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Geriatric Center of Excellence

Project ECHO

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Welcome to the Positive Approaches to Dementia Care ECHO

January through December 2025

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Disclosure

This project is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant number U1QHP53034, Geriatrics Workforce Enhancement Program, for $1,001,457. This information or content and conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by, HRSA, HHS or the U.S. Government.

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Schedule

- Session 1 – Dementia: What's Retained?
- Session 2 – What is a Positive Approach to Care?
- Session 3 – Sensory Changes
- Session 4 – Communicating Effectively
- Session 5 – Personal Care
- Session 6 - How to Identify Unmet Needs
- Session 7- What's Behind Aggression in Dementia?
- Session 8- Combativeness and De-escalation
- Session 9- Disinhibition
- Session 10 – Perseveration
- Session 11- Depression

Dementia: What's Retained, Not Just What's Lost

Beth A. D. Nolan, Ph.D.

Chief Public Health Officer

Teepa Snow Positive Approach to Care Mentor

As brain cells die the brain shrinks in size

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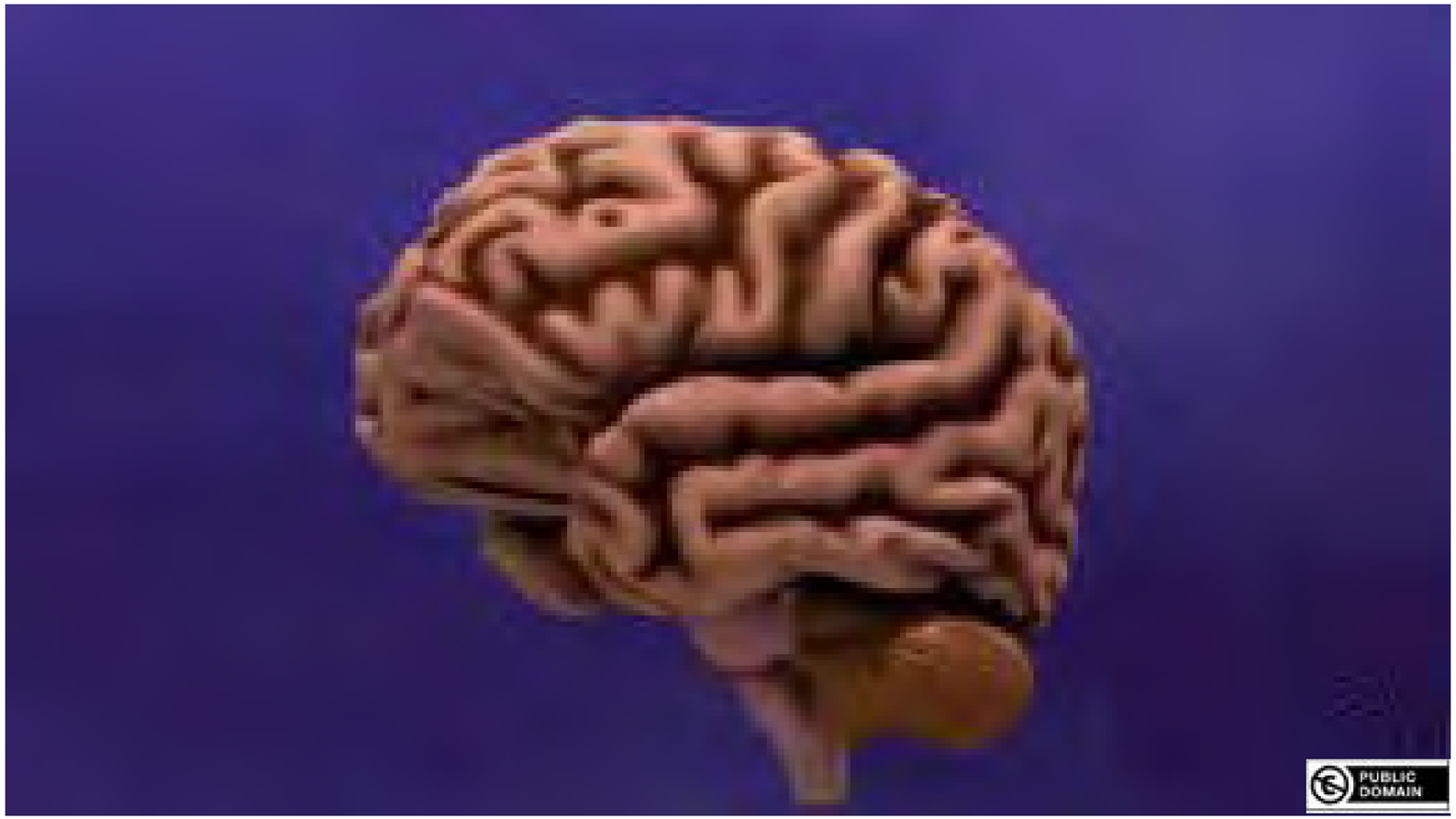
Let's see what changes inside:



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WHICH ONE?

Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD

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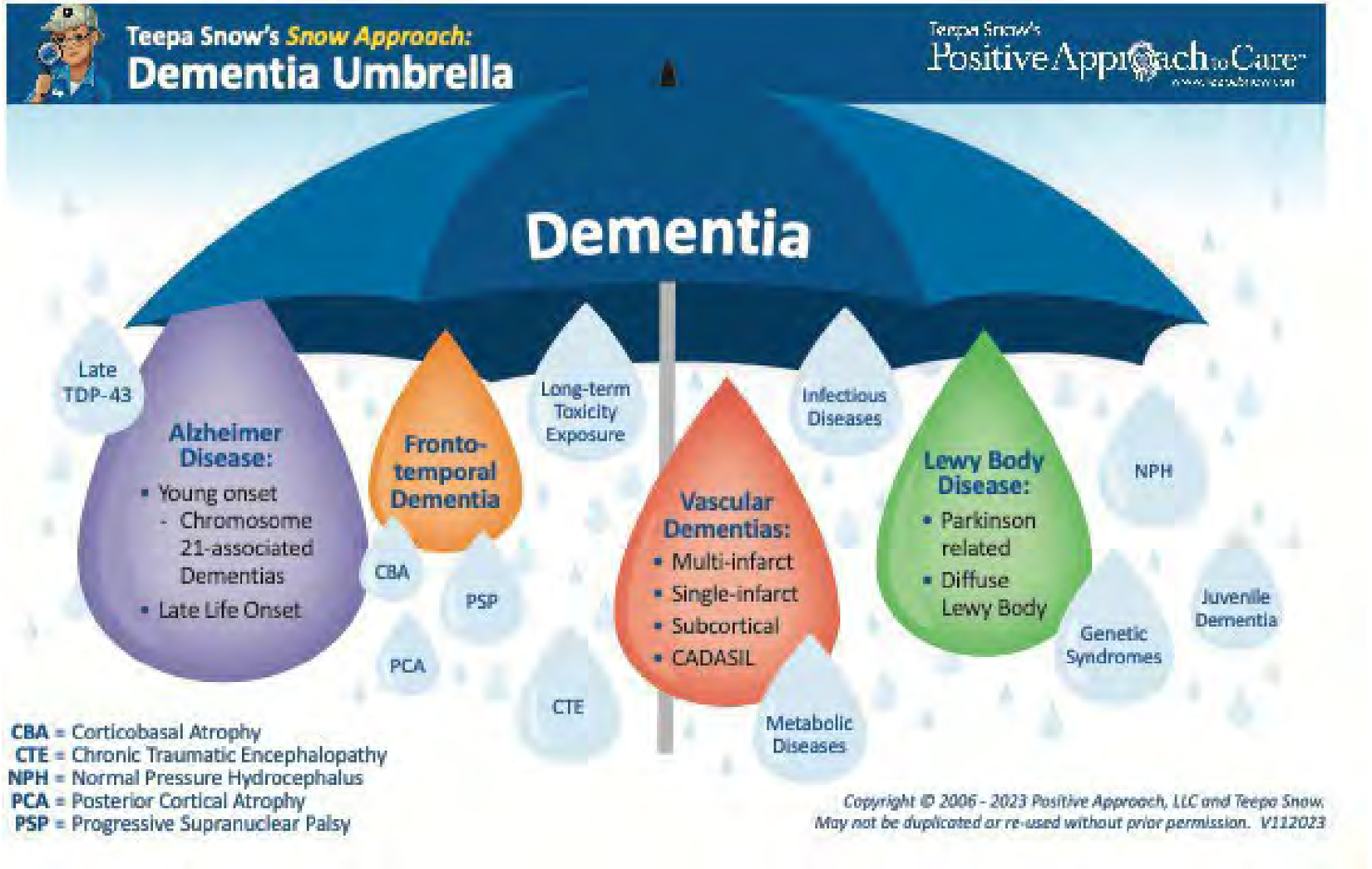
A better understanding of the difference between dementia and Alzheimer…



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Four Truths About Dementia:

1. At least 2 parts of the brain are dying- one related to memory and another part
2. It is chronic – can't be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually

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Four More Truths About Dementia:

1. Things do not work the way they *used to* – abilities are changing
2. This is a *new normal* – can't go back to before
3. It is not going to *stabilize* and yet change can be dealt with – with support
4. Getting *support* that works is essential as things continue to change

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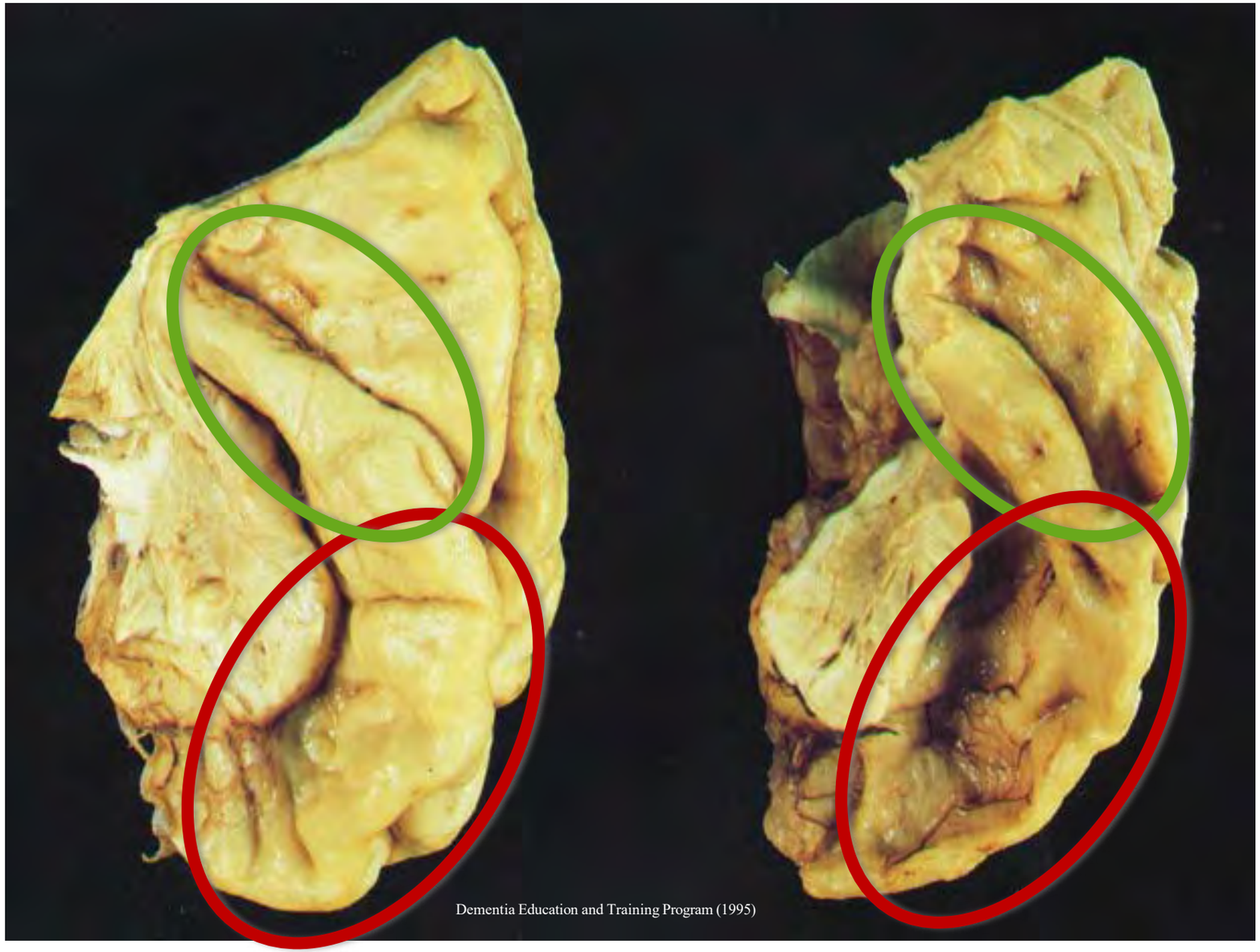
Hearing Sound Unchanged

BIG Language CHANGE



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Limit Words – Keep it Straight Forward!

Visual matched WITH verbal using **Positive Action Starters**:

- First, **Reflect:** matched intensity with sincerity (if needed).
- **Short & Simple:** *It's about time for…* tap your watch/wrist.
  Or *Here's your socks.* Hold up sock.
- **Step by Step:** *Let's go this way.* Point.
- **Choice:** *Coffee or tea?* Raise coffee cup then tea bag.
- **Help:** *I could use your help.* Implied compliment on skill.
- **Try:** *Let's just try.* Pointing to the exercise band.

Acknowledge their response/reaction…. **And then WAIT!!!**

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 2: *What is a Positive Approach to Care?*

Wednesday February 19, 2025 2:00-3:00 p.m. (EST)

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What is a Positive Approach to Care?

Teepa Snow, MS, OTR/L, FAOTA

Founder and CEO, Positive Approach to Care®

Co-Founder, Snow Approach Foundation, Inc.

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The GEMS® States of Brain Change:

Sapphire State: Typical Aging

Diamond State: Clear, Sharp, Faceted, Highly Structured

Emerald State: On the Go with Repeating Patterns

Amber State: Caution Light, Caught in a Moment of Time

Ruby State: Red Light on Skills, Hidden Depths

Pearl State: Hidden Within in a Shell, Quiet Beauty

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Why Use the GEMS® States?

They help us:

- Understand the different brain states that we all experience, so we may recognize our own state and its impact on our interactions
- Get beyond the terms *dementia* and *Alzheimer* and speak with less negativity and stereotyping
- Enable us to offer effective support for an individual's specific brain state
- Focus on abilities, rather than just disabilities

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Sapphire State:

- Typical aging brain
- Able to be flexible and adaptable
- Able to consider the perspectives of others
- Able to support the other GEMS States

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Diamond State:

- Sharp, hard, rigid, inflexible, can cut
- Many facets, still often clear, can really shine
- Are usually either *joiners* or *loners*
- Can complete personal care in familiar place
- Usually can follow simple, prompted schedules
- Misplaces things and can't find them
- Resents takeover or bossiness
- Notices other people's misbehavior and mistakes
- Varies in self-awareness
- Uses old routines and habits
- Controls important roles and territories, uses refusals

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Emerald State:

- Changing color
- Not as clear or sharp, more vague
- On the go, need to *do*
- Flaws may be hidden
- Time traveling is common
- Are usually *doers* or *supervisors*
- Do what is seen, but miss what is not seen
- Must be in control, but not able to do it correctly
- Do tasks over and over, or not at all

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Amber State:

- Amber Alert - Caution!
- Caught in a moment
- All about sensation and sensory tolerance, easily over or under-stimulated
- May be private and quiet, or public and noisy
- Limited safety awareness
- Often focused on their own needs and wants
- Lots of touching, handling, tasting, mouthing, manipulating
- Explorers, get into things, invade space of others
- Do what they like and avoid what they do not like

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Ruby State:

- Big, repetitive, strong movements are possible
- Rhythm: can sing, hum, pray, sway, or dance
- Notices exaggerated facial expressions
- Can react to emotion in tone of voice
- Limited skill in mouth, eyes, fingers, and feet
- Can mimic or copy big actions and motions
- Monocular vision – loss of depth perception
- Balance and coordination very limited
- Basic needs will require monitoring and support

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Pearl State:

- Hidden in a shell: still, quiet, easily lost
- Beautiful and layered
- Spends much time asleep or unaware
- Unable to move, bed or chairbound, frequently falls forward or to side
- May cry out or mumble often, increases vocalizations with distress
- Can be difficult to calm, hard to connect with
- Knows familiar from unfamiliar
- Primitive reflexes
- The end of the journey is near, multiple systems failing
- Connections between the physical and sensory world are less strong but we are often the bridge

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Teepa Snow's GEMS® State Model allows us to recognize how every brain can change based on internal and external factors. While dementia will cause chemical and physical changes to one's brain, other factors, such as discomfort, stress, or hunger, can affect all of our abilities in the moment. Observing these changes and recognizing what abilities are available in this moment are key to connecting and offering the *just right* support.

Sapphire

True blue
Healthy brain
Normal aging
Flexible
Adaptable
Optimal cognition
Can vary pace
Sometimes misses a word
Can provide support for other GEMS States with proper self-care and support
Less peripheral awareness with age

Diamond

Clear – Sharp
Many facets
Lives by habit and routine
Likes familiar, dislikes change
Blames or dismisses errors
Short delays possible
Word-finding changes
Can cut and shine
Scuba vision

Emerald

Green
On the go with purpose
Flawed
Seeks independence or connections
Repeats
Misses details
One thing at a time
Misses or skips words
Travels in time and place
Binocular vision

Amber

Changing yellow
Caught in a moment of time
More curious than cautious
Focused on sensory needs
Lives in the moment
Copies actions, not tasks
Highly varied response speed
Language challenged
Resists dislikes, seeks likes
Can confuse objects

Ruby

Strong red
Retains strength, not skills
Big/strong actions
Has rhythm
Notices tone of voice
In motion or still
Typically very slowed
Chatty or silent
Imitates actions
Monocular vision

Pearl

Hidden in a shell
Ruled by reflexes
Short moments of connection
Mostly immobile
Expresses unmet needs with distress
Reacts to touch
Extended delays are common
Single sounds or words
Can recognize familiar and liked
Limited visual regard

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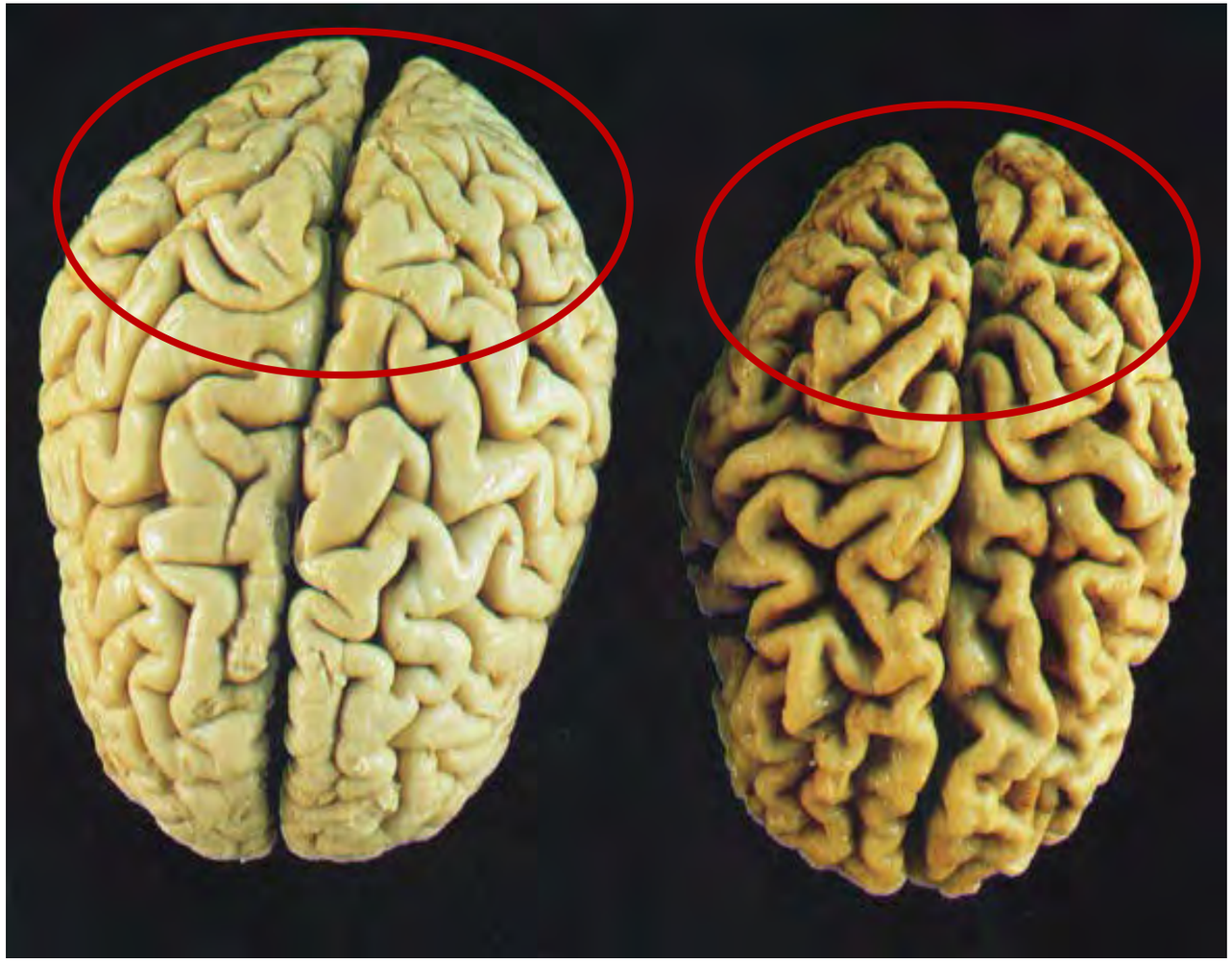
Vision Center: Big Changes



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Visual Field Changes by GEMS State:

Sapphire State: Loss of Peripheral Awareness with Typical Aging

Diamond State: Scuba Mask/Tunnel Vision

Emerald State: Binocular Vision

Amber State: Binocular + Object Confusion

Ruby State: Monocular Vision

Pearl State: Loss of Visual Regard

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 3: *Sensory Changes in dementia and how to support: An eye on vision*

Wednesday March 19, 2025 2:00-3:00 p.m. (EST)

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The GEMS® States of Brain Change

Sapphire State: Typical Aging

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GEMS® Dementia Abilities

Based on Allen Cognitive Levels

- A Cognitive Disability Theory – OT based
  - Focus on abilities, rather than just disabilities
- Creates a common language and approach to providing:
  - ✓ Environmental support
  - ✓ Caregiver skill, support, and cueing strategies
  - ✓ Expectations for retained ability and lost skill
  - ✓ Promotes graded task modification
- Each Gem state requires a special 'setting' and 'just right' care
  - ✓ Visual, verbal, touch communication cues
- Each can shine
- Encourages in the moment assessment of ability and need
  - ✓ Accounts for chemistry as well as structure change

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Progression of the Condition and Every Brain Throughout the Day

To the tune of

"THIS OLD MAN"

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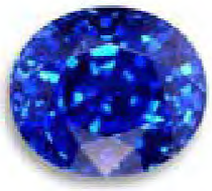

SAPPHIRE true, with change, we're key

The choice is ours, and we are free

To change our habits, to read, and think and do

We're flexible, we think it through!

DIAMOND bright, share with me

Right before, where I can be

I need routine and some different things to do

Don't forget, **I** get to **choose**!

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EMERALD– Go, I like to do

I make mistakes, I may be through!

Show me only one – step – at – a – time

Stay a friend, and I'll be fine

AMBER – HEY!, I touch and feel

I seek sensations- I'm rarely still

I can do things, if I copy you

What I need is what I do!

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RUBY – skill, it just won't go

Changing something must go **slooooooow**

Use your body to show me what you mean

Guide, don't force me. Don't use speed!

Now a **PEARL**, I'm deep within

But I still feel things through my skin

Keep your offers always clear and slow

Use your voice to calm my soul.

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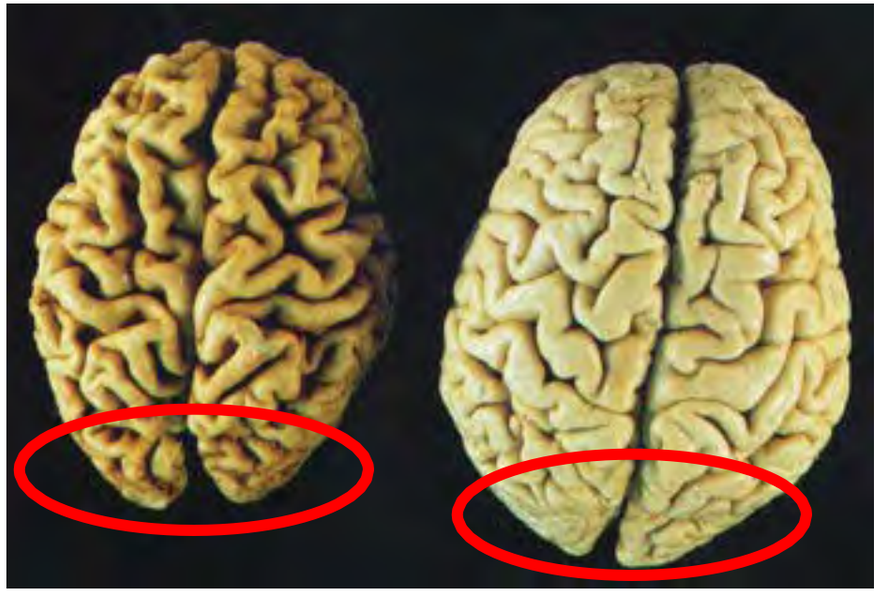
Vision Changes

With each new state of vision change, there is a decrease in safety awareness.



Dementia Education and Training Program. (1995). *Alzheimer's: A Broken Brain* [Brochure]. [Tuscaloosa, AL]: Dementia Education & Training Program.

BIG VISION CHANGES

1. Loss of Peripheral Awareness
2. Tunnel Vision
3. Binocular Vision
4. Binocular + Object Confusion
5. Monocular Vision
6. Loss of Visual Regard

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25

Visual field at age 25

If alert and attentive

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No cognitive impairment; Changing Processing Speed

75

Visual field at age 75

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Early signs of dementia
Even slower processing speed

Visual field with tunnel vision

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Middle of dementia

Social vision or task vision – not both

Visual field with binocular vision

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Late-State of Dementia
No depth perception– one piece at a time

Visual field with monocular vision

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Late-State of Dementia

- Visual field with monocular vision
- Opening and closing eyes

Visual Cues by GEMS State

- **Diamond** – Message in scuba field
- **Emerald** – Objects in binocular field
- **Amber** – Object use demonstrated in binocular field
- **Ruby** – Hand or hand plus face in monocular field
- **Pearl** – Facial expression 18” away in midline

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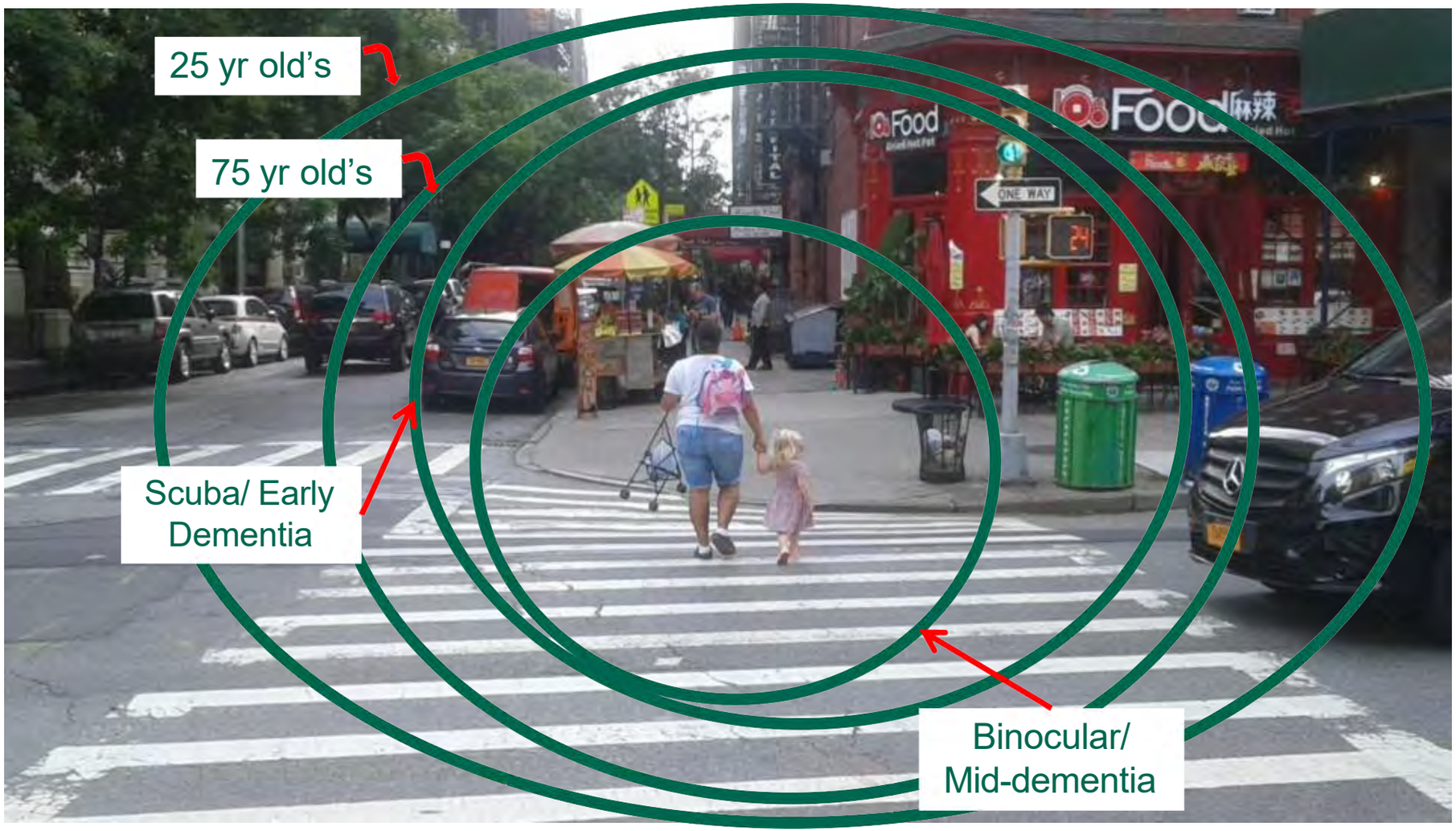
Visual Fields by Age and Brain State



e.g., Armstrong, R. A. (2009). Alzheimer's disease and the eye. *Journal of Optometry, 2*(3), 103–111.

Trick, G.L., Trick, L.R., Morris, P., & Wolf, M. (1995). Visual field loss in senile dementia of the Alzheimer's type. *Neurology, 45*, 68–74.

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 4: *Adapting the Care Approach for Changes in Hearing and Language*

Wednesday April 16, 2025 2:00-3:00 p.m. (EST)

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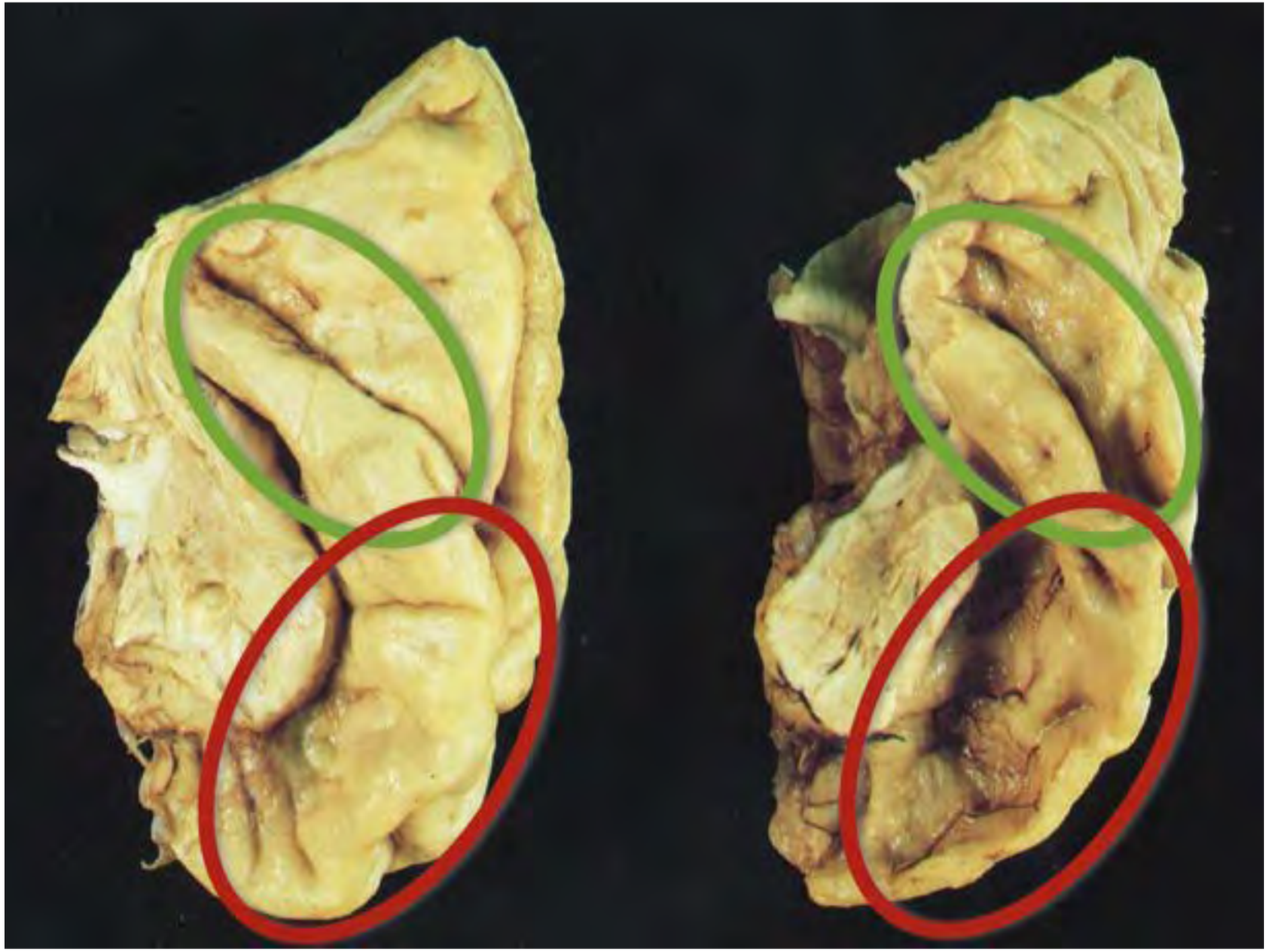
Hearing Sound Unchanged

BIG Language CHANGE



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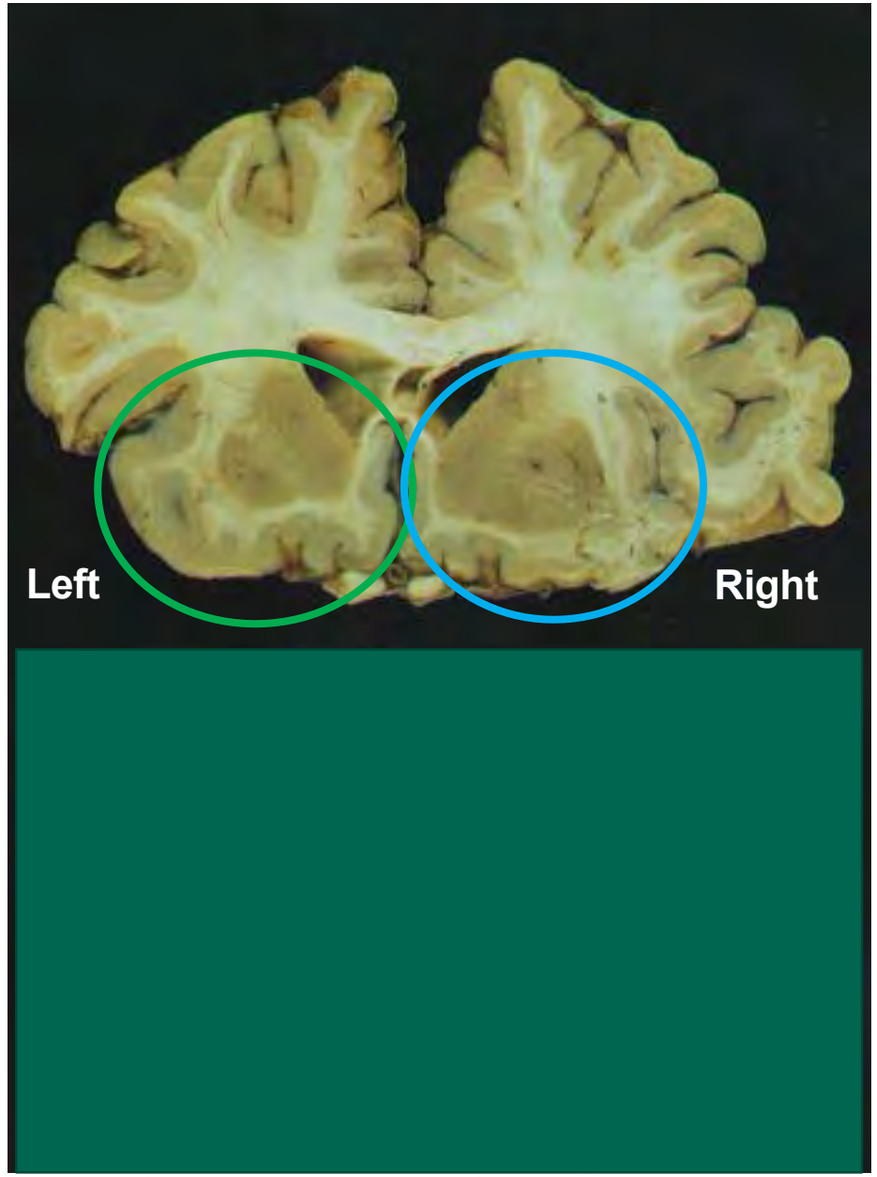
Left Temporal Lobe

1. Vocabulary
2. Comprehension
3. Speech Production

Right Temporal Lobe

1. Forbidden Words
2. Social Chit Chat
3. Rhythm of Speech
4. Music, Poetry, Prayer, Counting
5. Automatic, Autonomic Movement



Dementia Education and Training Program (1995)

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Asked:

"Shut the door, Buddy"

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Positive Action Starters (PAS)

First, **Reflect:** matched intensity with sincerity (if needed).

Second, matched visual cues WITH verbal using **PAS** :

- **Short & Simple:** *It's about time for…* tap your watch/wrist.

  Or *Here's your socks.* Hold up sock.
- **Step by Step:** *Let's go this way.* Point.

  Or *Lean forward.* Motion forward with hand.
- **Choice:** *Coffee or tea?* Raise coffee cup then tea bag.
- **Help:** *I could use your help.* Implied compliment on skill.
- **Try:** *Let's just try.* Pointing to the exercise band.

Limit words: Keep it Straight Forward

Acknowledge their response/reaction…. **And then WAIT!!!**

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 5: *A Positive Approach to Personal Care Challenges*

Wednesday May 21, 2025 2:00-3:00 p.m. (EST)

Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD

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Vision Changes

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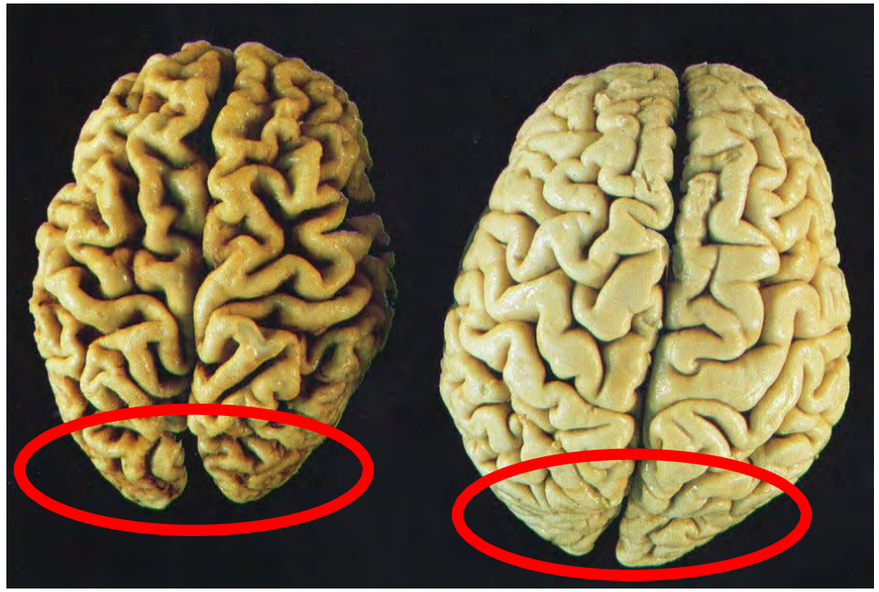

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BIG VISION CHANGES

1. **Loss of Peripheral Awareness**
2. Tunnel Vision
3. Binocular Vision
4. Binocular + Object Confusion
5. Monocular Vision
6. Loss of Visual Regard

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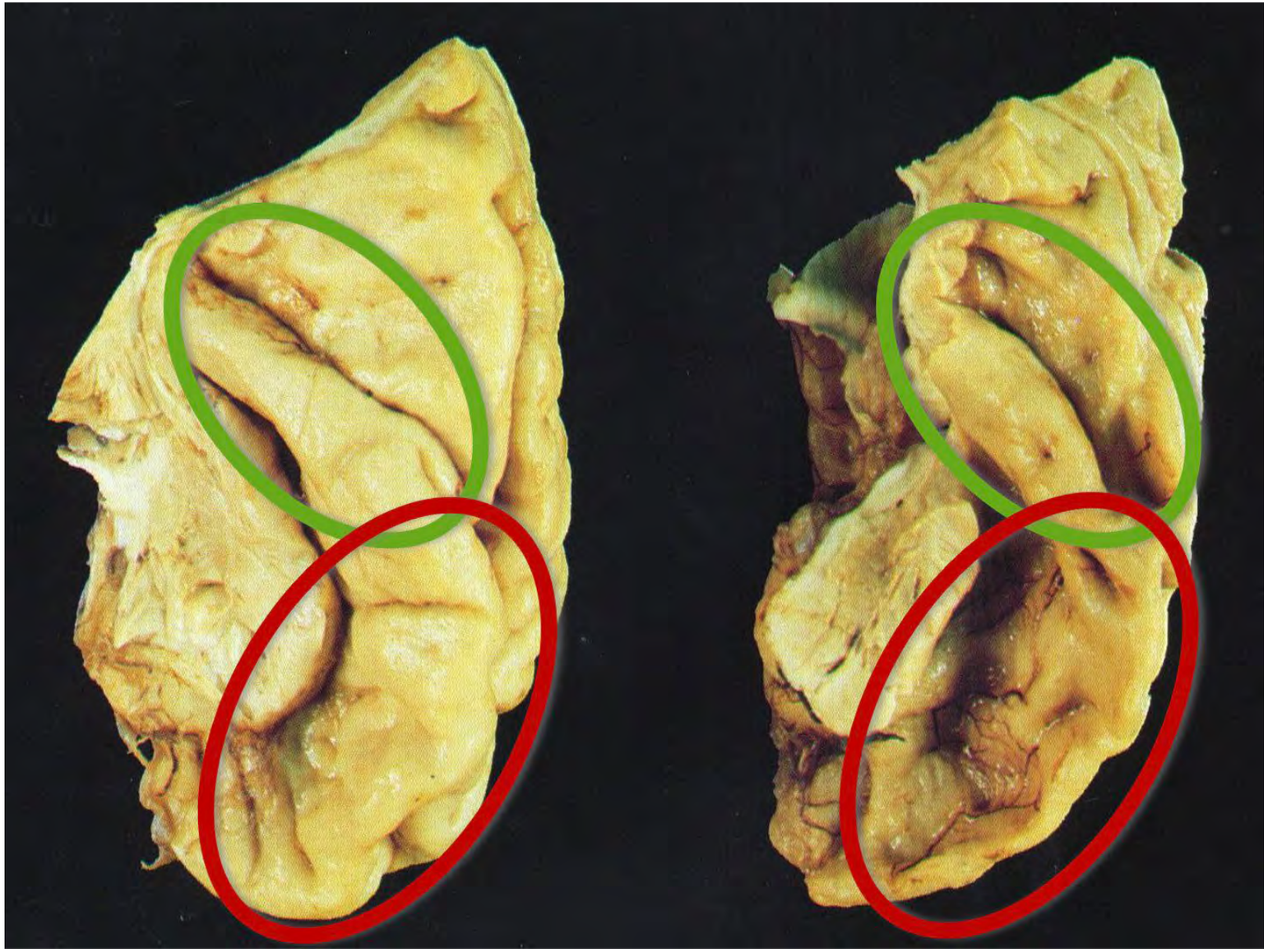
Hearing Sound Unchanged

BIG Language CHANGE



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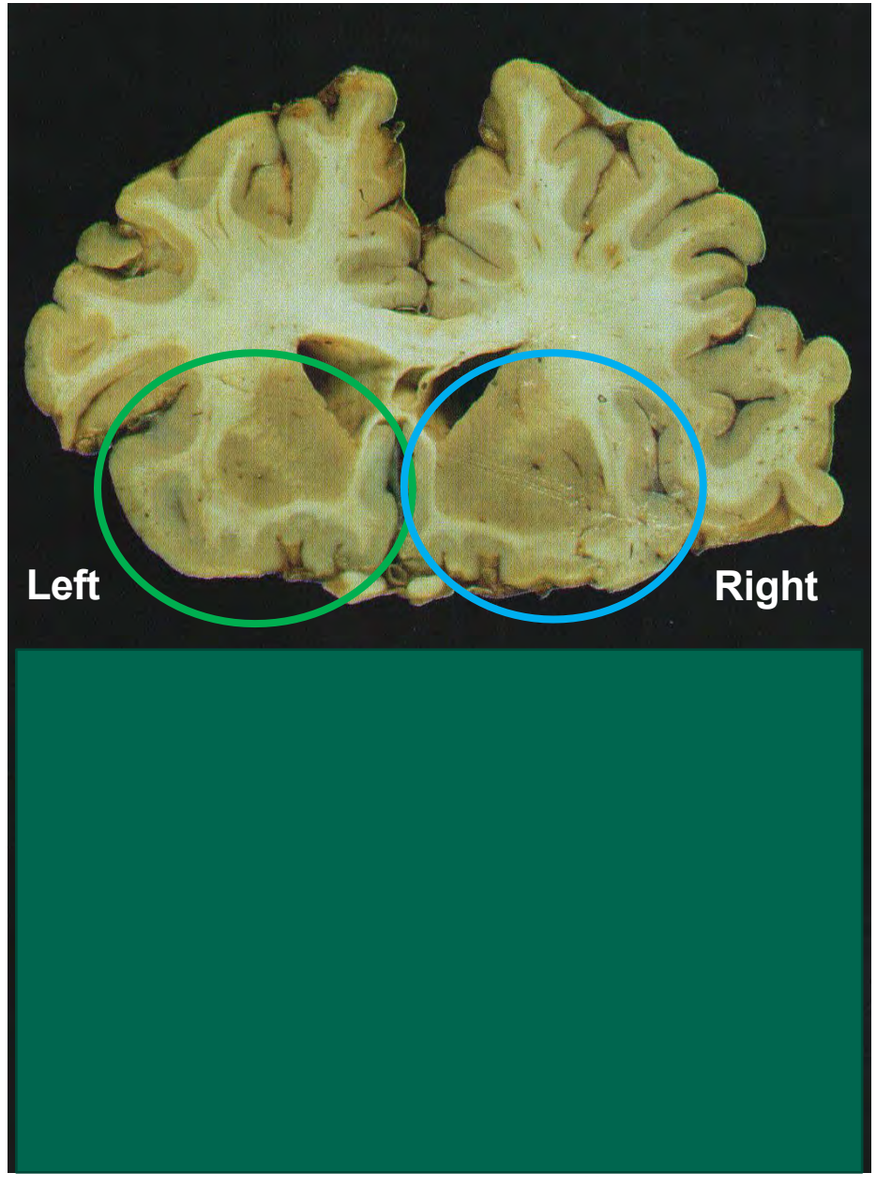

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- **Try:** *Let's just try.* Pointing to the exercise band.

Limit words: Keep it Straight Forward

Acknowledge their response/reaction…. **And then WAIT!!!**

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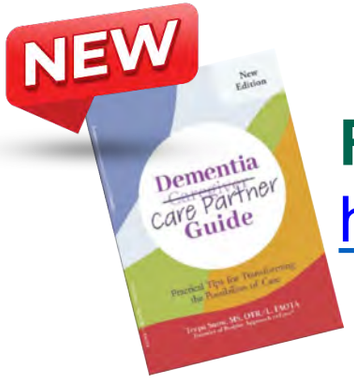

Read: Dementia Care Partner Guide
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Welcome to the Positive Approaches to Dementia Care ECHO

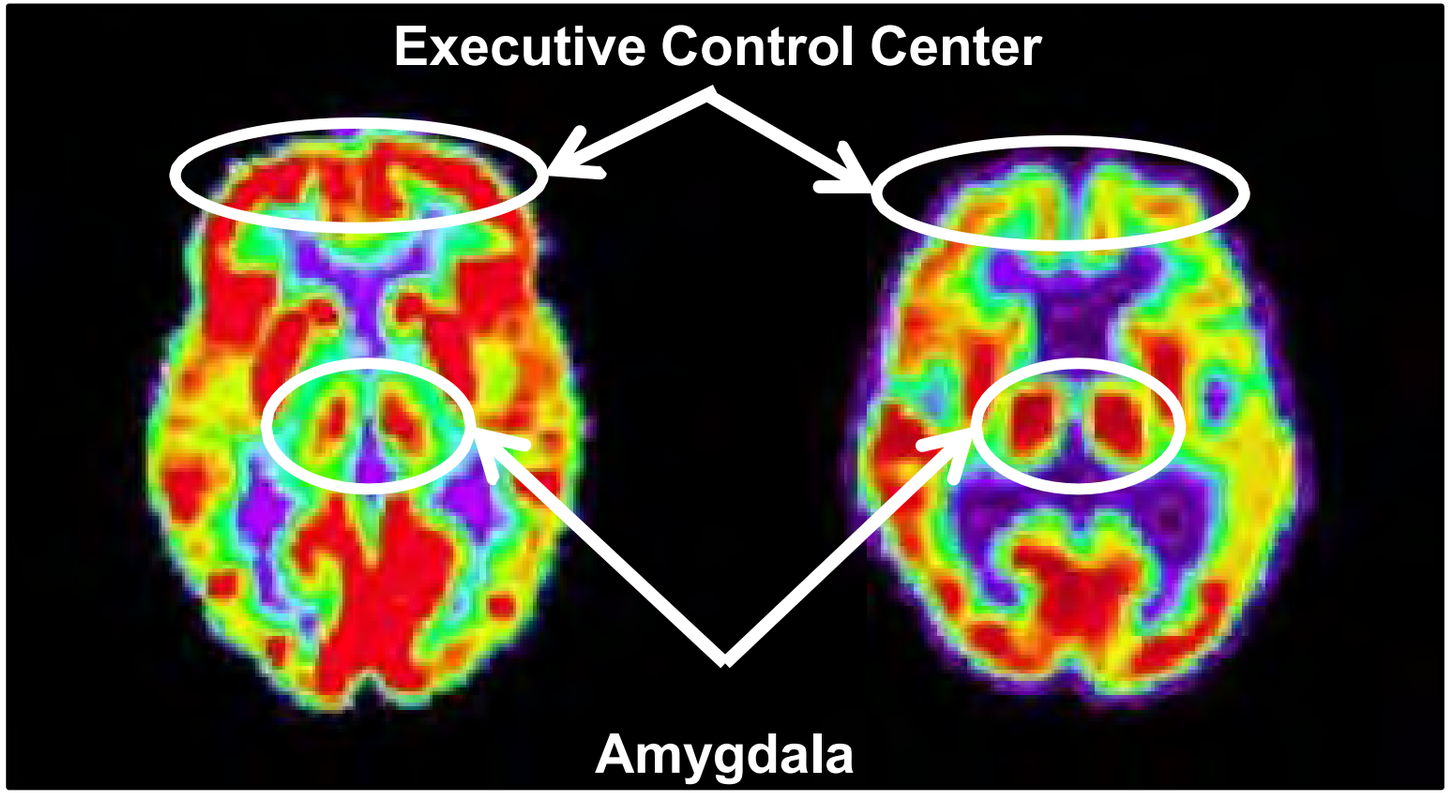
Session 6: How to Identify Unmet Needs

Wednesday June 18, 2025 2:00-3:00 p.m. (EST)

Positron Emission Tomography (PET)

Neurotypical Aging

Early Alzheimers



When the amygdala is fired up, the executive control center is less effective

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Supportive Communication Pattern

Watch Olivia try to use her new skill to support Teepa AND herself to help Teepa meet her need!

You can find the video here: https://www.youtube.com/watch?v=gLDK8i2cuss

G. Small, UCLA School of Medicine

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Left Temporal Lobe – and significant changes:

1. Vocabulary
2. Comprehension
3. Speech Production

Right Temporal Lobe - retained abilities:

1. Forbidden Words
2. Social Chit Chat
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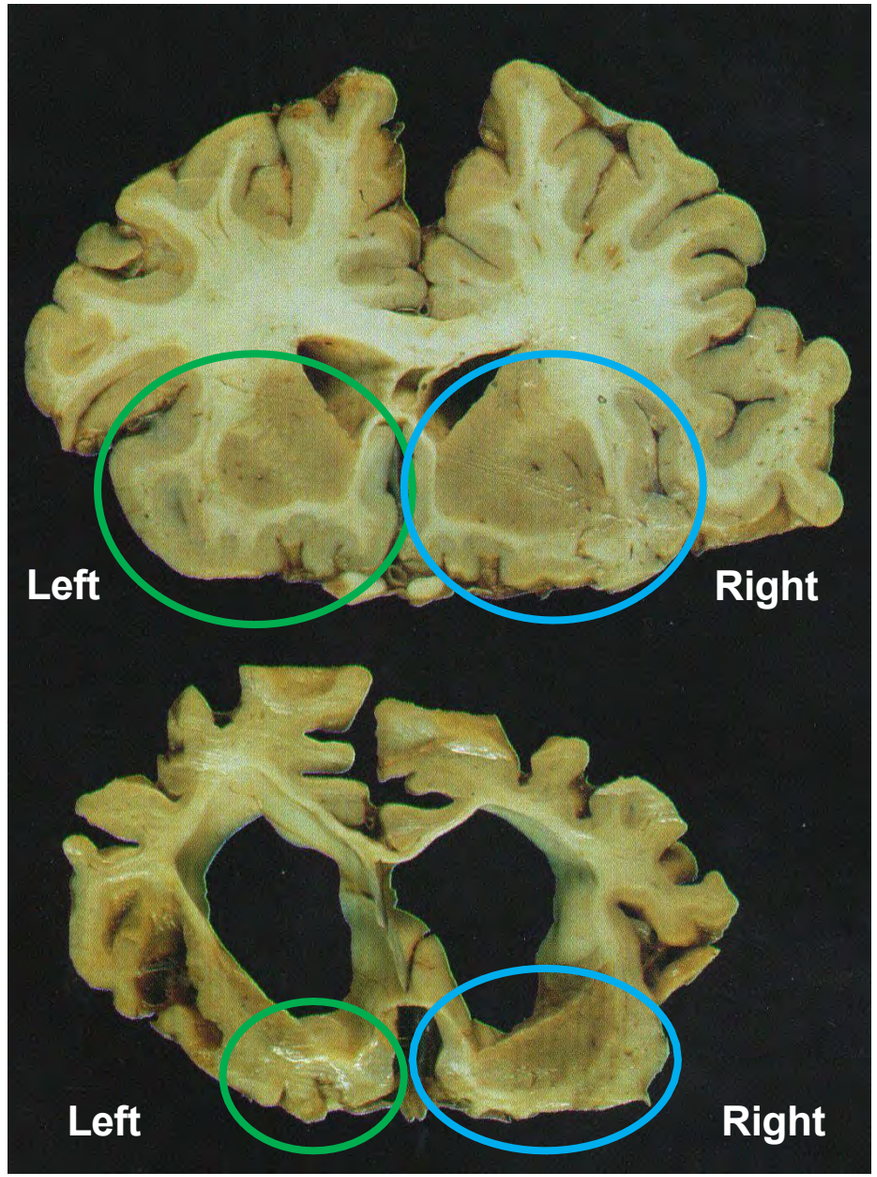

Dementia Education and Training Program (1995)

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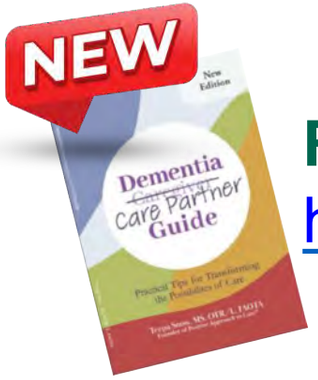

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 7: *What's Behind Aggression in Dementia?*

Wednesday July 16, 2025 2:00-3:00 p.m. (EST)

Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD

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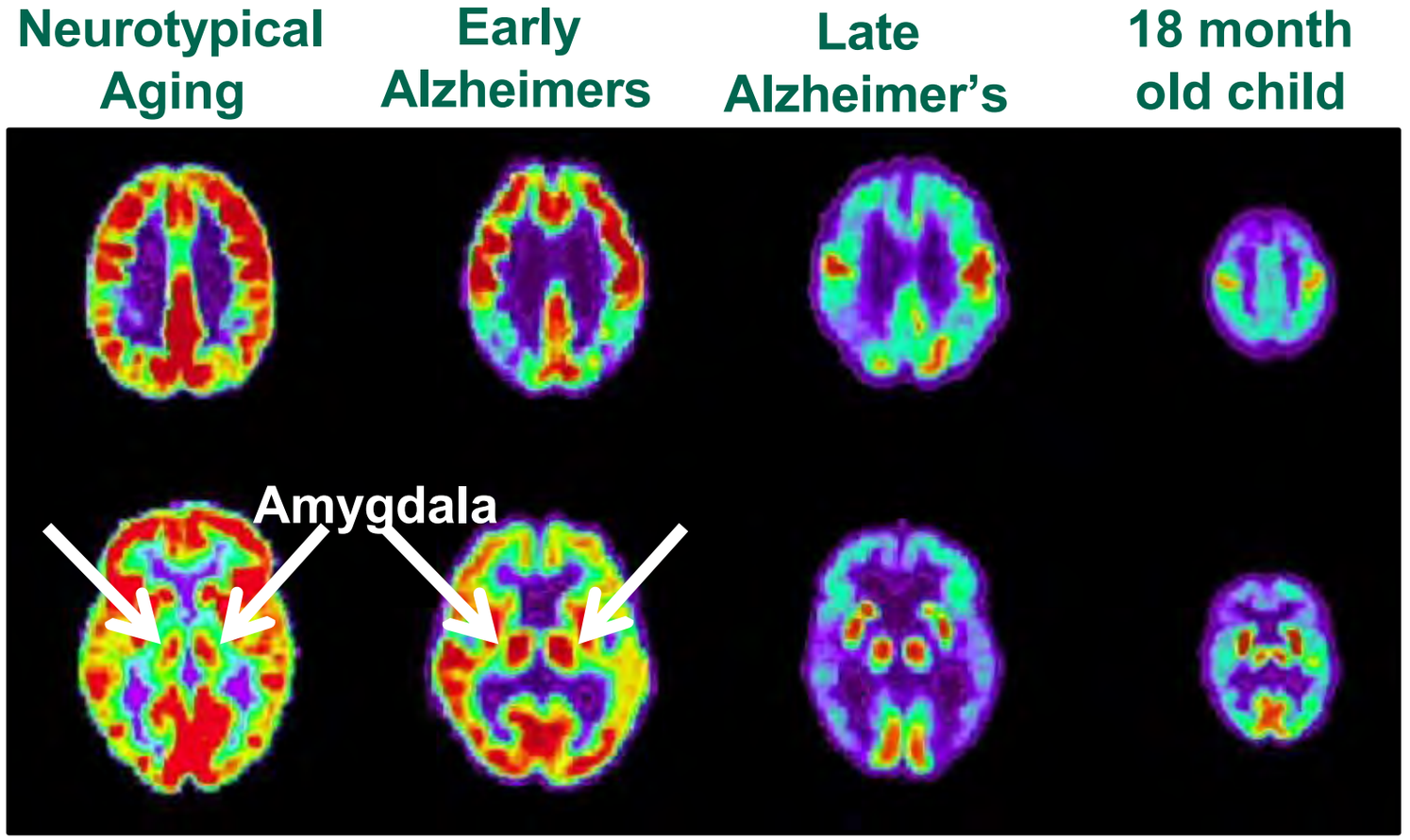

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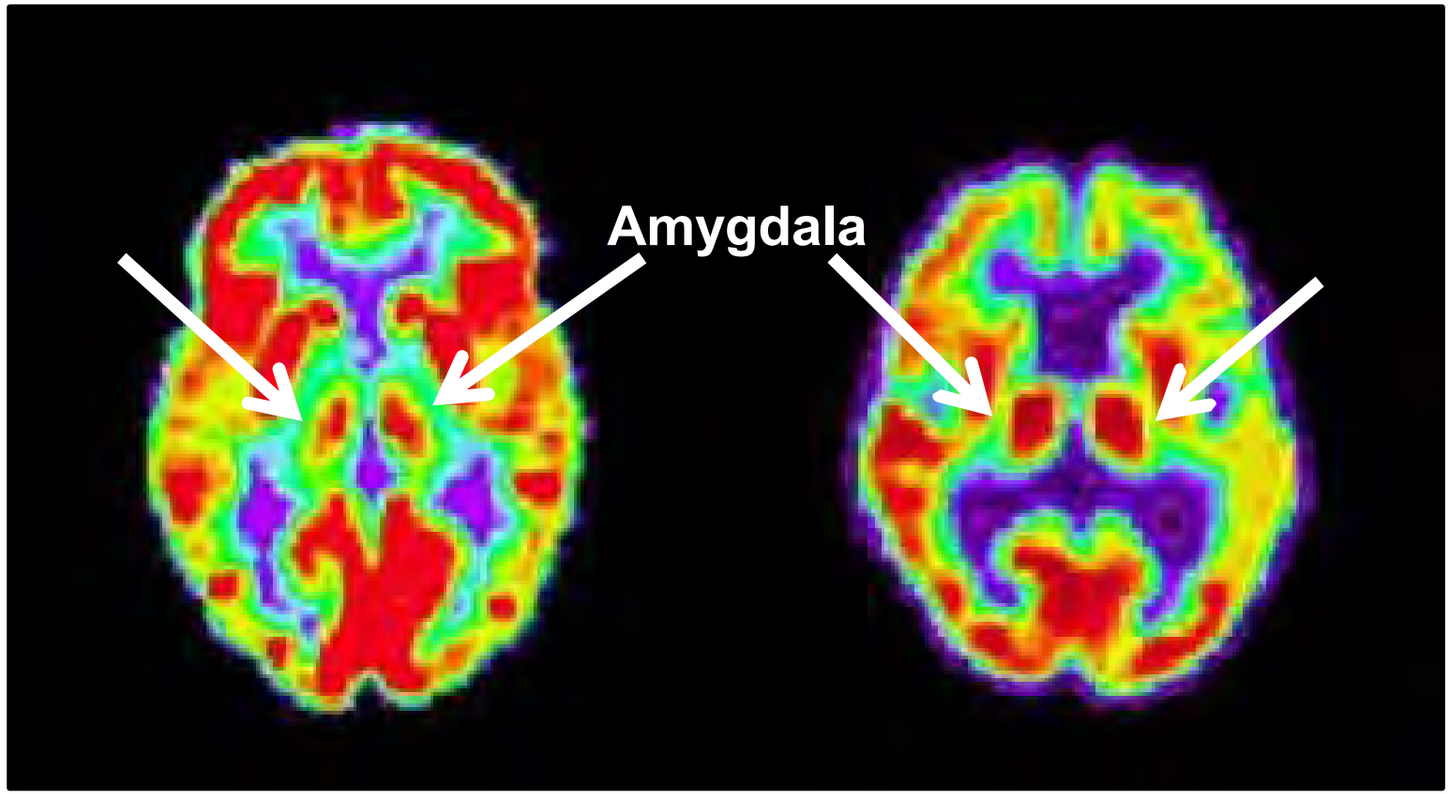

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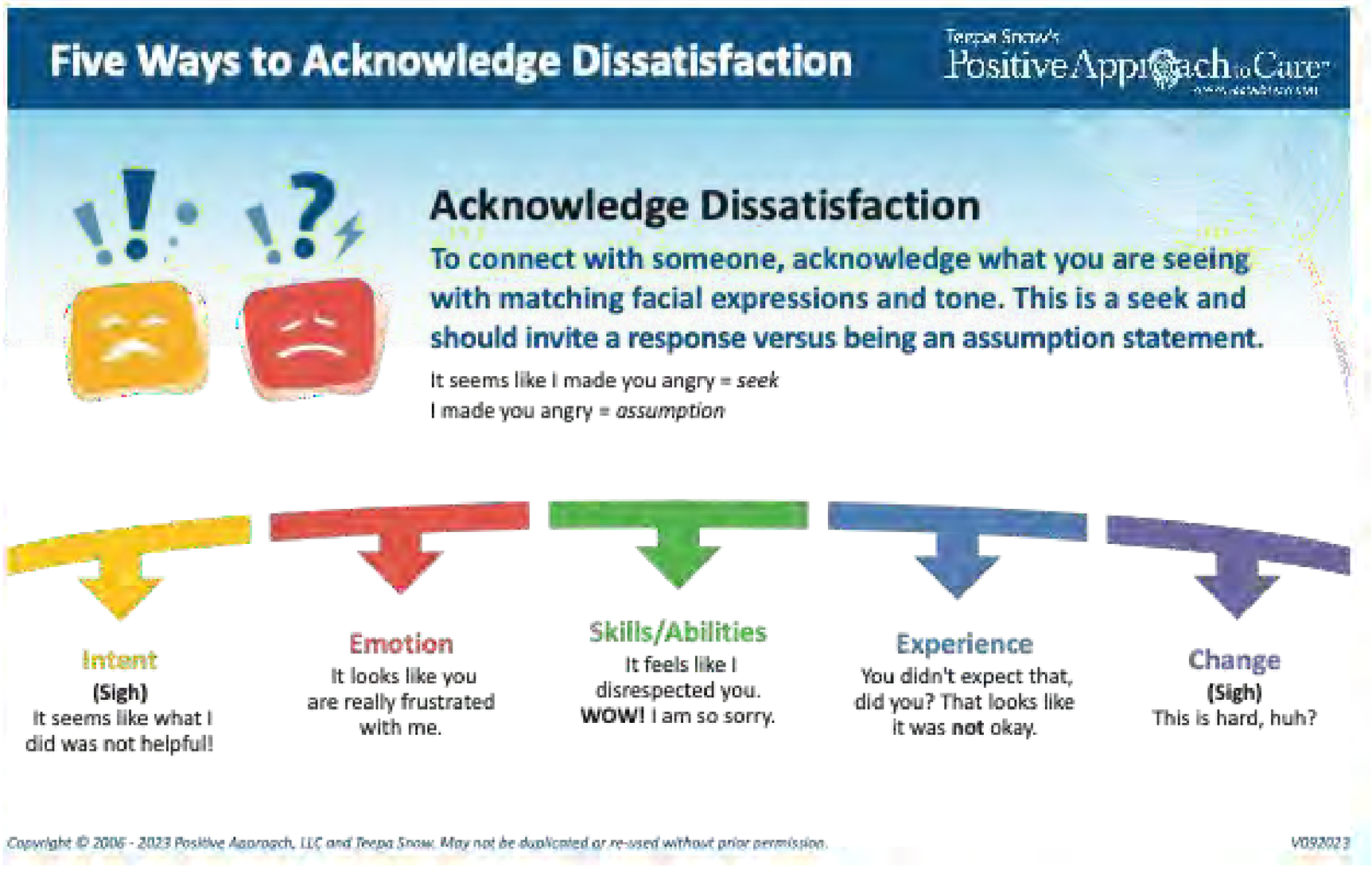
The Power of the Apology



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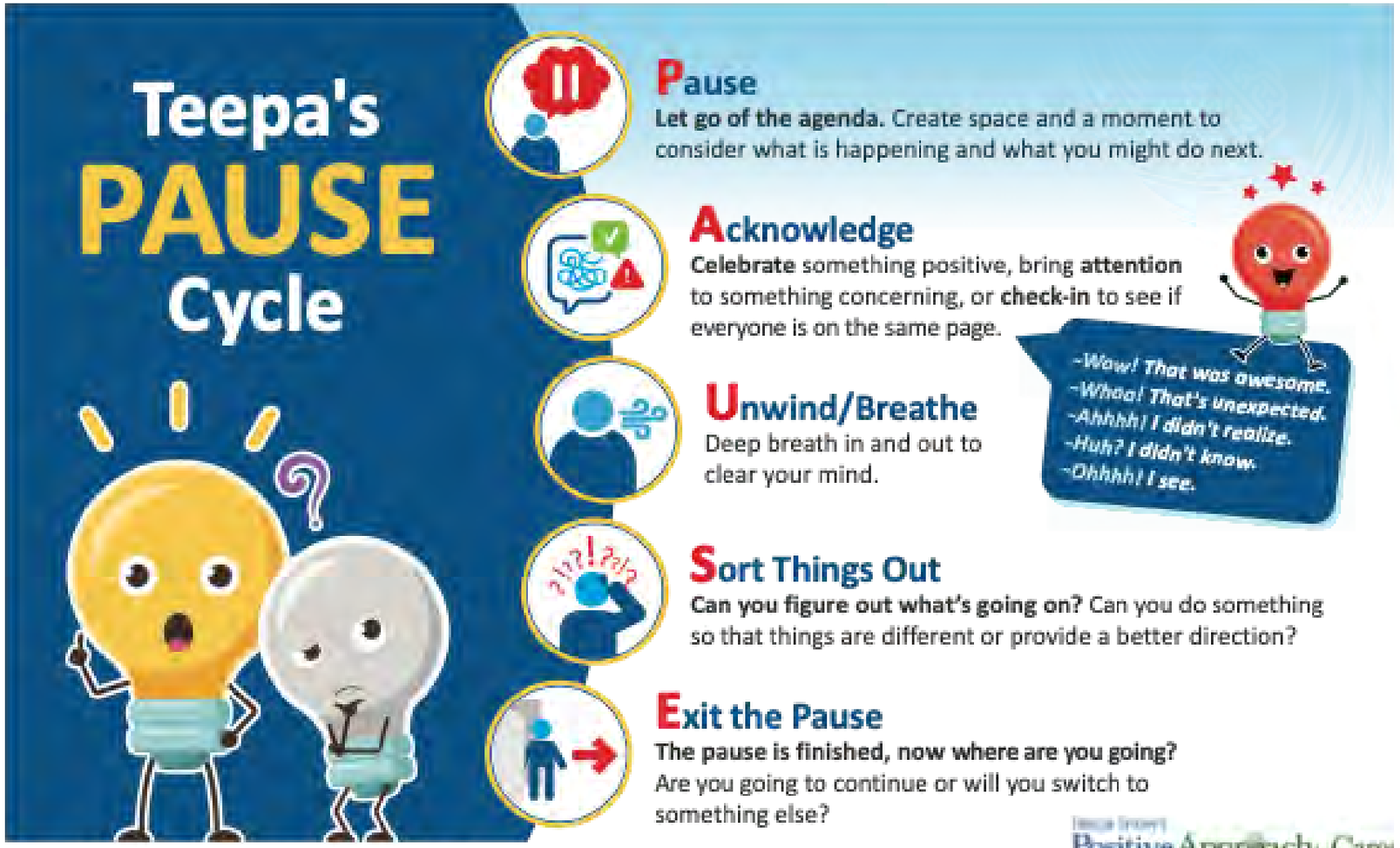
The Power of the Pause



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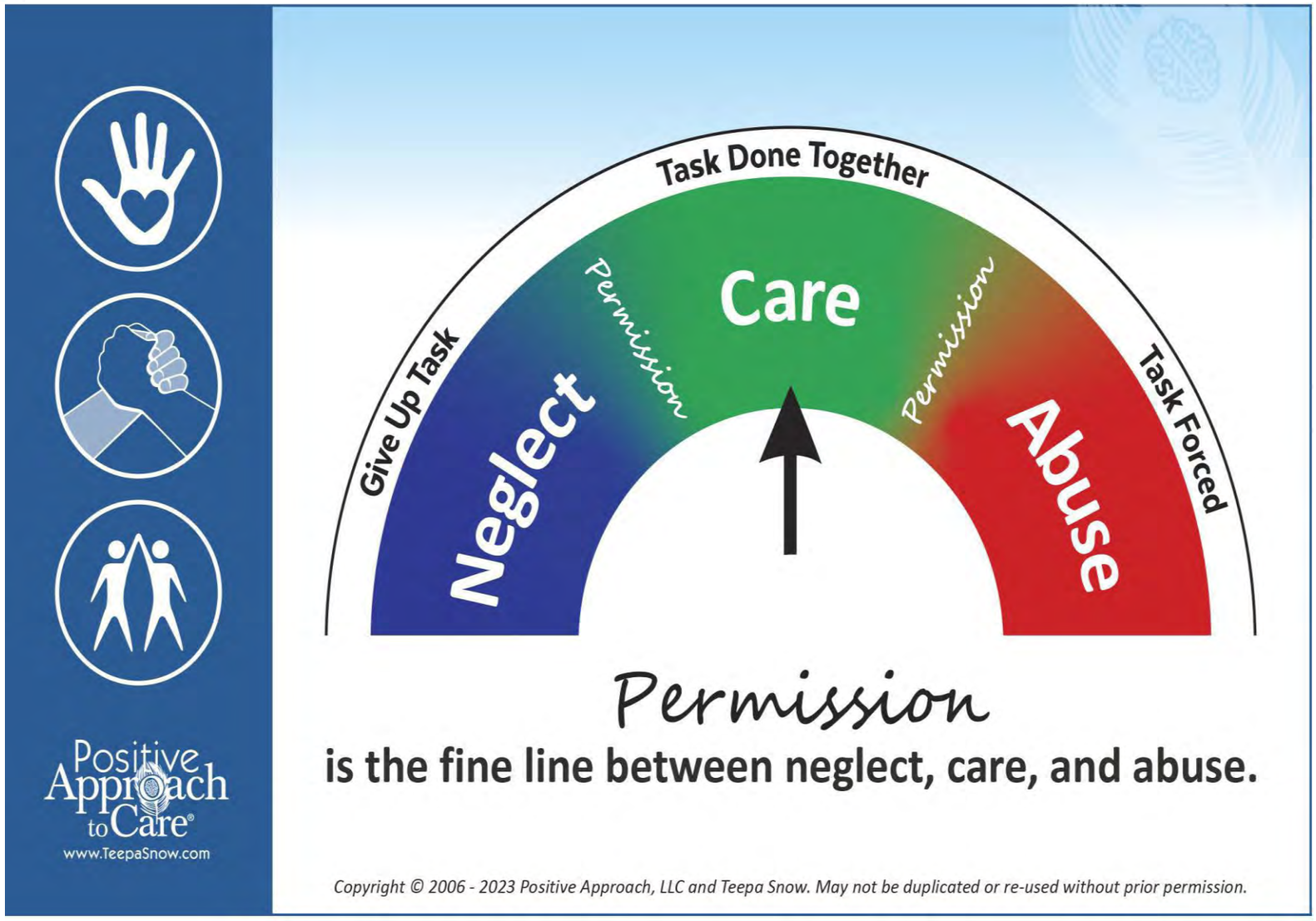

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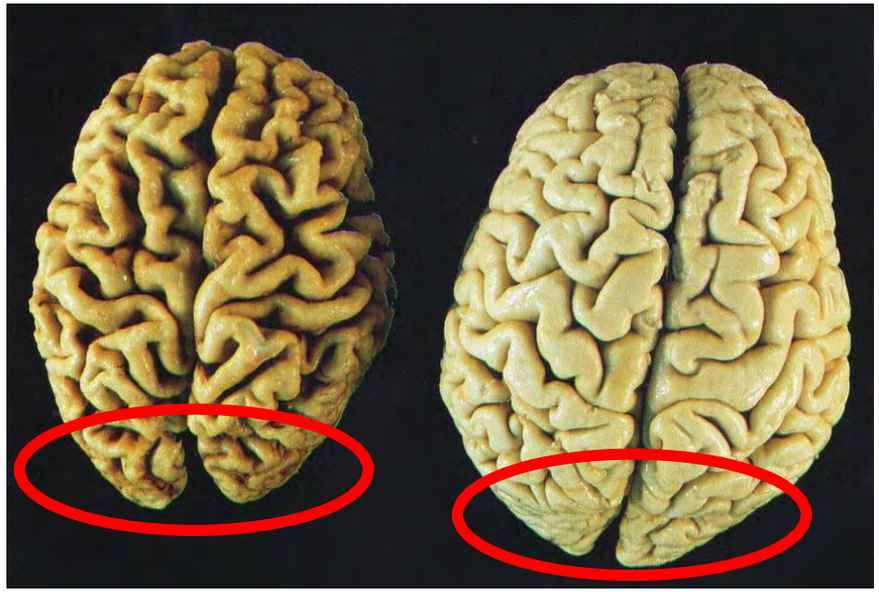

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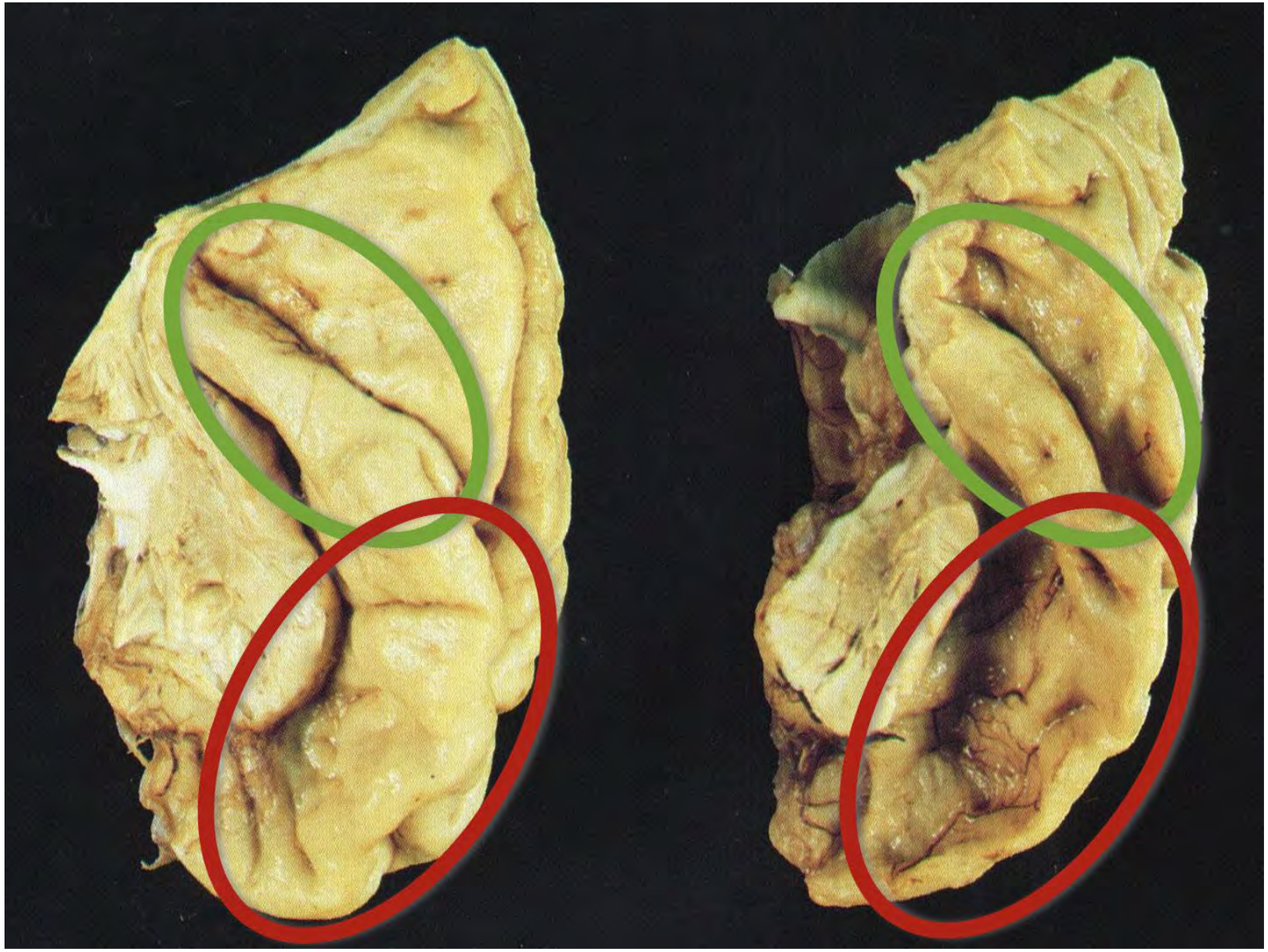
BIG Language CHANGE



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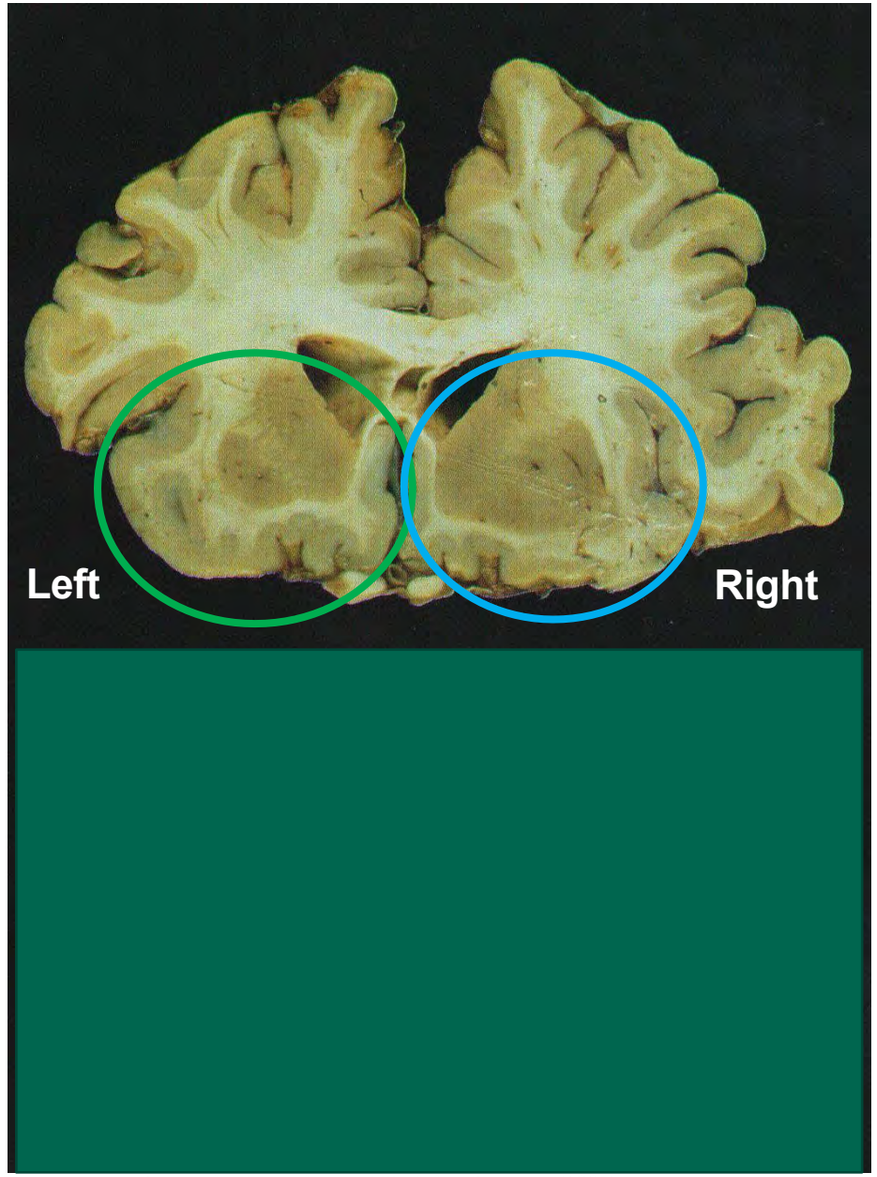

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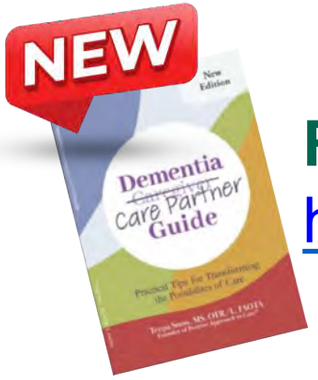

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 8: *Combativeness and De-escalation*

Wednesday August 20, 2025 2:00-3:00 p.m. (EST)

Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD

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Examples of What is Usually Called "Challenging" Behaviors

- 'Losing' Important Things
- Getting Lost – time, place
- Unsafe task performance
- Repeated calls & contacts
- Refusing help & care
- 'Bad mouthing' about staff
- Making up stories - confabulation
- Undoing what is done
- Swearing/cursing, sex talk, slur
- Making 911 calls
- Mixing day & night
- Sleep problems
- Not following care/rx plans
- No initiation – can't get started
- Not talking any more
- Infections & pneumonias
- Paranoid/delusional thinking
- Shadowing - following
- Eloping or Wandering
- Hallucinations
- Getting 'into' things
- Threatening caregivers
- Problems w/intimacy & sexuality
- Being rude - intruding
- Feeling 'sick' – not doing 'anything'
- Use of drugs or alcohol to 'cope'
- Striking out at others
- Contractures & immobility
- Falls & injuries
- Problems w/ eating or drinking
- Perseveration – can't stop repeating
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5 Emotional Indicators of Distress & Top 5 Human Needs

5 Emotional Expressions

Anger:	irritated – angry – furious
Sadness:	dissatisfied – sad – hopeless
Isolation:	missing someone – lonely – abandoned missing freedom – trapped – imprisoned
Fear:	anxious – scared – terrified
De-valued:	disengaged – bored – purposeless/useless distracted – antsy – exit seeking

Input: nourishment, hydration, medication, O2

Energy: Wake-sleep cycles, Revved up/Tired out.
Energy from within, from without

Elimination: Getting rid of excess waste products
(e.g., urine, feces, sweat, saliva, mucus, hair)

Discomfort: Liking or not liking… 4Fs and 4Ss

Friendly Familiar Functional Forgiving; *Sensory Social Space Surface-to-Surface*

PAIN!!: Physical Social Emotional Spiritual (joints, internal/external systems)

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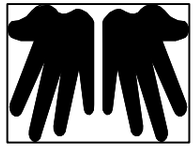
How you help… connect

- **See (Visual cues)**

- **Hear (Verbal cues)**



- **Touch (Tactile cues)**

  - 4th – Emotionally
  - 5th – Personally (Individually / Spiritually)

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Three Zones of Human Awareness

- 6 ft away or more - **Public Space** –
  Visual Interactions / Awareness

- 6 ft to arm's length - **Personal Space** –
  Conversations & Friendship

- Touch/Physical Contact - **Intimate Space** –
  Intense Physical Closeness

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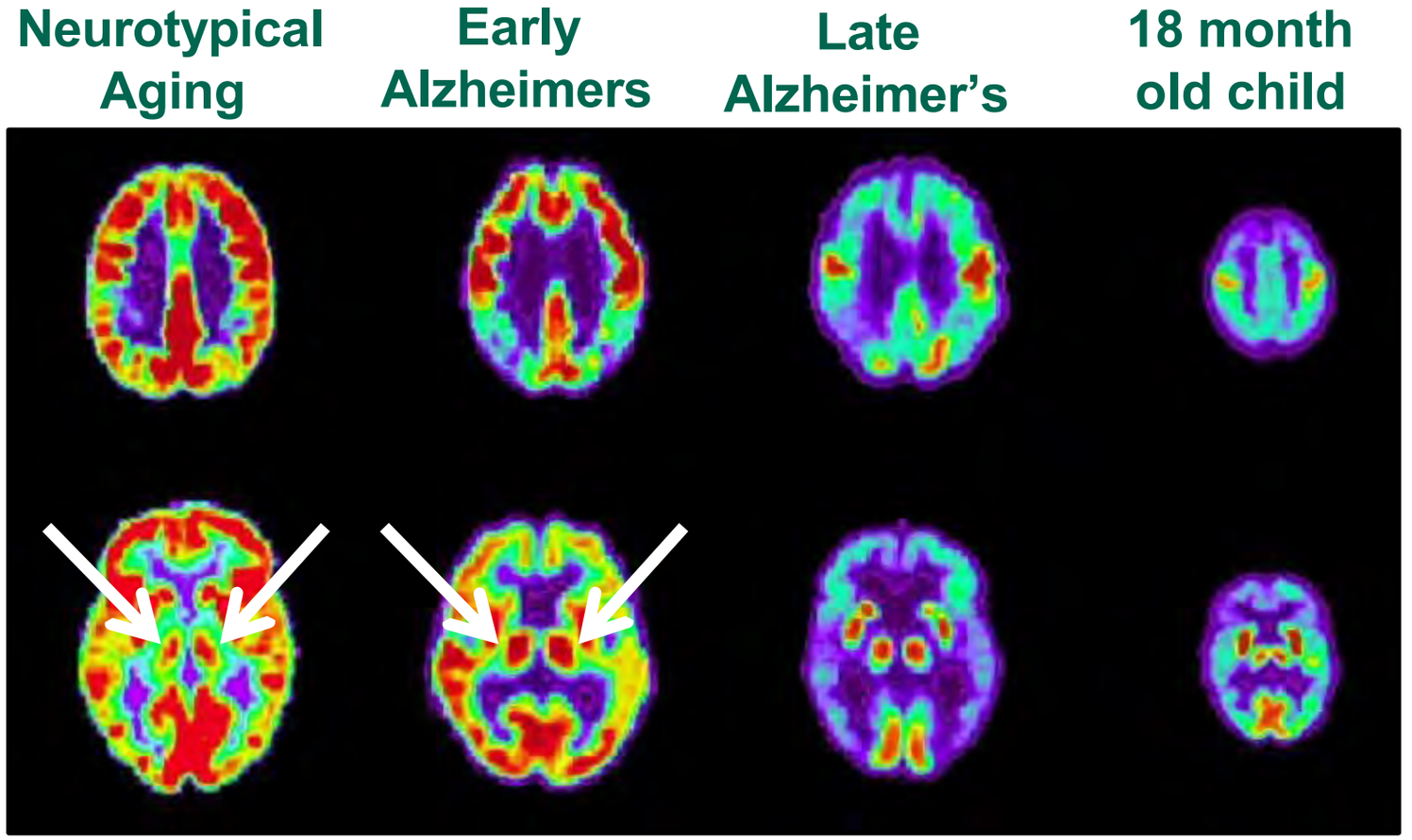

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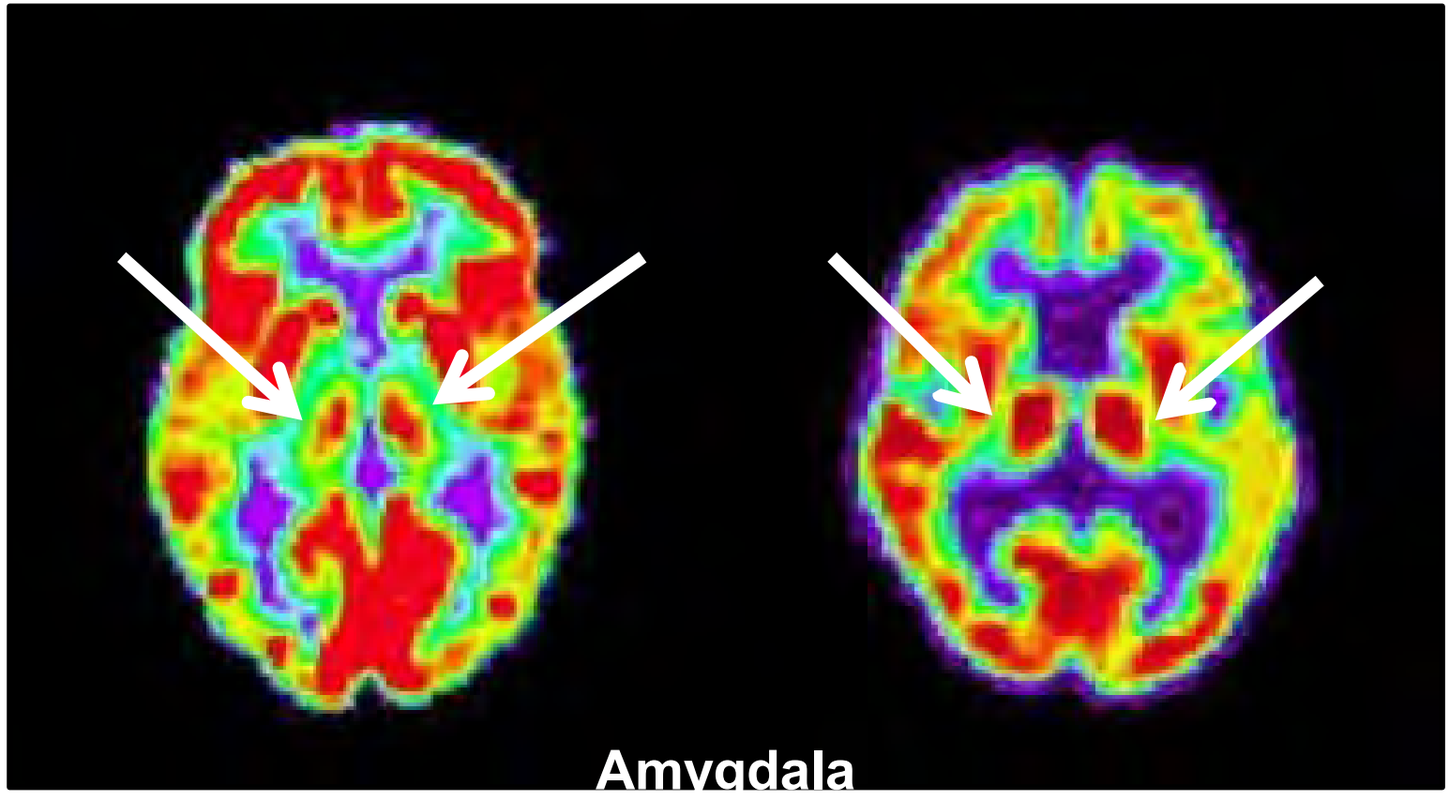

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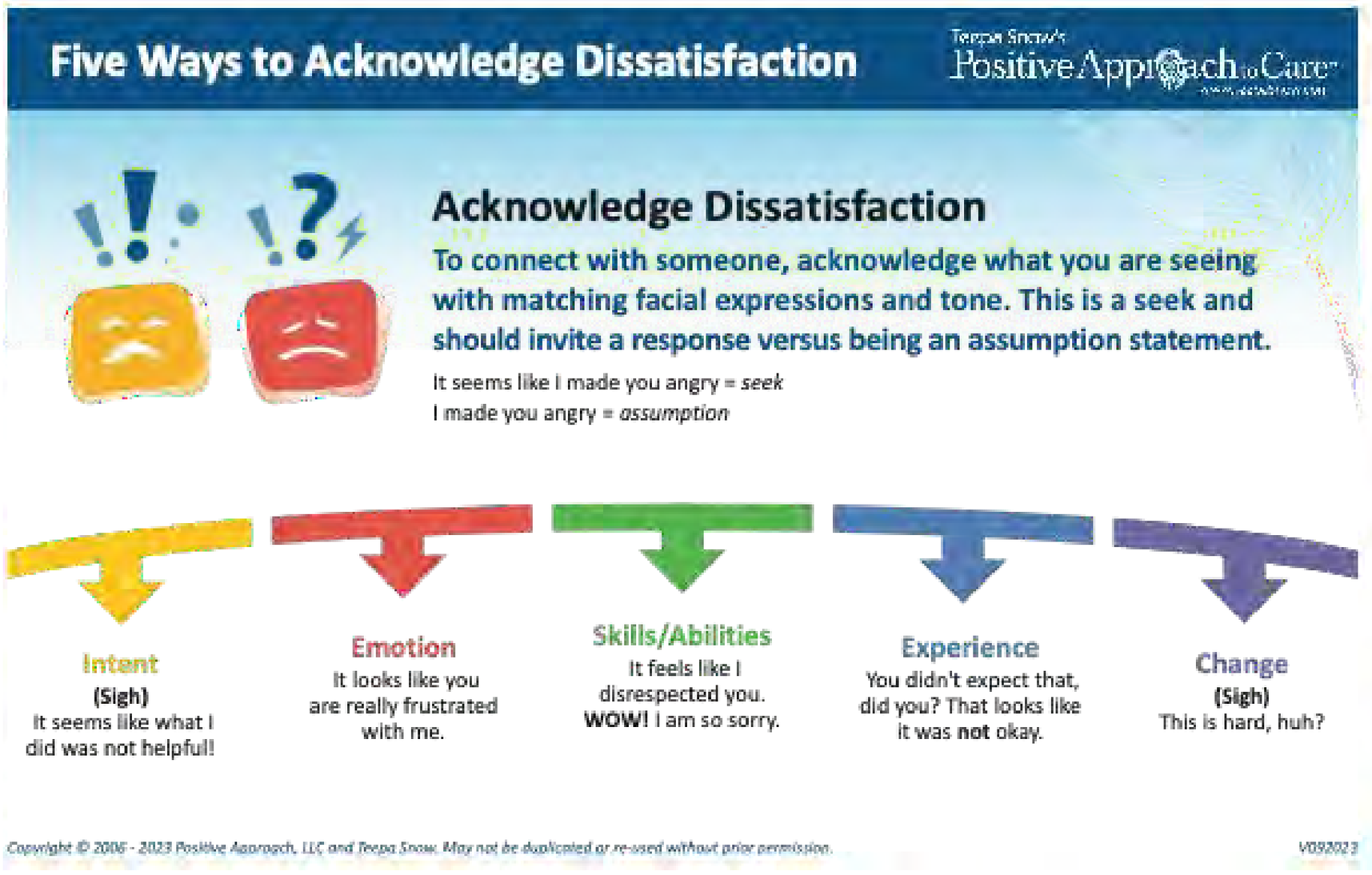

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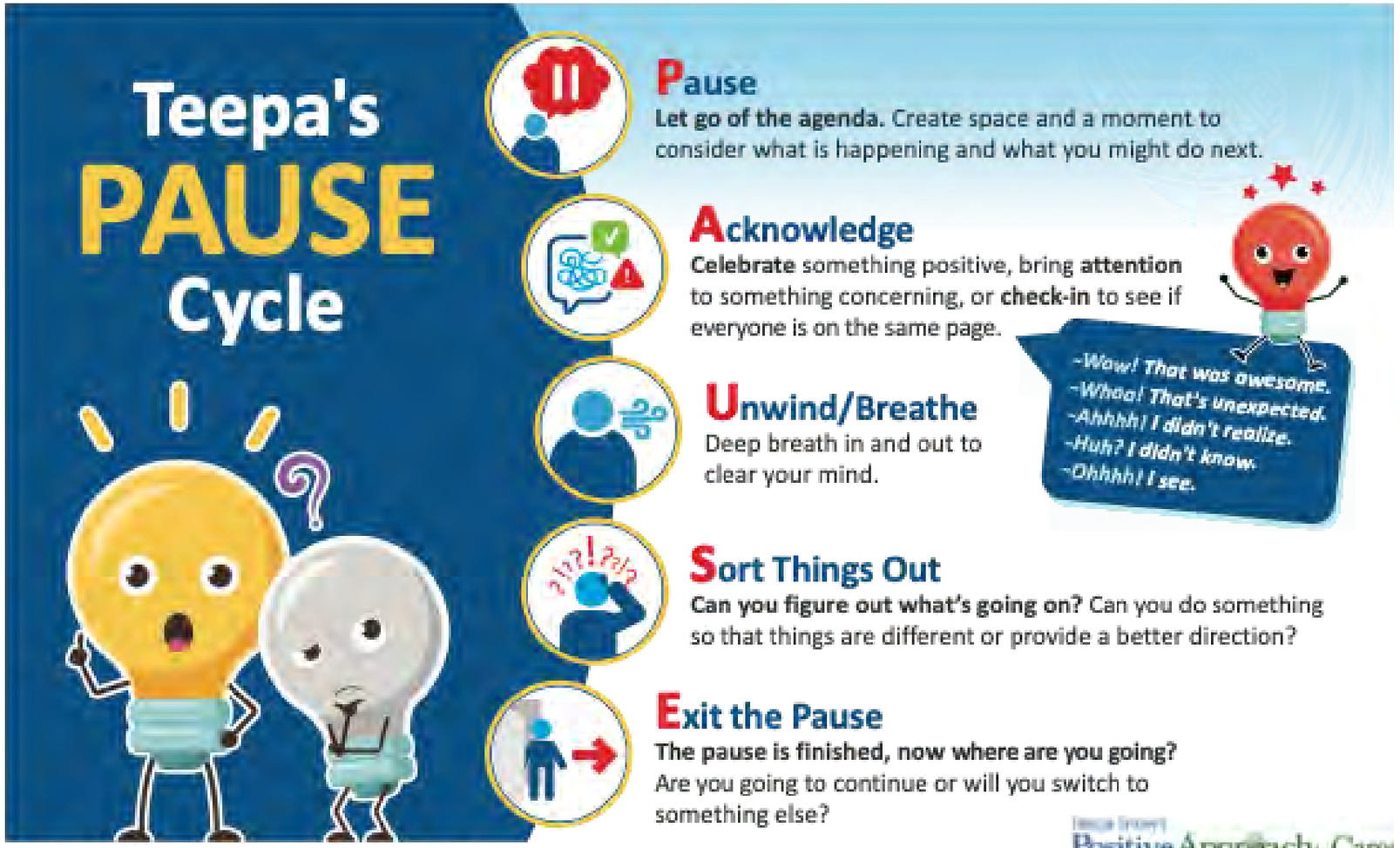

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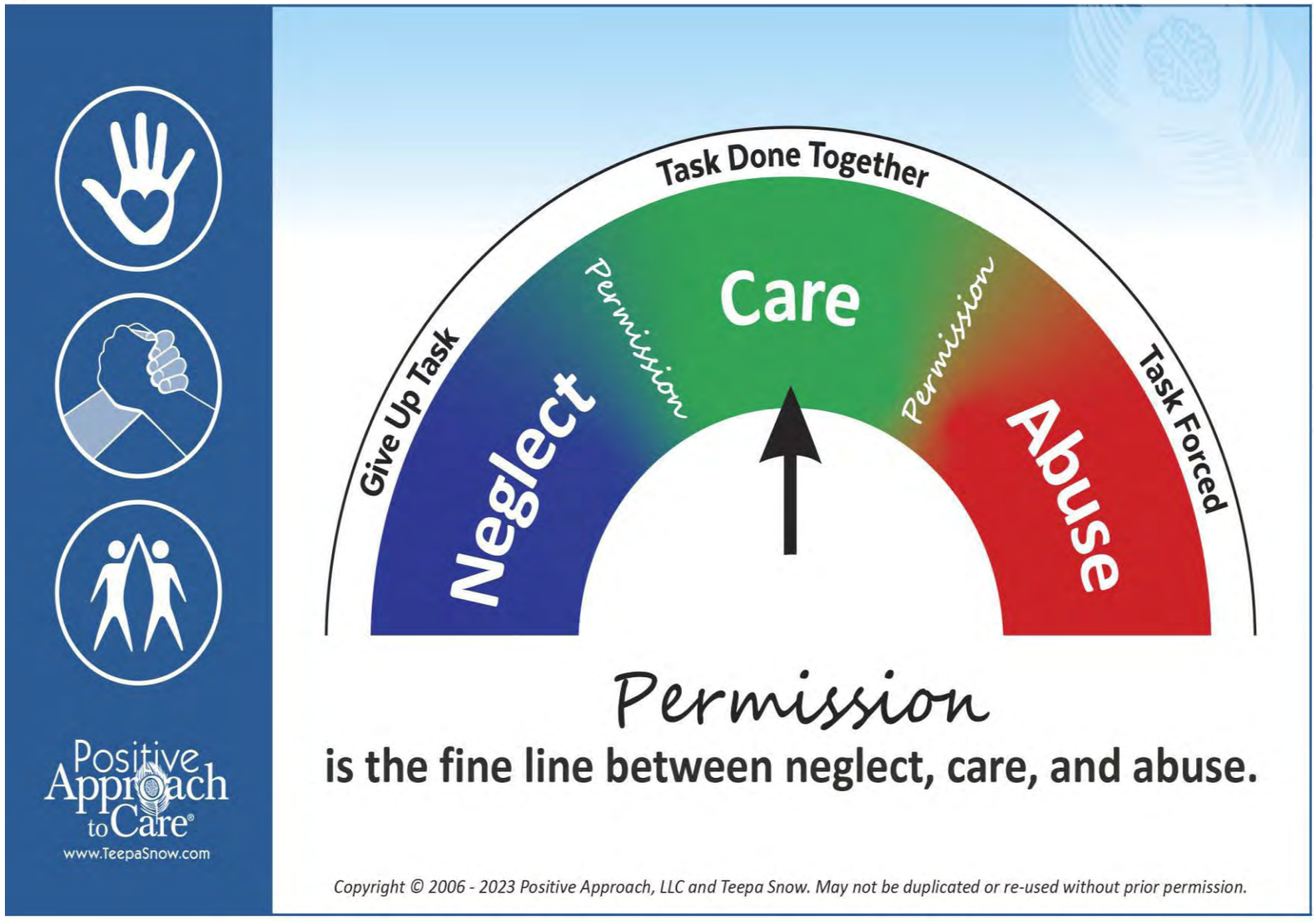

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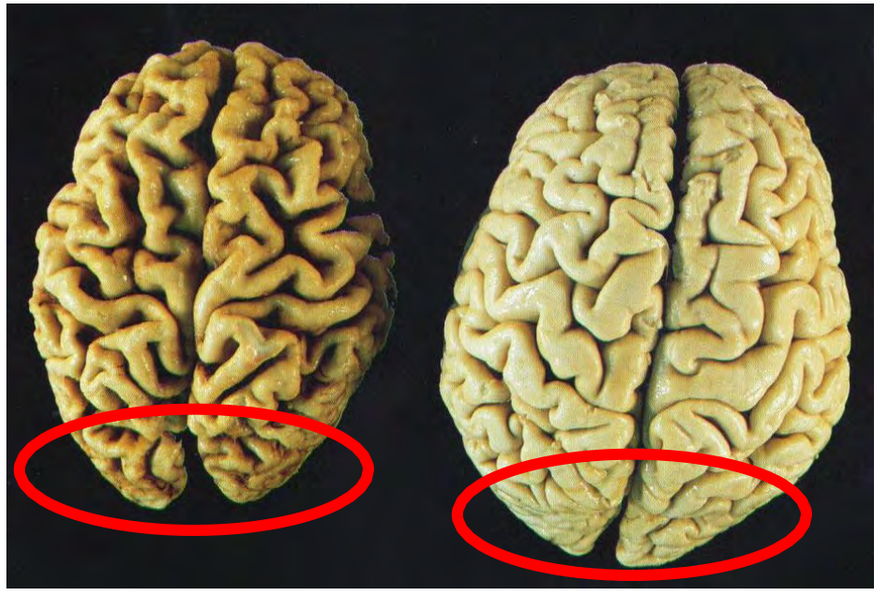

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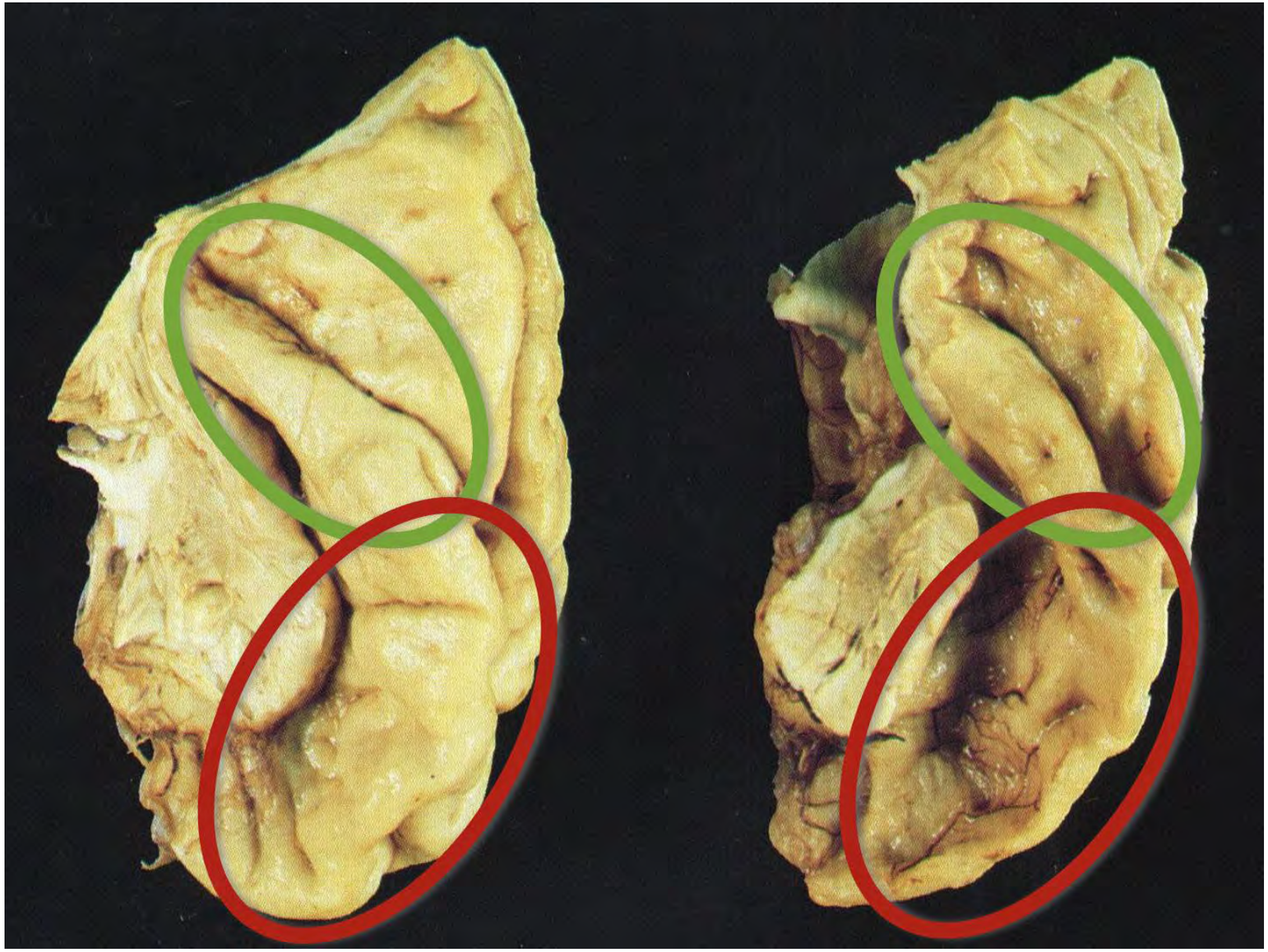

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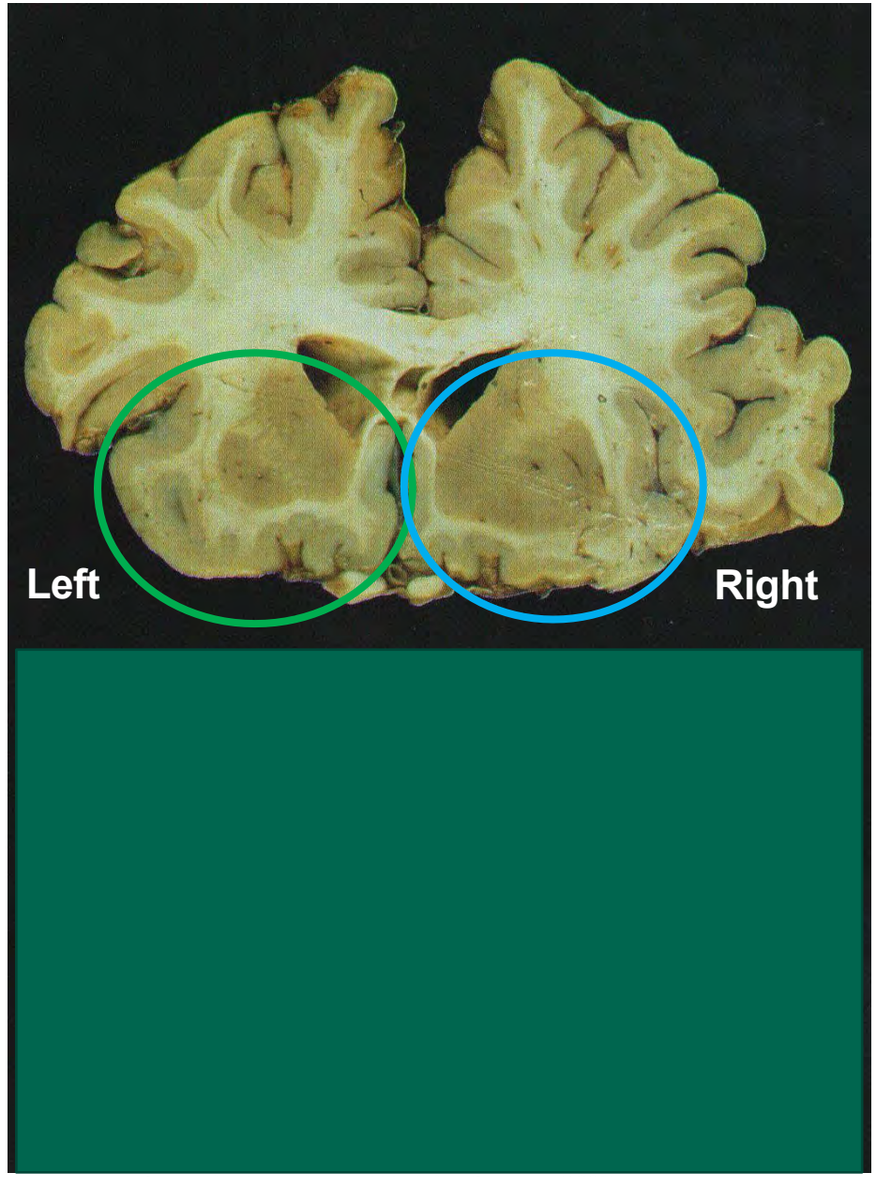

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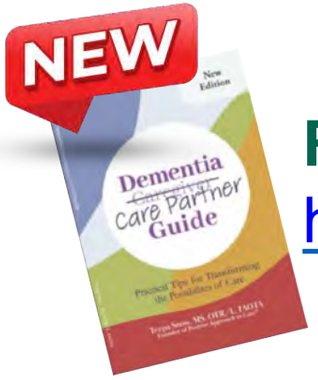

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Welcome to the Positive Approaches to Dementia Care ECHO

Session 9: *Disinhibition: Unfiltered Behaviors, Emotions, Impulses*

Wednesday September 17, 2025 2:00-3:00 p.m. (EST)

Disinhibition:
What's happening in the brain?

Beth A. D. Nolan, Ph.D. - Chief Public Health Officer

Teepa Snow's Positive Approach to Care ®

Br John-Richard Pagan, MA-MFT, CG

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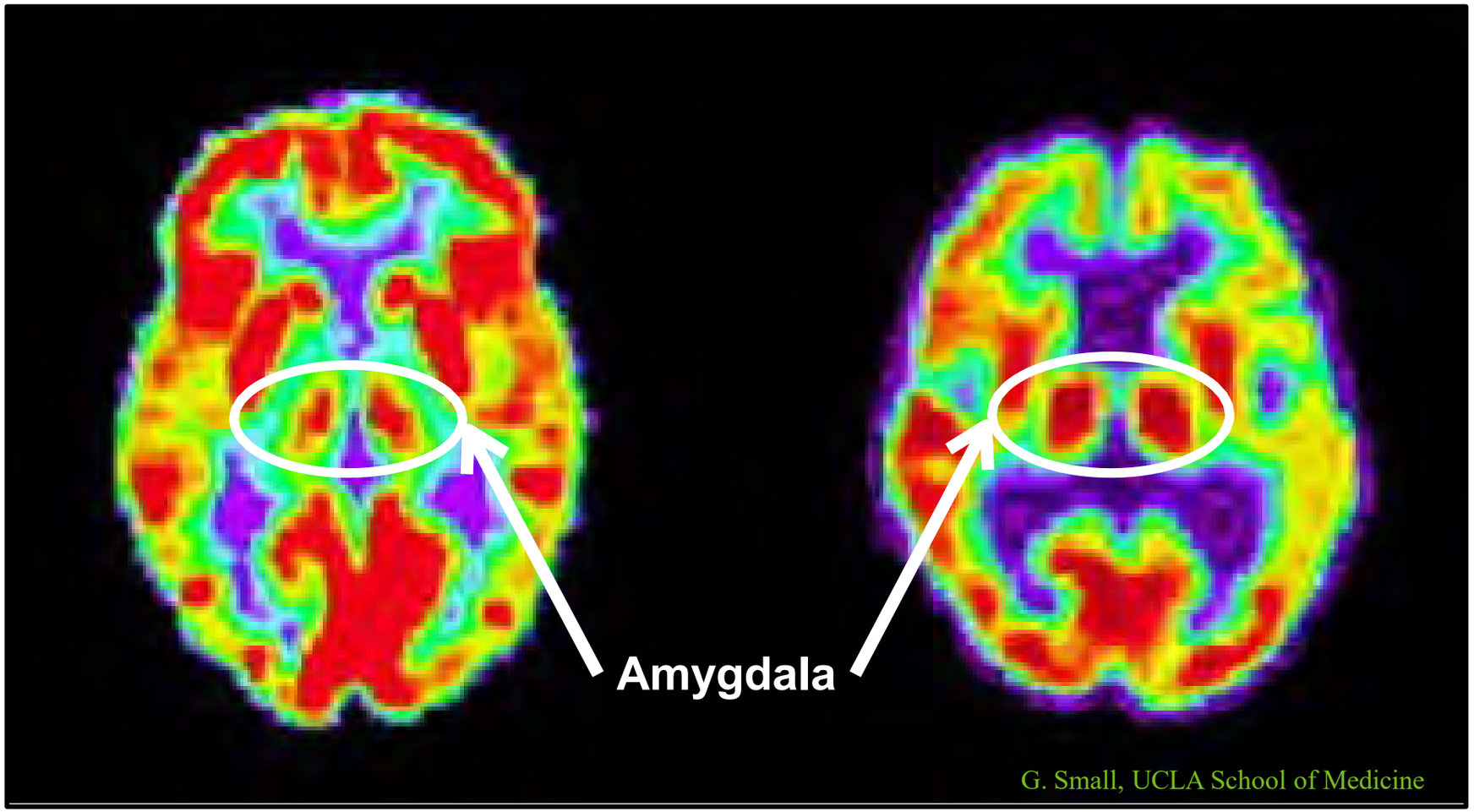

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6 Pieces of the Puzzle for Individuals: Problem Solving Model

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  Or *Here's your socks.* Hold up sock.
- **Step by Step:** *Let's go this way.* Point.

  Or *Lean forward.* Motion forward with hand.
- **Choice:** *Coffee or tea?* Raise coffee cup then tea bag.
- **Help:** *I could use your help.* Implied compliment on skill.
- **Try:** *Let's just try.* Pointing to the exercise band.

Acknowledge their response/reaction…. **And then WAIT!!!**

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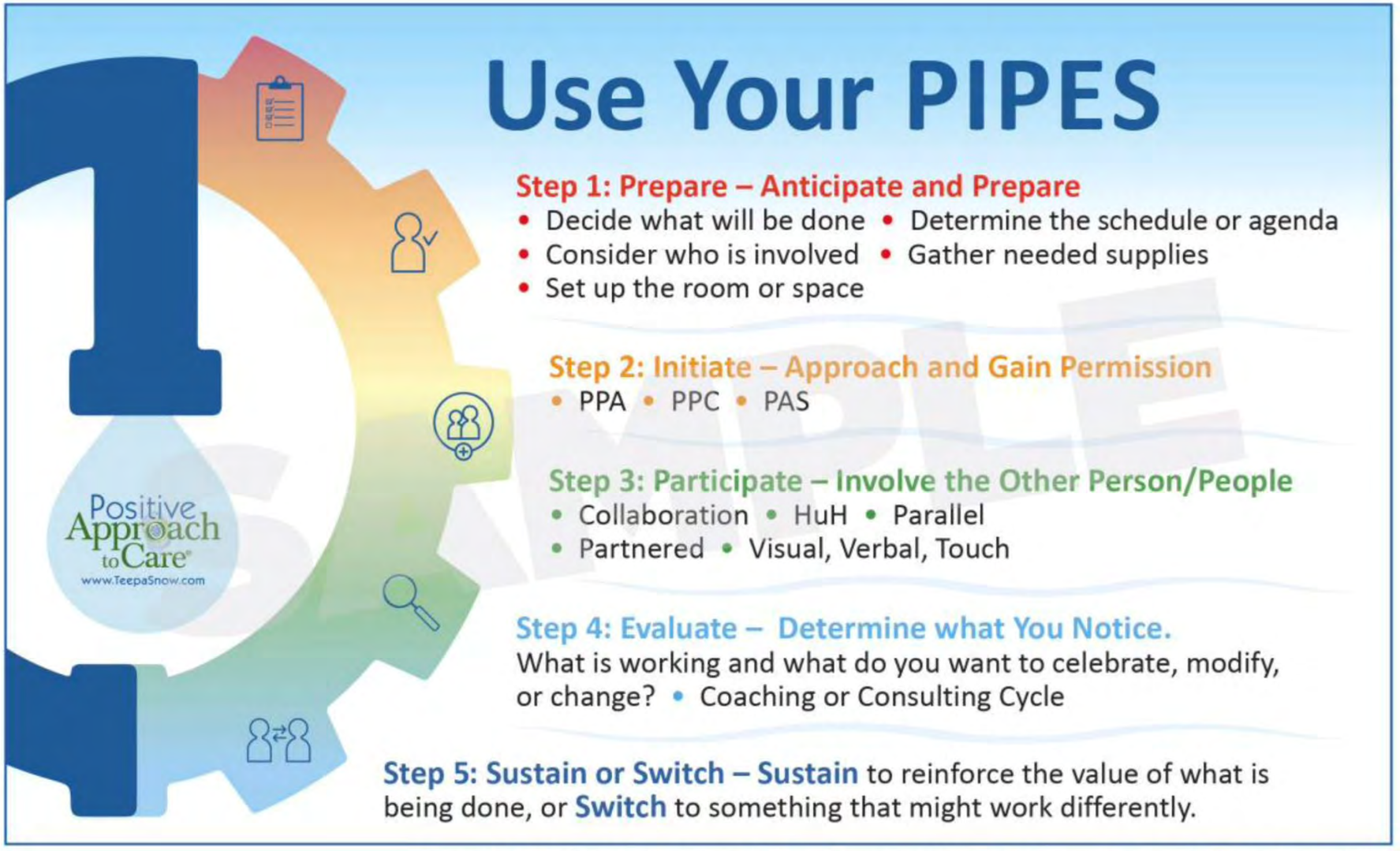
5 Ps



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5 Ps

- ❑ Place
- ❑ People
- ❑ Props
- ❑ Programming
- ❑ Possibilities

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Use Your PIPES Around the 5Ps

1. Place - What is the physical space involved?

- What in the setting or environment needs to change?
- What is missing?
- What is working well?
- What is not working well?

2. People - Who are the people involved?

- What do we know about them?
- What do they need to be aware of?
- What do they need to know how to do?
- Have they ever seen better interactions or outcomes?

3. Props - What are the physical and visual objects involved?

- What are the objects and items around, and do they meet expectations?
- Are there substitutions or alternatives available to better match interests and abilities?

4. Programming - What is the planned use of time involved?

- How is time being used and how long do people have to wait for support?
- How much time does staff have to offer support for each person?
- What do the rhythms of each day look like for the various people involved?
- Is there balance for all involved of:
  - *Purposeful engagement*
  - *Pleasurable enjoyment*
  - *Personal care completion*
  - *Rest and restoration periods*

5. Possibilities - What are the possible changes involved?

- What could we try, or what is a new pathway or synaptic pattern we want to attempt?
- How will we know if we are making any meaningful progress?
- Which of the other Ps could/should we vary?

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6 Pieces of the Puzzle for Individuals: Problem Solving Model

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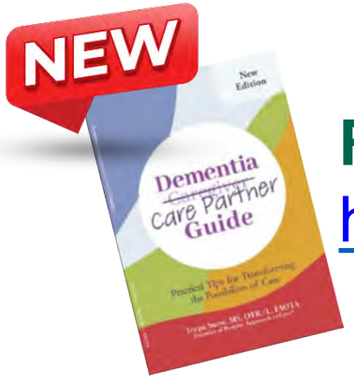

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Examples of Words We Use for "Challenging" Behaviors (when we don't understand)

Getting 'into' things
'Losing' Important Things
Getting Lost –in time or place
Unsafe task performance
Repeated calls & contacts
Refusing showers & care
'Bad mouthing' about staff
Making up stories
Undoing what is done
Swearing/cursing, sex talk, slur
Making frequent 911 calls
Mixing day & night (Sleep problems)
Not following care/rx plans
Just 'sits there' —no initiation
Not talking any more
Infections & pneumonias

Public urination
Paranoid/delusional thinking
Shadowing - following
Eloping or Wandering
Hallucinations
Threatening caregivers
Problems w/intimacy & sexuality
Being rude - intruding
Feeling 'sick' –
Use of drugs or alcohol to 'cope'
Striking out at others
Contractures & immobility
Falls & injuries
Problems w/ eating or drinking
Repeating—Perseveration
Undressing in public
Not changing when needed

5 Emotional Indicators of Distress & Top 5 Human Needs

5 Emotional Expressions

Anger:	irritated – angry – furious
Sadness:	dissatisfied – sad – hopeless
Isolation:	missing someone – lonely – abandoned missing freedom – trapped– imprisoned
Fear:	anxious – scared – terrified
De-valued:	disengaged – bored – purposeless/useless distracted – antsy – exit seeking

5 Human Needs

Input: nourishment, hydration, medication, O2

Energy: Wake-sleep cycles, Revved up/Tired out.
Energy from within, from without

Elimination: Getting rid of excess waste products
(e.g., urine, feces, sweat, saliva, mucus, hair)

Discomfort: Liking or not liking… 4Fs and 4Ss
Friendly Familiar Functional Forgiving; *Sensory Social Space Surface-to-Surface*

PAIN!!: Physical Social Emotional Spiritual (joints, internal/external systems)

Teepa Snow's *Snow Approach:*

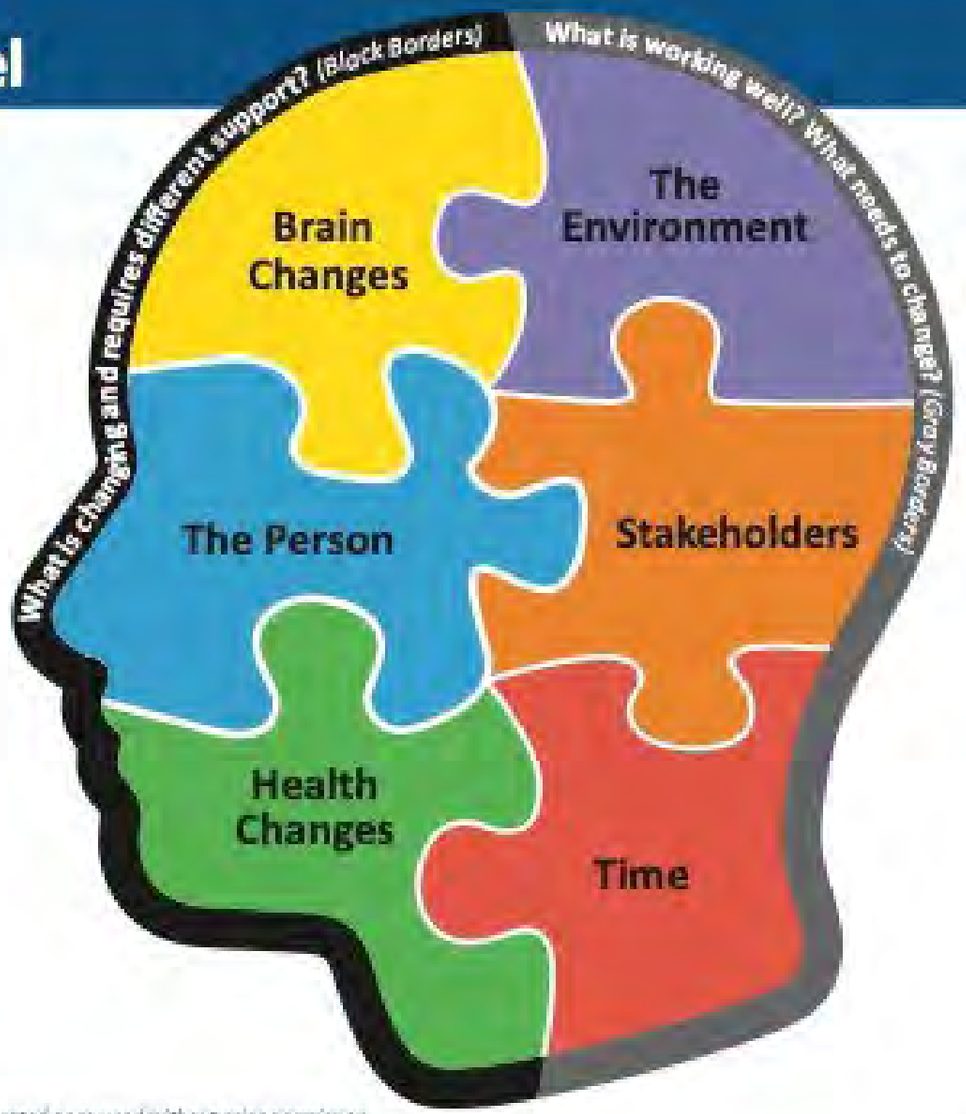
Problem Solving Model

For Individuals:

Six Pieces of the Puzzle

Life can be challenging for all people and figuring out the cause for distress and what helps is critical.

Using these six categories organizes our investigation and keeps us focused and alert.



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What is changing and requires different support? *(Black Borders)*

Brain Changes

Dementia

- Type(s)
- Awareness of changes?

Delirium? Depression or Anxiety?
GEMS State(s)

- Changed abilities
- Retained abilities
- Variability
- Onset and duration

The Person

Past and Present

- Life story – history
- Personality traits
- Preferences – likes/dislikes
- Key values
- Joys and traumas
- Roles – watch-talk-do
- Notable positive changes?
- Notable negative changes?

Health Changes

Health Conditions and Physical Fitness

- Intake, throughput, output
- Meds and supplements
- Emotional and psychological condition
- Sensory systems function
- Health beliefs of note
- Recent changes
  - Acute episode of illness
  - New/worsening chronic illness

The Environment

The 5Ps (Place, People, Props, Programming, Possibilities) explore:

The Four Fs

- Friendly
- Familiar
- Functional
- Forgiving

The Four Ss

- Space (intimate, personal, public)
- Sensations (see, hear, feel, smell, taste)
- Surface to Surface Contact (clothing on body, water/air/sun on skin)
- Social (people, activity, role, expectations)

Stakeholders

Care Partner and Others Around

- Agenda(s)
- Awareness, knowledge, skill
- Confidence, competence
- History and background
- Key values
- Personality traits
- Preferences
- Relationship(s)
- Roles - observer, supervisor, carer

Time

Time Awareness

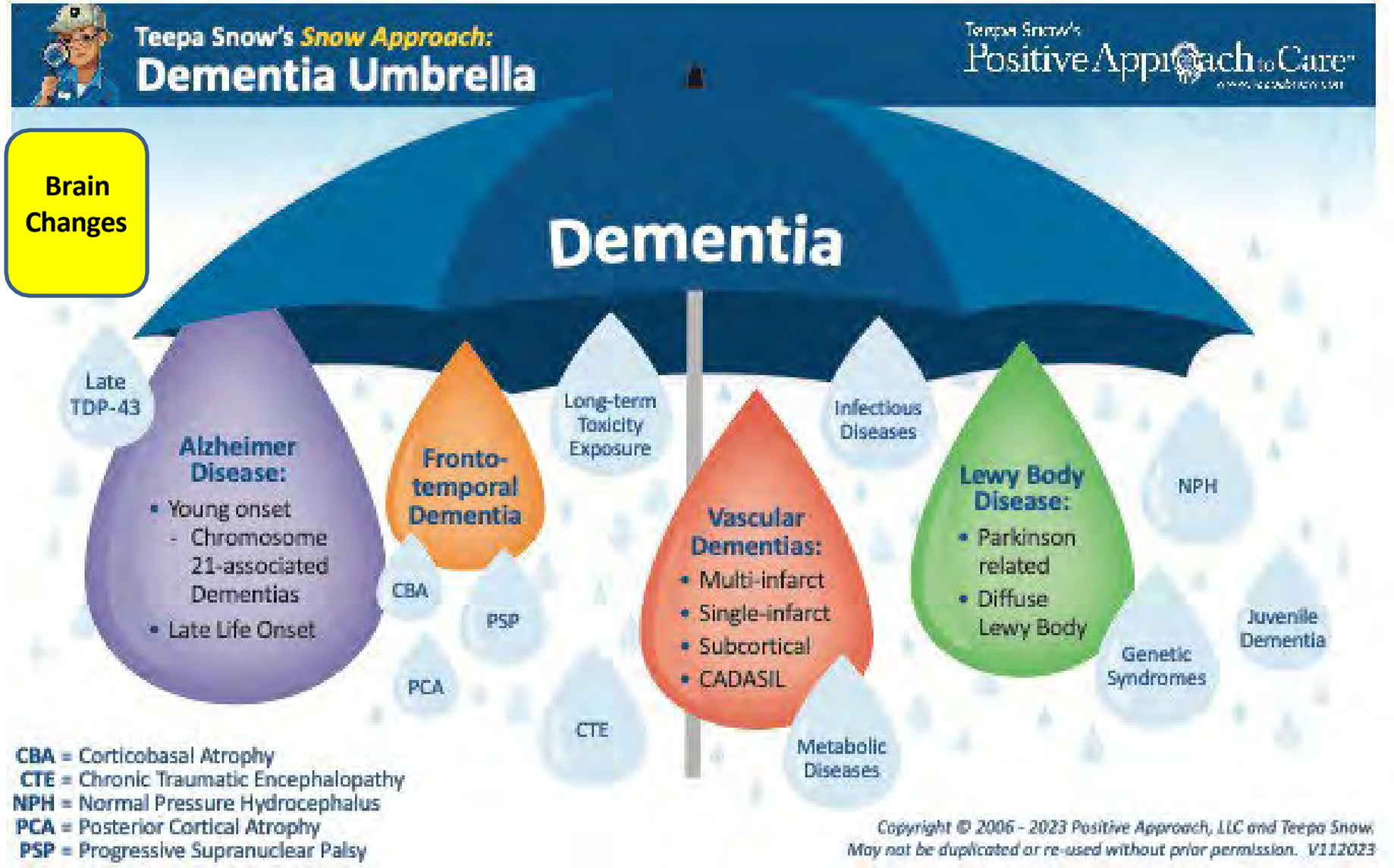
- In the moment, in the present, in the past
- Time of day, week, month, year (season)
- Passage of time (how long since?)

Balance in Four Categories

- Productive: gives value
- Leisure: fun – playful
- Wellness and self care
- Restorative: calm – recharge

Wait Time vs. Engagement in Life Time

What is working well? What needs to change? *(Gray Borders)*



Brain Changes

Four Truths About All Dementias:

- At least two parts of the brain are dying
- It keeps changing and getting worse – progressive
- It is not curable or fixable – chronic
- It results in death – terminal

Alzheimers

- New details lost first
- Recent memory worse
- Some language problems, mis-speaks
- More impulsive or indecisive
- Gets lost – time/place
- Several forms and patterns
- Young onset can vary from late life onset
- Down Syndrome is high risk
- Notice changes over time
- Related to beta-amyloid plaques and tau pathologies

Lewy Body

- Movement problems – Falls
- Visual disturbances
- Delusional thinking
- Fine motor problems – hands and swallowing
- Episodes of rigidity and syncope
- Insomnia – sleep disturbances
- Nightmares that seem real
- Fluctuations in abilities
- Drug responses can be extreme and strange
- Related to synuclein protein malformations

Vascular

- Sudden changes in ability – some recovery
- Symptom combinations are highly variable
- Can have bounce back and bad days
- Judgment and behavior *not the same*
- Spotty losses
- Emotional and energy shifts
- Least predictable
- Caused by problems with blood flow, oxygen, nourishment of brain cells

Frontotemporal

- Many types
- Frontal: impulse and behavior control changes
  - Says unexpected, rude, mean, odd things
  - Apathy – not caring
  - Problems with initiation or sequencing
  - Dis-inhibited: sex, food, drink, emotions, actions
- Temporal: language change
  - Difficulty with speaking – missing/changing words
  - Rhythm OK, content missing
  - Not getting messages
- Related to tau pathologies

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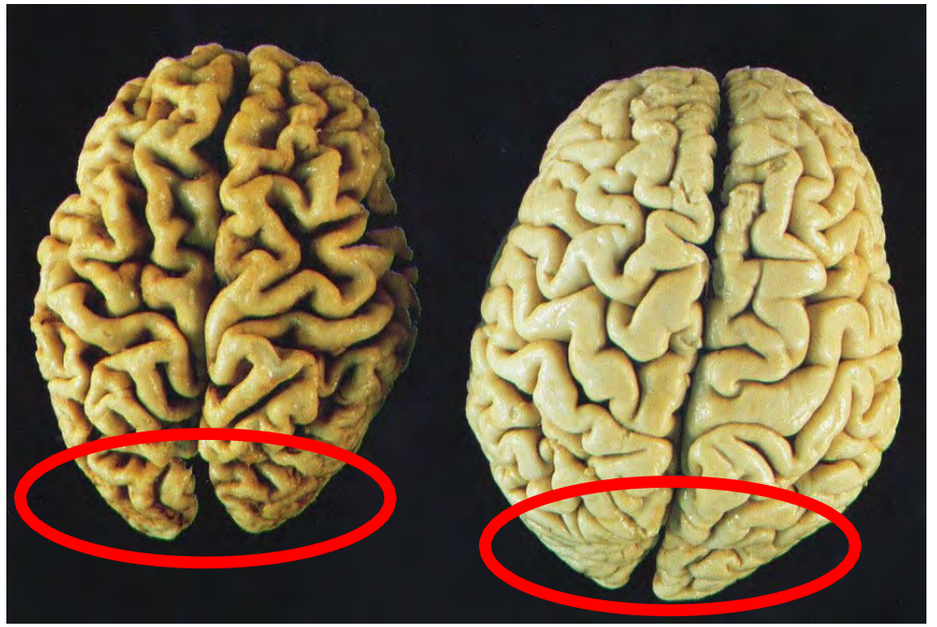
Brain Changes

Vision Changes

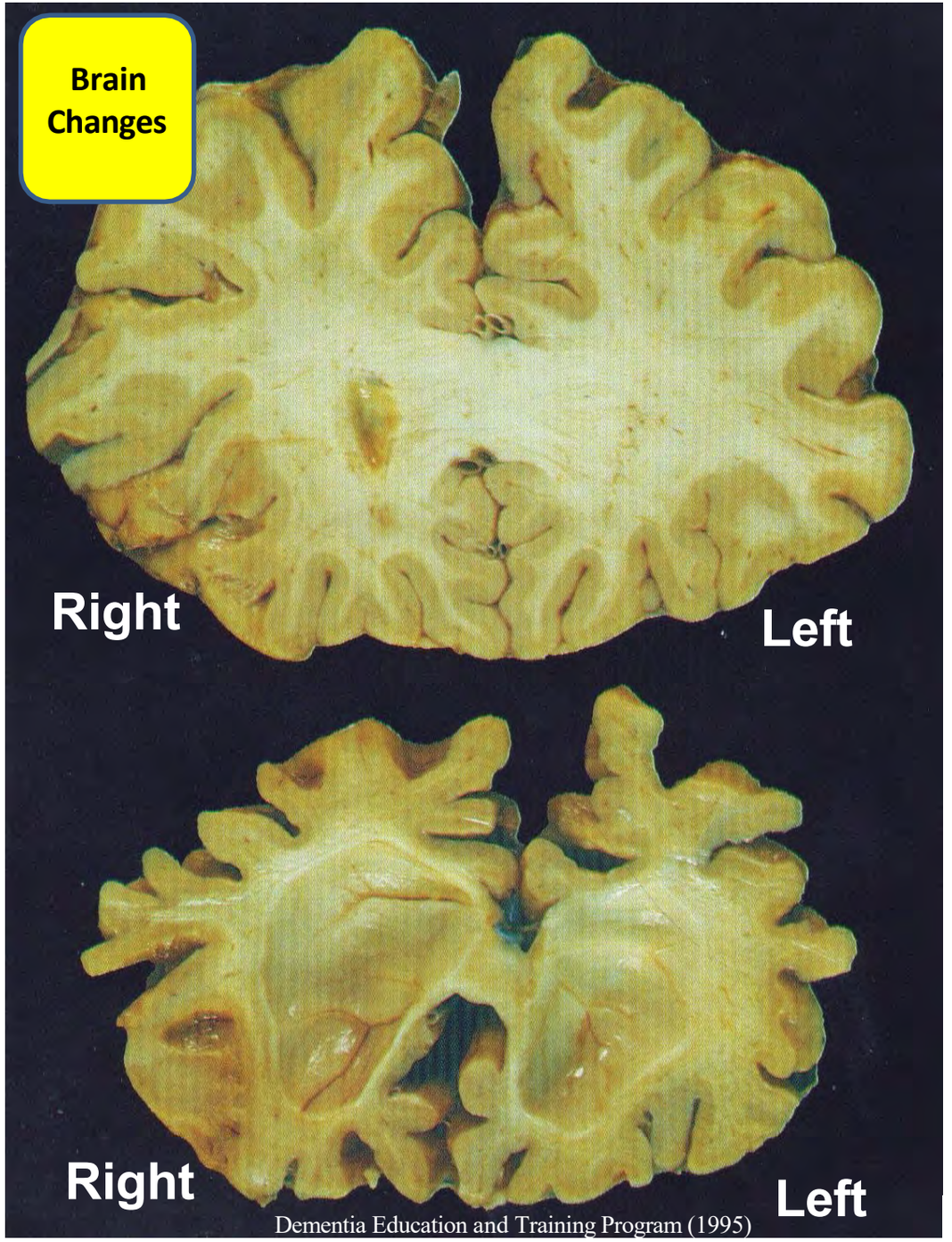
With each new level of vision change, there is a decrease in safety awareness.



Dementia Education and Training Program (1995)

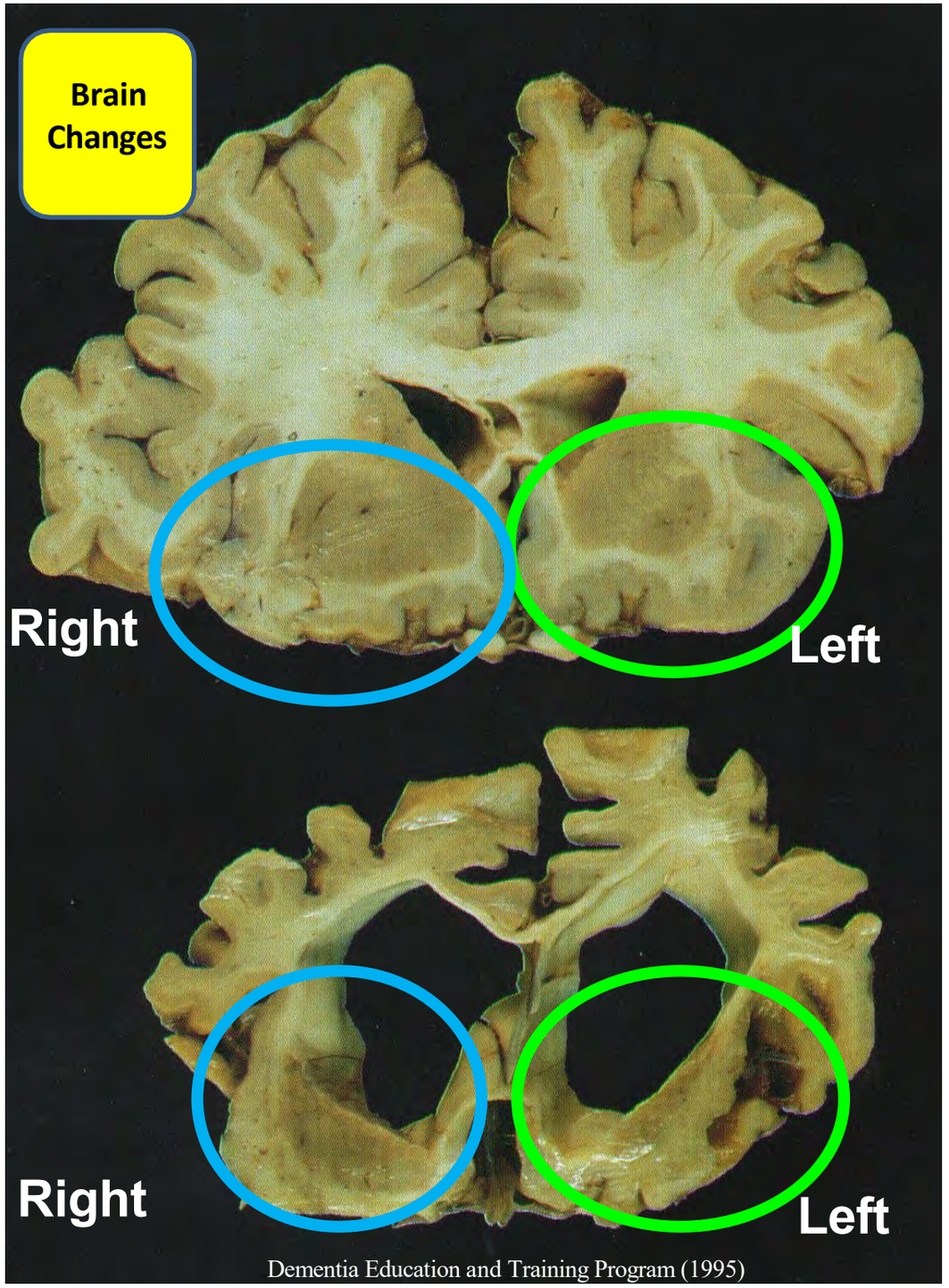
BIG VISION CHANGES

1. **Loss of Peripheral Awareness**
2. Tunnel Vision
3. Binocular Vision
4. Binocular + Object Confusion (discriminating senses)
5. Monocular Vision
6. Loss of Visual Regard



Executive Control Center

1. Impulse Control
2. Be Logical
3. Make Choices
4. Start-Sequence-Complete-Move On
5. Self Awareness
6. See Others' Point of View



Left – LOST

Formal Speech & Language Center

1. Vocabulary
2. Comprehension
3. Speech Production

Right – RETAINED

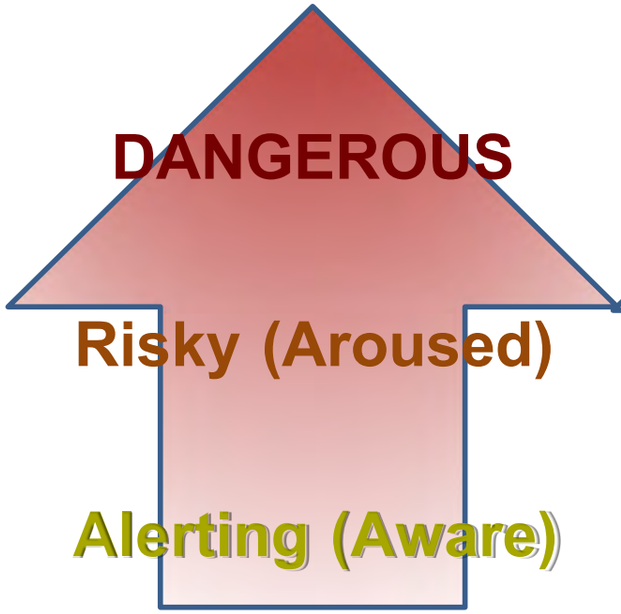
Automatic Speech Rhythm – Music

1. Expletives
2. Social Chit Chat
3. Rhythm of Speech
4. Automatic Autonomic Movement
5. Music Poetry Prayer & Counting

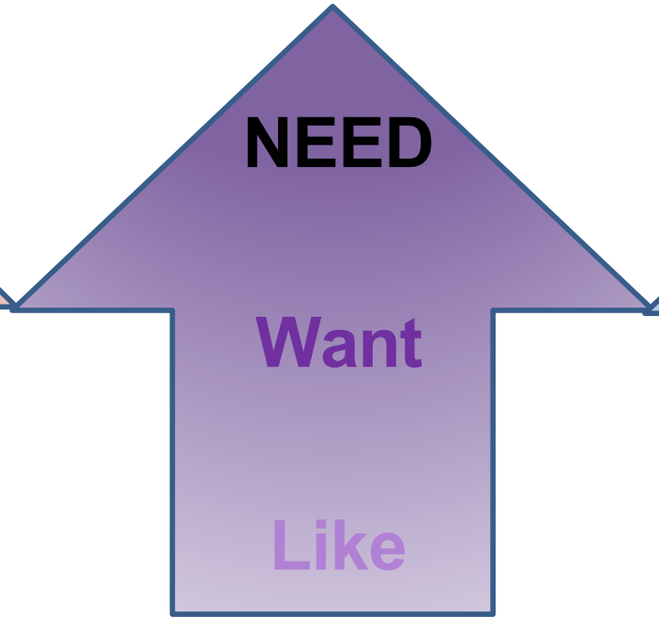
Brain Changes

3 Functions of the Amygdala

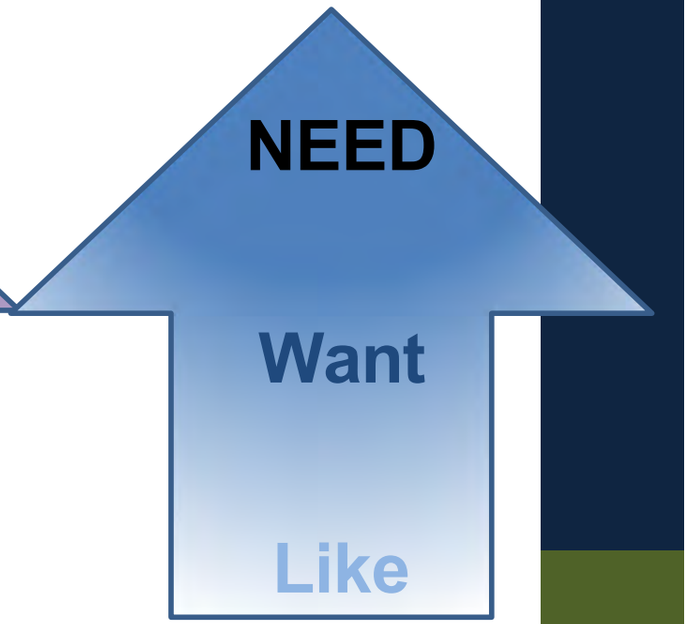
1. Threat Perceiver
Noticing what is:



2. Needs Meeter
Getting what we:

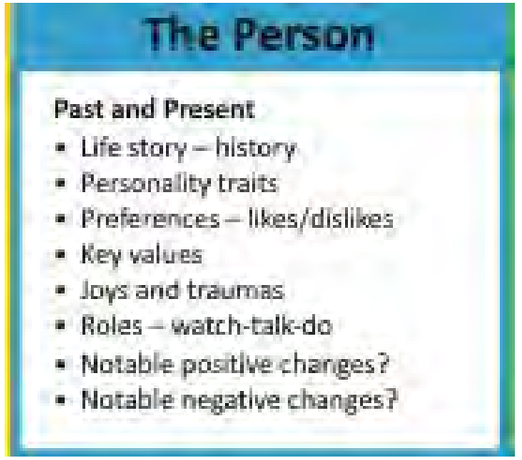


3. Pleasure Seeker
Getting what we:



Knowing the Person:

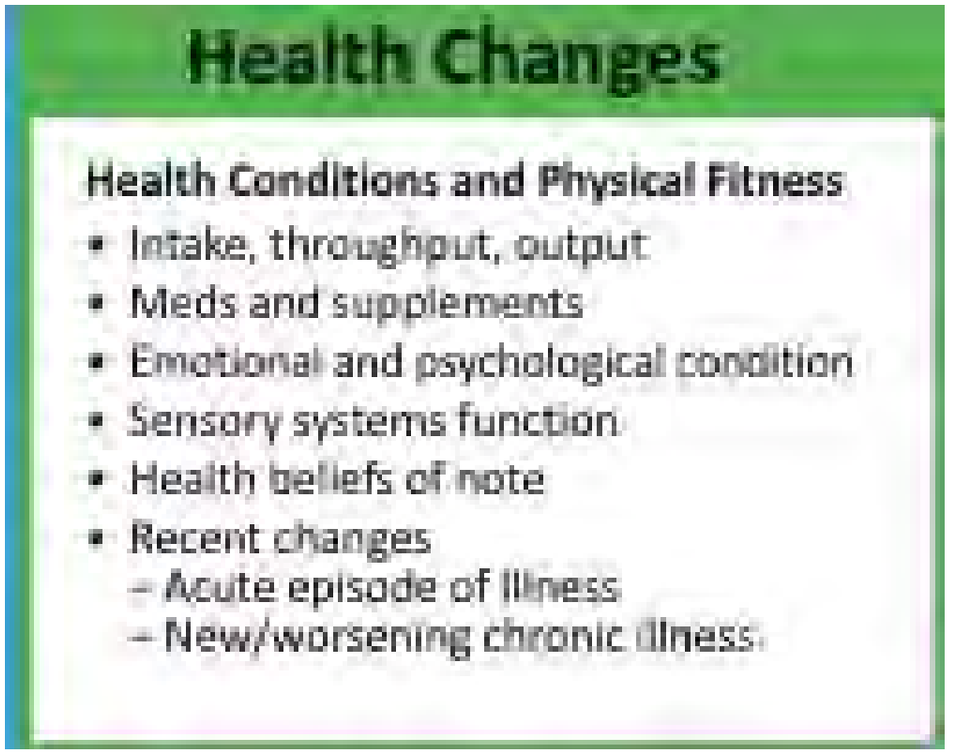
- History
- Values and beliefs
- Habits and routines
- Personality & stress behaviors
- Work and family history
- Leisure and spiritual history
- ‘Hot buttons’ and comforts



- Some ‘stuff’ we think that people do on purpose may really just be <u>who</u> they are

The Third Piece of the Puzzle:

- Other medical conditions
- Psychological or psychiatric conditions
- Sensory status: vision, hearing, sense of touch, balance, smell, taste
- Medications
- Treatments



The Fourth Piece of the Puzzle:

Physical

Sensory

Social

The Supportive Sensory Environment:

What You Hear

Environment

What You See

What You Smell/Taste

What You Feel

What You Hear:

Environment

Supports:

Quiet

Purposeful music

Familiar cues

Positive human sounds

Impairs:

Constant background noise

Intrusive sounds

Care noise

Negative human sounds

The Sixth Piece of the Puzzle:

Other People and Their Behaviors:

- Care Partners
- Family Members
- Friends
- Us!

PPA Resource Card

Positive physical Approach™

If in a public space and you start the interaction:

- Get into their **visual range**, pausing approximately six feet away
- Place your **open hand** next to your face, smile and greet by name
- Offer your hand in a **handshake position**
- If they extend their hand, **approach slowly** from the front with your hand extended
- Move from handshake to **Hand-under-Hand®** position
- Move from the front to their side, getting into a **supportive stance**
- Get at or below their **eye level** by kneeling or squatting, but **don't lean in**
- Use a **Positive Personal Connection (PPC)** and wait for their response – *see back*
- Deliver a message using cues and a **Positive Action Starter (PAS)** – *see back*

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People Us!

Positive Physical Approach™

1. **Stop** moving 6 ft out
2. **Greet**: *Hi* sign; say name
3. Move **into a handshake**
4. **SLOWLY** come in from front

5. **Supportive Stance**
6. Move into **HuH®**
7. Move to side; **Get low**

People Us!

Positive Action Starters (PAS)

1. **Help –** Be sure to compliment their skill in this area, then ask for help. *"I could use your help…"*
2. **Try –** Hold up or point to the item you would like to use, possibly sharing in the dislike of the item or task, *"Well, let's try this."*
3. **Choice –** Try using visual cues to offer two possibilities or one choice with something else as the other option. *"Coffee or Tea?"* *"This? Or something else?"*
4. **Short and Simple –** Give only the first piece of information, *"It's about time to …"*
5. **Step by Step –** Only give a small part of the task at first, *"Lean forward…."*

People Us!

Beliefs

We are key to make life worth living

We must be willing to STOP
and BACK OFF–
be willing to change ourselves

People with dementia are doing the BEST they can

…. but then so are we.
But we have the power to change.

People
Us!

Care Partner Skills

- Greet before you treat: Positive Physical Approach™
- Build a team
- Give cues in specific sequence: give a visual, then verbal, then touch
- Respect space and the person
- Do 1 thing at a time
- WAIT for a response before going on EACH cue
- Not working? Stop and back off
- Try something different
- Be willing to say I’m sorry

People Us!

The Fifth Piece of the Puzzle:

The Day and How it All Fits Together:

Daily routines and programming

Filling the day with valued engagement

GEMS® State programming

Examples of Meaningful Activities:

Time

- **Productive Activities:** sense of value and purpose
- **Leisure Activities:** having fun and interacting
- **Self-Care and Wellness:** personal care of body and brain
- **Restorative Activities:** re-energize and restore spirit

Time

How Do You Spend Your Day?

1. Productive

- Make Me Feel Valued & Needed

2. Leisure Activities – Having Fun

- meeting social & solitary preferences
- active/passive options

3. Self Care & Wellness

- Taking care of body & mind
- Personal care, physical activity & mental stimulation

4. REST & Restoration

- Sleep, recharging batteries, & spiritual well-being

Time

#1 Productive Activities

- Helping another person
- Helping by leading or helping leaders
- Completing community tasks
- Making something
- Sorting things
- Fixing things
- Building things
- Organizing things
- Caring for things
- Counting things
- Folding things
- Marking things
- Cleaning things
- Taking things apart
- Filling or emptying things
- Moving things
- Holding/carrying things
- Cooking/baking
- Setting up/breaking down
- Other ideas….

Time

#2 Leisure Activities

Active:

Socials
Sports
Games
Dancing
Singing
Visiting
Hobbies
Doing, Talking, Looking

Passive:

Entertainers
Sport program/event
Presenters
Living room or lobby sitting
TV programs: watched
Activity watchers
Being done to

Time

#3 Self-Care & Wellness

Cognitive

- Table top tasks
  - Matching, sorting, organizing, playing
- Table top games
  - Cards, board games, puzzles…
- Group games
  - Categories, crosswords, word play, old memories

Physical

- Exercise
- Walking
- Strengthening tasks
- Coordination tasks
- Balance tasks
- Flexibility tasks
- Aerobic tasks
- Personal care tasks

Time

#4 Rest and Restorative Activities

- Sleep/naps
- Listen to quiet music with lights dimmed
- Look at the newspaper
- Look at a calm video on TV screen
- Rock in a chair
- Swing in a porch swing
- Walk outside
- Listen to reading from a book of faith
- Listen to poetry or stories
- Listen to or attend a worship service
- Stroke a pet or animal
- Stroke fabric
- Get a hand or shoulder massage
- Get a foot soak and rub
- Listen to wind chimes
- Aromatherapy

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Depression and Apathy in Persons Living with Dementia

Teepa Snow, MS, OTR/L, FAOTA

Founder and CEO, Positive Approach to Care®

Co-Founder, Snow Approach Foundation, Inc.

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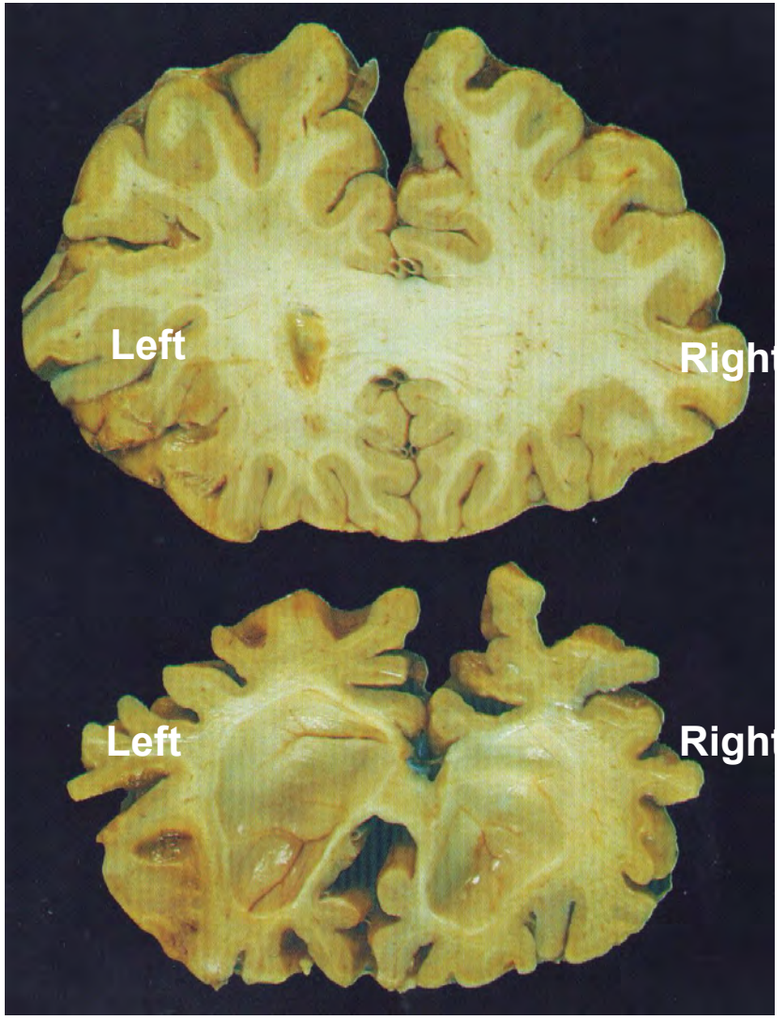

Dementia Education and Training Program. (1995). *Alzheimer's: A Broken Brain* [Brochure]. [Tuscaloosa, AL]: Dementia Education & Training Program.

Prefrontal Cortex – Executive Control Center

Six Functions:

1. Be Logical
2. Impulse Control
3. Make Choices
4. Start-Sequence-Complete-Move On
5. Accurate Self-Awareness
6. Adapt to Others' Point of View

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Apathy versus Depression versus Willfulness:

Different Symptoms and Different Issues:

- I am feeling hopeless and helpless in this situation
- I am not able to be interested anymore, I know it should be important, and yet I just can't care one way or the other – it takes too much energy – everything is blunted
- I am not going to be controlled by others, I have always been in charge of myself and my life and I will not give it up!

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Apathy versus Depression versus Willfulness:

How to sort it out:

- Stay curious
- Offer options for a sense of control that are not about *doing* versus *not doing*
- Acknowledge how hard it is, and ask for 5 minutes of effort and then the person can stop
- Create an opportunity that this built with step-by-step support that will result in a positive outcome that is noticeable to the person

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How Can We Help?

1. Positive Physical Approach™ (PPA)
2. Positive Personal Connectors (PPC)
3. Positive Action Starters (PAS)
4. Hand-under-Hand® (HuH)
5. Validation
6. Reflection
7. Visual-Verbal-Touch (V-V-T) Cues

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Positive Action Starters (PAS)

First, **reflect:** match their intensity and affect, be sincere,

Second, match visual cues with verbal:

Limit words: Keep it Straightforward

- **Short & Simple:** *It's about time for…* Tap your watch/wrist. Or *Here are your socks.* Hold up socks.
- **Step by Step:** *Let's go this way.* Point in the direction. Or *Lean forward.* Make the motion with your hand.
- **Choice:** *Coffee or tea?* Raise coffee cup, then tea bag.
- **Help:** *I could use your help.* Implied compliment on skill. Or - *I'm asking for a big favor!*
- **Try:** *Let's just try.* Point to the exercise band.

Acknowledge their response/reaction…. **and then wait!**

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Other Strategies for Responding to Apathy:

- Change your *ask*:
  - Instead of “Do you want to?” try “First…then..”
  - Say, “Let’s just try this…”
  - Provide simple choices
  - Sensory connections: music, temperature
- Simplify
- Watch for time of day
- Try again
- Realize it’s not a choice; they may truly feel that they cannot do it

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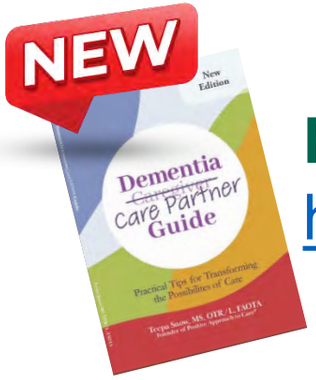

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Summary of Learnings

Themes and Key Takeaways

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Key Takeaways and Themes

- Wrap Up:
- Discussing depression
  - We can go through moments of depression or depressive episodes in our lives. Consider that could this been situational
  - She doesn't seem helpless or hopeless or that she doesn't care (she does care for her cats)
  - She seems willful and responding to a loss of independents
- Approach
  - What are those who she accepts care from more accepted? She responds to a more friendly, slow, and patient approach. Treating her as a human and not demanding, asking for permission
  - Use what she is engaged in already to help get to the goal
- Engagement
  - She is less engaged in gardening and going outside, but can we bring in potted plants (cat grass and catnip) to keep her engaged
- Care planning
  - Putting together information about how important animals are for her to feel comfortable if she is relocated

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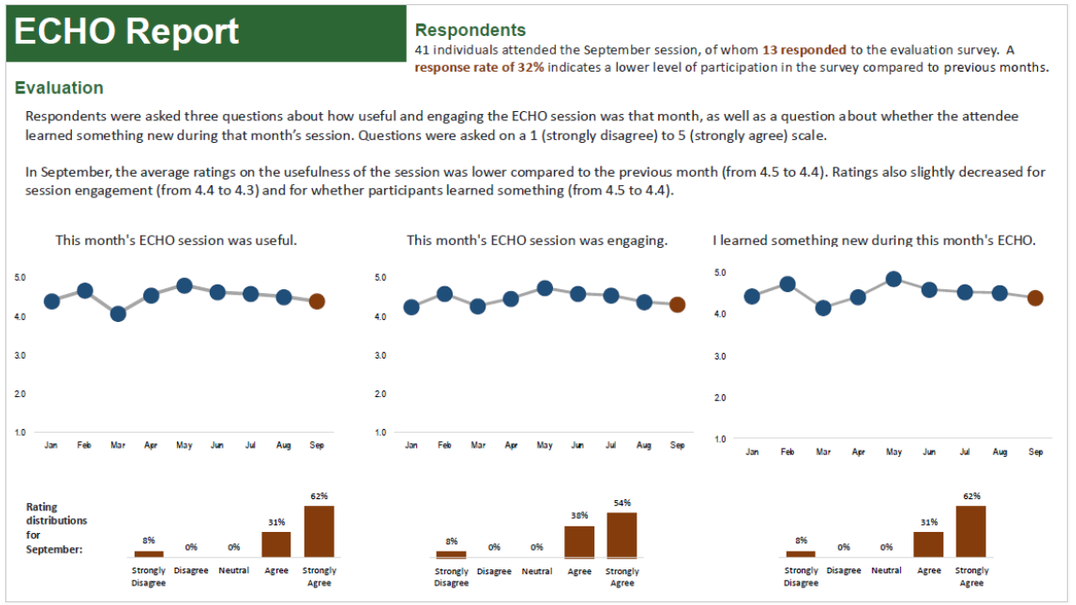
Wrap-Up

ECHO Program Meeting Evaluation Survey

https://dartmouth.co1.qualtrics.com/jfe/form/SV_0PROT8HIorYu1gO



ECHO Report

Respondents

41 individuals attended the September session, of whom **13 responded** to the evaluation survey. A **response rate of 32%** indicates a lower level of participation in the survey compared to previous months.

Evaluation

Respondents were asked three questions about how useful and engaging the ECHO session was that month, as well as a question about whether the attendee learned something new during that month's session. Questions were asked on a 1 (strongly disagree) to 5 (strongly agree) scale.

In September, the average ratings on the usefulness of the session was lower compared to the previous month (from 4.5 to 4.4). Ratings also slightly decreased for session engagement (from 4.4 to 4.3) and for whether participants learned something (from 4.5 to 4.4).