## Welcome! Challenging Behaviors

**Recognizing Unmet Needs** 

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 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! <u>Please use the Q&A feature to submit your questions.</u> 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 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 link to the PDF of today's slides.

**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!

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## When we talk situations,

What are we talking about?

List situations you get asked about:

**Crises! Problems! Behaviors!** 

### **Examples of Challenging Situations**

- No financial/health care Power of Attorney
- Losing Important Things
- Getting Lost
- Unsafe task performance
- Repeated calls and contacts
- Refusing
- Bad mouthing you to others
- Making up stories
- Resisting/refusing care
- Swearing/cursing, sex talk, racial slurs, ugly words
- Making 911 calls
- Mixing day and night
- No solid sleep time or sleeping all of the time
- Not following care/rx plans
- No initiation
- Perseveration

- Paranoid/delusional thinking
- Shadowing
- Eloping or Wandering
- Seeing things and people
- Getting into things
- Threatening caregivers
- Undressing in public
- Not changing clothes or bathing
- Problems w/intimacy & sexuality
- Being rude
- Feeling sick
- Use of drugs or alcohol to cope
- Striking out at others
- Falls and injuries
- Contractures and immobility
- Infections and pneumonias
- Problems eating or drinking

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### Introduction: Beliefs

 The <u>relationship</u> is MOST critical NOT the outcome of one encounter

We are a KEY to make life WORTH living

 People living with **Dementia** are Doing the BEST they can

We must be willing to CHANGE ourselves

# Believe: It Takes TWO to Tango ... or Tangle

Learn to DANCE with our partner
 We must be willing to STOP & BACK
 OFF

Being 'right' doesn't necessarily translate into a good outcome

### Why Is Life So Difficult for Those Involved?

#### MANY abilities are affected

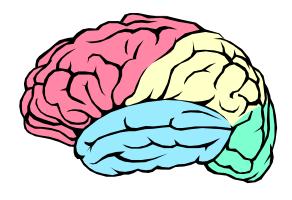
- Thoughts
- Words
- Actions
- Feelings

#### It is variable

- Moment to moment.
- Morning to night
- Day to day
- Person to person
- Place to place

#### It is progressive...

- More brain dies over time
- Different parts get hit
- Constant changing





- Specific brain parts
- Typical spread
- Some parts preserved

# Understanding and Responding to Challenging Situations and Unexpected Behaviors

What is happening?

Why is it happening?

What helps?

What Makes it WORSE/BETTER?

What can we do to MAKE IT BETTER?

How can we PREVENT it in the first place?

## LOOK AGAIN – What Makes *SITUATIONS* Happen?

#### - SIX pieces...

#### - The Person:

- The person and who they have been
- Personality, preferences, and history

#### - Health, Wellness, and Fitness:

Other medical conditions, sensory status, and medications

#### - Brain Changes:

The type and level of cognitive impairment ... NOW

#### - The Stakeholders:

- People How the helper helps
- Approach, behaviors, words, actions, and reactions

#### - The Environment:

- setting, sound, sights

#### - Time:

- The whole day... how things fit together Snow, Positive Approach, LLC - to be reused only with permission.

#### **The Person**

Think of the person first and the brain change second. Consider:

Who they were

Personal history: joys/traumas

Life Roles: professional/family

Who they are becoming

Preferences: likes/dislikes

Personality traits

Core values

#### Fitness, Health, Wellness

Remember other health challenges and previous lifestyle choices contribute to the situation. Consider:

- · Ability to intake food/fluid
- Medication/supplement side effects
- Emotional/psychological stressors
- Sensory system function/sensitivity
- Personal healthy beliefs/choices
- · Recent change: acute illnesses

#### **Brain Change**

Dementia is a syndrome, a collection of symptoms.

Consider:

- Diagnosed type(s) of dementia
- Delirium might present as dementia
- Self-awareness of change
- Onset and duration of Symptoms
- Current GEMS<sup>™</sup> ability level
- Retained and changed abilities

#### **Stakeholders**

All individuals who interact with a person living with dementia (PLWD). Consider their:

- History with PLWD
- Awareness of the whole situation
- Knowledge of a changing brain
- Hands on dementia skill training
- Current relationship with PLWD
- Personal Agenda

#### **Environment**

Brain change impairs the nervous system and affects experience. Consider the four Fs and Ss of a setting:

- Does it feel Friendly and Familiar?
- Is it <u>Functional</u> and <u>Forgiving?</u>
- Sharing <u>S</u>pace: Am I comfortable with public, personal, and intimate interaction?
- Response to <u>Sensation</u>: What happens when I see, feel, hear, smell, or taste something?
- Sensitivity to <u>Surfaces</u>: Notice responses to textures I touch, stand, or walk on.
- <u>S</u>ocial experiences: As my tolerance changes expectations of me will need modifying

#### **Time**

Are days structured and meaningful for a person? Notice if someone is experiencing time differently than you are. Consider these categories of time:

- Productive: offers value and purpose
- <u>Leisure</u>: preferred, fun and playful
- · Wellness: gives self-care
- · Restorative: calms and recharges
- · Waiting: not natural or comfortable
- Where or What: becomes curious about a person's experience of place and time of day



## Top Ten Unmet Needs of People Living with Dementia



## Five Expressions of Emotional Distress

## Five **Physical** Needs

#### **Angry**

irritated - angry - furious

#### Sad

dissatisfied – sad – hopeless

#### Lonely

solitary - lonely - abandoned/trapped

#### **Scared**

anxious - scared - terrified

#### **Bored**

disengaged – bored – useless

#### Intake

hunger or thirst

#### **Energy**

tired or revved up

#### **Elimination**

need to go or did

#### **Discomfort**

temperature or sensations

#### PAIN!!!

joints, internal or external systems

## To Communicate...

## When Someone is DISTRESSED

First – CONNECT with the Positive Physical Approach

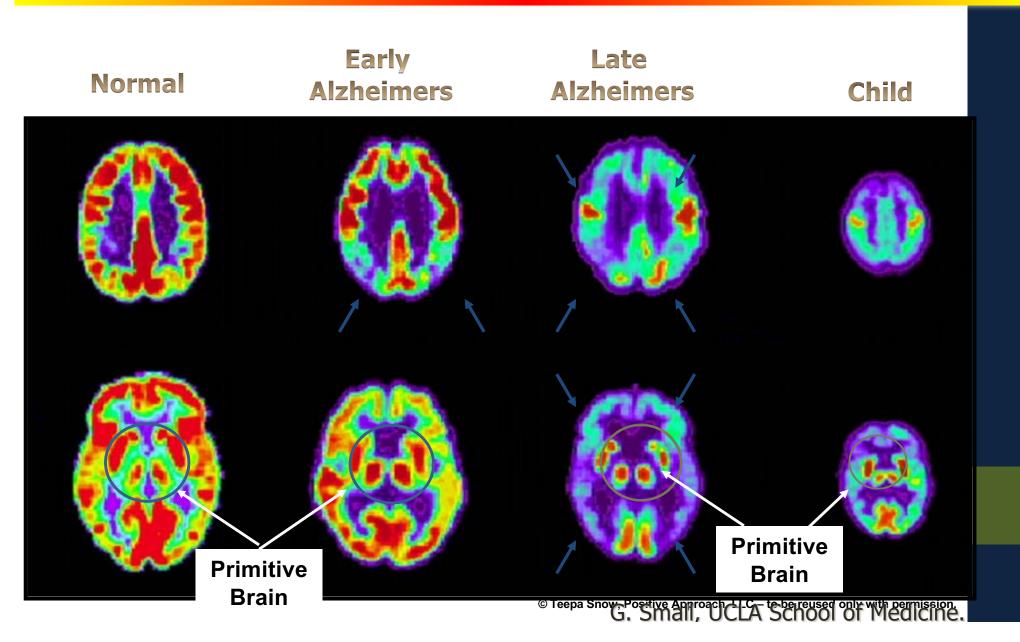
Then – Try Supportive Communication

Finally - Move together to a NEW place

### For ALL Communication

- If what you are trying is NOT working...
- STOP
- Back off
- THINK IT THROUGH... THEN
- Re-approach -
- Try something slightly different

## Positron Emission Tomography (PET) Alzheimers Disease Progression vs. Normal Brains



## Primitive Brain is in Charge of:

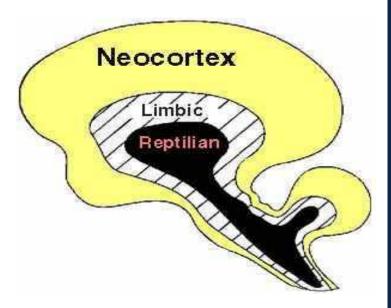
- Autonomic protective fright, flight, fight
- Pleasure seeking needing joy

#### Thriving – Running the Engine

- Vital systems
- Wake-sleep
- Hunger-thirst
- Pain awareness and responses
- Infection recognition & control

#### Learning New and Remembering it

- Information
- Places Awareness
- Time Awareness

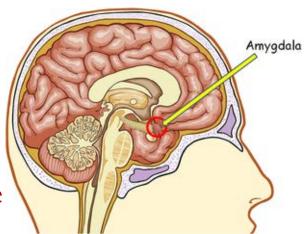




## It's all about our AMYGDALA

### The Amygdala:

- Part of our <u>Limbic System</u>
- Threat perceiver
- Pleasure Seeker
- Part of the *engine* controlled by the Neo-Cortex
- Two parts left and right
  - Left Amygdala –
  - Right Amygdala –



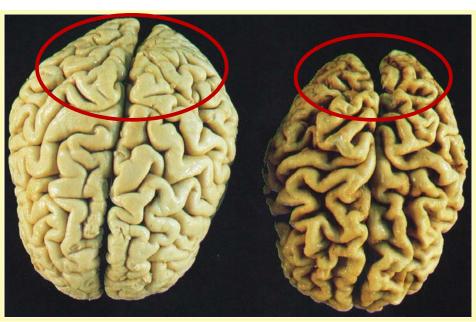
## **Amygdala in Control**

When your primitive brain takes over...

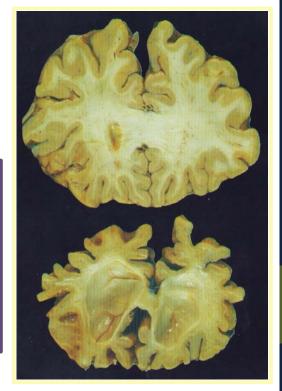
Left
Temporal
LobeLanguage
and
Speech



Frontal Prefrontal
CortexEmotions,
Behavior,
Judgement,
Reasoning



Occipital
LobeTunnel
Vision



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### **DANGER!**

## Left Amygdala turns ON

and.....

Fight, Flight, Fright

## When I'm HURTING... I Need RELIEF

Right Amygdala turns ON

and.....

I NEED IT NOW!!!

## Amygdala

Right

**NEED** 

Want

Likes

Left

**DANGEROUS** 

**Aroused/ Risky** 

Alert/ Aware

## Visual Verbal Touch: How you help... connect



Sight or Visual cues



Verbal or Auditory cues



Touch or Tactile cues

### **Confrontational**

If we stay standing in the front instead of moving to the side we can accidentally be perceived as confrontational. The person may feel trapped and threatened.

If we lean in closer so we can be seen clearly, it can feel like you are confronting them and is unsettling.



## ...vs Supportive Stance

You are not blocking their visual field and they don't feel trapped.





## **Visual Cues**

- -Signs
- Pictures
- -Props Objects
- -Gestures
- -Facial expressions
- Demonstrations



## **Verbal Cues**



- -Keep it simple
- Directed
- Matched to visual cues

## **Touching Cues**



- Place an item or tool in hand
- Touch with a finger or hand
- Hand guidance
- Hand on shoulder or back
- Hand-under-Hand<sup>TM</sup> contact
- -Hug

## True or False?

- False When communicating with someone living with dementia, using reality orientation is an effective strategy.
- True A common mistake care partners make is trying to get the person with dementia to understand the facts as they see them.
- True Without realizing it, care partners can be perceived by the person with dementia as being confrontational through body language and positioning.
- True In order to survive, there are 5 basic physical needs that must be met: (1) hunger/thirst, (2) wake/sleep cycles and rest, (3) elimination, (4) comfort/personal preferences, and (5) pain relief.
- False As a care partner, it is important to point out what the person living with dementia is doing wrong.

## **GEMS™ States...**Where is the Person in the progression?

Sapphires – True Blue – Slower BUT Fine

Diamonds - Repeats & Routines, Cutting

Emeralds – Going – Time Travel – Where?

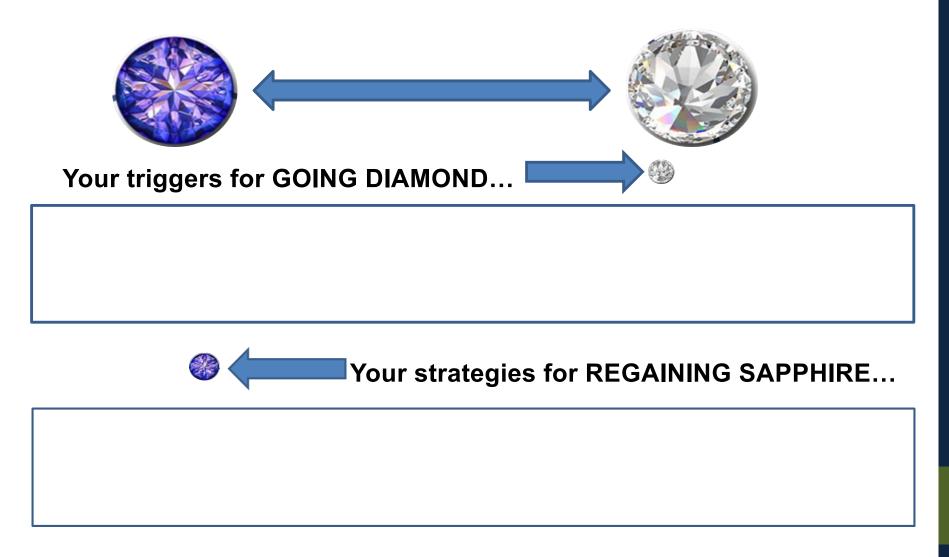
Ambers – In the moment - Sensations

Rubies – Stop & Go – Big Movements

Pearls - Hidden in a Shell - Immobile



## How do you go between Sapphire and Diamond?



## When we don't have the help we need, we tend to...

- We miss early signals
- We ignore it or put up with it
- We see if it gets worse
- We worry
- We <u>react</u> or <u>over-react</u> instead of <u>responding</u>

## Who are the stakeholders?

YOU...

AND OTHERS

#### The Stakeholders

- People around the person living with dementia
- Staff
- Friends
- Family
- Everyone who might have an impact

### What should stakeholders avoid???

- Arguing
- Ignoring problem behaviors
- Trying a possible solution only once
- Giving up
- Letting them do whatever they want to
- Forcing them to do something

## So WHAT should we do???

Build... and use Skills!

Remember... who has the healthy brain!

**Believe...** People with dementia are doing The BEST they can in any given moment!

## Remind others... you WILL make mistakes

Learn to recognize Your UH-OH's!

STOP what you are doing!

Back OFF & Re-think!

Possibly Change Something

Try Again!

Let it go...

FORGIVE Yourself! - You are HUMAN!

## **GET HELP!**

- Support for YOU
- Help with the person
- Check out options home care, day care, residential care
- Check out places visit, observe, reflect
- Plan ahead when NOT if
- Act before it is a crisis
- Watch yourself for signs of burn-out
- Set limits... It's a marathon!

## **Specifically for Care Partners of Someone Living with Dementia**

- You need HELP
- -From someone who understands

- You need TIME
- -Truly away—physically, emotionally and spiritually

- You need to try to LISTEN!!!

## Let Go:

- How it "used to be"

- How it "should be"

- How you "should be"

- I am who I was, but I'm different!

## Identify

- What you're good at...and what you're not

- Who can help...and how they can help

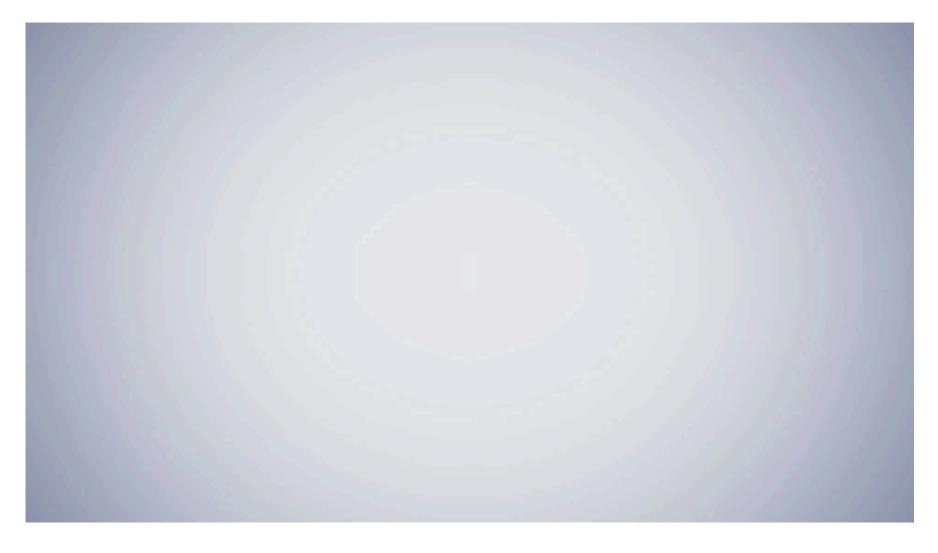
- What really matters

- Not EVERYONE is meant to be a care partner for someone with dementia!

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## **Teepa Snow and Leona**





## Upcoming Webinar

Thursday, November 5, 2020 • 10-11:30 am HST End of Life Care and Letting Go: Providing Care in the Final Stages of Dementia

NEW! Tuesday, November 10, 2020 • 10-11:30 am HST SPECIAL Follow-up to Nov 5<sup>th</sup> session Advanced Care Planning and Dementia: Kokua Mau

Thursday, November 12 2020 • 10-11:30 am HST Dining with Dementia: Techniques to Bring Joy to the Table

You will receive an email link to register for this webinar.

## 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 <a href="www.halekuike.com">www.halekuike.com</a> earn about future Positive Approach to Care (PAC) workshops!

To learn more about PAC visit www.teepasnow.com



## 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!