



Family Caregiver Education Series

**Living with Dementia:
Understanding Behavior
as Communication**

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Upcoming Family Caregiver Webinar

- **Thursday, January 11, 2024**
Teepa Snow's GEMS Stage Model
10:00 – 10:45 a.m.; followed by Q and A

2024 Webinar Schedule is now online

Register: HopeHospice.com/family



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Session Agenda

- Dementia and Communication
- Dementia-Related Behaviors
- Identifying and Understanding Triggers
- Responses and Strategies
- Questions and Answers



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Key Take-aways from *Dementia Basics*

- Dementia is not a disease, but a group of symptoms that impair thinking and behavior.
- There are many underlying diseases that can cause dementia including Alzheimer's; stroke/TIAs; Parkinson's Disease and Lewy Body Dementia.
- All dementias are chronic, progressive, and terminal.
- Memory and language tend to decline first, but ultimately all brain functions are impacted.
- Persons with dementia communicate their needs and wants through their behaviors; care partners must learn to "read" those behaviors and respond appropriately.



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Communication

- The expression of our needs, wants, perceptions, knowledge, and emotions
- The exchange of thoughts and information
- The basis of all relationships
- Non-verbal and verbal
- Listening is more important than talking



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Dementia Changes Communication

- Difficulty finding words
- Over-reliance on familiar words
- Describe objects if can't recall word
- May not understand 25% of spoken words
- Loses train of thought; disorganized speech
- Increased use of gestures; non-verbal communication
- May revert to native language
- Can become socially isolated



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Communication remains possible . . .

. . . if care partners make an effort to change the way we communicate.

- Look for the emotions behind the words
- Acknowledge the frustration associated with:
 - Speaking, but not being understood
 - Not understanding others
- Recognize the person's:
 - Confusion
 - Anguish and anxiety
 - Need for respect and validation; partnering, not parenting



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Dementia-Related Behaviors

- When language declines, behavior becomes a means of communication for the person living with dementia
 - Expresses needs, wants, and feelings
 - Responds to what's happening in the environment
- 80% of all persons living with dementia exhibit dementia-related behaviors
- Always assume that all behavior has a purpose



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Common Dementia-Related Behaviors

- Resisting care
- Agitation/anxiety
- Repetitive behaviors
- Aggression (physical and verbal)
- Sundowning
- Hallucinations, delusions, paranoia
- Wandering
- Sexual behavior/loss of inhibitions



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Typical Causes of DRBs

- **Health and comfort**
 - Physical pain/discomfort
 - Need to toilet; hunger, thirst
 - Reactions to grooming
 - Fatigue
- **Environmental**
 - Temperature, noise, light, clutter
 - Reactions to others
- **Emotions**
 - Sad, lonely, depressed, bored
 - Overwhelmed, confused, frustrated, frightened



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A closer look at what's behind the triggers

■ Emotions

- Emotional center of the brain tends to remain intact
- Fight or flight response is instinctive, automatic
- Emotions are still very real, yet unable to express needs; leads to frustration, confusion, fear

■ Communication Skills

- Deficits causing misunderstandings, miscommunication
- Unable to tell you, so they “show” you

■ Social

- Negative interactions with others
- Some reactions have no basis in reality
- Loss of social skills due to isolation



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Person-Centered Care Responses

- Check for pain, and see if basic needs are met (ex., toileting, hunger, thirst, sleep, human contact)
- Assume that the person is scared and/or confused
- Try to address the need rather than the behavior
- Break down all tasks into simple steps; limit options
- Avoid asking questions that rely on short-term memory
- Engage in meaningful activities – distract
- Never be punitive – not being deliberately difficult
- Respond to feelings, not words
- Remember: They are trying to communicate through behavior



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Positive Physical Approach

Teepa Snow, M.S., O.T.

- Approach slowly from front
- Use first or preferred name
- Introduce yourself every time
- Try to stay at eye level, ideally on person's dominant side
- Offer your hand, palm up



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Dementia-Related Behaviors

- Resisting care
- Agitation
- Aggression – physical and verbal
- Sundowning
- Hallucinations and delusions
- Wandering



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Resisting Care

- Choose the time of day that is best for the PLWD
- Create and maintain a calm environment
- Check for physical ailments or limitations
- Break the tasks of caregiving into small increments throughout the day
- Include the PLWD in decisions as appropriate
- If at first unsuccessful, take a break and try again later



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Agitation

- Look for early signs and triggers
- Monitor for pain or discomfort
- Limit alcohol and caffeine
- Try to involve in an activity; distract
- Encourage appropriate exercise such as walking or sit and stretch if not ambulatory
- Listen and reassure



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Responding to Aggression



- Try to anticipate and diffuse triggers:
 - Pain: medical condition, constipation, unmet needs, etc.
 - Setting: over-stimulation, crowds; sudden change in routine
 - Frustration over loss of abilities, esp. communication
 - Feeling helpless, disrespected, or ignored
 - Loneliness, lack of validation from others, mistrust
 - Reaction to others, including care partner
- Take a deep breath, speak calmly, distract, give plenty of space, or leave the room
- Reassure and acknowledge feelings
- Focus on the person, not the behavior
- Unsafe situation? Leave and call for help



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Sundowning

- *A group of symptoms/behaviors that occur late in the afternoon and into the night*
- Make late afternoon and early evening a quiet time
- At dusk, close the curtains/blinds to minimize shadows
- Reduce noise (including TV), clutter, and number of people in the room.
- Distract with a favorite snack.



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Hallucinations and Delusions

- **Hallucination:** *sensation that does not exist*
- **Delusion:** *false, persistent belief; paranoia is most common delusion*
- Rule out medical causes
- Validate the experience; don't explain, argue or use logic; try not to get defensive if you are accused
- Reinforce that the person is safe and that you care
- Have extra sets of frequently lost items
- Investigate suspicions; rule out elder abuse
- Turn off the TV; the programming may be the cause of the confusion



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Wandering

- 60% of patients with dementia wander away from home and get lost.
- Do not correct or argue (for example, if they want to go home or to work).
- Validate the need and communicate acceptance.
- Initiate a conversation about home or work.
- Assure that s/he is safe and not alone.
- *Sign up for a monitoring plan . . .*
MediAlert® <https://www.medicalert.org/protection>



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www.medicalert.org/protection

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- Vaccination Records
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\$24.99 Basic

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Review: Person-Centered Care Responses

- Check for pain, and see if basic needs are met (ex., toileting, hunger, thirst, sleep, human contact, safety)
- Do not argue or try to convince
- Try to address the need rather than the behavior
- Break down all tasks into simple steps; limit options
- Avoid asking questions that rely on short-term memory
- Engage in meaningful activities – distract
- Never be punitive – not being deliberately difficult
- Respond to feelings, not words
- Remember: They're trying to communicate through their behaviors



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Don't forget to complete the online evaluation upon leaving the webinar – or when you get the link in the follow-up email tomorrow

THANK YOU!

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