

Progression of Dementia:
Discovering GEMS™
Seeing More Than LOSS!

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Structural Brain Failure

- One way street
- Depending on type of dementia, changes happen in different areas resulting in different changes
- Currently, medications DO NOT impact

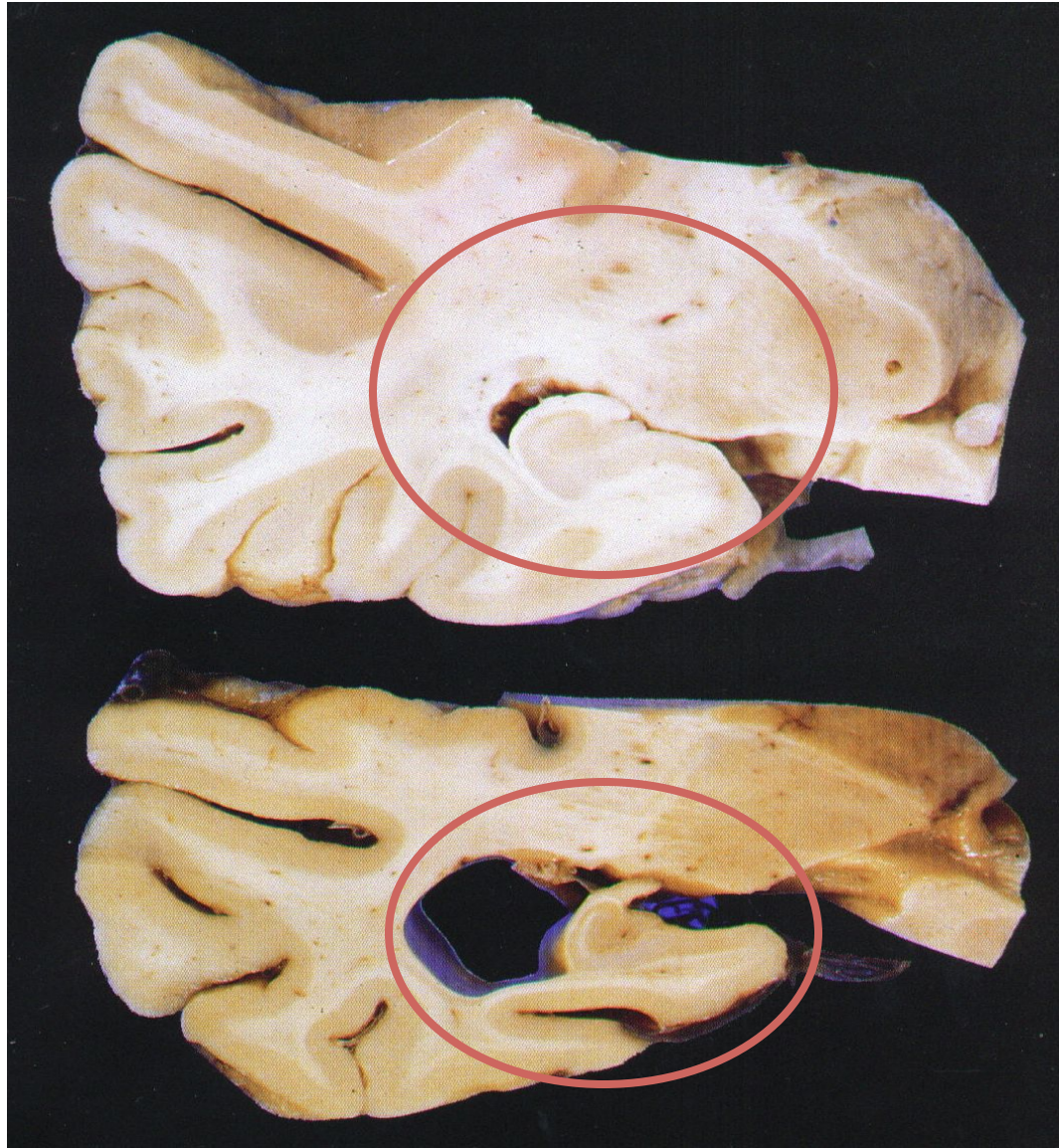


Normal Brain



Alzheimers Brain

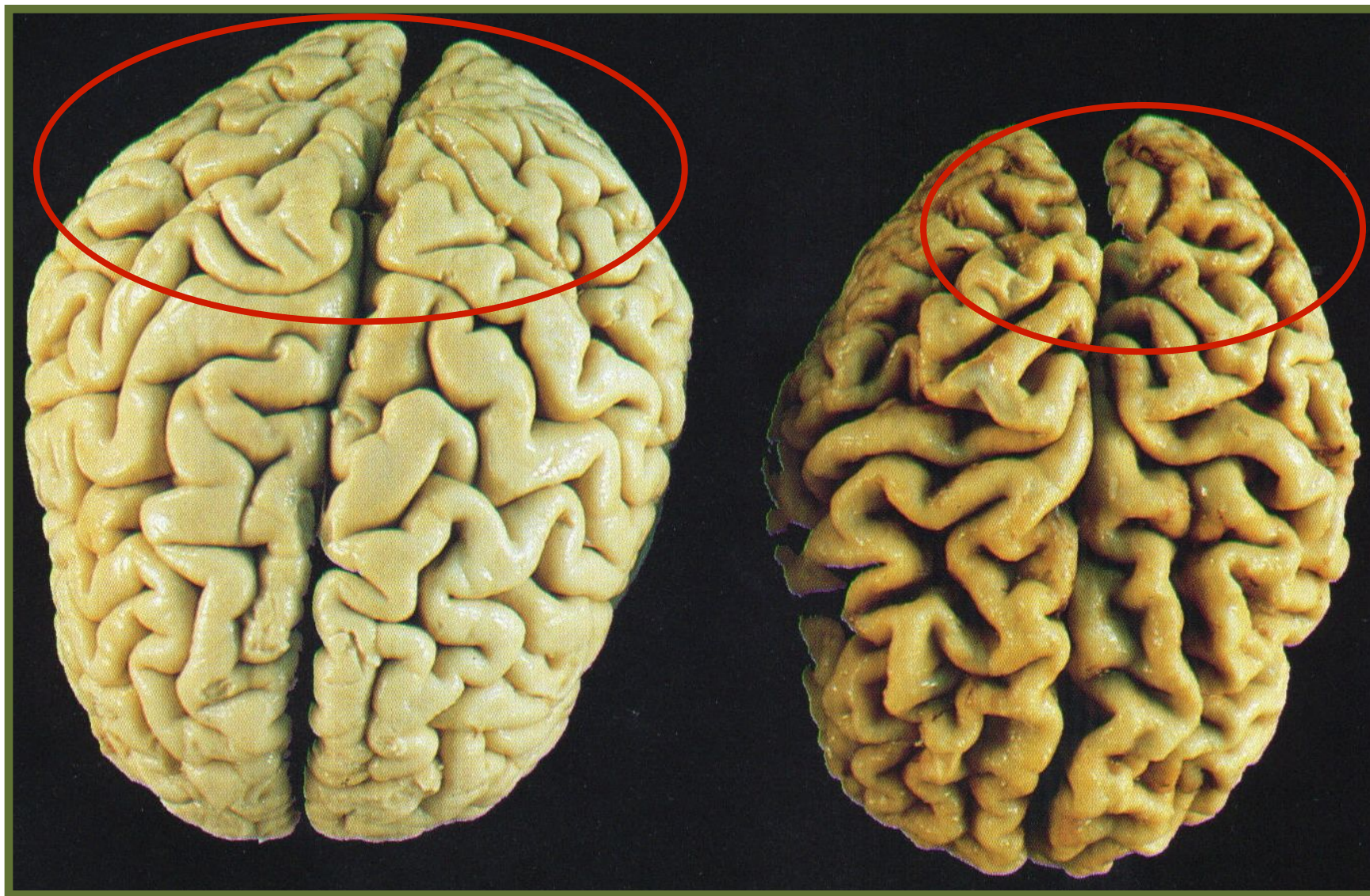
Memory



Memories

- Losses
 - Where & when you are
 - What is going on
 - Where you want to go
 - What you want to do
- Preserved abilities
 - Confabulation!
 - Emotional memories
 - Motor memories

Vision

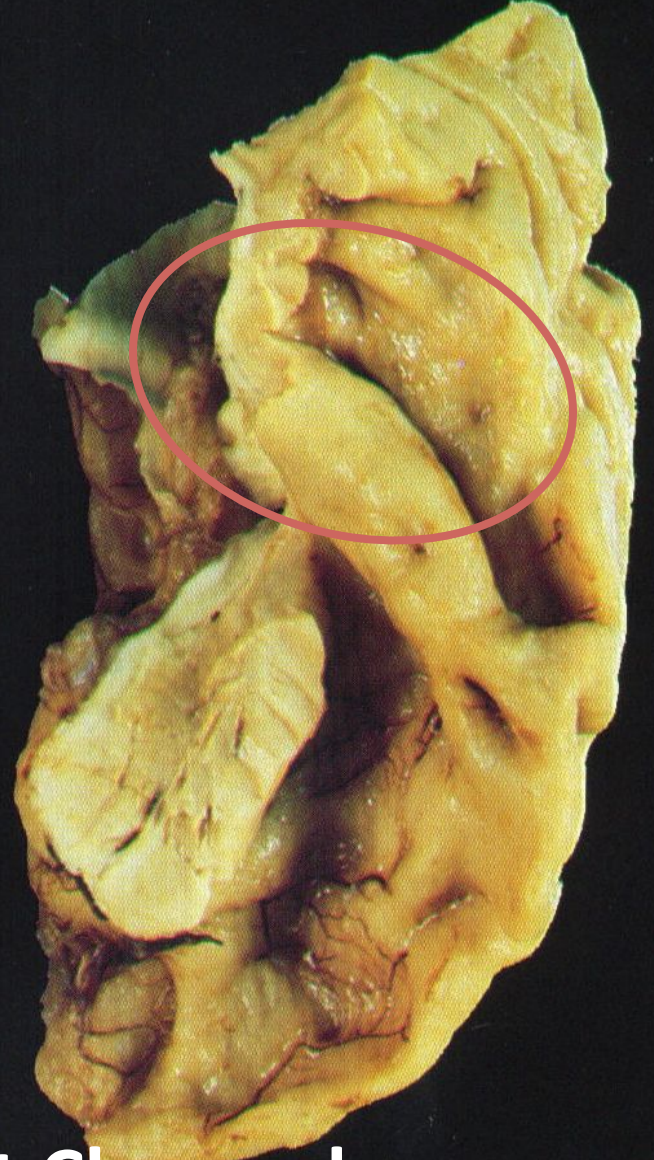


Vision

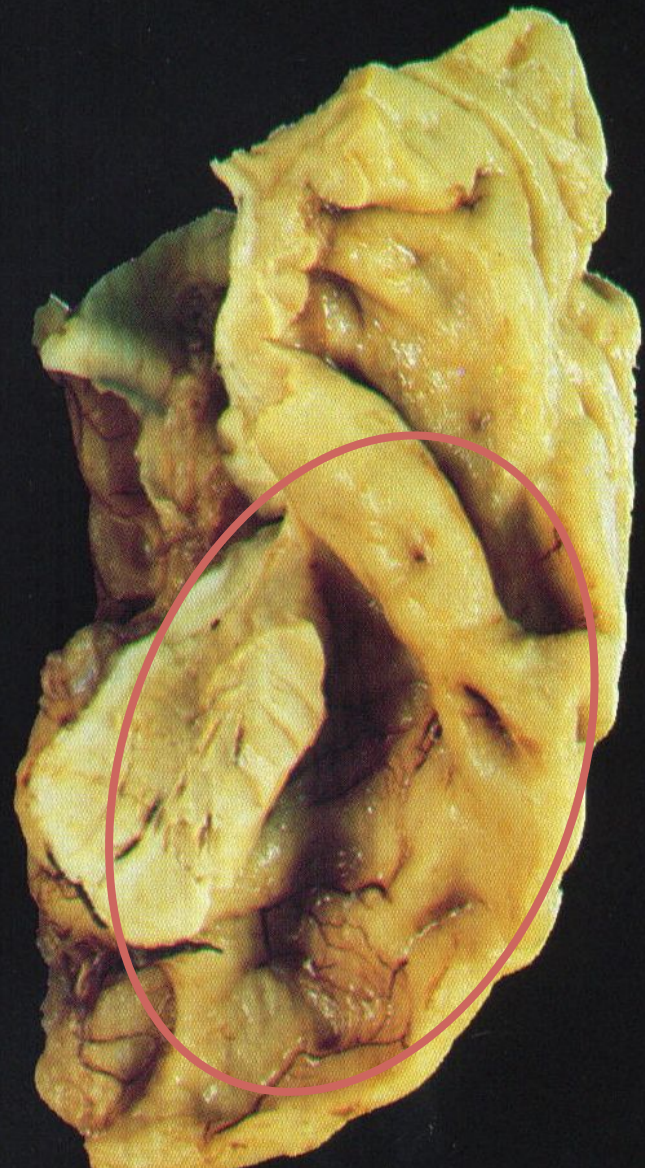
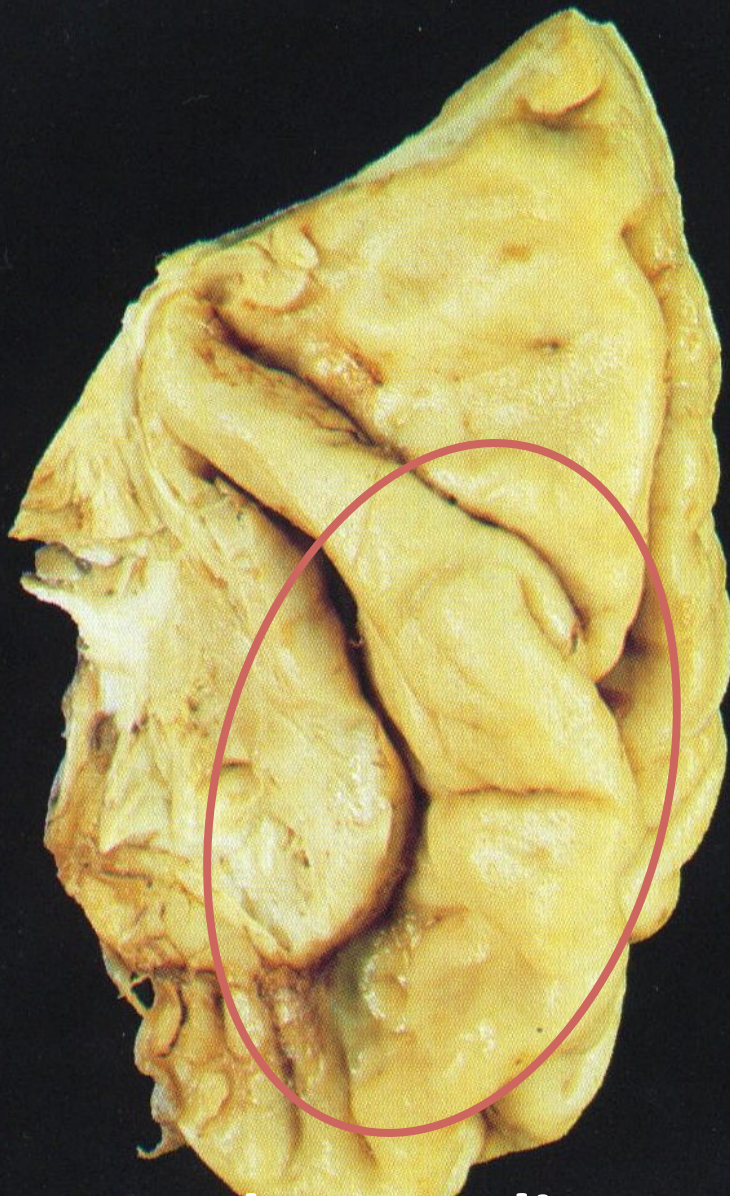
- Reduction in visual field
- Binocular vision
- Monocular vision

RESULTS

- Change in depth perception
- Risk of injury & fall
- Startles



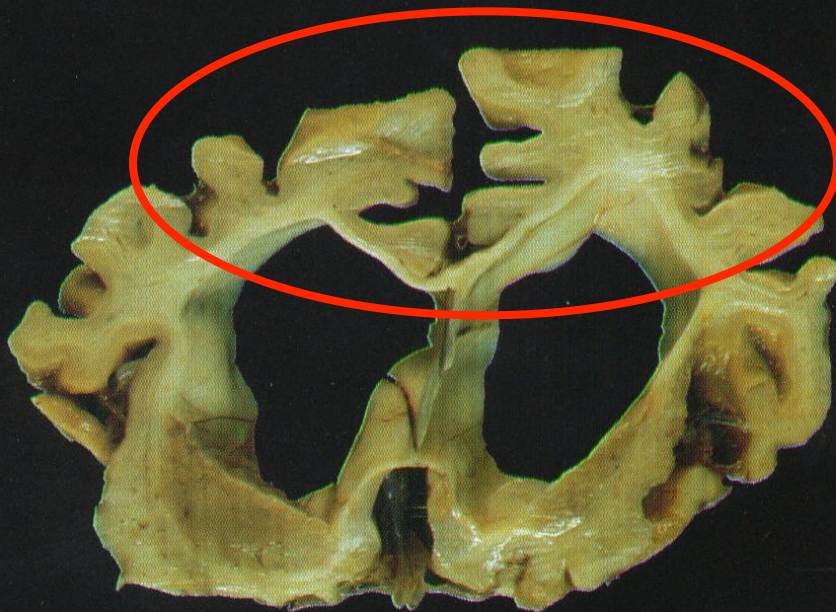
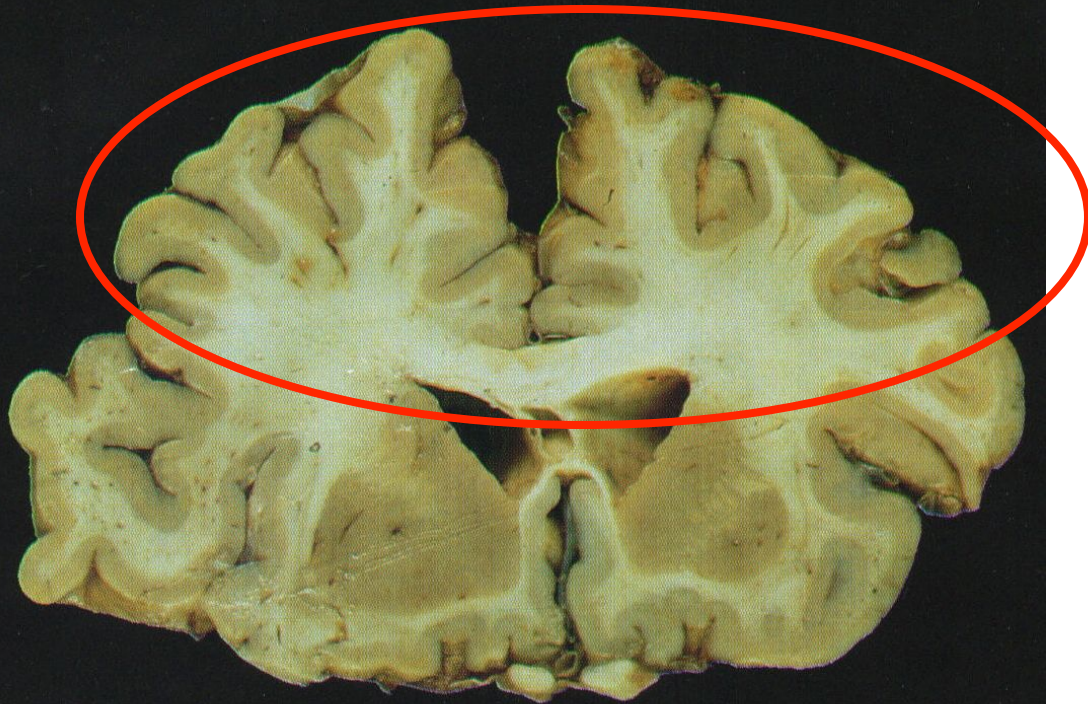
Hearing Sound – Not Changed



Understanding Language – BIG CHANGE

Issues of Understanding

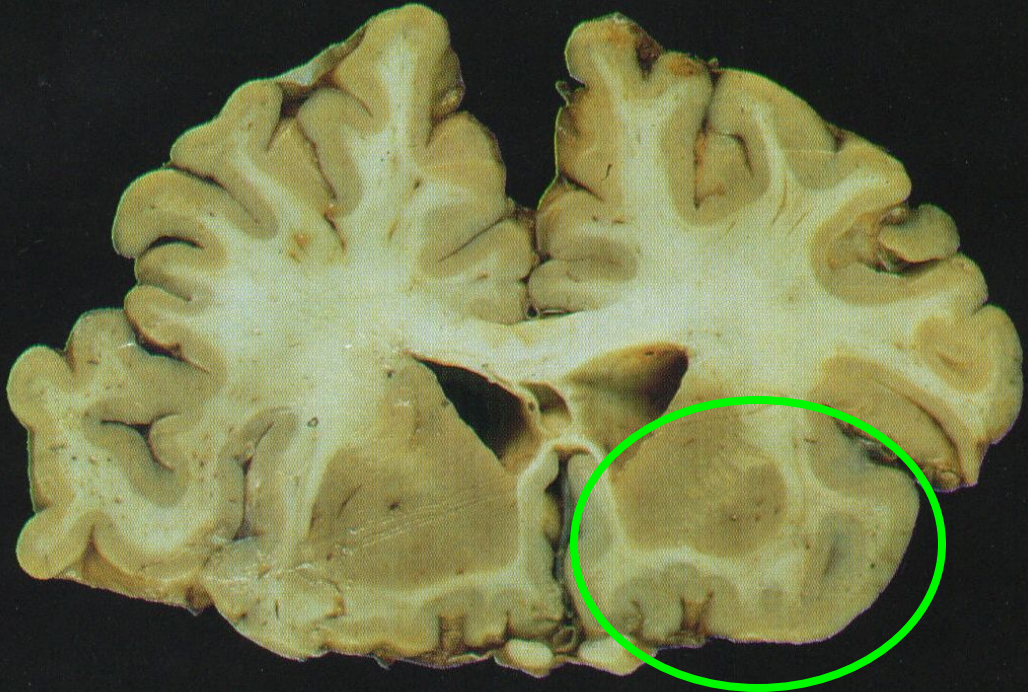
- **Losses**
 - Can't interpret information
 - Can't make sense of words
 - Gets off target
- **Preserved abilities**
 - picks up on facial expression
 - picks up on tone of voice



**SENSORY MOTOR
STRIP**

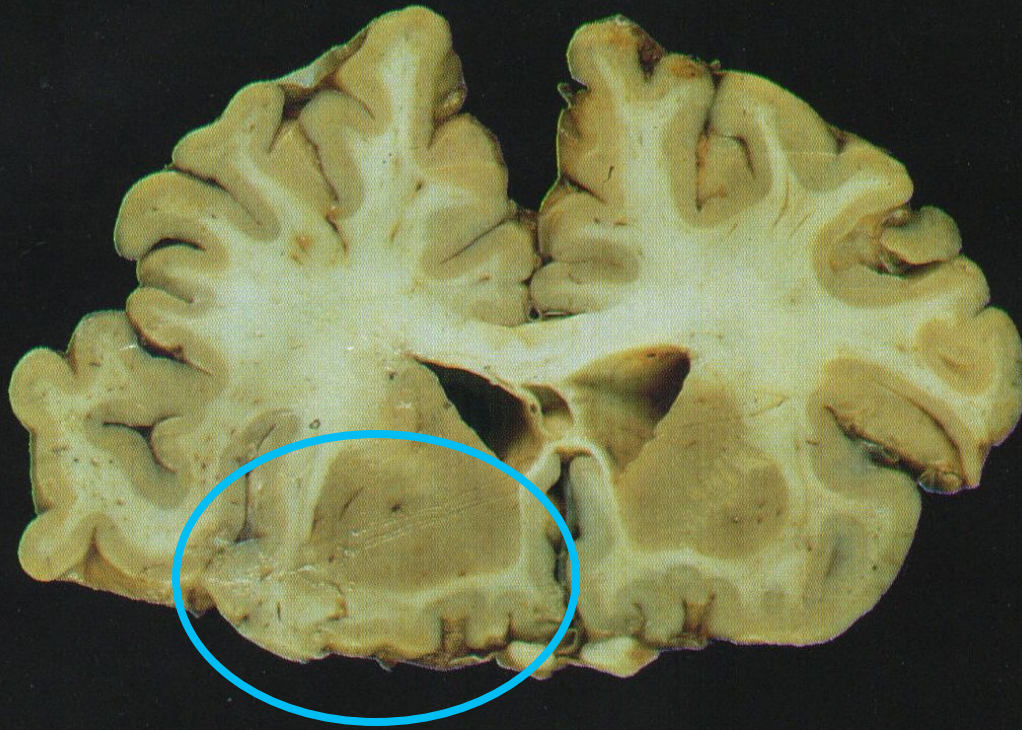
Sensory Changes

- Losses
 - Awareness of body and position
 - Ability to locate and express pain
 - Awareness of feeling in most of body
- Preserved Abilities
 - 4 areas can be sensitive
 - Any of these areas can be hypersensitive
 - Need for sensation can become extreme



**EXPRESSIVE
LANGUAGE**

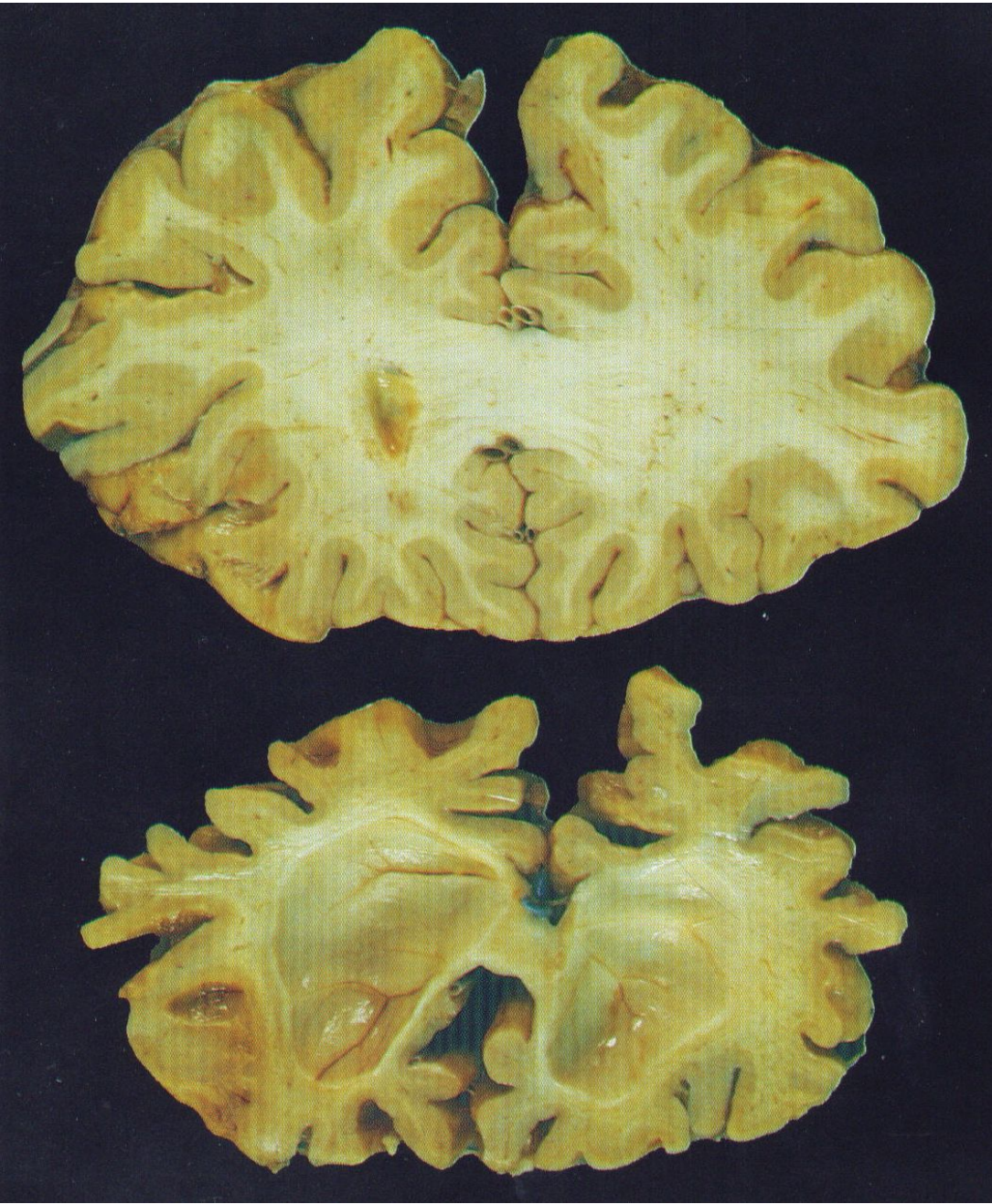




**OTHER
LANGUAGE**

Language Issues

- Losses
 - Can't find the right words
 - Not able to say what you mean
 - Can't make needs known
- Preserved abilities -
 - automatic speech
 - singing
 - swearing
 - turn taking



Frontal lobe
Impulse control

Issues of Impulses & Emotions

- Losses
 - becomes labile and extreme
 - think it - say it
 - want it - do it
 - see it - use it
- Preserved
 - desire to be respected
 - desire to be in control
 - regret after action

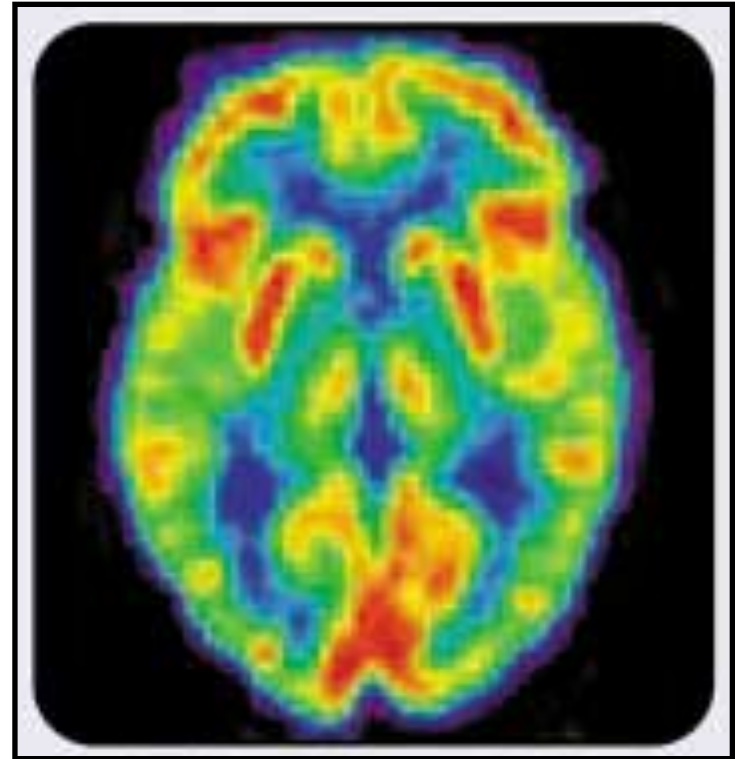
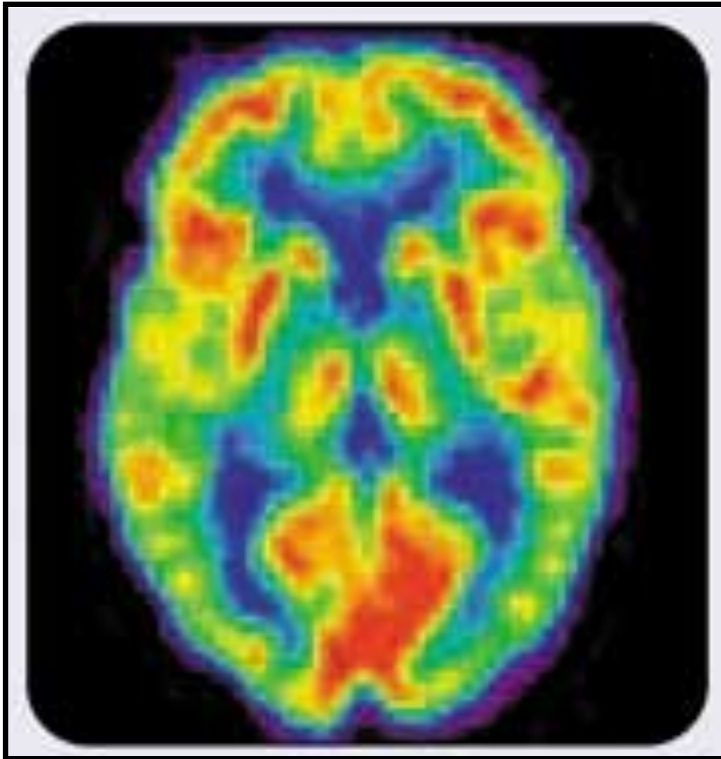
Self-Care Changes

- Losses
 - initiation & termination
 - tool manipulation
 - sequencing
- Preserved Abilities
 - motions and actions
 - the doing part
 - cued activity

Chemical failure

- Fluctuations
- Extremely good moments and...
Extremely bad moments
- Different in different situations
- Different at different times of the day
- Especially: visits with health care professionals, lawyers, DMV, family from out of town

PET and Aging



PET Scan of 20-Year-Old Brain PET Scan of 80-Year-Old Brain

Positron Emission Tomography (PET)

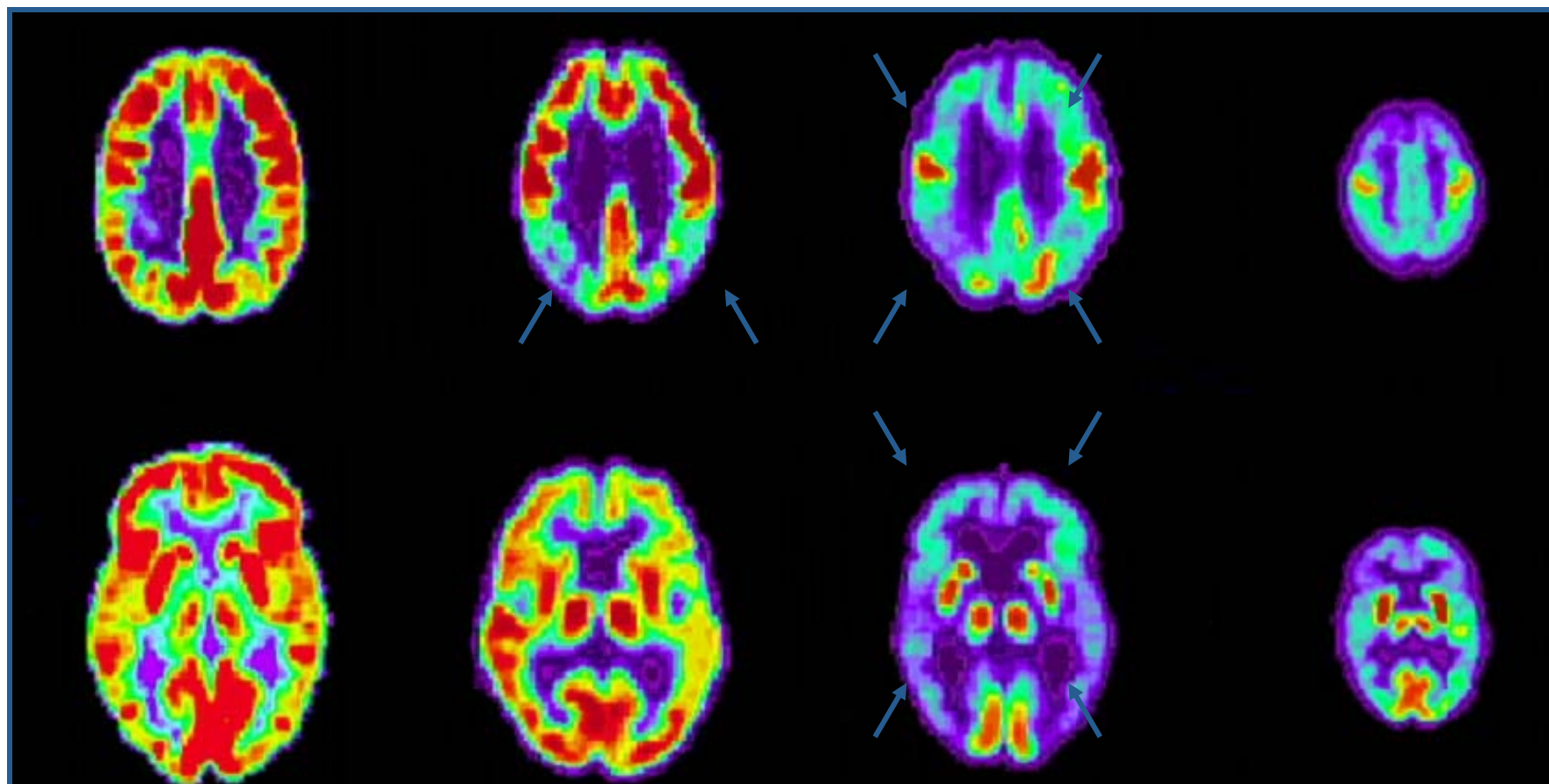
Alzheimer's Disease Progression vs. Normal Brains

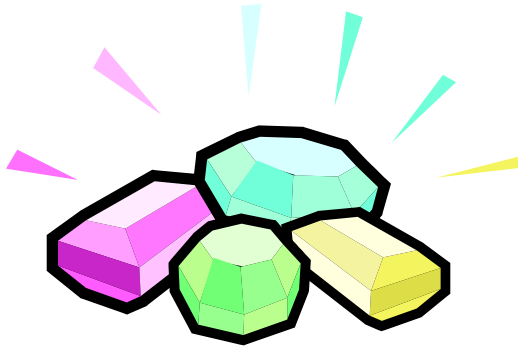
Normal

Early
Alzheimer's

Late
Alzheimer's

Child



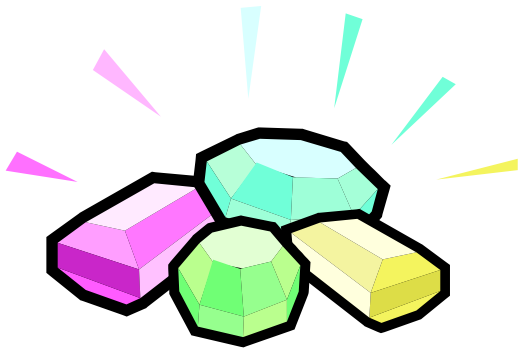


Caregiving Gems & Progression of dementia

Adapted from work of

Teepa Snow, Melanie Bunn & Claudia Allen





Understanding the model

All people with dementia are precious
Levels might change depending on situation
Everyone's journey will be different
Emphasis on what people **can** do...
not just what they can't do



ACTIVITY

- Using what you know about changes in structural and chemical brain function on behavior, communication/interaction, visual procession, function, memory, reason & decision making
- Think about...
- Then discuss...
- How to adapt cuing, support/care/helping & the environment to a person functioning at each level

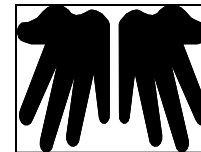
Think about it!!! Talk about it!!!

- How might you modify cuing?

- Sight or Visual cues

- Verbal or Auditory cues

- Touch or Tactile cues



- How do we change our support/care/helping?
- How do we work with the environment?

First Connect Then Do

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



Diamonds:

Living in the present



Still Clear

Sharp - Can Cut

Hard - Rigid - Inflexible

Many Facets

Can Really Shine



Diamonds

What still works?

- Do well in familiar places & situations
- Use old routines & habits
- Control important 'roles' & 'territory' / maintain control
- Very 'independent' *or* seeking constant reassurance
- Can manage self care
- Can manage routine IADLS with supervision
- Can use visual cues & signage
- Expresses needs verbally
- Real? Fake? - Hard to be sure



Diamonds

Where do they struggle?

- Has trouble with new routines and locations
- Place & time confusion
- Resents take-over
- Becomes anxious and frustrated easily
- Gets lost or confused
- Misplaces things
- Misinterprets what's going on
- Word finding problems
- Losing ability to abstract
- Logic problems
- Lose ability to see others' perspective
- May or may not have insight into losses
- May try to "escape"



Diamonds, How do we help? Accepted not Corrected

- Keep to routine & be prepared to help more with changes (traveling)
- If something works or seems to help, get an extra
- Don't worry about the small mistakes/unusual choices
- For the future:
 - **Notice** how they do things now
 - **Ask** how they used to do things
- Cues and clues
- Fill in the blanks
- “I’m sorry, I’m so sorry, I’m so very sorry”
- Be willing to be the one who’s wrong (apologize)
- Learn how to help instead of taking over
- Simpler is better

Think about it

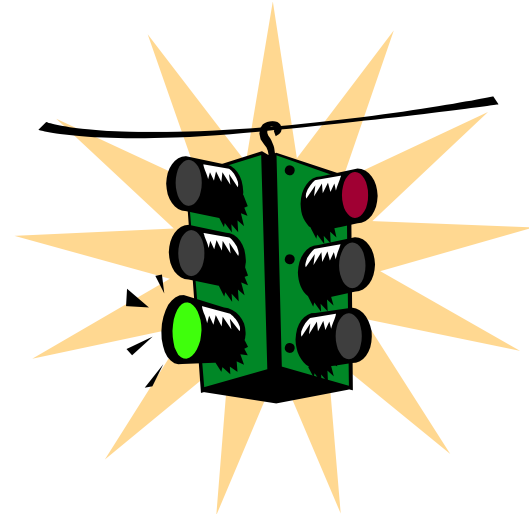
Talk about it

- How might you modify cuing?
- How do we change our support/care/helping?
- How do we work with the environment?



Emeralds:

Living in the past



Changing color

Not as Clear or Sharp - Vague

Good to Go – Need to ‘DO’

Flaws are Hidden

Time Traveling



Emeralds

What still works?

- Uses visual information to figure out what to do
- Able to do familiar activities from the past...with support
- Does tasks repetitively
- Follows samples & demos
- Likes to be in control of self and environment
- Uses language to tell stories, express some needs
- Two Kinds of DOING (Doers or Supervisors)
- Still aware of some social norms/relationships
- Aware/interested in engaging/helping others
- Having a 'job' or 'purpose'
- Being an 'adult'
- Getting finished & doing something else
- Wants to be busy



Emeralds

Where do they struggle?

- Have trouble with order of tasks & activities
- Skips steps
- ‘Don’t need your help’
- Has a mission in mind
- May do things over and over if visual cue there
- Living in the past—expectations, routines
- May leave to go where used to be
- Can’t do an activity without visual prompt
- Specifics and content in speech are poor
- Doesn’t like to be done to—may be hard to “help”
- Limited attention span—gets it done then finished
- Still wants privacy for private activities



Emeralds

How do we help?

- Anticipate when the problems might occur and prepare to help before the problem starts
- Help with sequencing
- Use visual cues
 - Keep tools in sight
 - Offer tools
- Reduce distractions
- Maintain routines
- Try to help do things the way they used to:
 - Recent past
 - Remote past
- Focus energy on the most important part of the activity
- Right place, right time, right response

Empathetic Communication: Verbal

Meet them where they are

- Start with the feelings
 - “Looks like”, “sounds like”
 - “Seems like”, “feels like”
 - Don’t be afraid
- Get more information
 - “Tell me about...”
 - Repeat words and phrases
 - Move to remembering
- Move from talking to doing
 - “Could you help me?”
 - “Would you try?”
 - Related to topic
 - Familiar and positive



Think about it

Talk about it

- How might you modify cuing?
- How do we change our support/care/helping?
- How do we work with the environment?



Ambers:

Living in the moment

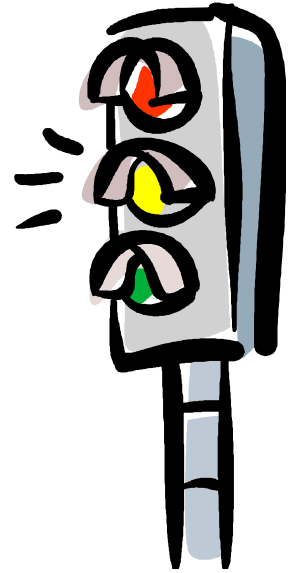
Amber Alert

Caution!

Caught in a moment

All about Sensation

Explorers



Ambers



What still works?

- Respond to visual cues
- Aware of parts of things
- LOTS of touching, handling, mouthing, manipulating
- Focus on fingers/mouth
- All about sensation...
- Do what they like & avoid what they don't
- Can still use hands and fingers
- Can still do, once you get them started
- Respond to emotions of individuals & environment
- Can still use social phrases
- Communicate with "fill in the blank"
- Can still imitate...one step at a time

Ambers



Where do they struggle?

- Don't do what you want them to do
- Get into things/carry them around
- Invasive (other's things, personal space)
- May trigger behaviors in other residents
- Put things in mouth
- Trouble stopping
- May leave—following visual and tactile cues
- Don't respond well to verbal cuing
- Not able to use words to express needs
- Losing understanding of what things are/trouble with tools
- Don't like to be handled ...but need the help

Ambers

How do we help?



- Visual cues
 - Gestures
 - Demonstration
- Verbal cues
 - Simplify
 - Concrete
- Tactile cues
 - Attention
 - Hand under hand
- Think about the environment
- Avoid doing too much handling
- Back off change, something and try again
- Break it down
 - Specific tasks
 - Groups of tasks

Think about it

Talk about it

- How might you modify cuing?
- How do we change our support/care/helping?
- How do we work with the environment?



Rubies:

Living in a bubble

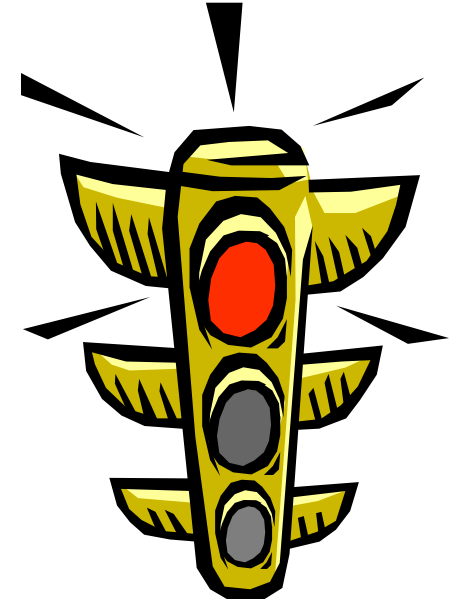
Hidden Depths

Red Light on Fine Motor

Comprehension & Speech Halt

Coordination Falter

Wake-Sleep Patterns are Gone





Rubies

- ***What still works?***
- Big movements – dance walk, roll, rock, rhythm
- Hands, not fingers
- Tends toward movement unless ‘asleep’
- Follows gross demonstration & big gestures for actions
- Responds to emotions
- ***Where do they struggle?***
- Fine motor skill lost – mouth & hands
- Limited visual awareness
- Major sensory changes
- Major losses in mobility
- Minimal language
- Not able to do without assistance—but not like it
- Poor appetite and intake



Rubies

How can we help?

- Visual
 - Big gestures
 - Exaggerated demonstration
- Verbal
 - Single words
 - Tone of voice
- Tactile
 - Hand under hand
 - Move them the way they move themselves
- They can't monitor for themselves
- Time to start stopping?
 - Medications?
 - Treatments?
- Focus on comfort
 - Pain
 - Temperature

Think about it

Talk about it

- How might you modify cuing?
- How do we change our support/care/helping?
- How do we work with the environment?



Pearls:

Living inside themselves

Hidden in a Shell

Still & Quiet

Easily Lost

Beautiful - Layered

Unable to Move – Hard to Connect

Primitive Reflexes on the Outside



Pearls

- ***What still works?***
- Still hear
- Able to feel touch or vibration
- Smells still connect
- Can still respond...if we watch carefully
- Still “in there”
- Can still “connect”
- Moments of clarity possible
- May need permission to “go”
- ***Where do they struggle?***
- Extinct reflexes return
- Pulling in—fetal position
- Connections between the physical and sensory world are less strong
- Bed/chair bound
- Limited ability to sit/stay upright
- Problems with swallowing and eating
- Lose ability to maintain basic life functions



Pearls

How do we help?

- Use your approach
- Slow down your movements and your words
- Move with the person instead of against them/in circles
- Think about what you're doing and how you're doing it and is there a better way?
- Avoid triggering reflexes
- Use rhythm and singing
- Focus on comfort and person's expressed wishes
- Food for sensory experience rather than nutrition
- Keep skin, mouth moist
- Use the senses

Think about it

Talk about it

- How might you modify cuing?
- How do we change our support/care/helping?
- How do we work with the environment?

What's the same through progression?

- Order of cuing: visual, verbal, tactile
- Slow down
 - Slowed processing
 - Observe response
- Still human: basic needs, basic responses
- Still a person: with individual
- Be willing and able to change yourself!

What's different through progression?

- Strength of response to type of cuing: visual, verbal, tactile
- Response time