



Activities in Dementia Care: Filling the Day with Meaning

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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

- Knowing the person
- Review of the GEMS States Model
- Filling the Day with Meaning
- Key Engagement Opportunities
- Making a Schedule
- Engagement Resources
- Q&A

Dementia

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; Batters disease)
- Toxicity: induced by long-term exposure
 - Wernicke-Korsakoff Syndrome (WKS; Alcohol-induced dementia)
 - Methamphetamine induced

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.**

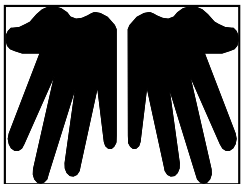
How you can help...



- Sight of Visual cues.



- Verbal or Auditory cues.



- Touch or Tactile cues.

To Know the Person...

- What do You KNOW about their past?
- What type of Dementia do they have?
- What else do they HAVE?
- What Level are they at?
- What is NOT the same as usual... be specific!!!

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





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

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



Six Pieces of the Puzzle

<p><u>The Person</u></p> <p>Think of the person first and the brain change second. Consider:</p> <ul style="list-style-type: none"> • <u>Who they were</u> <p>Personal history: joys/traumas</p> <p>Life Roles: professional/family</p> <ul style="list-style-type: none"> • <u>Who they are becoming</u> <p>Preferences: likes/dislikes</p> <p>Personality traits</p> <p>Core values</p>	<p><u>Fitness, Health, Wellness</u></p> <p>Remember other health challenges and previous lifestyle choices contribute to the situation. Consider:</p> <ul style="list-style-type: none"> • Ability to intake food/fluid • Medication/supplement side effects • Emotional/psychological stressors • Sensory system function/sensitivity • Personal healthy beliefs/choices • Recent change: acute illnesses 	<p><u>Brain Change</u></p> <p>Dementia is a syndrome, a collection of symptoms. Consider:</p> <ul style="list-style-type: none"> • 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
<p><u>Stakeholders</u></p> <p>All individuals who interact with a person living with dementia (PLWD). Consider their:</p> <ul style="list-style-type: none"> • History with PLWD • Awareness of the <i>whole</i> situation • Knowledge of a changing brain • Hands on dementia skill training • Current relationship with PLWD • Personal Agenda 	<p><u>Environment</u></p> <p>Brain change impairs the nervous system and affects experience. Consider the four Fs and Ss of a setting:</p> <ul style="list-style-type: none"> • Does it feel Friendly and Familiar? • Is it Functional and Forgiving? • Sharing Space: Am I comfortable with public, personal, and intimate interaction? • Response to Sensation: What happens when I see, feel, hear, smell, or taste something? • Sensitivity to Surfaces: Notice responses to textures I touch, stand, or walk on. • Social experiences: As my tolerance changes expectations of me will need modifying 	<p><u>Time</u></p> <p>Are days structured and meaningful for a person? Notice if someone is experiencing time differently than you are. Consider these categories of time:</p> <ul style="list-style-type: none"> • <u>Productive</u>: offers value and purpose • <u>Leisure</u>: preferred, fun and playful • <u>Wellness</u>: gives self-care • <u>Restorative</u>: calms and recharges • <u>Waiting</u>: not natural or comfortable • <u>Where or What</u>: becomes curious about a person's experience of place and time of day

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?

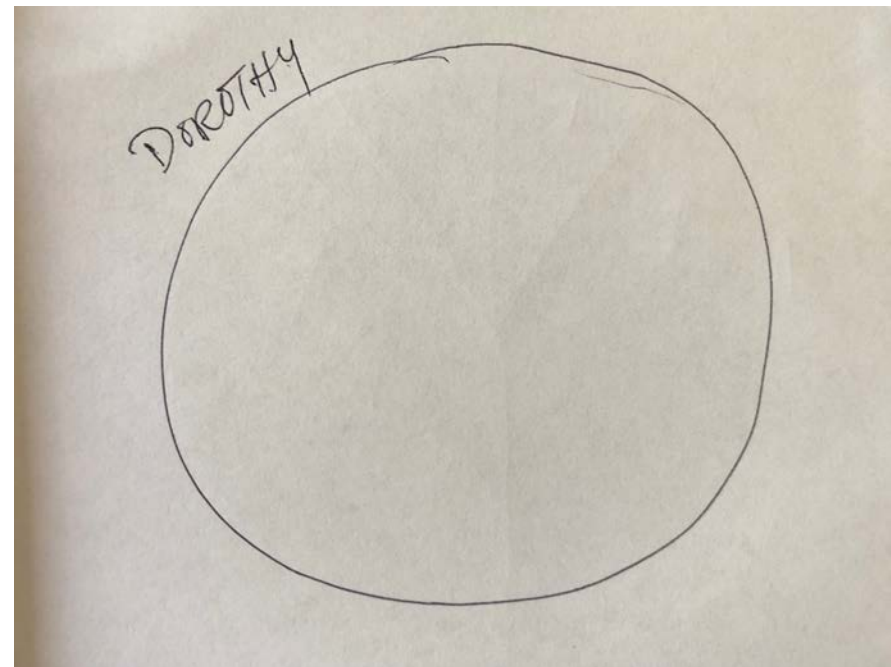
1. Draw a circle
2. Make pie chart showing your 24 hour day

Productive – Activities that make you feel valued

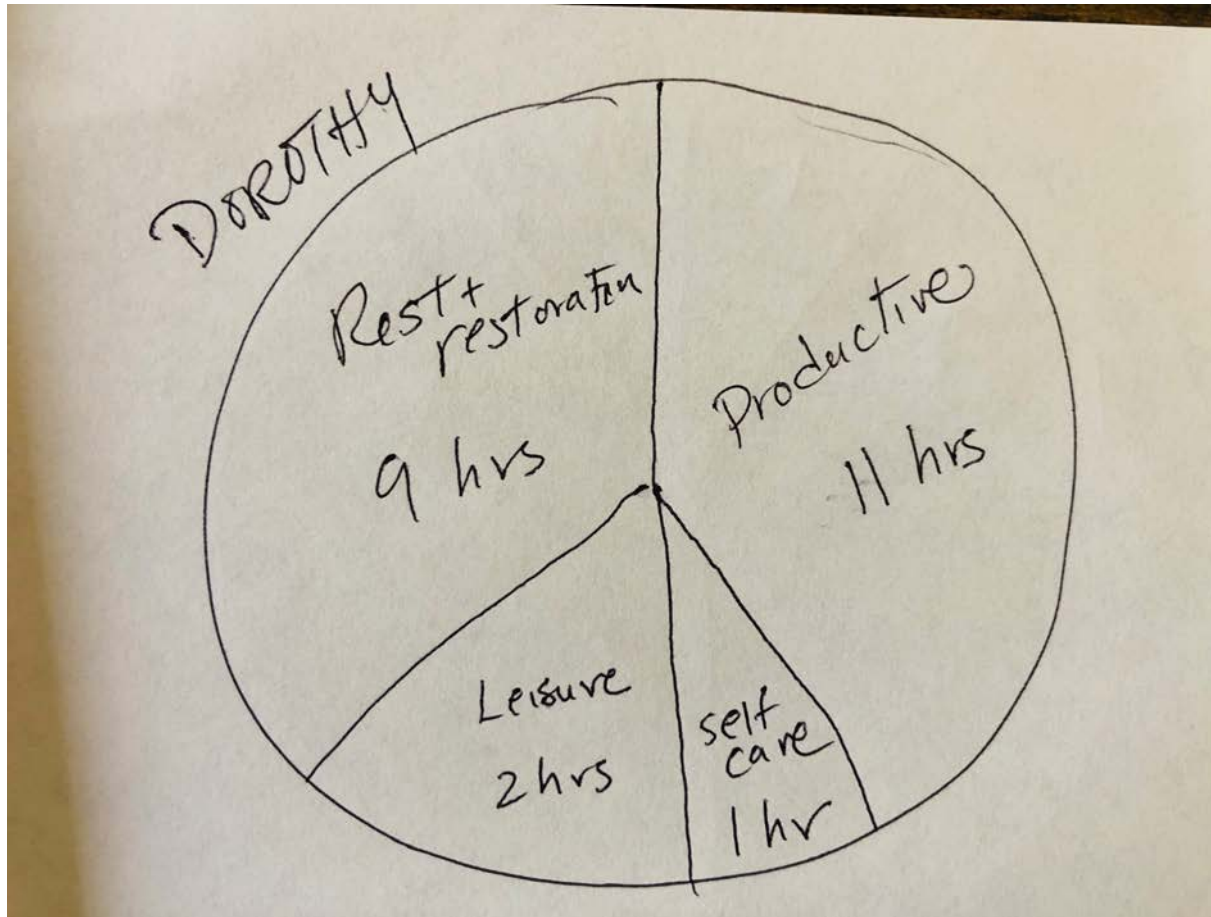
Leisure – Having fun! Activities that meeting social & solitary preferences, can be active or passive options

Self Care – Taking care of the body and mind

Rest/Restoration –
Recharging your batteries



Dorothy's typical day



Looking at your pie chart, which wedge would you like to make bigger?

Jot down ONE small thing you can do for yourself today in that category

Choose something that only takes 15 minutes at most.

Small achievable goals add up!!

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

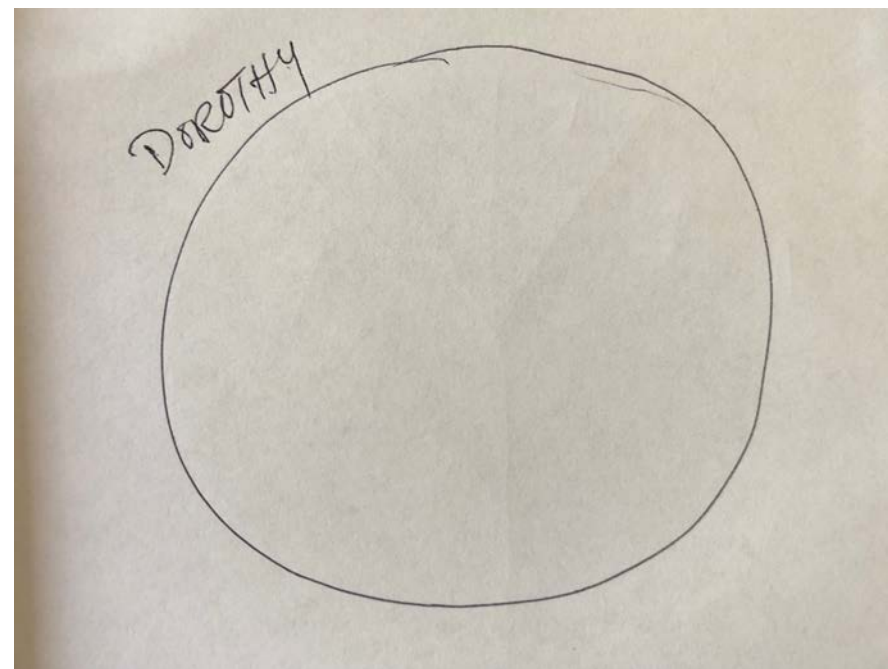
Leisure – Having fun! Activities that meeting social & solitary preferences, can be active or passive options

Self Care – Taking care of the body and mind

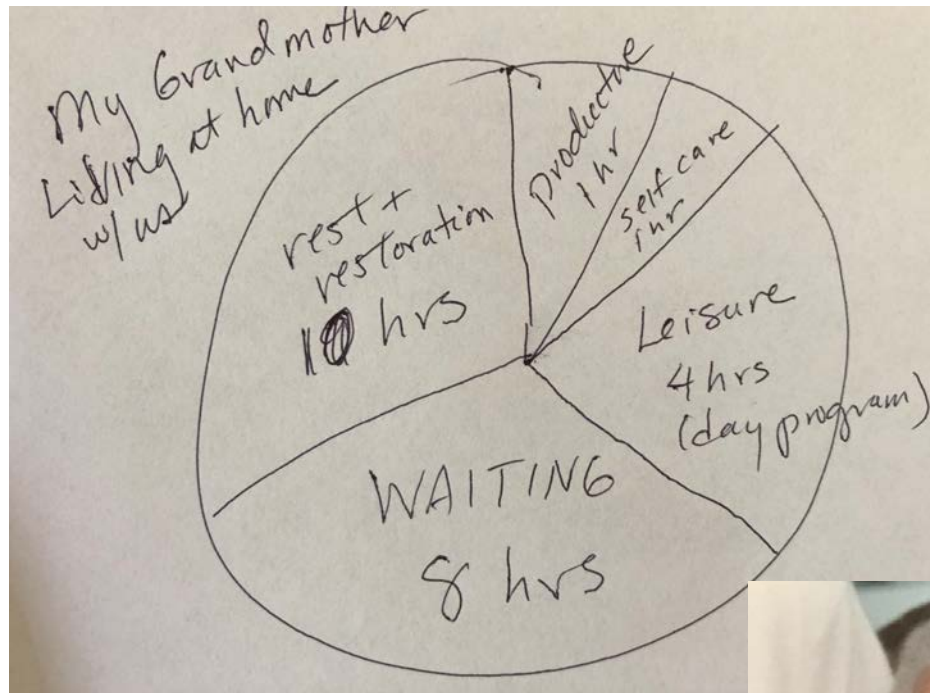
Rest/Restoration –
Recharging your batteries

ADD a new one – WAITING

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



My Grandmother Dorothy's typical day



Looking at your loved one's pie chart, which wedge would you like to make bigger?

Jot down ONE small thing you can help them do today in that category

Choose something that only takes 15 minutes at most.

Small moments of engagement add up!!

Design Each Day

Make a schedule and follow it

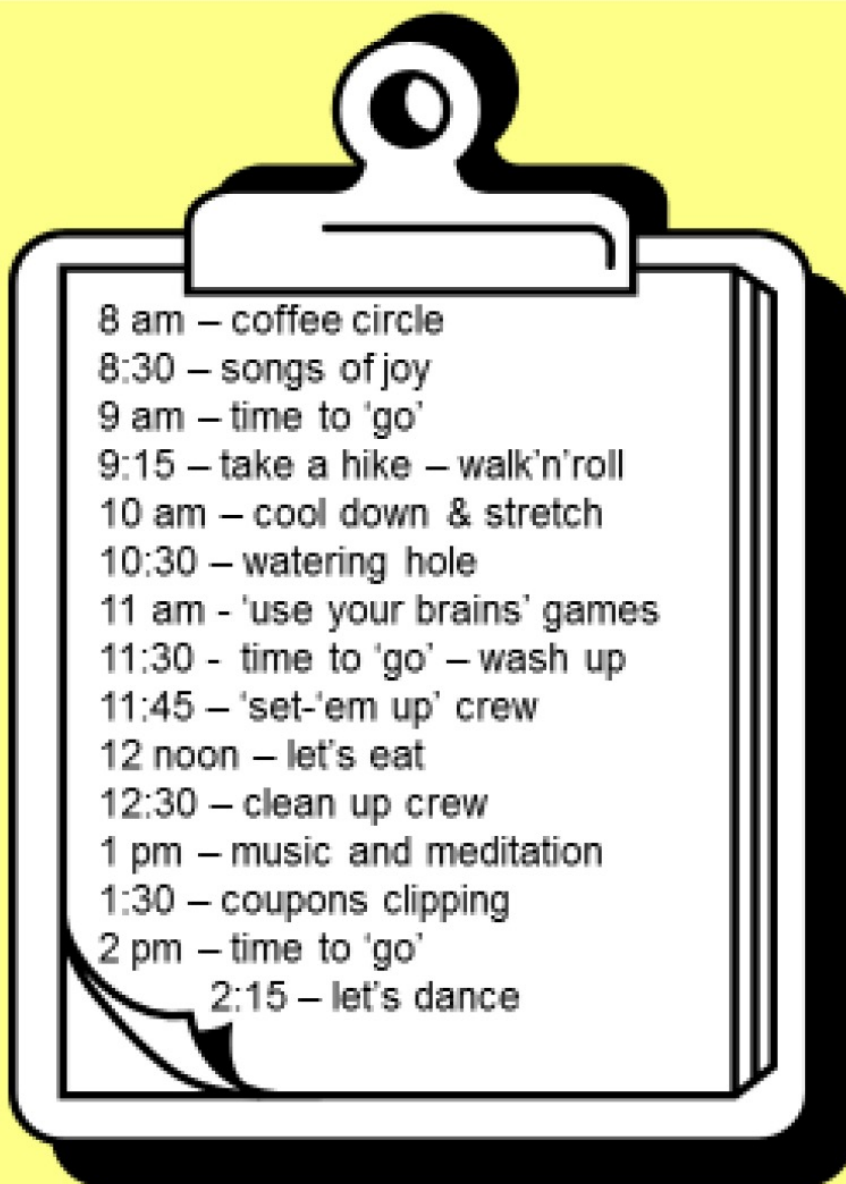
Be structured, BUT allow flexibility.

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

True or False?

- True** Knowing what a person living with dementia can still do is as important as knowing what they can't do anymore.
- False** Leisure activities are the most important and should fill most of the day.
- True** Getting to know a person living with dementia's past personal history (work, hobbies, etc) can help caregivers create meaningful engagement for them.
- True** Waiting time can be a brain stressor for people living with dementia.
- False** Having a written activities schedule is not important for home caregivers.

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.

Beliefs that Make a Difference:

- People with Dementia are Doing the BEST they can.
- Learn to DANCE with your partner.
- Be the KEY - make life WORTH living.
- What we choose to do MATTERS.
- Be willing to CHANGE ourselves.
- Be Responsive vs. Reactive to the Behavior.
- Be willing to STOP, take a Time Out & Try Again

Engagement Resources

Positive Approach to Care • www.teepasnow.com

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

Dementia Education and Skill Building Resources

Golden Carers • 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.paradisegalleries.com/collections/baby-dolls>

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!





Thank you!

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

Visit halekuike.com to learn about Hale Ku'ike's memory care homes.

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

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



QUESTIONS ??😊
