


Changing the Culture of
Dementia Care
One Mind at a Time



GEMS®
Dementia **Aware**
Dementia **Knowledgeable**
Dementia **Skilled**
Dementia **Competent**

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Best Practices in Dementia Care:

Building Hands-On Skills for
Communication and Interactions

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Reality Check #1:

**As a Caregiver,
You Will Make Mistakes!**

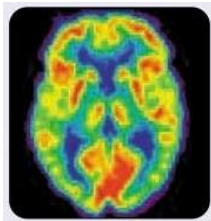
Get Over It!!!!

Uh-Ohs Lead to Ah-Has!

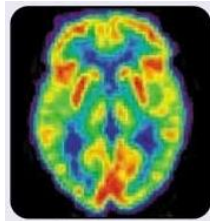
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PET and Aging:



PET Scan of 20-Year-Old Brain



PET Scan of 80-Year-Old Brain

ADEAR, 2003

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As we age,
our processing speed may
slow, but we do not lose
function in our brains, unless...

Something Goes Wrong With Our Brains

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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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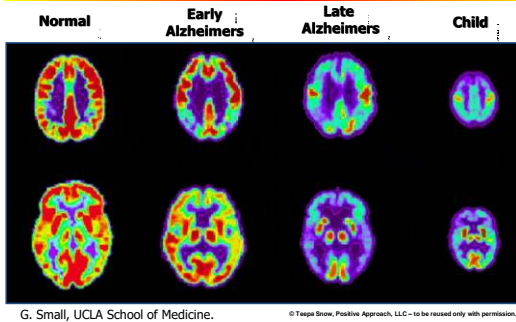
Brain Failure

The person's brain is dying

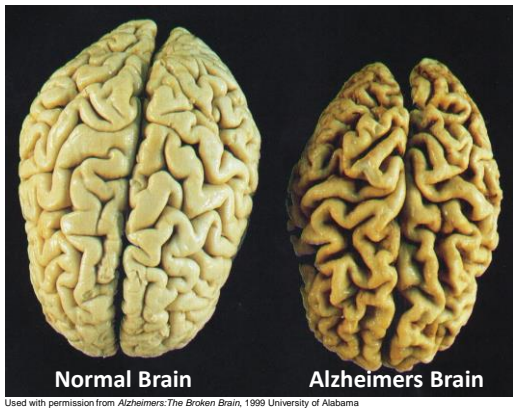
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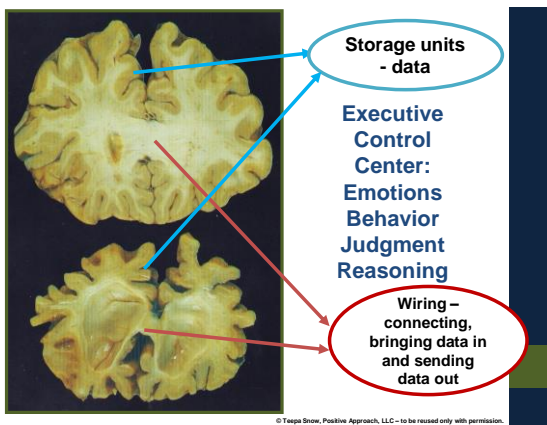
Positron Emission Tomography (PET) Alzheimers Disease Progression vs. Normal Brains



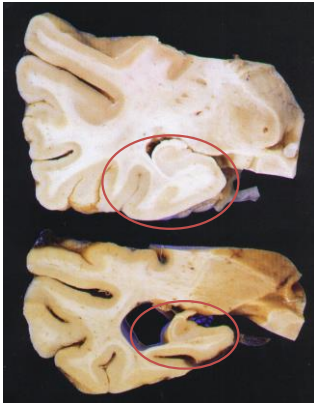
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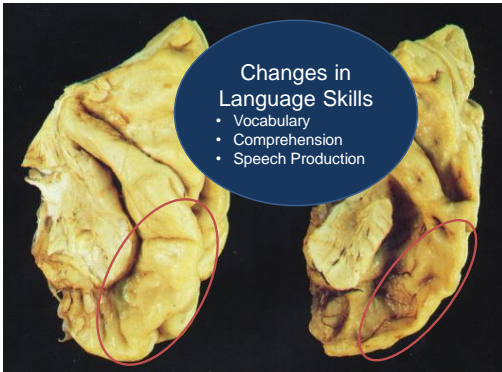


Hippocampus Big Changes:

- Learn and remember
- Way-finding
- Passage of time

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Changes in Language Skills

- Vocabulary
- Comprehension
- Speech Production

Understanding Language – Big Change

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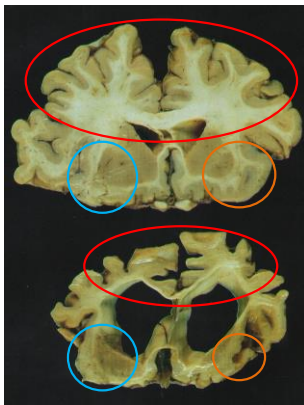
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Hearing Sound – Not Changed

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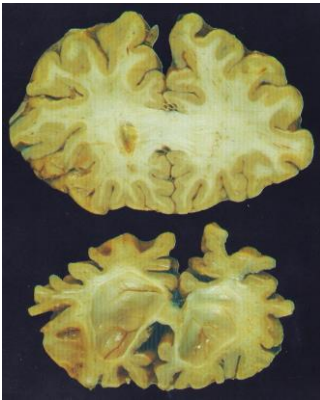
Sensory Strip
Motor Strip
White Matter
Connections:
Big Changes

Automatic
Speech
Rhythm – Music
Expletives:
Preserved

Formal Speech
and Language
Center:
Huge Changes

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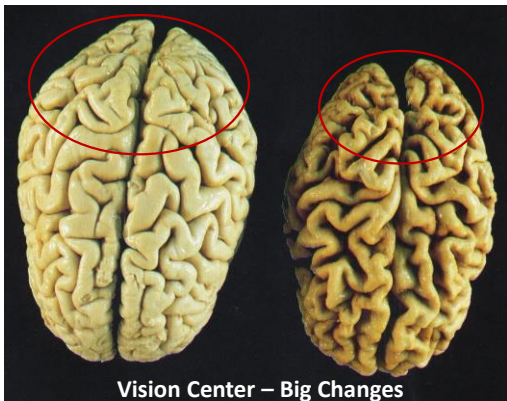


Executive
Control
Center
Changes:

- Being logical, reasonable, rational
- Controlling impulses
- Making decisions
- Initiating-sequencing-terminating-transitioning
- Being self-aware
- Seeing other perspectives

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Vision Center – Big Changes

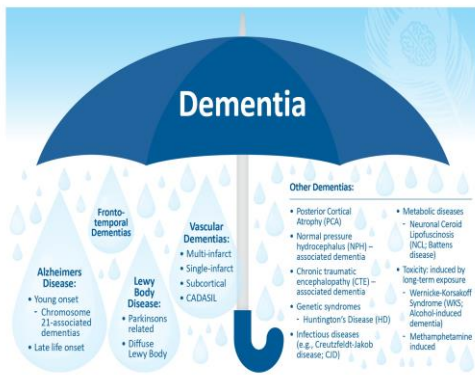
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Dementia does not equal Alzheimers does not equal Memory Problems

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Four Truths About All Dementias:			
<ul style="list-style-type: none"> At least two parts of the brain are dying It keeps changing and getting worse – progressive 		<ul style="list-style-type: none"> It is not curable or fixable – chronic It results in death – terminal 	
Alzheimers <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> Movement problems – Falls Visual disturbances Delusional thinking Fine motor problems – hands and jawclenching 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> Many types Frontal: impulsive and behavior control changes <ul style="list-style-type: none"> Says unexpected, rude, mean, odd things Apathy – not caring Problems with initiation or sequencing Dis-inhibited: sex, food, drink, emotions, actions Temporal: language change <ul style="list-style-type: none"> Difficulty with speaking – missing/changing words Rhythm OK, content missing Not getting messages Related to tau pathologies

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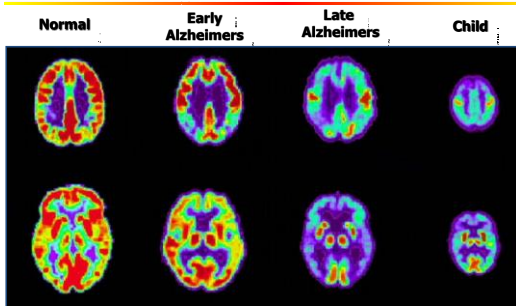
Alzheimers:

- New information lost
- Recent memory worse
- Problems finding words
- Misspeaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months – 1 year

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Positron Emission Tomography (PET) Alzheimers Disease Progression vs. Normal Brains



G. Small, UCLA School of Medicine.

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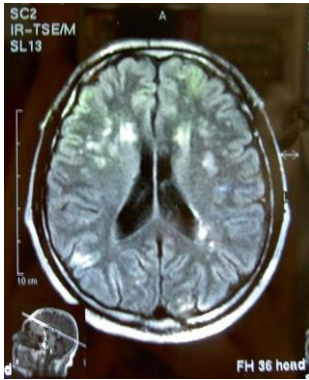
Vascular Dementia:

CT Scan:

The white spots indicate dead cell areas
caused by mini-strokes

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Latest Thinking About Vascular Dementia?

- Lots of similarity with Alzheimer's
- Manage blood flow issues carefully!
- Watch for and manage depression

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Latest Thinking about Lewy Body Treatment:

- Use AChIs
- Add Namenda early
- Be very careful about anti-psychotic meds
- Parkinson's meds may help movement but may make hallucinations and delusions worse
- Anti-depressants and anti-convulsants may be used to help anxiety, sleep, and depression but can increase confusion, movement, and drowsing

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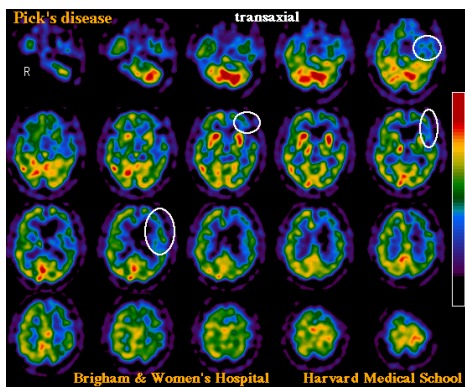
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Pick's Disease:

PET Scan

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Latest Thinking About FTD Treatments:

- Consider Namenda earlier
- Look at SSRI medications
- May use medications used to treat OCD
- May not use AChI Medications

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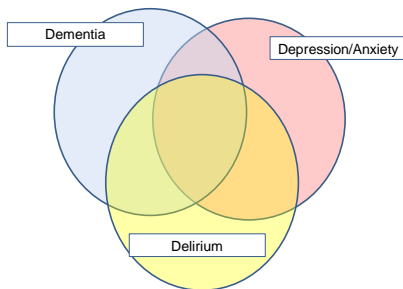
Delirium, Depression/Anxiety, Dementia:

What's What?

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The Real Three D's:



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The Reality:

- It is not 3 clean or neat categories
- The 3 are often mixed together
- Which 'D' is causing what you are seeing now?
- Are all three D's being addressed?
 - Immediate
 - Short-term
 - Long-term

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Determine First: Is This Delirium?

- Delirium can be dangerous and deadly
- Get a good behavior history, look for change
- Assess for possible pain or discomfort
- Assess for infections
- Assess for med changes or side effects
- Assess for physiological issues: dehydration, blood chemistry, O₂ sat
- Assess for emotional or spiritual pain

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Delirium:

- Onset: sudden, hours to days
- Duration: short, can be either cured or leads to death
- Alertness and Arousal: fluctuates, hyper or hypo
- Orientation responses: highly variable
- Mood and Affect: highly variable
- Causes: physiological, psychological
- Tx Condition: identify and treat what is wrong
- Tx Behavior: manage for safety only, it is short-term so don't mask symptoms

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Likely Causes of Delirium:

- Infection: UTI, URI, sepsis, etc.
- Dehydration
- Drug effect: side effect, interactions, sudden stop, taking incorrectly
- Sleep deprivation: poor sleep
- Pain or discomfort, including impaction
- Sensory deprivation: vision, hearing, balance
- TIAs or little strokes in brain
- Alcohol use
- New onset illness: diabetes, hypothyroidism, etc.
- Nutritional issues: intake or processing problems
- Anesthesia: post-surgical

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Is there Dementia or Depression/Anxiety?

- Often impossible to distinguish/separate depression and anxiety
- Depression/anxiety is treatable
- Many elders with depression describe themselves as having 'memory problems' or having somatic complaints
- Look for typical and atypical depression
- Look for changes in appetite, sleep, self-care, pleasures, irritability, 'can't take this' comments, residence or schedule changes

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Depression/Anxiety:

- Onset: recent, weeks to months
- Duration: until treated or death
- Alertness and Arousal: not typically changed
- Orientation responses: "I don't know," "I can't say," "Why are you bothering me with this?" or "I don't care"
- Mood and Affect: flat, negative, sad, angry
- Causes: situational, seasonal or chemical
- Tx of Condition: meds, therapy, physical activity
- Tx of Behavior: schedule changes and environmental support, combined with meds

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Likely Profiles of Depression/Anxiety in Elderly:

- Combination causes
- First episode in late life not uncommon
- Re-emergence of previous undiagnosed depression
- Resistance to seeking help
- If situational depression not addressed, it often escalates
- Depression = somatic pain complaints

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Dementia:

- Onset: gradual, months to years
- Duration: progressive until death
- Alertness and Arousal: gradual changes
- Orientation responses: right subject, but wrong info, angry about being asked, or asks back
- Mood and Affect: triggered changes
- Causes: brain changes, 70-80 different types
- Tx Condition: chemical support with AChEIs and glut mod
- Tx Behavior: environment, help, activity, drugs if needed

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Dementia Care:

How You Do What You Do Matters!

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Communication: Understanding the World With The Five Senses:

- 1st – What you see
- 2nd – What you hear
- 3rd – What you feel/touch
- 4th – What you smell
- 5th – What you taste



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How Do You Get Information from People Living with Dementia about What They Want, Need, or Think?

- What they show you – how they look
- What they say – how they sound
- What they do – physical reactions

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Three Reasons to Communicate:

1. Get something done
2. Have a conversation
3. Help with distress

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Five Skill Areas:

1. Getting Connected
2. Hand-under-Hand® Assistance
3. Ways of Cueing and Helping
4. Time-Out Signal
5. Progression of Dementia

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1. Getting Connected:

Connect and form a relationship
first, then work on getting them
to do something!

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Connect:

- 1st – Visually
- 2nd – Verbally
- 3rd – Physically
- 4th – Emotionally
- 5th – Individually

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To Connect, Use the Positive Physical Approach™:

- Pause at edge of public space (6 feet)
- Greet with your open hand next to your face, smile
- Call the person by name, if possible
- Move your hand into handshake position
- Approach slowly and within visual range
- Move from a handshake to Hand-under-Hand® position
- Shift into a Supportive Stance on their side
- Get low by standing or kneeling, but don't lean in
- Make a connection and wait for their response



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A Positive Approach

(To the Tune of Amazing Grace)

Come from the front

Go slow

Get to the side,

Get low

Offer your hand

Call out the name then wait...

If you will try, then you will see

How different life can be.

For those you're caring for!

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Then, Connect Emotionally and Personally:

Make a connection:

- Offer your name: "I'm (name) and you are...?"
- Offer a shared background: "I'm from (place) and you're from...?"
- Offer a positive personal comment: "You look great in that!" or "I love that color on you."
- Notice how the person is feeling: "Sounds like you aren't liking it here" or "You look like you're having a great time!"

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2. Hand-under-Hand®

Protects aging, thin, fragile, forearm skin



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High Risk:



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Hand-under-Hand® Position:



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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

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3. Ways of Cueing or Helping:



- Sight or Visual cues



- Verbal or Auditory cues



- Touch or Tactile cues

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Always Remember V-V-T:

- Always use this sequence to cue:
 1. Visual
 2. Verbal
 3. Touch
- Make cues bigger and slower as the dementia progresses, and pause longer
- Give feedback cues that are positive!

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Visual Cues:

- Signs
- Pictures
- Props/Objects
- Gestures
- Facial Expressions
- Demonstrations

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4. Time-Out Signal:



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5. Progression of Dementia: The GEMS®

Sapphires
Diamonds
Emeralds
Ambers
Rubies
Pearls



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- Based on Allen Cognitive Levels
- Cognitive Disability Theory – OT based
- Creates a common language and approach to providing:
 - Environmental support
 - Caregiver support and cueing strategies
 - Setting expectations regarding retained abilities and lost skills
- Promotes graded task modification for success

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Why Use The GEMS®?

- Until we begin to see the beauty and value in the person has at this point, we will never care for them as we should
- Gems are precious and unique, provide a common language and characteristics
- Use familiar concepts to talk about a difficult subject
- Focus on what is valued
- Allow to us to get beyond the words 'dementia' and 'Alzheimer's disease'
- Open the door to talking about changes
- Allow us to speak in a 'code' to protect dignity

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The GEMS® Progression of Dementia: Seeing What Remains



Sapphires – True Blue – Slower but Fine
Diamonds – Repeats and Routines, Cutting
Emeralds – Going – Time Travel – Where?
Ambers – In the Moment - Sensations
Rubies – Stop and Go – Big Movements
Pearls – Hidden in a Shell - Immobile

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Sapphires



- Us on a good day
- Clear and true to ourselves
- May feel 'blue' over changes
- Some are 'stars' and some are not
- Can typically choose our behavior
- May have other health issues that affect behaviors
- Recognize life experiences, achievements and values
- Can follow written info and hold onto it

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Diamonds



- 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
- Notifies other people's misbehavior and mistakes
- Vary in lack of self-awareness
- Use old routines and habits
- Control important roles and territories, use refusals

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Emeralds:



- 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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Ambers:



- 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
- No safety awareness
- Ego-centric
- 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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Rubies:



- Hidden depths
- Major loss of fine motor finger and mouth skills, but can do gross motor skills like walking, rolling, rocking
- Comprehension and speech halted
- Wake-sleep patterns very disturbed
- Balance, coordination, and movement losses
- Eating and drinking patterns may change
- Tends toward movement unless asleep
- Follows gross demonstration and big gestures for actions
- Limited visual awareness
- Major sensory changes

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Pearls:



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

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With All GEMS® States, Always Make Sure You Are Connecting Before a Task Attempt!

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Then, Get it Going!

- Give simple and short information
- Offer concrete choices
- Ask for help
- Ask the person to try
- Break the task down to single steps at a time

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Give Simple Information:

- Use Visual (gesture or point) combined with Verbal:
 - “It’s about time for...”
 - “Let’s go this way.”
 - “Here are your socks.”
- Don’t ask questions you don’t want to hear the answer to
- Acknowledge the response/reaction to your info
- Limit your words and keep it simple
- Wait!!!!

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To Connect With Someone Who is Distressed:

Use Supportive Communication

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What is Supportive Communication?

- Repeat a few of their words with a question at the end
 - Listen
 - Then:
 - Offer empathy:
 - “Sounds like...
 - “Seems like...
 - “Looks like...
 - Listen
- Avoid confrontational questions
 - Use just a few words
 - Go slow
 - Use examples
 - Fill in the blank
 - Listen!!!

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More Supportive Communication:

Validate emotions:

- Early: “It’s really (label emotion) to have this happen” or “I’m sorry this is happening to you”
- Mid-stage: Repeat their words with emotion
 - Listen for added info, ideas, thoughts
 - Explore the new info by watching and listening
- Late: Check out the whole body
 - Face, posture, movement, gestures, touching, looking
 - Look for the need under the words or actions

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Once Connected and Communicating:

Move Forward:

- Add new words
- Move to a new place or location
- Add a new activity

Early: Redirection

- Same subject
- Different focus

Later: Distraction

- Different subject
- Unrelated but enjoyed

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For All Communication:

- If what you are trying is not working:
- Stop!
- Back off
- Think it through, then:
- Re-approach
- Try something slightly different

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Resisting Resistance Just Increases Resistance:

If It Isn't Working:
Stop and Back Off!
Think About It
Try Again, But Change Something

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Five Ways to Say “I Am Sorry!”

- I'm sorry, I was trying to help
- I'm sorry I made you feel (emotion) angry, irritated, frustrated, sad, isolated....
- I'm sorry I made you feel (intellectual capacity or relationship unequal) like a child, stupid, like an idiot...
- I'm sorry that happened (their perspective)
- I'm sorry, this is hard! (for both of you)

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Dementia can be Treated:

- With knowledge
- With skill building
- With commitment
 - With flexibility
 - With practice
 - With support
- With compassion

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I Will Change!

To the tune of
This Little Light of Mine

By Teepa Snow

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I am gonna meet and greet
Before I start to treat
I am gonna meet and greet
Before I check your feet
I am gonna meet and greet
Before I help you eat

How I start sets us up to succeed!

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No more just 'gettin' it done'
I'm gonna do with you
No more just 'gettin' it done'
I'm gonna help you through
No more just 'gettin' it done;
We're gonna work, we two,

Cause if I do it all, we both lose!

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I'm gonna laugh and dance with you
Not just watch and frown
I'm gonna laugh and dance with you
Not just stand around
I'm gonna laugh and dance with you
We'll really go to town

For the power of joy I have found!

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Progression of the Condition

To the tune of 'This Old Man'

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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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**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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**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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**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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**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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**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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