads pneumonia or another severe infection leading to sepsis and kidney failure (renal failure).

## **Progressive Supranuclear Palsy (PSP)**

This dementia causes issues with coordinated movement, gait, and balance. The hallmark feature of PSP is a progressive inability to coordinate eye movements. Related to the FTDs and Parkinson's groups, the features of this dementia also include depression, social and behavioral dysfunction, apathy towards life, hobbies, others, and depression. There is not usually a noticeable cognitive decline.

**Pseudobulbar Effect is when a person suffers forced crying or laughing that is uncontrolled. This is not uncommon in this dementia and many other forms as well. Remember even if it is laughing, it is not funny, not pleasant for the person with dementia. She is not in control of her behavior and this causes increased anxiety if not treated.**

The face is masked and immobile, and she will have difficulty with swallowing (dysphasia), making speech, and balance. The slowed and stiff gait increases her risk of falls.

This person may also exhibit embarrassing behaviors in social settings, saying or doing inappropriate things. She will appear to have no facial emotion or emotional blunting. To outsiders, she may appear indifferent to others. The brain stem, which controls balance and eye movements, is atrophied and contains deposits of an abnormal form of tau protein. The decline to death is typically rapid.

## **FTD with Motor Neuron Disease, also known as FTD with ALS**

This dementia affects approximately 10 to 15 percent of the people with FTD. The muscles atrophy, are stiff, and the person has difficulty with fine motor movements. She may experience fine muscle twitches and cramps.

The arms and legs on one or both sides of the body may be affected, and eventually more motor system functions will become impaired. Shortness of breath, falls, muscle twitches, exaggerated reflexes, and difficulty swallowing with coughing due to food or saliva in the windpipe. Death occurs from aspiration pneumonia, sepsis, and kidney failure (renal failure).

## **Communication FrontoTemporal Dementias**

### **Primary Progressive Aphasia (PPA)**

This dementia affects a person's ability to speak, read, write and understand what others are saying. Swallowing safely becomes a concern near the end of the disease. Death is typically from aspiration pneumonia, sepsis, and kidney failure (renal failure). There are three clinical subtypes of PPA.

### **Nonfluent/Agrammatic Variant Primary Progressive Aphasia**

A person with this dementia form begins to have a loss or deterioration in her ability to produce speech. At first, her speech becomes hesitant, and she begins to "talk around" the missing words, then she begins to talk less and less, eventually becoming mute. Behavior and personality changes will not occur until the late stages of dementia (Stages Five, Six and Seven). Difficulty swallowing leads to death by aspiration pneumonia, sepsis, and kidney failure (renal failure).

### **Semantic Variant Primary Progressive Aphasia**

This person demonstrates a progressive failure to recognize nouns or to recognize common objects (cat, book, glass of milk), while other cognitive

abilities are unchanged. Eventually the speech becomes difficult to understand as the person with dementia can no longer generate the key words in sentences. Difficulty recognizing common objects and faces helps confirm this diagnosis. FTD behaviors will not be exhibited until the late stages of dementia. Swallowing issues indicate death from aspiration pneumonia, sepsis, and kidney failure (renal failure).

### **Logopenic Variant Primary Progressive Dementia**

This dementia causes the resident to have an inability to retrieve words. She will present with a slow speech pattern dotted with pauses for significant word-finding problems. The ability to understand long and complex sentences is lost and eventually mutism is present. Reading and writing abilities continue to function a bit longer, but eventually decline as well. Neuroimaging demonstrates a loss of blood volume, blood flow, and neural activity in the left Temporal and Parietal Lobes. Swallowing again becomes an issue in the late stages and death occurs from aspiration pneumonia, sepsis, and kidney failure (renal failure). This variation of FTD may be closely related to Alzheimer's pathology.

### **Challenges**

- Poor family involvement due to the loss of emotion from the person with dementia, which may lead to divorce before the dementia diagnosis is made
- Younger age of the person with dementia causes increased stress for family and professional caregivers.
- Rapid decline is difficult for caregivers.

- Lack of facial and vocal affect may frighten caregivers.
- Lack of emotion may frighten caregivers.

## **Parkinson's Disease Dementia (PDD)**

### **Named for Dr. James Parkinson**

#### **Area(s) of the Brain**

This dementia begins in the Basal Ganglia in the central part of the brain and then spreads into the rest of the brain. Memory functions, the ability to pay attention, make sound judgements, and demonstrate executive functioning become impaired. It is theorized that there is a strong connection between the Lewy Bodies protein alpha-synuclein, Parkinson's Disease, and Parkinson's Disease Dementia.

Complicating the disease research is the presence of tau neurofibrillary tangles and APOE protein plaques found in Alzheimer's Dementia. Visual hallucinations similar to Lewy Bodies Dementia may be experienced, delusions that have a paranoid slant, muffled or soft speech, difficulty interpreting visual information, depression, irritability, anxiety, depression and sleep disturbances including REM Sleep Behavior Disorder (kicking and punching in sleep) are also present.

LBD and PDD are now considered "first cousins" and caregivers should anticipate if the person has LBD, the PDD will join and vice versa, causing a form of Mixed Dementia.

NOTE: Hallucinations and delusions in PDD are thought more likely to be related to medication than the disease.

## **Falls**

- Common falls are distinctly different from other dementias. People with Parkinson's Disease Dementia (PDD) stiffen and fall forward, landing on their faces or stiffen and fall backwards, cracking the crown of the skull on impact.
- The falls are frequently due to a sudden loss of consciousness.
- Parkinson's Disease Dementia falls are very similar to Lewy Bodies falls.

## **Order of Progression**

- Being diagnosed late in life increases the likelihood that Parkinson's Disease will become Parkinson's Disease Dementia.

## **Anticipated Behavior**

- Slowed movements
- Muscle stiffness
- Tremor, shuffling while walking
- Masked face
- Paranoid and delusional belief
- The onset of cognitive decline
- Changes in mood and behavior begin

## **Challenges**

- Caregiver death due to the stress of care, falls, choking

# **Wernicke-Korsakoff's Syndrome**

**Named for Dr. Carl Wernicke and Dr. Sergei Korsakoff**

## **Area(s) of the Brain**

There are multiple variations of this dementia. Wernicke Encephalopathy is recognized by features such as changes in vision and eye functioning and leg tremors. Other features include a decrease in mental alertness and an increase in confusion. This is usually the result of long term alcoholism causing a thiamine (vitamin B-1) deficiency, although it can also be caused by cancer, severe intestinal problems and malnutrition. Immediate treatment with hospitalization is required to monitor the intake of thiamine.

Clinical features include jerky eye movements, droopy upper eyelids, double vision, an altered mental status, poor balance, and difficulty walking. These should be documented for the physician. Persons with this dementia often appear malnourished and underweight. She frequently will have low blood pressure, a low body temperature, and new memory issues. This person may appear to be drunk even when sober. This can occur with the daily drinker or the binge drinker.

If left untreated, Wernicke Syndrome progresses to Korsakoff Syndrome. This dementia is marked by memory loss and challenges to perform the ADLs and the IADLs. She will experience more and more difficulty learning new information, as damage continues in the Medial Temporal Lobe.

This area of the Temporal Lobes contains the Hippocampus and Limbic Systems, so she will be unable to learn new information as these areas are

severely damaged. Instead, she will begin to demonstrate a behavior called confabulation.

Many caregivers may misinterpret confabulation with lying, but it is not. Rather it is a unique fallback position the brain appears to use. When she cannot find the correct information because of brain damage, her brain will try to fill in the missing gap of information with something similar.

The Thanksgiving party gets related as the Fourth of July party. She will be unaware she is confabulating and may become defensive if challenged about the facts. Her behaviors may become agitated, aggressive, impulsive, or she may withdraw from others in the community.

Death is caused by dementia complications, lung infections (pneumonia followed by sepsis -- blood poisoning from overwhelming infection, which leads to kidney failure).

## **Falls**

- This person may fall in any direction depending upon how long she abused alcohol and what other medical conditions are present.

## **Order of Progression**

- Damage to the Amygdala, mild Frontal Lobe atrophy, moderately severe damage to the Medial Temporal Lobe and atrophy.

## **Anticipated Behavior**

Among dementias, this group has the highest rate (28 percent) of reported scatological behavior, primarily coprophagia (eating one's own feces)

- Some people may become impulsive and grab or snatch at times.

## **Challenges**

- Due to history of addiction and drinking related behaviors, family involvement may be sporadic.

## **Dementias of the Huntington's Type (HD)**

### **Named for Dr. George Huntington**

#### **Domains:**

- **Huntington's Dementia**
- **Juvenile Huntington's Disease**
- **Huntington's Chorea**

#### **Area(s) of the Brain**

The mutation of a normal gene causes the degeneration and death of the nerve cells in the Basal Ganglia. This area of the brain which coordinates movement and the genetic mutation is passed from parent to child. The child has a fifty percent chance of having the gene.

In the middle stages of the disease, she will begin to have challenges with speaking and with swallowing. A speech therapist should be ordered by the physician to do a swallow study test. These tests will continue until death.

Walking can now be very difficult and if she develops Chorea. Her jerking limbs will make it especially difficult to walk safely. Nonetheless, she will continue to attempt to walk. The jerking movement in her limbs will also make performing or assisting her with her ADLs very challenging. As her memory becomes more damaged, she may have obsessive behaviors or fixations on

items. Concentrating and staying on task are becoming more difficult for her to do and she may become verbally agitated.

Many of the dementias are very similar by the end stage of the disease due to the overall or global loss of brain tissue or damage. Likewise, persons with Huntington's Dementia require total care and are an especially high risk for choking.

Symptoms of the disease typically begin between the ages of 30 and 50, with life expectancy after the onset of symptoms estimated at 10 to 15 years. With this inherited disease, a child is typically not tested until the age of 18, unless she is showing symptoms.

### **Falls**

- This dementia causes multiple variations of falls due to the movement disorder inherent in this form.

### **Order of Progression**

- This group has the highest suicide rate of any of the dementias. This is thought to be due to the genetics of this disease.
- Early symptoms begin with difficulty learning new things, affecting Short Term Memory. She will begin having difficulty making daily decisions. She will display mood swings and involuntary movements, or twitching will begin affecting her balance and coordination. Falls and stumbles will begin.

### **Anticipated Behavior**

- Abnormal and jerking body movements (Chorea)
- Slow bodily movement
- Increased muscle activity

- Fidgeting
- Declining cognitive skills
- Depression
- Irritability
- Anxiety
- Some patients may progress to exhibiting psychotic behaviors.

### Challenges

- This is a genetic disorder inherited from a parent that affects a person's ability to think, feel, and move.
- Communication, walking, mood changes, poor decision-making skills, memory loss, and swallowing mark the progression of the disease.
- This group has the highest suicide rate of any of the dementias.

## **Chronic Traumatic Encephalopathy (CTE)**

**Named for causation and type of damage (commonly called football or sport dementia)**

### Early Onset CTE

- **Mood:** depression, irritability, hopelessness
- **Behavior:** impulsivity, explosivity, aggression
- **Cognitive:** memory impairment, executive dysfunction, dementia
- **Motor:** parkinsonism, ataxia (lack of voluntary coordination of muscle movements –gait abnormality, eye movement abnormality, and changes in speech), dysarthria (slurred speech)

- **Note:** Early Onset CTE cases have a higher prevalence of motor dysfunction and are especially sensitive to alcohol

### **Late Onset CTE**

- **Mood:** depression, irritability, hopelessness
- **Behavior:** impulsivity, explosivity, aggression
- **Cognitive:** memory impairment, executive dysfunction, dementia
- **Motor:** parkinsonism, ataxia (lack of voluntary coordination of muscle movements –gait abnormality, eye movement abnormality, and changes in speech), dysarthria (slurred speech)

There is a recognized Mixed CTE in both forms which includes features of more than one domain.

### **Areas of the Brain**

Repeated blows or strikes to the head resulting in a shearing effect in the frontal lobes and temporal lobes from striking against the interior frontal bone. The occipital lobes are damaged by striking the rear of the cranium and the brain stem is twisted by strikes from the side.

Damage includes significant atrophy of the cerebral hemispheres, medial temporal lobe, thalamus, mammillary bodies, and the brainstem. Testing for CTE via spinal fluid indicates extremely high numbers of tau proteins.

### **Falls**

- There is not enough research yet to determine specific fall markers.
- The athleticism of these persons combined with the motor damage to the brain makes each case unique.

# ***BONUS MATERIAL:***

## ***Some Behaviors in Dementia***

### **Dementia Specific Behavior**

Physically or verbally aggressive – Vascular

Physically aggressive (especially with alcohol) - CTE

Hallucination (a person sees, hears or smells something that is not there)  
– Alzheimer's, Lewy Body, Parkinson's, Vascular

Delusion (a person has a belief that is not real) – Alzheimer's, Lewy Body,  
Vascular

Bathing or other ADL Challenges – Any dementia

Sundowning – Any dementia

Physical/Personal Space Violation, lack of empathy, early loss of language  
possibly leading to agitation, public masturbation – FTD

Paranoia, Persecutory, Suspicious – Any Dementia

Anxiety – Vascular, FTD, Parkinson's

Generalized Anxiety Disorder - 38-72 % of all dementias

Coprophagia - eating feces – WKD

Odd Speech or Word Use – Communication FTDs

### **Anxiety or Pain Behaviors**

Restlessness, easily fatigued, difficulty concentrating, picking, scratching,  
rocking, pilling, spitting, yelling, grabbing, calling out, anxious body

movement, physical or verbal agitation, short tempered, change in eating habits, gritting or grinding teeth, wringing hands, biting or chewing nails

Also

Hitting, kicking, pinching, facial grimaces, frowning, furrowed brow, sad expression, breathing differently, being very still or very agitated, frightened, closed eyes or rapidly blinking, sighing, moaning, groaning, chanting, tense body posture, guarding, restlessness, gait or mobility changes, change in routine, appetite change, increased confusion

### **Scatological Behaviors**

Pica - eating substances with no nutritional value

Coprophagia - eating feces - WKD

Scatolia - smearing feces, (usually to get the hand clean)

Urinating - corners, trashcans, plants (it's usually a guy thing)

Defecating in strange areas (usually can't find a bathroom)

### **Depressive Behaviors**

angry, annoyed, agitated, aggressive, withdrawn, tearful, change in appetite, change in sleep, irritable, sudden explosions of behavior followed by no recognition that the behavior occurred

### **Self-Soothing Behaviors**

Humming, singing, talking, rocking or repetitive movements, breathing slowly, pilling, folding, following, playing, baby dolls

### **Sensory Changes Effect Behavior**

Vision - Moves from 3D to 1D, loss of peripheral vision, floor tapping, left eye vision loss (Stage Six, also called Occipital Blindness.)Hearing -

Inability to translate sound, inability to track sound, difficulty hearing higher pitch voices or sounds

Taste and Smell - Retains ability to taste and smell sweets

Touch - pilling, rubbing, folding behaviors

### **Sexual Behaviors**

Change in Sexual Orientation behavior

Sexual Interests—Increase or Decrease

Accusations of Sexual Infidelity -LBD

Public Nudity - FTD

Sex Talk – Viagra – Porn – FTD, LBD

Hypersexual –LBD, Vascular, FTD

Misinterpreting Environment

Not Recognizing Family Members

Resident with Resident attraction

**Anosognosia** – The inability to recognize you have dementia

### **Caregivers Cause Behaviors!**

Stop asking why, stop arguing, stop correcting the Person With Dementia.

### **FIVE THINGS TO REMEMBER**

1. People with Dementia are unaware they have dementia. They do not feel they are impaired or not thinking cognitively. This is called Anogonosia.
2. People with Dementia are demonstrating damage in the hippocampus area when they begin to repeat questions.

3. A healthy human brain weighs about three pounds. By the end of dementia, a person's brain may weigh only one pound.
4. People with Dementia do not appear physically ill until the end stages of the disease. It is not unusual for persons in stage six to suffer a spiral or twist and turn hip fracture. Broken bones indicate the brain is now too damaged to maintain the skeletal structure and the end of life is coming.
5. Everything a Person With Dementia is doing is related to the damage occurring in her brain.

## **Four: Staging Dementia**

All dementias, with the exception of Chronic Traumatic Encephalopathy (CTE), are staged using a global deterioration scale of seven declines marked by changes in the person's behaviors.

The CTE dementias have four domains of Mood, Behavior, Cognition, and Motor. They are currently evaluated on a four-stage tool.

**Stage I in CTE** presents with:

Headaches, loss of attention, difficulty concentrating, followed by short-term memory issues, depression (atypical presentation with anger, annoyance, agitation, aggressive behaviors or outbursts), aggressive tendencies, explosivity (especially with alcohol), and decreased executive function.

**Stage II in CTE** presents with:

Mood swings, headache, and increased depression. There is also an increased loss of executive function, heightened impulsivity, suicidal thoughts or ideations, and increasing challenges with language use and comprehension.

**Stage III in CTE** presents with:

Increased loss of short-term memory, continued decline and loss of executive function, increased difficulty with concentration and attention, increase in explosivity, increased depression, great mood swings, physical

and verbal aggression, visuospatial challenges. Apathy is frequently noted and a greater presentation of cognitive impairment is observed.

**Stage IV in CTE** presents with:

Severe loss of cognitive abilities for short-term and long-term memory, a dementia diagnosis, profound loss of attention and concentration, increased paranoia and depression, visuospatial impairment, gait disruption, loss of language, explosivity, aggression, and parkinsonian movements.

## **Other Tools for Staging Dementias**

### **DBAT**

The other forms of dementia are staged on the Dementia Behavioral Assessment Tool (DBAT) and the FrontoTemporal Symptoms and Staging Tool. When using the DBAT be alert to how the person's family or caregivers are reporting the behaviors. The variations are a clue to the type of dementia.

For example, in most forms of dementia, a common Stage Five behavior is to accuse caregivers or family members of theft or infidelity. But in Dementias of the Lewy Bodies Type, this is a behavior seen earlier in the disease during Stage Three.

Most presentations of dementia will help monitor the person as they progress steadily and in sequence through the behaviors and stages. In other words, they go down a slippery slope. But if the dementia is a form of Vascular Dementia, then expect behaviors to be related to where in the brain lobes the vascular activity has occurred. For example, a person with stroke

activity might be well aware of today's date, but not able to remember how to transfer from a sitting to a standing position because the stroke impacted that particular area of the brain.

Persons with vascular dementias will appear to stairstep through the stages. This person suffers a vascular event, such as a stroke or heart attack, recovers, stabilizes or appears to, then has another event.

### **FTD Symptoms and Staging Tool (FTDSST)**

The FTD Symptoms and Staging Tool divides this cluster of dementias into their domains and then marks an X in the box with the behavior, if that particular behavior is associated with that form of FTD.

In Stage Six of the tool there are no more X marks because by Stage Six, all dementias are considered the same due to the amount of brain damage.

### **PAINAD**

This tool allows the caregiver to measure the level of pain in a person with dementia. Because of damage to the temporal and parietal lobes, the person with dementia cannot alert caregivers to pain. PRN orders -also known as orders for pain medication "as needed" are not effective due to the inability of the person with dementia to recognize or request pain medication. An estimated 50 percent of the behaviors displayed by a person with dementia are pain related, so routine evaluations for pain are necessary to provide proper care.

## **Actively Dying Assessment Tool (ADAT)**

The Actively Dying Assessment Tool allows for professional and family caregivers to track and recognize the signs and stages of the final part of life. Beginning in the final months, the tool provides the expected behaviors and physiological changes occurring in people who are actively dying.

## **Activities of Daily Living (ADLs) and Instrumental Activities of Daily Living (IADLs)**

These tools allow for caregivers to recognize and report the loss of abilities displayed by the person with dementia. These tools provide professionals and caregivers with an understanding of decline in the person's abilities.

## **USE THE TOOLS!**

These staging tools give family members, physicians, and caregiving staff the best picture of how progressed the disease is for the Person With Dementia. Rechecking the tools every two months will give an indication of the rate of progression of the disease and decline in the Person With Dementia. Share them with families and professionals for the best outcomes.

## Dementia Behavioral Assessment Tool (DBAT)

<b>STAGE 1 - NORMAL AGING</b>	
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	No cognitive changes evident. Normal aging, normal brain function.
<b>STAGE 2 - EARLY STAGE</b>	
Mild Cognitive Impairment (MCI)	Minimal brain tissue loss
Stage thought to last - unknown amount of time	Ages 40 to 55/60
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Fleeting moments of cognitive loss
<input type="checkbox"/>	Recovers relatively quickly from mistakes, may correct self
<input type="checkbox"/>	Misplaces familiar objects
<input type="checkbox"/>	Forgets names he/she knows well
<input type="checkbox"/>	No problems completing tasks or at social functions
<input type="checkbox"/>	Exhibits appropriate concern over memory function
<input type="checkbox"/>	Vacillates between seeking medical care and ignoring symptoms
<input type="checkbox"/>	Functions effectively at work and at home
<input type="checkbox"/>	Highly functional social skills
<input type="checkbox"/>	Requires complete cognitive testing to determine illness
<input type="checkbox"/>	Responds to cognitive therapy
<input type="checkbox"/>	Scores well on orientation test
<input type="checkbox"/>	Amnesia <sup>1</sup> beginning to be expressed
<input type="checkbox"/>	<b>STAGE 3 - MIDDLE STAGE</b>
Beginning Dementia	Minimal brain tissue loss
Stage thought to last 1 - 4 years	
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Memory deficit evident in intensive interview
<input type="checkbox"/>	Attempts to conceal deficits and denies any cognition difficulties
<input type="checkbox"/>	Expresses concern regarding deficits (mild/moderate anxiety)
<input type="checkbox"/>	Problems performing in demanding situations (work or social)
<input type="checkbox"/>	Co-workers/family members beginning to be aware of increasing challenges
<input type="checkbox"/>	Can get lost traveling to new areas
<input type="checkbox"/>	Exhibits signs of cognition but may retain little new information
<input type="checkbox"/>	Name/word finding difficulty more frequent
<input type="checkbox"/>	Challenged to remember new names
<input type="checkbox"/>	May appear depressed
<input type="checkbox"/>	Demonstrates high social skill level
<input type="checkbox"/>	Uses humor to avoid answering questions
<input type="checkbox"/>	No noticeable physical changes, but may begin stumbling or falling or sleeping excessively
<input type="checkbox"/>	Beginning to skip steps in tasks
<input type="checkbox"/>	Able to score well on orientation test, but not on cognition exam
<input type="checkbox"/>	At times appears befuddled or confused
<input type="checkbox"/>	Amnesia <sup>1</sup> and Aphasia <sup>2</sup> present - needs new information repeated

<b>STAGE 4 - MIDDLE STAGE</b>	
Moderate Dementia	4 ounces brain tissue loss
Stage thought to last 1- 4 years	Equivalent of 12 years old to adulthood
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Decreased knowledge of current and recent events
<input type="checkbox"/>	Memory deficits regarding personal history, may look to spouse to answer questions
<input type="checkbox"/>	Decreased ability to perform serial subtractions (100 - 7, 93 - 7, 86 -7, etc.)
<input type="checkbox"/>	Difficulty with immediate recall - for example, what time is doctor's appointment?
<input type="checkbox"/>	Difficulty with complex tasks such as driving, finances, shopping, bathing
<input type="checkbox"/>	Denial of deficits, with or with out agitation and annoyance
<input type="checkbox"/>	Withdraws from challenging situations - refuses to complete tasks, may make excuses
<input type="checkbox"/>	Increased anxiety/frustration over abilities or loss of abilities
<input type="checkbox"/>	Difficulty telling jokes, stories - starting to mix up stories
<input type="checkbox"/>	Decreased facial affect (emotion on face)
<input type="checkbox"/>	Increased depressive symptoms, possibly Atypical <sup>8</sup> : anxiety, anger, agitation, aggression
<input type="checkbox"/>	May hesitate when trying to correctly identify family members or close friends
<input type="checkbox"/>	Can have normal cognition for hours or days, then become quite confused
<input type="checkbox"/>	May become lost in tasks
<input type="checkbox"/>	Greater language challenges, word-finding difficulty
<input type="checkbox"/>	Begins to have stumbles or falls
<input type="checkbox"/>	Begins to shadow caregiver and may begin to have difficulty with ADLs <sup>6</sup> or IADLs <sup>7</sup>
<input type="checkbox"/>	May begin keeping lists of family names, phone numbers, etc.
<input type="checkbox"/>	Exhibits greater desire for sweet foods
<input type="checkbox"/>	May score well on orientation test, dementia evident on cognition exam
<input type="checkbox"/>	Amnesia <sup>1</sup> , Aphasia <sup>2</sup> , Agnosia <sup>3</sup> and Anosognosia <sup>4</sup> present, some paranoia present
<b>EARLY STAGE 5 - LATE STAGE</b>	
Moderately Severe Dementia	1/2 to 1 pound of brain tissue loss
Stage thought to last 1- 3 years	Equivalent of 12 - 8 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Disorientation to time (date, day of week, season, etc.) or place
<input type="checkbox"/>	Immediate memory relatively intact - knows self and family
<input type="checkbox"/>	May need assistance choosing and layering clothing, but denies need for IADL/ADL
<input type="checkbox"/>	May crave sweets over other foods
<input type="checkbox"/>	Begins to have falls
<input type="checkbox"/>	Hunting and gathering stage, wanders from room to room collecting items
<input type="checkbox"/>	Urinary incontinence begins – monthly to weekly to daily
<input type="checkbox"/>	Wears clothing appropriately (hearing aid, glasses, carries purse)
<input type="checkbox"/>	*Feeds self (may need meal set-up)
<input type="checkbox"/>	Sleep disturbances, excessive sleeping or napping
<input type="checkbox"/>	Can score well on an orientation test, but not a cognition test
<input type="checkbox"/>	Wanders looking for a way out (purposeful wandering/ Sundowning)
<input type="checkbox"/>	Follows simple instructions for ADLs, verbal cues needed for tasks
<input type="checkbox"/>	Unexplained tearfulness or extreme laughter
<input type="checkbox"/>	Catastrophic reactions - may be easily annoyed, agitated, verbally or physically aggressive
<input type="checkbox"/>	Hallucinations, accusatory behavior, excessive sleeping - report to doctor
<input type="checkbox"/>	Amnesia <sup>1</sup> , Aphasia <sup>2</sup> , Agnosia <sup>3</sup> , Anosognosia <sup>4</sup> and Apraxia <sup>5</sup> evident to outsiders

<b>LATE STAGE 5 - LATE STAGE</b>	
Moderately Severe Dementia	Equivalent to 8 - 4 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	May begin having chronic Urinary Tract Infections (UTIs)
<input type="checkbox"/>	Appears severely depressed with increased loss of facial affect
<input type="checkbox"/>	Increased fall risks, may not recognize severity of the fall especially to the head
<input type="checkbox"/>	Coordinated movement/function beginning to be affected
<input type="checkbox"/>	Begins to be lost in current time
<input type="checkbox"/>	Difficulty recognizing self in a mirror
<input type="checkbox"/>	Challenged to recall family members, may confuse daughter with mother, etc.
<input type="checkbox"/>	Accuses family members, caregivers of theft, infidelity, lying, increased paranoia possible
<input type="checkbox"/>	Automatic "yes/no" speech functions, but without understanding
<input type="checkbox"/>	May begin using curse words as temporal lobes become damaged
<input type="checkbox"/>	Changes in visual perception increasing, bumps into objects, peripheral vision damaged
<input type="checkbox"/>	Difficulty interpreting background noise
<input type="checkbox"/>	Challenged to perform rehab for injuries, may appear stubborn to therapist/family
<input type="checkbox"/>	Cannot give accurate information, verbal skills damaged
<input type="checkbox"/>	Caregivers may confuse behavior for purposeful action – lying, etc.
<input type="checkbox"/>	Physical appearance beginning to be affected
<input type="checkbox"/>	Pilling or rubbing hand motions common, may enjoy folding items
<b>STAGE 6 - LATE STAGE</b>	
Severe Dementia	1 - 1 ½ pounds of brain tissue loss
Stage thought to last 1- 3 years	Equivalent to 4 – 2 year old
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Unable to recall most recent events
<input type="checkbox"/>	Repetitiveness in motion or speech or memory
<input type="checkbox"/>	May be in constant motion, wanders/walks for hours
<input type="checkbox"/>	Removes/won't wear clothing appropriately
<input type="checkbox"/>	Disregards eyeglasses, dentures, hearing aids (Agnosia <sup>3</sup> ) - may throw them away
<input type="checkbox"/>	Refuses to change clothing, unable to complete IADLs and a few ADLs
<input type="checkbox"/>	*Feeds self with set-up, cues and assistance
<input type="checkbox"/>	Bowel incontinence begins
<input type="checkbox"/>	Sleep disturbances - may increase sleep, may require little sleep
<input type="checkbox"/>	Catastrophic reactions may occur - great resistance to care giving, bathing
<input type="checkbox"/>	Purposeless wandering/Sun-downing (wandering without an agenda)
<input type="checkbox"/>	Cannot complete a two-stage command, such as pick up a piece of paper and fold it
<input type="checkbox"/>	Apraxia <sup>5</sup> advanced, gait altered (small shuffling steps)
<input type="checkbox"/>	Aphasia <sup>2</sup> increased, great language loss, uses bits and pieces of words or sounds
<input type="checkbox"/>	Weight loss beginning, may lose ½ or more of body weight
<input type="checkbox"/>	Difficult to engage with caregiver, challenged to initiate conversation
<input type="checkbox"/>	Disheveled appearance
<input type="checkbox"/>	Fall risk continues to increase until wheelchair bound, risk for fractured bones increases
<input type="checkbox"/>	Difficult to perform rehab for injuries
<input type="checkbox"/>	Almost total loss of facial affect
<input type="checkbox"/>	May suddenly use complete sentence, then only words or sounds



<b>STAGE 7 - LATE STAGE</b>	
Very Severe Dementia	1 ½ - 2 pounds of brain tissue loss
Stage thought to last 1- 2 years	Equivalent to 2 year old - Infant
<input checked="" type="checkbox"/>	<b>BEHAVIORAL CHARACTERISTICS</b>
<input type="checkbox"/>	Frequently no speech at all – mostly grunting or word sounds
<input type="checkbox"/>	*Cannot feed self --- chipmonking or holding food in cheeks, high risk for choking
<input type="checkbox"/>	Unable to sit up independently, unable to hold head up
<input type="checkbox"/>	Loss of basic psychomotor skills (unable to walk w/o assistance)
<input type="checkbox"/>	Hyper oral (may put everything in mouth)
<input type="checkbox"/>	Requires total care, displays great muscular flexation, hands curl, arms and legs pull up
<input type="checkbox"/>	Extreme risk for skin breakdown leading to wounds
<input type="checkbox"/> <input type="checkbox"/>	Spends majority of day asleep or semi-alert, but understands tone of caregiver
<input type="checkbox"/>	Extreme weight loss
	Loss of ability to smile – indicates death is near

**Use the Actively Dying Assessment Tool (ADAT) to assess Stage 7 care needs. ADAT is available online at [www.tamcumplings.com](http://www.tamcumplings.com).**

**Amnesia<sup>1</sup> - the inability to use or retain short-term or long-term memory**

**Aphasia<sup>2</sup> - the inability to use or understand language**

**Agnosia<sup>3</sup> - the inability to use or recognize common objects or people**

**Anosognosia<sup>4</sup> - the inability to recognize impaired function (not denial) in memory, general thinking skills, emotions and body functions**

**Apraxia<sup>5</sup> - the inability to use coordinated and purposeful muscle movement**

**ADLs<sup>6</sup> - Katz's Index of Independence in Activities of Daily Living - bathing, dressing, toileting, transferring, continence and feeding**

**IADLs<sup>7</sup> - Lawton-Brody Instrumental Activities of Daily Living - the ability to use a telephone, shopping, food preparation, housekeeping, laundry, mode of transportation, responsibility for own medication**

**Atypical Depression<sup>8</sup> is a form of depression more commonly seen in dementia. Person appears aggressive - either verbally or physically or both, angry, anxious, agitated and/or annoyed.**

**\*Food preparation moves from regular to mechanically chopped to finger foods to pureed. Your doctor will write an order for a speech therapist to evaluate your loved one's ability to chew and swallow food and liquids.**

The Frontotemporal Dementia Symptoms and Staging Tool

FTD-SST

Frontotemporal Dementia Stages and Symptoms	Behavioral & Personality FTD		Communication and Language FTD			Motor and Movement Disorder FTD			
	bvFTD--Behavioral Variant FTD**	Pick's Disease**	PPA--Primary Progressive Aphasia	Semantic Dementia**	Logopengic Variant PPA**	ProSupra Nuclear Palsy--PSP**	Corticobasal Ganglionic Degeneration	FTD with Motor Neuron Disease	ALS with Dementia
Frontotemporal Dementia (FTD) is named because it primarily affects the frontal lobes and the temporal lobes. It is the most common dementia between the ages of 40-60. Sometimes referred to as Frontotemporal Lobar Degeneration, the term FTLN is actually the post mortem name.									
<b>Stage 1 - Normal Aging</b>									
<b>Stage 2 - Typical First Signs and Early Depression Symptoms*</b>									
alterations in alertness									
apathy									
slow withdrawal of emotional responses									
agitation									
bursts of anger									
*signs of disinterest									
*apathy not related to being sad									
*little insight into being sad									
*no self-awareness of changes in mood									
*increased irritability									
*poor concentration									
*lack of attention during interaction									
*sadness or negative mood									
*poor appetite or increased over-eating									
*insomnia or hypersomnia									
***if sleeping more than 14 hours a day, increased risk for infections and atrophied muscles									
<b>Stage 3 - Early Stage Symptoms</b>									
sudden interest in drinking	x								
gradual loss of empathic response	x	x							
decreased insight into behavior	x	x							
shoplifting	x	x							
increase in weight -- 40 lbs in 6 months	x	x							
self-centered behavior	x	x							
uncaring behavior	x	x							
withdrawal from people and activities	x	x							

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increase in spontaneous behavior such as: inappropriate friendliness, speaking candidly, revealing personal information to strangers, becoming angry during routine tasks at job or at home, may appear restless or irritable	x	x	x							
unusual eating habits such as: food fixation (eating too much of a specific food) great craving for sweets, sucking and chewing on objects (pens, combs, spoons, etc.,) hyperoral, shovel food	x	x	x							
ignores social etiquette and boundaries such as: getting too close when speaking to others, tendency to hug, touch, talk in inappropriate or intimate ways (new behaviors for this person)	x	x	x							
displays poor judgement	x	x	x	x						
loss of facial empathy -- masked face	x	x				x				
decreased interest in spouse, children, and family	x	x	x	x	x	x	x	x	x	
very mild short term memory loss	x	x	x	x	x	x	x	x	x	
personal hygiene changes	x	x	x	x	x	x	x	x		
math skills good	x	x	x	x	x	x	x	x	x	
visual ability good	x	x	x	x	x	x		x	x	
mild word finding difficulty (anomia)			x	x	x					
apathetic appearance in whole body			x	x	x			x		
difficulty moving whole body or parts of body						x	x	x	x	
struggles to form words (dysarthia)			x	x	x	x				
trembling limbs						x				
balance problems						x				
tipsy walking gait						x				
exhibits doll's eyes -- an inability to coordinate eye movements or aim the eye quickly up and down						x				
acalculia -- difficulty with math						x	x			

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stiff muscles in motion or when still							X		
clumsy with one side of body (asymmetrical decline)							X		
stiffness in one arm, followed by stiffness in one leg (paratonia)							X		
alien hand movements -- hand pushes away other objects or other hand							X		
magnetic hand -- hand seems drawn to other hand or other people's hands							X		
fasciculations (muscle twitches or flutters)								X	
muscle jerks								X	
muscle cramps								X	
loss of muscle tone								X	X
increase in falls and falls with injury						X	X	X	X
difficulty doing skilled hand movements with one or both hands or arms (apraxia) may result in difficult buttoning shirt, turning book pages, shaving, applying makeup, eating, writing, etc.						X	X	X	X
<b>Stage 4 - Early Middle Stage</b>									
judgement	X	X							
rational thought	X	X							
personality changes	X	X							
impulse control	X	X							
little concern about losses	X	X							
Rapid Eye Movement Disorder (REMD) -- Sleep disturbances	X	X							
trashing, kicking, punching, striking out while sleeping	X	X							
can read and write accurately	X	X		X	X				

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loss or changes in executive function: manage time and attention, switch focus, plan and problem solve, integrate past experience with present	x	x				x			
difficulty expressing words -- nonfluent aphasia			x						
incorrect grammar			x	x					
difficulty naming objects or recognizing familiar words or faces			x	x					
performs ADLs			x	x	x				
slow response to conversation			x	x	x				
slow, weak, slurred, breathy, nasal speech (dysarthia)			x					x	
speaks at a normal rate -- fluent aphasia, but may be difficult to understand				x					
difficulty understanding speech of others				x					
expresses appropriate emotions				x					
slow rate of speech					x				
can repeat short, single words					x				
outbursts of laughing or crying						x			
akinesia -- absence or slowed movement						x	x		
bradykinesia -- lack of spontaneous movement							x		
shortness of breath due to weak muscles								x	x
<b>Stage 5 - Late Middle Stage</b>									
loss of insight									
repetition of behaviors									
memory problems	x	x							
severe cognitive deficits	x	x							
language skills functional late	x	x							
visuospatial skills are still functional	x	x							
great loss of affect -- masked face	x	x	x	x	x	x	x	x	x
increased sleep for day and night	x	x	x	x	x	x	x	x	x

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difficulty swallowing (dysphagia)	x	x	x	x	x	x	x	x	x
urinary incontinence	x	x	x	x	x	x	x	x	x
severe loss of empathy	x	x	x	x	x	x	x	x	x
difficulty adjusting mood to situation	x	x				x	x	x	
emotional ups and downs	x	x					x		
hesitance and slowed speech			x	x	x	x	x		
loss of language fluidity			x	x	x				
mutism			x	x	x				
decreased motor movement skills						x	x	x	x
short term memory loss						x	x	x	x
muscle atrophy						x	x	x	x
struggles to form words (dysarthria)						x	x		
abnormal posturing or frozen movements							x	x	
unaware of one side of body							x		
inability to balance -- sitting or walking							x		
reflexes are over active								x	
<b>Stage 6 - Late Stage Symptoms</b>									
short term/long term memory affected									
may stay in constant motion, walks or moves for hours									
disheveled appearance									
beginning of severe weight loss									
bowel incontinence begins									
can feed self at times									
great loss of language/mutism									
difficult to engage									
appears lost in own world									
loss of total facial affect -- masked									
gait is greatly affected									
combative or aggressive behavior									

The Frontotemporal Dementia Symptoms and Staging Tool

FTD-SST

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difficult to rehab									
disregards eyeglasses, hearing aids, dentures									
<b>Stage 7 - End Stage Symptoms</b>									
unable to sit erect									
unable to walk									
speech is lost									
unable to hold head erect									
extreme risk for falls									
extreme risk for skin breakdown									
semi-alert or asleep most of day									
loss of ability to chew and swallow food properly									
disinterest in food or drink									
extreme weight loss									
total care for all ADLs									
loss of ability to smile -- indicative death is near									
<p>**Some of the FTDs are recognized as a tauopathy disease. Tau is a protein found in the brain's cellular structure. Once tau begins to fold incorrectly in the cells, it disrupts and destroys the brain's ability to function. Alzheimer's Disease is also a tauopathy. This probably helps explain why persons with FTD eventually begin to have many of the same late symptoms as persons with Alzheimer's disease.</p>									

## Actively Dying Assessment Tool (ADAT)

The Final Months	
Significant change in health	Adult Failure to Thrive' diagnosis may be made
Clear and vivid dreams are reported	Withdraw from social/family activities
Talks about missing a loved one	Less interest in food and drink
The Final Weeks	
Less eye contact, more withdrawn	Conversations with people not there
Looking and/or reaching beyond and above	Reports people are telling him/her to "Come on"
Reports seeing/talking to favorite persons	May report strange feelings in limbs
Increased risk of falling	Tires easily
Less interest in food or drink	Voice weakens easily
<i>Don't Be Afraid of Silence</i>	
The Final Days	
May have fever followed by sweats	Pulse and breathing start to slow
Even less interest in food or drink	Kidney and liver function start to slow
General restlessness displayed	Circulation slowing - reposition every 2 hrs
Leg tremors may occur	May begin breathing through the mouth
<i>May Have Sudden Alert Time and Ravenous Hunger</i>	
Have You....	
cried in front of your loved one.	said "I am hurt."
said "I love you."	said "I am lost."
said "I am sad." or "I am angry."	said "I will miss you."
given your loved one permission to go.	talked about death.
The Final Hours	
Fever may come and go	Kidney function very slow, urine becomes dark
Overall calmness, but may pick at covers or PJ's	Mottling - blue/purple color in feet or hands
May not respond to sound or speech	Pressure wounds may open (bed sores)
Eyes may not follow movement around room	Heart rate slows
Exhibits 'doll's eyes'	Respiration slows to < 14 breaths per minute
Trembling/twitching in limbs/sometimes violent	Odor may be present
Gurgling in throat ("Death Rattle")	Apnea begins (stops breathing between breaths)
Bruising from blood clotting system failing	Cheyne-Stokes (Chain-Stokes) breathing
Semi-comatose appearance	Final Breath
Breathing through mouth	May make a "pa" sound or spittle/foam at mouth
Death	
Body appears to shrink almost immediately	Eyes flatten
Body becomes pale, cool and gray	Body may have slight settling movement
Eyes and mouth typically remain open	Body may release urine or stool
Grief After Death, You may...	
feel numb. Be careful driving for several months.	feel agitated and have angry outbursts.
feel physically worse or develop colds.	momentarily forget your loved one is gone.
feel regretful over lost time.	feel forgetful and have trouble concentrating.
feel anger over your loss.	experience a moment of seeing her/him again.
feel physically ill.	have dreams about your loved one.
feel strange sensations in your body.	feel little support. Grieving takes years, not days.

## PHYSICAL SELF-MAINTENANCE SCALE

### (ACTIVITIES OF DAILY LIVING, OR ADLs)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

A. Toilet		
1.	Care for self at toilet completely; no incontinence	1
2.	Needs to be reminded, or needs help in cleaning self, or has rare (weekly at most) accidents	0
3.	Soiling or wetting while asleep more than once a week	0
4.	Soiling or wetting while awake more than once a week	0
5.	No control of bowels or bladder	0
B. Feeding		
1.	Eats without assistance	1
2.	Eats with minor assistance at mealtimes and/or with special preparation of food, or help in cleaning up after meals	0
3.	Feeds self with moderate assistance and is untidy	0
4.	Requires extensive assistance for all meals	0
5.	Does not feed self at all and resists efforts of others to feed him or her	0
C. Dressing		
1.	Dresses, undresses, and selects clothes from own wardrobe	1
2.	Dresses and undresses self, with minor assistance	0
3.	Needs moderate assistance in dressing and selection of clothes.	0
4.	Needs major assistance in dressing, but cooperates with efforts of others to help	0
5.	Completely unable to dress self and resists efforts of others to help	0
D. Grooming (neatness, hair, nails, hands, face, clothing)		
1.	Always neatly dressed, well-groomed, without assistance	1
2.	Grooms self adequately with occasional minor assistance, e.g., with shaving	0
3.	Needs moderate and regular assistance or supervision with grooming	0
4.	Needs total grooming care, but can remain well-groomed after help from others	0
5.	Actively negates all efforts of others to maintain grooming	0
E. Physical Ambulation		
1.	Goes about grounds or city	1
2.	Ambulates within residence on or about one block distant	0
3.	Ambulates with assistance of (check one)	
4.	a ( ) another person, b ( ) railing, c ( ) cane, d ( ) walker, e ( ) wheelchair	0
5.	1. Gets in and out without help. 2. Needs help getting in and out	
6.	Sits unsupported in chair or wheelchair, but cannot propel self without help	0
7.	Bedridden more than half the time	0
F. Bathing		
1.	Bathes self (tub, shower, sponge bath) without help.	1
2.	Bathes self with help getting in and out of tub.	0
3.	Washes face and hands only, but cannot bathe rest of body	0
4.	Does not wash self but is cooperative with those who bathe him or her.	0
5.	Does not try to wash self and resists efforts to keep him or her clean.	0
*****For scoring interpretation and source, see note following the next instrument.		

## INSTRUMENTAL ACTIVITIES OF DAILY LIVING SCALE (IADLs)

In each category, circle the item that most closely describes the person's highest level of functioning and record the score assigned to that level (either 1 or 0) in the blank at the beginning of the category.

<b>A.</b>	<b>Ability to Use Telephone</b>	
1.	Operates telephone on own initiative; looks up and dials numbers.	1
2.	Dials a few well-known numbers.	1
3.	Answers telephone but does not dial.	1
4.	Does not use telephone at all.	0
<b>B.</b>	<b>Shopping</b>	
1.	Takes care of all shopping needs independently.	1
2.	Shops independently for small purchases.	0
3.	Needs to be accompanied on any shopping trip.	0
4.	Completely unable to shop.	0
<b>C.</b>	<b>Food Preparation</b>	
1.	Plans, prepares, and serves adequate meals independently.	1
2.	Prepares adequate meals if supplied with ingredients.	0
3.	Heats and serves prepared meals or prepares meals but does not maintain adequate diet.	0
4.	Needs to have meals prepared and served.	0
<b>D.</b>	<b>Housekeeping</b>	
1.	Maintains house alone or with occasional assistance (e.g., heavy-work domestic help).	1
2.	Performs light daily tasks such as dishwashing, bed making.	1
3.	Performs light daily tasks but cannot maintain acceptable level of cleanliness.	1
4.	Needs help with all home maintenance tasks.	1
5.	Does not participate in any housekeeping tasks.	0
<b>E.</b>	<b>Laundry</b>	
1.	Does personal laundry completely.	1
2.	Launders small items; rinses socks, stockings, etc.	1
3.	All laundry must be done by others.	0
<b>F.</b>	<b>Mode of Transportation</b>	
1.	Travels independently on public transportation or drives own car.	1
2.	Arranges own travel via taxi but does not otherwise use public transportation.	1
3.	Travels on public transportation when assisted or accompanied by another.	1
4.	Travel limited to taxi or automobile with assistance of another.	0
5.	Does not travel at all.	0
<b>G.</b>	<b>Responsibility for own Medication</b>	
1.	Is responsible for taking medication in correct dosages at correct time.	1
2.	Takes responsibility if medication is prepared in advance in separate dosages.	1
3.	Is not capable of dispensing own medication.	0
<b>E.</b>	<b>Ability to Handle Finances</b>	
1.	Manages financial matters independently (budgets, writes checks, pays rent and bills, goes to bank); collects and keeps track of income	1
2.	Manages day-to-day purchases, but needs help with banking, major purchase	1
3.	Incapable of handling money	0
<b>Score:</b>		___

**Scoring Interpretation:** For ADLs, the total score ranges from 0 to 6, and for IADLs, from 0 to 8. In some categories, only the highest level of function receives a 1; in others, two or more levels have scores of 1 because each describes competence that represents some minimal level of function.

These screens are useful for indicating specifically how a person is performing at the present time. When they are also used over time, they serve as documentation of a person's functional improvement or deterioration.