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## Communication and Dementia

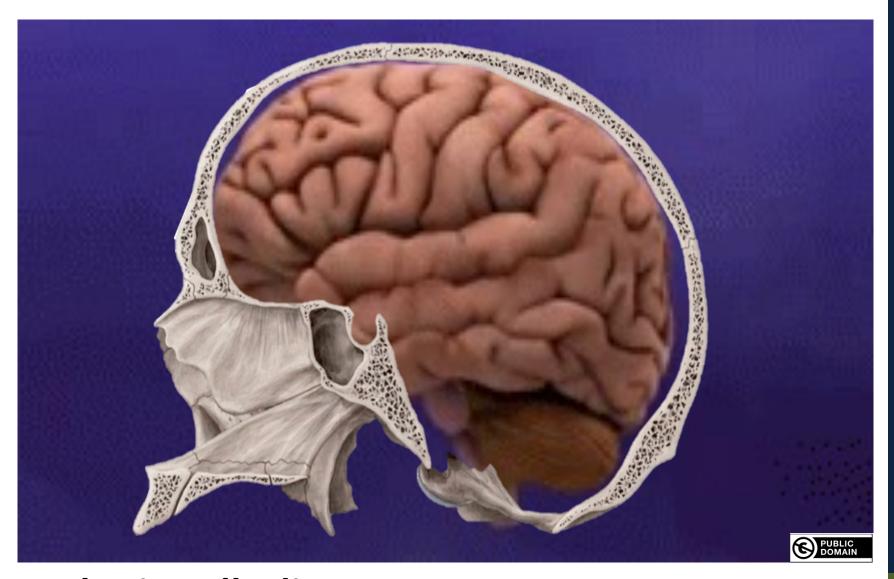


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## Four Truths About Dementia:

- 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



As brain cells die the brain shrinks in size

### Let's see what changes inside:



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# Advice The Usual (but not bad!) Advice

- 1. Let go of the past to be in the moment
- 2. Go with their flow
- 3. Be willing to try something new
- 4. Be willing to learn something different
- 5. Be willing to see it through another's eyes
- 6. Be willing to fail and try again



https://www.aacnnursing.org/5b-tool-kit/themes/person-centered-care

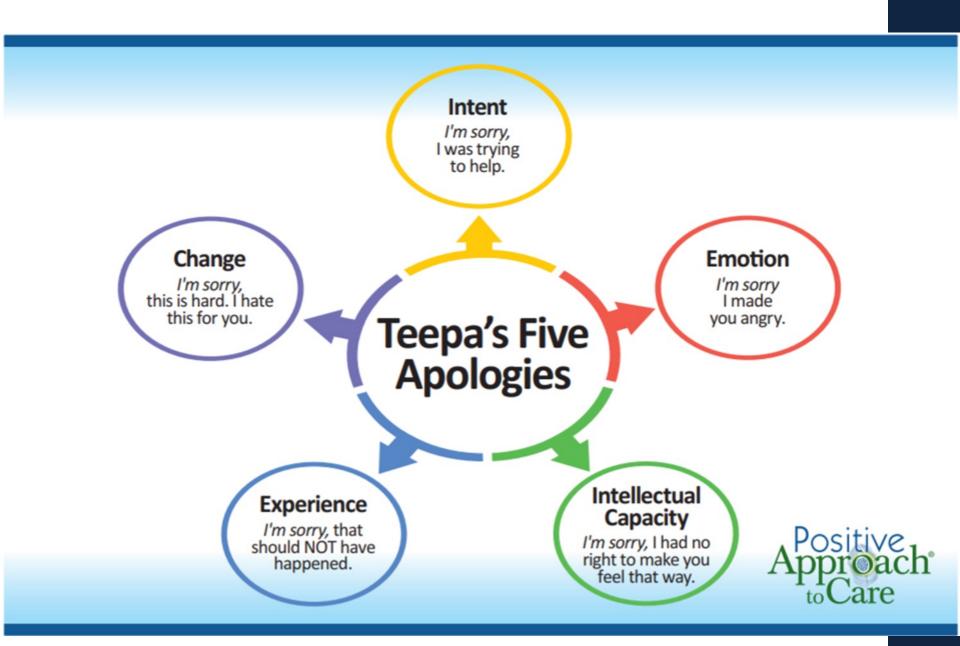
### 6 GUIDING PRINCIPLES TO A TRAUMA-INFORMED APPROACH

The CDC's Center for Preparedness and Response (CPR), in collaboration with SAMHSA's National Center for Trauma-Informed Care (NCTIC), developed and led a new training for CPR employees about the role of trauma-informed care during public health emergencies. The training aimed to increase responder awareness of the impact that trauma can have in the communities where they work.

Participants learned SAMHSA'S six principles that guide a trauma-informed approach, including:



Adopting a trauma-informed approach is not accomplished through any single particular technique or checklist. It requires constant attention, caring awareness, sensitivity, and possibly a cultural change at an organizational level. On-going internal organizational assessment and quality improvement, as well as engagement with community stakeholders, will help to imbed this approach which can be augmented with organizational development and practice improvement. The training provided by CPR and NCTIC was the first step for CDC to view emergency preparedness and response through a trauma-informed lens.



### **Vision Changes**

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

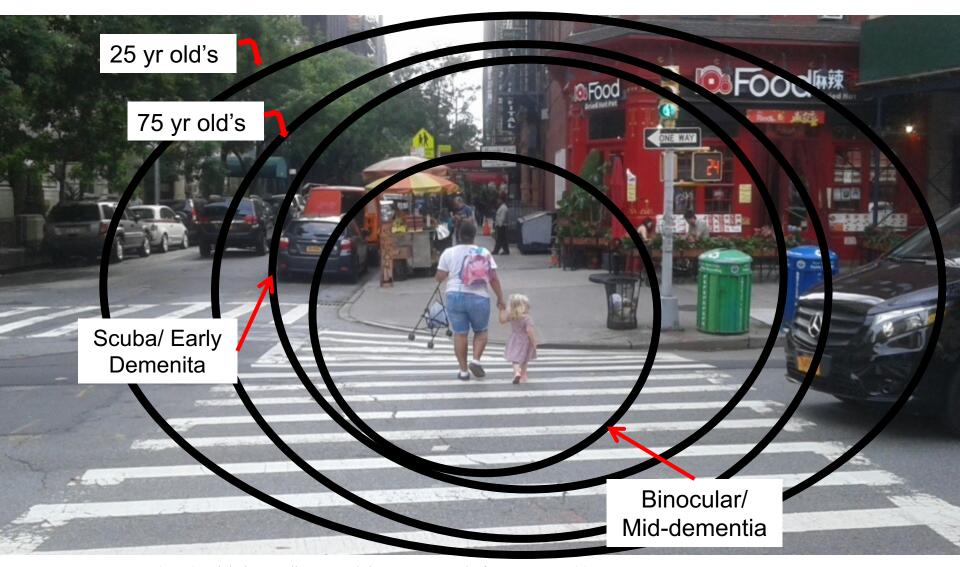


Dementia Education and Training Program (1995)

### BIG VISION CHANGES

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

### Visual Fields by Age and then by State of Brain Change



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.

Visual Field with Monocular Vision
Late in dementia
Problems with depth perception
Stairs or crosswalk???





### **How Can We Best Support?**



Come from the front?

It's the RELATIONSHIP!

# How Did Teepa Better Support Lauren? With Lauren's Visual Changes?

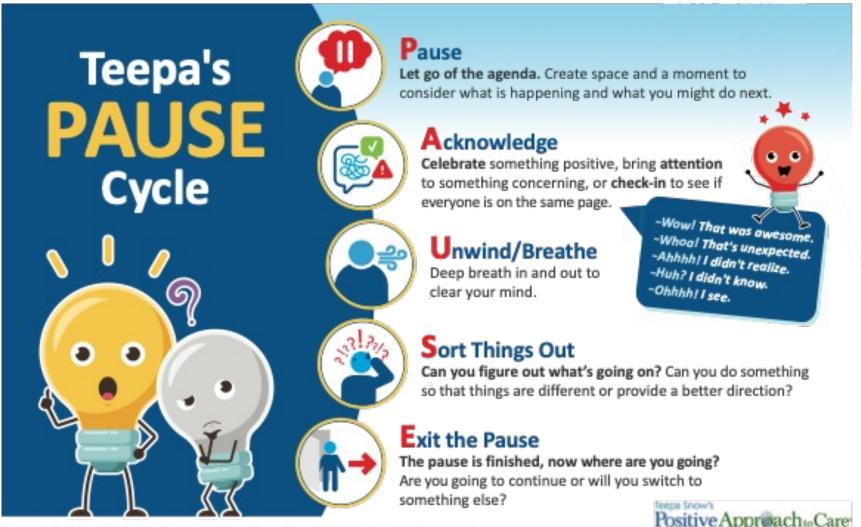
- Waited for her visual regard
- Got low
- Respected space



- Connected
- Got Lauren going
  - Used Positive Action Starters

PAC Eating-Lauren.MP4

### Are we learning the power of the Pause??



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### 3 Ways We Take In Data

### 3 Zones of Human Awareness

### **Public Space**

- 6 ft or more away
  - for awareness



### **Visual**

What we see

### **Personal Space**

- 6 ft to arm's length
  - for conversation



### Verbal

What we hear

### **Intimate Space**

- Arm's length or closer
  - for intense closeness



### **Touch**

What we touch & feel

### **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





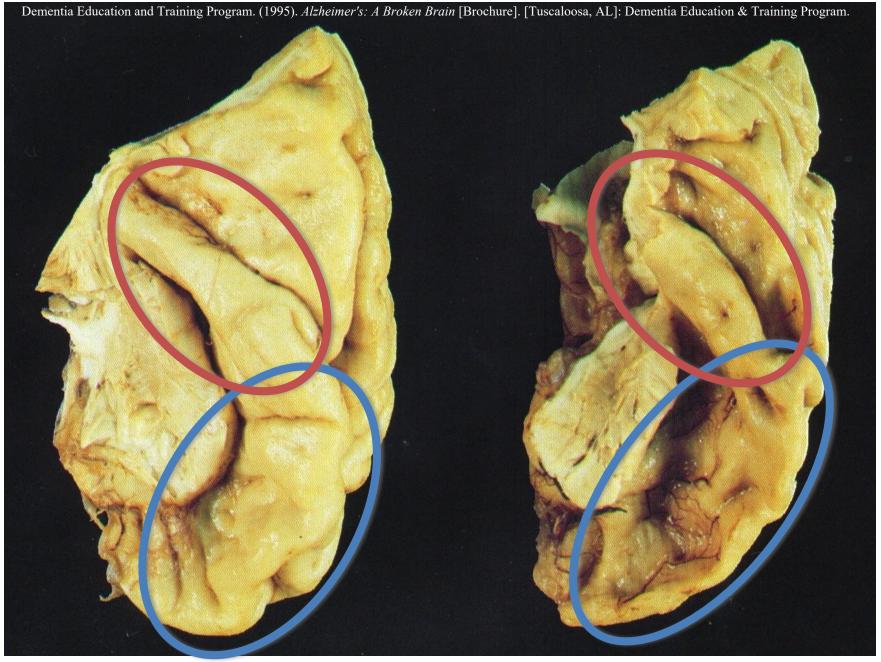
### **Positive Physical Approach**™

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

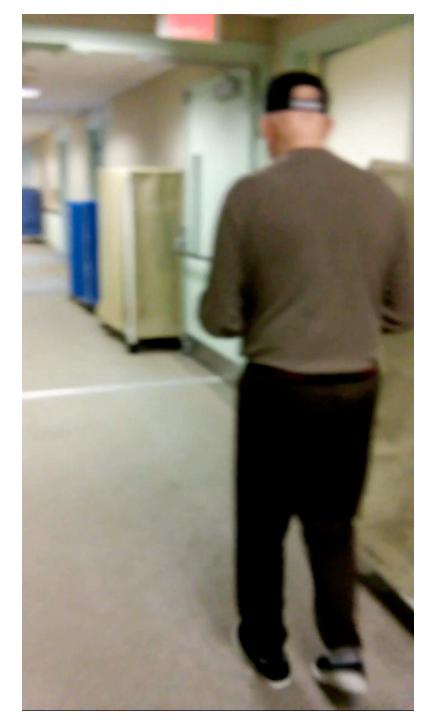


- 5. **Supportive Stance**
- 6. Move into HuH®
- 7. Move to side; **Get low**





BIG Language CHANGE Hearing Sound: Unchanged



Ask:
"Shut the door,
Buddy"

### **Give SIMPLE INFO**

- Visual matched WITH verbal
  - •It's about time for... tap your watch/wrist
  - Let's go this way. Point
  - •Here's your socks. Hold up their sock
  - Coffee or tea? Raise coffee carafe then tea bag
- DON'T ask questions you DON'T want to hear the answer to...
- Acknowledge their response/reaction
  - Try replacing "yes, but" with "yes, and..."
- LIMIT words Keep it SIMPLE

### And then WAIT!!!!

### 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...."

### **Uses of Hand-under-Hand**®







### Use of Hand-under-Hand®:

- Connecting: comforting and directing gaze
- Guiding and helping with movement
- Uses established nerve pathways
- Getting eye contact and attention
- Providing help with fine motor
- Offering a sense of control, even when you are doing almost everything
- Gives advanced notice of possible problems
- Allows you to do with, not to





### Permission is the fine line between neglect, care, and abuse.

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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:

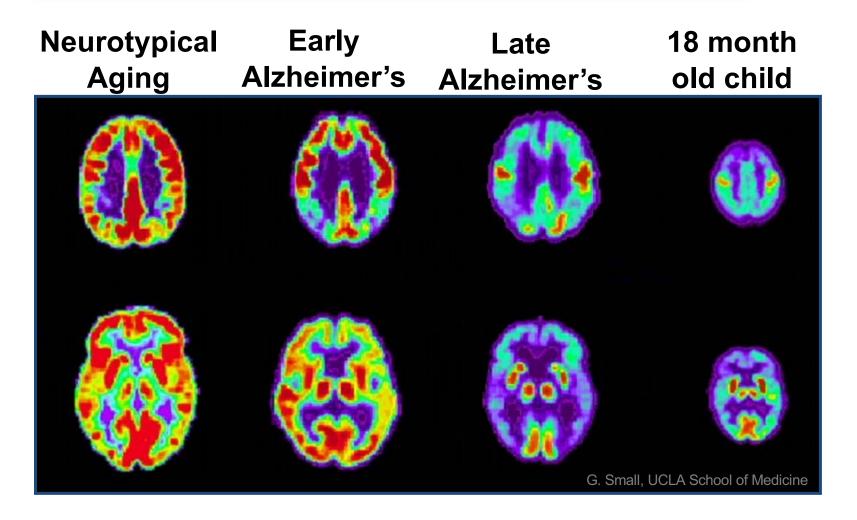
- Us
- Person living with brain change's comfort
- Using time to connect and determine what will work and what is not okay
- Using multi-modal cues to connect and communicate
- Right to informed consent
- Guiding/supporting to see what is possible at the time
- Only doing what is within the boundaries 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

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





### **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- trapped

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)

#### Intent

Thank you for helping, it made a difference, or I noticed and it mattered

### Change

Thank you, for making that change, even though it was hard

### **Teepa's Five Appreciations**

### **Emotion**

Thank you that feels better OR Thanks for the emotional support – I felt it

### **Experience**

Thank you, I'm so glad that happened! Thank you for trying or doing what you did!

### Intellectual Capacity

Thank you, your expertise made a difference.



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