

What is my resident/patient with dementia trying to tell me?

This packet describes possible causes of and solutions for addressing 12 behaviors you may witness in the people who are living with dementia. This advice, gathered from Agrace’s experienced clinical staff, may help you avoid needing the final section—on caregiver burnout.

People who have dementia may not be able to ask for what they need by speaking or even gesturing. What may seem to be a “challenging behavior” may be their way of expressing that a need is not being met. **It’s up to you, as a caregiver, to be a detective—to figure out what unmet need is causing the behavior you see.**

CHIMBOP (Figure 1) lists seven common medical problems that can be expressed through behavior. But as detectives, we should not stop there. Think about basic human needs like hunger, thirst and companionship. If you were too hungry, thirsty, exhausted, confused or lonely, you might do anything to get relief, even if it hurt someone else. Is that the case for a person in your care?

ABC: As you analyze the behavior of a person with dementia, consider any triggers that may have caused the behavior. What happened just before you noticed it? The ABC method (Figure 2) is a problem-solving approach that can help you detect triggers by logging a person’s behaviors, to watch for trends. For example, is the person agitated only when they hear the sound of a vacuum cleaner? How else could that sound be interpreted?

The ABC approach also asks you the *consequence* of a behavior, because if it doesn’t cause harm to the person with dementia or become a safety risk to their caregivers and others around them, perhaps nothing needs to change. Some actions that bother others are comforting to people with dementia, and you may not need to try to correct or change the behavior.

Person-centered solutions: Solutions for addressing a challenging behavior should be “person-centered.” Consider the person’s history, background, previous occupation or hobbies, family, likes and dislikes. For example, a lifelong dairy farmer might seem upset in the early morning if he or she thinks the cows need to be milked. What could you do to redirect this energy and relieve worry?

Approach with care: Whenever you approach a person with dementia, you are a stimulus. Approach slowly, and allow time for the person to respond. The energy of your presence affects how the person will respond. Try to remain positive and compassionate in all interactions.

CHIMBOP Reversible Causes	
C	Constipation
H	Hypovolemia, hypoglycemia
I	Infection
M	Medications
B	Bladder catheter or outlet obstruction
O	Oxygen deficiency
P	Pain

Figure 1, *Journal of Hospice & Palliative Nursing*, 2016

ABC Problem-solving Approach
A = Antecedent (trigger). What caused the behavior?
B = Behavior: What is the behavior?
C = Consequence: What are the consequences of the behavior, and how serious are they?

Figure 2, *A Train Education*, 2018

Interventions for Professional or Family Caregivers of People with Dementia

1 Disorientation/Confusion

Possible Causes

- Infection, such as a urinary tract infection (UTI)
- Constipation
- Overstimulation (loud noises, too many people/caregivers, startling approach)
- Lack of sleep/abnormal sleep cycle
- Change in environment (changing rooms or the view out a window)
- New caregiver
- Change in routine
- New medication or recent changes
- Visual changes—depth perception or peripheral vision decreases

What You Can Do

- Observe for signs of infection (for example, discolored/foul-smelling urine, urinary frequency, fever, productive cough); if you have concerns about infection, contact an RN or the Agrace team
- Identify last bowel movement, offer toileting,
- Make sure the person is clean/dry
- Limit daytime sleeping; encourage bedtime routine
- Give physical reminders/familiar objects (family photos, familiar bedding, similar room set-up)
- Gain trust from the person; start slowly to build rapport
- Redirect with activities of interest
- Make the person aware of current time and place, if appropriate
- Make sure there is high contrast in table settings (between plate and food) and in furniture (for example, between the bedding and floor color)

2 Wandering

Possible Causes

- Physical symptoms (pain, anxiety)
- Needs toileting
- Want to go home
- Past lifestyle (need to pick kids up off the bus, must get to work)
- Boredom
- Visual cues (doors, elevators)

What You Can Do

- Identify if the person is experiencing pain; do they verbalize pain, is there repetitive movement, is their facial expression different?
- Offer toileting
- Have familiar objects available so person feels at home and comfortable
- Offer/redirect to meaningful activity (for example, folding clothes, working with plants)
- Offer outlet for energy, exercise
- Remove visual cues; face away from door or from frequently used door
- Direct the conversation away from “going outside”

3 Depression

- Possible Causes**
- Loneliness
 - Mourning loss of independence
 - Not at home/unfamiliar environment
 - Physical symptoms, such as pain
 - Lack of activity
 - Unusual sleep pattern

- What You Can Do**
- Offer companionship/utilize volunteers
 - Pet therapy
 - Discuss familiar objects (family pictures, magazines, game)
 - Meaningful activity
 - Encourage bedtime routine
 - Collaborate with family and friends to find ways to bring joy to the person
 - Offer an object for comfort (teddy bear, stress ball, baby doll)

4 Combativeness, Agitation or Anger

- Possible Causes**
- Infection (such as a UTI)
 - Constipation
 - Overstimulation (e.g. loud noises, too many people/caregivers, confrontational approach, startling)
 - Pain
 - Fear (water, dark, differences in caregivers)
 - History of trauma (assault, combat)
 - Lack of control
 - An episode of incontinence

- What You Can Do**
- Ensure the safety of the person and others (family, staff, other residents)
 - Observe for signs of an infection (for example, discolored/foul-smelling urine, urinary frequency, fever, productive cough); if you have concerns about infection, contact an RN or the Agrace team
 - Identify last bowel movement, offer toileting and make sure the person is clean/dry
 - Limit caregivers to decrease stimulation and distraction
 - Redirect to activity of interest
 - Observe for discomfort, trauma or fever
 - Encourage independence
 - Provide calming environment (limit noise and alarms, play soothing music)
 - Validate their feelings
 - Mirror their emotions and facial expressions so they can see you understand how they are feeling (for example: If a person is frustrated because she does not want to go to her doctor appointment, you can also show frustration while communicating with the her; this validates her feelings and helps diffuse the situation)

5 Refusal to Bathe

Possible Causes

- Cold room and/or water that is too hot or cold
- Modesty, lack of privacy or cultural norms about bathing
- Mourning loss of independence
- History trauma (such as sexual abuse)
- Fearful of water
- Does not understand task
- Discomfort about gender of caregiver

What You Can Do

- Provide warm room and towels
- Ensure water temperature is comfortable to the person being bathed
- Offer bath blanket to preserve dignity
- Encourage independence throughout
- Use simple terms when explaining next steps (for example, “I’m going to take off your shoes now.”)
- Give time to respond
- Use alternative bathing method (bed bath) or try again at a different time of day
- Use different words (rather than “bath” say “clean up/ freshen up/wash up”)
- Provide soothing environment (dimmed lights, favorite music, aroma therapy)

6 Hallucinations

Possible Causes

- Infection (such as a urinary tract infection (UTI))
- Medication changes
- Dehydration
- Blood sugar levels too high or low
- Near death awareness (visions that feel real to the person, such as “seeing” loved ones who have died, or talk of leaving, traveling, waiting to go somewhere)
- Dementia worsening/physical changes to the brain

What You Can Do

- Observe for signs of an infection (for example, discolored/foul-smelling urine, urinary frequency, fever, productive cough); if you have concerns about infection, contact an RN or the Agrace team
- Review medications
- Offer fluids
- Check blood sugar levels if there is history of diabetes
- If hallucination is bothersome, get rid of it (squish bug, escort child out of the room)
- Do not disagree with their reality unless the person asks what time/day it is or where they are
- Identify if objects are being misinterpreted (for example, confusing a sprinkler head on the ceiling for a bug)
- Allow the person to talk about seeing deceased loved ones or “going home” if it doesn’t bother them and provides comfort; ask questions, engage in conversation and pay attention to what is being said, as family may appreciate knowing this

7 Verbal Repetition

- Possible Causes**
- Boredom
 - Anxiety (for example misses family/friends)
 - Loneliness
 - Physical need (hungry, thirsty, needs toileting)
 - Pain

- What You Can Do**
- Redirect to another meaningful activity
 - Observe for discomfort
 - Provide companionship
 - Offer drink or food
 - Offer toileting
 - Discuss familiar, comforting objects (family pictures, magazines, game)

8 Difficulty Communicating

- Possible Causes**
- Hard of hearing
 - Inability to speak
 - Dementia disease progression
 - Language barrier
 - History of stroke
 - Memory loss

- What You Can Do**
- Hearing device (hearing aids, pocket talker)
 - Use a communication or picture board to help identify needs
 - Use nonverbal cues, such as gesturing, demonstrating or facial expressions
 - Use an interpreter service or language line
 - Observe non-verbal indicators of discomfort, address the source of discomfort
 - Refer to the person's history to remain person-centered with communication (review patient chart, patient preference card, family, primary caregivers)

9 Sun-downing (Late-day Confusion or Agitation)

- Possible Causes**
- Change in environment
 - Room lighting
 - Change in medications
 - Unusual sleep pattern
 - Lack of daily routine

- What You Can Do**
- Surround with familiar objects, distract with a favorite or meaningful activity
 - Lights should be brighter during the day and dim/soothing in the evening
 - Review medications, discuss them with the Agrace team
 - Discourage daytime sleeping to help promote sleep at night
 - Establish a daily routine to meet the person's needs

10 Pocketing Food/Refusal to Eat

Possible Causes

- Memory loss
- Pain in mouth, unable to chew
- Not hungry
- Texture of food
- Losing ability to swallow
- Dentures no longer fit properly
- Transitioning to end-of-life

What You Can Do

- Observe for mouth sores or reddened areas
- Ensure dentures are fitting properly
- Offer different types of food
- Offer different preparation of food, such as soft or pureed
- Ask family/caregivers about—and offer—favorite food and drink
- Continue to offer food, but DO NOT force feed
- Teach family/caregivers about other things that may comfort someone who doesn't want to eat, such as their presence
- Make sure mouth is clean, moisten mouth with toothettes, clean dentures and teeth, apply lip balm

11 Restlessness/Anxiety

Possible Causes

- Constipation
- Pain
- Needs toileting, or had episode of incontinence
- Unfamiliar environment
- Unusual sleep pattern
- Physical needs (hungry or thirsty)
- Change in medications
- Troubling memories or thoughts

What You Can Do

- Identify last bowel movement
- Observe for source of pain
- Offer toileting, and ensure person is clean/dry
- Establish regular bedtime routines
- Offer food and drink
- Redirect to a meaningful activity (for example, folding clothes, working with plants)
- Offer an object for comfort (teddy bear, baby doll, stress ball)
- Assist with relaxation techniques (deep breathing, meditation)
- Provide calming environment (dimmed lights, soothing music)
- Help them get to their “happy place”—a favorite place, scent or song
- Help them reminisce through conversation or music

12 Paranoia

- Possible Causes**
- New environment or caregiver
 - History of trauma or difficult life experiences
 - Medication changes
 - Disease progression (illness is getting worse), dementia
 - Abuse or neglect (current or past)
 - Isolation
 - Infection (such as in urinary tract); observe for fever, cough or urinary frequency/odor and report any signs to RN or Agrace team
 - Unusual sleep pattern

- What You Can Do**
- Provide reassurance /validation (“It’s upsetting when we can’t find our things.”)
 - Orient to surroundings, *if appropriate*
 - Do not argue
 - Redirect to meaningful activity or conversation; help find their “happy place”
 - Establish a daily routine
 - Remove or hide any triggers (doors, cords)

Caregiver Burnout

- Possible Causes**
- No breaks
 - High staff-to-patient ratio in a long-term care setting
 - Increased resident/patient activity
 - Complex family relationships and issues
 - Lack of training or resources
 - Stress in caregiver’s personal life

- What You Can Do**
- Mindfulness, finding a reasonable work-life balance
 - Attend support groups
 - Find constructive peer support with other staff
 - Schedule respite stay (for hospice patients living in private home)
 - Complete educational trainings (self-care, time management)
 - Validate feelings, normalize
 - Hold family meetings to help with collaboration, review goals/plan of care
 - Request/arrange for volunteers; this allows specialized one-to-one care, companionship and socializing for which a caregiver may have limited time

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