



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

---

**Dorothy Arriola Colby**

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

June 17, 2023

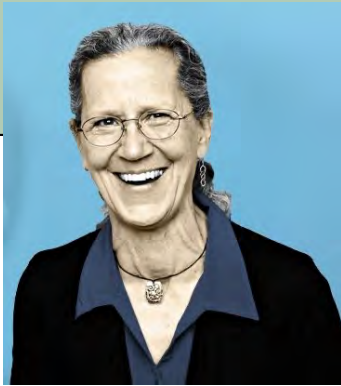
# Sponsored by



CATHOLIC CHARITIES  
HAWAI‘I  
CIRCLE OF CARE FOR DEMENTIA



These caregiver workshops are made possible by the Elderly Affairs Division of the City & County of Honolulu through Federal Older Americans Act funding.



## Teepa Snow's Philosophy

# Positive™ Approach to Care

## 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 – 4<sup>th</sup> Piece of the Puzzle
- Environment – 5<sup>th</sup> Piece of the Puzzle
- Time – 6<sup>th</sup> 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**

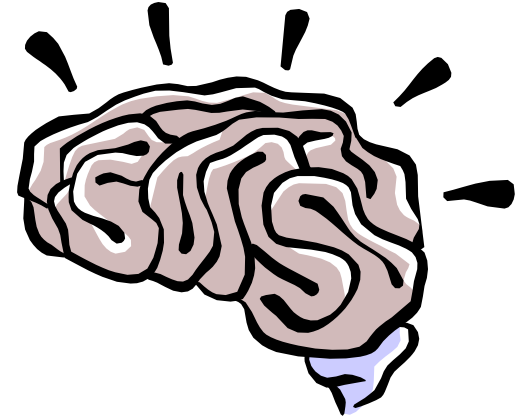
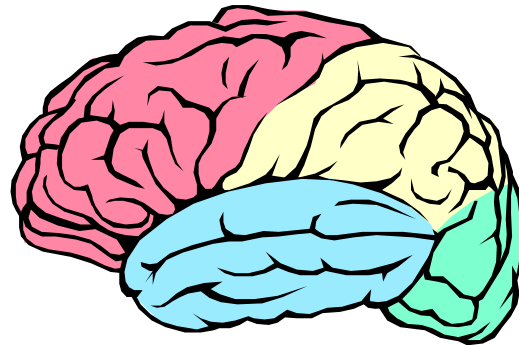
- Moment to moment
- Morning to night
- Day to day
- Person to person
- Place to place

- **Some changes are predictable BUT complicated**

- Specific brain parts
- Typical spread
- Some parts preserved

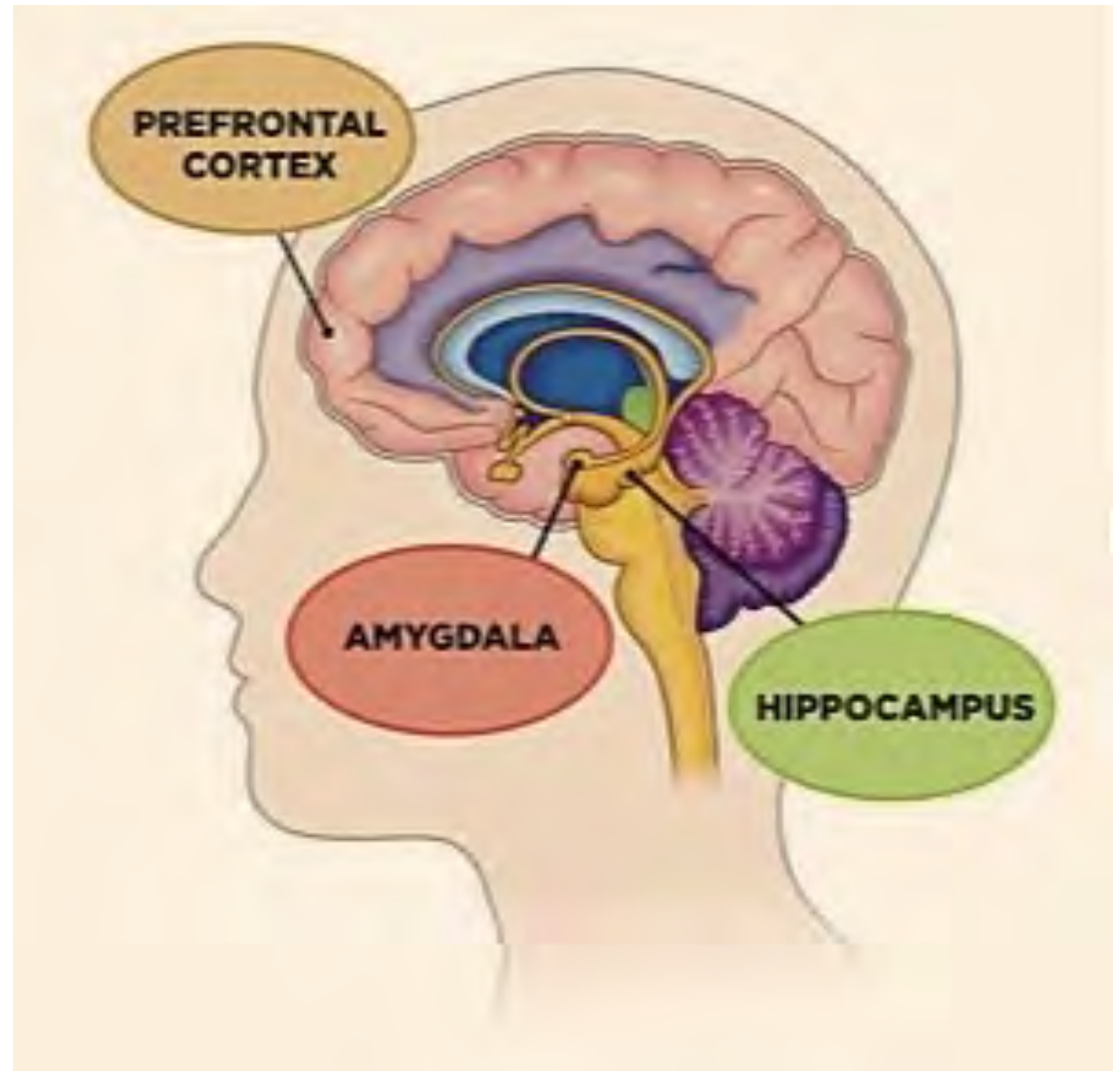
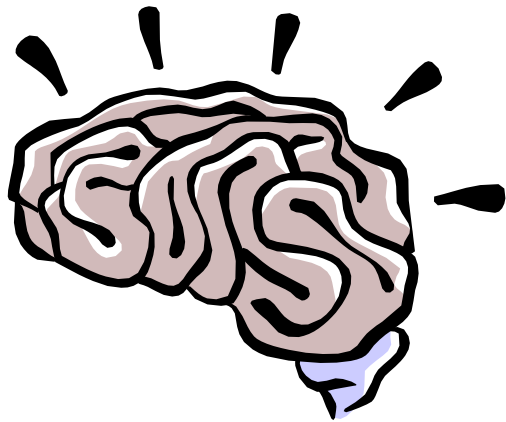
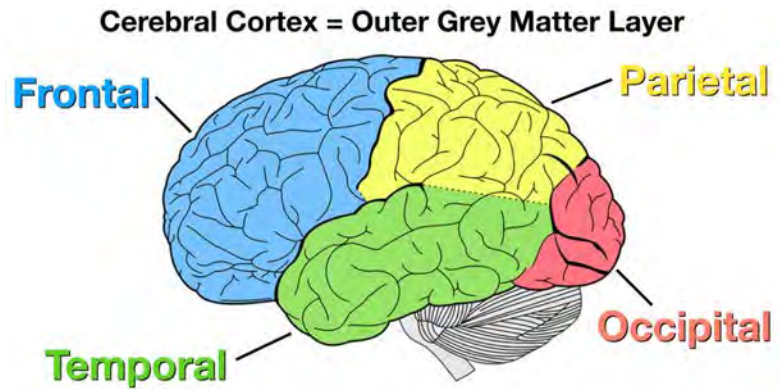
- **It is progressive...**

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





# It's All About Brain Change



# 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

# Stakeholders – 4<sup>th</sup> 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

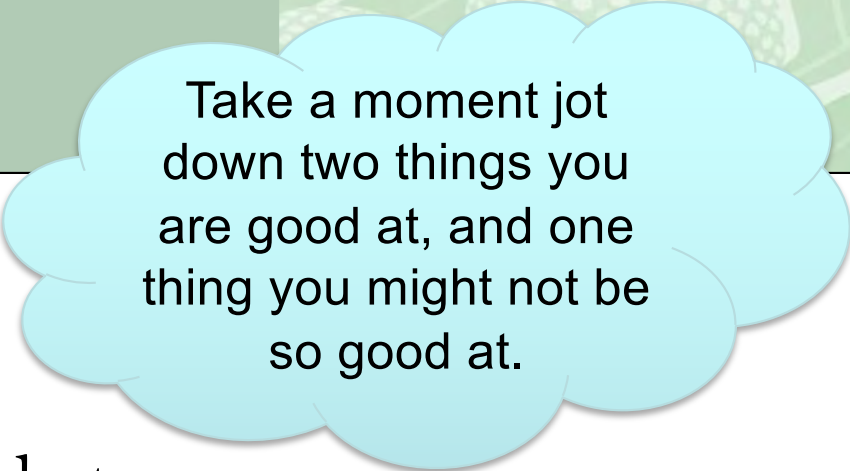
- You need HELP
  - From someone who understands
- You need TIME
  - Truly away—physically, emotionally and spiritually
- You need to try to LISTEN!!!

# 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 – 5<sup>th</sup> 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

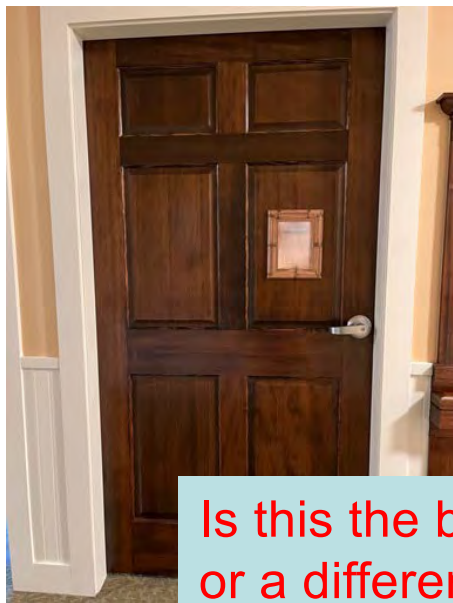


Which kinds of doors would you want to highlight or minimize?

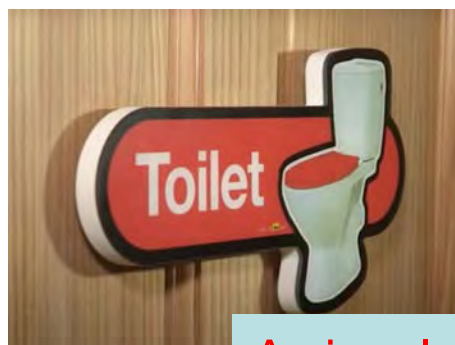


# Seeing through their eyes...and brains..

- 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?



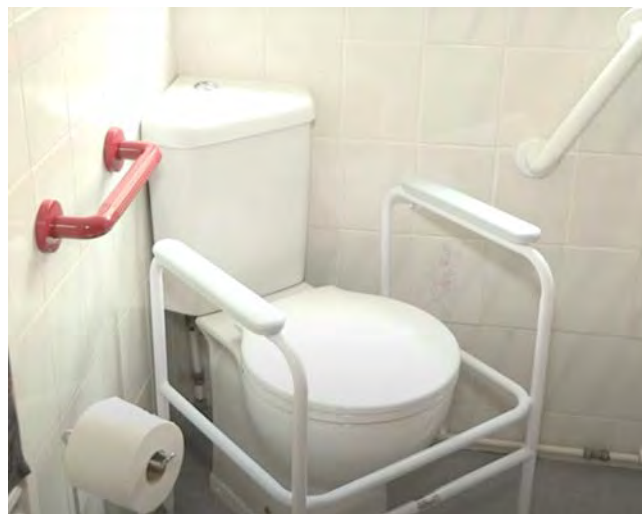
Or is it this?  
Or maybe this is a urinal?

# 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?

# Time – 6<sup>th</sup> Piece of the Puzzle

## How do we fill our day?

- 1. Productive** – Activities that make you feel valued
- 2. Leisure** – Having fun! Activities that meeting social & solitary preferences, can be active or passive options
- 3. Self Care** – Taking care of the body and mind
- 4. Rest/Restoration** – Recharging your batteries

# How do YOU fill YOUR day?

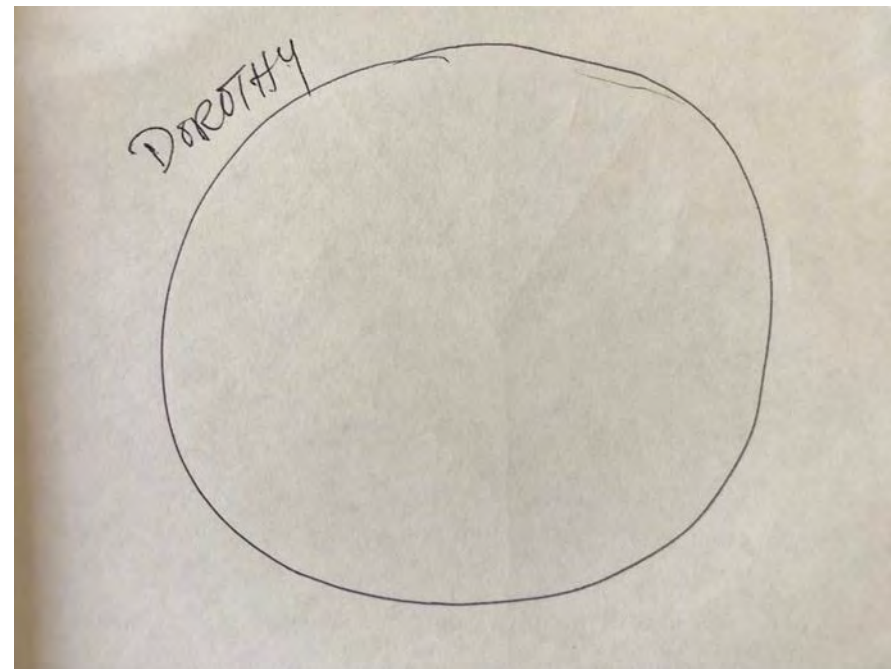
1. Draw a circle
2. Make pie chart showing your 24 hour day

**Productive** – Activities that make you feel valued

**Leisure** – Having fun! Activities that meeting social & solitary preferences, can be active or passive options

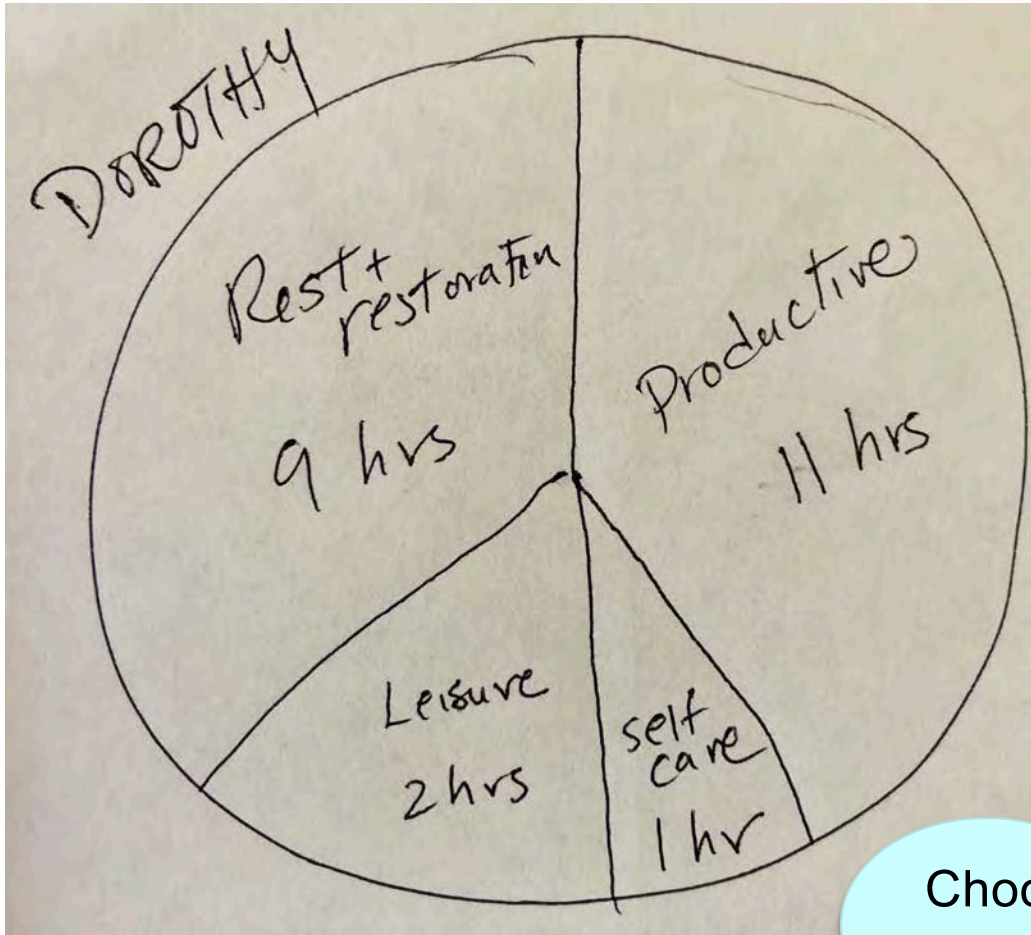
**Self Care** – Taking care of the body and mind

**Rest/Restoration** –  
Recharging your batteries





# Dorothy's typical day



Take a moment to look at your pie chart. Which wedge would you like to make bigger?

Get even more specific...Jot down ONE small thing you can do for yourself in that category?

Choose something that only takes 10-15 minutes at most. Small achievable goals add up over time!

# Productive Activities

- Helping another family member or resident
- Helping staff members
- Completing community tasks
- Completing home/place care tasks
- Making something
- Sorting things
- Fixing things
- Building things
- Caring for things
- Counting things
- Folding things
- Marking things
- Cleaning things
- Taking things apart
- Moving things
- Cooking/baking
- Setting up/breaking down
- Telling others 'how to'



# Leisure Activities

## Active

- Socials
- Sports
- Games
- Dancing
- Singing
- Visiting
- Hobbies
- Doing, Talking, Looking

## Passive

- Entertainment event
- Sport Program/event
- Presenters
- Shopping Mall/Beach Sitting
- TV programs – watched
- Activity watchers
- Being done to



# Self-Care & Wellness Activities

## Cognitive

- Table top tasks (i.e. matching, sorting, organizing)
- Table top games (i.e. Cards, board games, puzzles).
- Group games (i.e. Categories, crosswords, word play, old memories).

## Physical

- Exercise and/or Walking
- Strengthening tasks
- Coordination tasks
- Balance tasks
- Flexibility tasks
- Aerobic tasks
- Personal care tasks



# Rest & Restorative Activities

- Sleep – Naps
- Listen to quiet music with lights dimmed
- Look at the newspaper
- Look at a calm video on TV screen
- Rock in a chair
- Swing in a porch swing
- Walk or sit outside
- Listen to reading from a book of faith
- Listen to poetry or stories
- Listen to or attend a worship service
- Stroke a pet or animal
- Stroke fabric
- Get a hand or shoulder massage
- Get a foot soak & rub
- Listen to wind chimes
- Aroma therapy



## Which of these activities does your loved one living with dementia do during the day?

- Watch television (on as background entertainment)
- Read -- magazines, newspaper, etc.
- Watch the news or nature show on TV
- Play board games, jigsaw puzzles
- Exercise – walking, dancing, physical therapy
- Do brain puzzles – crossword, sudoku, word search, etc.
- Help with household chores – laundry, cooking, cleaning
- Garden and do yard work
- Take naps

# How does your loved one with dementia fill their day?

1. Draw a circle
2. Make pie chart showing their 24 hour day

**Productive** – Activities that make you feel valued

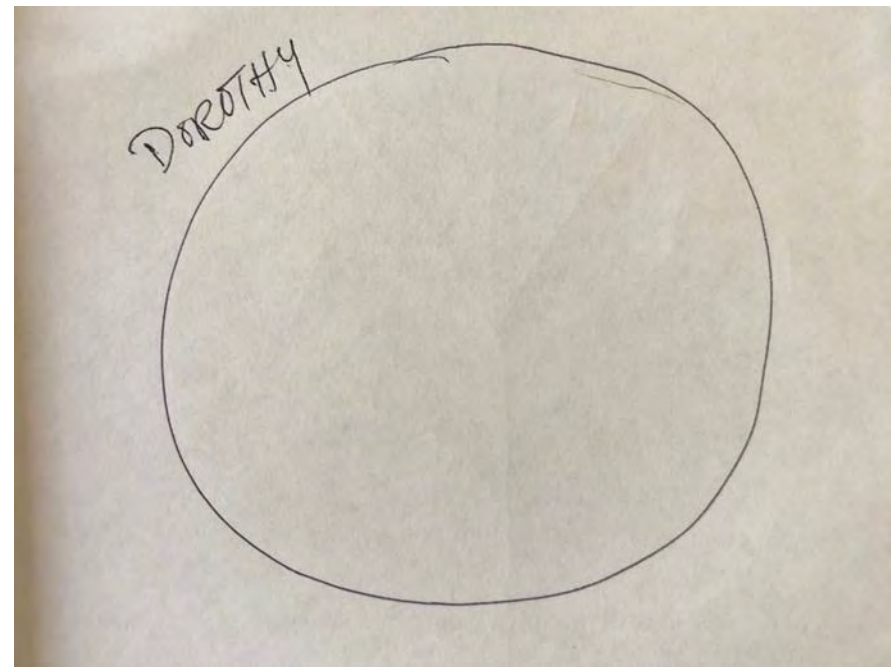
**Leisure** – Having fun! Activities that meeting social & solitary preferences, can be active or passive options

**Self Care** – Taking care of the body and mind

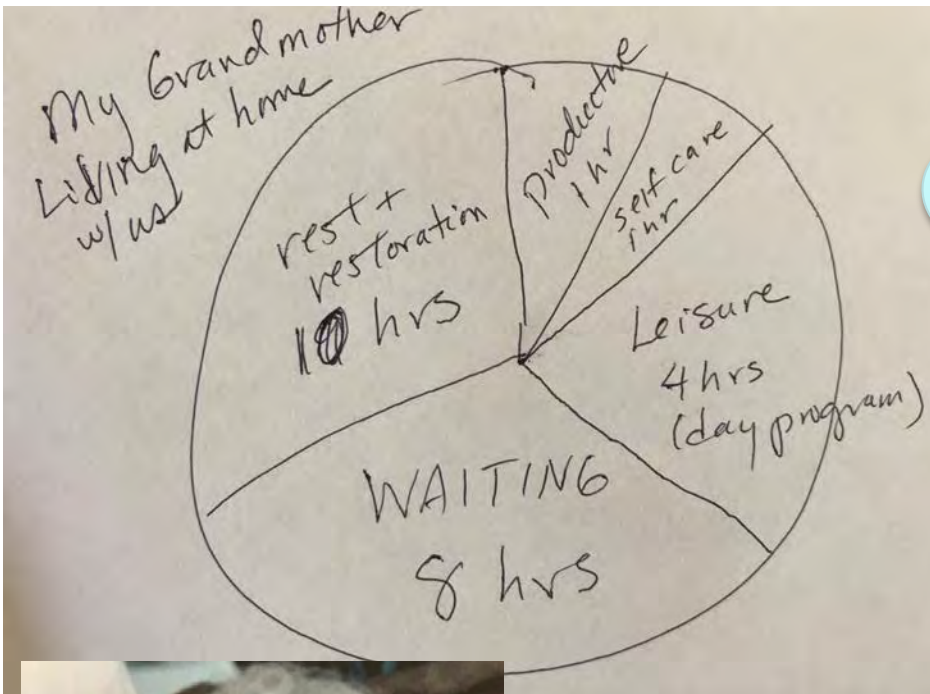
**Rest/Restoration** –  
Recharging your batteries

**ADD a new one – WAITING**

...waiting for help, waiting for a meal, waiting for activities to start...



# My Grandmother Dorothy's typical day



Take a moment to look at your loved one's pie chart. Which wedge would you like to make bigger?

Get even more specific...Jot down ONE small thing you can help them do today in that category?

Choose something that only takes 10-15 minutes at most. Small moments of engagement add up over time!



# Design Each Day

**Make a schedule and follow it**

Be structured, BUT allow flexibility.

**Create Group Schedules**

**BUT**

also build *individual* schedules.

Not everything is for everybody!



8 am – coffee circle  
8:30 – songs of joy  
9 am – time to 'go'  
9:15 – take a hike – walk'n'roll  
10 am – cool down & stretch  
10:30 – watering hole  
11 am - 'use your brains' games  
11:30 - time to 'go' – wash up  
11:45 – 'set-'em up' crew  
12 noon – let's eat  
12:30 – clean up crew  
1 pm – music and meditation  
1:30 – coupons clipping  
2 pm – time to 'go'  
2:15 – let's dance

**Offer a variety of activities every day**

Leisure, work, rest, self-care, groups and 1:1, passive and active

**Create a FLOW for the day**

Build up and then slow down  
Circadian rhythms

**Build a Foundation of Familiar and Favorite Activities**

Add a few special events and something different

# Sample Engagement Schedule



## Resident Engagement Schedule

Daily leisure, productive, wellness, self-care, rest and restoration activities.  
This is a sample schedule. Daily activities will vary.

7:30-9:00 am	<b>BREAKFAST</b>
9:00 am	<p><b>Greet the Day Together!</b></p> <p><b>Sing-Along to Familiar Anthems</b> <i>Star Spangled Banner, Hawai'i Pono'i, and God Bless America</i></p> <p><b>Chit-Chat</b> <i>Historical and news events, seasonal topics, weather</i></p>
9:30 am	<p><b>Exercise</b> <i>Movements for range of motion, flexibility, balance and strength</i></p>
10:15 am	<p><b>Garden Walk</b> <i>Get outside for some sunshine and smell the flowers</i></p>
10:30 am	<b>SNACK</b>
11:00 am	<p><b>Creative Corner</b> <i>Arts &amp; crafts projects to reflect seasons, holidays, different cultures and interests</i></p>
12:00 pm	<b>LUNCH</b>
1:00 pm	<p><b>Rest &amp; Restoration</b> <i>Table-top tasks (matching, sorting, cutting), quiet music, hand massage, manicures, reclining, napping</i></p>
1:30 pm	<p><b>Taking Care of Business</b> <i>Folding laundry, baby &amp; pet care, cooking, helping prepare supplies for future activities</i></p>
2:15 pm	<p><b>Brain Games</b> <i>Cognitive exercises (puzzles, trivia, memory and word games) and table games (bingo, board and card games)</i></p>
3:00 pm	<b>SNACK</b>
3:30 pm	<p><b>Music &amp; Movement</b> <i>Seated dance, singing, and musical performances</i></p>
4:30 pm	<p><b>Garden Walk</b> <i>Outdoor walk before dinner to stimulate the senses Washing up for dinner</i></p>
5:00 pm	<b>DINNER</b>
6:30 pm	<p><b>Evening Cinema</b> <i>Dining room is transformed into a movie theater for a movie from the 1940s-early 1960s.</i></p>

# Engagement Tips

- Offer options that support some life-long skills/abilities/interests (i.e. hotel housekeeper, child care worker, engineer, marathon runner).
- Offer information on purpose/value and life roles (i.e. employment, family history, etc.)
- Note past experience or abilities that prompted the “ask”.
- Use “either/or” not yes/no options.
- Rest breaks can involve quiet and peaceful stillness, chatting and snacks/drinks.
- Heavy work & movement without words.
- Circadian rhythms can drive engagement patterns. Look for changes that may signal distress

# More Engagement Tips...

- Support old connections with newer technology (i.e. Facetime, Skype, ZOOM).
- Consider separating those who just play to play and those who play to win (i.e. competitive vs. having fun).
- Be happy with “satisfied” or “less sad/lonely”.
- Some individual’s find joy in work.
- Life-long exercise, routines, and cognitive stimulation activities are easiest to start with.
- Try variations, make it short and simple – then back to basics.
- Expect some push back and say “I’m sorry a lot!” – mean it
- Get permission for changes before modifying.

# Engagement Resources

**Positive Approach to Care** • [www.teepasnow.com](http://www.teepasnow.com)

15-min Video: <http://bit.ly/PACMeaningfulEngagement>

Dementia Education and Skill Building Resources

**Golden Carers** • [www.goldencarers.com](http://www.goldencarers.com)

Activities Planning & Resources

Free & Paid Subscription options

**AARP Memory Activity Book**

<http://bit.ly/AARPMemoryActivities>

**Supplies Sources**

Ben Franklin – arts and crafts

Amazon.com

Nasco • <https://www.enasco.com/c/Senior-Activities-Nasco>

Paradise Galleries, realistic baby dolls • <https://www.paradisega>

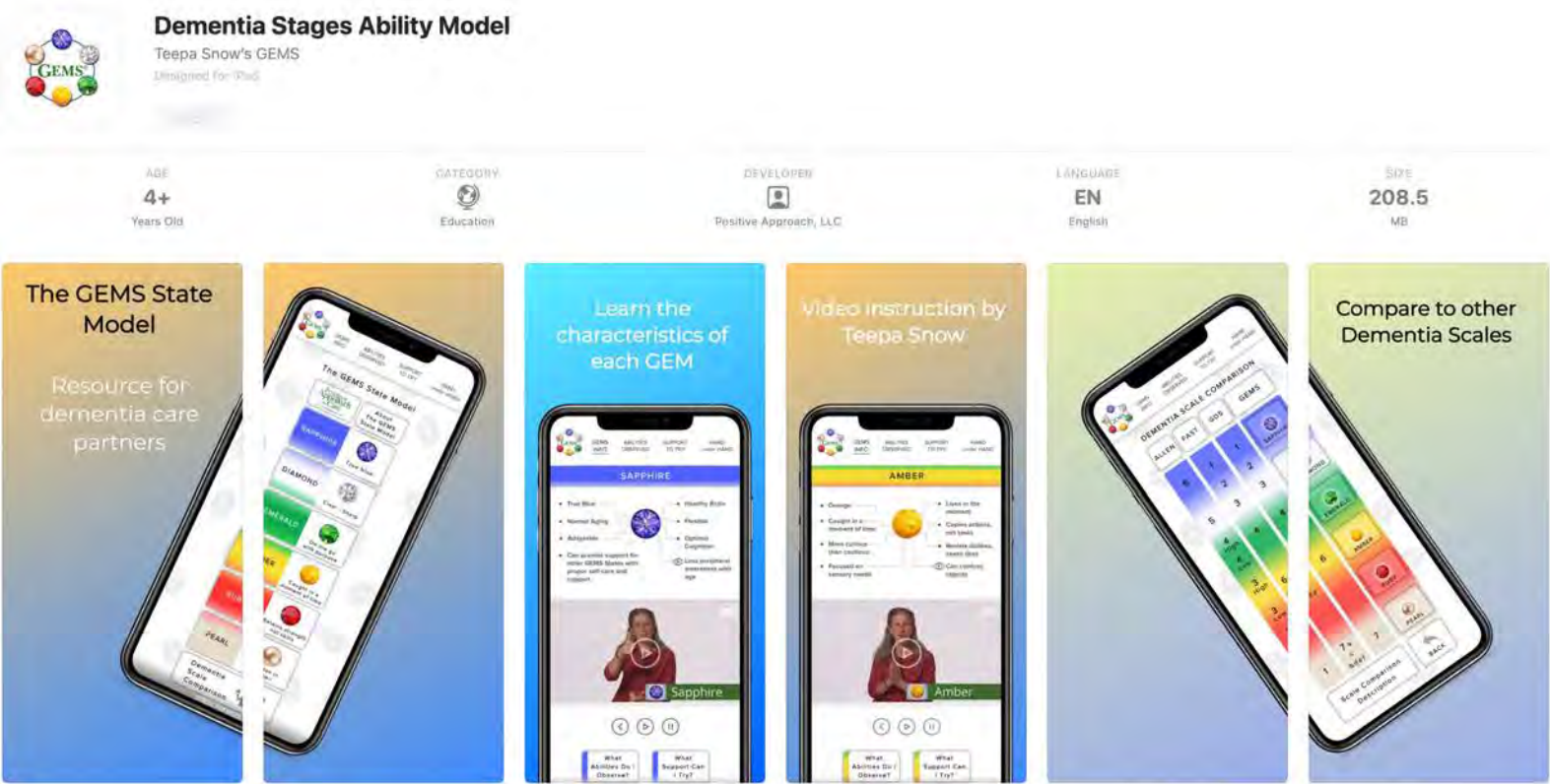


**Supplies don't have to be purchased!** There are so many things around the house that can become a regular part of activities and engagement!

**Friends of the Library of Hawaii**

- Very inexpensive books, puzzles, art and coloring, music, LPs, DVDs, and more!!
- Bookstores at many library branches, Kaneohe Library Bookstore is a hidden gem!!
- Annual Sale at Ward Village – June 17-25, 2023

# GEMS App – Apple & Google



**Apple** – [bit.ly/GEMSappApple](https://bit.ly/GEMSappApple)

**Google** – [bit.ly/GEMSappGoogle](https://bit.ly/GEMSappGoogle)



# Next Workshop

Session 6 – Saturday, July 29th, 10am – noon

## Dining with Dementia Bringing Joy to the Table



- Learn to understand visual, verbal and physical interaction skills to optimize engagement in meals.
- Learn interventions to support meals and drinks that provide pleasure and interest, while minimizing risk and optimizing nourishment and hydration.
- Explore ways to address concerns and reach consensus regarding late life care and end of life support when eating and drinking are becoming no longer safe or desired.

# 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](http://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>.



# QUESTIONS ??😊

---