

BEHAVIOR IS COMMUNICATION

*UNDERSTANDING BEHAVIOR AS A FORM OF
COMMUNICATION*

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National Task Group on Intellectual
Disabilities and Dementia Practices

- Our mission is to advocate for services and supports for people with intellectual disability and their families who are affected by Alzheimer's disease and dementias.
- 2010
- Education and training, advocacy at the federal government level, quality care guidelines, publications, early detection and screening tool (EDSD).
- Previously an affiliate of the American Academy of Developmental Medicine and Dentistry. Now an independent not-for-profit organization incorporated in Maine with federal 501 (C) 3 status pending.
- All volunteer organization – no staff.
- Presidents: Matt Janicki, PhD and Seth Keller, MD

Website: www.the-ntg.org

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QUICK REVIEW

- Your brain has dozens of different parts, and each part controls specific functions (ex. vision, hearing, emotional control, memory, judgment and reasoning, language, nonvoluntary reflexes, etc.)
- Alzheimer's and other irreversible forms of dementia damage the brain which is why you see changes in behavior.
- Dementia is not a disease! "Dementia" is another word for cognitive impairment (changes in thinking and memory that impact ability to function in daily life)...it is a symptom that needs evaluating and is not caused by any one disease!

QUICK REVIEW

- 100s of conditions can cause cognitive impairment (“dementia”) and there are many potentially treatable causes of “dementia.” Alzheimer’s is the most common cause of irreversible “dementia.”
- Increased risk of Alzheimer’s for people with Down syndrome and at a younger age.
- Establishing a baseline level of functioning at an early age can help identify onset of cognitive impairment. (EDSD)
- Diagnosis is NEVER made on the basis of one office visit or a cognitive screening tool (ex. MMSE, Mini-Cog, etc.)...a screening tool is a starting point – not an end point!
- Alzheimer’s is a diagnosis of exclusion.



The 5 Most Important Things You Need to Know About Behaviors of Dementia

1. BEHAVIOR IS COMMUNICATION

ALL BEHAVIOR HAS MEANING

BEHAVIOR IS A RESPONSE TO A SITUATION

- Caused by loss of ability to use language to express a need
- Can be physical, psychological, emotional, or social
- Could it be:
 - Interactions – More on this shortly
 - Over stimulation or under stimulation – Noise, movement, too many words used by caregiver
 - Pain – More on this shortly
 - Depression or anxiety – Very common in dementia and generally respond well to medication
 - Sensory impairments - Hearing, vision, touch
 - Fatigue - One theory for “sundowning”
 - Physical environment – Lack of wayfinding, color contrast, lighting
 - Perceived threat, fear
 - Change in routine



REFRAME YOUR THINKING

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

2. SUDDEN CHANGE IS NOT PROGRESSION

ALWAYS RULE-OUT DELIRIUM WHEN BEHAVIOR CHANGES SUDDENTLY

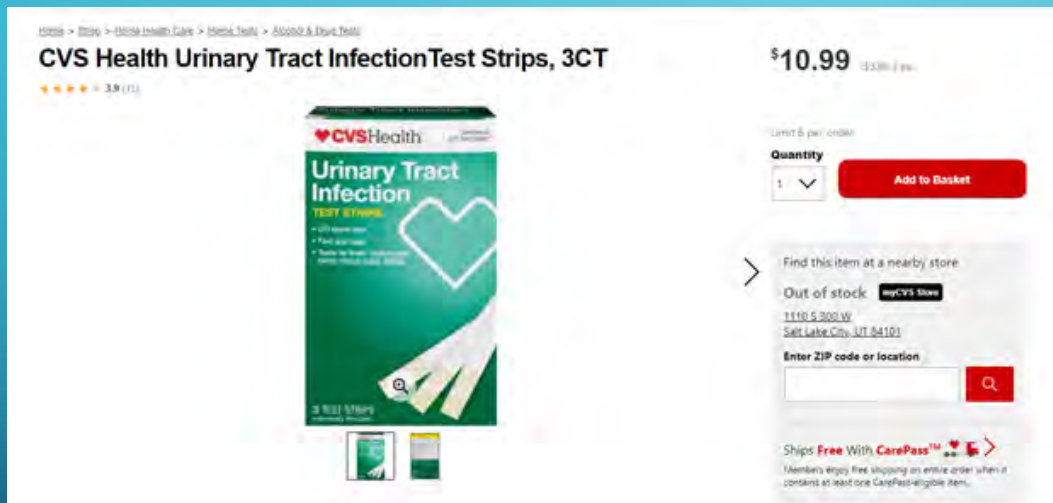


Sudden and Acute Hyperactive OR Hypoactive OR Mixed Medical Emergency

COMMON CAUSES:

- Top 3 - Urinary Tract Infection, Impaction, Pneumonia (COVID-19)
- Severe or chronic illness – stroke, heart attack, worsening lung/liver/kidney disease
- Metabolic imbalance – ex. low sodium or calcium
- Medication
- Infections
- Dehydration, malnutrition
- Sleep deprivation
- Pain
- Surgery that includes anesthesia

RESOURCE:



- Buy without a prescription.
- Not 100% accurate.
- hold them in your urine stream or dip them in a sample of your urine.
- Test for a substance (called nitrite) produced by most UTIs. Certain types of strips also test for white blood cells (leukocytes). Some types of dipsticks can test for both nitrite and leukocytes.
- Area on the end of the strip changes color if you have an infection.

3. IS IT SOMETHING I DID?

ARE YOUR RESPONSES OR EXPECTATIONS TRIGGERING THE BEHAVIOR?



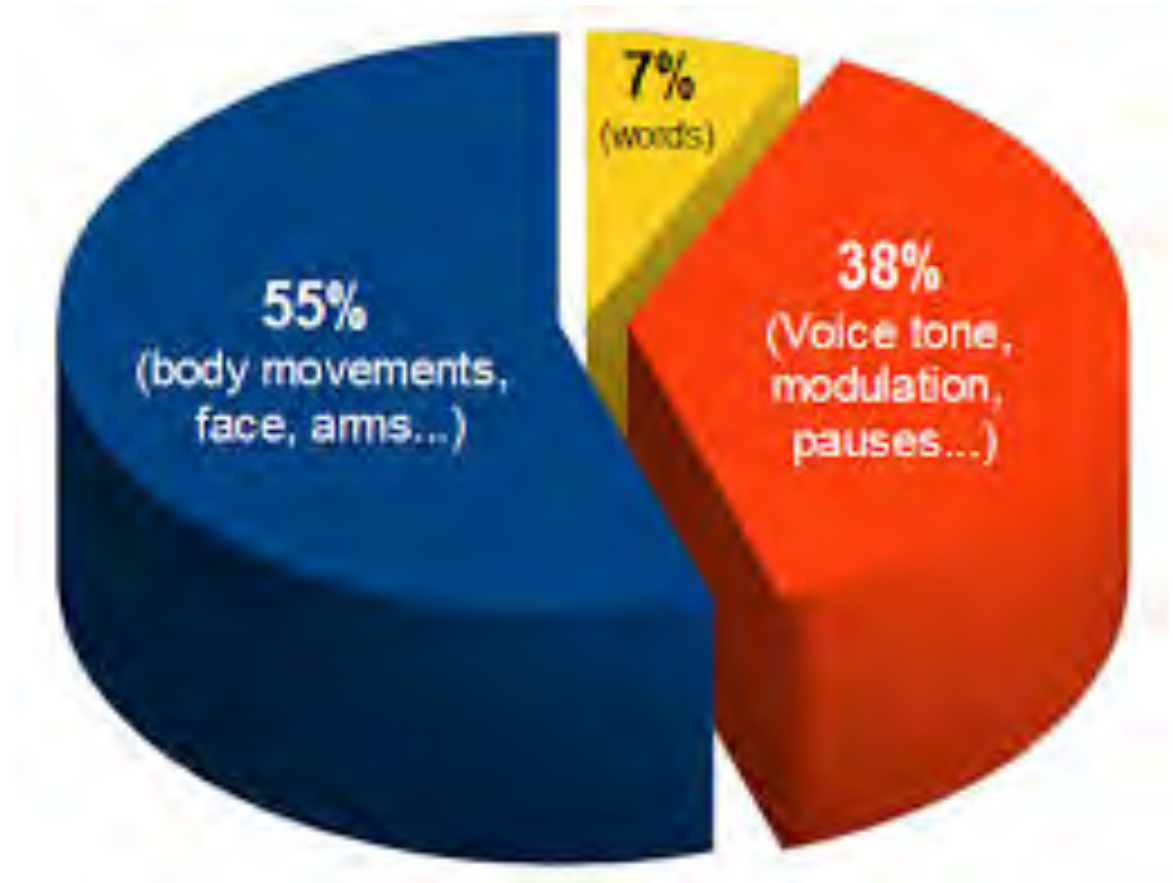
phillipmartin.info



90% of catastrophic behaviors in people with dementia are induced by caregivers and the environment.

Bawley E (1997) Designing for Alzheimer's Disease. Strategies for creating better care environments.

The
7-38-55
Rule
of
Communication.



PICK YOUR BATTLES

- Whose problem is it?
- If it's not a safety issue, ignore it.



EMOTIONAL CONTAGION

- Individuals tend to express and feel emotions that are like those of others.
- We not only observe another person's emotions, they also affect our own emotional state.

**What is your
voice, body
language, facial
expression
conveying?**



"Emotions are far more contagious than any disease. A smile or a panic will spread through a group of people far faster than any virus ever could."

- Seth Godin

STRATEGIES

Anxiety looks like anger

NEVER ARGUE - Arguing or explaining will only agitate the person more

Validate – “You must be feeling very frustrated/scared/confused...”

Don't reorient – Ex. “I want to go home.” Try, “Tell me about home.” Then distract and divert to another activity.

Therapeutic fiblets

Apologize, even if you've done nothing wrong

Step away and try again later

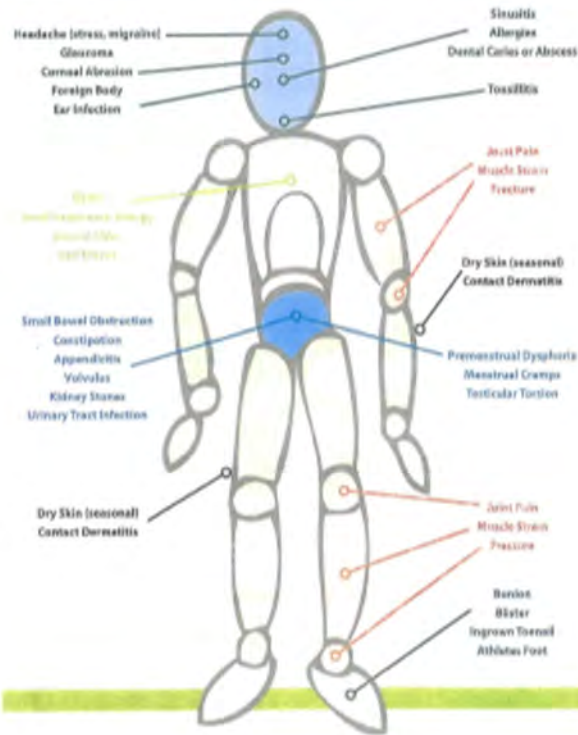
Music

Control your emotions!!!!

4. UNTREATED/UNDERTREATED PAIN

WHAT CONDITIONS DOES THIS PERSON HAVE THAT COULD CAUSE PAIN?

Body Map of Common Pain Syndromes



Think head to toe

PAIN ASSESSMENT

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1. Review the medical record:
 - GERD, osteoporosis, arthritis, diabetic neuropathy, migraine hx, heart disease, sinusitis, etc.
2. Onset of new acute medical condition?
 - Delirium...not disease progression!
 - Dental pain, glaucoma, ingrown toenail, constipation, UTI, sitting/lying in one position, undiagnosed fracture
3. Medical evaluation
4. Pain relief – Paracetamol (Tylenol) preferred. Ibuprofen and aspirin ok but higher risk of side effects. Opioid-type drugs for serious pain. *Adequate dose on regular schedule!*





PRN

“PAIN RELIEF NEVER”

5. FEAR AND CONFUSION

THE DAILY COMPANIONS OF A PERSON WITH DEMENTIA

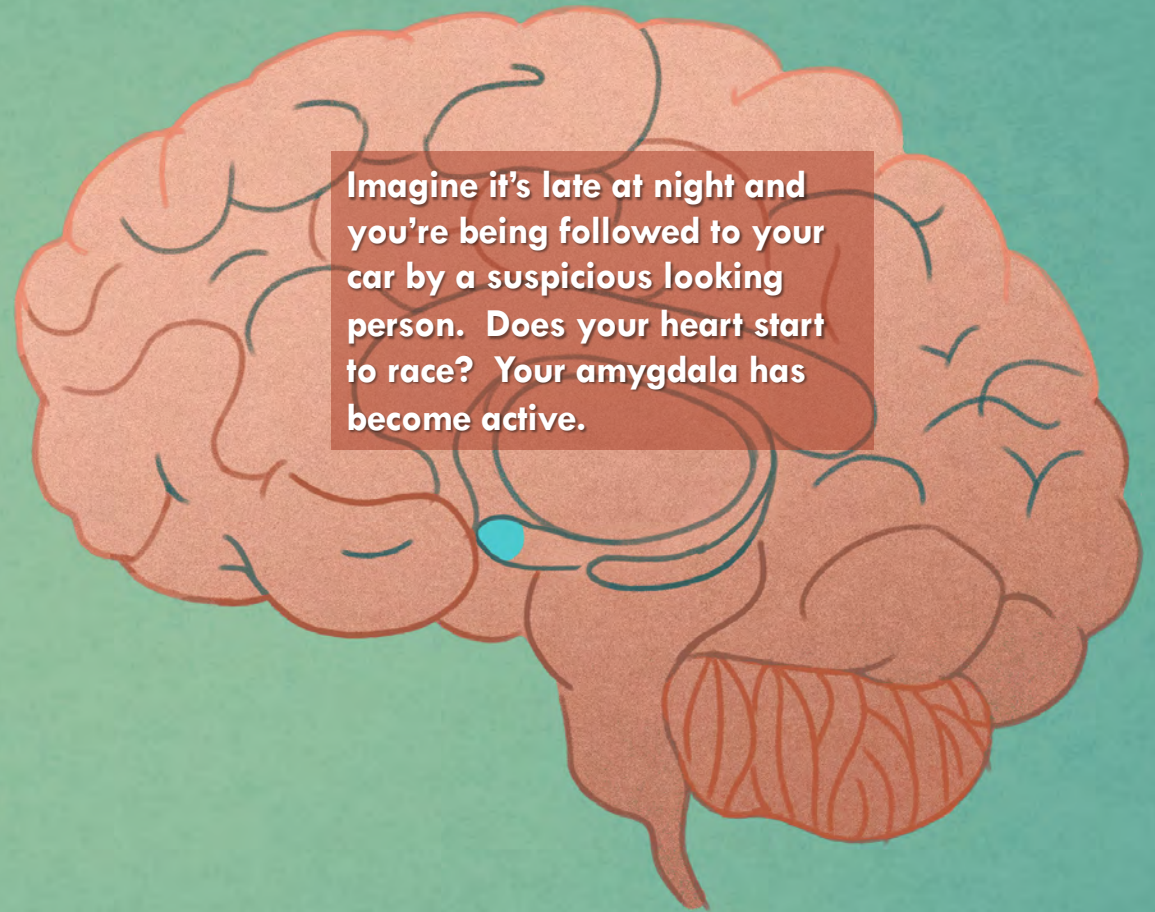
The Amygdala

Location

- Deep within temporal lobes
- Part of the limbic system

Functions

- Autonomic responses associated with fear
- Emotional responses
- Processing and consolidating memory
- Hormonal secretions



Imagine it's late at night and you're being followed to your car by a suspicious looking person. Does your heart start to race? Your amygdala has become active.

HENRY, J., THOMPSON, C., RUFFMAN, T., LESLIE, F., WITHALL, A., SACHDEV, P., & BRODATY, H. (2009). THREAT PERCEPTION IN MILD COGNITIVE IMPAIRMENT AND EARLY DEMENTIA. *THE JOURNALS OF GERONTOLOGY. SERIES B, PSYCHOLOGICAL SCIENCES AND SOCIAL SCIENCES*, 64 5, 603-7 .



Findings: People with dementia overattribute the level of threat posed by normatively judged nonthreatening situations.

EVERYDAY LIFE

You woke up this morning and couldn't make any sense of where you are or why you're there. Nothing looks familiar to you. There's someone in the room, s/he seems to want you to do something and is giving you instructions but it's a like they're speaking another language.

“This is why I find myself avoiding/delaying: Although it seems like a simple task (it used to be), it now becomes very overwhelming because of too many questions in my mind and audio stimulation.

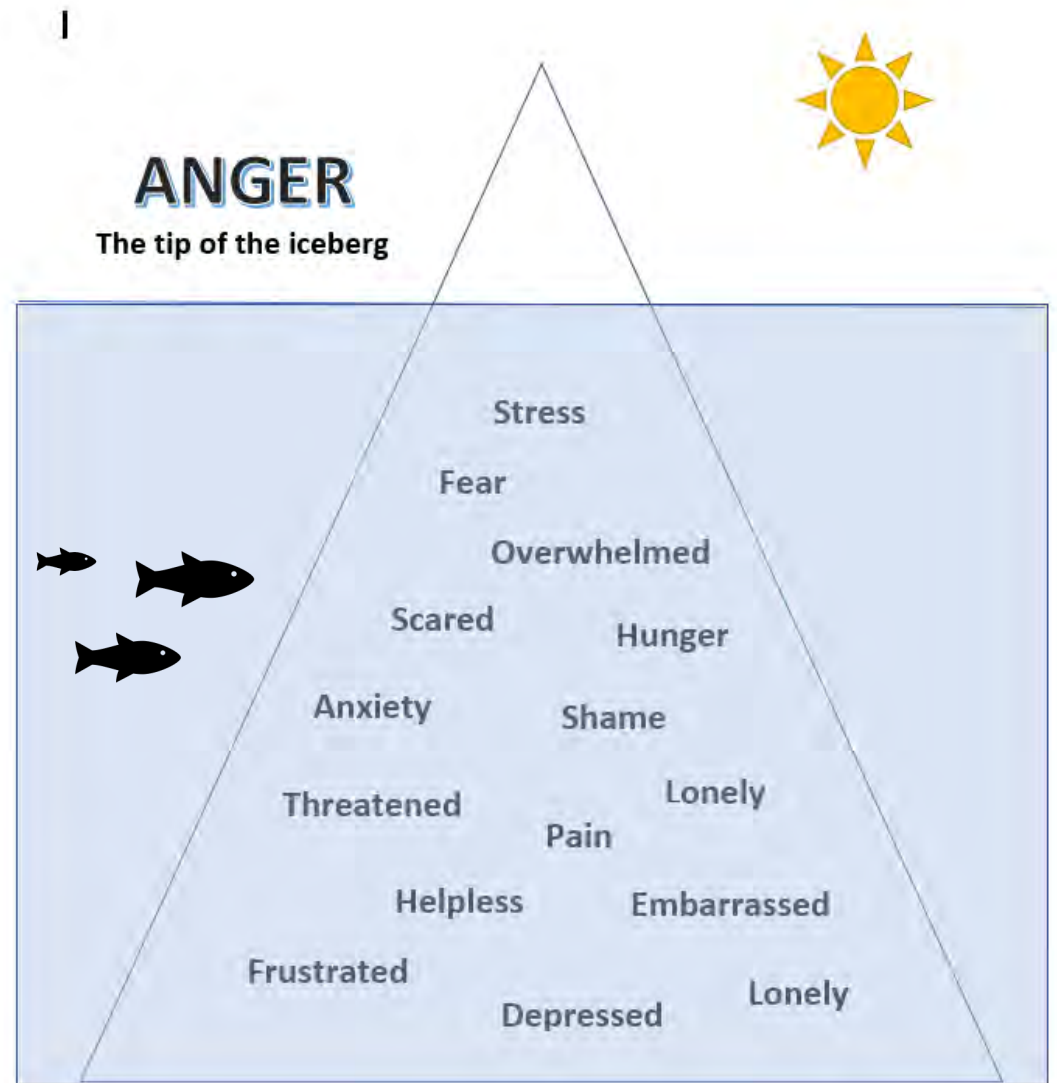
- *Sound of water*
- *Pressure of water*
- *Temperature of water*
- *Physical balance while trying to wash*
- *Too many parts to wash, did I already wash my face or do I still need to do it?*
- *Should I wash my hair? Which bottle is the shampoo? Conditioner?*

If someone is trying to help me, it is even more overwhelming because they are trying to instruct me and I don't understand. Their voices over the water makes me want to cry or scream – I am trying, and it is too much! I feel like they are grabbing at me and they try to go so fast, it's confusing!

At most I can handle 2 to 3 stimulus at any given time. Shower environment (eyes)+ water sound (ears) + water temperature (skin) = I can't handle it! Add more stimulation and I am going to start struggling, becoming confused and agitated. It feels like each of the senses are under attack in multiple ways.”

WORDS FROM A PERSON WITH DEMENTIA

**Anger is a secondary emotion...
focus on the underlying
emotion, not the anger.**



FINAL THOUGHTS

GENERAL MANAGEMENT OF BEHAVIORS

- What happened BEFORE the behavior?????
- Give the person “tasks” that match his/her level of ability and realize this will change over time.
- Learn to validate, redirect, and re-approach
- Routine is essential
- Control the level of stimulation in the person’s environment
- Be proactive: a moment of proaction is worth hours of reaction
- Put yourself in the person’s shoes...would I be comfortable with this approach, task, way the person is talking to me, etc.????

MEDICATIONS FOR BEHAVIORS

- “Smoke detector analogy”
- Consider pharmacologic interventions only when non-pharmacologic interventions consistently fail and the person is in danger of doing harm to self or others, or when intolerable psychiatric suffering is evident.
 - No FDA-approved medication for behaviors of dementia.
 - Monitor for worsening functional or cognitive status, sedation, falls or delirium
 - Regularly attempt to wean or discontinue the medication as soon as possible
 - Regularly monitor the behavior to evaluate effectiveness of medication, if started
 - Catastrophic reactions a risk in Lewy body dementia



thank you!

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PART II: ENVIRONMENT AND SENSORY: YOU CAN'T CHANGE THE PERSON BUT YOU CAN CHANGE THE PHYSICAL ENVIRONMENT

**SETTING UP THE
ENVIRONMENT TO REDUCE
CONFUSION; COST-
EFFECTIVE
MODIFICATIONS; GOALS OF
SAFETY AND COMFORT**

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“The Senses are what connects us to the universe and other beings in the universe. In fact, that is the only thing that does!”
Temple Grandin,
The Autistic Brain

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Participants will be able to apply some practical tips -

- **Changing the environment to accommodate sensory impairments through inexpensive modifications**
- **Sensory Impairments, IDD, and Dementia – Visual, Hearing, Taste/Smell, Touch, Vestibular/Proprioceptor (Location and movement through space)**

To learn to ask the question: How can you change the environment rather than the person?

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Contextual function and behavior



Functioning, Cognitive capacity, and Behavior changes must always be considered in the context of the physical and sensory environments.

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Sensory processing and sensory impairments are often overlooked in

Screening and Assessment for dementia – Differential Diagnosis

Causes for loss and decline over the lifespan

Causes for “inappropriate behaviors”

Causes for “behaviors” after diagnosis



For example Being frightened by looking in a mirror:

- **Can be a reaction due to:**
 - **Visual impairment**
 - **Sensory processing**
 - **Mistaking as a framed picture**
 - **Not remembering this is you! (very common in Alzheimer's disease)**

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○ **The Built Physical Environment as the producer of sensory information**

- **Influences our behavior and functioning**
- **The physical environment**
 - **Enhances functioning**
 - **Impedes functioning**
 - **Increases/decreases feeling of safety**
 - **May increase inappropriate behaviors**
 - **Environmental fit even more important**
 - **Never take for granted the physical environment**
 - **Each person's reality unique, change the environment not the person**

The Seven Senses and Sensory Integration

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Auditory

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Visual



Taste



Tactile



Smell



Vestibular

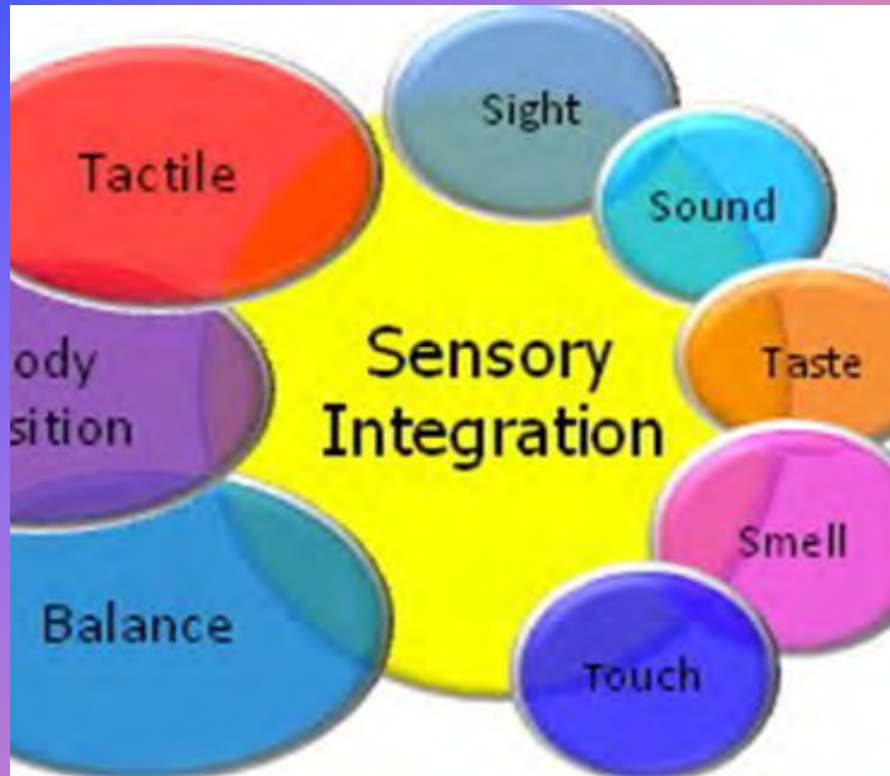


Proprioceptor



Seven Senses

- All work together through sensory processing which can also be impaired or dysfunctional
- Sensory information is what connects each person to the physical and social environment
- Functional sensory processing helps each adult respond “appropriately” to the environment.
- Need to be able to discriminate, modulate, and integrate the senses.
- Likelihood of Preferred Sense(s) for learning, taking in information from the environment



Sensory Processing: How does it work?

Sensory Integration – Bringing it all together

Each sense has receptors in cells of the body and are sent to the brain.

Any disruption in reception, transfer, or integration will affect the response to the information.

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Visual Impairments

- **Increase with age**
- **Adults with Down syndrome age into risk factors about 20 – 25 years earlier than the general population**
- **Likely affected by dementia**
- **Brain damage making it difficult to interpret the visual information from the environment**

The reality of the world with visual impairment

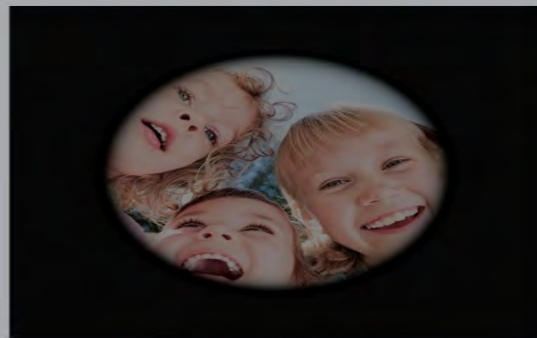
Diabetic Retinopathy



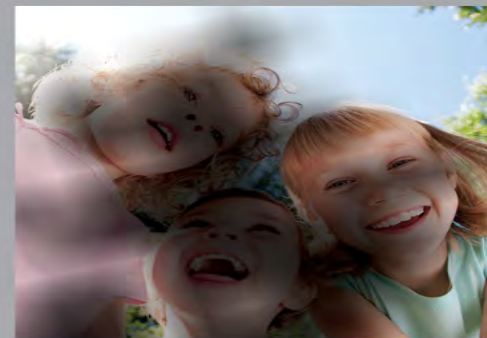
Cataracts



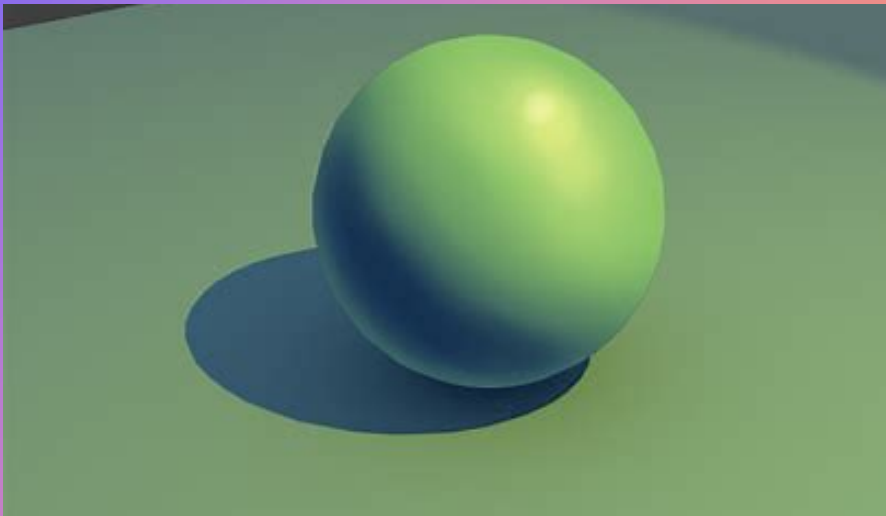
Retinitis



Glaucoma



Macular Degeneration



Change the environment

- **Contrasting colors: floors to wall, objects to background**
- **Doors to walls**
- **Objects such as dishes, towels, any object you want someone to use (do not assume if they can't find the object or use the object it is dementia)**
- **Furniture to background colors**
- **Change the object for ease of use**



Which photo is it easier to find the furniture to sit on?

- Blankets or quilts on the back of furniture
- Chairs with arms and firm seats
- Avoid visual or auditory clutter
- Create safe pathways





Auditory - Hearing

- **Pay attention to the sounds in the environment**
- **Reduce those sounds that are meaningless such as sounds of fans, dishwashers, radio and TV on at the same time**
- **Add soft materials such as textiles on the wall**
- **Eliminate sounds that have irritated or frightened in the past**

Hearing aids do not restore hearing to original hearing

- Hearing impairments increase with age especially for adults with Down syndrome
- Brain damage from Alzheimer's disease may meant sounds are no longer received as they were in the past by the brain
- Reduce background noise
 - Awareness
 - Lighting
 - Soft materials





Smell and Taste

- Medications
- Reductions in sensory receptors
- Confusion in reception of information
- Removal from smells and taste
- Need for smaller portions, meals
- Reduction in other senses

Suggestions

- **Bake prior to meals**
- **Know favorite foods and smells**
- **Know foods despised and avoid (for me that is onions!)**
- **Textures may be painful or disliked**
- **Make food and drink fun, easy to eat, What is most important in a meal**
- **Some people like to eat alone others like company but not a cast of 1000s**
- **Check oral health**
- **5 – 6 snacks a day rather than 3 large meals**

Pureed foods

Catherine Conway, MS, RDN, CDN, CDCES, Chief of Nutritional Services, YAI, New York, NY

- NOT THIS



- THIS





Tactile/Touch

- **Importance of touch/being touched**
- **Avoidance wearing certain clothing**
- **Touching every object, person**
- **Need for movement**
- **Sense of different textures can be important to enhance experience**
- **Taste and texture**
- **ADLs and tactile**



Textures and contrasting colors

- **What do colors tell you?**
- **Use them to provide contrast for objects to background and create pathways**

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Movement, Dementia and the Environment

- **We use all our senses to move throughout our environment. If any one is faulty or integration of information is not possible, it is likely that mobility will be affected.**
- **The right to move throughout our environment freely is a basic right as well as a need for optimal functioning.**
- **The inability to plan movement probably impaired by dementia.**
- **Changes in movement can be clues to changes in sensory processing/impairments.**

Proprioception

- Proprioception system integrates the input from the five senses to create meaning of the environment and your place in it.
- Awareness of the position of one's body.
- Individual with AD literally "*lost in space and time.*"
- Think of AD as a problem of *location in space.*
- Can not perform functions of daily living if can not locate in space.
 - Ex. Could you solve a complex math word problem while free falling on a roller coaster?



Vestibular

- Inner ear and brain
- Controls balance
- Located in the part of the brain that is damaged first in AD
- We develop a “cognitive map” for movement using landmarks that may now be forgotten or misinterpreted
- Location and directional movement is disrupted if visual stimuli are removed (such as in the dark).
 - Can be restored but not easily within AD even within familiar surroundings
 - Connecting of movement to other events and locations (episodic memory) likely impaired.





WALKING PATHS FOR MOVEMENT

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Assess the environment and make changes to sensory information not the person. Could this be perceived as a toilet, especially by men?





Fake bus stops, Does it matter if people want to sit and watch? What is important in our physical environments? Rethink support!



**FAMILIAR
OBJECTS ARE
IMPORTANT**

Regression back
in time and
memory



Conclusion



The importance of using the environment to enhance the use of each sensory system and reduce sensory processing dysfunction.



**Change the environment not the person!
Assess, Diagnose, and Support from the perspective of the individual!**



Never take the environment for granted!