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
- Elopement/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

- 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 misunderstanding
- Getting confused about time or place – getting lost while driving, missing several appointments
- 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 from 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

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 Disease
- Early - Young Onset
- Normal Onset

Vascular Dementia (Multi-Infarct)

Fronto-Temporal Lobe Dementia

Other Dementia
- Genetic syndromes
- Metabolism
- HIV/AIDS
- Drugs/toxic exposure
- Mass effects
- Traumatic
- Other
- Secondary (HIV/AIDS, head injury)
- Depression
- Anxiety
- Substance abuse
- Hypothyroidism

Infections
- Bacteria, viruses
- Fungi

Parkinson's

White matter diseases

Mass effects

Depression

Other mental conditions

Infections – BBB cross

Fronto-Temporal Lobe Dementia
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 & syncopy
- 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

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

<table>
<thead>
<tr>
<th>Normal</th>
<th>Early Alzheimer’s</th>
<th>Late Alzheimer’s</th>
<th>Child</th>
</tr>
</thead>
<tbody>
<tr>
<td><img src="image1.png" alt="Normal Brain" /></td>
<td><img src="image2.png" alt="Early Alzheimer’s Brain" /></td>
<td><img src="image3.png" alt="Late Alzheimer’s Brain" /></td>
<td><img src="image4.png" alt="Child Brain" /></td>
</tr>
</tbody>
</table>

![Normal Brain](image5.png) ![Alzheimer’s Brain](image6.png)
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

Vision Center – BIG CHANGES
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 1\textsuperscript{st}? 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 comb 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 comb 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)
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

Sapphires - True Blue - Slower BUT Fine
Diamonds - Repeats & Routines, Cutting
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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

• IADLs
  – Money management
  – Transportation - Driving
  – Cooking
  – Home maintenance & safety
  – Caring for someone else
  – Pet maintenance
  – Med administration

• 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

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’
**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...

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**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**
The ability to understand what is being said...

The ability to use words and language...

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.

<table>
<thead>
<tr>
<th>Typically Lost – can’t use</th>
<th>Preserved – can or may use</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Memory skills</strong></td>
<td><strong>Memory skills</strong></td>
</tr>
<tr>
<td>- immediate recall</td>
<td>- long ago memories</td>
</tr>
<tr>
<td>- short term memory</td>
<td>- emotional memories</td>
</tr>
<tr>
<td>- clarity of time and place</td>
<td>- confabulation</td>
</tr>
<tr>
<td>- depth of categorical information</td>
<td>- procedural memories</td>
</tr>
<tr>
<td>- relationships &amp; specifics</td>
<td>- awareness of familiar versus unfamiliar</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Understanding skills</th>
<th>Understanding skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>- interpretation of abstract meaning</td>
<td>- 'gets' the concrete meaning</td>
</tr>
<tr>
<td>- early - misses ¼ words</td>
<td>- picks out familiar or meaningful words</td>
</tr>
<tr>
<td>- later – misses ½ words</td>
<td>- covers well</td>
</tr>
<tr>
<td>- subtle emotions, 'unspoken' agreements</td>
<td>- facial expressions that are consistent</td>
</tr>
<tr>
<td>- at the end – most words</td>
<td>with the message being sent</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Language use skills</th>
<th>Language use skills</th>
</tr>
</thead>
<tbody>
<tr>
<td>- specific word finding</td>
<td>- desire to communicate</td>
</tr>
<tr>
<td>- descriptive abilities</td>
<td>- ability to use hands or actions to describe</td>
</tr>
<tr>
<td>- reading for content</td>
<td>- reading aloud</td>
</tr>
<tr>
<td>- content of speech</td>
<td>- rhythm of speech</td>
</tr>
<tr>
<td>- spoken communication</td>
<td>- para-verbal communication (how you say it)</td>
</tr>
<tr>
<td>- words</td>
<td>- music and song</td>
</tr>
<tr>
<td>- meaningful ‘yes’ and ‘no’</td>
<td>- automatic speech</td>
</tr>
<tr>
<td>- socially acceptable expressions of emotion</td>
<td>- swearing, sex words, ‘socially unacceptable’ words</td>
</tr>
<tr>
<td>- verbal communication of needs and desires</td>
<td>- non-verbal communication of needs and desires</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th>Emotional &amp; Impulse control skills</th>
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</tr>
</thead>
<tbody>
<tr>
<td>- ability to ‘demand’ respect</td>
<td>- desire to be respected</td>
</tr>
<tr>
<td>- ability to limit or control emotions</td>
<td>- ability to feel emotions and have needs</td>
</tr>
<tr>
<td>- ability to control impulsive speech</td>
<td>- say what is on your mind – with errors</td>
</tr>
<tr>
<td>- ability to control impulsive actions</td>
<td>- do what you want to do</td>
</tr>
<tr>
<td>- don’t act out when ‘pushed’</td>
<td>- sometimes, feel badly after its done</td>
</tr>
<tr>
<td>- ability to keep private thoughts and and actions in private places</td>
<td>- sometimes, behaving differently in ‘public’ if cues are strong</td>
</tr>
</tbody>
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<table>
<thead>
<tr>
<th>Motor Skills &amp; Sensory Processing</th>
<th>Motor Skills &amp; Sensory Processing</th>
</tr>
</thead>
<tbody>
<tr>
<td>- at first very little as far as skills go</td>
<td>- the movement patterns for pieces of tasks</td>
</tr>
<tr>
<td>- later – initiation or getting started</td>
<td>- gross motor movements last longer than fine motor</td>
</tr>
<tr>
<td>- later – parts of tasks get left out/skipped</td>
<td>- can often do the mechanics – BUT not safely or well</td>
</tr>
<tr>
<td>- mis-interprets sensory information</td>
<td>- looks for stuff – seeks out things</td>
</tr>
<tr>
<td>- organized scanning is lost</td>
<td>- mouth (lips, tongue), fingers and palms, soles of feet, &amp; genitalia or ‘private body parts’</td>
</tr>
<tr>
<td>- visual field is restricted</td>
<td>- recognize faces, voices – familiar from not familiar</td>
</tr>
<tr>
<td>- may become hypersensitive OR hyposensitive to touch, sound, light...</td>
<td></td>
</tr>
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- 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.
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
   Emotionally
   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
<table>
<thead>
<tr>
<th>Areas to Explore</th>
<th>What Did You Find Out?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Preferred Name</td>
<td></td>
</tr>
<tr>
<td>Preferred Hand</td>
<td></td>
</tr>
<tr>
<td>Living Situations &amp; history</td>
<td></td>
</tr>
<tr>
<td>(where are you from today &amp; originally, who do &amp; did you live with, what type places did you live in (house, apt, farm…))</td>
<td></td>
</tr>
<tr>
<td>Marriage history &amp; status</td>
<td></td>
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<tr>
<td>(who’s involved, has been involved, and how do you feel about them?)</td>
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<tr>
<td>Family history &amp; membership</td>
<td></td>
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<tr>
<td>(who’s who and how do you feel about them? Think about several generations....)</td>
<td></td>
</tr>
<tr>
<td>Work history</td>
<td></td>
</tr>
<tr>
<td>(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? )</td>
<td></td>
</tr>
<tr>
<td>Leisure history</td>
<td></td>
</tr>
<tr>
<td>(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? )</td>
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</tr>
<tr>
<td>Spiritual history</td>
<td></td>
</tr>
<tr>
<td>(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?)</td>
<td></td>
</tr>
<tr>
<td>Personal care practices &amp; history</td>
<td></td>
</tr>
<tr>
<td>(eating habits, sleeping habits, grooming &amp; bathing habits…)</td>
<td></td>
</tr>
<tr>
<td>Time Use History</td>
<td></td>
</tr>
<tr>
<td>(schedules &amp; routines…. When do you and would you like to do things?)</td>
<td></td>
</tr>
<tr>
<td>Important Life Events</td>
<td></td>
</tr>
<tr>
<td>(what are some things that were very important to or happened to you? Do others know about these events?)</td>
<td></td>
</tr>
<tr>
<td>Hot Buttons</td>
<td></td>
</tr>
<tr>
<td>(what are things/activities /topics/actions that really tend to upset you?)</td>
<td></td>
</tr>
<tr>
<td>Chill Pills</td>
<td></td>
</tr>
<tr>
<td>(What helps you calm down, what do you do when you are upset?)</td>
<td></td>
</tr>
</tbody>
</table>
Alzheimer’s Disease
- Young onset
- Late onset

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

Other Dementias
- Genetic conditions
- Metabolic diseases
- Drug toxicity
- White matter diseases
- Mass effects
- Depression & Mental Illnesses
- Infections
- Parkinson’s
- Plus more

Fronto-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

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 (Multi-infarct) Dementias

Lewy Body Dementia

Fronto-Temporal Lobe Dementias

Other Dementias
- Young onset
- Late onset
- Vascular (Multi-infarct) Dementias
- Lewy Body Dementia
- Fronto-Temporal Lobe Dementias
- Other Dementias
  - Genetic conditions
  - Metabolic diseases
  - Drug toxicity
  - White matter diseases
  - Mass effects
  - Depression & Mental Illnesses
  - Infections
  - Parkinson’s
  - Plus more
Is this a Problem Behavior that NEEDS to be fixed?

It’s time to PROBLEM-SOLVE!

YES

Does the behavior put someone at RISK?

NO

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!

YES

It’s time to PROBLEM-SOLVE!

NO

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!

RETHINK & Problem solve again!

Are things better?

YES

CELEBRATE!

NO
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
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!
**Preferred Name:** ____________________________  **Language Skills:** (native tongue) ____________________________

**Gem(s):** ____________________________  **Hearing:** Deaf HoH 1:1-OK Group-OK

**Personality trait:**
- __ Introvert  (private, alone time, SPACE, quiet)
- __ Extrovert  (common areas, talking, close, touching)
- __ Mixed

**Overall Activity Preferences:** ___ Doer ___ Talker ___ Watcher

**Sensory Preferences:** (little/lot, same/different, details)
- Sights
- Sounds
- Touch/Physical contact
- Movement
- Smells
- Tastes

**Sensory Dislikes:** (speed, variety, types, specifics)
- Sights
- Sounds
- Touch/Physical contact
- Movement
- Smells
- 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:**
- ___ animals
- ___ plants/flowers
- ___ music
- ___ people or children or babies
- ___ belongings or objects
- ___ places/scenery/landmarks or pictures/art

**Major Dislikes:**
- ___ animals
- ___ plants/flowers
- ___ music
- ___ people or children or babies
- ___ belongings or objects
- ___ places/scenery/landmarks or pictures/art