

Seeing People as Precious GEMS®

What Happens and What Can I Do in the Progression of Dementia?



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Speaker Disclosures

Beth Nolan is the Director of Research and Policy for Positive Approach® LLC



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Objectives:

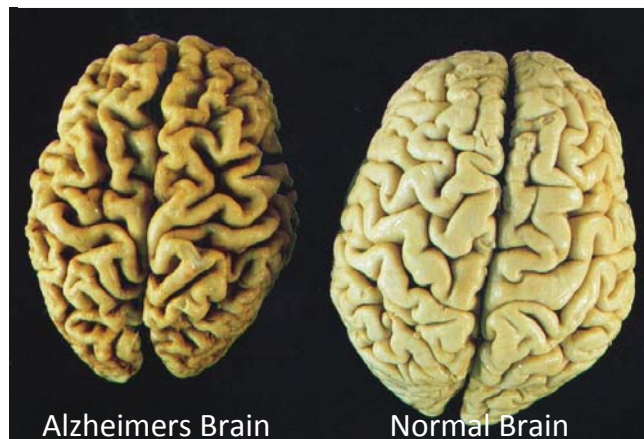
1. Describe the utility of a GEMS[®] dementia progression classification system vs other loss-focused systems of classification
2. Identify the skills and strengths of each of the 6 GEMS[®] states
 - Identify 1 way to facilitate communication at each state



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Four Truths About Dementia

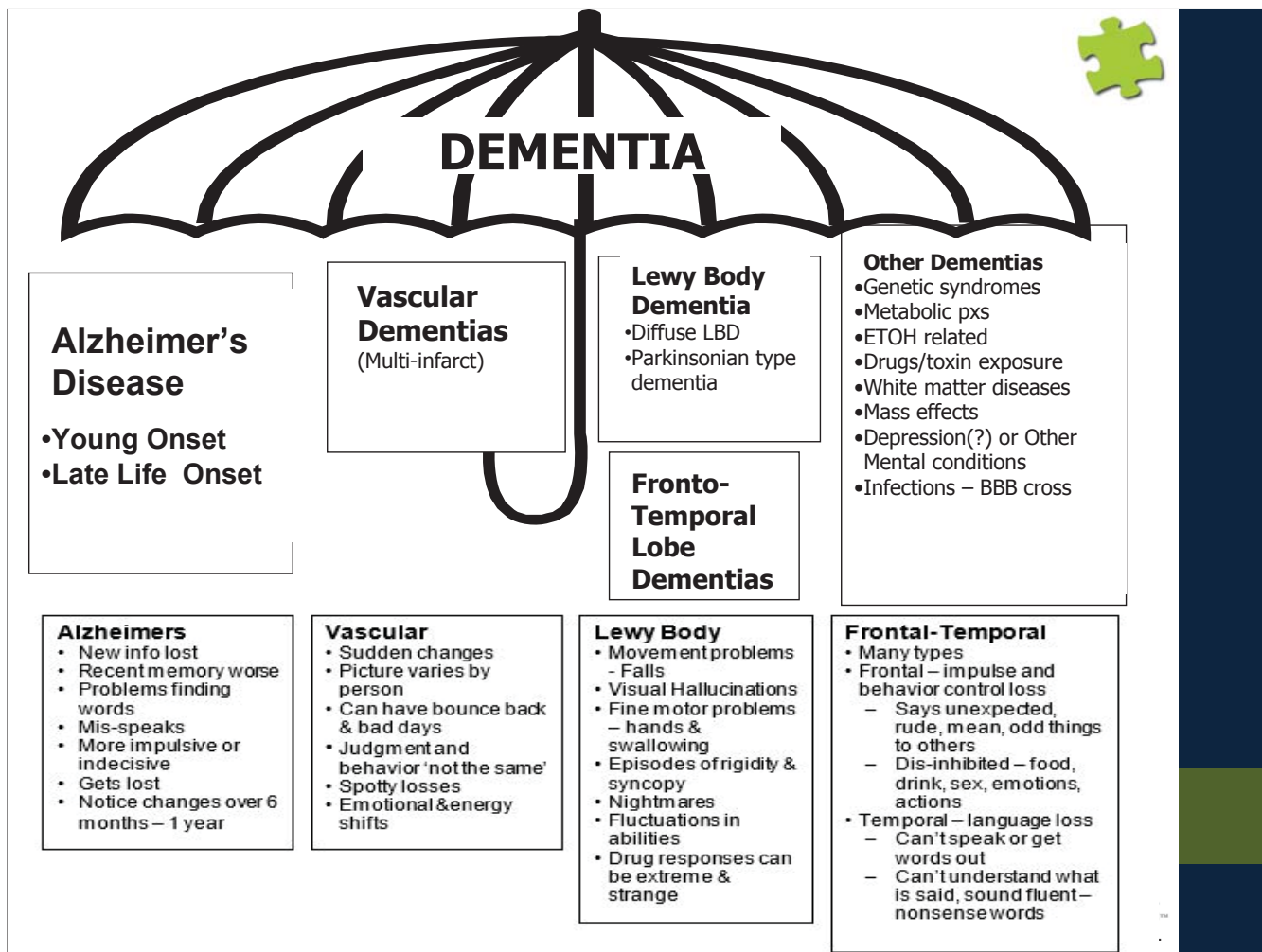
1. At least 2 parts of the brain are dying
2. It is chronic and can't be fixed
3. It is progressive and will get worse
4. It is terminal



Used with permission from The Broken Brain:
Alzheimer's. 1999 University of Alabama



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Global Deterioration Scale

1. **No cognitive decline**
2. **Very mild cognitive decline**
 - (Age Associated Memory Impairment)
3. **Mild cognitive decline**
 - (Mild Cognitive Impairment)
4. **Moderate cognitive decline**
 - (Mild Dementia)
5. **Moderately severe cognitive decline**
 - (Moderate Dementia)
6. **Severe cognitive decline**
 - (Moderately Severe Dementia)
7. **Very severe cognitive decline**
 - (Severe Dementia)

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 - (Severe Dementia)

So what CAN they do?
What scale addresses that?



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GEMS[®] Dementia Abilities

Based on Allen Cognitive Levels

- A Cognitive Disability Theory – OT based
- Creates a common language and approach to providing:
 - ✓ Environmental support
 - ✓ Caregiver 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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The GEMS...



Sapphires: True Blue – Healthy Brain

**Diamonds: Routines & Routines Rule –
Clear/Sharp**

**Emeralds: Green/On the Go with Purpose–
Naturally Flawed**

**Ambers: Caught In a moment of time –
Caution Required**

**Rubies: Deep & Strong –
Others stop seeing what is possible**

**Pearls: Hidden in a Shell –
Beautiful Moments to Behold**



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Progression of the Condition

To the tune of *This Old Man*



The LIVING GEMS®



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SAPPHIRE true, you and me



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!



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Sapphire

True Blue: Optimal Cognition, Healthy Brain



- Optimal Cognition: flexible in capacity
- Slowing down: needs more time to process
yet not change ability
- True to self: likes/dislikes are the same
- Able to learn: takes practice
- Stress, fatigue, or pain can induce Diamond moments
- Time to recharge or heal can restore to Sapphire



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Vision Changes

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



**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



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DIAMOND bright, share with me



Right before, where I can be

I need routine *and* different things to do

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

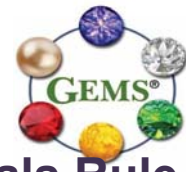


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Diamond

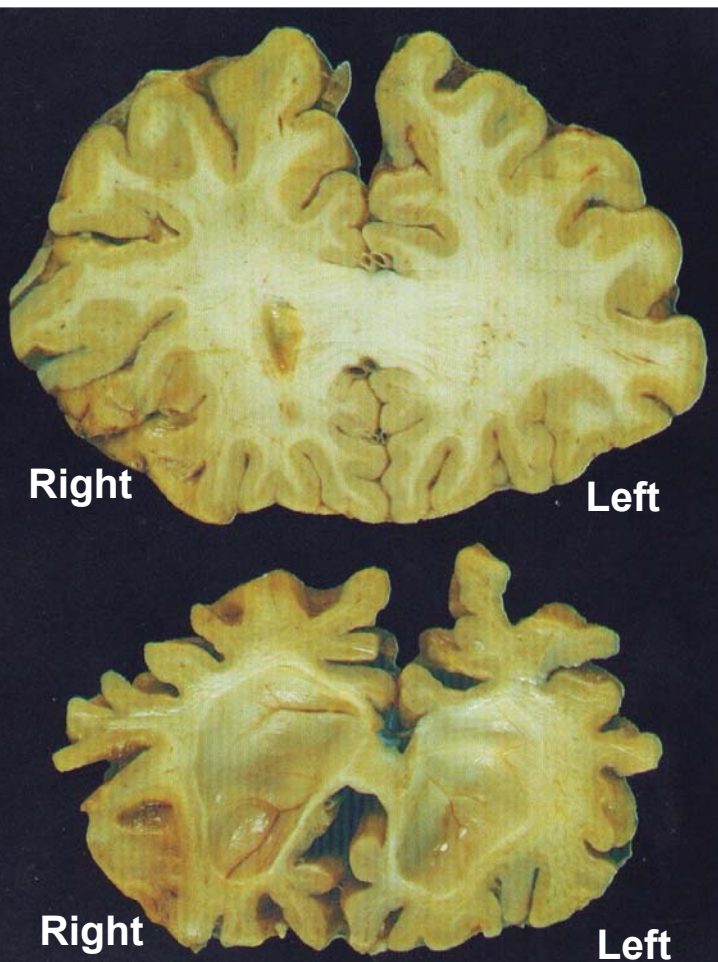
Clear and Sharp; Routines and Rituals Rule



- Routines and Rituals Rule: likes familiar
- May resist change or won't let things go
- Rigid under pressure: limited perspective
- Becoming protective: may be territorial
- Repeats self: hard to integrate new information
- Can cover mistakes in social interaction



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Executive Control Center

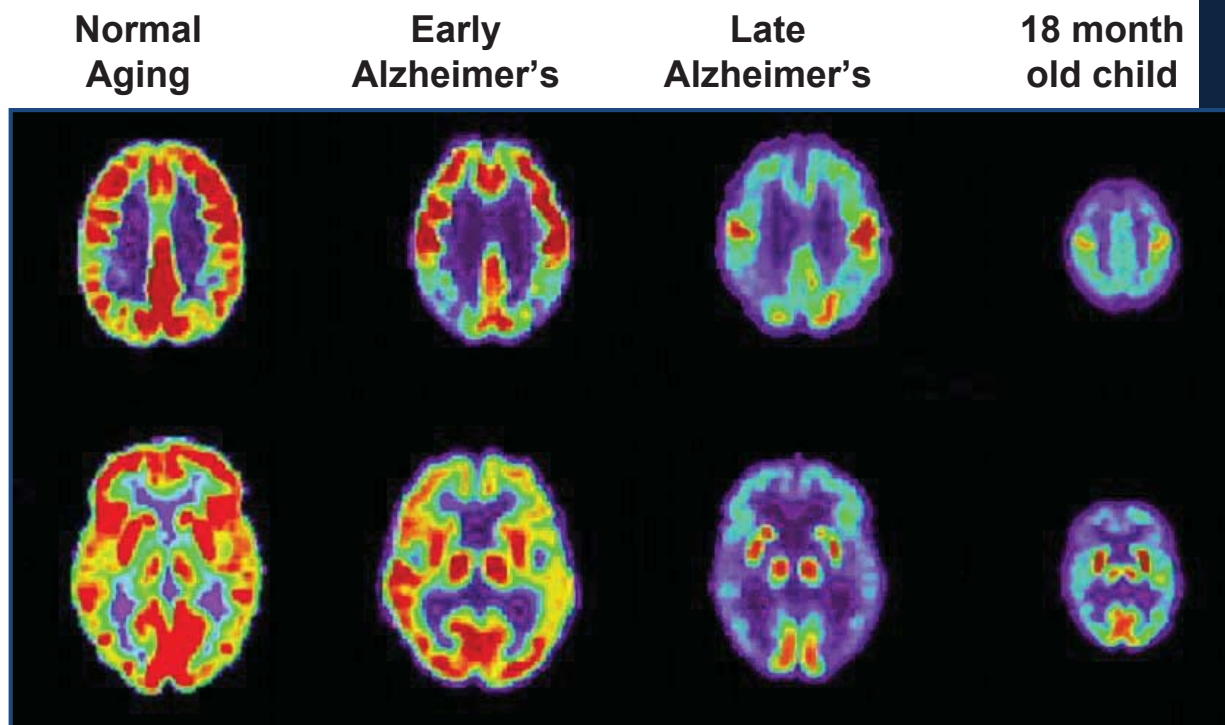
- Impulse Control
- Be Logical
- Make Choices
- Start-Sequence-Complete-Move On
- Self Awareness
- See Others' Point of View



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Positron Emission Tomography (PET)

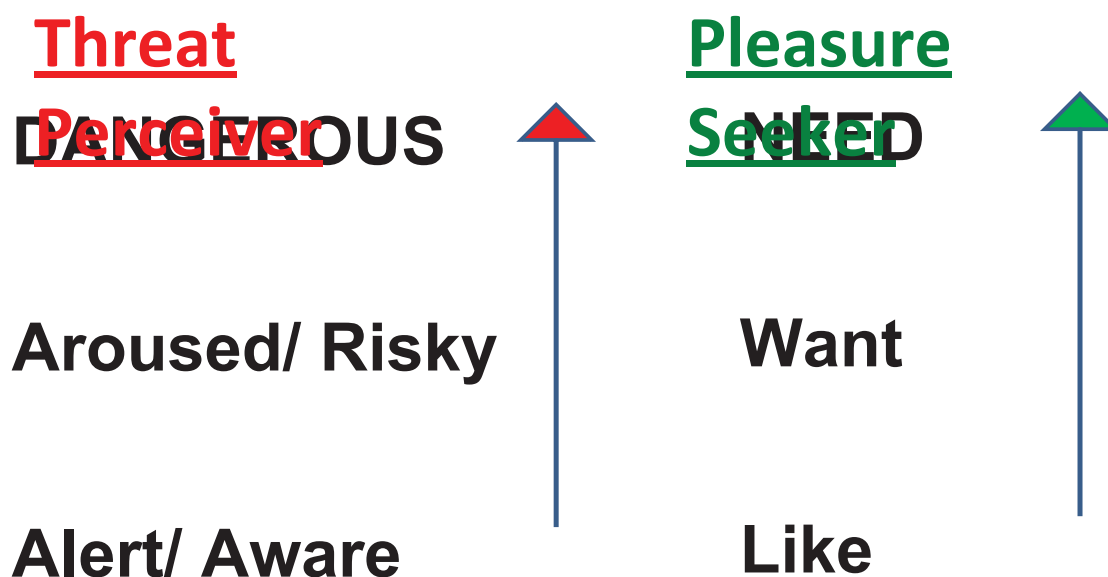
Alzheimer's Disease Progression vs. Normal Brains



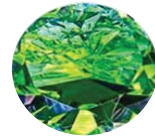
G. Small, UCLA School of Medicine

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Amygdala



EMERALD – go, I like to do



I make mistakes, but I am through!

Show me only one step at a time

Break it down and I'll be fine!

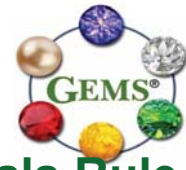


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Emerald

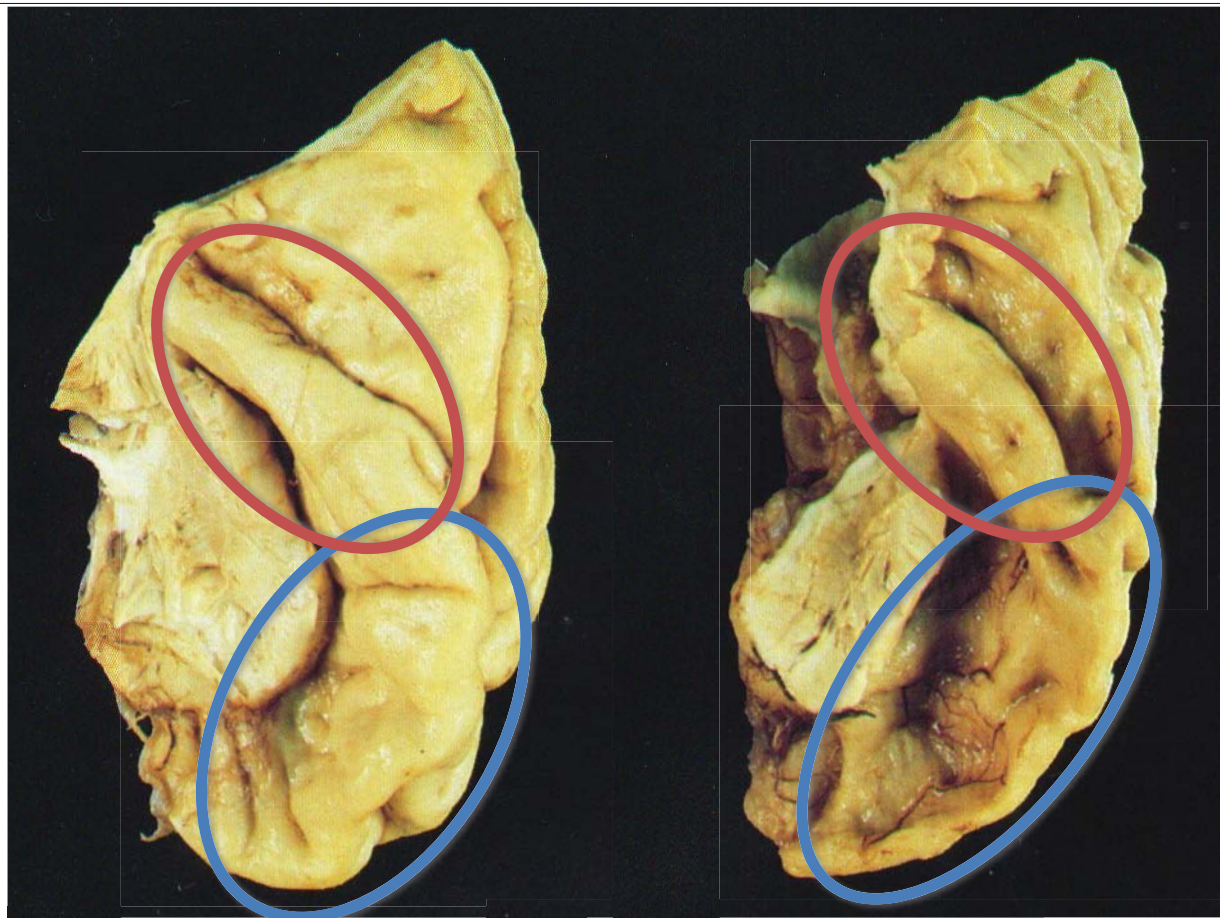
Clear and Sharp; Routines and Rituals Rule



- Desires independence: noticeable ability change
- Vocabulary and comprehension diminishing
- Communication becoming vague
- May neglect personal care routines
- On the go: needs guidance and structure
- Difficulty finding way to and from places
- May be lost in time






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BIG Language CHANGE Hearing Sound – Unchanged

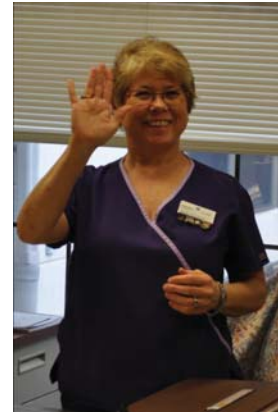
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3 Zones of Human Awareness	3 Ways to We take in Data
1. Public Space <ul style="list-style-type: none"> • 6 ft or more away -for awareness 	1. Visual What we see 
2. Personal Space <ul style="list-style-type: none"> • 6 ft to arm's length -for conversations 	2. Verbal What we hear 
3. Intimate Space <ul style="list-style-type: none"> • Arm's length or closer -for intense closeness 	3. Touch What we touch & feel 

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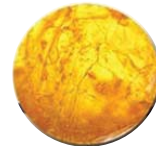
Positive Physical Approach™

1. **Stop** moving 6 ft out
2. **Greet:** *Hi* sign (open by face), say name
3. Move hand **into a handshake** position
4. **SLOWLY** come in from the front
-within visual range (or starts there)
5. Move into **Supportive Stance**
6. Hand shake—move into '**Hand-under-Hand**®'
7. Move to side; **Get low** —sits or kneels
8. Make **connection** (wait for their response!)
9. Deliver a message – using V-V-T cues



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AMBER – HEY!, I touch and feel



I work my fingers - rarely still

I can do things, if I copy you

What I ***need*** is what I do!



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Amber

Caught in a Moment of Time: Caution Required



- Focused on sensation
- Will react to how things: look, sound, feel, smell, taste
- Lives in the moment: not socially aware
- No safety awareness: typically very busy
- Difficulty understanding and expressing needs
- No ability to delay needs or wants
- Needs help with tasks: may resist
- Hard to connect with: may exhaust care partners



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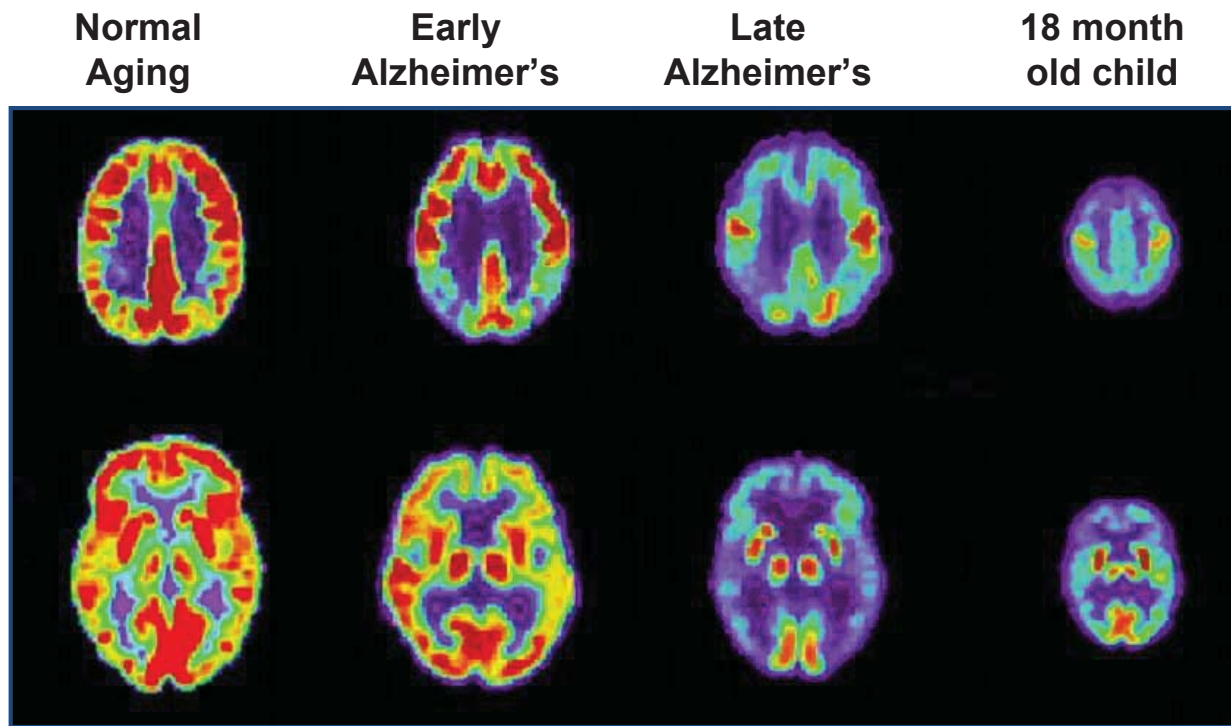
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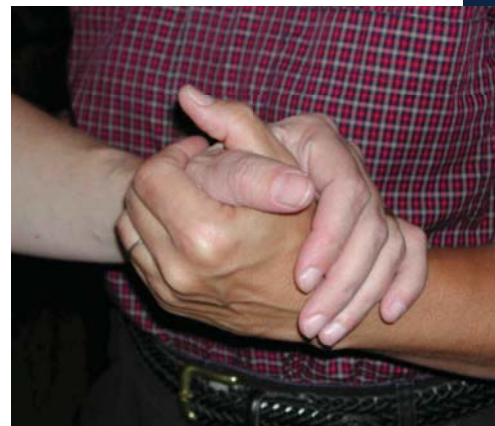


G. Small, UCLA School of Medicine

PAC TRAINING™

Hand-under-Hand™ Assistance

- Helps assist doing WITH, not *for*
- Helps protect their:
fingers, wrist, arm
- Helps protect us:



- Gives you cues before a PLWD wants to strike out
- Gives them something to squeeze/grab onto
- Helps direct gaze – eye-hand coordination
- Pressure in the palm is calming

PAC
TRAINING™

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Hand-under-Hand® Assistance

Protects aging, thin, fragile, forearm skin



PAC
TRAINING™

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High Risk



PAC
TRAINING™

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RUBY – skill – it just won't go



Changing something must go **slow**

Use your body to show me what you need

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



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Ruby

Deep and Strong;

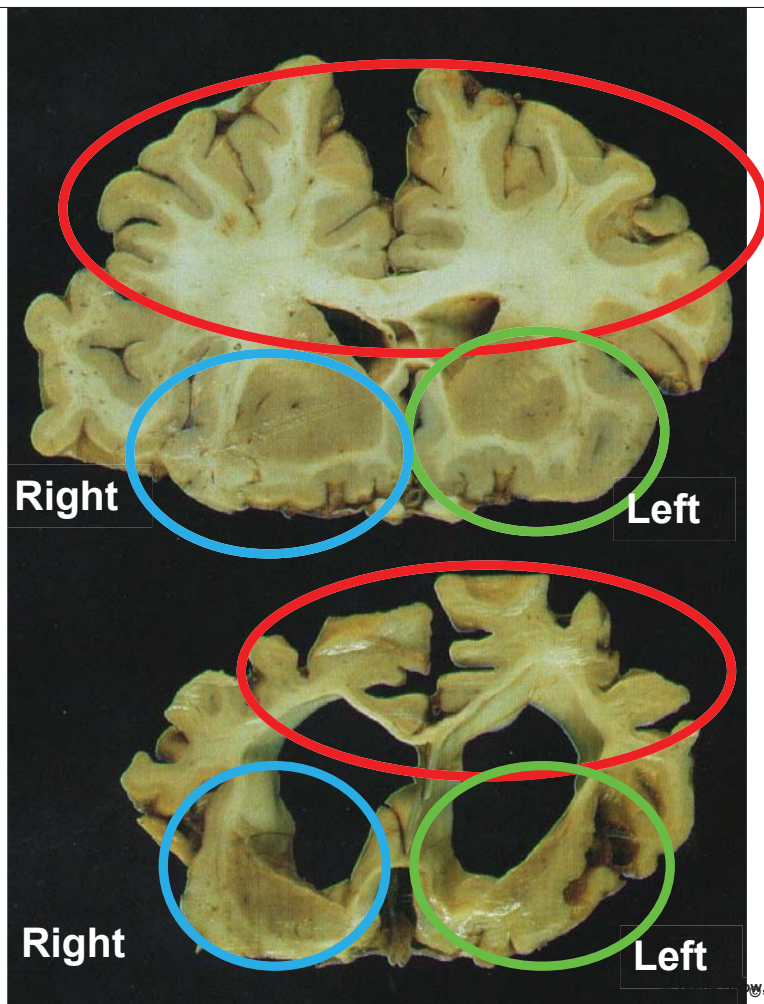
Others Stop Seeing What is Possible



- Retains rhythm: can sing, hum, pray, sway, and dance
- Understands expressions and tone of voice
- Losing ability to understand language
- Limited skill in mouth, eyes, fingers, and feet
- Can mimic big movements: gross motor abilities
- Loss of depth perception; monocular vision
- Falls prevalent: can only move forward
- Care Partners will have to anticipate unmet needs



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**Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES**

**Automatic Speech
Rhythm – Music
Expletives
PRESERVED**

**Formal Speech &
Language
Center
HUGE CHANGES**



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Now a PEARL, I'm near the end



But I still feel things through my skin

Keep your handling always firm and slow

Use your voice to calm my soul.



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Pearl

Hidden Within a Shell; Beautiful Moments to Behold



- Person is still there
- Moments of connection take time and will be short
- Knows familiar: unmet needs may cause distress
- Unable to move by themselves: fetal position, still and quiet
- Primitive reflexes have taken over: difficulty swallowing
- Brain failure shuts down body: diminishes need to eat or drink
- Care Partners need to give permission to let go



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Contractures



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How to Help:PEARLS



- Hand under Hand help & care
- Check for reflexes – modify help and approach to match needs
- Guide movements
- Use calm, rhythmic movements and voice
- Come in from back of extremities to clean
- Stabilize with one hand and work with other



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Progression of the Condition: Skills and Strengths



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GEMS Skills and Strengths: Receptive Language Changes

- Sapphires: crowded & loud spaces more challenging, high pitched harder
- Diamonds: Slower, missing consonants
- Emeralds: missing about 1/4 words, needs pauses
– better with rhythm
- Ambers: 2-4 words; catches some key words out of context
- Rubies: social chit-chat, music, rhythm, tone of voice
- Pearls: familiar and friendly, calm or excite



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GEMS Skills and Strengths: Expressive Language Changes

- Sapphires: word finding a little slower, pauses
- Diamonds: varies with affect, word finding problems, mis-speaking at times of stress
- Emeralds: repeats phrases or words, gets stuck in social, intonation matters
- Ambers: repetitive, variable volume, echo
- Rubies: less articulated speech, babble, hum or sing, rhythmic vocalizations
- Pearls: sounds to single words, responsive



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GEMS Skills and Strengths: Dexterity – Hand Skills

- Sapphires: still intact slightly slower
- Diamonds: Slower, limited w/ bilateral skilled integration
- Emeralds: individual actions are there, sequencing is challenging, more forceful
- Ambers: heightened use of hands, skilled tool use decreased, strong
- Rubies: whole hand with limited finger use – hold and carry, difficulty with release
- Pearls: grasp strong, limited opening



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GEMS Skills and Strengths: Body Skills

- Sapphires: sustained - slower
- Diamonds: details not as good, globally Ok
- Emeralds: better with dominant side, errors
- Ambers: strong more than skilled, limited safety awareness
- Rubies: whole body not segmented, front ok back not
- Pearls: reflexive, great trouble with gravity or speed or movement



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GEMS Skills and Strengths: People Awareness Skills

- Sapphires: sustained – slower to ID
- Diamonds: recent ?, older/deeper better
- Emeralds: recognize like/not like,
- Ambers: can get lost in old-new relationships, will like or not like in the moment
- Rubies: like or not like, familiar versus not
- Pearls: voices, faces, touches, smells familiar or not



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GEMS Skills and Strengths: Place Awareness Skills

- Sapphires: sustained → turned around
- Diamonds: familiar feels best → gets lost in community & in unfamiliar places
- Emeralds: if OK with what is seen is OK, if not OK seeks the old familiar –task or social
- Ambers: OK if “here” feels OK, otherwise will go “there”
- Rubies: may or may not have a destination more a movement or stillness pattern
- Pearls: is what is experienced comforting



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GEMS Skills and Strengths: Time Awareness Skills

- Sapphires: lifelong – crunched or expanded
- Diamonds: more the past than now
- Emeralds: lost in episodes or caught in loops
- Ambers: in the moment not the task or sequence
- Rubies: in the experience, not the time
- Pearls: time has much less meaning



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GEMS Skills and Strengths: Situation Awareness Skills

- Sapphires: sustained → tough to think
- Diamonds: old emotions drive new interactions
- Emeralds: has moments of time travel
- Ambers: more sensory awareness than intellectual awareness, immediate not big picture
- Rubies: only in moments, less body aware
- Pearls: more inside than externally aware



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***Thank you for creating
Dementia Competent World!***

**GIMME 5!
(5 minutes a day for PPA™)**



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