

Understanding and Caring for a Person with Dementia

Christi Clark, ALA, CMIS

Education and Outreach Coordinator

- Dementia isn't a specific disease. Instead, dementia describes a group of symptoms affecting thinking, language and social abilities severely enough to interfere with daily functioning.

Progressive, Degenerative Disease

Instrumental Activities of Daily Living

(activities necessary for living independently.)

- Driving
- Shopping
- Meal Prep
- Money Management
- Medication Management

Activities of Daily living (6 basic)

- Eating
- Bathing
- Dressing
- Toileting
- Bowel and Bladder Maintenance
- Transferring and Ambulating

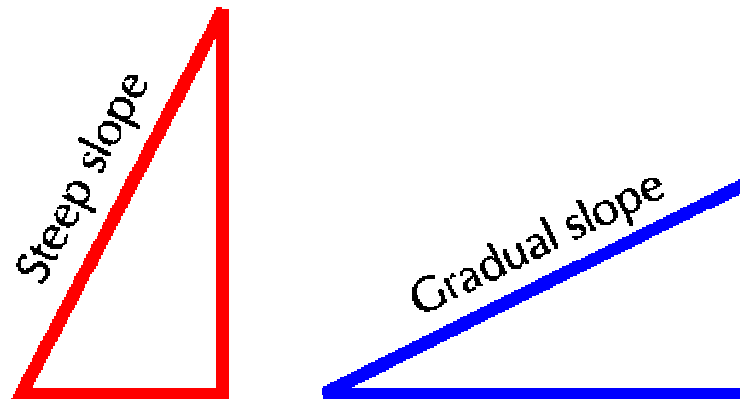
Common Behaviors in all Dementias

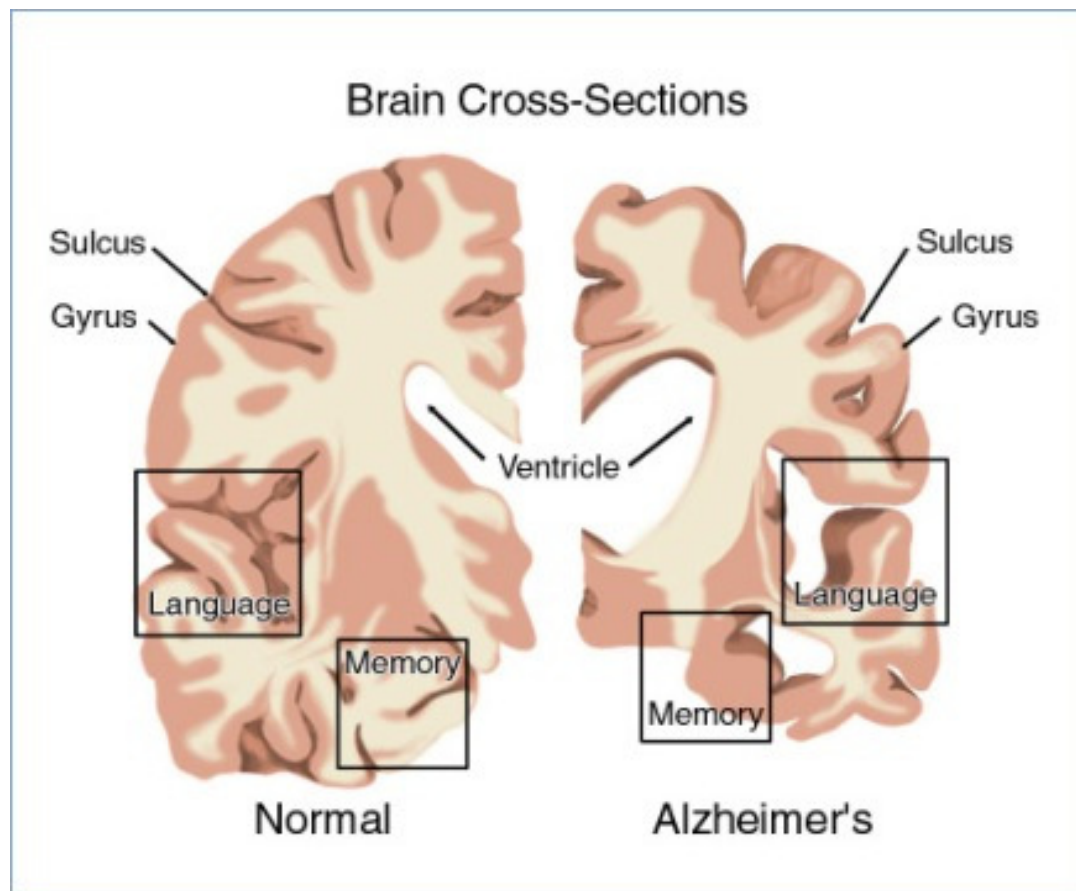
- Progressive memory loss
- Language problems
- Impaired abstract thinking (date, numbers, time)
- Poor judgment and reasoning
- Difficulty with impulse control
- Poor coping skills. Becomes frustrated easily
- Loss of initiative
- Becomes easily overwhelmed
- Gradual loss of ability to care for self

- Alzheimer's Disease (AD)
- Vascular Dementia
- Lewy Body Dementia (LBD)
- Frontotemporal Degeneration (FTD)
- Parkinson's Disease
- Creutzfeldt-Jakob Disease (CJD)
- Normal Pressure Hydrocephalus (NPH)
- Huntington's Disease (HD)
- Wernicke-Korsakoff Syndrome (WKS)
- Mixed Dementia

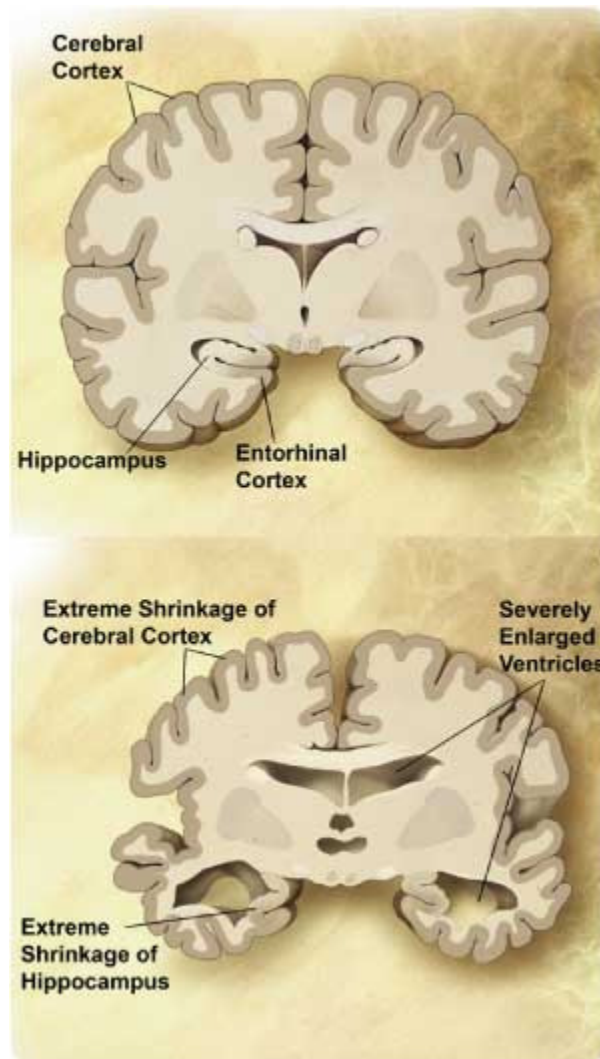
Most Common Form of Dementia:

Progressive, degenerative disease of the brain which leads to memory impairment, loss of ADL's, behavioral issues, and ultimately death.



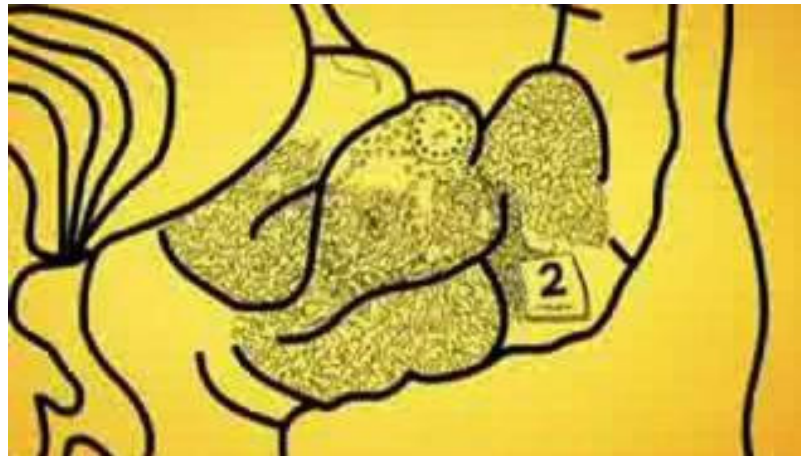


www.ahaf.org



www.elements4health.com

What is Alzheimer's Disease Video

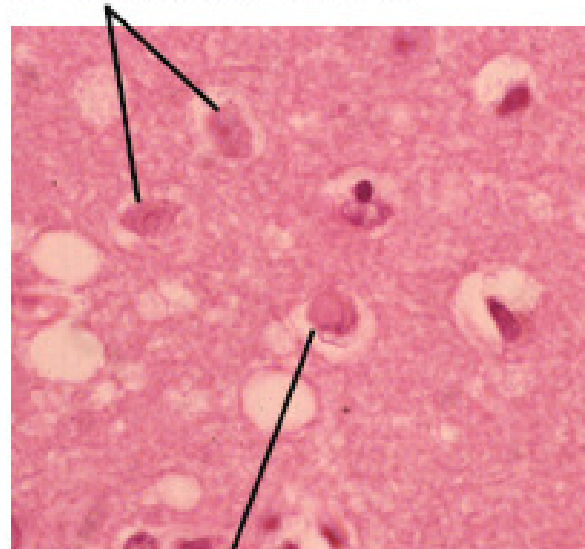


- Occurs because of brain injuries such as microscopic bleeding and blood vessel blockage. The location, number and size of the brain injury determines how the individual's thinking and physical functioning are affected.



- Abnormal clumping of a protein called alpha-synuclein that is deposited in the cortex of the brain.

Nerve cells in cerebral cortex



Cortical Lewy body
(Haematoxylin and eosin stain)

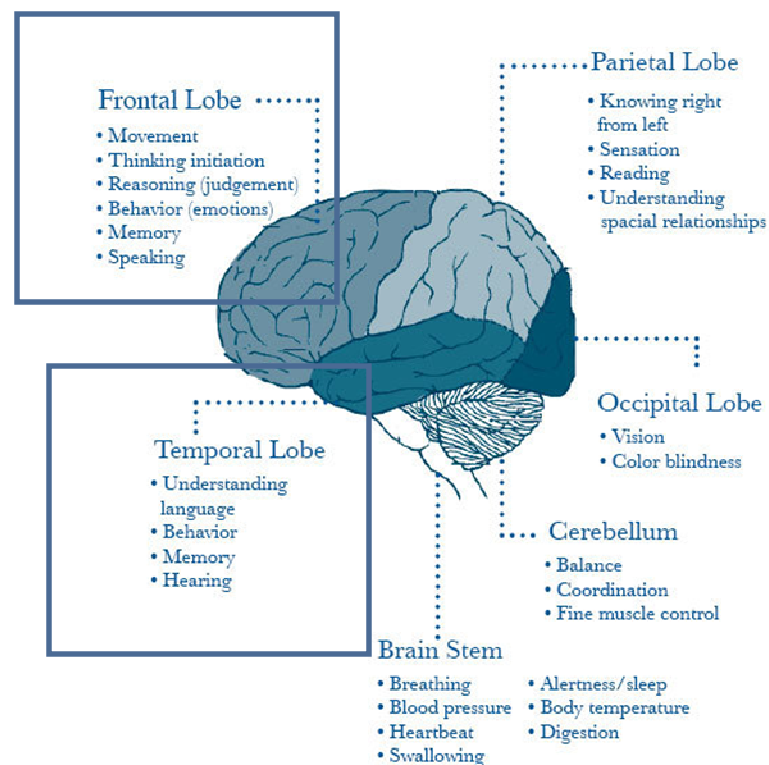
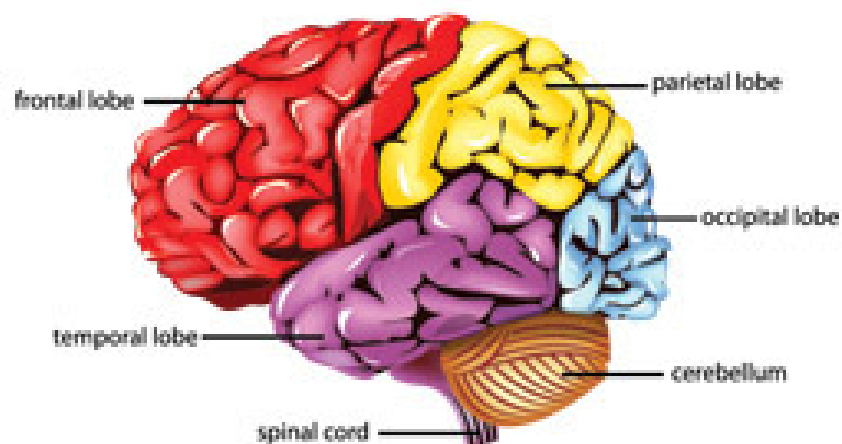
- Similar to Alzheimer's and these individuals have initial or early symptoms such as sleep disturbances, well-formed visual hallucinations, and muscle rigidity or other parkinsonian movement features.
- Fluctuating Cognition

FTD

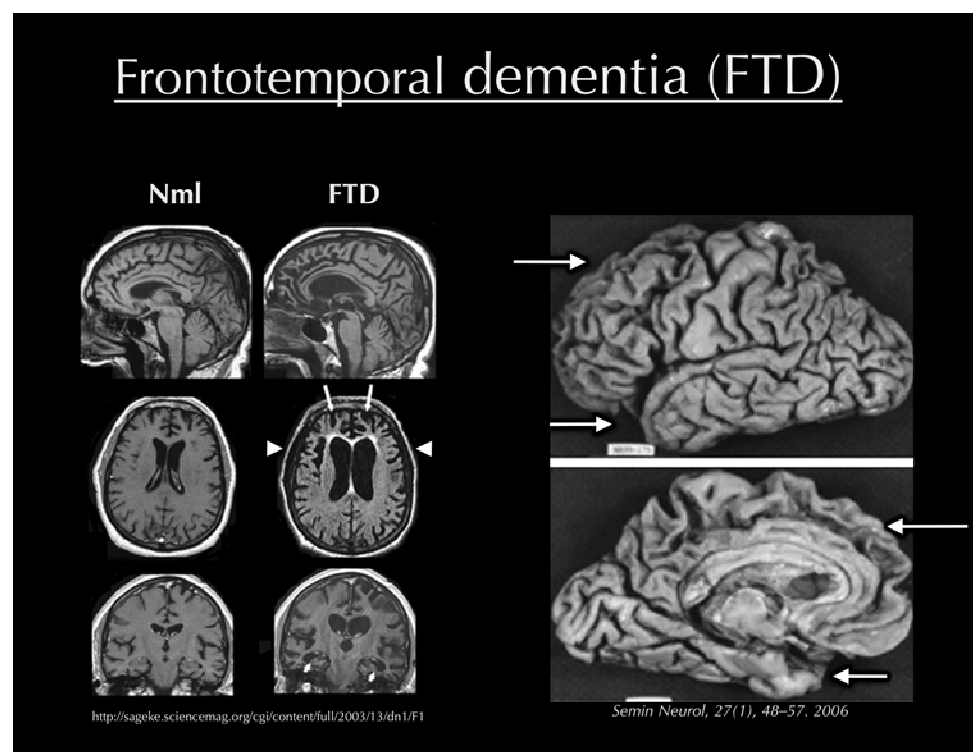
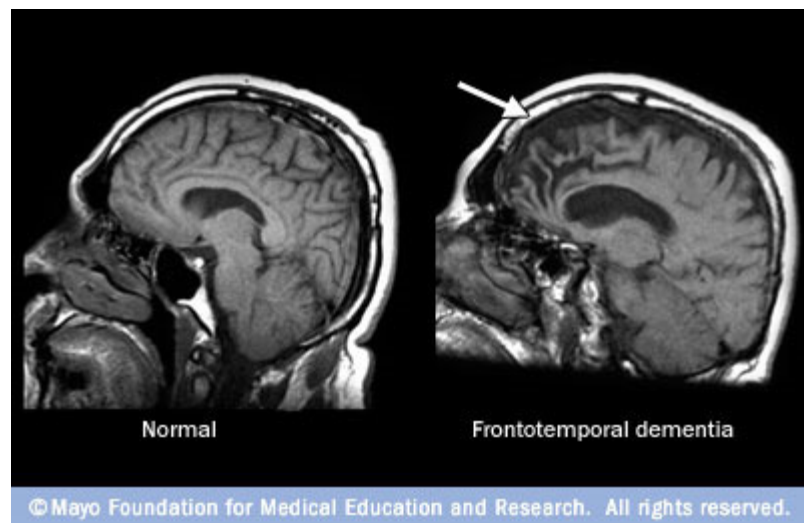
- Frontotemporal Degeneration
 - A disease process that results in progressive damage to the anterior temporal and/or frontal lobes of the brain.

Lobes of the Brain

Parts of the Human Brain



FTD – Brain Scan



FTD Hallmarks

- Gradual, progressive decline in behavior and/or language that often has a relatively young age at onset (mid-50s to 60s), but has been seen as early as 21 and as late as 80 years.

FTD Hallmarks

- As the disease progresses, it becomes increasingly difficult to:
 - plan or organize activities
 - behave appropriately in social or work settings
 - interact with others
 - care for oneself, resulting in increasing dependency

FTD vs Alzheimer's Disease

- Brain imaging helps with differential diagnosis
- Both characterized by atrophy of the brain and gradual progressive loss of brain function
- FTD is primarily a disease of behavior and language dysfunction
- AD is loss of memory

Behavioral

- Typically Seen As:

- Changes in personality, emotional blunting or loss of empathy that result in increasingly inappropriate social behavior
- Become less involved in routine daily activities and withdraw emotionally from others
- Disinhibited when in public or with strangers

Behavioral

- Unusual Behaviors:

- Swearing, overeating (especially carbs), drinking, impulsivity, shoplifting, hypersexual behavior and deterioration in personal hygiene habits.

- Decreasing Self-Awareness:

- Little insight into appropriateness of behavior
- Little to no concern for its effect on others

Behavioral

- Repetitive Behaviors:

- May display repetitive, stereotyped behaviors, such as hand clapping, humming the same song over and over, walking to the same place every day.

The person with dementia...

- Has difficulty keeping up with conversation
- May not understand your words
- Has limited attention span
- May have word finding problems
- May be increasingly emotional

Six steps to approaching the person with dementia

- Approach from the front
- Establish eye contact
- Call the person by name
- Get down to eye level-out of swinging range
- Let them initiate touch
- Provide one step at a time direction

Initiating Conversation

- Speak slowly & clearly.
- State one request at a time
- Always explain what you are going to do
- Use lots of hand gestures
- Watch the person closely for his reaction

Understanding their world

- Don't ask questions that rely on memory
- **Avoid arguing or correcting**
- Use humor, but avoid sarcasm
- Encourage reminiscing
- Avoid pronouns (it, she, they..)
- Use simple explanations. Details often overwhelm and cause anxiety

Strategies

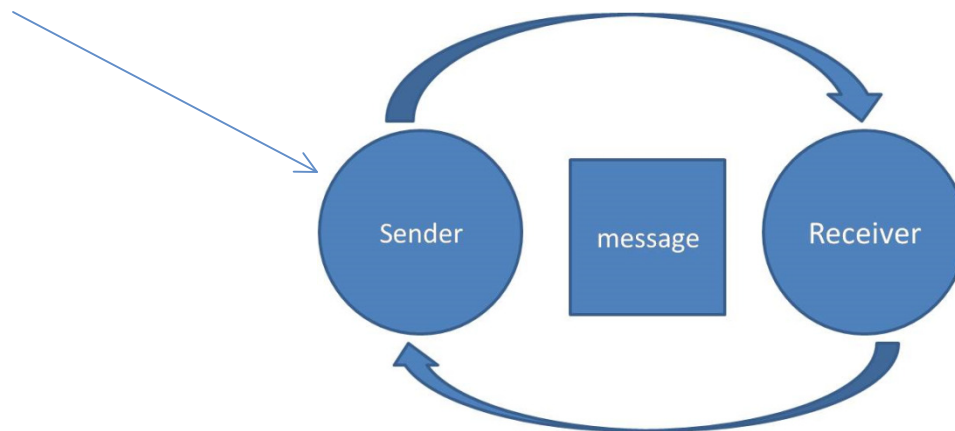
- Offer guided choices
- Validate emotions rather than facts
- Avoid over-stimulation
- Model appropriate behavior
- Fill in lost words
- Use events to measure time
- If you sense anxiety or agitation - back off

What They Can Retain

- People with dementia retain the ability to understand nonverbal communication long after their understanding of words is lost.
- This is the type of communication caregivers must rely on.

Nonverbal communication: tone, volume, body movement, facial expressions, gestures

In dementia caregiving the burden of successful communication is on the person sending the message (the caregiver) not on the receiver (the Person)



- The progressive loss of the ability to understand and to be understood can lead to frustration, isolation and worsening of normal behavior changes

Behavior is a form of communication

- The progressive loss of the ability to understand and to be understood can lead to frustration, isolation and worsening of normal behavior changes

Behavior is a form of communication

- As language declines, behavior and body language become the most effective means of communication for the person with dementia
- While the ability to verbally communicate or understand declines, real emotions remain.
- If we can understand and respond to these emotions, we can dramatically minimize behavior challenges

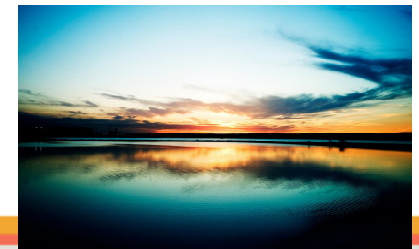
- Behavior is Communication
 - Our job is to figure out the meaning...
 - Why do they do that?
 - What are they trying to say?
 - Interpret behavior in the context of one's life experience...

- Behavioral Changes with Dementia
 - Slower Reaction Time
 - Reluctance to try new things
 - Easily provoked over little things
 - Mood swings
 - Uncharacteristic suspicion or jealousy
 - Hoarding, rummaging, pacing
 - Socially inappropriate behavior
 - Avoid situations where failure occurs
 - Delusions, Hallucinations
 - Inability to dress properly or manage self care

- We need to look for the emotions behind the behaviors
- We have to validate their emotions
- Don't say NO and never argue (you will never win)

- Ask ourselves the 6 W's:
 - What is happening?
 - Why is the behavior happening?
 - Who is involved?
 - Where does the behavior happen?
 - When does the behavior usually happen?
 - What next?

- Physiologic causes
 - hypothalamus- disruption of normal circadian rhythm (24 hour sleep wake)
 - cognitive and sensory impairments
 - fatigue
- Environmental causes
 - loss of light, staffing changes, fewer activities



- Routines are important
- Exercise
- Minimize daytime napping-especially late afternoon
- Avoid stimulants-caffeine
- Exposure to daytime light
- Minimize unnecessary noise and distractions that may be contributing to sensory overload

- Symptoms can occur at any disease stage
- Symptoms tend to worsen or become more severe as the disease progresses and are often most pronounced in the moderate and severe disease stages of Alzheimer's disease
- **Significant cause of “caregiver burnout”. perhaps most devastating symptom for families and caregivers**
- Economic Toll- symptoms lead to earlier placement in long term care facility, contribute to financial loss for society, patients and families

- Assess for patterns- has the symptom gradually gotten worse? was it noticed suddenly? does it tend to occur at any particular time of day or is it almost always present ?
- Report and discuss behaviors (both disruptive and positive) to coworkers and during case conferences.
- **It's a team approach and communication amongst all team members is essential and will improve care and quality of life for patients**
- The Team- caregivers, clinicians, doctors, patients, and families

- Recognize that the behaviors are not willful
- Never confront- the patient is always right! the world is as they see it
- Distract and redirect
- Remove the source of irritation
- Recognize the signs of impending disturbance
- Simplify Instructions, provide one step directions
- Be attentive to functional limitations and strengths.

- Encourage engagement in activities that are enjoyable but not stress provoking
- Be a detective-watch body language, note patterns, look for possible environmental triggers
- Help to establish routine
- Simplify
- Provide encouragement
- **Your Safety Matters-** remove yourself and other residents and seek help if threatening and potentially dangerous behaviors are occurring

- Minimal effectiveness- may not exert effect when symptoms are occurring and effects may linger much longer than desired
- Often not recommended over nonpharmacologic management- the power of the human touch, environment, recognizing the patient's world
- Notable risks- increased confusion, memory loss, delirium, falls, drug interactions, side effects



- Basic principles- start low and go slow, make only one medication change at a time, less is often best, even nonprescription medications can have dangerous side effects.
- You can make a difference- report changes- you may know most about a residents behavior or symptoms.

- Alzheimer's Association: www.alz.org
- Lewy Body Association: www.lbda.org
- The Association for FTD: www.theaftd.org
- <http://brain.northwestern.edu/pdfs/Disease%20Summaries/ppa.pdf>
- <http://memory.ucsf.edu/education/diseases/ppa>
- <http://www.mayoclinic.org/diseases-conditions/frontotemporal-dementia/care-at-mayo-clinic/research/con-20023876>
- <http://www.ftd-boston.org/>
- Dr. Cynthia Sullivan: Where the Heck Did I Put My Keys; When Memory Fails
- Christi Clark: Communication Techniques & Understanding The Person With Dementia
- Brigid Reynolds: Management of Behavioral Symptoms in Dementia

Things that could be exacerbating the behaviors:

- UTI
- Dehydration
- Lack of Sleep
- Pain
- Bowel Blockage/Constipation

*Most Importantly,
Know the person with dementia is doing the
best they can.*

Thank you!

Christi Clark

Phone: 703.204.4664

Email: Christi.clark@insightmcc.org