



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



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



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



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



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



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



The Living GEMS[®]

From the Perspective of the Person Living with Dementia (PLwD)

“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.”



SAPPHIRE

“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.”



AMBER

“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.”



DIAMOND

“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.”



RUBY

“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.”



EMERALD

“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.”



PEARL



GEMS, Seeing More Than Just Loss Understanding Dementia Progression Patterns

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Hale Kū'ike Director of Community Engagement
Positive Approach to Care Certified Trainer

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Teepa Snow's
Philosophy



The Positive Approach to Care encourages Care Partners to:

- Respond to a person's change in cognition and abilities in a way that is not hurtful or offensive.
- Understand that, with practice, common *reactions* to the person with dementia can become thoughtful *responses* that improve the quality of life for everyone involved.
- Recognize that the person with dementia is *doing the best they can* and that if something isn't working, it's the responsibility of the Care Partner to change their approach and behaviors toward the person with dementia.
- Notice the environment surrounding the person with dementia and make changes as necessary.




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Today's Agenda

- Explore the role that our feelings and thoughts play in our perceptions of dementia
- Discuss the importance of words, language, descriptions
- Describe various GEMS characteristics
- Match GEMS to states of being in dementia
- Compare and contrast ability-focused vs. loss-focused approaches
- Q&A

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Dementia

Fronto-Temporal Lobe Dementias

Alzheimer's Disease:

- Young onset
- Late life onset

Lewy Body Disease:

- Parkinsons related
- Diffuse Lewy Body

Vascular Dementias:

- Multi-infarct
- Single-infarct
- Subcortical
- CADASIL

Other Dementias:

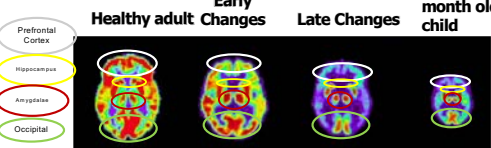
- Posterior Cortical Atrophy (PCA)
- Pick's disease (PJD)
- Normal pressure hydrocephalus (NPH)
- Chronic traumatic encephalopathy (CTE) - associated dementia
- Genetic syndromes - Huntington's Disease (HD) - Down Syndrome-associated dementia (ID)
- Infectious diseases (e.g., Creutzfeldt-Jakob disease; CID)
- Metabolic diseases
- Neuronal Ceroid Lipofuscinosis (NCL; Batten disease)
- Toxicity: induced by long term exposure - Alzheimer-Konradoff Syndrome (WKS); Alcohol-induced dementia; Methamphetamine induced

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Positron Emission Tomography (PET) Dementia Progression vs. Normal Brains

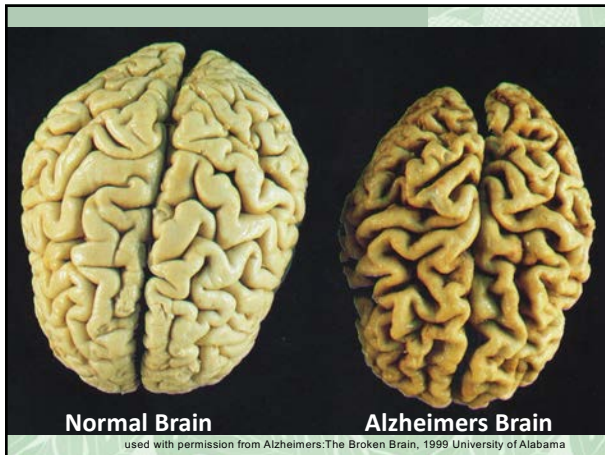
Color code
Red = high activity
Yellow = Mid
Blue = low
Purple = no activity

Healthy adult **Early Changes** **Late Changes** **Healthy 18-month old child**



G. Small, UCLA School of Medicine.

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My Grandmother Dorothy

Born in 1909 in Kobe Japan

In hindsight, first signs of dementia appeared in 1985

Not diagnosed until about 1992.

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Common Dementia Level Descriptions

<ul style="list-style-type: none"> • Normal • Very Mild • Mild • Moderate • Moderately Severe • Severe • Very Severe 	<ul style="list-style-type: none"> • Early • Middle • Late 	<ul style="list-style-type: none"> • 1 to 3 • 1 to 5 • 1 to 7 • 6 to 1
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Thinking about your feelings...

Which would you give 👍 or 👎

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Thinking about Gemstones

- **Sapphire**
- **Diamond**
- **Emerald**
- **Amber**
- **Ruby**
- **Pearl**

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- **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

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How you look at Dementia Matters!

- It is NOT all about loss
- It is NOT “untreatable”
- It is NOT unpredictable
- Behaviors DON'T come out of nowhere
- Dementia DOESN'T just affect the person with the disease – it impacts all of us


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Why use GEMS?

- There are three systems – all use numbers
- Each has value – together confusing
- People are not numbers
- Until we begin to see the beauty and value in what the person is at this point in time— we will never care for them as we should
- Gems are precious and unique – common language and characteristics

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Gem Dementia Abilities

Based on Allen Cognitive Levels

- A Cognitive Disability Theory – OT based
- Creates a common language and approach to providing:
 - ✓ Environmental support
 - ✓ Caregiver support and cueing strategies
 - ✓ Expectations for retained ability and lost skill
 - ✓ Promotes graded task modification
- Each Gem state requires a special 'setting' and 'just right' care
 - ✓ Visual, verbal, touch communication cues
- Each can shine
- Encourages in the moment assessment of ability and need
 - ✓ Accounts for chemistry as well as structure change


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How Do the GEMS Help?

- Use familiar concepts to talk about a difficult subject
- Focus on what is valued
- Allow us to get beyond the words – dementia and Alzheimer's
- Open the door to talk about changes
- Allow us to speak in "code" to protect dignity


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Let's Think!

- Connect the GEMS to States in Dementia
 - Characteristics
 - Abilities
 - Changes/Losses
 - Interests
 - Settings that Work
 - Cues that Help
 - Behaviors that Hurt

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Sapphires



- True Blue
- Optimal Cognition,
- Healthy Brain


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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


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Sapphires:

- **Optimal Cognition: flexible in capacity**
- **Normal aging will slow, yet not change ability**
- **More time to process with stress**
- **True to self: likes/dislikes are the same**
- **Able to learn: takes more practice**
- **Stress, fatigue or pain induce Diamond moments**
- **Time to recharge or heal can restore to Sapphire**

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Diamonds

- **Clear and Sharp**
- **Routines and Rituals Rule**

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Diamonds

- Still Clear
- Sharp - Can Cut
- Hard - Rigid - Inflexible
- Many Facets
- Can Really Shine
- \$\$\$\$\$



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Diamonds:

- **Routines and Rituals Rule: likes familiar**
- **May resist change or won't let things go**
- **Rigid under pressure: limited perspective**
- **Becoming protective: may be territorial or isolate**
- **Repeats self: hard to integrate new information**
- **Can cover mistakes in social interaction**
- **Symptoms may or may not be dementia related**

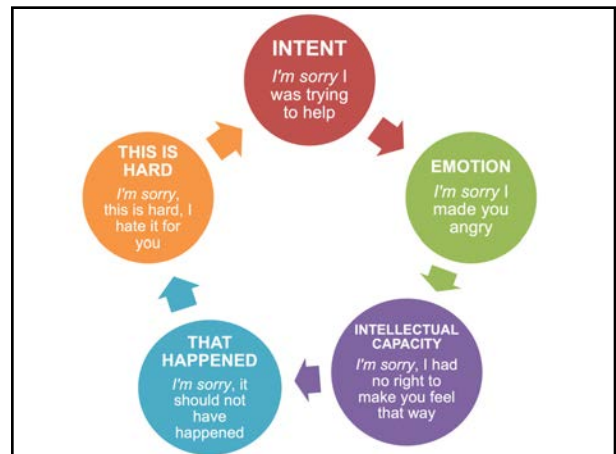
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How do you go between Sapphire and Diamond?



- How can you recognize you are GOING DIAMOND?
- What are your triggers for GOING DIAMOND?
- What are your strategies for REGAINING SAPPHIRE?
 - Pause
 - Step back
 - Recognize you need help

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Emeralds


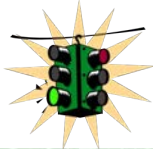


**On the Go with a Purpose
Naturally Flawed**

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Emeralds

- Changing color
- Not as Clear or Sharp - Vague
- Good to Go – Need to 'DO'
- Flaws are Hidden
- Time Traveling

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Emeralds:




- Desires independence: noticeable ability change
- Vocabulary and comprehension diminishing
- Communication becoming vague
- May neglect personal care routines
- On the go: needs guidance and structure
- Difficulty finding way to and from places
- May be lost in time

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Ambers





- Caught in a Moment of Time
- Caution Required

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Amber

- Amber Alert
- Caution!
- Caught in a moment
- All about Sensation
- Explorers

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Ambers:




- Caution Required
- Focused on sensation
- Will react to how things: look, sound, feel, smell or taste
- Lives in the moment: not socially aware
- No safety awareness: typically very busy
- Difficulty understanding and expressing needs
- No ability to delay needs or wants
- Needs help with tasks: may resist
- Hard to connect with: may exhaust care partners

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Rubies



- **Deep and Strong**
- **Others Stop Seeing What Is Possible**

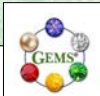
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Rubies





- Hidden Depths
- Red Light on Fine Motor
- Comprehension & Speech Halt
- Coordination Falters
- Wake-Sleep Patterns are Gone

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Rubies:



- Others stop seeing what is possible
- Retains rhythm: can sing, hum, pray, sway and dance
- Understands expressions and tone of voice
- Losing ability to understand language
- Limited skill in mouth, eyes, fingers, and feet
- Can mimic big movements: gross motor abilities
- Loss of depth perception; monocular vision
- Falls prevalent: can only move forward
- Care Partners will have to anticipate unmet needs

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Pearls



- Hidden Within a Shell
- Beautiful Moments to Behold


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Pearls





- Hidden in a Shell
- Still & Quiet
- Easily Lost
- Beautiful - Layered
- Unable to Move – Hard to Connect
- Primitive Reflexes on the Outside

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Pearls:




- Person is still there
- Moments of connection take time and will be short
- Knows familiar: unmet needs may cause distress
- Unable to move by themselves: fetal position, still and quiet
- Primitive reflexes have taken over: difficulty swallowing
- Brain failure shuts down body: diminishes need to eat or drink
- Care Partners need to give permission to let go

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Grandma Dorothy & her sister Gladys in 1996



Born in 1909 in Kobe Japan

In hindsight, first signs of dementia appeared in 1985


Not diagnosed until about 1990.

Moved in with my parents in 1992

Passed away in 2001 at home under hospice care

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All individuals, whatever their state of being, in the right setting and with the right care, can shine!



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Progression of the Condition

- To the tune of *This Old Man*



Note: Each verse is sung progressively slower

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Sapphire true, you and me

The choice is ours, and we are free

To change our habits, to read, and think and do

We're flexible, we think it through!

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Diamond bright, share with me

Right before, where I can be

I need routine *and* different things to do

Don't forget, I get to choose!

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Emerald – Go, I like to do

I make mistakes, but I am through!

Show me only one step at a time

Break it down and I'll be fine!

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Amber – Hey!, I touch and feel

I work my fingers, rarely still

I can do things, if I copy you

What I *need* is what I do!

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Ruby – skill – it just won't go

Changing something must go slow

Use your body to show me what you need

Guide, don't force me, don't use speed!

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Now a Pearl, I'm near the end

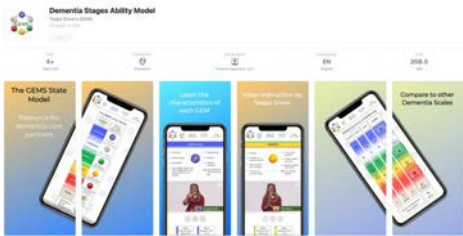
But I still feel things through my skin

Keep your handling always firm and slow

Use your voice to calm my soul.



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GEMS App – Apple & Google



Apple – bit.ly/GEMSappApple

Google – bit.ly/GEMSappGoogle

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Next Workshop

Session 3 – Saturday, May 20th, 10am – noon



**It's All in Your Approach:
Making Positive Connections**

- Learn to improve your ability to approach, connect and provide care with those living with dementia.
- Learn how to recognize and address sensory needs and tolerance, including Visual-Verbal-Touch, and the 3 zones of human awareness.
- Practice of Positive Approach to Care™ "care partnering" techniques including Positive Physical Approach™ (PPA) and Hand Under Hand™ (HUH) and modifications by level of dementia.

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Thank you!

Thank you so much for your desire to learn and your commitment to making a positive difference!

To learn more about the Hawaii Circle of Care for Dementia visit, <https://www.catholiccharitieshawaii.org/hawaii-circle-of-care-for-dementia/>

To learn more about the Teepa Snow and the Positive Approach to Care visit www.teepasnow.com

Hale Ku'ike is committed to dementia education for staff, and for the wider Hawaii community. Starting in 2020 Hale Ku'ike co-sponsored dementia education webinars with Catholic Charities and the recordings are available on-line at <https://www.catholiccharitieshawaii.org/caring-for-persons-living-with-dementia-webinars-and-presentations/>. Additional 2021 dementia workshop series recordings are available on our website at <https://www.halekuike.com/videos/#webinar>.

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