

# Coping with Behavior Change in Dementia

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# Eva's story

- The importance of stories
  - Giving stories back
  - Knowing the person
  - Learning to adapt our communication
- 



# Our job in dementia care is to...

- Care for a person, not a disease
- Make him/her feel safe & supported
- Make him/her feel life is still worth living
- Do unto others
- Build relationships
- Learn to know that person – past & present



# What do you think of when you hear these phrases?

- Challenging behaviors
  - Behavior problem
  - Combative
  - Wandering
  - Toileting
- 



# Thinking about the language we use

- Words have an impact – on our thought, on how we view the world, on others
  - Discipline influences our word choices
  - Setting influences our word choices
  - Caregiver versus care partner
- 



# How we view behavior change

- “Behavior change” versus “difficult/challenging behavior”
- Behavior as a form of communication
- Often reflects an unmet need or desire, such as being hungry, tired, in pain
- Our job is to learn how to interpret the meaning behind the behavior



# Becoming a behavior detective

- Changes in the brain +
  - Unmet needs +
  - Strong feelings +
  - The need to communicate
  
  - Putting all the pieces together
- 



# Some key questions

- What is happening?
  - Where does the behavior occur?
  - When does the behavior usually occur?
  - Who is affected by the behavior?
  - Is it really a problem?
- 

“I couldn't sleep.”

©Cartoonbank.com



*“I couldn't sleep.”*



# More key questions



- What was going on right before the behavior occurred?
- What feeling is the person with dementia expressing at the time of the behavior?
- Is the behavior a variation on a coping strategy that the person always used?
- Or, is it related to an old life pattern?
  - John & the mailbox

<b>When</b>	<b>Doing before Where</b>	<b>Who</b>	<b>What</b>	<b>What was tried</b>	<b>Result</b>
Wed 4pm	Asleep TV on	Jones aft. Staff	Shouts agitated	Snack	Threw it
Fri 3pm	Walking	Jones aft. staff	Shouts Tries to leave	Walk 1- on-1	Calmed down



# Warning signs

- Verbal
  - Raised voice, swearing
- Non-verbal
  - Threatening actions, pacing, agitated behaviors



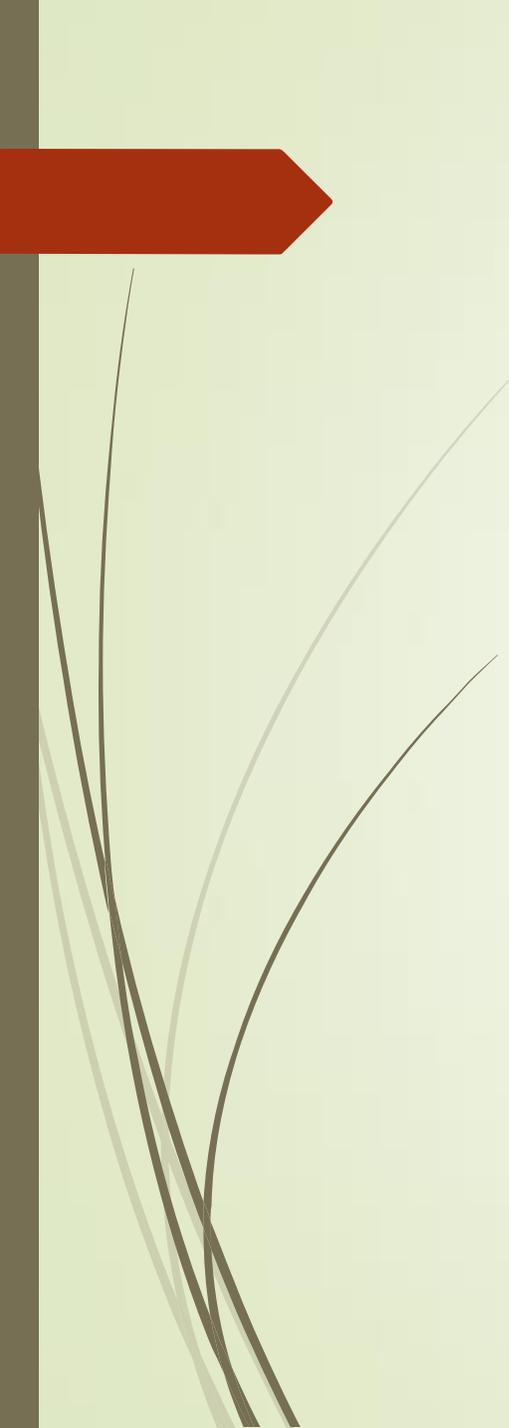
# Why behavior change may be occurring

- **Type of Dementia**
- **Environmental** factors
- **Caregiver's approach** to communication
- **Internal needs** of the person with dementia
- **Person's past** history
- **Task-related** factors



# Common behavior change in Alzheimer's disease

- Memory loss that causes suspiciousness
- Repetitive questions due to inability to retain information
- Agitation or aggression during ADL care
- Delusional thinking
- Difficulty with familiar tasks
- Mixing up day and night
- Gradual loss of executive functions: planning, organizing, judgment, insight



# Common behavior change in Lewy Body & Parkinson's dementias

- Extreme fluctuations day to day
- Visual hallucinations starting early in the disease – often of people
- Sleep disruption common and may act out dreams
- ADL difficulty as dementia progresses
- Often characterized:
  - LBD cognitive changes early; movement disorders later
  - PD movement changes early; cognitive changes later



# Common behavior change in frontotemporal dementia (behavioral variant)

- More drastic personality changes: apathy; impulsivity; obsessive behaviors; lack of insight; lack of empathy; disinhibition
- Anti-social behaviors that cause problems in public places, including sexual acting-out
- Refusal to give up control of finances, driving, etc., sometimes resulting in catastrophes



# Common behavior change in vascular dementia

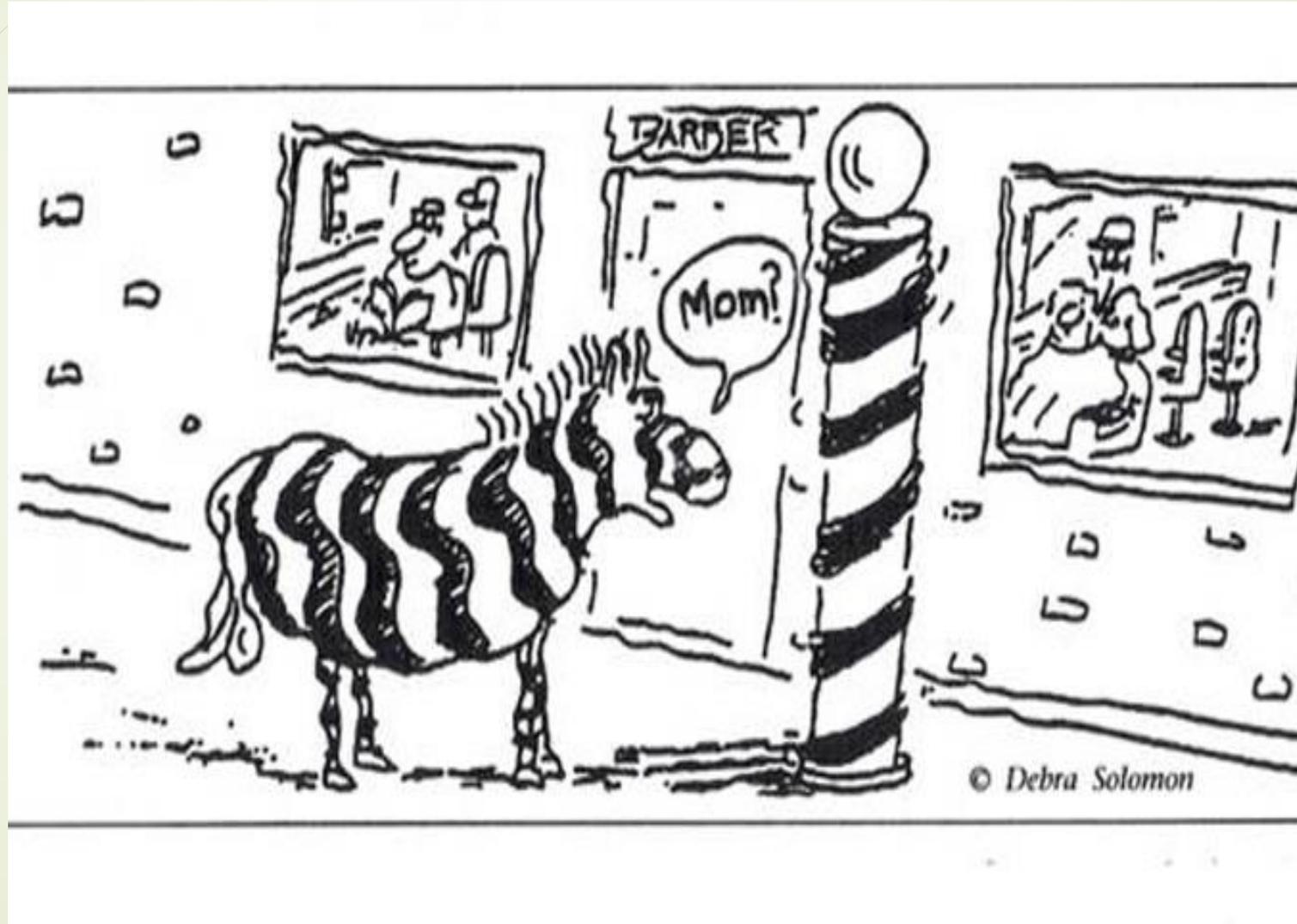
- Hard to pinpoint because very variable due to the nature of vascular dementia
- Auditory hallucinations not uncommon



# The environment

- Where did the behavior occur?
- Have there been any changes made in the room?
- Is the environment
  - unfamiliar?
  - too hot or cold?
  - too confusing
  - too large
- Is there adequate light for the person? (hallucinations & light)

# Cuing behavior: "Mom?"





Dear Mom,

This is your room. I live only a few miles away. I will come to visit you in a day or two.

I am so happy you live here!

Love, Jack, your son



# The environment

- Are there a lot of people in the room?
  - What is the emotional environment of the room?
  - Is the behavior related to the weather?
  - Or the specific time of day?
  - Are there meaningful cues to help people find their way?
  - Are there opportunities for privacy?
- 

# Environmental interventions

Often helpful for short term memory loss:

- Whiteboards, simple calendars, schedules
- Labeling cupboards, drawers
- Medication reminders, automatic pill dispensers
- Talking clocks, clocks that give date, am/pm
- One button phones, radios

THURSDAY

11:06 a.m.

AUGUST 28, 2014

DayClock



Often it is easier to  
change our behavior  
than to try to change the  
person with dementia

- Dorothy's story



The task for us is to learn  
the language of  
dementia.



# Language challenges – variation depending on type

- Expressive language – ability to find words
  - Circumlocution
  - Spontaneous speech vs. answering questions
  - Ritualized sayings
- Receptive language – ability to understand words
  - Loss of abstract thinking ability
- Likely to be more impaired in hospital or unfamiliar surroundings



# Communication basics

- Be at her eye level
  - Get her attention before speaking
  - Keep sentences simple
  - **Slow down**
  - Use touch to keep attention
  - Identify self as needed
  - Explain what is happening
  - Keep your body language & face pleasant & relaxed
  - Don't test memory
- 



# Other communication strategies

- Create a social bond
- Use visual cues if needed
- Don't undermine or correct
- Respond to feelings
  
- In late stages of dementia:
  - Very simple language
  - Use touch, music, silence



# Internal needs of the person (we all have them!)

- Recent change in medications?
- Changes in the person's vision or hearing?
- Does she need the bathroom?
- Is she
  - Hungry?
  - Thirsty?
  - Too hot? Too cold?



# Internal needs

- Is the seating comfortable?
- Is she
  - Constipated or impacted?
  - Sick?
  - Tired?
- How is the person feeling?



# Pain is...

- Often unidentified
- Often under medicated
- Sometimes a result of too much sitting, especially in wheelchairs
  
- **Is the person uncomfortable or in pain?**



# Personal history

- What do we know about this person's personality?
  - What about mental health history?
  - What significant life events may be affecting behavior?
  - Is the behavior a variation of a past coping style?
- 

# Personal history

- What do we know about work history & routines?
  - Betsy wants to go home
- Is there information about home routines?
  - related to tasks
  - related to daily life
- What about past interests, hobbies, musical tastes, food tastes?
- Details of early life, such as family, school, community, work, religion?



# The task the person is doing

- Is the task too complex or unfamiliar?
- Is the routine familiar?
- Are ADL\* routines consistent?
- Does the person enjoy doing the activity?

\*Activities of Daily Living = care of our bodies: bathing, dressing, brushing teeth, etc.



# Behaviors during personal care tasks

What would you want??



# Seminal Study in 1990

- Established a link in NH residents between
  - level of cognitive impairment,
  - ADL impairment and
  - different types of agitated behaviors.

“Cognitive impairment and ADL impairment were strongly related to agitated behavior.... aggressive behaviors correlated positively with ADL impairment.”

Cohen-Mansfield, Marx, & Rosenthal (1990).



# A common problem!

- Aggressive behaviors during personal care reported
  - By 65% of community caregivers
  - By 86% of staff in nursing homes

Cited in Sloane et al. (2004).



# Common causes of bathing problems: Emotional reactions

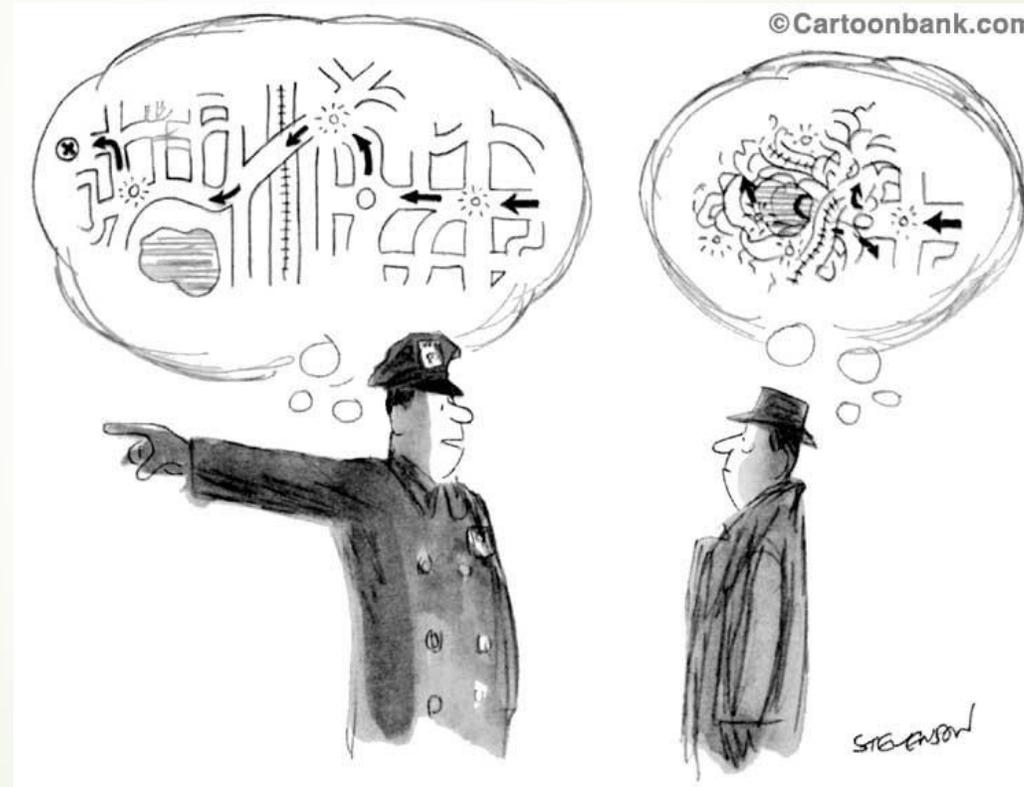
- Person may not recognize that she needs help
- Person may feel
  - humiliated,
  - embarrassed,
  - frustrated,
  - angry,
  - fearful,
  - confused,
  - as though personal space is invaded.



# Common causes of bathing problems: Care partner's emotional reactions

- Frustration
  - Impatience
  - Anger
  - Embarrassment
  - Despair
- 
- Often resistance to the task builds up on both sides when it's been unpleasant.

# Common causes of bathing problems: Poor communication





# Common causes of bathing problems: Physical or medical conditions

- Memory loss – person believes she is bathing regularly
- Mobility problems: balance, wobbliness
- Range of motion limitations
- Arthritis pain or limitations
- Extreme fatigue
- Vision problems
- Spatial problems or misinterpreting what one sees



# Common causes of bathing problems: The environment

- Temperature of room
- Water temperature
- Getting in and out of tub
- Lack of grab bars
- Lack of privacy
- Environment unfamiliar
- Floor patterns
- Lack of color contrast





# Where to start?

- Describe the whole bathing procedure. Where do you think the problems are?
- What do you think the person / your relative is feeling?
- What are you feeling?
- What physical limitations does your relative have?
- What's the environment of the bathroom like?
- What's your relative's past history with bathing?
- Are your expectations realistic?



# Creating a positive bathing environment

- Think about your approach
- Focus on the person /your relative – not the task
- Think about past history
- Provide choices as much as possible
- Use music, food or other pleasant distractions if that's helpful
- Showering together



# Creating a positive bathing environment

- Make sure bathroom is warm enough
  - Make sure water temperature works for person
  - Make it safe with adaptations as needed
  - Keep partially covered if helpful
  - Separate hair washing if that's an issue
  - Have a place to sit down if fatigued
  - Follow with something pleasant
- 

# Adaptations





# Your approach: Things to think about

- How to bring up the subject
  - What choices you can provide
  - How to stay relaxed and pleasant
  - Prepare the bathroom ahead of time
  - Try a calendar or a regular schedule
  - Find someone else to assist with this task
- 

# Bathing study in a Nursing Home

Compared 1) no-rinse towel bed bath,  
2) person-centered bathing, and 3) control  
group

- 69 residents with dementia and agitation/aggression during bathing
- Bed bath group = 60% decrease in behaviors
- PCC group = 53% decrease in behaviors
- Control group = no change

Sloane et al. (2004).



# No rinse towel bed bath

- Individuals bathed in bed with warm no-rinse soap towels.
- Remain partially covered at all times.
- Staff trained in person-centered bathing techniques

Barrick et al. (2008).

# No rinse products





# Person-centered bathing

- Focus on person rather than task
  - Relationship building
  - Choices provided
  - Person kept partially covered
  - Modifying temperature of room & shower spray
  - Using distractions (food, music)
  - Using products recommended by families
- 



# Helping care partners with bathing

- Assist in understanding how complicated bathing is
- Analyze bathing situation with them
- Try to pinpoint triggers
- Consider room adaptations
- Discuss how to make more person-centered
- Role play conversations as needed



# Case Study # 1



# Common causes of difficulty when helping someone go to the bathroom

- Emotional causes
- Physical/medical causes
- Environmental causes
- Communication issues

(Notice I am not saying “toileting.”)

# Color contrast





# Assisting in the bathroom

- Analyze bathroom situation
    - What is making it difficult?
  - Is incontinence a problem?
  - Try to pinpoint triggers
  - Consider room adaptations
  - Consider clothing adaptations
  - Discuss how to make more person-centered
  - Role play conversations as needed
- 



# Incontinence suggestions

- Medical check up – avoid infections!
  - Schedule for going to the toilet
  - Padded, washable underwear
  - Depends or similar disposable undergarments
  - No rinse wipes
- 



# Spatial abilities

- Ways to assess through observation:
  - Watch person eat: use of utensils; food on plate – what's eaten, what's not
  - Watch person reach for things: glass, salt shaker
  - Watch person sit down
  - Watch person during activities
- Visual impairment vs. spatial impairment vs. visual recognition (agnosia)



# Spatial problems: significance

- Require much more ADL help
- Insecure and more dysfunctional out of routines
- “Functional blindness”
- Difficulty learning way around

## Interventions:

- Need simple, multisensory directions
  - Adapt meal setting or serving
  - Create routines
  - Give frequent reassurance and orientation
- 



# Sequencing tasks

- Can the person follow multi-step directions?
- Can the person figure out the order to do things? (e.g., position self, pull down pants, sit on toilet)
- Three step command (medical model MMSE)
- Implications:
  - Simplify instructions
  - Give one step at a time
  - Allow plenty of time



# Assisting with dressing

- Requires fine motor skills; range of motion; spatial skills; sequencing; executive functions, i.e., organization & planning abilities
- Study analyzed dressing in 20 NH residents
- Ave. time spent = 4 minutes
- Efficiency versus quality

Cohen-Mansfield et al. (2006).



# Assisting with dressing

- Giving limited choices
  - Laying out in order
  - Explaining in simple terms
  - Visual demonstrations
  - Multiples of same outfit
  - Clothing adaptations
  - Backing off
  
  - Don't take away independence prematurely!
- 



# Assisting at mealtime, (when necessary)

- Make it social
  - Simplify place setting & table
  - Use color contrast
  - Simplify meal
  - Serve smaller portions
  - Serve one food at a time
  - Use finger foods
- 





Other common behavior changes  
that challenge us



# Walking/“Wandering”: Not just one behavior!

Many possible causes of the behavior, in fact not just one behavior

- Walking for exercise
- Walking to get some place
- Walking to try to meet an unmet need
- Walking to escape from an unpleasant situation or environment
- Walking from boredom or loneliness

**Interventions follow from causes**



# Walking/ “Wandering”

- Don't just label as wandering
- Help families **assess the intention & the risk**
- Together, create a list of strategies to try
- Put safety measures in place, i.e., Safe Return, Project Lifesaver International, ID, GPS systems, recent photo of person, bright clothing, safety devices in the home
- Nighttime considerations, i.e., lighting, commodes, snacks, locks, extra help



# Socially (In)Appropriate Behavior

- Social skills often remain intact late in disease, depending on type of dementia
- Social inappropriateness a sign of frontal lobe damage, which also impacts executive functions
  - Usually lack of insight
- Implications
  - Difficult for families
  - Often leads to isolation
  - Placement and services can be difficult
- Interventions – be creative
  - Careful grouping with other people
  - Frequent redirection
  - Behavioral approaches



# Agitation

- Evaluate situation, describe accurately & in detail
- Create strategies based on possible causes

“Agitation in persons with dementia is manifested in a wide variety of verbal and physical behaviors that deviate from social norms, including irrelevant vocalizations, screaming, cursing, restlessness, wandering, strange movements, and handling things inappropriately.” p. 64



# Case Study #2



# Problem Solving



- Discuss & define problem
- Think about what information you have that may be relevant
- Gather information: log, history, etc.
- Identify warning signs
- List possible causes
- Try different responses
- Keep lists of what works & what makes problem worse
- Remember: Nothing works all the time!



A friend is someone  
who knows the song in your heart,  
and can sing it back to you  
when you have forgotten the words.

- Author unknown

# Suggested Books for Staff and Families

- Barrick, A.L., Rader, J., Hoefler, B., Sloane, P.D., & Biddle, S. (2008). *Bathing without a Battle: Person-Directed Care of Individuals with Dementia*, Second Ed., Springer Publishing. (Also available as a training DVD.)
- Bell, V. & Troxel, D. (Second Edition, 2017). *The Best Friends Approach to Alzheimer's Care*.
- Gitlin, L. & Piersol, C.V. (2014). *A Caregiver's Guide to Dementia: Using Activities and Other Strategies to Prevent, Reduce and Manage Behavioral Symptoms*. Camino Books.
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