

Understanding Behaviors in Dementia

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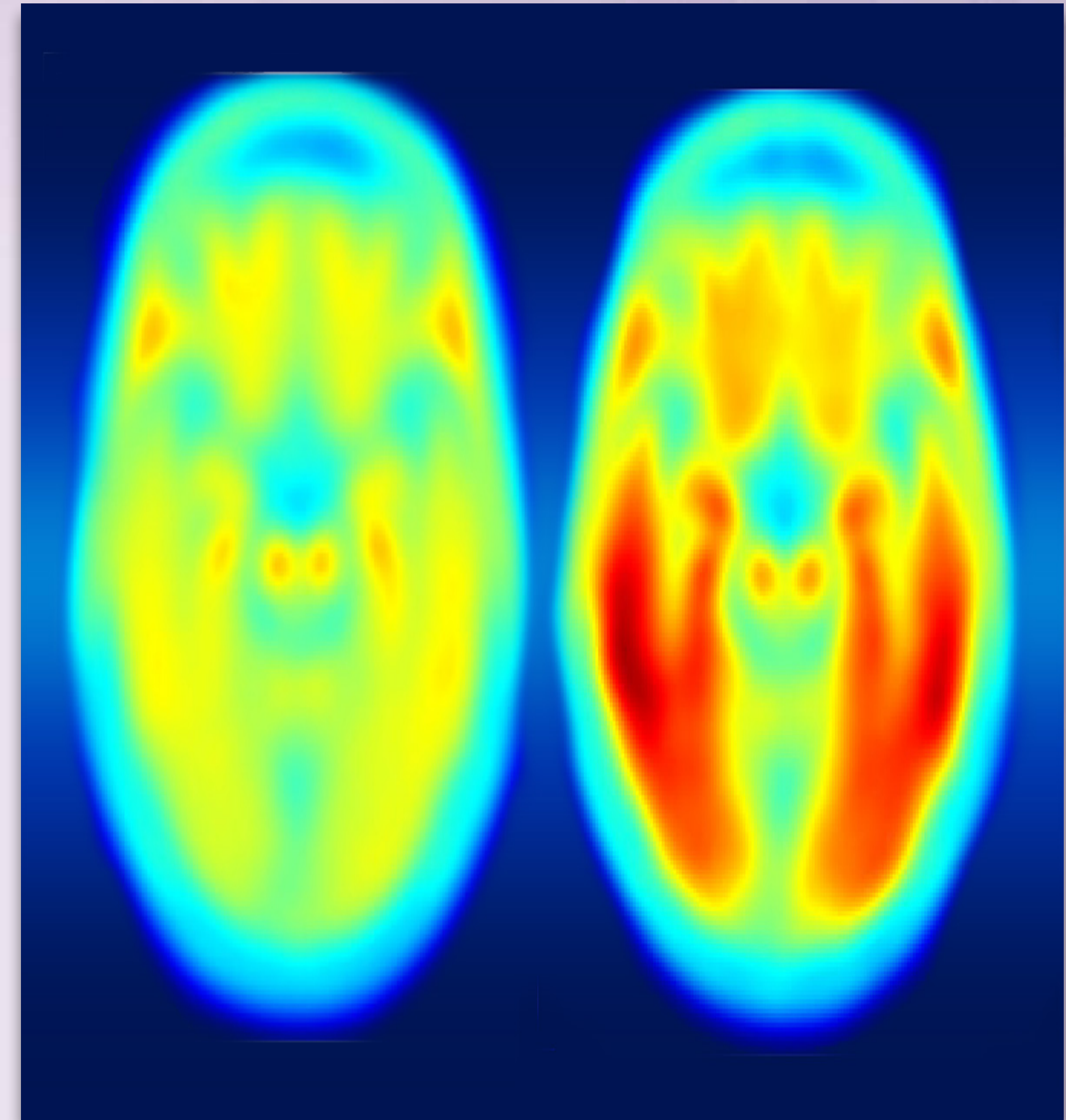


Characteristics of Alzheimer's dementia

Alzheimer's dementia, is characterized by noticeable memory, thinking or behavioral symptoms that impair a person's ability to function in daily life, combined with biomarker evidence of Alzheimer's-related brain changes.

Behavior and language difficulties are a common symptom in people with dementia and may help identify the stage in which the person is in during the progression.

Approximately 30% to 90% of patients with dementia suffer from behavioral disorders and language difficulties.



Behavioral disorders

Alzheimer's disease and related dementia's is NOT a normal part of aging.

Psychological symptoms and behavioral abnormalities are common and prominent characteristics of dementia. These symptoms may include:

Depression - is often the most common and first, symptom/syndrome of AD, ranging from 20% to 60% in most epidemiological studies, and 10% to 30% meet criteria for a major depressive disorder.

Anxiety psychosis - occurs in 50% to 80% of patients with AD. There is evidence that, anxiety is associated with loss of serotonergic neurons in AD.

Agitation - common phenomenon in dementia with various causes, such as undiagnosed medical problems or pain, environmental or social drug side effects, sleep disturbances, delirium, and depression

Aggression - physical aggressiveness is one of the most serious and challenging behavioral disturbances in dementia with a number of adverse consequences, including injury, chronic distress, and patient abuse

Sleep disturbances - in AD patients are characterized by fragmented sleep or disruption in the day-night sleep cycle and worsen as dementia progresses



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Behavioral disorders

- Behavioral disorders, such as verbal or physical aggression, loss of bladder control, and wandering, are a major source of caregiver burden contributor to be admitted long-term care
- The social and psychological skills of the caregivers, as well as the presence and competence of the social support, may help determine where the person with dementia who exhibits behavioral problems can live at
- In the past, programs have primarily focused on the early detection and management of cognitive deficits, whereas behavioral disturbances have been neglected
- Now, treatment of behavioral problems can improve the quality of life of the patient and their caregiver and may help avoid premature being admitted to long-term care



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Relationship between disturbances and dementia

- The relationship between these disturbances and the severity of dementia has NOT been clarified
- There is some evidence that some symptoms such as depression and anxiety are more common during slight to moderate stages, whereas others, such as, behavioral problems like aggression, seem to occur more in advanced dementia
- In more severe stages, advanced cognitive impairment, and behavioral dysfunctions may become less problematic
- There is also studies that have shown different behavioral disturbances in patients with different types of dementia.



Personality changes in Alzheimer's dementia

- Personality changes are most common in AD and affect approximately 70% of patients, including disinterest, in environment or inappropriate social behavior.
- In contrast to the negative impact, of deficient, social support, a positive atmosphere may affect the patient's physical and psychological well-being
- Relatives and caregivers often have difficulties in accepting the patient's loss of established roles and functions in partnerships or families.
- The caregiver's skills handling these problems have a high impact, on the development of behavioral disturbances.



Video Clip 1



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Cause of behavioral symptoms in dementia

- The behavioral symptoms seen in dementia are not due to one factor .They are often multifactorial and related to the severity of the disease.
- Loss of neurons has been considered as a major pathophysiological hallmark in AD.
- Neuropathological alterations and changes in brain metabolism in the mesotemporal and frontal brain areas appear to be related to psychotic symptoms.



Assessment of behavioral and psychological symptoms

The basis of the diagnosis of behavioral and psychological symptoms of dementia (BPSD) comprises a clinical interview, direct observation of the patient with dementia, and/or a proxy report, from a caregiver or other observers.



Communication Difficulties

- Language performance is both influenced by normal aging and by development of dementia.
- Language difficulties are a major problem for most patients with dementia, especially as the disease progresses and goes from moderate to severe stage.
- Early signs that communication of a person with dementia is affected are the difficulties of word finding, especially when naming people or objects.
- As the disease progresses, it leads to forgetting names of family members, friends, confusion about family relationships, and often affected persons no longer recognize members of their family.



Behavior and Communication

- Behavior and communication for people with dementia and their caregivers can be very challenging.
- It is often necessary to adapt to the way of behavior and communication to avoid stress and negative feelings in a person with dementia.
- As the disease-causing dementia progresses, behavior and communication problems are increasing as well.
- Oftentimes, family caregivers and staff are in situations where their communicative behavior (verbal, but also nonverbal) needs to show support, compassion, care, and desire to help.



Video Clip 2



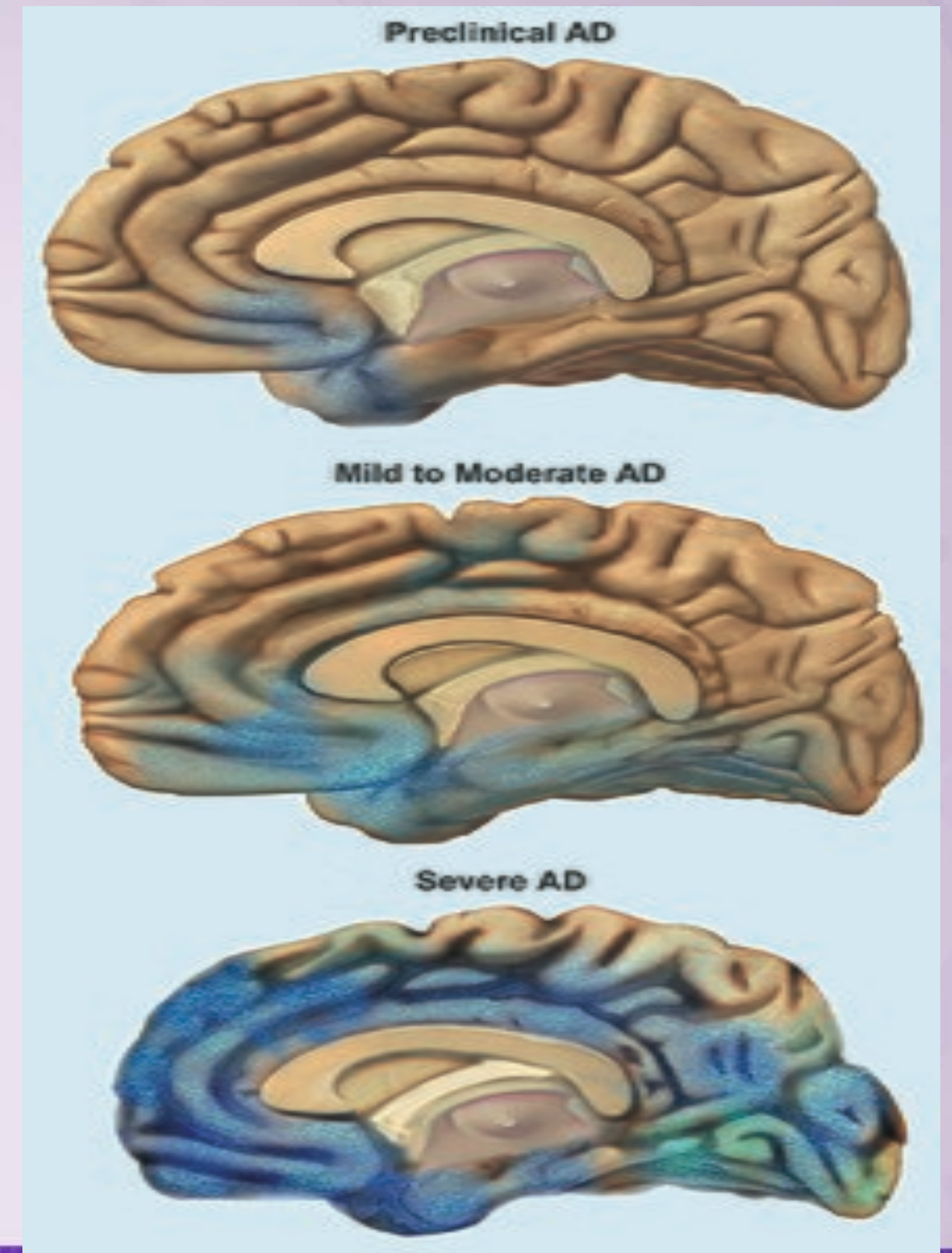
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Stages of Alzheimer's Dementia

Mild Alzheimer's Dementia - In the mild stage of Alzheimer's dementia, most people are able to function independently in many areas but are likely to require assistance with some activities to maximize independence and remain safe.

Moderate Alzheimer's Dementia - In the moderate stage of Alzheimer's dementia, which is often the longest stage, individuals may have difficulties communicating and performing routine tasks, including activities of daily living (such as bathing and dressing); become incontinent at times; and start having personality and behavioral changes, including suspiciousness and agitation.

Severe Alzheimer's Dementia - In the severe stage of Alzheimer's dementia, individuals need help with activities of daily living and are likely to require around-the-clock care.



Alzheimer's Association. 2021 Alzheimer's Disease Facts and Figures. Alzheimer's Dement 2021;17(3)

Dementia's Impact by Stage



Early

- Word finding
- Substitution
- Comprehension – more trouble with reading or directions
- Repetition
- Talking less



Moderate

- Decreased conversation
- Increasing repetition
- Less able to make needs known
- Comprehension increasingly impaired
- Revert to native/primary language



Advanced

- Speaks less
- “Word salad”
- Relies on gestures/ non-verbal communication



Communication through Behavior

Communication expresses our thoughts, wishes and feelings.

EARLY

- Frustration
- Withdrawal
- Paranoia
- Repetition

MODERATE

- Resistance
- Impulsivity
- Delusions
- Restlessness
- Inability to describe needs/
concerns

ADVANCED

- Behavior becomes primary communication



Common Communication Challenges to Avoid

- Arguing
 - *No one ever won an argument with a person with Alzheimer's disease!*
- Explaining/Reasoning
 - *"You know you can't: ...drive...stay alone anymore"*
- Correcting
 - *"That's not the how it happened!"*
- Saying
 - *"Don't you remember?"*
- Unwanted reminders
 - *"I've told you three times already!"*
- Giving too much information
 - *"After breakfast, you need a shower then we are going shopping and visit our friends...."*
- Preannouncing upcoming events
 - *"You have an appointment at the Memory Clinic in two weeks"*
- Speaking for the person/speaking down to the person
 - *"I may have Alzheimer's disease but: I am not stupid... Not a child.... Still an adult...."*



Universal Principles for Communication

Set/maintain a positive tone

- Watch your body language!
- Take a breath if you are feeling frustrated, overwhelmed, fatigued
- Maintain a sense of humor

Always respond to emotion **first** and provide reassurance

Make sure your person is getting **what you are saying**

- Watch his/her reaction (or lack of!)
- Try to simplify/repeat and if that does not work use gestures



Be sure to have your person's **attention**

- Use touch as appropriate

Minimize background noise or **other distracters**

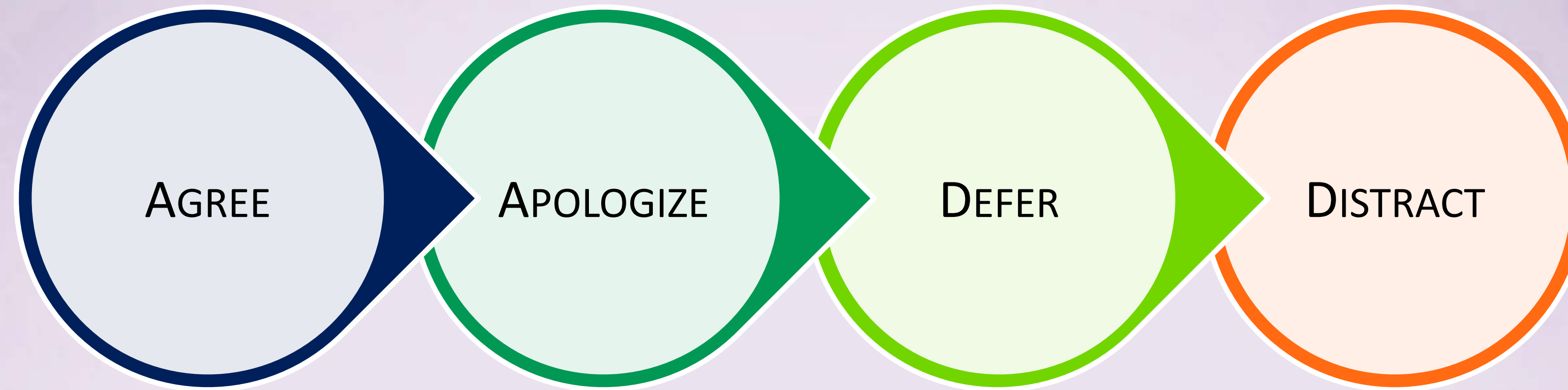
- Shut off/turn down TV, radio
- Draw the curtains or pull up the door
- When out or in a group setting, try more 1:1 discussion, move off to the side to eliminate noise

Keep your message simple and to **the point**

- Give instructions (one step at a time) as needed
- On bad days, talk less



Communication Strategy #1: DON'T ARGUE!



- “I can see how you think that!”

- Respond to the emotion
- “Oh, I’m sorry, I didn’t understand it that way.”
- “I see I upset you. I was wrong.”

- “Why, that’s a great idea, but first I must...”

- “I like what you are wearing?”
- (clothes, jewelry, etc.)
- “Offer something to eat or engage in an activity



Strategy #2: Don't Explain/Reason/Convince/Coerce!

Accept

- Your person is doing their best
- The ability to use logic is gone

Simplify

- Keep your message simple and vague
- Limit the details
- "I'm on it" "Everything is under control"

Avoid

- "Yes/No" questions if you don't want to hear "No!"
- "Don't you remember?" – The person has memory loss and can't remember

Be positively directive

- Hold your hand out and say, "I'd love for you to come with me!"
- Give directions in a nice way.



Strategy #3: Don't Rush!



- How can you help your person? Ask him/her what would be helpful
- Take cues on when to step in

- Blank appearances, ignoring, glassy-eyed may mean he/she is not understanding language

- Pictures, words, starting/filling in the steps are all effective ways to assist when communication fails



Strategy #4: Therapeutic Fibbing

This technique is not about lying, deceit or disrespect – it is about getting along and avoiding confrontation

It might not work for everyone and will need some practice

Try this:

Communicate in more general terms

- Be vague or omit details that may cause upset
- “You know Dad, he’s always busy. He’ll be here soon!”

Twist/change the facts

- “We can’t go today – it is a holiday...closed....too late...”
- “I know you want to go to work today but it is the weekend”



Behaviors: Look for the trigger

- Behaviors typically have a cause (trigger)
- Ask yourself:
 - Why did this happen?
 - What has changed?
 - What are they trying to tell me?
- Once identified, our role is to eliminate/modify the trigger, or help our person navigate more effectively



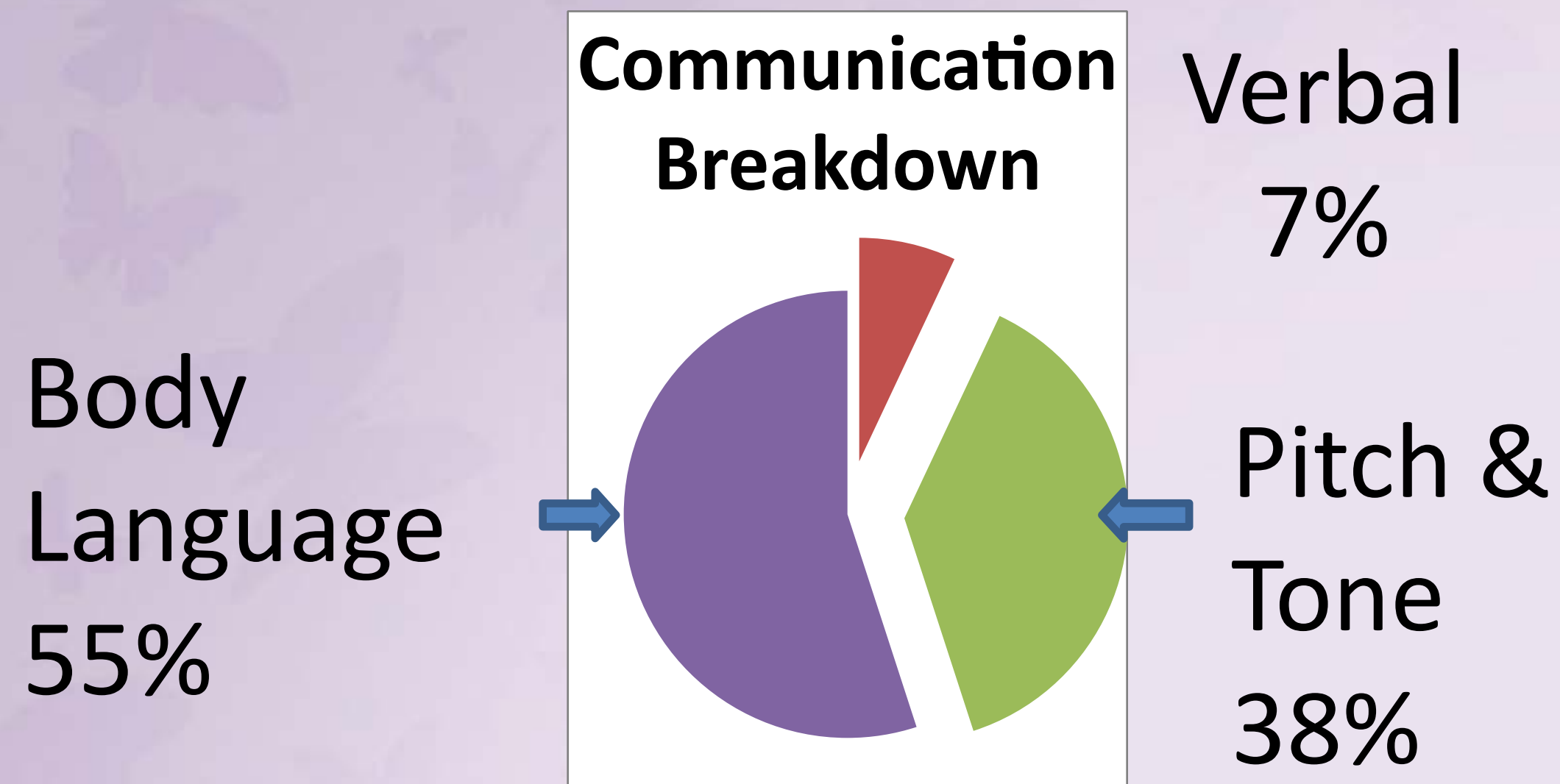
Typical triggers:



- Change in Routine
- Providing personal care
 - Puts caregivers in a potentially intrusive position. Person can feel their privacy is being invaded.
- Pain
 - May not be able to identify the pain sensation, so it is expressed through actions.
- Environment
 - *Too much, or too little* stimulation can cause problems, as well as a *change* in environment.
- Unmet Need
 - Being tired, hungry, thirsty, having to go to the bathroom, or otherwise uncomfortable may not be expressed verbally



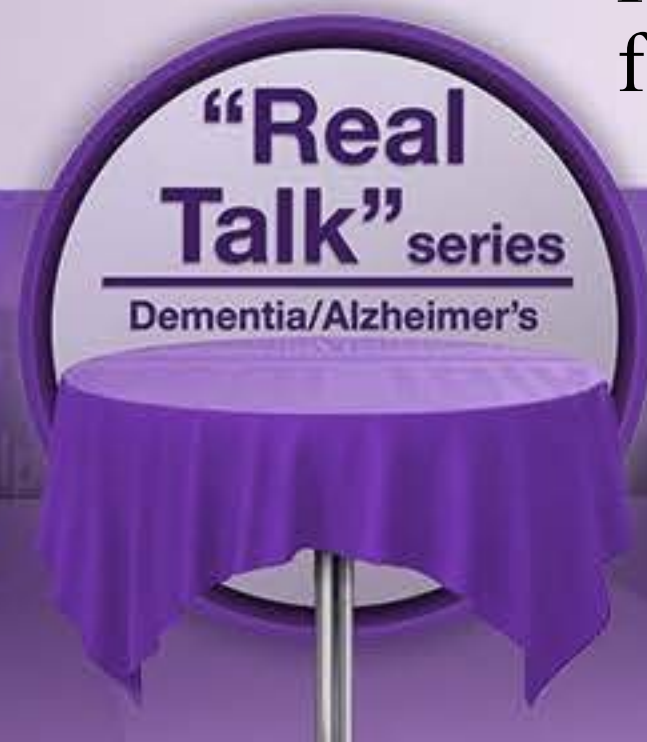
Special Issue: When Words Fail



- Remember that 90% of communication is non-verbal
- There will likely be windows of clarity – savor the moment

Try this:

- Approach your person from the front
- Identify yourself
- Use touch as a meaningful form of communication
- Keep your words simple
- Read familiar passages, look at favorite pictures, listen/sing to favorite songs, say familiar prayers, enjoy favorite treats together, provide words of affirmation and affection, reminisce your favorite memories of



When to contact the medical provider

- Often a shift in our interventions can minimize most of the behaviors discussed
- If there is an abrupt change in behavior, mental status or function– contact the medical provider
 - If you suspect pain or infection
 - If a chronic condition may be acting up
- If you suspect depression
- If there are hallucinations, delusions or paranoia
- If there is violence
- If everything you have tried has not worked



Video Clip 3



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Summary

- There are significant changes in communication throughout dementia
- We must learn new ways to communicate and avoid frustration and arguments
- All new skills require practice and time
- Despite your best efforts, you will have times when you feel impatient or upset
- Practice forgiveness of self and focus on your successes
- Share the lessons you learn with others
- Give yourself credit for learning new skills under very difficult circumstances



Being Dementia Friendly

- When dealing with a loved one with dementia, remember the person, not the disease
- When dealing with the challenging behavior, remember it's the disease not the person



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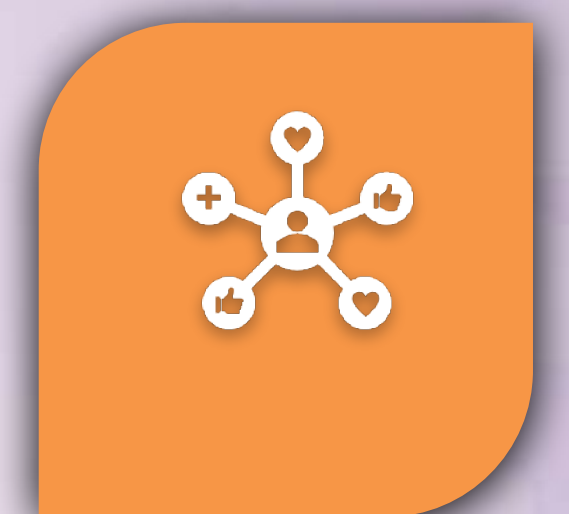
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Quality of Life Mental Stimulation BRAIN Quality of Life Mental Stimulation BRAIN Quality of Life Mental Stimulation BRAIN
Love Dementia Care Confusion Love Dementia Care Confusion Love Dementia Care Confusion
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Angela S. Johnson

*"In memory of my two grandmothers:
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