

#### **NOTICE:**

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Dementia Aware
Dementia Knowledgeable
Dementia Skilled
Dementia Competent

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# Demystifying Resistance:

**Becoming a Better Detective** 

## What Are the Most Common Issues That Come Up???

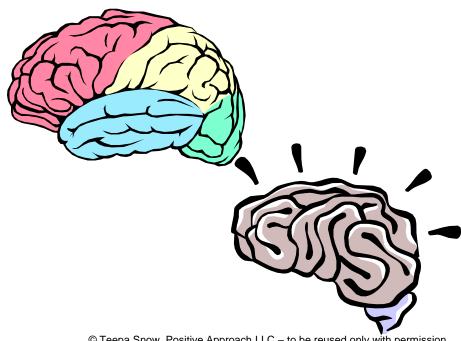
- Not going to the MD
- No F-PoA or HC-PoA
- 'Losing' Important Things
- Getting Lost
- Unsafe task performance
- Repeated calls & contacts
- Refusing
- 'Bad mouthing' you to others
- Making up stories
- Resisting care
- Swearing & cursing
- Making 911 calls
- Mixing day & night

- Shadowing
- Eloping or Wandering
- No solid sleep time
- Getting 'into' things
- Threatening caregivers
- Undressing
- Being rude
- Feeling 'sick'
- Striking out at others
- Falls & injuries
- Infections & pneumonias
- Seeing things & people
- Not eating or drinking
- Contractures & immobility

## Why Do These Things Happen?

- EVERYTHING is affected
  - Thoughts
  - Words
  - Actions
  - Feelings
- It is progressive
  - More brain dies over time
  - Different parts get hit
  - Constant changing
- It is variable
  - Moment to moment
  - Morning to night
  - Day to day
  - Person to person

- Dementia is predictable
  - Specific brain parts
  - Typical spread
  - Some parts preserved



## Caring for Someone with Dementia is Stressful!!!

- Takes more time than other caregiving
- Behaviors are distressing & challenging
- Its really a 24/7 job
- 70-80% is done by family or friends
- Still a stigma it can be isolating

## **Beliefs**

- People with Dementia are Doing the BEST they can
- We must learn to DANCE with our partner
- We are a KEY to make life WORTH living
- What we choose to do MATTERS
- We can change the WORLD with help
- We must be willing to CHANGE ourselves
- We must be willing to STOP & BACK OFF

## How Can We Become Better Care Partners?

Be willing to try something new
Be willing to learn something different
Be willing to see it through another's eyes
Be willing to fail & try again

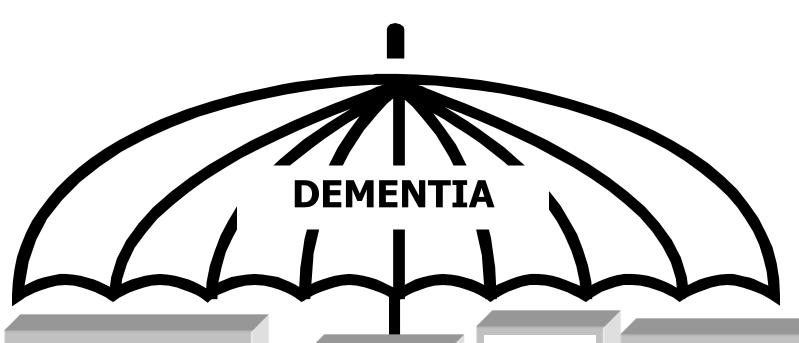
By managing your own behavior, actions, words & reactions you can change the outcome of an interaction.

## It's the *relationship* that is MOST critical

NOT the outcome of one encounter



## The person's brain is dying



## Alzheimer's Disease

- •Early Young Onset
- Normal Onset

Vascular Dementias (Multi-infarct)

U

Lewy Body Dementia

Fronto-Temporal Lobe Dementias

#### **Other Dementias**

- Genetic syndromes
- Metabolic pxs
- •ETOH related
- •Drugs/toxin exposure
- •White matter diseases
- Mass effects
- •Depression(?) or Other Mental conditions
- •Infections BBB cross
- Parkinson's

## Alzheimer's

- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months 1 year

### Vascular Dementia

- Sudden changes
- Picture varies by person
- Can have bounce back & bad days
- Judgment and behavior 'not the same'
- Spotty losses
- Emotional & energy shifts

## Lewy Body Dementia

- Movement problems Falls
- Visual Hallucinations
- Fine motor problems hands & swallowing
- Episodes of rigidity & syncopy
- Nightmares
- Fluctuations in abilities
- Drug responses can be extreme & strange

## Fronto-Temporal Dementias

- Many types
- Frontal impulse and behavior control loss
  - Says unexpected, rude, mean, odd things to others
  - Dis-inhibited food, drink, sex, emotions, actions
- Temporal language loss
  - Can't speak or get words out
  - Can't understand what is said, sound fluent nonsense words

### What is Dementia?...

#### It is BOTH

a chemical change in the brain

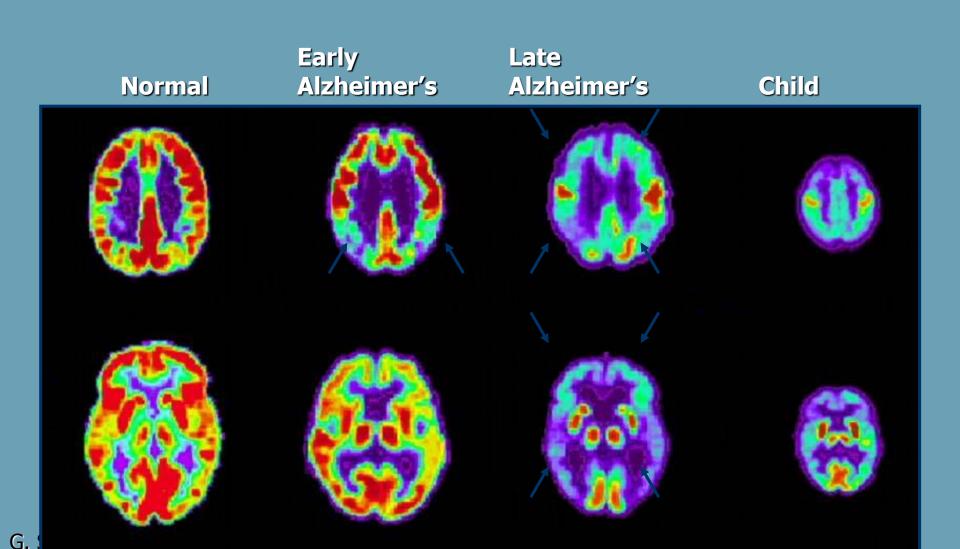
#### AND

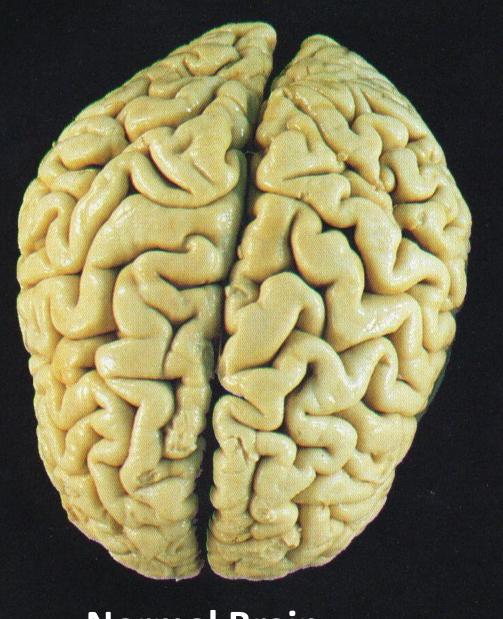
a structural change in the brain

• So...

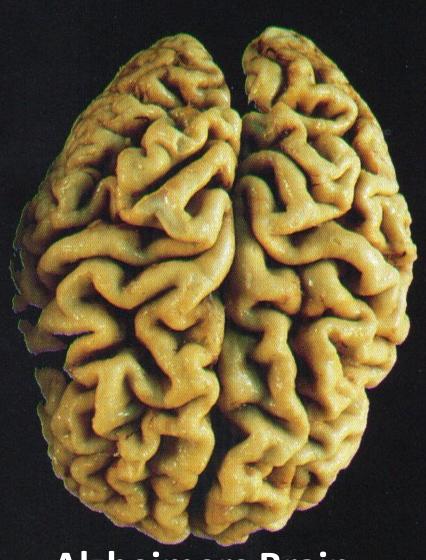
Sometimes they can & sometimes they can't

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

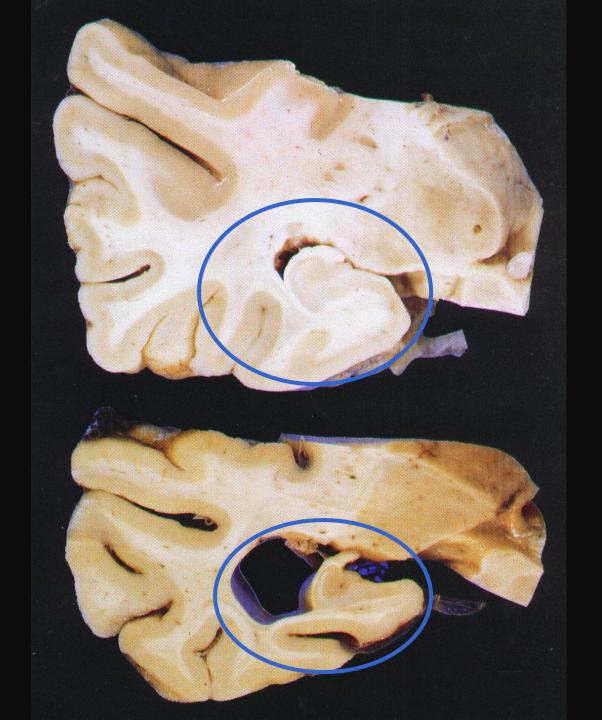




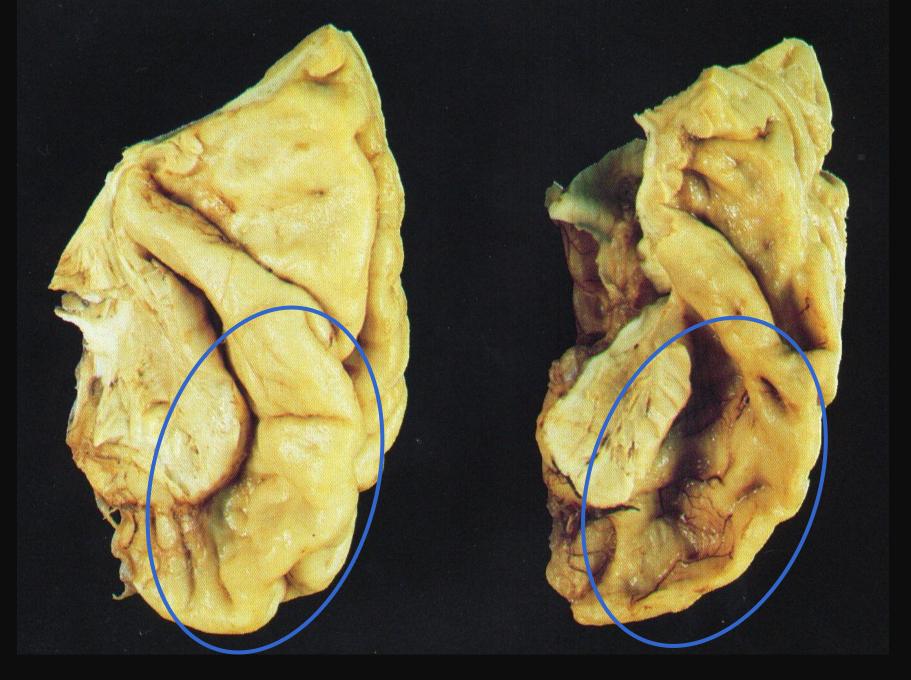
**Normal Brain** 



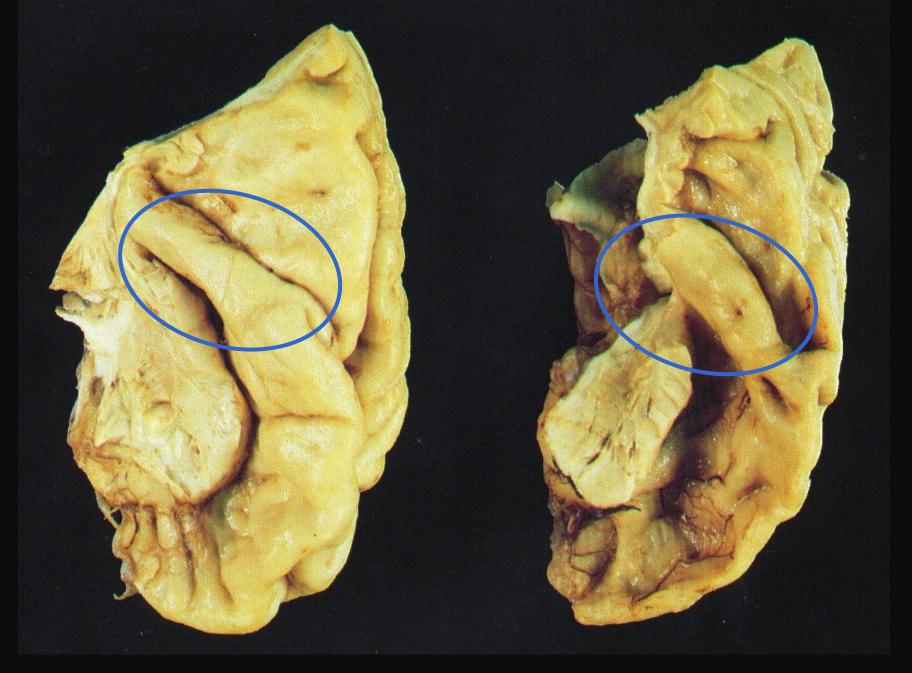
**Alzheimers Brain** 



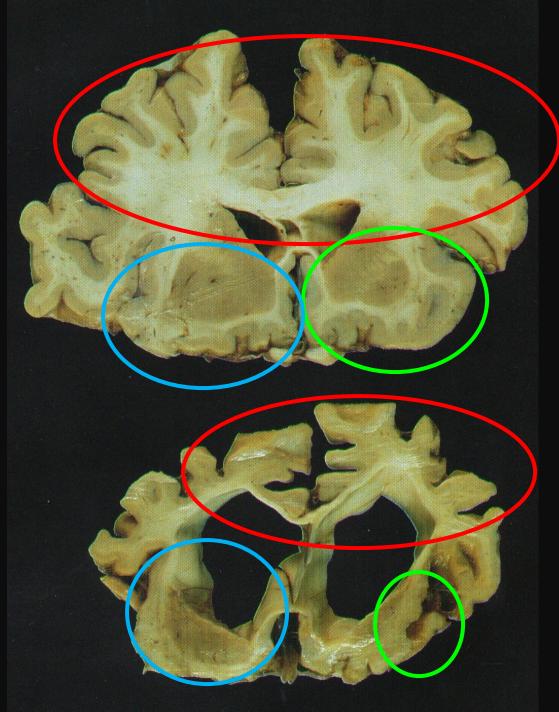
Learning &
Memory
Center
Hippocampus
BIG CHANGE



**Understanding Language – BIG CHANGE** 



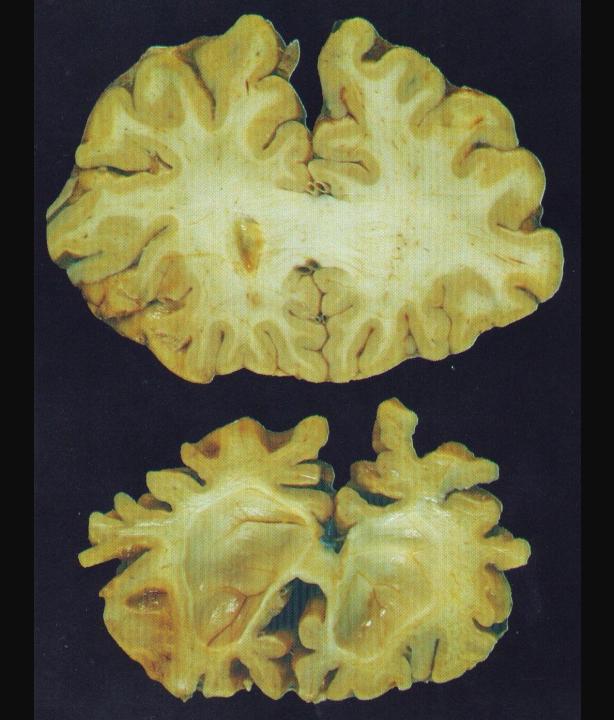
**Hearing Sound – Not Changed** 



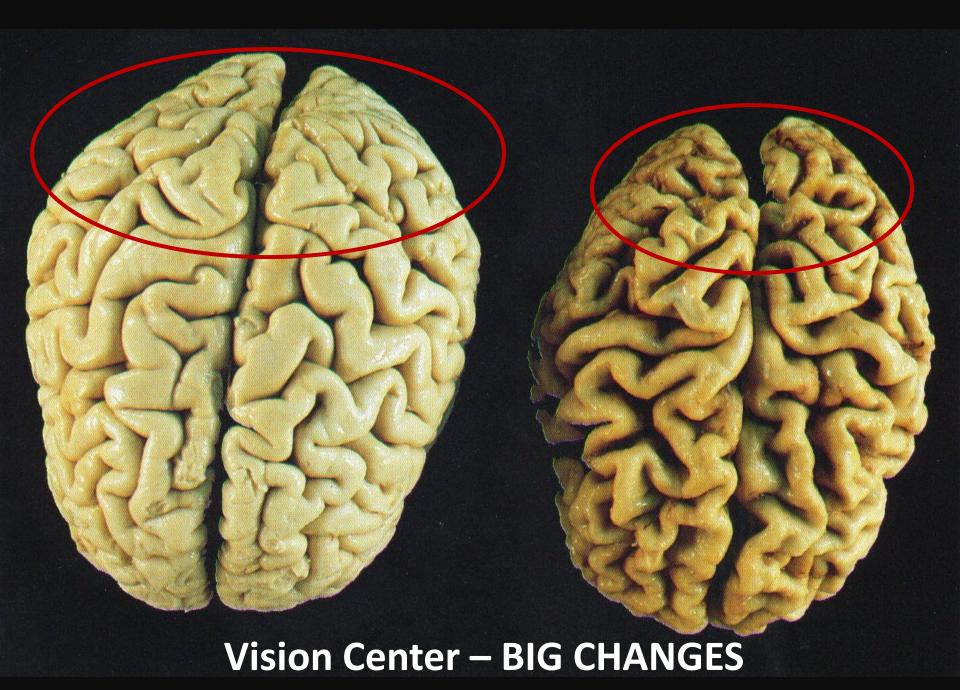
Sensory Strip
Motor Strip
White Matter
Connections
BIG CHANGES

Automatic Speech
Rhythm – Music
Expletives
PRESERVED

Formal Speech & Language Center HUGE CHANGES



Executive
Control Center
Emotions
Behavior
Judgment
Reasoning



## So... what is happening?

- Memory damage
  - Can't learn new things
  - Forgets immediate past
  - Does time & space travel
  - Uses old memories like new
  - May not ID self or others correctly
  - CONFABULATES
  - Follows visual cues
  - Seeks out the familiar
  - Can get stuck on an old emotional memory track

- Language damage
  - Has very concrete understanding of words
  - Misses 1 our of 4 words may miss "Don't..."
  - Word finding problems
  - Word salad problems
  - COVERS
  - Follows your cues
  - Gets very vague & repeats
  - Uses automatic responses
  - Mis-speaks

## So... what is happening?

- Impulse Control Problems
  - Say whatever they are thinking
  - Swear easily
  - Use sex words or racial slurs when stressed
  - Act impulsively
  - Not think thru consequences
  - Can't hold back on thoughts or actions
  - Responds quickly & strongly to perceived threats
    - Flight, fight, fright

- Performance Problems
  - Thinks they can do better than they can
  - Can sometimes DO BETTER under pressure – sometimes worse
  - Uses old habits
  - Attempts can be dangerous or fatal
  - They will tell you one thing and then do another...
  - Families may over or under 'limit' activities

## REALLY Ask Yourself...

Is this Behavior a Problem Behavior

OR

is this a "So What" Behavior

### Is it a Problem BEHAVIOR?

- Risk to that person (physical, emotional, physiological risk)?
- Risk to the caregiver?
- Risk to Others?
- Is the RISK REAL and IMMEDIATE?
- If NOT, it is a 'SO WHAT' behavior

## If it is a 'SO WHAT' Behavior...

Leave it ALONE!

Figure out how to let go of it ...

Let it go!

## If it is a PROBLEM...

- Describe the behavior OBJECTIVELY
  - WHO?
  - WHAT?
  - WHERE?
  - WHEN?
  - WHAT helps... WHAT makes it worse?
  - Frequency & Intensity?

### SIX Pieces to the Puzzle

- Personal history and preferences
- Type & level of dementia
- Other conditions & sensory losses
- Environmental conditions
- Care partner approach and behaviors
- What happened full day & all players

## **Knowing the Person**

- History
- Values and beliefs
- Habits and routines
- Personality and stress behaviors
- Work & family history
- Leisure and spiritual history
- Hot buttons & comforts

### Health & Illness

- Mobility problems?
- Pain?
- Sensory problems?
- Mental health issues?
- Other diagnoses of importance?

## Intervention & Programming to:

- physical activity
- mental activity
- social activity
- spiritual involvement
- well-being and self-worth
- minimize 'risky', challenging, or 'dangerous behaviors
- reduce anxiety or distress

## Some KEY Helping Behaviors

- A Positive Physical Approach
- Strong & Desirable Visual Cues
- Short & Effective Verbal Cues
- Minimal & Familiar Tactile Cues
- Use what you know about the person
- Change the environment to help

## 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!

## Positive Progression GEMS...



Diamonds

**Emeralds** 

**Ambers** 

**Rubies** 

Pearls



### **Diamonds**



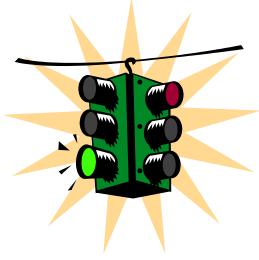
Still Clear
Sharp - Can Cut
Hard - Rigid - Inflexible
Many Facets
Can Really Shine

### **Diamonds**

- Clear, sharp, can cut, lots of facets, rigid
- MY WAY only!
- My space, my things!
- Seek out authority the boss
- Others may not notice
- Can't do it a 'new' way
- Can't reason thru



#### **Emeralds**



Changing color

Not as Clear or Sharp - Vague

Good to Go - Need to 'DO'

Flaws are Hidden

Time Traveling

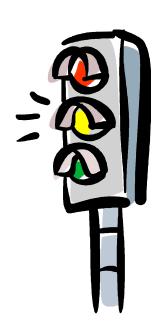
### **Emeralds**

- Getting cloudy, on the go, doing stuff
- Refusing help or need to do things
- Already did or will when I need to!
- Getting lost in time and place
- Wants respect, does better with friendly
- Gets stuck on topics or one idea
- VISUAL cues are important
  - Hide or show



## **Ambers**

Amber Alert
Caution!
Caught in a moment
All about Sensation
Explorers



### **Ambers**

- In the moment, be alert, caution
- Exploring with hands, fingers, touch, taste
- Not completing things
- Not liking to be 'messed with'
- Busy with 'getting into' spaces, belongings, food, 'playing'
- Being touched is TOTALLY different than touching



#### Rubies



Hidden Depths

Red Light on Fine Motor

Comprehension & Speech Halt

Coordination Falters

Wake-Sleep Patterns are Gone

### **Rubies**

- Fine motor is stopping
  - Mouth
  - Fingers
  - Feet
- Roaming or sleeping
- Gross movement
- Hard to switch from one to the other
- Patterns are less predictable



#### **Pearls**



Hidden in a Shell
Still & Quiet
Easily Lost
Beautiful - Layered
Unable to Move - Hard to Connect
Primitive Reflexes on the Outside

### **Pearls**

- Oyster shells look pretty ugly hidden treasure, still
- Movement is stopping
- More time asleep or not-alert
- Little language some quiet some not
- Frail, weight loss, contractures, infections
- Reflexes coming back, swallowing problematic

## How can we help... better?

It all starts with your approach!

#### Connect

- 1<sup>st</sup> Visually
- 2<sup>nd</sup> Verbally
- 3<sup>rd</sup> Physically

- 4<sup>th</sup> Emotionally
- 5<sup>th</sup> Individually Spiritually

## How you help...



Sight or Visual cues

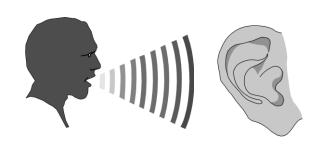


Verbal or Auditory cues



Touch or Tactile cues







## To Connect

# Use the Positive Physical Approach

## Your Approach

- Use a consistent positive physical approach
  - pause at edge of public space
  - approach within visual range
  - approach slowly
  - offer your hand & make eye contact
  - call the person by name
  - stand to the side to communicate
  - respect intimate space
  - wait for a response

## **Hand-Under-Hand Position**



### Your interaction...

- Communicate with awareness
  - look, listen, think!
  - give your name
  - make an empathetic observational statement
    - "You look busy..."
    - "It looks like you are tired..."
    - "It sounds like you are upset..."
  - wait for a response





#### Give information

- Keep it short and simple
  - "It's lunch time"
  - "Let's go this way"
  - "Here's your socks"
- Use familiar words and phrases
- Use gestures and props to help



## **Encourage Engagement**

- ask a person to try
- ask a person to help you
- give simple positive directions - 1 step at a time

- use props or objects
- gesture
- demonstrate
- guide
- distract
- redirect

## Daily Routines & Client-Centered Programming

- Old habits and routines
- Patterns during the 24 hrs
- A time to rest, work, play...socialize
- Your needs... my time

## To Cope with Challenging Behaviors...

- Where will you start???
  - An idea
    - Care partner education
    - Care partner skill building

#### Connect

- 1<sup>st</sup> Visually
- 2<sup>nd</sup> Verbally
- 3<sup>rd</sup> Physically

- 4<sup>th</sup> Emotionally
- 5<sup>th</sup> Individually Spiritually

### Then...

- Observe & document the risky behavior thoroughly
  - what is the pattern
  - when does it happen
  - where does it happen
  - who is involved
  - what is said, done, attempted
  - what makes it better... worse

## Is it really a problem? ... A RISK

• If NO - leave it alone

- If YES its time to problem solve
  - call the team together
  - put on the thinking caps

## REMEMBER Explore all of the following -

- Personal background information
- Type of dementia & level of cognition
- Health & sensory information
- Environmental issues
- Caregiver approach & assistance
- Habits, schedules & time of day

## Re-look at the problematic challenging behavior...

What does the person need?

What is the meaning of the the behavior?

Do you understand the risky behavior better?

#### Make a PLAN!

- Who will do what
- When will it be done
- How will it work
- What environmental change is needed
- What props are needed where will they be

## Implement your plan!

- Keep track of progress
- Document what is happening
- Communicate among the team members

Rethink - if it isn't working....

CELEBRATE - if it is!

## Believe -

People
Are doing
The BEST they can!

#### **GET HELP!**

- Support for YOU
- Help with the person
- Check out options home care, day care, residential care
- Check out places visit, observe, reflect
- Plan ahead when NOT if
- Act before it is a crisis
- Watch yourself for signs of burn-out
- Set limits... It's a marathon!

## Specifically for Caregiver of People with Dementia

- You need HELP
  - From someone who understands

- You need TIME
  - Truly away—physically, emotionally and spiritually

You need to try to LISTEN!!!

#### Let Go:

How it "used to be"

How it "should be"

How you "should be"

## Identify

What you're good at...and what you're not

Who can help...and how they can help

What really matters

 Not EVERYONE is meant to be a caregiver for someone with dementia!

## Final Suggestions

- Back off, change something and try again
- Adopt a "SO WHAT" mentality
- Try a support group
- Accept yourself, and the people with dementia
- Look for the JOY!!!

## I Will Change!

(to the tune of This Little Light of Mine)

By Teepa Snow

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!

No more just "Getting' it Done" I'm gonna DO with you No more just "Getting' it Done" I'm gonna help you thru No more just "Getting' it Done" We're gonna work, we two

Cause if I do it ALL, we BOTH LOSE!

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!



Learn more about Teepa at www.teepasnow.com.

#### Visit www.pinesofsarasota.org/amazon for Teepa Snow DVDs of the following titles:

- Activities: "Filling the Day with Meaning"
- Progression of Dementia: Seeing Gems Not Just Loss
- It's All In Your Approach
- The Art of Caregiving
- The Journey of Dementia
- Lewy Body Dementia: It Isn't Alzheimer's or Parkinson's Disease-What Everyone Needs to Know
- End of Life Care & Letting Go
- Maintain Your Brain: Dementia Risk Reduction & Life After Diagnosis
- Dental Care for People with Dementia
- Improving Emergency Services for Dementia Patients
- El Arte de Cuidar Spanish ONLY Version of "The Art of Caregiving"
- Coming soon: Frontotemporal Dementias
- Coming soon: Improving Hospital Stays for People with Dementia

