MANAGING BEHAVIORS IN PALTC – HOW TO DO IT BETTER
PRESENTED BY KIMBERLY BRYANT, MHA, LNHA, CMDCP
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KIMBERLY BRYANT BIO:

Teepa Snow PAC Certified Public Trainer

CMDCP #305576

Doctoral Candidate Gerontology – National University

Masters in Healthcare Administration – University of Phoenix

Licensed Nursing Home Administrator – Colorado

Current Administrator at Falcon Heights in Colorado Springs

AGENDA

- Behavior Management using an understanding of where the person living with dementia is based on the GEMS from Teepa Snow
  - PLwD = Person Living with Dementia
  - BPSD = Behavioral and Psychological Symptoms of Dementia
- Non-Pharmacological Interventions
- Dementia Training Programs

GEMS ARE AN EASY WAY TO DESCRIBE THE PERSON LIVING WITH DEMENTIA BASED ON THEIR RETAINED ABILITIES.

EARLY

- **Sapphire – True Blue – This is all of us. As we age, we are slower, sometimes forgetful, but able to adapt and re-orient.**
- **Diamond – Still sharp and clear, territorial, unable to remember new things, repeats things over and over, retells old stories**

MODERATE

- **Emerald – makes mistakes, wants to do things, forgets all the steps for a task, gestures, uses visual information, always on the go**
- **Amber – Live in the moment, low sensory tolerance but all about sensations**

LATE

- **Ruby – walks a lot, sleeps a lot, unable to start a task, follows others, needs rest breaks, fine motor skills impaired**
- **Pearl – the body looks terrible, reflexive movements only, little speech, limited awareness, contractures and stiffness**

6 GEMS® You Need to Know For A Positive Approach to Dementia Care - Positive Approach to Care (teepasnow.com)

WHY ARE THE GEMS IMPORTANT

- Knowing where a resident falls on the Gems scale will allow you and your team to be successful in working with them.
- Mild dementia – BIMS of 13-15 – Saphire or Diamond
- Moderate dementia – BIMS of 8-12 – Emerald or Amber
- Severe dementia – BIMS of 0-7 – Ruby or Pearl
- Understanding the GEM state will teach the team how to approach a person living with dementia, have a successful interaction, reduce the incidence of behaviors, and therefore a reduction of psychotropic medication should follow.

BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD)

- BPSD prevalence: 11 - 90% in the community, 75% in hospitals, and 82% in nursing homes (Holle et al., 2017).
- BPSD is associated with
  - Poorer outcomes
  - Decreased quality of life
  - Caregiver burnout
- Pharmacological Options
  - Limited effectiveness
  - Started when non-pharm tools have not been placed in our toolbox
  - Sedation often seen as effectiveness
  - Often does not address this behavior

BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA (BPSD) – IT'S AN UNMET NEED EITHER PHYSIOLOGICAL OR PSYCHOLOGICAL

- An unmet need or approaching a PLwD (Person Living with Dementia) in the wrong manner can create a behavior
- Most of us who work with this population understand that there will be out-of-the-norm behaviors for PLwD. We know that other people's actions or an unmet need often cause behaviors.
  - These needs can be hunger, boredom, pain, illness, fear, the need to toilet, thirst, loneliness, a sense of loss, or being overstimulated or under-stimulated.
  - A lack of meaningful activities can also indicate an unmet need causing BPSD (Gitlin et al., 2021).
- BPSDs that cause distress to the PLwD or the caregiver:
  - Aggression, Apathy, Wandering, Agitation, Hoarding, Rummaging, Hypersexuality, unusual verbalizations, etc.

JOANNA FROM COLORADO SPRINGS SHE HAS EARLY ONSET ALZHEIMER'S

- Listen to Joanna, a PAC Core Team Member who is living with dementia, share her response to a recent advertisement for an antipsychotic medication to be used to "reduce agitation" in people living with Alzheimer's.
- https://youtu.be/vfaX6fAExDA?si=yuigkDqvnG5QDVUI
- Joanna lives in Colorado Springs and is a lovely woman. She is a valuable member of the Best Practices in Dementia Care Group in Colorado Springs.

WHAT WAS JOANNA TALKING ABOUT?

- **Approach, Approach, Approach**
- **This is not how we approach the disease but how we approach the person.**
  - If a resident is angry, you do not go up to them and say "HI!" with a big toothy grin, because they will probably become aggressive with you. A better way is to approach cautiously stop at 6 feet and say, "Wow you look upset."
- My experience tells me that our teams do not always pay attention to our residents with dementia and just **blame them for the behaviors** that they probably caused.
- **Understanding a resident's preferences and past will allow for you to know the person and adapt your approach** to ensure their safety and well-being.
  - Often residents "get into trouble" because they are bored and if you do not know anything about them you will be unsuccessful in re-directing them.
  - Understanding the life and accomplishments of a person will allow you to have a conversation with them that will engage them in a meaningful activity.
  - Everyone has preferences for foods, activities, colors, television shows, and clothing. Just because a person is living in a nursing home does not mean these preference disappear.
  - If you know that a person likes a specific type of music, then that might be a good thing to help them when agitated.
  - If you know that a resident is wandering because they think it is time to go to work and they worked as a janitor, provide them a meaningful activity.

NON-PHARMACOLOGICAL INTERVENTIONS.

- **KNOW YOUR RESIDENT!**
  - What was his/her life like? Did he/she have a career? Was trauma in his/her life: Fires, floods, sexual assault, near drowning, combat? What did he/she love? What did he/she NOT love?
  - Do these give insight into an **unmet need**?
    - Yes, especially if they are "stuck" in the past.
    - Example: I helped care for a resident who had all kinds of behaviors and extreme exit-seeking behaviors. When we asked about her former occupation, we found that she cleaned the food court at the mall for a living. So, we let her clean the dining room. However, 3 pm that was when it was "time to go home" and she was done with work. Allowing her to "work" in the dining room gave her purpose.
    - Example: I served another resident who was a childcare provider and loved children. We gave her twin baby dolls. She loved them and stopped exit-seeking. However, she then would not leave her room because no one could take care of the babies. This one backfired but all of these things are trial and error.
  - Think about the things in your life that are important, such as a cup of coffee with your favorite creamer in the morning. Do you think most nursing homes have your creamer or will have your coffee for you in the morning?

EXAMPLES

Hallucinations can sometimes be relieved if the PLwD is asked to describe the hallucinations and show them to others.

- Grandma and Bob – The fire and yard mess
  - My husband's grandma was having some hallucinations at home and would call us at all hours of the night and day to have Bob come and fix the issue she was experiencing. A few times, Grandma would call telling us "The whole thing is going to catch fire and it's red and swirling around the tree and they are all going to die." When he went over to help her she would describe the outside as swirling red with things all over the yard. He would then take her outside and ask her to "Show me." When he took her outside the hallucination was gone. She would ask him what happened, and he would tell her that it must have been a doer of good deeds who cleaned it up for her. Her response was "Oh, well that was nice of them." This happened several times over the course of a year.

Highly distressed PLwD can be calmed down by matching their tone and repeating what they say. This allows them to feel they are being heard.

- Former Nun with hand-wringing
  - I had a resident who had been a nun. She left the religious life to have a family and then wanted to return to the religious life. The church did not allow her to return to being a nun, according to her daughter. This resident would walk around the community wringing her hands and saying repeatedly "They won't let me go, they won't let me go." This was extremely distressing to her. I went to her one day after watching Teepa's Challenging Behaviors videos. With a similar expression and tone, I repeated back to her what she was saying. I started with a tone and level of distress similar to hers and gradually lowered the tone until she was able to calm down.
  - When you repeat back what they are saying, they feel heard and validated which calms them down.

ANOTHER EXAMPLE

- Last week Grandma fell into the door jam. When I got there, the staff was telling her, "No, don't get up." Grandma was the woman in charge all of her life and telling her what to do was a bad idea. She got up.
- There were several people standing around her and she was getting more and more agitated. I finally told everyone except the RN to leave because they were surrounding her and overwhelming her. After they left, she then promptly dismissed the RN. She told her to get out. The team was so fixated on the fall and the injury to her face that they forgot to take a moment and remember that her comprehension does not allow for her to be logical about falling and hurting herself. The RN was trying to convince her to go to the hospital (as healthcare professionals, we have to fix people). As a family, we have decided that we will limit hospital visits. She is 96 with advanced dementia. The effects of a hospital visit in her case can be more traumatic that helpful.
- Once everyone had left, she allowed me to change her clothes and then we went to get a cup of coffee. Since it was 7 am, I knew that she always had coffee first thing in the morning. She calmed down and then went to breakfast.

- The initial approach could have been better.
- Learn about your resident, adjust your approach. Keep trying.

DEMENTIA TRAINING REQUIREMENTS AND PROGRAMS

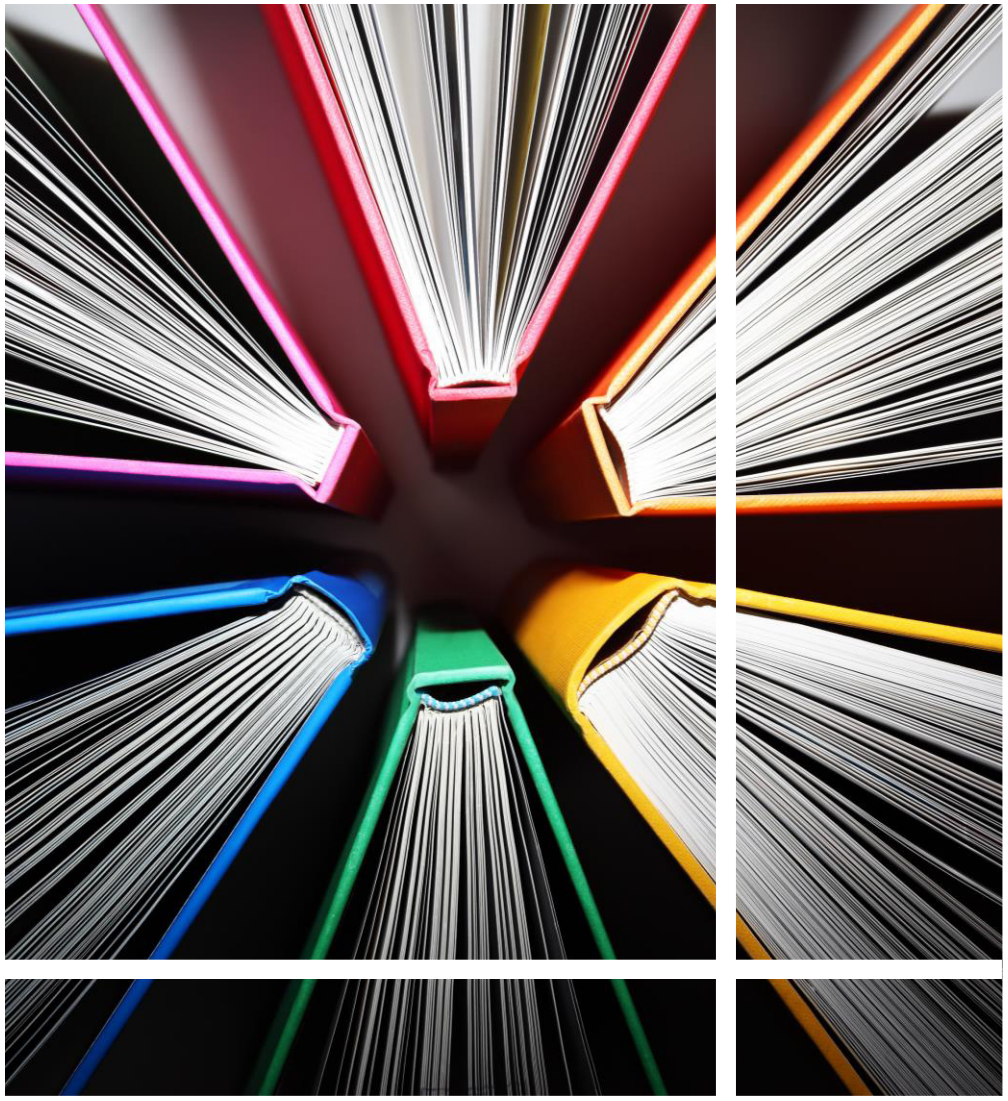
- Dementia Training Requirements:
  - In effect 1/1/24
  - Existing staff must have 4 hours of dementia training within 120 days.
  - New hires must have 4 hours of dementia training within 120 days.
  - Minimum or 2 hours further training every 2 years.
- There are a significant number of training programs available to long-term care providers. However, there is a theme among all of them that approach and knowing who the person living with dementia was in the past can help determine who they are today.
- The new regulations for nursing homes and assisted living state that there must be four hours of training on dementia care to include dementia and related disabilities, person-centered care of residents with dementia, ADLs for residents with dementia, dementia-related behaviors, and communication. This training must be completed within 120 days of 1/1/24 for existing staff and within 120 days of the start of employment for new hires. Then a minimum of 2 hours every two years is to be provided. The training must be current information from recognized experts, agencies, or academic institutions. The instructor must have 2+ years of experience working with PLwD and related disabilities, have received specialized training from recognized experts, agencies, or academic institutions in dementia disease, and have completed the training being offered or similar training that meets the minimum standard of the regulation.

TEEPA SNOW POSITIVE APPROACH TO CARE (PAC)

Teepasnow.com

PAC Certification since 2019

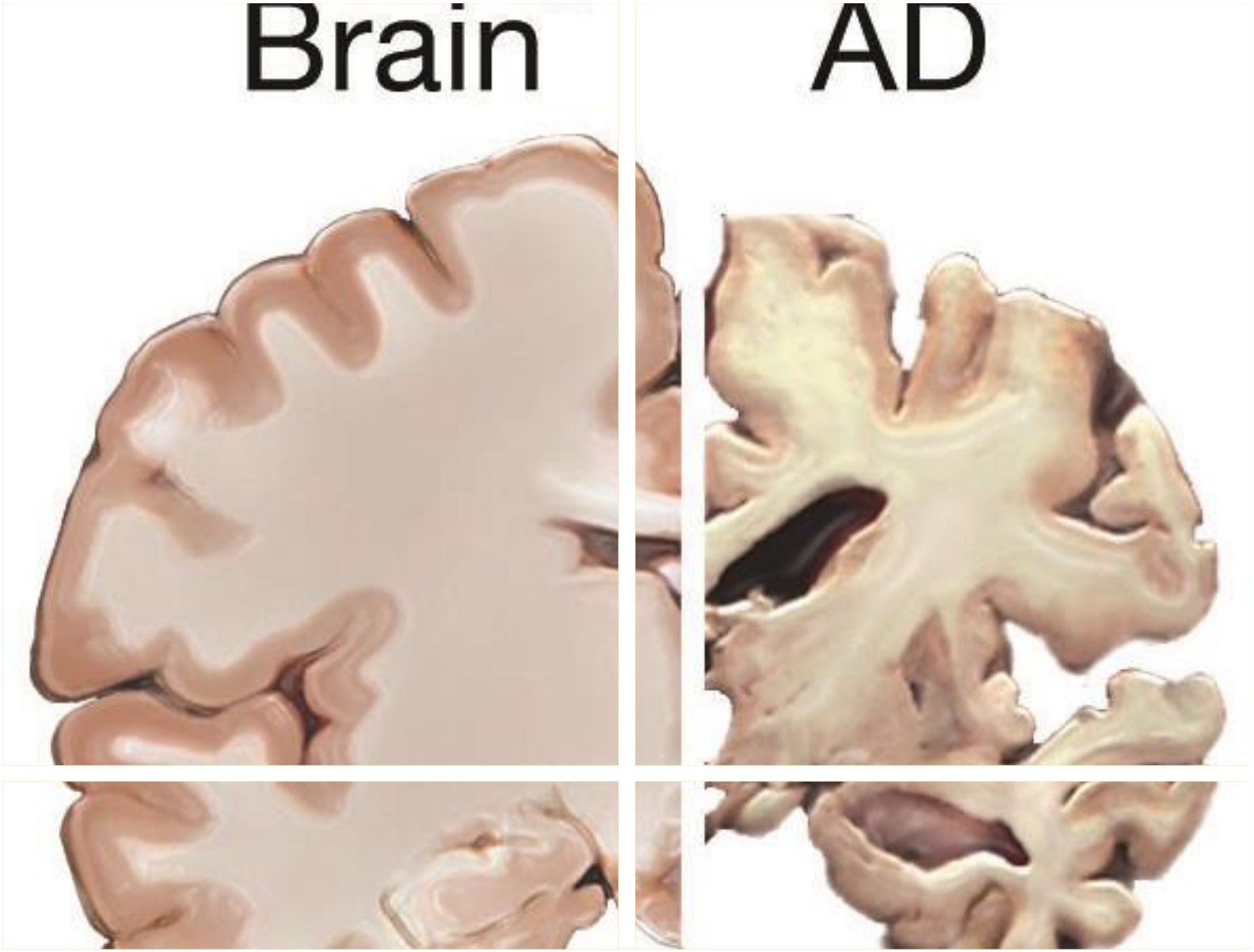
- Not a quick process for certification 8 hours of online videos, 3 days in classroom, 4 weeks of working with a mentor and submitting videos before certified.
- Teaches about the GEM states
- Effective in the approach with a PLwD



PROGRAMS AND TRAININGS AVAILABLE

- Teepa Snow's Positive Approach to Care
- NCCDP – National Council of Certified Dementia Practitioners
- Certified Montessori Dementia Care Professional
- The Eden Alternative
- The Dawn Method
- Virtual Dementia Tour
- Alzheimer's Association – Project ECHO and Pathways to Dementia Care
- Validation
- Dementia Capable Care
- On and on…..

QUESTIONS?



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ADDITIONAL RESOURCES:

The LIVING GEMS®

The GEMS model recognizes the dynamic nature of the human brain and its abilities. Unlike other cognitive models, it acknowledges that everyone's abilities can change in a moment. Modifying environments, situations, interactions, and expectations will create either supportive positive opportunities or result in distress and a sense of failure. Just as gemstones need different settings and care to show their best characteristics, so do people. Rather than focusing on a person's loss when there is brain change, seeing individuals as precious, unique, and capable encourages a care partnership and is the core of this model. Providing supportive settings for everyone, including care providers, allows them to use what they have to be their best. The GEMS advocate that everyone living with brain change when given the opportunity will shine. ***Teepa Snow and Positive Approach® to Care Team***

SAPPHIRE ~ *True Blue ~ Optimal Cognition, Healthy Brain*

- True to self: personal preferences remain basically the same
- Can be flexible in thinking and appreciate multiple perspectives
- Stress/pain/fatigue may trigger Diamond state: back to Sapphire with relief
- Able to suppress and filter personal reactions: chooses effective responses
- Selects from options and can make informed decisions
- Processes well and able to successfully transition
- Aging doesn't change ability: processing slows, more effort/time/practice needed

"My brain is healthy - true blue. If I am aging normally or distressed, it may be hard for me to find words. I can describe what I am thinking so you understand. I may talk to myself because I am giving myself cues and prompts. I can learn new things and change habits, but it takes time and effort. Honoring my choices and preferences, when possible, is important. I need more time to make decisions. Give me the details and let me think about it before you need an answer. I am able to remember plans and information but supports are helpful. I may like specific prompts such as notes, calendars, and reminder calls. Health changes in vision, hearing, balance, coordination, depression, anxiety, pain, or medication may impact my behavior, but my cognitive abilities remain the same."

DIAMOND ~ *Clear and Sharp ~ Routines and Rituals Rule*

- Displays many facets: behavior and perspective can shift dramatically
- Prefers the familiar and may resist change: challenged by transitions
- More rigid and self-focused; sees wants as needs, when stressed
- Personal likes/dislikes in relationships/space/belongings become more intense
- Reacts to changes in environment; benefits from familiar; functional/forgiving
- Needs repetition and time to absorb new/different information or routines
- Trusted authority figures can help: reacts better when respect is mutual

"My overall cognition is clear and sharp. When happy and supported, I am capable and shine in my abilities. When distressed, I can be cutting and rigid and may see your help as a threat. I have trouble seeing other points of view and may become less aware of boundaries or more possessive about my relationships, personal space, and belongings. I have many facets so people see me differently depending on the situation. This can cause conflict among my family, friends, or care team as it's hard to tell if I am choosing my behavior or truly have limits in my ability. I can socially engage and have good cover skills. People will vary in their awareness of what is happening to me. I want to keep habits and environments as they have always been even if they are problematic for me or others. I am often focused on the past, personal values, or finances. I will need help to make changes in my life; it's hard for me. I can be in a Diamond state for reasons other than dementia."

EMERALD ~ *Green and On the Go With a Purpose ~ Naturally Flawed*

- Sees self as able and independent with limited awareness of changes in ability
- Lives in moments of clarity mixed with periods of loss in logic/reason/perspective
- Understanding and use of language change: vague words and many repeats
- Cues and support help when getting to/from places and doing daily routines
- Awareness of time, place, and situation will not always match current reality
- Strong emotional reactions are triggered by fears, desires, or unmet needs
- Needs to know what comes next: seeks guidance and assistance to fill the day

"I am flawed; it is part of being a natural emerald. I tend to be focused on what I want or need in this moment and may not be aware of my own safety or changing abilities. I can chat socially, but I typically miss one out of every four words and cannot accurately follow the meaning of longer conversations. I won't remember the details of our time together, but I will remember how your body language and tone of voice made me feel. I may hide or misplace things and believe someone has taken them. My brain will make up information to fill in the blanks which makes you think I am lying. If you try to correct me or argue I may become resentful or suspicious of you. I am not always rational, but I don't want to be made to feel incompetent. My brain plays tricks on me, taking me to different times and places in my life. When I am struggling I may tell you 'I want to go home.' To provide the help and assistance I need you must go with my flow, use a positive, partnered approach, and modify my environment."

AMBER ~ *Caught in a Moment of Time ~ Caution Required*

- Focused on sensation: seeks to satisfy desires and tries to avoid what is disliked
- Environment can drive actions and reactions, without safety awareness
- Visual abilities are limited: focus is on pieces or parts not the whole picture
- What happens to or around an Amber, may cause strong and surprising reactions
- Enters others' space and crosses boundaries attempting to meet own needs
- Has periods of intense activity: may be very curious or repetitive with objects or actions
- Care is refused or seen as threatening due to differences in perspective and ability

"Like a particle trapped in an amber, I am caught in a moment of time. It may surprise you to see how I take in the world around me. I may not know you or see you as a whole person. I react to you based on how you look, sound, move, smell, and respond to me. I like to do simple tasks over and over and may need to repeatedly move and touch, smell, taste, take or tear items apart. While it may exhaust or frustrate you, it soothes me. I don't recognize danger; you will have to safeguard my environment. I'm intolerant to discomfort because my mouth, hands, feet, and genitalia are highly sensitive due to changes in my nervous system. Therefore, activities like eating, taking medication, mouth care, bathing, dressing, and toileting may distress me. Please notice my reaction and stop if I am resisting. I can't help myself and one or both of us may get hurt emotionally and/or physically. If this happens, wait a few minutes, connect with me, and try a different approach; possibly substituting one area of focus for another."

RUBY ~ *Deep and Strong in Color ~ Others Stop Seeing What is Possible*

- Makes use of rhythm: can usually sing, hum, pray, sway, rock, clap, and dance
- When moving can't stop, when stopped can't get moving: needs guidance and help
- Big, strong movements are possible, while skilled abilities are being lost
- Danger exists due to limited abilities combined with automatic actions or reactions
- Tends to miss subtle hints, but gets magnified facial expressions and voice rhythms
- Can mimic actions or motions, but will struggle to understand instructions/gestures
- Able to pick up and hold objects, and yet not know what to do with them

"As the deep red of a ruby masks detail, my obvious losses make my remaining abilities harder to notice. Although my fine motor skills have become very limited, remember I am able to move and do simple things with my hands. You will need to anticipate, identify, and respond to all of my needs, even though I may not be aware of them. Plan to create a supportive environment, help with the details of care, and structure my day. Just as a crossing guard directs traffic, you will need to guide my movement and transitions. I can rarely stop or start on my own and switching gears is a challenge. Move with me first, then use your body to show me what you want me to do next, going one step at a time. Hand-under-Hand® assistance helps me to feel safe and secure and to know what to do. Danger is part of my life due to losses in visual skills, chewing abilities, balance, and coordination. You can reduce the risks to me, but not eliminate them. I can still have moments of joy when you are able to provide what gives me pleasure."

PEARL ~ *Hidden Within a Shell ~ Beautiful Moments to Behold*

- Will frequently recognize familiar touches, voices, faces, aromas, and tastes
- Personhood survives, although all other capabilities are minimal
- Understanding input takes time: go slow and simplify for success
- In care, first get connected by offering comfort then use careful and caring touch
- Changes in the body are profound: weight loss, immobility, systems are failing
- As protective reflexes are lost, breathing, swallowing, and moving will be difficult
- Care partners benefit from learning the art of letting go rather than simply giving up

"While hidden like a pearl in an oyster shell, I will still have moments when I become alert and responsive. I am near the end of my life. Moments of connection create a sense of wholeness and value between us. Use our time together not just to provide care, but to comfort and connect with me. To help me complete life well, it's important to honor my personhood when making medical or care decisions; please don't talk about me as though I am not still here. I respond best to familiar voices and gentle rhythmic movements. I am ruled by reflexes and will startle easily. My brain is losing its ability to control and heal my body. Be prepared to see me having difficulty breathing or swallowing. My body may no longer desire food and drink as I prepare to leave this life. I may not be able to stop living without permission from you. Your greatest gift at this time in my life is to let me know that it is ok to go."

Positive Approach® to Care

BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS OF DEMENTIA

BPSD is associated with poor outcomes for PLwD including reduced quality of life, increased healthcare use, and nursing home placement. BPSD can also lead to burnout for caregivers especially if not provided with proper tools for addressing BPSD (Kales et al., 2023). Pharmacologic options for neuropsychiatric symptoms (NPS) have limited efficacy or modest benefits and have significant risks including mortality, and often do not address the behaviors that are distressing to caregivers (Gitlin et al., 2021). The prevalence of PLwD who have BPSD is estimated between 11 and 90% in the community, 75% in hospitals, and 82% in nursing homes (Holle et al., 2017).

Most caregivers and healthcare professionals are not provided with the appropriate tools to deal with BPSD and often we resort to medications where there is little evidence of efficacy including psychotropic medications, antidepressants, and antiepileptics often a result of BPSD causing distress to the care provider. As we know this often results in a sedation of the PLwD and does not address the BPSD. We need a first line of defense that does not include medications. Non-pharmacologic interventions are the best line of defense for BPSD (Gitlin et al., 2021).

- PLwD = Person Living with Dementia
- BPSD = Behavioral and Psychological Symptoms of Dementia

QUESTIONS TO ASK WHEN A RESIDENT IS HAVING BPSD

Questions to Ask	Questions to Ask	Questions to Ask	Possible intervention
Are they hungry?	When did they eat last?	How much are they eating?	Offer a snack
Are they thirsty?	When did they have a drink last?	How much are they drinking?	offer a drink
Are they wet?	When were they changed last?		Change them
Are they dirty?	When were they changed last?		Change them
Are they tired?	How much did they sleep last night?	Have they taken a nap today?	offer a place to rest
Are they cold?	Are they dressed appropriately?	What is the temperature of the room?	Provide a sweater
Are they hot?	Are they dressed appropriately?	What is the temperature of the room?	Put on cooler clothing
Are they scared?	Of What?		reassure them
Is it too loud?	What noise is happening in the court?		Adjust the volume of the tv or Alexa or take them to a quieter place
Is it too quiet?	What noise is happening in the court?		Adjust the volume of the tv or Alexa or engage them in an activity
Are they uncomfortable?	When were they repositioned last?		Re-position them
Are they in Pain?	Have they had pain medicine and when?		Ask nurse for pain medicine or reposition them
Are they lonely?			Provide companionship
Are they bored?	Is there a group activity?		Provide a meaningful task

AROMATHERAPY

Madeliene Kerkoff

Lavender

Frankincense

Melissa

AROMATHERAPY EXAMPLES

Pain

Unrest

Agitation