

Welcome!

GEMS, Seeing More Than Just Loss

Understanding Dementia Progression Patterns

Start time: 10:00 am HST

You should hear music playing now.

Check that your computer is not muted and the volume is turned up. There is no phone dial up required.

Thank you for joining us!



CATHOLIC CHARITIES
HAWAII
CIRCLE OF CARE FOR DEMENTIA

Catholic Charities Hawaii 2020 Dementia Workshops for Caregivers of Persons Living with Memory Loss are made possible by a grant from the Administration for Community Living, U.S. Department of Health and Human Services, given to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.

Please help us support this grant by completing this short 5-question pre-test poll. You will be asked to complete the same questions in a post-test at the end of the webinar. All answers are anonymous.

Thank you for your participation!

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Zoom Webinar Guide

Q&A: Everyone is muted and in “listen only mode,” but we still want to hear your questions! Please use the Q&A feature to submit your questions. There is the option to ask anonymously if desired.

Chat: If you have any technical issues during the webinar, please use the chat to let us know. Questions regarding content should be submitted through the Q&A feature.

Recording: Today’s webinar is being recorded for future viewing. You will receive a link to the recording after the event.

Slides: Presenter will be sharing PowerPoint slides. You will receive a PDF of today’s slides after the event.

CEUs: There are no CEs for this event. You will receive a printable PDF certificate of completion noting the topic and duration of the webinar.

Caregiver Survey: At the end of this webinar we would like to ask you to fill out a confidential survey. We value your feedback and always want to make improvements!

Today's Presenter



Dorothy Arriola Colby
Hale Ku'ike
Director of Community Engagement
Positive Approach to Care Trainer



AGENDA

Explore the role that our feelings and thoughts play in our perceptions of dementia 01

Discuss the importance of words, language, descriptions 02

Describe various GEMS – characteristics 03

Match GEMS to States of Being in Dementia 04

Compare and contrast ability-focused vs. loss-focused approaches 05

Q&A 06

Dementia

An infographic featuring a large blue umbrella with the word 'Dementia' written on it. Below the umbrella, several light blue raindrops of varying sizes contain text about different types of dementia. The background is a light blue gradient with a faint brain illustration in the top right corner.

Fronto-Temporal Lobe Dementias

Alzheimers Disease:

- Young onset
- Late life onset

Lewy Body Disease:

- Parkinsons related
- Diffuse Lewy Body

Vascular Dementias:

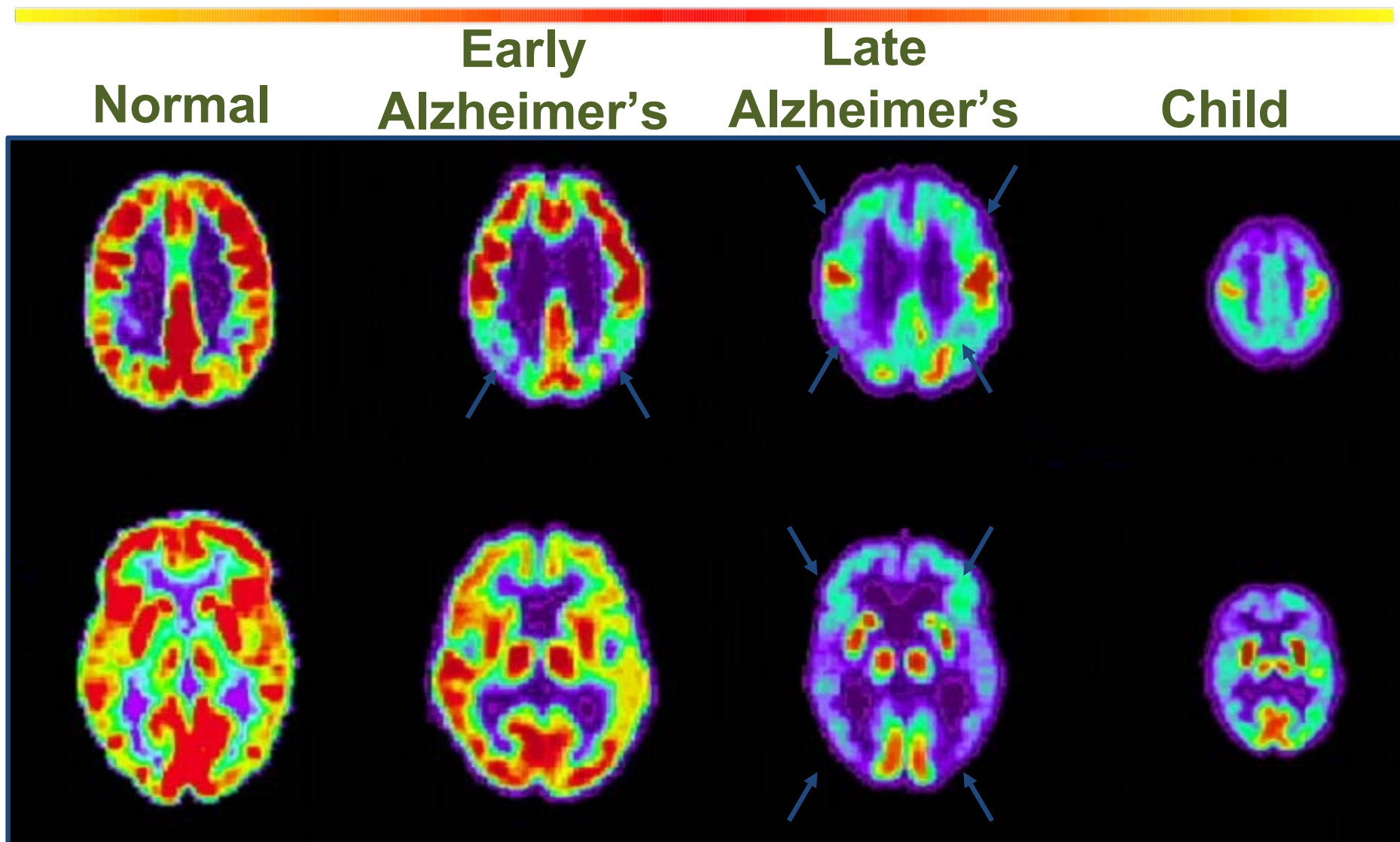
- Multi-infarct
- Single-infarct
- Subcortical
- CADASIL

Other Dementias:

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

Positron Emission Tomography (PET)

Alzheimer's Disease Progression vs. Normal Brains



G. Small, UCLA School of Medicine.

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Normal Brain

Alzheimer's Brain

Common Dementia Level Descriptions



- Normal
- Very Mild
- Mild
- Moderate
- Moderately Severe
- Severe
- Very Severe

- Early
- Middle
- Late

- 1 to 3
- 1 to 5
- 1 to 7
- 6 to 1

Thinking
about your
feelings...

How many
would you
give 👍
or 👎

Thinking about Gemstones



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





- **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**



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



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



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



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



Let's Think!

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

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

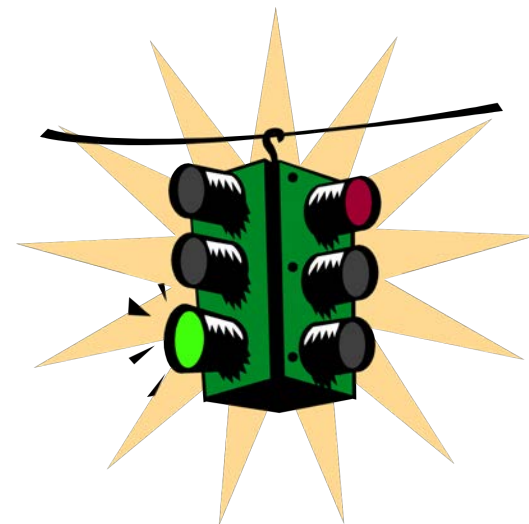
Diamonds

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



Emeralds

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



Amber

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



Rubies

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



Pearls

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





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

**Positive
Approach®
to Care**



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

Diamond: Teepa Snow responding to repetitive stories and questions.



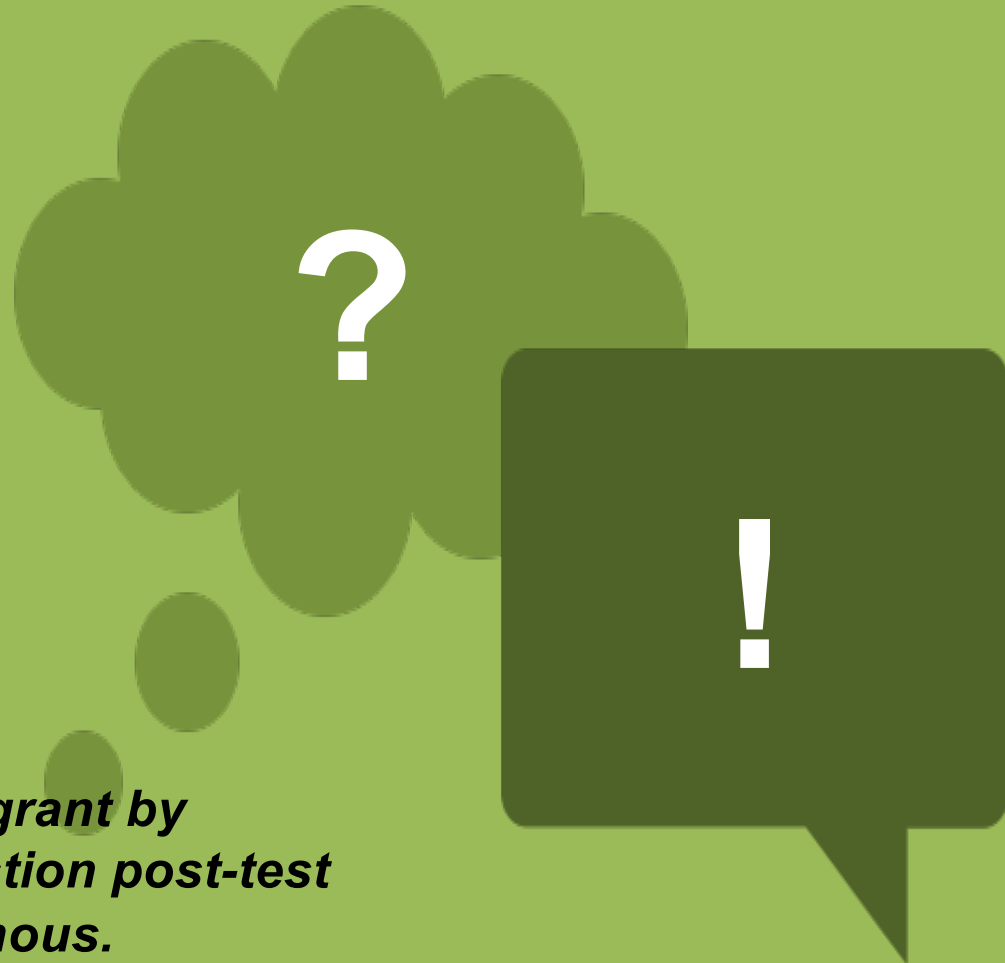
Amber:
Teepa Snow supporting a woman combing
her hair. Note her slow pace, simple words
and visual and touch cues.



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



Q&A



Please help us support this grant by completing this short 5-question post-test poll. All answers are anonymous.

Thank you for your participation!

Upcoming Webinars

Sept 23, 2020 • 10-11am HST

Caregiver Stress: Taking care of YOU!

October 1, 2020 • 10-11:30am HST

It's All in Your Approach: Making Positive Connections

October 15, 2020 • 10-11:30am

Challenging Behaviors: Recognizing Unmet Needs

You will receive an email link to register for these and all future webinars.



Thank you!

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

Please also help us support this grant by completing a short anonymous demographic and quality survey after this webinar. Your feedback is important to us, and helps us to keep providing these free educational events to our community.

To learn more about the Hawaii Circle of Care for Dementia visit,
www.catholiccharitieshawaii.org/dementia/

Visit www.halekuike.com learn about future Positive Approach to Care (PAC) workshops!

To learn more about PAC visit www.teepasnow.com



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