

**Trying to Provide
Best Quality Care
Throughout the Journey of
Dementia:
Understanding Progression and How to
Modify Support, Care, and
Environments**

Examples of Challenges

- No F PoA or HC PoA –
- Going to MD problems
- 'Losing' Important Things
- Getting Lost – time, place, situation
- Unsafe task performance
- Repeated calls & contacts
- Refusing help & care
- 'Bad mouthing' you to others
- Making up stories - confabulation
- Undoing what is done
- Swearing/cursing, sex talk, racial slur, ugly words
- Making 911 calls
- Mixing day & night
- Sleep problems – too much or too little
- Not following care/rx plans - denying
- No initiation – can't get started
- Perseveration – can't stop repeating
- Not talking any more
- Paranoid/delusional thinking
- Shadowing - following
- Eloping or Wandering
- Seeing things & people not there - hallucinations
- Getting 'into' things
- Threatening caregivers
- Undressing in public – not changing when needed
- Problems w/intimacy & sexuality
- Being rude - intruding
- Feeling 'sick' – not doing 'anything'
- Use of drugs or alcohol to 'cope'
- Striking out at others
- Falls & injuries
- Dehydration & malnourishment
- Contractures & immobility
- Infections & pneumonias
- Issues w/ eating or drinking

How Does It Start???

Because we miss it, we make mistakes

- Issues are inconsistent
- Worse when tired or sick OR in unfamiliar or uncomfortable setting
- BUT... Otherwise... they seem OK

MCI

- The beginning of NOT NORMAL COGNITION
 - Memory
 - Language
 - Behavior
 - Motor skills
- Not life altering – BUT definitely different... for you

Ten Early Warning Signs

- | | |
|---|--|
| <ul style="list-style-type: none"> • memory loss for recent or new information – repeats self frequently • difficulty doing familiar, but difficult tasks – managing money, medications, driving • problems with word finding, mis-naming, or mis-understanding • getting confused about time or place - getting lost while driving, missing several appointments | <ul style="list-style-type: none"> • worsening judgment – not thinking thing through like before • difficulty problem solving or reasoning • misplacing things – putting them in 'odd places' • changes in mood or behavior • changes in typical personality • loss of initiation – withdraws form normal patterns of activities and interests |
|---|--|

Is This ALWAYS Dementia?

- Some form of DEMENTIA
- Symptom of another health condition
- Medication side-effect
- Hearing loss or vision loss
- Depression
- Delirium
- Pain-related

Screening Options

- OLD – MMSE
- New
 - AD-8 Interview
 - SLUMS – 7 minute screen
 - Animal fluency – 1 minute # of animals
 - Clock Drawing – 2 step
 - Full Neuropsychological testing panel

AD8 Dementia Screening Interview

- Does your family member have problems with judgment?
- Does your family member show less interest in hobbies/activities?
- Does your family member repeat the same things over and over?
- Does your family member have trouble learning how to use a tool, appliance, or gadget ?
- Does your family member forget the correct month or year?
- Does your family member have trouble handling complicated financial affairs ?
- Does your family member have trouble remembering appointments?
- Does your family member have daily problems with thinking or memory?
- Scores:
 - Changed, Not Changed, Don't Know

Animal Fluency

- Name as many animals as you can
- Give one minute – (don't highlight time limit)
- Count each animal named (not repeats)
- Establish Baseline versus Normal/Not Normal
 - 12 normal for > 65 and 18 for <65
 - Compare you to you OVER time

Clock Drawing

- Give a BIG circle on a blank sheet of paper
- Ask to draw the face of a clock - put in the numbers
- Watch for construction skills & outcome
- Ask to put hands on the clock to indicate 2:45
- Watch for placement and processing
- Scoring: 4 possible points
 - 1-12 used correct quadrants
 - minute hand correct hour hand correct

SLUMS

- Orientation – day of week, month, state (3)
- Remember 5 items – ask later (5)
- \$100 – buy apples \$3 and Trike \$20
 - What did you spend? What is left? (2)
- Animal fluency (0-3) (<5, 5-9, 10-14, >14)
- Clock drawing (4) – numbers in place, time right
- Number reversals (2) – 48 – say 84...
- Shapes (2) – ID correct, which is largest
- Story recall (8) – recall of info from a story – 4?s

SLUMS - rating

High School Education

- 27-30 – Normal
- 21-26 – MNCD (MCI)
- 1-20 - Dementia

Less than High School

- 25-30 – Normal
- 20-24 – MNCD (MCI)
- 1-19 - Dementia

TWO Mimics to KNOW

(copy cats & concurrent illnesses)

- Delirium = **Rapid changes in thinking & alertness**
(seek medical help immediately)
- Depression = **chronic unless treated, poor quality, I "don't know", "I just can't" responses, no pleasure**
Typical and atypical
sad
mad - can look like agitation & confusion
(this condition can improve with attention & treatment)
- These signal a vulnerable brain – heads up!

Mimics of Dementia

- Depression
 - can't think
 - can't remember
 - not worth it
 - loss of function
 - mood swings
 - personality change
 - change in sleep
- Delirium
 - swift change
 - hallucinations
 - delusions
 - on & off responses
 - infection
 - toxicity
 - dangerous

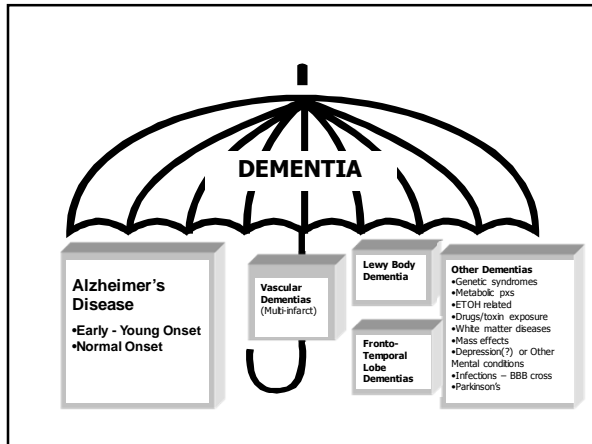
Drugs that can affect cognition

- Anti-arrhythmic agents
- Antibiotics
- Antihistamines - decongestants
- Tricyclic antidepressants
- Anti-hypertensives
- Anti-cholinergic agents
- Anti-convulsants
- Anti-emetics
- Histamine receptor blockers
- Immunosuppressant agents
- Muscle relaxants
- Narcotic analgesics
- Sedative hypnotics
- Anti-Parkinsonian agents

Washington Manual Geriatrics Subspecialty Consults edited by Kyle C. Moylan (pg 15) – published by Lippincott, Wilkins & Williams , 2003

Dementia – What Changes?

- Structural changes –permanent
 - Cells are shrinking and dying
- Chemical changes - variable
 - Cells are producing and sending less chemicals
 - Can ‘shine’ when least expected – chemical rush



Alzheimer's –Two Forms

Young/Early Onset
Normal Onset

Alzheimer's

- New info lost
- Recent memory worse
- Problems finding words
- Mis-speaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 m – 1 yr
- Lasts 8-12 years

Young Onset

- 3 groups – genetics, Down's, life style
- Young family – kids often involved
- Mis-diagnosis & non –diagnosis is common
- Work may be first place to notice
- Relationships are strained early - misunderstanding
- Services are a problem – usually
- Finances are problematic

Vascular Dementia

- Sudden changes – stepwise progression
- Other conditions: DB, HTN, heart disease
- So, damage is related to blood supply/not primary brain disease: treatment can plateau
- Picture varies by person (blood/swelling/recovery)
- Can have bounce back & bad days
- Judgment and behavior ‘not the same’
- Spotty loss (memory, mobility)
- Emotional & energy shifts

Lewy Body Dementia

- Movement problems - Falls
- Visual Hallucinations – animals, children, people
- Fine motor problems – hands & swallowing
- Episodes of rigidity & syncope
- Nightmares or Insomnia
- Delusional thinking
- Fluctuations in abilities
- Drug responses can be extreme & strange
 - Can become toxic, can die, can become unable to move
 - Can have an OPPOSITE reactions

Fronto-Temporal Dementias

- Many types
- Frontal – impulse and behavior control loss (not memory issues)
 - Says unexpected, rude, mean, odd things to others
 - Dis-inhibited – food, drink, sex, emotions, actions
 - OCD type behaviors
 - Hyperorality
- Temporal – language loss
 - Can’t speak or get words out
 - Can’t understand what is said, sound fluent – nonsense words

FTDs

- FvFTD – frontal variant of FTD
- FTD – frontal-temporal lobe dementia
- TLD – non-fluent aphasia
- TLD – fluent aphasia

Temporal Lobe Non-Fluent Aphasia

- Can't NAME items
- Hesitant speech
- Not speaking
- Worsening of speech production over time
- Echolalia
- Mis-speaking
- Word salad
- Receptive inability
- Other skills intact – early
- 25% never develop global dementia

FvFTD

- Mis-behavior
- Impulsivity
- Dis-inhibition
- Inertia
- Obsessive compulsive behaviors
- Inattention
- Lack of social awareness
- Lack of social sensitivity
- Lack of personal hygiene
- Becomes sexually over-active or aggressive
- Becomes rigid in thinking
- Stereotypical behaviors
- Manipulative
- Hyper-orality
- Language may be impulsive but unaffected OR may be reduced or repetitive

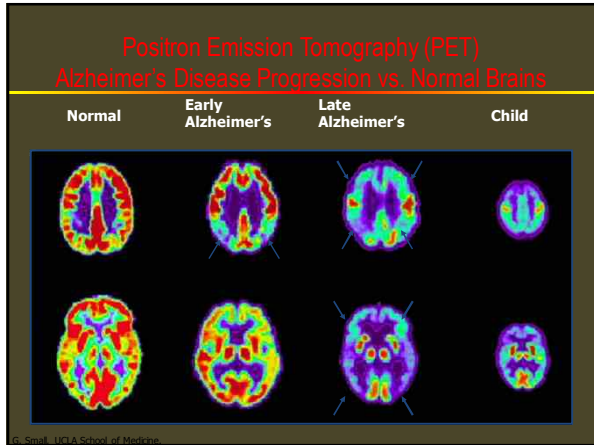
FTD (Pick's Disease)

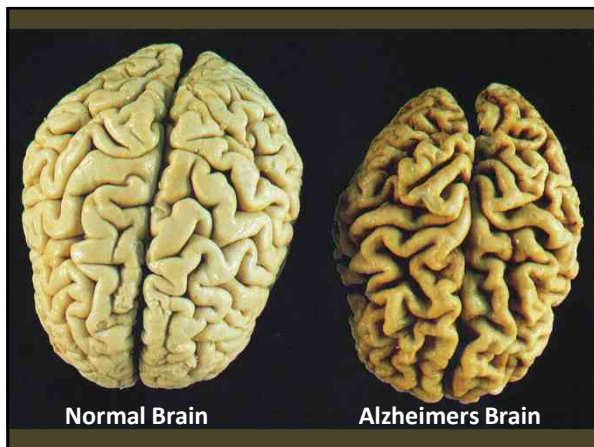
Frontal Issues

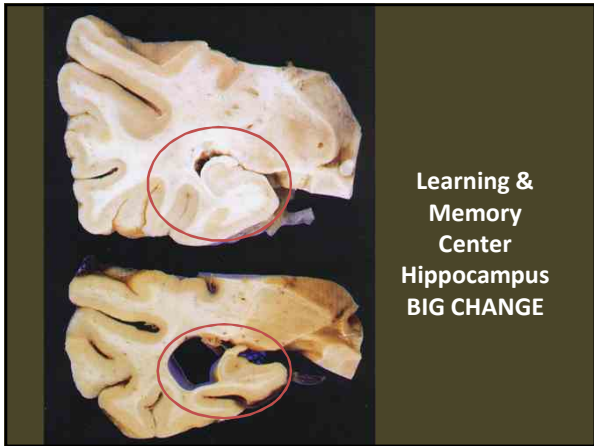
- Poor decision making
- Problems sequencing
- Reduced social skills
- Lack of self-awareness
- Hyper-orality
- Ego-centric
- Dis-inhibited – food, drink, words, actions
- OCD behaviors early
- Excessive emotions

Temporal Issues

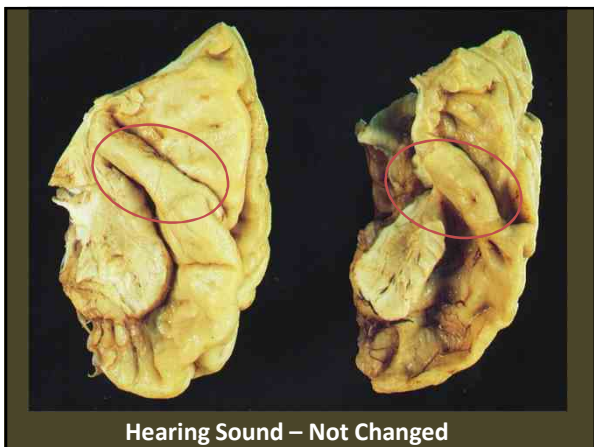
- Reduced attempts to talk
- Reduced content in speech
- Poor volume control
- Public use of 'forbidden words'
- Sing-song speech
- Can't understand others' words

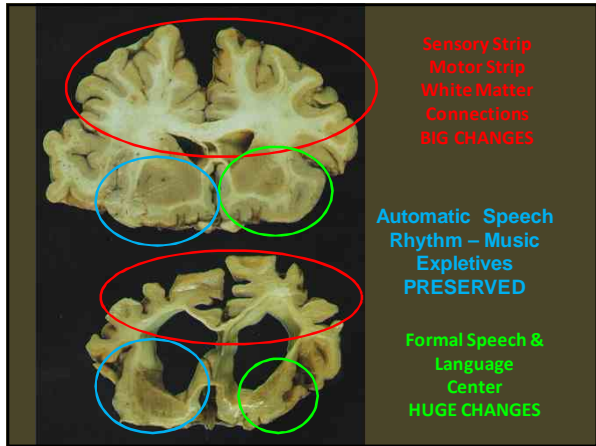




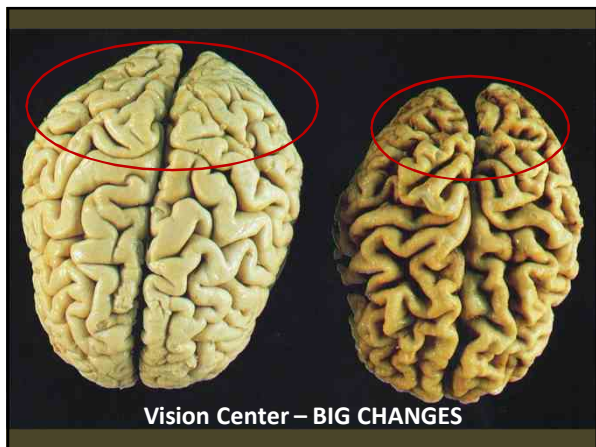












The Basics for Success...

- Be a Detective NOT a Judge
- Look, Listen, Offer, Think...
- Use Your Approach as a Screening Tool
- Always use this sequence for CUES
 - Visual - Show
 - Verbal - Tell
 - Physical - Touch
- Match your help to remaining abilities

Some Basic Skills

- Positive Physical Approach
- Supportive Communication
- Consistent & Skill Sensitive Cues
 - Visual, verbal, physical
- Hand Under Hand
 - for connection
 - for assistance
- Open and Willing Heart, Head & Hands

First Connect - Then Do

- 1st - Visually
- 2nd - Verbally
- 3rd - Physically

- 4th - Emotionally
- 5th - Spiritually - Individually



To Connect

Start with the
Positive Physical Approach

Your Approach



- Use a consistent positive physical approach
 - pause at edge of public space
 - gesture & greet by name
 - offer your hand & make eye contact
 - approach slowly within visual range
 - shake hands & maintain hand-under-hand
 - move to the side
 - get to eye level & respect intimate space
 - wait for acknowledgement

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!

**Partnering & Doing With:
Building Skills to Connect &
Getting Things Done**

Developed by Teepa Snow, MS, OTR/L, FAOTA
Positive Approach, LLC - 2013

Five Skill Areas

- Getting Connected
- Ways of Cueing & Helping
- Hand-under-hand Assistance
- Progression of Dementia
- Time Out Signal – for Me & You

1st Skill
Getting Connected

BEFORE You try to get the person to 'Do Something' 1st - Get Connected

**Make a Connection
Say Something Nice
Form a Positive Relationship
BEFORE You ASK**



Five Ways to Connect

- Greet or Meet
- Say something NICE
- Be friendly - Share about you
- Notice something – Share what you see
- Be curious – learn something

• Greet - Meet

- Use their preferred name
- OR Give your name & “and you are...”

• Give a compliment - “You... “look great”, “are working hard”, “are good at that”, “are smart”...

- use what they value - beauty, strength, brains, humor

• Share something... likes, places, people

- “I’m from __ and you’re from?” “I love coffee, & you...”


• Notice - Make a positive comment about ‘stuff’


- Gesture to yourself then point to the item & say – “what a beautiful...”, “I love that..”

• Be Curious - Find out - past life – may need to choices - “Are you from ___ or elsewhere?”

Practice
'Getting Connected'
Use PPA
Practice EACH Option

Take the Making Positive
Connections Quiz


2nd Skill
Cues – Getting and Giving
How Do I Help???



Check Out Your Partner

BEFORE you get started

Use your **SENSES**

Are they? How are they?

Looking

Listening

'Feeling/Doing'

Smelling

Tasting



**How Do You *GET*
Information from People
About What They Want or
Need or Think**

What they show you- How they look

What they say – How they sound

What they do – Physical reactions

How they smell – What might be going on

**How Do We *GIVE*
Information?**

Visual Cues - Show

Verbal Cues - Tell

Tactile Cues - Touch

How you help...



• Sight or Visual cues



• Verbal or Auditory cues



• Touch or Tactile cues

What should You Use 1st?



Show!!!!



Ways to Show visual cues

- Signs
- Pictures
- Props – Objects
- Gestures
- Facial expressions
- Demonstrations

**Show Your Partner...
NO Words!**

- You are hungry
- You are tired
- You want to leave
- You want to go to the bathroom

Partner...

- What are they trying to tell you?
- How could you tell?

**Show Your Partner...
NO Words!**

- You are thirsty
- You want to go outside
- Your left foot is hurting
- You want to go get a tissue

Partner...

- What are they trying to tell you?
- How could you tell?



Auditory – Verbal – Telling Cues

- What Do We Tend to DO?
- What Should We Do for Success?
- What should we STOP doing?

What Do We Tend to Do with our Auditory Cues?

- Get too loud!
- Sound like our mothers on a bad day!
- Talk TOO MUCH!



**What Should We Do
with Our Auditory
Cues?**

Keep it short & simple
Keep it directed
Keep it matched to what we
show

**Practice:
Giving Cues**

What Works and What Does NOT?

**Tell your partner to do the
following**

give all instructions at one time – say it once

- Name 8 animals
- Get up, turn around 3 times, sit down, and then give you their left shoe
- Describe how to get to a bathroom from here
- Gesture how to brush your teeth, shave your face, and comb your hair

Trade Places...

Tell your partner to do the following
give all instructions at one time – say it once

- Get up, turn to the left 2 times, point to your left elbow, then rub your right knee, sit down
- Name 10 colors
- Describe how to butter a piece of bread
- Pretend you have a brush and combe your hair, then light a candle with a match, then dial a phone number on a rotary phone

**Try It Again
BUT
Keep IT SHORT!**

Only ONE thing at a time!!!
Then PAUSE
Then give another cue....

Tell your partner to do the following
 give one at a time – just use the words

- Get up, side step to the right 3 steps, turn to the left – side step 3 steps back point to your forehead and grimace
- Describe how to put sugar and milk in a cup of coffee and stir it in
- Gesture how to button a shirt, put on earrings, sharpen a pencil
- Name 9 town in Florida

Tell your partner to do the following
 give one at a time – just use the words

- Get up, turn to the left 2 times, point to your left elbow, then rub your right knee, sit down
- Name 10 colors
- Describe how to butter a piece of bread
- Pretend you have a brush and combe your hair, then light a candle with a match, then dial a phone number on a rotary phone

Now Let's Talk

- What happened?
- How was it different for each of you?
- What was hardest?
- What if you add in dementia?
- What if... you were
 - proud - scared
 - angry - HoH
 - blind -listening for another rhythm??

NOW
Combine Your Cues

Start with Visual Cues
 +
 Matching Verbal Cues

(SHOW then TELL)

Tell your partner to do the following

give one at a time – use VISUAL clues 1st
 reinforce numbers, objects, and directions

- Name 8 animals
- Get up, turn around 3 times, sit down, and then give you their left shoe
- Describe how to get to a bathroom from here
- Gesture how to brush your teeth, shave your face, and comb your hair

Tell your partner to do the following

give one at a time – use VISUAL clues 1st
 reinforce numbers, objects, and directions

- Show me how many children you had in your family (brothers and sisters)
- Get the person to write a sentence about what they are wearing
- Imaging you are rolling out pie dough, stirring a pot of soup, flying a kite
- Name 6 vegetables that are green

What Are Some Good Words to Use...

**To Get Started?
To Keep It Going?
To End?**

Positive Verbal Cues to Help DO Something OR Get Something Done

Getting Things Started
Reinforce & Encourage
End with Thanks

5 Ways to Start - Get it Going!


- Give SIMPLE & Short Info
- Offer concrete CHOICES
- Ask for HELP
- Ask the person to TRY
- Break the TASK DOWN to single steps at a time



To Give SIMPLE INFO

- USE VISUAL combined VERBAL (gesture/point`
 - “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... (“Do you want to...”, “Are you ready to...”, “I need you to...”)
- Acknowledge the response/reaction to your info...
 - USE THEIR WORDS (with a ? OR in agreement)
- LIMIT your words – Keep it SIMPLE
- WAIT!!!!





Give Concrete Choices

- Two choices – NOT TOO MUCH or TOO Little
 - “this or that”
 - gesture or have options showing
- Offer one specific & the rest
 - “___ or something else”
- Two BIG categories ... then dig down
 - Something to eat or something to drink? ... DRINK
 - Hot or cold? ... COLD
 - Sweet or plain? PLAIN
 - Water or something else (switch to specific & the rest)

“Could You Help Me?”

- Combine your Agenda with the ASK...
- THINK AHEAD.... What and How could they help?
 - Give an opinion
 - Help make a choice - decide
 - Help you get ready... or clean up
 - Do something for you OR someone else
 - Supervise you and keep an ‘eye on’ something
 - Get something started or finish something

“Could You Give it a Try?”

- Allows the person to FAIL & NOT be a FAILURE
- Allows for ‘not aware’ of need situations (bathroom issues, changing clothing, eating...)
- Acknowledges the value of EFFORT not outcome
- Allows for ‘self-image’ concerns
- Make you more of a PARTNER, not a BOSS

Break IT DOWN into Smaller Steps

- Getting started – what comes first?
- Sequencing... what next?
- Switching to the NEXT thing... changing gears
- Noticing what to do...
 - “Here you go... (offer the next item)
 - Gesture to next
 - Use automatic cues for movement
 - ‘come to me’, ‘come look’, this way – pointing
 - Demo – what you want

Let’s think back....

Tell your partner to do the following
give all instructions at one time – say it once

- Name 8 animals
- Get up, turn around 3 times, sit down, and then give you their left shoe
- Describe how to get to a bathroom from here
- Gesture how to brush your teeth, shave your face, and comb your hair

**How did that...
Go?
Feel?**

When we did it this way...

Tell your partner to do the following
give one at a time – use VISUAL clues 1st
reinforce numbers, objects, and directions

- Name 8 colors
- Get up, turn to the left 2 times, sit down, & then point to their right knee
- Describe how to get back to here from the front door of the building
- Gesture how to brush your hair, put on blush, blow out a candle

**What was different?
Which did you like better?
WHY?**

For EVERYTHING we do we LIKE to get Feedback...

**Did I do it right?
Am I doing OK?**

That doesn't change with AGING or dementia!

Always let the person know you noticed!

Give Feedback to Keep It Going!

- Verbal
 - Make a positive comment – keep it adult
 - Say “Yes!”, “That’s It!”, “OK”
 - If struggling - “Good effort”, “This is hard...”
- Visuals
 - Use head nods & smiles
 - Use thumbs up
 - Look excited & interested
- Remember – SUPPORT ... don’t interrupt!

**When you are done....
Let me know YOU CARE!**

THE Way to Finish ALL
Interactions

Thanks!

**Now for Touch...
ONLY after you try the
Visual + Verbal**

Try This: Set-up

- Your partner has crumbs all over their shirt
- Their ‘significant other’ is coming down the hall.... This person doesn’t like seeing the person looking bad!
- Person has no limitations
- Person has only movement problems
- Person has visual & comprehension issues –
 - Diving mask, missing ¼ words
 - Binoculars, missing ½ words
 - Monocular, missing words – leaving rhythm

Care Partner

- Just use WORDS
 - No issues – Say “You have crumbs on your shirt.”...
- Just use Verbal and Touch
 - Physical issues – Say “You have crumbs on your shirt. May I get them for you?” Listen to response - then WIPE
- Use Verbal, LOOK Friendly, THEN Touch
 - Diving mask – say “You have on your. Let me get it you!” – NOD yes & smile - WIPE
 - Binoculars – Say “You have your. Let get it you! OK?” – Nod and smile, then WIPE.
 - Monocular – MUMBLE, smile & nod, WIPE.

**What Happened?
How Did It Feel?
What Do You Think?
Why?
What Can We Change?**

Tactile – Touch Cues

Touching a body part
Handing the person an item
Using Hand under hand assist

Five Skill Areas

- Getting Connected
- Ways of Cueing & Helping
- Hand-under-hand Assistance
- Progression of Dementia
- Time Out Signal – for Me & You

Take the Matching Cues
Quiz

Practice Each of These!

1. Get the person to stand and take a walk
2. Get the person to go to the bathroom
3. Get the person to go get a drink
4. Get the person to take off a shoe
5. Get the person to sit down and rest

Practice this

- Person is seated – s/he is supposed to exercise
- Get her/him up and walking for at least 10 feet
- REMEMBER –
 - PPA
 - Get Connected
 - Use a positive interaction skills
- REPEAT – using less than **10 words**

3rd Skill
How to Help
Using Hand Under Hand
Guidance and Assistance

Doing With
When the Person CAN'T DO IT
or Doesn't Get What You are
Showing or Saying

Hand-Under-Hand Assistance



Practice: Using Hand Under Hand

- 1- to comfort
- 2- to start a task
- 3- to use a tool or utensil
- 4- to help with detail
- 5- to guide/direct with movement

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, this is HARD!" (for both of you)
- "I'm sorry that happened (their perspective)"

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4th Skill:
Progression of Dementia
Recognizing GEM Levels


Seeing the Value at Each Stage
of the Condition

Creating the Right Setting &
Providing the Right Care

**Progression of
Dementia**

What Level Is the
Person At?

Now for the GEMS...



Sapphires
Diamonds
Emeralds
Ambers
Rubies
Pearls



Now for the GEMS...

Sapphires – True Blue – Slower BUT Fine

Diamonds – Repeats & Routines, Cutting

Emeralds – Going – Time Travel – Where?

Ambers – In the moment - Sensations

Rubies – Stop & Go – No Fine Control

Pearls – Hidden in a Shell - Immobile


**5th Skill:
Know When to Signal
TIME OUT**

Use Time Outs
Help Others with Time Outs
Monitor Yourself & Others

**I Noticed Something!
or
HELP!**

Using the Time-Out Signal
VISUAL CUES for each other

Time Out Signal



**Practice
Using the Time Out Signal
with Each Other**

Go out into the community in
2's or 3's and practice:

- Watching each other
- Signaling each other
- Giving each other feedback

Five Skill Areas

- Getting Connected
- Ways of Cueing & Helping
- Hand-under-hand Assistance
- Progression of Dementia
- Time Out Signal – for Me & You

Part 2


How Do We Measure Progression?

- Screening - Assessment
- Observed Behavior & Demonstrated Skills
- Three Scales Used
 - 1-3 - Alzheimers (Early, Middle, Late)
 - GDS - 7 point scale (1-7)
 - Cognitive Disability Theory - ACL (6-1)

Gem Levels = Allen Levels

- Not numbers - Each is precious & unique
- Each requires a special 'setting'
- Each requires the 'just right' care
 - Visual, verbal, touch cues
- Each can shine
- Dynamic & Fluid - in the moment behavior
 - Accounts for chemistry as well as structure
- Takes 2 concepts & connects
 - familiar & new, better use & application

Now for the GEMS...



- Sapphires
- Diamonds
- Emeralds
- Ambers
- Rubies
- Pearls



Now for the GEMS...

- Sapphires - True Blue - Slower BUT Fine
- Diamonds - Repeats & Routines, Cutting
- Emeralds - Going - Time Travel - Where?
- Ambers - In the moment - Sensations
- Rubies - Stop or Go - No Fine Control
- Pearls - Hidden in a Shell - Immobile



Sapphires

Us on a good day...
 Clear & True to Themselves
 May feel 'blue' over changes
 Some are 'stars' and some are not
 They can CHOOSE



Sapphires

- Can connect the dots - make contracts
- May have other health issues that affect behaviors
- Recognize life experiences, achievements & values in interactions
- Can follow written info & hold onto it
- Will still need us to work with them
- Can typically CHOOSE their behaviors



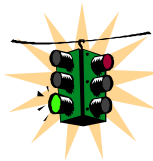
Diamonds



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



Emeralds



Changing color
Not as Clear or Sharp - Vague
Good to Go - Need to 'DO'
Flaws are Hidden
Time Traveling



Ambers



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



Rubies



Hidden Depths
Red Light on Fine Motor
Comprehension & Speech Halt
Coordination Falters
Wake-Sleep Patterns are Gone



Pearls




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



Diamonds



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



Diamonds

Are Joiners or Are Loners

Use Old Routines & Habits

Control Important 'Roles' & 'Territory'

Real? Fake? - Hard to Be Sure

Diamonds - Level 5

- Uses Routines & Old Habits to function
- Can complete personal care in 'familiar place'
- Follows simple prompted schedules - mostly
- Misplaces things and can't find them
- 'Resents takeover' or bossiness
- Notices other people's mis-behavior & mistakes
- Territorial - refusals!
- Varies in lack of self-awareness

Diamond Interests

- What they feel competent at
- What they enjoy & who they like
- What makes them feel valued
- Where they feel comfortable but stimulated
- What is familiar but intriguing
- What is logical and consistent with historic values & beliefs
- Who is in charge - the boss



Common Diamond Issues

- | | |
|--|---|
| <ul style="list-style-type: none"> • IADLs - Money management - Transportation - Driving - Cooking - Home maintenance & safety - Caring for someone else - Pet maintenance - Med administration | <ul style="list-style-type: none"> • Unfamiliar settings or situations - Hospital stay - Housing change - Change in family - Change in support system - MD visits - New diagnoses - Traveling or vacations |
|--|---|



Visual Cues that Help

- Personalized room
- Way finding signs
- Highlighted schedules
- Familiar & inviting environments
- Familiar set-ups for tasks or activities
- Personal approach with a smile
- Place cards at table settings
- Wear name tags on right side



Verbal Cues that Help

- Knock before entering
- Use Sir and Ma'am, be respectful
- Ask permission to do things in the room
- Offer positive comments
- Issue invitations not orders
- Ask for help or input
- Frame as a 'RULE' for everyone
- Acknowledge their skill, ask for their support or understanding --- a favor

Watch how you talk...

- **How** you say it...
- **What** you say...
- How you **respond**...



Tactile Cues that Help

- Hand shake greetings
- Return of friendly affection touches
- Responsive hugs
- Hand-under-hand comforting
- Back rubs - with permission
- Hand & foot massages - 'pampering'
(getting used to us touching & doing)



So What Helps?

Apologize! - "I'm SORRY!" - "I didn't mean to..."

- Friendly NOT bossy - leader to leader
- "Let's try" - temporary...
- Share responsibility not take over
- Use as many 'old habits' as possible
- Give up being 'RIGHT'
- Go with the FLOW
- Give other 'job' when taking away another



Be Prepared for REPEATS


- For repeated questions or requests
 - Don't share so early
 - be careful about emotional information
 - Make sure you are connected to respond
 - Repeat a few of their words in a ???
 - Answer their question
 - THEN
 - Go to new words (use enthusiasm)
 - A new place
 - Add a new activity (possibly related)




For OLD Stories

- Use "Tell me about it"
 - to accept the story
 - To reduce risk of 'paranoia-like' thinking
- Store them for the future
 - Write them down
 - Share them with others
 - You will possibly need them for supportive communication later
- Learn several - prompt for 'switch up'


**Use empathy
&
Go with the flow**




Reality
Orientation



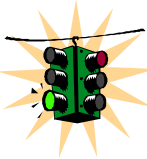
Telling
Lies

 **BAD Helper Habits to BREAK**

- Saying "Don't you remember..."
- Not recognizing or accepting differences
- Trying to force changes in roles or responsibilities
- Trying to take over completely
- Taking responsibility for saying "NO"
- Accepting things at face value
- Arguing



Emeralds



Changing color
Not as Clear or Sharp - Vague
Good to Go - Need to 'DO'
Flaws are Hidden
Time Traveling



Emeralds

Two Kinds of DOING
Doers or Supervisors

Does What is Seen - Misses What is Not
Must be in Control - Not able to do it Right
Does tasks - Over and over OR Not at All



Emerald Interests

- Doing familiar tasks
- Doing visible tasks
- Historic tasks and people and places
- Engaging with or helping others
- Finding important people or things
- Having a 'job' or 'purpose'
- Being an 'adult'
- Getting finished & doing something else



Common Emerald Issues

- Doesn't do care routinely - thinks did
- Makes mistakes in sequence - unaware
- Repeats some care routines over & over
- Resists or refuses help
- Gets lost - can't find where to do care
- Limited awareness of 'real needs' -
– Hunger, thirst, voiding, bathing, grooming...
- Has other 'stuff' to do...



More Emerald Issues

- Afternoon or Evening - "Got to go home"
- Daytime - "Got to go to work"
- Looking for people/places from the past
- Losing important things - thinking others stole/took them
- Doing private things in public places
- Having emotional meltdowns
- Treating strangers like friends and visa versa



Visual Cues that Help

- The environment
 - Overall look (friendly, fun, familiar, forgiving)
 - Surfaces to work on or do things on
 - Places to sit (paired chairs)
 - Set up Props (objects that 'say' what to do)
 - Highlighted areas (light, color contrast, clutter reduction, organized)
 - Hidden - what is NOT to be done, what is already done, what 'triggers' distress



More Visual Cues that Help

- You
 - Facial expression
 - Friendly
 - Concerned
 - Gestures
 - Invite with gestures and your face
 - Indicate next item to use, or options
 - Offer items
 - Offer an item in correct orientation
 - Present two to pick from



Verbal Cues that Help

- Tone of Voice
 - Friendly
 - Interested
 - Concerned
- Reduce and Focused words
 - Use preferred name for attention
 - Match words with gestures or offering
- Listen and use their words to connect



More Verbal Cues

- When becoming distressed
 - Use PPA - Let them come to you, if possible
 - Listen - Get emotionally connected to where they are
 - Use empathic comments
 - Listen for key words
 - Go with their FLOW - don't push for the change
 - THEN Use redirection, NOT distraction



Physical Cues that Help

- Limit this form of helping!
 - Match it with a visual & verbal cue combo
- Offer objects - don't put hands on
- Share the task -
 - Give them something to do while you do your part
- Do 'it' with/to someone else first, then approach them



More Physical Cues

- When distressed
 - Match your touch to their preferences
 - Hand-under-Hand FIRST
 - Back rub - if interested
 - Hug - show first
 - Increase space and distance, if cued
 - BACK OFF, if it is not working



How to Help

- Learn about "SO WHAT!"... is it worth it?
- Provide 'subtle' supervision for care
- Provide visual prompts to do
 - Gestures, objects, set-up, samples, show
- Hide visual cues to 'stop'/prevent
 - Put away, move out of range, leave
- Use the environment to cue - SHOW
- Use 'normal', humor, friendliness, support

Connect

- ID common interest
- Say something nice about the person or their place
- Share something about yourself and encourage the person to share back
- Follow their lead - listen actively
- Use some of their words to keep the flow going
- Remember its the FIRST TIME! - expect repeats
- Use the phrase "Tell me ABOUT ..."

Do's

- Go with the FLOW
- Use SUPPORTIVE communication techniques
 - Use objects and the environment
 - Give examples
 - Use gestures and pointing
 - Acknowledge & accept emotions
 - Use empathy & Validation
 - Use familiar phrases or known interests
 - Respect 'values' and 'beliefs' - avoid the negative


DON'Ts

- Try to CONTROL the FLOW
 - Give up reality orientation and BIG lies
 - Do not correct errors
 - Offer info if asked, monitoring the emotional state
- Try to STOP the FLOW
 - Don't reject topics
 - Don't try to distract UNTIL you are well connected
 - Keep VISUAL cues positive



What NOT to DO...

- DO NOT point out errors - or focus on 'wrong'
- DO NOT offer - physical assist 1st
- DO NOT offer "Let me HELP you"
- DO NOT try to 'go back and fix it...'
- DO NOT continue arguing about 'reality'
- DO NOT treat like children...
- Do NOT react... remember to respond


 **BAD Helper Habits to Break!**


- Noticing and pointing out errors
- Telling not asking - "You need to..."
- Too little or too much - talking, showing, touching
- Trying to take over - offering "HELP"
- Putting hands on - 'fussing'
- Reality orientation or lying
- Trying to use 'distraction'



Ambers

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





Ambers

Private & Quiet OR Public & Noisy
All About Sensory Tolerance & Needs
Touching - Tasting - Handling - Exploring
Attraction - Avoidance
Over-stimulated - Under-stimulated
No safety awareness
Ego-centric



Level 3 - Amber

- LOTS of touching, handling, mouthing, manipulating
- Focus on fingers and mouth
- Get into things
- All about sensation...
- Invade space of others
- Do what they like
- AVOID what they do NOT



Amber Interests

- Things to mess with (may be people)
- Places to explore
- Stuff to take, eat, handle, move...
- Visually interesting things
- People who look or sound interesting OR places that are quiet and private
- Textures, shapes, movement, colors, numbers, stacking, folding, sorting...



Amber Issues

- Getting into stuff - taking stuff
- Bothering others
- Not able make needs known
- Not understanding what caregivers are doing
- Not liking being helped/touched/handled
- Not like showers or baths
- Repetition of sounds/words/actions



Visual Cues that Help

- Automatic social greeting signals
- Lighted work surfaces with strong props
- Demonstrations - work along side
- Model the actions
- Do the action one time, then offer the prop
- Show one step at a time
- Show a NEW item, then cover the old



Verbal Cues that Help


- Call name
- Use simple noun, verb, or noun + verb
 - "Cookie?"
 - "Sit down"
 - "Let's go" (with gesture)
- Give simple positive feedback
- Listen for their words, then
 - use a few and leave a blank at the end of the sentence




Physical Cues that Help

- Show the motion or action wanted
- Touch the body part of interest
- Position the prop for use - light touch
- Show the motion on yourself
- Use hand under hand guidance
- Offer the prop once started - encourage their use of the item

Hand-Under-Hand Assistance

-  **How to Help**
- Provide step-by-step guidance & help
 - Give demonstration - show
 - Hand-under-hand guidance after a few repetitions, uses utensils (not always well)
 - Offer something to handle, manipulate, touch, gather
 - Limit talking, noise, touch, other activities
 - **SUBSTITUTE** don't **SUBTRACT**

-  **To Connect with Ambers**
- **Make an Emotional Connection**
 - Use props or objects
 - Consider **PARALLEL** engagement at first
 - Look at the 'thing', be interested, share it over....
 - Talk less, wait longer, take turns , **COVER** don't confront when you aren't getting the words, enjoy the exchange
 - Use automatic speech and social patterns to start interactions
 - Keep it short - Emphasize the **VISUAL**

 **BAD Helper Habits to Break!**

- Talking too much, showing too little
- Keep on pushing
- Doing for NOT with
- Stripping the environment
- Leaving too much in the environment
- Getting in intimate space
- Over or under stimulating
- Getting loud and forceful



Rubies



Hidden Depths
Red Light on Fine Motor
Comprehension & Speech Halt
Coordination Falters
Wake-Sleep Patterns are Gone



Rubies

Balance & coordination
Eating & drinking
Wake time & sleep time



Level 2 - Ruby

- Big movements - walking, rolling, rocking
- Hand actions - not fingers
- Tends toward movement unless 'asleep'
- Follows gross demonstration & big gestures for actions
- Limited visual awareness
- Major sensory changes
- Major movement skill loses
- Fine motor skill lost - mouth & hands



Ruby Interests

- Walking a routine path
- Going forward
- Watching others - checking them out
- Being close or having space
- Things to pick up, hold, carry, push, wipe, rub, grip, squeeze, pinch, slap
- Things to chew on, suck on, grind
- Rhythmic movements and actions



Ruby Care Issues

- Safe mobility - fatigue, wandering, & falls
- Intake - amount and safety
- Hydration - interest, amount, safety
- Rest time & place - night time waking
- Shadowing others - invading places
- Not staying - not settling for meals
- Reactions to hands on care - sensation
- Identifying & meeting needs



More Ruby Issues

- Contractures
- Skin well being - bruises, tears, rashes
- Pressure or friction
- Infections - UTI, yeast, URI, pneumonias
- Swallowing
- Circulation



Visual Cues that Help

- Demonstrate what you want
- Give big movements to copy
- Move slowly & with rhythm
- Present cues in central visual field about 12-18 inches out
- Hold things still - allow exploration
- Offer your hand
- Smile while offering support



Verbal Cues that Help

- Call name to get attention - at 6' out
- Use 'song' to connect
- Give 1-3 words only
- Combine verbal direction with gesture or demo
- Give one 'action' cue at a time
- Match tone/inflection to intent
- Give positive 'Strokes' with attempts



Physical Cues that Help

- Hand-under-hand
- Touch body part to be moved or used
- Place hand/foot then gesture
- Offer comfort touch as desired before task attempt
- Back rubs -
 - Flat and slow - to calm
 - Finger tips and quick circles - to awake




How to Help

- SLOW yourself DOWN
- Hand under hand
- Move with first - then guide
- Learn about patterns of 'needs'
- Use music and rhythms - help get or stop movement
- Use touch with care
- Combine cuing & do SLOW




BAD Helper Habits to Break!


- Touching too quickly - startling
- Leaning in - intimate space invasion
- Talking too loudly
- 'Baby-talking'
- Not talking at all
- Not showing by demonstrating
- Trying to understand what is said, by being confrontational



Pearls




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



Pearls

- The end of the journey is near
- Multiple systems are failing
- Connections between the physical and sensory world are less strong
- We are often the bridge - the connection
- Many Pearls need our permission to go -
 - They are still our moms, dads, spouses, friends
 - They will go in their own time
 - IF we don't try to change what is



Level 1 - Pearl

- Immobile - can't get started
- Bed or chair bound - frequently falls to side or forward
- Has more time asleep or unaware
- Has many 'primitive' reflexes present -Startles easily
- May cry out or mumble 'constantly'
- Increases vocalizations with distress
- Difficult to calm
- Knows familiar from unfamiliar
- Touch and voice make a difference in behaviors



Pearl Interests

- Internal cues
- Pleasant and familiar sounds & voices
- Warmth and comfort
- Soft textures
- Pleasant smells
- 'Good' tastes
- Smooth and slow movement
- Just right touch and feel



Primitive Reflexes to Consider

- Startle reflex -
 - Sudden movement causes total body motion
- Grasp reflex-
 - touch palm - grips hard can't release
- Sucking reflex -
 - sucks on anything near mouth
- Rooting reflex -
 - Turns toward any facial touch and tries to eat



More Reflexes

- Bite reflex
 - Any touch in mouth causes bite down
- Tongue thrust
 - Anything in mouth causes tongue to push forward and out
- Withdrawal - rebound
 - Pull away from stretch
- Gag reflex -
 - Any touch to tongue causes gag



Typical Positioning - Why?

- Constant muscle activity causes 'contractures' - shortening - can't relax
- Stronger muscles cause typical 'fetal' positioning
- Pulling against contractures is painful
- Shortened muscles cause some areas to:
 - Not get air - become 'raw' or 'irritated'
 - Rub or press against other body parts
 - Get too much pressure - can't move off



Pearl Care Issues

- Not interacting much
- Crying out - can't make needs known
- Skin & hygiene problems
- Weight loss
- Reflexes make care challenging
- Repeated infections
- Not eating or drinking
- Not able to sit up safely



Visual Cues to Help

- Get into supportive position
- Place your face in the central field of vision
- Make sure light comes from behind the person - into your face
- Bring up lights carefully
- Move slowly so they can follow you
- Place items to be used in central field



Verbal Cues to Help

- Keep your voice deep & calm
- Put rhythm in your voice
- Tell what you are doing and what is happening while you give care
- Reflect emotions you think you see
- Offer positive comments & familiar phrases as you offer care
- Quiet down, if signaled to do so



Touch Cues to Help

- Use firm, but gentle palm pressure at joints to make contact
- Always try to maintain contact with one hand while working with the other
- Once physically connected keep it
- Use flats of fingers and palms for care
- Always use hand under hand when doing something 'intense'



How to Help

- Hand under hand help & care - or hand on forearm, if hand/arm movement is poor
- Check for reflexes - modify help & approach to match needs
- GO SLOW
- Use calm, rhythmic movements & voice
- Come in from back of extremities to clean
- Stabilize with one hand & work with other



How to Help?

- Gather all supplies for the task before getting started
- Increase warmth of the room for bathing
- Use warm towels & light weight blankets
- **GO SLOW**
- Use circular, rotational movements to relax joints for care
- Provide skin care - fragile & dry skin



BAD Help Habits to BREAK

- Hurry - *Get it done quickly*
- Don't talk to - talk over or about
- Don't check for primitive reflexes prior to helping
- Use both hands to give care
- Clean from the front - use prying motions
- Focus on tasks not the relationship
- Forget to look for the Pearl

Enhancing Understanding of Dementia & Building Skills for Better Care and Outcomes



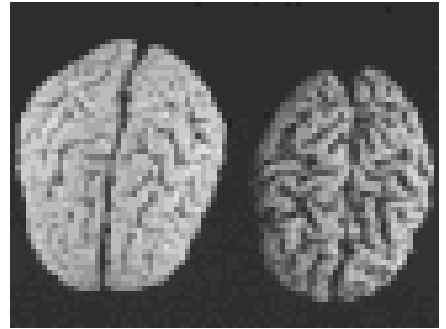
The Latest Skills in Providing Effective Hands-On Help with Improved Outcomes

Teepa Snow, MS, OTR/L, FAOTA

- ◆ Dementia Care & Training Specialist, Positive Approach, LLC
- ◆ Consulting Associate, Duke University School of Nursing

What is Dementia?

- ◆ It is NOT part of normal aging! It is a disease!
- ◆ It is more than just forgetfulness - which is part of normal aging
- ◆ It makes independent life impossible



Dementia

- ◆ is an umbrella term that includes many cognitive loss conditions
- ◆ includes some reversible conditions - so should be checked out carefully

Alzheimer's Disease -

- ◆ is the most common type of dementia
- ◆ is caused by damage to nerves in the brain and their eventual death
- ◆ has a expected progression with individual variations - about 8-12 years
- ◆ will get worse over time - we can't stop it!
- ◆ is a terminal disease - there is NO known cure at this time!

Vascular Dementia (Multi-Infarct) -

- ◆ is caused by damage to the *blood supply* to the nerves in the brain
- ◆ is spotty and *not* predictable
- ◆ may *not* change in severity for long periods, then there are sudden changes

Lewy Body Dementia -

- ◆ problems with movement – falls & stiffness
- ◆ visual hallucinations & nightmares
- ◆ fluctuations in performance – day/day

Frontal-Temporal Dementias -

- ◆ Problem behaviors – poor impulse control
- ◆ Difficulty with word finding
- ◆ Rapid changes in feelings and behaviors

Symptoms Common to Most Dementias... Over time...

- ◆ It affects a person's entire life...It causes the brain to shrink & stop working
- ◆ It steals memories - the most recent first, but eventually almost all...
- ◆ It steals your ability to use language ... leaves you with some 'skills'
- ◆ It steals your ability to understand what others mean & say
- ◆ It steals reasoning and logic
- ◆ It robs you of relationships
- ◆ It makes even the 'familiar' seem odd and scary
- ◆ It steals your ability to care for yourself and move around safely
- ◆ It robs you of impulse control - takes away emotional and mood control

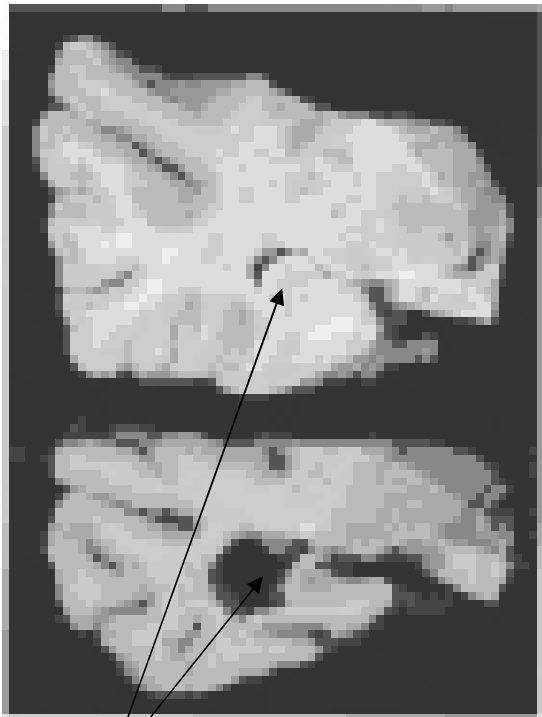
Drug Treatment for Alzheimers

- ◆ Drugs to improve chemicals in the brain so nerve activity might happen
- ◆ Drugs to treat depression
- ◆ Drugs to control distressing hallucinations, severe paranoia, or unprovoked violence
- ◆ No vaccines or cures...yet
- ◆ No way to stop the disease...yet

Prevention –

- Have a good family history for staying alert and 'with it' – genetics do play a part
 - ◆ Eat healthy & moderately (Heart-Smart)
 - ◆ Exercise your body --- 100 minutes/wk ***
 - ◆ Exercise your brain --- challenge yourself
 - ◆ Eat fish --- 1 time a week
 - ◆ Control your BP & sugar & weight
- ** consult your MD first

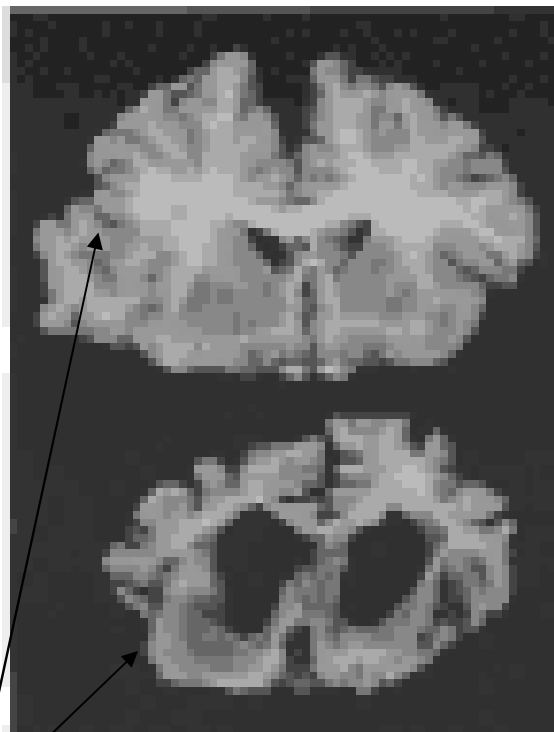
Normal



Alzheimer

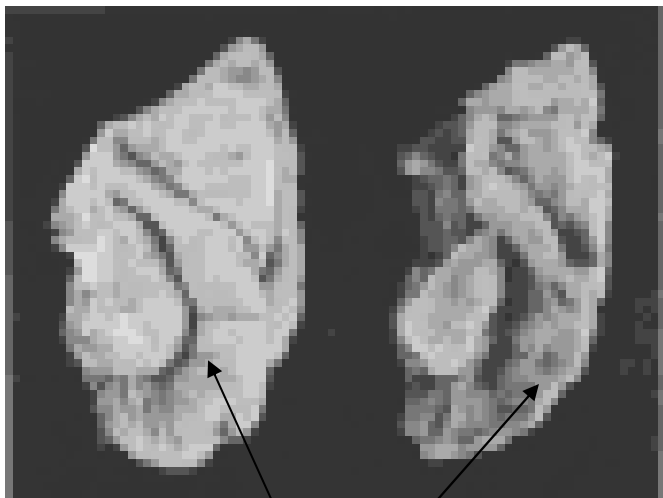
The ability to remember information...

Normal



Alzheimer

The ability to use words and language...

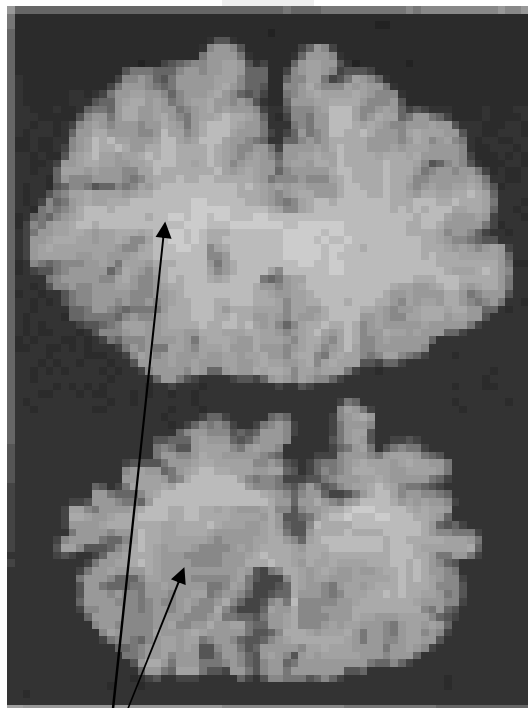


Normal

Alzheimer

The ability to understand what is being said...

Normal



Alzheimer

The ability to control your impulses, temper, & moods...

REALIZE ...

It Takes TWO to Tango ... or tangle...

- By managing your own behavior, actions, words & reactions you can change the outcome of an interaction.
- Being 'right' doesn't necessarily translate into a good outcome for both of you
- Deciding to change your approach and behavior WILL REQUIRE you to stay alert and make choices... it is WORK
- It's the relationship that is MOST critical NOT the outcome of one encounter

As part of the disease people with dementia 'tend to' develop typical patterns of speech, behavior, and routines. These people will also have skills and abilities that are lost while others are retained or preserved.

Typically Lost – can't use

Memory skills

- immediate recall
- short term memory
- clarity of time and place
- depth of categorical information
- relationships & specifics

Understanding skills

- interpretation of abstract meaning
- early - misses ¼ words
- later – misses ½ words
- subtle emotions, 'unspoken' agreements
- at the end – most words

Language use skills

- specific word finding
- descriptive abilities
- reading for content
- content of speech
- spoken communication
- words
- meaningful 'yes' and 'no'
- socially acceptable expressions of emotion
- verbal communication of needs and desires

Emotional & Impulse control skills

- ability to 'demand' respect
- ability to limit or control emotions
- ability to control impulsive speech
- ability to control impulsive actions
- don't act out when 'pushed'
- ability to keep private thoughts and actions in private places

Motor Skills & Sensory Processing

- at first very little as far as skills go
- later – initiation or getting started
- later – parts of tasks get left out/skipped
- mis-interprets sensory information
- organized scanning is lost
- visual field is restricted
- may become hypersensitive OR hyposensitive to touch, sound, light...

Preserved – can or may use

Memory skills

- long ago memories
- emotional memories
- confabulation
- procedural memories
- awareness of familiar versus unfamiliar

Understanding skills

- 'gets' the concrete meaning
- picks out familiar or meaningful words
- covers well
- facial expressions that are consistent with the message being sent

Language use skills

- desire to communicate
- ability to use hands or actions to describe
- reading aloud
- rhythm of speech
- para-verbal communication (how you say it)
- music and song
- automatic speech
- swearing, sex words, 'socially unacceptable' words
- non-verbal communication of needs and desires

Emotional & Impulse control skills

- desire to be respected
- ability to feel emotions and have needs
- say what is on your mind – with errors
- do what you want to do
- sometimes, feel badly after its done
- sometimes, behaving differently in 'public' if cues are strong

Motor Skills & Sensory Processing

- the movement patterns for pieces of tasks
- gross motor movements last longer than fine motor
- can often do the mechanics – BUT not safely or well
- looks for stuff – seeks out things
- mouth (lips, tongue), fingers and palms, soles of feet, & genitalia or 'private body parts'
- recognize faces, voices – familiar from not familiar

Progression of the Disease – Levels of Cognitive Loss

Diamond – *Early Loss – Running on Routine – Repeating Stories*

Some word problems and loss of reasoning skill
Easily frustrated by changes in plans or routines
Seeks reassurance but resents take over
Still does well with personal care and activities
Tends to under or over estimate skills
Seeks out authority figures when upset or frustrated
Points out others' errors, but doesn't notice own behavior
May have some awareness – "Just not right" – might blame others or self
Can't remember 'new' rules, locations, plans, discussions, facts

Emerald – *Moderate Loss - Just Get It Done! – Wanting a Purpose and a Mission*

Gets tasks done, but quality is getting to be a problem
Leaves out steps or makes errors and WON'T go back and fix it
Can help with lots of things – needs some guidance as they go
Likes models and samples – uses others' actions to figure out what to do
Asks "what /where/when" LOTS
Can do personal care tasks with supervision & prompts – often refuses "help"
Still very social BUT content is limited and confusing at times
May try to 'elope' /leave to get to a 'older' familiar time or situation OR get away from 'fighting'
Can't remember what happened AND can mis-remember it – goes back in time, at times

Amber – *Middle Loss - See It – Touch It – Take It – Taste It – Hunting & Gathering*

Touches and handles almost anything that is visible
Does not recognize other's ownership – takes things, invades space, gets 'too close'
Can still walk around and go places – 'gets into things'
Language is poor and comprehension very limited - does take turns
Responds to tone of voice, body language and facial expression
Loses the ability to use tools and utensils during this level
Does things because they feel good, look good, taste good – refuses if they don't
Stops doing when it isn't interesting anymore
Can often imitate you some – But not always aware of you as a person

Ruby – *Severe Loss – Gross Automatic Action – Constant GO or Down & Out*

Paces, walks, rocks, swings, hums, claps, pats, rubs....
Frequently ignores people and small objects
Doesn't stay down long in any one place
Often not interested in/aware of food – significant weight loss expected at this level
Can grossly imitate big movements and actions
Generally enjoys rhythm and motion – music and dance
Doesn't use individual fingers or tools (more eating with hands)
Either moves toward people and activity (feels like a shadow) or leaves busy, noisy places (ghost)
Chewing and swallowing problems are common – soft, ground, or puree food may be needed
May not talk much at all, understands demonstration better than gestures or words

Pearl – *Profound Loss - Stuck in Glue – Immobile & Reflexive*

Generally bed or chair bound – can't move much on own
Often contracted with 'high tone' muscles - primitive reflexes reappear
Poor swallowing and eating
Still aware of movement and touch
Often sensitive to voice and noise - startles easily to sounds, touch, movement...
Difficulty with temperature regulation
Limited responsiveness at times
Moves face and lips a lot, may babble or repeatedly moan or yell
Give care in slow, rhythmic movements and use the flats of fingers and open palms
Keep your voice deep, slow, rhythmic and easy as you talk and give care

A Positive Physical Approach for Someone with Dementia

1. **Knock** on door or table - to get attention if the person is not looking at you & get permission to enter or approach
2. **Open palm near face and smile** – look friendly and give the person a visual cue – make eye contact
3. Call the person by **name** OR at least say **“Hi!”**
4. Move your hand out from an open hand near face to a greeting **handshake** position
5. **Approach the person from the front** – notice their reaction to your outstretched hand - start approaching or let the person come to you, if s/he likes to be in control
6. **Move slowly** – one step/second, stand tall, don't crouch down or lean in as you move toward the person
7. Move toward the right **side of the person** and offer your hand - give the person time to look at your hand and reach for it, if s/he is doing something else – offer, don't force
8. **Stand to the side** of the person at arm's length – respect personal space & be *supportive* not confrontational
9. **Shake hands** with the person – make eye contact while shaking
10. Slide your hand from a 'shake' position to **hand-under-hand** position – for safety, connection, and function
11. Give your name & greet – “I'm (name). It's good to see you!”
12. **Get to the person's level** to talk – sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
13. NOW, deliver your message...

Approaching When The Person is DISTRESSED!

TWO CHANGES –

1. *Look concerned* not too happy, if the person is upset
2. *Let the person move toward you, keeping your body turned sideways* (supportive – not confrontational)
3. After greeting... try one of *two* options...
 - a. “Sounds like you are (give an emotion or feeling that seems to be true)???”
 - b. Repeat the person's words to you... If s/he said, “Where's my mom?” you would say “You're looking for your mom (pause)... tell me about your mom...”
If the person said “I want to go home!”, you would say “You want to go home (pause)... Tell me about your home...”.

BASIC CARD CUES – WITH Dementia

- Knock – Announce self
- Greet & Smile
- Move Slowly – Hand offered in 'handshake' position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly -make a 'nice' comment or smile
- Give your message... simple, short, friendly



Communicating - Talking

First -

ALWAYS use the **positive physical approach!**

Then -

- Pay attention to the **THREE** ways you communicate

1 - How you speak

- **Tone** of voice (**friendly** not bossy or critical)
- **Pitch** of voice (**deep** is better)
- **Speed** of speech (**slow and easy** not pressured or fast)

2 - What you say

THREE basic reasons to talk to someone

1 - To get the person to **DO something (5 approaches to try)**

- 1 - give a short, direct message about what is happening
 - 2 - give simple choices about what the person can do
 - 3 - ask the person to help you do something
 - 4 - ask if the person will give it a try
 - 5 - break down the task - give it one step at a time
- ** only ask "Are you ready to..." If you are willing to come back later **

2 - Just to have a **friendly interaction - to talk to the person**

- ◆ go slow - Go with Flow
- ◆ acknowledge emotions - "sounds like..., seems like..., I can see you are..."
- ◆ use familiar words or phrases (what the person uses)
- ◆ know who the person has been as a person what s/he values
- ◆ use familiar objects, pictures, actions to help & direct
- ◆ be prepared to have the same conversation over & over
- ◆ look interested & friendly
- ◆ be prepared for some emotional outbursts
- ◆ DON'T argue... - BUT don't let the person get into dangerous situations

REMEMBER - the person is doing the BEST that s/he can
AND GO with the FLOW!

3 - Deal with the person's **distress or frustration/anger**

- ◆ Try to figure out what the person really **NEEDS or WANTS**
("It sounds like..." "It looks like..." "It seems like..." "You're feeling...")
- ◆ Use **empathy** not forced reality or lying

- ◆ Once the person is listening and responding to you **THEN** -
 - **Redirect** his attention and actions to something that is OK **OR**
 - **Distract** him with other things or activities you know he likes & values

Always BE CAREFUL about personal space and touch with the person especially when s/he is distressed or being forceful

3 - How you respond to the person

- ◆ use positive, friendly approval or praise (short, specific and sincere)
- ◆ offer your thanks and appreciation for his/her efforts
- ◆ laugh with him/her & appreciate attempts at humor & friendliness
- ◆ shake hands to start and end an interaction
- ◆ use touch - hugging, hand holding, comforting **only IF** the person wants it

If what you are doing is NOT working -

- **STOP!**
 - BACK OFF - give the person some space and time
 - Decide on what to do differently...
 - *Try Again!*

Key Points About 'Who' the person Is....

- preferred name
- introvert or extrovert
- a planner or a doer
- a follower or a leader
- a 'detail' or a 'big picture' person
- work history - favorite and most hated jobs or parts of jobs
- family relationships and history - feelings about various family members
- social history - memberships and relationships to friends and groups
- leisure background - favorite activities & beliefs about fun, games, & free time
- previous daily routines and schedules
- personal care habits and preferences
- religious and spiritual needs and beliefs
- values and interests
- favorite topics, foods, places
- favorite music and songs - dislike of music or songs
- hot buttons & stressors
- behavior under stress
- what things help with stress?
- handedness
- level of cognitive impairment
- types of help that are useful

Communication - When Words Don't Work Anymore...

Keys to Success:

- Watch movements & actions
- Watch facial expressions and eye movements
- Listen for changes in volume, frequency, and intensity of sounds or words
- Investigate & Check it out
- Meet the need

It's all about Meeting Needs...

- Physical needs
- Emotional needs

Probable Needs:

Physical

- Tired
- In pain or uncomfortable
- Thirsty or Hungry
- Need to pee or have a BM or already did & need help
- Too hot or too cold

Emotional

- Afraid
- Lonely
- Bored
- Angry
- Excited

What Can You Do?

- *Figure it out...Go thru the list*
- *Meet the need... Offer help that matches need*
- *Use visual cues more than verbal cues*
- *Use touch only after 'permission' is given*

Connect – Visually, Verbally, Tactilely

Protect Yourself & the Person – use Hand Under Hand & Supportive Stance techniques

Reflect – copy expression/tone, repeat some key words, move with the person

Engage – LISTEN with your head, your heart, and your body

Respond – try to meet the unmet needs, offer comfort and connection

***** IF IT DOESN'T seem to be working – STOP, BACK OFF – and then TRY AGAIN – changing something in your efforts (visually, verbally, or through touch/physical contact)*****

When Helping Physically to Do THINGS...

Remember to do things WITH the person, NOT TO the person!

Always CONNECT first

Visually
Verbally
Physically
Emotional
Spiritually

Take it slow – look for and wait for responses before moving on... Double check CUES!

Take a look around - Check out the environment or setting and set-up –

Is it clear what is supposed to happen?

Is it possible something is triggering the behavior or refusal?

Is it possible to create a stronger sense of privacy and competence?

Does the person feel OK, having you there?

Are you respecting intimate space & personal space?

If what you are trying is NOT working, STOP and BACK OFF!

Think about what might be getting in the way, change something, then try to re-approach

Make Sure – you are:

Limiting verbal information

Sending POSITIVE and FRIENDLY non-verbal cues

Taking your time to CONNECT

Letting the person know what you want – THINK about ONE step at a time

Show them what you want – model it, gesture through it, point to it...

Respecting personal & intimate space

ALWAYS, be willing to give up your agenda if you are having trouble getting the connection – you can always come back and try again, if they like you!

If it seems like they are getting upset with you...

Consider saying, “I’m sorry, I am bothering you, I didn’t mean to...”

Consider asking for a very ‘short’ commitment –

“Help me for 2 minutes & then I will leave”

Consider saying “Do you want to be alone?”

Stop talking or TRYING for a while and see what happens

Types of Help - Using Your Senses

Visual -



Written Information - Schedules and Notes

Key Word Signs - locators & identifiers

Objects in View - familiar items to stimulate task performance

Gestures - pointing and movements

Demonstration - provide someone to imitate

Auditory -

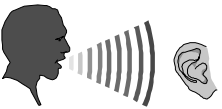
Talking and Telling - give information, ask questions, provide choices

Breaking it Down - Step-by-Step Task Instructions

Using Simple Words and Phrases - Verbal Cues

Name Calling - Auditory Attention

Positive Feedback - praise, "yes", encouragement



Tactile - Touch -

Greeting & Comforting - handshakes, hugs, 'hand-holding'

Touch for Attention during tasks

Tactile Guidance - lead through 'once' to get the feel

Hand-Under-Hand Guidance - palm to palm contact

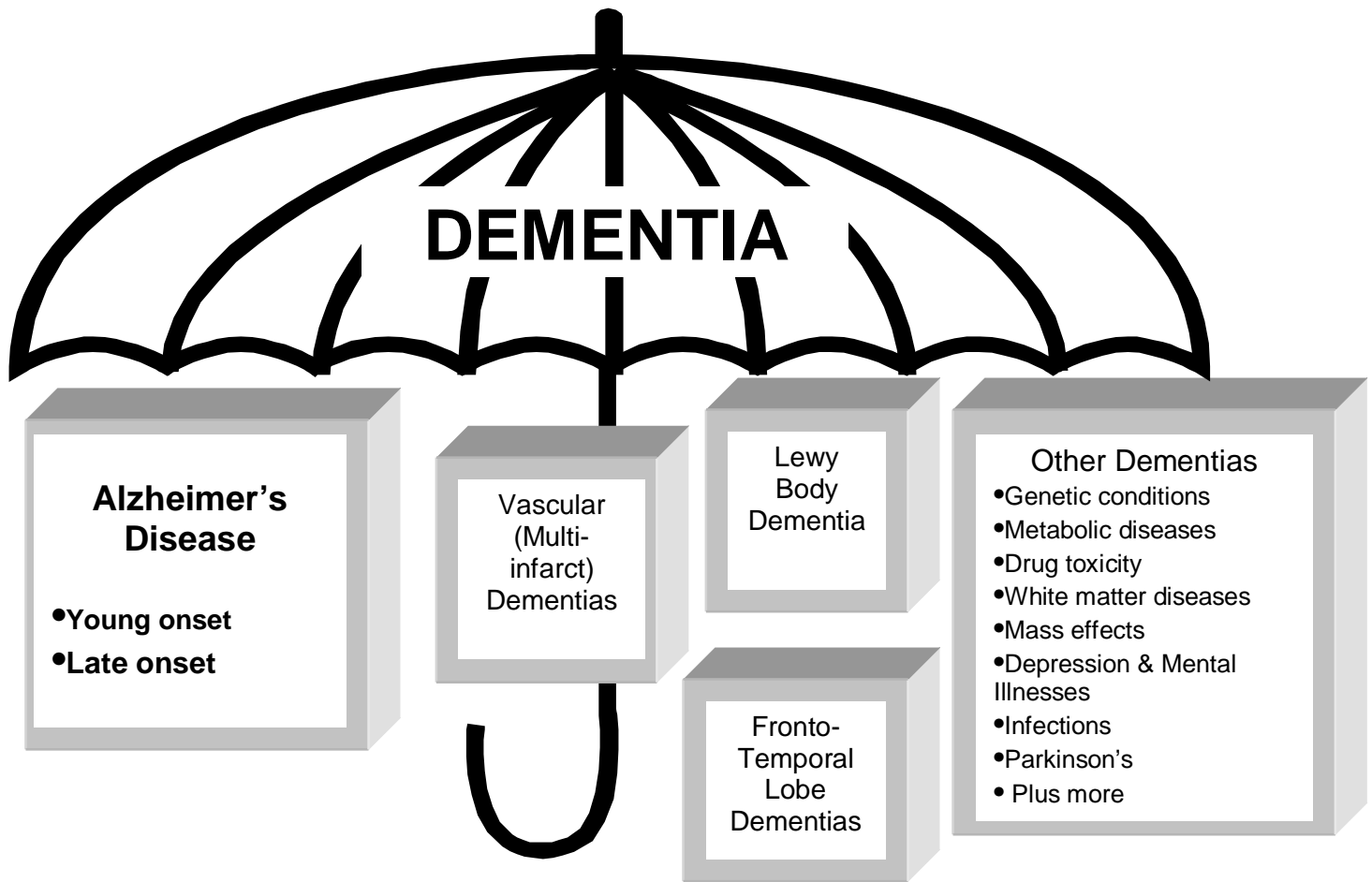
Hand-Under-Hand Assistance - physical help

Dependent Care - doing for & to the person



Personal History

Areas to Explore	What Did You Find Out?
Preferred Name	
Preferred Hand	
Living Situations & history (where are you from today & originally, who do & did you live with, what type places did you live in (house, apt, farm...))	
Marriage history & status (who's involved, has been involved, and how do you feel about them?)	
Family history & membership (who's who and how do you feel about them? Think about several generations....)	
Work history (what jobs have you had in your life? How did you feel about them? What are some jobs you would have loved to do, but never did?)	
Leisure history (what do and did you do for fun and in your spare time? How do you feel about 'having fun'? What would you like to do if you had the money? time? Skill?)	
Spiritual history (what religion do you and did you follow, how involved are you and were you, and how important is it to you? How do you feel about other religions?)	
Personal care practices & history (eating habits, sleeping habits, grooming & bathing habits...)	
Time Use History (schedules & routines.... When do you and would you like to do things?)	
Important Life Events (what are some things that were very important to or happened to you? Do others know about these events?)	
Hot Buttons (what are things/activities /topics/ actions that really tend to upset you?)	
Chill Pills (What helps you calm down, what do you do when you are upset?)	



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

- Frontal-Temporal**
- 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

Is this a Problem Behavior that NEEDS to be fixed?

Does the behavior put someone at RISK?

YES

NO

It's time to **PROBLEM-SOLVE!**

This is **not** really a **PROBLEM** behavior for the person with dementia. It may be irritating or embarrassing for the caregiver, but it is really a...
'SO WHAT' behavior

Learn to let it go!
Leave it alone!
Don't sweat the small stuff!

1st

Describe the behavior in detail---

- **Where** does it happen?
- **When** does it happen?
- **Who** is involved?
- **How** does it start? Stop?
- **What** is said? done?
- **What** makes it worse? better?

Then

Answer these questions---

- Could the level of dementia explain some of this behavior?
- Could how the person was approached or helped have some impact?
- Does the person have other medical or psychiatric conditions that might be active?
- Could personal history (work, leisure, family, religion, personality, routines...) play a role?
- Could the environment or cues in it be causing some of the trouble?
- Could the time of day or personal habits be a factor?

BRAINSTORM
with the Puzzle Pieces

Come up with a PLAN of ACTION!

- decide on **what** to do
- decide **who** will do what
- decide **how** to do it
- decide **when** to start it & when to look again
- set a **goal**
- **DO IT!**

Are things better?

NO

RETHINK & Problem solve again!

YES

CELEBRATE!

A Positive Physical Approach for Someone with Dementia

1. **Knock** on door or table - to get attention - signal your approach
2. **Stop moving** at the boundary between public & personal space – **6 ft out** - get permission to enter or approach
3. **Open hand motion near face and smile** – look friendly and give the person a visual cue – make eye contact – open hand near face – cues eyes to look there
4. Call the person by preferred **name** OR at least say “**Hi!**” – avoid endearments
5. Move your hand out from near your face to a greeting **handshake** position – make sure they notice you hand out to shake – then stand tall and move forward **SLOWLY**
6. Approach the person from the **front** – come in within 45 degrees of center - visual
7. **Move slowly** – one step/second, stand tall, don't crouch down or lean in as you move toward the person
8. Move toward the right **side of the person** and offer your hand - give the person time to look at your hand and reach for it, if s/he is doing something else – offer, don't force
9. Stand to the side of the person at arm's length – respect intimate space & be supportive not confrontational – but don't go too far back' – stay to the front - visual
10. **Shake hands** with the person – make eye contact while shaking
11. Slide your hand from a 'shake' position to **hand-under-hand** position – for safety, connection, and function
12. Give your name & greet – “I'm (name). It's good to see you!”
13. **Get to the person's level** to talk – sit, squat, or kneel if the person is seated and stand beside the person if s/he is standing
14. NOW, deliver your message...

Approaching When the Person is DISTRESSED! -Some CHANGES –

1. *Look concerned* not too happy, if the person is upset
2. *Let the person move toward you, keeping your body turned to the side* (supportive – not confrontational) –
3. *If the person is seated & you DON'T get permission to enter personal space – turn sideways & kneel at 6' out – offer greeting & handshake again – look for an OK to come into their personal space – it will usually come at this time (submissive posture)*
4. After greeting... try one of *two options*...
 - a. “Sounds like you are (give an emotion or feeling that seems to be true)???”
 - b. Repeat the person's words to you... If s/he said, “Where's my mom?” you would say “You're looking for your mom (pause)... tell me about your mom...” If the person said “I want to go home!”, you would say “You want to go home (pause)... Tell me about your home...”.

BASIC CARD CUES – WITH Dementia

- Knock – Announce self
- Pause at 6 ft
- Greet & Smile
- Move Slowly – Hand offered in 'handshake' position
- Move from the front to the side
- Greet with a handshake & your name
- Slide into hand-under-hand hold
- Get to the person's level
- Be friendly -make a 'nice' comment or smile
- Give your message... simple, short, friendly



Five Ways to Say I'm Sorry – With or Without Words

If it seems like they are getting upset with you...

- 1. “I’m Sorry. I was trying to help “ can add (“I didn’t mean to hurt you: or “I didn’t mean to startle you”**
- 2. “I’m sorry, I made you (identify the FEELING) ANGRY... SAD... FRUSTRATED... ANXIOUS... UPSET...”**
- 3. “I’m sorry, the way I acted/spoke to you/behaved made you feel LESS, STUPID, INCOMPETENT...” “ You are one of smartest/most competent people I know” “I’m sorry I treated like a child, I had no business doing that”**
- 4. “I’m sorry that happened! That Should not be happening...” (validate they have a right to feel the way they feel, think what they think – NO correcting)**
- 5. “I’m sorry this is HARD!” – show some emotion, use this when the person is clearly struggling and frustrated with themselves and their losses OR when you are really struggling with how to be helpful, make a connection, or figure out what they want/need.... Let them know you GET IT!**

'This Is ME' Sheet

(Add a current photo/head shot)

Preferred Name: _____

Language Skills: (native tongue) _____

Gem(s): _____

Hearing: Deaf HoH 1:1-OK Group-OK

Personality trait:

Comprehension: None 1-word Simple OK

Introvert (private, alone time, SPACE, quiet)

Speech: None Nonsense Echo Repeats Accurate

Extrovert (common areas, talking, close, touching)

Mixed _____

Overall Activity Preferences: Doer Talker Watcher

Sensory Preferences: (little/lot, same/different, details)

Sensory Dislikes: (speed, variety, types, specifics)

Sights

Sights

Sounds

Sounds

Touch/Physical contact

Touch/Physical contact

Movement

Movement

Smells

Smells

Tastes

Tastes

Productive – Work/Jobs – Valued Roles

History:

Current Possibilities:

Leisure – Play – Fun (Passive activities & Active activities)

History:

Current Possibilities:

Wellness – Self-care – Physical Fitness & Brain Fitness

History – Body Fitness:

Current Body Possibilities:

History – Brain Fitness:

Current Brain Possibilities:

Rest – Restorative – Re-energize – Spiritual

History:

Current Possibilities:

Major Life Events of Note: (positive or negative)

Favorites:

Major Dislikes:

animals

animals

plants/ flowers

plants/flowers

music

music

people or children or babies

people or children or babies

belongings or objects

belongings or objects

places/scenery/landmarks or pictures/art

places/scenery/landmarks or pictures/art