Challenging Behaviors In Dementia Care

What Causes Distress or Resistance?

Mismatch between:
- What we expect versus what actually happens
- What we can do versus what is needed
- What was versus what is
- What we want versus what we get
- What we want versus what the other wants
- Who we are with versus who we want to be with
- Where we are versus where we want to be
- Who we are versus who we want to be

Resisting Resistance Just Increases Resistance!

If something isn’t working, Stop and Back Off!
Think about it
Try again, but change something!
Example of Challenges:

- No financial or health care POA
- Losing important things
- Getting lost
- Unsafe task performance
- Repeated calls and contacts
- Refusing
- ‘Bad mouthing’ you to others
- Making up stories
- Resisting care
- Swearing and cursing
- Making 911 calls
- Mixing day and night
- Shadowing
- Eloping or wandering
- No solid sleep time
- Getting ‘into’ things
- Threatening caregivers
- Undressing
- Being rude
- Feeling ‘sick’
- Striking out at others
- Falls and injuries
- Infections and pneumonias
- Seeing things and people
- Not eating or drinking
- Contractures and immobility

What Happens?

Traditionally:
- We wait till it gets dangerous or at least risky
- We blame
- We ‘knee-jerk’ react
- We treat the immediate
- We become ‘parental’
- We become judges
- We give up
- We go through the motions
- We go to medications first

Non-Traditionally:
- Adopt a “so what?” mindset for ‘annoying’ behaviors
- Become a detective
- Get everyone involved, early and often
- Re-check and monitor
- Change what is easiest first
- Change what can be controlled
- Celebrate all improvements
- Start by changing OURSELVES

So What Can You Do????

Six Pieces of the Puzzle:
1. Personal history and preferences
2. Level and type of dementia
3. Other health conditions and sensory losses
4. Environmental conditions
5. Care partner approach and behaviors
6. The day and how it all fits together

What Can You Control or Not Control?

CONTROL:
- The environment: setting, sound, sights
- The day and how things fit together
- How you choose to help

NOT CONTROL:
- The person and who they have been: personality, preferences, history
- The type and level of dementia now
- Other medical conditions, sensory status, and what the medications do to/for the person

The First Piece of the Puzzle:

The person and who they have been: personality, preferences and history
Knowing the Person:
- History
- Values and beliefs
- Habits and routines
- Personality and stress behaviors
- Work and family history
- Leisure and spiritual history
- ‘Hot buttons’ and comforts

Some ‘stuff’ we think that people do on purpose is really just who they are.

Lifelong Personality Traits and Preferences Matter!
We are more of who we have always been, Unless We have always been covering up who we really are and we decide to ‘let go’ Or Dementia robs us of our ability to be the way we want to be Or Dementia causes us forget how we are ‘supposed to be’ and lets us be ‘free’

Personal Preferences Matter:
- We like what we like!
- With dementia, the ‘likes’ can change
- The challenge is to honor what is important but change what is needed
- Our willingness to meet the person’s changing needs is essential
- Changes are made harder by our sense of loss and grief

Some Personal Preferences:
- Appearance
- Behaviors
- Language
- Daily Routines
- Foods and Drinks
- Music
- Touch, Textures, Noise, Space
- Worship and Spiritual practices

Personality Traits:
- Introvert - Extrovert
- Lots of Details - Big Picture only
- Logical - Emotional
- Planning Ahead - Being in the Moment
Which is Best?
There is no best or better, just different!

The Second Piece of the Puzzle:
The Level and Type of Dementia

So, 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, eventually
- It changes everything over time
- It is not something the person can control
- It is not always the same for every person
- It is not a mental illness
- It is real
- It is hard at times

What is Dementia?
It is BOTH
a chemical change in the brain
AND
a structural change in the brain
So...
Sometimes they can and sometimes they can’t

Four Truths About Dementia:
1. At least 2 parts of the brain are dying— one related to memory and another part
2. It is chronic – can’t be fixed
3. It is progressive – it gets worse
4. It is terminal – it will kill, eventually

Brain Failure
The person’s brain is dying
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.

Learning and Memory Center: Hippocampus: BIG CHANGE

Understanding Language – Big Change

Hearing Sound – Not Changed

Sensory Strip
Motor Strip
White Matter Connections: Big Changes!
Automatic Speech Rhythm – Music Expletives: Preserved
Formal Speech and Language Center: Huge Changes!
Executive Control Center: Emotions Behavior Judgment Reasoning

Vision Center – BIG CHANGES

Dementia does not equal Alzheimer’s does not equal Memory Problems

Alzheimer’s:
- New information lost
- Recent memory worse
- Problems finding words
- Misspeaks
- More impulsive or indecisive
- Gets lost
- Notice changes over 6 months – 1 year

Vascular Dementia:
- Sudden changes
- Picture varies by person
- Can have good and bad days
- Judgment and behavior ‘not the same’
- Spotty losses
- Emotional and energy shifts
- 3-30 year duration

Alzheimer’s Disease
- Young Onset
- Late Life Onset

Vascular Dementia

Fronto-Temporal Dementia

Lewy Body Dementia

Other Dementias
- Cerebral syndromes
- Metabolic
- ETOM related
- Drug/Toxin exposure
- White matter diseases
- Depression/Anxiety or other mental conditions
- Infections – BBB cross

Parkinson’s

Dementia does not equal Alzheimer’s does not equal Memory Problems
Lewy Body Dementia:
- Movement problems, falls
- Visual hallucinations
- Fine motor problems: hands, swallowing
- Episodes of rigidity and syncopy
- Nightmares or insomnia
- Fluctuations in abilities
- Drug responses can be extreme and strange

Fronto-Temporal Dementias:
- Many types
  - Frontal: impulse and behavior control loss
    - Says unexpected, rude, mean, odd things to others
    - Disinhibited about food, drink, sex, emotions, actions
    - Becomes ‘stuck’ or obsessed about ‘things’
  - Temporal: language loss
    - Can’t speak or get words out
    - Can’t understand what is said, uses nonsense words

Progression of Dementia: The GEMS®

Sapphires:
- Us on a good day
- Clear and true to ourselves
- May feel ‘blue’ over changes
- Can typically choose our behavior
- May have other health issues that affect behaviors
- Recognize life experiences, achievements and values
- Can follow written info and hold onto it

Diamonds:
- Sharp, hard, rigid, inflexible, can cut
- Many facets, still often clear, can really shine
- Are usually either Joiners or Loners
- Can complete personal care in familiar place
- Usually can follow simple prompted schedules
- Misplace things and can’t find them
- Resent takeover or bossiness
- Notice other people’s misbehavior and mistakes
- Vary in lack of self-awareness
- Use old routines and habits
- Control important roles and territories, use refusals

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Why Use GEMS® States?
- Uses familiar concepts to talk about a difficult subject
- Focuses on what is valued rather than on a number or amount of ‘decline’
- Like people, gems are precious and unique, with common characteristics
- Allow to us to get beyond the words ‘dementia’ and ‘Alzheimer’s’
- Opens the door to talking about changes
- Allow us to speak in a “code” to protect dignity
Emeralds:
- Changing color
- Not as clear or sharp, more vague
- On the go, need to ‘do’
- Flaws may be hidden
- Time traveling is common
- Are usually Doers or Supervisors
- Do what is seen, but miss what is not seen
- Must be in control, but not able to do it correctly
- Do tasks over and over, or not at all

Ambers:
- Amber Alert - Caution!
- Caught in a moment
- All about sensation and sensory tolerance, easily over or under stimulated
- May be private and quiet or public and noisy
- No safety awareness
- Ego-centric
- LOTS of touching, handling, tasting, mouthing, manipulating
- Explorers, get into things, invade others’ space
- Do what they like and avoid what they do not

Rubies:
- Hidden depths
- Major loss of fine motor finger and mouth skills, but can do gross motor skills like walking, rolling, rocking
- Comprehension and speech halted
- Wake-sleep patterns very disturbed
- Balance, coordination, and movement losses
- Eating and drinking patterns may change
- Tends toward movement unless asleep
- Follows gross demonstration and big gestures
- Limited visual awareness
- Major sensory changes

Pearls:
- Hidden in a shell: still, quiet, easily lost
- Beautiful and layered
- Spends much time asleep or unaware
- Unable to move, bed or chair bound, frequently fall forward or to side
- May cry out or mumble often, increases vocalizations with distress
- Can be difficult to calm, hard to connect
- Knows familiar from unfamiliar
- Primitive reflexes
- The end of the journey is near, multiple systems are failing
- Connections between the physical and sensory world are less strong but we are often the bridge

The Third Piece of the Puzzle:
- Other medical conditions
- Psychological or psychiatric conditions
- Sensory status: vision, hearing, sense of touch, balance, smell, taste

Health and Illness:
- Mobility problems?
- Pain?
- Sensory problems?
- Mental health issues?
- Other diagnoses of importance?
What Else Could Be Going On?
- Another medical condition
- Medication side-effect
- Hearing loss or vision loss
- Depression/anxiety
- Acute illness
- Delirium
- Severe but unrecognized pain
- Other things

Drugs That Can Affect Cognition in Elders:
- Anti-arrhythmic agents
- Antibiotics
- Antihistamines - decongestants
- Tricyclic antidepressants
- Anti-hypertensives
- Anti-cholinergic agents
- Anti-convulsants
- Anti-emetics

Histamine receptor blockers
Immunosuppressants
Muscle relaxants
Narcotic analgesics
Sedative hypnotics
Anti-Parkinsonian agents

The Fourth Piece of the Puzzle:
The Environment:
  Physical
  Sensory
  Social

Supportive Environments:
Include Two Factors:
- What you like
- What’s good for you

Supportive Environments: The 3 Positive P’s
1. Physical Environment
2. People: the ways they act and respond
3. Programming
Find a balance, not too much or too little

The Fifth Piece of the Puzzle:
People and Their Behaviors
- Care Partners
- Family Members
- Friends
- You!
What Shouldn’t We Do?
- Argue
- Make up stuff that is not true
- Ignore problem behaviors
- Try a possible solution only once
- Give up
- Let them do whatever they want to
- Force them to do things

So What Should We Do?
Remember who has the healthy brain!

How Can We Help Better?
It all starts with your approach!
Be a Care Partner, not a Care Giver!

Key Care Partner Skills:
- Greet before you treat
- Build a ‘team’
- Give cues in a specific sequence
- Respect space and the person
- Wait for a response before going on
- Do one thing at a time
- Stop and back off if it isn’t working
- Try something different as you approach

Positive Physical Approach™
- Pause at edge of public space (6 feet)
- Greet with your open hand next to your face, smile
- Call the person by name, if possible
- Move your hand into handshake position
- Approach slowly and within visual range
- Move from a handshake to Hand-under-Hand®
- Shift into a Supportive Stance alongside them
- Get low by standing or kneeling, but don’t lean in
- Make a connection and wait for their response

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 and short information
- Offer concrete choices
- Ask for the person for their help
- Ask the person to try
- Break the task down to single steps at a time

Give Simple Information:
- Use a Visual Cue (gesture/point) combined with a Verbal Cue:
  - “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/reaction to your information
- Limit your words and keep it simple
- WAIT!!!!

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 that happened, it shouldn’t have
- I’m sorry, this is HARD!

Examples of Meaningful Activities:
- Productive Activities: sense of value and purpose
- Leisure Activities: having fun and interacting
- Self-Care and Wellness: personal care of body & brain
- Restorative Activities: re-energize and restore spirit
Productive Activities:

- Helping another person
- Helping staff
- Completing community tasks
- Making something
- Sorting things
- Fixing things
- Building things
- Organizing things
- Caring for things
- Counting things
- Folding things
- Marking things
- Cleaning things
- Taking things apart
- Moving things
- Cooking/baking
- Setting up or breaking down
- Other ideas

Leisure Activities:

Active:
- Socials
- Sports
- Games
- Dancing
- Singing
- Visiting
- Hobbies
- Doing, Talking, Looking

Passive:
- Entertainers
- Sport program/event
- Presenters
- Lobby sitting
- TV programs: watched
- Activity watchers
- Being done to

Self-Care and Wellness Activities:

Cognitive:
- Table top tasks:
  - Matching, sorting, organizing, playing
- Table top games:
  - Cards, board games, puzzles
- Group games:
  - Categories, crosswords, word play, old memories

Physical:
- Exercise
- Walking
- Strengthening tasks
- Coordination tasks
- Balance tasks
- Flexibility tasks
- Aerobic tasks
- Personal care tasks

Rest and Restorative Activities:

- Sleep, naps
- Listen to quiet music with lights dimmed
- Look at the newspaper
- Look at a calm video on TV screen
- Rock in a chair
- Swing in a porch swing
- Walk outside
- Listen to reading from a book of faith
- Listen to poetry or stories
- Listen to or attend a worship service
- Stroke a pet or animal
- Stroke fabric
- Get a hand or shoulder massage
- Get a foot soak and rub
- Listen to wind chimes
- Aromatherapy

Teepa’s Rules:

- Music at least TWICE a DAY
- Something productive for each Emerald resident
- Play with people, but keep it adult, watch for cues
- Smooth out transitions
- If they can do something, support their doing, don’t do to them or for them
- Encourage helping and ALWAYS say THANK YOU
- Respect space preferences: introverts/extroverts
- Match sensory experience to preferences: sight, sound, smell, touch, taste

Now that you are aware of the Six Pieces of the Puzzle, reframe ‘problem behaviors’ as ‘unmet needs’

Get interested, excited, and be challenged!
Top Ten Unmet Needs:

**Unmet Physical Needs:**
- Hungry or thirsty
- Tired or over-energized
- Elimination: need to/did
- Temperature: too hot/cold
- Pain:
  - Joints - skeleton
  - Inside systems (head, chest, gut, output)
  - Creases or folds of skin
  - Surfaces that contact other surfaces

**Unmet Emotional Needs:**
- Angry
- Sad
- Lonely
- Scared
- Bored

Describe the Behavior:

- If possible, get another person to watch or consider recording to investigate
- Use objective language to describe the ‘behavior’
- Investigate what is going on when the ‘behavior’ is NOT happening
- Check it out from all perspectives

Investigate Carefully!

From Microscope to Telescope:
- Use a sensory approach: look, listen, feel, smell, taste, move
- Check out the environment
- Look at public, personal, intimate space issues
- Get in their ‘shoes’ and position
- Pay attention to cues
- Look at timing, sequencing, and responses

Build a Team, Don’t be a Lone Ranger!

Why Do You Need Others?

- Life happens 24/7
- Six Pieces make it complicated and multi-factorial
- The Six Pieces affect everyone, including you
- Each person will have a different perspective and information
- To optimize positive outcomes, it is best to all:
  - Have a common goal and game plan
  - Move in a planned, consistent direction
  - Check in regularly
  - Make adjustments as needed
  - Celebrate the “ah-ha” moments, share the “uh-ohs!”

Believe:

People with dementia are doing the best they can!
What you leave behind is not what is engraved in stone monuments, but what is woven into the lives of others.

-Pericles