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.”
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?
  o John & the mailbox
<table>
<thead>
<tr>
<th>When</th>
<th>Doing before</th>
<th>Who</th>
<th>What</th>
<th>What was tried</th>
<th>Result</th>
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</thead>
<tbody>
<tr>
<td>Wed</td>
<td>Asleep TV on</td>
<td>Jones aft. Staff</td>
<td>Shouts agitated</td>
<td>Snack</td>
<td>Threw it</td>
</tr>
<tr>
<td>4pm</td>
<td></td>
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<td></td>
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<tr>
<td>Fri</td>
<td>Walking</td>
<td>Jones aft. staff</td>
<td>Shouts Tries to leave</td>
<td>Walk 1-on-1</td>
<td>Calmed down</td>
</tr>
<tr>
<td>3pm</td>
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</table>
Warning signs

• Verbal
  o Raised voice, swearing

• Non-verbal
  o 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
  o unfamiliar?
  o too hot or cold?
  o too confusing
  o 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
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:
  o Very simple language
  o 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
  o Constipated or impacted?
  o Sick?
  o 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?
  o Betsy wants to go home

• Is there information about home routines?
  o related to tasks
  o 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.”

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
  o humiliated,
  o embarrassed,
  o frustrated,
  o angry,
  o fearful,
  o confused,
  o 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
  o 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:
  o Simplify instructions
  o Give one step at a time
  o 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


References

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