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Coping with Challenging Situations in Dementia Care

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Describe This Object to Your Partner without Naming It



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Describe This Object to Your Partner without Naming It



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Now describe this, without naming the items or using specific numbers



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Example of Challenges:

- | | |
|-----------------------------------|-----------------------------|
| Issues with financial or HC POA | Eloping or wandering |
| Belongings being stolen or lost | Issues with sleep time |
| Getting lost or leaving places | Getting 'into' things |
| Unsafe task performance | Threatening caregivers |
| Repeated calls and contacts | Dressing-bathing issues |
| Refusing/resisting support/care | Being rude - interrupting |
| 'Bad mouthing' you to others | Feeling 'sick' - not doing |
| Confabulation- telling stories | Striking out at others |
| Lack of or variable awareness | Apathy - nothing is good |
| Swearing, racial slurs, ugly talk | Falls and injuries |
| Making 911 calls | Infections and pneumonias |
| Mixing day and night | Seeing things and people |
| Shadowing | Not eating or drinking |
| Going into others' spaces | Over-eating - glucose |
| Drug or alcohol misuse issues | Contractures and immobility |
| Bathroom & hygiene issues | Conflicts among carers |
| Intimacy/physical touching issues | |

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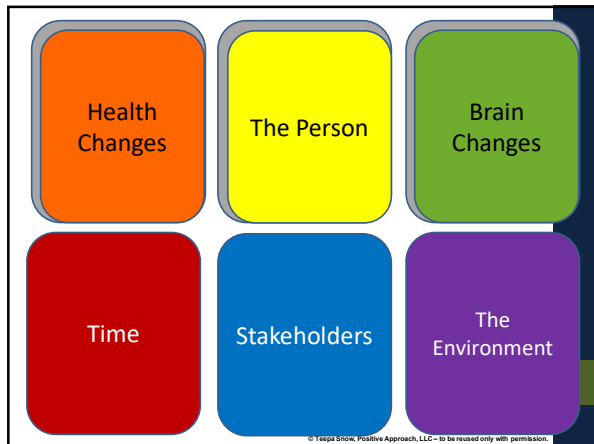
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So What Can You Do? Six Pieces of the Puzzle:

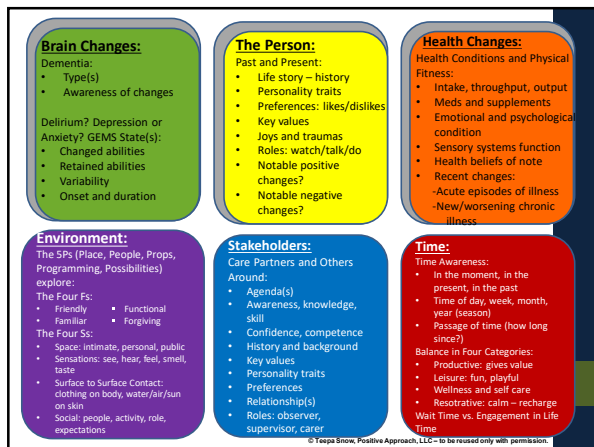
1. The Person
2. Brain Changes
3. Health Changes
4. Stakeholders
5. Environment
6. Time Use - Balance

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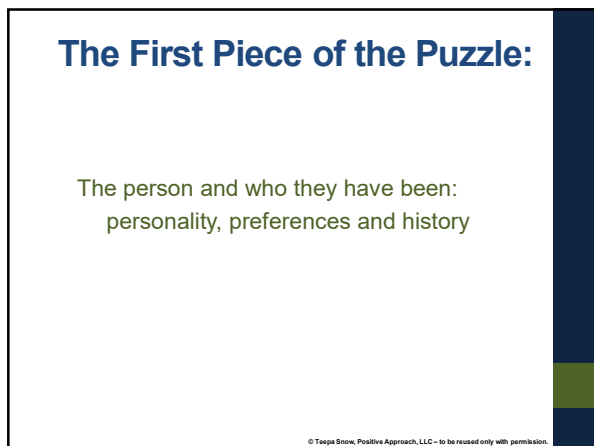
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Knowing the Person:

- History
- Values and beliefs
- Habits and routines
- Personality and stress behaviors
- Work and family history
- Leisure and spiritual history
- 'Hot buttons' and comforts
- Traumas – possible triggers for distress

Some 'stuff' we think that people do on purpose is really just who they are

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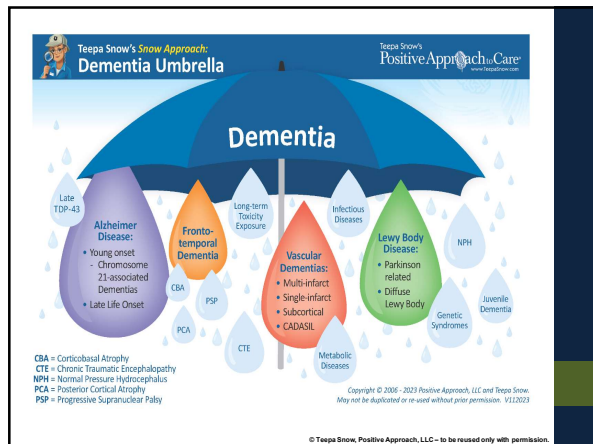
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The Second Piece of the Puzzle:

- Type(s) of dementia involved
- Other possible causes for brain changes
 - Anxiety
 - Depression
 - Delirium
- Awareness of the changes
- GEMS® State(s)

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Diamond State:




- 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
- Misplaces things and can't find them
- Resents takeover or bossiness
- Notices 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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Emerald State:




- 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

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Amber State:



- 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
- Egocentric
- Lots of touching, handling, tasting, mouthing, manipulating
- Explorers, get into things, invade space of others
- Do what they like and avoid what they do not like

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Ruby State:



- 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 for actions
- Limited visual awareness
- Major sensory changes

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Pearl State:



- 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 failing
- Connections between the physical and sensory world are less strong but we are often the bridge

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The Third Piece of the Puzzle:

Other medical conditions
Psychological or psychiatric conditions
Sensory status: vision, hearing, sense of touch, balance, smell, taste
Medications
Treatments



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The Fourth Piece of the Puzzle:

People and Their Behaviors

- Care Partners
- Family Members
- Friends
- You!

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Examples of Care Partner Skills:

- **Positive Physical Approach™**
- **Hand-under-Hand®**
- **Visual-Verbal-Touch Cues**
- **Positive Action Starters**

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Moving into Person Centered Care with Brain Change


Neglect	Care	Abuse
<p>Focused on:</p> <ul style="list-style-type: none"> You Rule following Right to refuse Not having time or knowing how to negotiate Unaware of language changes, only using words to communicate Assuming the person understands what I say Company/supervisor said not to do it if the person refuses <p>Success = Document the refusal and move on to the next task/person</p> <p>Failure = Families or regulators are not satisfied</p>	<p>Focused on:</p> <ul style="list-style-type: none"> Us Person living with brain change's comfort Using time to connect and determine what will work and what is not okay Using multi-modal cues to connect and communicate Right to informed consent Guiding/supporting to see what is possible at the time Only doing what is within the boundaries of what the person can tolerate <p>Success = We are both okay with what we do</p> <p>Failure = I could not figure out how to connect or communicate - no relationship and no care</p>	<p>Focused on:</p> <ul style="list-style-type: none"> Me Task completion Not negotiating Unaware of language changes, only using words to communicate Believing the person doesn't understand what I believe needs to be done based on my training and experience Company/supervisor said to get the task done <p>Success = Document completed tasks, behaviors, or injuries</p> <p>Failure = I couldn't get the task done or I had to go back later</p>

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To Connect, Use the 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® position
- Shift into a Supportive Stance on their side
- Get low by standing or kneeling, but don't lean in
- Make a connection and wait for their response



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Hand-under-Hand® Support:



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PIPES

- Prepare:** think it through, rehearse
- Initiate:** get started – begin
- Participate:** engage with... shared
- Evaluate:** how is it going (+ 0 -)
- Sustain or Switch:** keep going or doing something different – back to PIPES

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Five Ps:

- **Places:** and spaces
- **People:** plus animals, those not there
- **Props:** stuff that is around us, or not
- **Programming:** what is being done or not – how and why
- **Possibilities:** what else? – time, trauma, unmet need

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Dementia Cue Card

What to Look For:

- **Inappropriate control:** does private things in public, is easily irritated, may unexpectedly reach for or touch others or objects
- **Immediate recall of information:** cannot hold onto information during a conversation, loses track of data from moment-to-moment, has a hard time with sequencing or following through with a task, repeats stories with an encounter, forgets what you said, repeatedly asks or shares without recalling having done so, believes you are lying
- **Loss of short-term memory:** doesn't remember last contact with you, unable to recall accurate information from the recent past, believes you are lying, doesn't follow through, unable to give accurate information
- **Word-finding:** is vague, uses the wrong words, gets off-target
- **Confabulation:** makes up information, unaware of inconsistencies, argues
- **Judgment changes:** choices don't make sense or are inconsistent with past values
 - Drivers inappropriately for the situation
 - Tries to get away or resist, even though surrounded or outnumbered
 - Refuses help even though needing it
- **Gets lost in place or time:** gets lost driving or walking, goes back in time
- **Retained social skills:** covers for mistakes, agrees without understanding
- **Emotional distress:** fearful, angry, or happy – inappropriate for situation

How To Check It Out:

- Ask questions that require explanations (not just yes or no)
 - Listen for errors, vague or off-target comments, slowed or impaired understanding of what was said, repeats, extreme emotional reactions, or distractibility, but:
 - Do not point out or highlight inappropriate behaviors or try to argue reality
 - Seek out additional information from significant others – in a separate space
 - Notice increase or decrease in frequency, intensity, or volume of speech
 - Notice changes in visual, verbal, or physical reactions or abilities
- Some Important Facts:**
- As many as 50% of those over 85 will have some form or degree of dementia
 - Dementia is progressive: symptoms and abilities change over time
 - 5-10% of people 70 and younger have dementia
 - Dementia has many forms with different symptoms and progression patterns
 - Behavior or word-finding changes, rather than memory changes, may be the first signs of dementia
 - Dementia is inconsistent: good/bad days, times, and moments
 - Alzheimer's, Lewy Body, Frontotemporal, and Vascular are common forms
 - Leaving an area and getting lost or disoriented can easily happen
 - Becoming distressed with confinement or confrontation can quickly happen
 - Visual field awareness is limited in most dementias, object recognition varies

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What Do People Living with Dementia Need?

- Daily Routine!
- Help to fill their day with meaning
- A Balance of:
 - Productive activity: feeling valued
 - Leisure activity: having fun
 - Self-care activity: wellness, health, personal care
 - Restorative activity: sleep, rest, and re-energizing
- A Match-Up for Preferences:
 - Large Group, Small Group, 1:1, Alone
 - Active versus passive
- Sensory options: visual, auditory, tactile, olfactory, gustatory

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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 and brain
- Restorative Activities: re-energize and restore spirit

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Productive Activities:

- | | |
|-----------------------------------|--------------------------|
| Helping another person | Counting things |
| Helping family members/caregivers | Folding things |
| Completing community tasks | Marking things |
| Making something | Cleaning things |
| Sorting things | Taking things apart |
| Fixing things | Moving things |
| Building things | Cooking/baking |
| Creating something | Setting up/breaking down |
| Caring for things | Other ideas |

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Leisure Activities:

Active:

Socials
Sports
Games
Dancing
Singing
Visiting
Hobbies
Doing, Talking, Looking

Passive:

Entertainers
Sport program/event
Presenters
Living room or lobby sitting
TV programs: watched
Activity watchers
Being done to

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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

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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

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Top Five Human Needs
Five Expressions of Emotional Distress

Five Expressions of Emotional Distress	Five Human Needs
Angry irritated – angry – furious	Intake O ₂ , hydration, nourishment, chemicals, minerals
Sad dissatisfied – sad – hopeless	Energy Flow Circadian rhythm Energy inward (sleep), Energy outward (rhythm of active and still)
Lonely solitary – lonely – abandoned/trapped	Output CO ₂ , urine, feces, sweat, saliva, tears, and other waste
Scared anxious – scared – terrified	Comfort 4 Fs - friendly, familiar functional, forgiving 4 Ss – sensory, social, spatial, surfaces
Lacking Purpose disengaged – bored – useless	Avoid or Remove Pain Physical, emotional, spiritual

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

Get interested, excited, and be challenged!

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