

# Understanding Your Brain and the Changes that Occur with Dementia

## Introduction: Beliefs

- The relationship is most critical, not the outcome of one encounter
- We are a key to make life worth living
- People living with dementia are doing the best they can
- We must be willing to change ourselves

**What do you believe about relationships and language?**

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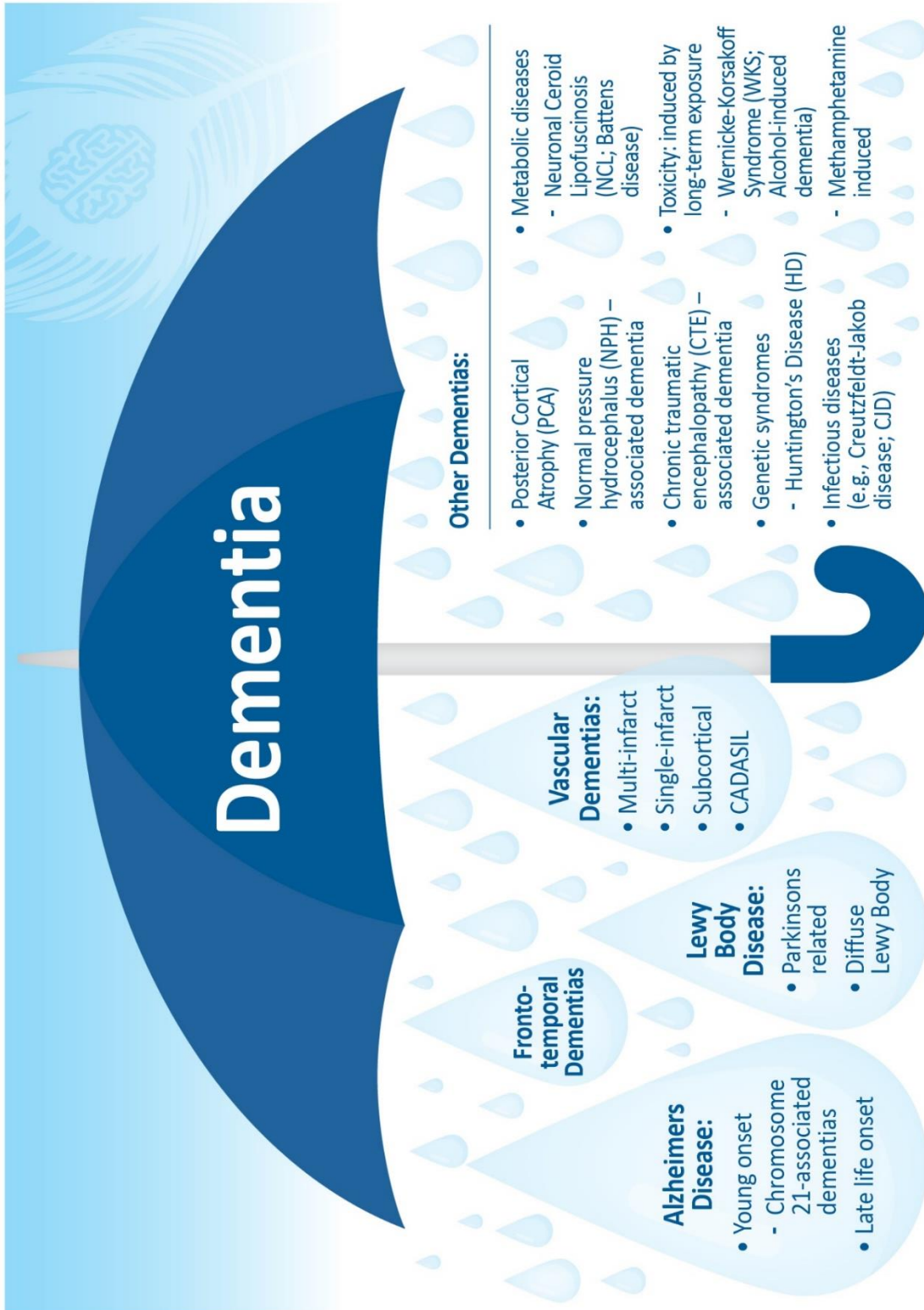
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# Positive Approach to Care Language

## Key Phrases and Ways of Talking About Dementia and Care

Commonly Used Phrase or Word	PAC Language	Reasoning
Demented Person	Person Living with Dementia (PLwD)	People who are living with dementia and are able to let others know have asked for this to be used – at an international level.
Alzheimers Patient	Person Who Has Alzheimers (if accurately diagnosed or Person Living with Dementia if not sure of type)	A person is a <u>person</u> , not a patient, unless being treated and seen by a medical professional in a medical setting. Even then, that person is still a person first and a patient second and has dementia/Alzheimers, but should not be defined by that diagnosis.
Dementia Sufferer or Victim	Doing the best he or she can while living life with dementia (Alzheimers, Lewy body dementia, Frontotemporal dementia, Alcohol-related dementia, Vascular dementia, etc.); sometimes struggling and sometimes finding joy and pleasure	People living with various forms of dementia may at times experience challenges and frustrations: emotionally, physically, intellectually, socially, etc. It is <u>not</u> our job or role to label that person as suffering – only that person can say where he or she is at that moment. There will also be moments of joy and celebration when living with this condition. Being a victim implies you are not able to do anything about it. We are able to guide, assist, and support so that challenges are addressed and needs are met.
Hand-Over-Hand or Doing It For The Person	Hand-under-Hand® 	Hand-under-Hand® uses body-to-body communication. It helps the PLwD by giving them a sense of what is happening, what is expected, and what is going to happen next. It also provides an opportunity for body-to-body feedback that is gentle and subtle, rather than having the person hit, grab, or refuse.

<p>Feeding, Bathing, Changing Someone</p> <ul style="list-style-type: none"> <li>• “She’s my feeder”</li> <li>• “He’s my shower”</li> </ul>	<p>We do tasks <u>with</u> people, not <u>to</u> people.</p> <p>Care supports the person’s living of their life.</p> <ul style="list-style-type: none"> <li>• “Help her eat”</li> <li>• “Help him shower”</li> </ul>	<p>Supporting the PLwD and helping them in doing the activity/task may include partial or full assistance with set-up, prompts, guidance, and physical support.</p>
<p>Caregiver or Carer or Caretaker</p>	<p>Care Partner</p>	<p>Care partners are here to <u>support</u> and help the person, not to <u>give</u> them something they may not want or need. When we work in partnership, there is a mutual benefit to be achieved. Everything we do with a PLwD should include permission, shared tasks, and appreciation for their help. The role of the care partner will continuously change as the condition changes, but it must always be a partnership.</p>
<p>Burden</p>	<p>Choose to Support</p>	<p>If at any time the care partner begins to feel or sense that caring is becoming a burden, then a <u>pause</u> and <u>time-out</u> is essential to maintain positive relationships and physical/mental health.</p>
<p>Behaviors</p>	<p>Expressive Communication</p>	<p>As people move through different GEMS® states, with changing communication abilities and heightened amygdala responses, at times they express their <u>unmet needs</u> in the only way they can. It is our healthy brains that need to step back, become a detective and try to figure out what need is being unmet that is underlying this communication.</p>
<p>Walkie Talkies</p>	<p>People who still have verbal and physical abilities</p>	<p>Defining people this way removes their humanness. We like to focus on preserved abilities in a positive way.</p>
<p>Aggressive</p>	<p>Has a fight response when the amygdala is triggered</p>	<p>People are doing the best they can with what they have left. Aggression is a form of expressive communication: something isn’t working.</p>



# Dementia

## Other Dementias:

- Posterior Cortical Atrophy (PCA)
- Normal pressure hydrocephalus (NPH) – associated dementia
- Chronic traumatic encephalopathy (CTE) – associated dementia
- Genetic syndromes
  - Huntington’s Disease (HD)
- Infectious diseases (e.g., Creutzfeldt-Jakob disease; CID)
- Metabolic diseases
  - Neuronal Ceroid Lipofuscinosis (NCL; Batten’s disease)
- Toxicity: induced by long-term exposure
  - Wernicke-Korsakoff Syndrome (WKS; Alcohol-induced dementia)
  - Methamphetamine induced

## Vascular Dementias:

- Multi-infarct
- Single-infarct
- Subcortical
- CADASIL

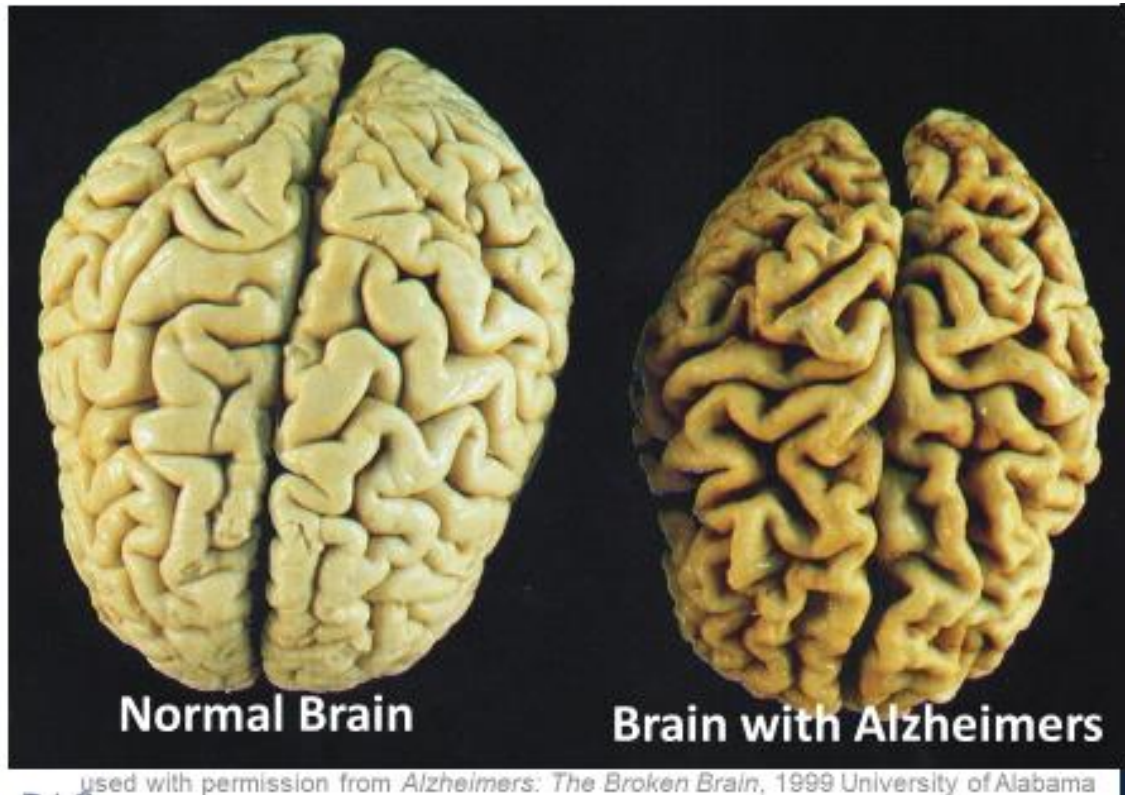
## Lewy Body Disease:

- Parkinsons related
- Diffuse Lewy Body

## Fronto-temporal Dementias

## Alzheimers Disease:

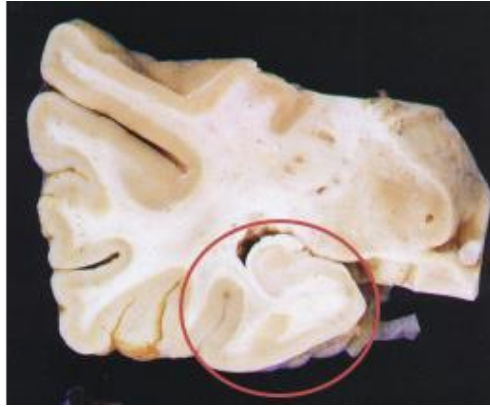
- Young onset
  - Chromosome 21-associated dementias
- Late life onset



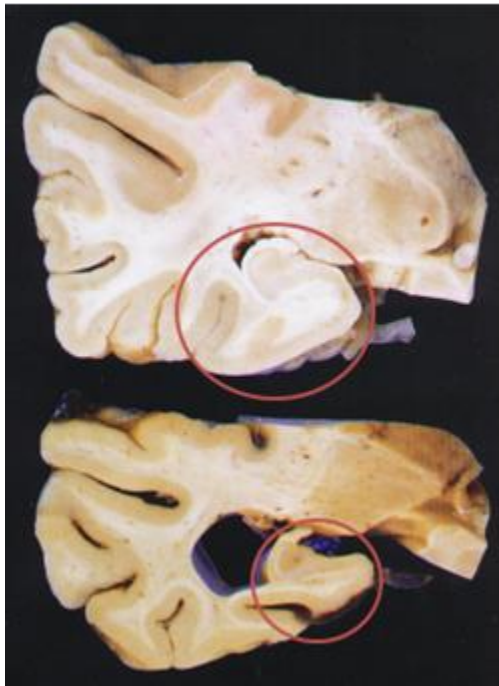
## **Dementia ≠ Alzheimers ≠ Memory Problems**

### **Four Truths About All Dementias:**

- 1.
- 2.
- 3.
- 4.



**The hippocampus is responsible for learning and remembering, time awareness, and way finding. What do you think people would say or do that would be different if their hippocampus was changing?**



**How could you be supportive of a person who has changed in their ability to have accurate time awareness, changes in time awareness, and a change in how they learn and remember?**

# Amygdalae:



## The primitive brain is in charge of:

- **Survival**
  - Autonomic protective: fright, flight, fight, or hide and seek
  - Pleasure-seeking: meeting survival needs and finding joy
- **Thriving: Running the Engine**
  - Maintain vital systems (BP, BS, Oxygen Saturation, Temperature, Pain)
  - Breathe, suck, swallow, digest, void, defecate
  - Circadian rhythm
  - Infection control
- **Learning New and Remembering:**
  - Information
  - Places: spatial orientation
  - Passage of time: temporal orientation

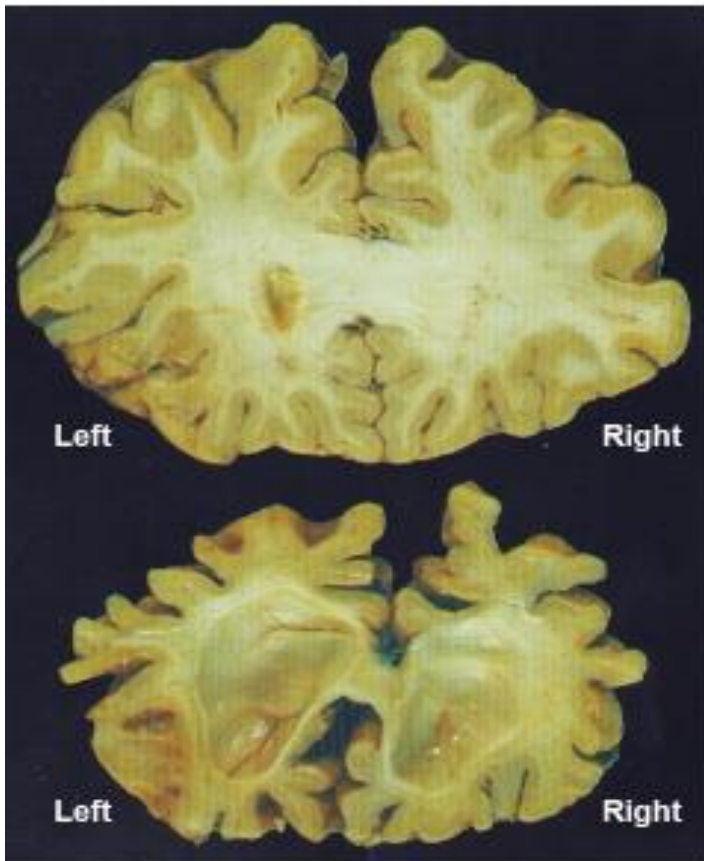


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**What are some cues that your amygdala is turned on?**

**What cues should you look for in others?**



## **Executive Control Center**

- **Impulse Control**
- **Be Logical**
- **Make Choices**
- **Start-Sequence-Complete-Move On**
- **Self-Awareness**
- **See Another's Point of View**

**Which of the skills of the executive control center will you be using most as you are supporting a person with a changing brain?**



## Visual Changes:

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

1. Less Peripheral Awareness
2. Tunnel Vision
3. Binocular Vision
4. Object Use Confusion
5. Monocular Vision
6. Limited Visual Regard



## GEMS® State Vision Changes:

**Sapphires:** Loss of about 45 degrees of visual field

**Diamonds:** Tunnel vision

**Emeralds:** Binocular vision

**Ambers:** See parts, not whole; loss of object recognition

**Rubies:** Monocular vision

**Pearls:** Movement, familiar/unfamiliar

**What does it feel like to have scuba, binocular, and monocular vision?**

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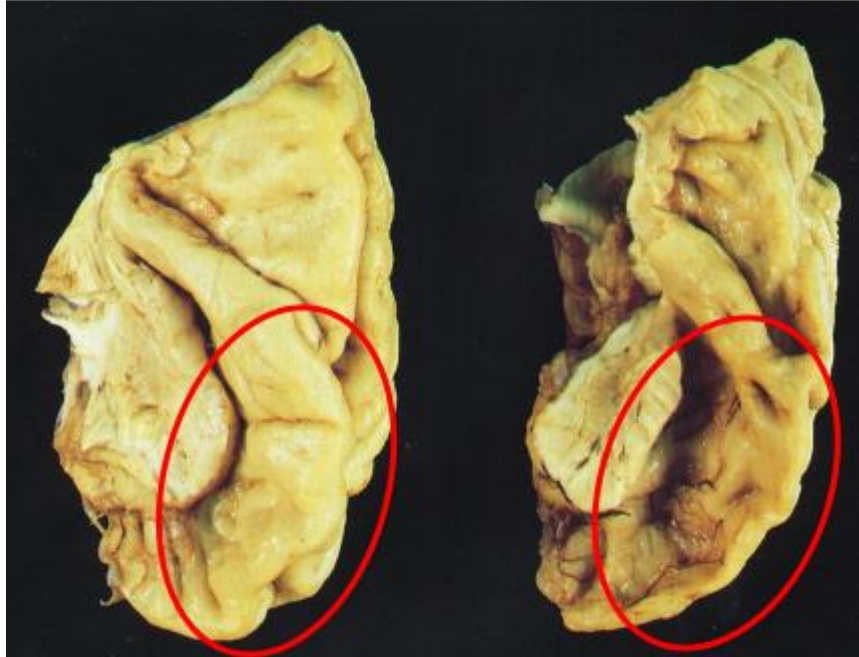
**How will you show others the importance of vision change with dementia?**

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**Understanding Language: Big Change**



**Hearing Sound: Not Changed**

**What do you think is being communicated in the sentences below?**

**Don't you think unless someone like cares a whole awful, nothing is going to get it's not?**

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**Early in this, people will miss out of four. How long before you get do you think?**

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## PPA Using the 3 Zones as a Guide:

- Get into visual range in **public space**, pausing at the edge of **personal space** (approximately 2 arms length away)
- Greet and smile with your hand held still by your face
- Slowly extend hand for a handshake
- After the person you are approaching gives permission by extending their hand, move slowly into a handshake allowing you to enter **intimate space**
- Move from handshake to Hand-under-Hand ® position
- Move from the front to the side, getting into a **supportive stance**
- Get to or below their eye level
- Use a PPC or PAS phrase (Positive Personal Connection/ Positive Action Starter)



## Positive Personal Connections (PPC):

- 1. Greet or Meet:** Introduce yourself, use their preferred name. “Hi \_\_\_\_\_, I am \_\_\_\_\_” or “I am \_\_\_\_\_ and you are \_\_\_\_\_?”
- 2. Say Something Nice:** Indicate something about them of value. “That is a beautiful shirt!”
- 3. Be Friendly:** Share about yourself, then leave some silence. “My daughter’s name is the same as yours! I’ve got three daughters.”
- 4. Notice Something:** Point out something in the environment. “Have you seen the new plants they put in the front room?”
- 5. Be Curious:** Explore a possible unmet like, need or want. “Would you like to listen to some music?”

## Positive Action Starters (PAS):

- 1. Help:** Compliment their skill in this area, then ask for help. “You’re so handy with puzzles, could you help me with this one?”
- 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. I’ve never really liked brushing my teeth either!”
- 3. Choice:** Try using visual cues to offer two possibilities or one choice with something else as the other option. “Should we wear the red shirt or the blue shirt today?”
- 4. Short and Simple:** Give only the first piece of information. “It’s about time to get our shoes on.”
- 5. Step by Step:** Only give a small part of the task at first. “Lean forward.”

**How is PPA™ plus PPC plus PAS a dynamic assessment that leads to a shared relationship when done well?**

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**What are your strengths and goals for growth in your own PPA™ practice?**

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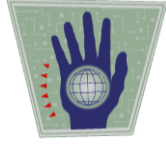
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## **Top Five Unmet Needs:**



### **Physical Needs:**

**Hydration and Nourishment**

**Wake-sleep and active-rest cycles**

**Elimination: all forms**

**Find Comfort: 4Fs and 4Ss**

**Pain-free:**

- **Physical – body**
- **Emotional – relationships**
- **Spiritual – belonging/purpose**

### **Signals of Emotional Distress:**

**Angry**

**Sad**

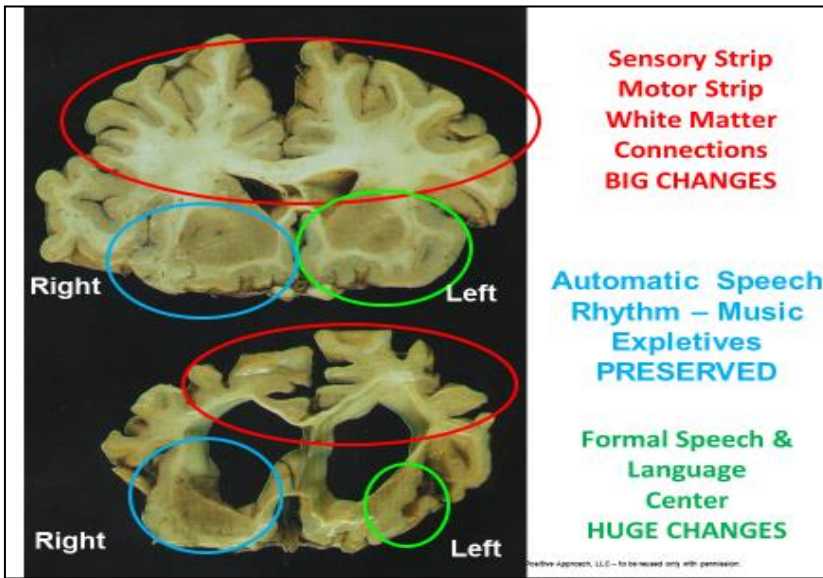
**Lonely**

**Scared**

**Bored/Lacking Purpose**

**How do you feel when one or more of your physical unmet needs is not met? What might you see a person living with dementia do when one or more of these needs is not met and they are having difficulty with language?**





### Touch Cues:

- Place an item or tool in hand
- Touch with a finger or hand
- Hand guidance
- Hand on shoulder or back
- Hand-under Hand® contact
- Hug

**Why is the order of the cues so important?**

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**How will you get others to see this?**

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