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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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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.
Understanding Challenging Behaviors

What causes challenging situations?
Is it just the person and their dementia?
When we talk situations,

What are we talking about?

List situations you get asked about:
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
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
Top TEN REAL ISSUES for the Person Living with Dementia!

Unmet Physical Needs

- Hungry or Thirsty
- Tired or Over-energized
- Elimination – need to/did
- Discomfort – not right for me
  - Temperature, texture, fit, senses
- IN PAIN!!!
  - Joints - skeleton
  - Inside systems (head, chest, gut, output)
  - Creases or folds & skin
  - Surfaces that contact other surfaces

Unmet Emotional Needs

- Angry
- Sad
- Lonely
- Scared
- BORED
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
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
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
SO…

NOW…

You are connected

• VISUALLY
• VERBALLY
• TACTILELY

NEXT…

• Connect EMOTIONALLY
• Go with THEIR FLOW
  • Don’t BLOCK – Reality Orientation
  • Don’t DIRECT - Lie
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
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!!!
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
For ALL Communication

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

Remember…

**who**

has the healthy brain!

Believe…

People with dementia are doing THE BEST they can!
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?
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
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....
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
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...
Another Complication: Progression

More changes over time

Not a stable condition
GEMS™ States…
Where is the Person in the progression?
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
How do you go between Sapphire and Diamond?

Your triggers for GOING DIAMOND…

Your strategies for REGAINING SAPPHIRE…
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 –
DANGER!

Left Amygdala turns ON

and.....

Fight, Flight, Fright
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
When I’m HURTING…
I Need RELIEF

Right Amygdala turns ON
and…..

I NEED IT NOW!!!
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**
Who are the stakeholders?

YOU...

AND OTHERS

The Stakeholders

• People around the person living with dementia
• Staff
• Friends
• Family
• Everyone who might have an impact
What should stakeholders avoid???

- Arguing
- Making up stuff that is NOT true
- 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 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!
Thank you so much for your desire to learn and your commitment to making a positive difference!

Visit these websites to learn more:

www.teepasnow.com
www.dorothycolby.com
www.halekuike.com
UNDERSTANDING DEMENTIA

WHEN: 2nd Saturday of each month, 2:00-4:00 pm
WHERE: 15 Craigside, Ground Floor Theater
COST: $25 (register at dorothycolby.com)

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Understanding the Difference
January 9 • May 14 • September 10

GEMS™, More Than Just Loss:
Dementia Progression Patterns
February 13 • June 11 • (New Date) October 29th

Using a Positive Physical Approach™ to Care
March 12 • July 9 • November 12

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Recognizing Unmet Needs
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Positive Approach to Care™ seminars, developed by dementia
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Certified Positive Approach to Care™
Trainer with more than 15 years of
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HOW CAN I HAVE A POSITIVE RELATIONSHIP WITH MY LOVED ONE WITH DEMENTIA?

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