Coping with Challenging Situations in Dementia Care

What Works Better?
Seeing It From Their Side

REALIZE …

• It Takes TWO to Tango
...
  or two to tangle…

Being ‘right’ doesn’t necessarily translate into a good outcome for both of you
It’s the relationship that is MOST critical

NOT the outcome of any 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**.

What **behaviors** are we talking about?

List **BEHAVIORS** you would consider ‘Challenging’
My Examples

- No F PoA or HC PoA –
- Going to MD problems
- ‘Losing’ Important Things
- Getting Lost – time, place, situation
- Unsafe task performance
- Refusing help & care
- ’Bad mouthing’ you to others
- Making up stories – confabulation
- 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
- Contractures & immobility
- Infections & pneumonias
- Problems w/ eating or drinking

How Do Our Lists Compare?

Match?
Mis-Match?
Why?

What If We Categorize...

- Annoying – not a big issue, but wearing over time – takes time away from other responsibilities
- Risky – could cause harm to self or others, not always dangerous, but can be unpredictable as to when it will be ‘serious’
- Dangerous – puts the person, the care provider, other people, or equipment in jeopardy or at immediate risk for injury
We tend to *immediately REACT* Dangerous Behaviors

Try to ‘stop’ the Risky Behaviors when we see them

Expect or ‘put up with’ the Annoying Behaviors... until...

Rethink ‘Challenging Behaviors’ REFRAiME as *Unmet Needs* OR *Efforts to Meet Needs*

Top TEN!

**Unmet Physical Needs**
- Hungry or Thirsty
- Tired or Over-energized
- Elimination – need to/did
- Discomfort – not right for me
  - Temperature, texture, fit, senses
- IN PAIN!!!
  - Joints: skeleton
  - Inside systems (head, chest, gut, output)
  - Creases or folds & skin
  - Surfaces that contact other surfaces

**Unmet Emotional Needs**
- Angry
- Sad
- Lonely
- Scared
- BORED
What Makes ‘BEHAVIORS’ Happen?

• SIX pieces...
  – The type & level of cognitive impairment ... NOW
  – The person & who they have been
    • Personality, preferences & history
  – Other medical conditions & sensory status
  – The environment – setting, sound, sights
  – The whole day... how things fit together
  – People - How the helper helps -
    • Approach, behaviors, words, actions, & reactions

What is Dementia?...

It is BOTH
• a chemical change in the brain
AND
• a structural change in the brain

• So...
  Sometimes they can & sometimes they can’t
Four Truths About Dementia

- At least 2 parts of the brain are dying
  - One related to memory & the one other
- It is chronic – can’t be fixed
- It is progressive – it gets worse
- It is terminal – it will kill, eventually

PET and Aging

PET Scans of 20-Year-Old Brain and 80-Year-Old Brain

ADEAR, 2003

Learning How to Communicate When Dementia is in the Picture

How You Do What You Do Matters!

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Communicating Using ALL Five Senses and Connectors

Understanding the world – FIVE Senses
- 1st – what you see
- 2nd – what you hear
- 3rd – what you feel/touch
- 4th – what you smell
- 5th – what you taste

Getting Info In – FIVE Senses
- 1st – Vision
- 2nd – Hearing
- 3rd – Touch
  - temperature
  - texture
  - pressure
  - movement
- 4th – Smells
- 5th – Tastes
Giving Information

- 1st – Show
- 2nd – Tell
- 3rd – Touch
- 4th – Scents & Aromas
- 5th – Tastes

Connect

- 1st – let them see you – use props & demo
- 2nd – use a FEW words – match to ‘show’
- 3rd – offer friendly touch then guide
- 4th – match then guide emotions to safety
- 5th – Know the person & use preferred name

PET and Aging

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

ADEAR, 2003
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>
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Brain atrophy

- the brain actually shrinks
- cells wither then die
- abilities are lost
- with Alzheimer’s area of loss are fairly predictable
- ... as is the progression
- BUT the experience is individual...
**Memory Loss**

- **Losses**
  - Immediate recall
  - Attention to selected info
  - Recent events
  - Relationships
- **Preserved abilities**
  - Long ago memories
  - Confabulation!
  - Emotional memories
  - Motor memories
Hearing Sound – Not Changed

Understanding

- **Losses**
  - Can’t interpret words
  - Misses some words
  - Gets off target

- **Preserved abilities**
  - Can get facial expression
  - Hears tone of voice
  - Can get some non-verbals
  - Learns how to cover

Auditory - Verbal Cues

Keep it simple
Directed
Matched to visual cues
Sensory Changes

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

Self-Care Changes

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

- Losses
  - Can’t find the right words
  - Word Salad
  - Vague language
  - Single phrases
  - Sounds & vocalizing
  - Can’t make needs known

- Preserved abilities
  - singing
  - automatic speech
  - Swearing/sex words/forbidden words

Tactile – Touch Cues

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

Hand-Under-Hand Assistance
Executive Control Center
Emotions
Behavior
Judgment
Reasoning

Impulse & Emotional Control

• Losses
  – becomes labile & extreme
  – think it - say it
  – want it - do it
  – see it - use it

• Preserved
  – desire to be respected
  – desire to be in control
  – regret after action
Vision
- Losses
  - Edges of vision – peripheral field
  - Depth perception
  - Object recognition
  - Linked to purpose
  - Slower to process – scanning & shifting focus
- Preserved
  - "see" things in middle field
  - Looking at… curious

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

Five Skill Areas
- Getting Connected
- Ways of Cueing & Helping
- Hand-under-hand Assistance
- Progression of Dementia
- Time Out Signal
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

Getting Connected

Say Something Nice
Form a Relationship FIRST!

Getting Connected

• Do Introductions
  – Give your name … and you are…
• Give a compliment
  – beauty, strength, brains
• Share something…
  – “I’m from ____ and you are from….?”
• Make a positive observation
  – “those are beautiful flowers/children…”
• Find out about the person
Ways of Cueing and Helping
Visual Cues - Show
Verbal Cues - Tell
Tactile Cues - Touch

How you help...
- Sight or Visual cues
- Verbal or Auditory cues
- Touch or Tactile cues

How Do You Get Information from Residents 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

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Progression of Dementia
What Level Is the Person At?

Stages – in a positive way

GEMS a positive approach...
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
Positron Emission Tomography (PET)
Alzheimer’s Disease Progression vs. Normal Brains

Normal  Early Alzheimer’s  Late Alzheimer’s  Child

G. Small, UCLA School of Medicine
Three Reasons to Communicate

• Get something DONE
• Have a conversation
• Help with distress

Communication – Getting the person to DO Something

Form a relationship FIRST
Then Work on Task Attempt

Connect

• 1st – Visually
• 2nd – Verbally
• 3rd – Physically
• 4th – Emotionally
• 5th – Individually
To Connect

Use the Positive Physical Approach

Your Approach

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Hand-under-Hand
protecs aging, thin, fragile, forearm skin
High Risk

Hand-Under-Hand Position

THEN – Connect Emotionally

• Make a connection
  – Offer your name – “I’m (NAME) and you are...”
  – Offer a shared background – “I’m from (place) and you’re from...”
  – Offer a positive personal comment – “You look great in that ...” or “I love that color on you...”
THEN – 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

ALWAYS REMEMBER – V-V-T

• Always use this sequence to CUE:
  – VISUAL
  – VERBAL
  – TOUCH
• Make cues ‘bigger’ and SLOWER as the dementia progresses – pause longer
• GIVE FEEDBACK CUES – positive!!!!

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…
• Acknowledge the response/react to your info…
• LIMIT your words – Keep it SIMPLE
• WAIT!!!!
When Words Don’t Work Well...

- Hand-under-Hand
  - Uses established nerve pathways
  - Allows the person to feel in control
  - Connects you to the person
  - Allows you to DO with not to
  - Gives you advance notice of ‘possible problems’
  - Connects eye-hand skills
  - Use the dominant side of the person

Use of Hand Under Hand

- Connecting – comforting and directing gaze
- Guiding and helping with movement
- Getting eye contact and attention
- Providing help with fine motor
- Offering a sense of control, even when you are doing almost everything

Use Supportive Communication

- Repeat a few of their WORDS with a ? at the end
- LISTEN...
- Then –
  - Offer EMPATHY
    - “Sounds like...”
    - “Seems like...”
    - “Looks like...”
- LISTEN...
- AVOID Confrontational QUESTIONS...
- Use just a FEW words
- Go SLOW
- Use EXAMPLES...
- Fill in the BLANK...
- LISTEN!!!
More Supportive Communication...

• Validate emotions
  – EARLY – “It’s really (label emotion) to have this happen” or “I’m sorry this is happening to you”
  – MIDWAY – repeat their words (with emotion)
    • LISTEN for added INFO, IDEAS, THOUGHTS
    • EXPLORE the new info BY WATCHING & LISTENING
  – LATE – CHECK OUT the WHOLE Body –
    • Face, posture, movement, gestures, touching, looking
    • Look for NEED under the words or actions

Once Connected & Communicating...

• Move FORWARD
  – ADD New Words...
  – Move to a New Place – Location
  – Add a NEW Activity
• EARLY – Redirection
  – Same subject
  – Different focus
• LATER – Distraction
  – Different subject
  – Unrelated BUT enjoyed

For ALL Communication

• If what you are trying is NOT working...
• STOP
• Back off
• THINK IT THROUGH... THEN
• Re-approach –
• Try something slightly different
Five Ways to Say “I Am Sorry!”

• “I’m sorry, I was trying to help”
  – For movement - add: “I didn’t mean to hurt you”
• “I’m sorry I made you feel(emotion) angry, irritated, frustrated, sad, isolated....”
• “I’m sorry I made you feel (intellectual capacity or relationship unequal) like a child, stupid, like an idiot...”
• “I’m sorry that happened (their perspective)
• “I’m sorry, this is HARD!” (for both of you)

Dementia can be treated

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

What Do You THINK About Challenging Behaviors Now?
What Can You Choose to DO?