

# Welcome!

## End of Life Care & Letting Go

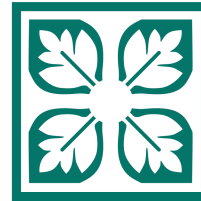
### Providing Care in the Final Stages of Dementia

**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 link to download the PDF of today’s slides.

**CEUs:** There are no CEs for this event. You will receive a link to download 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!

# A G E N D A

Why is dementia different at end of life?

01

Different care approaches to consider

02

Letting go vs. giving up

03

Indications of the end of the journey

04

Comfort care and dementia

05

Pearls, the final beautiful GEM State

06



# Why is **Dementia** Different as the End of the Journey Approaches?

- It has taken a LONG TIME
- The person has changed, and changed, and changed, and changed....
- You have lost the person, even as they remain
- You have changed over the journey
- How it WAS is NOT how it IS...
- What should happen/work , DOESN'T...

# What are the Different Care Approaches to Consider?

- Health Promotion
- Curative
- Restorative - Rehabilitative
- Maintenance
- Compensatory
- Palliative



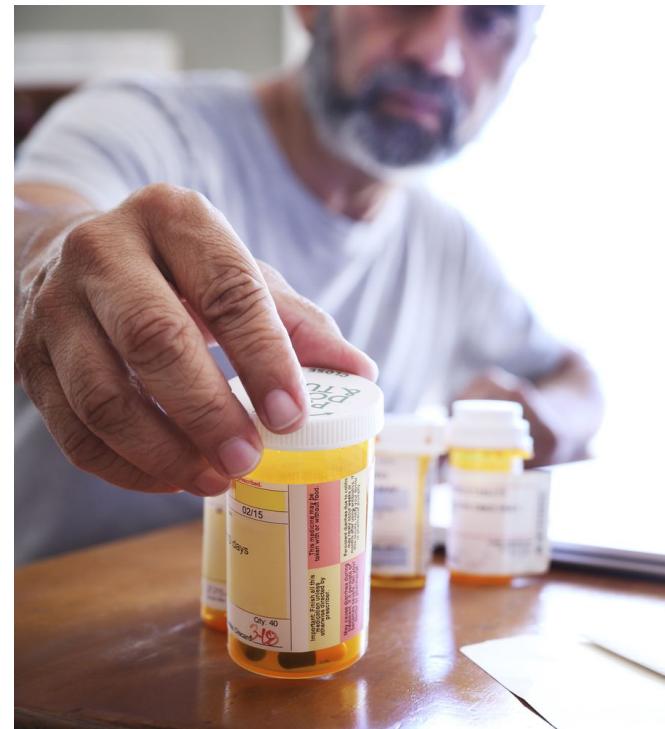
# Health Promotion

- Check Ups
- Annual vaccinations
- Lower the numbers
- Increase activity level
- Eat well – moderately
- Monitor all conditions for careful control
- DO WHAT YOU SHOULD to be the BEST YOU CAN BE!



# Curative

- Fix what is wrong
- Test to figure out what is happening then DO SOMETHING ABOUT IT:
  - Surgery
  - Medications
  - Treatment
- Full recovery of function
  - GOOD as NEW!



# Restorative

- Recovery of SOME degree of function or ability
- Focuses on the PERSON regaining skills and abilities with help
  - Rehab personnel
  - Special equipment
  - New techniques
- Not perfect, but BACK to a higher level of function



# Maintenance

- Maintaining the Status Quo – Keepin' ON
- Not losing ground
- Depends on:
  - Physical environment not changing
  - Caregiver consistency
  - Sustained abilities of the person
  - All other things staying the same
- It's HARD WORK ... SO...
  - 'IS what I have worth keeping???'





# Compensatory

- Providing what the person can't do to 'fill in the gaps so that LIFE GOES ON....
- Supportive
  - Physical environment changes
  - Caregiver cueing and helping changes
  - Expectations change
  - Schedules and routines change to accommodate
- End Point is the Same –
  - How we get there changes



# Palliative



- Comfort Care
- TOP PRIORITY –
  - Honor personal preferences and choices
  - Manage Pain, Distress, Anxiety, Fear, Discomfort
- Identify & seek to meet social, physical, psychological, and spiritual needs
- Let go of FIXING and MOVE ON to Comforting



# Acute Illness vs. Dementia

- You can FIX IT!
- IT gets better & goes away
- It lasts only a SHORT time
- Doctors KNOW what to do to make it better
- The person goes back to how they were pre-illness
- You can't change it
- It keeps getting WORSE No matter what you do!
- It lasts a LONG time – YEARS
- Doctors can offer only help – they can't fix it
- You can't go home again – The person is NEVER the same

# Letting Go vs. Giving Up

- When is it time?
- How will you know?
- What is enough?
- Who should help decide?
- How to balance OLD wishes/promises and the current realities
- How can we make it happen?
- What do we do instead?

# So When Should You Say WHEN!

- Cost versus benefit to the person
- What is *possible* VERSUS what is PROBABLE
- Best Case Outcome – Is it worth it?
- Big Picture for the person
- What did they tell you before?
- Who are they... are they still able to be that person?
- Is this about them or about you or about someone else???

# Positron Emission Tomography (PET)

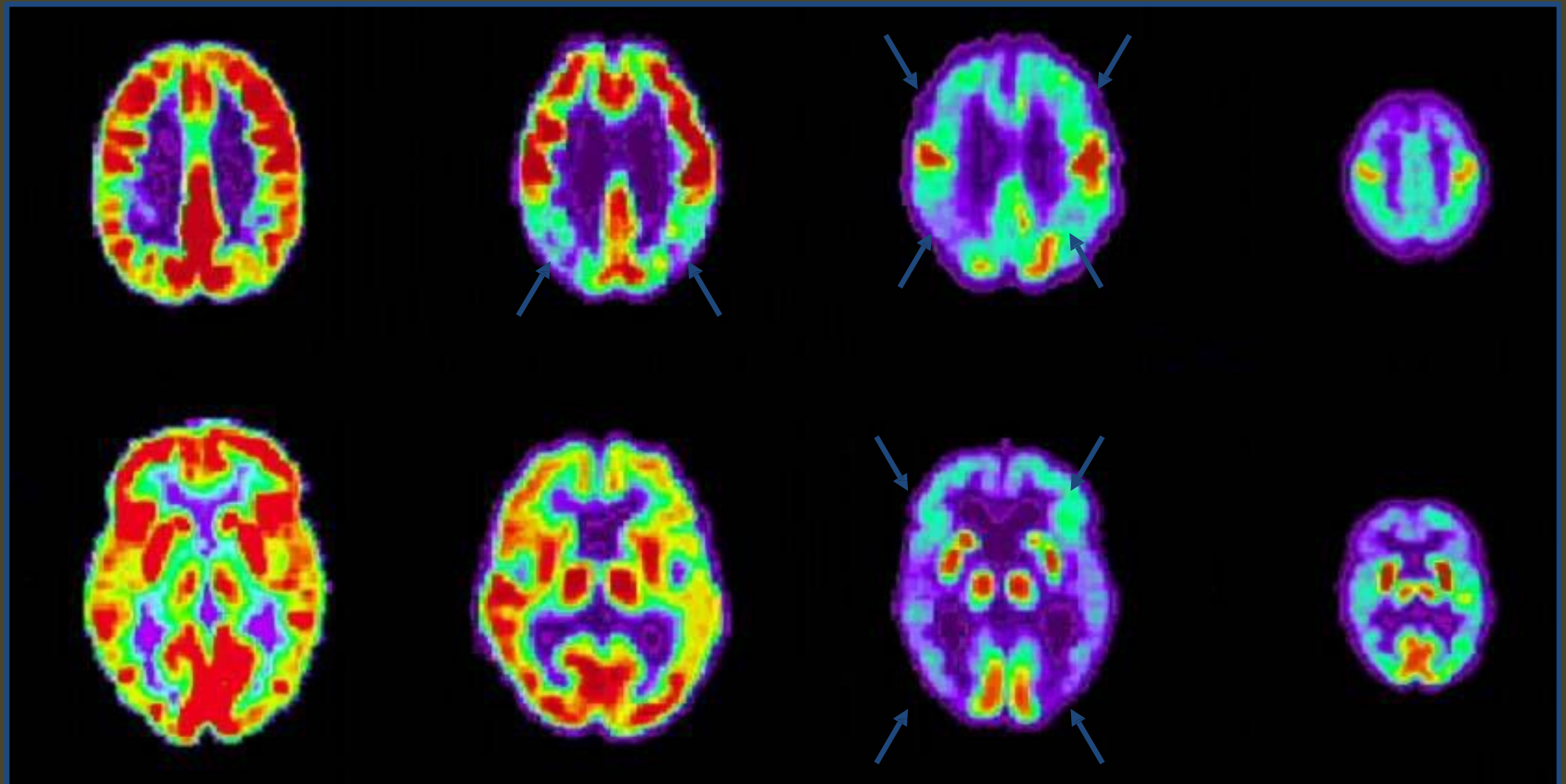
## Alzheimer's Disease Progression vs. Normal Brains

**Normal**

**Early  
Alzheimer's**

**Late  
Alzheimer's**

**Child**







**Normal Brain**



**Alzheimers Brain**



# 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



# Indications that You Are Getting Near the End of the Journey...

**Ambers... Rubies ... Pearls**

# Signs that it may be time...

- Repeated infections
- Antibiotics seem ineffective
- Refusals to eat – even favorite items
- Holding food in mouth – spitting it out
- Soft coughs – wet voice
- Stop moving – curling up
- Sleeping a lot
- Lots of low grade fevers
- Primitive reflexes show up
- Withdrawal from those around – closing eyes
- Drifting in and out
- Says 'good-bye'
- Talks about 'going home'
- Asks permission to go
- Albumin drops very low
- Wounds won't heal
- Can't keep weight on
- Skin and bones
- Moaning – not actively communicating



# What does this Mean?

- Reduce or stop monitoring – if there is not a ‘treatment’ that will be pursued
- Provide what the person wants or needs NOT what is ‘best’ for them
- Provide comfort –
  - Assess for and manage pain, discomfort, or distress
- Give permission to GO....

# What Does This Mean?

- Don't treat infections, IF...
- Don't force INTAKE
- Don't Push Fluids or Put in IVs
- Don't Force movement
- Don't Just 'DO CARE' – and leave alone
- Don't Force Interaction
- Treat the discomfort of infections...
- Offer tastes, textures
- Offer fluids – decide about thickened...
- Use touch, massage, controlled repositioning
- Be present, balance offerings of silence & space with communication & contact

# Changes Near the End

- Primitive reflexes become strong
- Flexor tone pre-dominates – can't move out
- Temperature control is broken
- Skin & bones – not hungry or thirsty
- Spends more time drowsy or 'inside'
- Infections are common
- Startles easily – harder to calm
- Pain – stiffness, immobility, dry mouth/skin...

The care that WORKS is  
COMFORT CARE!!!





# Pearls



Hidden in a Shell

Still & Quiet

Easily Lost

Beautiful - Layered

Unable to Move – Hard to Connect

Primitive Reflexes on the Outside



# Pearls

- The end of the journey is near
- Multiple systems are failing
- Connections between the physical and sensory world are less strong
- We are often the bridge – the connection
- Many Pearls need our permission to go –
  - They are still our moms, dads, spouses, friends
  - They will go in their own time
  - IF we don't try to change what is



## ***Pearl Traits***

- Immobile – can't get started
- Bed or chair bound – frequently falls to side or forward
- Has more time asleep or unaware
- Has many 'primitive' reflexes present -Startles easily
- May cry out or mumble 'constantly'
- Increases vocalizations with distress
- Difficult to calm
- Knows familiar from unfamiliar
- Touch and voice make a difference in behaviors



# Pearl Interests

- Internal cues
- Pleasant and familiar sounds & voices
- Warmth and comfort
- Soft textures
- Pleasant smells
- 'Good' tastes
- Smooth and slow movement
- Just right touch and feel





# Pearl Care Issues

- Not interacting much
- Crying out – can't make needs known
- Skin & hygiene problems
- Weight loss
- Reflexes make care challenging
- Repeated infections
- Not eating or drinking
- Not able to sit up safely



# Visual Cues to Help

- Get into supportive position
- Place your face in the central field of vision
- Make sure light comes from behind the person – into your face
- Bring up lights carefully
- Move slowly so they can follow you
- Place items to be used in central field



# Verbal Cues to Help

- Keep your voice deep & calm
- Put rhythm in your voice
- Tell what you are doing and what is happening while you give care
- Reflect emotions you think you see
- Offer positive comments & familiar phrases as you offer care
- Quiet down, if signaled to do so



# Touch Cues to Help

- Use firm, but gentle palm pressure at joints to make contact
- Always try to maintain contact with one hand while working with the other
- Once physically connected keep it
- Use flats of fingers and palms for care
- Always use hand under hand when doing something 'intense'

# What IF There are NO WORDS?

- Observe their CUES to you
  - Visual
  - Auditory
  - Touch & movement – or lack of it
  - Olfactory – any unusual smells or odors
  - Taste – changes in eating/drinking/preferences
- Use your other cueing systems
- Make your cues BIGGER & SIMPLER & SLOWER

# Teepa Snow and Pearl



# Upcoming Webinars

**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



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

*Thank you for your participation!*

# 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/](http://www.catholiccharitieshawaii.org/dementia/)

Visit [www.halekuike.com](http://www.halekuike.com) learn about future Positive Approach to Care (PAC) workshops!

To learn more about PAC visit [www.teepasnow.com](http://www.teepasnow.com)



[halekuike.com](http://halekuike.com)