





Welcome to the Positive Approaches to Dementia Care ECHO

January through December 2025



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.



Schedule

- Session 1 Dementia: What's Retained?
- Session 2 What is a Positive Approach to Care?
- Session 3 Sensory Changes
- <u>Session 4 Communicating Effectively</u>
- 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



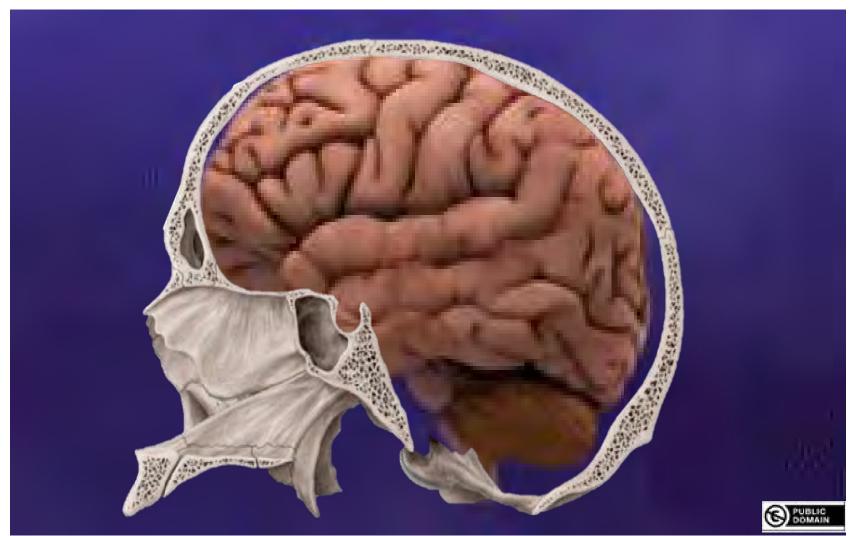
Dementia: What's Retained, Not Just What's Lost

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



Let's see what changes inside:



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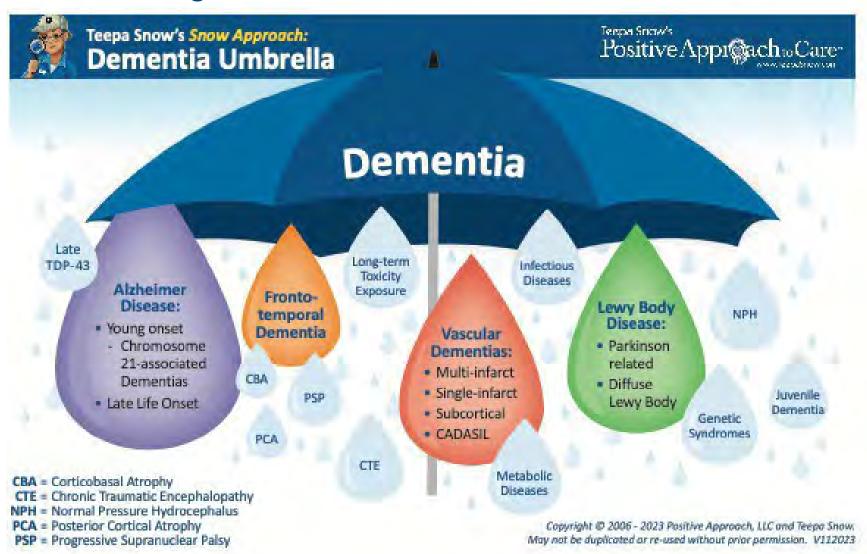
Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD





A better understanding of the difference between dementia and Alzheimer...





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



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



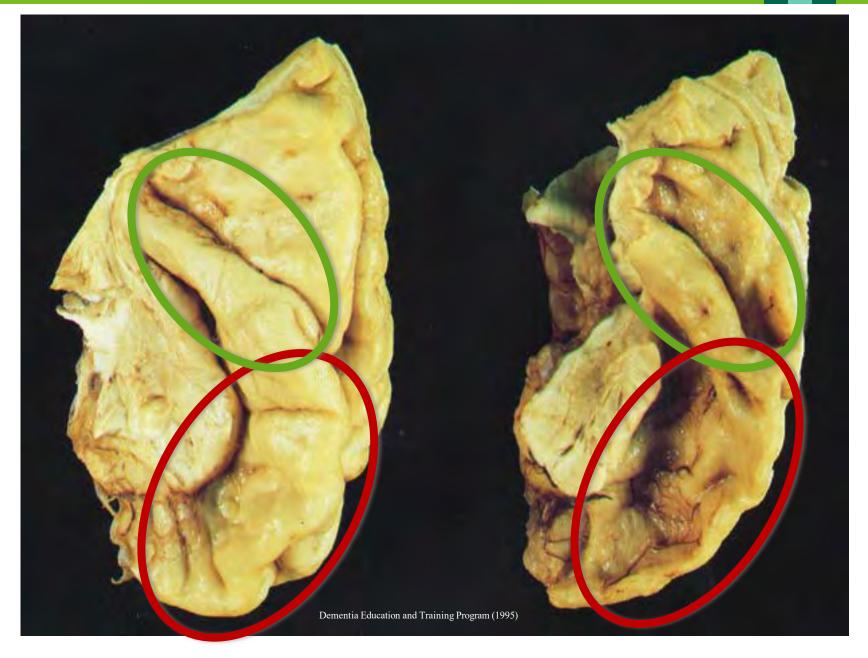




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Hearing Sound Unchanged

BIG Language CHANGE





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)





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.



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



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



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





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





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





Amber State:



- AmberAlert Caution!
- Caughtin a moment
- All about sensation and sensory tolerance, easily over or understimulated
- 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





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





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



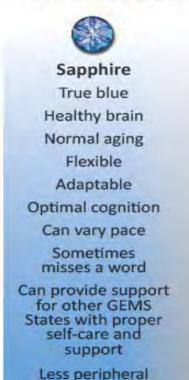




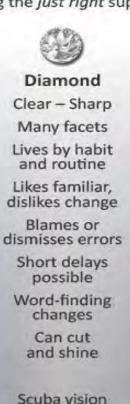


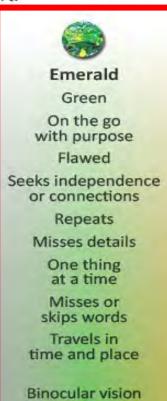
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Teepa Snow's GEMS® State Model allows us to recognize how every brain can change based on internal and external factors. While dementia will cause chemical and physical changes to one's brain, other factors, such as discomfort, stress, or hunger, can 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.

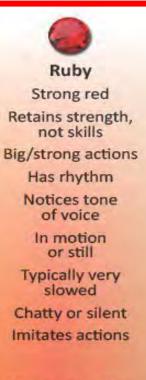


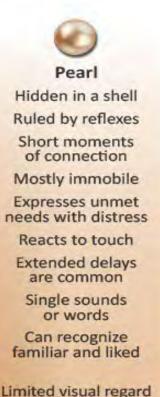
awareness with age





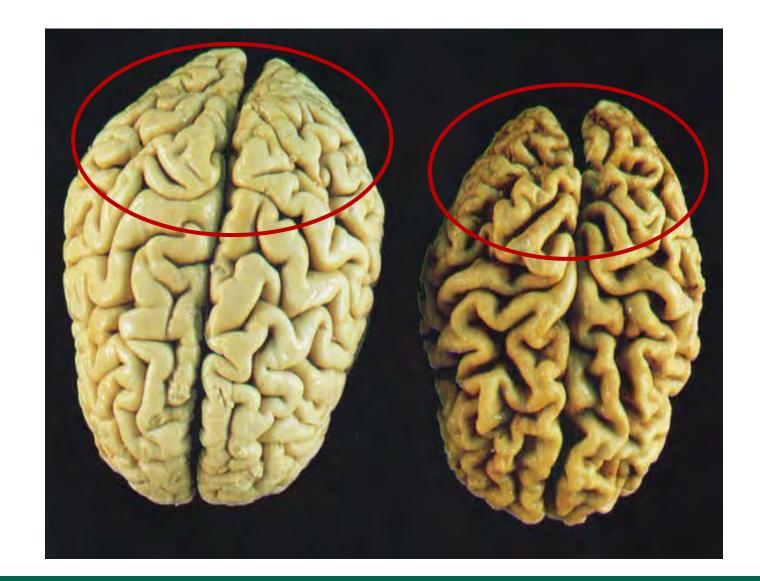








Vision Center: Big Changes





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)



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 a Shell, Quiet Beauty



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"







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**!



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!









RUBY – skill, it just won't go
Changing something must go sloooooow
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.







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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Visual field at age 25 lf alert and attentive





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75



No cognitive impairment;

Visual field at age 75





Early signs of dementia

Even slower processing speed





Visual field with tunnel vision





Middle of dementia

Social vision or task vision – not both



Visual field with binocular vision





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

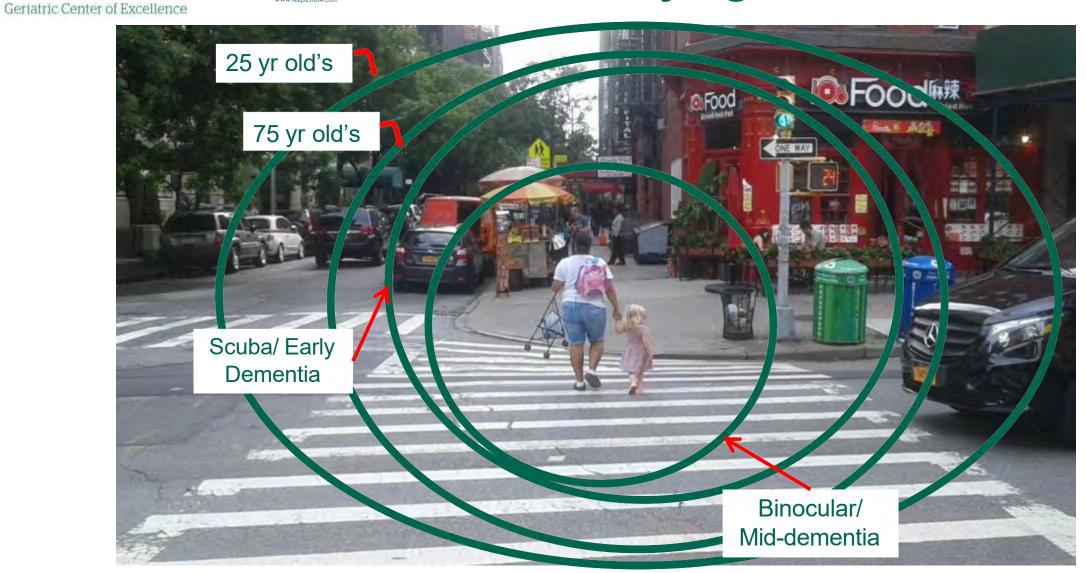
- Diamond Message in scuba field
- Emerald Objects in binocular field
- Amber Object use demonstrated in binocular field
- Ruby Hand or hand plus face in monocular field
- Pearl Facial expression 18" away in midline







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

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

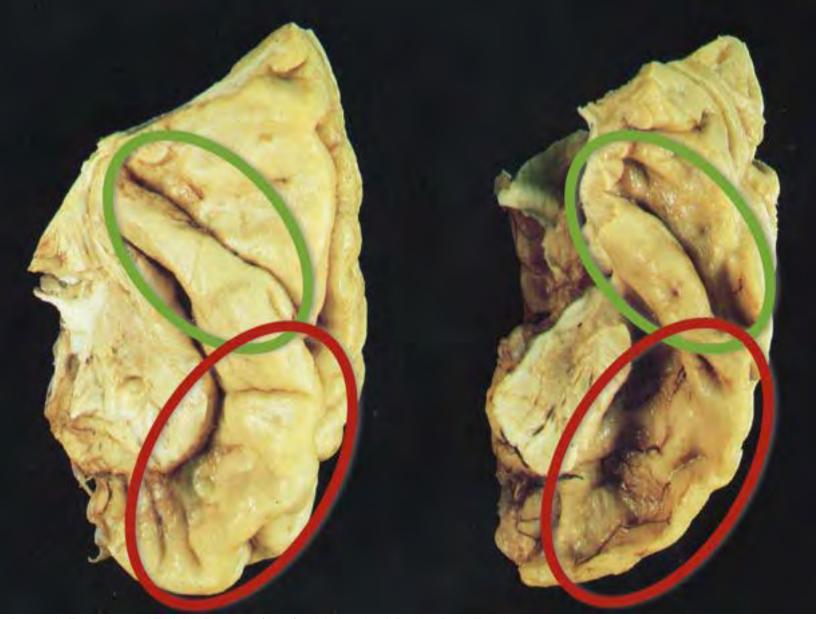






Hearing Sound Unchanged

BIG Language CHANGE



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

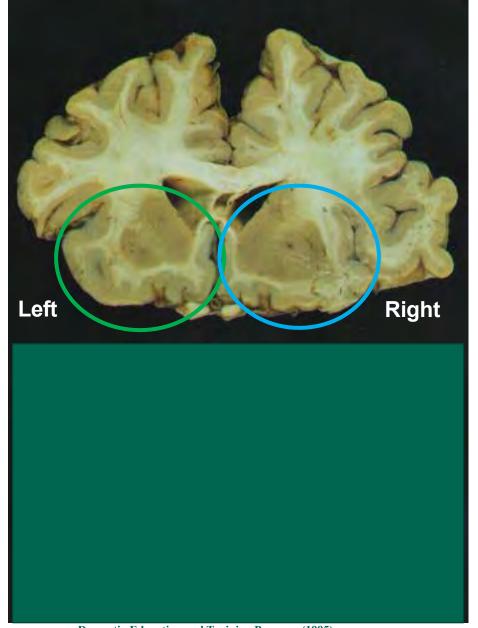


Left Temporal Lobe

- 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

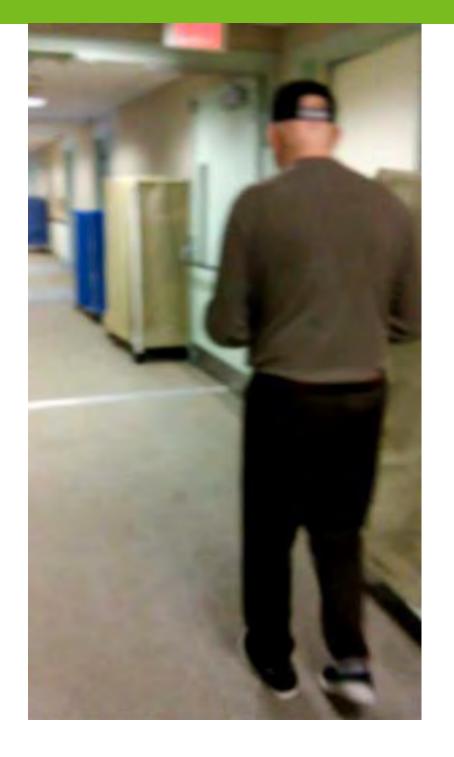


Dementia Education and Training Program (1995)



Asked:

"Shut the door, Buddy"





Positive Action Starters (PAS)

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

Second, matched <u>visual</u> cues WITH <u>verbal</u> using **PAS**:

Limit words:
Keep it
Straight
Forward

- 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.

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





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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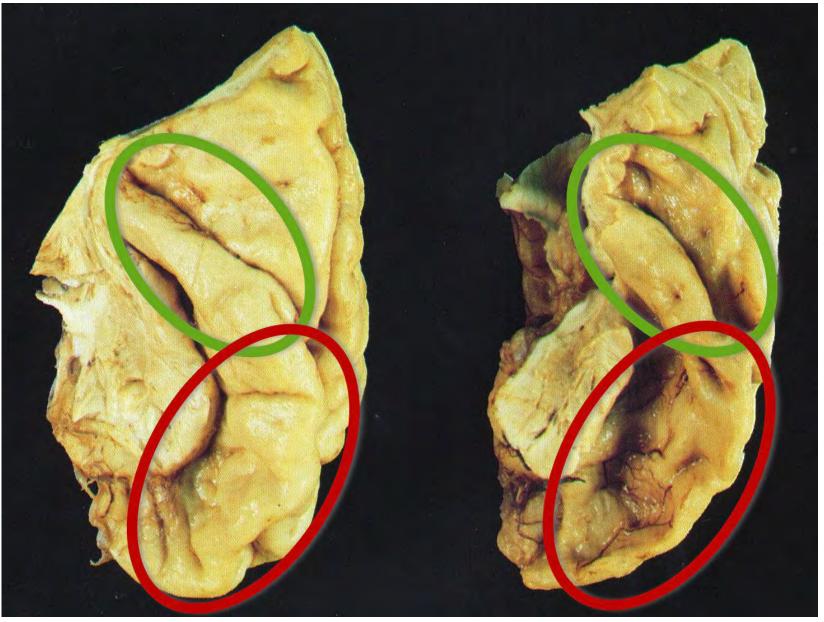




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Hearing Sound Unchanged

BIG Language CHANGE



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

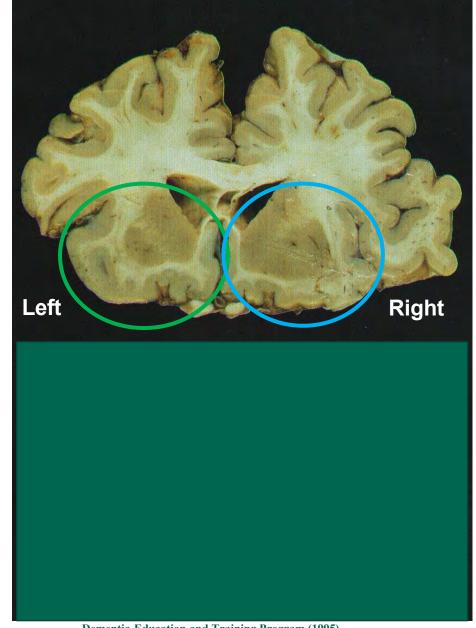


Left Temporal Lobe

- 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)



Positive Action Starters (PAS)

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

Second, matched <u>visual</u> cues WITH <u>verbal</u> using **PAS**:

Limit words:
Keep it
Straight
Forward

- 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.

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



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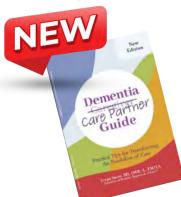
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Br John-Richard Pagan, MA-MFT, CG

Joanna Fix, PhD









Welcome to the Positive Approaches to Dementia Care ECHO

Session 6: How to Identify Unmet Needs

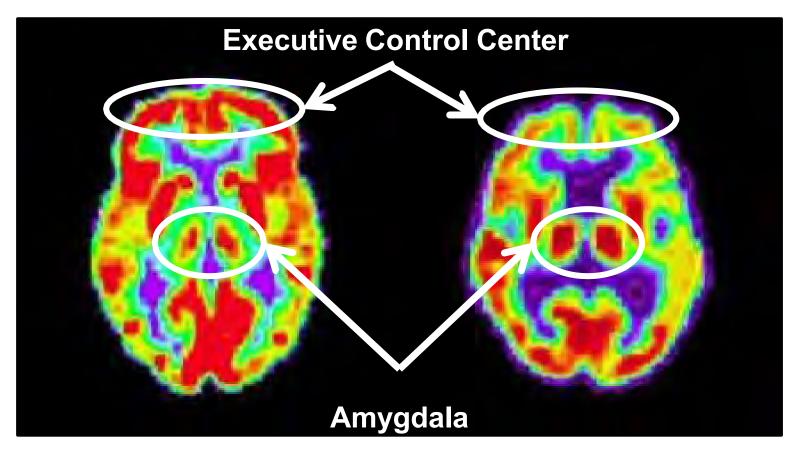
Wednesday June 18, 2025 2:00-3:00 p.m. (EST)



Positron Emission Tomography (PET)

Neurotypical Aging

Early Alzheimers



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



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



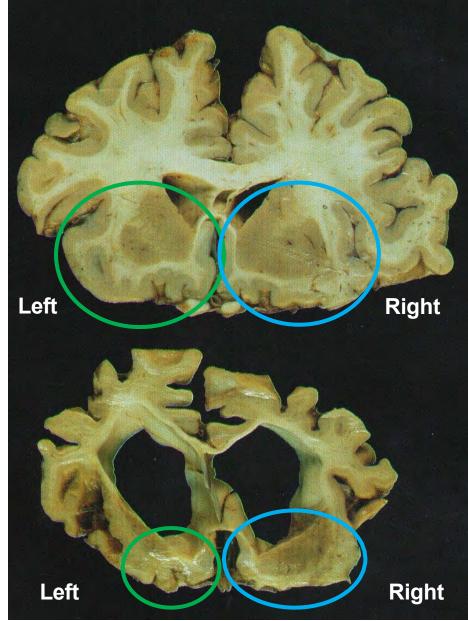


<u>Left Temporal Lobe – and significant changes:</u>

- 1. Vocabulary
- 2. Comprehension
- 3. Speech Production

Right Temporal Lobe - retained abilities:

- 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)



Positive Action Starters (PAS)

- First, and every time **Reflect:** matched intensity with sincerity. Second, matched <u>visual</u> cues WITH <u>verbal</u> using **PAS**:
 - Short & Simple: It's about time for... tap your watch/wrist. 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.

Or Here's your socks.

Limit words:
Keep it
Straight
Forward

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



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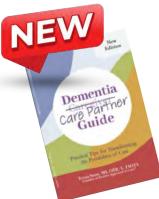
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Welcome to the Positive Approaches to Dementia Care ECHO

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

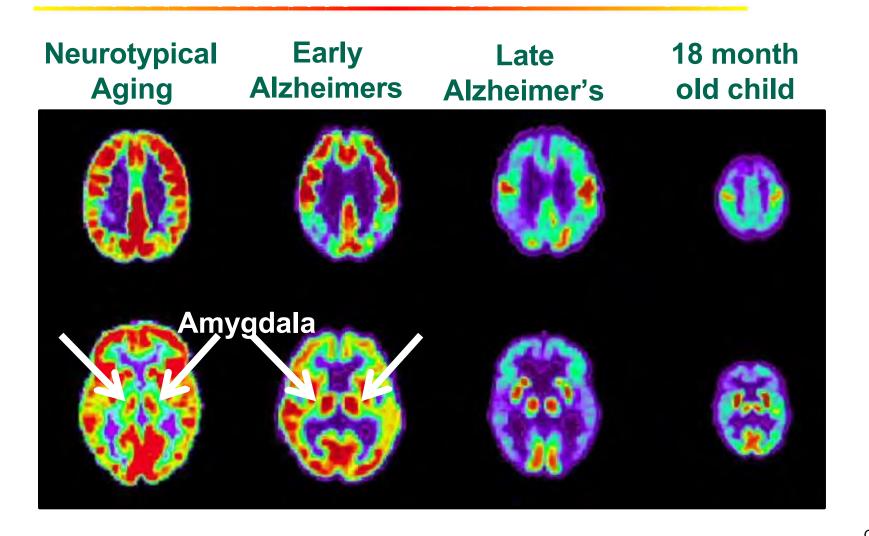
Joanna Fix, PhD







Positron Emission Tomography (PET) Alzheimer's Disease Progression vs. Neurotypical Brains



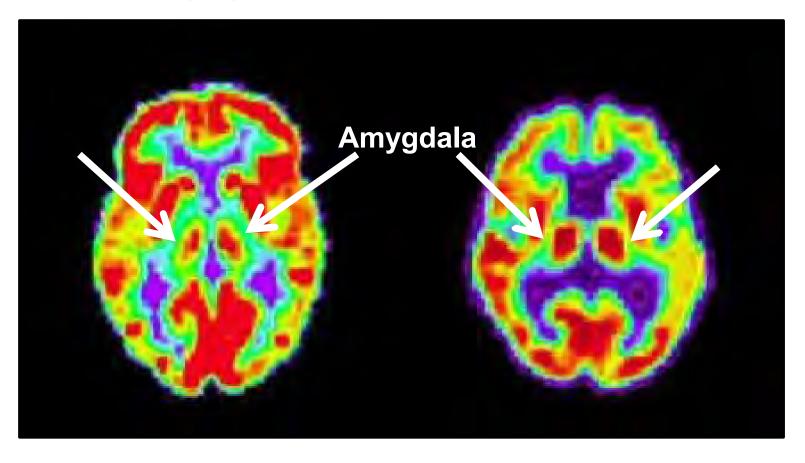




Positron Emission Tomography (PET) Alzheimer's Disease Progression vs. Neurotypical Brains

Neurotypical Aging

Early Alzheimers





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The Power of the Apology

Five Ways to Acknowledge Dissatisfaction





Acknowledge Dissatisfaction

To connect with someone, acknowledge what you are seeing with matching facial expressions and tone. This is a seek and should invite a response versus being an assumption statement.

It seems like I made you angry = seek
I made you angry = assumption



Intent

(Sigh)
It seems like what I
did was not helpful!



Emotion

It looks like you are really frustrated with me.



Skills/Abilities

It feels like I disrespected you. WOW! I am so sorry.



Experience

You didn't expect that, did you? That looks like it was **not** okay.



Change

(Sigh) This is hard, huh?







The Power of the Pause



Exit the Pause

The pause is finished, now where are you going? Are you going to continue or will you switch to something else?

Positive Approach, Care

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Moving into Person Centered Care with Brain Change

Neglect

Focused on:

- You
- Rule following
- Right to refuse
- Not having time or knowing how to negotiate
- · Unaware of language changes, only using words to communicate
- Assuming the person understands what I say
- Company/supervisor said not to do it if the person refuses
- Success = Document the refusal and move on to the next task/person
- Failure = Families or regulators are not satisfied

Care

Focused on:

- Us
- Person living with brain change's comfort
- Using time to connect and determine what will work and what is not okay
- Using multi-modal cues to connect and communicate
- Right to informed consent
- Guiding/supporting to see what is possible at the time
- Only doing what is within the boundaries of what the person can tolerate
- Success = We are both okay with what we do
- Failure = I could not figure out how to connect or communicate - no relationship and no care

Abuse

Focused on:

- Me
- Task completion
- Not negotiating
- Unaware of language changes, only using words to communicate
- Believing the person doesn't understand what I believe needs to be done based on my training and experience
- Company/supervisor said to get the task done
- Success = Document completed tasks, behaviors, or injuries
- Failure = I couldn't get the task done or I had to go back later



Vision Changes

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



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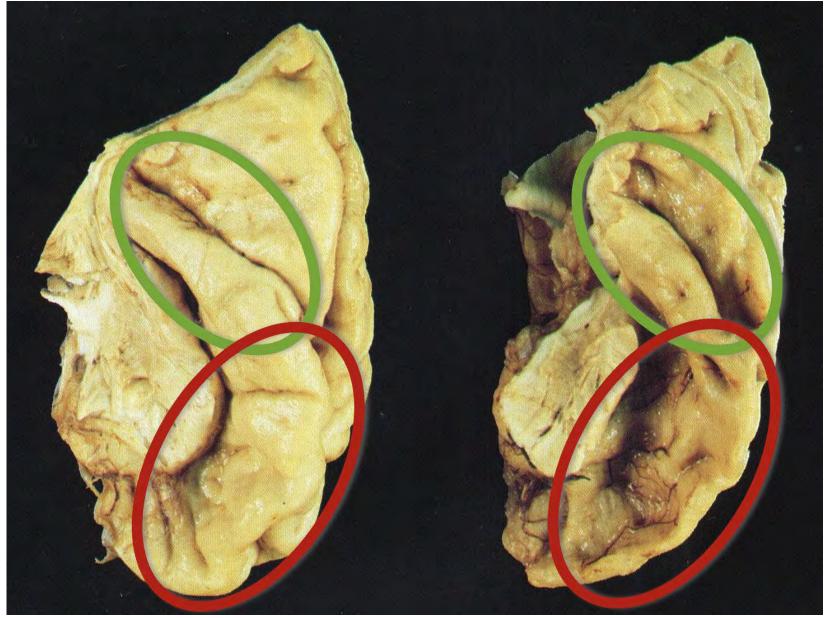




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Hearing Sound Unchanged

BIG Language CHANGE



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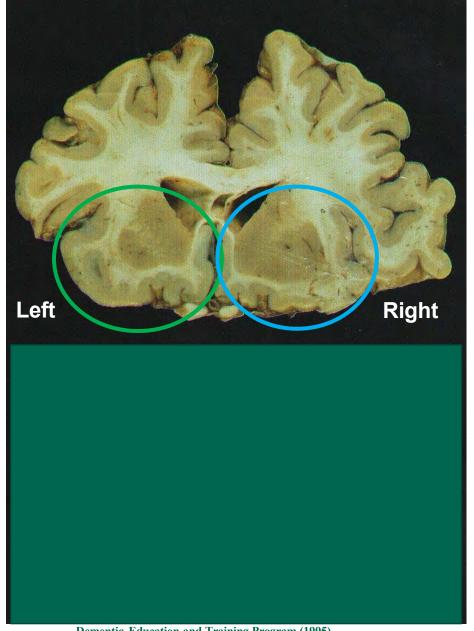


Left Temporal Lobe

- 1. Vocabulary
- Comprehension
- **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)



Positive Action Starters (PAS)

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- Help: I could use your help. Implied compliment on skill.
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Acknowledge their response/reaction.... And then WAIT!!!



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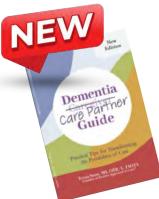
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Welcome to the Positive Approaches to Dementia Care ECHO

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





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
- Undressing in public OR not changing when needed



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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)





How you help... connect



See (Visual cues)



• Hear (Verbal cues)



Touch (Tactile cues)

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



Three Zones of Human Awareness

- 6 ft away or more - <u>Public Space</u> – Visual Interactions / Awareness



- 6 ft to arm's length - <u>Personal Space</u> – Conversations & Friendship



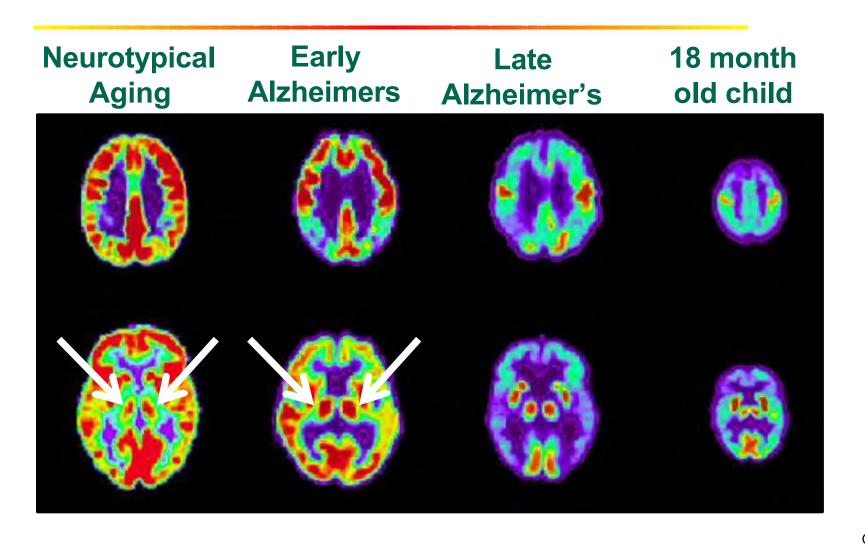
Touch/Physical Contact - <u>Intimate Space</u> –
 Intense Physical Closeness







Positron Emission Tomography (PET) Alzheimer's Disease Progression vs. Neurotypical Brains

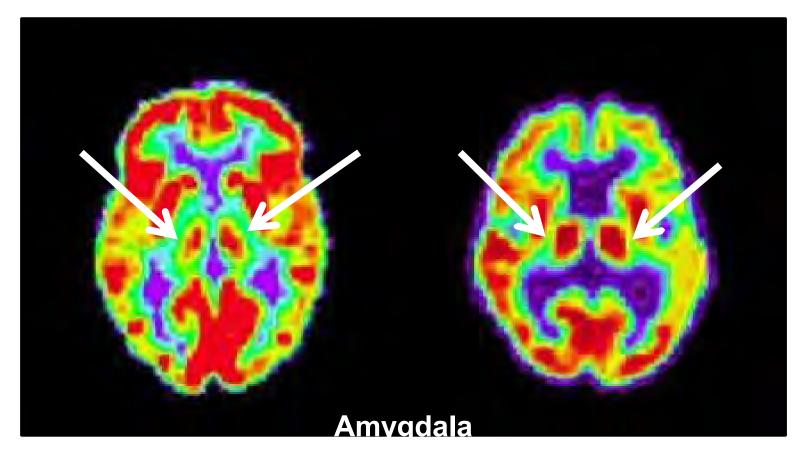




Positron Emission Tomography (PET)

Neurotypical Aging

Early Alzheimers





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The Power of the Apology

Five Ways to Acknowledge Dissatisfaction





Acknowledge Dissatisfaction

To connect with someone, acknowledge what you are seeing with matching facial expressions and tone. This is a seek and should invite a response versus being an assumption statement.

It seems like I made you angry = seek
I made you angry = assumption



Intent

(Sigh)
It seems like what I
did was not helpful!



Emotion

It looks like you are really frustrated with me.



Skills/Abilities

It feels like I disrespected you. WOW! I am so sorry.



Experience

You didn't expect that, did you? That looks like it was **not** okay.



Change

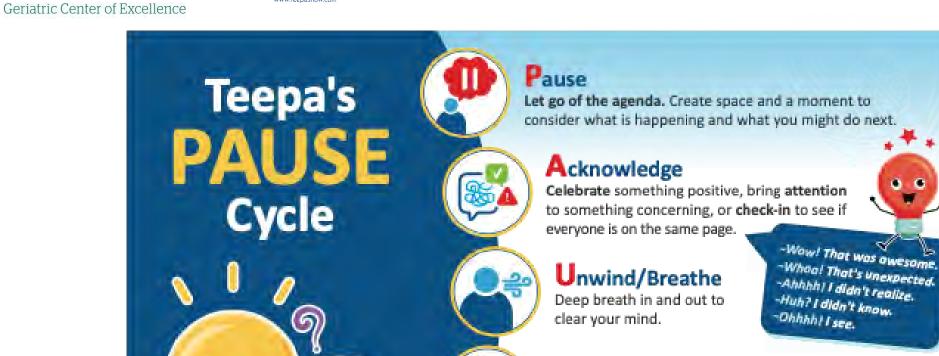
(Sigh) This is hard, huh?







The Power of the Pause



Sort Things Out

Can you figure out what's going on? Can you do something so that things are different or provide a better direction?

Positive Approach, Care

Exit the Pause

The pause is finished, now where are you going? Are you going to continue or will you switch to something else?

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Moving into Person Centered Care with Brain Change

Neglect

Focused on:

- You
- Rule following
- Right to refuse
- Not having time or knowing how to negotiate
- · Unaware of language changes, only using words to communicate
- Assuming the person understands what I say
- Company/supervisor said not to do it if the person refuses
- Success = Document the refusal and move on to the next task/person
- Failure = Families or regulators are not satisfied

Care

Focused on:

- Us
- Person living with brain change's comfort
- Using time to connect and determine what will work and what is not okay
- Using multi-modal cues to connect and communicate
- Right to informed consent
- Guiding/supporting to see what is possible at the time
- Only doing what is within the boundaries of what the person can tolerate
- Success = We are both okay with what we do
- Failure = I could not figure out how to connect or communicate - no relationship and no care

Abuse

Focused on:

- Me
- Task completion
- Not negotiating
- Unaware of language changes, only using words to communicate
- Believing the person doesn't understand what I believe needs to be done based on my training and experience
- Company/supervisor said to get the task done
- Success = Document completed tasks, behaviors, or injuries
- Failure = I couldn't get the task done or I had to go back later



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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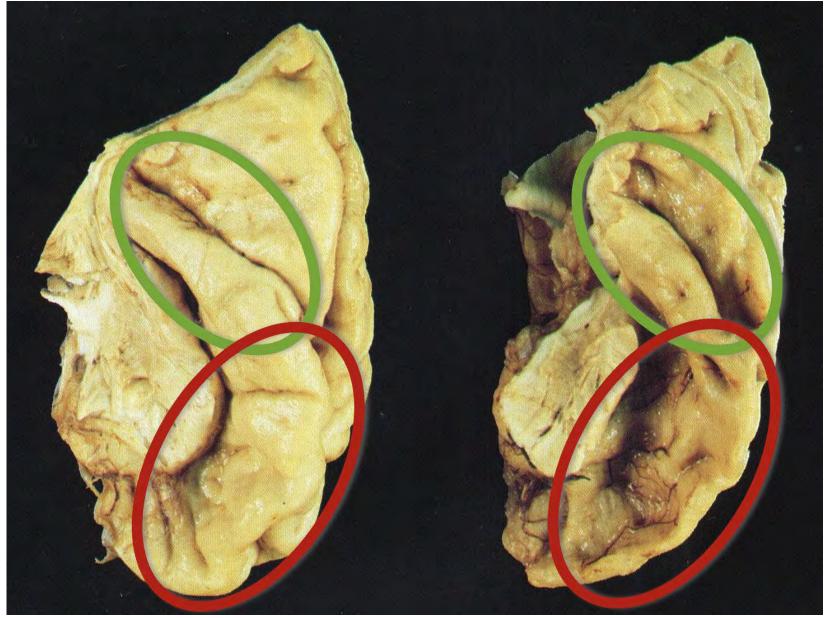




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Hearing Sound Unchanged

BIG Language CHANGE



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

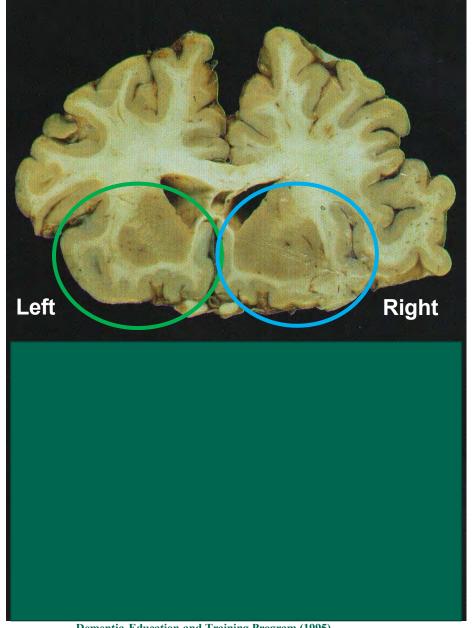


Left Temporal Lobe

- 1. Vocabulary
- Comprehension
- **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)



Positive Action Starters (PAS)

First, and every time **Reflect:** matched intensity with sincerity.

Second, matched <u>visual</u> cues WITH <u>verbal</u> using **PAS**:

Limit words:
Keep it
Straight
Forward

- 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.

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



Scan for Handouts

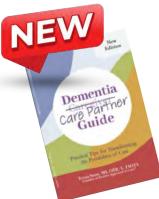
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Welcome to the Positive Approaches to Dementia Care ECHO

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

Joanna Fix, PhD

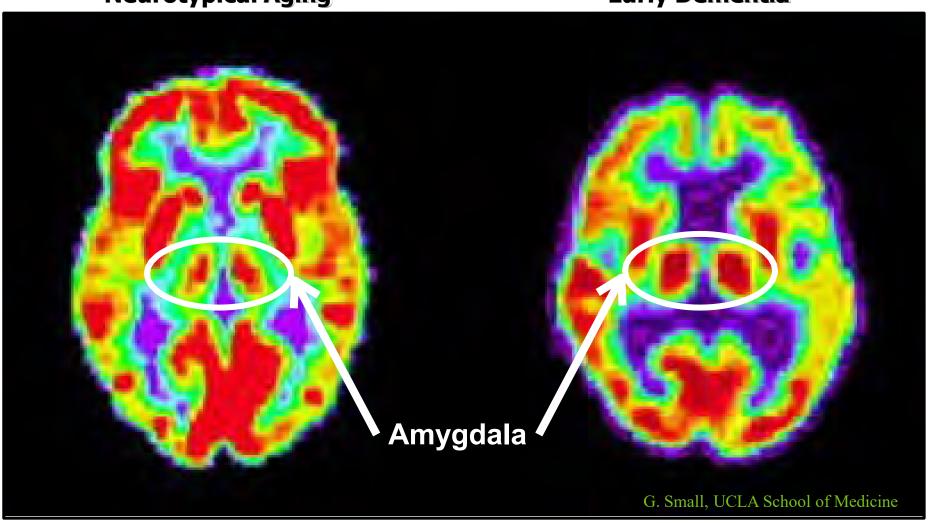




Positron Emission Tomography (PET)

Neurotypical Aging

Early Dementia







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6 Pieces of the Puzzle for Individuals: Problem Solving Model



Positive Action Starters (PAS)

First, and every time Reflect: matched intensity with sincerity.

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.
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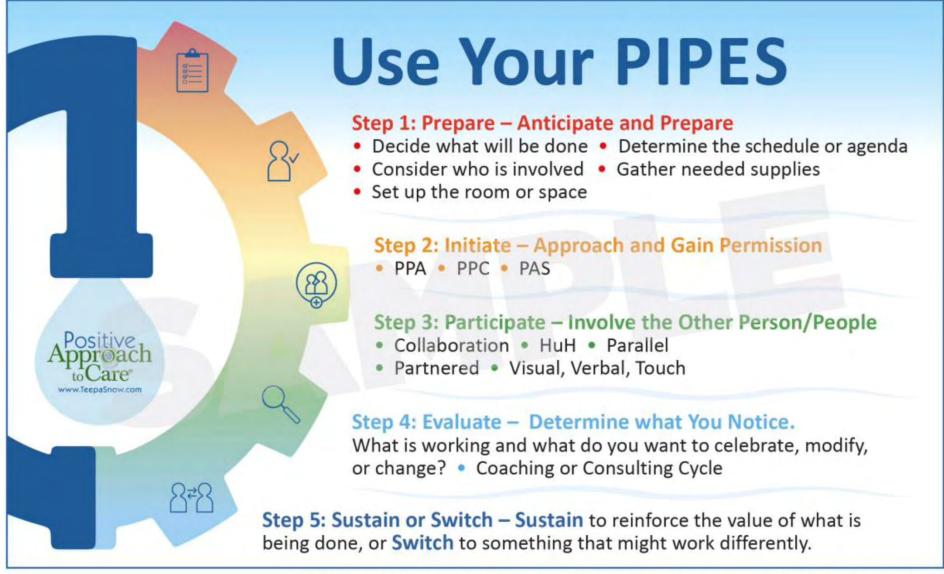






5 Ps

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5 Ps

- □ Place
- People
- Props
- Programming
- Possibilities



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?







6 Pieces of the Puzzle for Individuals: Problem Solving Model



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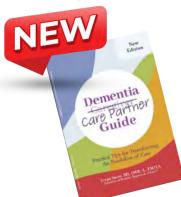
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Examples of Words We Use for "Challenging" Behaviors (when we don't understand)

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



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5 Human Needs

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

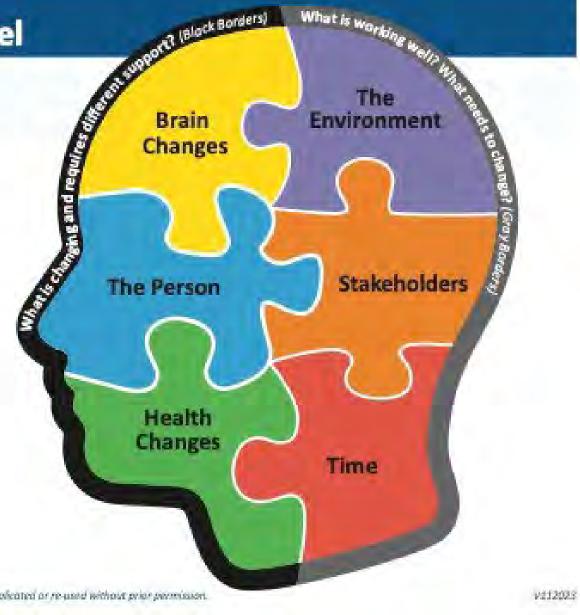


For Individuals: Six Pieces of the Puzzle

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

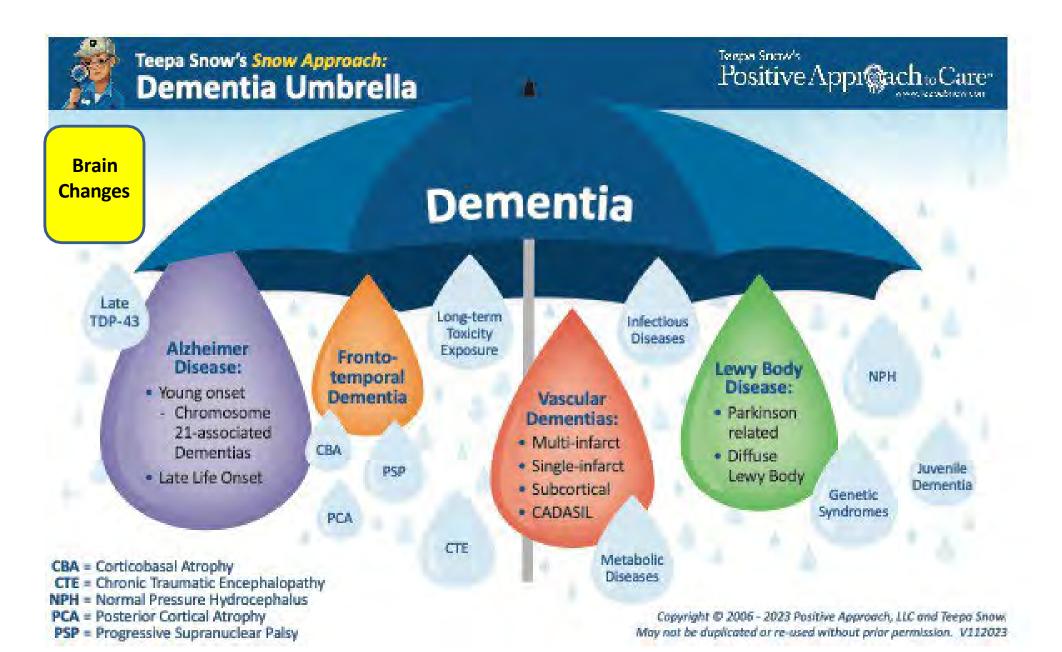
Using these six categories organizes our investigation and keeps us focused and alert.





What is changing and requires different support? (Black Borders) **Health Changes Brain Changes** The Person Past and Present Health Conditions and Physical Fitness Dementia. Life story – history · Intake, throughout, output Type(s) · Awareness of changes? Personality traits Meds and supplements Preferences – likes/dislikes Emotional and psychological condition. Delirium? Depression or Anxiety? Key values Sensory systems function **GEMS State(s)** Health beliefs of note Jovs and traumas. Changed abilities · Roles - watch-talk-do Recent changes Retained abilities - Acute episode of Illness Notable positive changes? Variability - New/worsening chronic illness Notable negative changes? Onset and duration The Environment Stakeholders Time The 5Ps (Place, People, Props, Care Partner and Others Around Time Awareness Programming, Possibilities) explore: . In the moment, in the present, Agenda(s) in the past: · Awareness, knowledge, skill The Four Fs · Time of day, week, month, year (season) Friendly * Functional · Confidence, competence Passage of time (how long since?) * Forgiving · History and background Familiar Balance in Four Categories Key values The Four 5s Personality traits. · Productive: gives value · Space (intimate, personal, public) Leisure: fun – playful · Preferences Sensations (see, hear, feel, smell, taste). Weliness and self care Relationship(s) Surface to Surface Contact · Restorative: calm - recharge Roles - observer, supervisor, carer (clothing on body, water/air/sun on skin) Wait Time vs. Engagement in Life Time Social (people, activity, role, expectations)

What is working well? What needs to change? (Gray Barders)



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 betaamyloid 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





Vision Changes

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

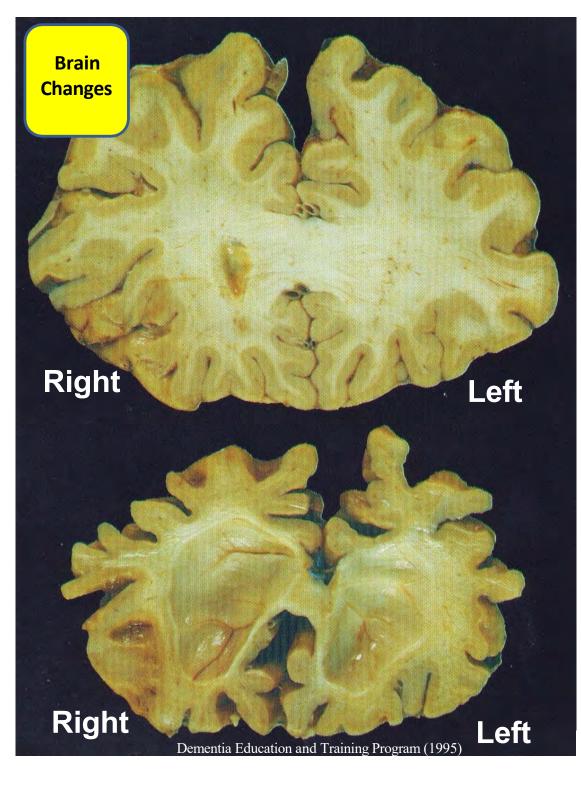


Dementia Education and Training Program (1995)

BIG VISION CHANGES

1. Loss of Peripheral Awareness

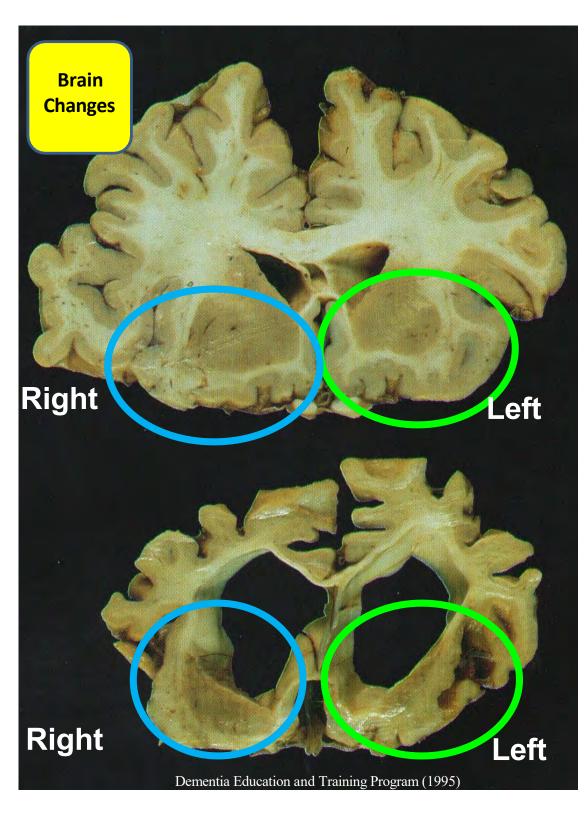
- 2. Tunnel Vision
- 3. Binocular Vision
- 4. Binocular +Object Confusion(discriminating senses)
- 5. Monocular Vision
- 6. Loss of Visual Regard



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

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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

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3 Functions of the Amygdala

3. Pleasure 1. Threat 2. Needs Meeter Seeker **Perceiver Getting what we: Getting what w Noticing what is: NEED NEED DANGEROUS** Risky (Aroused) Want Want Alerting (Aware) Like Like

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 who they are

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?

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

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 Fourth Piece of the Puzzle:

The Environment

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

The Four Fs

Friendly

- Functional
- Familiar
- 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)

Physical Sensory Social

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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!

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

PPA Resource Card



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







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**



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...."

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



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

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



Examples of Meaningful Activities:

- 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



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



#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....



#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



#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



#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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