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HADI

Hawai'i Alzheimer's
Disease Initiative

A PROJECT OF THE UH CENTER ON AGING

www.hawaii.edu/aging/hadi



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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.

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Understanding Challenging Behaviors

What causes challenging situations?
Is it just the person and their dementia?

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When we talk situations, What are we talking about?

List situations you get asked about:
Crises! Problems! Behaviors!

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Examples of Challenging Situations

- | | |
|---|--|
| <ul style="list-style-type: none"> • 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 | <ul style="list-style-type: none"> • 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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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

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<p align="center"><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 align="center"><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 align="center"><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 align="center"><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 align="center"><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 align="center"><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"> • 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



Top Ten Unmet Needs of People Living with Dementia

<p align="center">Five Expressions of Emotional Distress</p> <hr/> <p align="center">Angry irritated – angry – furious</p> <p align="center">Sad dissatisfied – sad – hopeless</p> <p align="center">Lonely solitary – lonely – abandoned/trapped</p> <p align="center">Scared anxious – scared – terrified</p> <p align="center">Bored disengaged – bored – useless</p>	<p align="center">Five Physical Needs</p> <hr/> <p align="center">Intake hunger or thirst</p> <p align="center">Energy tired or revved up</p> <p align="center">Elimination need to go or did</p> <p align="center">Discomfort temperature or sensations</p> <p align="center">PAIN!!! joints, internal or external systems</p>
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To Communicate...

When Someone is **DISTRESSED**

First – **CONNECT** with the
Positive Physical Approach (PPA™)

Then – Try Supportive Communication

Finally – Move together to a **NEW** place

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To Communicate...

Be a *Detective* **NOT** a *Judge*

Try to figure out **WHAT** is being communicated

- Words
- Thoughts
- Actions
- Needs
- Beliefs

DON'T assume or presume

DON'T discount me because of **HOW** I deliver the message

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To Communicate and Figure It Out

1. CONNECT

- Visually
- Verbally
- Physically
- Emotionally
- Individually

HOW?

- PPA™
- Supportive Communication

Supportive Communication

- Empathy
- Validation
- Exploration
- Acknowledgement

Move Forward

- New words
- New place
- New Activity/Focus

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**SO...
NOW...**

You are connected

- VISUALLY
- VERBALLY
- TACTILELY

NEXT...

- Connect EMOTIONALLY
- Go with THEIR FLOW
 - Don't BLOCK – Reality Orientation
 - Don't DIRECT - Lie

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To Connect EMOTIONALLY:

- SEND visual signal of connection
 - LOOK CONCERNED/Match their emotion
- SEND a verbal signal of connection
 - USE the RIGHT TONE OF VOICE
- SEND a physical signal of connection
 - Give a light SQUEEZE or SANDWICH the hand
 - Offer a OPEN PALM on Shoulder or Back
 - Offer a HUG – IF the person is seeking more contact

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Use Supportive Communication

Repeat a few of their WORDS with a ? at the end

LISTEN...

Then –

- Offer EMPATHY
 - “Sounds like...
 - “Seems like...
 - “Looks like...

LISTEN...

AVOID Confrontational
QUESTIONS...

Use just a FEW words

Go SLOW

Use EXAMPLES...

Fill in the BLANK...

LISTEN!!!

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More Supportive Communication

- Validate emotions
- EARLY – “It looks like you are (emotion)” or “It sounds like...”
- “I’m sorry this is happening to you”
- “This is hard... You are not liking this at all...”
- MIDWAY – repeat their words (with emotion)
 - LISTEN for added INFO, IDEAS, THOUGHTS
 - EXPLORE the new info BY WATCHING & LISTENING
- LATE – CHECK OUT the WHOLE Body –
 - Face, posture, movement, gestures, touching, looking
 - Look for NEED under the words or actions

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Once Connected and Communicating...

Move FORWARD

- ADD New Words...
- Move to a New Place – Location
- Add a NEW Activity

EARLY – Redirection

- Same subject
- Different focus

LATER – Substitution (Distraction)

- Different subject
- Unrelated BUT enjoyed

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For ALL Communication

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

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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

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What shouldn't we do???

- Argue
- Make up stuff that is NOT true
- Ignore problem behaviors
- Try a possible solution only once
- Give up
- Let them do whatever they want to
- Force them to do it

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So WHAT should we do?

Remember...

who

has the healthy brain!

Believe...

People with dementia are doing
THE BEST they can!

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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?

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Why Is Life So Difficult for Those Involved?

MANY abilities are affected

- Thoughts
- Words
- Actions
- Feelings

It is variable

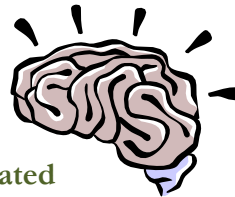
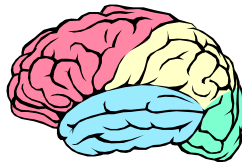
- Moment to moment
- Morning to night
- Day to day
- Person to person
- Place to place

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



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Without Help, What Do We Tend to DO?

We miss early signals

We REACT or OVER-REACT

We wait to see if it gets worse

We worry

We ignore it or put up with it... until....

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What If We Categorize...

- **Annoying** – not a big issue, but wearing over time – takes time away from other responsibilities
- **Risky** – could cause harm to self or others, not always dangerous, but can be unpredictable as to when it will be **serious**
- **Dangerous** – puts the person, the Care Partner, other people, or equipment in jeopardy or at immediate risk for injury

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We tend to...

- *dig* into the **Dangerous Behaviors**
- try to *care plan* or respond to the **Risky Behaviors** when we see them
- expect or *put up with* the **Annoying Behaviors** until...

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Another Complication: Progression

- More changes over time
- Not a stable condition

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GEMS™ States...

Where is **the Person** in the progression?



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Review the GEMS™

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



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How do you go between Sapphire and Diamond?



Your triggers for GOING DIAMOND... 

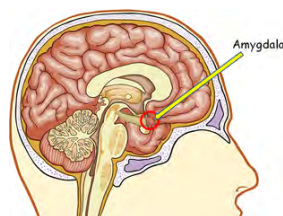
 Your strategies for REGAINING SAPPHIRE...

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It's all about our AMYGDALA

The Amygdala:

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



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DANGER!

Left Amygdala turns ON

and.....

Fight, Flight, Fright

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Amygdala in Control

When your primitive brain takes over...

Left Temporal Lobe- Language and Speech

Frontal Prefrontal Cortex- Emotions, Behavior, Judgement, Reasoning

Occipital Lobe- Tunnel Vision

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

Right Amygdala turns ON

and.....

I NEED IT NOW!!!

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Amygdala

Right

NEED

Want

Likes



Left

DANGEROUS

Aroused/ Risky

Alert/ Aware



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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

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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!

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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!

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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!

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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!!!

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Let Go:

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

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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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Time to practice! Put on your detective hat!

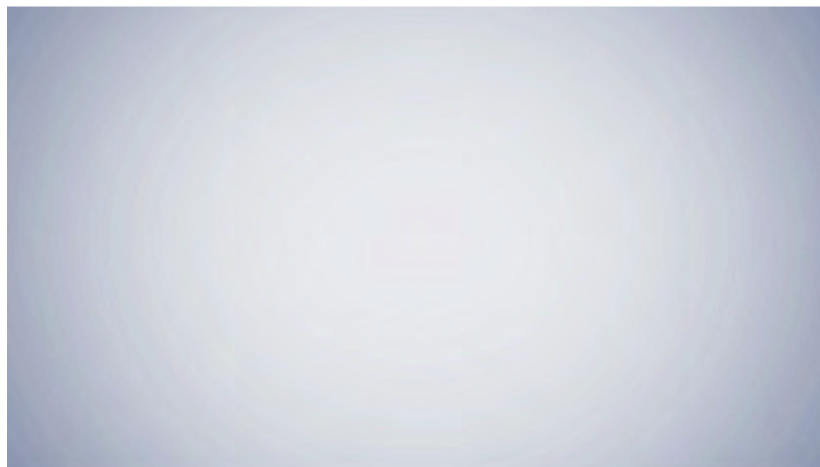
- 80 year old woman named Leona living in a care home uses a maraca to repeatedly hit the chairs in the living room. She moves from chair to chair tap tap tapping each chair all over before moving to the next chair. The noise irritates the other residents and they start yelling at her. Another resident tried to take the maraca away from Leona and Leona hit her. When the caregiver tries to take the maraca away she yells, “Don’t touch it!” and “I’m not done!”
- She will not stop this activity even when she clearly needs to go to the bathroom. She has incontinence accidents and refuses to get cleaned up. She fights and hits the caregivers while they get her cleaned up from the accident.
- Leona worked as a housekeeper her whole life and raised four boys on her own after her husband died. She lived at home until six months ago when she moved into the facility. She does not like to participate in activities that are “just playing.” She does enjoy the music activities and can fold laundry happily for an hour straight.

Examine the six pieces of the puzzle for Leona.

What do you think Leona thinks she is doing with the maraca?

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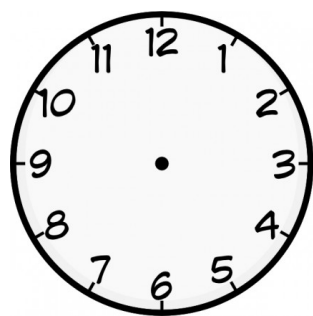
Teepa Snow and Leona



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What Are You Going to Do About It?

- What Specific **Awareness** Do You WANT TO WORK ON?
- What Specific **Knowledge** Do You WANT TO WORK ON?
- What Specific **Skill** Do You WANT TO WORK ON?



Give it
FIVE
minutes
a day!

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