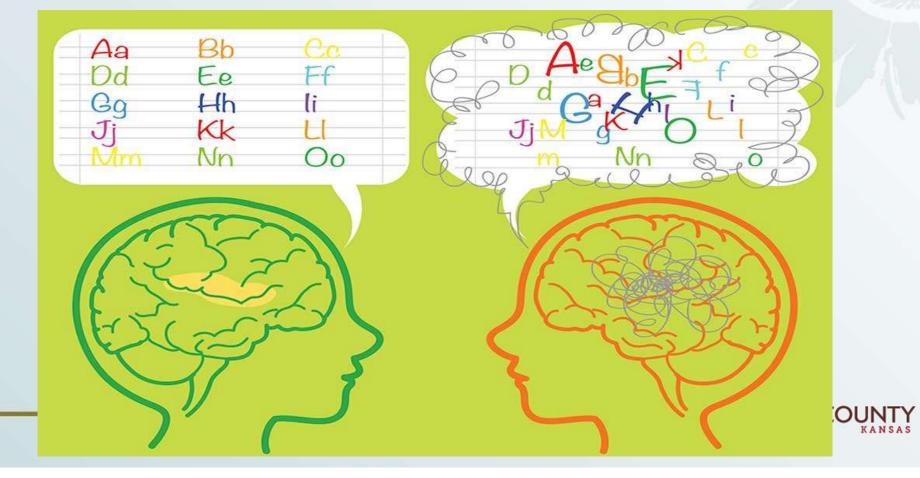
Dementia Related Behavior and the 4 Golden Rules

Heather Brown, MS, Training and Development Specialist Johnson County Developmental Supports



Dementia is an Information Processing Problem



The information you take in and process also determines your behavior



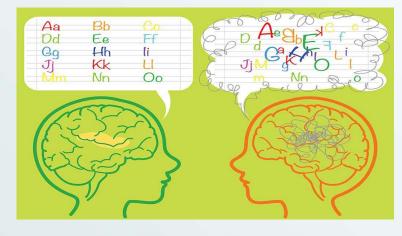
How should you behave here?



KANSAS

Dementia is an Information Processing Problem

- Sensory Issues- with all 5!
- Vestibular Sense (balance)
- Proprioceptive Sense
- Loss of time, space, location





Proprioceptive Sense

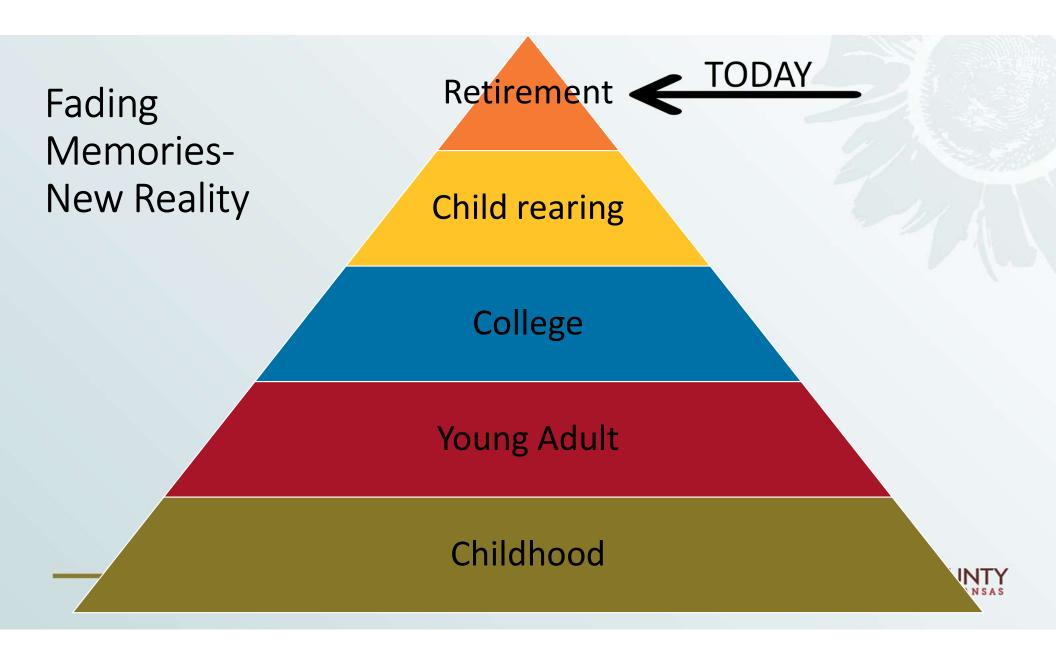


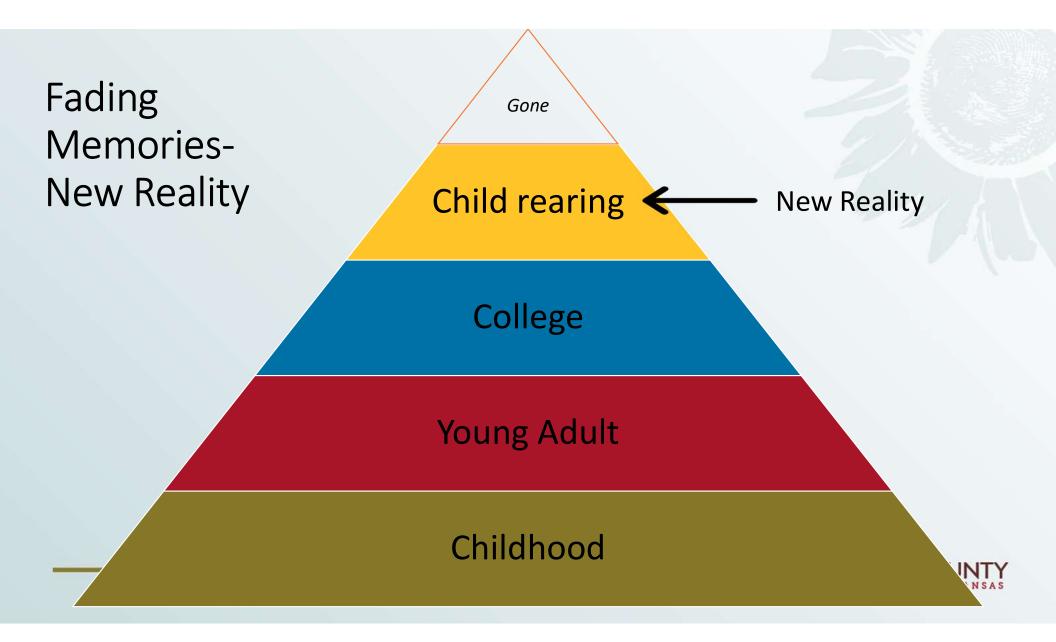


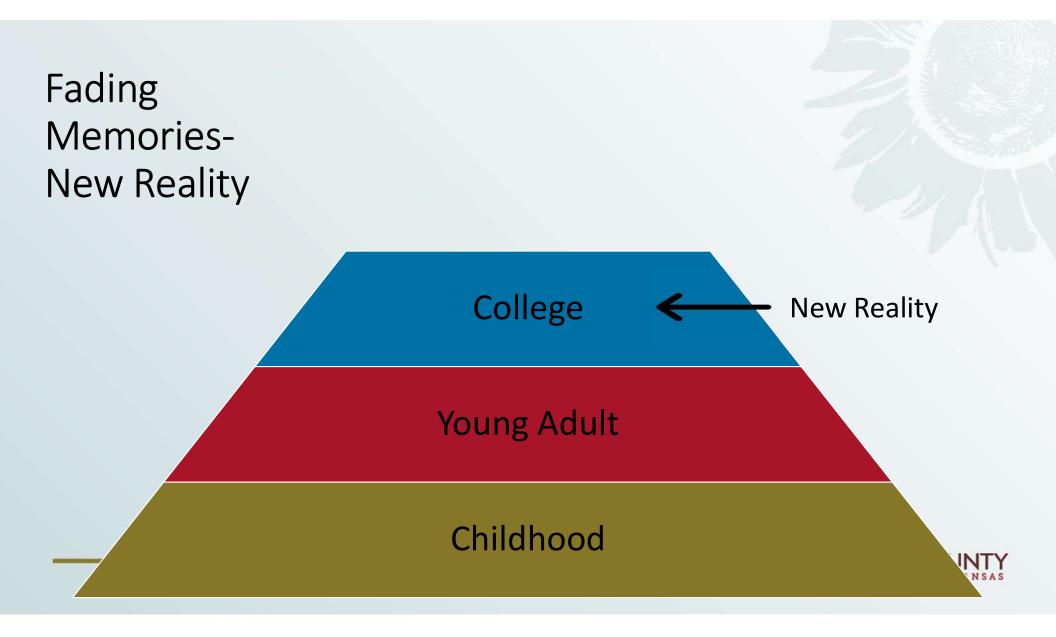
Proprioceptive Sense

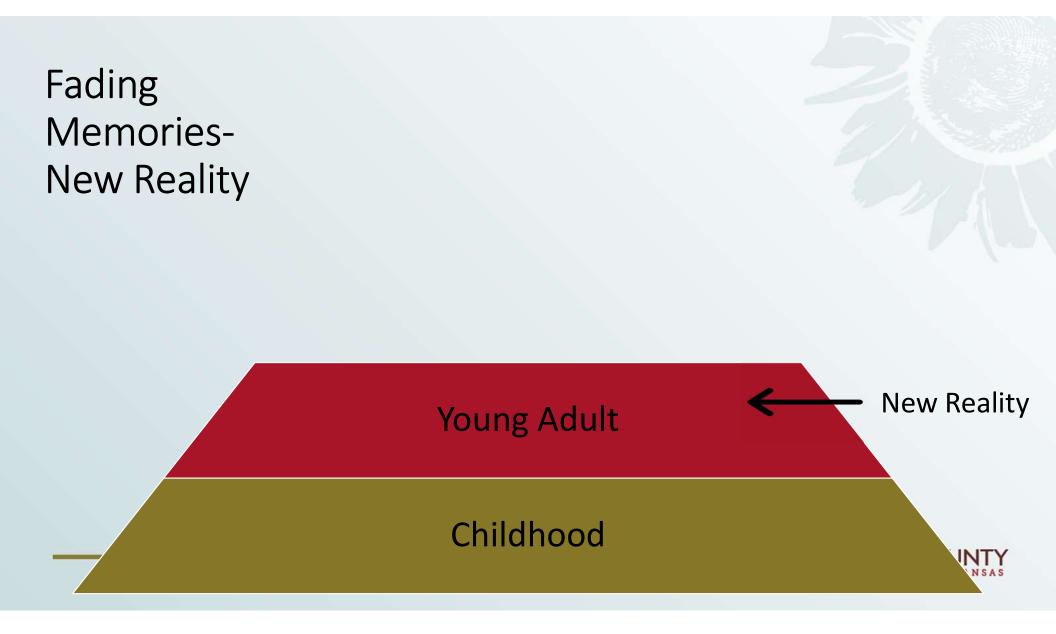












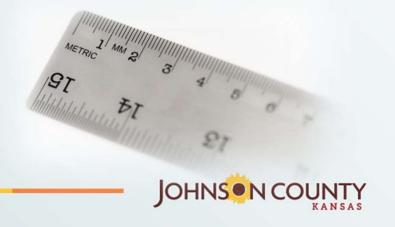
Fading Memories-New Reality





Caregiving- Knowing the Stages of Dementia

- A Yardstick or Estimate
 - It's a general measure of the person's decline
- Used to determine appropriate supports and accommodations
 - Based on needs and abilities



• Normal functioning.	 Mild memory problems for recent events. Mild problems with word and name retrieval. Starting to have difficulty with complex tasks. Repeat questions. Mood and personality changes 	 Increased memory loss and confusion. Trouble completing multi- stage tasks. Sleep-wake cycle disrupted. Disorientated to time and place. Poor judgment. Difficulty with ADL's. Wandering. 	 Inability to communicate. Swallowing problems. Incontinence. Increased sleeping. Weight loss. May be confined physically. Total assistance with ADL's.
	changes. • Increased supervision.	 Impulsive behavior. Safety issues emerge. Unsafe to be left unsupervised. 	

Stage-Based Considerations

Early Stage

- Screen with NTG-EDSD, document changes
- Observation & reporting of functional changes to a team.
- Support functioning and maintain quality of life
- Planning

Mid-Stage

- Modify/adapt environment to support functioning and safety
- Increase staff supervision and supports
- Maintain routine and structure as much as possible

Late Stage

- Specialized re-training of staff including mobility, eating, and comfort care
- Increased use of adaptive equipment and procedures
- Grief support family, staff, friends
- Hospice / Palliative Care



Dementia Related Behaviors

- Changes in behavior can occur in all stages of a person's dementia
 - Unpredictability = stress for caregivers
- Range from Annoying > Agitated > Combative
 - Repetitive questions > pacing / yelling > hitting / spitting



Wandering / Elopement

- The person is looking for clues to tell them where they are
- When they don't recognize any clues, they begin searching
- This causes them to leave their environment- they're looking for clues!



Repetitive Questions Rummaging Hoarding

Rummage Boxes and Fidget Quilts







Verbal Outbursts Physical Aggression Resistance to Personal Care Inappropriate Sexual Expression



Paranoia Hallucinations Sleep-Wake Disorders Sundowning



Behaviors can seem inappropriate, childlike, or impulsive.

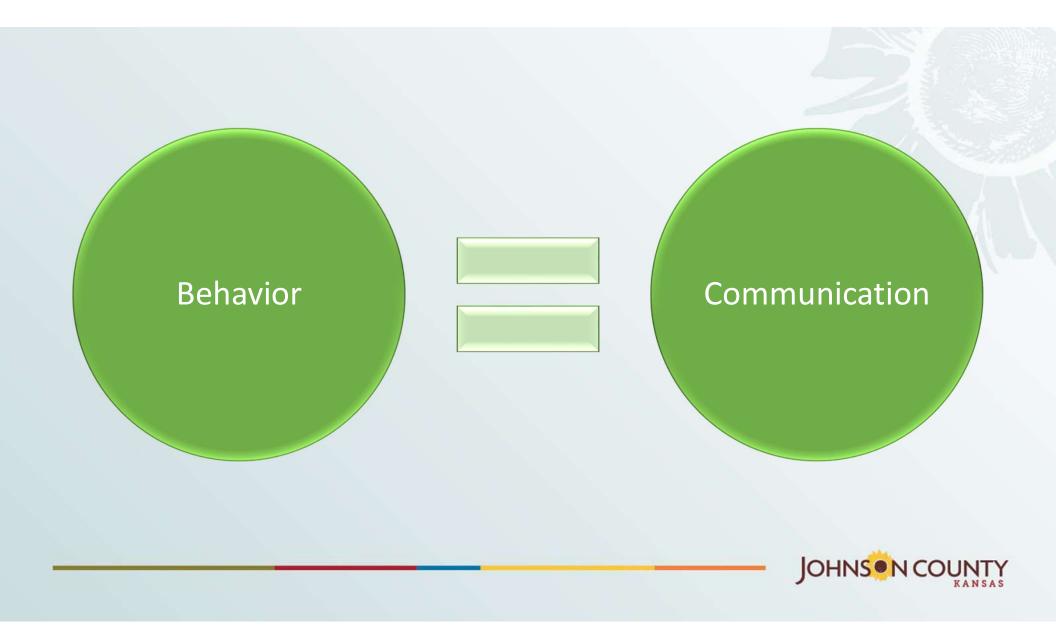
"The person with dementia isn't giving you a hard time, they're *having* a hard time."



Almost ALL behaviors do NOT occur out of the blue, but rather they are triggered by something, internally or externally.

As Caregivers, it's our responsibility to figure out what those triggers are.





Active vs. Passive

Active

Passive

I know what I need or want, but I'm having trouble saying it, so I'm going to do something to try and get you to understand Something is wrong, but I may not know what it is, so I can't tell anyone

I begin acting differently as a result of what's wrong



3 Most Common Behavior Triggers

Caregiver Interactions Pain Environment



Caregiver- YES, it's our fault sometimes

- Did I argue? Did I tell the person No?
- Was I rushing the person?
- What message was my body language sending?
- Was I overestimating what the person was capable of doing?
 - Too many steps to the task
 - Too many prompts
 - Not enough time to respond



Trigger: Pain

- Existing medical conditions that may cause pain?
 - Arthritis, migraines, osteoporosis, GERD
- Recent change in medications?
- Temperature- too hot, too cold?
- Possible new acute illness?
 - UTI, impaction, constipation,
 - Sudden change in mental status = delirium



Trigger: Emotional Pain

- Pain is also emotional!
- Mental Illness-related
 - Depression, anxiety
- Frustration, loss, feeling scared, overwhelmed, feeling threatened



Remember: Validate Emotions



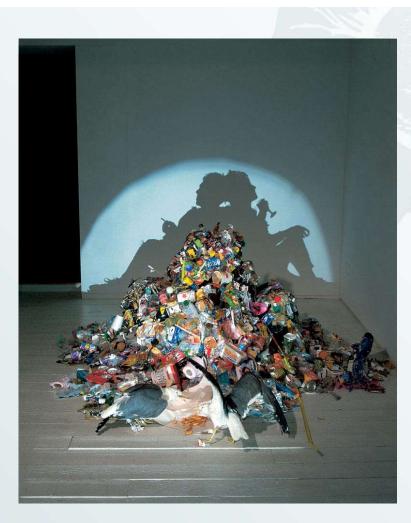
Trigger: Environment

- New or unfamiliar setting, change in routine
- Change in staff
- Noise
- Lighting and Shadows
- Large number of people
- Lost- no orienting cues for way finding.



Shadows







Physical

- Reducing potential for fear and disorientation by modifying/adapting environment
 - Ex. Reduce clutter, increase lighting, limit choices.





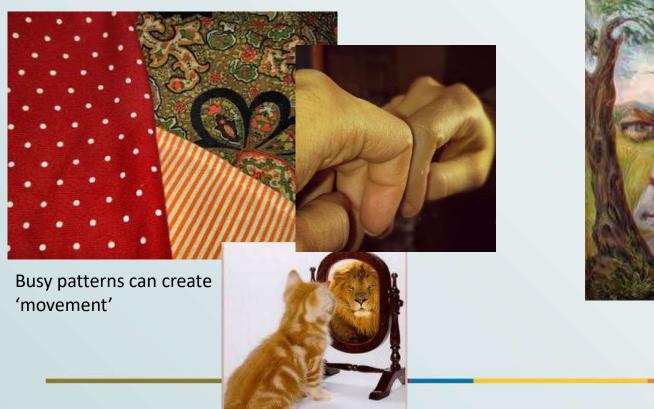
Too much visual stimulation can cause anxiety and unrest Provide limited options that still allow choices





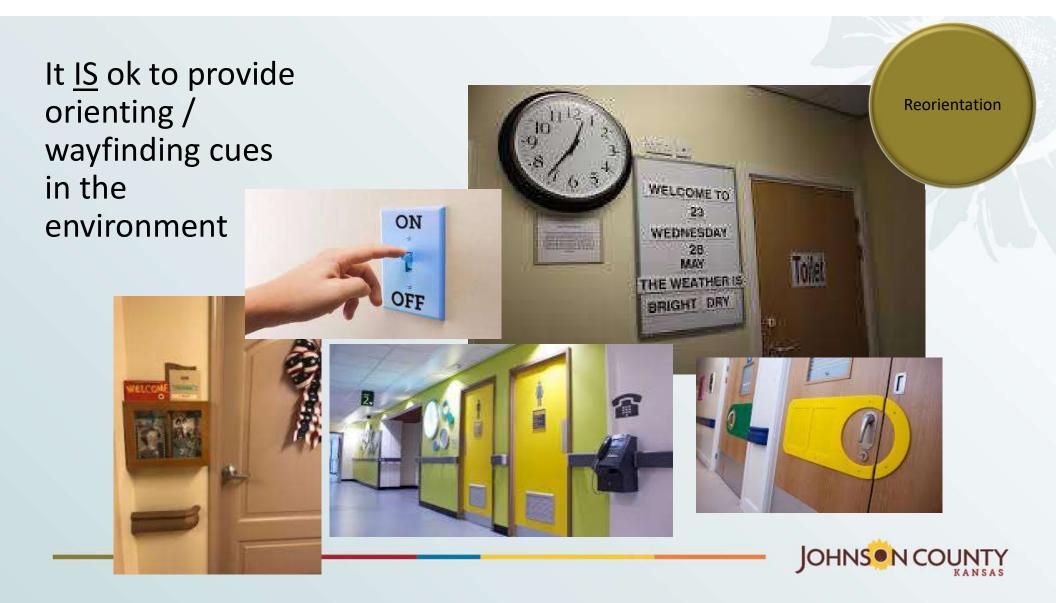
Physical

 Reducing potential for fear and disorientation by modifying/adapting environment
 Ex. Reduce clutter, increase lighting, limit choices.





Be mindful of artwork and decoration selections



4 Golden Rules



Rule #1: Difficult Behaviors Cannot be Changed with Words



What CAN you do?

- Change your approach to the person
- Change your reaction and response to their behavior
- Change the environment



Rule #2: Don't say "NO" and NEVER ARGUE

You can't reason with someone who has lost their ability to process thoughts in a logical and rational matter

YOU WILL LOSE EVERYTIME

Arguing = Frustration, Fear, Anxiety



No One Cares if You're Right.



Rule #3: Reduce Fear and Validate Emotions

Loss of ability to express and cope with fears Ability to self-sooth decreases significantly

Not Understanding, becoming confused, hallucinations-

These feelings and experiences can be terrifying and overwhelming, and they can't tell you how they're feeling



Focus and respond to the *emotions,* because THAT'S what they need you to understand



"I'm Scared."

It doesn't matter WHY they're scared.

But the fact that they're scared is worth your time and attention.

When YOU experience this emotion, does it help to share it with others? That others recognize you're feeling this way?



Validation

- Focus is on emotions, not what's causing them
- Empathy and Understanding, Reassurance
- Acceptance of person's reality and personal truth of their experience, regardless of their confusion
- Can reduce stress, anxiety, agitation, challenging behaviors



Rule #4: It's THEIR Reality, and You Must Enter it

You can't bring the person out of their dementia You have to step into their world, because that's where they are Meet them there

Validate their emotions

This builds empathy, a sense of trust, reassurance, security



Remember.....

- The goal is not to be right
- You can't bring them out of dementia, you must enter their reality
- As a person's most recent memories fade away, memories of years past will become their new reality.
- It's not lying, it's respecting their reality



Who has to change?

- We do!
- Trying to change or control behavior will be met with resistance
 - Because we're not addressing the root of the issue
- Accommodate the behavior
- Change our own behavior or the environment



Bryan tells you that his mother was here today, and he's very happy he got to see her!

BUT- Bryan's mother died 6 years ago.

What would you say to Bryan?



You hear Shawn screaming in her room. When you go in to find out what's going on, she tells you there are spider snakes crawling all over her bed, the walls, and the ceiling.

How would you respond?



- Doris takes all of her clothes out of her closet on a daily basis
- Every morning after breakfast, Adrian asks staff repeatedly what's for dinner
- Kay goes outside in the afternoons with a pitcher of water, and pours it off the deck while singing the same song everyday. She cries while singing



- After putting her pajamas on, Sharyl always comes out of her bedroom and strips down to her underwear
- When his roommates arrive home every day, Jeff paces around the house and screams until it's time to eat dinner



Summary

- Behavior is communication
- Common Triggers: Pain, Staff, Environment
- 4 Golden rules:
 - Don't try to change behaviors with words
 - Don't argue
 - Validate emotions
 - Enter their reality



Thank You!

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