



Challenging Situations in Dementia Care Putting Together the Pieces of the Puzzle

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March 30, 2022

Sponsored by



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HAWAI'I
CIRCLE OF CARE FOR DEMENTIA



Supported in part by grant No. 90ADPI0011-01-00 from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy. The grant was awarded to Catholic Charities Hawaii for the Alzheimer's Disease Program Initiative.



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.



Today's Agenda

- What are challenging behaviors?
- What makes these situations happen?
Examining the 6 pieces of the puzzle.
- What can you control? Or Not?
- Stakeholders – 4th Piece of the Puzzle
- Environment – 5th Piece of the Puzzle



When we talk situations,

What are we talking about?

- **Think about the situations that come to mind**
- **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

Introduction: Beliefs

- The relationship 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

Why Is Life So Difficult for Those Involved?

■ **MANY** abilities are affected

- Thoughts
- Words
- Actions
- Feelings

■ **It is variable**

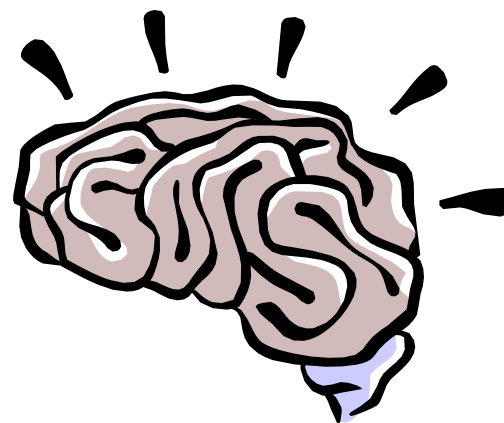
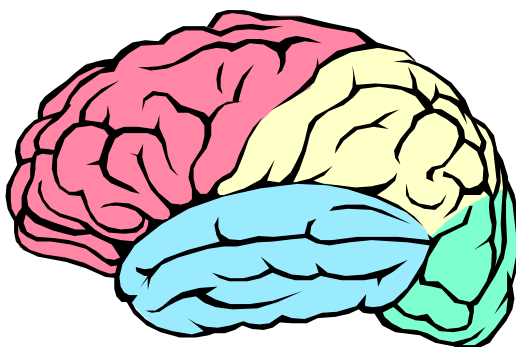
- Moment to moment
- Morning to night
- Day to day
- Person to person
- Place to place

■ **Some changes are predictable BUT complicated**

- Specific brain parts
- Typical spread
- Some parts preserved

■ **It is progressive...**

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



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

What can you control? Or Not?

Control

- The environment – setting, sounds, sight
- The whole day and how things fit together
- How helper helps with approach, behaviors, words and reactions

Not Control

- The person and who they have always been with personality, preferences and history
- The type and level of impairment now
- Other medical conditions and sensory status

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™ 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 **F**riendly and **F**amiliar?
- Is it **F**unctional and **F**orgiving?
- Sharing **S**pace: Am I comfortable with public, personal, and intimate interaction?
- Response to **S**ensation: What happens when I see, feel, hear, smell, or taste something?
- Sensitivity to **S**urfaces: Notice responses to textures I touch, stand, or walk on.
- **S**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
- Leisure: 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

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- Functional and Forgiving?
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- Leisure: preferred fun and playful
- Work: one's self-care
- Restoration: calm and recharges
- Waiting: not natural or comfortable
- Where or What: becomes curious about a person's experience of place and time of day

**INTRODUCED IN
CHALLENGING
BEHAVIORS
WEBINAR**

**CHALLENGING
BEHAVIORS/
ACTIVITIES
WEBINARS**

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Stakeholders – 4th Piece of the Puzzle

Who are the stakeholders?

YOU...

AND OTHERS

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



Take a moment jot down the stakeholders in your person living with dementia's life

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 react or over-react instead of responding

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 yourself and 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

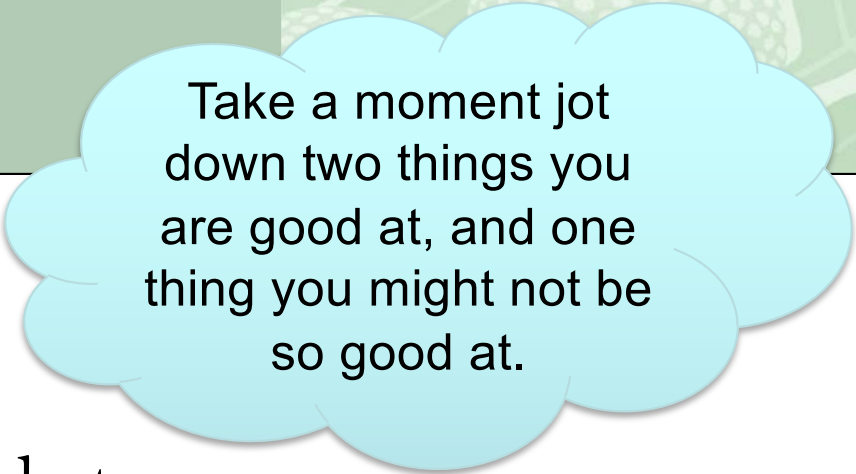
- You need HELP
 - From someone who understands
- You need TIME
 - Truly away—physically, emotionally and spiritually
- You need to try to LISTEN!!!

Let Go:

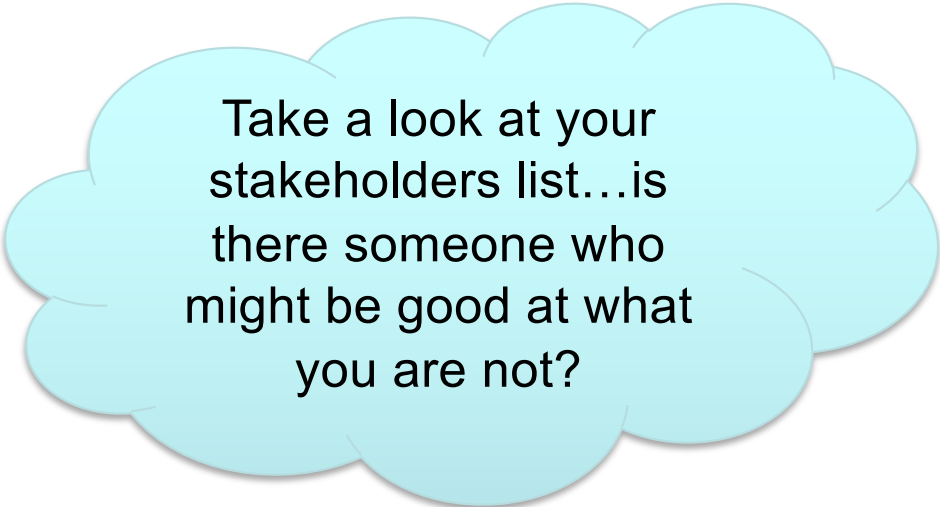
- How it “used to be”
- How it “should be”
- How you “should be”
- I am who I was, but I’m different!

Identify

- What you're good at
...and what you're not
- What other stakeholders are good at
...and what they are not
- Who can help
...and how they can help
- What really matters,
finding priorities
- Not EVERYONE is meant to
be a care partner for someone with dementia!



Take a moment jot
down two things you
are good at, and one
thing you might not be
so good at.



Take a look at your
stakeholders list...is
there someone who
might be good at what
you are not?

Environment – 5th Piece of the Puzzle

Physical – Sensory – Social

Four F's

- Friendly
- Familiar
- Functional
- Forgiving

Four S's

- Space
- Sensations
- Surfaces
- Social

Environment

Dementia Friendly Environments

- Physical surroundings can work well, or pose great challenges...both at home and in long-term care settings
- Each area of our surroundings has a purpose and can be set up to encourage that purpose.
 - Kitchen and Dining
 - Bedroom
 - Toilet and Bathroom
 - Gardens
- Lighting
- Assistive Technology
- Relaxing Environment
- Noise Levels



<https://www.scie.org.uk/dementia/supporting-people-with-dementia/dementia-friendly-environments/>

Environment

Visual Information

- What do I see?
- Am I noticing what you want me to focus on?
- Do I recognize what it is?
- Do I know how what do with it?
- If the answer is no, what is the consequence?
- If the answer is no, what can we change or make adjustments to?

Seeing through their eyes...and brains..

- Highlight what you want the person to notice
- Minimize or remove from view what you don't want the person to focus on



High contrast color
between door and
door frame and wall



Matching color door, door frame and wall



Which kinds of doors would you
want to highlight or minimize?

Seeing through their eyes...and brains..

- Finding the bathroom, why is it so hard?!
- My wayfinding is broken...I don't have a map in my head like before



Is this the bathroom
or a different kind
of room?



A visual cue using words
and images might help

Leaving the door open so
toilet is visible is a visual
cue too

Are there other
rooms that I have
trouble finding that
we could try putting
visual cues on?

Seeing through their eyes...and brains..

- Now where is that darn toilet?! Why is it so hard to find?
- I have a hard time noticing things that blend into backgrounds, or are surrounded by clutter



High contrast
toilet seat to
stand out visually



Contrasting
floor and wall
colors to make
white toilet
stand out from
all angles

Seeing through their eyes...and brains..

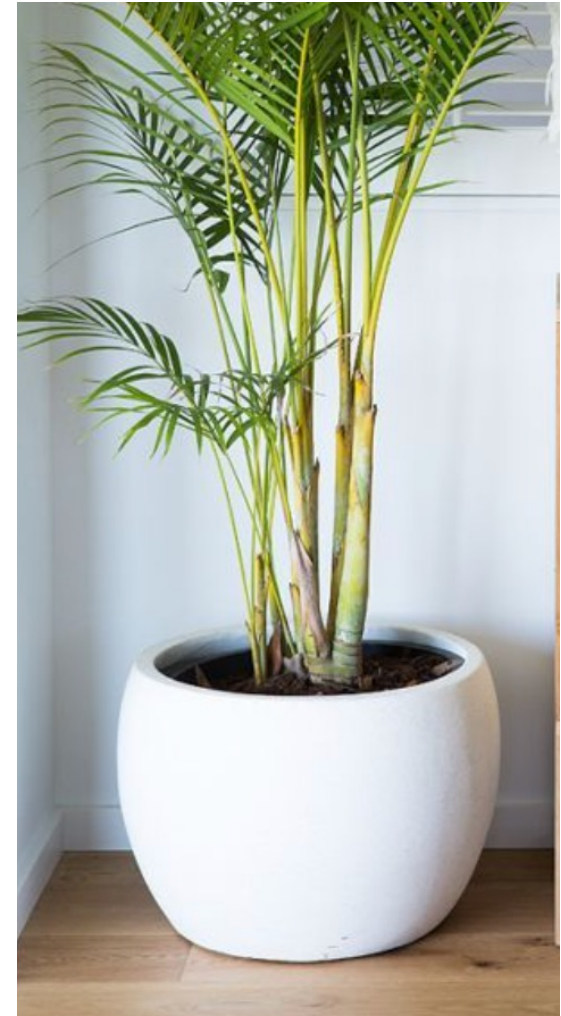
- Is this the toilet? Sure looks like one!
- I have trouble with object recognition.



This might be the toilet....



Or is it this?



Or is it this?
Or maybe this is a urinal?

Seeing through their eyes...and brains..

- Contrast is your friend!
- Make what you want noticed stand out!



Which bar of soap is easier to see?



Which grab bar is easier to see?



Which cup is easier to see?

Environment

Small changes can make a big difference

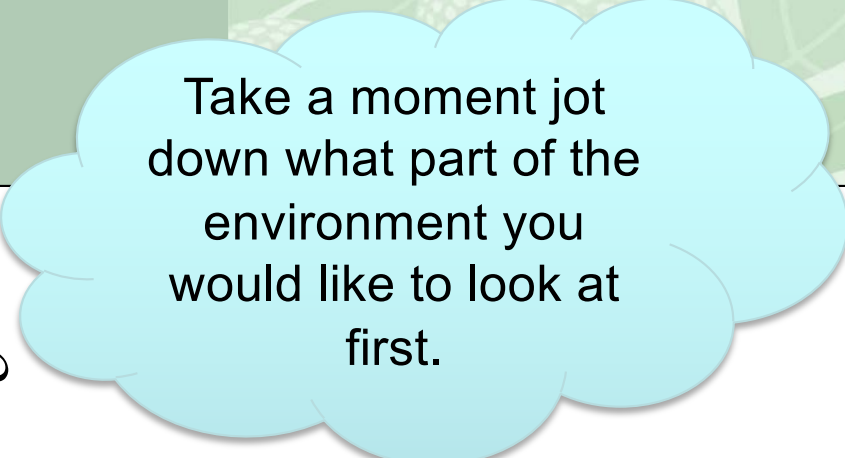
- It is OK to start with something very small.
- If your change doesn't work at first, step back and take a fresh look, make adjustments.
- It is hard to look objectively at our own familiar environment. Enlist a set of fresh eyes to help you
- Remember that the “mistakes” that the person living with dementia is making can be clues to how they are perceiving their environment



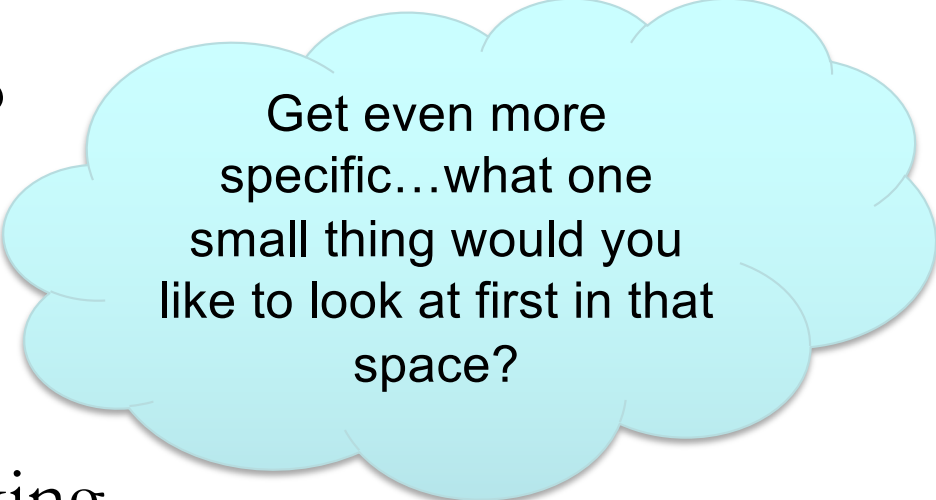
Red sticker put on switch plate to make it stand out from wall and switch

Identify

- What part of the environment is the place of frequent challenges?
- What specific challenging situations are happening in that space?
- Be a detective and take time to observe the environment without judgement.
- Enlist a fresh set up eyes to help you look. Sometimes making a recording and viewing it back can help you see and hear things you wouldn't notice in real time.



Take a moment jot down what part of the environment you would like to look at first.



Get even more specific...what one small thing would you like to look at first in that space?

True or False?

- False** People living with dementia can control their challenging behaviors if they really want to.
- False** Challenging situations can't be helped because people living with dementia are so confused.
- True** It is important for caregivers to build a support team, both for themselves and their loved one, as early as possible.
- False** A dementia-friendly environment must incorporate beautiful interior design.
- True** Environmental changes can help a person living with dementia maintain independence and reduce challenging behaviors.

Thank you!

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

Visit bit.ly/HKworkshops learn about future FREE dementia webinars on the first Wednesday of each month.

Visit halekuike.com to learn about Hale Ku'ike's memory care homes and view 2021 webinar recordings.

To learn more about Positive Approach to Care visit www.teepasnow.com

To view recordings of 2020's dementia webinars visit Catholic Charities' Hawaii Circle of Care for Dementia www.catholiccharitieshawaii.org/dementia/








The REACH Community Dementia Caregiving Program is now available in Hawaii!

Resources for Enhancing Alzheimer's Caregiver Health



Are you a caregiver in the home for someone living with Alzheimer's disease, another related dementia or memory loss?

REACH Community is a highly successful evidence-based caregiver training & support program that has been proven to:

-  **Improve overall caregiver self-care, confidence, health, and emotional well-being**
-  **Reduce feelings of stress and burden from caregiving**
-  **Improve caregiver management of problem behaviors related to dementia**
-  **Empower the caregiver with self-care and self-efficacy techniques and strategies**
-  **Ensure the highest quality of care & safety possible for the person with memory loss**

The 4- session training is FREE and personalized to your needs.

Sessions are offered on a one-to-one basis by a Certified Hawaii REACH Community Coach in your home, by telephone, or using a telehealth virtual connection – whatever is agreed upon by you and your assigned Coach. You will receive a Caregiver Manual as part of the program. REACH increases caregivers' knowledge of dementia and the caregiving role and teaches them skills to help themselves and their loved one.

**For more information, call Catholic Charities Hawaii Senior Intake Line at 527-4777
Or email info@catholiccharitieshawaii.org**



The Hawaii REACH Community Program in Hawaii is made possible by a grant to Catholic Charities Hawaii from the Administration on Community Living/Administration on Aging for the *Alzheimer's Disease Program Initiative*