



INDIAN + COUNTRY
ECHO

LEADING THE WAY ➡➡➡

*Growing the Ability to Deliver Quality Healthcare to
American Indian and Alaska Native People.*

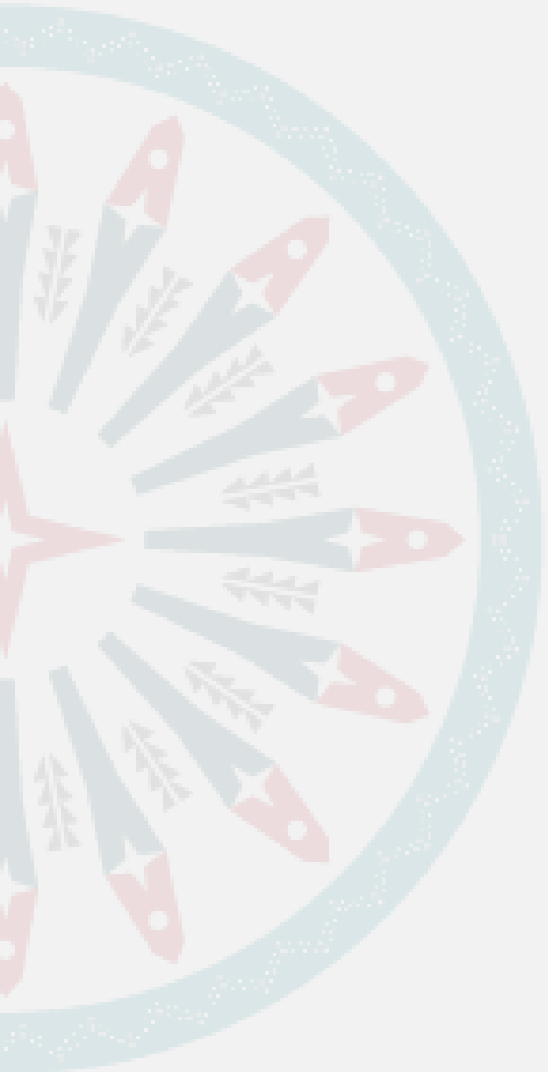
The Science and Strategies for Managing Behavioral Symptoms of Dementia

Allison Lindauer, PhD, APRN, Oregon Health &
Science University, Oregon Alzheimer's Disease
Research Center, lindauer@ohsu.edu



Objectives

- Learn how to assess challenging behaviors
- Identify common triggers for behaviors associated with dementia
- Review the ABC approach to behaviors
- Apply the ABCs to case studies



DEFINITIONS

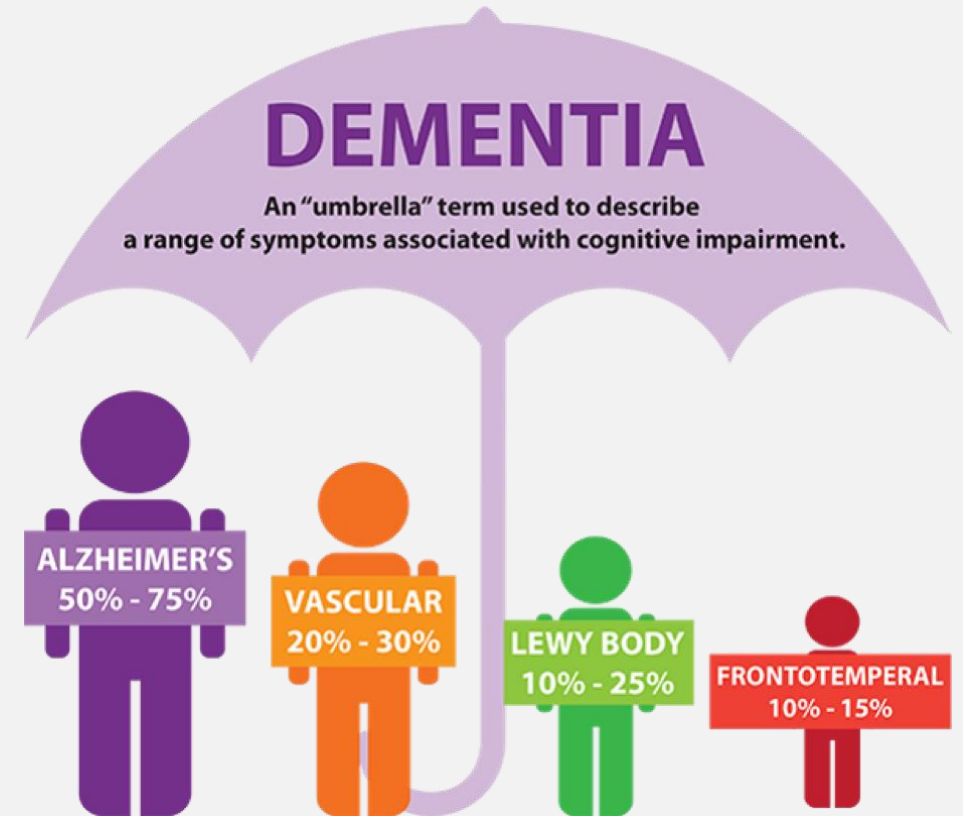
WHAT IS DEMENTIA?

“Dementia” is an umbrella term describing a variety of diseases and conditions that develop when nerve cells in the brain (called neurons) die or no longer function normally.

The death or malfunction of neurons causes changes in one’s **memory, behavior and ability to think.**

WHAT IS THE DIFFERENCE BETWEEN DEMENTIA AND ALZHEIMER'S DISEASE?

- Dementia is the main, “umbrella” term
- Alzheimer’s disease is a *type* of dementia
- Other types include vascular dementia,
- Lewy Body Dementia, and Frontotemporal Dementia



WHAT DO WE MEAN BY BEHAVIORS?

“Behaviors” are tools that help us communicate. Most of the time we use words with the behaviors to deliver a clear message.

smiling, clapping, frowning, yelling

BEHAVIORS



BEHAVIORS



WHAT DO WE MEAN BY “CHALLENGING BEHAVIORS”

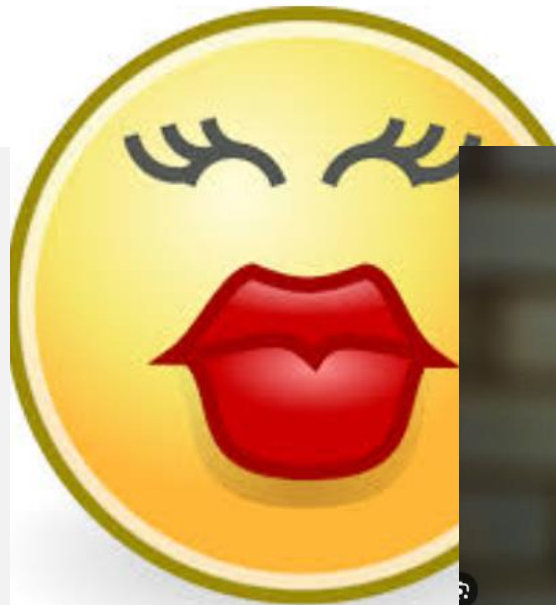
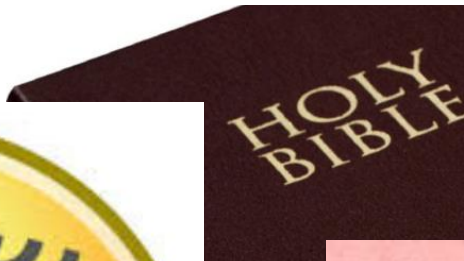
Challenging behaviors are those that cause distress in a family.

Wandering
Crying
Irritability
Clinging
Yelling

We all exhibit
“behaviors.”

We are distressed because we do not understand why they occur or how to help.

BEHAVIORAL SYMPTOMS



CHALLENGING BEHAVIORS AND DEMENTIA

OFTEN DUE TO A NEED...

- Pain
- Constipation
- Hunger
- Thirst
- Fatigue
- Boredom

BUT DEMENTIA CAUSES DIFFICULTY WITH...

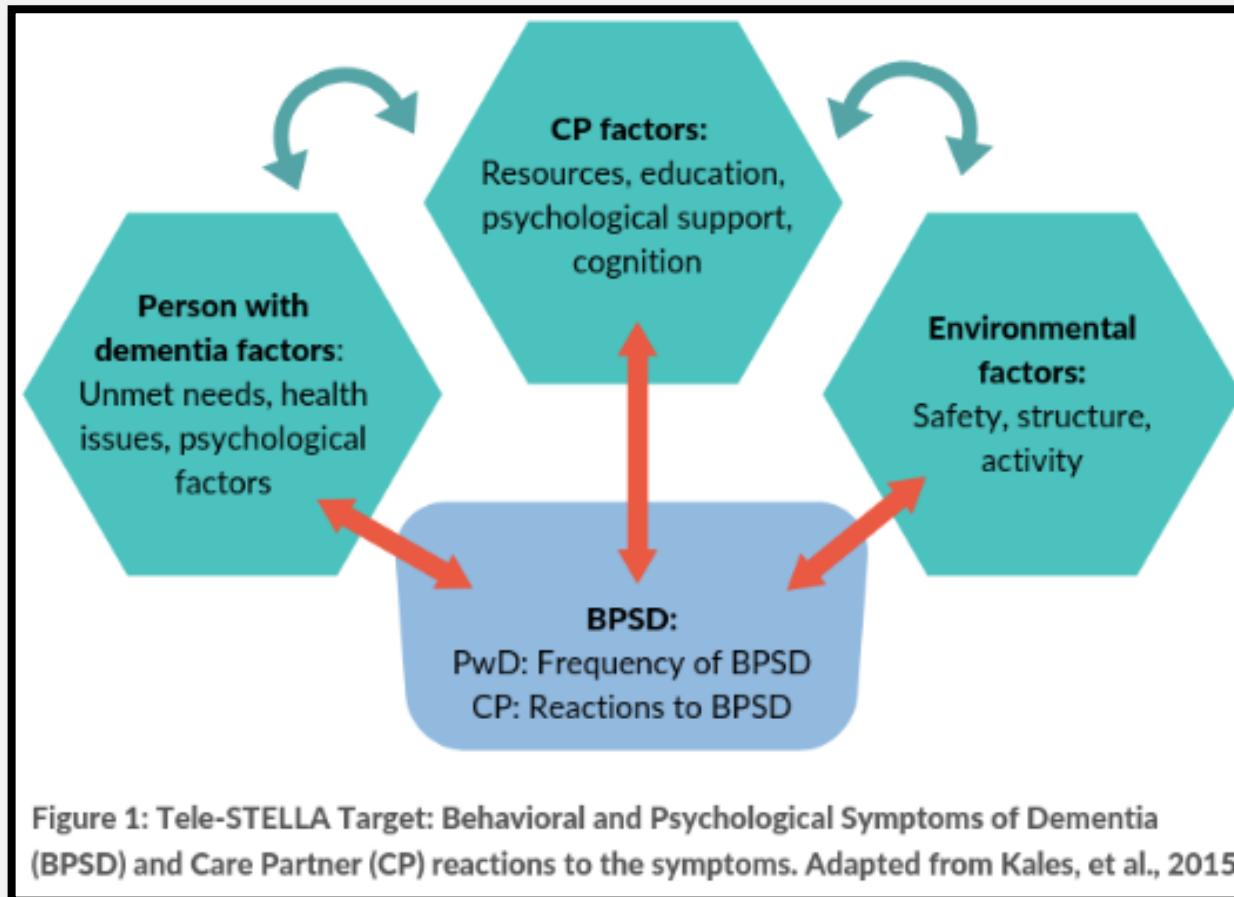
- Understanding the problem
- Linking the problem to the need
- Stating the problem
- Knowing the right words
- Saying the right words
- Communicating appropriately

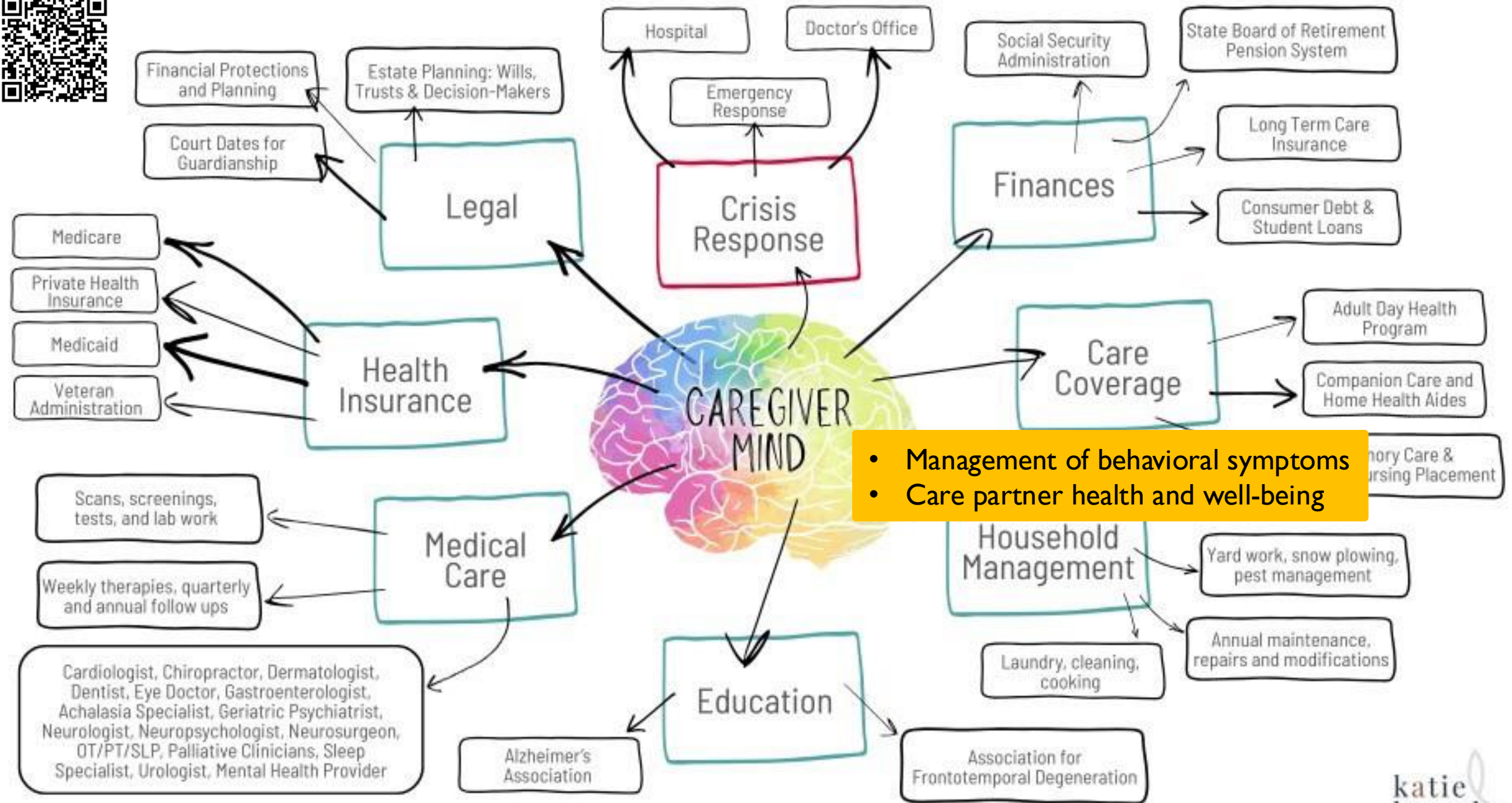
AN EXAMPLE



BEHIND THE SYMPTOMS

BEHAVIORAL SYMPTOMS





- Management of behavioral symptoms
- Care partner health and well-being

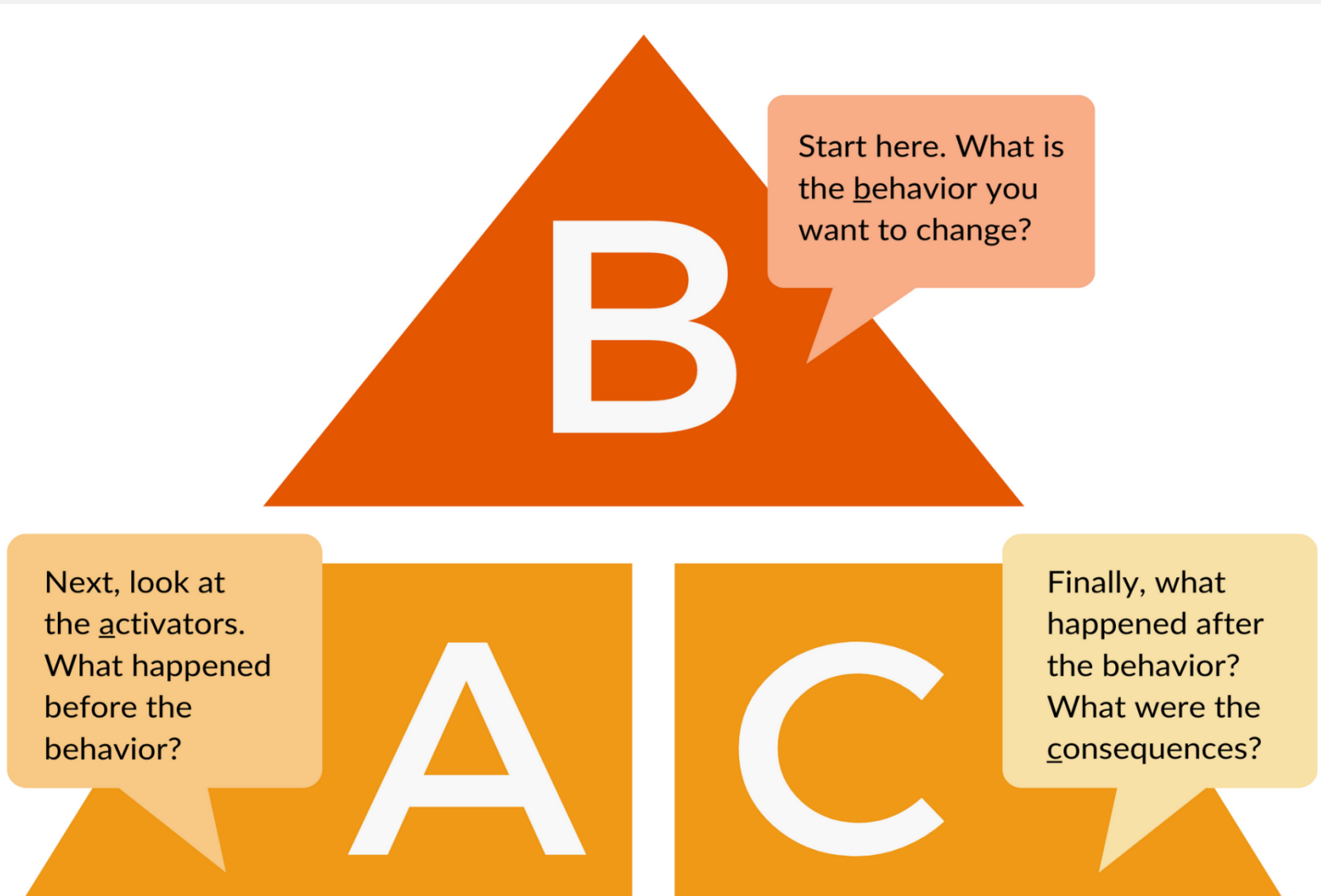
CHALLENGING BEHAVIORS

- Reminders of the changing person and the disease is progressing
- These overt signs of change can lead to caregiver burden, depression and grief
 - “She’s just not my mom anymore”
 - “It’s like a bare room, there’s nothing left of what was familiar”
 - “There but not there.”

REVIEW

- Behavioral symptoms are a result of many factors
- These symptoms occur in both the person with dementia and their family member
- Sometimes we know why a behavior occurs
- Sometimes we do not

APPROACH TO UNDERSTANDING BEHAVIORS



ABC'S AND BEHAVIOR



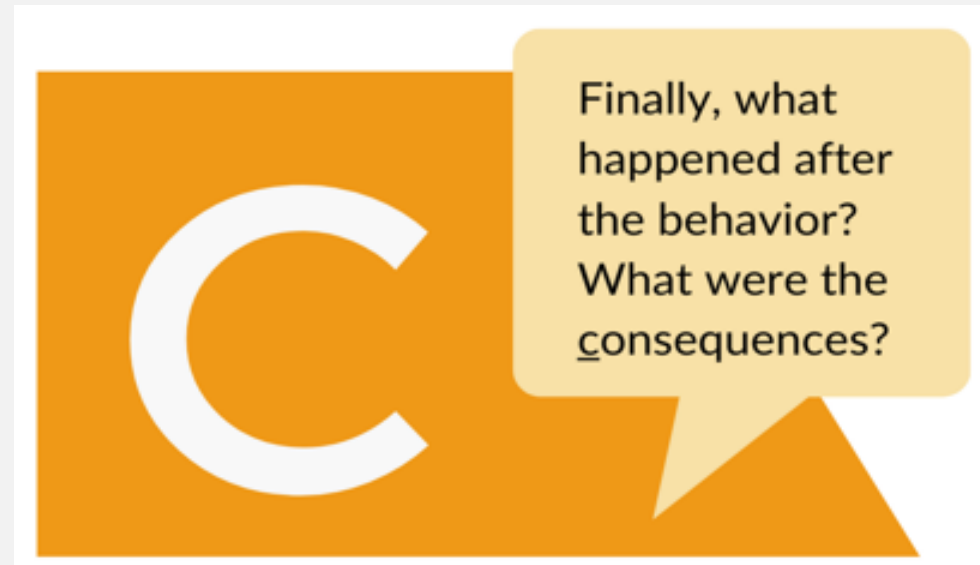
What is the behavior you want to change?

ABC'S AND BEHAVIOR



Describe what happens before the behavior.

ABC'S AND BEHAVIOR



What can you change?

Case Study: George

- George has moderate Alzheimer's disease
- George lives at home with his wife Eden
- Today he feels hot and has a headache
- He sees the window with the air conditioner
- He walks over to the window (near the door) to cool off
- His head hurts

Case Study: George

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Disease
process

Environment

Pain

Lifetime
patterns

Case Study: Eden

- Eden, George's wife, is exhausted.
- George has been up pacing all night. He has “run away” twice in the last week
- She worries for his safety
- She feels trapped as the caregiver
- She wishes someone would help her. She calls her daughter in Georgia every day to talk about her worries. She cries on the phone.

Case Study

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- George has been up pacing all night. He has "run away" twice in the last week
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Fatigue

Disease process

Anxiety

Depression

BEHAVIORAL SYMPTOMS

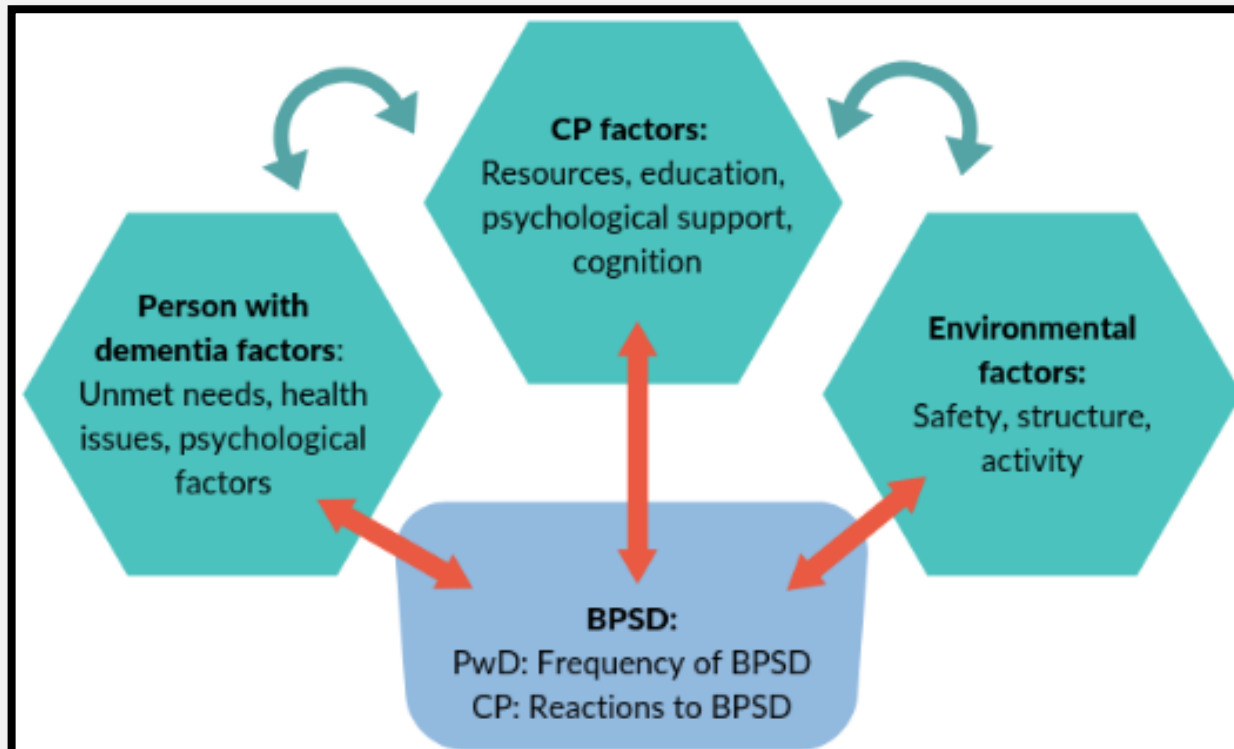
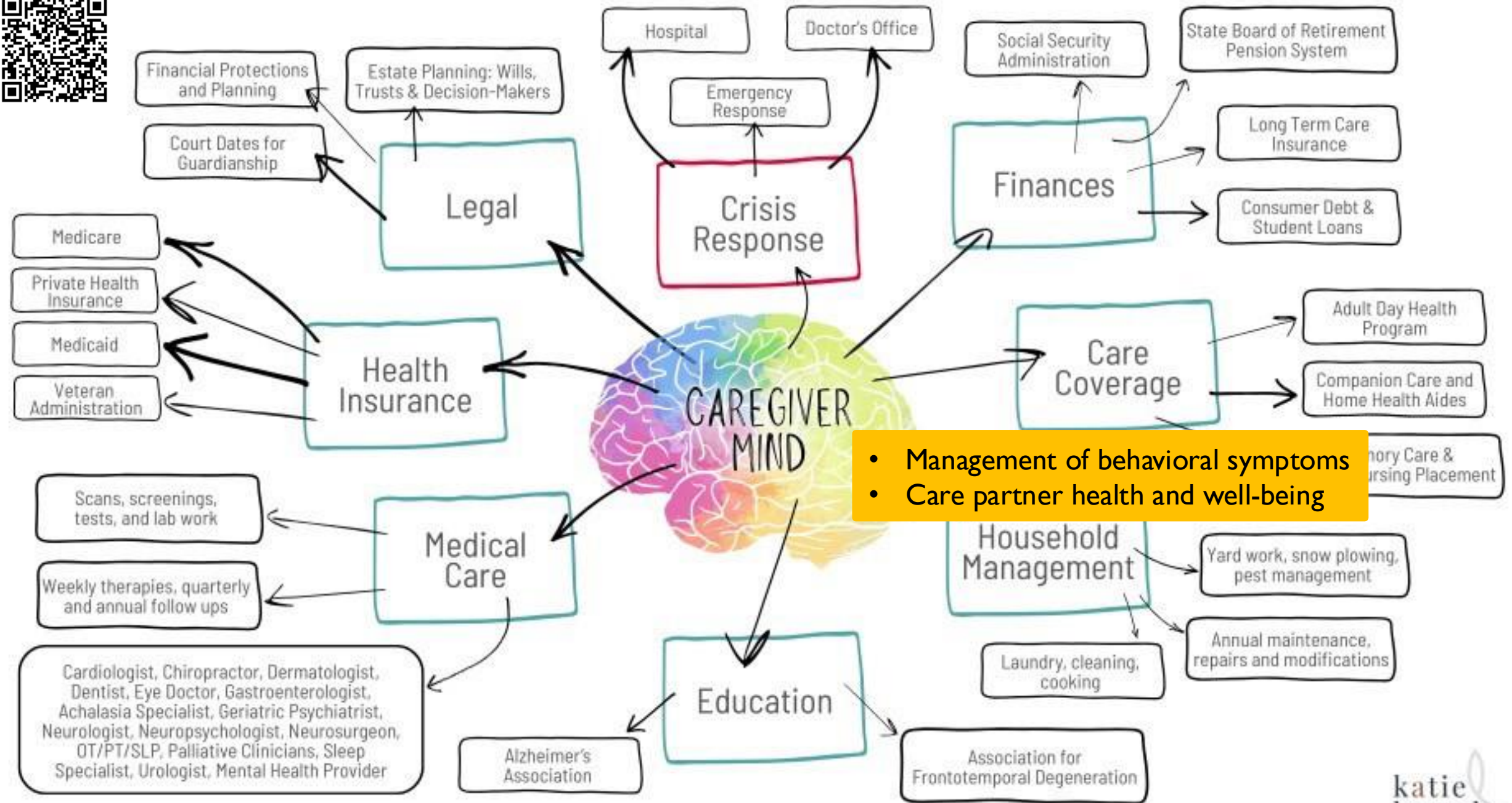


Figure 1: Tele-STELLA Target: Behavioral and Psychological Symptoms of Dementia (BPSD) and Care Partner (CP) reactions to the symptoms. Adapted from Kales, et al., 2015

Case Study: Take 1

- Eden sees George walk to the door
- She yells “Stop George!”
- She runs over to George and touches his arm
- George is alarmed and swings out to hit Eden
- Eden puts her arm around George’s shoulder to direct him away from the window
- George is frightened and pushes Eden away

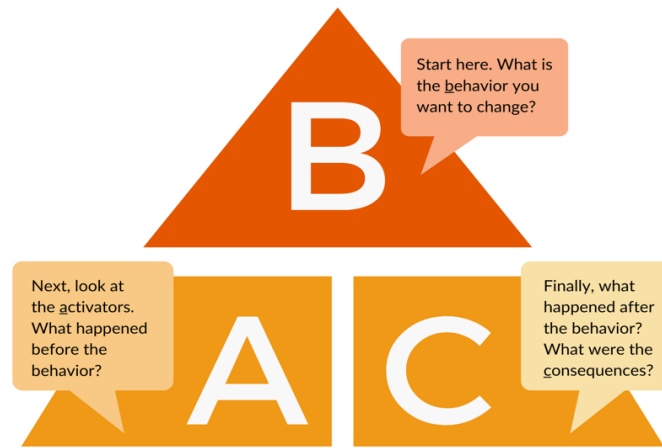


- Management of behavioral symptoms
- Care partner health and well-being

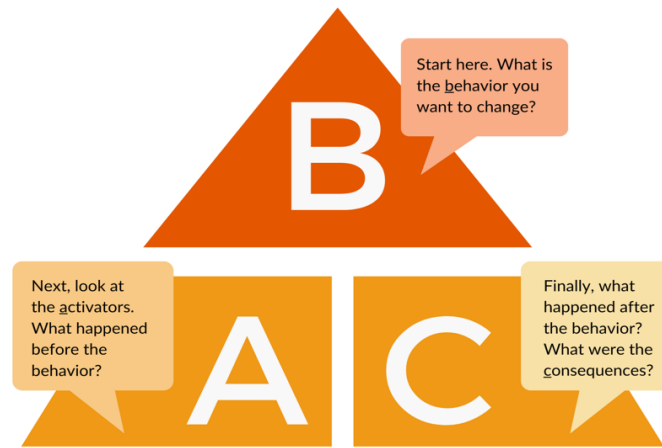


First, describe the behavior in detail (what do you see and hear?)



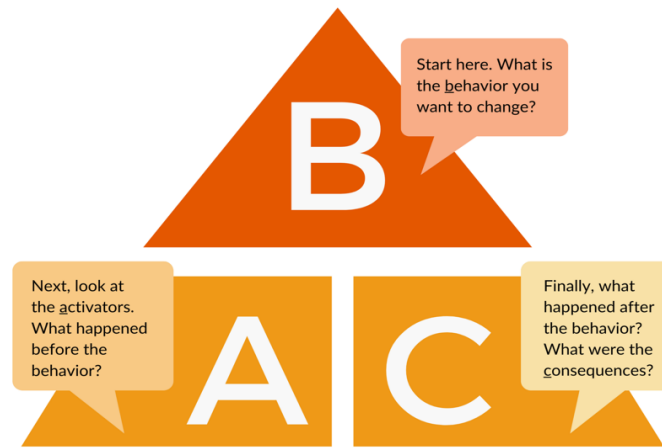


Naming the behavior can provide care partners a sense of control and confidence in managing these symptoms resulting in decreased burden.



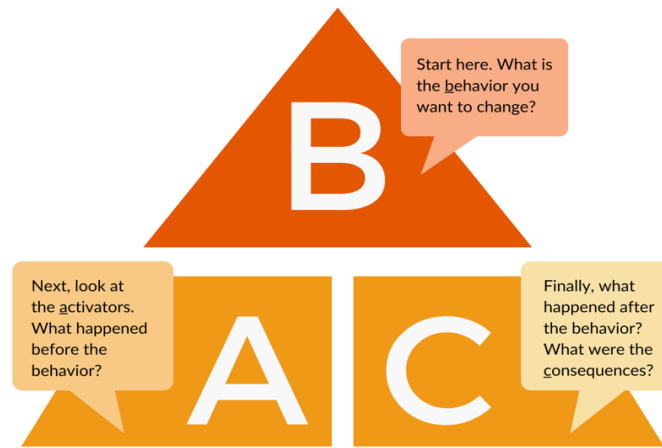
Eden's description of the behavior:

“George tries to run away from the house.”



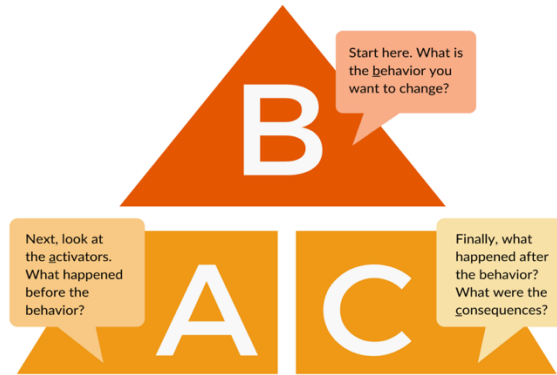
Dawn discusses the “activator.”

“Every afternoon George starts pacing, then he heads for the door. He doesn’t tell me he wants to go outside.”



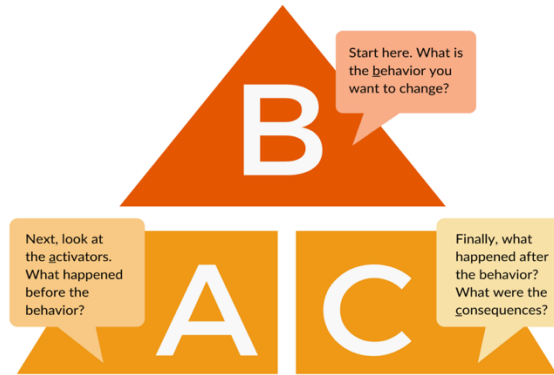
Dawn discusses the “activator.”

“Every afternoon George starts **pacing**, then he **heads** for the door. He doesn’t tell me he wants to go outside.”



What can you change?

- I'm going have slide lock put on our door
- I'll put bells on our door
- I'll make a list of distractions
- I'll make an appointment with our doctor to discuss George's leaving the home



How do the ABCs help Eden?

- I'm going have slide lock put on our door
- I'll put bells on our door
- I'll make a list of distractions
- I'll make an appointment with our doctor to discuss George's leaving the home

Buys time

Early warning

Pleasant events

Engage others

Case Study: Distractions

- Offer George an NA beer
- Iced tea
- Put on his favorite music
- Show him the book with Golden Retrievers
- Take a walk together
- Put on a movie
- “Let’s put our feet up”
- “Can I take off your boots?”

Case Study: Take 2

- Eden sees George walking across the room. The door is locked, so she doesn't have to worry about him leaving
- She **stops** and watches George
- She takes a deep breath to **drop** her anxiety
- She plays his favorite song on her phone
- George turns around, but looks upset
- “How about a cold beer, George?”
- He follows her to the kitchen
- Eden **rolls** with this—his beer is NA, he sits down. Life is good for a couple of minutes

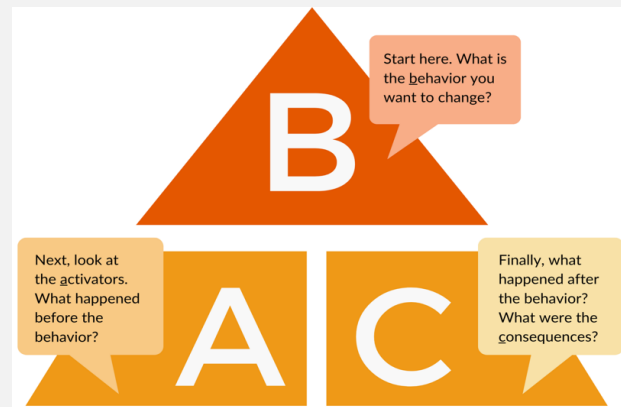
Case 2

DAWN AND ROCHELLE'S STORY

Rochelle has advanced Alzheimer's disease. She is a retired customer relations representative and has five children.

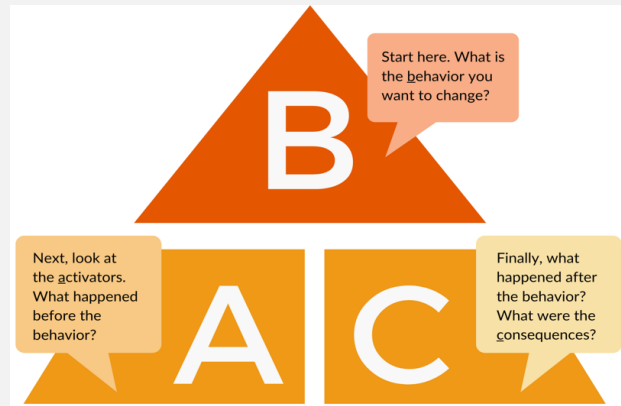
Dawn, one of her daughters, retired early from her work as an accountant to take care of her mother full time.

Dawn has a brother, Sam, Rochelle's son, who lives three blocks away. Rochelle's other three daughters live out of state.



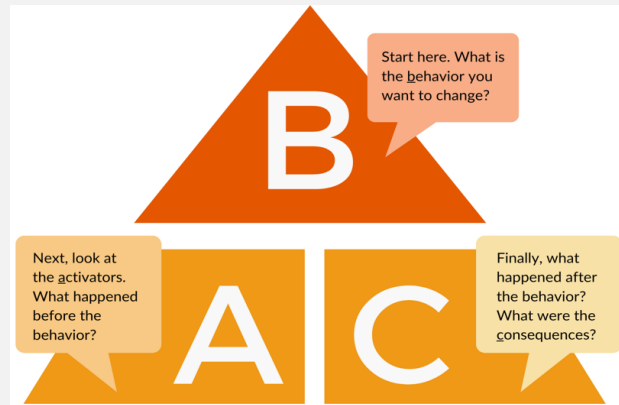
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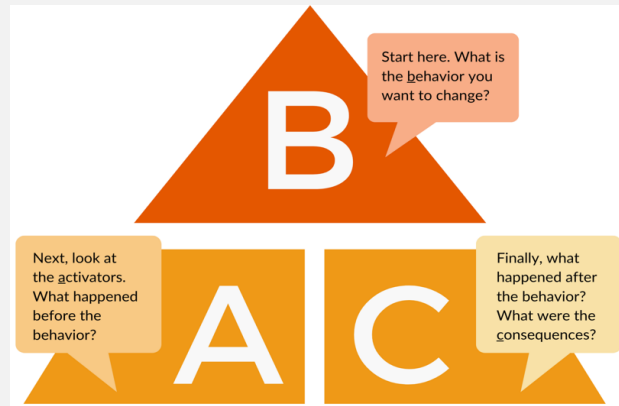
Dawn's description of the behavior.

“Mom wakes up grumpy every morning. She grabs at my arms and hair and sometimes bruises my arms.”



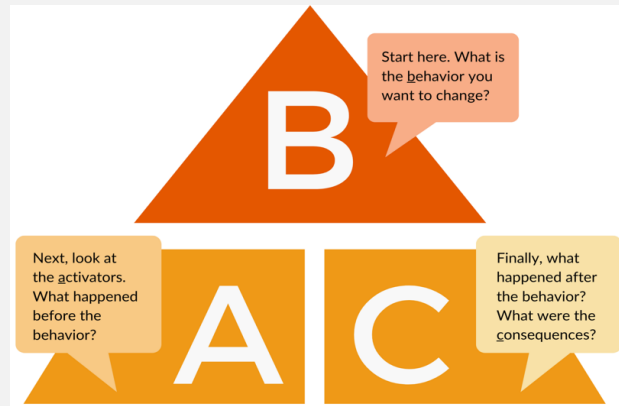
Dawn discusses the “activator.”

*Mom grabs at me when **I try to help her get out of bed**; I try help her sit up and pivot so her legs dangle by the bed.*



What can Dawn change?

She now sees that the behavior of grabbing Dawn occurs only when Dawn tries to move her mom out of bed in the morning.



Dawn now:

- Recognizes the behavior
- Understands when it happens
- Has information for a change plan

MAKE A PLAN TO CHANGE THE BEHAVIOR

Dawn makes a list of things she can try:

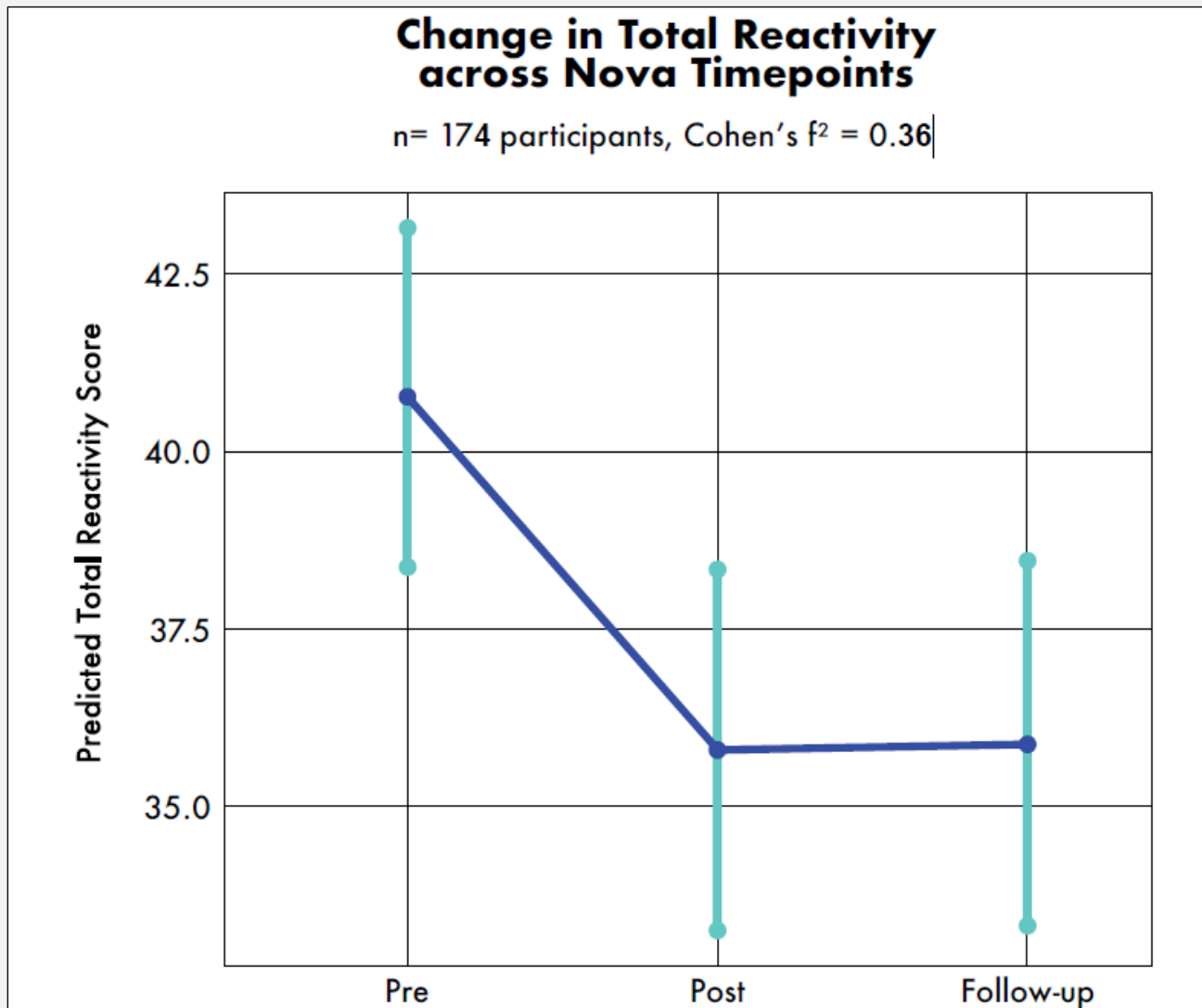
1. Let Rochelle sleep in.
2. Bring her breakfast in bed.
3. Rub cream on her knees.
4. Ask her PCP for suggestions.

BETTER?

- Dawn took Rochelle into their nurse practitioner. He noted that she is supposed to be on Tylenol twice daily for back pain. Dawn had stopped this because Rochelle *was not complaining of pain*.
- Their NP explains that she is complaining of pain, but with her behaviors, not so much her words. He advises Dawn on how to use the Tylenol.
- Their NP also orders home physical therapy.
- Two weeks later, Rochelle's behaviors have decreased by about 50%. Not perfect, but they are both happier.

TRY IT!

RESULTS: BURDEN



Total reactivity declined from pre- to post-Nova by 4.73 points and by 5.66 points at follow-up (both $p < .001$; Cohen's $f^2 = 0.36$; paired $d = -0.33$ and -0.44).

Cohen's f^2
conventional
thresholds:
Small: 0.02
Medium: 0.15
Large: 0.35



REVIEW

- We all communicate through our behaviors.
- For people with dementia, this may their only way to communicate their needs.
- The ABC analytic approach has been proven to be helpful.
- Because it requires work and creativity, it helps to have others involved.

WHERE TO FIND ABC TRAINING



<https://www.caregiver.org/resource/star-c-managing-difficult-behaviors/>

STELLA-FTD

Do You Care for a Family Member with FTD?



WHAT IS STELLA-FTD?

An online research study to help family care partners manage FTD-related challenges through live, expert-led group sessions.

LOCATION

Open to care partners residing within the United States.

DIAGNOSES

- Behavioral Variant FTD (bvFTD)
- Primary, Progressive Aphasia (PPA)
- FTD with ALS
- Corticobasal Syndrome
- Progressive Supranuclear Palsy

503-494-7647

THANK YOU!